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Full length article

Caesarean scar pregnancy: Parents lived experience

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ABSTRACT

Objective: Caesarean scar pregnancy (CSP) is a rare and high-risk complication of caesarean birth. To date, studies have described the associated maternal and fetal morbidity; however, the lived experience of parents has yet to be addressed. Here, we aim to describe the experience of CSP as reported by women and partners with a history of CSP.

Methods: This is a multi-center study involving participants from two centers, one located in Ireland and one in the UAE. Each woman had experienced one or two pregnancies complicated by CSP. An Interpretative Phenomenological Analysis (IPA) approach was applied to collect and analyze data. Interviews were conducted virtually between January 2023 and November 2024. Twelve participants were included; three couples (n = 6) and six women participants interviewed alone (n = 6).

Results: Women who participated had a median (IQR) age of 34 years (33–39), and all had at least one prior caesarean delivery. Five overall themes were identified relating to the experience of CSP, namely "lack of knowledge", "hurried decision making", "feeling isolated", "becoming pregnant again", and "the impact on relationships". Parents found the decision to end a wanted pregnancy extremely difficult, which was compounded further by the acute isolation they felt being diagnosed with such a rare complication. Participants had no prior knowledge of this condition and struggled to assess risk in the context of uncertainty as to future outcomes.

Conclusion: This study presents the lived experiences of CSP, highlighting how couples struggled with limited prior knowledge and perceived urgency of making life changing decisions. Contemplating future pregnancies was difficult given the uncertainties surrounding potential risks. By presenting the perspectives of patients and their partners for the first time, this study offers unique insights into their experiences, providing valuable information for healthcare providers to consider in future research and in delivering care to this rare group of patients.

Introduction

Caesarean scar pregnancy (CSP) is a rare complication where the gestational sac is implanted into a caesarean niche [1,2]. The diagnosis is made on ultrasound, more accurately assessed transvaginally, and can be made from as early as 5 weeks gestation [3]. As the myometrium (the muscle of the uterus) is thinned and deficient where a CSP implants, with advancing gestation there is a significant risk to the mother, such as of uterine rupture, bleeding, and development of Placenta Accreta Spectrum (PAS) [1–4]. In a *meta*-analysis of 40 cases of expectant management of CSP, 9.9 % of women experienced a uterine rupture, and 15 % required hysterectomy following rupture [5]. In cases where the pregnancy progressed to the third trimester, 70 % developed PAS [5].

As a consequence, patients with CSP are often counselled to terminate the pregnancy in the first trimester, to avoid such complications [6]. However, if the pregnancy continues, many will progress to the third trimester, with live birth rates upwards of 60 % reported, albeit with a high incidence of maternal morbidity from hemorrhage and

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caesarean hysterectomy [1,5]. Importantly, not all CSPs are the same, as ultrasound findings and outcomes vary [1,6]. Therefore, some types of CSPs are thought to be at lower risk of serious complications than others [5,6].

As the diagnosis of CSP often involves difficult decision-making due to the associated risks of maternal morbidity and fetal loss associated with continuing the pregnancy, when termination deemed the most appropriate course of treatment, it is likely to be associated with significant psychological sequalae for women and support partners. As caesarean birth rates continue to rise [7], it is likely CSP will become a more frequently faced pregnancy complication, and therefore understanding its impact on women and families is important.

CSP is considered a pre-cursor of PAS, with many patients who have either undiagnosed CSP or opting for expectant management developing PAS in the second and third trimester [5,6]. We have previously described the significant psychological sequalae for women and their partners with a PAS pregnancy [8–10], suggesting that CSP may also be associated with similar challenges. However, CSP represents a unique subset of PAS patients which likely have additional experiences and hence this study is needed to explore this further.

Therefore, the aim of this study is to undertake an in-depth exploration of the lived experience of women and their partners who have had a pregnancy complicated by CSP. While exploring the impact of this rare complication, we will also comment on the commonalities of the experience with those patients experience a PAS pregnancy.

Methods

This qualitative interview study was conducted between two tertiary referral centers; one located in Ireland and a second center in UAE. Ethical approval was granted by the hospital ethics committee (EC33.2022 and Corniche Hospital April 2024) and participants provided written, informed consent to participate. We applied an Interpretative Phenomenological Analysis (IPA) approach to analyze interviews conducted with eligible participants. IPA was selected as the most appropriate methodology for this study as the primary aim was to explore a specific phenomenon that has not been previously described [11]. In keeping with IPA, we aim to explore the meaning that participants attach to their experience of CSP [11,12]. We used IPA to gain an in-depth understanding of the experience of CSP and what it is like to be diagnosed with CSP, making decisions around management and the postnatal period/aftermath of having had a CSP.

Participants were eligible to participate if they had experienced and received care and management for CSP in one of the two participating centers and had indicated to the research team that they would like to participate in future research; women were contacted by the research team by email and if they indicated they would like to participate, were sent a participant information leaflet and consent form. Study participation was confirmed by written consent and again at the beginning of each interview. Eligibility criteria were as follows; experienced a pregnancy complicated by CSP within the past five years and were aged over 18 years. Partners were eligible when their partners had met the above inclusion criteria and were aged over 18 years. Where a couple consented to participate, they were given the choice to either be interviewed together or separately. For those who did not have fluency in English, a translator was used for the interviews (n = 3).

Interviews were conducted virtually by AH (clinical psychologist), HB (obstetrician) and JL (midwife) between January 2023 and November 2024 across both sites. The interview guide was developed based on informal discussions with the patient advocacy group, and in keeping with IPA consisted of open-ended, non-directive questions, with prompts used to allow a more in-depth exploration of the participants' experiences. Interviews were recorded using the audio function in Zoom (Zoom Video Communications Inc. 2016) with participant consent and transcribed using Sonix (Sonix, Inc. San Francisco, 2021). All audio files and transcripts were coded and given a unique study identifier plus the letter M or F (M = mother and F = father).

An IPA approach was used to develop key themes relating to the lived experience of CSP [11,12]. To ensure methodological rigor throughout the coding, theme identification and analysis, the researcher who conducted the interview performed an initial coding of the data. Then, each researcher who conducted the interviews (AH, HB, JL) reviewed, confirmed and validated each theme at a research meeting, confirming themes were in keeping with the content from each interview. Finally, peer validation was performed by two additional researchers (NC and AKA) who had not been involved in the interview process, to ensure themes that emerged were credible and in keeping with the interviews.

Public and patient involvement was engaged throughout the research process. A patient advocacy group, Placenta Accreta Ireland (which also supports families impacted by CSP), provided feedback on the study design and methodology. Furthermore, themes were reviewed by a patient advocate (NC) to ensure themes were in keeping with the stories and experience of a wider patient group.

In this study, participants self-identified themselves as mothers or fathers and hence are referred to as such throughout the results and analyses. We recognize that parents may identify in diverse ways and that these heteronormative labels may not always be relevant or applicable and therefore using this terminology is not intended to exclude any other person who has experienced CSP and who self identifies differently.

Results

Twelve participants were included in total (3 couples consisting of a mother and father, and 6 mothers interviewed individually). There were six participants from each center, with a median (IQR) maternal age of 34 (33–39). All mothers who participated in this study had at least one prior caesarean delivery, with four having two or more. Participants were between 8 months–4 years after their pregnancy with CSP. CSP management was as follows; seven participants underwent surgical termination (one participant had two CSPs), one participant had two CSPs with the first ending in surgical termination, followed by another CSP with expectant management and hysterectomy for PAS at 31 weeks, while one patient had a uterine rupture and hysterectomy at 19 weeks.

For mothers who chose to be interviewed alone, this was mostly for practical reasons such as childcare, and there was no sense of differences in the experiences shared by those interviewed individually or with partners. Furthermore, there was no sense that there were noticeable differences in the experience of those cared for in different centers.

Five overarching themes emerged, namely "lack of knowledge", "hurried decision making", "feeling of isolation", "becoming pregnant again", and "the impact on relationships" (Fig. 1). Additional supporting quotes for each theme are shown in Table 1.

Lack of knowledge

Despite all mothers having at least one caesarean delivery, none had been told about the CSP or were aware that this was a possible complication of caesarean delivery. Participants expressed disappointment and regret that this was never discussed, for example one mother said *"I wasn't aware of this complication until my diagnosis. Caesarean sections have so many complications… at the time when the decision was made for a caesarean section, I was never aware of this condition. I wish I had been counselled about the complications or outcomes after a caesarean section with future pregnancies. It's not something they discussed with me at the time of making that decision."* (CSP M4), while others felt *"…it's frustrating. There was no information it was a shock to be told this"* (CSP M5). Furthermore, in some cases there was lack of knowledge by healthcare providers of complications of caesarean and missed opportunities for diagnosis, for example one participant who was not diagnosed until late in the second trimester said *"I think it was missed…it probably wouldn't have changed anything. But I mean, I think had it been earlier, maybe it might*

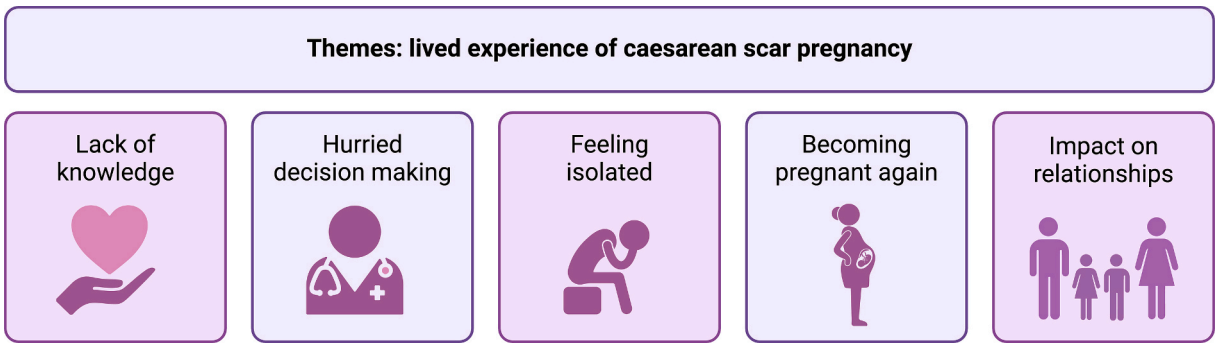

Fig. 1. Summary of themes relating to "experience of csp".

have been a better…it's a bit "what if" (CSP M8).

Hurried decision making

Of the nine mothers who participated, eight who were diagnosed in the first trimester had a termination of pregnancy in the first trimester; two participants had two CSPs, one of whom had a termination with the first CSP and continued the pregnancy in the second CSP, while the other mother had a termination for both CSPs. Participants interviews suggest directive counselling, with the expert leading the decision very strongly and suggesting termination as the only safe option. For example, one participant said "*And they just kept saying, you know we would recommend you stop the pregnancy now … they couldn't guarantee that we would get pregnant again… I mean, such a difficult, such a hard decision to take."* (CSP M1). There was a sense of urgency with a quick decision needing to be made, for example one participant said "*So the [doctor] said that they needed to perform [surgery] pretty much immediately. For my safety, essentially" (CSP M3)*. For some, this resulted in a sense of not having enough time or information to consider the difficult decision to end a wanted pregnancy, as suggested by one participant who experienced two CSPs who said "*I feel both times I was rushed… I don't even have answers completely for myself, for me to take this decision. There is not enough information and resources given to people when we ourselves don't have any information."* (CSP M9). Decision making was made more difficult where conflicting information was being given as to the risk of pregnancy continuation, for example "*One of the doctors said it is a scar pregnancy, you must get admitted. Then after a few discussions, they would say the scar cannot pop…but then other doctors would come in the evening and say your uterus could rupture, you will lose the baby, you would lose your uterus. So I was conflicted between 3 or 4 doctors telling me that I can continue and face the risk at the end….I said that I need a bit more time."* (CSP M9).

However, while directive counselling to end the pregnancy was evident from the interviews, the serious risk of continuing the pregnancy was understood and four expressed no regret regarding their decision "*I felt that this was the loss of something that was part of me, my baby. But I had to make that decision, and I don't regret it at all. I knew it was the only and best decision for me. I knew this pregnancy was dangerous for me and surgery was the right thing to do."* (CSP M4), while another said "*When I had that surgery and there was still a heartbeat, it felt like a piece of my heart was being taken out of me. But I had to do it for my health and for my family."* (CSP M6).

For the couple with two CSPs who opted to continue the pregnancy with the second CSP, the thought of repeatedly experiencing further CSP was a motivator to try continuing the second time, as well as a perception that the counselling from healthcare providers was less bleak than on the first occasion *"…I didn't feel so comfortable having to go through that again and possibly again and again. So, the second time, we sort of said, let's see what happens. And if we make it through this and [mother] makes through it healthy, and the baby makes it through great. But we have two kids already… The choice, I think, for the second pregnancy was we can't do this a third time, so we'll try. The doctors seemed a bit more confident the second time." (CSP F2)*. This was not without its own associated stress, with constant worry about the possible outcome of the pregnancy at the forefront "*I would put the kids to bed and often cry a lot at night. Just worrying. Had we made the right decision or how was this all going to go in the end?"* (CSP M2). In contrast, the other participant with two CSPs was counselled for termination of pregnancy on both occasions with no option of continuing explored on either occasion "*I was told that it is a scar pregnancy, and you don't really have a choice to continue. You'll have to terminate it. So, I didn't know if the baby had a heartbeat or not…there was no question of what your decision is?" (CSP M9)*.

Feeling isolated

As CSP remains a very rare pregnancy complication, it is not surprising that participants spoke of their sense of isolation and feeling that they were the only ones who had experienced this rare type of pregnancy. It was challenging for participants as not only had they never heard of the condition, but had no person who would relate to their experience, as illustrated by one participant who said *"..it is quite isolating to have to be the only one that has experienced this and nobody around you to relate at all. There's something only happening to me and not anybody else"* (CSP M9). Some tried to find understanding in peer-to-peer support but found there was no group suitable for them "*I have messaged different groups on social media, but none of them seemed to know [CSP], it's always fallopian tube ectopic pregnancy."* (CSP M1). Others suggested such support would have been helpful, especially when considering further pregnancies *"I don't know if they would give me the contact of, you know, another patient… but something I should think about and ask way before I get pregnant again."* (CSP M9).

Given the rarity of the condition, participants wanted clear information and explanations, as well as something tangible to take home and consider later as the information being given was at times very complex, one participant said "*Our situation was so unique in that it's a really rare condition…. And we felt well taken care of but small things like layman's terms, information for each of the scans or updates that would help. Something that you could take home and read over and think about."* (CSP M2).

For one participant, missed opportunities for an earlier diagnosis led to feelings of isolation, stemming from not feeling heard or listened to, despite having an instinct that something was wrong. "*I felt very stupid because no one believed me and they said my pain was not as bad as I thought I was saying it was… My gut was like this isn't right and I wish I had said I'm not going home." (CSP M8)*.

Becoming pregnant again

All participants in the study had a desire for future pregnancies. To what degree this was discussed, or patients were counselled varied and was dependent on the individual clinical circumstances. For fathers, the

Table 1
Supporting quotes for each theme.

Theme	Supporting quotes
Lack of knowledge	*"I had never really heard of ectopic pregnancies before, so I suppose I was blasé. I didn't know what really was going on. So they had called in [the doctor] and they had their junior doctors with them…there were so many people in this tiny little room and they were all kind of talking, but it didn't make any sense to me what was going on…. none of them had seen this before. I suppose they had learned about it in college, but they had never actually seen it face to face." (CSP M1)* *"I suppose we didn't really understand at that point until we got up to (the other hospital). We knew something was up, and it wasn't good." (CSP F1)* *"There was no written information about my pregnancy…there was not that much information." (CSP M2)* *"And the research that was there for scar ectopic pregnancies was always seemingly very small sample sizes. And I don't have a scientific background. So even just reading the excerpts from papers was enough to confuse me about what the actual dangers were." (CSP F2)* *"The [doctor] was quite good at explaining what a scary topic was because obviously we we'd never heard of it and how rare it was as well." (CSP M3)* *"I had never heard of a complication like this. I didn't know about caesarean scar pregnancies, even though I have many relatives and family members who had caesarean sections but never experienced CS scar pregnancies. So, this was a really big surprise and a big shock for me to learn about this medical condition. I have had four caesarean sections…"(CSP M6)* *"Most of the family members and all of my friends are coming to know of [CSP] from me because I have experienced it. We've had so many family members who've had caesarean…but even then they've had multiple caesareans and they've never even heard of such a thing, or never have been warned by any doctors" (CSP M9)*
Hurried decision making	*"One of the doctors was like this is a very serious situation. … they were saying that the baby would not survive the second trimester. And if we were to go ahead with this, the pregnancy, that they would have to do a hysterectomy straight away. And so like, we had just had a baby and we were only starting our family and then they were talking about a hysterectomy and it was all, you know, it was crazy, I suppose, at the time." (CSP M1)* *"..they had said to us she was eight weeks pregnant at this stage and they said that like the longer it goes on, the more complicated it can get. They said we really need to kind of get a decision straight away…For me, I think pretty much straight away I would have said terminate the pregnancy [because of the risk to her]". (CSP F1)* *"The doctors told me it would be dangerous to my life if I continued with the pregnancy, and I don't exactly remember what the complications would have been if I had continued with it, but I just trusted the doctor's opinion and decided to proceed with the curettage and evacuation." (CSP M4)* *"They said this condition is very complicated for me, and my health. That's why it's better do to the evacuation otherwise I might lose my uterus. I didn't want to risk it because I want one more baby…. when I heard the baby's heartbeat the first time, I did not know I had this condition. They did not mention it to me the first scan I had. It was very hard. I felt so sad. I cannot explain how sad. It was so difficult, especially because I heard the baby's heartbeat." (CSP M5)* *"I was offered evacuation or termination of pregnancy. I was advised that if I did not wish to proceed with evacuation, there was a higher risk of having an attached placenta, which would make the pregnancy high risk and put me at risk of losing my uterus or even my life in a case of massive bleeding. At that time, I was thinking of my children who need their mother. So, my husband and I immediately decided to proceed with evacuation…. This was an extremely difficult decision to make and a painful experience. It was especially difficult for me because I heard the heartbeat multiple times, so coming to that decision was not easy." (CSP M6)* *"In that scan I heard the baby's heartbeat for the first time and was told that this is a caesarean scar ectopic, and I needed admission and surgery to evacuate the pregnancy the next day. The next day I had the suction evacuation…. they told me I could have a ruptured uterus and massive bleeding and could have difficulty getting pregnant after that, and that there's a chance of hysterectomy. I had the same counselling in both hospitals. I was very anxious and fearful, but I decided to go ahead with termination." (CSP M7)* *"I knew that I had no choice, that I knew I was dying. Like I knew that. So I knew that I didn't even let myself think about it as a choice. It was just, you have to do this." (CSP M8)* *"But then I, I made a decision to terminate purely because I didn't want to lose the baby and the uterus and also my health with the already the two kids that I have was important. I was not in a position to risk it for just one child." (CSP M9)*
Feeling isolated	*"Well, I was really scared. And I couldn't find enough information about what it was or what it was going on. Everything that I could find was about more common ectopic pregnancies." (CSP M1)* *"This decision we've made, we'll do it. And so we do everything that we're supposed to do up until that point, and we've done everything we can. But then at that stage, I remember when we all got out of the car to walk up to the doors of the hospital, say goodbye to her that it definitely hit me on the drive home. That I could wake up tomorrow and go into hospital, and it could be the last time I see my wife. If something was to go wrong." (CSP F2).* *"That was that was tough because it was going into the hospital, you know where they I think it was the early pregnancy scanning area. So, you know, you were surrounded by pregnant women and you know, I was going in to check on a, an orange sized hematoma in my uterus rather than, you know, a baby. I guess it made it impossible for us to move on from it because it was still a real live problem." (CSP M3)* *"This pregnancy was very desired because I have been trying to get pregnant for 10 years. I had multiple IVF cycles many of them failed and many ended in miscarriage. This was the only spontaneous pregnancy after 10 years of trying. I was very happy to hear the fetal heart, but to be told that this pregnancy is stuck to the caesarean scar at the same time was devastating. I wished I could keep this pregnancy." (CSP M7)* *"So when you've gone through something that you don't know anybody else who's even come close to it, and you knowing that there's other people who've lived it is really helpful because you can start to process that, okay, this is part of the world. This is part of life. It's really awful. That happened to me. But it had to happen to somebody and it's happened to other people and they know you can talk to them about it in greater detail." (CSP M8)* *"So not having an answer to an issue that you are physically facing is quite it's almost defeating sometimes because you don't know what to do." (CSP M9)* *"I'll put the post-surgery for the last one. I was probably in tears for a month, bawling my eyes out every corner because I was pregnant for a good, you know, close to two and a half months. So yeah, a very long time to, you know, go ahead with termination. And I was completely filled with regrets." (CSP M9)*
Becoming pregnant again	*"And they just kept saying, you know we would recommend you to stop the pregnancy now…they couldn't guarantee that we would get pregnant again or they couldn't guarantee really anything, I suppose." (CSP M1)* *"I had a caesarean scar ectopic pregnancy before this one. And we didn't go ahead with the pregnancy. So then when I got pregnant again, they wanted me to come in at six weeks for a scan. They were like it won't really happen again…but obviously when we went in again they said that the baby was implanted again near the scar. But it was a slightly different position. And they were a bit more hopeful then that I would get to 25 weeks. So we decided this time we would go ahead with the pregnancy." (CSP M2)* *"Knowing that that there are no more kids. I always wanted four, but that's because I had three siblings, and that's what I*

(continued on next page)

Table 1 (*continued*)

Theme	Supporting quotes
	thought was you did… Three is more than enough. So my stance on that has totally changed. But I know that it's different when the option is no longer there." (CSP F2) *"I still believe we made the right decision. And I suppose at the time it was for her to get pregnant again, was unsure, we didn't know if could or would happen…you don't know what's coming down the road. And if she does get pregnant there's the risk of complications… I was thinking (our daughter) might never have a sibling and they could never guarantee that anyway." (CSP F1)* *"So a little bit sad as each time, you know, each milestone is achieved with him, it's kind of like, oh, it's the last time." (CSP M3)* *"My husband is a bit anxious about the future. He asked me if we might go through the same thing with a future pregnancy, if it can happen again. I don't feel the same way. I don't feel anxious at all. I feel calm and believe that whatever happens, happens." (CSP M6)* *"They had told me that since you've had this one time, there is a chance that it could occur again. I am hopeful, I would love to have another child… I am willing to try again one more time. I feel like if I have a scar pregnancy again, I might stop trying [to get pregnant]." (CSP M9)* *"I would feel very differently about it if things hadn't worked out, but we're going to have another baby on Monday, I still do think about how different life could be if we had made a different decision, did we make the right choice? I think about it all the time, there's probably not a week that goes by that I'm like, did we make the right choice?" (CSP M1)*
The impact on relationships	*"It was really hard to look at (my daughter) and be like, how could we stop a pregnancy when you have something so beautiful? You know, it was really hard." (CSP F1)* *"I think definitely in this position, the mother's situation is far worse as she is the one that physically has to go through it. But there's definitely some emotional impact on the dad. I think that's really downplayed a lot, but it definitely is real." (CSP F2)* *"I think, yes, I kind of take that tongue in cheek because, you know, at the end of it all, we're absolutely delighted. And, you know, we've come through a lot to get here. So maybe it just adds a bit of perspective to things." (CSP F3)* *"And so it's not taking things for granted. Like not like when you're younger, you spend so long trying not to get pregnant. And then then the one thing you want in life, it can be so hard to get. I see so many of my friends and they can't get pregnant. And I feel like after everything we've been through and here we are now, ready to have another baby, we're just so lucky. We're so blessed that it all worked out, but I mean, yes, we've been through pain and but we have a good and happy and healthy outcome." (CSP M1)* *"…it's traumatizing in itself to terminate a pregnancy because of course, friends around me that are having so, so much difficulty for years even conceiving a child. And you conceive and you have to go through termination. So for nothing with my husband, actually, my husband and me, we are on the same page about mostly everything that I spoke about." (CSP M9)*

priority was the mother's health and safety, regardless of another chance to have a further pregnancy, for example one father said "*I still believe we made the right decision. And I suppose at the time it was [she] would get pregnant again, was unsure, didn't know if could happen or would happen."* (CSP F1). Similarly, another father reported feeling grateful for having a healthy child and not wanting to take any risk for the mother's health "*But I think after it all happened, we were very much leaning on the fact that we already had a daughter. And how lucky we were that that was the case. And, you know, I think there was obviously a high risk that we wouldn't be able to have any more kids."* (CSP F3).

For mothers, there were mixed emotions of considering a further pregnancy, more children were wanted but the risk of a further CSP and its associated risk was at the forefront of their minds *"..with the option opening up again of being able to potentially have another pregnancy, I think that then arose a load of complex emotions … they advised me to wait 9 to 12 months after the surgery for recovery and then we actually did get pregnant straight away…. And I guess the chances of a second scary pregnancy are much higher…"* (CSP M3). This sentiment was shared by other participants, who also suggested their families were very worried about their health and future pregnancies, for example one mother said "*..my family don't want me to have more children. They say I have already have three kids. Why risk my health again with another pregnancy? They asked me to stop trying to get pregnant…. now we are trying for pregnancy, but we are scared that this might happen again."* (CSP M5).

Although the risks of CSP and recommendation for termination of pregnancy was advised by healthcare providers, participants were not advised to not pursue further pregnancies, for example one mother said, "*I've never been told that I should not try for another child."* (CSP M9). Furthermore, there was no sense from participants that they had been advised of specific risks of future pregnancy or how likely it was to happen again, with most saying they were advised to have an early pregnancy scan in any future pregnancy to rule out a CSP.

Two participants had a hysterectomy, one for PAS at 31 weeks and another for uterine rupture at 19 weeks. This irrevocable infertility resulted in a sense of guilt and thinking over the decisions they had made that led up to this point, even though their family was self-declared as complete, the finality of a hysterectomy was difficult "*It's hard to think when you don't have the choice what to do. And then I guess sometimes I get upset thinking, obviously we ended one pregnancy, and this one worked out, and I start to think, but what if we'd gone ahead with the other one? Would that have worked out?. I guess feel guilty…"* (CSP M2). Furthermore, a sense of wishing they could accept the loss of fertility was evident, with other mother saying "*"Like, we we're still kind of thinking about surrogacy and that. So that now occupies a lot of my mind. And we did IVF… I would have accepted I think I can only have two children, and now I just I mean, I wish I could accept that I only have two children because my life would be less stressful."* (CSP M8).

Impact on relationships

Being diagnosed and making decision around CSP was identified as a very difficult and sad time by all participants. It was evident from interviews, both those who were interviewed together as a couple or alone, that this impacted relationships. One mother said the experience had taken a toll on her other children, as they were old enough to understand their mother had been very unwell, she said "*So I think they [my children] were so relieved when we came home…our son, just burst out crying. He was so happy to finally meet his brother and get a chance to have a cuddle with him, and that the whole thing was over, and you could just see the relief kind of on his face that it was now all over."* (CSP M2).

Fathers commented on how the experience had brought them closer, one father said, "*We're so blessed that all worked out, but I mean, yes, we've been through pain and but we have a good and happy and healthy outcome."* (CSP F1) while another said their relationship was strengthened after this difficult experience "*I think a positive thing that we found that we definitely became a lot closer to each other. Because we had to rely on each other and be strong for each other. We kind of got through it together and come out stronger"* (CSP F2). Mothers acknowledged the impact their high-risk pregnancy had had on their partner, with one saying *"It was pretty awful. It was horrifically traumatic for him. He very much thought that I was going to die." (CSP M8)*.

Discussion

This study presents the lived experience of mothers and fathers with a history of CSP. We present the initial challenge faced by couples from being diagnosed with a rare and unfamiliar pregnancy complication, the decision-making process and how counselling influences this, and ultimately facing the future and further pregnancies.

We found counselling regarding decision making is expert directed and focused on ending the immediate maternal risk of the current CSP.

While in this sample termination was advised as the only safe option, advice not to become pregnant again did not feature. Current evidence to guide practice is limited. Both the Royal College of Obstetricians and Gynaecologists (RCOG) and the Society for Maternal Fetal Medicine (SMFM) have published recommendations for care for CSP [13,14]. Both societies recommend women are counselled on the significant risks associated with expectant management where a fetal heart is present, and that such pregnancies are ended to avoid serious maternal morbidity and mortality [13,14]. Even in cases where there is no fetal heart present, they caution against expectant management as it may still be associated with maternal risks such as hemorrhage, it may take many weeks or months for the pregnancy to resolve and other rare complications such as arteriovenous malformations may occur [14–17]. However, these recommendations are based on limited data and are possibly based on more severe forms of CSP where there is minimal residual myometrium [1,18].

In the era of rising caesarean births, CSP will become an increasingly common pregnancy complication. Therefore, it is important to ensure counselling for women/couples is based on high quality evidence, with clear guidance available on the potential risks of pregnancy continuation and psychological, physical and fertility consequences of pregnancy termination. Guidance on which women and clinicians may safely rely on when the pregnancy is continued is urgently needed to ensure the best outcomes that can be achieved. This study suggests that women are likely to follow medical advice to end a pregnancy where the risks are presented as serious and life-threatening; however, ensuring these risks are balanced against the possible outcome of continuing a pregnancy is critical if women are to give informed consent for the treatment and management offered. Furthermore, more information is needed on the risks of subsequent pregnancies, with current evidence suggesting the recurrence rate may be as high as 30 % [4]. However, pregnancy complications that women experience post-CSP are largely unknown, meaning clinicians are poorly equipped to accurately counsel these women.

In the absence of robust data, this presents significant challenges for clinicians providing care for these patients. Importantly, there is global variation in the availability of reproductive services, where safe and legal termination of pregnancy is not provided as a treatment option. This presents unique challenges when caring for women with CSP, and data on these pregnancy outcomes and clinician experiences of providing care in these contexts is urgently required if evidence-based care is to be offered to women with this rare complication.

A key theme from this study was the lack of knowledge of CSP as a complication of caesarean delivery. Therefore, we suggest counselling for non-medically indicated caesarean should include the possible risk of CSP and PAS, and in particular, that women are informed that CSP can occur after one caesarean section. This is important if clinicians are to support women in making fully informed decisions regarding mode of birth. Both this study and our previous PAS research suggests discussion of these complications is not being included in any meaningful way for women undergoing caesarean [8,19].

This study has several strengths and limitations. This study adds the voice of the mother and father with CSP to the literature, which to our knowledge has not been previously described. This is particularly important given the rising caesarean delivery rate and increasing levels of maternal mortality worldwide. Furthermore, the study was developed with liason with a patient advocacy group, ensuring key stakeholders were involved in all stages of the research process. This is a particular strength as it ensures trustworthiness of the data as each step of the research process, from initial study design to theme analysis, was conducted in keeping with a wider group of patient advocates. Moreover, analysis was carried out by an interdisciplinary research team with experience in obstetrics, clinical psychology, and midwifery. Finally, this is a multi-centered study that included two culturally different populations, meaning the results are more applicable to a wider population.

This study also has several limitations. Firstly, study is limited by the small number of participants. However, given the rarity of this population, access to such individuals is inherently challenging. Furthermore, the sample did not include women without a living child and therefore their decision-making process (in particular around termination of pregnancy) may not be represented by the participant experiences in this study. Counselling by healthcare providers may also differ. This study included two sites which both had termination of pregnancy available for cases of CSP, meaning that sites where this service is not available are not represented. Therefore, future research in this area is also required when the pregnancy is continued in a context of limited reproductive services/options for management.

This study presents parents' experiences of CSP. The challenges of experiencing such a rare complication while facing difficult, life-changing decisions was evident. This is an important area that, until now, has received little attention. As CSP may become more common with rising caesarean birth rates and increased awareness/improved diagnostics, it is vital to understand the needs of parents to ensure as clinicians we continue to strive to provide personalized, evidence-based care. Furthermore, this study highlights that more work is urgently needed to understand the natural progression of various types of CSP and the implications for future pregnancies so that clinicians are better equipped to provide evidence-based counselling.

Consent for publication

Written, informed consent was provided by each participant.

Availability of data and materials

Data obtained for this study was in the form of interview transcripts from participants. These are not publicly available or upon request from the authors to protect patient confidentiality. Sample quotes which support the themes presented within the manuscript are shared within the text and supporting tables.

CRediT authorship contribution statement

Helena C Bartels: Conceptualization, Data curation, Formal analysis, Funding acquisition, Investigation, Validation, Writing – original draft, Writing – review & editing. **Antje Horsch:** Data curation, Formal analysis, Supervision, Writing – review & editing, Investigation, Methodology. **Naomi Cooney:** Conceptualization, Investigation, Methodology, Project administration, Resources, Writing – review & editing. **Donal J Brennan:** Conceptualization, Data curation, Supervision, Writing – review & editing. **Yasmin Sana:** Data curation, Formal analysis, Resources, Software. **Andrea Agten-Kaelin:** Conceptualization, Formal analysis, Resources, Software, Writing – review & editing, Investigation, Methodology. **Joan G Lalor:** Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Software, Supervision, Writing – original draft, Writing – review & editing.

Ethics approval and consent to participate

Participants provided written, informed consent. Ethical approval was granted by the two hospital ethics committees according in accordance with the Declaration of Helsinki.

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Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence

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