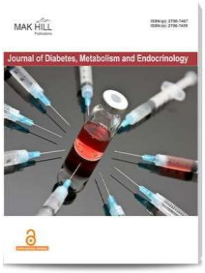

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Research Article

A Phenomenological Study of Lived Experiences of Pregnant Women Diagnosed with Fetal Anomalies in an Antenatal Ward of Nishtar Hospital Multan.

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Abstract: Background: ***Objective:*** To explore how pregnant women experienced a confirmed fetal anomaly diagnosis, negotiated pregnancy-related decisions and used personal, relational and spiritual resources while receiving care at a tertiary antenatal service. ***Study Design:*** Descriptive phenomenological qualitative study. ***Place and Duration of Study:*** Antenatal ward and linked outpatient pathway, Department of Obstetrics and Gynaecology, Nishtar Hospital, Multan, Pakistan, from January to June 2024. ***Methods:*** Women aged 20-40 years with a confirmed major fetal anomaly in the second or third trimester were selected purposively for maximum variation. Fifteen individual interviews lasting 43-78 minutes were organised around a semi-structured guide. Interviews were transcribed verbatim, translated where required and analysed through Colaizzi's seven-step method. Reflexive notes, an audit trail, peer review and participant reflection were incorporated to support trustworthiness. ***Results:*** The participants had a median age of 29 years and median gestational age of 25 weeks. Five interrelated themes described the experience: the pregnancy story breaking without warning, living between certainty and doubt, negotiating agency within relationships, protecting the self while remaining pregnant and asking for care that holds the whole person. Diagnostic shock was intensified by repeated testing, inconsistent explanations and lack of privacy. Spousal presence, faith, selective disclosure and practical information helped women regain a degree of control. Decisions were rarely individual events; they developed through prognosis, family consultation, religious meaning and perceived feasibility of treatment. ***Conclusion:*** A fetal anomaly diagnosis reshaped maternal identity, family relationships and expectations of antenatal care. Consistent explanations, non-directive counselling, private communication and integrated psychological and spiritual support should accompany diagnostic and obstetric management.

Keywords: Fetal abnormalities; Pregnancy; Prenatal diagnosis; Phenomenology; Coping; Qualitative research.

INTRODUCTION

Prenatal ultrasonography and genetic testing can identify structural or chromosomal conditions before birth. The clinical value of diagnosis is clear, yet the moment of disclosure may abruptly transform an expected pregnancy into an experience of uncertainty, anticipatory grief and altered maternal identity. Recent phenomenological work has shown that women describe simultaneous cognitive, emotional and bodily disruption after fetal abnormality is confirmed [1]. Even when a suspected anomaly is later excluded and a healthy infant is born, the interval of uncertainty may remain psychologically significant [2]. These findings indicate that a technically accurate diagnosis is only one part of the care pathway; how the information is explained and supported also shapes the woman's experience.

Pregnancy decisions after an anomaly diagnosis are rarely reducible to a simple choice between continuation and termination. Couples may move repeatedly between hope, fear, duty and practical calculation as they interpret prognosis and possible disability [3]. In Muslim communities, religious reasoning may interact with family authority, maternal responsibility and differing interpretations of what constitutes acceptable action [4]. Contemporary counselling literature therefore recommends repeated, coordinated and non-directive conversations rather than a single information-heavy encounter [5]. Such care must acknowledge that patients can need emotional containment before they are ready to understand probabilities or consider options.

The support required also varies by diagnosis and anticipated pathway. Parents facing congenital heart disease have described needs that change from confirmation through birth and postnatal care [6]. Women carrying fetuses with surgically correctable

anomalies may struggle to translate specialist terminology into a realistic understanding of neonatal treatment [7]. When termination is considered, the perceived clarity, timing and continuity of the diagnostic process can influence whether parents later regard the decision as informed [8]. These studies reinforce the value of examining experience across diagnosis, relationships and health-system encounters rather than treating distress as an isolated psychological symptom.

Spousal support is associated with how women cope with fetal anomaly diagnoses, although the quality of support may matter more than simple physical presence [9]. Evidence for formal psychological interventions remains limited and heterogeneous, which makes careful assessment of local needs essential before programmes are introduced [10]. In Pakistan, clinicians also work within legal, ethical, religious and resource constraints that can produce uncertainty around counselling for severe anomalies [11]. International qualitative research describes stigma, difficult decisions and unmet post-diagnosis support but its meanings cannot be assumed to transfer unchanged to Multan [12]. The present study therefore explored the lived experiences of pregnant women with fetal anomalies at Nishtar Hospital, focusing on emotional responses, decision-making, coping and interactions with family and healthcare services.

MATERIALS AND METHODS

Study design and reporting

A descriptive phenomenological design was used to examine the meaning women assigned to an anomaly diagnosis during an ongoing pregnancy. The approach prioritised first-person description and sought common structures across individual accounts without testing a predetermined behavioural model. Reporting was organised with reference to the Consolidated Criteria for Reporting Qualitative Research checklist [13] and the Standards for Reporting Qualitative Research [14].

Setting and duration

The study was situated in the antenatal ward and linked obstetric outpatient pathway of Nishtar Hospital, Multan. The service receives urban and rural referrals from southern Punjab, including women sent for confirmation of ultrasound findings and management planning. Recruitment and interviews were scheduled between January and June 2024. A private counselling room away from the main ward bay was selected whenever clinical circumstances allowed.

Participants and sampling

Purposive maximum-variation sampling was planned across age, parity, residence, gestational age, anomaly category and anticipated prognosis. Eligible participants were pregnant women aged 20-40 years, in the second or third trimester, with a major fetal anomaly confirmed by a consultant obstetrician or radiologist. Women had to be clinically stable, able to converse in Urdu, Saraiki, Punjabi or English and willing to discuss their experience. Women were excluded when a finding remained unconfirmed, an acute medical emergency prevented a private interview or a severe cognitive or psychiatric crisis impaired informed participation. Women who had already delivered or completed a termination were not included because the phenomenon of interest was living through the diagnosis during an ongoing pregnancy.

Sample size and recruitment

The target was guided by information power rather than a numerical formula: a focused question, specific sample, rich interviews and case-level analysis supported a relatively small sample [15]. Twenty-three women were assessed through the clinical pathway. Four did not meet the eligibility criteria, three declined and one could not arrange an interview. Fifteen women completed interviews and were included. Preliminary analysis proceeded alongside data collection. No materially new meaning units appeared after interview 13, then two further interviews were examined to test the stability and range of the developing structure.

Data collection

A female interviewer trained in qualitative interviewing and not responsible for participants' direct clinical decisions conducted face-to-face interviews. The guide began with an open invitation: 'Please tell me about the time you first learned that something might be different with your baby.' Prompts explored the diagnostic journey, understanding of prognosis, changes in everyday life, relationships, faith, decision-making, communication with staff, coping and desired support. Interviews lasted 43-78 minutes. Participants chose the language and could have a support person nearby but not inside the room unless requested. With permission, interviews were audio-recorded. The interviewer also documented pauses, visible distress, contextual events and immediate reflexive impressions. Participants could pause or stop without affecting care.

Data management and analysis

Recordings were transcribed verbatim. Urdu, Saraiki and Punjabi passages were translated into English for analysis; selected quotations were checked by a second bilingual reviewer for conceptual equivalence. NVivo was used only to organise transcripts, codes and analytic memos. Analysis followed Colaizzi's seven-step procedure: repeated reading, extraction of significant statements, formulation of meanings, clustering of meanings, development of an exhaustive description,

condensation into the fundamental structure and return of a plain-language summary for participant reflection [16]. Coding remained inductive. Two researchers independently reviewed four information-rich transcripts, discussed interpretive differences and refined the codebook. The full team then examined negative cases and variations associated with prognosis and pregnancy decision.

Trustworthiness and reflexivity

Credibility was supported through open interviewing, participant reflection and examination of cases that did not fit early interpretations. Dependability was addressed through a dated audit trail linking transcripts, meaning units, codes, theme memos and decisions. Confirmability was strengthened by reflexive journaling and peer review by an obstetric and a non-obstetric researcher. Transferability was supported through description of the tertiary referral setting and maximum variation in participant characteristics. The team acknowledged that clinical backgrounds could encourage problem-solving responses. Interviewers therefore used bracketing notes and delayed advice until after the recorded conversation.

Ethical safeguards

No human participants were enrolled. Ethics approval and informed consent were therefore not applicable. The planned safeguards included voluntary participation, de-identification, secure storage and a distress protocol. The protocol specified pausing the interview, checking immediate safety and offering referral to obstetric, psychiatric or psychological support when distress persisted. Clinical staff would receive no interview content beyond an urgent safety concern disclosed with the participant's knowledge.

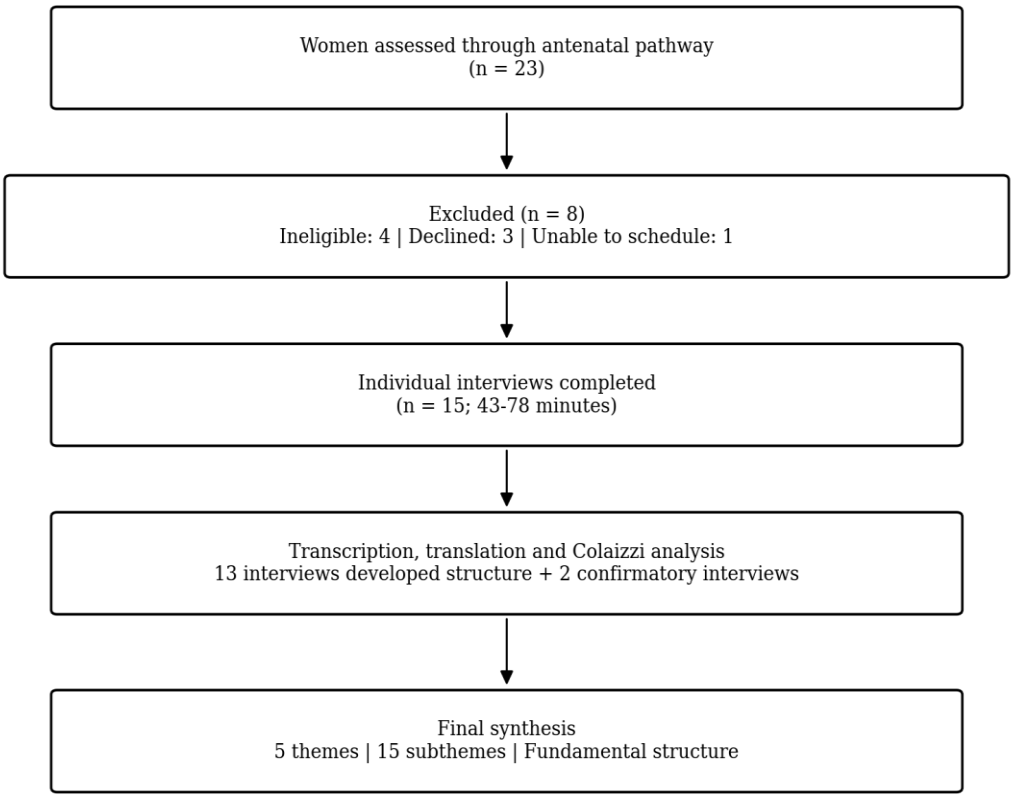

Figure 1: Study flow and analytic progression

RESULTS

Fifteen women contributed accounts. Median age was 29 years (IQR 26-34) and median gestational age was 25 weeks (IQR 22-29). Nine lived in urban areas and six travelled from rural districts. Five were nulliparous. Six pregnancies had a lethal or life-limiting prognosis, six had a potentially treatable condition and three had an uncertain prognosis. Eight women intended to continue the pregnancy, four were considering termination and three remained undecided. The analysis produced five interconnected themes and 15 subthemes.

Table I: Characteristics of participants (n = 15)

Characteristic	Distribution
Age, years	Median 29 (IQR 26-34)
Age group, years	20-24: 3 (20.0%); 25-29: 5 (33.3%); 30-34: 4 (26.7%); 35-40: 3 (20.0%)
Gestational age, weeks	Median 25 (IQR 22-29)
Gestational group	18-22 weeks: 4 (26.7%); 23-27 weeks: 6 (40.0%); >=28 weeks: 5 (33.3%)
Residence	Urban: 9 (60.0%); Rural: 6 (40.0%)
Parity	Nulliparous: 5 (33.3%); 1-2 previous births: 7 (46.7%); >=3 previous births: 3 (20.0%)
Education	No formal/primary: 3 (20.0%); Secondary: 5 (33.3%); Higher secondary: 3 (20.0%); Graduate or above: 4 (26.7%)
Anomaly category	Central nervous system: 4 (26.7%); Cardiac: 3 (20.0%); Renal/urinary: 2 (13.3%); Skeletal: 2 (13.3%); Chromosomal: 2 (13.3%); Multisystem: 2 (13.3%)
Prognostic grouping	Lethal/life-limiting: 6 (40.0%); Major potentially treatable: 6 (40.0%); Uncertain: 3 (20.0%)
Decision at interview	Continue pregnancy: 8 (53.3%); Considering termination: 4 (26.7%); Undecided: 3 (20.0%)

Theme 1: The pregnancy story breaking without warning

The diagnosis was experienced as a rupture between the pregnancy participants had imagined and the pregnancy they now had to inhabit. Several described the ultrasound room as the point at which ordinary expectations stopped. Technical phrases were remembered more clearly than surrounding explanations because fear narrowed attention. P03 said, 'I watched the doctor's face before I understood his words. When he became quiet, I felt the floor had moved.' (quotation).

Initial responses included disbelief, crying, bodily numbness, anger and self-blame. Some women searched their diet, medicines or past actions for a cause. Reassurance that they had not caused the anomaly was helpful only when repeated after the first disclosure. P11 explained, 'Everyone told me not to blame myself but my mind kept returning to every tablet and every meal.' (quotation). Women with previous healthy children were not protected from shock; instead, they contrasted the current pregnancy with earlier uncomplicated experiences.

Maternal identity was disrupted before any final decision. Participants continued to feel fetal movement, attend appointments and imagine the baby while also hearing language about poor survival or disability. This coexistence created guilt around both attachment and emotional withdrawal. One participant avoided buying clothing because preparation felt dangerous. Another continued speaking to the fetus because stopping felt like abandonment.

Theme 2: Living between certainty and doubt

Uncertainty was not limited to prognosis. Women described waiting for repeat scans, laboratory reports, senior review and family availability. Each interval reopened the possibility that the diagnosis might be wrong. P06 stated, 'They said we need another scan. That sentence gave me hope but it also kept me awake because I did not know whether the hope was real.' (quotation). Women valued clinicians who separated what was known, what remained uncertain and what would happen next.

Information overload and information scarcity could occur in the same encounter. Participants recalled hearing unfamiliar anatomical terms yet leaving without an answer to practical questions about survival, pain, delivery or neonatal treatment. Internet searches sometimes improved vocabulary but often amplified fear through severe images and unverified stories. Women wanted short verbal explanations supported by written information in plain Urdu and a named person for follow-up questions.

Repeated investigations also carried financial and logistical consequences. Rural participants described travel, accommodation, missed wages and arranging childcare. These costs shaped how quickly further tests could be completed. P14 said, 'The report was not the only thing we were waiting for. We were waiting for money for the next journey.' (quotation). Diagnostic delay was therefore experienced as both medical uncertainty and household strain.

Theme 3: Negotiating agency within relationships

Participants rarely portrayed pregnancy decisions as solitary. Husbands were often the first confidants and could buffer distress by attending consultations or translating medical language for relatives. Support became less helpful when

reassurance dismissed fear or when a husband deferred entirely to elders. P02 said, 'He told me the decision was mine but I still needed him to sit with me inside that decision.' (quotation).

Mothers-in-law, parents and siblings influenced interpretation of diagnosis and the perceived acceptability of options. Some participants welcomed collective responsibility. Others felt their own bodily and emotional stakes were overshadowed by opinions about family reputation, future fertility or disability. Clinician recommendations could acquire the force of a command even when presented as options, particularly when women were distressed or had limited formal education.

Faith was central but not uniform. Prayer, consultation with a trusted religious scholar and belief in divine purpose offered comfort. The same framework could intensify fear of moral wrongdoing when information about severity or permissible choices was unclear. P09 reflected, 'Faith did not remove the decision. It gave me a language to carry it but I still needed honest medical answers.' (illustrative quotation). Women preferred clinicians who respected religious concerns without assuming a single interpretation or replacing medical counselling with personal opinion.

Theme 4: Protecting the self while remaining pregnant

Coping involved alternating engagement and retreat. Women sought information, made lists of questions, prayed, maintained routine or focused on caring for other children. At other times they avoided calls, social gatherings or conversations about baby preparations. P05 said, 'Some days I wanted every detail. On other days even one question from a relative felt too heavy.' (quotation). These shifts were not inconsistent; they allowed participants to regulate exposure to distress.

Selective disclosure was a common protective strategy. Participants feared pity, blame, gossip or repeated requests to explain the diagnosis. Urban and rural women both described social pressure, although rural participants reported fewer opportunities for anonymous specialist or psychological support. One woman chose a single sister to update the extended family. Another asked her husband to answer all telephone calls after appointments.

Hope changed form across the diagnostic pathway. For some, hope meant reversal of the diagnosis. For others, it meant a safe delivery, comfort for the baby, a clear decision or the ability to face a future pregnancy without fear. P12 said, 'At first hope meant the scan would become normal. Later it meant I would not be alone whatever happened.' (quotation). This reframing helped women regain agency without requiring unrealistic optimism.

Theme 5: Asking for care that holds the whole person

Participants valued calm explanations, eye contact, privacy and acknowledgement that the fetus was also their baby. Compassion was experienced through small acts: allowing a husband into the discussion, checking understanding, giving time before requesting a decision and arranging the next appointment before discharge. P01 said, 'The doctor drew the heart and then asked me to explain it back. That was the first time I felt I could breathe.' (quotation).

Women were distressed when serious information was delivered in busy areas or by several clinicians using different terms. They wanted one coordinated pathway joining obstetrics, radiology, neonatology, paediatric surgery, genetics and mental health support according to the diagnosis. A named liaison person was viewed as more realistic and valuable than repeated unscheduled referrals.

Psychological support was acceptable when framed as a routine part of fetal anomaly care rather than evidence that a woman was unable to cope. Participants also requested guidance for husbands and close family because relatives did not know what to say. P15 summarised, 'Do not only tell the mother to be strong. Tell the family how to stand beside her.' (quotation). The fundamental structure was an effort to preserve personhood and maternal agency while medical uncertainty, relational expectations and moral meaning competed for attention.

Table II: Thematic structure of the lived experience

Theme	Subthemes	Analytic meaning
The pregnancy story breaking without warning	Diagnostic rupture; self-blame; disrupted maternal identity	The expected pregnancy was replaced by an unfamiliar reality before women could absorb clinical detail.
Living between certainty and doubt	Waiting for confirmation; uneven information; material cost of uncertainty	Repeated tests produced both hope and fear, with travel and financial pressures shaping the diagnostic journey.
Negotiating agency within relationships	Spousal presence; family authority; faith and moral reasoning	Decisions emerged through relationships, yet women wanted their embodied stake and preferences to remain central.

Protecting the self while remaining pregnant	Alternating engagement and retreat; selective disclosure; changing forms of hope	Coping involved regulating exposure to distress rather than following a single stable strategy.
Asking for care that holds the whole person	Compassionate explanation; continuity and privacy; integrated support	Women valued coordinated care that joined medical facts with emotional, relational and spiritual support.

Table III: Cross-theme variation and implications for care

Dimension	Pattern across accounts	Service implication
Prognostic clarity	Women with a clear life-limiting prognosis focused on comfort, moral acceptability and family meaning. Uncertain prognosis prolonged repeated checking and delayed commitment to a plan.	State what is known, unknown and time-sensitive; schedule a defined review point.
Pregnancy decision	Women continuing pregnancy reframed hope toward preparation and meaningful time. Undecided women sought repeated conversations without pressure.	Offer decision-neutral counselling and diagnosis-specific pathways for continuation, termination and palliative care.
Family involvement	A supportive spouse could share practical and emotional work. Dominant relatives could reduce the woman's sense of agency.	Ask whom the woman wants present and confirm her understanding and preference privately.
Residence and resources	Rural travel, missed wages and accommodation costs intensified waiting and limited access to repeated specialist consultations.	Coordinate same-day reviews where possible and provide a named telephone contact.
Information preference	Readiness for detail changed over time; internet searching sometimes increased fear.	Use staged explanations, teach-back and concise written information in the preferred language.

DISCUSSION

This study explored how women made sense of a fetal anomaly diagnosis during an ongoing pregnancy. The central finding was that distress did not arise from diagnosis alone. It developed through the interaction of disrupted expectations, uncertain prognosis, repeated investigations, family negotiation and the quality of clinical communication. Women rebuilt a workable sense of agency through changing forms of hope, faith, selective disclosure, spousal presence and practical information. The five themes therefore support a model of care that treats emotional and relational needs as part of diagnostic safety rather than an optional addition.

The diagnostic moment was remembered as a rupture, with early explanations only partly retained. Longitudinal accounts after second-trimester abortion similarly show that emotional meaning changes over time and that immediate reactions do not capture the whole experience [17]. Decision-focused literature also demonstrates that prognosis, personal values, disability perceptions and access to care intersect rather than operating as independent determinants [18]. The present findings extend that interpretation by showing how waiting and household costs can narrow the practical space in which a woman exercises choice. Clinicians should therefore stage information, use teach-back and provide a written plan for unresolved questions.

Women wanted accurate detail but differed in how much they could absorb. Research on rapid prenatal exome sequencing indicates that additional information helps parents assemble a fuller picture even without a definitive diagnosis [19]. Information became useful when translated into implications for pregnancy, delivery and neonatal care. Spousal involvement was more complex than presence alone. Work examining men after termination shows that partners may suppress grief to maintain a supporting role [20]. Couple-sensitive counselling should include partners without shifting authority away from the pregnant woman.

Themes concerning grief, changing hope and altered maternal identity are consistent with a synthesis of families continuing affected pregnancies [21]. Chinese parents after termination likewise described shock and an urgent need for social support [22]. Pandemic-era research showed how isolation and discontinuity worsened pregnancy-loss care [23]. Privacy and continuity were salient in a crowded referral pathway. A quiet disclosure space and named coordinator could reduce repeated retelling and contradictory messages.

Faith functioned as a coping resource and a setting for moral uncertainty. Phenomenological research on support needs after termination emphasises that cognitive, emotional and behavioural responses require coordinated attention [24]. A broader review of coping strategies found substantial diversity in acceptance, planning, avoidance, spiritual practice and support-seeking [25]. The alternating engagement and retreat described here should therefore not be labelled non-compliance. Clinicians can instead ask what information a woman is ready to receive today and whether she wants a trusted family or religious adviser involved.

Uncertainty was intensified by ambiguous clinician language and internet searches. Qualitative work with women awaiting confirmation after a suspicious screen similarly identifies physician uncertainty, misinformation and family pressures as sources of worry [26]. Reviews of decision-making after a positive screen show that experiences can influence attitudes toward future pregnancies and testing [27]. Another qualitative study of the screening process found unmet health-system needs across testing and possible abortion pathways [28]. These comparisons support a structured counselling checklist covering diagnostic confidence, expected course, options, costs, warning signs, follow-up contacts and future reproductive implications.

Participants requested compassionate care that recognised attachment regardless of pregnancy decision. Parents facing fatal fetal anomaly have also described the importance of consistent care, safe environments and acknowledgement of grief [29]. Genetic counsellors working under restrictive abortion environments report that legal context can alter counselling and access [30]. In Pakistan, the ethical environment is similarly complex, which makes non-directive documentation and referral pathways important. Birth plans among women continuing affected pregnancies show that hope can include comfort, meaningful time and respect rather than cure alone [31]. Genomic sequencing research likewise shows that parents may value information for preparation even when it cannot change the outcome [32].

The call for integrated support is consistent with perinatal palliative-care research in which parents identify unmet physical, psychological, social and spiritual needs [33]. A systematic review of termination for fetal anomaly also found recurring needs for sensitive communication, continuity and appropriate follow-up [34]. Importantly, even women whose suspected anomaly is later excluded may continue to carry the emotional effects of uncertainty [35]. Services should therefore offer a brief psychosocial assessment at disclosure, repeat it after definitive testing and provide follow-up regardless of whether the pregnancy is continued, terminated or ultimately considered unaffected.

The study has limitations. Its single tertiary-centre setting and small purposive sample limit transferability to primary care, private practice and other regions of Pakistan. Only pregnant women were represented, so the accounts do not show partners', clinicians' or religious advisers' perspectives. Women who had already delivered or completed termination were excluded, which restricts insight into bereavement and longer-term adjustment. Translation may have reduced some linguistic nuance despite bilingual checking. Finally, women in acute crisis or those declining an interview may have held different experiences. Future multicentre longitudinal work should include couples and follow participants across diagnosis, decision, birth or termination and subsequent pregnancy.

CONCLUSION

Women living with a fetal anomaly diagnosis experienced a simultaneous disruption of pregnancy expectations, maternal identity and family decision-making. Clear staged explanations, respectful inclusion of chosen relatives, attention to faith and a named multidisciplinary contact helped restore agency. Antenatal services should integrate private disclosure, teach-back, routine psychosocial assessment and diagnosis-specific referral pathways. Multicentre longitudinal qualitative research is needed to examine how these needs change after birth, termination and in later pregnancies.

Declarations
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Conflicts of interest: There are no conflicts of interest.

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