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REVIEW ARTICLE

Delivering unexpected news via obstetric ultrasound: A systematic review and meta-ethnographic synthesis of expectant parent and staff experiences

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Abstract

Expectant parents report negative experiences of receiving unexpected news via ultrasound. There is a need to improve communication in this setting, but a lack of understanding on how to achieve this. This systematic review aimed to synthesise findings from qualitative studies exploring experiences of expectant parents or healthcare professionals when a fetal abnormality or unexpected finding was identified via ultrasound. MEDLINE, EMBASE, CINAHL and PsycINFO were searched using three blocks of terms (fetal abnormalities; ultrasound; experiences). Qualitative studies exploring the disclosure of pregnancy complications during ultrasound examinations were included and analysed using meta-ethnographic synthesis. The review was conducted according to PRISMA and eMERGe guidelines. The review identified 28 studies. News delivered via ultrasound can be viewed as a journey involving five phases (expectations of ultrasound scans; discovery; shock; decisions and planning; adaptation). How well this is navigated depends upon the extent to which information needs and support needs are met. Ultrasound is a uniquely challenging situation to communicate difficult news as there is the potential for news to be communicated immediately. Care quality could be improved by the provision of written information and the use of correct terminology to describe abnormalities.

KEYWORDS

antenatal care, diagnostic studies, Doppler ultrasound

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1 | INTRODUCTION

Around 12% of pregnancies end in miscarriage or stillbirth and in 5% an anomaly is identified.¹⁻³ Ultrasound is a key tool for identifying or confirming these complications.⁴ This news is often unexpected, and expectant parents may experience depression, anxiety and trauma as a result.^{5,6} Immediately following this news, parents may need to make important decisions regarding further invasive testing or termination in the event of fetal anomaly, or management options, in the event of pregnancy loss. The manner in which complications are initially communicated has a significant emotional impact, and better experiences can enable a more supported pathway of decision-making and wellbeing.⁴

There is a growing awareness of a need to improve news delivery via ultrasound, but a lack of understanding and consensus on how this can be achieved. At present, the communication of pregnancy complications identified via ultrasound varies across health systems and organisations; parents may be informed immediately by the healthcare professional (HCP) conducting the scan or later informed by their referring physician.⁷ Studies suggest that parents continue to report low overall satisfaction with care at this point,⁸ experiencing insensitive language from staff,⁹ delays in receiving information¹⁰ and feeling confused.¹¹ HCPs also describe these events as challenging; they struggle to manage parents' distress and report vicarious grief.¹²

1.1 | The current review

Reviews have investigated communication practises in relation to prenatal diagnosis, but none have focused on experiences of news communicated via ultrasound in particular.¹³⁻¹⁵ Ultrasound differs to other diagnostic tests due to the potential for results to be communicated immediately: HCPs have no time alone to formulate their initial communication with parents. A number of qualitative studies have now been conducted in this area, but these have often focused on specific complications in single countries. Clinicians need a breadth of understanding and linked recommendations which encompass the range of complications they may need to communicate. Identifying commonalities across countries could also contribute to the development of international recommendations regarding news delivery practice. Furthermore, existing studies have been conducted in either expectant parents or staff; synthesising the experiences of these groups together could identify barriers to optimal care delivery and inform interventions.

This systematic review synthesised findings from qualitative empirical studies which explored the views, experiences and preferences of expectant parents or HCPs when a fetal abnormality or unexpected finding was identified during a prenatal ultrasound examination. The aim was to determine themes which could enhance understanding, improvements and consensus on news delivery practice.

2 | METHODS

This review was reported in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA; Table S1)

and the Meta-Ethnography Reporting Guidelines (eMERGe; Table S2).^{16,17} The protocol was registered on PROSPERO (registration number: CRD42017073000; URL: https://www.crd.york.ac.uk/PROSPERO/display_record.php?RecordID=73000; Appendix S1).

2.1 | Eligibility criteria

Studies were included if they:

- Included expectant parents or HCPs delivering news of pregnancy complications via ultrasound examination.
- Reported experiences or preferences for communication of prenatal complications identified or confirmed by ultrasound examination.
- Used an empirical qualitative or mixed methods design.
- Were conducted in settings where obstetric ultrasound scans were undertaken or discussed.

2.2 | Exclusion criteria

We excluded:

- Grey literature.
- Studies not written in English.
- Studies into communication of results from prenatal tests which occurred remote from the time of ultrasound (eg, blood tests, amniocentesis), or where the diagnostic test being discussed was unclear.
- Studies which grouped together experiences of receiving news via ultrasound with communication of news identified via other prenatal tests.
- Studies including participants who had received news of multiple pregnancies.

2.3 | Search strategy and data sources

MEDLINE, EMBASE, CINAHL and PsycINFO were searched by one reviewer (MP) from inception to 5 July 2017, updated to 7 July 2018 and then 2 August 2019. The search strategy included combinations of three blocks of terms (fetal abnormalities; ultrasound; experiences) using medical subject headings (MESH terms) and text-words (see Appendix S2). Reference lists of eligible studies and systematic reviews were also read.

2.4 | Study selection

Study selection comprised two stages. In Stage 1, titles and abstracts were screened, and in Stage 2, full-texts of studies retained from Stage 1 were screened according to the eligibility

criteria. 10% of abstracts were independently screened by two reviewers (AD and JJ). The kappa statistic indicated reliability between reviewers ($k = 0.71$), so remaining abstracts were screened by one reviewer (AD). Two independent reviewers screened all full texts (AD and JJ).

2.5 | Data extraction

We extracted the following descriptive information:

- Study: country, aims, research design, recruitment method, research setting, data collection method, data analysis approach.
- Participants: sample size, gender, response rate, ethnicity, whether expectant parents or healthcare staff; healthcare staff discipline; fetal condition/s identified.

All qualitative data from the studies was extracted into a second document. This included participant quotes (first-order data) and their study-author interpretations (second-order themes). Data extraction was conducted independently by two reviewers (JJ and AD or RS) for 50% of studies to establish reliability. Remaining data extraction was completed by one reviewer (JJ).

2.6 | Method of quality assessment

The Critical Appraisal Skills Programme (CASP)¹⁸ was used to assess the relevance, rigour and credibility of included studies. Two reviewers conducted this independently (JJ, AD), resolving disagreements through discussion. Scores ≤ 5 were considered "low", scores of 6/7 were considered "moderate", scores of 8/9 were considered "high" and scores of 10 were considered "higher". CASP scores were used to rank studies; the highest ranking study was the first from which data was extracted and analysed.¹⁹

For quality assessment characteristics see Figure S1. Most studies were rated as "high" ($n = 11$; 39%) or "moderate" ($n = 11$; 39%). Five studies were rated "low" (18%) and one was rated "higher" (4%).

2.7 | Data synthesis

Data were synthesised using a meta-ethnographic approach focused on reciprocal translation.²⁰ Meta-ethnography was chosen as it enables analytical rather than descriptive synthesis²¹ and can make knowledge accessible to policy makers and professionals.²² To enhance rigour, we involved a research team with different skills, approaches and opinions in the analysis.²³ In the first phase, two authors (JJ and JA) independently read the extracted first- and second-order data. In the second phase, these authors independently grouped second-order themes capturing similar concepts together into clusters. The authors then compared and contrasted their respective clustering of the data, to ensure triangulation. In

the third phase of "reciprocal translation", the lead author (JJ) synthesised concepts together across the studies within each of the agreed clusters to elucidate more refined third-order constructs.²⁴ Starting with the highest quality study represented in each cluster,¹⁹ the lead author summarised key themes within the first- and second-order constructs of the first paper; she then summarised key themes in the second highest quality study, highlighting similarities to the first and new concepts. Within each cluster, any studies in parents were synthesised first; staff studies were then translated into these. This process progressed systematically until all papers within each cluster had been translated into each other. For an example reciprocal translation, see Appendix S3. Alongside this, a Translation Table was created, which included all first- and second-order data (Table S3). Third order themes were created using the reciprocal translations, cross-checked with the Translation Table to ensure consistency with the original data. These translations were then checked for consistency with the original data by JA and ST. All authors reviewed the third-order themes.

The initial data synthesis was conducted following the first searches update (which were conducted in July 2018). However, three further papers were identified following the second searches update and reference list review, which was conducted in August 2019. The second-order themes in these papers were grouped into existing clusters by the lead author (JJ) and then included in the existing reciprocal translations (eg, see Appendix S3) and Translation Table (Table S3).

3 | RESULTS

A total of 28 studies were included (Figure 1 and Table 1). Twenty-four were in expectant parents and four were in HCPs. These were published between 1994²⁵ and 2018^{26,27} and included 637 participants (581 expectant parents/56 staff). HCPs were obstetricians,^{26,28} nurses and midwives²⁹ and sonographers.³⁰ The number of obstetricians included in the studies within the review was 34, the number of nurses and midwives was 13 and there were 9 sonographers. Studies were conducted in Italy,³¹ Sweden,^{9,11,29,32-35} the United Kingdom,^{27,30,36} the United States,³⁷⁻⁴⁰ Australia,^{28,41-43} Norway,^{26,44,45} Ireland,⁴⁶⁻⁴⁹ Germany²⁵ and Canada.¹⁰ Seven studies reported ethnicity data. In two, all participants were White,^{38,40} in two, >90% of participants were White^{10,36} and in three, >10% of participants were from a non-White ethnic group.^{27,37,39} Most studies used qualitative interviews ($n = 23$) and five used mixed methods.^{25,30,31,39,40} Eleven studies focused on the communication of a specific ultrasound finding (eg, Spina Bifida); the remaining 17 considered communication of multiple types of ultrasound finding. For articles which were excluded following full-text screening with reasons, see Appendix S4.

3.1 | Reciprocal translations

The analysis identified seven main third-order themes which suggested that news delivered via ultrasound is a journey

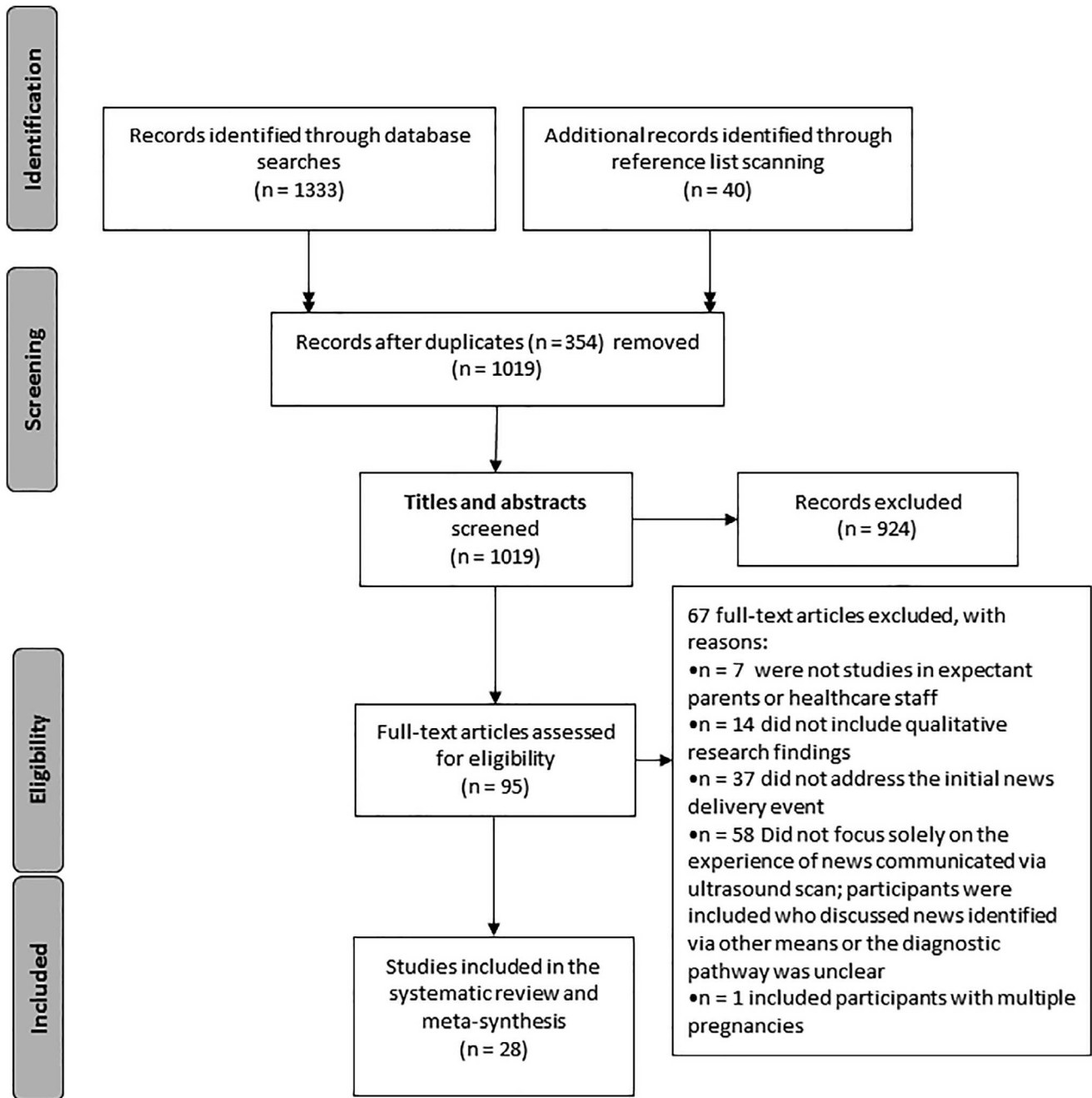


FIGURE 1 PRISMA flow diagram

involving five phases (Expectations of ultrasound scans; Discovery; Shock; Decisions and planning; Adaptation), and how well this journey is navigated depends upon the extent to which two key needs are met (Information needs and Support needs). The “Support needs” theme had three further subthemes: Professional care needs; Support for professionals and Other forms of support (Figure 2 and Table 2). See Table S3 for the Translation table containing details of all first, second and third order constructs. Where both studies in expectant parents and staff contributed to a theme, the findings from expectant parents are outlined first, followed by the findings in staff.

3.1.1 | Expectations of ultrasound scans

When there were no concerning pregnancy symptoms, routine ultrasound scans were usually anticipated positively by parents, and some brought several family members.^{10,34,36,46} Parents going for routine scans drew on cues such as the baby kicking to reassure themselves their pregnancy was healthy.^{43,46} However, parental expectations were less positive when there were concerning symptoms such as bleeding.²⁹ Some parents in these situations waited anxiously for scans to confirm the viability of their pregnancy and overestimated the diagnostic capabilities of ultrasound.²⁷

TABLE 1 Study characteristics

| Source | Country | Aims | Participant group, sample size and response rate (%) | Ethnicity, proportion % | Male sex, proportion % | Recruitment method | Research setting | Fetal condition/s identified | Methods | Data collection method | Analytic approach |
|-----------------------------|----------------|---|--|-------------------------|------------------------|--|---|--|---|------------------------|--|
| Aite et al ³¹ | Italy | To assess the applicability of the Drotar model for expectant parents receiving a prenatal diagnosis of congenital malformation | Expectant parents; n = 50 (74%) | Unclear | 0 (0%) | Women counselled at an institution for prenatal surgical consultation over a 3-year period were invited to participate; specific recruitment method unclear | Setting of the interviews is unclear | Abdominal wall defects, intestinal atresia and diaphragmatic hernia | Mixed methods. Qualitative portion of the study consisted of responses to open questions in the interview | Unclear | Unclear |
| Asplin et al ¹¹ | Sweden | To explore women's experiences of information received regarding fetal malformation identified by ultrasound | Expectant parents; n = 27 (100%) | Unclear | 0 (0%) | Purposeful sampling. Participants were informed at their ultrasound unit about the study verbally and with written information. They were later contacted by telephone to confirm participation | Participants were interviewed either in the ultrasound unit, at the office of the interviewer, or at their home or work | Range of fetal malformations (Gastroschisis; Partial term agenesis; Diaphragmatic hernia; Unspecified stomach malformation; Cardiac anomaly; Omphalocele; Increased nuchal translucency; Cardiac anomaly; Spina bifida; oesophageal atresia; Cardiac anomaly; a missing thumb; Diaphragmatic hernia; hydrops, polyhydramnion normal; Lymphangioma normal; Dandy-Walker malformation; Hydrocephaly monosomy; Short extremities; Hygroma; Idiopathic hydrops; Multiple malformation) | Qualitative semi-structured interviews | Face to face | Qualitative content analysis |
| Baillie et al ³⁶ | United Kingdom | To explore the experiences of women in relation to having false positive results from obstetric ultrasound screening | Expectant parents, n = 24 (82%) | Caucasian (92%) | 0 (0%) | Women who were referred to the Fetal Medicine Unit were given a Patient Information Sheet and told about the study by the consultant doctor. If they were willing to be contacted after diagnostic results were known, he asked them to leave a signed consent form or to post this. Consenting and eligible participants were then contacted by phone | Participants were interviewed either in a private room at the clinic, their home or their place of work | False positive chromosomal abnormality results | Qualitative interviews | Face to face | Interpretive Phenomenological Analysis |

(Continues)

TABLE 1 (Continued)

| Source | Country | Aims | Participant group, sample size and response rate (%) | Ethnicity, proportion % | Male sex, proportion % | Recruitment method | Research setting | Fetal condition/s identified | Methods | Data collection method | Analytic approach |
|-----------------------------|---------------|--|--|--|------------------------|---|---|---|--|--------------------------------|--|
| Black ³⁷ | United States | To describe the experiences of expectant parents as they interpreted and made meaning of the fact that their fetus had a significant disability, with a focus on how facts were presented to them and how they constructed their personal truth | Expectant parents, n = 25 (response rate unclear) | White (60%); Black (20%); Hispanic (20%) | 10 males (40%) | Purposeful sampling used; participants were recruited via a maternal-fetal medicine clinic, specific recruitment methods unclear | Interviews were conducted in participants' homes | Range of fetal anomalies including diaphragmatic hernia, Renal agenesis, Acrania/Anencephaly, Skeletal dysplasia, Cardiac defect, Nonimmune hydrops, Trisomy 18, Trisomy 21 | Qualitative interviews | Face to face | Unclear |
| Bratt et al ³² | Sweden | To explore expectant parents' experiences of counselling and need for support during pregnancy following diagnosis of a cardiac defect. A second aim was to use this information to inform a follow-up programme for support after the first counselling | Expectant parents, n = 12 (86%) | Unclear | Six males (50%) | Participants were informed about the study at an appointment at the fetal cardiology centre and provided consent there | Interviews were conducted at a location of the participant's choice | Congenital heart disease | Qualitative interviews | Face to face | Qualitative content analysis |
| Bryar ³⁸ | United States | To explore the experiences of women undergoing second-trimester pregnancy termination for fetal anomalies | Expectant parents, n = 3 (60%) | White (100%) | 0 (0%) | Women were provided with a letter explaining the study at their follow-up appointment at a private outpatient perinatal practice, 4 weeks after their pregnancy termination procedure | Participant's homes | Fetal chromosomal abnormalities or central nervous system disorders (specific diagnoses not provided) | Unstructured qualitative interviews | Face to face | Phenomenological qualitative analysis |
| Chaplin et al ¹¹ | Australia | To explore parents' experiences and decision-making processes following prenatal identification of Spina Bifida and/or Hydrocephalus | Expectant parents, n = 15 (26%) | Unclear | 4 (27%) | Through Spina Bifida and Hydrocephalus Queensland (SBH Queensland). Invitation letters were sent to families of children aged up to 7 years with Spina Bifida and/or Hydrocephalus | Setting of the interviews is unclear | Spina bifida/hydrocephalus | Qualitative semi-structured interviews | Face to face or over the phone | Qualitative analysis (specific method not described) |

TABLE 1 (Continued)

| Source | Country | Aims | Participant group, sample size and response rate (%) | Ethnicity, proportion % | Male sex, proportion % | Recruitment method | Research setting | Fetal condition/s identified | Methods | Data collection method | Analytic approach |
|--------------------------------------|---------------|---|--|--|------------------------|---|---|--|---|------------------------|------------------------------|
| Cristofalo et al ³⁹ | United States | To explore women's experiences, and to provide information to guide practitioners when a Choroid Plexus Cyst is identified prenatally | Expectant parents, n = 35 (45%) | White (88.2%); African American (5.9%); Asian (5.9%) | 0 (0%) | Women told about the study by a sonographer/obstetric practitioner after their ultrasound results had been discussed with them by the attending physician | Setting of the interviews is unclear | Isolated choroid plexus cysts | Qualitative interviews involving open ended and specific questions as part of a mixed methods study | Unclear | Thematic content analysis |
| Edvardsson et al ²⁶ | Norway | To explore obstetricians' experiences and views of the use of ultrasound in clinical management of pregnancy | Obstetricians, n = 20 (response rate unclear) | Unclear | 5 (25%) | Participants recruited as part of a larger study, via hospital heads of obstetrics and gynaecology | Setting of the interviews is unclear | Range of fetal anomalies discussed | Qualitative interviews | Unclear | Qualitative content analysis |
| Edvardsson et al ²⁸ | Australia | To explore obstetricians' experiences of ultrasound for clinical management of complicated pregnancy and their perceptions of expectant parents' experiences | Obstetricians, n = 14 (response rate unclear) | Unclear | 4 (29%) | Participants recruited as part of a larger study; hospital department heads provided names and contact details of participants and helped set up interview dates | Interviews conducted in the hospitals participants worked in | Range of fetal anomalies discussed | Qualitative interviews | Face to face | Qualitative content analysis |
| Jansson and Adolfosson ²⁹ | Sweden | To explore experiences of midwives' and nurses' when a missed miscarriage is identified during a routine ultrasound scan | Nurses and midwives, n = 13 (response rate unclear) | Unclear | Unclear | Participants were identified via departmental heads and informed of the study | Interviews conducted at participants' workplaces, at their reception desk or the clinic consultation room | Missed miscarriage identified during routine ultrasound scan | Qualitative semi-structured interviews | Face to face | Content analysis |
| Lalor and Begley ⁴⁶ | Ireland | To explore women's experiences when a fetal abnormality is identified during a routine ultrasound examination, and the factors that influenced their preparedness | Expectant parents, n = 38 (61%) | Unclear | 0 (0%) | Women were initially informed about the study by a clinician. Women who indicated a willingness to participate by phoning or returning an "indication of interest" form to the researcher were then sent an information pack and consent form | Interviews were conducted in participants' homes | Range of fetal anomalies (Anencephaly; Renal agenesis; Trisomy 13, 18 and 21; Limb abnormality; Skeletal disformity; Turners syndrome; diaphragmatic hernia; Abdominal wall defects; Talipies) | Qualitative unstructured interviews | Face to face | Grounded theory |

(Continues)

TABLE 1 (Continued)

| Source | Country | Aims | Participant group, sample size and response rate (%) | Ethnicity, proportion % | Male sex, proportion % | Recruitment method | Research setting | Fetal condition/s identified | Methods | Data collection method | Analytic approach |
|-----------------------------|---------|--|--|-------------------------|------------------------|---|---|--|-------------------------------------|------------------------|---------------------------------------|
| Lalor et al ⁴⁷ | Ireland | To explore the information-seeking behaviour of women after an abnormality has been identified via ultrasound scan | Expectant parents, n = 41 (63%) | Unclear | 0 (0%) | Women were initially informed about the study by a clinician. Women who indicated a willingness to participate by phoning or returning an 'indication of interest' form to the researcher were then sent an information pack and consent form | Interviews were conducted in participants' homes | Range of fetal anomalies (Anencephaly; Renal agenus; trisomy 13, 18 and 21; Limb abnormality; Skeletal disformity; Turners syndrome; diaphragmatic hernia; Abdominal wall defects; Talipies) | Qualitative unstructured interviews | Face to face | Longitudinal grounded theory approach |
| Lalor et al ⁴⁸ | Ireland | To explore women's experiences of encounters with caregivers following identification of fetal abnormality during a routine ultrasound scan | Expectant parents, n = 38 (response rate unclear) | Unclear | 0 (0%) | This data was collected during a follow-up to a previous study. Women had initially been informed about the study by a clinician, and those who indicated a willingness to participate by phoning or returning an 'indication of interest' form to the researcher were then sent an information pack and consent form | Interviews conducted in participants' homes | Range of fetal anomalies (Anencephaly; Renal agenus; trisomy 13, 18 and 21; Limb abnormality; Skeletal disformity; Turners syndrome; diaphragmatic hernia; Abdominal wall defects; Talipies) | Qualitative unstructured interviews | Face to face | Constant comparative method |
| Larsson et al ³³ | Sweden | To develop a theoretical understanding of parents' experiences and responses when their fetus was found to have Choroid Plexus Cysts during a routine ultrasound examination | Expectant parents, n = 19 (100%) | Unclear | 9 (47%) | Participants were recruited as part of a larger study. Participants had already given written consent as part of this and so were contacted by phone and asked to participate in this study. A time for the interview was arranged following verbal consent during this phone call | Interviews were conducted at a university or in the participants' homes | Isolated choroid plexus cysts | Qualitative interviews | Face to face | Grounded theory |

TABLE 1 (Continued)

| Source | Country | Aims | Participant group, sample size and response rate (%) | Ethnicity, proportion % | Male sex, proportion % | Recruitment method | Research setting | Fetal condition/s identified | Methods | Data collection method | Analytic approach |
|-------------------------------|---------------|--|--|-------------------------|------------------------|--|--|---|---|---------------------------|-------------------------------|
| Larsson et al ³⁴ | Sweden | To develop a theoretical understanding on parental experiences when their fetus is found to have a fetal abnormality during a routine ultrasound scan | Expectant parents, n = 16 (89%) | Unclear | 7 (44%) | Participants were recruited as part of a larger study. Participants had already given written consent as part of this and so were contacted by phone and asked to participate in this study. A time for the interview was arranged following verbal consent during this phone call | Unclear | Range of fetal anomalies (Kidney dysplasia; Trisomy 18; Fetal hydronefrosis; Multiple malformations; Club foot; Cardiac anomaly; Duodenal atresia; Cleft lip; Heart misplacement) | Qualitative interviews | Face to face | Grounded theory |
| Lokmic et al ⁴² | Australia | To explore parental experiences following prenatal diagnosis of Lymphatic Malformations | Expectant parents, n = 10 (response rate unclear) | Unclear | 5 (50%) | Participants were recruited from an anomalies clinic at a children's hospital, specific methods unclear | Participants were interviewed at a children's hospital or by telephone | Lymphatic malformations | Qualitative semi-structured interviews | Face to face or telephone | Thematic analysis |
| Marokakis et al ⁴³ | Australia | To explore parents' experiences of counselling after prenatal diagnosis of congenital kidney and urinary tract anomalies | Expectant parents, n = 17 (40%) | Unclear | 8 (47%) | Purposive sampling used. Participants recruited via letter to their home address | Interviews conducted by telephone | Posterior urethral valves, Multicystic dysplastic kidney | Qualitative semi-structured | Telephone | Conceptual framework analysis |
| McKechnie et al ⁴⁰ | United States | To explore parents' caregiving motivation to manage maternal-fetal and infant healthcare and to examine links between parents' motivation to manage healthcare and their distress symptoms following a fetal diagnosis and afterbirth treatment of their infant's Complex congenital heart disease | Expectant parents, n = 12 (response rate unclear) | White (100%) | 6 (50%) | Participants were recruited via a tertiary care centre as part of a larger study; specific recruitment methods unclear | Interviews conducted at participants' homes or at the hospital | Complex congenital heart disease | Mixed methods. Qualitative portion of the study consisted of semi structured interviews | Face to face | Content analysis |

(Continues)

TABLE 1 (Continued)

| Source | Country | Aims | Participant group, sample size and response rate (%) | Ethnicity, proportion % | Male sex, proportion % | Recruitment method | Research setting | Fetal condition/s identified | Methods | Data collection method | Analytic approach |
|---------------------------------|----------------|---|---|---|------------------------|---|--|---|--|------------------------|--|
| Meaney et al ⁴⁹ | Ireland | To explore the impact of death of one twin in the perinatal period. | Expectant parents, n = 9 (60%) | Unclear | 4 (44%) | Expectant parents who had experienced a perinatal death during or following a twin pregnancy were recruited, but the specific method of recruitment is unclear | Participants interviewed within a private room at the hospital | Hydrops fetalis secondary to cystic hygroma, Holoprosencephaly, Trisomy 13, Anencephaly, Bilateral Cleft Lip, Ventriculomegaly | Qualitative interviews | Face to face | Interpretive phenomenological analysis |
| Mitchell ¹⁰ | Canada | To examine how women perceive ultrasound when they receive unexpected abnormal ultrasound findings | Expectant parents, n = 42 (24% of those who were contacted via the hospital anomaly database responded. Response rate not available for participants who responded to advertisements) | Euro-Canadian (93%) | 0 (0%) | Two recruitment methods: participants were either (a) contacted by the hospital via the hospital anomaly database as part of a larger study, or (b) responded to advertisements or information about the study from their physician | Setting of the interviews is unclear | Range of fetal anomalies (Anencephaly; Renal agenesis; Hydrocephaly; Renal anomalies; Spina bifida; Club foot; Cleft palate; Choroid plexus cysts) and first trimester fetal demise | Qualitative semi-structured interviews | Face to face | Qualitative content analysis |
| Norton and Furber ²⁷ | United Kingdom | To explore women's experiences of care in an early pregnancy assessment unit (EPAU) | Expectant parents, n = 10 (33%) | White European (80%); South-Asian (20%) | 0 (0%) | The Early Pregnancy Assessment Unit nursing team handed our information sheets about the study | Interviews were conducted at participants' homes or university premises, dependent upon their preference | Miscarriage | Qualitative interviews | Face to face | Interpretive phenomenological analysis |
| Oscarsson et al ³⁵ | Sweden | To explore women's reactions to the discovery of fetal hydronephrosis in the context of uncertainty regarding the prognosis | Expectant parents, n = 10 (response rate unclear) | Unclear | 0 (0%) | Eligible women were identified via hospital records and invited to interview | Interviews were conducted in a quiet room at a university hospital clinic | Fetal hydronephrosis | Qualitative semi-structured interviews | Face to face | Constant comparative method |
| Rådestad et al ⁹ | Sweden | To explore experiences of receiving in utero death news via ultrasound | Expectant parents, n = 26 (response rate unclear) | Unclear | 0 (0%) | Participants responded to advertisements via the Swedish National Infant Foundation website, which is a member of the International Stillbirth Alliance | Participants were interviewed in their own home or at another location comfortable for them. | Still-birth/in utero death after 28 weeks gestation | Qualitative interviews | Face to face | Qualitative analysis (specific method not described) |

TABLE 1 (Continued)

| Source | Country | Aims | Participant group, sample size and response rate (%) | Ethnicity, proportion % | Male sex, proportion % | Recruitment method | Research setting | Fetal condition/s identified | Methods | Data collection method | Analytic approach |
|-------------------------------------|----------------|---|--|-------------------------|------------------------|---|---|---|---|------------------------|------------------------------|
| Schuth et al ²⁵ | Germany | To document the emotional and cognitive needs of parents affected by fetal malformation in as much detail as possible | Expectant parents, n = 80 (response rate unclear) | Unclear | 24 (30%) | Participants were identified via hospital records; specific recruitment methods unclear | Setting of the interviews is unclear | A range of fetal anomalies (Hydrocephalus; Spina bifida; Anencephaly; Multiple malformations; Hypoplastic left heart syndrome; Transposition of the great arteries; Ventral wall defect; Down's syndrome; Turner's syndrome; Tay-Sachs syndrome; Cleft palate; Coccydeal teratome; Osteogenesis imperfecta) | Mixed methods | Unclear | Content analysis |
| Simpson and Bor ²⁰ | United Kingdom | To explore the experiences of obstetric sonographers imparting diagnostic information which may be considered "bad news" to expectant mothers | Obstetric sonographers, n = 9 (100%) | Unclear | Unclear | Participants were recruited at their place of work; specific recruitment methods unclear | Interviews were conducted at participants' places of work (one of two London hospitals) | Range of fetal anomalies discussed (Spina bifida; short limbs; combination of soft markers; echogenic papillary muscles) and fetal demise. Twins/multiple pregnancy and female baby also considered as possible 'bad news' events | Mixed methods. Qualitative portion of the study consisted of qualitative interviews | Face to face | Theme analysis |
| Sommersest and Sundby ⁴⁴ | Norway | To describe and understand some pregnant women's thoughts, feelings and dilemmas of choice when unexpected findings were diagnosed after a routine ultrasound examination | Expectant parents, n = 22 (response rate unclear) | Unclear | 0 (0%) | Two recruitment methods: participants were either (a) recruited via a hospital ultrasound laboratory or (b) responded to advertisements distributed via a Norwegian network for women with different ultrasound experiences | Interviews were conducted at or near participants' homes | Range of fetal anomalies including lethal abnormalities and soft sign markers | Qualitative semi-structured interviews | Face to face | Unclear |
| Trulsson and Rådestad ⁴⁵ | Norway | To explore why induction of delivery should not be delayed more than 24 hours from the diagnosis of intrauterine demise for most women | Expectant parents, n = 12 (response rate unclear) | Unclear | 0 (0%) | Participants were recruited via a university hospital, but the specific recruitment method is unclear | Unclear | Still-birth/in utero death after 24 weeks gestation | Qualitative interviews | Unclear | Phenomenological methodology |

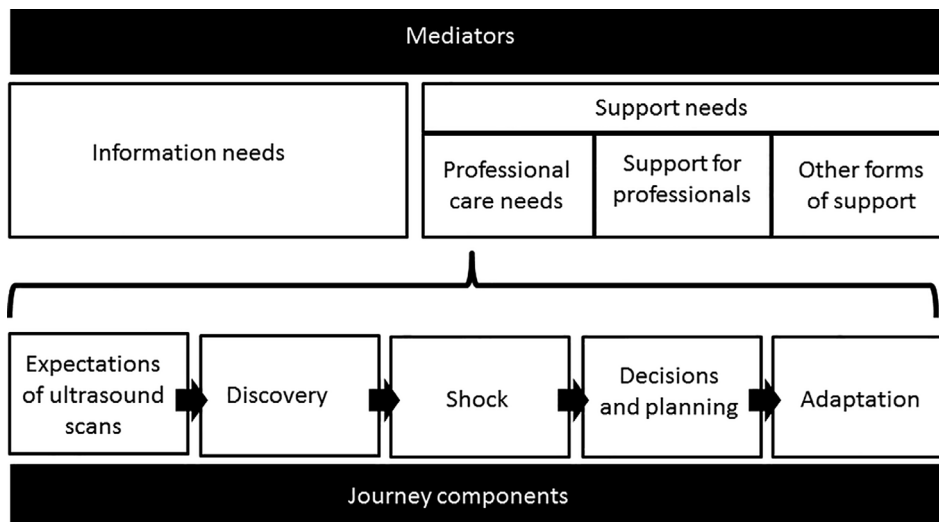


FIGURE 2 Third-order themes identified in the synthesis suggested that news delivered via ultrasound is a journey involving five phases. How well this journey is navigated depends upon the extent to which information needs and support needs are met

TABLE 2 Studies represented within each theme

| Study | Theme 1: Expectations of Ultrasound scans | Theme 2: Discovery | Theme 3: Shock | Theme 4: Decisions and planning | Theme 5: Adaptation | Theme 6: Information needs | Theme 7a: Support needs (professional care needs) | Theme 7b: Support needs (support for professionals) | Theme 7c: Support needs (other forms of support) |
|---|---|--------------------|----------------|---------------------------------|---------------------|----------------------------|---|---|--|
| 1. Sommerseth and Sundby ⁴⁴ | | | √ | √ | | | | | |
| 2. Lalor and Begley ⁴⁶ | √ | | √ | | | | | | |
| 3. Larsson et al ³³ | | √ | | √ | √ | √ | | | √ |
| 4. Asplin et al ¹¹ | | | | | | √ | √ | | |
| 5. Jansson and Adolfsson ²⁹ | √ | √ | √ | | | | √ | | |
| 6. Lalor et al ⁴⁸ | | √ | | | | √ | √ | | |
| 7. Larsson et al ³⁴ | √ | √ | √ | √ | | √ | √ | | |
| 8. Bratt et al ³² | | | | √ | | √ | √ | | √ |
| 9. McKechnie et al ⁴⁰ | | | | | √ | | √ | | |
| 10. Edvardsson et al ²⁸ | √ | √ | √ | | | | √ | | |
| 11. Marokakis et al ⁴³ | √ | | √ | | | √ | √ | | √ |
| 12. Baillie et al ³⁶ | √ | | √ | √ | √ | | | | |
| 13. Bryar ³⁸ | | √ | √ | √ | √ | | | | |
| 14. Cristofalo et al ³⁹ | | | √ | √ | | √ | | | |
| 15. Mitchell ¹⁰ | √ | √ | | | | √ | | | |
| 16. Oscarsson et al ³⁵ | | | √ | | √ | √ | | | |
| 17. Simpson and Bor ³⁰ | | √ | √ | | | | | √ | |
| 18. Edvardsson et al ²⁶ | √ | | | √ | | √ | √ | √ | |
| 19. Lalor et al ⁴⁷ | | | | √ | | √ | | | |
| 20. Lokmic et al ⁴² | | | √ | √ | √ | √ | | | |
| 21. Black ³⁷ | | | | √ | √ | √ | | | |
| 22. Chaplin et al ⁴¹ | | | √ | √ | | √ | √ | | √ |
| 23. Aite et al ³¹ | | | √ | | √ | | | | |
| 24. Meaney et al ⁴⁹ | | | | √ | √ | | | | |
| 25. Schuth et al ²⁵ | | | √ | √ | | | | | |
| 26. Norton and Furber ²⁷ | √ | | | √ | √ | √ | √ | | |
| 27. Rådestad et al ⁹ | | √ | √ | | | | | | |
| 28. Trulsson and Rådestad ⁴⁵ | | √ | √ | √ | | | √ | | |

Obstetricians sensed parents' misperceptions regarding scans²⁶ and explained this by highlighting that ultrasound is frequently used when complications are not expected.²⁸ This lack of understanding in parents made the task of communicating news harder for staff.^{26,28}

3.1.2 | Discovery

Parents described details of the news delivery event^{9,10,33,34,38,45,48} and were attuned to the body language of the HCP, the length of the scan and which part of the baby the HCP was focusing on.^{9,33,34,38} They were aware when the HCP had identified something unexpected and wanted information immediately.^{9,10,34,45,48} Parents attended to the specific words used by the HCP^{9,10,34,38,48} and wanted clear information to be communicated kindly; they felt frustrated by vague terminology.^{10,38,48}

HCPs aimed to provide clear information²⁸⁻³⁰ but experienced barriers, including the challenges of communicating uncertain scan findings,²⁸ balancing clarity with sensitivity³⁰ and leaving the room to gain a second opinion.³⁸ They used euphemisms^{29,30} to reduce parental distress.³⁰ Similar to expectant parents, staff were also aware of the specific phrases and behaviours they adopted when delivering news.²⁸⁻³⁰

3.1.3 | Shock

On hearing the news, parents went into shock.^{9,25,31,34,36,38,39,41-46} Shock was a consistent reaction with physical, emotional, cognitive and behavioural impacts.^{9,31,34,39,44,45} Parents struggled to mentally process information at this time.^{25,31,39,43,45} Expectant parents felt overwhelmed if offered termination at the initial disclosure event and decisions which were made about pregnancy management options during this phase were not always maintained over following weeks.^{9,36,44} Persistent underlying hope was common; for some parents this was a hope that uncertain findings would turn out to be clear; for others this was "denial" in response to certain but unwanted news.^{31,34,39,44} Male partners' reactions to the news appeared to be less extreme than women's.^{29,30}

Staff found shock reactions challenging; some felt a responsibility to reduce parents' immediate distress and avoid causing psychological harm.^{28,30}

3.1.4 | Decisions and planning

Parents progressed from their initial shock to consider the decisions and provisions that would need to be made.^{25,27,32-34,36-39,41,42,44,45,47,49} Feelings of anxiety were common.^{33,36,39,47} The specific components of this phase varied according to the complication identified, but in all situations, parents needed time to process the news and to ask questions.^{25,36,38,45} They did not want to be asked to make decisions immediately^{25,37,38} but they needed follow-up appointments and test results quickly.^{36,47} Parents were keen to understand the opinions of their HCPs^{36,44} but wanted HCPs to

support them to make their own choices.^{25,27,37} When parents had experienced a miscarriage or still-birth, management options were often limited.^{27,45} In these situations, parents appreciated it when staff made efforts to provide any options that were available, for example, around timing or location of the delivery.^{27,45} Parents were often motivated to reduce uncertainty about the future.^{32,33,36,38,39,41,47} Those planning the birth of a baby wanted information about what would happen during and after birth^{32,34,41,42}; those considering invasive testing valued the certainty this could offer.^{33,39,47}

Obstetricians experienced moral challenges when supporting parents with these challenges.²⁶

3.1.5 | Adaptation

Parents talked about how they adapted to their situation.^{27,31,33,35-38,40,42,49} The specific components of this phase varied according to the complication identified and parents' decisions (regarding testing and termination), but three experiences were common across situations. The first was the need to develop new coping strategies to meet their situations, whether this was managing persistent uncertainty, loss or parenthood.^{31,33,35,37,38} The second was equivocal adaptation; some parents suggested their situation left a psychological imprint.^{27,31,33,36,38,49} The third was the importance of others' reactions: parents needed to be supported and to have their losses acknowledged^{27,37,49} and those who had babies with disabilities wanted their children to be accepted.⁴² No studies in HCPs addressed this phase.

3.1.6 | Information needs

Psychologically, information helped to reduce parental uncertainty and the anxiety this engendered.^{11,24,27,33,34,39,41,47} Practically, information helped parents to make decisions around invasive testing and pregnancy management and to prepare for babies with health conditions.^{10,27,34,35,41,42,47} Parents needed to be able to speak to HCPs and to ask questions.^{11,27,33,35,39,41,42,47} Parents appreciated it when HCPs used visual aids including ultrasound.^{10,37,48} Parents were sometimes unfamiliar with the abnormality which had been identified and needed to learn about this.^{33,35,39,42,43,48} Having the correct terminology was important, as it helped parents to communicate the abnormality to others and to search the internet more effectively.^{32,33,41,42} Internet searching was common^{11,27,32,35,37,39,42,43,47}; in some cases this fulfilled non-medical information needs, such as understanding the experiences of others in their situation.^{39,42} Some parents described negative experiences of online searching.^{32,35,39,43,47} Individual differences for information provision were evident: while some parents wanted information as quickly as possible, others felt overwhelmed.^{35,41,47} All parents appreciated written information which could be read at their own pace.^{32,42,43,48}

Obstetricians were aware of the benefits of information which could be provided via ultrasound images, and used these to help parents create memories, where abnormalities were fatal.²⁶

3.1.7 | Support needs (professional care needs)

Parents needed to feel listened to and cared for by HCPs.^{11,27,32,40,41,45,48} They appreciated it when HCPs did not rush them and made eye contact during conversations.^{27,34,40,41,45,48} When pregnancy outcome was uncertain, parents wanted balanced information.⁴¹ A positive approach was important for parents continuing with pregnancies; they wanted to be treated as parents and for their babies to be treated as persons in their own right.^{11,34} Short waits between appointments were important: even brief delays were distressing.^{32,48} Parents wanted the phone number of an HCP they could contact with questions.^{32,43} Some parents wanted psychological support.^{34,43,48}

HCPs were aware of the need to give parents time to talk and to show empathy^{28,29} and some offered parents a phone number.^{26,29} Barriers to ideal care provision were uncertainty in the diagnosis, the fear of causing anxiety and time pressures.²⁶

3.1.8 | Support needs (support for professionals)

No parent studies addressed this theme. Studies in HCPs found that delivering unexpected news was challenging for HCPs.^{26,30} Some said it carried a high emotional toll; they both feared these events occurring and then ruminated on them once they had passed.^{26,30} Some HCPs drew on the positive aspects of their work and collegial support to cope.³⁰

3.1.9 | Support needs (other forms of support)

Parents drew on the support of family and friends to help them to mentally adjust to their situation, reach decisions and to cope.^{32,33,41} Parents benefited from the support of other parents who had been in the same situation,^{32,41,43} although some found they accessed inaccurate information via these forums.⁴³ No studies in HCPs addressed this theme.

4 | DISCUSSION

4.1 | Summary of the main findings

The delivery of challenging news identified via ultrasound could be viewed as a journey involving five phases. First was expectations prior to the scan. Parents generally anticipated their scans as positive, social events. HCPs reported that misperceptions of the purpose of scans made communicating difficult news harder. Second was the discovery experience; parents and professionals recounted specific details of difficult news events including the exact phrases used by HCPs. Parental shock followed these discoveries, which impaired their information processing capacity. Identification of complications required parents to engage in planning and decision-making they had not anticipated; this phase engendered anxiety in parents and professionals. Once these phases had passed parents engaged in adaptation to their new, unexpected situation. The extent to which two key needs were met strongly influenced how well this journey

was navigated. The first need was for information, which was sought from HCPs and the internet. The second was the need for support, which was sought from HCPs, peer support networks and friends and family. HCPs also described needing support to manage these challenging events.

4.2 | Strengths and limitations

The review was strengthened by the inclusion of a pre-specified protocol registered on PROSPERO and the use of CASP criteria to establish study quality. It used a meta-ethnographic approach; this allows the properties of primary qualitative data to be preserved while enabling new, higher level insights to be generated.¹⁹ It was limited by a lack of data from ethnic minority participants.^{10,36-40}

4.3 | Interpretation

This is the first systematic review exploring parent and staff experiences of news of pregnancy complications identified via ultrasound. Our findings converge with three reviews addressing experiences of prenatal diagnosis more broadly. Our findings regarding parents' needs concur with results from an integrative review into mothers' experiences of prenatal diagnoses which found that HCPs' communication skills helped them cope.¹³ Our results also converge with a review of qualitative studies into experiences of lethal prenatal diagnoses, which suggested that parents valued timely, written information about the diagnosis.¹⁴ In line with a literature review into breaking bad news in prenatal settings, our results suggested that expectant parents wanted HCPs to communicate their findings in clear but sensitive terms.¹⁵ Our results differed from these previous reviews by identifying the experience of receiving news via ultrasound as a journey which begins with expectations of ultrasound scans. Unlike other prenatal tests, parents often positively anticipate their scans as a social event. Also unique to ultrasound is the nature of the examination: parents are in a dark room, often in silence, and women are lying down. In this setting, every behaviour of the HCP is salient. Shock was a common experience in parents in our review; the ultrasound setting amplifies this.

4.4 | Practical and research recommendations

Clinicians can take three steps to improve care quality. First, they could avoid euphemisms and use correct terminology. Most parents will search online and having correct terms enables them to access suitable information more quickly. It also helps them communicate the finding to others. Second, clinicians could provide written information; parents usually go into shock after receiving news, but can process written information at their own pace. Third, clinicians could allow themselves to experience uncertainty and offer parents their knowledge, including both best and worst possible future scenarios, rather than promote their own views.

The review supported the policy of disclosing news of complications immediately in the ultrasound room. At present the United

Kingdom is one of the only countries where sonographers routinely communicate the initial news of all types of complications.⁵⁰ In other countries including the United States and Australia, disclosure depends on the type of complication, the discipline of the HCP conducting the scan and their relationship with the referring clinician.^{7,51,52} Our results suggest organisations should promote immediate disclosure.²⁷

The review identified four studies in HCPs: two of these were in obstetricians,^{26,28} one was in nurses and midwives²⁹ and one was in sonographers.³⁰ In several countries internationally, including Australia and the United Kingdom, sonographers conduct the majority of prenatal ultrasound scans. As such, sonographers were likely under-represented in the current review findings, and further research should be conducted to explore their experiences and draw on their expertise to inform practise improvements.

The review highlighted a need for evidence-based guidance for managing the challenges of news delivery which are specific to ultrasound. Guidance exists but does not outline specific behaviours HCPs should use.⁵³ Our results suggest these details are important; interventions should provide guidance on the exact behaviours and phrases which could be employed in relation to different pregnancy complications. Second, there are certain situations which HCPs find particularly challenging, including the communication of news which is uncertain and communicating when parents have brought families with them.^{26,28,30} Evidence-based guidance should address these.

News delivery interventions are effective for improving practitioner communication skills⁵⁴ and sonographers who have received these report lower burnout.⁵⁵ However, only two trials have tested news delivery interventions in obstetrics and these did not focus on ultrasound settings.^{56,57} Our results suggest that positive experiences of care are possible but not widespread. Future research is needed to develop and test ultrasound news delivery interventions to improve HCP confidence and parent experiences.

The review found that misconceptions of the purposes of scans made communication of unexpected findings harder for sonographers. Potential interventions to mitigate this may include improving the information provided to expectant parents before a scan booking is made; it could also include asking expectant parents to complete a detailed consent form immediately prior to receiving a scan. However, studies would be needed to assess the effectiveness of these interventions.

5 | CONCLUSION

Ultrasound is a unique context for the delivery of challenging news due to parents' misperceptions regarding the purpose of ultrasound examinations, the potential for news to be delivered immediately and the possibility of initially identifying unclear findings. Immediately after receiving news, expectant parents go into shock which impairs their information processing ability. HCPs can support parents during this phase by using clear terminology, providing written information and offering balanced information when communicating uncertain findings.

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CONFLICT OF INTEREST

Members of the authorship team (J. J., J. A.) have previously been awarded funding from the Society and College of Radiographers to undertake research into news delivery via ultrasound. The lead author has received personal payments for delivering workshops on news delivery via ultrasound for the Society and College of Radiographers and Canon Medical Systems Ltd.

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SUPPORTING INFORMATION

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

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