ORIGINAL ARTICLE

Prenatal counselling for congenital anomalies: a systematic review

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ABSTRACT

Objective Prenatal diagnosis of fetal anomalies may arouse fear, anxiety and distress in parents, and counselling may assist parents to cope with the diagnosis. This systematic review aimed to (1) synthesise the evidence on the impact of non-genetic, prenatal counselling after fetal diagnosis of a congenital anomaly on parental knowledge and psychological adjustment and (2) identify parents' preferences for the timing and format of counselling.

Method Five electronic databases were systematically searched to identify studies assessing prenatal counselling provided to parents after prenatal diagnosis of one or more structural congenital anomalies. Data were extracted using predefined data forms, according to the preferred reporting items for systematic reviews and meta-analyses guidelines, and synthesised.

Result Twenty four articles were included for review; most articles reported results of retrospective surveys and the quality of included studies was variable. Only three studies assessed parental anxiety, and each reported a significant decrease in anxiety following prenatal counselling. Parents expressed a preference for counselling on all aspects of their baby's anomaly as soon as possible after prenatal diagnosis, and desired written, visual and web-based information resources, and support group contacts.

Conclusion Although prenatal counselling reduced parental anxiety, further research is needed to adequately assess the impact of prenatal counselling on other psychological outcomes. © 2016 John Wiley & Sons, Ltd.

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INTRODUCTION

Congenital anomalies occur in 2 to 4% of live births,[1,2] with a significant proportion detected before birth by routine ultrasound and other screening techniques.[3] Prenatal diagnosis of a congenital anomaly can have significant emotional and psychological consequences for parents of affected babies, with many experiencing shock, sadness, anger, fear, guilt and grief.[4,5] After diagnosis, a significant proportion of parents report levels of anxiety and depression warranting clinical intervention.[5,6] Additionally, parental uncertainty and limited knowledge may later contribute to parenting difficulties.[7]

Given the psychological stress and uncertainty associated with a prenatal diagnosis, it would be expected that parents may benefit from the provision of prenatal counselling, defined as any health professional consultation with parents during pregnancy in which information relevant to their child's congenital anomaly is provided. Evidence for the efficacy of prenatal counselling is, however, piecemeal and to our knowledge, there has been no systematic review of the psychological outcomes associated with prenatal counselling. Thus, the aims of this systematic review were twofold. First, to synthesise the available evidence on the impact of non-genetic, prenatal counselling after prenatal diagnosis of a congenital anomaly on parental psychological adjustment and knowledge. Second, to identify parents' preferences regarding the timing and format of prenatal counselling. This review is likely to benefit health professionals involved in prenatal counselling by providing a comprehensive review of parents' experiences of, and preferred approaches to, prenatal counselling, thus better informing health professionals' counselling practice.

METHODS

The preferred reporting items for systematic reviews and meta-analyses statement guidelines were followed to identify and screen publications, and extract data.[8]

Search strategy

In March 2015, a search of five electronic bibliographic databases (Medline, Embase, PsycInfo, CINAHL and Scopus) was conducted using relevant keywords and subject headings. Search terms were identified in Medline to develop a search strategy, which was then adapted to the other databases (Table 1). Hand searches of the reference lists of included

Table 1 **Search strategies used in each electronic database**

Database	Search terms	Number of records found	Number of unique abstracts selected	Number of unique articles selected
Medline (1946–present)	exp congenital abnormalities and exp parent and (exp counselling or exp patient education as topic)	226	28	11
	exp congenital abnormalities and exp attitude and (exp counselling or exp patient education as topic) and exp prenatal diagnosis	56	1	0
	exp congenital abnormalities and (exp counselling or exp patient education as topic) and (exp stress, psychological or exp anxiety or exp depression or exp 'Quality of Life')	75	8	1
Embase	exp congenital disorder and exp parent and (exp counselling or exp education) and (exp parental attitude or exp satisfaction)	64	5	0
	exp congenital disorder and exp parent and (exp counselling or exp education) and (exp anxiety or exp depression or exp stress or exp psychological well-being)	228	4	0
PsycInfo (1806–present)	exp congenital disorders and exp parents and (exp counselling or exp parent training)	13	3	0
	exp congenital disorders and (exp counselling or exp parent training)	59	2	0
	exp congenital disorders and exp parents and exp attitudes	54	3	0
	exp congenital disorders and exp parents and (exp anxiety or exp distress or exp stress or exp well being or exp 'depression (emotion)')	59	2	0
CINAHL	exp abnormalities and exp parents and exp counselling	32	0	0
	exp counselling and exp abnormalities	51	0	0
Scopus	parent and (counselling or education) and (congenital anomaly or congenital abnormality or birth defect or congenital malformation or congenital disorder)	473	4	0
Other Sources (citation searches and reference list hand searches)		352	44	12
Total				24

articles were undertaken, as well as citation searches using Scopus.

Eligibility criteria

Prenatal counselling' was defined *a priori* as any health professional consultation with parents during pregnancy in which the parents may be provided with information relevant to their child's congenital anomaly. This definition was not limited to any particular theoretical model. Genetic counselling, however, was excluded as there are already existing recent reviews examining the process and outcomes of genetic counselling.[9,10]

Studies were included for review if they met the following *a priori* defined criteria:

(1) Described or made specific mention of prenatal counselling delivered to parents of a baby with a prenatal diagnosis of one or more congenital anomalies.
(2) Included diagnosis of at least one structural congenital anomaly.
(3) Assessed the process of and/or psychological outcomes associated with prenatal counselling.
(4) Published in a peer-reviewed format.

Studies were excluded if:

(1) Counselling was undertaken in the postnatal period only.
(2) The definition of counselling deviated from that outlined earlier or included genetic counselling only.
(3) Case studies, conference/dissertation abstracts, letters, commentaries and non-research articles.
(4) Not written in English.

Study selection

Study selection involved screening search results for titles and abstracts that met the eligibility criteria. The full texts of selected abstracts were examined to assess eligibility for review. Eligible studies were appraised using QualSyst, a tool designed to enable assessment of study quality and risk of bias using a validated checklist and scoring system.[11] Two investigators (S. M. and S. K.) independently appraised all eligible studies, then collaborated to reach consensus and allocate a final QualSyst quality assessment score. Given the lack of a single, recommended 'cut-off' score, and the limited number of published studies addressing the outcomes of interest in this review, all identified studies were appraised according to the QualSyst framework.

Data extraction

Data were extracted using a predefined form developed using the participants, interventions, comparators, outcomes and study design approach.[8] Outcomes included any psychological outcome assessed in relation to prenatal counselling (e.g.

parental anxiety and emotional distress), as well as the effect of prenatal counselling on parental knowledge about their baby's medical condition and information recall. To identify parents' preferences for prenatal counselling, data were also extracted on parental perceptions of the timing of counselling, health professionals involved, topics covered, additional resources or services provided and any suggestions for improving counselling.

RESULTS

Studies identified

The search of databases, citations and reference lists yielded 1743 records, of which 24 studies met eligibility criteria and were included for review (Figure 1). The full text of one record could not be obtained, therefore, was not included despite potential eligibility.[12] Of the 24 included studies (Table 2), there were 17 quantitative studies, six qualitative studies and one mixed-methods study. One study was a randomised control trial (RCT), and one was a pilot study. There were no systematic reviews or meta-analyses. The quality of studies included was variable, with scores ranging from 0.44 to 0.91 (see Tables S1 and S2 for quality assessment results). Potential limitations and biases identified in the reviewed studies are presented in Table S3. The most common limitations were insufficient data to assess if sample size is appropriate ($n = 12$), incomplete control of confounding factors and/or control of confounders insufficiently described ($n = 11$) and investigators not blinded when it was possible to do so ($n = 11$).

Included studies were undertaken in the following countries: the USA ($n = 6$), UK ($n = 4$), Sweden ($n = 3$), Italy ($n = 3$), Australia ($n = 2$), Switzerland ($n = 2$), Belgium ($n = 1$), Netherlands ($n = 1$), Ireland ($n = 1$) and Canada ($n = 1$). The timing of outcome assessment varied widely between studies. In most studies, parental outcomes were assessed after birth ($n = 10$) with assessments occurring between 24 h and 30 years after the child's birth. Nine studies assessed parental outcomes before the birth of the baby, with the timing of assessment varying from immediately after the prenatal consultation to up to 7 weeks post-counselling. Three studies assessed

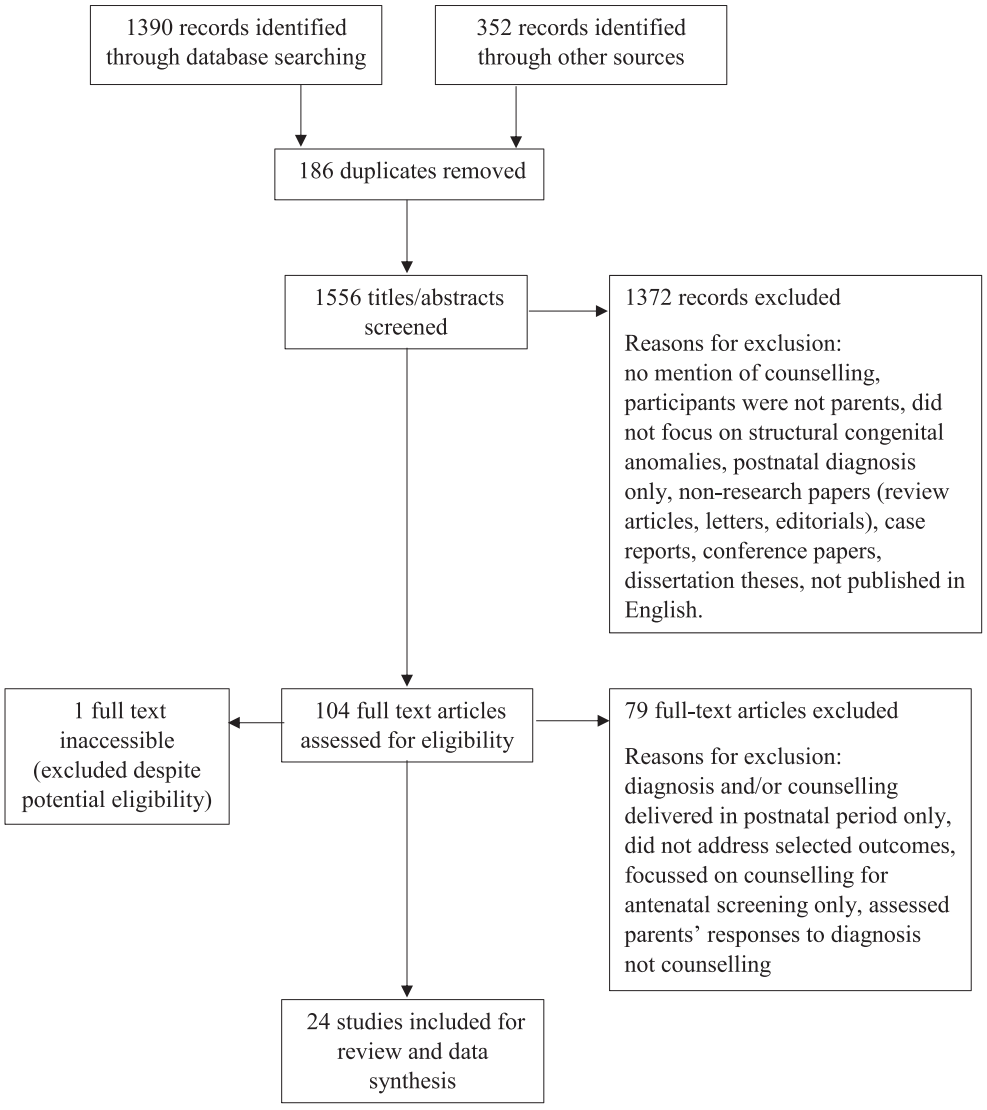

Figure 1 **Flowchart for the process of selection of eligible studies**

Table 2 **Summary of articles included for review**

Study	Country	Type of anomaly	Study design	Measures	Participants	Quality assessment score[a]
Aite *et al.*[14]	Italy	Gastrointestinal surgical anomalies	Quantitative, case control study	Spielberger State-trait Anxiety Inventory (STAI)	Mothers with prenatal diagnosis given multidisciplinary counselling ($n = 16$) and mothers with prenatal diagnosis not given multidisciplinary counselling ($n = 16$)	0.91
Aite *et al.*[36]	Italy	CDH	Quantitative, cross-sectional study	Non-validated questionnaire assessing parental experience of counselling and understanding of the diagnosis	Mothers ($n = 37$) and fathers ($n = 37$) seen for prenatal counselling	0.88
Aite *et al.*[13]	Italy	CCAM and CDH	Quantitative, non-randomised pre-post intervention study	STAI	Mothers who took part in surgical consultation for CCAM ($n = 21$) or CDH ($n = 23$)	0.83
Alkazaleh *et al.*[16]	Canada	Various anomalies	Quantitative, cross-sectional study	Non-validated questionnaires to examine maternal counselling experiences and preferences	Mothers who received a prenatal diagnosis ($n = 76$)	0.77
Arya *et al.*[33]	USA	CHD	Quantitative, cross-sectional study	Non-validated questionnaires to rank importance of counselling topics according to participants	Parents of children with CHD ($n = 41$) and cardiologists ($n = 39$)	0.79
Asplin *et al.*[17]	Sweden	Various anomalies	Qualitative study	A semi-structured interview to explore maternal experiences of diagnosis and counselling	Mothers who received a prenatal diagnosis ($n = 27$)	0.85
Berggren *et al.*[30]	Sweden	CLP	Quantitative, cross-sectional study	Non-validated questionnaires to explore parental experiences and perceived quality of counselling	Parents who received prenatal ($n = 40$) or postnatal ($n = 58$) counselling	0.63
Caldera *et al.*[35]	Australia	CHD	Pilot study	Non-validated questionnaires to assess parental experience of, and satisfaction with the addition of a CD-ROM to counselling	Parents who received a prenatal diagnosis ($n = 14$)	0.44
Carlsson *et al.*[28]	Sweden	CHD	Qualitative study	A semi-structured interview to explore parental experiences	Mothers ($n = 5$) and fathers ($n = 6$) who received a prenatal diagnosis	0.85
Cockayne *et al.*[31]	UK	Spina bifida	Qualitative study	A structured interview to explore parental experiences	Parents who received a prenatal diagnosis ($n = 11$)	0.55
Cope *et al.*[18]	UK	Various anomalies	Randomised control trial with mothers randomised to 4 information groups (standard practice, non-technical letter, audiotape, and combined letter and audiotape).	STAI, Beck's Depression Inventory and a semi-structured interview for information recall	Mothers who received a prenatal diagnosis of an anomaly ($n = 61$) or soft markers indicating possibly anomaly ($n = 25$), and mothers with a healthy pregnancy ($n = 25$)	0.88
Davalbhakta and Hall[26]	UK	CLP	Quantitative, cross-sectional study	Non-validated questionnaires to examine parental counselling experiences and perceived quality of information delivered	Parents who received prenatal ($n = 27$) or postnatal diagnosis ($n = 63$)	0.46
Dennett *et al.*[24]	USA	CDH	Quantitative, longitudinal study	Short Form 36 to assess parental well-being at 3 time-points; prenatal, 2 weeks post-surgery and 6 weeks post-surgery	Parents who received prenatal ($n = 26$) or postnatal ($n = 15$) counselling	0.67

(Continues)

Table 2 **(Continued)**

Study	Country	Type of anomaly	Study design	Measures	Participants	Quality assessment score[a]
Engels *et al.*[25]	Belgium	CDH	Quantitative, non-randomised pre-post intervention study of web-based information	Non-validated questionnaires to examine parental counselling experiences, understanding of the diagnosis and surgery, and satisfaction with web-based information	Mothers who received counselling prior to fetoscopic surgery for CDH ($n = 102$)	0.67
Hilton-Kamm *et al.*[34]	USA	CHD	Quantitative, cross-sectional study	Non-validated online survey to explore parental experiences of diagnosis and perceptions or counselling	Parents of children with CHD ($n = 841$)	0.71
Hunfeld *et al.*[19]	Netherlands	Various anomalies	Quantitative, cross-sectional study	Counsellor Rating Form-short Version (CRF-S), the Satisfaction Scale, a topic recall checklist, and the Global Affect Measure to assess physician-parent communication	Mothers referred for fetal anomaly scan ($n = 24$)	0.75
Kemp *et al.*[15]	UK	Surgical anomalies (excluding urologic, orthopaedic and neurological	Quantitative, non-randomised pre-post intervention	STAI	Parents who received a prenatal diagnosis ($n = 45$) and mothers with a healthy pregnancy ($n = 30$)	0.71
Kuttenberger *et al.*[27]	Switzerland	CLP	Quantitative, cross-sectional study	Non-validated questionnaires to examine parental counselling experiences and perceptions	Parents who received a prenatal ($n = 12$) or postnatal ($n = 61$) diagnosis	0.78
Lalor *et al.*[20]	Ireland	Various anomalies	Qualitative study	In-depth, unstructured interviews to explore maternal experiences	Mothers who received a prenatal diagnosis ($n = 38$)	0.9
Matthews *et al.*[22]	USA	CLP	Quantitative study	Medical chart review and non-validated questionnaires to explore parental experiences	Parents who received prenatal diagnosis ($n = 9$)	0.64
Menahem and Grimwade[23]	Australia	CHD	Qualitative study	Non-validated questionnaires to explore parental perceptions of counselling and understanding of the diagnosis	Parents who received a prenatal diagnosis of CHD ($n = 30$)	0.65
Miquel-Verges *et al.*[21]	USA	Various anomalies	Qualitative study	Semi-structured interviews 1 week after counselling and 1 week after delivery to examine parental expectations and experiences or counselling	Mothers who received a prenatal diagnosis ($n = 22$)	0.9
Rey-Bellet & Hohlfeld[29]	Switzerland	CLP	Mixed methods study	Non-validated questionnaires with semi-open questions to explore parental counselling experiences and perceptions	Parents who received a prenatal diagnosis of CLP ($n = 29$)	0.55/0.65
Robbins *et al.*[32]	USA	CLP	Quantitative study	Structured interviews to explore parental perceptions and satisfaction of counselling	Mothers who received a prenatal or postnatal diagnosis of CLP ($n = 253$)	0.71

CDH, congenital diaphragmatic hernia; CAM, congenital cystic adenomatoid malformation; CHD, congenital heart disease; CLP, cleft lip/palate.
[a]Quality assessment scores were calculated according to the scoring system and criteria of the QualSyst tool. For mixed methods studies, quantitative and qualitative components were assessed separately, and two summary scores were calculated (quantitative/qualitative).

parental outcomes both before and after the baby's birth, and two studies did not specify the time between counselling and assessment.

Participants

Studies ranged in sample size from 9 to 841 parents. In nine studies, only mothers were included. There was variability in the degree of paternal involvement in the remaining 15 studies, and most quantitative studies ($n=10$) did not record parent gender.

Congenital anomaly

In studies that examined a single anomaly (or anomalies in a single organ system), the most common anomalies examined were cleft lip and/or palate (CLP; $n=6$), congenital heart disease (CHD; $n=5$), congenital diaphragmatic hernia (CDH; $n=3$) and neural tube defects ($n=1$). One study compared responses of parents given a diagnosis of CDH or congenital cystic adenomatoid malformation.[13] Other studies focussed on gastrointestinal surgical anomalies,[14] surgical anomalies,[15] or a variety of anomalies.[16–21]

Counselling

There was heterogeneity across studies regarding what was considered a 'counselling session' with four studies including counselling as part of the diagnostic process rather than a separate consultation.[19,20,22,23]

Aite *et al.*[13] used a psycho-educational model to guide prenatal counselling. This was the only study to describe the theoretical basis underpinning counselling, with most of the remaining studies describing the structure of counselling only.

Impact of prenatal counselling on parental psychological adjustment

Three studies from two different groups, examined the impact of counselling on parental anxiety using the Spielberger State-trait Anxiety Inventory.[13–15] All provided counselling in a multidisciplinary format and all found that parents reported lower anxiety after counselling compared with before. Kemp *et al.* suggested that uncertainty about prognosis was associated with heightened anxiety despite counselling; however, this conclusion was based on a small sample size.[15] Dennett *et al.*[24] used the Short Form 36 to assess health-related quality of life reported by parents of children with CDH who received prenatal counselling compared with those who did not and found no significant difference between the groups for mental or physical wellbeing. However, the group that received prenatal counselling appeared to have children with more severe disease as indicated by longer hospital stays, leading the authors to conclude that prenatal counselling may be beneficial.

Cope and co-investigators conducted a RCT to explore whether the format of information provided after counselling influenced parental anxiety scores.[18] They found that parents who were provided with an audio recording or a non-technical letter had lower anxiety scores than parents who received standard counselling and an ultrasound report. Irrespective of information format, parental anxiety scores were the highest after counselling in those with more severe fetal anomalies. One qualitative study also found that mothers reported lower anxiety after prenatal counselling.[21] No other qualitative study specifically reported on the impact of prenatal counselling on parental psychological adjustment.

Impact of prenatal counselling on parental knowledge and recall

Three studies examined the impact of prenatal counselling on parental knowledge about their baby's condition and information recall. Hunfeld *et al.*[19] assessed recall by asking mothers to record details of the anomaly 1 week after counselling. The researchers compared this record to the information provided during the videotaped consultation. All mothers ($n=24$) were able to accurately recall the location of the anomaly and most ($n=22$; 92%) correctly recalled the severity of the anomaly, however, fewer mothers could recall the prognosis ($n=12$; 80%) or cause ($n=10$; 56%). A more recent study found that information recall was improved by provision of a website containing relevant information.[25] In contrast, the RCT conducted by Cope *et al.* did not find any improvement in recall after providing supporting information, despite the reported reduction in parental anxiety.[18]

Timing of counselling

The timing of prenatal counselling varied because of waiting times and individual centre protocol.[20,26,27] Most parents preferred to attend counselling as soon as possible after prenatal diagnosis to reduce the stress associated with waiting and facilitate timely decisions about pregnancy termination if indicated.[16,17,20,28]

> *If I could have seen [the fetal medicine specialist] straight away, I would definitely take it. The waiting was the worst. It really wasn't nice.*[20]

A minority expressed satisfaction with being given some time to 'digest' or process the diagnosis before counselling.[29]

Regarding preferences for prenatal or postnatal counselling, there were mixed results from two studies involving parents of children with CLP. Berggren *et al.*[30] found no difference in satisfaction with clinical care between parents who received prenatal versus postnatal counselling; however, 57% of parents who learned of the diagnosis after delivery would have preferred to receive the baby's diagnosis prenatally. Another study of CLP found that 92% of parents who received prenatal and postnatal counselling were satisfied with the care provided, compared with 71% of parents who received postnatal counselling only.[26]

Health professionals involved in prenatal counselling

Various professionals were involved in prenatal counselling, often depending on the type of anomaly (Figure 2). Parents expressed a preference for the counsellor to be a knowledgeable and empathetic health professional who would be involved in their child's future care.[14,20,23,26,27,31,32] In one study, parental preference was based on who could provide information earliest.[16] A multidisciplinary approach was found to be beneficial in reducing anxiety,[14] with parents appreciating the presence of both a surgeon and nurse.[15]

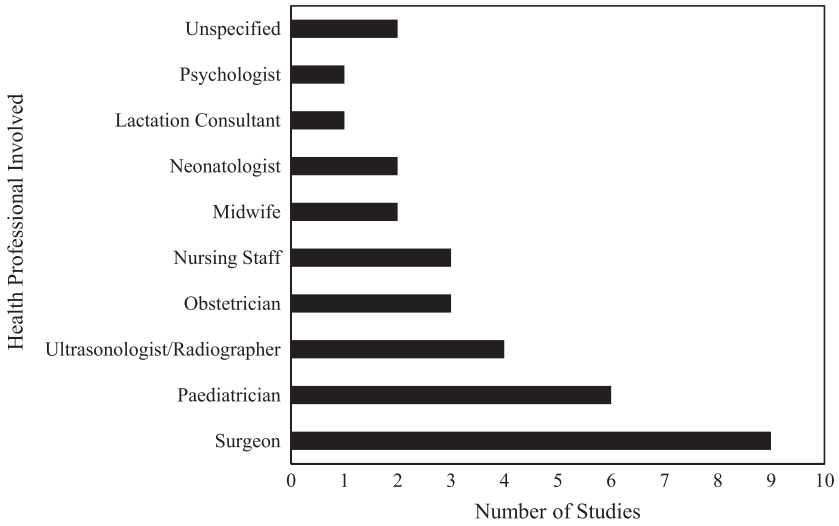

Figure 2 **Health professionals involved in prenatal counselling**

Topics covered

Topics covered during counselling are summarised in Table 3. Whilst collectively parental preferences appear to align with the topics covered, satisfaction with counselling varied across studies. One study compared how parents and cardiologists ranked the importance of counselling topics for CHD and found that parents consistently ranked topics as more important than cardiologists.[33] The only exception to this was pregnancy termination; a topic ranked higher by cardiologists, than parents. In a small study involving parents of babies with spina bifida, however, the importance of receiving information to assist decisions about termination was highlighted.[31]

Additional services and resources

Eight studies reported on the provision of information about relevant support groups or charity organisations; overall, this information was well received and utilised by parents.[13,14,21,26,29,31,32,34] Parents in eight studies received written information, which was perceived as useful, although not as important as the face-to-face consultation.[13,15,16,21,26,28,29,34]

> *I don't want to read a load of stuff that makes me more worried than I need to be…It feels much better to talk to the doctor or hospital staff who know our specific case.*[26]

In the pilot study by Caldera *et al.*,[35] all 14 parents responded positively regarding the usefulness of a CD-ROM containing further information about CHD after prenatal counselling. This finding was supported by parents in other studies who perceived the use of diagrams or photographs of affected children as beneficial during prenatal counselling.[20,27,28,34]

Many studies examined the potential benefit of web-based information. Some parents found online sources useful in providing further information about their baby's condition,[29] whilst others reported difficulties locating reliable websites.[28] Nevertheless, parents in three studies recommended counselling include the provision of online resources.[20,28,34] In the study by Engels *et al.*,[25] a physician-developed website was perceived as adding value beyond face-to-face counselling.

Improvements

The most common improvements suggested by parents were ensuring consistency of information, extending the length of consultations and using understandable language without medical jargon. The largest study included was an electronic survey of 841 parents of children with CHD. Suggested improvements included provision of more information about support groups and long-term outcomes.[34] An interesting finding of this study was the variability in parental understanding of the term 'rare' and the fact that use of this term led many parents to believe their child had little chance of survival.

DISCUSSION

Receiving a prenatal diagnosis of a congenital anomaly is challenging for parents, and many report high levels of psychological distress after diagnosis. Counselling may assist parents to cope during this difficult time. This systematic review identified 24 studies examining either the impact of prenatal counselling on parental knowledge and psychological adjustment, or parents' preference for the timing and format of counselling. Whilst a small number of studies ($n = 3$) found that prenatal counselling was associated with reduced parental anxiety, there is very little evidence of the effectiveness of counselling in relation to other psychological outcomes, including overall parental psychological well-being and knowledge about their baby's medical condition. Despite this, studies show that parents have a preference for prenatal counselling to be made available as soon as possible after diagnosis by a knowledgeable health professional, and that counselling include the provision of detailed information, as well as additional resources such as written and web-based information, and information on available support services.

A primary aim of prenatal counselling is to educate parents about their child's congenital anomaly. The intense emotions experienced during counselling may hinder parents' ability to understand the information provided and parents may want and benefit from additional information, including pathways

Table 3 **Topics covered during prenatal counselling and additional topics suggested by parents**

Topics covered	Additional topics suggested by parents
Description of the anomaly	
Natural history	
Risk of other malformations or chromosomal abnormalities	
Causes	Genetics
Additional diagnostic tests (if applicable)	
Management	Management
Treatment options	Issues around travelling for treatment
Timing of treatment	Preparation for surgery
Length of hospital stay	Detailed description of necessary treatment(s)
Hospital success rates	
Risks and complications	
Need for resuscitation and/or NICU stay	
Pain management	
Need for follow up	
Prognosis	Prognosis
Quality of life	Positive and negative outcomes
Level of disability	Survival rates
Long-term outcomes	
Survivors	
Pregnancy and delivery procedures	
Date of delivery	
Mode of delivery	
Procedures during and after delivery	
Feeding	
Termination of pregnancy options	
Team member roles	
Insurance options	Other administration issues
Financial resources	
Travel to treatment centres	

NICU, neonatal intensive-care unit.

to additional support groups, written and visual education materials, and accurate and reliable web-based resources.[36] Whilst parents place high value on the doctor–parent conversation, these additional resources may be incorporated into prenatal counselling practice to support parents' learning about and adjustment to their child's diagnosis.[28] In addition, counselling should aim to address the needs of each parent,[6] and further evidence into the unique experiences and needs of fathers in particular is needed.

Although this review focussed on non-genetic, prenatal counselling for structural congenital anomalies, studies and reviews examining parental experiences of counselling for chromosomal abnormalities report similar findings. Parents of children with Down syndrome or soft markers for chromosomal abnormalities have also been found to desire early information from a knowledgeable health professional.[37,38] Our findings relating to parents' need for visual/written resources and information about support groups were similar to reports of parents' needs during counselling after a postnatal diagnosis of Down syndrome,[37] and genetic counselling for parents of children with sex chromosome abnormalities.[39] The similar parental preferences in these different contexts may reflect the shared emotional challenges and informational needs following the diagnosis of any congenital abnormality.

Also noteworthy is the fact that included studies were variable in terms of study design, quality and timing of outcomes assessment. Variation in assessment timing may influence parental responses and recall. All studies were published relatively recently (between 1998 and 2015), reflecting the rising interest in prenatal counselling as prenatal ultrasound screening and rates of prenatal diagnosis increase.[40,41]

Limitations

This review has several limitations. First, there was an over-representation of some anomalies, such as CLP and CHD, potentially limiting the generalisability of findings. The heterogeneity of methodologies used made it difficult to pool results and precluded meta-analysis. Similarly, differences in

what was considered a 'counselling session' made comparisons across studies difficult. Exclusion of conference abstracts, unpublished theses, and articles not written in English may increase the potential for publication bias. Finally, despite making all efforts possible to capture all published studies meeting the predefined eligibility criteria, it is conceivable that relevant articles not indexed under or specifically mentioning 'counselling' may not have been captured by the search strategy employed. It is also worth noting that included articles only assessed parental outcomes and not outcomes for the affected child. An important pretext for counselling should be to commence planned and co-ordinated care of the child and this warrants further study.

Recommendations

This review provides insight into parental preferences for non-genetic, prenatal counselling for structural congenital anomalies identified during pregnancy. The findings of the review emphasise the importance of a patient-centred counselling approach and provide evidence for the following recommendations.

First, prenatal counselling should be offered as soon as possible after parents receive their baby's diagnosis. Second, the health professionals involved in prenatal counselling should be knowledgeable, empathetic and ideally those who will be involved in the future care of the child. Third, counselling should comprehensively cover all aspects of the condition diagnosed, as outlined in Table 3. Supplementary resources should be provided, including information booklets containing additional written and visual information, links to reliable web-based resources, and avenues for further support for parents and families. Finally, information should be presented in a consistent manner across consultations, using simple, non-jargonistic language.

Further research is needed to better understand the impact of prenatal counselling on parental psychological adjustment, as well as later child adjustment, with future studies adopting a more rigorous and comprehensive approach to the assessment of psychological outcomes across time.

CONCLUSION

Although there is little evidence surrounding the effectiveness of prenatal counselling, its positive impact on parental anxiety supports its continuity. Prenatal counselling should incorporate the parental preferences highlighted in this review. Further research is needed to adequately assess the efficacy of prenatal counselling with a focus on other psychological outcomes. To enable wider generalisability, research focussed on other highly prevalent anomalies should be undertaken, as well as studies exploring the potential differences in the experiences and needs of mothers and fathers. Finally, changes to counselling practices according to the findings of this review should be studied to assess the efficacy and acceptability from both parents and health professionals.

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WHAT'S ALREADY KNOWN ABOUT THIS TOPIC?

- Prenatal diagnosis of a congenital anomaly may result in significant psychological distress for parents of affected babies.
- Parents may attend counselling sessions to assist in gathering information about their baby's condition, adjusting to the diagnosis and making decisions about their baby's care.
- Previous theoretical reviews have recommended various counselling approaches; however, there has been no systematic review of the evidence on prenatal counselling for congenital anomalies.

WHAT DOES THIS STUDY ADD?

- This is the first systematic review to examine the efficacy of non-genetic, prenatal counselling for congenital anomalies diagnosed during pregnancy.
- Prenatal counselling was found to reduce parental anxiety; however, there is limited evidence for the impact of counselling on other psychological outcomes.
- Parents prefer to receive comprehensive information about their baby's condition from a knowledgeable health professional as soon as possible after prenatal diagnosis, supplemented by written, visual and web-based resources.

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