

# Preeclampsia from a Patient Perspective

MARIA ANDERSSON

DEPARTMENT OF CLINICAL SCIENCES LUND | FACULTY OF MEDICINE | LUND UNIVERSITY



## Preeclampsia from a Patient Perspective

# Preeclampsia from a Patient Perspective

Maria Andersson



**LUND**  
UNIVERSITY

DOCTORAL DISSERTATION

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*Faculty opponent*

Mirjam Lukasse, Professor at University of Sørøst, Norway

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**Abstract:**

**Background:** Preeclampsia is a leading cause of maternal and fetal mortality. Although antenatal care can identify women at risk, limited research has explored women's experiences with preeclampsia despite its significant impact.

**Aim:** This thesis aims to enhance the understanding of women's experiences with preeclampsia in order to improve clinical care, support, and mental health outcomes. This includes assessing the quality of care and information provided, examining the emotional and psychological effects of preeclampsia on both women and their partners during the postpartum period, as well as evaluating the accuracy of an innovative home blood pressure monitoring mobile phone application during pregnancy.

**Methods:** Studies I & II: Qualitative interviews were conducted with 9 and 15 women, respectively, and analyzed using phenomenological and manifest content methods. Study III: A longitudinal study with 37 women and 13 partners examined depression, anxiety, and co-parenting at 2 and 6 months postpartum using mixed linear models. Study IV: The Anura™ application for blood pressure monitoring was evaluated in normotensive, high-risk, and preeclamptic pregnancies using paired t-tests and Bland-Altman plots.

**Results:** Studies I & II: Women described preeclampsia as distressing and unexpected. They cited a lack of consistent information and significant stress from being separated from their newborns. They emphasized the need for clear, repeated communication and tailored support. Study III: Rates of postnatal depression and anxiety were comparable to those in normotensive populations. Support and closeness in co-parenting were associated with improved mental health outcomes. Conversely, women whose partners reported low levels of perceived support experienced increased anxiety. Study IV: The Anura™ application demonstrated accuracy in normotensive pregnancies but was less reliable in high-risk pregnancies and cases of preeclampsia, showing significant discrepancies in blood pressure readings. Most women expressed a positive experience of using the Anura application.

**Conclusions:** Improved care for preeclampsia requires standardized, individualized support and clear communication throughout pregnancy and the postpartum period. Co-parenting support should involve both parents in order to enhance mental health outcomes. While the Anura™ application shows promise for use in normotensive pregnancies, it is not yet reliable for clinical use in high-risk pregnancies or preeclampsia.

**Key words:** Blood pressure, Coparenting, Experience, Mental health, Partners, Pregnant women, Pregnancy hypertension, postpartum Anxiety, postpartum Depression, postpartum

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‘Learn to do by knowing and to know by doing’ – John Dewey







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## Preface

I absolutely adore being a midwife in the maternity ward; it's more than just a job to me— it's my passion. I never even considered doing anything else. But then, an unexpected opportunity knocked on my door, one that I simply couldn't resist. About seven years ago, I was offered a role as a research midwife at Lund University, focusing on preeclampsia. It felt as though a whole new world had opened up before me. Suddenly, research was something both interesting and exciting.

As I delved into this research, I noticed something missing, not just within our team, but across the field of preeclampsia research. I often found myself chatting with women who had experienced preeclampsia during their pregnancies, either in the hospital, as part of our studies, or while working as a clinical midwife. Their stories resonated with me deeply. Their questions, fears, and hopes often went unanswered or unaddressed. It became increasingly clear that their voices were absent from the research dialogue. The patient perspective was the vital link that was missing.

Despite the seriousness of preeclampsia, there was surprisingly little focus on women's experiences and needs. This realization ignited a fire within me. Suddenly, research became more than just a job; it became a mission. My journey into research wasn't without its challenges, though. I had to dust off my textbooks and dive back into studying to refresh my skills. Reading in English and grappling with statistics felt like climbing Mount Everest at times.

But amidst the struggles, there were moments of pure joy. Connecting with these women, hearing their stories, and knowing that our research could make a real difference kept me motivated. It's been a rollercoaster ride full of ups and downs, victories, and setbacks. As I near the finish line, I can't help but feel immensely proud of how far I've come. This journey has transformed me in ways I never could have imagined, and I wouldn't change a thing..., well, maybe a few things; my main supervisor knows what I mean! 😊

# Abstract

**Background:** Preeclampsia is one of the leading causes of maternal and fetal mortality globally. Antenatal care has been crucial in reducing maternal mortality rates by enabling the early identification of women at risk. However, there's a noticeable gap in exploring women's lived experiences of preeclampsia. Despite its profound impact, few studies have focused on this crucial aspect.

**Aim:** The overall aim of this thesis was to enhance the understanding of women's experiences with preeclampsia from their perspective, with the goal of improving clinical care, support, and mental health outcomes. This included assessing the quality of care and information provided, examining the psychological effects of preeclampsia on both women and their partners during the postpartum period, as well as evaluating the accuracy of an innovative blood pressure monitoring technology during pregnancy. Through these insights, the studies aim to develop better support strategies and interventions for families affected by preeclampsia.

**Methods:** *Study I* employs a qualitative design, where interviews were conducted with nine women diagnosed with preeclampsia using Amedeo Giorgi's descriptive phenomenological method. *Study II* was also a qualitative interview study, utilizing manifest content analysis by Graneheim and Lundman with 15 women who experienced preeclampsia. Studies III and IV were both designed as prospective longitudinal studies. *Study III* focuses on questionnaire data from n=37 women diagnosed with preeclampsia and their partners, n=13. The study assessed depression, anxiety, and thoughts and feelings about co-parenting at two and six months postnatal. Mixed linear models were used to explore links among those variables. A pilot analysis of paired data from n=12 couples further addressed links between partners' mental health symptoms and their perceptions of co-parenting. *Study IV* was an evaluation of a new mobile phone application (Anura™) to track blood pressure in normotensive pregnant women, high-risk pregnancies from early pregnancy, and preeclamptic women from diagnosis. Statistical analyses include descriptive statistics, power analysis, paired t-tests, Bland-Altman plots, and post hoc tests.

**Results:** In *Studies I* and *II*, preeclampsia was described by participants as an unexpected and distressing experience. The women reported a lack of information about the condition and its long-term health risks. They highlighted the need for detailed, consistent, and repeated communication, both oral and written, from healthcare professionals. Increased stress and anxiety, along with feelings of despair due to separation from their newborns in neonatal care, underscored their significant need for emotional and practical support throughout their experience. In *Study III*, despite having



experienced preeclampsia, rates of postnatal depression and anxiety among participants were similar to those observed in normotensive pregnancy populations, with depressive symptoms decreasing over time. These symptoms were highly comorbid and independent of fetal sex or the severity of the diagnosis. However, a higher level of education was associated with greater depressive symptoms. Perceived support from and closeness to one's co-parent was the strongest predictor of good mental health. Interestingly, when partners reported feeling lower support and closeness in their co-parenting relationship, the women's anxiety levels were higher. *Study IV* showed that the Anura™ application works well in normotensive pregnancies. However, in high-risk pregnancies and in women with preeclampsia, there are discrepancies between blood pressure results obtained using the application and those measured manually. The paired blood pressure measurements obtained using ANOVA were divided into three study groups and analyzed for each trimester. The results revealed no significant differences across the three trimesters for normotensive women. In high-risk pregnancies, there were no significant differences in systolic blood pressure (SBP) between the first and second trimesters, but a significant difference was noted between the first and third trimesters ( $p<.001$ ). Women with preeclampsia showed significant differences in both SBP and diastolic blood pressure (DBP) during the second and third trimesters ( $p<.001$ ).

**Conclusions:** *Studies I and II* underscore the need for improved care for women with preeclampsia. Women emphasized the importance of consistent, detailed, and repeated information to reduce uncertainty and fear. Standardized education early in pregnancy, combined with harmonized and individualized support throughout antenatal, maternity, and inpatient care, is essential. Fragmented care and significant stress, particularly due to separation from their newborns, highlight the urgent need for better support and tailored postpartum follow-up. Future research should focus on enhancing care planning and addressing these gaps to improve long-term outcomes. *Study III* shows that perceived support from and closeness to a co-parent (partner) may protect both women and their partners from postnatal depression and anxiety, even in the event of severe preeclampsia. Our results highlight the link between one parent's mental health and the other's experience of co-parenting. Support efforts should, therefore, focus on strengthening the co-parenting relationship and include both partners. *Study IV* shows that the Anura™ application is accurate in predicting blood pressure in women with normotensive pregnancies and is well-accepted by the women. High satisfaction with the contactless measurement technology indicates a willingness to recommend its use in future home and clinical settings. However, the accuracy of the contactless blood pressure monitoring technology used by Anura™ is not yet sufficiently reliable for use in a clinical setting for high-risk pregnancies and women diagnosed with preeclampsia.

# Populärvetenskaplig sammanfattning

## *Bakgrund*

Preeklampsi är en av de främsta orsakerna till mödra- och fosterdödlighet globalt. Det drabbar 3–8 procent av alla gravida kvinnor, vilket motsvarar cirka 8,5 miljoner kvinnor årligen. Tillståndet definieras som hypertoni ( $\geq 140/90$  mmHg) efter graviditetsvecka 20 i kombination med maternell organsvikt, och/eller intrauterin tillväxthämning. Symtomen kan variera från en diffus känsla av sjukdom och mild huvudvärk till svår huvudvärk, synfenomen som till exempel flimmer för ögonen, bröst- och buksmärta och, i extrema fall, epilepsiliknande kramper. Preeklampsi är också associerat med en ökad risk för att utveckla hjärt-kärlsjukdomar som kronisk hypertoni samt diabetes senare i livet. De löper dessutom en högre risk att utveckla stroke, vaskulär demens samt neurologiska störningar som kan påverka koncentrationen och kognitiva funktioner. Det ofödda barnet drabbas ofta, tillväxthämning ses i cirka 25 procent av fallen. Idag orsakar preeklampsi cirka 15 procent av alla för tidiga födselar globalt, då enda behandlingen är att sätta igång förlossning oavsett graviditetslängd.

Förutom de fysiska konsekvenserna kan preeklampsi också påverka kvinnans och partners psykiska hälsa, vilket i sin tur kan ha en negativ inverkan på relationen och barnets anknytning till förälderna. Trots den djupa påverkan på många nivåer finns en märkbar kunskapslucka när det gäller att utforska kvinnors upplevelser vid preeklampsi. Endast ett fåtal studier har tidigare fördjupat sig i detta ämne.

Mödravården har spelat en avgörande roll i att minska mödradödligheten i modern tid. I det nationella mödravårdsprogrammet ingår det att identifiera riskfaktorer för preeklampsi tidigt i graviditeten. Detta omfattar blodtrycksmätning, screening för proteinuri och kartläggning av kvinnornas sjukdomshistoria. Faktorer som diabetes, kronisk hypertoni, njursjukdomar, BMI över 30 och etnicitet är exempel på några riskfaktorer som beaktas. Barnmorskan har en central roll i att tidigt identifiera kvinnor med ökad risk för preeklampsi. Kvinnor med hög risk remitteras till en läkare för profylaktisk behandling med acetylsalicylsyra, vilket minskar risken att utveckla preeklampsi.

Dagens mödravård erbjuder den gravida kvinnan cirka åtta till tio planerade besök under graviditeten. Trots detta finns en risk att ett stigande blodtryck inte alltid upptäcks i tid. Genom att erbjuda kvinnor möjlighet att mäta sitt blodtryck i hemmet, och inte bara vid mödravårdsbesöken, kan man potentiellt tidigare identifiera ett stigande blodtryck. Mobilapplikationer som använder smartphones möjliggör en ny lösning för att övervaka blodtrycket på ett enkelt och billigt sätt.

## *Syfte*

Det övergripande syftet med denna avhandling var att studera patientperspektiv vid preeklampsi, för att öka förståelsen av kvinnors upplevelser och deras erfarenheter av sjukdomen. I studierna har kvaliteten på vården och informationen som givits studerats. Vidare har de psykologiska effekterna av preeklampsi, hos både kvinnor och deras partners, utvärderats efter barnets födelse. I *studie IV* utvärderades användarvänligheten och precisionen av en ny mobilapplikation, ANURA™ som använder mobilkameran och AI-teknik för att mäta blodtrycket. Denna applikation har tidigare aldrig studerats på gravida.

Med ökad kunskap inom dessa område avser vi bidra till utvecklingen av bättre stödstrategier och interventioner, under och efter graviditeten, för alla gravida och för familjer som har drabbats av preeklampsi. Genom hembloodtrycksmätning ger man gravida kvinnor en möjlighet att ta eget ansvar för sin hälsa vilket kan medföra en ökad medvetenhet och en tidigare upptäckt av preeklampsisymptom.

## *Metoder*

*Studie I* and *II* är båda kvalitativa studier där kvinnors upplevelser av att ha genomgått en graviditet komplicerad av preeklampsi studerats genom intervjuer. I *studie I* användes Amedeo Giorgis beskrivande fenomenologiska metod på nio inkluderade kvinnor, och i *studie II* genomfördes analyserna med Graneheim och Lundman innehållsanalys. Totalt inkluderades 15 kvinnor med preeklampsi. *Studierna III och IV* följer en prospektiv longitudinell design. *Studie III*, är en prospektiv enkätstudie relaterat till psykisk ohälsa. Totalt inkluderades 37 kvinnor som diagnostiserats med preeklampsi samt deras partners ( $n = 13$ ), samtliga män. Studien utvärderade depression, ångest och tankar och känslor kring hur man är förälder tillsammans (samband), två och sex månader efter förlossningen. Enklare och mer komplexa statistiska modeller användes för att utvärdera sambanden mellan tankar och känslor och psykiskt mående. I *studie IV* jämfördes blodtrycksmätningar gjorda med mobilapplikationen Anura™ med manuella blodtrycksmätningar gjorda av barnmorskor eller annan vårdpersonal. Anura™ möjliggör mätning av blodtrycket med hjälp av mobilkameran, utan att använda en blodtrycksmanschett. Tekniken är baserad på en innovativ metod kallad transdermal optisk avbildning, som mäter olika nyanser av rött. Syresatt blod är ljusrött och mindre syresatt venöst blod är mörkare. Med hjälp av en AI algoritm beräknas färgskillnader vilket ger blodgenomströmningen i huden och ett mått på blodtrycket.

## *Resultat*

I *Studie I and II* framkom det att kvinnorna upplevde preeklampsi som ett oväntat och skrämmande tillstånd. Kvinnorna rapporterade en generell brist på kunskap om sjukdomen och dess långsiktiga hälsorisker under graviditeten samt postpartum. Kvinnorna lyfte fram ett behov av att få mer detaljerad, konsekvent och upprepad information, både muntligt och skriftligt. De upplevde en ökad stress och ångest, blandat med känslor av förtvivlan orsakad av separation från det nyfödda barnet som vårdades på neonatalavdelningen. De underströk ett betydande behov av känslomässigt och praktiskt stöd under hela vårdtiden.

I *Studie III* visade resultaten att förekomsten av depression och ångest efter förlossningen hos kvinnor med preeklampsi var jämförbar med andra representativa grupper i samhället utan preeklampsi. Dessutom framkom det att depressiva symtomen tenderade att minska spontant över tid. Depression och ångest förekom ofta samtidigt, oavsett kön eller svårighetsgrad av preeklampsidiagnosen. En högre utbildningsnivå var associerad med högre symtomnivåer. Det mest avgörande för en god psykisk hälsa var upplevelsen av stöd och närhet i relationen till partnern. Kvinnornas symptom på ångest var högre och associerat med partnerns upplevelse av lägre stöd och närhet i föräldraskapet. *Studie IV* visade att Anura<sup>TM</sup> applikationen fungerar bra i graviditeter med normalt blodtryck, men vid högrisk graviditet och hos kvinnor med preeklampsi var det signifikant skillnad mellan blodtrycksvärden erhållna med Anura<sup>TM</sup> jämfört med manuellt uppmätta blodtryck. De tre studiegrupperna analyserades separat för respektive trimesterperiod. För de friska kvinnorna sågs inga signifikanta skillnader i blodtrycksmätningarna i de tre trimesterna, vilket visade att Anura<sup>TM</sup> fungerade väl i denna grupp. I högriskgraviditeter fanns inga signifikanta skillnader för det systoliska blodtryck i första och andra trimestern, däremot en signifikant skillnad mellan första och tredje trimestern ( $p < .001$ ). Kvinnor med preeklampsi visade signifikanta skillnader för både det systoliska och diastoliska blodtrycket, i andra och tredje trimestern ( $p < .001$ ) vilket betyder att applikationen inte är tillförlitlig för dessa två grupper.

## *Slutsatser*

Sammanfattningsvis visar resultaten i denna avhandling på ett stort behov av en förbättrad vård med konsekvent, detaljerad och upprepad information för kvinnor som drabbats av preeklampsi. Kvinnorna upplevde vården som fragmenterad och kände en betydande stress, särskilt vid separation från det nyfödda barnet. De önskade ett bättre stöd och förbättrad uppföljning postpartum. Stöd och närhet i samföräldraskap visades kunna skydda båda föräldrarna från depression och ångest, efter en komplicerad graviditet. Resultaten visade ett samband mellan den ena förälderns psykiska hälsa och



den andres upplevelse av medföräldraskap. Stödinsatserna bör därför även fokusera på samföräldrarelationen och omfatta både kvinnan och hennes partner.

Hemblodtrycksmätning med hjälp av Anura<sup>TM</sup> fungerar väl i graviditeter med normalt blodtryck. Kvinnorna uttryckte en hög tillfredsställelse med Anura<sup>TM</sup> användningen och kunde rekommendera dess användningen i framtiden. Noggrannheten var dock inte acceptabel för högriskgraviditeter och kvinnor som diagnostiserats med preeklampsi. Applikationen kommer därför, utifrån insamlade data, att anpassas för att på ett korrekt sätt mäta blodtrycket även i dessa patientgrupper.

## List of Papers

### *Paper I*

Hansson T, **Andersson ME**, Ahlström G, Hansson SR. Women's experiences of preeclampsia as a condition of uncertainty: a qualitative study. *BMC Pregnancy Childbirth*. 2022 Jun 28;22(1):521. doi: 10.1186/s12884-022-04826-5.

### *Paper II*

**Andersson ME**, Rubertsson C, Hansson SR. The experience of provided information and care during pregnancy and postpartum when diagnosed with preeclampsia: A qualitative study. *Eur J Midwifery*. 2021 Sep 8; 5:37. doi: 10.18332/ejm/139488.

### *Paper III*

**Andersson M.E**, Hansson S.R. and Psouni E. (2024). Follow-up on Mental Health and Coparenting after Preeclampsia: Mothers' and Partners' Perspectives two and six months Postpartum. *Submitted manuscript*

### *Paper IV*

**Andersson M.E**, Rubertsson C. Psouni E. Erlandsson L. and Hansson S.R. (2024). Evaluating the feasibility of using a smartphone application to monitor blood pressures of women with a healthy or high-risk pregnancy and preeclampsia. *Submitted manuscript*

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## Additional work

Kalapocharakos, G., Salehi, D., Steding-Ehrenborg, K., **Andersson, M.**, Arheden, H., Hansson, S. R. & Hedström, E. Cardiovascular effects of severe late-onset preeclampsia are reversed within six months postpartum. *Pregnancy Hypertension*. 2020 Jan 19. doi.org/10.1016/j.preghy.2019.12.005

Karolina Linden, Nimmi Domgren, Mehreen Zaigham, Verena Sengpiel, **Maria E. Andersson**, Anna Wessberg. Being in the shadow of the unknown. Swedish women's lived experiences of pregnancy during the COVID-19 pandemic, a phenomenological study. *Women and Birth*. 2021 Sep 35:5. doi.org/10.1016/j.wombi.2021.09.007

Raoust, G., Thies-Lagergren, L., Bergström, J., **Andersson, ME.**, Hansson, SR., & Selberg, R. (2023). Navigating the tensions: Swedish midwives' boundary work and experiences of their role in obstetric emergencies. *Submitted manuscript*

Holst, M. Rix F, **Andersson, ME.** Rubertsson, C. Hansson, SR. The role of breastfeeding in blood pressure regulation in preeclamptic and normotensive pregnancies - a case control study. *Manuscript in preparation*

## Abbreviations

AI	Artificial Intelligence
AHC	Antenatal Health Care
ANOVA	Analysis of Variance
ASA	Acetyl Salicylic Acid
BMI	Body Mass Index
CRS	Co-parenting Relationship Scale
CVD	Cardiovascular Disease
DBP	Diastolic blood pressure
EPDS	Edinburgh Postnatal Depression Scale
FGR	Fetal Growth Restrictions
GH	Gestational hypertension
GMDS	Gotland Male Depression Scale
GW	Gestational week
ICM	Confederation of Midwives
IUGR	Intra Uterine Growth Restriction
IUFD	Intrauterine Fetal Death
HELLP	Hemolysis, Elevated Liver enzymes, Low Platelets
NICU	Neonatal Intensive Care Unit
PASS	Perinatal Anxiety Screening Scale
REDCap	Research Electronic Data Capture
SBP	Systolic blood pressure
SD	Standard Deviation
WHO	World Health Organization

# Introduction

For a considerable time, biomedical research has been the primary focus for improving outcomes and care for women affected by preeclampsia. Most current research endeavors to elucidate the underlying disease mechanisms and identify new biomarkers for predicting and diagnosing preeclampsia more effectively [1-3]. While biomedical research is undoubtedly crucial, there remains a noticeable gap in exploring women's lived experiences with preeclampsia. Despite its profound impact, few studies have delved into this critical aspect. Women who have shared their experiences depict preeclampsia as a terrifying and life-threatening condition, often highlighting a lack of adequate care, particularly concerning psychosocial support [4-6]. Women who have experienced both premature birth and preeclampsia often describe feelings of intense fear and an experience of being close to death [7]. It is indeed surprising and disconcerting that such an important topic has been relatively under-explored in research.

Understanding how preeclampsia affects women on both personal and interpersonal levels– and gathering their perspectives on improving care– is crucial, given the long-term effects of the condition and its significant impact on maternal and infant mortality worldwide. It is essential to prioritize research that includes the voices and experiences of those directly affected to ensure more effective and compassionate care [8]. Although Swedish healthcare is generally ranked high in international comparisons, it receives a low ranking in one critical area: the care is not designed based on the patient's needs and perspectives [9]. Furthermore, Swedish healthcare is ranked lower than that of comparable countries when it comes to meeting patients' individual needs and involving them in their own care [9]. On the other hand, Swedish maternity care maintains high-quality in international comparisons. Analyses based on the Swedish Medical Birth Registry do not indicate any deterioration in birth outcomes in Sweden over the past five years [10]. Research shows that patient-centered care leads to better health outcomes and reduced societal costs. This shows that Sweden has a great opportunity to improve its healthcare by making it more patient-centered [11]. Thus, regarding preeclampsia, a deeper understanding of women's perspectives is required. This thesis aims to contribute to the understanding of women's experiences with preeclampsia from a patient perspective and to enhance the provision of safe, high-

quality care. By highlighting the health risks associated with preeclampsia, this research seeks to improve knowledge among women about the condition and its long-term effects on both mothers and their children. Ultimately, the primary goal is to effectively prevent health issues, followed by diligent monitoring and treatment during pregnancy, postpartum, and throughout their lives.

To achieve these objectives, this thesis has employed qualitative research methods, including deep and semi-structured interviews and quantitative research methods, with women who have experienced preeclampsia, to gain in-depth insights into their experiences and perspectives. This research project is guided by the woman-centered care model, which emphasizes the importance of individualized care and the active involvement of patients in healthcare decisions. Understanding the patient perspective is crucial for developing patient-centered care approaches that address both the medical and psychosocial needs of women with preeclampsia, ultimately leading to better health outcomes. By integrating these insights into clinical practice, healthcare providers can foster a more empathetic and supportive environment for women affected by preeclampsia. It is my hope that this thesis will provide my midwife and medical colleagues with a deeper understanding of patients' experiences with preeclampsia, enabling them to deliver the best possible care to women facing this challenging condition.



© Artwork by midwife Gabriella Aichholzer Hedström

# Background

## Preeclampsia

Preeclampsia is a pregnancy complication characterized by the onset of hypertension after 20 weeks of gestation, in combination with maternal organ dysfunction and/or intrauterine growth restriction (IUGR) [12-14]. It is further classified into early-onset (<34 weeks gestation) and late-onset ( $\geq 34$  weeks gestation). Early-onset preeclampsia is more often associated with impaired placental development, leading to pronounced fetal growth restriction [15-17]. Recent research indicates that even women with mild symptoms of preeclampsia may experience permanent damage to their blood vessels [18]. The typical clinical manifestation of the HELLP syndrome is pain under the right arcus in combination with *Hemolysis*, *Elevated Liver* enzymes, and *Low Platelets* (HELLP) [13]. This syndrome is a severe form of preeclampsia affecting several organs (liver, kidneys) [15]. Eclampsia is the most serious complication of preeclampsia and affects approximately 1 – 2 percent of patients with severe preeclampsia [15]. It is defined by general convulsions that can occur before, during, or after childbirth [14]. Eclampsia is difficult to predict and may occur without previous symptoms [13, 14].

## Symptoms

The symptoms of preeclampsia are usually vague [15], which can result in delayed diagnosis [4]. The patient may describe a general feeling of malaise and/ or a slight headache, pain in the upper part of the abdomen, symptoms from the eyes such as flickering or sensitivity to light, sudden increased swelling of the face, hands, or feet, and in severe cases convulsions [12]. Women with preeclampsia or eclampsia have an increased risk of persistent cognitive dysfunction several months or even years after pregnancy. These symptoms are most likely caused by general endothelial damage, which also affects the blood vessels in the brain, making them more permeable, causing localized edema [19-21]. The risk of convulsions increases in cases of severe preeclampsia, but eclampsia can occur without any prodromal symptoms. It is observed in approximately 1/2000 births in Europe and in 1/100 to 1/1700 births in low- and middle-income countries. Pulmonary edema is another severe aspect of preeclampsia,

though its underlying mechanisms are not yet fully understood. It is responsible for up to 50% of deaths related to preeclampsia [22]. The symptoms of HELLP are non-specific and should be ruled out with repeated evaluations of liver enzyme levels and platelet counts in pregnant women presenting with nausea and upper abdominal pain. Its symptoms are sometimes mistaken for gastritis, reflux, the flu, gallbladder disease, or other abdominal conditions. In other words, preeclampsia is nowadays considered a syndrome that can manifest in many ways, ranging from mild symptoms to life-threatening convulsions and coagulation disorders. It also affects the unborn child significantly and causes IUGR in 25% of cases and 15% of all premature births in the world [12].

## Preeclampsia – a historical perspective

Preeclampsia was first described by the ancient Egyptians and later by the Greeks, who coined the term *eclampsia*, which means "lightning from a clear sky" [23]. The description is a figurative analogy to the clinical course observed, where apparently healthy pregnant women would suddenly experience convulsive attacks. It was not until the 18<sup>th</sup> century that it was realized that these convulsions stopped after childbirth and were different from epileptic convulsions. Just over 100 years later, a connection between proteinuria and preeclampsia was recognized. In 1849, the term toxemia was coined. The hypothesis was then that waste products from the bodies of the mother and child accumulated in the blood, irritating the central nervous system. It was not until 1897 that the association between hypertension and eclampsia was established [23].

The first midwife training started in Sweden in 1708, and in 1711, a midwifery regulation was introduced, which said that only trained midwives were allowed to practice the profession [24]. With England as a model, the Swedish Antenatal Health Care system (AHC) was established during the 1930s. In 1938, antenatal care became free of charge for women through state subsidies. In 1955, standardized instructions for preventive maternal and child health care were introduced, with detailed instructions and significantly more checkups [25]. Following this, the standard care involved midwives screening all pregnant women through blood pressure measurements and urine tests during their antenatal visits [26]. Antenatal care has been the most important contributing factor in reducing maternal mortality in modern times. The visits were structured to detect women at risk of preeclampsia, ensuring that they were treated in a hospital environment, as the mortality rate from this condition remained high [24]. In 2019, Sweden published national guidelines for hypertensive

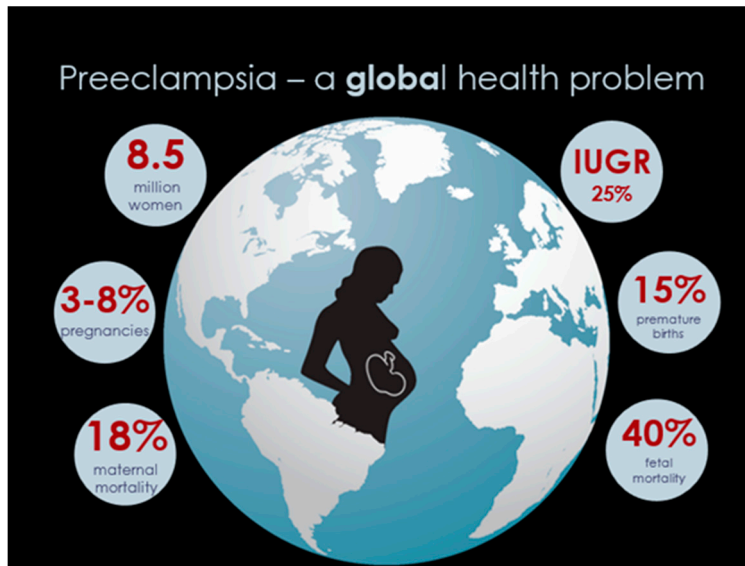


diseases during pregnancy, emphasizing the need to screen for risk factors for preeclampsia and to initiate prophylactic treatment with low-dose aspirin [12]. Nonetheless, there are many questions about preeclampsia that remain unanswered. Despite numerous efforts, there is still no curative treatment or effective screening method to identify preeclampsia at an early stage, leaving the condition still shrouded in obscurity.

## Preeclampsia – a global perspective

Preeclampsia is one of the most common causes of maternal and fetal mortality worldwide, affecting 3–8% of all pregnant women, which corresponds to 8.5 million women globally [27] (see figure 1). It causes approximately 500,000 fetal deaths and 76,000 maternal deaths worldwide each year [28], which equates to one death every 11 minutes [8]. In Sweden, preeclampsia results in approximately 1 death per 100,000 women [13]. While maternal mortality has decreased by 44 percent globally over the last 25 years, significant disparities remain.

In 2020, approximately 287,000 women lost their lives during or after pregnancy and childbirth. Nearly 95% of these deaths took place in low- and middle-income countries [29]. The majority of these deaths can be prevented by providing timely and effective care for women presenting with such complications [8]. In Africa and Asia, nearly one-tenth of all maternal deaths are associated with hypertensive disorders of pregnancy [8]. Over 99% of maternal deaths related to hypertensive disorders occur in low- and middle-income countries [30]. In Sweden, preeclampsia is also the most serious hypertensive disorder of pregnancy and affects 3–4% of pregnant women [13, 14]. According to the 2021 annual report from the pregnancy registry, the incidence of preeclampsia has increased from 3.0% in 2018 to 3.8% in 2021. This upward trend continued in 2022 with an incidence of 3.8%, reaching 4.0% in 2023 [31]. The global annual healthcare costs associated with preeclampsia are estimated to be 18–22 billion USD [32].



**Figure 1.** Preeclampsia and health problems from a global perspective (Hansson, S.R.)

## Etiology

Preeclampsia is regarded as a syndrome, and its exact cause is still not fully understood. However, inadequate placentation and/or placental dysfunction are recognized as central factors in its development. [33]. The two-step model of preeclampsia describes the disease in two phases. First, insufficient trophoblast invasion leads to poor blood flow and hypoxia in the placenta. This triggers systemic inflammatory and vascular responses in the mother, resulting in vascular endothelial damage, organ failure, and the clinical manifestations of preeclampsia. Early-onset preeclampsia (before gestational week (GW) 34) is often associated with placental insufficiency, intrauterine growth restriction, and a more severe course. Late-onset preeclampsia, which occurs after GW 34, is more common and typically has a milder course. It is less associated with placental insufficiency and is more closely related to the mother's constitutional risk factors.

Uneven blood perfusion results in oxidative stress and placental damage [2]. This causes leakage of fetal cells, placenta debris, and microparticles into the maternal circulation, which give rise to inflammation and general endothelium damage [34].

Endothelial damage is one of the underlying causes of organ dysfunction and contributes to the specific manifestations seen in the kidneys, liver, heart, lungs, clotting system, and brain [35]. In this context, it should be mentioned that 10–15% of patients

with eclampsia and 12–18% of those with HELLP syndrome have normal blood pressure upon arrival at the hospital [36]. With onset of preeclampsia before gestational week 32, IUGR is present in approximately 30% of the cases, while at onset after gestational week 32, the risk of IUGR drops to less than 9% [14].

During a normal pregnancy, the cardiovascular system is modulated from the beginning of pregnancy to ensure adequate blood supply to the fetus. Maternal blood volume gradually increases by approximately 40–50% between GW 5 and 16 [15]. By 24 GW, cardiac output increases by 45% compared to non-pregnant women, and blood volume rises to 140% by the time of delivery. This, along with a higher heart rate and greater stroke volume, results in increased cardiac output [15]. In normal pregnancies, blood pressure generally decreases during the early and mid-stages of pregnancy, reaching its lowest point between 18 and 20 GW and returning to pre-pregnancy levels by the third trimester [37–39]. These cardiovascular changes are usually benign and are typically fully restored within one year of delivery [40]. In preeclampsia, however, peripheral vascular resistance remains elevated, and a general endothelial damage contributes to generalized edema.

## Classification and risk factors

The classification of hypertension according to the Swedish guidelines is defined as a blood pressure of  $\geq 140$  and/or 90 mmHg. [14]. It is important to note that the definition of hypertension differs among societies. For instance, the American College of Cardiology/American Heart Association revised their hypertension threshold to 130/80 mmHg [41]. Preeclampsia is defined as hypertension after 20 weeks of gestation, in combination with either IUGR and/or maternal organ dysfunction [12]. Severe preeclampsia is characterized by hypertension of  $\geq 160/110$  mmHg, with organ engagement/clinical symptoms, and/or delivery due to preeclampsia before gestational week 34.

The risk of developing preeclampsia is greater in the first pregnancy (4%), and the risk of recurrence is 15% after one pregnancy complicated by preeclampsia, increasing to 32% after two such pregnancies [33]. Risk factors for preeclampsia are well-described and used as part of the risk assessment in the first trimester. There are several known risk factors for preeclampsia, grouped into two categories: high risk and moderate risk factors (Table 1) [15, 42]. Midwives at the MHC units screen all pregnant women during their antenatal care visits to identify those at high risk.

**Tabel 1. Risk factors for preeclampsia**

Clinical risk factors	
<b>High risk</b>	Autoimmune diseases, such as SLE or APS Previous preeclampsia or eclampsia Previous GH with delivery before GW34 or IUGR or IUFD or ablatio Diabetes type 1 or 2 Multiple births Renal disease, proteinuria at enrollment Chronic hypertension IVF with egg donation
<b>Moderate risk</b>	Nulliparity Heredity for preeclampsia Body mass index >30 Age >40 years Pregnancy interval >10 years SBP >130 or DBP >80 mmHg at enrollment African origin Verified obstructive sleep apnea "White coat hypertension" Previous gestational hypertension

SLE= systemic lupus erythematosus, APS=antiphospholipid syndrome, GH=gestational hypertension, IVF= in vitro fertilisation, SBP=systolic blood pressure, DBP=diastolic blood pressure

According to Swedish guidelines, early prophylaxis treatment with low-dose acetylsalicylic acid (ASA) is given to high-risk groups and to women with three or more moderate risk factors, starting in the first trimester [12]. A low dose, 75 mg of ASA, is prescribed from 12 GW until 36 GW [14]. Acetylsalicylic acid has been shown to reduce the incidence of preeclampsia by half when given to high-risk patients [43].

## Treatment for preeclampsia

Treatment for preeclampsia is largely symptomatic, with antihypertensive drugs to manage blood pressure, magnesium sulphate to prevent and treat eclampsia, and steroids for fetal lung maturation [12]. To date, the only "cure" is to terminate the pregnancy, either through induction of labor or by Caesarean section. This decision can be difficult, since it has consequences for both the mother and the child, particularly in pre-term situations. When a woman experiences a seizure, magnesium sulphate is given, and blood pressure is stabilized before an emergency Caesarean section is performed [14]. In these situations, the mother's life is prioritized over that of her unborn baby [15]. In cases of severe preeclampsia, magnesium sulphate is recommended as a prophylactic treatment to prevent seizures. It is the most effective medication for preventing further convulsions in patients with eclampsia [12].

International guidelines recommend the induction of delivery no later than 37 GW for women diagnosed with preeclampsia [8]. In severe preeclampsia, induction should be considered starting at 34 GW [13, 14].

## Preeclampsia – long-term health risks

### Cardiovascular disease, stroke, and diabetes

The impact of preeclampsia does not end when the woman gives birth. Preeclampsia is associated with an increased incidence of cardiovascular disease (CVD) (28), compared to women with normotensive pregnancies. It is well established that there is a relationship between preeclampsia and, both short- and long-term risk for CVD, especially a positive association between the severity of PE and the risk of CVD later in life [44]. Women with preeclampsia have up to a 4-fold increased risk of having heart attacks and are three times more likely to have a stroke within 10 years of delivery [45]. They also have an increased risk of developing hypertension at a younger age compared to women with normotensive pregnancies [46].

Patients with hypertensive disorders of pregnancy, particularly those with pre-existing chronic hypertension, face an increased risk of developing heart failure within the first five years after giving birth [47]. Women who give birth before 37 GW due to preeclampsia have an eight-fold higher risk of CVD related mortality compared to women with normotensive pregnancies who give birth after 37 GW [48]. Women who experience preeclampsia during their pregnancy also have a 20-fold greater risk of developing chronic hypertension compared to normal pregnancies [49]. Multiple risk factors for preeclampsia coincide with traditional risk factors for CVD, such as hypertension, diabetes mellitus, and metabolic syndrome. This indicates a shared pathological pathway between preeclampsia and CVD [50]. In a review evaluating women's knowledge about their healthcare, six out of seven studies indicated that women had limited or no awareness of the association between hypertensive disorders of pregnancy and CVD [51]. Preeclampsia also affects the babies. Neonates are more likely to be born with congenital heart disease and kidney disorders [52]. These children are at a greater risk of experiencing problems with blood pressure and related cardiovascular conditions throughout their lives, particularly if they were born with intrauterine growth restriction [52]. Studies also show that the sex of the unborn child can influence the risk and progression of preeclampsia. Women carrying male fetuses often have a slightly higher risk of developing preeclampsia, particularly severe forms, compared to those carrying female fetuses. This is believed to be due to differences in placental function, growth patterns, and genetic factors.

## **Cognitive impairment**

Women affected by preeclampsia and eclampsia are at an elevated risk of experiencing persistent cognitive dysfunction for several months or even years after pregnancy. Observational studies have demonstrated a correlation between previous eclampsia and preeclampsia, with scarring in the white matter and a decreased volume of the cerebral cortex several years after delivery [53]. Another study indicates that preeclampsia might be a risk marker for early cerebrovascular damage, [54] with a higher risk of developing vascular dementia [55] and Alzheimer's disease [56]. Some studies have indicated that women who experience preeclampsia show long-term cognitive decline compared to those with normotensive pregnancies[57]. Impaired memory and concentration difficulties have been reported to persist for up to 35–40 years after childbirth. Women who experienced preeclampsia along with complications such as pulmonary edema and/or eclampsia exhibited impaired cognitive function following the onset of the disease compared to women with normotensive pregnancies [53]. Among patients diagnosed with new-onset postpartum preeclampsia, 60% had never previously been diagnosed with hypertension and presented with severely elevated blood pressure and symptoms [58]. Consequently, individuals who are readmitted postpartum without a prior hypertension diagnosis face a higher risk of eclampsia, stroke, and severe maternal mortality [59].

Preeclampsia appears to lead to both acute and chronic cerebrovascular disease [21]. The exact mechanisms behind cerebral dysfunction in preeclampsia remain unclear, but current research suggests involvement of blood-brain barrier dysfunction, neuroinflammation, and cerebral edema [19, 20]. These symptoms are likely attributed to endothelial damage in the brain's blood vessels, leading to increased permeability and resulting in localized brain edema. Mild neurological effects may include concentration disorders, behavioral abnormalities, and minor visual impairments.

## **Postpartum mental health**

Postpartum depression is defined as a major depressive episode with onset usually within 4–6 weeks after childbirth, although it can occur later within the first-year postpartum. It is common and affects about 12% of healthy mothers with no previous history of depression [60]. Postpartum anxiety, however, is less studied and more common than depression immediately after birth, with symptoms typically decreasing within the first two weeks. Compared to healthy pregnant women, those with preeclampsia report higher levels of perceived stress and lower levels of social support [61]. They also describe being more negatively affected by their experiences [62, 63]. Women with hypertensive disorders of pregnancy are also at an increased risk of

developing postpartum depression, anxiety, and post-traumatic stress disorder [64]. There are also studies showing an association between preeclampsia, HELLP syndrome, and depression [65].

Postpartum depression may be the most frequently underdiagnosed and undertreated complication in obstetrics [66]. A recently published thesis revealed that women whose babies were admitted to the NICU had a threefold increased risk of developing symptoms of depression and/or anxiety. Furthermore, each 100gram decrease in birth weight was associated with a 5% increase in the risk of maternal postpartum depression and/anxiety [67].

The Diagnostic Statistical Manual (DSM-5) of mental disorders includes postnatal depression in the broader term perinatal depression, which encompasses both the prenatal and postnatal periods. In Sweden, the percentage of pregnant women who received treatment for prenatal mental illness in 2022 varied from 6.4 to 16% [68].

In fact, postnatal health challenges are faced by both birthing mothers and their partners (commonly fathers), where 5–10% are afflicted by depression and 5–15% by anxiety [69]. Several terms are used in the scientific literature regarding mental health challenges for fathers following the birth of their child. In the present dissertation, the term postpartum will be used in relation to conditions that afflict women, related to the pregnancy and birth. In all contexts and discussions that concern both birthing parents (women, who experience partum and postpartum) and non-birthing parent (most commonly fathers), the term *postnatal* will be used instead.

## The role of the midwife

Midwifery has a long tradition and is often said to be the oldest profession in the world. As early as 2500 BC, the midwife was described as a guide for women who give birth independently [70], which can be interpreted as embodying woman-centered care in today's modern society. There have been trained professional midwives in Sweden since the 18<sup>th</sup> century [24], and the Swedish Association of Midwives was formed in 1886. Today, Swedish midwives work within a broad spectrum of women's reproductive health care, supporting women throughout their life cycle– from young schoolgirls to aging women. In fact, the MHC was introduced in the 1950s, with the main purpose of identifying preeclampsia at an early stage [15]. The Swedish AHC provides screening for all pregnant women during the antenatal care program, with the midwife serving as the primary caregiver [71]. The evolution of midwifery in Sweden is regarded as a key factor in the country's low maternal mortality rates [72]. In normal pregnancies,

women typically do not see a doctor. Supporting midwifery has been recognized as a crucial element in reducing maternal and perinatal morbidity and mortality. Today, the AHC program does not routinely screen for depression during pregnancy, and about 50–90% of women are offered postpartum screening, depending on which part of the country they live [73].

Thus, in Sweden, midwives independently handle normal pregnancies within the fields of reproductive, perinatal and sexual health, using an ethical and holistic approach based on science and proven experience [74]. However, the concept of 'normal' poses some problems, since what is considered normal can vary over time and between cultures. Two generations ago, normal childbirth in Sweden looked very different from today. From a global perspective, home births are often the norm, whereas in Sweden, hospital births are recommended [75]. That being said, the number of pregnancies and births involving women with pre-existing health conditions or those labeled as 'high-risk' at some point during pregnancy is on the rise [76]. If complications arise during childbirth, e.g., profuse bleeding, cardiotocography changes, prematurity, or high blood pressure, these situations are always handled together with a specialist in obstetrics and gynecology. Complex pregnancies and childbirths are managed through a collaborative, non-hierarchical hub-and-spoke system, where midwives, obstetricians, and other medical professionals work closely together at all levels of care. This cooperative approach is thought to be a key factor in Sweden's low maternal and neonatal morbidity and mortality rates [77]. From this perspective, it is best to have joint responsibility for women at risk of developing pregnancy hypertension and related complications [13, 14].

## **Screening for preeclampsia**

As previously mentioned, midwives play a central role in providing antenatal care. Currently, there are no standardized examinations or laboratory tests available to identify women at an early stage who are at an increased risk of developing preeclampsia. Instead, a sophisticated algorithm, known as the FMF model, has been described as a valuable tool for early risk detection of preeclampsia [78]. This model incorporates maternal risk factors, mean arterial pressure, the pulsatility index of the uterine artery, and the biomarker placental growth factor. However, this algorithm is complex and not widely available, presenting a challenge for obstetricians and midwives in identifying high-risk pregnancies and initiating prophylactic treatment with ASA early in pregnancy. Consequently, there is a pressing need for a cost-effective and easily accessible test to predict preeclampsia, enabling the earlier identification of at-risk women before the clinical onset of the condition.





Control of blood pressure at the MHC© Artwork by midwife Gabriella Aichholzer Hedström

## Blood pressure measurements

The accuracy of blood pressure measurements, especially during pregnancy, is well established, with the sphygmomanometer being the recommended method. Before the assessment, the patient should avoid smoking for at least 30 minutes and remain seated in a relaxed state. Measurement should be performed after 5 minutes of sitting silently, using the correct size of the cuff. If the patient's upper arm circumference is 33 cm or greater, a larger blood pressure cuff should be used. The right arm should be at the level of the right atrium, legs uncrossed, and the woman's back fully supported [12, 36]. Blood pressure should be measured at every prenatal care visit throughout pregnancy [25], and validated blood pressure cuffs should be used to ensure accuracy.

## Woman-centered care in midwifery

Midwifery care prioritizes the needs, preferences, and well-being of women throughout pregnancy, childbirth, and the postpartum period [79]. Women-centered midwifery care focuses on the individual woman's needs, autonomy, and right to choose, control, and continuity of care from a familiar midwife. This approach considers each woman's unique circumstances and health status, ensuring that the whole person, not just clinical symptoms, is addressed.

However, midwives often report challenges in providing woman-centered care, especially within medically led care models and complicated pregnancies. This is particularly crucial for women with preeclampsia, who are vulnerable and whose psychosocial needs may be overlooked [80, 81]. The International Confederation of Midwives (ICM) supports a philosophy of partnership, cultural sensitivity, and self-care for women, while also advocating for self-determination [82]. Midwives' professionalism is essential for delivering high-quality, women-centered care, as outlined in Swedish midwifery standards [83]. However, a gap often exists in the care of women with preeclampsia, where medical concerns dominate, and the woman's emotional needs are under-addressed. To improve care, a more holistic approach is needed one that integrates both medical and emotional aspects, ensuring that women with preeclampsia are supported not only in their physical health but also in their psychosocial well-being. This requires greater involvement of women in their care decisions and a stronger focus on addressing their emotional needs.

## Theoretical framework in midwifery

Women-centered care is a central concept for midwifery [84]. However, theoretical frameworks are not as obvious and not used in midwifery care, especially in the context of high-risk pregnancies. In different countries and care settings, various theoretical models have emerged concerning midwifery care. In the Nordic context, one notable model that has been developed to enhance midwifery care is the primacy of the good midwife in midwifery services: an evolving theory of professionalism in midwifery [83]. This theoretical framework describes the midwife's professional competence, including both professional and individualized care, as well as the midwife's wisdom, interpersonal competence, and personal development. What is required of the midwife is an ability to establish a professional relationship with the woman while putting herself in the woman's situation, to be able to treat her with respect, and provide care tailored to her individual needs. The framework also assumes that the midwife will be faced with various tasks in their professional practice. These must be combined with the experience and knowledge of the midwife to create a good relationship in the meeting with the woman. With this approach, women feel well cared for, and communication between the midwife and the woman improves, ensuring a supportive and trusting relationship [83].

Another relevant theoretical framework, even though it dates to the 1980s, is Jean Ball's care model. Jean Ball, an English midwife, developed this model, which remains highly applicable today. This theory emphasizes the social context of a woman's life during her transition to motherhood. Known as the "deck-chair theory" of maternal emotional

well-being, Ball identifies pregnancy and the postpartum period as critical times for adapting to the new role of motherhood. The primary objective of maternity care, according to this model, is to facilitate a woman's successful transition to motherhood, encompassing physiological, psychological, and emotional aspects. Maternal well-being is influenced by factors such as personality, previous experiences, and life crises. These elements intersect with the care provided by midwives and other healthcare professionals, societal attitudes and resources, and support from families [85].

This two-care model can serve as an excellent tool for facilitating effective communication and support, particularly with women who have preeclampsia. By considering the social context of a woman's life and emphasizing the holistic nature of care, this framework can help midwives in engaging with patients in a supportive and understanding manner. It ensures that both the physical and psychological needs are addressed, fostering a holistic approach to their well-being.

## The patient's perspective

Despite being one of the most severe obstetrical complications, there is a notable scarcity of research describing women's experiences with preeclampsia. In the few qualitative studies that have been published, women frequently characterize preeclampsia as a terrifying and life-threatening condition, marked by insufficient care and inadequate psychosocial support. These experiences often clash with their expectations of pregnancy and childbirth [6, 86]. Furthermore, there is limited understanding of women's and families' needs [4, 5], the support required during hospital stays [6], and access to information [5]. These studies highlight an unmet need for information and understanding about preeclampsia. A feeling of not being seen or heard during childbirth contributed to a negative experience [87]. Research has also shown that many women are unaware of their heightened risk [51, 88]. A recently published study examined patients' awareness of future cardiovascular risks following preeclampsia or gestational hypertension. The study revealed that women who were informed about their heightened risk demonstrated greater adherence to both antihypertensive treatment and follow-up visits [89]. All interventions introduced during labor and birth, therefore, need to be evaluated from the woman's perspective [90]. By understanding and prioritizing patients' perspectives, midwives and other healthcare providers can better adapt treatment plans and interventions. This increases the chances that treatment will be accepted and followed, which can improve outcomes for both mother and child. In addition, preeclampsia can be a stressful and anxiety-filled experience [91].

## **Separation from the newborn baby**

Even the experience of being separated from her newborn child, when the mother suffers from preeclampsia, remains largely unexplored. There is a discrepancy between the most recent evidence-based understanding of zero separation and current practices in newborn care [92]. Research shows that the separation of a mother and her child can have several negative effects. For mothers, these include an increased risk of depression, a sense of loss of control, and challenges with breastfeeding. For newborns, the impacts may involve heightened stress levels, impaired neurological development, and difficulties in forming secure attachment bonds. Ensuring that mothers and newborns remain together is recognized as a safe and beneficial practice for fostering healthy birth outcomes [93]. Despite this understanding, the separation of neonates and mothers is a common occurrence as a result of neonatal care needs or poor maternal health postpartum. This separation entails a further risk of negative impact on the early relational development and has been described as particularly traumatic for mothers. These challenges reveal further unmet needs during the postpartum period. For mothers of premature infants, being seriously ill while navigating both physical and psychological suffering adds complexity to their responsibility to care for their beloved infants [7]. The experience of having a newborn in the neonatal intensive care unit (NICU) was characterized as a transition from fear to hope, as the newborn's life is sustained outside the womb [63]. However, the separation of the mother and the newborn, especially when one or both require specialized care, remains a significant challenge [64].

## **Partner's perspective**

The experiences of partners of birthing women are even less explored. Having a partner diagnosed with preeclampsia often places them in an unexpected and unfamiliar situation, leaving them emotionally stretched and in need of time to process and heal [94]. Partners of women who undergo a complicated pregnancy and childbirth are more likely to encounter mental health challenges compared to partners of women with uncomplicated pregnancies/births. These challenges occur at a time when they are also expected to provide support and care for their birthing partners [95]. The experience for partners is marked by a shared focus on supporting their partner through the condition. Many partners express a strong desire to participate actively in the care process but indicate that they would appreciate more direct invitations and information about the situation [96]. These findings underscore the importance of providing professional support tailored to the partners of women affected by preeclampsia in order to aid in their transition to parenthood [94].

## **Parenthood**

The consequences of mental health problems in the postnatal period extend beyond the affected parent. They potentially have negative consequences not only for the parent-child relationship and the child's well-being but also for the entire parenting system and family dynamics [97, 98]. During the past two decades, there has been increasing evidence of the multiple ways in which parents influence each other's thoughts, feelings, and behaviors related to parenting [99-101]. The adjustment of co-parents when the family faces difficulties, as well as their mental health during the postpartum period, is closely interconnected [102, 103]. Research indicates that each parent's mental health difficulties have a unique and significant negative impact on a child's development [104-106]. Such challenges often compromise parenting behaviors [107, 108].

## **Informed consent**

The right to give consent for care during childbirth and access to information are fundamental rights for women during pregnancy and childbirth [109]. Care should be designed and delivered, as much as possible, in consultation with the patient. The Swedish Patient Act [110] stipulates that, as a fundamental principle, healthcare should not be administered without the patient's consent. Central to this principle is the respect for the patient's autonomy, dignity, and active involvement in healthcare decisions [110]. Being actively engaged in the decision-making process during labor and childbirth has been shown to have a more profound effect on women's childbirth experiences compared to factors such as labor pain and medical interventions [111-113]. Several studies have linked a lack of participation in decision-making to negative or even traumatic birth experiences [87, 114]. In light of this evidence, there has been increasing attention over the past decade to childbirth situations characterized by a lack of informed consent and a disregard for women's autonomy [115, 116]. Informed consent entails women making decisions based on clear and accurate information provided by their caregivers. Conversely, shared decision-making involves both the caregiver and the patient collaboratively assessing the best available evidence to make informed decisions together. This approach supports the patient in considering various options and fosters a sense of partnership and trust in the decision-making process [117].

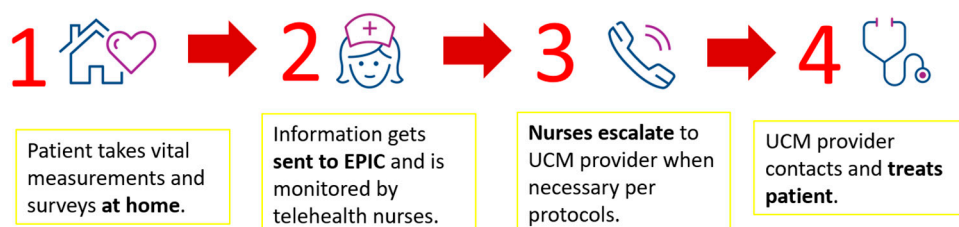
## Postpartum follow-up care

Postpartum care represents a critical phase in the continuum of maternal health care, demanding heightened attention. The healthcare system must enhance its efforts to provide early and comprehensive follow-up care postpartum, addressing various aspects such as breastfeeding support, blood pressure control, and both physical and mental well-being [68]. According to the latest Swedish guidelines, AHCs are mandated to ensure that women receive prompt follow-up care within the first one to two weeks after leaving the maternity ward, with multiple visits scheduled if needed [12]. Subsequently, the standard postpartum care visits should occur between 6 to 16 weeks after birth [13]. However, according to the patient association for preeclampsia, these guidelines are not always followed [118]. Many women also feel that it is unclear where they should seek care and support after giving birth [68].

A possible improvement to postpartum care could involve adapting a model introduced in Chicago, the STAMPP-HTN, Systematic Treatment and Management of Postpartum Hypertension [119]. All pregnant women with high blood pressure are referred to a cardiologist, who specializes in the care of pregnant women. In this program, each woman receives a free blood pressure cuff that is connected to her smartphone. In addition, women are given a purple bracelet, which gives them free passage to the maternity ward six weeks postpartum. The women take their blood pressure at home daily, and the data is automatically entered into their medical journal. In the event of high blood pressure readings, the chain of events, as described in the four steps shown in Figure 2, is activated.



## STAMPP-HTN : RPM Workflow



**Figure 2.** STAMPP smartphone application, bracelet, and flowchart

Currently, there is no preventive treatment to reduce the long-term increased risk of CVD and stroke in women who have experienced preeclampsia during pregnancy. Therefore, it is especially important that information is shared regarding lifestyle factors and emphasize the importance of annual blood pressure check-ups. All women who experience hypertension during pregnancy and/or at childbirth must receive oral and written information about their condition [12]. They must also be informed about recognizing symptoms of preeclampsia and eclampsia and instructions to contact the maternity ward without delay if symptoms arise. For women discharged with ongoing antihypertensive medication, a return visit to the specialist MHC doctor should be scheduled within two weeks. According to the new Swedish guidelines, women with new-onset hypertension or preeclampsia must have a follow-up visit with the midwife 8–10 weeks postpartum [13, 14]. However, data from 2022 indicates that the percentage of women who came to follow-up visits at MHC 4–16 weeks after childbirth varied from 75 percent to 96 percent. Moreover, women born outside the Nordic countries came to these visits less often [68].

A recently published study revealed that among women without any pregnancy complications, approximately 2% exhibited narrowing of the heart's coronary arteries [120]. In contrast, among women with a history of preeclampsia or gestational hypertension, the corresponding figure was approximately 5%. To mitigate the long-term risk of developing CVD, it is crucial for these women to regularly monitor key risk factors, such as blood pressure, blood sugar levels, and cholesterol.

Breastfeeding has positive long-term effects on women by reducing the risk of developing metabolic syndrome [121]. In postmenopausal women, a longer duration of lactation is linked to a lower occurrence of hypertension, diabetes, high cholesterol, and CVD [122]. In a recently published review and meta-analysis, the results showed that breastfeeding is linked to a reduced maternal risk of CVD outcomes [123]. An important role of the midwife is to encourage breastfeeding and, if necessary, provide breastfeeding advice and support.

Women diagnosed with severe preeclampsia require time to recover from the trauma before they can make lifestyle changes. Motivation for these changes during pregnancy is connected to obtaining early information and witnessing concrete results [124].

## Preeclampsia patient associations

Since 2000, the Preeclampsia Foundation in the United States has been dedicated to advocating for increased awareness and attention to preeclampsia within broader maternal health initiatives. The Foundation aims to identify and support improvements in healthcare across all settings while also promoting the empowerment and engagement of women through effective preeclampsia education [125]. Action on Preeclampsia (APEC) was established in the United Kingdom in 1991, with key aims to raise public and professional awareness of preeclampsia, enhance care, and alleviate or prevent the physical and emotional suffering caused by the disease [126].





Until spring 2021, there was no organization like this in Sweden. The Swedish patient association for preeclampsia, *Preeklampsiföreningen*, (Appendix C), was established in 2021 by a group of women who had experienced preeclampsia, eclampsia, and/ or HELLP syndrome, with support from the Working and Reference Group, Preeclampsia-ARG, a part of the Swedish Association for Obstetrics and Gynaecology (SFOG). Over the past three years, the association has collected and published patient stories on its website, organized digital meetings for women to share their experiences, and maintained a presence on social media such as Facebook and Instagram. The association has also delivered lectures on its work and the patient perspective in various healthcare educational settings. The primary purpose of the patient association is to provide support and advocate for the interests of women who have experienced preeclampsia, as well as for their partners, relatives, and children. Additionally, the association endeavors to raise awareness and educate the public, healthcare providers, institutions, and authorities about preeclampsia and the experiences of patients, with the ultimate goal of enhancing care for those affected [127].

Preeclampsia-ARG strongly encourages midwives and other healthcare professionals to inform women about the Swedish patient association platform. Their website provides a straightforward description of preeclampsia, along with information on available resources and opportunities to connect with others facing similar challenges. Additionally, the association aims to advocate for improved care by submitting comments on proposed enhancements to the social management board. Below are some of their suggestions.

*“A woman diagnosed with preeclampsia, deemed to be at high risk, should be assigned a designated patient-responsible physician (PAL) or a contact midwife at the specialized maternity care unit. This practice aims to address issues related to the lack of continuity in care.”*

*“The starting point should always be joint care - caring for the family together. The care must be organized in a way that considers the needs of the mother, the child, and the other parent. Good communication about the state of health should be maintained between the departments, especially in cases where the family is separated.”*

*“When women who have just given birth are cared for in the intensive care unit, differences need to be considered. The woman may be more awake than other patients but still needs peace and quiet. As a new mother who has recently been delivered, the midwifery skills must also be included during the intensive care period. This should deal with questions such as breastfeeding, abdominal discomfort after childbirth, and other aspects of the postpartum period. Care should enable and facilitate breastfeeding and respect the woman's wishes.”*

*“Postpartum care needs to be strengthened, and there is a need for good and adapted information, both written and oral, for the women and their relatives. Referral management for follow-up should be reviewed and improved and, in addition, better knowledge and resources are needed in primary care.”*

The association has identified several issues with the current follow-up care system, which fails in one or more of the following areas: women are not informed about their increased risks, referrals to other healthcare providers are not made, and there is insufficient and inconsistent knowledge in primary care. The association frequently receives questions about what follow-up should entail and the health risks associated with preeclampsia, indicating that the current information and follow-up care are inadequate or not effectively communicated. Please feel free to read more about the association's work and patients' experiences with preeclampsia on the patient association's website ([www.preeklampsi.se](http://www.preeklampsi.se)).

# Rationale

When this research project was initiated, the patient perspective was largely unexplored and limited, and the experiences of women were rarely investigated. Antenatal care has been the most crucial factor in reducing maternal mortality in modern times. However, there is a lack of scientific evidence regarding women's experiences. Investigating the experiences of women diagnosed with preeclampsia from their perspective could provide valuable insights, especially given the limited research in this field.

Evidence-based research on health risks for women has continually been advancing, as has research at the cellular level exploring biomarkers, new mechanisms, and pharmaceuticals.

Swedish maternity care faces challenges in identifying preeclampsia early on and in providing prophylactic treatment, which is necessary for improving outcomes during and after pregnancy for high-risk pregnancies. Previous studies have indicated that preeclampsia increases the risk of mental health issues during the postpartum period. Identifying ways to predict anxiety and/or depression in women with a history of preeclampsia, as well as in their partners, could significantly enhance their quality of life. The results in this thesis can be used to improve healthcare for women who develop hypertensive diseases during pregnancy. These results can provide women, their partners, relatives, and healthcare personnel with new evidence and information, ultimately leading to improved care and, most importantly, better patient experiences in cases of complicated pregnancies.

# Aims

## Overall aim

The overall aim of this thesis was to enhance the understanding of women's experiences with preeclampsia in order to improve clinical care, support, and mental health outcomes. This includes assessing the quality of care and information provided, examining the emotional and psychological effects of preeclampsia on both women and their partners during the postpartum period, as well as evaluating the accuracy of an innovative home blood pressure monitoring mobile phone application during pregnancy.

## Specific aims

**Study I:** To describe women's experiences with preeclampsia in order to improve the support and care provided during and after pregnancy.

**Study II:** To explore women's experience during pregnancy and the postpartum period related to the information and care they received concerning preeclampsia.

**Study III:** To investigate postnatal symptoms of depression and anxiety, and associations with perceived coparenting quality, in women who experienced preeclampsia and their partners.

**Study IV:** To evaluate the reliability and accuracy of the mobile phone application, Anura™ for blood pressure measurement in normotensive pregnancies, high-risk pregnancies, and women diagnosed with preeclampsia, compared to manual cuff measurements. Additionally, the study evaluates women experience using the Anura™ application.

# Material and methods

## Methods used in the thesis

### Overview of the studies

The thesis applies both quantitative and qualitative approaches. This section provides an overview of the methodologies used, summarized in Table 2. *Study I* is a qualitative interview study using a descriptive phenomenological method consisting of a five-step structure. *Study II* is a qualitative interview study using descriptive manifest content analysis. *Study III* is a prospective longitudinal self-report study using questionnaires administered at two and six months postnatal. *Study IV* is a prospective longitudinal study involving blood pressure and questionnaires.

**Table 2. Overview of the different studies included in this thesis**

Study	Design	Data collection	Included participants	Data analysis
I	Qualitative Descriptive Research Design	Individual open interviews	Women with preeclampsia n=9	Descriptive phenomenology according to Amedeo Giorgi
II	Qualitative Descriptive Research Design	Individual Semi-structured Interviews	Women with preeclampsia n=15	Manifest content analysis based on Graneheim and Lundman
III	Prospective Self-report Study Design	Questionnaires	N=50 participants. Women with preeclampsia n=37 and their partners n=13, 12 couples	Descriptive and comparative statistics, mixed linear models analysis
IV	Prospective Longitudinal Study Design	Blood pressure measurements comparing manual and TOI technology, questionnaires	Normotensive pregnant women n=132, Women with high-risk pregnancies n=40, Women with preeclampsia n=98	Descriptive and comparative statistics

## Qualitative methods

Qualitative research methods can deepen our understanding of medicine. Rather than seeing qualitative and quantitative approaches as incompatible, they should be viewed as complementary [128]. The research process should follow methodological principles that promote transparency, question existing assumptions, and adopt a reflective approach [129]. Interviews serve as an effective method for gathering detailed, in-depth data. Qualitative descriptive methods are particularly valuable when exploring new research areas, as they aim to describe and understand individuals' experiences of various phenomena without preconceived notions, employing an open-minded approach [130, 131]. In qualitative studies, four criteria are used to ensure good reliability: credibility, transferability, dependability, and confirmability [132]. Reliability refers to the consistency of the results and whether the same outcomes can be achieved when the study is conducted by different researchers at different times [133]. Descriptive methodology entails the researcher maintaining proximity to the raw data and refraining from extensive interpretation. Qualitative research focuses on understanding social reality. This approach posits that social reality is a fluid concept, shaped by an individual's own constructed and creative abilities [132]. These aspects are further elaborated in the methodological considerations section.

Given our focus on patients' experiences and the relatively under-explored nature of the topic, we opted to conduct in-depth interviews in *Study I* using a phenomenological descriptive approach, according to Amedeo Giorgi [134]. Giorgi's humanistic method has its foundation in Husserl's phenomenological philosophy [135]. The term phenomenology comes from the Greek word *phainomenon*, which means "that which appears," referring to how things appear to us in our consciousness [136]. Phenomenology aims to describe the world and our experience of it as it appears, before all theories or criticisms [130]. During the interviews, the objective was to gather data that provided a diverse and comprehensive description of the phenomenon. The richness and variety of the descriptions ultimately contributed to a more robust outcome. Women were encouraged to share their experiences of preeclampsia as freely as possible, allowing them to recount how they personally navigated the phenomenon. To minimize bias from our own assumptions, the interviewer asked as few questions as possible [137]. The interviews were conducted until no new information emerged from the participating women, at which point saturation was reached [138]. The fact that interviews were conducted until saturation was achieved is important because it ensures that the study captures a broad and representative picture of the participants' experiences, without missing important themes or perspectives.

In *Study II*, we employed a qualitative approach, utilizing a descriptive research design with manifest content analysis based on Graneheim and Lundman's methodology

[139]. Content analysis is a versatile method that can be utilized in various ways and to different types of data. This approach can be employed to examine written text, with the goal of achieving a concise and comprehensive description of the phenomenon under investigation. It is connected to hermeneutics, the oldest tradition in text analysis. Scholars have suggested that a hermeneutical approach is essential when analyzing text, as it emphasizes that understanding a text goes beyond merely counting its elements, a technique often used in quantitative content analysis [136]. In this study, we wanted to gain a deeper understanding and knowledge of the information the women received about preeclampsia during pregnancy, their hospitalization, and the postpartum period. During the interviews, the aim was to encourage the women to reflect on their experiences.

## Quantitative methods

Using questionnaires to collect information is one of the more common methods in research. Surveys are an effective tool for collecting data from large populations. A response rate of approximating 60% should be the goal for most research [140], while others state that for online surveys where there is no previous relationship with the recipients, a response rate of 30% is often considered acceptable. Unfortunately, response rates have been falling across the Western world, according to Statistics Sweden. A study shows that using surveys instead of interviews can increase the reporting of sensitive data, resulting in more accurate measurements when validated against other data sources [141]. Quantitative research mainly focuses on measurement, causality, generalization, and replication. Measurements involve quantifying or qualitatively assessing properties or behaviors to collect data. Causality refers to establishing cause-and-effect relationships between variables. Generalization means applying results from a sample to a larger population, and replication involves repeating a study to verify the results [132].

Stress, depression, and anxiety in preeclampsia are crucial to address, as these mental health conditions not only affect the mother's well-being but can also have long-term consequences for her, her partner's health, as well as the child's development and overall well-being. To better understand the impact of preeclampsia on the mental health of both women and their partners, as well as its effects on their parenting, we designed *Study III* as a prospective longitudinal self-report study. Questionnaires were administered at 2 and 6 months postnatal to women who experienced preeclampsia. Their partners were also invited to participate to provide a comprehensive view of both maternal and paternal mental health, along with their thoughts and feelings on parenting. This study is part of a larger longitudinal project that will follow these

women and couples up to 12 months postnatal, with additional findings to be shared in future publications.

*Study IV* is a quantitative, prospective longitudinal study that tracked the same group of participants over time, collecting numerical blood pressure data at multiple intervals to observe changes, trends, and relationships. This study employed blood pressure measurements using both traditional blood pressure cuffs in the arm and the TOI technology [142, 143] via the Anura™ mobile phone application, along with questionnaires. The primary objectives were to assess the accuracy of Anura™ blood pressure measurements in normotensive pregnant women, high-risk pregnancies, and women diagnosed with preeclampsia, compared to standard manual cuff measurements. Additionally, we evaluated the women's experiences using the smartphone application to potentially improve future care during pregnancy. The decision to focus on these objectives was informed by insights gathered during interviews conducted in *Studies I* and *II*, leading to a critical question: How can we help women better understand the risks associated with high blood pressure and preeclampsia during pregnancy, and how can they easily monitor these risks themselves?

*Study IV* shifted the focus from women's experiences to evaluating the reliability and accuracy of a smartphone application for blood pressure measurement during pregnancy, allowing for home blood pressure monitoring and increasing women's involvement in their health. The accuracy of the Anura™ application was compared across three groups: women with normotensive pregnancies, those with high-risk pregnancies, and those diagnosed with preeclampsia. Additionally, participants completed a digital questionnaire within the application, providing feedback on their experiences using Anura™ as well as reporting their psychological well-being at 8-12 weeks, 20 weeks, and 37 weeks gestation.



# Study design and data collection

## Study setting

The four studies originate from separate study populations, with some overlap between *Studies III* and *IV* (n=23). While all four studies are independent, *Studies I* and *II* share the same ethics approval, whereas *Studies III* and *IV* have their own separate ethical approvals.

## Study I:

### *Design and data collection*

Recruitment and data collection took place from January to March 2019 at two different university hospitals in southern Sweden during the women's postpartum stay. The first and second authors of the study identified, informed, and invited women to participate. The women who were included received both oral and written information about the study and provided their signed consent. The inclusion criteria were diagnosed with preeclampsia, delivered within the past 5 days, age over 18 years, and proficiency in understanding and speaking Swedish. Exclusion criteria included other pregnancy complications and infant death. A total of nine (Table 3) newly delivered women, aged from 25 to 41 years, were included in the study.

The interviews were performed by the first author in a private room at the maternity unit or in a private part of the NICU. All the women were asked an opening question: - "Would you like to tell me about your experiences of living with preeclampsia?" In some cases, clarifying follow-up questions were posed, such as: "Can you tell me more about how you were feeling? Can you say something more about that?" The interviews ranged from 25–60 minutes and were recorded and transcribed verbatim. Typically, for these types of studies, three in-depth interviews are sufficient to achieve results that can be generalized, but additional interviews may be conducted if deemed necessary [144]. In our study, some interviews were quite brief, so we included more women to gain a deeper understanding of the phenomenon.

**Table 3. Characteristics of women in study I (n=9)**

Characteristics	n (%)
Age (years), mean $\pm$ SD	30.4 $\pm$ 10.6
BMI, mean $\pm$ SD	25.8 $\pm$ 6.8
Primigravity	2 (22%)
Medical condition:	
<i>Family high blood pressure</i>	3 (33%)
<i>IVF</i>	2 (22%)
<i>Asthma</i>	2 (22%)
<i>Depression</i>	1 (11%)
<i>DVT, APC resistance</i>	2 (22%)
Gestational age:	
<i>Preterm birth (&lt;37 weeks)</i>	4 (31+0 – 36+0)
<i>Term birth (&gt;37 weeks)</i>	5 (37+1 – 38+3)
Mode of delivery:	
<i>Vaginal</i>	2 (22%)
<i>Cesarean section</i>	7 (77%)
Gestational Weight:	1500 – 3115g (mean 2060g)
Newborn in NICU:	5 (56%)
Days in hospital care:	
<i>Antenatal</i>	1 – 14 days
<i>Postpartum</i>	3 – 7 days

BMI= body mass index, DVT= Deep Vein Thombosis, NICU=Neonatal Intensive Care Unit, IVF= In Vitro Fertilization, APC=Activated Protein C Resistance

## Study II

### *Design and data collection*

In this study, women were recruited consecutively between July and December 2019 from two maternity units in southern Sweden. The inclusion criteria were primiparous women diagnosed with preeclampsia and multiparous women diagnosed with preeclampsia but with no history of the condition in a previous pregnancy. The first author visited or contacted the hospitals daily to identify potential participants. Eligible women were approached either at the MHC unit or the NICU. The interviews were conducted 1–6 weeks postpartum at a mutually agreed location, such as the participants' private homes or a separate room at the hospital. The interview guide (Box 1) was developed based on clinical experience and validated after a pilot interview, which revealed no need for modifications [139, 145]. Semi-structured, face-to-face

interviews were conducted utilizing open-ended questions to enable women to freely discuss the information and care they received regarding preeclampsia during their pregnancy, at the time of diagnosis, and postpartum. Follow-up questions were used to delve deeper into the women's experiences and to gain a comprehensive understanding. Interviews continued until no new information was obtained from the participants, indicating that data saturation had been reached [138]. Each interview lasted an average of 25–50 minutes. All interviews were audio-recorded and transcribed verbatim by the first author [145].

#### Box 1. Interview guide

Engagement question
Can you tell us what information you received at the maternal healthcare when you were informed that you had preeclampsia? Additionally, what information did you receive during the rest of your pregnancy and before being discharged from the hospital?
<i>Subsequent questions</i>
When did you first realize you had preeclampsia?
What did you know about preeclampsia before your pregnancy?
How did you receive information about preeclampsia, and what was your experience with the process of obtaining that information?
What challenges did you face in connection with receiving information? When and how often do you think would be best to receive such information?
What were your information needs, and to what extent were they met?
Can you describe any difficulties you experienced when receiving the information?
If you could change something about the information or the way it was provided, what would you change?
<i>Exit question</i>
Is there anything additional you would like to say about the information and care you received regarding preeclampsia?
<i>Probes in order to minimize misunderstandings</i>
Could you please elaborate on that?
Can you give an example of what you mean?
Is there anything else you would like to add about that?

## Study III

### *Design and participants*

This study is part of a longitudinal project following women diagnosed with preeclampsia and their partners from childbirth up to 12 months postpartum. The project includes four measurement points: at inclusion (T0), and at two (T1), six (T2), and twelve (T3) months postnatal.

### *Data collection*

The study took place at two different university hospitals in southern Sweden. The inclusion criteria were women diagnosed with preeclampsia, 18 years of age or older, and proficient in Swedish. Partners were encouraged to participate if they were 18 years or older and understood Swedish. For data collection, participants reported their experiences with mental health and the quality of co-parenting collaboration and interaction, through self-reported instruments presented in a digital survey distributed individually using the digital platform RedCap (Table 4). All women and their partners were recruited at the hospital by the thesis author. Socio-demographic background information was collected through surveys administered at 2 months postnatal. Medical data were obtained from participants' medical records using the Obstetrix system after childbirth. Measurements addressing depression and anxiety, collaboration in co-parenting at two and six months postnatal were evaluated using validated survey questionnaires.

To assess mental health, we utilized the Edinburgh Postnatal Depression Scale (EPDS) and the Gotland Male Depression Scale (GMDS), along with the Perinatal Anxiety Screening Scale (PASS). We also assessed the quality of the co-parenting relationship, i.e., the relationship between the child's two parents specifically regarding parenting responsibilities, with the Co-parenting Relationship Scale (CRS). The longitudinal project includes additional measures. However, the results from these measures, as well as the data collected at 12 months postnatal, are not part of this study and will be reported in a future publication.

**Table 4. Time-points for inclusion for study III**

Time-points	Background information	EDPS	GMDS	PASS	CRS
At inclusion (T0)	X				
2 months postnatal (T1)		X	X	X	X
6 months postnatal (T2)		X	X	X	X

EDPS= Edinburgh Postnatal Depression Scale, GMDS= Gotland Male Depression Scale, PASS= Perinatal Anxiety Screening Scale, CRS= Co-parenting Relationship Scale

### Edinburgh Postnatal Depression Scale (EPDS)

The EPDS is a screening tool used to detect symptoms of depression in women postpartum, but it can also be used during pregnancy [146], through a self-report form that evaluates ten typical symptoms of depression such as sadness, social withdrawal, chronic fatigue, sleep difficulties, or self-injurious behaviour. The time frame refers to the past seven days. In Sweden, a cut-off score of  $\geq 12$  is recommended for screening major depression in mothers [147] and partners [69]. We also used a cut-off score of  $\geq 9$  as indicative of minor depression, consistent with other studies focusing on postnatal depression in men [69, 103, 148].

### Gotland Male Depression Scale (GMDS)

The GMDS is a tool specifically developed to identify and measure depression in men, as men often show different symptoms of depression than women. It is important to assess atypical depression symptoms in both men and women because these symptoms may differ from typical depression symptoms and therefore risk being overlooked during diagnosis and treatment [97, 98, 103, 149]. The scale measures thirteen atypical depression symptoms such as irritability, low stress tolerance and impulse control, frequent anger outbreaks, extreme and risky behaviours, and bodily symptoms. A score  $\geq 13$  indicates significant depression symptoms and is used as the cut-off [150, 151].

### Perinatal Anxiety Screening Scale (PASS)

The PASS is a tool used to identify and measure anxiety during pregnancy and the postpartum period [152]. The cut-off scale is specifically designed to capture different types of anxiety that may be specific to this period, and it is broader than traditional anxiety scales that often do not consider the unique circumstances of pregnancy and new parenthood. A total score of  $\geq 26$  indicates a high likelihood of perinatal anxiety at clinical levels [152, 153]. It measures concerns such as worry or anxiety about everyday problems, calmness about the pregnancy, the ability to care for the child, feelings of anxiety, and obsessive thoughts.

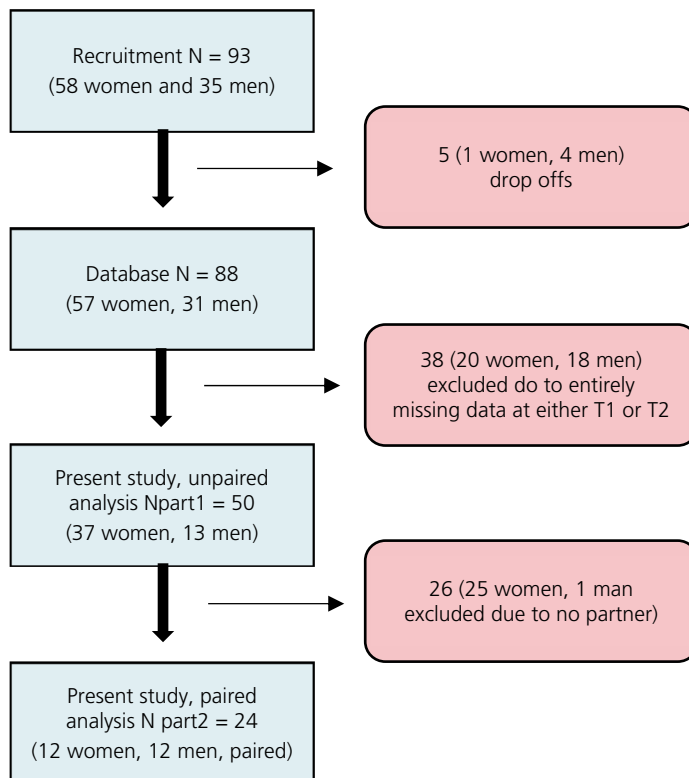
### Co-parenting Relationship Scale (CRS)

The CRS is a tool used to measure the quality of interaction and collaboration between parents in their shared parenting [154, 155]. It assesses several aspects of their relationship that influence both parenting practices and the child's well-being. The CRS [154] is a 35-item self-report questionnaire assessing co-parent communication and behaviors in specific situations. Based on the Swedish validation of the CRS [155], subscale scores were calculated. Subscale 'Support and Closeness' reflects the degree of closeness and support between parents in their shared parenting. It measures how much parents feel they support and remain close to each other in their parenting roles.

‘Endorsement’ measures the extent to which one parent expresses appreciation or approval of the other parent’s approach to parenting. It involves acknowledging and affirming each other’s parenting responsibilities and efforts. ‘Disagreement’ reflects the occurrence and frequency of disagreements between parents on matters related to the child’s care. It also evaluates how these disagreements affect their relationship. These subscales provide valuable insights into different aspects of cooperation and the relationship between parents, serving as important indicators of whether the interaction is harmonious or conflictual.

### *Recruitment and Participants*

A total of  $n = 93$  (58 women, 35 men) consented to participate in the study. After accounting for missing data in the surveys, a total of 37 women and 14 men were included in the final analyses. The first part of the analysis includes all participants, while the second part includes 24 participants, or 12 couples (Figure 3).



**Figure 3.** Flowchart of participants, recruitment to current study III analyses

Of the 58 women who were recruited for the study, one dropped out, and twenty were excluded due to missing data at T1 or T2 (Figure 3). Among the excluded women, one had severe preeclampsia, and the others had preeclampsia. Among the included women (n=37), 27% had severe preeclampsia, and 5.4% had HELLP syndrome (Table 5).

Table 5. Recruited and included women in Study III

Female participants	Preeclampsia	Severe preeclampsia	HELLP
Included n=37	25	10	2
Not included n=21	20	1	0
Total recruited	45	11	2

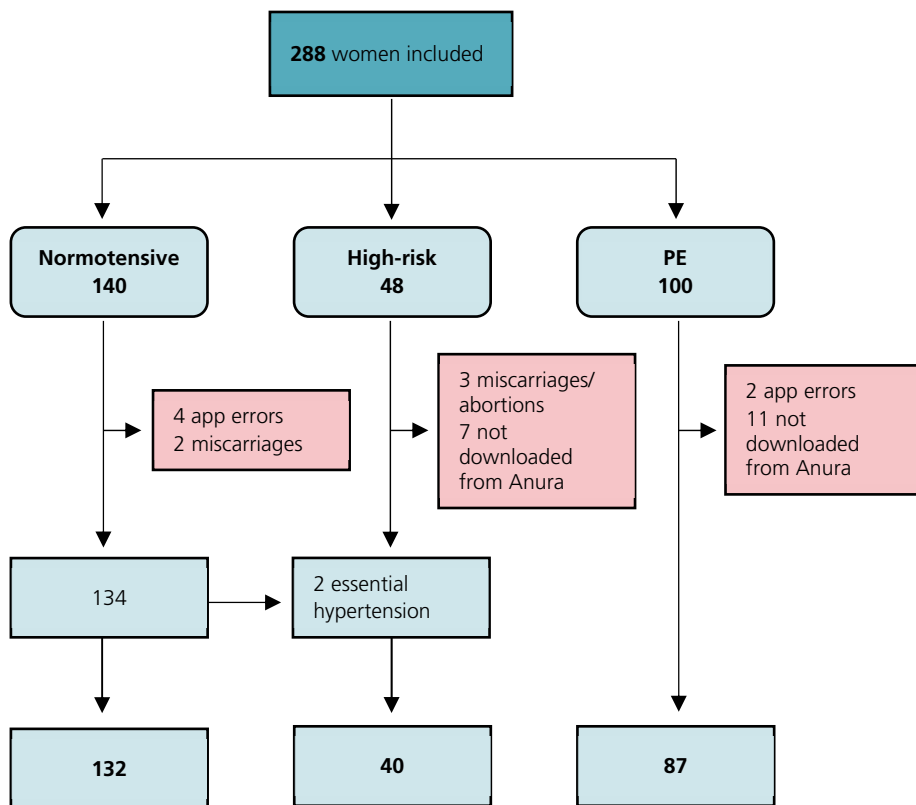
## Study IV

### *Design and participants*

This study is part of a prospective longitudinal study design aimed at following normotensive pregnant women, women with high-risk pregnancies from early pregnancy, and women diagnosed with preeclampsia from the time of diagnosis.

### *Data collection*

The study involved recruiting women attending antenatal care at two maternity healthcare units and nine MHCs in southern Sweden from March 2022 to December 2023. Additionally, women diagnosed with preeclampsia were recruited upon admission to the University hospital in Malmö/Lund. In total, 288 pregnant women were included in the study. Of these, 29 women were excluded due to technical problems with downloading the Anura application, problems with downloading raw data from the application dashboard, or miscarriage. Figure 4 shows a flowchart of the included women.



**Figure 4.** Flowchart of the included women in study IV.

The inclusion criteria for the study were: pregnant women, including those who were normotensive, those with high-risk pregnancies, and those diagnosed with preeclampsia or severe hypertension; women who possessed a smartphone capable of downloading the application used in the study; women aged 18 years or older; and (4) women who understood Swedish. Demographic and medical data for each participant were collected by the thesis author from their medical records, stored in the medical record system Obstetrix [156]. Although we also requested data from the Swedish pregnancy registry, which is linked to the Obstetrix system, this was not feasible, since we had no ethical approval to do so. Information on how to download and install the Anura application was provided to participants either by the midwives or by the thesis author.





Scanning of the blood pressure in the Anura application  
© Artwork by midwife Gabriella Aichholzer Hedström

Blood pressure was measured in two ways: first, by the midwife, using a standard blood pressure cuff or a validated automatic blood pressure monitor during each scheduled antenatal care visit, and second, by the women themselves at home and during antenatal visits, using the Anura application installed on their personal smartphones. The process of downloading and using the Anura application, as well as the various steps involved, are detailed in Appendix D. These sections provide a comprehensive guide on how participants were instructed to download and utilize the application for blood pressure monitoring. The midwife or the author of this thesis then demonstrated how to use the Anura application to scan the participant's face (Figure 5). These steps ensured that participants were properly guided through the process of using the Anura application for consistent and accurate blood pressure monitoring.

The women were encouraged to measure their blood pressure at home at least once a week, after resting for 15 minutes. For the Anura measurements, each facial video was processed by DeepAffex, the AI technology used to analyze the data obtained from the TOI, resulting in blood pressure measurements, as well as other variables such as heart rate, stress, and an overall health score (Figure 5) [157]. At each antenatal care visit, the women were asked to scan their faces using the Anura application, and then manually enter their blood pressure readings, measured by the midwife, into the Anura

application. Additionally, at 37–39 weeks of gestation, the women completed a survey (Box 2), using a four-point scale to rate their experience with the Anura application. Women in the preeclampsia group were recruited at the hospital either by a midwife (n=3) or by the thesis author (n=97).



**Figure 5.** How you measure blood pressure using the Anura application

**Box 2.**

Survey questions about the womens' experience of the Anura application
1. Were you worried about your privacy while using the Anura application?
2. How did you experience seeing your blood pressure in the application?
3. Did you feel more responsible for your health when using the application?
4. Did it feel safe to use the application and measure your blood pressure?
5. Did you experience better control of your health with the application?
6. Did you experience increased understanding of your own health with the application?
7. What did you think of sitting still and looking into the camera during the measurement?
8. What do you think about the length of time it takes to measure blood pressure in the application?

# Analyses

## Study I

First, the interviews were audio recorded, then listened to and transcribed verbatim to gain a thorough understanding of the content and grasp the overall context, the transcribed interviews were read and re-read with an open mind. The analyses followed Giorgi's descriptive phenomenological method [158, 159], which involves a five-step process aimed at gaining insight into the key elements that constitute and generate the essence of the phenomenon. These steps included bracketing preconceptions to ensure an unbiased approach to the data [160]. A detailed description of the data analysis process is shown in Box 3.

### Box 3.

Data analysis process according to Giorgi in five steps
1. The verbatim transcriptions of the interviews were read thoroughly to gain an overall impression.
2. Unique meaning units were identified within the transcribed text. These units consist of one or more sentences or paragraphs, i.e., a new meaning unit for each new content of the text.
3. The meaning units were reflected upon and then thematized based on the women's point of view.
4. The thematized meaning units were further concentrated to produce the essential significance units.
5. In the last step, emerging constituents were identified, which are the parts that form the essential structure of the phenomenon.

Once all nine interviews were analyzed using these five steps, several common or united constituents emerged, converging to reveal the essence of the phenomenon [161, 162]. During the analysis, we alternated between examining the text as a whole and focusing on its individual parts. This approach allowed us to understand each part within the context of the entire text and to comprehend the whole text through its individual components [130, 134]. After completing the analysis, the essence and constituents were reviewed and discussed by the three primary researchers (authors TH, MA, and GA).

## Study II

The analyses were conducted in two steps. The first step involved a manifest content analysis, and the second step was a latent content analysis. Both steps followed an inductive approach based on the framework of Graneheim and Lundman [139]. The interviews were transcribed verbatim. The transcriptions were then read multiple times to identify content related to women's experiences of being diagnosed with preeclampsia. The primary focus of qualitative content analysis is to describe the

content by identifying patterns within the text, considering both similarities and differences, which is achieved through the inductive approach. Manifest content pertains to what is explicitly stated in the text, while latent content delves into the text's underlying message or "what is said between the lines" [136]. A detailed description of the data analysis steps is provided in Box 4.

**Box 4.**

Data analysis process according to Graneheim and Lundman in five steps
1. The entire text is read through repeatedly to get a feel for the whole.
2. Sentences or phrases that contain information relevant to the research questions are selected. The surrounding context is included so the meaning remains. These sentences or phrases are called meaning units.
3. The meaning units are condensed in order to shorten the text while still retaining the entire content.
4. The condensed units are coded and grouped into categories that reflect the central message of the interviews. These categories constitute the manifest content.
5. Finally, main themes are formulated, revealing the latent content of the interviews.

The codes were compared and grouped by two independent investigators (authors MA and CR). Examples of the analysis process, from meaning units to themes and main themes, are presented in Table 5 in the results section of *Study II*. All authors reviewed the final analysis for integrity and contributed to the final interpretation of the data.

### Study III

The statistical analyses were conducted using IBM SPSS Statistics for Windows, Version 28.0 and Jamovi (The Jamovi Project, 2023) [163].

To test for potential selection bias in the sample, we first carried out chi-2 analysis related to attrition, which showed no significant differences between the included and excluded participants, or by sex.

Descriptive statistics were used to summarize, describe, and visualize the data in a simple and easy-to-understand way, which facilitates analysis and presentation of the results. Continuous variables were presented as minimum, maximum, and mean  $\pm$  standard deviation (SD). Categorical variables were presented as numbers (n) and proportions (%). Next, scale cut-offs from the EPDS, GMDS, and PASS continuous data were applied, and zero-order (Pearson) correlations were calculated for all outcome variables. Missing data on mental health symptoms and co-parenting (in total, < 20%) were missing at random; these missing data were imputed using estimated means and 50 iterations. Furthermore, as EPDS and GMDS depression and PASS anxiety scores

were highly correlated, a principal components analysis was conducted on these measures. A single component gathered all measures. Thus, mental health composite scores were calculated using the regression method.

To address the first study question, data from 37 women and 13 men were analyzed using mixed linear models with repeated measures (at 2 and 6 months postnatal). The analyses considered sex, preeclampsia severity, and mental health difficulties (depression and anxiety symptoms) as outcomes. Co-parenting quality (support/closeness, endorsement, and disagreement) and relevant background factors (education level, gestational age, delivery complications, and NICU care) were included as covariates. Significant covariates were identified in the initial models, refined with co-parenting measures, and incorporated into a final model predicting composite mental health difficulties, focusing on time-based interactions.

The second question was addressed as a pilot analysis, using data from 12 couples (24 participants) with complete data. A non-parametric test is a type of statistical test that does not assume that the data follow a specific distribution; for example, if the samples are small, and it is difficult to assume that the data are normally distributed. Due to the small sample size, non-parametric paired tests were used: the Wilcoxon signed-rank test for comparisons and the Spearman correlation test for associations. Spearman's rank correlation is used to measure the strength and direction of the monotonic relationship between two variables when the data are not normally distributed. The Spearman coefficient gives a value between -1 and +1, where +1 indicates a perfect positive correlation, 0 indicates no relationship, and -1 indicates a perfect negative correlation.

## Study IV

The statistical analyses were conducted by the thesis author under the supervision of Professor Kang Lee from the University of Toronto, with support from the main supervisor. We used the IBM SPSS Statistics for Windows, Version 28.0.

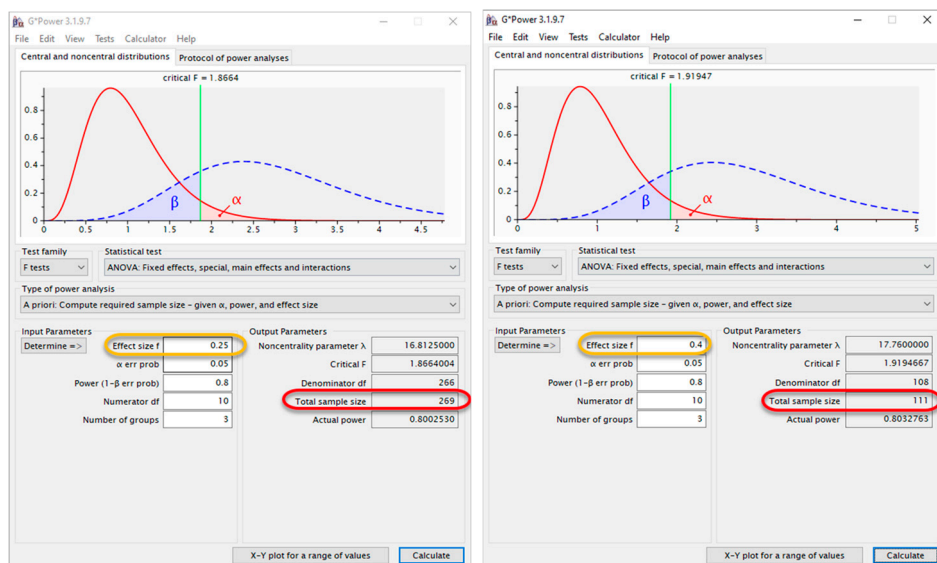
### *Power*

Statistical power is a measure used in hypothesis testing to indicate the probability that a statistical test will correctly reject a false null hypothesis, meaning it detects a true effect when it exists. In other words, power shows the probability of avoiding a type II error, which occurs when an effect that truly exists is not detected. High statistical power means that the test has a greater chance of identifying a real effect if it exists. Power is influenced by several factors, including effect size and significance level. A larger effect size makes it easier to detect true effects, thus increasing power. Conversely, a lower significance level (e.g.,  $p=0.01$ , instead of 0.05) makes it more difficult to reject

the null hypothesis, which can reduce the power [164]. Typically, a statistical power of 0.8 or 80% is sought, which means there is an 80% chance of detecting a real effect in a study.

In collaboration with scientists at NuraLogix Corporation (creators of the Anura application), statistical power was calculated using G\*power [165] to determine how many women we needed to include in each group. To achieve adequate power of 80% with a significance level of 0.05 and a medium effect size ( $f=0.25$ ), a total sample size of 269 was required, with  $n=90$  for each of the three groups (normotensive, high-risk, and preeclampsia). It is recommended to use the sample size calculated with a medium effect size. However, if we based the information provided with a large effect size ( $f=0.4$ ), a total sample of 111 would be required, with  $n=37$  for each of the three groups (Figure 6).

Based on these calculations, we decided that including 100 women in each group was reasonable for this study. However, we did not achieve the intended power for all groups, as only 48 women were included in the high-risk group.

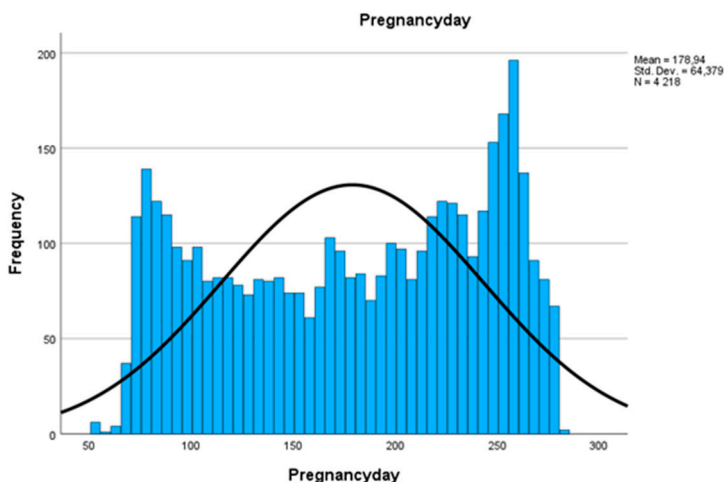


**Figure 6.** G\*power analysis

### *Distribution Analysis*

Many statistical tests and confidence intervals assume that the data are normally distributed. This assumption applies to tests such as t-tests and ANOVA. When the data are normally distributed, these tests can be used directly, making them highly effective

tools for statistical analysis [164]. Therefore, we began by examining whether the data were normally distributed. When analyzing the entire study group, the data showed a normal distribution for the women's age ( $32.42 \pm 4.53$ ), weight ( $71.98 \pm 14.42$ ), height ( $167.78 \pm 5.94$ ), and BMI ( $25.55 \pm 4.89$ ). The distribution of the number of measurements taken at different gestational days of pregnancy, among all included participants, regardless of group, also followed a normal distribution, though slightly more measurements were performed at the beginning and end of pregnancy (Figure 7).



**Figure 7.** Distribution of pregnancy days. Std Dev= standard deviation

### *Paired t-test*

Since the data exhibited a normal distribution, we proceeded with the analysis using a paired t-test. The paired t-test is ideal for comparing mean values between two groups, assessing whether there is a significant difference in blood pressure measurements obtained through different methods (e.g., manual vs. Anura blood pressure measurements) or across distinct groups (e.g., normotensive women vs. women with preeclampsia) [164].

### *Anova*

Given the study design with multiple groups, ANOVA was used to scrutinize mean values across the groups. ANOVA is well-suited for discerning significant inter-group variations based on their means and variability. It was used to determine if there were differences in measurements across the three trimesters within each of the three study groups. However, the ANOVA post hoc test could not be performed for the

preeclampsia group, because there were only measurements from the second and third trimesters. None of the participants developed preeclampsia during the first trimester. Furthermore, most of the women with preeclampsia were included after diagnosis.

### *Regression analyses*

Regression analysis is a statistical method used to examine the relationship between one or more independent variables (predictors) and a dependent variable (outcome) [164]. By using linear regression analysis, we quantified the difference between the two methods and assessed whether there was a statistically significant difference between the blood pressure values obtained with a manual blood pressure cuff compared to Anura's blood pressure measurements. The model shows whether there is a systematic difference between the two types of measurements and the magnitude of this difference.

### *Scatter plots*

Scatter plots were integrated as they supplement ANOVA and t-tests by providing visual clarity on blood pressure variations among the study groups and measurement methods. Scatter plots excel in depicting relationships between variables, such as SBP and DBP. For instance, scatter plots can highlight linear correlations between SBP and DBP or reveal clusters indicating distinct blood pressure profiles among individuals. Furthermore, they can identify outliers, potentially flagging measurement errors or health anomalies.

### *Bland Altman*

To further assess the agreement between the blood pressure measurement methods and detect systematic discrepancies, a Bland-Altman analysis was conducted. Bland-Altman plots visually represent the agreement between different measurement techniques (e.g., manual vs. Anura measurements), considering individual variability, by comparing each participant's measurements. This personalized approach enhances accuracy by mitigating variations that could otherwise skew statistical interpretations [164]. The upper limit of agreement (UoA) in Bland-Altman analysis represents the higher end of the range of agreement between the two methods, and the lower LoA represents the lower end of this range. When there is variation in the LoA, it means that the differences between the methods are not consistent across the range of measurements. For example, the new method may show larger discrepancies for certain SBP or DBP values compared to others. This variation may indicate that the method being evaluated is less reliable at higher or lower blood pressure values or that it performs differently depending on the situation or measurement context.



### *Signal-to-Noise Ratio*

The Anura application automatically generates 32 different indices based on its computational models (Appendix A). It also calculates the signal to noise ratio (SNR) to indicate the strength of the blood flow signals relative other non-blood flow rhythmic noises [166]. The Anura application requires an SNR >1 db for heart rate measurements and SNR >2 dB for BP measurements. A SNR of 1 indicates that blood flow signals are 10 times stronger than other rhythmic signals, while a SNR of 2 means that blood flow signals are 100 times stronger.

## Ethical considerations

In any research project, it is essential to carefully weigh the benefits and potential risks to participants [167, 168]. This approach aligns with the ethical principles guiding healthcare professionals in general, and midwifery specifically, including non-maleficence, autonomy, justice, and beneficence, as well as adherence to local laws and regulations [169]. The primary benefit of this research is to generate new insights into the experiences of living with preeclampsia, which can help midwives and healthcare professionals improve care in the future.

All studies within this thesis adhered to the World Medical Association's Declaration of Helsinki (2013) [168], and participant privacy was protected in line with the General Data Protection Regulation (GDPR 2016/679/EU) [170]. Ethical approval was granted by the Regional Ethics Committee at Lund University, Lund, for all four studies: *Studies I* and *II* in January 2019 (Dnr 2019-04240), *Study III* in August 2021 (Dnr 2021-03530), and *Study IV* in July 2021 (Dnr 2021-03216). Informed consent was obtained from all participants, including the partners in *Study IV*, ensuring their autonomy and understanding of the research.

However, there are potential risks involved, particularly the stress and anxiety that may arise as participants reflect on their experiences. After careful consideration, the research team concluded that the benefits of gaining valuable insights into patient care outweighed the emotional risks for participants. Nevertheless, measures were taken to minimize distress, such as offering flexibility in interviews and ensuring that participants could withdraw at any time without providing a reason.

The thesis author, or another midwife, explained the study's purpose both verbally and in writing. Participants were reassured that their involvement was voluntary, confidential, and that they could terminate their participation at any time. We recognized the risk of participants feeling pressured to take part, especially in clinical

settings, and addressed this by giving them ample time to decide whether to participate. In *Study III*, participants could contact a clinical psychologist with experience of working with parents during the perinatal period, for discussion, consultation, or support.

In *Study I*, interviews were conducted in private hospital settings, while *Study II* allowed women the option to choose their preferred interview location. With most opting for their homes, this created a more comfortable and personal environment, and fostered trust and open communication, as participants felt more at ease in familiar surroundings.

Data confidentiality was strictly maintained throughout the research. In *Studies I* and *II*, each participant was assigned a unique code number, and no personal identifiers were included in the data. In *Study III*, electronic data were collected through RedCap, utilizing consented email communications and secure storage for all materials. For *Study IV*, facial videos were processed securely using DeepAffex AI, with encrypted data transmission and the use of participant codes.

As a midwife, I also adhered to the International Confederation of Midwives (ICM) Ethical Code, ensuring that every step of the research process was guided by the principles of autonomy, non-maleficence, justice, and beneficence [171]. All study materials, including patient consents, recorded interviews, and data analyses, are securely stored at Lund University, Sweden.

## Methodological considerations

In this thesis, both qualitative and quantitative methods were used. Ethical approval was obtained from the relevant committees, and participants were informed of their rights, including confidentiality and the option to withdraw from the study at any time.

A key strength of this work is its combination of qualitative and quantitative research on preeclampsia from a patient-centered perspective. These methods complement each other effectively. Quantitative research provides objective and measurable data on incidence, risk factors, and outcomes, helping to identify general trends and patterns. Qualitative research, on the other hand, offers deeper insights into patients' personal experiences, emotions, and needs, uncovering nuances that quantitative data alone might overlook. Together, these approaches provide a more comprehensive understanding of preeclampsia from a patient centered perspective, enabling the development of better-tailored and more effective healthcare interventions.

## Trustworthiness

In qualitative studies, strengths and weaknesses are typically evaluated in terms of trustworthiness, which encompasses concepts such as credibility, dependability, confirmability, and transferability [129, 172]. Graneheim and Lundman highlight these concepts as foundational to qualitative research. *Credibility* refers to confidence in the truth of the research findings and data, influenced by factors such as the rigor of data collection and the characteristics of participants. It is achieved by accurately representing participants' experiences through careful participant selection, robust data collection, and triangulation. It also involves assessing similarities within and differences between categories [139]. *Dependability* pertains to the consistency and stability of the data over time and under varying conditions. This is ensured through meticulous documentation of the research process, enabling replication. *Confirmability* ensures the objectivity and neutrality of data interpretation, minimizing researcher bias. It is attained by verifying that the research findings are free from bias and traceable to their original sources. *Transferability* relates to the extent to which findings can be applied to other contexts. It is supported by providing rich, detailed descriptions of the research context, allowing readers to evaluate whether the findings are applicable to other settings [173]. Ultimately, it is up to the readers to decide whether the findings are transferable to their specific contexts [139].

## Qualitative studies in the thesis

In *Studies I and II*, purposive sampling was used to select participants, a method well-suited for identifying individuals likely to provide relevant and valuable insights [174]. Purposive sampling is a non-probability technique where researchers intentionally select participants with specific characteristics or qualities relevant to the study. This approach is commonly employed in qualitative research to ensure the sample yields in-depth and rich information pertinent to the research question.

In these two studies, women were chosen based on predefined criteria that aligned with the study's objectives. The researchers applied their expertise and judgment to identify participants best positioned to provide valuable insights. Purposive sampling was particularly advantageous for these studies, as it allowed us to focus on a specific subset of the population (women with preeclampsia) to explore the complex phenomena associated with the condition and gather detailed information from knowledgeable patients. Additionally, purposive sampling facilitated diversity in terms of age and parity among participants. However, greater diversity could have been achieved by including more women from different ethnic backgrounds, rather than focusing

primarily on Swedish participants. This limitation should be considered when interpreting the study's results.

Individual interviews were chosen because the topic was considered too sensitive for group discussions [133]. Additionally, coordinating interviews with multiple women simultaneously was unlikely to be feasible. In *Study I*, we used one open-ended question, while in *Study II*, semi-structured face-to-face interviews were conducted. Unstructured interviews can carry the risk of including inappropriate questions, such as those related to religion, family planning, or sexual orientation [175]. In contrast, structured interviews reduce bias by ensuring consistency in the questioning process. For instance, implementing behavior-based interviews for fellowship applications has been shown to reduce racial bias in applicant assessments [176]. Since structured interviews rely on pre-determined questions and trained interviewers, they are less likely to involve inappropriate or illegal inquiries [177].

In *Study II*, structured questions allowed for follow-up prompts, such as: "Could you be more specific?" However, probing was applied minimally and consistently across participants to avoid prompting them toward specific responses [175]. Structured interviews offer several advantages, including reduced bias, as all participants are asked the same questions and evaluated using the same criteria. They also demonstrate greater predictive validity, as research suggests that structured interviews are better at predicting outcomes, such as job performance, compared to unstructured ones. Additionally, structured interviews align with legal and ethical compliance by adhering to relevant laws, regulations, and ethical guidelines, including data protection, informed consent, and ethical approval processes.

To collect detailed and rich data, building trust with participants was crucial. This trust was facilitated by allowing the women to select the time and place for their interviews. They were also informed that they could stop the interview at any point if they wished. This approach encouraged open communication and allowed the women to ask direct questions about the study, likely increasing their comfort and willingness to share their experiences [178]. This was particularly evident in *Study II*, where conducting interviews in the women's home environments fostered a deeper level of openness.

Analyzing content "close to the text," which focuses on the *manifest content*, provides a suitable starting point for qualitative analysis. As researchers gain greater knowledge and analytical skills, they can progress to interpreting deeper, underlying meanings within the text. Manifest content is often organized into categories, while *latent content* is typically represented by themes that convey the underlying messages [173]. In *Study II*, we conducted a manifest content analysis using an inductive approach, aiming to remain as close to the text as possible. Despite these efforts, there is always an inherent

risk of inadvertently introducing subjective interpretations during the analysis. An inductive approach involves identifying recurring patterns in the material without any predetermined assumptions, allowing for an open analysis of the data based on participants' stories and experiences [179]. This method preserves a close connection to the data while minimizing the influence of preconceived ideas. In contrast, *Study I* employed a descriptive phenomenological approach. This analytical method is characterized by maintaining a critically reflective stance, setting aside prior knowledge of the phenomenon, and avoiding existential claims.

In both interview studies, we conducted individual analyses before comparing and discussing our findings to reach a consensus. This collaborative approach minimized the risk of overinterpretation and helped ensure we stayed as close to the original text as possible, while setting aside preconceptions. Furthermore, one of the authors conducting the analyses was not involved in the interviews, which may have further reduced the risk of overinterpretation, as this individual had not previously heard the women's stories.

By applying these rigorous methods, our interviews provided a rich and nuanced understanding of the experiences and needs of women with preeclampsia. This patient-centered perspective has the potential to inform improved care and support for affected women.

## Reliability and Validity

In quantitative studies, strengths and weaknesses are typically evaluated in terms of *reliability* and *validity*, which are key for assessing the quality and accuracy of the methods employed. These concepts ensure the credibility of the study and the accurate interpretation of its results [145]. *Reliability* refers to the consistency and stability of a measurement or instrument, indicating the extent to which it produces the same results in repeated measurements under similar conditions. High *reliability* suggests that the method is dependable and free from random errors, which enhances the replicability of the study and strengthens the generalizability of its findings. *Validity*, on the other hand, concerns whether a measurement tool or method accurately measures what it is intended to measure. High *validity* ensures that the conclusions drawn from the study are accurate, with a credible link between the collected data and the phenomenon under investigation. It also ensures that results are not influenced by external factors and can be generalized to other populations or contexts.

In *Study III*, the *reliability* and *validity* were important when evaluating mental health, as we assessed the well-being of women and men at two and six months postnatally

using depression and anxiety rating scales. High *reliability* ensured that the instruments minimized random errors, allowing for consistent results across measurements. This was crucial to ensure that any changes in anxiety or depression scores accurately reflected participants' actual mental state, rather than inconsistencies in the measurement tools. We also measured co-parenting, with the scales demonstrating high internal consistency. High *validity* ensured that the scales accurately captured symptoms and provided true reflections of mental health. To ensure a comprehensive analysis, we measured both typical and atypical depression symptoms, aligning with current debates in psychiatry about overlooked mental illness, particularly among women. This approach enhances the *validity* of our study, supported by well-tested, internationally used, and Swedish-validated scales. By using reliable and validated scales, we ensure that our interventions are based on accurate and credible data.

In *Study III*, all four screening tools for depression and anxiety demonstrated high *reliability* and *validity*. The PASS has shown strong convergent *validity* with other anxiety measures, temporal stability, and superior diagnostic accuracy compared to similar instruments [148]. The EPDS, with well-documented *validity* and *reliability* [51], has been validated in a Swedish context [177-179] and for use with men [180]. The GMDS also exhibits robust evidence of both *validity* and *reliability* [181, 182]. In the present study, the GMDS scale exhibited strong *reliability*, even with the majority of participants being women. Similarly, the CRS demonstrates high *reliability* and construct *validity* [149], with additional validation in a Swedish context [150].

In *Study IV*, we compared two blood pressure measurement methods, making *reliability* and *validity* critical. High *reliability* ensured consistency within each method, while high *validity* confirmed that blood pressure was measured accurately, allowing for meaningful comparisons. Blood pressure was measured using the Anura application and compared to the manual blood pressure cuff, which is considered the gold standard when used correctly due to its high *reliability* and *validity*. However, *Study IV* had several limitations. The number of blood pressure measurements recorded by women using the Anura application varied across the three groups. The sample size was insufficient, particularly in the high-risk group, and the limited number of measurements in certain trimesters may have affected reliability and validity. Additionally, only 31% of participants completed the questionnaire evaluating their experience with the Anura application, warranting caution when interpreting these results. On the other hand, a strength of *Study III* was that the questionnaires used to assess participants' mental health had been validated in other large studies. While the questionnaires in *Study IV* had not been validated in prior studies, they were approved by the patient association's board. Nevertheless, the low response rate in *Study IV* may have negatively affected the *reliability* and *validity* of the results.

Non-response bias can arise when individuals in a sample or population do not complete a questionnaire. This occurs when certain individuals are less likely to respond, which can distort the sample's representation. For example, a survey with a 30% response rate inherently has a non-response bias of 70% [140]. In *Study IV*, the response rate was 31%, while *Study III* achieved a 54% response rate. This suggests that non-response bias may have influenced the results of both studies, albeit to varying extents. Researchers should be mindful of this challenge when designing studies, as recruiting pregnant women to participate can be particularly difficult. This has been confirmed by staff at several MHC centers. Additionally, the COVID-19 pandemic has led to increased reluctance among women to take part in research studies.

### Quantitative studies in the thesis

In *Study III*, the low response rate is the main limitation. A low response rate can negatively affect both *validity* and *reliability*, but in different ways. If a large percentage of respondents do not participate, there is a risk that the results may not accurately represent the wider target group. Those who choose to participate might have unique characteristics that do not reflect the larger population, reducing external validity. In *Study III*, we used attrition analysis to identify potential biases in the sample (those who provided complete T1 and T2 data compared to those who did not). The use of generalized linear mixed models was motivated, as these models do not require assumptions about the normal distribution of variables. However, fewer responses can lead to greater *variability* in the data, making it more difficult to obtain stable and consistent results. For medium-sized effects (0.15) and the four predictors in our final model, we achieved only nearly a medium effect size (0.6) with the number of participants (n=50) in the study. This is before considering the repeated measures (at two, T1 and six, T2 months postnatal), which, according to the rule of thumb, require doubling the number of participants in such a design. Therefore, the analyses were underpowered, and all results should be regarded as preliminary. If the drop-off is systematic, it could affect the *reliability* of the measurements. Despite the low response rate, the results still provide valuable insights, especially if they support previous research or if non-response is not systematic.

To determine whether the methods used in *Study IV* were consistent, statistical analyses, such as Bland-Altman and correlation analyses, were applied to compare the results between the two methods and assess their agreement. Paired t-tests were employed, as they are well-suited for comparing repeated measurements within the same group. This test assumes an approximately normal distribution, which is a common feature in physiological measurements, such as blood pressure [164]. The t-

test is robust and effective for modest sample sizes, which are typical in studies with limited participants. Independent t-tests were used to compare blood pressure measurements across different groups of women, while paired t-tests were applied to evaluate differences between blood pressure measurement methods within the same group. By employing these t-tests, it was possible to determine whether the observed differences in blood pressure measurements were statistically significant or due to chance.

Scatter plots provided a visual representation of relationships and trends between continuous variables, which helped to identify outliers. However, with larger datasets, these plots became cluttered and difficult to interpret, requiring additional statistical analyses. To complement scatter plots, Bland-Altman analyses were used to evaluate the agreement between the Anura application and the gold-standard manual blood pressure measurements. These plots revealed systematic biases and deviations, which were essential for assessing the *reliability* and accuracy of the Anura application. Bland-Altman analyses are particularly useful for detecting any systematic errors or biases between two methods, but their *reliability* depends on sufficient sample sizes, which posed a limitation in some subgroups. These differences observed between blood pressure readings suggest that the Anura application either overestimated or underestimated blood pressure compared to manual measurements, especially in the preeclampsia group, where the discrepancies were most pronounced. The Bland-Altman analysis, thus, highlights the potential margin of error in the Anura measurements, which may be important to consider in clinical use.

In *Study IV*, regression analyses were also employed to examine the relationship between dependent and independent variables, adjust for confounding factors, and identify trends. While regression analyses are robust and provide valuable insights, they require large datasets and can result in complex models that are challenging to interpret. Throughout the study, adjustments were made to the analytical methods as new challenges emerged. ANOVA and t-tests provided overall comparisons of means, while Bland-Altman analyses offered detailed insights into the individual measurement agreement between the two methods. These combined approaches strengthened the findings of the study by providing multiple perspectives on the data. While mixed linear analyses could have offered even higher *reliability* by handling repeated measurements and more complex data structures, they were not applied due to resource and knowledge constraints.

The sample size for *Study IV* was determined using G\*Power to reduce the risk of a type II error. Ideally, the study would have included approximately 100 women per group, as recommended by the power analysis. However, several challenges were encountered during recruitment. Technical difficulties with the Anura application



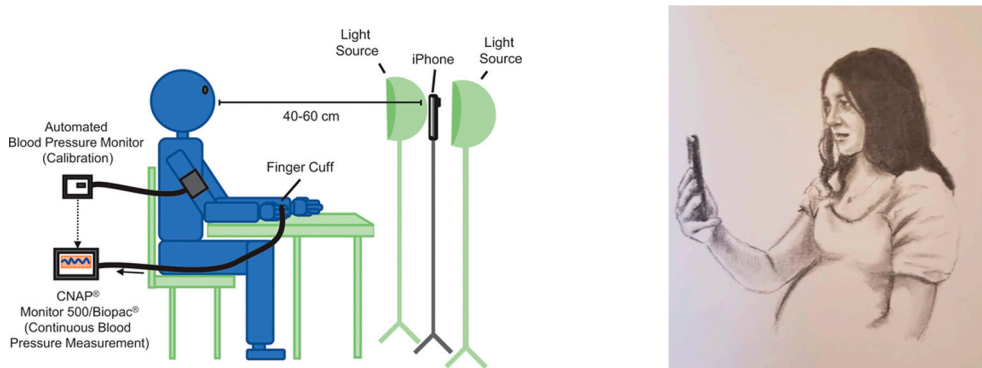
during the early stages of the study led to participant dropouts. Recruitment at maternity centers also faced limitations, particularly in enrolling women from the high-risk group. To address these issues, the recruitment period was extended, and more women from the normotensive group were included. Despite these adjustments, the high-risk group remained underrepresented.

Both *Study III* and *Study IV* utilized prospective longitudinal designs, which allowed for the establishment of a clear temporal sequence between exposures and outcomes. This approach strengthened causal inferences and facilitated the observation of changes over time, providing valuable insights into developmental patterns and individual variations. Moreover, prospectively collected data minimized the risk of recall bias compared to retrospective designs. However, these advantages were tempered by several challenges. Long-term follow-up required significant time and resources, leading to delays in obtaining results and publishing findings. Participant attrition was a notable issue, especially in *Study IV*, where technical problems with the Anura application hindered participants from logging in and scanning blood pressure, resulting in drop-offs. In *Study III*, non-response to questionnaires, particularly from partners, further limited the completeness of the data. Managing and analyzing longitudinal data necessitated the use of advanced statistical methods, which added complexity to the studies. Furthermore, the results may be influenced by the specific characteristics of the cohort, which could limit their generalizability to other populations.

Despite these limitations, the methodological adaptations and statistical approaches applied in *Studies III* and *IV* contributed to robust and meaningful results. The combination of diverse statistical analyses, including Bland-Altman plots, regression analyses, and t-tests, provided a detailed evaluation of the agreement between measurement methods and highlighted both the strengths and weaknesses. These findings underscore the importance of flexibility and careful consideration in the design and implementation of longitudinal studies.

In *Study IV*, women used their personal smartphones to perform blood pressure measurements manually under varying lighting conditions. This approach differed significantly from previous studies, where the Anura technology was evaluated under tightly controlled conditions, using optimal lighting, tripod-mounted smartphones, and a single standardized device for all measurements (Figure 8). In our study, environmental factors, such as movement and lighting, known to affect the accuracy of contactless blood pressure measurement technologies, were not controlled (Figure 8). The women were instructed to sit and hold their phones steady at arm's length for 30 seconds during the measurement, ensuring that the display in the Anura application showed at least three stars to indicate adequate lighting [180]. However, factors such as room lighting and arm movements, especially among women with preeclampsia who

are often admitted to hospitals, could have influenced the measurement's accuracy. Women with preeclampsia, for example, often need dim lighting due to their symptoms, which may further compromise the reliability of the measurements [142, 143]. Movement and lighting are factors that often affect the accuracy of contactless measurement technologies using smartphones [166, 181].



**Figure 8.** Differences in blood pressure measurements in a laboratory setting (Lou et al., 2019) and in the Anura study.

Different statistical methods were utilized to evaluate the collected data, each with its own set of advantages and disadvantages. For comparisons across multiple groups, such as trimesters, analysis of variance (ANOVA) was applied to identify significant differences, followed by post hoc tests to determine which groups differed. Similar to the paired t-test, ANOVA assumes normal distribution and equal variance; failure to meet these assumptions can compromise the validity of the findings.

In *Study IV*, The Anura application automatically calculated the SNR to index the strength of the blood flow information relative to other non-blood flow rhythmic noises [166]. The system requires a  $\text{SNR} \geq 1$  dB for heart rate measurements and  $\text{SNR} \geq 2$  dB for blood pressure measurements. Filtering out recordings with a  $\text{SNR} \geq 2$  dB for blood pressure measurements improves the overall accuracy and *reliability* of the data. However, this significantly reduces the sample size, potentially affecting the statistical power of the study. This could limit the generalizability of the results, but the remaining high SNR recordings are expected to be more reliable. Therefore, it is important to clearly report how much data was excluded and why. This allows others to interpret the results, knowing that data from individuals with movement artifacts was removed. Data from stable recordings, with minimal movement artifacts, are more likely to reflect the true physiological state of participants, leading to more valid conclusions.

Recruiting postpartum women for survey participation posed several challenges. Many women experience emotional and physical stress after childbirth, making it difficult for them to find the time and energy to participate in research. Factors such as fatigue, cognitive symptoms, and the sensitive nature of mental health topics, such as depression and anxiety, can further discourage participation, even with the promise of anonymity. Building trust through personal contact was identified as a potentially effective strategy for improving participation rates. Personalized postpartum follow-ups, where researchers or healthcare providers offer support and foster a sense of involvement, can make participants feel more comfortable and willing to engage.

Women with preeclampsia or those in the later stages of pregnancy face even greater barriers to participation. The demands of their condition, including severe physical symptoms and cognitive impairments, often leave them with little capacity to complete surveys. Addressing these challenges requires a thoughtful and empathetic approach, such as reducing the burden of participation, ensuring flexibility in data collection methods, and considering the specific needs of these vulnerable populations. These considerations are crucial for improving response rates and ensuring the robustness of data collected in clinical research.

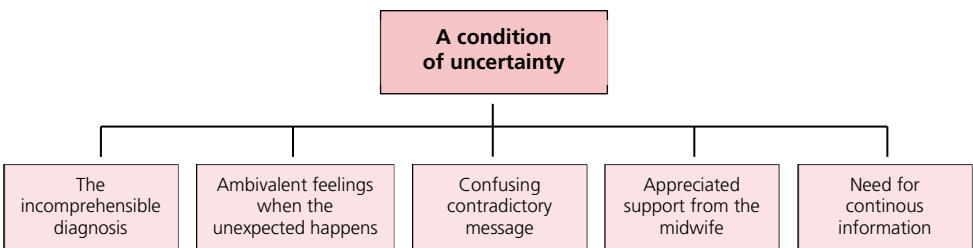
# Results

Results from the four included studies are summarized. To get a deeper insight into the tables and figures of each study, please refer to the original articles included.

## Summary of the findings in Studies I–IV

### Study I

In *Study I* [182], the experiences of women diagnosed with preeclampsia were explored through open interviews. Being diagnosed with preeclampsia and experiencing a pregnancy impacted by potential complications and outcomes encapsulates the core essence of women’s experiences with this condition, described as *A condition of uncertainty*. The women found themselves often posing more questions than they received answers. They struggled to grasp the complexity of their diagnosis, both for themselves and for their unborn baby. Preeclampsia was described as an unexpected, uncertain, and unknown condition. The essence of their experiences was identified through five key constituents, as described in Figure 9.



**Figure 9.** The essence of their experiences and the five constituents

Regarding the first constituent, *the incomprehensible diagnosis*, it appears that women with preeclampsia often lacked prior knowledge about the condition and found its symptoms indistinguishable from normal pregnancy symptoms. This lack of awareness

led to difficulties in accepting the diagnosis and the necessary medical interventions. Many women felt the need for a specific diagnostic test for preeclampsia to confirm its severity. Unfortunately, no such test exists today.

In the second constituent, *Ambivalent feelings when the unexpected happens*, women experienced mixed emotions of fear and relief when their preeclampsia condition deteriorated rapidly, often resulting in an emergency caesarean section instead of a planned vaginal delivery. These sudden changes were traumatic, particularly when anesthesia was required, leaving women with a need to process their experiences and seek emotional support.

Regarding the third constituent, *Confusing contradictory messages*, the study revealed that women received inconsistent information from different healthcare providers about the severity of their condition. This inconsistency caused confusion and anxiety about when to seek care, as women struggled to understand and manage their condition based on conflicting advice.

In the fourth constituent, *Appreciated support from the midwives*, women highly valued the support and care they received from midwives at the MHC units. Midwives were often the first to suspect preeclampsia and guided women through further investigations and follow-ups. They provided much-needed reassurance and motivation, encouraging women to take their condition seriously.

For the fifth constituent, *Need for continuous information*, women expressed a need for ongoing, clear, and consistent information throughout the disease's progression and during the postpartum period. They emphasized the need for detailed explanations about medical procedures, medications, and potential outcomes for both themselves and their babies, highlighting a gap in communication and involvement in medical decisions.

This study highlights the importance of improved clinical management. Healthcare professionals should recognize that women require detailed, consistent, and repeated information about the severity and prognosis of preeclampsia to reduce feelings of uncertainty, confusion, and fear.

## Study II

*Study II* [183] explored women's experiences during pregnancy and the postpartum period regarding the information and care they received concerning preeclampsia. The women's experiences were illustrated in four main themes: fragmented information, lack of care planning, separation postpartum, and overall stress and worry, based on the ten sub-themes, as presented in Table 6.

**Table 6. Main themes and Sub-themes**

MAIN THEMES	SUB-THEMES
<b>I. FRAGMENTED INFORMATION</b>	<ul style="list-style-type: none"> <li>- Missing Overall Information</li> <li>- Lack of Knowledge and Understanding of Health risks</li> <li>- Inconsistent Information</li> <li>- Difficulties to "take in" Information</li> </ul>
<b>II. LACK OF CARE PLANNING</b>	<ul style="list-style-type: none"> <li>- Individualized Plan for Treatment and Follow-up</li> <li>- Timing and involvement in Care planning</li> </ul>
<b>III. SEPARATED POSTPARTUM</b>	<ul style="list-style-type: none"> <li>- A Feeling of Coming in Second Place</li> <li>- A Despair of Being Separated from the New-born</li> </ul>
<b>IV. OVERALL STRESS AND WORRY</b>	<ul style="list-style-type: none"> <li>- Experiencing Stress and Worry</li> <li>- A Request for Both Oral and Written Information</li> </ul>

Regarding the first theme, *Fragmented information*, it appeared that the women reported receiving incomplete and inconsistent information about preeclampsia throughout their pregnancy, hospital stay, and postpartum period. This fragmented information, provided by various healthcare professionals, often lacked details about long-term health consequences. During the stressful period of dealing with preeclampsia, many women struggled to fully understand the information provided to them. Information was often given casually rather than during focused, structured sessions, making it difficult for the women to comprehend the seriousness of their condition.

In the second theme, *Lack of care planning*, the women expressed a strong desire for more involvement in their care planning. They felt that no one took the time to explain the different steps in their treatment, the choices available, and the potential outcomes. This lack of individualized care planning was felt throughout their hospital stay and continued into the postpartum period. Women requested that information be shared at more appropriate times, especially when both their condition and their baby's status were stable, to better understand the seriousness of preeclampsia and the necessary medical interventions.

The third theme, *Separated postpartum*, demonstrates that the postpartum separation from their newborns, who were often admitted to the NICU, left women feeling

abandoned and like a second priority. While managing their own recovery from preeclampsia, they struggled to care for their babies, which required extra support and encouragement from healthcare professionals. The physical distance from their newborns added significantly to their stress and worry. Women expressed the need for better integration of care for both mother and baby to minimize the stress caused by this separation.

In the fourth theme, *Overall stress and worry*, the combination of fragmented information, lack of care planning, and concerns about future health risks led to significant stress and worry among the women. They were particularly anxious about the health of their unborn child and the potential for severe outcomes of preeclampsia. Women requested both oral and written information to better understand their situation. They found that written information was especially helpful, as it could be revisited during less stressful moments, allowing them to process their condition more effectively. Many women also resorted to searching the internet for additional information, which often increased their anxiety due to the inconsistent and sometimes alarming content they found online.

Taken together, these themes highlight the urgent need for improved communication, consistent care planning, and comprehensive support for women experiencing preeclampsia. Building on the findings from this study, my goal was to focus future research on developing tailored care plans and structured postpartum follow-up visits to improve care for women with pregnancies complicated by preeclampsia. This was presented as a poster at the Nordic Midwives Congress May 4–6, 2022, in Helsinki, Finland (Appendix A).

The two interview studies highlight a shared finding that women with preeclampsia experience a notable lack of information during pregnancy and postpartum. They emphasize a need for detailed, consistent, and repeated communication. Preeclampsia is often an unexpected and distressing experience, with women facing increased levels of stress, anxiety, and despair, particularly due to the separation from their newborns. Additionally, there is a significant gap in knowledge about the long-term health risks associated with preeclampsia.

### Study III

The results show the expected decline in postnatal depression and anxiety symptoms over the first six months after childbirth. The different measures of typical depression (EPDS), atypical depression (GMDS), and anxiety (PASS) symptoms were highly correlated, and principal component analysis indicated that these symptoms converted

into one component, which we termed the “mental health composite.” These results indicate comorbidity in postpartum depression and anxiety symptoms, in line with other research. Table 7 shows the proportion of participants with symptom levels indicating depression or anxiety. For typical depression symptoms, approximately 30% of women reported symptoms above the EPDS cut-off of  $\geq 9$ , indicating possible minor depression, while 11% reported symptoms suggesting possible major depression at T1. Importantly, none of the participants reported thoughts of self-harm at either T1 or T2. Regarding atypical depression symptoms (GMDS), approximately 11% of women reported symptoms above the cutoff ( $\geq 13$ ) at T1, and 16% at T2. For more detailed information, see Table 7 or Article 3 in the appendix. Additionally, the models for EPDS and PASS revealed a significant effect of time after childbirth, as symptoms decreased with time.

Importantly, perceived support/closeness in co-parenting were negatively linked to symptoms of poor mental health, while neither fetal sex nor the severity of preeclampsia had any impact. Somewhat surprisingly, there was no correlation between women’s and their partners’ perceptions of co-parenting. However, the partners of women with higher levels of anxiety reported lower support and closeness in co-parenting, highlighting a possible asymmetry in how parents experience and influence each other’s mental health. An unexpected result was that higher education was associated with higher levels of depression and anxiety symptoms. This indicates that women with higher education levels experienced more severe mental health challenges.

A higher proportion of men (partners) than women had incomplete data (over 30% incomplete) and were therefore excluded from the study. Among the included women, a greater proportion had undergone induction of labor, and a greater proportion had been diagnosed with severe PE or HELLP syndrome compared to those who dropped out. However, no significant differences were found between the included and excluded participants in terms of gestational age at delivery, Caesarean section rate, postpartum bleeding as a proxy for complications, or newborns admitted to the NICU.



**Table 7. Respondents above cut-off for referral in the different measures**

Scale	N=37 Women	N=13 Men	Mean±SD Women PE	Mean±SD Women Sever PE	Mean±SD Men PE	Mean±SD Men Sever PE	Total mean Women/ men
EPDS T1 (2 m)			7.3±3.5	7.5±4.6	6.2±2.9	4.5±2.1	7.0/7.7
Cut-off ≥ 9	11 (30%)	2 (15.4%)					
Cut-off ≥ 12	4 (10.8%)	0 (0%)					
EPDS T2 (6 m)			5.9±3.4	7.3±6.9	4.3±3.2	5.0±4.4	5.6/6.5
Cut-off ≥ 9	5 (13.5%)	1 (7.7%)					
Cut-off ≥ 12	3 (8.1%)	0 (0%)					
GMDS T1 (2 m)			4.4±3.9	5.0±4.6	4.9±4.9	3.5±7.0	4.6/5.3
Cut-off ≥ 13	4 (10.8%)	1 (7.7%)					
GMDS T2 (6 m)			4.6±4.5	6.9±10.3	4.6±3.6	8.0± -	5.3/5.3
Cut-off ≥ 13	6 (16.2%)	7 (7.7%)					
PASS T1 (2 m)			16.1±11.1	15.6±10.3	10.3±8.9	10.0±7.1	15.1/14.3
Cut-off ≥ 26	7 (18.9%)	1 (7.7%)					
PASS T2 (6 m)			13.3±10.4	14.9±16.5	8.1±7.2	16.0±7.2	12.5/14.7
Cut-off ≥ 26	3 (8.1%)	0 (0%)					

Note: T1 = 2 months postnatal, T2= 6 months postnatal EPDS= Edinburgh Postnatal Depression Scale, GMDS= Gotland Male Depression Scale, PASS= Perinatal Anxiety Screening Scale, SD=standard division, m= months, PE=preeclampsia

In the paired data analyses, based on a subset of 24 participants, women and their partners, i.e., 12 couples, the Wilcoxon analysis showed that the difference in EPDS scores between women and their partners almost reached significance ( $p = 0.051$ ), with women reporting more symptoms than their partners (mean difference = 1.23). Women also reported higher perceived co-parenting support and closeness ( $p = 0.010$ ) and less disagreement ( $p = 0.021$ ) compared to their partners.

Spearman correlation analysis showed significant relationships for partners' EPDS scores (typical depressive symptoms), but no associations were found for GMDS (atypical depressive symptoms) or PASS (anxiety). Regarding co-parenting, partners' perceptions were unrelated across all dimensions (support/closeness, support, disagreement. (Tables 6 and 7 in *Study III*). A negative relationship was identified between women's anxiety symptoms and their partners' perceived CRS support, suggesting that the partners of women with higher levels of anxiety perceived less support and closeness in the co-parenting relationship.

## Study IV

In total, 288 pregnant women were included, with blood pressure data successfully downloaded from 259 women using the Anura application. Demographic analysis revealed significant differences ( $p < 0.001$ ) between the high-risk and preeclampsia groups compared to the normotensive group in terms of pregnancy length, age, height,

weight, BMI, and blood pressure. Both the high-risk and preeclampsia groups had significantly higher maternal age and BMI ( $p<0.001$ ) than the normotensive group. Nearly 47.5% of women in the high-risk group had a family history of high blood pressure, and 87.7% received prophylactic ASA treatment.

### *Regression analyses*

A regression analysis was first performed for all blood pressure readings taken with the Anura application (Table 8). Each blood pressure reading from the Anura application was then paired with the blood pressure measurement taken at the same antenatal visit using a manual cuff (Table 4 in *Study IV*). The regression analysis showed significant differences between Anura and manual cuff measurements in all trimesters for both the normotensive and the preeclampsia groups ( $p<0.05$  or  $p<0.001$ ), and in the high-risk group ( $p<0.001$ ) for SBP measurements in the second and third trimesters.

**Table 8. SBP and DBP for un-paired Anura measurements for each trimester**

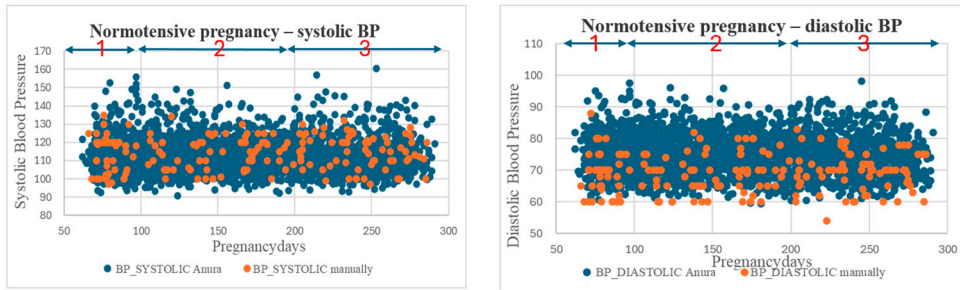
Characteristic/ Blood pressure	Normotensive	High-risk	Preeclampsia
Trimester 1 SBP min and max Mean $\pm$ SD	N=519* 96-156 73.9 $\pm$ 5.6	N=162 100-148 117.1 $\pm$ 8.7	-
Trimester 1 DBP min and max Mean $\pm$ SD	N=519 62-96 73.9 $\pm$ 5.6***	N=162 65-88 76.9 $\pm$ 5.4	-
Trimester 2 SBP min and max Mean $\pm$ SD	N=1268 91-160 112.4 $\pm$ 9.2*	N=315 94-150 114.8 $\pm$ 9.2***	N=11 101-144 116.7 $\pm$ 11.5*
Trimester 2 DBP min and max Mean $\pm$ SD	N=1268 59-98 74.4 $\pm$ 6.1***	N=315 60-95 77.1 $\pm$ 6.9	N=11 65-86 76.0 $\pm$ 7.0*
Trimester 3 SBP min and max Mean $\pm$ SD	N=997 93-153 112.9 $\pm$ 9.4*	N=293 93-148 114.1 $\pm$ 10.1***	N=640 31-160 120.2 $\pm$ 11.1***
Trimester 3 DBP min and max Mean $\pm$ SD	N=997 60-98 75.6 $\pm$ 6.5***	N=293 63-93 76.9 $\pm$ 6.7	N=640 63-96 79.3 $\pm$ 7.1***

\*=  $p<0.05$ ; \*\*\*= $p<0.001$ , 95% confidence interval. N=number of measurements. 1= first trimester (-13+6 GW), 2= second trimester (14+0-27+6 GW), 3= third trimester (28+1-42+0 GW), SBP= systolic blood pressure, DBP= diastolic blood pressure

The regression analysis for unpaired Anura measurements, presented in Table 8, was not included in the submitted article, as it was replaced by analyses that utilized paired blood pressure data from both Anura and manual measurements.

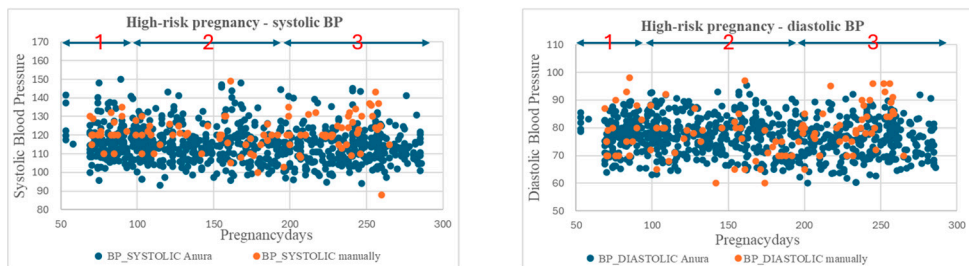
### Scatterplots

The scatterplots for normotensive women indicate that Anura tends to measure higher diastolic blood pressure (DBP) values compared to manual measurements, with several outliers observed in both DBP and systolic blood pressure (SBP) (Figure 7a). Additionally, no other visual differences in SBP or DBP measurements were observed across the three trimesters. The data points appear scattered without any discernible patterns, and no blood pressure values deviate significantly from the overall trend across the three trimesters. Furthermore, the distribution of data points does not show any indication of distinct clusters or uneven groupings (Figure 10).



**Figure 10.** Scatter plot distribution for all manual BP and Anura BP measurements in normotensive pregnancies. 1= Trimester 1, 2= Trimester 2, 3= Trimester 3

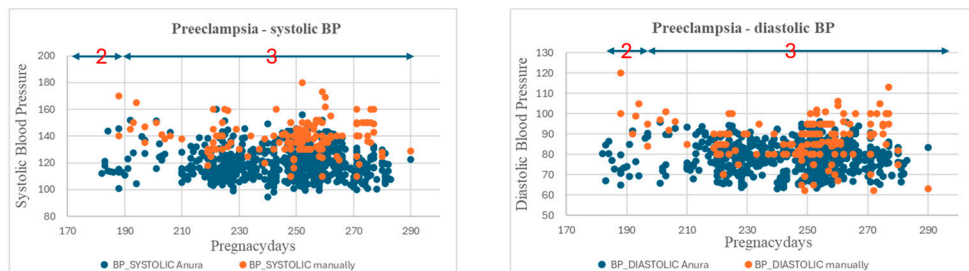
The scatterplots for the high-risk pregnancy group showed no apparent differences in BP measurements across the three trimesters (Figure 11). The data points are scattered without any clear pattern, and no blood pressure values deviated significantly from the overall trend. Although occasional outliers were present, the distribution of data points did not reveal distinct clusters or uneven groupings.



**Figure 11.** Scatter plot distribution for all manual BP and Anura BP measurements in risk pregnancies

The scatterplots for the preeclampsia group (Figure 12) indicate that the Anura application tends to measure lower SBP and DBP compared to manual blood pressure

measurements in the second and third trimesters. This discrepancy is most pronounced for SBP. Additionally, a few individual outliers are observed within the data.

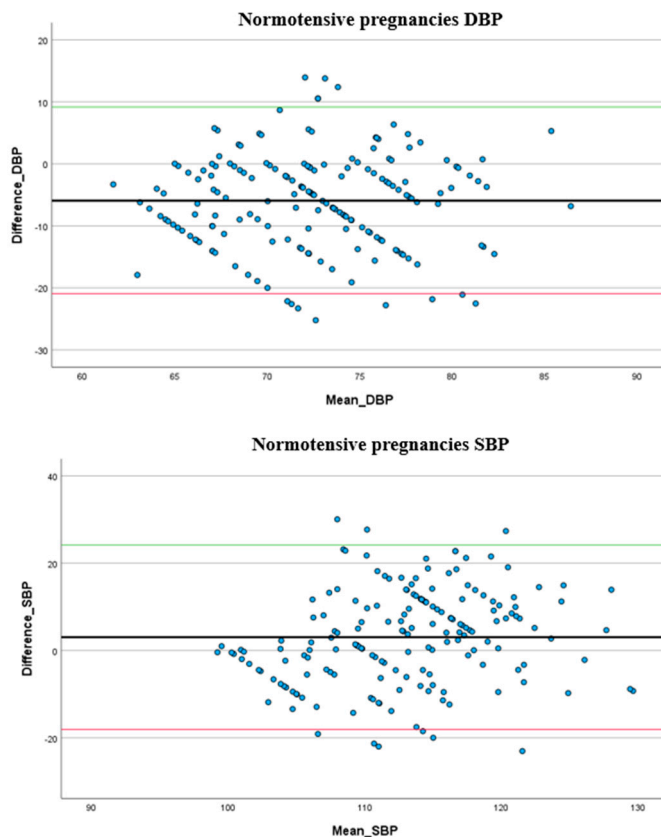


**Figure 12.** Scatter plot distribution for all manual BP and Anura BP measurements in preeclamptic pregnancies

These scatter plots were not included in the article as they only visually show the difference between the blood pressures. Instead, Bland-Altman analyses were included to show the numerical differences, as detailed below (Figure 13).

- In the normotensive group, the mean difference for SBP ( $SD \pm 7.7$ ) was 3.04, and for DBP, it was -5.93 ( $SD \pm 7.71$ ).
- In the high-risk group, the mean difference for SBP was -7.93 ( $SD \pm 11.0$ ), and for DBP, it was 1.29 ( $SD \pm 10.8$ ).
- In the preeclampsia group, the mean difference for SBP was 18.07, ( $SD \pm 18.1$ ) and for DBP, it was 8.19 ( $SD \pm 10.6$ ).

There was variation in the Bland-Altman plots regarding the upper and lower LoA for both the SBP and the DBP across all three groups.



**Figure 13.** Bland-Altman plot difference in DBP and SBP manual measurements and Anura in normotensive pregnancies.

For the Bland-Altman diagrams for high-risk pregnancies and preeclampsia, see *Study III*.

#### *ANOVA and Post-Hoc Test*

In the normotensive group, paired blood pressure measurements showed no significant differences when divided by trimester. ANOVA and post hoc tests (Table 9) showed no differences in the normotensive pregnant women, across the three trimesters ( $p=0.973$ ). In the SBP and the DBP, there were no differences between the three groups ( $p=0.242$ ). Thus, for the normotensive group, trimester did not have a significant effect on the differences between the two types of measurements for SBP and DBP.

The high-risk group showed no significant differences in SBP between the first and second trimesters ( $p=0.073$ ), but there was a significant difference between the first and third trimesters ( $p=0.042$ ). For DBP, there were no significant differences between the three trimesters ( $p=0.239$ ).

The preeclampsia group showed significant differences ( $p<0.001$ ) between the second and third trimesters for both SBP and DBP. Thus, for the preeclampsia group, gestational age had a significant effect on the differences between the two types of measurements for both SBP and DBP.

**Table 9. ANOVA univariate analysis of variance and Post Hoc-test for the three trimesters**

	Trimester 1	Trimester 2	Trimester 3
<b>Normotensive pregnancy (n)</b>	49	54	74
SBP Mean±SD	-2.94±10.90	-2.83±10.44	-3.26±11.07
DBP Mean±SD	4.55±7.16	5.82±6.01	6.94±7.71
<b>Risk-pregnancy (n)</b>	11	36	50*
SBP Mean±SD	-0.13±10.97	-8.63±9.82	-9.13±11.37
DBP Mean±SD	1.43±13.72	3.62±7.09	-0.41±12.25
<b>Preeclampsia (n)</b>	-	4***	125***
SBP Mean±SD		44.19±23.97	18.07±13.85
DBP Mean±SD		33.35±15.64	7.38±9.40

\*=  $p<0.05$ ; \*\*\*= $p<0.001$

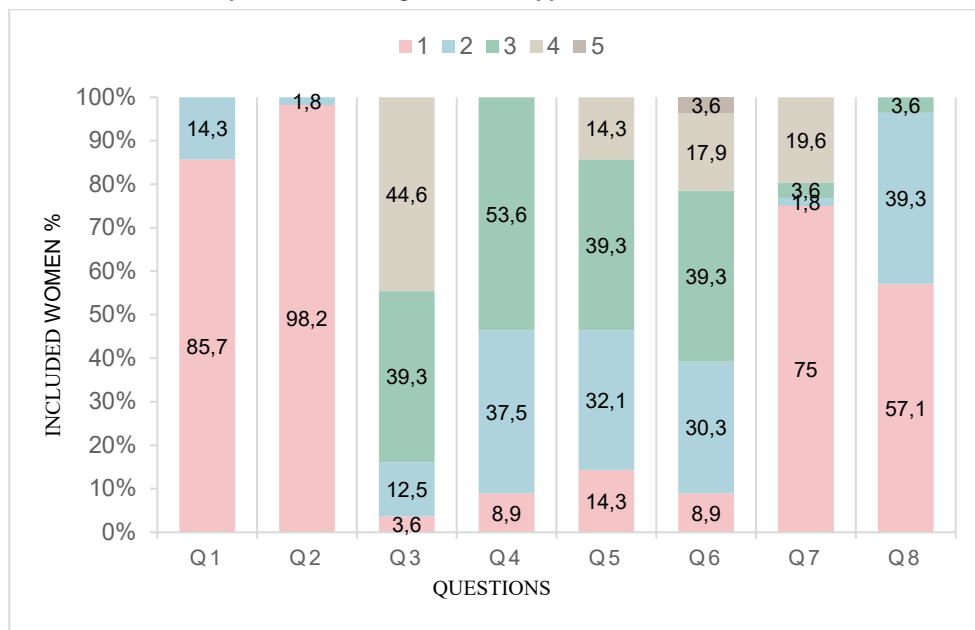
### *Experiences*

The response rate for the surveys evaluating participants' experiences with the Anura application was 31%, consisting of women with normotensive and high-risk pregnancies. Key findings indicate that most women, regardless of whether they had a normotensive or high-risk pregnancy, reported high satisfaction with the contactless measurement technology. Almost all women (91%) considered the application to be adequate or highly secure for use, and ~ 86% reported an increased understanding of their health status. Additionally, 85,7% expressed no concerns about privacy, and the majority found the application to be adequately or highly secure for use. These results indicate a strong willingness to recommend the application for use in both home and clinical settings. For more detailed information, see Box 5 and Table 10.

#### **Box 5. Survey questions**

Survey questions
1. Were you worried about your privacy while using the Anura application?
2. How did you feel about seeing your blood pressure results in the application?
3. Did using the application make you feel more responsible for your own health?
4. Did you feel safe using the application to measure your blood pressure?
5. Did the application help you feel more in control of your own health?
6. Did the application increase your understanding of your own health?
7. What was your experience of sitting still and looking into the camera during the measurement?
8. What are your thoughts on the length of time it takes to measure blood pressure in the application?

**Table 10. Women's experiences of using the Anura application**



Q= questions

In more detail, for Q1 and Q2, the only replies given were scores 1-2 (1: not concerned at all, 2: slightly worried). For Q3 replies were given for scores 1-4 (1: much more responsibility, 2: more responsibility, 3: somewhat more responsibility, 4: no more responsibility). For Q4 replies were given for scores 1-3 (1: a little bit safe, 2: safe enough, 3: very safe). For Q5 replies were given for scores 1-4 (1: much better control, 2: better control, 3: slightly better control, 4: no better control). For Q6 replies were given for all scores 1-5 (1: much better understanding, 2: better understanding, 3: somewhat better understanding, 4: no better understanding, 5: neutral). For Q7 replies were given for scores 1-4 (1: doing well, 2: it is somewhat unpleasant/uncomfortable, 3: it is unpleasant/uncomfortable, 4: neutral). For Q8 replies were given for scores 1-3 (1: it is just the right length, 2: it's okay, 3: it takes too long).

# Discussion

This thesis was conducted with the overall aim of increasing knowledge about preeclampsia from a patient perspective, with the goal of improving women's healthcare and psychological well-being during pregnancy as well as the postpartum period. By employing both qualitative and quantitative methods, the studies in this thesis have expanded our understanding of preeclampsia from the patient's viewpoint, revealing several valuable aspects that can improve the care provided to these women and their families.

## **Women's preferences and needs during and after childbirth in the context of preeclampsia**

Findings from *Studies I* and *II* highlight the gaps in the care and communication experienced by women with preeclampsia. Women reported receiving fragmented and inconsistent information about their condition, with a lack of detail regarding long-term health consequences and a desire for clearer explanations at the right time. They requested greater participation in care planning, something that was often lacking both during their hospital stay and postpartum. According to a report from the Swedish National Board of Health and Welfare, challenges remain in increasing the sense of security and participation among pregnant women and new parents [10]. By listening to and understanding women's perspectives, midwives, doctors, and other healthcare professionals can identify areas where care can be improved [184]. Clear communication and continuity in care are basic prerequisites for the patient to feel trust and security.

The interviews revealed that separation from their newborns, often admitted to the NICU, created additional stress and reinforced feelings of being deprioritized. This highlights the need for integrated care that focuses on the needs of both the mother and the newborn, with improved communication and continuity to reduce stress and promote well-being. Allowing mothers and babies to stay together after birth is not only safe but also conducive to a healthy attachment [185]. A systematic review concluded that effective communication between parents and healthcare providers is a key factor in ensuring parental well-being and satisfaction with care received during and after their infant's hospitalization in the NICU [186]. In *Studies I* and *II*, the



women also expressed a deep despair at being separated from their newborns. The Swedish National Board of Health and Welfare reports that joint care of mothers and their children is not possible in a third of Swedish hospitals [73], which should prompt policymakers to take action. Nevertheless, midwives and other healthcare professionals can still take concrete steps to improve communication, strengthen continuity of care, and promote well-being for women with preeclampsia.

Results from *Study II* showed that some women felt inadequately informed by their care providers, leaving them unable to actively participate in decisions about the progression of their labor and subsequent interventions. One woman's experience vividly illustrates this:

*"...nowhere in this whole process have I been involved ... I haven't been given a diagnosis ... the decision to be hospitalized ... the decision to be induced (for labor) ... nobody has explained the chain of events to me ... [crying] ... I had to accept all the decisions..."*

This case highlights a clear lack of consent and involvement in the decision-making process. Promoting woman-centered care and fostering collaborative decision-making between women and their midwives or other healthcare providers can help prevent such experiences. In the context of preeclampsia, this approach ensures that decisions such as those regarding medication management or the timing of childbirth are made jointly, aligning the woman's preferences with clinical best practices. Ultimately, this improves both the woman's experience and her health outcomes.

Developing personalized care plans and providing clear, consistent information about the expected steps in the process help address women's concerns and questions. Offering regular updates through face-to-face discussions and/or digital communication, when physical presence is not possible, ensures ongoing engagement, reassurance, and continuity of information. Assigning a designated midwife to be responsible for the patient throughout the hospital stay reduces fragmented communication and fosters a sense of continuity and trust. Moreover, providing access to counselors or psychologists, as well as implementing support groups for women in similar situations, can further enhance emotional well-being during postpartum care.

We can also create a calm and safe care environment with opportunities for privacy and rest. Additionally, midwives and other healthcare providers should facilitate the mother's involvement in her child's care, even under challenging circumstances, by supporting skin-to-skin contact, breastfeeding, or maintaining physical and emotional connection with the baby whenever possible.

I fully agree with what my opponent Mirijam Lukasse states on her international platform on obstetric violence:

*“I think it is important for midwives to consider all aspects of care to women in childbirth, including respectful and cultural appropriate care and offering women information if necessary so they can become active participants in their care”*

### **Screening for depression, anxiety, and co-parenting during and after pregnancy**

Globally, the prevalence of poor mental health is estimated to have increased by 30% during the last 30 years [187]. In Sweden, approximately 10–20 percent of pregnant or new mothers experience depression [188]. It is possible that a lack of consistent and repeated information may contribute to mental health problems among pregnant women and their partners. In *Study III*, we found that women with complicated pregnancies did not have higher incidences of postnatal depression and anxiety symptoms compared to the general population. Furthermore, there were no significant differences in levels of depression and anxiety symptoms between preeclamptic women and their partners after birth. However, preeclamptic women did exhibit higher levels of typical depressive symptoms two months after giving birth compared to normotensive women. Research regarding the association between preeclampsia and postnatal mental health has shown varying results [64]. Several studies indicate that women who experience preeclampsia are at an increased risk for both postpartum depression [189] and anxiety, likely due to the stressors and the impact that the complication can have on the birth experience and early parenthood. The lack of clear evidence regarding the relationship between preeclampsia and mental health may stem from differences in study populations, research methods, or the timing of follow-up assessments.

Results from *Study III* also revealed that both women and men exhibited atypical symptoms of depression and anxiety. Atypical symptoms, such as irritability, fatigue, and somatic complaints, are often less recognized than typical depressive symptoms, leading to underdiagnosis. Traditionally, the focus has been on women's mental health postpartum, potentially overlooking the symptoms in men, who may also suffer from depression and anxiety related to pregnancy-related trauma, their new roles, and responsibilities. Hormonal changes and physical recovery in women can exacerbate atypical symptoms. These results emphasize the need for antenatal care that involves both parents, normalizes conversations about mental illness for men, and acknowledges atypical symptoms in women. A more holistic model of care is required.

At six months postnatal, depression symptom levels were comparable between women and their partners from both complicated and uncomplicated pregnancies. This may be because time allows for emotional recovery, parents have had an opportunity to

adjust to their new roles, and support from their environment helps alleviate the burden. In addition, the development of effective coping strategies and the normalization of symptoms may play an important role in reducing depressive symptoms over time. Alternatively, this could be attributed to the limited sample size or the possibility that individuals who faced greater challenges at T1 may have dropped out of the study. Interestingly, the results showed that women and partners with higher education reported higher levels of depression and anxiety symptoms. This is confirmed by another study [155] but contradicts the general assumption that lower education levels would imply greater vulnerability to mental illness [190]. Caution is warranted given the limited statistical power. However, this may indicate that individuals with higher education have higher expectations of parenthood and themselves, which may create greater feelings of inadequacy or stress. It may also reflect an increased awareness and a greater willingness to report mental health symptoms in this group, rather than an actual increase in symptoms.

Moreover, in women with severe preeclampsia, the severity of the condition or the need for NICU care did not consistently correlate with higher levels of mental health problems in either the women or their partners. This could be due to insufficient statistical power, or it may suggest that couples who experienced more severe complications, such as severe preeclampsia or longer NICU stays, developed stronger coping strategies and psychological resources to manage their crisis. Severe cases might also receive more support from healthcare providers and their environment, or it is possible that parents who experienced the greatest stress did participate in the follow-up studies. Previous Swedish studies on complications related to preeclampsia and maternal mental health have found no significant difference in the prevalence of anxiety and depressive symptoms between preeclamptic women and a normotensive group [67]. Conversely, other studies have shown that the prevalence of depression increases with the severity of preeclampsia symptoms [189, 191]. Women with a history of preeclampsia who experienced adverse neonatal outcomes, such as low birthweight or the need for admission to the NICU, were found to be at a higher risk of developing anxiety and/or depression postpartum. A meta-analysis further indicated that women with a history of preeclampsia are at a greater risk of developing mental health disorders, including depression and anxiety [62]. A Danish cohort study reported that preeclampsia increased the risk of depression by a factor of 2.58 [192]. However, the findings in *Study III* did not align with these earlier results. Other studies have also confirmed that preeclamptic women do not have a higher risk of depression or anxiety compared to normotensive women [67, 193]. Nonetheless, a history of prior mental health disorders and a high EPDS score at enrollment in antenatal care were significant

predictors of postnatal depression [193]. This highlights the importance of identifying women with a history of depression during maternity care.

In terms of co-parenting, the most significant predictor of depression and anxiety symptoms was the level of support and emotional closeness between partners. For women, higher levels of anxiety were associated with their partners feeling less supported and emotionally connected in the co-parenting relationship. In other words, when partners felt less connected or supported by each other, it contributed to higher levels of anxiety in women. A close and supportive partnership promotes psychological well-being, helping parents cope with stress and challenges. Conversely, when partners feel unsupported, it can lead to isolation and feelings of inadequacy, thereby increasing anxiety levels in women. This emphasizes the importance of strengthening co-parenting relationships to prevent mental health issues.

A qualitative study on birth experiences following preeclampsia revealed that most women expressed anxiety and worry upon receiving the diagnosis [6]. However, by six months postnatal, these concerns typically subsided as women adapted to parenthood and gained reassurance from their own health and the well-being of their baby. This finding that depression symptoms decreased over time contradicts earlier research but aligns more closely with our data [97, 98, 103, 194]. It appears that in most cases, symptoms naturally resolve over time as couples adjust to their new roles and manage the stress of a complicated pregnancy, such as preeclampsia. This reduction in symptoms underscores the importance of continuous support and follow-up during the first six months postnatal. Early identification and treatment of mental health symptoms can facilitate faster recovery. If both women and their partners have better mental health over time, it can contribute to improved bonding and cooperation in parenting, thus benefiting both parents and children.

Further research is needed to better understand how midwives deliver woman-centered care in complicated pregnancy scenarios [195]. Woman-centered care is essential for providing holistic, empathetic, and personalized support to women with preeclampsia. This approach addresses not only the medical aspects of the condition but also the psychosocial and emotional needs of the woman and her partner. By educating and empowering women with information about their condition and respecting their choices, caregivers can help reduce anxiety, enhance their sense of control, and improve their overall care experience. Such care fosters dignity, emotional support, and better outcomes for both mother and baby, contributing to higher satisfaction and quality of life during and after pregnancy. Additionally, women feel more empowered and confident, which can reduce fear and anxiety about future pregnancies and childbirth.

### Home blood pressure measurement and new technology involving the patient

Home blood pressure measurements taken by pregnant women using a validated standard cuff have shown lower readings than those taken in clinical settings, along with a reduced need for antenatal care [196, 197]. However, many pregnant women find this method uncomfortable, inconvenient, and cumbersome, which leads to infrequent use and, consequently, failure to detect significant changes in blood pressure. The findings from *Study IV* suggest that the accuracy of the Anura application, compared to manual blood pressure measurements, remained reliable throughout pregnancy in normotensive women, confirming its usefulness for this group. However, significant discrepancies were noted in high-risk pregnancies and among women diagnosed with preeclampsia, indicating that the current algorithm is not sufficiently reliable for use in these patient categories. The blood pressure algorithm showed limitations in capturing individual variations in blood pressure, a finding also supported by a previous study with a similar design [198].

Women who used the Anura application generally had a positive experience. They appreciated the opportunity to use the technology and reported a sense of increased control over their health. E-health has the potential to foster optimism for a more inclusive and connected healthcare system, offering benefits such as enhanced patient engagement, personalized care, and improved access in remote or low-resource areas. It is anticipated that e-health will help meet the rising demands from population growth and the increased need for chronic condition monitoring [199]. The Anura application is particularly interesting as it allows women to measure their blood pressure without using a traditional cuff. Digitalization offers new opportunities for healthcare providers. Several systematic reviews have explored digital solutions aimed at improving hypertension management by supporting self-management [200, 201]. These interventions often incorporate a range of functions and strategies designed to engage patients effectively. Common components include education on high blood pressure and healthy lifestyle choices, supplemented by features such as self-monitoring, goal setting, reminders, motivational support, and access to social or professional assistance [202, 203]. Through digital services, individuals can monitor their health and access new tools for self-care. A recent Swedish national study, SCAPIS (Swedish CArdiopulmonary bioImage Study), utilizes Artificial Intelligence (AI) technology to identify risks of cardiovascular disease (CVD). The study has shown promising results in predicting individuals at risk for heart, vascular, or lung diseases, enabling preventive measures before these conditions develop. One innovative aspect of this study involves assessing microcirculation in the skin of the forearm using light, providing a relatively low-cost method for evaluation [204]. Although AI is on the rise, its application in measuring blood pressure in pregnant women remains limited.

## **How can care be improved during pregnancy and postpartum?**

Inadequate pain management in the immediate postpartum period can lead to increased blood pressure, heart rate, cardiac output, and maternal myocardial oxygen consumption. These factors collectively elevate the risk of maternal cardiac decompensation during this critical time [205]. Therefore, it is crucial that women with preeclampsia receive adequate pain management, both during childbirth and postpartum. Breastfeeding for at least six months is linked to a lower risk of postpartum hypertension [206] and has been shown in observational studies to reduce the risk of CVD for the mother [123]. Women who breastfeed show improvements in metabolic and inflammatory markers, which may help explain the documented benefits for future cardiovascular health [121]. To improve care, focus can be placed on promoting and supporting breastfeeding through individualized counseling and integrated postpartum care. Regular health checks that include blood pressure monitoring and metabolic health can help women prevent cardiovascular risks.

The postpartum phase is a high-risk period for maternal decompensation in preeclamptic patients, as the organs may become unable to maintain normal function due to the strain of overload. Research confirms that the prevalence of heart failure in preeclamptic women is relatively underexplored and underreported [207]. Preeclampsia is a significant risk factor for future heart failure, which remains the most common cardiovascular complication during pregnancy and the postpartum period [208]. Healthcare professionals must recognize that women with preeclampsia may experience neurocognitive symptoms related to cerebral swelling, which occurs due to fluid retention and high blood pressure. This swelling can impair brain function and lead to cognitive and behavioral changes. Women with preeclampsia may experience difficulties with memory, particularly short-term memory. These women may struggle to recall recently acquired information or forget recent actions or statements, which can make them appear confused or disoriented. Due to cerebral swelling, these women may also find it difficult to process and absorb new information and attempts to understand or process new facts or instructions may feel overwhelming. Given memory issues and difficulties with information processing, it may be necessary to repeat information several times. Simple and clear instructions are essential, and healthcare providers should be patient to ensure that the woman understands. These cognitive limitations are direct consequences of preeclampsia and may indicate serious cerebral involvement. It is crucial that healthcare providers are aware of these symptoms and approach them with care and patience. Additionally, when relatives are informed about these cognitive symptoms, they can provide reminders and explanations, helping the woman better understand her condition and symptoms.

Women who experience complications during their first pregnancy or childbirth are less likely to have additional children [209]. This is particularly true for women who suffer from heart problems, ruptured uterus, severe psychiatric conditions and, to a lesser extent, severe preeclampsia and blood clots, which are also linked to a lower likelihood of subsequent pregnancies (ref). Therefore, adequate support and follow-up in maternity care are critical for women who have had serious complications during pregnancy or childbirth. Many women report that they did not fully process their traumatic experiences related to complicated pregnancies. Here too, postpartum counseling should include a reflective review and follow-up to ensure the woman receives the necessary psychological support before attempting pregnancy again.

According to the Swedish national guidelines [12], all women with preeclampsia or gestational hypertension should have their blood pressure monitored 5–7 days postpartum. For those continuing antihypertensive treatment, a follow-up with a physician is recommended within two weeks, followed by another visit 8–12 weeks postpartum. However, practical implementation often falls short due to resource limitations. After 12 weeks postpartum, women typically transition out of regional care, and follow-ups are transferred to local healthcare centers, where expertise in managing such conditions may be limited. Women who develop hypertension or preeclampsia but do not require pharmacological treatment are advised to undergo regular monitoring due to their increased risk of developing hypertension and cardiovascular disease later in life. These women are often referred to local health centers, but limited knowledge among general practitioners can lead to inadequate follow-up care. Research highlights the significant need for improved postpartum care for these women, including systematic and comprehensive follow-up plans at later stages.

In a postpartum follow-up study [210], a woman with a previous history of preeclampsia said.

*“I don’t think you can absorb that information until you’re ready for it. And I don’t think you’re ready until you’ve given birth, recovered from preeclampsia, and some time has passed. Because you’re in quite a state of shock afterwards. I was at least. I was shocked at how things could go so fast and so wrong.”*

According to the results of *Studies I and II*, many women with preeclampsia are unaware of the increased health risk for CVD and stroke and do not understand the importance of monitoring their blood pressure throughout their lives. The Swedish National Board of Health and Welfare’s investigation shows gaps in postpartum care, highlighting that healthcare providers often fail to detect mental illness and breastfeeding issues after childbirth. Moreover, women are often unclear where to turn for help.

There is also a need for additional screening regarding women's mental health and signs of depression after a pregnancy complicated by severe preeclampsia. Our results in *Study II* [183] suggest that midwives and obstetricians should pay more attention to women's emotional stress, their need for personalized and detailed information, and ensure a comprehensive follow-up plan postpartum. *Study III* indicates that support for families affected by preeclampsia should also focus on the co-parenting relationship during postnatal follow-up, including both women and their partners. This study highlights the importance of addressing co-parenting dynamics in postpartum care for families affected by preeclampsia, recognizing its impact on both parents' mental and emotional health. Supporting both parents in their shared role can help reduce the risk of anxiety and depression, promoting more harmonious family dynamics. Key interventions include couples therapy to improve communication and education on parenting strategies to manage stress and conflict. The finding that perceived support and closeness in co-parenting was the strongest predictor of mental health, while factors such as NICU stay and preeclampsia severity were not, underscores the importance of psychosocial support. If confirmed, this suggests that postnatal care should adopt a holistic approach that strengthens co-parenting dynamics to reduce mental health risks and enhance family well-being. A potential clinical recommendation is to implement standardized preeclampsia education early in pregnancy to raise awareness of its symptoms. Such an educational program should be assessed through intervention-based research.

In *Study IV*, several (n=25) women either lacked a registered diagnosis of preeclampsia or hypertension in their medical records or had an incorrect ICD-10-SE code (see supplementary Table S1). This means that the number of women who develop high blood pressure during pregnancy or postpartum is inaccurately recorded in the Swedish national registry, putting these women at risk of not receiving appropriate treatment in future pregnancies. In our study, 12% of the 288 women included did not receive the correct diagnosis. In Sweden, there are approximately 105,000 births per year. If 12% of women with high blood pressure during pregnancy are missed, this would amount to approximately 12,600 women per year who are not receiving appropriate follow-up postpartum and may be unaware they had hypertension or preeclampsia during pregnancy. In addition, this leads to incorrect statistics being reported in the national pregnancy registry.

*Studies I and II* have played a pivotal role in integrating the patient perspective into the Swedish national guidelines for hypertensive disorders in pregnancy [12]. The inclusion of midwives in the Swedish Society of Obstetrics and Gynecology's Work and Reference Group for Preeclampsia, ARG, has facilitated a collaborative approach that enhances healthcare delivery from the patient's perspective. Moreover, this group has



spearheaded the development of new regional guidelines that provide patient information at crucial stages, including diagnosis, discharge, and follow-up, as well as guidelines for ASA prophylaxis [13]. The information is currently available in both Swedish and English, with plans for translation into additional languages underway.

The patient perspective has been integral to educational materials about preeclampsia, especially through the ARG group. This approach has been positively received, enriching healthcare professionals' training by providing a deeper understanding of patients' experiences. As a result, I have contributed a chapter on the patient perspective for a forthcoming book on preeclampsia aimed at healthcare professionals, scheduled for publication in Spring 2025. This represents an important step toward integrating patients' voices into the professional context. A particularly significant consequence of my research is the establishment of a patient association founded by five women who had preeclampsia. I had the opportunity to assist from the start and provide guidance. Together, we have developed strategies to connect with this patient group, established media contacts, and engaged in the development of new guidelines and the Swedish National Board of Health and Welfare's consultation response. Their work is invaluable in building a supportive community and increasing awareness and support for women experiencing preeclampsia.

Collaboration with the patient association is vital for improving care for this patient group. Patients' experiences are crucial for enhancing care, and it is equally important for healthcare personnel and researchers to receive feedback, recognizing the impact of their work on the care provided to women with preeclampsia and their families. A recently published article by a woman discussing her experience with preeclampsia and stillbirth emphasizes the emotional toll of her journey, the importance of research in understanding and treating preeclampsia, and the healing power of sharing her story [211]. She remarked:

*“... we never underestimate the power of the work that you do, and as a group of people what you can do together “.*

Midwifery, when practiced by educated, trained, licensed, and regulated midwives, is associated with more efficient resource utilization and improved outcomes. Our findings advocate for a systemic shift in maternal and newborn care, moving away from pathology identification and treatment for a minority to providing skilled care for all. This transition emphasizes preventive and supportive care, empowering women through respectful relationships tailored to their needs, and promoting normal reproductive processes. First-line management of complications and accessible emergency treatment are also essential. Midwifery plays a pivotal role in this approach, highlighting the need for effective interdisciplinary teamwork across both facility and

community settings. Future planning for maternal and newborn care systems can benefit from utilizing a quality framework to guide workforce development and resource allocation [212].

The diagnosis of hypertension during pregnancy significantly impacts women. Key findings for midwifery practice involve ensuring access to multidisciplinary continuity models of care and facilitating support for these women [6]. Postpartum care for women with hypertension during pregnancy should be enhanced by ensuring that all affected women receive follow-up, ideally six months postpartum. This follow-up should include personal consultations with highly skilled midwives who can provide comprehensive information, address questions, and facilitate referrals to an obstetrician when necessary.

# Summary of findings

The main findings of this thesis are shown in Table 11:

**Table 11. Summary of the findings in this thesis**

Study	Results
I	The women's experiences of preeclampsia were characterised by a condition of uncertainty, meaning that it was an unexpected, an unknown situation. This essence was generated from five identified constituents: 1) incomprehensible diagnosis, 2) ambivalent feeling when the unexpected happens, 3) confusing contradictory messages, 4) appreciated support from the midwife, and 5) the need for continuous information
II	Suffering from preeclampsia was experienced as stressful, as illustrated by four themes: 1) fragmented information, 2) lack of care planning, 3) separation postpartum, and 4) overall stress and worry.
III	The proportion of women with preeclampsia and their partners experiencing clinical levels of postnatal depression and anxiety was similar to community samples (women without preeclampsia, and their partners), with symptoms decreasing over a six-month period. Notably, however, atypical symptoms of depression did not decrease among women. Perceived support and closeness in co-parenting emerged as the strongest predictor of symptom levels, while women's anxiety influenced their partner's sense of support and closeness. Contrary to other research, the severity of preeclampsia or the need for NICU care did not predict more severe symptoms. However, women with higher education levels showed more severe mental health challenges.
IV	The Anura application worked well in pregnancies with normal blood pressure; however, in high-risk pregnancies and among women with preeclampsia, there was a significant difference between blood pressure values obtained with Anura compared to manually measured blood pressure. For normotensive women, no differences were seen in the blood pressure measurements in the three trimesters, which showed that Anura was effective in this group. In high-risk pregnancies, there were no differences for systolic blood pressure in the first and second trimesters, but a significant difference emerged between the first and third trimesters. Women with preeclampsia showed significant differences for both systolic and diastolic blood pressure during the second and third trimesters. Despite these differences, there was high satisfaction with the contactless measurement technology, indicating a willingness to recommend its use in future home and clinical settings.

# Clinical implications

Further research should explore whether providing both written and verbal information about preeclampsia during hospital admission, and reinforcing it on multiple occasions, could enhance women's understanding and ability to manage their situation. Our findings indicate that midwives and obstetricians need to focus more on addressing the emotional strain experienced by these women, offering tailored and comprehensive information, and ensuring a clear and detailed plan for postpartum follow-up visits.

In general, women were positive about using their smartphones to monitor their blood pressure. Our aspiration is for the Anura application to evolve into a comprehensive tool that can support all pregnant women, especially those with high-risk pregnancies, not only to predict elevated blood pressure at earlier stages, but also to identify those at risk of developing preeclampsia.

Furthermore, I have engaged leading figures in maternity care and informed midwives and other healthcare providers about the association to promote cooperation. Through lectures, both in clinics and in midwifery training programs, I have been able to increase the understanding of research results and strengthen the relationship between healthcare staff and the patient organization, which can contribute to improved care for patients. In collaboration with colleagues, I have also included the patient perspective in national and regional guidelines, incorporating insights gained in the two first studies.

However, many women have been incorrectly classified in Obstetrix, either receiving the wrong diagnosis or none at all. This procedure must be reviewed to ensure healthcare providers or responsible parties make accurate diagnoses in the future. If healthcare providers fail to make the correct diagnosis, this leads to errors in the registries and compromises the validity of future research studies.

The importance of an active patient association cannot be overstated. With strong dedication, women and their families can access the support that current care systems often lack. Additionally, the association plays a crucial role in disseminating accurate information and dispelling myths and misconceptions that may easily arise. This empowers well-informed patients to understand their risks and advocate for appropriate preventive treatments, as well as proper care during and after pregnancy. Moreover, a

patient association can influence policymakers to ensure that the necessary infrastructure is in place to address evolving medical needs. Finally, the association can emphasize the need for increased funding in research focused on women's sexual and reproductive health.

I plan to conduct a pilot study focusing on preeclamptic women, with the goal of enhancing postpartum follow-up for those who had hypertension during pregnancy.

# Conclusions

Overall, this thesis has contributed to an increased understanding of the patient perspective among women with preeclampsia. It also offers new insights into the need for more individualized care, structured postpartum follow-ups, and improved communication strategies to better support women and their partners during pregnancies complicated by preeclampsia. The results from the Anura application show promising results, allowing for the introduction of E-health into maternal antenatal care, empowering women to take greater responsibility for their health, both during and after pregnancy.

# Future perspectives

- Women with preeclampsia and their partners often express a need for more support, particularly due to the stress and separation from their newborn. Future studies should focus on how healthcare providers can better support both mothers and partners during this challenging period.
- Partners, including fathers and co-mothers, may also experience perinatal mental health challenges. Future research should explore these experiences to help healthcare providers better identify the risk of depression and offer targeted support for both parents, particularly in high-risk pregnancies. Additionally, there is a need to investigate the specific co-parenting support required during the postnatal period to enhance the well-being of both parents and promote effective shared caregiving.
- Artificial Intelligence is upcoming but has so far had limited application in measuring blood pressure. Future studies should focus on refining the Anura application's settings by using data from high-risk and preeclamptic pregnancies to improve its accuracy for all pregnant women. It would also be valuable to develop a prediction model that can alert and warn women when too many factors indicate a worsening of their health situation.
- A follow-up aim for *Study IV* is to develop a prediction model, a statistical tool designed to forecast future outcomes based on historical data and specific variables. For example, this model should be able to predict the likelihood of a pregnant woman developing preeclampsia by analyzing factors such as age, blood pressure, genetic markers, and other relevant clinical variables measured by the AI algorithm. The model could be trained on available datasets where outcomes are already known and then tested on new data to evaluate its predictive accuracy. A robust prediction model could enable early identification of high-risk patients, facilitating more informed decisions regarding treatment and follow-up care. However, this aspect will be addressed in a future project, investigating parameters to develop a prediction model that alerts and warns women when too many factors indicate a worsening health situation.

- There is a need for more systematic postpartum follow-up for women after a pregnancy complicated by preeclampsia [210], since the risk of cardiovascular disease is so much higher for these women. The knowledge that these women have an increased risk of developing cardiovascular disease and stroke later in life is relatively new. More research is needed, but healthcare systems should already introduce systematic follow-up for affected women. This should include providing information, offering lifestyle advice, and helping them understand the long-term health risks they face.



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# Appendices

## Appendix A



### The experience of provided information and care during pregnancy and postpartum when diagnosed with preeclampsia - A qualitative study\*

MARIA E. ANDERSSON<sup>1,2</sup>, CHRISTINE RUBERTSSON<sup>1,2</sup> AND STEFAN R. HANSSON<sup>1,2</sup>

#### Conclusions

- The women experienced fragmented obstetrical care and information when diagnosed with preeclampsia.
- The women experience a lack of knowledge about preeclampsia and the long-term health risks.
- Preeclampsia can be an unexpected and frightening experience that all healthcare professionals must be aware of.
- Women need more support due to increased stress, anxiety and a despair over being separated from their newborn babies.

#### Method

A qualitative study was conducted with semi structured face to face interviews with 15 women diagnosed with preeclampsia. The transcribed text was analyzed using content analysis.

#### Results

The women expressed a general lack of information, also described as fragmented. Suffering from preeclampsia was experienced as stressful, illustrated in four themes

Themes	Sub-Themes
<b>Fragmented information</b>	Missing Overall Information Lack of Knowledge and Understanding of Health risks Inconsistent Information Difficulties to "take in" Information
<b>Lack of care planning</b>	Individualized Plan for Treatment and Follow-up Timing and involvement in Care planning
<b>Separated postpartum</b>	A Feeling of Coming in Second Place A Despair of Being Separated from the New-born
<b>Overall stress and worry</b>	Experiencing Stress and Worry A Request for Both Oral and Written Information

#### Background

Despite preeclampsia being one of the most severe obstetrical complications there is only scant research describing women's experiences of preeclampsia and care. These studies highlights an unmet need for more information and understanding about preeclampsia. The aim of the study was therefore to explore women's experiences during pregnancy and the postpartum period regarding the provided information and care when diagnosed with preeclampsia.

"...that they explain even more ... even if they ask me... "have you understood" ... but I don't know what to ask."

"... nowhere in this whole process have I been involved about ... that I haven't been given a diagnosis... the decision to be hospitalized ... the decision to be induced (for labor) ... nobody has explained the chain of events to me ... [crying]... I had to accept all the decisions."



#### What's next?

Future research will investigate specific care planning and follow up postpartum to improve care for women with a pregnancy complicated by preeclampsia

#### Contact

<sup>1</sup> Department of Obstetrics and Gynecology, Institution of Clinical Sciences Lund, Lund University, Sweden.

<sup>2</sup> Skane University Hospital (SUS), Maine/Lund, Sweden.

<sup>3</sup> Department of Health Sciences, Medical Faculty, Lund University, Lund, Sweden.

Maria Andersson: maria.andersson.5171@med.lu.se

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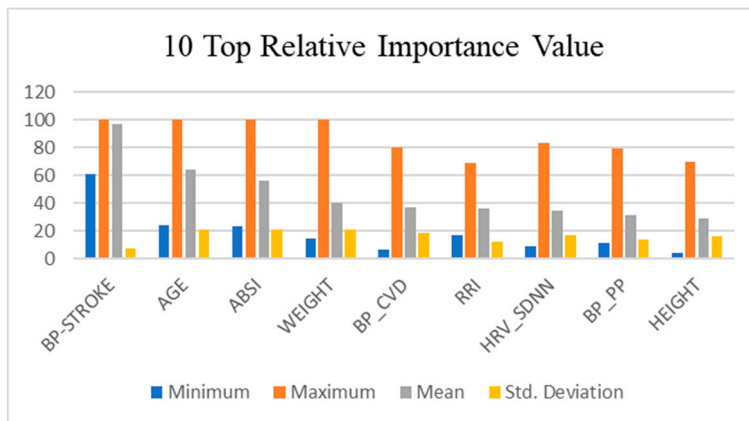
## Appendix B

### AI prediction model

There are other measured variables (n=31) in Anura that could potentially be used to develop a predictive model. This model could provide warnings to women, encouraging them to seek care when necessary. These variables will be studied in future studies.

Can the Anura TOI variables identify women at risk for preeclampsia in the first, second, and third trimesters and be used as a screening tool without additional measurements? How good is the model and how much variance does it have?

The Anura TOI system is capable of making several physiological assessments and can predict over 30 different variables. The prediction model in Figure 14 shows the top 10 most important variables. Table 12 shows descriptive statistics from model training using the 31 variables in Anura. The model shows that Anura TOI can distinguish between the groups. The top three predictors are: stroke (mean  $97.1 \pm 7.2$ ), age (mean  $64.6 \pm 21.4$ ), and the Anura Body Shape Index (ABSI) (mean  $56.6 \pm 18.9$ ). For other variables, see Table 6. The percentage of incorrect predictions for all variables in the model ranged from a minimum of 25.5% to a maximum of 35.4% (mean  $29.5 \pm 2.2$ ). The case processing summary for the training set was 69.3%, and for the testing test, it was 30.7%.



**Figure 14.** Top 10 Relative importance values from Anura machine learning with mean and SD, BP=blood pressure, ABSI= Anura body shape index, CVD= Cardiovascular disease risk RRI= Beat to beat interval, PP= Pulse pressure

**Table 12. Relative importance values in % from Anura machine learning for all women**

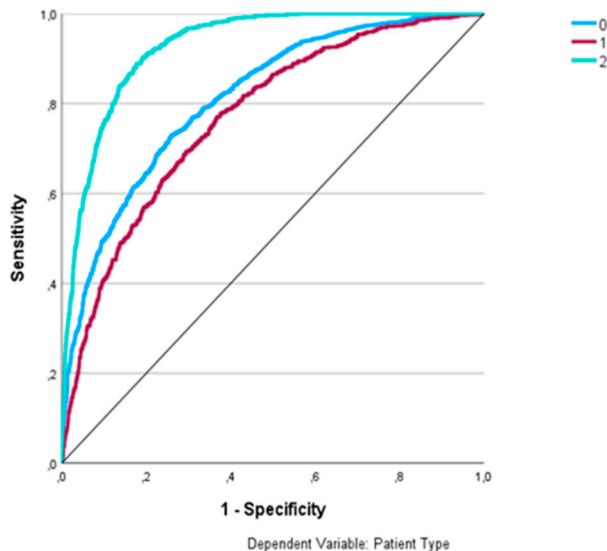
Value	Minimum	Maximum	Mean	Std. Deviation
BP-STROKE	60.9	100	97.15	7.234
AGE	24,2	100	64.61	2135
ABSI	23,3	100	56.64	21.34
WEIGHT	15	100	39.97	21.22
BP_CVD	7	80,5	36.9	18.49
RRI	16,8	69,1	36.42	12.27
HRV_SDNN	8,9	83,8	34.38	16.99
BP_PP	11,3	79,2	31.26	14.047
HEIGHT	4	69,6	29.42	16.46
ROI21_TOI	5,7	80,8	28.60	17.17
ROI19_TOI	7,2	59,1	28.16	12,125
BMI_CALC	8,7	80,5	36.95	18.49
BP_HEART_ATTACK	4,3	68,6	27.6	13.83
VITAL_SCORE	8,6	44,2	22.71	8.70
WAIST_CIRCUM	5	53,3	23.84	9.77
BP_DIASTOLIC	4	65,3	21.34	10.21
BP_SYSTOLIC	2,4	80,1	21.16	13.55
WAIST_TO_HEIGHT	4,2	52,2	21.09	11.48
MSI	3,6	45,7	20.54	10.33
PHYSIO_SCORE	4,6	79,2	19.54	13.33
BP_MAP	5,3	66,7	19.85	13.39
BP_TAU	3,1	45	18.26	9.72
HEALTH_SCORE	3,4	37,8	17.54	8.98
MENTAL-STRESS INDEX	3,8	38,5	17.47	8.55
ROI23_TOI	3,9	34,5	17.36	8.23
SNR	4,5	49,4	17.22	9.85
BR_BPM	3,1	55,5	17.1	11.29
HEART_RATE	3,9	38,7	16.09	8.61
BP_RPP	2,8	33,6	15.4	7.66
BP_HEARTZ	3,1	55,3	15.27	9.52
HR_BPM	4,4	48,1	15.16	9.66

BP=blood pressure, ABSI= Anura body shape index, CVD= Cardiovascular disease risk , PP= Pulse pressure, RRI= Beat to beat interval, ROI19\_TOI=Blood flow wave form index for one region of the face, SNR= Signal to noise ratio of the blood flow signals

Figure 15 shows the receiver operating characteristic (ROC) curve and area under the curve (AUC) for normotensive pregnant women, high-risk pregnancies, and the preeclamptic group. The ROC AUC indicates how well the model can distinguish between these three groups. The machine learning model predicts women at high risk for preeclampsia and has a ROC AUC for the normotensive group at 0.81, the risk group at 0.77, and for the preeclamptic group at 0.93.

If  $AUC=1$  (100 percent), then the test gives perfect answers. If  $AUC<0.5$  (50 percent), the test performs no better than chance.

An ROC curve is a graphical representation of the predictive power of a classification model with a binary outcome. It is generated by plotting the true positive rate (y-axis;  $FP/(FP+TN)$ ) against the false positive rate (x-axis;  $TP/(TP+FN)$ ). The true and false positive rates evaluate the accuracy of the model's classifications. It is the probability in which the model correctly or incorrectly classifies the individual respectively, 0.69.



**Figure 15.** The ROC curve for the three groups  
0= normotensive pregnant women, 1=risk pregnancy, 2=preeclampsia

### Machine learning in the three groups across the three trimesters

Then we did a prediction model for the second and third trimester. Data will be presented in future studies.

# Till dig som haft preeklampsi

Har en haft preeklampsi, eklampsi eller HELLP så är det väldigt viktigt att kolla sitt blodtryck minst en gång om året.

**Varför?** Du har minst dubbel så hög risk för hjärt- och kärlsjukdom efter att du haft någon form av preeklampsi. Du bör följa ditt blodtryck årsvis på till exempel vårdcentralen eller hälsocentralen även om det efter förlossningen gått tillbaka och du befinner dig inom gränsvärden för normalt blodtryck.

Läs mer på [preeklampsi.se](http://preeklampsi.se)



**Preeklampsiföreningen**

Patientföreningen för preeklampsi, eklampsi och HELLP



# Appendix D

## Nedladdning av Anura applikationen och enkäter

### Installation av Anura i Iphone och Android

1. Laddar ner Anura lite från App store eller Anura från Google play på telefonen.
2. När appen är nedladdad, innan ni loggar in i Anura, OBS! stäng appen.
3. Öppna din kamera och scanna QR koden för studien.



Om du inte kan godkänna appen ladda ner en QR läsare och försök igen.

4. Nu kommer Anura upp och den säger **close app**.
5. Stäng appen och öppna sedan appen på din telefon.
6. Logga in i Anura och skriv mailadress och lösenord, som du fått av barnmorskan. **Log in** INTE sign up. Det ska stå Lunds universitet, Lund eller Anura när du loggat in. Gör det inte det scanna QR koden igen!
7. Skriv in ålder, kön, längd, vikt, om du röker, har högt blodtryck eller har diabetes och spara (save profile).
8. Scanna ansiktet för blodtrycket (tar 30 sekunder).

Nu kommer det upp en cirkel du ska scanna ditt ansikte i. Håll telefonen stilla i väl upplyst rum. Minst 3 gröna stjärnor ska det synas för att blodtrycket ska bli rätt. Du ska ha suttit och vilat minst 5 minuter innan du skannar ansiktet.

Nu visas din puls och blodtryck i telefonen och när du skrollar framåt ser du andra uppgifter, tex risk för hjärt- och kärlsjukdomar.

Skrolla fram till enkäter (surveys) och tryck på Agree. Nu kommer enkäterna upp. **Record blood pressure**” och skriver in blodtrycket som barnmorskan mätt med blodtrycksmanschetten och klickar sedan i **Continue**. Nu är det klart. Klicka på back och Done. Nu är du åter i cirkeln för att scanna ansiktet. Stäng appen.

Följ instruktionen i patientinformationen, med det lilla röda hjärtat på, för hur/när du svarar på enkäterna i vecka 8-12, 30, 37-39, **3-7 dagar (3 days postpartum) efter du fött barn och ca 2 månader efter du fött barn (2 mounth postpartum)**. För att komma åt enkäterna måste du först scanna ditt blodtryck i appen. Du hittar enkäterna på samma ställe som där du skriver in ditt blodtryck, under surveys. Glöm inte att ta blodtrycken i appen en gång om dagen hemma och ända fram till du kommer till efterkontrollen hos barnmorskan.

Har du frågor eller problem med appen, så ring eller skicka ett sms till barnmorska Maria Andersson, som har ansvar för studien. 0705365579

## Appendix E



### INFORMATION FOR YOU WHO HAVE PREECLAMPSIA OR HIGH BLOOD PRESSURE

You have been admitted to our maternity ward or delivery ward for observation due to high blood pressure, or suspected/or confirmed preeclampsia. The purpose of this observation is to monitor your condition for any signs of deterioration and to ensure safe and secure care for both you and your baby. Since symptoms vary for each patient, you may receive different instructions and treatment from those given to others.

#### **High blood pressure/preeclampsia during pregnancy**

Blood pressure is considered elevated if it exceeds 140/90 mmHg.

- if high blood pressure is detected or known before the 20th week of pregnancy, it is called chronic hypertension (high blood pressure).
- if blood pressure rises above this level after the 20th week of pregnancy, it is called gestational hypertension.
- if blood pressure is elevated in combination with albumin in the urine or you show other signs of preeclampsia after the 20th week of pregnancy, it is defined as preeclampsia.

Preeclampsia occurs in varying degrees of severity. Most cases are mild, and women give birth to healthy babies. However, sometimes preeclampsia can develop into a more serious form, which can mean greatly increased blood pressure, protein in the urine, and symptoms affecting many different organs in the body. It may also have an impact on the placenta, which leads to the child not growing as expected. It is known that underlying diseases, such as diabetes, kidney diseases, rheumatic diseases, and IVF with egg donation, and maternal age over 40, increase the risk of developing preeclampsia.

The condition can also be hereditary. If your mother or sister had preeclampsia, you also have an increased risk of developing the disease.

Symptoms of preeclampsia:

- severe headache that does not subside with painkillers (paracetamol)
- pain in the upper part of the abdomen
- symptoms affecting the eyes (flickering lights or sensitivity to light)
- rapid weight gain or increased swelling of the face, hands, or feet
- nausea or vomiting in late pregnancy
- decreased urine output
- general malaise

In very rare cases, convulsions (eclampsia) can occur. If this occurs outside the hospital, call an ambulance immediately for transport to the maternity ward.

### **Treatment of hypertension/preeclampsia**

If you have chronic high blood pressure, it may worsen during pregnancy. If you take medication for your high blood pressure, the dosage may need to be adjusted or the medication may need to be changed, in consultation with your doctor. Rest is crucial, and sick leave is often recommended. Sometimes, medication is required to lower blood pressure, which is often administered while in hospital for closer monitoring.

### **What happens in the body during preeclampsia?**

Preeclampsia results from reactions in the placenta and blood vessels. It is not known why some women develop preeclampsia. Some women think that they may have contributed to their condition because they were stressed during pregnancy; however, research has not been able to show that stress triggers preeclampsia.

### **Why should I take it easy and rest?**

If YOU have preeclampsia, our recommendation is that you be admitted to the women's clinic for monitoring. It is important that the environment is as calm as possible, so that you can really rest. Rest lowers your blood pressure. If you watch TV, read, or are exposed to bright light, it can increase blood pressure. In more severe forms of high blood pressure/preeclampsia, you may be transferred to the maternity ward for closer monitoring. Daily checks of your general condition, weight, blood pressure, pulse, blood and urine samples will be conducted. Sometimes, careful control of the fluid balance is needed, which means that we measure how much you drink and urinate.

Blood samples may be taken as needed, based on individual assessments. The baby will be monitored using CTG and ultrasound. A doctor will visit daily, and you always have the opportunity to ask questions. Our goal is to keep you and your partner informed about your care plan. If you don't understand something, please ask!

Feel free to read about other patients' experiences with preeclampsia on the patient association's website: [www.preeklampsi.se](http://www.preeklampsi.se)

### **Childbirth**

Vaginal delivery is usually the best for both mother and baby. Sometimes, it is important to start labor (induction), and in some cases prematurely. If you get preeclampsia early, the goal is to keep the baby in the womb as long as both the baby and mother are healthy. Most often, labor starts when the pregnancy reaches week 37+0. Sometimes, a caesarean section may be necessary, but it is not a delivery method that you choose unless absolutely required.

### **NICU-care for newborn babies**

In Malmö and Lund, there are neonatal wards dedicated to the care of children born prematurely and those with special needs. If your baby is born before 28 GW, both you and your child will be cared for in Lund. We strive to keep mother and child together, but unfortunately, this is not always possible. You will need to stay in the OB for the first few days to monitor your blood pressure and general well-being.

Welcome to the women's clinic! Please do not hesitate to ask questions! It is better to ask as many times as needed, so that you feel well informed and secure under the current circumstances.

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# Paper I






RESEARCH

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# Women's experiences of preeclampsia as a condition of uncertainty: a qualitative study

Therése Hansson<sup>1,2\*</sup> , Maria E. Andersson<sup>3,4</sup>, Gerd Ahlström<sup>5†</sup> and Stefan R. Hansson<sup>3,4†</sup>

## Abstract

**Background:** Preeclampsia is a severe condition that annually affects about 3–8% of pregnancies worldwide. Preeclampsia is thereby one of the most common pregnancy complications for both mother and child. Despite that, there is limited research exploring the women's perspective of experiencing preeclampsia.

**Aim:** The aim of this study was to describe women's experiences of preeclampsia to improve the support and care given during and after pregnancy.

**Methods:** A qualitative descriptive interview study was undertaken. Nine women, diagnosed with preeclampsia, were recruited from a maternity unit in southern Sweden. The descriptive phenomenological method according to Amadeo Giorgi was used to analyse the data.

**Results:** The women's experiences of PE were expressed as A condition of uncertainty, meaning that it was an unexpected and unknown situation. This main result consisted of 1) incomprehensible diagnosis message, 2) ambivalent feeling when the unexpected happens, 3) confusing contradictory messages, 4) appreciated support from the midwife, 5) need for continuous information. The nature of preeclampsia can sometimes deteriorate rapidly both for the mother and/or the child, often resulting in conversion from a planned vaginal spontaneous delivery to an emergency Caesarean section. The women narrated diffuse symptoms, and they experienced that they got contradictory information from different health care professionals regarding the severity of their disease. Detailed and continuous information is requested throughout the course of the disease, and the postpartum period.

**Conclusion:** This qualitative study reveal a need for improved clinical management. Health care professionals must be aware that women and their partners need detailed, consistent and repeated information about severity and prognosis to diminish the condition of uncertainty, confusion and fearful experience. The clinical implication would be a standardized preeclampsia education for pregnant women early on in the pregnancy, to raise awareness of preeclamptic symptoms. Furthermore, there is a need for harmonized guidelines and individualized support to the woman and her partner both at the antenatal care and the maternity ward and inpatient care at the hospital.

**Keywords:** Preeclampsia, Experience, Qualitative research, In-depth patient interviews, Phenomenology, Outcomes

## Introduction

Preeclampsia (PE) is one of the most common severe pregnancy complications for both mother and child [1], a condition that affects about 3.5% pregnant women in Sweden [2] annually, and about 3–8% of all pregnant women worldwide [1]. Preeclampsia contributes to high maternal (18%) and fetal (40%) mortality globally [1, 3]. The cause of PE is partly unknown but inadequate

<sup>†</sup>Gerd Ahlström and Stefan R. Hansson contributed equally.

\*Correspondence: therese.k.hansson@skane.se

<sup>2</sup>Ystad Hospital, Ystad, Sweden

Full list of author information is available at the end of the article



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placentation and or placenta dysfunction plays a central role [4]. Uneven blood perfusion results in oxidative stress and placenta damage [5]. This in turn causes leakage of fetal cells, placenta debris and microparticles into the maternal circulation, which give rise to inflammation and general endothelium damage, a hallmark of PE [6]. Endothelial damage is believed to be the underlying cause for organ dysfunction and specific manifestations from the kidneys, liver, heart, lungs, clotting system and the brain [1, 7]. The disturbed placenta function in PE also affects the fetus and causes fetal growth restrictions (FGR) in 25% of the cases and 15% of all premature birth [7, 8].

The definition of PE, is high blood pressure,  $\geq 140$  mmHg systolic blood pressure (sBP) and  $> 90$  mmHg diastolic blood pressure (dBP), after the 20<sup>th</sup> gestation week, combined with organ engagement including FGR [9]. Early-onset PE is defined as delivery due to PE before 34 weeks of pregnancy [7, 9].

Treatment of PE is largely symptomatic, with antihypertensive drugs to manage the blood pressure, magnesium sulphate to prevent and treat eclampsia and steroids for the fetal lung maturation. To date, the most definitive treatment is delivery and removal of the placenta, which generally stops progression of the disorder. However, this is a decision that can be difficult since it has consequences for both mother and child [1, 7]. International guidelines recommend induction of delivery no later than 37 gestational weeks in women diagnosed with preeclampsia [10].

Preeclampsia is associated with long-term sequelae for the mothers. There is evidence that there is an increased risk for PE women to develop hypertension, stroke, type II diabetes and cardiovascular disease later in life [11], but also for depression and posttraumatic stress syndrome [12, 13].

In qualitative studies, women often describe PE as a frightening and life-threatening condition, with lack of care and low psychosocial support, experiences that often collides with their expectations of pregnancy and childbirth [14, 15]. Instead, they experience anxiety, associated with hospitalization, multiple controls, emergency Caesarean sections (CS), premature babies and separation from their child [16]. Studies show that women with a complicated childbirth where the baby needs treatment at the Neonatal Intensive Care Unit (NICU) find it to be a traumatizing experience to be separated from their child [16, 17].

There is a need for continuous information about their own health, and especially about their child's wellbeing. Family centred care is recommended for social support and for development of the parent-child relationship after pregnancy complications such as PE [16, 18].

A recent narrative synthesis, based on 10 studies, showed a lack of knowledge and understanding about PE as a disease among women and their families [19]. Some PE women did not experience any symptoms at all, or not the "classical" ones, which led to delayed diagnosis of early-onset PE [19]. Suffering from PE is very stressful and the women also experience fragmented care and information [19]. These studies indicate that there is a great need for additional support, patient information and education regarding PE among pregnant women [17–19]. It is also important to get the women to attend their antenatal routine care [19], something that is highlighted in several studies [18, 20, 21].

Despite the fact that Sweden has a well-developed maternal health care system, free of charge and with good accessibility, there is still a lack of knowledge regarding PE among pregnant women.

Worldwide, few studies describe women's experiences of having PE. By using the descriptive phenomenological method the knowledge gap could be diminished when the focus is centered on the women's voices and thereby new information and nuances can appear, that otherwise could be lost. The aim of this study was therefore to describe women's experiences of PE in order to improve support and care given during, as well as after a pregnancy complicated by PE.

## Methods

### Design and research perspective

A qualitative descriptive interview study was performed. The data was analysed using a phenomenological approach of psychological and human science according to Amadeo Giorgi [22–24]. Phenomenology aims to describe our experience of the world as it appears, before all theories and criticisms. The researcher puts the world in brackets, to peel away his/her preconceptions and beliefs about how the world works, also called phenomenological reduction [20]. The theoretical understanding develops in the light of understanding the lifeworld, which is the sum of physical surroundings and experiences that make up an individual's world. According to phenomenology, to gain knowledge, the lifeworld precedes the theory and should be studied first and foremost [25, 26].

### Participants

The selection of a purposeful sample was carried out at a maternity unit in southern Sweden. The unit has approximately 5500 deliveries annually and the PE incidence is about 3.6% [2]. The inclusion criteria were diagnosed with PE, delivered within 5 days,  $> 18$  years, understanding and speaking Swedish. For a period of three months,



the admitted women that met the inclusion criteria and accepted participation in the study were included.

Exclusion criteria were other pregnancy complications and fetal/infant death. The exclusion criteria were chosen to focus on and refine the PE experience. Situations with fetal/ infant death are associated to PE but still rare. Those situations are such a trauma for the women that we found it unethical to burden them with a study.

In total nine (*n* = 9) newly delivered PE women were included.

Table 1 describes the characteristics of the participants with PE, and complicating factors, mode of delivery and hospitalization time. Seven out of nine women were delivered by CS, only one during general anaesthesia. Three women presented with early onset PE, and seven out of nine babies were SGA (two IUGR after correlated with birth weight). After CS, the women spent their first hours in the post-operative unit, separated from their children, who were with their partners or in NICU (Table 1).

Data collection

The included women received oral and written information regarding the study, and gave their signed informed consent based on voluntary decisions. The interviews

were performed in a private room at the maternity unit, or in a private part of the NICU, and were recorded digitally. In three of the nine interviews, the fathers attended.

The interviews consisted of one opened-ended question, which allowed the women to freely speak about their experiences and their lifeworld, without leading their answers into a given direction. All the women received this opening question: -Would you like to tell me about you experiences of living with PE? In some cases, there were a clarifying follow-up question, in order to explain the answer, e.g.:—“Can you tell me more about how you were feeling? Can you say something more about that?” The researcher assumed the phenomenological attitude, to sit back and be like an open book, and lay aside all preconceptions to let the woman speak about her experiences [24]. The interviews lasted between 25–60 min and were transcribed verbatim.

Data analysis

The analyses were conducted according to Giorgi’s descriptive phenomenological method [22, 27], consisting of a five steps structure, to gain insight about the constituents that are parts of and generates the essence of the phenomenon.

The five steps in the analysis were performed by the first author (TH) with bracketing of the preconceptions [24]: 1. The verbatim transcribed interviews were read thoroughly to obtain an overall impression; 2. Unique meaning units were identified in the transcribed text, and these units consist of one or more sentences or paragraphs i.e. a new meaning unit for each new content of the text; 3. The meaning units were reflected upon and then thematised based on the women’s point of view; 4. The thematised meaning units were further concentrated to produce the essential significance units; 5. In the last step, constituents were emerging, which are the parts that generates the essential structure of the phenomenon [24]. When all nine interviews were analysed according to these five steps, several common/united constituents were revealed, merged to the essence and the phenomenon appeared [28, 29]. After the analysis, the essence and the constituents were reviewed and discussed with two researchers (G.A, M.A).

Results

Being diagnosed with PE, and having a pregnancy affected by possible complications and outcomes, leads to the main essence of the phenomenon of women’s experiences of PE, described as “a condition of uncertainty”. Women found themselves posing more questions than they got answers, trying to grasp the complexity of their PE diagnosis, for both themselves and their unborn baby. PE was described as an unexpected, uncertain, and

**Table 1** Characteristics of women with preeclampsia in the study (*N* = 9)

Characteristics	
Age (years), mean ± SD	30.4 ± 10.6
BMI, mean ± SD	25.8 ± 6.8
Primigravity, n (%)	2 (22%)
<b>Medical condition, n (%):</b>	
Family high bloodpressure	3 (33%)
IVF	2 (22%)
Astma	2 (22%)
Depression	1 (11%)
DVT, APC resists	2 (22%)
<b>Gestational age, mean ± SD:</b>	
Preterm birth (< 37 weeks)	4 (31 + 0—36 + 0)
Term birth (> 37 weeks)	5 (37 + 1—38 + 3)
<b>Gestational Weight, g (mean):</b>	
1500–3115 g (mean 2060 g)	
<b>Mode of delivery, n (%):</b>	
Vaginal	2 (22%)
Caesarean section	7 (77%)
<b>Newborn in NICU, n (%):</b>	
5 (56%)	
<b>Days in hospital care:</b>	
Antenatal	1–14 days
Postnatal	3–7 days

BMI body mass index, DVT Deep Vein Thrombosis, NICU Neonatal Intensive Care Unit, IVF In Vitro Fertilisation, APC Activated Protein C Resistance

unknown condition. The essence is generated from five identified constituents, described with representative quotes (Fig. 1).

**The incomprehensible diagnosis message**

Several of the women in the study had little knowledge of PE, and some women expressed that they did not know it was a serious condition. They expressed that the PE-symptoms were diffuse, and hard to distinguish from normal pregnancy symptoms; this was especially problematic for nulliparous mothers. Women experiencing the PE diagnosis as incomprehensible stated that they were feeling great and that they did not notice anything different during their pregnancy. Their PE was only detected by blood pressure and proteinuria measurements. These women expressed having problems accepting the diagnosis, the extra controls and sometimes the need of admission to the hospital. The pregnant women wished there was a specific diagnostic test for PE to confirm their diagnosis and the severity of the disease.

*“But it’s not dangerous to have PE, but it’s not meant that you should walk around with it. So I’m just glad that she (the midwife) discovered it.” (Interviewee number 7, 29 years, nulliparous).*

The fathers that were present during the interviews, at the maternity unit in the hospital or the NICU, affirmed the women’s experiences and concerns. Together the parents tried to grasp what happened.

*“- I think it’s scary that I didn’t have any symptoms”. Father:- “And there were no alarm bells when you didn’t have the usual symptoms (of PE), like blurry vision and headaches” Woman:- “And it’s the same father for both of my children”. Father:- “It’s scary that it can be a silent disease. In a way it’s like a tumour, you don’t see that it’s growing, but it is”. Woman:- “Yes and then BOOM, it’s just there, and I had to be hospitalized”. (Interviewee number 9, 29 years, two parous).*

The women described a scary feeling of central chest pain/sternum before their condition worsened. They also talked about a diffuse feeling that something was wrong.

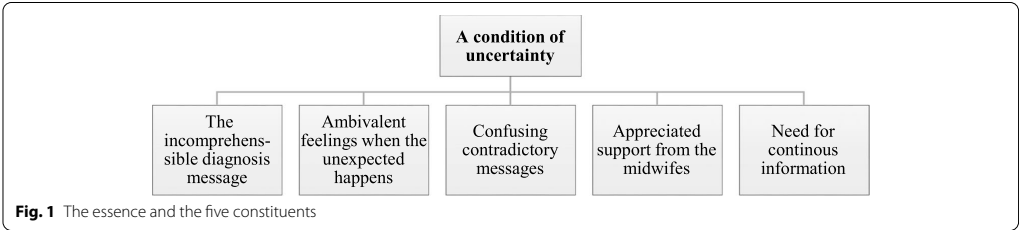
*“I just felt, I can’t breathe! It felt just like someone was standing on my chest, and pressed, like with a shoe, really hard. I almost panicked! And I also felt that something is wrong, but it’s just the breathing that I can pinpoint. (Interviewee number 9, 29 years, two parous).*

The PE-diagnosis was not something they expected, and it can be a fearful experience. The women expressed that they did not know how to address the diagnosis, what to do with the information. They reacted on the Swedish word for PE, which sounds alarming, “pregnancy toxication”. It was also a shock for some of the women to comprehend that she was diagnosed with PE.

*“- I was frightened when I got PE. I had all the symptoms, it was only that I didn’t have the proteinuria. When they said that I had protein, I knew, and I thought that now everything can happen. I can die and my baby can die, we can die both. But I thought that I was in the hospital, so it’s a good chance”. (Interviewee number 2, 34 years, two parous).*

**Ambivalent feelings when the unexpected happens**

Women expressed ambivalent feelings, both fear and relief, when their PE-condition deteriorated rapidly, and sometimes resulted in conversion from a planned vaginal spontaneous delivery to an emergency CS. The women often told about their birth experience that differed from what they had expected. They experienced a sudden decline in their own or their babies’ wellbeing, which lead to decisions to convert from a planned vaginal delivery to an emergency CS. These unpredictable births were very traumatic, especially if the mothers were anesthetised. The women also expressed a need to talk to somebody about their traumatic experiences, and one woman had already talked twice to the counsellor at the maternity unit.



**Fig. 1** The essence and the five constituents

*“I had very intense birth pains, but I didn’t open. So the doctor then decided that it was going to be a planned Caesarean section, within an hour. Then I was rolled up (into the operation room), and they prepared me, everything became extremely acute and I was sedated. And then, ...// I think it was her (the baby) heart sounds, that; she didn’t feel well at all.// We had planned that my husband would be beside me, and we would both see her when she., but then something happened, I don’t know what, and I was sedated and he had to go out, and he didn’t see anything until they had picked her out. It was very daunting.” (Interviewee number 8, 25 years, nulliparous).*

Women with prolonged labour or women who experienced a rapid deterioration in their health status, said that they were relieved and welcomed a decision to convert the mode of delivery to a CS. In addition, women with a previous experience of a pregnancy complicated with PE welcomed a planned CS, even if the baby was slightly premature.

*“Oh, I was so relieved! Because I felt that I would not..., and just because she (the baby) was so weak, she might not have pressed herself down, so. I was very relieved! (Interviewee number 6, 29 years, nulliparous).*

### Confusing contradictory messages

The women in the study described that they got confused about the contradictory and different messages from different health care professionals, regarding the severity of their PE. The women expressed that this lack of consensus between antenatal- and inpatient care regarding the PE severity, made them worried and confused whether or not to seek care, and left them in a condition of uncertainty.

*“What I have experienced here is that when I went to the hospital for controls, they were not worried at all, they had higher barriers to what was alarming compared to the MHC, so it’s a bit confusing actually. I have not been able to figure out what is what, so I think that they can’t hold me responsible for it. Instead of just taking a test and say that it is PE, or not.” (Interviewee number 1, 27 years, nulliparous).*

After being admitted to the hospital, the women received contradictory messages from doctors and midwives regarding their condition. This inconsistency in information regarding their own and their babies’ condition was very disturbing for the women.

*“And then you meet different doctors every day, new messages all the time, because everybody had different experiences. Yes, because, some said, mostly midwives and nurses, well, if we only get your blood pressure down and stable, I’m sure you can be discharged and go home. And one doctor said, you will leave with the baby on the “outside”. So it was very contradictory, that is, whom should I listen to in this. If everyone can just agree, so I know how to relate to my condition” (Interviewee number 9, 29 years, two parous).*

### Appreciated support from the midwives

The midwives at the Maternal Health Care (MHC) were greatly appreciated by the women, for their support and care. The women in this study said that their midwife was the first health care professional that informed them of possible PE diagnosis and that sent them to the hospital or made an appointment to the primary health care physician. They appreciated the midwives for taking their condition seriously and their motivating conversations to get them to continue coming for tests and surveys.

*“They knew that I had a problem with the placenta, and then it got a little bit serious, and she (the midwife) listened very carefully to what I told her about my symptoms. And she told me, you have to come, you have to come, so that it doesn’t become a bigger problem” (Interviewee number 2, 34 years, who previously lost a baby due to PE).*

The women were grateful for the midwives’ competent guidance during more investigations and follow-ups.

*“When my blood pressure got high, my midwife at the MHC told me about PE, and that I would try to go on sick leave. Because stress, after all, is never a good combination. So that I still think that they took it really seriously at the check-up, I was sent straight from there to the specialist maternity ward for the first time. The midwife said, “you are not going to go to work today, you are going to go there and do this, and pack your stuff and your papers and prepare because I cannot say what they will answer. So it felt like there was a seriousness here at the MHC.” (Interviewee number 9, 29 years, two parous).*

### Need for continuous information

The women stated that they required detailed, consistent and continuous information, throughout the course of the disease and in the postpartum period. Being diagnosed with PE and all its complications that follows is very concerning for the woman. They all expressed a

need for more information, to help them in a condition of uncertainty. They did not know the outcome of the situation, what would happen to themselves or to their babies. A need for continuous information was expressed, from both of the parents.

*"- There has been a lot of information these days, it is still a bit unclear what is what, and what was said? Then, it is nice to be two to hear the information (looks at her husband). There are so many new impressions all the time. I think it has been so much throughout the whole pregnancy. Still, now afterwards, for both me and her (looks at her daughter). (Interviewee number 7, 29 years, nulliparous).*

The women did not realize why multiple blood samples, clinical examinations and medications were needed. They described a lack of information, and did not experience involvement in medical decisions.

*"- And then they came with medicine, and said take it! But I don't want to take it, I have to talk to a doctor first. So I said, what's the plan, should I take medicine all my life? Should I be sent home today? They have to be a little clearer, and not say that all the blood samples looks great. You need a doctor to explain to you why you have to take your medicine". (Interviewee number 5, 41 years, nulliparous).*

Women hospitalized for several days before the birth appreciated that personnel from the NICU came and informed them about the unit, in case the baby would need to stay there after delivery. Other women and partners were more unprepared for the separation of the new family after the CS, when the mother recovered for a couple of hours at the post-operative unit.

*"The days I was hospitalized before the birth, I received information from the personnel from NICU. They came and informed what to expect if you had a premature baby, how the routines and rooms were organized. So it felt good to know, that it was a room for four and so... (Interviewee number 9, 29 years, two parous).*

## Discussion

The main findings in this study showed that experience of PE is a condition of uncertainty. This phenomenon is characterised in terms of incomprehensible diagnosis message, ambivalent feelings when the unexpected happens, confusing contradictory messages, appreciated support from the midwife, and the need for continuous information. The women described vague symptoms, feeling lack of information and receiving contradictory information from health care professionals, combined

with a worrying feeling that the condition quickly can deteriorate and become life threatening for both mother and child.

The results show that it was incomprehensible experiences for nulliparous women to distinguish between normal pregnancy or PE symptoms, and frightening for those with previous experiences or knowledge of PE. The Swedish routine monitoring at the MHC is designed to find serious illnesses among pregnant women, including gestational hypertension and PE. It is important that midwives have a responsiveness to symptoms that can belong to the PE syndrome, to listen, as well as inform and guide the pregnant women regarding further management [30]. The findings in this study shows that women with PE do not always present with the classical symptom, but experience other bothersome symptoms, or show no symptoms at all. Carter et al. [19], made a narrative synthesis of factors that affected women's help-seeking behaviour regarding PE. They found that there is still a lack of understanding and knowledge of PE, which prevent women from seeking timely and appropriate medical support. The review included studies from several countries, such as Brazil, USA, Bangladesh, and Jamaica. In Jamaica, there was a demarked decline in the incidence of eclampsia six month after women had been offered information via pictorial cards, posters and antenatal education. This led to an increased awareness among women and the health professionals, and made pregnant women more alert to prodromal symptoms, and thereby seek medical advice at the hospital at an earlier time point in pregnancy [31].

This unawareness of PE symptoms can lead to delayed help-seeking, and a deteriorated condition for both mother and child [19]. In fact, this is an important contributing factor to why women in low- and middle-income countries die from this condition [19]. Partly this is also due to a lack of midwives worldwide. World Health Organization (WHO) has calculated that with enough midwives performing family planning and interventions for maternal and newborn health, about 80% of these mother and/or children's deaths could be prevented [32].

The unawareness of PE symptoms was also found in a study from the UK, where several women expressed a surprise when they suddenly were admitted to hospital due to high blood pressure and proteinuria measured during their routine antenatal clinic appointment [20]. However, women that already had experienced PE were more aware and recognised potential signs and symptoms at an earlier stage and sought care [20]. These findings are in line with one of the women in this study, who previously had lost a baby due to PE in gestational week 25. Furthermore, women who previously experienced PE can be shocked and frightened when diagnosed with

PE again, because they understand the life-threatening nature of the disease.

In this study, four out of the nine women experienced central chest pain/pressure when their condition deteriorated, and all of them were delivered by CS. In the descriptions of PE, abdominal pain is often said to be epigastric and/or localized under the right arcus, or upper abdominal pain [7]. Four women in this study placed their hand on the central part of their sternum. They described an intense painful pressure and restricted breathing ability. This description was surprising but mentioned by several of the women.

The women in this study talked about ambivalent feelings when the unexpected happened, like a sudden admission or a conversion to CS. Since PE is unpredictable and can change the natural course of a healthy pregnancy, the unprepared woman may have to be admitted to hospital, have an immediate delivery or emergency CS, and become a mother to a premature baby. This can be a traumatic situation and a heavy burden both physically and emotionally for the mother, and women with these unexpected experiences may have a higher risk of developing PTSD (posttraumatic stress disorder) and postnatal depression [33, 34]. Other studies have concluded that PTSD is more common after traumatic birth experience but that also depends on the individual woman's coping strategies, her beliefs and social network [35, 36]. Cowan et al. states that it is important that women who experienced severe PE get the opportunity to debrief in the aftermath, preferably with a multidisciplinary team [35].

The women needed to understand and accept their new situation and its consequences. They face both physical and psychological challenges along the way; their own illness, the recovery after a CS, their concerns about becoming a mother in general, and in addition maybe a baby that needs NICU or in the worst case dies. Different coping strategies are described in the literature, depending on the women's cultural-, beliefs-, and social systems as well as psychological robustness [19, 37, 38]. This knowledge is essential for professionals, as well as partners and family members, to understand and be able to support the woman [39].

A recently published study [17] has shown that women being in a stressful situation like this, are even if they receive information, are not always able to grasp the consequences, and that health care professionals must ensure that the information is repeated and understood [33, 40–42]. Something that also can add to the problem of being able to process information, is when women get severe PE and the HELLP syndrome (Haemolysis Elevated Liver enzymes and Low Platelet count), which has been shown to affect their mental capacity. Both this and other studies investigating women's experiences

of PE show an unmet need for information [16, 17, 42]. The information should preferably be repeated, from the time of diagnosis, throughout pregnancy, before and after childbirth, during the early postpartum period as well as later during the first year to follow up on both mental and physical health.

In this study, seven out of nine women were delivered by emergency CS. This suggests that it is important to inform both the parents that it is more common that women diagnosed with PE are delivered by CS and provide details about the potential family separation at an early stage of their hospitalization. International guidelines recommends vaginal delivery as it is safer and more favourable physiologically [7], yet women affected by PE have a higher risk of delivery by CS [43].

They also need information that prepares them for a potential longer postnatal stay for the condition to stabilize. Harrison et al. [44] concluded that women prefer detailed and realistic information as early as possible, and to take part in their health care decisions. Information consensus and harmonized guidelines between the antenatal- and inpatient care, regarding diagnosis, management and follow up plan, is something that reassures the pregnant woman that she is getting adequate care. These benefits are seen when working in well functioning obstetrical teams [45].

The women delivered by emergency CS were all surprised and sad to be separated for several hours from their new-borns and partners, while recovering at the postoperative unit. The fathers who attended the interviews were also surprised, confused and wondered where their wives were taken and when they were coming back. This enlightens the need to also support the woman's partner, who may have experienced a traumatic situation. Vearland et al. describes the partners experiences as – “becoming a family through reflection on life and death in a context of separation” [46].

In this study the midwives were greatly appreciated for their support and care, and helped the women understand the implications of the diagnosis. However, official information from maternity care providers appeared to be lacking, which led to an increased feeling of uncertainty in many of the women about the situation.

The results show that in order to facilitate early detection and promote a help-seeking behaviour an individual plan needs to be made based on risk factors and previous experiences. Recent studies support these findings, that varied views about management suggests the need for shared decision-making and educational tools [47, 48].

An important clinical implication would be to standardize an antenatal PE education for pregnant women, to be given during antenatal care, preferably combined with web-based training, and mobile phone applications,

to enhance further awareness of PE risk factors and symptoms.

### Methodological considerations

When exploring a new research area, the phenomenological approach is especially suited. The approach aims to describe and understand people's experiences of different phenomenon, without preconceptions and with an opened mind [23, 26, 49]. Using the phenomenological lifeworld approach is a major strength of this study, as it is suitable for gaining a deeper understanding of women's experiences of a pregnancy complicated with PE. Great care was taken to display the five steps in the analysis process, in order to achieve trustworthiness, to keep one's mind open through the whole process and to be sensitive to nuances and changes in meaning. The analysis is made as close as possible to the informants own words, and only concentration, not interpretation is made between the different steps. Compte, a French sociologist, meant that instead of imposing a meaning from the outside on the phenomenon, this methodical stance means to wait for the phenomenon to show its meaning to us [50]. The first author was constantly aware of bracketing her pre-understandings, both during the interviews and during the analyses. To increase the credibility, reliability and minimise bias in the results, two researchers (G.A, M.A) interacted by reviewing and giving comments, and critically examine all the steps of the analysis work [49]. Furthermore, all the women were hospitalized at the same maternity unit, and they were all treated according to the same routines and information procedures.

This study poses some methodological limitations. Firstly, this study involved nine women; however, it is not obvious that a larger number of cases would give a different result. The sample size in qualitative studies is valued from the information gained, the power is reflected in how comprehensive the description of the phenomenon is [51]. Furthermore, some fathers attended and gave their inputs in certain questions. This clarified the answers and extended the understanding, by incorporating their view of how PE affected their partners. However, these aspects need to be kept in mind when interpreting the results.

The transferability of qualitative studies is always questionable [40]. A relatively small range of gestation ages were included (range 31–38+3 GW). A wider range and/or more severe cases would maybe give different answers. The PE population in the catchment area mainly consists of Scandinavian women (Caucasian ethnicity). The lack of heterogeneity may affect the transferability of the results and may therefore not apply to other settings or ethnic groups. As well known, women from

Africa [52] and South America have a higher incidence of PE, and are more prone to develop severe PE and other obstetric complications [9, 52]. Also very young women and women over 40 are more susceptible to severe PE [9]. Therefore, future studies ought to plan for a multi-centre setting, to include women from different ethnicities, with different risk factors, gestation length, and severity to improve the transferability of the results.

Finally, the interviews were mainly performed on the day of discharge, which was not optimal due to disturbing factors such as information from various health care professionals and clinical examinations on both the mothers and their babies. At the same time, it was the time point when they had recovered to a level when they could be dismissed. This may affect how well the phenomenon was narrated.

### Conclusion and implications

This qualitative study reveal a need for improved clinical management. Health care professionals must be aware that women and their partners need detailed, consistent and repeated information about severity and prognosis to diminish the condition of uncertainty, confusion and fearful experience. The clinical implication could be a standardized preeclampsia education for pregnant women early on in the pregnancy, to raise awareness of preeclampsia symptoms. Such educational program needs to be evaluated in an intervention research. Furthermore, there is a need for harmonized guidelines at both the antenatal care and the maternity ward and inpatient care at the hospital. A multi-centre study consisting of a heterogeneous sample of women, and a study exploring the partners experience of unexpected pregnancy and delivery at the PE condition, might give valuable information on how to best support the new family.

### Abbreviations

BP: Blood Pressure; dBp: Diastolic Blood Pressure; sBP: Systolic Blood Pressure; BMI: Body Mass Index; CS: Caesarean section; FGR: Fetal Growth Restriction; GH: Gestational Hypertension; HDP: Hypertensive Disorders of Pregnancy; HELLP: Haemolysis Elevated Liver enzymes and Low Platelets; ICU: Intensive Care Unit; IUGR: Intra Uterine Growth Restriction; IVF: In Vitro Fertilisation; ISSHP: International Society for the Study of Hypertension in Pregnancy; NICU: National Institute for Health and Care Excellence; NICU: Neonatal Intensive Care Unit; PE: Preeclampsia; SGA: Small for Gestation Age; GW: Gestation Weeks; MHC: Maternal Health Care.

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### Authors' contributions

TH designed, performed and transcribed the interviews. TH, MA, GA performed the analysis and interpreted the results. TH drafted the manuscript and MA, GA, SH revised it critically. All the authors read and approved the final manuscript.



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## Availability of data and materials

The dataset analysed during the current study is available from the corresponding author on reasonable request.

## Declarations

### Ethics approval and consent to participate

The Regional Ethics Board of Lund University (2019–04240) approved the study. All patients were informed that their participation was voluntary and that they could choose to discontinue their participation at any time without further explanation and without affecting their given care. All the participants provided informed consent. All methods were carried out in accordance with relevant guidelines and regulations. The demographic data file and interview text was coded and did not include any personal identification numbers.

### Consent for publication

In accordance with the ethical approvals mentioned all participants consented for their data to be included in the published manuscript.

### Competing interests

The authors declare that they have no competing interests.

### Author details

<sup>1</sup>Institution of Clinical Sciences Lund, Lund University, Lund, Sweden. <sup>2</sup>Ystad Hospital, Ystad, Sweden. <sup>3</sup>Department of Obstetrics and Gynecology, Institution of Clinical Sciences Lund, Lund University, Lund, Sweden. <sup>4</sup>Skane University Hospital (SUS), Malmö/Lund, Sweden. <sup>5</sup>Department of Health Sciences, Faculty of Medicine, Lund University, Lund, Sweden.

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## Paper II





# The experience of provided information and care during pregnancy and postpartum when diagnosed with preeclampsia: A qualitative study

Maria E. Andersson<sup>1,2</sup>, Christine Rubertsson<sup>2,3</sup>, Stefan R. Hansson<sup>1,2</sup>

## ABSTRACT

**INTRODUCTION** Despite preeclampsia being one of the most severe obstetrical complications there is only scant research describing women's experiences of preeclampsia. The aim of this study was to explore women's experience during pregnancy and the postpartum period regarding the provided information and care concerning preeclampsia.

**METHODS** A qualitative study was designed. Semi-structured face-to-face interviews were performed with fifteen women who were diagnosed with preeclampsia and included at two maternity units located in southern Sweden. The material was analyzed using content analysis.

**RESULTS** Suffering from preeclampsia was understood as being stressful, illustrated in four themes: fragmented information, lack of care planning, separation postpartum, and overall stress and worry.

**CONCLUSIONS** The women experienced fragmented obstetrical care and information deficits when diagnosed with preeclampsia. Our findings indicate a need for additional support and professional guidance due to increased stress, worry, and despair of being separated from the newborn. Future research investigating specific care-planning and postpartum follow-up are suggested as steps to improve care for women with a pregnancy complicated by preeclampsia.

## AFFILIATION

<sup>1</sup> Obstetrics and Gynecology Unit, Section V, Department of Clinical Sciences Lund, Faculty of Medicine, Lund University, Lund, Sweden

<sup>2</sup> Skåne University Hospital (SUS), Lund, Sweden

<sup>3</sup> Department of Health Sciences, Faculty of Medicine, Lund University, Lund, Sweden

## CORRESPONDENCE TO

Maria E. Andersson. Obstetrics and Gynecology, Section V, Department of Clinical Sciences Lund, Faculty of Medicine, Lund University, BMC C14, 221 85, Lund, Sweden. E-mail: maria.andersson.5171@med.lu.se ORCID ID: <https://orcid.org/0000-0001-8785-7581>

## KEYWORDS

complicated pregnancy, experience, information, obstetric care, qualitative methods, preeclampsia

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## INTRODUCTION

Preeclampsia (PE) is one of the leading causes of both fetal and maternal morbidity and mortality. Yearly, around 3–7% of all pregnancies are affected, corresponding to a total of 8.5 million women worldwide<sup>1</sup>, of which 5000 occur in Sweden<sup>2</sup>. According to the National Swedish statistical database registry for pregnancy, the incidence of PE was 3.0% in 2019<sup>3</sup>. Preeclampsia is characterized by gestational hypertension together with proteinuria and/or other organ manifestations and/or fetal growth restriction, arising after

20 weeks of gestation<sup>2,4</sup>. To date, there is only symptomatic treatment available, the only 'cure' is to give birth either by induction of labor or by Caesarean section.

Preeclampsia is considered a syndrome and the etiology is still not fully understood. There are several known risk factors for PE, such as autoimmune diseases, diabetes, renal disease, chronic hypertension, own or familial history of PE, body mass index (BMI) >30 (kg/m<sup>2</sup>) and ethnicity, particularly women of African descent have an increased risk<sup>2,5</sup>. Women with hypertensive disorders of pregnancy

are also at an increased risk of developing postpartum depression, anxiety, and post-traumatic stress disorder<sup>6</sup>. Adding to this, it has been shown that women and their babies affected by PE, have an increased long-term risk of developing hypertension, stroke, and cardiovascular disease later in life<sup>1,7</sup>.

The Swedish Maternal Health Care system (MHC) provides screening for all pregnant women during the antenatal care program, with the midwife as the primary caregiver<sup>8</sup>. During a normal pregnancy, 6–9 visits to the midwife are recommended, but does not include routine visits to a doctor. According to the competence description for Swedish midwives, the midwife possesses the competence to: ensure patient-safe, person-centered, equal, available, and continuous care to adapt the care provided according to the individual needs of the patient<sup>9</sup>. Information and support must be provided so that the women can make their own decisions<sup>9</sup>. In fact, the MHC was introduced in 1950s with the main purpose to identify PE at an early stage. Screening involves blood tests, urine samples for protein analysis and blood pressure measurements<sup>2</sup>. For women, and their relatives, information is available at a public internet-based care guide: [www.1177.se](http://www.1177.se) (The National Healthcare Guide 1177 services, available in Swedish and translated to different languages), providing information about the pregnancy and about PE<sup>10</sup>. When high blood pressure is identified, the women are referred to a hospital-based specialized obstetric care unit. To date, antenatal care is the most important contributing factor to healthcare to reduce maternal mortality in modern times<sup>8</sup>.

Despite PE being one of the most severe obstetrical complications, there is only scant research reports describing women's experiences of PE and care. In the few qualitative studies that have been published, women often describe PE as a frightening and life-threatening condition, with lack of care and low psychosocial support, experiences that often collide with their expectations of pregnancy and childbirth<sup>11,12</sup>. Furthermore, there is a lack of knowledge regarding the understanding about the woman's and family's needs<sup>13,14</sup>, the need of support during hospital stay<sup>12</sup> and access to information<sup>14</sup>. These studies highlight an unmet need for information and understanding about PE.

The aim of the study was therefore to explore women's experiences during pregnancy and the postpartum period regarding the provided information and care concerning PE.

**METHOD**

**Setting**

The study was performed at two maternity units in southern Sweden. The units had a total of 9012 births in 2019 and the incidence of PE was 3.4%, with 0.3% as early onset (<34th week) PE<sup>5</sup>.

**Design**

A qualitative descriptive research design with an interview guide was used (Table 1) and semi-structured face-to-face interviews were performed. The interview guide was designed based on clinical experience and confirmed

after one pilot interview that resulted in no changes<sup>15,16</sup>. The questions were open-ended, allowing women to speak openly about the provided information and care concerning PE during pregnancy, at the time of diagnosis and postpartum. The narratives were followed up with subsequent questions, to gain a deeper understanding of the women's experiences such as: 'When did you realize you had preeclampsia and if you have any suggestions about your care, what kind of change would that be?'.

**Data collection**

Inclusion criteria were primiparous women diagnosed with PE and multiparous women with ongoing PE without a history of PE in a previous pregnancy. All the women were fluent in Swedish, but one preferred to speak in English during the interview. The participation was based on voluntary decisions and informed consent was signed before the interview. The participants were recruited consecutively between July and December 2019. The first author (MA) visited or called the hospitals daily, to identify possible patients to be included. The women were asked about participation at the maternal healthcare unit or in the neonatal intensive care unit (NICU) or by telephone if discharged from hospital. Two women declined to participate in the study. The interviews were performed 1–6 weeks postpartum at a mutually agreeable place such as the women's private home or a separate room at the hospital. The interviews were conducted until no additional information was obtained from the participating women, when saturation was reached<sup>17</sup>. The study was

*Table 1. Interview guide*

<b>Engagement question</b>
Can you tell us what information you received at the maternal healthcare, when you were told that you had preeclampsia and what information you received during the rest of your pregnancy and before you left the hospital?
<b>Subsequent questions</b>
When did you realize you had preeclampsia?
What did you know about preeclampsia before pregnancy?
How did you get the information and how did you experience the way to get the information?
What challenges were experienced in connection with information? When and how often would you like it?
What were your information needs and how were they met?
Can you describe if something felt difficult when you got the information?
If you had to change something, what would you change?
<b>Exit question</b>
Is there anything additional you would like to say about the information and the care you got about preeclampsia?
<b>Probes in order to minimize misunderstandings</b>
Can you please say more about this?
Can you give an example of that?
Can you tell me something else about that?

approved by the Regional Ethics Board of Lund University (2019–04240).

**Data analysis**

The analyses were conducted in two steps, the first step, according to a manifest analysis and the second step as a latent content analysis, with an inductive approach, based on Graneheim and Lundman<sup>18</sup>. All the interviews were audio-recorded and transcribed verbatim by the first author<sup>16</sup>. The interviews lasted on average 25–50 min. To initiate the data analysis, the interviews were listened to again and then read through several times to gain an overall assessment and understanding, always with the study’s purpose in mind. From the transcripts, patterns were identified followed by extracting words and sentences that were relevant to the study assigned as ‘meaning units. These meaning units were then condensed, while keeping the core of the text and assigned to certain codes<sup>18</sup>. The codes were compared and grouped by two independent investigators (MA, CR) into sub-themes on the basis of their similarity. The sub-themes were further aggregated into themes based on the underlying meaning expressed in the sub-themes. The various codes were compared based on differences and similarities and further sub-themes, which constituted the manifest content. Examples of the analysis process from meaning units to themes are given in Table 2. Finally, the underlying meanings, that is the latent content of the sub-themes, were formulated into four themes given in Table 3. All authors checked the final analysis for integrity and participated in the final interpretation of the data.

**RESULTS**

In total, fifteen women diagnosed with PE were included,

of which six developed severe PE and two the HELLP syndrome. Their characteristics are described in Table 4. The participating women’s experiences were illustrated in four themes: 1) Fragmented information, 2) Lack of care planning, 3) Separation postpartum, and 4) Overall stress and worry; with ten sub-themes as presented in Table 3, and based on quotations from the interviews.

**Fragmented information**

The women described as insufficient as well as inconsistent information about PE throughout the whole period: during pregnancy at the MHC, the hospital stay, and the postpartum period. In particular, the information given by several health professionals was fragmented and did not inform about the long-term health consequences. Most importantly, women with PE also described difficulties to ‘take in’ information during this stressful period and pointed out that the information was given en passant, not focused on a designated time such as the ward rounds.

*Missing overall information at the MHC*

The women described that in general they received a lot antenatal information, but the main focus was on a normal pregnancy. Many women were not able to explain why they had been monitored with blood pressure and tested for proteinuria. The midwife told them about the screening results, but they received little or no specific information about PE:

*‘Now (postpartum) I’ve understood why they take a blood pressure every time one is there. I didn’t realize why before.’ (PE15)*

All women with high blood pressure received information about what further PE symptoms to be aware of. However,

**Table 2. Examples of the analysis process from meaning units to themes**

Meaning unit	Condensed meaning unit	Code	Sub-theme	Theme
At the maternity ward itself ... there was not much information	Did not get much information on maternity care	Not so much information on maternity care	Missing overall information	Fragmented information
It feels like no one was talking to me ... about it ... risks ... the pros and cons of getting induced ... so I could prepare somehow	No one talked about the risks, pros and cons of induction, so you could prepare	No information about risks, pros and cons to be able to prepare	Inconsistent information	Fragmented information
A seated conversation with a doctor at the time of discharge ... a longer conversation afterwards ... and not only that the samples were good and here you get a note	Seated conversations with doctors at discharge, longer conversations about test results and more	Seated explanatory conversation with the doctor at the time of discharge	Individualized plan for treatment and follow-up	Lack of care planning
There they would probably have wanted ... on BB the child and mother are together ... and there they have control of both	Wish that mother and child are together as at BB and have control of both at the same time	The desire for mother and child to be cared for together	Despair of being separated from the newborn	Separated postpartum
It felt like you were left ... while I was still in the hospital ... here they only cared about him ... and they pushed me to have him in my arms for several hours ... and I felt bad ... it became a small collision between neonatal and my preeclampsia ... I felt a little neglected	They cared of only the child and that he would be in my arms even though I felt bad. Felt neglected.	A feeling of being alone and neglected	A feeling of coming in second place	Separated postpartum

BB: maternity hospital in Sweden.

they were not given any detailed explanation about PE, just the fact that it could become a serious pregnancy complication.

*Missing overall information during the hospital stay*

When the women were admitted to the hospital, due to risk for or confirmed PE, they described that they received inadequate information. They had to stay at the hospital for further observation but did not get ‘the whole picture’ or information about the specific screening procedures, including Doppler ultrasound measurements and the extended blood analysis. Some women did not understand their situation until the postpartum period:

‘... it feels like for the first time I actually got some kind of adequate information... it was after ... the birth ... and that feels a bit strange ... I spent almost two weeks in the hospital.’ (PE9)

*Missing overall information postpartum*

Even when discharged from hospital, many women reported that the given information about PE was too brief and was missing details about when and whom to visit for a check-up. No information about further risk of developing PE in a subsequent pregnancy or on the long-term health consequences, such as cardiovascular diseases:

‘... it is certainly something that they could have mentioned ... that until next time ... that there’s a greater likelihood I will get it the next time.’ (PE4)

The two women who developed the HELLP syndrome also experienced poor continuity and information postpartum. They received no information during the ward rounds, just secondhand information given by the nurses or midwives. Leading to some advice from one woman:

‘... at the maternity ward ... one of the first days I was

**Table 3. Four themes and ten sub-themes that emerged from the data**

Themes	Sub-themes
Fragmented information	Missing overall information
	Lack of knowledge and understanding of health risks
	Inconsistent information
	Difficulties to ‘take in’ information
Lack of care planning	Individualized plan for treatment and follow-up
	Timing and involvement in care planning
Separated postpartum	A feeling of coming in second place
	A despair of being separated from the newborn
Overall stress and worry	Experiencing stress and worry
	A request for both oral and written information

there ... a doctor should have come and talked to me ... “this is how the caesarean section went and this is how the situation looks now”... not wait until the day of discharge ... I knew they had rounds ... but the rounds never came to us.’ (PE8)

*Understanding of future health risks*

Overall, most women reported poor knowledge about PE and its long-term consequences. Many reported little understanding of their own health risks and did not know that PE could progress into eclampsia, especially that it could also continue into the postpartum period. The women who developed early-onset PE and had no high blood pressure at the MHC, had no knowledge about PE and, that symptoms, including headaches and signs of sickness, could be indicative of more severe PE. It also emerged that their partners and relatives had little knowledge about PE. Some women also expressed that they had little knowledge to be able to ask the right questions. They did not know what to ask and they were often left with several unanswered questions:

‘... that they explain even more ... even if they ask me ... “have you understood”... but I don’t know what to ask

**Table 4. Characteristics of women with preeclampsia in the study (N=15)**

Characteristics	n (%)
Age (years), mean ± SD	30.8 ± 7.11
BMI, mean ± SD	25.2 ± 4.6
Primigravity	14 (93)
Medical condition <sup>a</sup>	
High blood pressure	1 (6)
Family high blood pressure	4 (27)
Diabetes	1 (6)
In vitro fertilization (IVF)	2 (13)
Lichen planus	1 (6)
Gestational age	
Preterm birth*	9 (60)
Term birth**	6 (40)
Mode of delivery	
Vaginal	8 (53)
Induction	6 (40)
Assisted/vacuum extraction	2 (13)
Caesarean section	7 (47)
Newborn in NICU	6 (40)
Days in hospital care	
2–6	7 (47)
7–11	5 (33)
12–19	3 (20)

\*Birth before 37 weeks of pregnancy (27+3 – 36+6). \*\*Birth after 37 weeks of pregnancy (37+4 – 40+3). a Some women had more than one medical condition. BMI: body mass index (kg/m<sup>2</sup>).

*... because I don't even know what they are talking about.'* (PE10)

Few women received information about future health risks or could describe what they should be aware of in a future pregnancy.

#### *Inconsistent information*

Several women reported that they received inconsistent information, often given in unknown medical language. Furthermore, doctors gave slightly different information. The women felt powerless that they had minimal or no involvement in the decision making concerning them:

*'... nowhere in this whole process have I been involved about ... that I haven't been given a diagnosis... the decision to be hospitalized ... the decision to be induced (for labor) ... nobody has explained the chain of events to me ... [crying]... I had to accept all the decisions.'* (PE14)

#### *Difficulties to 'take in' information*

Several women did not realize the severity of the illness, until the time of discharge from the hospital or, in some cases, first several weeks postpartum. Some describe that they experienced a feeling of not been able to 'take in' the given information during the acute phase. However, when they were feeling better, they expressed a need for more information:

*'I got some information there (at hospital) ... that I didn't really take in ... it was a little hard to grasp and understand.'* (PE11)

#### **Lack of care planning**

Although the interview guide focuses on experiences about the given information on PE, the women expressed an urgent need for involvement in their own care and for care planning during the whole process, when admitted to the hospital, during the hospital stay, and in the postpartum period.

#### *Individualized plan for treatment and follow-up*

Overall, women described that no care planning involving them was done throughout their hospital stay. No caregiver took time to sit down and explain the different steps in the management plan, what choices and medical alternatives were available, and their potential outcomes:

*'... that no doctor came afterwards and sat down and talked ... about the c-section at all and what happens ... and what I can expect now ...'* (PE8)

#### *Timing and involvement in care planning*

The lack of care planning and information led to the fact that women did not understand the seriousness of the possible consequences of PE. They requested repeated information at a more appropriate time point when they felt better and when the situation regarding their baby was more stable. Some asked also for a consistent and summarized information regarding their situation:

*'It would have been nice (to understand) what is connected ... why you go to a growth assessment, ultrasound*

*... why you go to a blood flow measurement ... how all these parts come together ... how that can affect me and how it can affect my child.'* (PE3)

#### **Separation postpartum**

When the newborn was admitted to NICU several hurdles challenged their situation.

#### *The feeling of coming in second place*

Postpartum, the women described their despair and feelings of being abandoned. They were tired, had pain and tried to overcome the symptoms of PE. They felt sick and, at the same time, they wanted to be close to their baby; the neonatal staff also pointed out the importance and impact of skin-to-skin care. In addition, they were adjusting to motherhood. The need for support and encouragement from all the healthcare professionals was obvious in order to overcome the feelings of being alone in a difficult situation. The women separated from their children at NICU requested additional support and care:

*'It felt like you were left alone ... at the same time as I was still in the hospital ... here they only cared about him ... and they were pushing for him to be in my arms for several hours ... and I was feeling ill ... it became a little clash between the neonatal unit and my preeclampsia ... I felt a little pushed aside.'* (PE10)

#### *A despair of being separated from the newborn*

In addition, the women expressed stress when separated from their newborn and that they were too far away from their newborn at the NICU. The women also expressed the view that the staff should have the competence to be able to take care of both the mother and child as in the maternity ward in order to avoid separation:

*'That when you're prematurely born, should be the same as it is on the maternity ward ... because there ... babies and mothers are together... and there they check up on both.'* (PE3)

#### **Overall stress and worry**

The overall lack of information, lack of care-planning, and concerns about future health risks, made the women stressed and worried, underlining the need for both oral and written information. Instead, or as a complement to missing information, they had to search on the internet.

#### *Experiencing stress and worry*

Many women also described concerns about their unborn child and were, in general, less concerned about themselves. They described specific stressful situations such as when their blood pressure was high or when the blood analysis was abnormal:

*'... you are scared "shitless"... that you're going to ... that your body is going to shut down.'* (PE10)

Several women expressed that the word 'toxemia' PE itself, is signaling danger, building up even more stress and worries. At the same time, they expressed that the missing information in itself was frightening. They wanted

information about the worst-case scenarios, even if it scared them:

*'There was very little information about ... what it can lead to ... and maybe you don't want to say that ... because you don't want to scare someone.'* (PE11)

Several of the women in the study were emotionally affected by their experiences. Some cried during the interview and others were angry over their situation. They also described their concerns about a future pregnancy and the fear of becoming pregnant again.

#### *A request for both oral and written information*

Many of the women expressed a wish to receive both oral and written information. They wanted written information to be able to read when the chaos had settled down and not feel so stressed:

*'I would have liked more written information ... about what preeclampsia is ... and what could happen ... so that you ... can re-read it in peace.'* (PE8)

In order for the women to better understand their situation, they either asked friends or relatives or searched for information regarding symptoms, treatments and risk factors on the internet. The women searched for specific information, however, the results made them more confused and worried:

*'I have made sure to read up on it myself too ... on the National Health Information website ... read on the internet ... to fill in the blanks a little bit ... um ... but it's basically the same information ... the symptoms.'* (PE11)

## DISCUSSION

This study explored women's experiences during pregnancy and the postpartum period regarding the provided information and care concerning PE. The interview guide focused on the experiences of the given information about PE, but the women reported an urgent need for involvement in their care based on individual needs. The findings suggest that experiencing PE involved strong feelings of uncertainty and stress, described as: 1) general lack of information during antenatal and postpartum care; 2) a need for more support, due to increased stress and worry; 3) a despair of being separated from the newborn; and 4) a profound lack of knowledge regarding PE and the associated long-term health risks.

The women experienced a general lack of information, and which was fragmented. Repeated consistent information in a person-centered way could be more effective and helpful in meeting their needs, as revealed in our interviews. In addition, the data indicate that many women had difficulties in understanding the information they received regarding their condition and why they had to stay in the hospital. Healthcare professionals must ensure that women in this situation receive the information they need and that the information is understood<sup>19</sup>. Appropriate communication is one of the most difficult tasks in healthcare and several of the women did not experience involvement or informed consent in the medical decisions. Women in this study felt that they received information

without understanding the options or the advantages and disadvantages with the planned interventions. A person-centered approach and continuity of care is suggested to be more beneficial, which has been shown as a successful strategy for a mixed-risk population in a review by Sandall<sup>20</sup>. The participating women also felt that they had difficulties to 'take in' the information. One explanation could be that PE causes general swelling of the central nervous system<sup>21</sup>. Other studies have suggested an association between PE and cognitive functions<sup>22</sup>, further supporting the idea that it may be difficult to understand given information in the acute phase of the disease. In addition, many of the women with severe PE, who were separated from their newborn, particularly expressed stress, which is another factor that may influence the understanding of given information. There are also studies showing association between PE/HELLP and depression<sup>23</sup> and should be considered in future research.

As a consequence of the fragmented and limited information, many of the women felt extra stress and worry. Most of them expressed a concern for their unborn child when they were sick or got the diagnosis, rather than thinking about themselves. Similar findings have been described in an Australian study, where the majority (84.6%) of women reported that they were more worried about their babies<sup>14</sup>. The same study also reported that most (94.1%) of the women felt worried thinking about a future pregnancy, a concern that was expressed only by some women in our study. The women also expressed a need for more support and care for themselves during the time their babies were admitted to the NICU. Other studies confirm our results, that women want to take the opportunity and advantages of practicing the 'skin-to-skin' care at the NICU, even though it could be perceived as difficult due to their own situation<sup>24</sup>. Women with PE experienced more stress and less social support compare to healthy pregnant women<sup>25</sup>. Similar to findings from Australian and Ethiopian studies, our results show that there was a need for additional support during the hospital stay<sup>12,25</sup>. Some women cried during the interview, which should be taken as a warning sign. Particularly, women with severe PE might need help in processing the trauma, suggesting that stress management should be offered routinely<sup>26</sup>. Our results also confirm that there are certain individual needs, especially during the time the women are separated from their newborn. A more optimal organization of care where no separation occurs between parents and newborn would have been preferable. In fact, this is in line with recommendations from WHO. Our results indicate a need for more individual woman-centered care, which also has been described as important in other studies<sup>9,27</sup>. In complicated cases, a teamwork comprising professionals such as obstetricians, pediatricians, NICU nurses, psychologists and midwives should be aimed at so that maternal medical, psychological and care needs are addressed, including information and follow-up of the woman's partner who may have been extremely distressed in case of a life-threatening situation. Other studies have shown benefits of working in obstetrical teams<sup>28</sup>. Further



research may show how we could organize care in a different way to reduce the gaps revealed in our study.

It has been shown that PE is an unknown disease to many women until they actually developed it<sup>13,14</sup>. The knowledge that PE could have long-term consequences with increased risk of cardiovascular disease, diabetes, and stroke<sup>1,7,22</sup>, is often an unknown fact<sup>28</sup>, reported by women in our study. The care of women with PE is unfortunately full of gaps that need attention to become more individualized. About 3% women in Sweden develop PE compared to 1.7% who develop diabetes<sup>29</sup>. Prevention and screening for women, who are at increased risk for gestational diabetes, is performed successfully in Sweden, both during pregnancy and postpartum<sup>30</sup>. The midwives routinely inform the women about the importance of a follow-up visit and their general risks. Similar guidelines and routines might be successful to improve the care for women at risk and/or for women who develop PE. Considering the increased risk of cardiovascular diseases, specific postpartum counselling could be introduced as a routine to give written and oral information according to the new guidelines, which might help to improve long-term outcomes<sup>31</sup>. It is necessary for women diagnosed with PE to get appropriate information about maintaining a healthy lifestyle in order to reduce future risks of the disease. To date, there is neither systematic follow-up to evaluate these risks nor are the women given appropriate information about the additional risks and lifestyle interventions.

Further research needs to investigate if written and oral information about PE, during admission to the hospital and repeated on several occasions, may help the women to understand and cope with their situation better. There is also a need for extra screening regarding their mental health and signs of depression after a pregnancy complicated by severe PE. Our results suggest that midwives and obstetricians must pay more attention to the emotional stress of the women, their need for more personalized and detailed information, as well as providing a detailed plan for follow-up visits postpartum.

### Strengths and limitations

The content analysis was chosen to describe variations regarding similarities and differences in the reported experiences of women regarding the PE information they received. Content analysis is well established and clearly describes the analysis of data<sup>15,18</sup>. The inclusion to this study was at one university hospital with two large clinics at different municipalities. The results derived from the women's experiences may be transferrable to similar groups but cannot be generalized. The inclusion is limited to only Swedish speaking women. Particularly women from Africa could add knowledge because they have increased risk for severe obstetric complications, and non-Swedish speaking women may have reported a different experience, since they also have a language barrier to handle. Another limitation is that only one multiparous woman was included, which can be explained by the fact that PE is more prevalent in primiparas women.

Throughout the analysis process, several steps were taken to ensure reliability, credibility and trustworthiness<sup>15,18</sup>. Data saturation was reached after 13 interviews with no new topics arising, but two more women were included to confirm saturation. A strength of the study is that all researchers have interprofessional, clinical competence of this care. All the researchers were involved throughout the analysis process and discussions were conducted on how well the themes and sub-themes covered the data. Citations from the original text were selected to illustrate themes and sub-themes, to help the readers evaluate the credibility of the analysis process.

### CONCLUSIONS

The women experienced fragmented obstetrical care and information, when diagnosed with PE. Our findings indicate a need for additional support due to increased stress, worry and despair of being separated from the newborn. Future research investigating specific care-planning and postpartum follow-up visits is suggested as a step to improve care for women with a pregnancy complicated by PE.

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#### ETHICAL APPROVAL AND INFORMED CONSENT

The study was approved by the Regional Ethics Board of Lund University (2019-04240). The participation was based on voluntary decisions and informed consent was obtained before the interviews.

#### DATA AVAILABILITY

The data supporting this research are available from the authors on reasonable request.

#### PROVENANCE AND PEER REVIEW

Not commissioned; externally peer reviewed.



## Paper III





# **Mental Health and Coparenting after Preeclampsia: Mothers' and Partners' Perspectives Postpartum – a pilot study**

Maria E. Andersson <sup>1,2\*</sup>, Stefan R. Hansson <sup>1,2</sup> and Elia Psouni <sup>3</sup>

<sup>1</sup> Department of Obstetrics and Gynecology, Institution of Clinical Sciences Lund, Lund University, Sweden.

<sup>2</sup> Skane University Hospital (SUS), Malmö/Lund, Sweden.

<sup>3</sup> Department of Psychology, Lund University, Lund, Sweden

\* Correspondence: [maria.andersson.5171@med.lu.se](mailto:maria.andersson.5171@med.lu.se)

ORCID:

Maria Andersson: 0000-0001-8785-7581

Stefan Hansson: 0000-0002-7838-9074

Elia Psouni: 0000-0003-2758-5785

## Abbreviations

CRS = Co-parenting Relationship Scale

EPDS = The Edinburgh Postnatal Depression Scale

GMDS = Gotland Male Depression Scale

HELLP = Hemolysis, Elevated Liver enzymes, Low Platelets

PASS = Perinatal Anxiety Screening Scale

PE = Preeclampsia

NICU = Neonatal intensive care unit

## ABSTRACT

**Aims/Background:** Preeclampsia (PE) is a severe pregnancy complication affecting 3-8% of pregnant women and their children. Despite increased focus on screening and treatment during pregnancy, few studies have investigated personal and dyadic postnatal influences of a complicated pregnancy. The present pilot study investigated postnatal symptoms of depression and anxiety, and associations with perceived coparenting quality, in women who experienced PE and their partners.

**Design/Method:** A prospective longitudinal study with self-report measures concerning anxiety, typical and atypical symptoms of depression, and coparenting experiences and thoughts, was presented in a digital survey responded to by women with a PE diagnosis, and partners (men only), two and six months postnatally.

**Results:** Despite difficult pregnancies and births, the proportion of participants with clinical levels of postnatal depression and anxiety symptoms was similar to community samples, and symptom severity declined over time. Symptoms of postnatal depression and anxiety were highly linked, suggesting comorbidity. Higher education was associated with higher levels of symptoms, however neither participant sex nor severity of PE diagnosis had any impact. The strongest predictor of level of symptoms was perceived support and closeness in coparenting. Between partners, women's anxiety level was linked to how their partners experiencing lower levels of support and closeness in coparenting.

**Conclusion:** Perceived support and closeness in coparenting may counteract risk factors stemming from pregnancy and birth complications and protect both women and men from postnatal depression and anxiety. Our results also highlight intricate dyadic links between the one parent's mental health and the other parent's perceptions of coparenting. Support to families affected by preeclampsia should therefore target the coparenting relationship and include both partners.



**Keywords:** Postnatal mental health, Postnatal Anxiety, Postnatal Depression, Mothers, Fathers, Coparenting, Preeclampsia

## INTRODUCTION

Preeclampsia (PE) is a severe pregnancy complication associated with high maternal and fetal mortality. It affects 3–8 percent of pregnant women, which corresponds to 8.5 million women worldwide. The global annual healthcare expenses are estimated between 18-22 billion USD [1]. Preeclampsia is defined as hypertension (140/90 mmHg) after 20 weeks of gestation combined with maternal organ dysfunction and/or intrauterine growth restriction [2]. Women diagnosed with PE often describe their experiences as frightening [3-5]. Given the significant human and material costs PE incurs, there is increasing epidemiological/clinical [6, 7] research regarding early pregnancy screening, treatment, and associated long-term complications [8], yet few studies have focused on how PE may impact the women and their partners' postnatal experiences [9]. Such knowledge may reveal challenges and strengths related to mental health and parenting, to guide the provision of adequate support to these women and their families.

Meta-analytical evidence indicates an elevated risk for depression, anxiety and post-traumatic stress disorder postnatally among women with PE [10, 11]. Several factors may contribute to this risk, including severity of the condition, postpartum pain [12], separations from the new-born baby [11], cardiovascular dysfunction [8] and impaired cognitive function [13]. Furthermore, pregnancy and childbirth experiences in the presence of a PE diagnosis often contradict expectations [5, 14], which in itself may constitute a threat to postnatal mental health [15]. Women with PE often give birth preterm [1], and experience complications related to labour and feelings of lacking control, which can be perceived as stressful and traumatic. These feelings may be exacerbated by a perceived lack of adequate information in combination with impaired cognitive function [3, 5, 14].

Importantly, the separation of mothers with PE from their newborns immediately after birth [16, 17], results in limited skin to skin contact [18] and little interaction, breastfeeding

and caring of the newborn in the early postpartum. Mothers may also experience uncertainty over the intensive care unit procedures performed on their newborn child [19]. To make matters worse, both the women and their babies have an increased long-term risk of developing hypertension, stroke and cardiovascular disease later in life [6, 23]. All these factors may contribute to additional stress, which not only hinders recovery postpartum but may also negatively affect the emerging parent-child relationship with the newborn. Indeed, women with PE report higher levels of perceived stress [20] compared to healthy pregnant women.

Even in the absence of PE, mental health problems are more common among women in the postpartum period compared to women in general, showing increased prevalence of both depression [21, 22], and anxiety [23]. While mental health problems in the postpartum period are a complex phenomenon involving multiple, and often interlinked mechanisms, known individual antecedents include a previous history of mental illness, particularly depression, lower levels of education and lower income [24, 25]. There is also evidence of relational antecedents, including low levels of perceived social support, low relationship satisfaction, and paternal mental health problems [26].

Indeed, the fathers' postnatal mental health<sup>1</sup> has come to focus in the past decade, and results from several studies confirm increased risk of both depression [24, 27], and anxiety [28, 29] in the first postnatal year. Along with individual antecedents, similar to those that have been shown for women, including a history of mental illness, unemployment and lower income [28, 30], several relational antecedents have also been shown for postnatal depression [31] and anxiety [29] in fathers. Evidently, the consequences of mental health problems in the

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<sup>1</sup> Several terms are used in the scientific literature regarding mental health challenges for fathers following the birth of their child. In the present paper, we use the term postnatal mental health in all contexts and discussions that concern both birthing parents (mothers, who experience partum and postpartum) and non-birthing parents (most commonly fathers).

postnatal period extend beyond the affected parent, through mutual influences between the parents and subsequent negative impact on the parent-child relationship [32].

Besides mental health, the parents' resilience in general is also likely interconnected. Indeed, evidence illustrates multiple ways in which co-parents influence each other's thoughts, feelings, and behaviours [33-35]. Men whose partners go through a complicated pregnancy and childbirth are more likely to face mental health problems postnatally, coinciding to the time when they need to support and care for their partners [36], or at a later time point, when the families most often no longer are in contact with healthcare services [37]. Results from a PE study including men showed that men described their experiences related to the pregnancy and birth as unexpected and particularly distressing [9]. Thus, PE appears to elevate vulnerability for both parents in the postnatal period. Beyond the increased risk of postnatal health challenges, parents may feel overwhelmed by the burdens of a PE-complicated pregnancy and birth, face a more difficult recovery, and experience heightened concerns about their child's health. Challenges on health and emotions may also impact on the parents' ability to collaborate effectively.

Thus, the parents' PE-related vulnerability may significantly challenge their collaboration in coparenting during the postnatal period. Coparenting, defined as the way two or more adults collaborate and support one another in raising a child [33, 38], relies on respectful communication, shared decision making, and prioritization of the child's needs above personal differences. Research highlights that effective coparenting plays a crucial role in fostering the child's emotional, social, and cognitive development (Han et al., 2023), underscoring the importance of addressing the unique vulnerabilities associated with PE to support both parents and their child.

However, to our knowledge, the links between coparents' mental health and coparenting experiences in the postnatal period in the context of PE are unexplored. To address this

knowledge gap, the present study aimed to investigate postnatal mental health challenges, as well as perceived coparenting quality, in women who experienced PE and their partners. Based on previous research, both postnatal depression and postnatal anxiety were assessed. The study evaluated (1) links between mental health and coparenting experiences, as well as (2) potential links and influences between coparents' experiences.

## **METHODS**

### **Project setting and procedures**

The study was part of a longitudinal project at a University Hospital in Sweden aiming to follow women and their partners after a pregnancy complicated by PE during the first postnatal year. The project was approved by the Swedish Ethical Review Authority (Dnr masked for review). The hospital maternity clinics have about 10000 births and approximately 350 cases of PE per year [39]. For recruitment, 112 women and their partners were approached while at the maternity clinic, to present the project, its aims and protocols. The inclusion criteria were: (a) diagnosed with PE, (b) age 18 years or older, and (c) proficiency in Swedish. All participating partners were men. Participants received oral and written information about the project, had the opportunity to discuss with a midwife and were given time to consider their participation before consenting to be part of the study.

For data collection, the participants disclosed information regarding parenting and coparenting experiences and thoughts, as well as mental health symptoms, at two (T1), six (T2), and twelve (T3) months postnatally, through self-report instruments presented in a survey available on the digital platform Research Electronic Data Capture (RedCap) [40]. Three reminders were sent automatically via email. If no responses were received, an additional reminder was sent out by phone/SMS. The current study concerns longitudinal data collected between March 2022 and December 2023, including medical information at

recruitment immediately after the child's birth (T0), and mental health and coparenting data from T1 and T2.

## Participants

In total,  $n = 93$  individuals (58 women, 35 men) consented to participation in the project, representing 83% of those contacted. However, five individuals dropped out after recruitment, while 37 did not contribute with mental health data at T1 or T2. The current study is therefore based on data from 50 participants, (37 women/13 men) who contributed sufficient ( $>70\%$ ) data at both T1 and T2 (Figure 1 for a graphic summary).

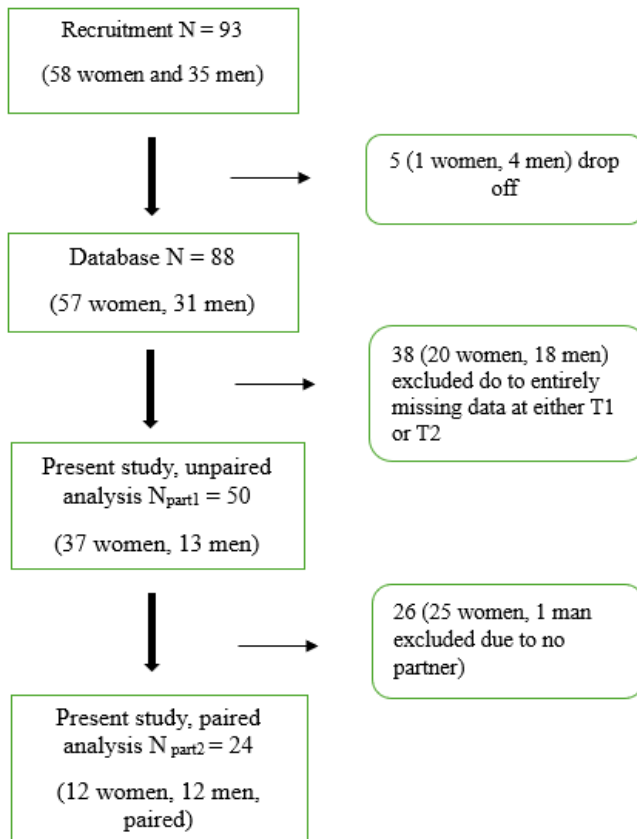


Figure 1. Flowchart of participants, recruitment to current study analyses

## **Material and Methods**

Medical obstetrical data was obtained from medical records (Obstetrix 2.18.0.100, Copyright © Cerner Sverige AB) [41] at recruitment, T0. Data from the questionnaires at T1 and T2 addressed depression, anxiety, and coparenting quality. All instruments were internationally established and validated, also for Swedish settings. Socio-demographic background information was collected through self-report questions in the survey at T1.

### ***Medical and Sociodemographic background***

We collected basic demographic data regarding age, level of education, mother tongue, and relationship status, as well as medical history related to mental health problems before and during pregnancy. Obstetrical variables related to stressors of potential significance included subtype of PE, gestational length, mode of delivery, maternal bleeding as well as the newborn's sex, weight, health status, admission to the NICU.

### ***Preeclampsia***

Current classifications of PE include PE, severe PE, haemolysis with elevated liver enzymes and low platelets (HELLP) syndrome, and eclampsia (Brown et al 2018). PE is characterized by high blood pressure, protein in the urine, and/or organ dysfunction including fetal growth restriction. Severe PE is defined by severe hypertension, gestational age at childbirth and/or level of organ dysfunction, and there may be additional symptoms such as headaches, visual disturbances, and upper abdominal pain. HELLP syndrome involves additionally damage to the liver and blood cells with a risk of coagulation disorders, while eclampsia is the most severe form, involving seizures in pregnancy or postpartum up to six weeks after delivery [2]. No eclampsia cases were diagnosed existed among the participants. Given that HELLP is a severe PE diagnosis, and that the number of participants with this diagnosis was very low, we

defined a dichotomous variable to capture severity of diagnosis, (a) PE and (b) severe PE (including the severe PE and HELLP sub-diagnoses).

### ***Postnatal Depression***

Since depression may be expressed as both typical and so-called atypical symptoms such as low stress tolerance and anger outbreaks [42] for both men and women [31], we assessed depressive symptoms combining two measures, the *Edinburgh Postnatal Depression Scale* (EPDS) [43] and the *Gotland Male Depression Scale* (GMDS) [44], in line with previous studies concerning men [29, 32, 35], and proposals that atypical symptoms ought to be considered also for women [31, 32]. Women are more affected by depression and anxiety disorders than men, with higher rates of comorbidity between the two and a threefold greater prevalence of atypical depression [45].

The EPDS is a 10-item self-report instrument capturing typical symptoms of depression in the postnatal period (e.g. “I have felt sad or miserable”). It has documented validity and reliability [51], also in a Swedish context [46-48], and is also validated for use in men [30]. While different cut-off scores have been proposed from validations of the scale in different countries, in Sweden, a cut-off score of  $\geq 12$  is recommended for screening major depression in mothers [48] and fathers [28]. Here, we also used a cut-off score of  $\geq 9$  as indicative of minor depression, consistent with studies focusing on postnatal depression in men [28, 32].

The GMDS was used here as it is one of few validated measures of screening for atypical symptoms of depression. It is a 13-item self-report instrument addressing atypical depressive symptoms including irritability, low stress tolerance and impulse control, frequent anger outbreaks, extreme and risky behaviours, and bodily symptoms (e.g. “Constant inexplicable tiredness”) [44]. Evidence of validity and reliability has previously been reported [49, 50]. A score  $\geq 13$  signifies significant depression symptoms and is used as cut-off [50, 51].



For both instruments, responses are given on a 4-point scale, with higher scores indicating higher frequency of the described symptom. Originally, the EPDS poses questions in a timeframe of one week, while the GMDS uses a four-week period for symptom estimation. To enhance response trustworthiness, the timeframe for experienced symptoms was adjusted to two weeks for both instruments. Internal consistency (Cronbach's  $\alpha$ ) in the present study was high,  $\alpha_{(T1)} = .75$  and  $\alpha_{(T2)} = .84$  for the EPDS, and  $\alpha_{(T1)} = .84$  and  $\alpha_{(T2)} = .91$  for the GMDS.

### ***Postnatal anxiety***

Anxiety was assessed with the *Perinatal Anxiety Screening Scale* (PASS) [52] comprising 31 symptoms of excessive worry and fear, e.g. "Sudden rushes of extreme fear", "Feeling jumpy or easily startled" rated on a 4-point scale, with higher scores indicating higher frequency of the symptom. A total score  $\geq 26$  indicates high likelihood of anxiety at clinical levels [52, 53]. The PASS has demonstrated stability over time, convergent validity with other anxiety measures, and higher diagnostic validity compared to other anxiety instruments [52]. In the present study, internal consistency (Cronbach's  $\alpha$ ) was  $\alpha_{(T1)} = .90$  and  $\alpha_{(T2)} = .93$ .

### ***Coparenting***

The *Coparenting Relationship Scale* (CRS) [38] is a 35-item self-report questionnaire assessing coparent communication and behaviours in specific situations. Example items include: "We often discuss the best way to meet our child's needs" and "My partner does not trust my abilities as a parent". The CRS has demonstrated high reliability and construct validity [38], also in a Swedish context [54]. Based on the Swedish validation of the CRS [54], subscale scores were calculated with high internal consistency for "support and closeness" ( $\alpha_{(T1)} = .90$ ,  $\alpha_{(T2)} = .89$ ), "endorsement" ( $\alpha_{(T1)} = .85$ ,  $\alpha_{(T2)} = .80$ ) and

“disagreement” ( $\alpha_{(T1)} = \alpha_{(T2)} = .81$ ). Items 31-35, that address non-parenting related conflict between the partners, were not included in the questionnaire (T1 and T2).

### **Data preparation and analysis plan**

Data analysis was carried out using the IBM Statistics SPSS version 28.0, and Jamovi (The Jamovi Project, 2023) [55].

To test for potential selection bias, we carried out analysis related to participant attrition. Chi-squared ( $\chi^2$ ) tests were used to compare background characteristics of included and excluded participants, also considering sex (women versus men). Descriptive statistics were then presented for continuous variables as minimum, maximum, and mean  $\pm$  standard deviation (SD). Categorical variables were presented in numbers (n) and proportions (%). Zero-order (Pearson) correlations were calculated for all outcome variables. We also created dichotomous variables based on scale cut-offs from the EPDS, GMDS and PASS continuous data.

After confirming that the missing data for mental health symptoms (EPDS, GMDS, PASS) and coparenting (CRS support/closeness, endorsement, and disagreement) were missing at random, we addressed the missing values through imputation. Specifically, estimated means (EM) were calculated, and the imputation process was repeated across 50 iterations to ensure accuracy and reliability. The proportion of missing data across all measures was below 20%. Little's MCAR test indicated satisfactory model convergence,  $\chi^2_{(63)} = 55.532, p = .737$ . Furthermore, as EPDS and GMDS depression and PASS anxiety scores were highly correlated, we conducted a principal components analysis (PCA) on these measures. The Bartlett test ( $\chi^2 = 191, p < .001$ ) and KMO measure ( $= .757$ ) suggested sample adequacy for conducting PCA. A single component gathered all measures, with very high loadings (EPDS = .918, GMDS = .917, PASS = .920). Thus, composite scores for mental health were calculated using the regression method.

The analysis was conducted in two parts, addressing question 1 using unpaired data, and question 2 using paired data from a subgroup of women and their partners. To address the first study question, concerning links between mental health and coparenting experience, data from all participants (N = 50) was analysed. We conducted mixed linear analyses based on repeated measures over time (2 months (T1) and 6 months (T2) postnatally), sex (women vs. men) and PE severity (PE vs. severe PE) as between-participants (grouping) variables, and mental health difficulties (depression and anxiety symptoms: EPDS, GMDS, PASS) as outcome. Coparenting variables (CRS support/closeness, endorsement, and disagreement, respectively) were covariates in the models.

An initial round tested models considering time, sex and PE-severity for each scale score (EPDS, GMDS, PASS, CRS) as outcome and background information (participant education level, gestational age at delivery, bleeding as proxy for delivery complications and whether the newborn required NICU care) as covariates. Significant covariates from these models were retained in a next round, that included coparenting (CRS / support/closeness, endorsement, and disagreement) as covariates. In a final round, a full model was estimated with the composite score of mental health difficulties (based on the PCA component) as outcome, and associated dimensions of coparenting quality as covariates. Given the limited sample size, only two-way interactions involving time were included in the models.

The second question, potential links and influences between coparents' experiences, was addressed through paired data analyses based on a subset of 24 participants, women and their partners, i.e. 12 couples with complete data. To account for the limited sample size, paired samples non-parametric tests were employed: the Wilcoxon sample rank test to compare values, and the Spearman correlation-test for associations.

## RESULTS

### Attrition analysis to explore potential bias in the included cases

A higher proportion of men (partners) than women had contributed incomplete data (over 30% incomplete) and were therefore excluded from the present study ( $\chi^2 = 3.921$ ,  $p = .048$ ). Among the included women, a higher proportion had undergone induction of labour ( $\chi^2 = 4.282$ ,  $p = .039$ ), and a greater proportion were diagnosed with severe PE or HELLP syndrome ( $\chi^2 = 4.836$ ,  $p = .028$ , see also Table 1), compared to those who were excluded. No differences were found between included and excluded participants in gestational age at delivery ( $\chi^2 = 17.832$ ,  $p = .085$ ), Caesarean section rate ( $\chi^2 = .864$ ,  $p = .353$ ), postpartum bleeding as a proxy for complications ( $\chi^2 = 47.872$ ,  $p = .131$ ), or neonatal intensive care unit (NICU) admissions ( $\chi^2 = 1.185$ ,  $p = .275$ ).

**Table 1.** Preeclampsia diagnoses among included and not included women

<b>Female participants</b>	<b>Total in project (n=58)</b>	<b>Present study (n=37)</b>	<b>Excluded (n=21)</b>
Preeclampsia	45	25	20
Severe preeclampsia	11	10	1
HELLP	2	2	0

### Participant demographics and health characteristics

Three (8.1%) of the participating women and two (15.3%) of the participating men were non-native Swedish speaking. Educational background varied: Among women, 29.0% had high school education, 45.2% had completed 3-4 years of university studies, and 25.8% had over 5 years of university education. Among men, 23.1% had high school education, 30% had completed 3-4 years of university studies, and 7.8% had over 5 years of university education.

Postpartum bleeding ranged from 101 to 2200 ml, with a mean of 597 ml (SD  $\pm$  486). The newborns' Apgar score ranged from  $< 7$  (n = 8 at 1 min, n = 3 at 5 and 10 min) to  $> 7$  for all other newborns (n = 39) at 1, 5 and 10 minutes. Birth weights ranged from 630 to 3980 grams (M = 2764 gr, SD = 870).

**Table 2.** Participant characteristics

Characteristics related to the birth	Women n= 37	Men n= 13
Age, years (%)		*
18-30	14 (45.25)	1 (12.5%)
31-40	15 (48.9%)	7 (53.8%)
41-50	2 (5.4%)	-
<b>Gestational age (week)</b>	28-40	34-40
Very preterm $<34$ weeks, n (%)	3 (8.1%)	-
Preterm birth ( $<37$ weeks), n (%)	15 (40.5%)	5 (38.5%)
Term birth ( $>37$ weeks), n (%)	22 (59.5%)	8 (61.5%)
<b>Mode of birth</b>		
Virginal, n (%)	15 (40.5%)	5 (38.5%)
Caesarean section, n (%)	22 (59.5%)	8 (61.5%)
Induction, n (%)	17 (45.9%)	7 (53.8%)
<b>Newborn in NICU</b>	17 (45.9%)	3 (23.1%)
<b>Preeclampsia</b>		
PE, n (%)	25 (67.6%)	10 (76.9%)
Severe PE, n (%)	10 (27%)	2 (15.4%)
HELLP, n (%)	2 (5.4%)	1 (7.7%)
<b>History of depression (n)</b>	13 (35.1%)	1 (7.7%)*
<b>Sex newborn</b>		
Girl, n (%)	19 (48.6%)	4 (30.7%)
Boy, n (%)	20 (51.4%)	9 (69.2%)

HELLP= Hemolysis, Elevated Liver enzymes, Low Platelets, PE= preeclampsia, \*5 missing data concerning age and previous depression

## Descriptive statistics

At T1, 11 women reported typical depressive symptoms above the EPDS cut-off  $\geq 9$ , indicating possible minor depression, while four reported symptoms suggesting possible major depression. At T2, five women reported symptoms suggesting minor depression, and three symptoms indicating major depression. Among men, typical depressive symptoms above the EPDS cut-off  $\geq 9$  were reported by two at T1 and one at T2. Importantly, none of the participants reported thoughts of self-harm (question 10 of the EPDS), neither at T1 nor at T2. Regarding atypical depression symptoms (GMDS), four women reported symptoms above cutoff ( $\geq 13$ ) at T1, and six at T2. Two men reported symptoms above cutoff ( $\geq 13$ ) at T1 and T2. The anxiety scale, PASS, indicated symptoms at clinical levels (above cutoff  $\geq 26$ ) for seven women at T1, and three at T2. Among men, one reported symptom above cutoff at T1. See Table 3 for % above cut-off values, means and SD.

**Table 3.** Respondents above cut-off for referral in the different measures

Scale			Mean $\pm$ SD				Total mean
	Women (n=37)	Men (n=13)	Women PE	Women severe PE	Men PE	Men severe PE	Women/Men
EPDS T1			7.3 $\pm$ 3.5	7.5 $\pm$ 4.6	6.2 $\pm$ 2.9	4.5 $\pm$ 2.1	7.0/7.7
Cut-off $\geq 9$	<b>11</b> (30%)	<b>2</b> (15.4%)					
Cut-off $\geq 12$	<b>4</b> (10.8%)	0 (0%)					
EPDS T2			5.9 $\pm$ 3.4	7.3 $\pm$ 6.9	4.3 $\pm$ 3.2	5.0 $\pm$ 4.4	5.6/6.5
Cut-off $\geq 9$	<b>5</b> (13.5%)	<b>1</b> (7.7%)					
Cut-off $\geq 12$	<b>3</b> (8.1%)	0 (0%)					
GMDS T1			4.4 $\pm$ 3.9	5.0 $\pm$ 4.6	4.9 $\pm$ 4.9	3.5 $\pm$ 7.0	4.6/4.6
Cut-off $\geq 13$	<b>4</b> (10.8%)	<b>1</b> (7.7%)					
GMDS T2			4.6 $\pm$ 4.5	6.9 $\pm$ 10.3	4.6 $\pm$ 3.6	8.0 $\pm$ -	5.2/4.9
Cut-off $\geq 13$	<b>6</b> (16.2%)	<b>1</b> (7.7%)					
PASS T1			16.1 $\pm$ 11.1	15.6 $\pm$ 10.3	10.3 $\pm$ 8.9	10.0 $\pm$ 7.1	15.1/14.3
Cut-off $\geq 26$	<b>7</b> (18.9%)	<b>1</b> (7.7%)					
PASS T2			13.3 $\pm$ 10.4	14.9 $\pm$ 16.5	8.1 $\pm$ 7.2	16.0 $\pm$ 7.2	12.5/14.7
Cut-off $\geq 26$	<b>3</b> (8.1%)	0 (0%)					

Note: T1 = 2 months postnatally, T2= 6 months postnatally; EPDS= Edinburgh Postnatal Depression Scale, GMDS= Gotland Male Depression Scale, PASS= Perinatal Anxiety Screening Scale, SD=standard deviation

### ***Associations among the study outcome variables***

The zero order correlations between the two facets of depression (typical symptoms/EPDS, atypical symptoms/GMDS) and anxiety (PASS) were high (Table 4), both at T1 and at T2, suggesting comorbidity of postnatal depression and anxiety symptoms. EPDS, GMDS, and PASS, respectively, showed strong correlations between T1 and T2.

**Table 4.** Zero order correlations for EDPS, GMDS and PASS (N=50)

	1	2	3	4	5	6
1 EPDS T1	1					
2 EPDS T2	.661**	1				
3 GMDS T1	.725**	.734**	1			
4 GMDS T2	.549**	.798**	.713**	1		
5 PASS T1	.682**	.430**	.651**	.416**	1	
6 PASS T2	.549**	.790**	.649**	.831**	.560**	1

Note: T1= 2 months postnatally, T2= 6 months postnatally. \*\*  $p < .01$  (2-tailed).

### **Part 1: Affected women's and partners' coparenting and mental health, and links between them**

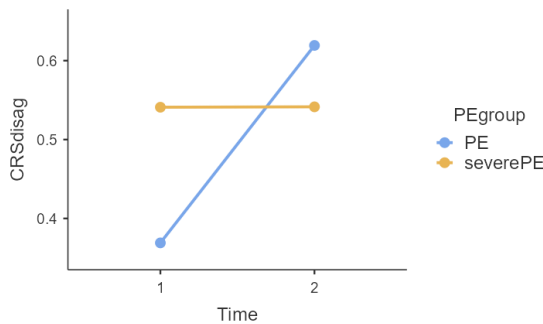
Table 5 summarizes CRS sub-scores for women/men and PE/severe PE, at T1 and T2, respectively. The mixed linear models for CRS support/closeness, CRS endorsement, and CRS disagreement, respectively, revealed no effects of time (T1 vs T2), sex or PE severity. However, higher levels of education were associated with lower scores on perceived support/closeness ( $\beta = -.61$ ,  $t = -2.89$ ,  $F_{(1, 34)} = 8.35$ ,  $p < .007$ ) and higher scores on conflict

(beta = .29,  $t = 2.12$ ,  $F_{(1, 35)} = 4.48$ ,  $p < .04$ ). Perceived conflict in coparenting increased between T1 and T2 for participants with PE (see Fig. 2).

**Table 5** Coparenting experiences and thoughts (CRS), means and standard deviations (N=50)

Scale	Mean±SD				Total
	Women PE (n=25)	Women severe PE (n=12)	Men PE (n=10)	Men severe PE (n=3)	Women (n=37)/Men (n=13)
CRS					
Support/Closeness T1	4.8±1.3	5.1±0.9	4.3±1.0	5.4±0.6	4.7/4.9
Support/Closeness T2	5.1±0.8	4.9±1.1	4.4±1.0	5.6±1.0	4.8/4.9
Endorsement T1	3.8±0.6	3.9±0.5	4.1±0.5	4.0±0.5	3.9/3.9
Endorsement T2	3.7±0.5	3.7±0.3	3.8±0.5	4.1±0.5	3.7/3.8
Disagreement T1	0.4±0.6	0.7±1.0	0.4±0.4	0.2±0.3	0.4/0.6
Disagreement T2	0.3±0.3	0.5±1.0	0.8±0.8	0.4±0.7	0.6/0.5

Note: T1 = 2 months postnatally, T2 = 6 months postnatally; SD= standard deviation



**Figure 2.** Interaction between PE severity group (PE, severe PE) and time (T1, T2) regarding perceived coparent disagreement

The separate models for EPDS and PASS revealed a main effect of time after childbirth. Independently of sex and PE severity, participants reported less severe typical depression symptoms ( $F_{(1, 34)} = 4.27$ ,  $p < .05$ ) and less anxiety ( $F_{(1, 34)} = 4.45$ ,  $p < .05$ ) at T2 compared to T1 (Post hoc Bonferroni corrected test  $t = 3.7$ ,  $p = .001$  for EPDS and  $t = 2.51$ ,  $p = .04$  for



PASS). Main effects and interactions regarding fetal sex, PE severity and covariates were not significant. The separate model for GMDS revealed no main effects or interactions.

The next round of analysis included the composite score as outcome and examined links to coparenting quality. When only background covariates were used (level of education, gestational week at childbirth, bleeding as proxy for delivery complications and need of NICU care), a significant effect of education was found ( $F_{(1, 32)} = 5.86, p = .021$ ). The positive estimate (association) ( $\beta = .45$ ) indicates that participants with higher education reported symptoms indicating more severe mental health challenges. This variable was retained in the final model, together with the three coparenting variables (CRS).

In the final model, besides a main effect of time ( $F_{(1, 55)} = 4.18, p = .048$ ) in the (expected) direction of less severe depression and anxiety symptoms overall at T2 as compared to T1, there was a main effect of coparenting (CRS) support and closeness ( $F_{(1, 55)} = 9.22, p = .004$ ). The negative estimate ( $\beta = -.393$ ) indicates that the more the perceived support by and closeness with the partner in parenting, the fewer the reported symptoms of depression and anxiety. No other effects or interactions were found, suggesting that overall symptom levels did not differ between women and men, and were independent of PE severity. Participant education level was no longer a significantly contributing variable.

## **Part 2: Links between affected women and their partners in mental health and parenting outcomes**

Wilcoxon analysis (Table 6) showed that the difference between women and their partners in EPDS scores almost reached significance ( $p = .051$ ), with women reporting more symptoms than their partners (mean difference = 1.23). Women also reported higher perceived coparenting support and closeness than their partners ( $p = .010$ ), and less disagreement in coparenting than their partners ( $p = .021$ ).

**Table 6.** Paired Samples T-Test (Wilcoxon), complete data from 12 couples and 24 observations at T1 and T2.

Scales	Mean (SD) women	Mean (SD) men	Wilcoxon <i>t</i>	<i>p</i>	Mean difference
EPDS	6.8 (3.3)	5.5 (2.9)	187.0	.051	1.40
GMDS	4.1 (2.9)	4.9 (3.8)	79.5	.350	-1.03
PASS	12.8 (7.6)	10.0 (7.3)	197.0	.184	2.91
CRS support	5.4 (.9)	4.7 (1.0)	206.5	.010	.74
CRS endorse	3.9 (.4)	3.9 (.4)	173.0	.520	.07
CRS disagree	.2 (.2)	.5 (.6)	37.0	.021	-0.32

Spearman correlation analysis showed significant associations between women's and their partners' EPDS (typical depressive symptoms) scores but no association regarding GMDS (atypical depressive symptoms) or PASS (anxiety) scores. Regarding coparenting, women's and their partners' perceptions were unrelated on all dimensions (Support/Closeness, Endorsement, Disagreement, see Table 7). Notably, there was a negative association between women's anxiety symptoms and their partners' perceived CRS support scores, indicating that the partners of women with higher levels of anxiety perceived less closeness and support in their coparenting relationship.

**Table 7.** Association between partners' scores: Spearman rank correlation

	EPDS women	GMDS women	PASS women	CRSsupp women	CRSendo women	CRSdisag women
EPDS men	.589**					
GMDS men	.338	.181				
PASS men	.019	-.151	.044			
CRSsupp men	-.383	-.085	-.475*	.086		
CRSendo men	-.085	-.111	-.400	-.071	-.125	
CRSdisag men	.366	.106	.377	.202	.193	.326

supp= Support/Closeness, endo= Endorsement, disag= Disagreement, rho= rank correlation, \*\*  $p < 0.01$ , \*  $p < 0.05$

## DISCUSSION

The present study investigated postnatal symptoms of depression and anxiety, as well as perceived coparenting quality, in women who experienced PE and their partners. To the best of our knowledge, this is the first study to examine links between mental health and coparenting, and links between coparents' experiences during the postnatal period in the context of PE. Results show the expected decline in postnatal depression and anxiety symptoms over the first six months after the child's birth. Importantly, perceived support/closeness in coparenting was negatively linked to symptoms of depression/anxiety, while neither the newborn's sex nor severity of PE had any impact. Somewhat surprisingly, women's and their partners' perceptions regarding coparenting were unrelated, while the partners of women with higher level of anxiety reported lower support and closeness in coparenting, highlighting a possible asymmetry in how parents experience and influence each other. An unexpected result was that higher education was associated with higher levels of symptoms.

The different measures of typical (EPDS) and atypical (GMDS) depression and anxiety (PASS) symptoms were highly associated, both within and between the time points, and converged into a mental health composite. These results indicate comorbidity in postnatal depression and anxiety symptoms, in line with previous research [35, 54]. The decrease in severity of symptoms over time is also in line with previous research about links and barriers in women and fathers with depression [27, 29]. Observing reduced symptoms of mental illness over time reflects the body's and psyche's natural recovery processes. This result is not only expected but also shows that the study's measurements captured realistic and biologically plausible trends, strengthening validity of the data.

## **Postnatal mental health among women with PE and partners**

Levels of depression among women in the present study align with meta-analytic prevalence for moderate to severe major depression at 4.7 percent in the first 3 months postpartum [22] and prevalence including mild depression at 13 percent, in line with other Swedish studies about depression symptoms in early pregnancy and in fathers postnatal [25, 56]. This, even though a substantial proportion among recruited women had experienced mental health problems before pregnancy, which constitutes a risk factor for postnatal mental health problems. Another study evaluating women with PE six months postpartum showed similar results [57]. Thus, while burdened with a risk from pregnancies and a delivery complicated by PE, women in the present study reported typical symptoms of depression at levels comparable to community samples. Symptoms of anxiety were, however, relatively high among women at T1, with 19% reporting symptoms suggesting an anxiety disorder [58], but anxiety levels dropped at T2.

Finally, women also reported atypical depressive symptoms. In fact, 10% reported levels of atypical symptoms indicative of depression at T1, and the proportion of women with symptom severity above the cut-off threshold increased to 15% at 6 months postnatally. While atypical depression symptoms were initially considered to co-occur with typical depression symptoms specifically in men, our findings highlight that these symptoms may be typical also among women, in line with previous suggestions in the literature [31, 32].

Although the study was limited by its small sample size and pilot nature, levels of depression among participating men were consistent with those reported in meta-analyses [25] and studies on community samples [26, 50]. The severity of depression symptoms decreased with time, unlike other research reports [25, 28-30]. The proportion of men with atypical symptoms indicating suspected depression was lower than reported elsewhere [28-30, 50]. Unlike other studies, levels of anxiety were low among men [29].

Interestingly, PE severity did not seem to be associated with parental mental health, consistent with a cohort study showing no differences in symptom levels between preeclamptic and normotensive women [58]. However, other research has linked severe PE to higher risk for postnatal depression [59, 60]. While medical uncertainty and the potential for adverse outcomes may elevate stress for both women [3, 4] and partners [36], our results suggest no differences in depression or anxiety symptoms based on PE severity. Similarly, despite evidence indicating a threefold increase in depression and anxiety risk for women with PE whose babies are admitted to NICU [61], no such differences were observed in this study.

While these are positive findings, self-selection bias may partly account for these discrepancies. It is also not possible to exclude effects from barriers to reporting mental health. Such barriers are particularly present among women [24] and men [59] in the postnatal period. Nor do our results reveal any group differences between women and men in levels of depressive and anxiety symptoms. Both women and men may experience similar psychological stressors during the postnatal period, such as lack of sleep, increased stress, and changes in life roles. Although women often face hormonal changes and physical symptoms related to the birth-giving, men may experience psychological stress related to changing social expectations and adjustment to parenthood.

### **Perceived coparenting collaboration and support a decisive factor**

Perceived support and closeness in coparenting was the factor with the strongest association with women's and men's well-being. Mean values regarding coparenting support and closeness were somewhat higher than in other Swedish data based on parents of children of all ages, but align well with previous reported levels among parents of infants and young children [54]. Levels of coparenting support and closeness shown in the present study may also reflect societal efforts in the direction of supporting shared parenting between partners. The National Board of Health and Welfare's report highlights the effects of structured parental support

programs in Sweden and their impact on children's behavioral problems and the quality of parenting [60].

Aligning with other research [31-32], perceived coparenting support and closeness was associated with lower levels of symptoms of depression and anxiety. This is particularly relevant during the first year after the birth of the child, when parenthood is formed and the relationship between the parents as coparents is established. For both birthing women and their partners, this period often means emotional, physical and relational changes, which makes interaction and support particularly important [24]. Research shows that the quality of the relationship between the parents, including cooperation and support, is not only a protective factor against postnatal mental health problems [e.g. 13, 28, 29] but also a promotor of good enough parenting [33]. A supportive collaboration between coparents during the first months could create a stable and potentially more sensitive caregiving environment for the child, which may be especially important in the presence of complications such as preeclampsia.

Somewhat unexpected, women's and their partners' perceptions regarding their coparenting collaboration were unrelated. This may reflect differences in how women and their partners deal with parenting challenges [34, 35], especially after a complicated pregnancy such as preeclampsia. Since shared experiences of support and cooperation can strengthen the relationship and the parents' mental health, it is important that care facilitates an open dialogue between the parents. By identifying and addressing these differences early, healthcare professionals can assist parents in developing a more cohesive co-parenting approach, ultimately benefiting their relationship and promoting the child's well-being.

Importantly, the partners of women with higher levels of anxiety reported lower perceived support and closeness in coparenting. These results are a first indication of dyadic interactions: the one partner's symptoms of anxiety are associated with perceptions, in the

other partner, of lesser togetherness and support. This aligns with previous research findings [22, 24, 29, 31, 32] that the psychological well-being of both parents is closely linked and suggests that an individual psychological challenge, such as anxiety, can create stress and reduce connectedness and support in co-parenting. Care should therefore not only focus on individual conditions but also support the entire family by promoting good communication and strong cooperation between the parents.

### **Higher level of education as a risk factor**

Previous research has indicated that women with a higher level of education tend to have better access to information about health, understanding of medical recommendations and the opportunity to seek support [61]. Higher education is often linked to an increased sense of self-confidence and control over the life situation, which can protect against mental health challenges during the demanding postnatal period. On the other hand, higher levels of education have previously been associated with lower levels of perceived support and closeness in coparenting in the light of marital difficulties [54]. Also in the present study, higher levels of education were associated with lesser perceived support and closeness, and more conflict, in coparenting. Furthermore, our findings revealed a consistent association between higher levels of education and increased symptoms of anxiety and depression, in both women with PE and partners. This relationship may reflect heightened awareness among more educated individuals regarding the risks associated with PE, including its immediate and long-term health implications. Additionally, higher educational attainment is often linked to more demanding professional roles and complex self-representations, which may be disrupted by the challenges of PE. The PE condition's potential to alter one's future prospects and expectations both personally and professionally could further exacerbate psychological distress in this population.

## Limitations

Due to the low number of participants, this ought to be considered a pilot study and its results be interpreted with caution. The aim was to recruit 100 women who developed preeclampsia during pregnancy, together with their partners. This would be equivalent to recruiting every third woman with preeclampsia who received care within a specific geographical region, and her partner, over a year. However, low response rates and missing data resulted in a low number of included participants. Many men were hesitant to participate, while many women provided only partial responses. The timing of data collection at two and six months after a complicated pregnancy and birth may contributed, as this period coincides with challenges of early parenthood and emotionally processing of a potentially traumatic birth experience. Inviting couples to follow-up visits with a midwife might offer couples the opportunity to discuss their experiences and create a structured environment for filling in the self-report instruments. Digital surveys outside of such a context may have been experienced as less personal and difficult to prioritize. Technical failures beyond our control with digital invitations to the surveys at T1 and T2 may also have negatively affected the response rates.

Other limitations must also be noted. First, results are based solely on self-report and reflect the participants' subjective experiences. A clinical interview would have been necessary for establishing diagnosis of anxiety disorder and/or clinical depression. Second, the measure used for assessing anxiety in the perinatal period (PASS) was developed based on experiences and symptoms of mothers [52]. While it has been previously used also with men [29], its validation for use with fathers is pending. Similarly, the measure used for assessing atypical depression symptoms in women was developed based on experiences and symptoms [44]. A third limitation stems from a risk of self-selection. Although the analysis of attrition indicated little or no difference between participants who completed the study and those who provided incomplete data, uncertainty remains as to whether those who both agreed to



participate and completed the study are representative of the wider population. For example, participants who are more motivated, have better mental health, or greater support from their partner, may be overrepresented, compared to those who are more burdened or experience poorer mental health. Reading difficulties and lack of habit with responding to digital surveys may have contributed to further unintended exclusion. To strengthen generalisability, replication is thus necessary. Finally, although data collection was based on repeated measures over time, our findings do not indicate a temporal precedence in the links between variables, making it impossible to know whether qualities in the coparenting relation are causal or consequential to mental health challenges.

### **Clinical Implications**

Generally, women with hypertension, preeclampsia or severe maternal morbidity describe a lack of care and low psychosocial support [5, 14], lack of understanding of their own [5] and their families' [6,7] need of support during the hospital stay [5] and their families' needs [62, 63]. Co-parenting support and closeness can be integrated into the care by creating routines that include both parents throughout the care process, from pregnancy to the postnatal period. Healthcare staff can help highlight needs and experiences of both parents, with a focus on strengthening their joint parenting collaboration. Workshops or discussion groups via midwife clinics and childcare centres can promote communication and support between parents.

Furthermore, postnatal depression and anxiety in one parent with preeclampsia can affect both parents' experience of support and collaboration in parenthood, emphasizing the importance of early identification, follow-up and, if necessary, treatment of these conditions. Our results show that higher education does not always act as a protective factor, which calls for targeted support also for highly educated parents, with approaches adapted to their needs and life situations. In a broader sense, these findings highlight the importance of tailoring

postnatal care to address the unique needs of families affected by preeclampsia, emphasizing support for mental health, effective communication, and collaboration between parents.

Notwithstanding the pilot nature of the present study, it puts forward the possibility that perceived support and closeness between partners in coparenting can buffer against postnatal mental health difficulties, underscoring the importance of fostering collaboration and support in parenting, especially in the context of challenges such as preeclampsia. Future research ought to investigate this possibility further, including the perspectives of affected women and their partners to identify effective ways to support their emerging parenting following a pregnancy complicated by preeclampsia.

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## **Authors contribution**

MA: Conceptualization; methodology; investigation; formal analysis; writing original draft preparation; writing review and editing; project administration.

SH: Study design; writing review and editing; supervision; funding acquisition.

EP: Conceptualization; study design; methodology; investigation; data curation and data preparation; formal analysis; visualisation; writing original draft preparation; writing review and editing; supervision; project administration.

## **Ethics approval**

This study was approved by the Regional Ethics Committee in Lund, Sweden (Dnr 2021-03530).

## **Consent to participate**

Informed consent was obtained from all included participants in the study.

## Competing interests

The authors declare no competing interests.

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## Paper IV







# Evaluating the feasibility of using a smartphone application to monitor blood pressure in normotensive pregnancies, high-risk pregnancies and women with preeclampsia

Maria E. Andersson <sup>1,2</sup>, Christine Rubertsson <sup>2,3</sup>, Elia Psouni <sup>4</sup>, Lena Erlandsson <sup>1</sup>, and Stefan R. Hansson <sup>1,2</sup>

<sup>1</sup> Department of Obstetrics and Gynecology, Institution of Clinical Sciences Lund, Lund University, Sweden.

<sup>2</sup> Skane University Hospital (SUS), Malmö/Lund, Sweden.

<sup>3</sup> Department of Health Sciences, Medical Faculty, Lund University, Lund, Sweden.

<sup>4</sup> Department of Psychology, Lund University, Lund, Sweden

ORCID:

Maria Andersson: 0000-0001-8785-7581

Christine Rubertsson: 0000-0001-7416-6335

Elia Psouni: 0000-0003-2758-5785

Lena Erlandsson: 0000-0003-4350-5909

Stefan Hansson: 0000-0002-7838-9074

## Abstract

**Background:** Antenatal care has been crucial in reducing maternal mortality. Currently, screening program of pregnant women includes blood pressure measurements, urine protein-tests, and identification of risk factors, although these methods have low sensitivity and specificity.

**Objective:** This study aimed to evaluate the reliability and accuracy of contactless blood pressure monitoring, by the Anura™ smartphone application, in normotensive and high-risk pregnancies as well as women with preeclampsia, compared to conventional manual cuff measurements. A secondary objective was to assess women's experience using the Anura™ application.

**Methods:** Three groups of pregnant women were recruited; normotensive pregnancies, high-risk pregnancies and women diagnosed with preeclampsia. They used the Anura™ smartphone application for a 30-seconds facial scan, alongside manually blood pressure measurements and answered a survey at gestational week 37-39, regarding their experience of using the Anura™ application

**Results:** Analyses whether the Anura™ measurements and the manual measurements of diastolic and systolic blood pressure were significantly different for the three trimesters in each of the three groups, showed that the Anura™ application accurately measured blood pressure in women with normotensive pregnancies. It was also well accepted by the women. A high satisfaction with contactless measurement technology indicated a willingness to recommend its use in future home and clinical settings. However, the accuracy of the Anura™ application is not yet sufficiently reliable for use in a clinical setting for high-risk pregnancies and women diagnosed with preeclampsia. The results showed a significant difference between the first and third trimester ( $P=.001$ ) in high-risk pregnancies when compared with manual BP monitoring. Measurements of blood

pressure in women with preeclampsia also showed significant differences, both in 2<sup>nd</sup> and 3<sup>rd</sup> trimesters ( $P=.001$ ). Most women expressed a positive experience of using the Anura™ application.

**Conclusions:** Future improvements of the application should focus on enhancing Anura™ blood pressure accuracy for all pregnant women.

**Keywords:** Blood pressure; Experiences; Mobile Telephone; Preeclampsia, Pregnancy; Self Blood Pressure Monitoring

## Introduktion

Antenatal care has been the most important healthcare intervention when it comes to reducing maternal mortality in modern times [1]. The current national antenatal care program in Sweden include screening of pregnant women, performing blood pressure (BP) measurements, urine dipstick tests (proteinuria), and recording medical history to identify risk factors [2, 3]. Home BP measurements by pregnant woman using a validated normal standard BP cuff have shown lower BP levels than those measured at the clinic and a reduced need for antenatal care visits [4, 5]. However, many pregnant women find this method to be uncomfortable, inconvenient and cumbersome, leading to infrequent use and, consequently, failure to discover significant BP changes associated with such pregnancy risks as preeclampsia (PE).

Preeclampsia is one of the most common causes of maternal and fetal mortality worldwide and affects 3 – 8 percent of all pregnant women, corresponding to a total of 8.5 million women annually [6-8]. It is defined as hypertension (140/90 mmHg) after 20 weeks of gestation in combination with maternal organ dysfunction and/or intrauterine growth restriction [3]. Risk factors for PE, such as diabetes, chronic hypertension, kidney diseases, BMI >30 or African origin, are used as part of risk assessment in the first trimester of pregnancy [9, 10] to provide prophylactic treatment with acetylsalicylic acid (ASA) to reduce the risk of developing PE. More complex screening algorithms including biomarkers and Doppler ultrasound, such as the fetal medicine foundation (FMF) model, have still not been evaluated in Sweden but recently so in Denmark [11]. The FMF model comprises a combination of maternal factors with measurements of mean arterial pressure, uterine artery pulsatility index, and serum placental growth factor levels [12]. The model is well validated but also complex, expensive and requires specially trained personnel to perform the Doppler ultrasound.

Thus, it is essential to develop a more user-friendly method, available for all pregnant women to identify those at risk of developing hypertension. A more straightforward and accessible BP monitoring solution would allow the women to be more involved in self-care, and their health.

Applications using smartphones may be such a solution for monitoring BP in a user-friendly way. For example, Anura™ is a smartphone application that could be used to monitor BP changes in pregnant women, in a non-invasive and convenient manner, allowing the women to measure their BP themselves without a BP cuff. Anura™ is based on a novel imaging methodology called transdermal optical imaging (TOI) and capitalizes on the fact that light can travel beneath the skin and be reflected due to the skin's translucent properties [13]. The reflected light can be captured by an optical sensor [14]. Transdermal optical imaging uses video-captured images and machine-learning algorithms to extract blood flow information from the facial epidermis. Based on a large video dataset from normotensive and hypertensive patients, along with their physiological measurements based on gold-standard medical devices, TOI uses machine-learning algorithms to build computational models to predict a variety of vital signs [15]. The variables include heart rate [15, 16], heart rate variability, stress index, breathing frequency [15], and diastolic and systolic BP [17]. Based on these models, the Anura™ application is now able to make these measurements in 30 seconds by simply asking the patient to take a 30 second video selfie (Figure 1). Thus, the application removes the need for cuffs or other technical equipment [16].



Figure 1. The user interface of the Anura™ application [18]

Transdermal optical imaging technology has been shown to accurately determine BP in non-pregnant normotensive participants with a precision comparable to clinical standards using manual measurements [16]. The systolic and diastolic BP predicted from TOI, resulted in measurements within  $5 \pm 8$  mm Hg of the reference measurements [17]. However, the Anura™ application has not been validated in pregnant women. To address this gap, the objective of this study was to evaluate the feasibility of the Anura™ application as a method for antenatal BP surveillance of pregnant women.

The primary aim of this study was to evaluate how reliable and accurate the Anura™ application is for BP measurement during pregnancy in normotensive pregnancies, high-risk-pregnancies and in women diagnosed with PE, compared to conventional manual cuff measurements. In addition to the BP measurements, we also evaluated women's experience of using the Anura™ application by a digital questionnaire.

We tested two contrasting hypotheses. Firstly, given the success of the Anura™ application in measuring BP in patients of various conditions [15-17], we hypothesized that the Anura™ application would be able to accurately capture the pregnant women's BP. Secondly, since pregnancy causes significant changes in the hemodynamic of pregnant women's vasculature [19], we hypothesized that the computational models based on the data from non-pregnant women may not be able to accurately measure women's BP and their changes during normal and complicated pregnancies.

## Methods

### Ethical permission

The study was conducted with ethical approval from the Swedish Ethical Review Board in Lund, Sweden (DNR 2021-03216), and performed in line with the principles of the Declaration of Helsinki.

### Design, setting and participants

Three groups of pregnant women were recruited; normotensive pregnancies, high-risk pregnancies and women diagnosed with PE. The study was part of a prospective longitudinal study aiming to follow pregnant women with vs. without high-risk factors from early pregnancy until 6-8 weeks postpartum. The study was conducted in southern

Sweden at two large hospital maternity health care units, and nine different antenatal health clinics (AHCs) in the region, from March 2022 to December 2023. The inclusion criteria were: 1. pregnant normotensive women, high-risk pregnancies, and women diagnosed with PE, 2. having a smartphone that could download the Anura™ application, 3. 18 years or older, and 4. understanding Swedish. Eligible women received oral and written information and signed an informed consent. All women had the opportunity to consider participating in the study or not. They were asked to use the Anura™ application to scan their faces to obtain BP measurements at each visit at the AHC or the hospital, where their BP also was measured by midwives or other healthcare professionals using a conventional manual cuff method. Women were also informed that if they experienced symptoms such as headache, general malaise, swelling, chest pain, or if their BP was 140/90 mmHg or above, they should contact their midwife or the delivery unit. Several women that were approached at the AHC declined to participate in the study (n=43). The reason given for not participating was mental illness, anxiety, concerns for their high BP, problems with the Anura™ application or no reason stated.

The normotensive pregnant women and those at high-risk, were recruited at the AHC. High-risk pregnancies, eligible for ASA treatment, were defined as having one high-risk factor or three moderate risk factors for PE [3, 20]. Women already diagnosed with PE were recruited when they were admitted to the hospital. Preeclampsia was defined as hypertension (140/90 mmHg) after 20 weeks of gestation in combination with maternal organ dysfunction and/or intrauterine growth restriction [3, 20]. The HELLP syndrome is a severe form of PE with general organ involvement, especially of the liver. In total n=288 were recruited for participation, but n=29 was excluded due to miscarriage, abortion, technical or download problems with the Anura™ application (Figure 2). The final group comprised 259 women, divided into three groups as follows: n=132 classified as normotensive pregnant women, n=40 classified as high-risk pregnancies, and n=87 in the PE group (Figure 2).

The TOI works by capitalizing on the translucent nature of facial skin and uses machine learning algorithms to obtain facial blood flow to predict various health markers [15]. By applying advanced machine learning methods, TOI has been found to effectively predict systolic BP (SBP) levels at 95% and diastolic BP (DBP) at 96% accuracy [17]. First the whole group was analyzed as a dataset and then divided into the three groups (normotensive, high-risk and PE). Their pregnancies were divided into the three pregnancy trimesters, defined as: first trimester (0-13+6 GW) = 0 - 93 days, second trimester (14+0-27+6 GW) = 94 - 187 days and the third trimester (28+1-42+0 GW) = 188 - 283 days.

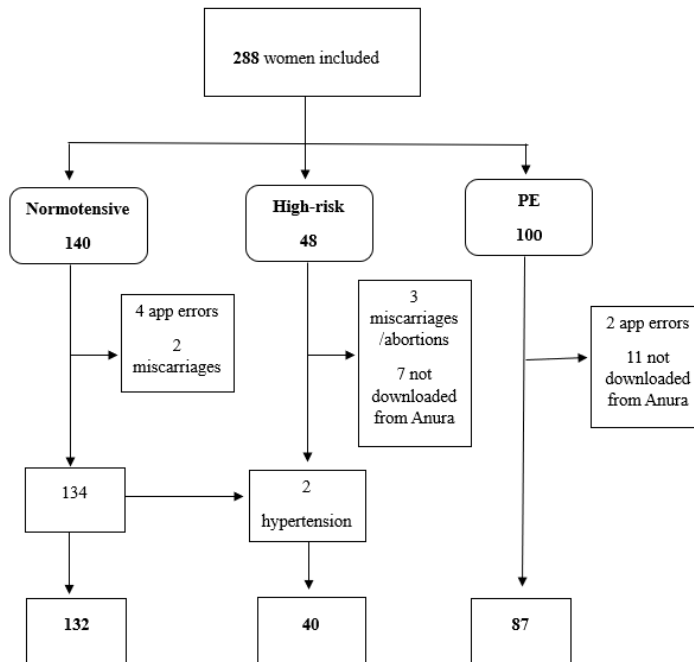


Figure 2. Flowchart for included women in the three study groups. App = application

#### Data Collection

Demographic data for the included women (Tables 1 and 2) was collected from the medical record system Obstetrics (version 2.18.0.100, Copyright © Cerner Sverige AB) [21]. In addition to the standard antenatal program [1], the women were asked to follow a scheme for BP measurements using the Anura™ application. The midwives or the first author of the study provided information about how to download the Anura™ application to their private smartphones. Basic personal information (weight, height, age, high BP or diabetes) was entered directly into the Anura™ application by the women.

Once the application was downloaded and registered, each woman was assigned a participant code. The code key was stored under lock and key. The BPs were measured in two ways: by the midwife using a standard BP cuff or a validated automatic BP monitor, and by the women using the Anura™ application. The results were automatically stored in the Anura™ application. The participants manually entered the DBP and SBP measured by the midwife into the Anura™ application.

The women also answered a survey at 37-39 GW regarding their experience of using the Anura™ application by filling out a questionnaire embedded in the application. The questionnaire contained study specific questions (Q1-Q8, presented in Supplemental figure 1) that were answered using a five-point scale.–The scores (1-5) explanation are as follows: Q1. The higher the score, the less concerned the women are Q2. The higher the score, the less concern about BP; Q3. The higher the score, the more responsible for one's own health; Q4. The higher the score, the safer one feels; Q5. The higher the score, the better control over their health; Q6. The higher the score, the more understanding about their own health; Q7. The higher the score, the better one feels; Q8. The higher the score, the more acceptance towards the duration of the measurement.

In addition, the women were encouraged to measure their BP at home at least once a week, after 15 minutes of rest. For each Anura™ measurement, the women scanned their faces for 30 seconds at 30 frames/second imaging. The application processed the image frames and used its local algorithms to extract blood flow information. Only the extracted facial blood flow information was packaged, encrypted, and sent to the cloud server in Europe owned by NuraLogix Corporation (Toronto, Canada). The data was processed by the DeepAffex (DFX) Artificial Intelligence Engine [22]. The Anura™ is in full compliance with the General Data Protection Regulation (GDPR). In addition, a written research agreement between Lund University and NuraLogix was signed to ensure data safety, privacy, and the freedom of data use by the research team.

### Data analyses

At first, to determine how many women to be included in each group, a calculation of statistical power was performed using G\*power [23]. To achieve adequate power of 80% with a significance level of 0.05 and a medium effect size ( $f=0.25$ ), a total sample of 269 was required with  $n=90$  for each of the three groups (normotensive, high-risk and PE).

Data from Anura™ was downloaded directly from a dashboard, minimizing the risk of missing data. The clinical data were manually extracted from medical records and double-checked to ensure completeness. All analyses were conducted using IBM SPSS Statistics for Windows, Version 28.0. A  $P$ -value  $< .05$  was considered statistically significant. Demographic data was analyzed using one way ANOVA (Analysis of Variance). All data points from the Anura™ application were downloaded from the NuraLogix DFX dashboard. For continuous variables, descriptive statistics were presented as minimum, maximum, and mean  $\pm$  standard deviation (SD). Categorical variables were presented in numbers ( $n$ ) and proportions (%). All calculations for BP were performed separately for SBP and DBP values. Paired-sample T-test by ANOVA and post-hoc test were used to calculate the difference in the BP measurements between the three groups and trimesters (Table 4, 5). All groups were presented with 95% confidence intervals to provide a measure of the precision of the estimates.

The Anura™ application automatically provided a signal to noise ratio (SNR) to index the strength of the blood flow information relative other non-blood flow rhythmic noises [15], and requires  $\text{SNR} \geq 1$  db for heart rate measurements and  $\text{SNR} \geq 2$  dB for BP measurements. A SNR of 1 indicates that blood flow signals are 10 times stronger than other rhythmic signals, and a SNR of 2 means blood flow signals are 100 times stronger.

Bland-Altman plots were used to show the comparisons of the Anura™ measurements against the manual or automated cuff measurements. In addition, we performed ANOVAs and post hoc test to assess whether the Anura™ measurements and the manual measurements of DBP and SBPs were significantly different for the three trimesters in each of the three groups. At last, we evaluated the women's experience of using the Anura™ application, and made a spider diagram and calculated these scores, using a weighted average. For example, for Question 2, ranging from "Very worried" to "Not worried at all," with scores from 1 to 5. The score is calculated as  $(2*1/56) + (5*55/56)$ .

## Results

### Demographics

Data from 259 women was successfully downloaded from the NuraLogix DFX dashboard. As indicated in Figure 2, data could not be downloaded for eleven PE women, but their demographic background data from medical records are still included in the PE group shown in Table 1, resulting in n=98 for this group (Figure 2).

ANOVA analysis of demographic data showed that the normotensive pregnancy group was significantly different ( $p<.001$ ) from the high-risk group and the PE group regarding pregnancy length, age, height, weight, BMI, DBP and SBP (Tables 1 & 2). The normotensive pregnancy group had significantly lower ( $p<0.001$ ) maternal age and BMI compared to the high-risk and PE groups. Nearly half (47.5%) of the women with high-risk pregnancies had a family history of high BP. Additionally, most of the women in the high-risk pregnancy group were receiving prophylactic ASA treatment (87.7%).

**Table 1.** Demographic characteristics of included women

Characteristic and risk factors for PE	Normotensive pregnancy n=132	High-risk pregnancy n= 40	Preeclampsia n = 98
ASA prophylaxis, n (%)	0	35 (87.5)	38 (38.8)
<b>High-risk factors:</b>			
Autoimmune disease	0	1 (2.5)	0
IUGR, IUFD, ablatio, n (%)	1 (0.8)	4 (10.0)	6 (6.1)
Diabetes, n (%)	0	0	6 (6.1)
Kidney disease, n (%)	0	0	1 (1.0)
Chronic hypertension, n (%)	0	5 (12.5)	13 (13.3)
IVF with egg donation, n (%)	0	5 (12.5)	3 (3.1)
Previous GH delivery before w 34, n (%)	0	1 (2.5)	0
<b>Moderate risk-factors:</b>			
Maternal age (years), min-max mean $\pm$ SD	19-43 31.8 $\pm$ 3.9	19-43 35.0 $\pm$ 5.2 ***	18-45 32.2 $\pm$ 4.8***
BMI at booking visit, min-max mean $\pm$ SD	19-37 24.4 $\pm$ 3.7	21-42 29.3 $\pm$ 5.3***	17-61 27.4 $\pm$ 6.9***
African origin, n (%)	0	2 (5.0)	5 (5.1)
Nulliparity, n (%)	56 (42.7)	8 (20.0)	56 (57.1)
Family history of high BP, n (%)	38 (29.0)	19 (47.5)	32 (32.7)
Pregnancy interval >10 years, n (%)	2 (1.5)	0	1 (1.0)
White coat of hypertension, n (%)	3 (2.3)	0	1 (1.0)
Family hereditary of PE, n (%)	6 (4.6)	9 (22.5)	12 (12.2)
Previous PE, n (%)	0	13 (32.5)	18 (18.4)
Multiple birth, n (%)	0	0	6 (6.1)
<b>Other risk factors</b>			
Mental illness, n (%)	19 (14.5)	7 (17.5)	20 (20.4)

ASA=acetylsalicylic acid, BMI=body mass index, BP=blood pressure, GH=gestational hypertension, IUFD=intrauterine fetal death, IUGR=intrauterine growth restriction, IVF=in vitro fertilization, PE=preeclampsia. \*\*\*=  $P<.001$

In the normotensive group two developed gestational hypertensions and were therefore transferred to the high-risk group (Figure 2). Three women developed PE, some weeks before childbirth and these BP was transformed to the PE group. Systemic diseases that were identified in the normotensive group were: one case of asthma, one case of Crohn's disease, one case of epilepsy, one case of gestational diabetes, six cases of



hyperthyroid and one case of polycystic ovary syndrome. The fetal sex of two children is unknown since they were born outside of our region. Characteristics for the included women and their newborns are shown in Table 2.

In the high-risk group (n=40), seven women developed PE and six developed gestational hypertensions. Eight had essential hypertension, one borderline high BP, one systemic lupus erythematosus or rheumatoid arthritis, and two had a previous history of postpartum depression. In addition, 27.5% had a regulated BP with medication at postpartum and 22.5% were still on antihypertensive medication when discharged. Women from the high-risk group also had significantly ( $P<.001$ ) longer hospital stays.

In the PE group (n=98), 12 women had a known family history of PE and six had essential hypertension. Additionally, one case developed HELLP syndrome. In the PE group, 73% had a regulated BP using medication at postpartum and about 66% were still on antihypertensive medication when discharged from the maternity unit. Women from the PE group also had significantly ( $P<.001$ ) longer hospital stays, their children's weight was significantly lower and 36.7% of their newborns were admitted to the neonatal intensive care unit (NICU).

**Table. 2** Characteristics of included women and their newborn children

Characteristic	Normotensive pregnancy n=132	High-risk pregnancy n=40	Preeclampsia n=98
Regulated BP postpartum, n (%)	1 (0.8)	11 (27.5)	72 (73.1)
Medication for hypertension at discharge, n (%)	1 (0.8)	9 (22.5)	65 (65.8)
SBP, min and max Mean $\pm$ SD	100-150 122 $\pm$ 9	120-180 135 $\pm$ 12***	130-190 156 $\pm$ 13***
DBP, min and max Mean $\pm$ SD	60-95 76 $\pm$ 8	70-110 87 $\pm$ 9***	80-120 98 $\pm$ 7***
Preterm birth < w 37, n (%)	1 (0.8)	1 (2.5)	36 (36.7)
Birth < w 34, n (%)	0	0	21 (21.4)
Gestational weeks of delivery, min and max Mean $\pm$ SD	28-42 39.4 $\pm$ 1.6	35-41 38.9 $\pm$ 1,3***	26-40 38.81 $\pm$ 2.9***
Vaginal delivery, n (%)	101 (77.1)	26 (65.0)	46 (46.9)
Induction of labor, n (%)	36 (27.5)	18 (45.0)	56 (56.0)
Vacuum extraction, n (%)	4 (3.1)	3 (7.5)	4 (4.1)
Caesarean Section, n (%)	24 (18.3)	9 (22.5)	51 (52.0)
Oxytocin augmentation, n (%)	35 (26.7)	9 (22.5)	16 (16.3)
Hemorrhage (ml), min and max Mean $\pm$ SD	100-2100 510 $\pm$ 344	100-3000 568 $\pm$ 559	100-2200 548 $\pm$ 429
Twins (%)	0	0	9 (9.2)
SGA (%)	1 (0.8)	0	27 (27.5)
Days in PP hospital care, min and max Mean $\pm$ SD	1-7 2.8 $\pm$ 1.3	1-22 3.9 $\pm$ 3.6***	2-44 9.8 $\pm$ 6.7***
NICU admission (%)	11 (8.4)	2 (5.0)	36 (36.7)
Newborn weight (g), min and max Mean $\pm$ SD	1900-4655 3616 $\pm$ 477	2550-4438 3480 $\pm$ 467	630-3830 2666 $\pm$ 792***
Newborn sex (%)			
Boy	60 (46.0)	18 (45.0)	49 (50.0)
Girl	71 (54.0)	18 (45.0)	49 (50.0)

BP= blood pressure, DBP=diastolic blood pressure, NICU = neonatal intensive care unit, SGA=small for gestational age, SBP=systolic blood pressure, \*\*\*=  $P<.001$

### Blood pressure measured with Anura™ application vs manual measurements

In total, there were n=4932 BP measurements registered in the Anura™ application in the three study groups: normotensive pregnancies n=2993, high-risk pregnancies n=853, and PE pregnancies n=1072. Of these measurements, n=539 had a corresponding manual BP cuff measurement taken at an antenatal care visit (normotensive pregnancies n=194, high-risk pregnancies n=108, and PE pregnancies n=237). Manual BP of the three groups and trimesters are shown in Table 3. For the PE group, there were few measurements in the second trimester, since most PE did not develop until the third trimester and only a few at the end of the second trimester.

**Table 3.** SBP and DBP for un-paired manual measurements for each trimester

Characteristic	Normotensive pregnancy	High-risk pregnancy	Preeclampsia
Blood pressure	Manual	Manual	Manual
Trimester 1 SBP min and max Mean ± SD	N=53 97-132 113±8.9	N=14 88-135 120±11.3	-
Trimester 1 DBP min and max Mean ± SD	N=53 54-80 69±6.1	N=14 64-114 78±12.1	-
Trimester 2 SBP min and max Mean ± SD	N=57 97-136 115±9.6	N=37 109-135 121±6.4	N=4 140-170 156±13.8
Trimester 2 DBP min and max Mean ± SD	N=57 60-83 70±5.6	N=37 70-92 80±4.8	N=4 99-120 106±9.7
Trimester 3 SBP min and max Mean ± SD	N=74 100-134 115±9.1	N=50 100-149 121±10.2	N=185 110-180 138±10.7
Trimester 3 DBP min and max Mean ± SD	N=74 60-88 70±6.8	N=50 60-97 77±10.4	N=185 63-113 87±84

DBP=diastolic blood pressure, SBP=systolic blood pressure

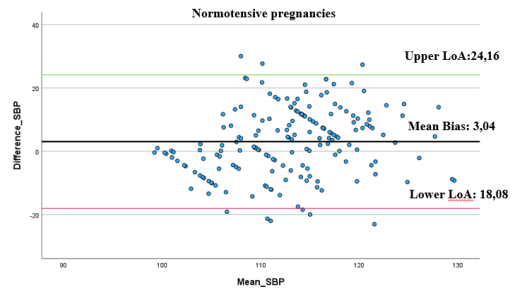
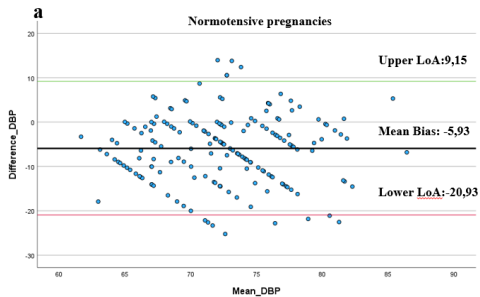
We paired the manual BP readings with the corresponding Anura™ BP readings and compared them pairwise, for each trimester using ANOVA (Table 4). In the normotensive group, no differences were found in SBP between the two types of BP measures in the first trimester. However, significant differences ( $P<0.05$ ) were observed for SBP in the second and third trimesters, and for DBP ( $P<.001$ ) in each trimester (Table 4). The high-risk pregnancy group showed no differences between manual and Anura™ measurements in SBP and DBP during the first trimester but showed significant differences ( $P<.001$ ) in the second and third trimesters for the SBP. For the PE group significant differences were observed for both paired SBP and paired DBP during the second trimester ( $P<.05$ ) and the third trimester ( $P<.001$ ).

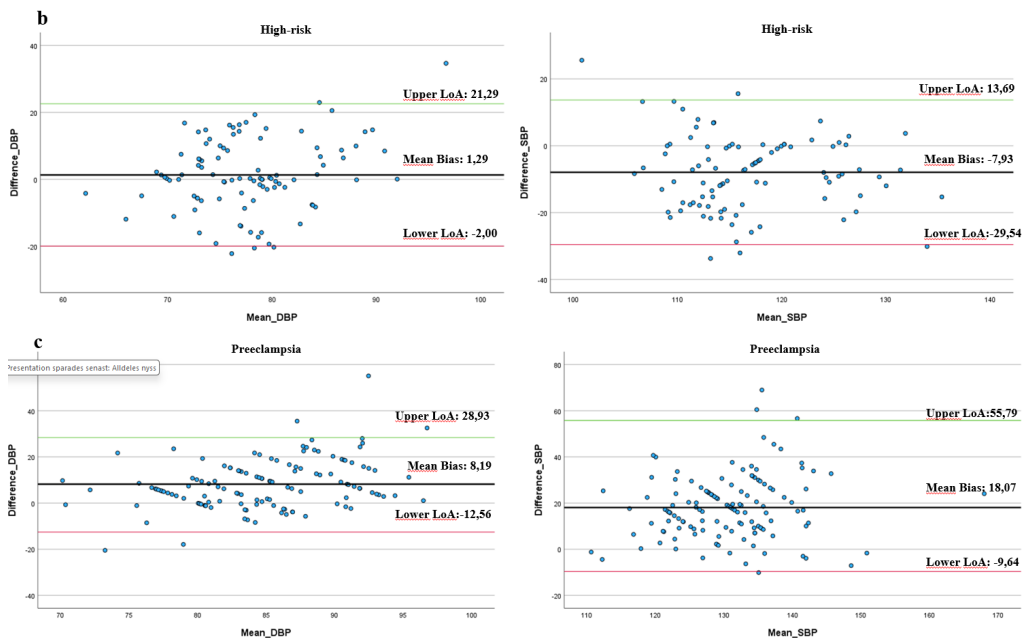
**Table 4.** SBP and DBP for paired manual BP and Anura™ BP

Characteristic	Normotensive pregnancy	Normotensive pregnancy	High-risk pregnancy	High-risk pregnancy	Preeclampsia	Preeclampsia
Blood pressure	Manual	Anura™	Manual	Anura™	Manual	Anura™
<b>Trimester 1</b>	N=49	N=49	N=11	N=11		
SBP min and max	97-132	96-133	88-135	103-134	-	-
Mean ± SD	114±9.1	110.9±7.4	120±12.5	119.9±8.9		
<b>Trimester 1</b>	N=49	N=49	N=11	N=11		
DBP min and max	54-80	66-84	68-114	66-88	-	-
Mean ± SD	69±6.1	73.6±4.7***	80±12.6	78.9±6.3		
<b>Trimester 2</b>	N=54	N=54	N=36	N=36	N=4	N=4
SBP min and max	97-135	99-130	109-135	99-128	140-170	101-128
Mean ± SD	114±9.5	111.2±7.3*	121±6.3	112.1±8.1***	156±13.8	112.1±11.9*
<b>Trimester 2</b>	N=54	N=54	N=36	N=36	N=4	N=4
DBP min and max	60-83	65-91	70-92	66-92	99-120	65-80
Mean ± SD	69±5.5	74.9±6.1***	79±4.6	75.9±6.7	106±9.7	72.6±6.9*
<b>Trimester 3</b>	N=74	N=74	N=50	N=50	N=125	N=125
SBP min and max	100-134	93-134	100-149	96-128	110-180	99-156
Mean ± SD	115±9.1	111.9±7.5*	121±10.2	111.9±7.5***	139±11.0	121.9±11.1***
<b>Trimester 3</b>	N=74	N=74	N=50	N=50	N=125	N=125
DBP min and max	60-88	63-93	60-97	63-90	63-113	63-96
Mean ± SD	70±6.8	76.6±6.9***	77±10.4	77.6±7.3	88±8.4	80.9±6.2***

\*= p<.05, \*\*\*=p<.001, 95% confidence interval, N=number of measurements

Additionally, Bland-Altman plots (Figure 3) were created to illustrate differences between the paired BP measurements. The Bland-Altman analysis for SBP in the normotensive group (Figure 3a) shows a mean difference of 3.04 (SD±7.7) and for DBP a mean difference of -5.93 (SD±7.7). In the high-risk group (Figure 3b), the SBP shows a mean difference of -7.93 (SD±11.0) and for DBP a mean difference of 1.29 (SD±10.8). For the PE group (Figure 3c), the SBP shows a mean difference of 18.07 (SD±18.1) and for DBP a mean difference of 8.19 (SD±10.6). There was a variation in the Bland-Altman plots of the upper and lower Limits of agreement (LoA) in both the SBP and the DBP in the three groups (Figure 3a-c).





**Figure 3.** Bland-Altman plot differences in DBP and SBP for manually and Anura™ measurements in a) normotensive pregnancies, b) high-risk pregnancies and c) preeclampsia.

DBP= Diastolic blood pressure, SBP= Systolic blood pressure, LoA=Limits of agreement.

Finally, ANOVA models were calculated, one for each group. The analysis showed the differences between Anura™ and manual measurements of SBP and DBP, for each trimester (Table 5). The paired BPs in the normotensive group showed no significant differences when the measurements were divided into the three trimesters. The ANOVA post hoc test showed no differences between the three groups in the paired SBP ( $F(2.94) = 0.027$ ,  $\text{Partial Eta}^2 = 0.011$ ,  $P = 0.973$ ), and not in the paired DBP ( $F(2.94) = 1.431$ ,  $\text{Eta}^2 = 0.016$ ,  $P = 0.242$ ). Thus, for the normotensive group, there was no difference in degree of convergence between the two types of measurements over gestational length time (trimesters). The ANOVA analysis in the high-risk pregnancy group showed differences in SBP between the first and third trimesters ( $F(2.94) = 3.264$ ,  $\text{Eta}^2 = 0.065$ ,  $P = .042$ ) but no significant differences between first and second trimesters ( $P = 0.073$ ). For the DBP analysis, there were no significant differences between the three groups in the three trimesters ( $F(2.94) = 1.453$ ,  $\text{Eta}^2 = 0.030$ ,  $P = 0.239$ ). The ANOVA analysis in the paired BPs of the PE group showed significant differences between the second and third trimesters in both SBP and DBP ( $P < 0.001$ ). The SBP showed a mean of  $44.19 \pm 23.97$  in the second trimester and  $18.07 \pm 13.85$  in the third trimester ( $F(2.94) = 16.465$ ,  $\text{Eta}^2 = 0.115$ ,  $p < .001$ ). For DBP, the second trimester had a mean of  $33.35 \pm 15.64$  and the third trimester had a mean of  $7.38 \pm 9.40$  ( $F(2.94) = 28.29$ ,  $\text{Eta}^2 = 0.182$ ,  $P < .001$ ). Thus, for the PE group, the trimester did have a significant effect on the differences between the two types of measures in SBP and DBP. The degree of convergence of the BP varied across trimesters.

**Table 5.** ANOVA analysis of variance in the three trimesters

	Trimester 1	Trimester 2	Trimester 3
<b>Normotensive pregnancy (n)</b>	49	54	74
SBP Mean±SD	-2.94±10.90	-2.83±10.44	-3.26±11.07
DBP Mean±SD	4.55±7.16	5.82±6.01	6.94±7.71
<b>High-risk pregnancy (n)</b>	11	36	50
SBP Mean±SD	-0.13±10.97	-8.63±9.82	-9.13±11.37*
DBP Mean±SD	1.43±13.72	3.62±7.09	-0.41±12.25
<b>Preeclampsia (n)</b>		4	125
SBP Mean±SD	-	44,19±23,97***	18,07±13,85***
DBP Mean±SD	-	33.35±15.64***	7.38±9.40***

\*=  $P<.05$ ; \*\*\*= $P<.001$

### The experiences of using Anura™

Figure 4 presents the replies from the women about their experience in using the Anura™ application, shown as percent for each response out of five, and for each of the eight questions (Q1-Q8). Among the 172 women with normotensive and high-risk pregnancies, 31% (n=56) evaluated their experience of using the Anura™ application (Figure 4). The women's predominant sentiment (n=48) expressed no concern regarding their privacy while using the application. Only eight women expressed some apprehension. All women, with one exception, reported no concerns about viewing the results of their BP in the Anura™. Furthermore, 31 women (55%) reported a higher degree of being responsible for their own health, while 25 women reported that they did not. Almost all women (91 %) considered the application to be adequate or highly secure for usage. Additionally, 48 women (89 %) reported positive feelings of being in control of their own health, whereas eight women did not report improvements by using the Anura™ application. Moreover, 42 women (78%) reported an increased understanding of their health status, whereas 10 women did not experience better understanding and two reported they were neutral. Only three women found the process of looking into the camera and measuring their BP to be unpleasant and two expressed dissatisfactions with the duration of the measurement process.

In more detail, for Q1 and Q2, the only replies given were scores 1-2 (1: not concerned at all, 2: slightly worried). For Q3 replies were given for scores 1-4 (1: much more responsibility, 2: more responsibility, 3: somewhat more responsibility, 4: no more responsibility). For Q4 replies were given for scores 1-3 (1: a little bit safe, 2: safe enough, 3: very safe). For Q5 replies were given for scores 1-4 (1: much better control, 2: better control, 3: slightly better control, 4: no better control). For Q6 replies were given for all scores 1-5 (1: much better understanding, 2: better understanding, 3: somewhat better understanding, 4: no better understanding, 5: neutral). For Q7 replies were given for scores 1-4 (1: doing well, 2: it is somewhat unpleasant/uncomfortable, 3: it is unpleasant/uncomfortable, 4: neutral). For Q8 replies were given for scores 1-3 (1: it is just the right length, 2: it's okay, 3: it takes too long).

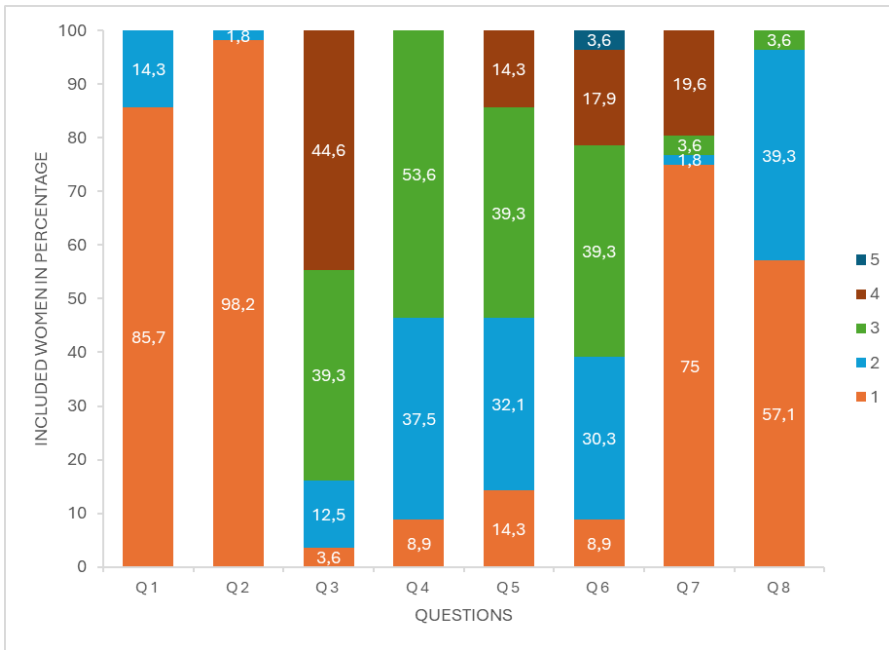


Figure 4. Experiences of using the Anura™ application. Columns represents the percentage for each score (1-5) for each of the questions (Q1-Q8).

## Discussion

The primary aim of our study was to evaluate how reliable and accurate the Anura™ application is for BP measurement in pregnancy, compared to manual cuffs for BP measurement. In addition, we asked the women about their experiences of using the application. To the best of our knowledge, this study is the first to validate the Anura™ technology in pregnant women, including those with high-risk pregnancies and women diagnosed with PE, with analyses further stratified across all three trimesters. The use of smartphones for medical monitoring has previously indicated a need for a user-friendly, independent BP monitoring method during pregnancy to enable identification of hypertension. Home monitoring can enhance early detection [4, 5] and management of pregnancy-related hypertension, while also empowering women to take an active role in their own healthcare [24].

The main finding in our study suggests that the accuracy of the Anura™ application compared to manual measurements did not change based on trimester in normotensive pregnancies, hence confirming the usefulness of the technology. For women with high-risk pregnancies, we found no significant differences between the Anura™ application compared to the manual cuff-based measurements for SBP between the first and second trimester. However, we observed significant differences in SBP in the third trimester. Moreover, for women diagnosed with PE, the Anura™ application was shown to not be reliable with the current settings and algorithms, which also was confirmed by Bland-Altman analysis. In addition, most women expressed a positive experience of using the Anura™ application, with positive feelings of being in control of their own health. Regarding the normotensive group the ANOVA analysis showed that

there were no significant differences in SBP and DBP, confirming the accuracy of the technology in a normotensive state. The Bland-Altman analysis confirmed this finding, showing that the normotensive group exhibited small differences between the two methods. Our findings in normotensive pregnant women are in line with previous research with male patients and non-pregnant female patients [17]. These findings suggest that the Anura™ application may be a viable tool to measure the BP in normotensive pregnancies. Regarding the high-risk pregnancies, the analysis showed significant differences for SBP in the third trimester. These results show that in high-risk pregnancies, the Anura™ application may be less reliable in the last part of pregnancy compared to earlier stages of pregnancy. The PE group demonstrated the most pronounced differences, with significant differences for both SBP and DBP. The results indicate that using the Anura™ application for BP screening in women with high-risk pregnancies or women diagnosed with PE, do not support the utility of this technique. These findings are further corroborated by another study who conducted BP measurements was not accurate in a perioperative setting using a similar technique, using video plethysmography for contactless measurement [25]. But this method has been reported to be highly accurate in predicting the respiratory- and heart rate of surgical patients in a clinical setting [25, 26]. The differences in Bland-Altman analysis suggest that in some cases the Anura™ technology either overestimated or underestimated the BP compared to the manual measurements, especially in the PE group where the deviations were the largest. These deviations are important to consider during further processing of the variables to improve the measurements in the Anura™ application in the future.

The high variation of the upper and lower LoA in the Bland-Altman plots may indicate that the Anura™ application might be less reliable at extreme BP values, or that its performance varies depending on the context or conditions of the measurements [27]. One possible explanation is that high-risk and PE women may have more oedema in their faces, which could interfere with TOI-technique to make accurate BP measurements. A physiological explanation for this inconsistency in BP may lie in the cardiovascular adaptations that occur during pregnancy. Normally, the blood volume increases during the first two trimesters and the peripheral vascular resistance decrease [28], leading to a 10–20 mm Hg reduction in BP. It reaches its lowest point at 18–20 weeks of gestation, and then returns to pre-pregnancy levels by the third trimester [29, 30]. In PE however, there is a maintained vascular resistance, as well as endothelial damage, that results in general oedema. Increased oedema and hemo-concentrated blood might impact the measurement quality when BP is measured using TOI. Our results indicate that the Anura™ measurements tended to show lower values compared to manual BP measurements for both DBP and SBP in the PE group, and to some extent also in the high-risk group. In PE, the vascular endothelial cells undergo changes that result in inflammation, impaired blood flow regulation, and increased vascular permeability [7, 31]. While most pregnant women experience swelling during their pregnancy, in normotensive pregnancies this predominantly does not occur until the third trimester [19].

In previous studies, where BP was determined by Anura™ with high accuracy in non-pregnant individuals [16, 17], the technology was evaluated under controlled conditions with optimal lighting, a tripod-mounted mobile phone, and using the same device for all measurements. In contrast, this study allowed the women to use their own mobile phones, holding them manually, and having varying lighting conditions.

Movement and lighting are factors that often affect the accuracy of contactless measurement technologies using a mobile phone [15, 32], factors not accounted for in this study. The women were instructed to rest in a sitting position and hold their mobile phones still at arm's length in front of their faces during the 30 seconds needed for measurements. They were to measure their BP only when at least three stars appeared in the Anura™ application. One star indicates poor lighting conditions, while five stars indicate perfect lighting conditions [33]. Any movements of the arm and varying light qualities in the rooms at AHC and at home could, of course, affect the measurements. This also applies to women admitted to the hospital with PE, who often had to dim the lights in their rooms due to symptoms and illness related to PE. Despite knowing that good lighting was necessary for accurate BP measurement, these suboptimal conditions may have impacted the performance of the Anura™ measurements. However, our results contribute to the advancement of contactless BP monitoring by highlighting the challenges of implementing this technology. These insights can be used to further improve the handling of the smartphone, lighting conditions and the algorithm in the future.

The use of smartphones for medical monitoring has increased in recent years. As information technology continue to develop, so do the opportunities to find new ways to measure BP with smartphone-based applications [34]. Compared to traditional monitoring, home BP monitoring during hypertensive pregnancies appears to be cost saving without compromising the safety of the pregnant mother [35]. It increases accessibility and convenience for the pregnant women, has the potential to decrease the number of hospital visits [4], enables early detection of abnormalities, and promotes better control and self-management of their health. It has also been shown that BP measured at home often is lower than in a clinical setting [36]. In addition, home measurements have shown reduced stress and anxiety and enables more individualized care which in turn can lead to better health outcomes for the women and their children. In a systematic review and meta-analysis [37] it was demonstrated that contactless monitoring technology using consumer-friendly cameras, such as smartphones, is accurate for measuring heart rate compared to other medical devices. However, more studies are needed to assess the accuracy of contactless BP measurements, particularly among pregnant women. In another review it was also highlighted that no applications for BP had undergone sufficient testing to be recommended in a clinical practice [38]. In a recently published study, the accuracy of contactless monitoring technology of heart rate was demonstrated, but suggested limitations in accurately measuring BP in a hospital setting. However, the study showed that contactless monitoring technology was both accurate and feasible for measuring respiratory rate in a hospital setting [25]. In an earlier study using Anura™, the SBP and DBP predicted from TOI fell within 5±8 mm Hg of reference measurements [17] but in our study these criteria were not met in the paired data for the three groups. In another study using Anura™, it was shown that TOI can determine heart rate, heart rate variability, and infer stress of an individual with high accuracy [15]. Given the Anura™ precise measurement of heart rate and stress, the application remains an interesting tool for assessing BP. By leveraging advanced machine learning techniques and enhancing the application's sensitivity, those responsible for the application may expand its utility and reliability.

In our study most women expressed a positive experience of using the Anura™ application. They also reported a higher degree of responsibility and control over their health. This agrees with another study that also found the participants to be satisfied



with the contactless technology and would recommend it for future clinical settings [25]. The women generally perceived the application as adequate and safe for use, with nearly all women reported no elevated anxiety when viewing their BP results. Concerns were raised by some participants regarding the accuracy of the measurements and the handling of their data, particularly in relation to privacy. These findings suggest that the application has the potential to be well-received by women during pregnancy, though addressing these concerns will be important for its future use.

#### Limitations and future solutions

Our study has several limitations. The BP measurements recorded by the women using the Anura™ application, varied in number for the three groups. There were more measurements using the Anura™ application compared to manual BP measurements. In addition, the PE group had more manual BP measurements compared to the groups with normotensive and high-risk women. Moreover, the achieved sample size for the groups is not adequate, since the high-risk group is underrepresented based on the power calculation. The limited number of measurements in certain trimesters and groups may have impacted the statistical power and reliability of the findings. Due to these limitations, future studies with larger sample sizes and better compliance are needed to further validate these observations in a clinical setting. During analysis, SNR values below 2, indicating movement during the recording, were filtered out to improve the accuracy and reliability of the data. While this step enhances data quality, it can introduce biases, reduce sample size, and affect the generalizability of the findings. Another limitation was that only 31% of the women answered the questionnaire evaluating their experiences of using the Anura™ application, so caution is advised when interpreting these results. Completing surveys through an application shortly before giving birth may not been an ideal time-point for the women. Additionally, we were unable to send reminders within the application. To improve compliance, future studies might consider alternative methods, such as providing the questionnaires directly by the midwife at the AHC or calling the women by phone to gather their perspective on the experience.

A key strength of this study is the validation of the contactless Anura™ technology against the golden standard for BP measurement, which has not been done before. Home BP measurements offer numbers of benefits [4, 5, 24] and the ability to measure cuffless BP in a home setting appears to be a promising solution for pregnant women in the future.

#### Conclusion

This study shows that the Anura™ application is accurate in measuring BP in women with normotensive pregnancies and is well accepted by the women. A high satisfaction with contactless measurement technology indicated a willingness to recommend its use in future home and clinical settings. The accuracy of contactless BP monitoring technology using the Anura™ application is however not yet sufficiently reliable for use in a clinical setting for high-risk pregnancies and women diagnosed with PE. Future studies will focus on retraining the Anura™ settings by using data from high-risk and PE pregnancies to improve the algorithm of the technology. Our aspiration is for the Anura™ application to evolve into a tool that can support all pregnant women, especially those with high-risk pregnancies, not only to predict elevated BP at earlier stages, but also to identifying those at risk of developing PE. This advancement would greatly

enhance proactive care and potentially mitigate complications associated with hypertensive disorders during pregnancy.

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#### Authors contributions

Conceptualization: MA (lead), CR, SH (equal) EP (supporting)

Data curation: MA

Formal analysis: MA, SH (lead), EP (supporting)

Funding acquisition: LE, SH

Investigation: MA, CR, SH

Methodology: MA

Project administration: MA (lead), CR, SH (equal), EF (supporting)

Resources: LE, SH

Supervision: CR, EP, LE, SH

Validation: MA, SH

Visualization: EF (lead), AB (supporting)

Writing – original draft: MA (lead), LE, SH (supporting)

Writing – review & editing: MA (lead), CR, EP, LE, SH (supporting)

#### Ethics approval

This study was approved by the Regional Ethics Committee in Lund, Sweden (Dnr 2021–03216).

#### Consent to participate

Informed consent was obtained from all included women in the study.

#### Conflicts of Interest

None declared.

#### Abbreviations

AHC	= Antenatal Health Clinic
ANOVA	= Analysis of Variance
ASA	= Acetylsalicylic acid
BMI	= Body mass index
CVD	= Cardiovascular disease
DBP	= Diastolic blood pressure
DFX	= DeepAffex
FMF	= Fetal Medicine Foundation
GDPR	= General Data Protection Regulation

GW	= Gestational week
HELLP	= Hemolysis, elevated liver enzymes, low platelets
LOA	= Limits of agreement
NICU	= Neonatal intensive care unit
PE	= Preeclampsia
SBP	= Systolic blood pressure
SD	= Standard deviation
SNR	= Signal to noise ratio
TOI	= Transdermal optical imaging

#### Data Availability

All data and associated protocols are available on request.

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## About the author

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**MARIA ANDERSSON**, a midwife at Skåne University Hospital in Malmö, has focused her dissertation on the patient perspective of women with preeclampsia. The dissertation analyzes how preeclampsia affects women and their partners, highlighting their needs and experiences, and emphasizes the importance of personalized care, structured postpartum follow-ups, and e-health as tools for improved self-care and more efficient healthcare. The aim is to inspire changes within maternal and maternity care, ensuring that every woman receives the support she needs to thrive both physically and mentally.

