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Full length article

## A life changing experience: An interpretative phenomenological analysis of women's experiences of placenta accreta spectrum



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### ABSTRACT

**Background:** The incidence of Placenta Accreta Spectrum (PAS) is increasing. This study explores women's personal experience of a pregnancy, birth and early postpartum period complicated by PAS.

**Methods:** A qualitative study involving seven women (age range: 33–44 years) following a pregnancy in the previous two years complicated by PAS was conducted. Using an Interpretative Phenomenological Analysis approach data were collected and analysed in 2019 and 2020 through face-to-face interviews. Interviews were transcribed verbatim.

**Results:** Women described their experience from diagnosis up to two years following the birth and focussed on the strategies they used to cope with an unexpected diagnosis of PAS. Six main themes emerged. In pregnancy, women were focussed on the diagnosis and managing family life from hospital "it's not until you are told", "sad but safe", "relying on others can be unbearable". In terms of the birth a 'fear of dying' related to self and baby was central. Postnatally key themes related to the ongoing consequences of the condition as "no one believed I could be feeling so much pain" and "it's not all over when you go home".

**Discussion:** Women who have experienced a pregnancy complicated by PAS experience significant challenges associated with long term hospitalization, post-operative pain and many express feelings of being generally worried lasting many months after their pregnancy. This study makes an important contribution to the growing body of research in PAS, namely that of the woman's own voice.

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### Introduction

Placenta Accreta Spectrum (PAS) describes a range of conditions that include placenta accreta, placenta increta, and placenta percreta [1]. The associated maternal morbidity and mortality, largely attributed to significant haemorrhage, is well documented [2–4] and numerous studies have demonstrated the importance of multi-disciplinary team care in the management of these complex cases [5,6]. The incidence of the condition continues to rise in parallel with a rising caesarean section rate [7].

However, there remains a paucity of literature describing women's lived experience of pregnancy, birth and early motherhood following a diagnosis of PAS. Management of PAS frequently involves prolonged antenatal stays in hospital for surveillance with a consequent restriction of normal activities, followed by major

abdominal surgery which is associated with a significant increased risk of maternal mortality [8]. In addition, due to preterm birth, many babies are admitted to the Neonatal Intensive Care Unit (NICU) and remain separated from their mothers. Preterm birth is associated with increased neonatal morbidity and mortality, and this adds to maternal anxiety after delivery.

Given these circumstances, it would seem that women with what can only be described as a traumatic birth-related experience might be at increased risk for the development of mental health complications, such as anxiety, depression and even symptoms of post-traumatic stress disorder (PTSD) when compared with women following a caesarean section for other indications. A literature search exploring the current state of the evidence on women's experience of this rare complication of pregnancy has focused mainly on the use of quality of life measures [9,10]. There is an urgent need to better understand the impact a diagnosis of PAS has on women if we are to optimize outcomes for those affected. The aim of this study was to explore women's experiences of PAS so that other women and clinicians could better understand the

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'underlying dynamics of the experience' and care planning could be optimised.

## Methods

The study design incorporated strategies from Interpretative Phenomenological Analysis where women following an experience of PAS were invited to talk with the researchers about their lived experience of receiving the diagnosis of PAS, the impact of antenatal hospital admission on self and family, their main concerns about the birth and the experience of early motherhood and recovery following a peripartum hysterectomy. The centre where the study was performed is a tertiary level unit with more than 9000 births within the city of Dublin. The hospital provides a placenta accreta multidisciplinary team (MDT) and between 10 and 20 women with PAS are treated in the unit every year.

Women were recruited through Placenta Accreta Ireland, a support and advocacy group for women and their families. Members of Placenta Accreta Ireland were approached and, if tentatively interested, given time to read an information sheet without the researcher present. Inclusion criteria were: pregnancy complicated by PAS within the past two years, ability to speak English and to consent and age over 18 years. Interviews were conducted over a four month period between November 2019 and February 2020. The interview guide was pre-determined based on informal interactions with women during support group meetings and were conducted by HB. The interview guide is included; as interviews progressed and new themes developed this guide was modified to allow exploration of new themes.

Interviews were recorded using a Dictaphone and transcribed manually verbatim. A demographic questionnaire was included at the beginning of the interview guide. No specific patient identifying information were recorded. Participants were given a unique study identifier in the transcripts to assure confidentiality for the analysis phase.

Transcripts were then analysed using the IPA methods described by Van Maanen [11,12]. Multiple analytic iterations were undertaken to cluster the codes into themes, which were then aligned with critical time points in the women's journey, pregnancy, birth and the early postnatal period at home.

The transcripts were reviewed for recurring themes, and coded systematically by HB, JL and MH. Each transcript was reviewed independently, and then in the context of the others to explore for experiences of similarity and uniqueness. The codes were then reviewed and themes developed based on the entire dataset to

ensure the overall themes were supported by women's experiences of the phenomenon. As the interviews progressed recurring experiences emerged and the interviewers took care to carefully compare findings by checking their assumptions with new participants. It became apparent that there were three key timepoints in the women's journey - pregnancy, birth and life after PAS once discharged home.

Ideally data are collected until saturation or equivalent is reached. However, this is a rare and difficult to access population and so the research team focussed on obtaining detailed accounts from the participants.

Rigour in the analytic process was ensured in two ways- first, two researchers (HB, MH) did the initial analysis followed by review and confirmation by three other members of the team (JL, DB, KM). The research team had previously reflected on possible personal sources of bias: as HB, DB and KM are members of the Placenta Accreta service this was identified as a possible bias in the research. Therefore it was critical to have input into the analysis by two independent researchers (JL and MH). This study is reported following the SRQR standards [13].

## Results

Data were collected from seven women who experienced a pregnancy and birth complicated by PAS in the previous two years. Table 1 provides a summary of the women's characteristics included in the study.

Six superordinate themes emerged which were related to distinct time points: during pregnancy, birth and the postpartum period (Table 2). The superordinate themes revealed the shared experiences of the interviewed women. In pregnancy the three main themes were "It's not until you are told", "sad but safe" and "relying on others can be unbearable". Around the time of birth 'fear of dying' related to self and baby emerged as key themes. Postnatally the key theme which emerged were "no one believed I could be feeling so much pain" and "it's not all over when you go home".

### "It's not until you are told"

This theme explores how women felt after receiving an unexpected diagnosis of PAS. PAS is a rare and complex pregnancy complication and a condition many women are not familiar with. For two women, they had never heard of PAS prior to being diagnosed in this pregnancy

**Table 1**  
Demographic characteristics of participants.

Patient	Age	Number of previous CS	Gestation at diagnosis (weeks)	Length of antenatal hospital stay (days)	Gestational age at delivery	Type of delivery	Months since birth
1	38	2	37	15	37	Cesarean hysterectomy, elective	24
2	33	2	34	20	36	Cesarean hysterectomy, elective	6
3	43	1	34	7	35	Caesarean section, elective	15
4	40	2	24	65	35	Caesarean hysterectomy, elective	12
5	39	3	6	56	28	Caesarean hysterectomy, elective	24
6	35	2	23	35	31	Caesarean hysterectomy, emergency	9
7	44	4	32	28	36	Caesarean section, elective	13

CS = Caesarean Section.

**Table 2**  
Superordinate themes and subthemes.

	Pregnancy		Birth	Postnatal period		
	<i>It's not until you are told</i>	<i>Sad but safe</i>	<i>Relying on others can be unbearable</i>	<i>'fear of dying'</i>	<i>No one believed I could be feeling so much pain"</i>	<i>It's not all over when you go home</i>
	Unexpected diagnosis	Long admission periods (feeling "fine" but a life-threatening condition) - trauma of a long stay	Separation from family	Handing over control to the team/losing self-control	Managing the house	Lack of postnatal care
	Unfamiliar condition	Separation from family and children	The challenges of organising your life from hospital	Fear of death- self and baby- not knowing if you are going to wake up	Post-operative analgesia	Lack of focus on mental wellbeing
	Information technically focussed	Avoiding MRI - hoping it might not be true (blunting)	Guilt at placing the burden on others	Leaving behind other children with no mother	Physical limitations	Post-operative complications
		Hoping to have "less severe" accreta (coping)	Guilt at asking for help	Reasons for requesting a general anaesthetic - pain during procedure, awake during potentially life threatening birth	Not just a straight forward caesarean section	It's so rare people just don't understand the impact Shame and stigma
		Meeting other women on the ward, providing "peer" support	Being away from work			Feeling guilty for asking others for help
			Hiding the tears (from others)			Feeling guilty at feeling so bad when both have survived
						Family support can be variable
						Family limiting condition . . . who to tell . . . blocking out (blunting) the seriousness of the condition
						Learning to live with the experience
Additional supporting themes	<i>"We had never heard of placenta accreta . . ." (P5)</i>	<i>"Because I looked normal and I wasn't bleeding, I worried that people might think I was being a bit of a drama queen as this was my third pregnancy and third bedrest. I didn't tell many people about the condition as I almost tried to convince myself and them that I only had accreta, not the far more serious versions of the disease, in creta and percreta." (P4)</i>	<i>"I am the organizer in my family and for all your control and power to be taken away and to have to rely on other people is unbearable. You feel so guilty and feel like such a burden." (P4)</i>	<i>"Ultimately you are giving up complete control and putting 100% trust in your consultants and their team to get you through this" (P2)</i>	<i>"The operation theatre was very calm but there was a lot of people in it. In hindsight I should have gone under general anaesthetic, because I was struggling during the whole operation with pulling I could feel. I kept thinking the epidural was wearing off. It was way too long to be awake for. I should never have had to decide between an epidural and a general anaesthetic, in my opinion it should have been a general anaesthetic". (P3)</i>	<i>"I was completely traumatized from all I had been through . . . I felt I had lost all of my confidence, worried excessively about our accreta baby and the older ones, I felt anxious a lot of the time exacerbated by tiredness". (P5)</i>
	<i>"When people asked me how did I manage . . . I would laugh and say that I cried myself to sleep - but it was true (unfortunately)"</i>	<i>". . . saying goodbye to my children &amp; not knowing if I would ever return to them in our home was immensely traumatic." (P5)</i>	<i>"I felt absolute terror the day of my surgery, my mind but also all parts of my body. Terror that my baby wouldn't survive being born so early . . . and that I would bleed to death and my children would have no mother." (P5)</i>	<i>"I'd been haunted for weeks prior about whether I'd survive the surgery, would I ever see my girls again, would they cope without having a mummy. worries about whether the baby would survive . . . would I ever get to meet him." (P6)</i>	<i>"The next day in hospital was possibly the worse day of my life. I was in horrendous pain, the baby was in ICU. I was encouraged to go down and feed the baby but I couldn't walk properly or cope . . . I had shoulder tip pain too so at one point I couldn't physically sit up.</i>	<i>"The loss of fertility hasn't yet seemed to matter to me, in fact I find it a relief that I cannot get pregnant again." (P6).</i>
		<i>"I knew I still needed to go through with the MRI. I kept hoping that there had been a mistake and that this was all a misunderstanding and I wouldn't be an accrete patient."</i>				<i>"They mainly didn't get it . . . once our baby was discharged and home, everyone assumed life was back to normal". (P5)</i>
		<i>". . . I was always too afraid to say out loud what I was thinking pre</i>				

**Table 2** (Continued)

Pregnancy	Birth	Postnatal period
<p>surgery in case I worried them". (P6)</p> <p>"I was hugely fortunate to be placed in a room with very friendly women with different conditions, we passed the days chatting" (P 5)</p> <p>"I felt much safer as an in-patient, my husband felt this even more than me. We understood that this was the best option for our situation." (P5)</p>		<p>I was in hysterics with pain." (P3)</p>

ICU – Intensive Care Unit.

MRI – Magnetic Resonance Imaging.

"Prior to being diagnosed with placenta accreta I had never heard of it. During my pregnancy I had a low lying placenta but I never gave it much thought . . ." (P3)

Two of the women interviewed had previously heard of placenta accreta. One of the women (P4) had a history of placenta previa in a previous pregnancy and recalls being told by her healthcare providers "at least you don't have accreta" while another woman (P7) "understood it was when the placenta attaches to the scar of a previous c-section".

For healthcare professionals, it can be challenging to explain a diagnosis to women without using medical jargon and relay the information in a way that can be understood by them and their family. Women reported the methods healthcare staff used to try and explain the condition.

"Doctors, anaesthetists came and went three days prior to the surgery to discuss what might happen and the complexity of the surgery. The surgeon did his best to explain with some basic drawings." (P1)

"Sad but safe"

This theme explores the coping methods women used while being admitted to hospital. All women commented on the difficulty of a prolonged hospital admission. Women reported on the challenges of organising your life from hospital and "hiding the tears" from visitors.

All women interviewed had at least one child at home and found the separation from their children particularly upsetting.

"I have a husband & two other children I found this extremely difficult not being at home in my 'ordinary' routine, making their lunch, going to work, cuddling them at night before bed. I couldn't talk about my children to my consultant or nurses as I would get too upset." (P2)

A suitable place to spend time with their children when they visited was also reported as very difficult by some women who were particularly concerned about their children disturbing other patients in their ward.

"Family visits were not too good either, as there was no space for my children to spend time with me & the café is way too small . . . I was worried that the children were too noisy for other patients and my children didn't want to be confined to a small space around a bed." (P2)

Women also reported that they found they had "lost all freedom and independence" and felt "felt completely useless" while trying to manage homelife whilst being in hospital.

When it came to telling others how they felt blocking out the seriousness of the condition and hiding one's feelings to protect loved ones was a recurrent theme.

"I did not tell friends or even family except for my husband and mother. I did not reveal what was wrong. In hindsight that was a mistake." (P1)

Other women found it difficult for both themselves and their family to fully understand the severity of the diagnosis.

"I really struggled with not 'feeling sick/unwell' but also knowing the worst was yet to come." (P2)

Some women reported the positive impact of meeting other patients in the hospital and the support this offered them.

" . . . my friend who I met on our ward and who had a bed right beside mine with the same diagnosis was also there for me that morning (for the birth) for support." (P 2)

While women found their hospital admission difficult, there was a general acceptance it was necessary. Many women reported feeling safer knowing that medical personal were there to look after them if an emergency arose.

"I was allowed home before Christmas . . . as much as I wanted to be back home, I wanted to be back in (hospital) more as I felt so safe there and knew that my baby would be okay if I was there." (P4)

"Relying on others can be unbearable"

This theme explores the change in role women experienced as a result of their diagnosis and hospital admission and the guilt they felt as a consequence. Women described the difficulty of not being able to organise the home, prepare their children for school and giving up work.

"I found this extremely difficult not being at home in my 'ordinary' routine, making their lunch, going to work, cuddling them at night before bed." (P2)

Guilt was a particularly strong theme reported by all the women interviewed. Women reported feeling guilty asking others for help and placing the burden on others.

“ . . . but other days the emotional side can override the logical and you just worry all the time and about everything . . . what if something goes wrong, what if I don't make it, what if I don't make and I am spending my last days here in hospital without spending time with my children”. (P2)

#### *Birth: 'fear of dying'*

This theme explores the experiences of women as the day of the birth arrived.

The day of the birth brought a feeling of “giving up control” resulting in a feeling of “absolute terror” (Table 2). The fear of death and contemplating mortality was felt by many women. The thought of death and the impact this would have on their other children became apparent for women as they were prepared for theatre.

“Honestly for a minute or two . . . I was worried he was going to take me away from my other boys (in other words, the baby inside me was going to kill me)” (P4)

“No one believed I could be feeling so much pain”

This theme explores the challenges women faced with pain, both during and immediately after the procedure and after going home. Women were unanimous in feeling they received inadequate pain relief, having to ask for pain relief multiple times and being met with disbelief at the level of pain they experienced. Women felt they were being pain relief as if they had a “straight forward caesarean section!”.

An important issue for many of the women was that of discomfort during the procedure (for those that had spinal anaesthesia) and post-operative pain. For the three women who had a spinal anaesthetic there was a sense of regret of not having been under general anaesthetic for the whole procedure (Table 2).

“The operation theatre was very calm but there was a lot of people in it. In hindsight I should have gone under general anaesthetic . . .” (P3)

Women reflected on their degree of pain in the post-operative period and the lack of regular analgesia.

“The spasms were bad but and I was given inadequate pain relief. I do not think I was given enough pain medication. I had severe back pain and was referred to physio. I was ashamed to admit I had a hysterectomy” (P1)

“It's not all over when you go home”

This theme explores women's experience of being back home after the birth. While many reported an initial feeling of relief at having survived and getting back home to their families, all women reported on-going worry and trauma from what they have been through. Women reported feeling “guilty for asking others for help”, guilty at feeling so bad when both them and their baby had survived and varying levels of family support.

“I was very grateful to be alive but did not discuss what had happened. I was afraid to admit to pain or feeling low in case it would somehow take away my ability to cope”. (P1)

Some women reported feeling relief that they would not be able to have another pregnancy.

“I haven't considered or processed the fact that I do not have any reproductive anatomy anymore” (P2)

A sense of having to live with the condition was evident “If anyone asks me to this day I say I'm still recovering which is the truth” (P3)

As the condition is so rare it was hard for people to understand what the women had experienced.

“People think once you are home you are fine, sometimes I felt like screaming you have no idea what me, my husband, my daughter and new born baby have gone through”. (P3)

#### **Discussion**

This study explores women's personal stories of their pregnancy complicated by PAS. Strong themes were developed from interviews, all of which were underpinned by feelings of loss, bewilderment, loneliness and pain, both mental and physical. Qualitative research provides a possibility to make new meanings and to allow the exploration and development of themes that the researchers had not considered prior to the study. The goal is therefore to answer “what and why?” rather than “how many?”. What is it like for women to have a diagnosis of PAS? Is it easier for them to be prepared or does that merely prolong the anxiety and worry? Using an inductive approach – moving from the data to a hypothesis – means that we can explore what people really mean and how they really behave and why.

Other studies have used questionnaires and studied postnatal outcomes of women with PAS [9,10]. In a questionnaire based study of 69 women [9], forty percent of women who had experienced PAS (n = 17 in total) met the criteria for probable post-traumatic stress disorder (PTSD). This was significantly higher than those who underwent an uncomplicated caesarean birth, but not different to those who underwent an emergency peripartum hysterectomy or severe postpartum hemorrhage. A second questionnaire-based study showed lower quality of life at six months in women who had experienced PAS when compared to those who had a complicated caesarean birth without hysterectomy [10]. These differences were not seen at one and two years postnatal and the researchers recommend including long term psychological morbidity as part of consent for PAS caesarean hysterectomy.

Our study suggests women who have experienced a pregnancy complicated by PAS face significant challenges in the antenatal period, at the time of birth and after their pregnancy. However, gaining an understanding of the challenges these women may experience is an opportunity to start putting the services in place to support them. Women and their family should be provided with easily understood information without medical jargon so they are left with an understanding of their diagnosis. Many women highlighted the challenges of organising the home where a long admission was needed, and strategies women used to cope who have experienced this may help other women going forward. Women were unanimous in their call for mental health support in the postnatal period, hence offering counselling in the antenatal period could provide women with coping strategies and have provide them with a familiar place to turn if they needed additional supports after the birth. Counselling can also prepare women for the day of birth and what to expect. Women have feedback they would prefer to be asleep for the duration of the procedure and the reasons for this should be clearly explained to women diagnosed with PAS with a discussion around risks and benefits.

Postnatally, women spoke of the need for improved pain management, particularly while still in hospital. The utilization of postnatal analgesia protocols ensures women are provided with regular analgesia and help manage breakthrough pain. Staff caring for women antenatally should also build realistic expectations for women so they understand the physical limitations they will have for the weeks and possibly months after the birth.



Women were keen to highlight the need for mental health support after the birth. While many women will not need additional care, it is essential to provide follow up to identify women who would benefit from them. Providing women with tools of how to talk about PAS and the lasting effects such as infertility may provide an outlet for women to express what they have been through and communicate their potential struggles with family and friends.

This study has a number of strengths and limitations. To our knowledge, this is the first qualitative research study exploring women's personal experience of PAS. Studies which place patients at the centre of research are important to allow us to truly understand the human impact illness has on people and their lives. IPA is appropriate in this study as the aim was to explore in detail how these women would make sense of their world after a pregnancy complicated by PAS. In addition IPA was chosen as it is particularly useful when undertaking fieldwork with small, homogenous samples.

The data is limited potentially by women and recall bias. Only one woman underwent an emergency caesarean hysterectomy and it may be possible that women in this situation would have a very different experience to those undergoing elective procedures, though the findings from Tol's paper [9] would suggest that this may not be true. All of the included women were treated in the same tertiary hospital, which may limit the application of the findings to a wider population. Another concern was social desirability bias – that participants would answer questions in a manner to be viewed favorably by the researcher [14].

In conclusion, there are numerous challenges for women both during and following a pregnancy complicated by PAS. There are learning points which clinicians and units can utilize which may improve women's PAS experience such as space to spend with family, maximizing post-operative pain relief and adequate psychological and mental health supports during both the antenatal and postnatal period. Future research in traumatic birth-related experiences should further explore interventions to minimize the potentially negative impact of this experience.

### Ethical statement

Ethical approval was granted by the National Maternity Hospital ethics committee (EC30 2019) and written informed consent was obtained from participants.

### Interview guide

Semi-structured interviews of women who experienced a pregnancy complicated by placenta accreta spectrum.

#### Part 1: Antenatal course

Prior to being diagnosed with placenta accreta, had you heard of this condition before?

If so, what was your understanding of placenta accreta?

Tell me about when you first were told you had placenta accreta?

What was it like being admitted and having to stay in hospital until the birth?

Tell me about family life? How it was affected by being in hospital?

#### Part 2: Time of delivery

Can you take me back to the morning of the birth and what was going through your mind?

Looking back now, is there anything that would have helped?

#### Part 3: Back home

So tell me about going home? What was it like for you?

Was it what you expected?

How did you manage?

Who did you tell? Where did you get practical and emotional support?

Was future fertility on your mind?

Part 4: Final thoughts

Is there anything I haven't asked that you would like to talk about?

Interview probes:

Tell me more about that . . . /How did that make you feel . . . / Could you give an example of that.

### Declaration of Competing Interest

The authors have no conflict of interest to declare

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All authors who contributed to the manuscript are named authors and approve the final manuscript.

### Appendix A. Supplementary data

Supplementary material related to this article can be found, in the online version, at doi:<https://doi.org/10.1016/j.ejogrb.2020.09.014>.

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