



Threat and adaptation: The maternal lived experience of continuing pregnancy after receiving a prenatal diagnosis of agenesis of the corpus callosum

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ABSTRACT

One stated objective of prenatal screening and diagnosis is the preparation for delivering a baby with medical needs or disability, however, psychosocial outcomes of parents who received a prenatal diagnosis suggest that this objective is not yet realised. Preparation may be complicated by diagnostic and prognostic uncertainty. A prenatal diagnosis that includes significant uncertainty due to the heterogeneous presentations, classifications, causes and outcomes is agenesis of the corpus callosum. As a neuroanatomical anomaly identified in the second or third trimesters, the diagnosis is likely to cause distress for expectant mothers, yet there is limited guidance for holistic support. To begin to address the paucity of research, this hermeneutic phenomenological study sought to explore, and provide a telling of the maternal experience of continuing pregnancy after a prenatal diagnosis of agenesis of the corpus callosum. Through interviews and a series of online, asynchronous and facilitated focus groups, lived experiences during pregnancy from the time of diagnosis to birth were explored with 26 mothers who participated in this international study. Themes were constructed through reflexive thematic analysis to describe the experience of the lived phenomenon. The first theme, *Under Threat*, included subthemes of *The Threat to the Life of the Baby* and *Threatened Image of the Expected Family*. The second theme, *Day to Day Toward Adaptation*, included subthemes of *Holding it Together and Falling Apart*, and *More Than Information, Searching for Meaning, Hope and Control*. To realise the commonly stated objective of prenatal diagnosis, to support maternal preparation, healthcare professionals require awareness of the profound, yet individual experience of prenatal diagnosis to adequately respond and support mothers through their continued pregnancies. Healthcare services should be designed to flexibly respond in a woman- and family-centred manner to reduce the threat and support maternal adaptation after a prenatal diagnosis.

1. Introduction

Two commonly stated objectives of prenatal diagnosis are to inform reproductive decisions and support preparation for birthing a baby with a known anomaly (Michie, 2020). If psychosocial outcomes are a marker of preparation, parents who continued pregnancy after receiving a prenatal diagnosis should show improved psychosocial outcomes compared to parents who received a postnatal diagnosis, reflective of this preparation. However, comparison studies have identified similar levels of state anxiety (Fontoura et al., 2018; Werner et al., 2019) and medical traumatic stress (Bevilacqua et al., 2021) in the postnatal period. Parents who received a prenatal diagnosis of congenital heart

disease also reported lower levels of life satisfaction and sense of coherence than parents who received a postnatal diagnosis (Bratt et al., 2019).

This potential discordance with one of the two objectives of antenatal screening is significant as a prenatal diagnosis can trigger antenatal distress. Between 35% and 66% of mothers who received a prenatal diagnosis experienced clinically relevant acute stress or met full diagnostic criteria for post-traumatic stress disorder (PTSD) (Aguar and Abrahão, 2022; Fonseca et al., 2011; Rychik et al., 2013). Antenatal mental health conditions influence postnatal outcomes (Eastwood et al., 2017; Grigoriadis et al., 2019) and may harbour further consequences for a developing fetus with a known anomaly (Kasparian, 2019).

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Maternal stress after prenatal diagnosis was flagged as a potential iatrogenic factor that influenced the earlier spontaneous birth and poorer postoperative outcomes of prenatally-diagnosed infants with transposition of the great arteries (Namachivayam et al., 2023).

Psychosocial outcomes and the pregnancy experience after a prenatal diagnosis warrant investigation. Research that explored experiences of mothers described shock at the unexpected news of a fetal anomaly, followed by a period of crisis, before adjustment and goal remodelling (Carlsson et al., 2017; Côté-Arsenault and Denney-Koelsch, 2016). Prognostic ambiguity, however, stalled progression toward adjustment (Côté-Arsenault and Denney-Koelsch, 2016) and delayed parental trajectories of connection to the fetus (McKechnie et al., 2015a). Prognostic ambiguity and diagnostic changes were associated with increased distress after a prenatal diagnosis (Oftedal et al., 2022) and uncertainty or contradictory information, increased parental feelings of being overwhelmed and emotionally exhausted (Marokakis et al., 2017). High uncertainty within a fetal anomaly diagnosis may hinder adaptation and maternal and fetal outcomes. A specific prenatal diagnosis associated with high uncertainty is agenesis of the corpus callosum (ACC).

ACC is a neuroanatomical anomaly characterised by the absence or atypical development of the corpus callosum, the largest interhemispheric pathway in the brain, which integrates cognitive and sensory information between the left and right hemispheres (Raybaud, 2010). Individuals born with an anomaly of the corpus callosum demonstrate highly variable neurodevelopmental outcomes, including typical development, developmental delays, mild to profound intellectual disability, or even early death (Shakes et al., 2020). Outcomes are attributed to additional neuroanatomical or extracranial anomalies and variable causes, including over 200 different syndromes (Smith et al., 2023). An atypical corpus callosum can present as the primary anomaly alongside secondary neuroanatomical changes, often termed *isolated ACC* (Shakes et al., 2020). These secondary features, described by Raybaud (2010), include an absent cavum septum pellucidum, poorly defined cingulate gyrus, lateral ventricles in a colpocephalic shape, a raised third ventricle, a rounded hippocampus and differences to the other interhemispheric commissures. Secondary anomalies have been interpreted as being included and excluded from the category of isolated ACC by different researchers, which increases prognostic ambiguity, as isolated and non-isolated ACC are associated with different outcomes (Shakes et al., 2020).

The high heterogeneity in presentation, interpretation, cause and outcomes of ACC increases the complexity of this diagnosis, which is commonly diagnosed after 18 weeks gestation and as late as 40 weeks (Smith et al., 2023). While there are recommendations for diagnosis and prognostication, there is a deficit of guidance to support parents through the high uncertainty of a prenatal diagnosis of ACC. Support for mothers who continue their pregnancies should be grounded by an exploration of the maternal experience of continuing pregnancy after a prenatal diagnosis.

2. Methods

2.1. Aim

This study aimed to provide a telling of the phenomenon of the maternal lived experience of pregnancy after receiving a prenatal diagnosis of ACC. This telling offers healthcare professionals insight into the complex experience, which may provide a foundation for empathy, understanding and systemic changes to improve the experience and outcomes of mothers. Patient experience should not be viewed as simply the interactions with healthcare professionals, but as multidimensional and multifaceted complex human experiences (Oben, 2020). Therefore, this study sought to explore the holistic experience of continuing pregnancy after a prenatal diagnosis of ACC.

2.2. Design

Hermeneutic phenomenology was the methodology for this study, informed by readings of Heidegger (1927/1962) and Gadamer (1975/2013) and selected due to the focus on uncovering and making manifest a phenomenon of experience (Moran, 2000). Three distinct features distinguish hermeneutic phenomenology from other qualitative methodologies: the interpretive focus on experiences-as-lived, involvement of the researcher and the dynamic and thoughtful reflecting and writing in analysis (Bynum and Varpio, 2018). Within Heidegger's adoption of hermeneutic phenomenology as methodology, he returned to primordial, pre-reflective accounts of his phenomenon of interest, and moved past a descriptive report of findings (Carr, 1999). Through a circular process of interpretation grounded by understanding and with a central tenant of temporality, Heidegger showed meaning as bound within historicity and facticity (Heidegger, 1927/1962). Gadamer progressed Heidegger's phenomenological methodology through his investigation that demonstrated the universality of hermeneutics for all understanding, in which fore-understanding and openness to new possibilities leads to new understandings through a "fusion of horizons" (Gadamer, 1975/2013, 305). Hermeneutic phenomenology framed how experience could be accessed and interpreted to disclose an experienced phenomenon which is temporally situated and open for reinterpretation. A benefit of this approach is that the telling is based on concrete, *as-lived*, accounts of experience rather than participants' reflections and perceptions, which continue to shift and change with time. The framing is demonstrated in the study design schematic (Fig. 1).

2.3. Ethical approval

This research study was approved by the Southern Cross University Human Research Ethics Committee, approval number: ECN-19-200.

2.4. Participant selection

Purposive sampling allowed recruitment of mothers with lived experience of the shared phenomenon of continuing pregnancy after a prenatal diagnosis of ACC. Inclusion criteria required confirmation that mothers (1) were the biological mother of a child prenatally diagnosed with ACC and who was between 6 months and 4 years at study enrolment; (2) spoke English as their first language; (3) lived in Australia, New Zealand, the United States of America, the United Kingdom or Canada; (4) had access to participate through online videoconferencing or focus groups; (5) were over 18 years and (5) provided consent. Child age boundaries reduced potential burden for pregnant or new mothers and to support recall. International sampling with health services and providers who were likely to be informed by similar English-based medical literature was selected to recruit an appropriately sized sample. While ACC may be one of the more common neuroanatomical anomalies identified during pregnancy, it remains a rare condition (Smith et al., 2023). As a study that included dialogic intersection (Vandermause and Fleming, 2011), conversational co-elicitation and exploration of experience between the researcher and participants, shared fluency in English was required to reduce additional translation-based complexities. Administrators of formal and informal ACC support organisations (Supplementary File 1) were asked to share the study flyer which directed interested mothers to email the lead researcher. There was no payment or reimbursement for participation.

2.5. Data collection and analysis

While there are variety of methods for data collection and analysis in hermeneutic phenomenology, the methodology guides the interpretative process of data collection and analysis, which commence together (Vandermause and Fleming, 2011). Two stages in this study were delineated by the method of interaction with participants; Stage 1

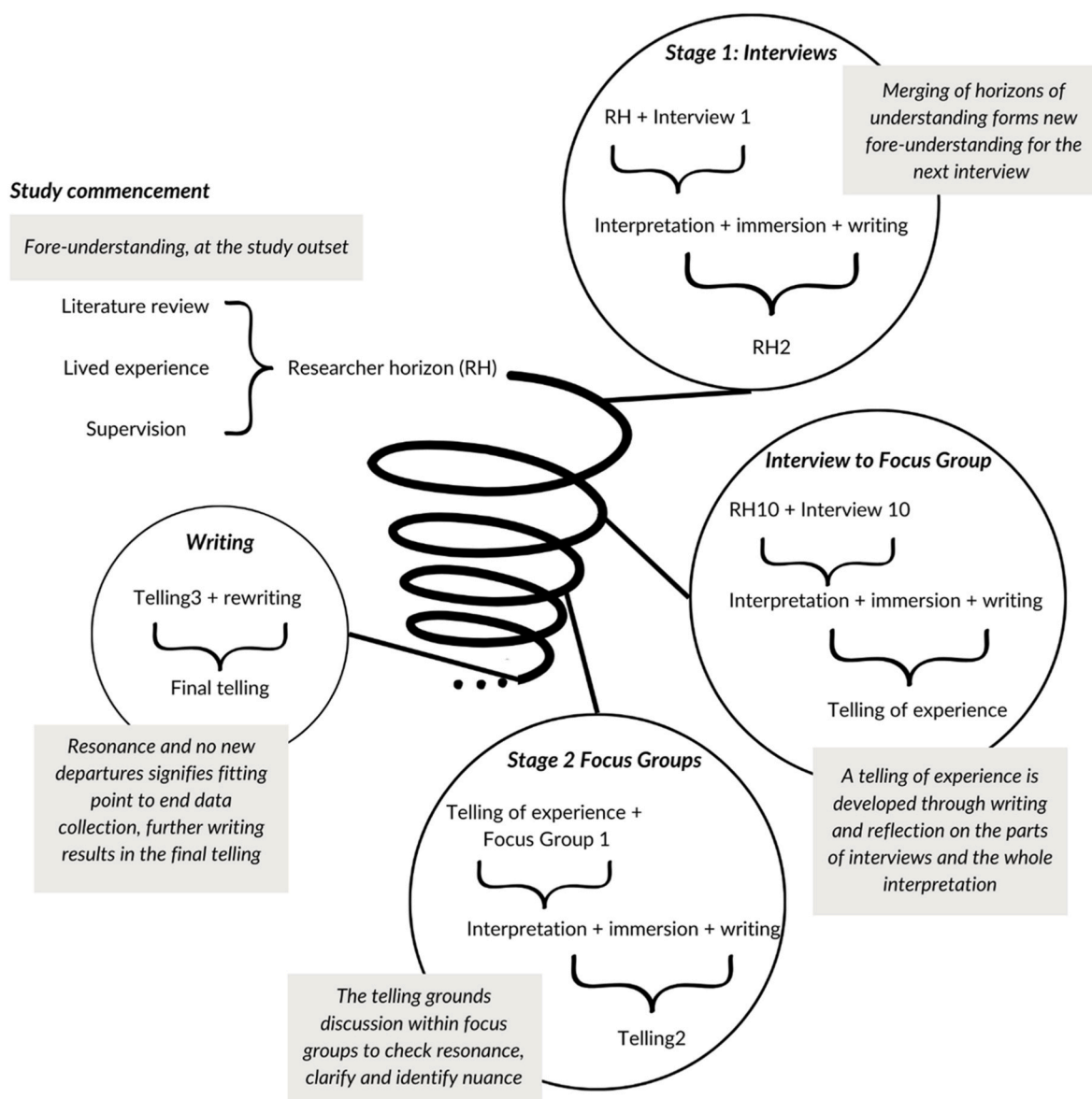


Fig. 1. Research design schematic.

involved one-on-one semi-structured interviews via videoconferencing and Stage 2 involved online, asynchronous and facilitated focus groups. Participants self-selected their involvement and were eligible to participate in both stages.

Interviews were semi-structured to guide the recall of experiences from the point of diagnosis through to birth and yield moments as-lived rather than participants' reflections. Transcription of recorded interviews was completed through Otter.ai (n.d.) and read in full alongside listening to the recording to begin immersion in the data and correct transcription errors. Transcripts were uploaded to NVivo (QSR International Pty Ltd, 2018) for further reading, inductive coding, chunking and re-splitting codes, mind mapping, writing and rewriting to disclose patterns and generate initial themes (Braun and Clark, 2021). Coding and condensing of like-codes followed each interview, and then shaped the horizon of understanding taken to the following interview, allowing the researcher to explore complexity. Interviews continued until diminished returns were noted, this point should not be confused with saturation which is incongruent with the epistemological assumptions of hermeneutic phenomenology and reflexive thematic analysis, as meaning is temporal, generated through interpretation and open for reinterpretation (Braun and Clark, 2021).

Online focus groups with up to eight mothers were engaged to confirm resonance from Stage 1 interpretations to increase study trustworthiness. Focus groups also allowed discussion to elucidate additional experiences for identifying nuance. Mothers participated in the 5-day, asynchronous discussion under usernames, Participant 1–8, allocated by the FocusGroupIt (n.d.) platform. Data were extracted via PDF and uploaded into NVivo (QSR International Pty Ltd, 2018) for coding and analysis. Confirmation of resonance and diminished returns signified a suitable end of Stage 2. Final analysis and interpretation occurred during the re-writing of the findings, as theme development was an ongoing process and reflected the approach described by Trainor and Bundon (2020). Reporting of this study was influenced by the Consolidated Criteria for Reporting Qualitative Research (Tong et al., 2007), although context-dependant information was prioritised in this report, and the checklist is comprehensively addressed in Supplementary File 2. Participant quotes do not include an identifier to mitigate the heightened potential of triangulation and reidentification of participants within research with families affected by rare conditions (Joseph, 2023).

Positionality of the researcher is also significant for framing the analytic process and theme development (Braun and Clark, 2021). This research was completed by a doctoral candidate who continued

pregnancy after a prenatal diagnosis of ACC eight years before the study’s conceptualisation. Her role within formal and informal peer support organisations surfaced additional considerations for recruitment, data collection and reflexive analysis, described in Supplementary File 2.

3. Findings

In total, 26 mothers who continued pregnancy after receiving a prenatal diagnosis of ACC participated in this study (Table 1).

Stage 1 comprised interviews with 10 mothers between December 2019 and April 2020. Interview recording commenced after introductions and consent, and averaged 71 min. Stage 2 comprised three online, asynchronous and facilitated focus groups between June 2020 and March 2022 (Table 2). Seven mothers who completed interviews chose to participate in the focus groups.

Table 1
Participant demographic information.

Demographic	N	%
Total participants	26	100
Country		
Australia	4	15.4
Canada	1	3.8
United Kingdom	3	11.5
United States of America	18	69.2
Mother’s age (years)		
18–22 years	1	3.8
23 - 27	2	7.7
28 - 32	5	19.2
33 - 37	7	26.9
38+	4	15.4
Not stated	7	26.9
Mother’s highest completed level of education		
High school	1	3.8
Vocational award	4	15.4
Bachelor degree	9	34.6
Postgraduate degree	1	3.8
Master degree	6	23.1
Not stated	5	19.2
Mother’s occupation		
Health professional	6	23.1
Educator	4	15.4
Stay at home mother	4	15.4
Business owner	3	11.5
Student	2	7.7
Other professional	2	7.7
Office worker	1	3.8
Not stated	4	15.4
Child’s prenatal diagnosis^a		
ACC	2	7.7
Complete ACC	4	15.4
Isolated complete ACC	5	19.2
DCC and ventriculomegaly ^b	10	38.5
ACC plus ^c	3	11.5
Uncertain specific diagnosis	1	3.8
Not stated	1	3.8
Child’s age at enrolment		
6 months to <1 year	3	11.5
1 - <2 years	10	38.5
2 - <3 years	7	26.9
3 - <4 years	6	23.1
Gestation of prenatal diagnosis		
18–22 weeks	12	46.1
23–27 weeks	6	23.1
28–32 weeks	4	15.4
>33 weeks	2	7.7
Not stated	2	7.7

ACC: Agenesis of the corpus callosum.

^a Prenatal diagnosis as reported and grouped.

^b Inclusive of ventriculomegaly, colpocephaly, enlarged ventricles and hydrocephalus expressed as an additional diagnosis to ACC prenatally.

^c Plus inclusive of a genetic variant or additional anomalies.

Table 2

Focus group participant numbers, words retrieved and interactivity within the group.

Focus Group	1	2	3
Mothers sent link (n)	8	8	10
Participants joined (n)	7	8	9
Participants withdrew after joining (n)	0	0	1
Words exported (n)	15,363	31,079	30,531
Posts to group (n)	135	156	134
Posts per participant, average (range)	12 (3–16)	15 (9–18)	14 (3–20)

Aus: Australia, UK: United Kingdom, US: United States of America, Can: Canada.

Two distinct themes of the experience of continuing pregnancy after a prenatal diagnosis of ACC were identified (Fig. 2). The first theme, *Under Threat*, encapsulated the immediate and ongoing threat presented with the prenatal diagnosis of ACC. The two subthemes, *The Threat to the Baby’s Life* and *Threatened Image of the Expected Family* encompassed the two dimensions of being under threat. The second theme, *Day by Day Toward Adaptation*, was constructed through mothers’ continual assimilation and accommodation as they moved through pregnancy. Actions undertaken by mothers disclosed two subthemes, *Holding it Together and Falling Apart* and *More than Information, Searching for Meaning, Hope and Control*. These two major themes and their two subthemes revealed the profound experience of continuing pregnancy after a prenatal diagnosis of ACC and were illuminated within the first stage of the study, although the specific labelling and categorisation was arrived at through the ongoing analysis and identification of nuance. The final focus group confirmed resonance with the interpretation and did not yield further points of departure.

3.1. Under threat

The expected pregnancy includes a series of normalised milestones and ends with the birth of a healthy baby. The prenatal diagnosis of ACC exposed possibilities that threatened the norm and as such, profoundly altered the experience of pregnancy. The complexities of ACC meant that possibilities remained, suspended in uncertainty, without closure. Accounts of lived responses, actions and emotions illuminated how the baby’s life and the image of the expected family were under threat.

3.1.1. The threat to the Baby’s life

The threat to the baby’s life was experienced in both a concrete and abstract manner. The indication of something unexpected through professionals’ demeanour or words during an ultrasound or follow up appointment surfaced the immediate threat to the baby’s life.

I can’t remember how long afterwards but the more experienced sonographer turned to us and said, ‘I’m really sorry but your baby is missing part of its brain. We’ll give you some time, we need to take you up to the ward’. They then both left the room. I asked my husband to repeat what she had said, he did. I remember discussing what that meant, was the pregnancy over? Was I being sent to the ward to terminate the pregnancy?

The threat to the baby’s life was often immediate, “So, I’m like, well, is the baby going to die?”, or triggered by the option of termination. This threat was evidenced by a commonly shared “shutting down”, a dissociative response disclosed through physiological responses, “I went completely numb”. The response included changes to sensory, cognitive and motor functions. “I couldn’t stand up; I was in complete shock. I couldn’t even get the words out of my mouth.” Dissociation was further identified by the impaired ability to take in information, “I feel like I blacked out at everything she said from that point on”. Mothers recounted inability to recall parts of the conversation, as exemplified by the mother who asked her own mother important information about the diagnosis after attending the appointment together. “When I was told, my mum was in the room with me, and I just shut off completely. I

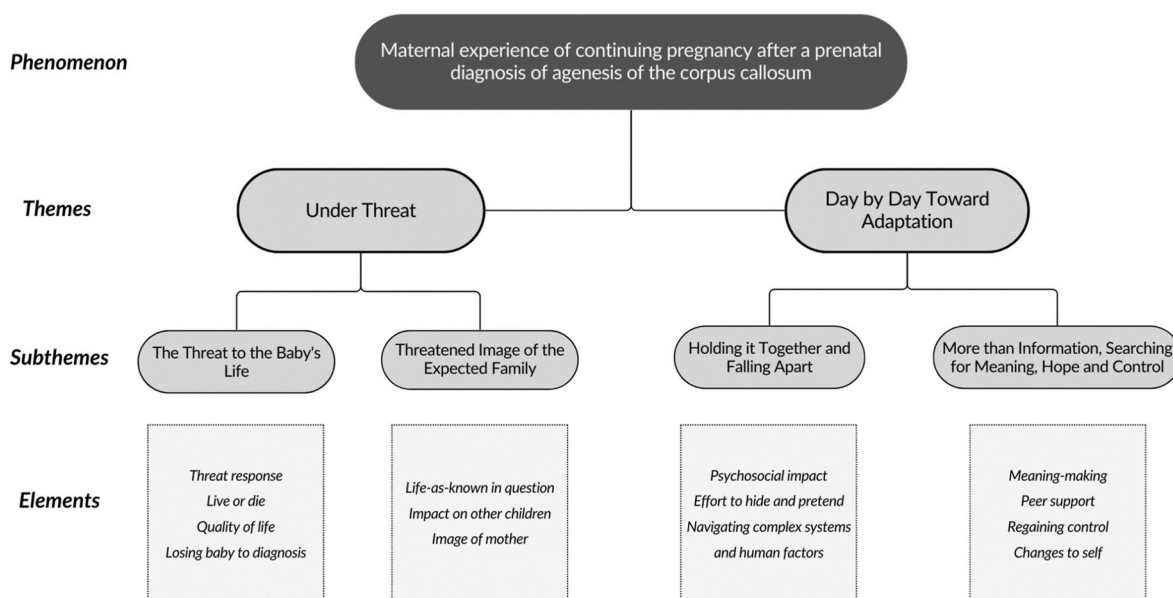


Fig. 2. Thematic map of the maternal experience of continuing pregnancy after a prenatal diagnosis of agenesis of the corpus callosum.

totally forgot what they even said, and my mum had to tell me later. It was like I blacked out.”

While many mothers experienced disassociation, a few mothers specifically denied a dissociative response to the news. “I don’t feel like I shut down that first day, because I wanted to soak up every bit of information to be able to google it later, but I did feel overwhelmed with it all.” Despite not shutting down, threat remained, highlighted through being overwhelmed and responses that included fear and worries. “I felt so vulnerable and scared and worried.” The baby’s quality of life was also under threat. “My biggest fear was, like, will they know love? Will they be able to know that I love them, will they be able to smile and stuff?” The threat to the baby’s life remained for many mothers, illuminated through their avoidance of buying baby clothes, preparing the nursery, or having a baby shower. “I chose to postpone the baby shower my home-school co-op friends wanted to throw until after [the baby] was here so that we would know more about him and know if he was going to make it.”

For a while, I didn’t want to name my baby, because the name I picked out I really loved, and I didn’t want to ‘waste’ the name on a baby that wouldn’t live. This is a thought I have only expressed once and never directly to anyone I am close with, not even my partner. I definitely have a lot of guilt associated with that, too.

The threat to the baby’s life was also experienced in an abstract manner, where the diagnosis and the uncertainty overshadowed the life and personhood of the baby. “I felt in some ways it was like a ticking time bomb I was carrying as we just were never sure what the future would look like once he arrived.” Actions of mothers sought to reclaim babyhood from diagnosis further disclosed the threat to baby’s life and flattened identity of the baby. “We did find out the gender of this baby as we felt she had become this terrible unknown that we were fearful of. We needed to humanise the whole experience.” However, the possibility of disability was consuming for some, overshadowing the baby’s individuality, who instead became a child with special needs. “I thought about that a lot during my pregnancy, it’s what made me the most depressed, thinking I was going to have a child with special needs”.

Appointments often perpetuated the threat to the baby’s life. “So many conversations with doctors were so cold and clinical. We needed to remember that we were talking about a tiny baby”. A “doom and gloom” focus or language that obscured the baby further suggested that professionals also reflected this threat. “Some specialists were horrific

and referred to our son as ‘the pregnancy’, urging us to terminate, this was at 35 weeks now.” The prenatal diagnosis triggered protocols that differed from the norm, as shared by a mother who received an unexpected phone call to ask her intent to continue or terminate her pregnancy; when her own mother took the phone in response to her distress and inability to talk, the caller stated, “she has a special needs baby, its protocol, we call and do that.” However, professionals also reduced this threat to the baby’s life and personhood, by supporting mothers to reclaim the baby from uncertainty.

She saw me being upset and started to ask me about my son, what his name would be, what kind of family he was coming into. She never mentioned his diagnosis but just talked about his future as if nothing on the paper mattered. It really helped me in the moment remember at the end of the day I was bring home a baby, not a diagnosis on a screen. She told from what she could see on the screen he was going to bring us joy, and laughter, and love just like how our other children did. She said she knew he would be loved and that’s all a baby really needs. I needed to hear those words and I’m very thankful that she was the last doctor I saw before I gave birth.

3.1.2. Threatened image of the expected family

The exposed possibilities meant that the expected family was under threat. “I was terrified that we had just had our last day together as a ‘normal’ [sic] family and after perhaps our lives would never look like this again.” With the suspended uncertainty, the threat to the family wasn’t easily contained. “That day we called our parents and took turns crying and wrapping our heads around a new parenting path we hadn’t planned for”. Mothers described fears of needing to “sacrifice everything”, that lives, as-known, were over and that the family may no longer be able to do things that are enjoyable or meaningful to them.

Mothers felt responsible for potentially hurting their family by choosing to have another baby that could have high medical or support needs. “Did my greed for another child cause this? Was I being punished for not being happy with what I had?” Feeling responsible for the diagnosis appeared intertwined with fears of not being “a good enough” mother. The image of the good mother in the expected family was threatened by the self-blame and guilt of causing the anomaly, “I broke my baby”. For one mother, the weight of this fear of causing her baby to suffer led to suicidal ideation. Within this fear of not being “enough” of a mother were concerns about coping with their baby’s potential needs or

their inability to continue to mother other children. “Would my other child’s needs be put on the backburner?” The threat to the image of mother within the expected family extended beyond responsibilities and tasks, the prenatal diagnosis of ACC thrust a mother’s love into question.

I was so afraid. I was like, what if the baby is like one of the babies who look weird and then I don’t love it because it doesn’t look cute. What kind of mum doesn’t love their baby because it’s not cute? Like, that’s horrible.

The mothers described the way their thoughts challenged some of their long-standing moral principles tied to reproduction and expected families. “I am also very pro-choice but for myself I always knew I could never have an abortion which made me feel all the more guilty when I considered it while pregnant with my daughter”. The image of the selfless or expected mother was under threat by both thoughts of continuing and ending pregnancies, evident through focus group discussions where mothers shared similar experiences despite divergent long-standing beliefs about termination. “I’m actually very pro-life and I felt the exact same way as you said! I felt so guilty having thoughts like ‘would it, my, life be easier without this baby?’ I felt terrible!” For some, the weight of decision-making about termination prompted mothers to consider how a miscarriage could be protective of the family, “that it would be okay if my baby didn’t pull through; both to save him from a life of possible endless suffering and pain, and to save our family from possibly having to see that”. However, this thought also simultaneously threatened the image of the mother.

It felt unnatural to all the sudden have these conflicting feelings; I love you more than anything, but I hate you right now. You’re so wanted and loved but it’s okay if you miscarry. I mean what parent thinks that? And how do you get over the guilt of those feelings after your child is born?

The expected family’s image was also threatened by the potential of becoming a different type of family than expected. “Were we about to become special needs parents?” These different types of families included the possible shift to a “one-income family” so a parent could remain home as carer, which also thrust into question the affordability of living in their house or current residential area.

3.2. Day by day toward adaptation

The mothers’ experiences of the days from diagnosis to birth varied greatly due to differences in healthcare systems, workplaces and roles and their own positionality in adapting to their changed pregnancy. As a time-limited and embodied experience, pregnancy demanded coping and self-regulatory processes as mothers moved through the days responding to the threat of the prenatal diagnosis of ACC. Mothers cycled through holding it together and falling apart, while they searched for more than information and yearned for meaning, hope and control.

3.2.1. Holding it together and falling apart

Accommodating the unexpected diagnosis was emotionally laborious, although the duration of accommodation processes varied. Mothers engaged a range of coping processes to “hold it together” to be present in appointments and tests, workplaces, and even at home. Proactive coping thresholds were often exceeded resulting in periods of falling apart, until the mother was able to re-establish some sense of equilibrium. The cyclical nature was highlighted through changes in thoughts and mood. “I would swing from trying to be so hopeful in 1 s and then falling apart other days”. Expressions of breaking down often occurred outside clinics, in bathrooms or the car, or at home, when they could no longer restrain themselves. “In the lift, a lady who had dementia or something akin to that said, in such a sweet, childlike voice, ‘oh dear, you have such sad eyes whatever is wrong?’ I just broke”.

Anxiety and dread within appointments were the resurfacing of the threat. “I felt the same feelings of worry and anxiety and when we were

waiting to be called for the ultrasound in our private waiting room I started to cry. The feelings just resurfaced every time.” For many, this ongoing threat reminder demanded an accommodative coping response so they could physically be present and engage at the appointment. “I mostly internalised everything and kept the anxiety hidden at appointments”. Difficult thoughts, emotions and somatic symptoms were not limited to appointments, though, disclosed through accounts of waking with nightmares, changes in appetite, loss of interest in usual activities, migraines, “severe panic attacks” and “ruminating” worries in addition to mood changes that were evident to others.

I have two very close friends who I think at the time we’re like walking on eggshells around me and trying really hard not to, like [upset me], because I think they could tell that there was something up, but I wasn’t in a place to talk about it yet.

Mothers engaged strategies to manage the emotional labour and somatic symptoms of stress, such as setting an alarm as a reminder to eat, journalling, walking, meditation or seeking mental health support. “I had to work actively each day to keep myself calm and not over-stimulated.” When asked, these strategies were often an attempt to hold it together specifically “for the health of the baby”. Accommodative coping also surfaced through the avoidance of triggers. For some mothers, this meant stopping talking to their baby to “shut down the connection”, avoiding the nursery, “the nursery was a no-go area” and isolating themselves, “I was closed off from everybody”. This avoidance sometimes meant mothers avoided both informal and formal supports. “My closest friends didn’t know about it.”

I was also already seeing a therapist when I found out about her anomaly but stopped going soon after because the therapist herself was pregnant and just about as far along as I was. I couldn’t bear to go anymore!

When avoidance was impossible, mothers attempted to hide their circumstances and hold it together, recalling they would “pretend to be happy and pretend to smile”. “When I went to work a couple days after the ultrasound, everyone was asking, ‘are you so excited?’ I had a really hard time putting on a happy face”. Pretending and hiding was a strategy to avoid exhausting questions, the “look of shock and horror” from others and insensitive comments. Hiding was also an attempt to protect the baby from the threat, as explored earlier, where the diagnosis may overshadow the baby. “I felt like our baby would never be looked at as a normal baby to whoever knows her diagnosis.” Hiding and pretending surfaced as experiences within workplaces, the public and appointments with professionals. The few mothers who were pregnant during COVID19, specifically disclosed the protective nature of staying home due to the reduced visibility and need to “concoct a fake smile if a stranger approached me about my growing bump”. Hiding was complex, as it sometimes meant hiding frustrations and challenges but also hiding hope and attempts to adapt.

I was ‘warned’ by more than one provider not to take too much to heart what I saw on Facebook, and that really just infuriated me because they were 100% accepting of some study from 30 years ago listing the disabilities of kids with ACC as one of their diagnoses. They had zero idea of what a child with isolated [ACC], as ours is, could be or do. Towards the end, I stopped bringing it up or discussing the baby’s future with those providers that I knew had the doom scenario in mind.

There were also mothers who sought and received support of friends and family. “My mother-in-law was brilliant, so positive, challenging us to embrace this.” Although mothers were sometimes forced to hold it together to manage questions or responses from family and friends, “but it added so much extra stress for me.” While worries and questions from others were challenging to manage, friends who had this “idealistic mindset that a miracle would happen” or who commended the mothers on their strength surfaced difficult emotions for the mothers. “This

[notions of strength] really made me mad and made me feel belittled”.

Mothers who encountered systems-based challenges had additional demands upon them to hold it together while they navigated complexities, such as the need to ring around services to find shorter wait times for tests, travel long distances, wait in clinic rooms “surrounded by all these women with their perfect pregnancies” and actively managing “the nightmare that was trying to get the MRI records transferred!” While mothers had typically accommodated the loss of their initial hopes for a certain type of birth, significant distress was caused by late and unexpected decisions to admit their new babies to the neonatal intensive care unit (NICU) for monitoring when there was no clear clinical need. Mothers who had expected a NICU admission due to a complex presentation of ACC felt prepared, although described feeling detached from their baby, “I felt like my baby boy hadn’t belonged to me either”. Yet, the abrupt and unplanned separation resulted in additional emotional labour while mothers tried to hold it together to challenge the decision to separate them from their new baby. The advocacy of a private midwife allowed one mother to remain with her baby, while another was threatened with child protective services when she was seeking understanding of the clinical need and indicators when her baby would return to her from NICU, thus resulting in significant additional distress to hold.

3.2.2. *More than information, Searching for Meaning, hope and control*

Mothers described their search for information as “obsessive”. Information was sought to reduce the vastness of possibilities presented within the incomplete or inconsistent information offered by healthcare professionals. “There was so much conflicting information at my doctors’ visits. No one was able to get me a definite answer on anything”. Initial communication about ACC was often with healthcare professionals who expressed limited experience with ACC and commonly focused on the “worst case scenario”, “like there was no sense that it could actually be ok”. Mothers who later met with specialists with expertise in ACC recounted receiving more balanced or favourable prognostic information. “All of a sudden, it was a completely different scenario ... she said, ‘I see this, I deal with this [I am] comfortable telling you that he has a very good chance of being fine’”.

The search was for more than just information, it was about making sense of what the possibilities meant for the baby and family, to reach a near enough understanding to contain the threat and ground preparation. “I needed to gather as much information as I could, as a means to processing what was happening and begin to set myself up for what the eventual outcome would be.” This meaning-making was typically the task of the mother or couple with limited professional support, “there was no counselling”, with exception of two mothers who engaged in therapeutic counselling. Meaning-making was illuminated through accounts of accommodating possibilities within the expected family life, at times reigniting hope and reducing the impact of the threat.

After the diagnosis, my husband and I talked about all the worst-case scenarios. We talked about our son possibly never learning to walk or to talk, could we handle that? What would life then look like for us? We are avid travellers and we talked about how we would possibly no longer be able to travel the world with our child like we dreamt of. Of course, we felt sad, zooming out on what our life could look like. My husband said something that touched me, he said, ‘our son will have his own joys and we will encourage them, maybe his thing is birds. So, then we would make it a goal to travel places based on seeking out birds for our son to marvel at. We would still keep true to ourselves, all the while catering to him as well’.

In searching of meaning, mothers found their way to ACC organisations or online support groups. Many mothers spoke of the benefits of these groups, specifically the access to real-life stories about what it means to live with ACC. “It was hard for me to accept what my child’s life would look like until I found the Facebook groups”. The groups showed the diversity of lived experiences and outcomes associated with

ACC and offered the chance to “talk to other parents and hear their stories and experiences, both scary and shockingly normal”. There was a difference in the way mothers discussed the “larger groups” and the “babies’ groups”, with the former described as “the most challenging” due to the confrontation of stories that included outcomes they had not yet accommodated. Although “seeing people ‘living that life’ in the larger groups made things seem more doable.” While there was visibility of the spectrum of outcomes, access to real-life stories reduced some of the uncertainty by showing “that if things were going poorly as doctors predicted that our kids are still lovable and perfect just the way they are”. Lived experience further grounded the possibilities in a way that statistics alone couldn’t. “These were real people with real children with real experiences and challenges. Doctors could not offer anything tangible or concrete for us”.

The birth year groups provided access to “woman and men whose babies were in the similar stages of development”, which not only included “information to know what questions to ask, what tests to inquire about and how to set up early intervention” but access to others with a shared experience, where mothers could be open and honest about what was happening. “I would talk to just people in the group about it because I didn’t want to [talk to] my mum and like, I didn’t want to talk to anyone else.”

The search for information, meaning and hope was also an effort to regain control when so much seemed out of control. The uncontrolled possibilities meant mothers set to unpack their prior assumptions of parenting to accommodate the uncertain outcomes and focus on what they could control as mothers to support their child. “It really forced me to re-evaluate what it meant to provide healthier support to our child”.

I felt like I wasn’t in control of the ACC or the outcome of how my daughters ACC would affect her, so reading for hours and scouring support groups for happy stories and anecdotes was within my control and it consumed me.

4. Discussion

This study disclosed that the maternal experience continuing pregnancy after a prenatal diagnosis of ACC is an experience of being under threat and moving day by day toward adaptation. The diagnosis exposed possibilities that threatened the baby’s life and image of the expected family. Adapting to the threat while moving through pregnancy after the prenatal diagnosis demanded cognitive and emotional coping responses, both proactive and defensive to allow mothers hold it together while they searched for information, meaning, hope and control.

Threat surfaced within some, but limited, prior studies that have explored experiences and psychosocial outcomes after a prenatal diagnosis. Threats to the baby’s health were connected with a loss of the self-value as a mother within an analysis of interviews with 16 mothers who received a prenatal diagnosis of cleft lip and/or palate in Taiwan (Hsieh et al., 2013). Maternal appraisals of threat or loss, rather than challenge, were identified within a cross-sectional study that used several psychosocial measurement scales with 40 mothers who continued their pregnancies after a prenatal diagnosis in the UK (Horsch et al., 2013). The authors also found that primary threat appraisal was positively correlated with anxiety and depression. While threat surfaced in these studies and suggested a connection to psychosocial outcomes, this dimension of experience may be potentially concealed in other literature by a focus on the shock of an unexpected diagnosis. The experience of prenatal diagnosis as a threat may be specific to certain diagnoses such as ACC or those with high uncertainty. Although noting the high incidence of PTSD among mothers who have received a prenatal diagnosis (Aguilar and Abrahão, 2022; Fonseca et al., 2011; Rychik et al., 2013), further research exploring threat in prenatal diagnosis and interventions to reduce threat appears warranted.

The acknowledgement of threat within the experience of receiving a prenatal diagnosis and the defence cascade in response to threat may

offer healthcare professionals a useful framework for understanding and the vast range of emotional responses from parents and the support they require. The automated and hard-wired defence to threat includes the physiological, sensorial and cognitive states, arousal, fight-or-flight, freeze and immobility within which a range of emotions and behaviours can be activated, including denial, anger, panic and dissociation (Kozłowska et al., 2015). These states may have implications for clinical care, for example, the physiological responses in the defence cascade may mean mothers struggle to hear and process news at the time of receiving a prenatal diagnosis. Many mothers in this study described lived experiences that suggested a dissociative response leading to confusion, inability to process news and ask questions or recall things discussed. Disassociation and lowering of consciousness is a normal neurobiological function when under threat (Paulsen and Lanius, 2014). Consideration of dissociation may be critical for informing support at the interpersonal and systems level. Acknowledgement of the potential for threat and peritraumatic reactions within prenatal diagnosis could underpin healthcare service design that supports clinicians to adapt communication and provide timely continuity within follow-up to accommodate disassociation. Trauma-informed prenatal care could be inclusive of the assessment of psychosocial needs, psychoeducation, streamlined referral to psychosocial supports and active follow-up as standard, rather than waiting for overt signs of distress considering the different physiological reactions of the threat response and the surfaced experience of holding it together for appointments.

Prenatal diagnosis is a unique practice in healthcare, in the sense that a diagnosis is received prior to birth and before a baby becomes known by their individual identity and personhood. A living person is understood not by their biological elements but by the interaction and qualities of the biological system of a human (Greve and Strobl, 2004). Prenatal diagnosis places significant focus on a diagnosis and biological elements before a baby's individual identity can manifest beyond imagined futures, which may perpetuate the threat of the loss of the baby to diagnosis. A diagnosis focus, often coupled with a focus on deficiency, may hinder the hopeful possibilities that are typically afforded to a baby without a diagnosis or disability (Johnson, 2023). Hope, after a prenatal diagnosis, was previously identified as a common and potentially important component of the maternal experience, which led to recommendations that healthcare professionals ensure they provide factual information about the diagnosis while also leaving room for positive emotions such as hope and optimism, as opposed to presenting a deterministic view which can undermine coping (Fonseca et al., 2011). This study disclosed that hope need not be just about typical development but can present through the accommodation of possibilities within the expected family life and through the reclamation of baby from diagnosis. High uncertainty within prenatal diagnosis may interrupt hope and attachment, influencing the environment, opportunities, and expectations a baby is born into. An interruption to bonding was not universal in this study but was common and remained a significant challenge for mothers to process years after their experience. These considerations highlight the critical need for further research and investment in supporting maternal adaptation to reduce potential harm, particularly in the climate of expanding prenatal testing.

This study disclosed mothers' many proactive and defensive actions as they moved through their pregnancy toward adaptation and that there was no single way to experience pregnancy after the prenatal diagnosis. Findings that some mothers enjoyed further ultrasounds and celebrated typical pregnancy milestones, while these experiences heightened distress for other mothers could be further considered in relation to the dual-process framework by Brandtstädter and Rothmund (2002). Assimilation-accommodation responses to divergences between desired and factual circumstances may ground individual adaptive processes. Assimilation comprises the maintenance of expectations and actions to incorporate circumstances into projections of the desired life course, reflected in mothers' accounts of self-care to protect their baby's development and within aspirations that incorporated space

for disability. Assimilation responses may also include denying the threat and challenging possibilities after a prenatal diagnosis, while these cannot be accommodated. Accommodation signifies processes that are not internally originated, which are cognitively and emotionally demanding due to the changing of internal structures, the modification of expectations and the creation of new schemas (Hanfstingl et al., 2022). Accommodation is a defence against an anxiety-arousing threat (Hayes et al., 2015). Accommodative responses were evidenced through the reorganisation of hopes, reevaluation of threatened future images, and defensive coping reactions. As the assimilation-accommodation framework incorporates individual and social influences within coping and adaptation, viewing the experience of prenatal diagnosis with consideration of the framework may ground research into supporting maternal adaptation after a prenatal diagnosis.

This study identified that access to supportive teams and streamlined services appeared to reduce the maternal experience of being overwhelmed. Patient journey mapping of an Australian high-risk midwifery model for women offered insight into the opportunity to improve the experience of prenatal diagnosis through holistic continuity of care, yet elicited challenges of discontinuity for parents before and after the specialist service (Psaila et al., 2023). A broad perspective of the complex human experience through prenatal diagnosis and into parenting, opposed to a narrow focus on prenatal diagnosis as an antenatal medical event could guide health policy that seeks to reduce systems gaps and improve psychosocial outcomes. Where continuity of care can't be achieved, a relational intervention such as the 15-Minute Interview may optimise communication to address the individual needs of the mother and family (McKechnie et al., 2015b).

5. Limitations

A phenomenological study does not intend to produce generalisable or representative findings and present an objective truth of a phenomenon. The findings of this study are specific to the participants' experiences and must be read with this limitation in mind. While eligibility criteria were broader, mothers who volunteered to participate were those who had engaged with ACC support groups before or after birth, spoke English as a first language, were in heteronormative parenting relationships during their prenatal diagnosis, had commonly completed education post-high-school and a high proportion were health professionals. Data collection and analysis was undertaken during COVID-19.

6. Conclusion

This hermeneutic phenomenological study provided a telling of the maternal experience of continuing pregnancy after receiving a prenatal diagnosis of ACC. The news of the suspected neuroanatomical anomaly was experienced as a threat to the life of the baby and the image of the expected family. Mothers engaged in active and defensive cognitive and emotional processes to hold it together while they searched for meaning, hope and control to accommodate their changed pregnancies and expectations. To realise the commonly stated objective of prenatal diagnosis, to support maternal preparation, healthcare professionals require awareness of the profound, yet individual experience of prenatal diagnosis to adequately respond and support mothers through their continued pregnancies. Healthcare services should be designed to flexibly respond in a woman- and family-centred manner to reduce the threat and support maternal adaptation after a prenatal diagnosis.

Data statement

To protect the anonymity of the mothers and in line with the ethics approval, data is not available for sharing, due to detailed experiences which may allow triangulation and reidentification.

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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 the work reported in this paper.

Data availability

The data that has been used is confidential.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.socscimed.2023.116391>.

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