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CLINICAL ARTICLE

Obstetrics

Patient centered care for placenta accreta spectrum: Exploring implementation of recommendations based on reported patient and healthcare provider experiences

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Abstract

Objective: Previously, we made recommendations for "family-centered care" for patients with placenta accreta spectrum (PAS). This study explored patients' experience of their care and how often these recommendations are utilized. Furthermore, we explored whether these recommendations are valued by healthcare providers and identify barriers to implementation.

Methods: This study consists of two surveys; one for patients with a history of PAS and a second survey for healthcare providers involved in PAS care. Surveys were circulated over an 8-week period between September and October 2024. Four overarching recommendations were investigated as follows; preparation for birth, supportive care, education of healthcare providers and postpartum care. Quantitative and qualitative data were obtained; content analysis was performed to identify themes from the patient and healthcare provider experiences.

Results: A total of 155 patients responded to the online survey. While some felt well prepared for the birth (96/155, 63%), most felt frustrated by the lack of treatment options and preparatory resources ($n = 122/155$, 78%). Less than half of patients were offered mental health referrals ($n = 69/155$, 44%), although when offered they were positively received. Only 40% ($n = 62/155$) of patients were offered specialist postpartum care. From the healthcare provider survey, which had 89 responses, possible barriers identified by healthcare providers to offer such support were cost, lack of insurance coverage and geographical distance. Qualitative content analysis revealed that patients strongly expressed a need for counseling, physical health support, and specialist postpartum care.

Conclusion: Previously published recommendations are strongly desired by patients, with positive experiences where these are offered. Healthcare providers acknowledge and value the need for supportive care, with barriers to implementation including cost

and limited resources. We suggest practical, low-cost measures to overcome these gaps.

KEYWORDS
barriers to care, education, lived experience, mental health, patient-centered care, placenta accreta spectrum, postpartum care, qualitative research, survey, trauma-informed care

1 | INTRODUCTION

Placenta accreta spectrum (PAS) is associated with significant mental and physical health sequalae.[1–3] In high-resource settings, the recommendations for management of PAS involves a centralized, multidisciplinary team approach in specialized tertiary centers, with access to advanced services such as expert ultrasound, cell salvage, interventional radiology, and intensive care for both mother and neonate.[4,5] In low-middle income settings, although the burden of PAS is greater, access to such specialist services is often not available. In an effort to improve PAS care in these regions, specific recommendations for such settings have been proposed, such as utilizing telehealth and aiming to concentrate expertise to the best resourced centers.[6]

Women with PAS and their families experience many challenges both during and after the pregnancy, including emotional distress, fear and anxiety, and surgical morbidity resulting in a deterioration of physical health.[7,8] Previously, we developed family-centered care recommendations aimed at improving the experiences of women with PAS and their families. Family-centered care refers to care which emphasizes collaboration between patients, their families and healthcare providers, ensuring they are actively involved in the planning, delivery and evaluation of healthcare. These recommendations included pre-emptively acknowledging the physical and mental health consequences of PAS with routine referral to physical therapy and mental health counseling and support, continuity of care by a specialist PAS multidisciplinary team, and postnatal follow up to include debriefing and beyond the standard 6 week check with their specialized team.[2,3]

These recommendations were made based on in-depth interview studies with women and their support partners in Ireland.[1,2] While studies from other countries such as the UK and the USA support the need for a supportive care pathway,[9,10] patients' experience of this aspect of care has not been rigorously studied. Furthermore, no previous studies evaluate healthcare providers' experiences and ability to provide the recommended care. Moreover, a distinct phenomenon is observed in maternal care deserts, particularly in low- to middle-income countries where mental healthcare for pregnant women remains insufficient.[11-13]

In the present study, we aimed to explore whether women with PAS are being offered supportive care as we have previously recommended,[2] and of their experience when supportive care is offered. Furthermore, we aimed to examine healthcare providers' knowledge of the physical and mental health sequalae of PAS, to identify the extent to which supportive services are currently being offered, and to identify barriers to implementation. This information is critical to appropriately power future prospective studies and inform clinical practice guidelines.

2 | MATERIALS AND METHODS

The present study consisted of two separate closed, descriptive surveys distributed over an 8-week period between September and October 2024. Ethical approval was granted by the National Maternity Hospital, Dublin ethics committee (EC17.2024) and informed consent was obtained from participants for both quantitative and qualitative data.

2.1 | Survey design and distribution

Two distinct surveys were developed: one targeting women with a history of PAS and one aimed at healthcare providers. Previously, we described recommendations for care for patients living with and beyond PAS, summarized as "family centered care" (Table S1).[1,2] This survey study explored how these recommendations are perceived and implemented by both patients (Survey 1) and healthcare providers (Survey 2). Recommendations were then grouped thematically, and four overarching themes were investigated (Figure 1), as follows; preparation for the birth, supportive care (both physical therapy and mental health resources), healthcare provider education, and postpartum care.

Following an initial draft of the patient survey, the questions were reviewed and discussed with representatives from two patient advocacy groups (the National Accreta Foundation [NAF] and Placenta Accreta Ireland [PAI]), and modifications were made based on their feedback before a final survey was released. For the healthcare provider survey, an international group of physician-scientists who have published about PAS provided feedback on the initial draft to ensure that the survey had content validity, avoided ambiguity and was suitable for distribution to an international community of those providing PAS care.[14] The final surveys were approved by all who reviewed the initial drafts. Prior to distribution, the surveys usability and technical functions were tested.

The surveys were distributed as follows; advocacy group leads (KT and NC) contacted women via their advocacy groups and sent a direct link to participate, including approximately 900 women.

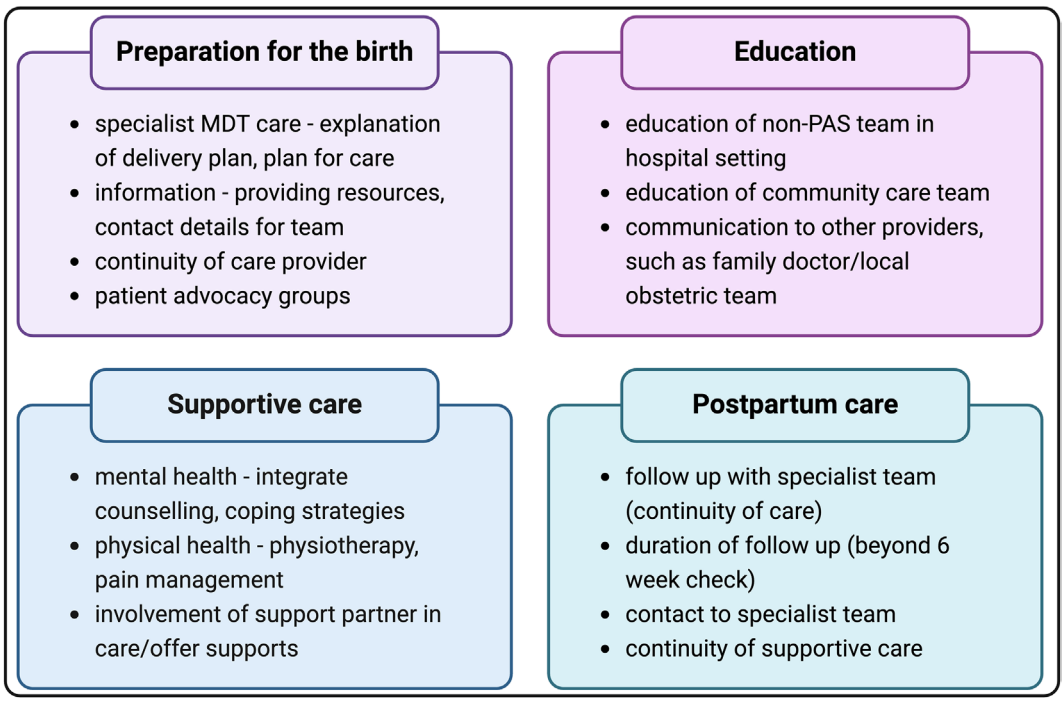

FIGURE 1 Recommendations for care, as previously described.[2] The family-centered care recommendations we previously described to support families experiencing a pregnancy complicated by PAS are summarized. The surveys distributed to patients and healthcare providers explored each of these recommendations.

Furthermore, information about the survey was circulated on the patient advocacy groups social media, with a link sent to women who responded. The healthcare provider survey was distributed through two PAS society groups—the International Society for PAS (ISPAS) and the Pan-American Society for Placenta Accreta Spectrum (PAS[2])—following approval of the final survey by the respective society boards. The survey was distributed to approximately 500 healthcare providers through the two society groups, of which 120 are active members. Only one answer was allowed per individual, and participation was voluntary. The surveys were initially distributed at the beginning of the 8-week period, with two further reminders sent during the study period. Surveys 1 and 2 are provided as supplementary materials. Each participant could only complete the survey once.

2.2 | Qualitative analysis

For qualitative data, narrative comments from participants were analyzed using content analysis.[15] To identify key themes within each recommendation, two researchers (HB, KF) reviewed narrative comments and assigned codes to highlight prominent themes in the data. The final themes were then selected. Once final themes were selected, a follow-up meeting with patient representatives and advocates was conducted to confirm whether the themes aligned with their experiences and perspectives.

Throughout this manuscript, the terms *family-centered care* and *patient-centered care* are used with distinct meanings. *Family-centered care* refers to our previously published recommendations derived from interviews with patients and their partners about their experience of PAS.[2] In contrast, as this study focused solely on the direct experiences of patients, we use the term *patient-centered care* to describe, report, and summarize the findings presented here in the current work.

3 | RESULTS

A total of 244 participants responded to the surveys, of whom 155 (63.5%) were patients and 89 (36.5%) healthcare providers. Demographics for patients and healthcare providers are summarized in Tables 1 and 2, respectively. A total of 72 (46%) of patients experienced PAS within the previous year, with a median (IQR) duration since the PAS pregnancy for patient participants of 2 (0–5) years. Overarching themes and specific areas where gaps and barriers to care implementation were identified are summarized in Table 3. Supporting quotes for each recommendation explored are presented in Table 4.

3.1 | Preparation for birth remains an area for improvement

Exploring "preparation for the birth", we found 96 (63%) of patients felt well prepared for several surgical outcomes including hysterectomy or uterine conservation (Table 5). Feeling well prepared for the

TABLE 1 Participant demographics—patients.

	N = 155 (%)
Age (median [IQR])	36 (33–40)
Duration since PAS pregnancy (years)	2 (0–5)
Region	
Europe	30 (20.0)
North America	114 (73.5)
Australia and New Zealand	6 (4.0)
Africa	1 (0.5)
Missing data	4 (2.5)
Number of previous vaginal births	
0	124 (80)
1	18 (11.5)
2	5 (3.5)
3	4 (2.5)
>4	0 (0.0)
Missing data	4 (2.5)
Number of previous cesarean births	
0	10 (6.5)
1	88 (56.2)
2	41 (27.0)
3	10 (6.5)
>4	2 (1.3)
Missing data	4 (2.5)
Cared for by a specialist PAS team	
Yes	94 (60.5)
No	57 (37.0)
Missing data	4 (2.5)
Did you have a hysterectomy?	
Yes	119 (76.5)
No	32 (21.0)
Missing data	4 (2.5)
Did you have a blood transfusion after the birth?	
Yes	122 (78.5)
No	29 (19.0)
Missing data	4 (2.5)

Abbreviations: IQR, interquartile range; PAS, placenta accreta spectrum.

TABLE 2 Participant demographics healthcare providers.

	N = 89 *N* (%)
Region of the world	
Europe	22 (24.7)
North America	27 (30.7)
South America	14 (15.7)
Central America	4 (4.5)
Asia	9 (10.0)
Australia and New Zealand	1 (1.1)
Africa	2 (2.2)
Middle east	3 (3.3)
Missing data	7 (7.8)
Working in a tertiary referral PAS center	
Yes	67 (75.2)
No	15 (17.0)
Missing data	7 (7.8)
Subspeciality	
Obstetrics and Gynecology	38 (42.5)
Gynecology	3 (3.5)
Maternal-fetal medicine	40 (45.0)
Gynecologic oncology	3 (3.5)
Anesthesiologist	3 (3.5)
Missing data	2 (2.0)
Years of experience in PAS care	
Less than 5 years	29 (32.5)
Between 6 and 9 years	18 (20.2)
Between 10 and 15 years	20 (22.5)
More than 15 years	13 (14.6)
Missing data	9 (10.0)
How many PAS cases, including all grades, managed in your center each year?	
Less than 5	12 (13.5)
6–10	21 (23.5)
11–15	13 (15.0)
16–20	10 (11.5)
More than 20	24 (26.5)
Missing data	9 (10.0)
How many cesarean hysterectomies are carried out for PAS in your center each year?	
Less than 5	25 (28.0)
6–10	20 (22.4)
11–15	7 (7.8)
16–20	5 (5.7)
More than 20	21 (23.6)
Missing data	11 (12.5)
How many cases are managed using focal resection and repair for PAS in your center each year?	
Less than 5	34 (38.2)
6–10	11 (12.5)

birth included being supported by and in regular contact with their team. For example, one participant stated, "*everything was outlined for me at my initial appointment with my accreta specialist and discussed monthly until 32 weeks, I was then seen weekly.*" In addition, participants felt well prepared for the birth where it was evident healthcare providers between their local and referral PAS center were in communication, with time given to explain emergency plans: "*My care included a contingency plan should I need to deliver immediately back home. My OB and accreta MFM collaborated on a plan… the accreta team started preparing for me at my delivery hospital from 20 weeks.*" On the other hand, some patient participants felt ill-prepared where

TABLE 2 (Continued)

	N = 89 *N* (%)
11–15	3 (3.5)
16–20	1 (1.1)
More than 20	9 (10.0)
Do not offer this treatment	21 (23.5)
Missing data	10 (11.2)
How many cases of PAS are managed using conservative management (leaving placenta in situ) in your center each year?	
Less than 5	30 (33.7)
6–10	3 (3.5)
11–15	0
16–20	0
More than 20	1 (1.1)
Do not offer this treatment	50 (56.2)
Missing data	5 (5.5)
How many cases of PAS are managed using conservative management initially (leaving placenta in situ) with planned delayed hysterectomy in your center each year?	
Less than 5	24 (27.0)
6–10	2 (2.2)
11–15	0 (0.0)
16–20	0 (0.0)
More than 20	1 (1.1)
Do not offer this treatment	53 (59.7)
Missing data	9 (10.0)

Abbreviation: PAS, placenta accreta spectrum.

no options or alternatives to hysterectomy were given once PAS was suspected, *"I was told the only option was hysterectomy." This resulted in some participants self-seeking a second opinion "I was living in [xx] where they only do hysterectomy as a way of treating it… I was not happy with that and looked at other places and found [another hospital] to deliver."* Furthermore, receiving mixed messages from healthcare providers contributed to patients feeling poorly prepared for the birth, for example one participant said *"There was a clear plan but miscommunication between hospital staff…the surgeon who was in charge on the day gave completely different information…"*

Conversely, most healthcare providers reported that they had extensive discussions with the patient and family in preparation for the birth involving several members of the multidisciplinary team (Table 6); however, some identified late diagnosis as a barrier to these discussions taking place, for example one healthcare provider said *"…sometimes we first meet patients and diagnose PAS cases at about 35 weeks (their [local hospitals] do not send them to the [our] hospital earlier)."* Other providers identified the need to improve how patients are counseled and expand treatment options, as suggested by one participant who said *"in our center, we are starting to offer focal resection, not only hysterectomy. We plan to begin routine follow-ups for patients. We started consulting patients during pregnancy (in the third trimester), not only before delivery."*

Patients used various resources to self-educate themselves on PAS, such as web sites and social media. Most ($n = 122$, 78%) reported that they were not provided with any educational resources by their healthcare team, which in some cases was intentional: "*I was told by my doctor not to research the condition*" (Table 5). From the healthcare provider perspective, most ($n = 83$, 96%) reported that they provide various forms of information to patients such as leaflets and social media sites, with some specifically recommending against internet searching the condition as caution against possible distress as a result: *"try to persuade them not to [internet search] it at diagnosis to avoid the antenatal 'priming' for PTSD."* However, patients reported that this type of counseling led them to have to find information themselves which was a frightening experience: "*I looked myself online but stopped at some point because it was too scary.*"

For others, their experience was so unique that it was challenging to find any suitable resources *"I had looked at the PAS website after my stillbirth… there seemed to be no resources for people like me… it is extremely isolating losing a child and your fertility all at once…"* Moreover, most patients ($n = 131$, 84%) reported that they were not told about any patient advocacy groups and had to seek this out themselves; some patients reported they "*would have used them if offered.*" Others who did use support groups found it their main source of information "*so much of my info and understanding of what is happening to my post-PAS body is coming from support groups and women sharing their stories.*"

3.2 | Patients want earlier and more frequent referral to supportive care

Regarding the overarching theme of "supportive care", 69 (44%) of patient participants were offered referral to mental health/counseling. Positive experiences of this service highlighted how it helped their recovery, with one participant saying, *"It saved me,"* while another commented, *"It greatly helped. I don't think I would have recovered the way I did if I didn't have this care."* On the other hand, poor experiences occurred when mental healthcare providers lacked understanding of PAS and its implications, with participants saying, *"I felt like there wasn't much information surrounding the topic and didn't benefit from [counseling]"* and *"the counsellor I was referred to didn't seem to understand the complexity of my trauma."* Furthermore, longer-term support was needed, with participants reporting that the service was not offered at the right time. For example, one participant said, *"I mostly needed help after delivery when I had no more contact with the team in charge of my case."* Another said, "*while it was nice to have that support, I wish this was proposed for longer after delivery because PTSD hit a few months after.*" For 64 (41%), mental health support was not offered, of whom 31 (20%) sought this service themselves. In some cases, referral was not made due to the service not being available. *"I asked for one in the hospital, and they didn't have someone to help me."*

Amongst the healthcare provider respondents, 48% ($n = 43$) do not routinely refer patients for counseling (Table 5). The main

TABLE 3 Patient and healthcare provided gaps and barriers to care.

Patient reported gaps	Patient reported barriers	Healthcare provider reported gaps	Healthcare provider reported barriers
Antenatal counseling			
Preparation for birth	• Time constraints • Lack of clear communication • Lack of benchmark or previous similar experience • Lack of provision of online resources • Lack of range of treatment options	• Patient understanding • Lack of high-quality online information	• Patient healthcare literacy • Concern that providing online resources "primes" for PTSD • Inability to adequately provide treatment options
Supportive care resources			
• Mental health • Physical therapy	Lack of resources	Lack of available resources	• Cost • Lack of resources
Postpartum care			
• Postpartum follow up care with specialist team	• Time constraints • Lack of clear communication how to contact specialist service • Lack of knowledge of care needed for support	• Postpartum care as routine part of specialist service	• Inability to adequately provide postpartum care—cost, distance, insurance • Lack of knowledge regarding care needs of postpartum patients

Abbreviation: PTSD, post-traumatic stress disorder.

perceived barrier to referral was cost or lack of resources (32%) and lack of availability (18%). Consequently, some providers tried to foster support through other avenues, reporting, "*this is not done routinely as we do not have the resources to provide it but we contact their family doctor and health visitor postnatally to inform them of the procedure and high risk of psychological sequelae.*" Those who routinely referred patients to mental healthcare were more inclined to acknowledge the significant psychological sequalae of PAS: "*…there is a heavy psychological burden for patients diagnosed and treated for PAS, with long-lasting effects.*"

Relating to physical health needs, most patient participants (60%, $n = 93$) reported that they were not offered any physical or pelvic floor physical therapy (PT). Some who were offered the service found it beneficial, although reported that it was not for long enough; "*They did have physical therapy come to the hospital while I was still admitted after the surgery to help me walk and teach me how to get out of bed and up and down stairs with minimal pain. That was really helpful. Would have loved more of a referral for after I got home.*" Many participants felt there was minimal understanding amongst physical therapists of PAS or its associated complications. For example, one participant said of her physical therapist: *"not good at all, as she didn't know much about vertical incisions and didn't provide the care I needed"* and "*the hospital physical therapist visited my room a few days post-surgery but was not knowledgeable about PAS surgery. I received exercises for cesarean section surgery.*" For others, while the service was offered, it was difficult to attend appointments for practical reasons whereby PT was, *"helpful but difficult to go to all appointments with a preemie newborn and 2 other young children at home."*

Most healthcare providers did not routinely offer physical therapy ($n = 61$, 68%), with cost or limited resources (31%) and lack of availability (21%) cited as the primary reasons. Some healthcare providers had not considered the need for this service "*…haven't thought of it for this population,*" while others acknowledged the importance of physical therapy and attempted to overcome resource limitations through creation of resources. One provider volunteered, *"…again, limited resources, so [I] am making an information resource for patients to access to provide exercises and advice on wound care/abdominal exercises, pelvic exercises, etc but then we are only allowed to refer to physio if specific concerns."*

Many patient participants felt that their support partner was not included in their care by the medical team nor provided with sufficient resources ($n = 95$, 61%), despite feeling that family support is necessary. "*This was definitely lacking. My partner was lost and did not know how to help. I wish someone had told him that he will need to get ready to take the whole household organization for a while and be extra present.*" Many healthcare providers were not able to offer psychological support to support partners ($n = 72$, 82%). Furthermore, 39% ($n = 35$) of healthcare providers reported that a support partner is not allowed in the operating room for the birth, with various reasons given such as hospital regulations, "*Unfortunately, the hospital regulations make it not possible for the husband to attend the operating theater,*" and space limitations, "*Sometimes we must do surgery in a very small operating room… in these situations, we prefer not to have the support person inside the operating room.*"

3.3 | Healthcare provider education is needed for continuity of care

We explored the theme of education of both hospital- and community-based healthcare providers outside of a core PAS care-team. While

TABLE 4 Content analysis—themes.

	Patient experience $N = 130$	Healthcare provider experience $N = 78$
Preparation for the birth	*"There weren't any options besides hysterectomy presented by my team"* *"I was told the only option was hysterectomy"* *"I was given the option to try and save my uterus, I declined"* *"As the severity of my case became clear, I was kept informed of the surgical plans"* *"I searched a lot for social media groups to connect with other moms who had the same diagnosis"*	*"Extensive discussion by obstetrician regarding details of the surgical procedure plus fertility future expectations. Extensive discussion with anesthesiologist regarding anesthetic plan, monitoring, pain management"* *"Counseling starts at the ultrasound room, soon after diagnosis. We keep on counseling at every antenatal care consultation"* *"Fully counseled with description of all possibilities. Ideally meet with all teams preoperatively remote from delivery to have time process information. Usually preoperative meeting of urology IR gyn onc if involvement in care anticipated…"* *"We have a PAS midwife who keeps regular checks with the patient. She is only likely to meet them once prior to delivery unless they are an inpatient with bleeding, then the team we visit the patient most days antenatally. And we have a postnatal clinic when we see them alongside the neonatologist, surgeon and midwife to debrief patients and go through everything including the histology"* *"We counsel them after diagnosis. We have a patient leaflet we provide and spend time meeting with various members of the MDT to counsel the patient about the diagnosis and their aspects of treatment and management plan"* *"I think it would be good to have a more dedicated clinic on initial diagnosis- as often they are told in fetal medicine and then may go home Google and so on and worry. Depending on consultant they see and how good they are at counseling. Whereas, if we could have funding for our midwife to be paid for more hours and to be in these clinics she could then take time to properly counsel them and signpost them to the relevant information should the patient wish"*
Supportive care • Mental health • Physical health • Involvement of support partner	**Mental health** *"It greatly helped. I don't think I would have recovered the way I did if I didn't have this care"* *"I was required to see a psychiatrist/psychologist after my birth. It was a very good experience"* *"I received wonderful care from the mental health team at my hospital."* *"It was helpful but I experienced so many life changes that I don't feel like I have truly dealt with the trauma of what happened during birth and with recovery"* *"I went once and it was helpful but I didn't really connect with the therapist so I ended up finding my own therapist. They didn't have experience with my particular situation though, as it was pretty rare"* *"I felt like there wasn't much information surrounding the topic and didn't benefit from it"* *"I had to chase 3 times. I began my mental health counseling when my son was 18 months old"* *"While it was nice to have that support I wish this was proposed for longer after delivery because PTSD hit a few months after"* *"Not great, it was only a couple of sessions before delivery and we did not have time to work through much. I mostly needed help after delivery when I had no more contact with the team in charge of my case"* *"The social worker was very helpful, but I would have preferred to have had someone to speak to about my condition PRIOR to my surgery so that I could manage expectations/ emotions"* *"I asked for one in the hospital and they didn't have someone to help me"* **Physical health** *"I saw a pelvic floor PT prior to delivery as well as after delivery and she was very very helpful"* *"It was helpful but was for a few days"* *"I believe it made all the difference in my recovery"*	**Mental health** *"…there is a heavy psychological burden for patients diagnosed and treated for PAS, since during counseling in the antenatal period, with long-lasting effects"* *"We provide birth trauma counseling with a trauma psychology specialist"* *"Women suffer with a lot of anxiety AND fear"* Evidence to prevent—*"Access to PAS physicians/team, patient advocacy groups, support groups"* **Referral to mental health** *"This is not done routinely as we do not have the resources to provide it but we contact their GP and health visitor post-natally to inform them of the procedure and high risk of psychological sequelae. We also tell the women to seek help if they feel it is needed"* *"Only those who seem in need of them according to the physician's assessment"* *"Sadly we don't have funding for this"* *"We counsel by ourself"* *"Not enough funding to refer everyone sadly. But if we were worried about a specific patient we can get the psychologist to see them on the ward. But postnatally they have to see their GP for referral to services"*

(Continues)

TABLE 4 (Continued)

	Patient experience $N = 130$	Healthcare provider experience $N = 78$
	"The care I received from the (hospital) was amazing I really benefited from going to the physio both during and after my pregnancy. The team gave me exercises and techniques to help me feel good again" *"It was okay, but not hysterectomy specific"* *"I felt so alone, I had to find resources and support all on my own and it was incredibly difficult"* *"Difficult as it was independent of the hospital and I had to explain to her what surgery I had had and why"* *"Physio after was fine. It mostly was around scar management. My body still does not feel right 10 months later and I have a lot of pain all over my body … I think there needs to be more access to physio postpartum to help woman get back to where they were prebirth physically"* *"I believe counseling should be an automatic referral when diagnosed. I was never offered any kind of mental health during that time. Also pelvic floor for anyone with hysterectomy. I was told nothing would change sexually after hysterectomy and that is just not true"* *"I wish there could be more support in the years after. It takes a while to figure out a new normal for both body and mind after such an ordeal and I've found that now, nearly 2 years out the support that might have been there early on is no longer as accessible"* *"Helpful but difficult to go to all appointments with a preemie newborn and 2 other young children at home"* **Involvement of support partners** *"My husband was very overwhelmed. We had a 3 year old at home and the possibility of losing me was very hard for him. My mom helped to talk with doctors and relay decisions and information to him. They included any support people as needed"* *"This was definitely lacking. My partner was lost and did not know how to help. I wish someone had told him that he will need to get ready to take the whole household organization for a while and be extra present"* *"My husband was with me and we knew I had placenta accreta. However my husband did not understand the risks until I was nearly dying in the emergency room"* *"Yes he was involved in hospital visits and care plan discussions after my diagnosis and the hospital accommodated him being there post-delivery despite covid restrictions"* *"My partner was involved in my care but we weren't provided resources other than a leaflet"*	**Physical health** *"Something I hadn't considered previously"* *"Haven't thought of it for this population and just referred if needed"* *"It actually I am trying to bring this in. Again limited resources, so am making an information resource for patients to access to provide exercises and advice on wound care/abdominal exercises, pelvic exercises etc. but then we are only allowed to refer to physio if specific concerns. And they told me all they would do is a telephone consultation to start as they do for all postnatal women, again due to limited resources"* **Partner involvement** *"This surgery is done in the general OR of the hospital where support persons are not allowed"* *"Unfortunately, the hospital regulation make it not possible for the husband to attend the operating theater"* *"If a hysterectomy is warranted patients are placed under general and partner leaves with the baby"* *"Hospital policy does not allow the support person into the operating theater (regional or general)"*
Education	**Hospital staff** *"I was in a specialty hospital with a whole team which was created for people with accreta. Every person I spoke to was well aware of the severity and complexities of the diagnosis"* *"The nursing staff was very helpful. They also made sure my mental health was ok daily by checking on me and also making me feel at home"* *"I was on an antepartum floor the staff was very knowledgeable"* *"Multiple members of my nursing team made comments that my daughter was "so cute we should definitely have more" after my unknown/unplanned hysterectomy. There was no support, and no acknowledgment of what I had been through"* *"This was so frustrating!! Thankfully I was in a mentally positive place, but more than once a postpartum nurse WHILE I was still admitted and recovering from surgery asked to talk with me about birth control!! I couldn't believe it. I gave this feedback to the hospital. Thankfully I was prepared for the surgery and it wasn't a surprise or an emergency—if it had been, those comments could have been really traumatizing!"* *"It felt like I was one of the first cases they had experienced at the hospital"* *"Most were very considered, but some did not really see that I had more than just a regular cesarean and needed a bit more support in the first days"* *"I felt there was a lack of knowledge especially amongst the midwives. The midwife assigned to the birth had no clue what she was going to. Majority of postnatal care was poor. Felt like an inconvenience"* **Communication to community team** *"I have had to tell my story to so many follow up doctors and they don't understand the implications or hurt that it causes to talk about the experience"* *"Nothing was sent to my doctors at all I had to transfer all info once I was better"* *"It's hard to know what was provided* versus *what was really read. I trust that my care team shared their notes and everything. But more than once in the weeks after my c-hyst, when I sought medical care for various issues, I had to explain that I had a hysterectomy. I was shocked how often I had to actually explain placenta accreta to medical health professionals"* *"They informed my GP correctly in terms of what happened, but no further guidance for care"* *"Just wish my Dr had read letters sent to them from the hospital. Then it wouldn't have been so upsetting when she started talking about adding to our family"*	**Hospital staff (providing teaching)** *"Regular teaching twice a year to nursing staff, to trainees every rotation"* *"Theater staff and postnatal ward staff"* *"We did a study day in [xx] and invited doctors, midwifes, sonographer, anesthetist and neonates from the region. I have also given teaching sessions to the midwives, in particular the postnatal ward midwife's as we were having issues with postnatal care. Then also given teaching to theater staff separately"* *"Little institutional support to fund anything with women's health"* **Communication to community team** *"We do not have family doctors. The patients return to our center or local hospital for check-up postpartum"* *"We discuss the procedure including need for postnatal mental health care with each woman's GP when she is diagnosed"*

TABLE 4 (Continued)

	Patient experience $N = 130$	Healthcare provider experience $N = 78$
Postpartum care	*"The review was a very positive experience. It made me feel seen, and acknowledged the significance this experience has had in my life. It gave me the opportunity to fully understand the surgical procedure and rationale"* *"I was very grateful that the OB wanted to follow up with me so we could talk about my recovery"* *"Actually can't fault it. I saw my specialist a few times in the hospital and a couple of the big wigs who were also in my surgery"* *"My baby died as a result of what happened. I had my normal follow up and then just a phone call appointment. No other services were offered to me"* *"Sent to a different doctor in network of the hospital that did the surgery"* *"Just the appointment to remove the catheter and then the 8-week follow-up appointment"* *"Had my 6 week postpartum check where I was told I should get my tubes tied and sent on my way"* *"I feel like I was discharged super early even though I said I didn't feel ready. I was discharged at 4 days post op because that's all insurance would allow for a cesarean section…I had a hysterectomy"* *"I had multiple postpartum nurses wanting to do fundal checks and push on my belly. I had to remind them a few times that I did not have a uterus"* *"There was no room for me on the postpartum floor, so I was moved to the Cancer wing on the other side of the hospital since my main doctor was a Gynecologic Oncologist. The staff on that floor had no clue how to care of a postpartum mother. It was a horrible experience"* *"Honestly I felt very alone once discharged. I had an appointment for a 6 week check-up back at the hospital which I had to reschedule because I had mastitis on that day. I tried to get an appointment for the next available date but was told it was a long wait so did not see someone from maybe 2 months after my accreta delivery. I have no point of contact and any one I spoke to just dealt with me as if I was a normal cesarean section patient"* *"At 6 weeks but it was extremely brief and felt I didn't have the opportunity to ask more questions"* *"A 7 week check up at the hospital instead of 6 week check-up at g.p. My debrief was canceled unexpectedly the day before it was to take place which was disappointing"* *"Awful, inconsistent, and only focused on the visible scar that now runs down half of my abdomen"* *"I feel the care I received postpartum was ok. I did end up have panic attacks and PTSD which led to a fear of going back/avoidance. My GP dealt with most of that but therapy/ medication was never really suggested. I ended up in therapy 3 years later after my sons therapist recognized the signs of my distress/anxiety…"* *"No support or services were offered to me. The only discussion regarding what I had been through is that I should feel 'lucky to be alive.' I was made to feel guilty for feeling anything other than grateful. I was also told not to take any pain medications, as I should be able to meditate through it. I suffered in so many ways mentally and physically and felt too overwhelmed with a new baby to advocate for myself"* *"I was not offered support outside of the medical care I needed. If it wasn't for the additional mental health support I sought on my own, I think my experience would've been much worse"* *"It was insufficient and traumatic. I was asked aggressively about birth control 2 weeks after having a hysterectomy. My provider counted me as a win because I did not die. It was cold, unfeeling, and horrible"* *"It was very brief and more of a quick physical check to make sure the wound was healing well"* *"Lacking of emotional support specific to accreta patients"* *"I wish there were more follow-up opportunities. I did feel comfortable sending messages/ emails with questions or issues, and they were very responsive"* *"I feel like this would have allowed me to process the information better and understand what happened during my delivery to meet with an actual member of the delivery team"*	*"Currently limited to 6-week postpartum, but have capability for longer term follow up with generalist colleagues and am building this capacity. Many patients live very far out and have limited transportation/insurance"* *"Unfortunately for only 30–40 days after delivery"* *"Most patients are referred from outside our center and go back to their local health care provider after delivery"* *"When they lose insurance coverage with Medicaid, they lose care"* *"Need to improve our postnatal care on the postnatal ward which is feedback we receive from patients. Like most of obstetrics they are happy with their antenatal and intrapartum care then feel more abandoned and struggling postnatally"* *"We follow everyone up at around 3 months postnatal. And offer further follow up if they feel required, but can only think of 1 patient who wanted this over the last year"* *"3 months. But I keep in touch with the ones more worried about and they have our email address they can contact us whenever they want. We are also in process of trying to set up a patient support group, which is what the women are telling us they would like- so I hope this will help improve their postnatal processing and recovery"* *"After 6 weeks most patients are still struggling with the situation/loss of their uterus."*

Abbreviations: PAS, placenta accreta spectrum; PTSD, post-traumatic stress disorder.

some patient participants found that hospital staff were well informed about PAS, *"The nursing staff were very helpful. They also made sure my mental health was ok daily by checking on me and also making me feel at home,"* most perceived that healthcare staff were poorly prepared for their care needs ($n = 101$, 65%) (Table 7). For example, one participant said, *"most were very considerate, but some did not really see that I had more than just a regular cesarean and needed a bit more support in the first days."* Furthermore, the majority (75% ($n = 117$)) found communication with and understanding by their community provider was poor, meaning they were often left having to tell their story repeatedly to their non-PAS team providers, *"I have had to tell my story to so many follow up doctors and they don't understand the implications or hurt that it causes to talk about the experience."*

Many healthcare providers acknowledged they had not provided any education to hospital staff such as midwives or nurses ($n = 61$, 68%) nor to community care providers ($n = 58$, 65%). However, others reported training non-PAS providers at regular intervals *"regular teaching twice a year to nursing staff, to trainees every rotation,"* and

TABLE 5 Supportive care measures—patient experience.

	N = 155, *n* (%)
Were you provided with a clear surgical plan (such as possibility of hysterectomy, false positive?)	
Yes	96 (63.0)
No	55 (34.5)
Missing data	4 (2.5.)
Educational resources used[a]	
Information leaflet	9
Website	59
Podcast	9
Social media	53
Videos	13
I did not use any educational resources	66
Missing data	2
Did your healthcare team provide any resources?[a]	
Information leaflet	8
Website	7
Podcast	0
Social media	4
Videos	0
My healthcare team did not provide any educational	122
Resources	5
Missing data	4
Did your healthcare team make a plan for postnatal pain management during the pregnancy?	
Yes	40 (26.0)
No	112 (72.0)
Missing data	3 (2.0)
Were you offered a referral to speak with a counselor (psychologist) or with the perinatal mental health team?[a]	
Yes, during my pregnancy	19
Yes, after my pregnancy	31
Yes, when I requested it	19
No	64
No, but I sought it out myself without a referral	31
Missing data	11
Were you offered a referral to physiotherapy/pelvic floor therapist/physical therapist?[a]	
Yes, during my pregnancy	7
Yes, after my pregnancy	22
Yes, when I requested it	13
No	93
No, but I sought it out myself without a referral	20
Missing data	11
Were you provided with contact details for the PAS team during your pregnancy, such as an email or phone number?	
Yes	39 (25.0)
No	111 (71.6)
Missing data	5 (3.4)
Were you told about any patient advocacy/support groups for those impacted by placenta accreta by your healthcare team?	
Yes	17 (11.0)
No	131 (84.5)
Missing data	7 (4.5)
Was your support partner/person included in your care and also provided resources?	
Yes	53 (34.0)
No	95 (61.5)
Missing data	7 (4.5)

Abbreviation: PAS, placenta accreta spectrum.

[a]More than one response/participant.

had provided education after identifying areas of concern, for example "*…teaching sessions to the midwives, in particular the postnatal ward midwives as we were having issues with postnatal care… also given teaching to [operating] theater staff separately.*"

3.4 | Postpartum care specific to PAS is lacking

Under the final recommendation of "postpartum care", we found that only 40% (*n* = 62) of patients were provided follow up care with their PAS team, although 96% (*n* = 60) of those who were not offered follow up reported that they wanted this care (Table 7). Of those who received follow up, this extended to 6 weeks for 42% (*n* = 37) and to 3 months for 43% (*n* = 38), with only 9% having care extended beyond 3 months with the PAS team. More than half (*n* = 86, 55%) had no contact details for their team in the postpartum period. Patients wanted to follow up with their specialist team *"[my family doctor] took very good care of me but it was outside her scope. I don't know why the MFM team didn't take part in my care,"* felt isolated after discharge "*honestly I felt very alone once discharged….I have no point of contact and any one I spoke to just dealt with me as if I was a normal cesarean section patient….I strongly believe had a received some attention postpartum I would not have suffered so badly with post traumatic anxiety which began six months after delivery*" and wanted more time for debriefing: *"It was very brief and more of a quick physical check to make sure the wound was healing well."*

Approximately a third of healthcare providers (*n* = 30, 33%) reported not offering postnatal follow up, and those who do mostly limit this to the first 6 weeks (*n* = 30, 51%) (Table 8). While healthcare providers acknowledged longer postpartum follow up was needed—*"After 6 weeks most patients are still struggling with the situation"*—this was often not possible to provide due to lack of resources "*When they lose insurance coverage, they lose care.*" Other healthcare providers perceived longer support was not needed, "*We follow everyone up at around 3 months postnatal. And offer further follow up if*

TABLE 6 Supportive care measures—healthcare providers.

	N = 89, *N* (%)
Are you aware of any mental health/psychological implications for a pregnancy complicated by PAS?	
Yes	61 (68.6)
No	26 (29.2)
Missing data	2 (2.2)
Are you aware of any guidelines or supportive measures that are recommended for a pregnancy complicated by PAS?	
Yes	42 (47.3)
No	38 (42.7)
Missing data	9 (10.0)
With whom do your PAS patients have scheduled visits in the antenatal period?	
Patients see the same PAS doctor/healthcare provider at each visit, as feasible (excluding leave, etc)	47 (52.8)
Patients see advanced practice providers (NP, CNM) or residents/fellows (physician trainees) with PAS physician supervision	16 (17.9)
Patients see their private or regular obstetrical provider with transfer to the PAS team only just before delivery admission	20 (22.5)
Missing data	6 (6.8)
Is a support person, such as the patient's partner, allowed in the operating room during the surgery/birth?	
Yes—for the entire surgery	12 (13.4)
Yes—for a portion of the delivery, but not the hysterectomy	31 (34.8)
No	35 (39.3)
Missing data	11 (12.5)
Does your center have a dedicated clinical nurse or midwife for the PAS service?	
Yes	18 (20.3)
No	56 (62.9)
Missing data	15 (16.8)
Which of the following methods of educating and providing information to patients do you use?[a]	
Information leaflet/resources from our center	33
Information leaflet created by someone else	19
Social media (such as Instagram, Twitter)	9
Website	16
Patient advocacy resources such as podcast, videos	7
I don't know of any resources to refer patients too	6
Are patients with PAS routinely offered referral to perinatal mental health or counseling?	
Yes	35 (39.3)
No	43 (48.3)
Missing data	11 (12.4)
If yes, when are they offered referral? (*n* = 43)	
During pregnancy	10
After pregnancy	15
Upon request	28
If no, are there any reasons for not referring patients for counseling or perinatal mental heath? (*n* = 43)	
Do not think it's needed	1 (2.5)
Cost/limited resources	14 (32.5)
This service is not available in our center	8 (18.6)
I do not feel comfortable discussing mental health	0 (0.0)
Lack of insurance coverage	6 (13.9)
Low patient acceptance	7 (16.2)
Other	6 (13.9)
Missing data	1 (2.5)
Are patients with PAS offered referral to physiotherapy/pelvic floor therapist/physical therapist in your center?	
Yes	20 (22.5)
No	61 (68.5)
Missing data	8 (9.0)
If yes, when are the offered referral? (*n* = 28)	
During pregnancy	7 (25.0)
After pregnancy	7 (25.0)
Upon request	14 (50.0)
Missing data	0 (0.0)
If no, are any reasons for not referring patients for physiotherapy/physical therapy? (*n* = 61)	
Do not think it's needed	6 (9.8)
Cost/limited resources	19 (31.1)
This service is not available in our center	13 (21.3)
Lack of insurance coverage	9 (14.7)
Low patient acceptance	6 (9.8)
Other	6 (9.8)
Missing data	2 (3.5)
Are partners/family members of individuals with PAS routinely offered referral for mental healthcare services or counseling?	
Yes	6 (6.7)
No	73 (82.0)
Missing data	10 (11.3)

Abbreviation: PAS, placenta accreta spectrum.

[a]More than one response/participant.

they feel required but can only think of 1 patient who wanted this over the last year," or not desired due to geographical distance from the PAS center *"some patients live far from the center and not want to come."*

Based on participant responses, barriers to implementation of previously published family-centered care recommendations[2] are described with possible solutions suggested (Figure 2).

TABLE 7 Education and postnatal care—patient experience.

	N = 155, *n* (%)
Did you feel healthcare staff not directly involved in the PAS team were well informed on the care needs of women with PAS?	
Yes	49 (31.6)
No	101 (65.4)
Missing data	5 (3.0)
Did you find your PAS team provided adequate information about your PAS pregnancy and care needs to your community care providers after you were discharged from hospital?	
Yes	32 (21.6)
No	117 (75.4)
Missing data	5 (3.0)
After the birth, did you have any postnatal/postpartum follow up after the pregnancy with your PAS team?	
Yes	89 (57.4)
No	62 (40.1)
Missing data	4 (2.5)
If no, would you have wanted to follow up with your PAS team if it was offered?	
Yes	60 (96.0)
No	2 (4.0)
If yes, were you followed up by someone you already knew from the PAS team from your pregnancy? (continuity of care)	
Yes	57 (64.0)
No	32 (36.0)
If yes, please tick when after the birth you were offered postnatal/postpartum follow up	
Within 6 weeks	37 (42.5)
Between 6 weeks and 3 months	38 (43.1)
Between 3 and 6 months	7 (7.8)
More than 6 months	2 (2.2)
I decided a plan with my healthcare team	4 (4.4)
Were you provided with clear contact details for the PAS team for how to get in touch after the birth if any problems arose?	
Yes	56 (36.1)
No	86 (55.9)
Missing data	13 (8.0)

Abbreviation: PAS, placenta accreta spectrum.

TABLE 8 Education and postnatal care—healthcare providers.

	N = 89, *N* (%)
Do you provide a postnatal pain management plan for PAS patients which is discussed with them during the pregnancy?	
Yes	40 (44.9)
No	48 (54.0)
Missing data	1 (1.1)
Do you provide education to PAS patients on postnatal recovery such as wound care, caring for their scar?	
Yes	45 (50.5)
No	41 (46.0)
Missing data	3 (3.5)
Has the PAS service in your center provided any education to staff not directly involved in the PAS service, such as midwives, nurses?	
Yes	26 (29.2)
No	61 (68.5)
Missing data	2 (2.3)
Has the PAS service in your center provided education to staff caring for women on the postnatal wards after the birth, such as midwives and nurses?	
Yes	28 (31.5)
No	50 (56.0)
Missing data	11 (12.5)
Has the PAS service provided education or training to community care providers (such as general practitioner or family doctor)?	
Yes	22 (24.7)
No	58 (65.2)
Missing data	9 (10.1)
Does your multidisciplinary team provide postnatal (postpartum) follow up for patients cared for in your PAS service?	
Yes	52 (58.4)
No	30 (33.7)
Missing data	7 (7.9)
If yes, for how long is postnatal/postpartum care provided? (*n* = 58)	
4–6 weeks	30 (51.7)
6 months	10 (17.2)
12 months	2 (3.4)
As long as the patient needs	16 (27.7)

Abbreviation: PAS, placenta accreta spectrum.

4 | DISCUSSION

We found that recommendations for patient-centered care for PAS are highly valued by patients; however, resources are often not available or not specific to the unique challenges faced by this population. Healthcare providers appear motivated to deliver this model of care and acknowledge its importance but also face barriers such as cost, and resource limitation and lack of knowledge about PAS amongst non-PAS healthcare providers.

PAS is a rare and often misunderstood condition.[16,17] Therefore, it is challenging for both healthcare providers and patients to find reliable, accurate and up-to-date information. While variations in care exist between centers and geographical settings, we suggest that societies such as IS-PAS and PAS,[2] patient advocacy groups, and national and international obstetrical societies, collaborate to continue to build resources to expand education for healthcare providers and the public. While PAS remains relatively rare, its complexity and acuity have profound impacts on patients and their families. Without funding to more comprehensively address these clinical care and research gaps, centers must pool their efforts to provide high-quality resources for all aspects of care and expand the "team" concept beyond the surgical multidisciplinary team to include

Recommendation	Potential barriers	Solutions
Referral to support services • mental health. • physiotherapy/PT.	• Limited cost/resources. • Service not available. • Not requested by patients. • Not considered by healthcare providers.	• Create/use existing resources - websites, podcast, videos - self-educate. • Educate on potential mental health sequelae - provide contact details for team/longer term support. • Refer to patient advocacy groups - peer to peer support.
Education • non-PAS specialist hospital staff. • community providers.	• Knowledge gaps not recognised, such as on postnatal ward. • Rare condition; few cases to learn for ancillary staff.	• Brief, high level education session on primary care needs of PAS patients - highlight differences to standard caesarean, avoid prescriptive routine postnatal package for hysterectomy patients (such as contraception, future family planning). • Prioritise analgesia and pain management while inpatient. • Signpost ancillary staff where to ask for help from specialist team.
Postpartum follow up • with specialist team. • beyond 6 weeks. • education on recovery expectations.	• Lack of resources/insurance beyond 6 week check. • Geographical distances. • Lack of knowledge regarding longer term health sequelae/ time taken to process events of pregnancy and birth.	• Create/use existing resources - self-educate patients. • Healthcare providers to highlight to patient what to expect from first year of recovery; physical recovery, emotional processing may not occur until at least 6 months later. • Offer virtual follow up for debrief. • Communicate to local care provider on possible physical and mental health sequelae. • Utilise support of patient advocacy groups - peer to peer valuable resource.

FIGURE 2 Barriers to implementation and potential solutions. We describe the recommendations made and summarize potential barriers to implementation as found from participant responses in this study. Possible solutions to these are then described to ensure services take a holistic, patient-centered focus.

primary care providers, physical and mental health support personnel, such as counselors, psychiatrists and physical therapists, to improve postpartum and life-long post-PAS care.

Our data shows that patients want more direct access in the postpartum period to their specialist team to allow patients and families to debrief when they are better prepared to understand and process their PAS experiences. One or two brief discussions in the immediate postpartum period or within the traditional 6-week follow up period is insufficient. Where cost and geographical barriers exist, telemedicine or virtual visits are a solution. The Covid pandemic highlighted that healthcare services were rapidly able to adapt to provide such care—overcoming barriers such as access to software, GDPR compliance and update local facilities—this indicates that these services likely already have the capacity to provide such care and can effectively respond to patient needs as they arise when required. It is important to note that even in high volume centers, the overall number of women needing support will be relatively small, with the majority of centers in this study caring for less than 20 cases per year. Hence, debriefing and providing patient centered care should be reasonably achievable in centers providing this specialist care. Patients report that they have no reference point for what to expect and feel hugely isolated by their diagnosis,[1,2] and healthcare providers can make meaningful improvements that require little resources or cost. For example, this can be achieved by ensuring patients are well prepared antenatally by providing clear explanations about what to expect, both physically and mentally. While healthcare providers in this study reported extensively preparing patients antenatally, this was not reflected in the patient experience. Possible sources for this disconnect may be the use of medical terminology that patients and families may not understand, or that discussions are being had within the team meetings rather than with patients, hence the discrepancy in how much providers think they communicate and how often patients actually receive the communication. Finally, it is one thing to conceptualize an experience, yet very different to live through it, and experiences differ for each individual patient. It is possible that no amount of antenatal counseling can fully prepare patients or families, and providers and patients alike must acknowledge this limitation.

To improve patients' perception of post-PAS care, simple measures such as providing a clear point of contact for the PAS specialist team upon discharge is a low-cost option that may make patients feel less isolated and provides an opportunity to refer patients to resources or follow up with a later virtual visit at a time that the patient feels is most appropriate. Alternatively, teams can include a generalist obstetrician-gynecologist or advanced practice provider as part of the larger team who can provide longitudinal well-woman care. Some groups are working on a packet of care information to provide patients and their primary care providers in hopes that it may bridge gaps in postpartum PAS continuity of care. We previously developed a decision-aid specific for anesthesiology care in PAS as an example of a tool designed to bridge care gaps.[18]

Patient participants within our study utilized the benefits of peer-to-peer support frequently. Our data supports that healthcare providers can and should refer patients to reliable patient advocacy

groups who partner with healthcare providers to provide accurate information and patient support. Where these do not exist locally, efforts to refer to international groups or find local advocates are encouraged as this is a low-cost option for healthcare providers who do not have resources to provide longer term support.

As previously described, the postnatal period is a particularly challenging time for patients.[2] This study supports these findings and that patients need additional support during this time. We found that healthcare providers acknowledge the need for longer term care during this time but are often constrained by funding and insurance obstacles. Of note, this varied by geographical location of healthcare provider respondents, with lack of insurance only identified as a limitation by those in North America and Asia. As above, these barriers may be overcome by simple measures such as providing contact details for the team, leaflets and videos to educate patients, refer to patient advocacy groups and virtual follow up. Several patient advocacy groups and PAS societies have developed such resources which are freely available. In well-resourced settings providing PAS care, it is essential that postnatal care extends beyond the 6-week visit. Our results highlight the prolonged psychological impact of PAS and the time it takes to process the events of the pregnancy and birth. We acknowledge that health services are delivered and funded differently in various settings. For example, we found that in lower-resourced settings, participants often met patients later in pregnancy due to delayed diagnosis. Additionally, they were caring for a larger number of patients, and patients had to travel considerable distances for care, limiting their ability to return for postnatal follow-up. However, we do not believe these challenges should be significant barriers to providing the recommended patient-centered care. Even when patients are diagnosed later in pregnancy, there is still an opportunity for a focused discussion about PAS and what to expect. Moreover, as noted, postnatal telehealth communication remains a feasible option even in low-resource settings. Access to patient advocacy groups, which is available even in these settings, can provide additional support, particularly when healthcare services are limited. We acknowledge other hospital based resources, such as physiotherapists and mental health with expertise in women's health, may not be available in low-resource settings. However, both in high and low resourced settings, healthcare providers must recognize the significant impact a PAS diagnosis has on patients and utilize the resources available to them, as well as the practical and simple recommendations such as we suggest here to support them.[19]

Our study had several strengths and limitations. Strengths include use of surveys, not only of patients and families, but also of healthcare providers directly involved in PAS care. Surveys were developed in collaboration with patient advocacy groups, led by women who have personally experienced PAS, and by physician scientists who both provide clinical care and conduct clinical research about PAS to strengthen content validity. Furthermore, healthcare providers from both low- and high-resource settings were represented, with input from clinicians from both settings in study design, analysis and clinical recommendations.

The study was limited by the sampling strategy, which involved contacting patients via patient advocacy groups, hence patients who do not avail themselves of this support are not represented, resulting in selection bias. Furthermore, response rates were low amongst former patients and providers and a larger sample size may reveal additional findings. We suspect many patients may opt out of participation to avoid reliving emotional trauma, and providers may opt out due to competing demands for time. While this introduces selection bias, our results are consistent with previous PAS studies exploring patient experiences.[8–10] Furthermore, the small number of healthcare providers may limit the generalizability of the results as many healthcare services are not represented. However, provider responses were provided by those who are actively involved in direct PAS patient care. While the range of 0–5 years since PAS may introduce recall bias for patients, most respondents had been treated within 1 year of the survey, reducing the risk of lack of recall. Furthermore, given the significance of the experience, it is likely participants will be able to recall many aspects of it, as suggested by patients with PAS in previous studies.[1,10] Responses from patients treated between more than 1–5 years provide insight to the longer-term impacts of PAS, an area that has been neglected in PAS research. A further limitation is that the surveys were distributed only in the English language. Finally, there is limited representation of patients from low-resource settings, meaning the perspectives and expectations of these patients—which may differ from those in high-resource areas—are underrepresented in this study. This data will serve to inform future prospective, well-designed multicenter studies.

In summary, this study has several key messages. First, it is clear more focussed follow up care in the postpartum period is required. Second the traumatic nature of PAS continues to be underrecognized and undertreated. Finally, the physical challenges patients face remain underestimated. Therefore, we propose the solutions as outlined in Figure 2, all while ensuring these patients receive high quality MDT input throughout their antenatal and postpartum journey.

In conclusion, family-centered recommendations for PAS care should be implemented and expanded in centers that provide a specialist PAS service. Patients and families desire more holistic, continuous and longitudinal care within systems that support women and families to ensure optimal physical and psychological outcomes following PAS treatment.

AUTHOR CONTRIBUTIONS

Helena C. Bartels: Conceptualization, methodology, formal analysis, data curation, writing—original draft, writing—review and editing, funding acquisition. **Karin A. Fox:** Conceptualization, methodology, data curation, writing—review and editing. **Rozi Aditya Aryananda:** Conceptualization, methodology, writing—review and editing, funding acquisition. **Kristen Terlizzi:** Conceptualization, methodology, writing—review and editing. **Naomi Cooney:** Conceptualization, methodology, writing—review and editing, funding acquisition. **Albaro José Nieto-Calvache:** Conceptualization, methodology, writing—review and editing. **Joan G. Lalor:** Methodology, formal

analysis, data curation, writing—original draft. **Donal J. Brennan:** Conceptualization, methodology, writing—review and editing, funding acquisition, supervision.

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CONFLICT OF INTEREST STATEMENT

Karin A. Fox: Elsevier, Inc. Associate Editor, American Journal of Obstetrics & Gynecology; Deputy Editor AJOG MFM; Wolters Kluwer, UpToDate Chapter Author: Uterine Tamponade; Board Member, International Society for Placenta Accreta Spectrum (IS-PAS); Board Member, Pan-American Society for the Placenta Accreta Spectrum (PAS2). The remaining authors have no conflict of interests to declare.

DATA AVAILABILITY STATEMENT

Research data are not shared.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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