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Family experiences of antenatal counselling of spina bifida: a systematic review

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AUTHOR CONTRIBUTIONS

SA performed the systematic review, removed duplicated, screened the articles, scored their quality, and systhesised the data. SA reviewed the final draft of the paper and suggested imrpvoements. She approved the final version of the paper submitted.

EVH assisted with the literature search design, scored the papers for quality, resolved disagreement on inclusion of papers between the other authors, helped synthesise the data and interpret findings. ECH reviewed the final draft of the paper and suggested imrpvoements. She approved the final version of the paper submitted.

ARH helped with the literature search design, screened the articles, assisted with syntesis of data and interpretation. ARH wrote the paper and incorporate changes suggested by the co-authors to reach a final draft.

ABSTRACT

Objective: To describe families' experiences of antenatal counselling of spina bifida.

Design: Systematic review

Methods: Medline, CINAHL, PsycInfo, and Embase databases were searched using a combination of MeSH headings and text / abstract terms. Case reports, survey results and qualitative interview data were included. The quality of research was evaluated using the CASP checklist.

Results: 8 papers were included. Families described shock and grief at diagnosis, with some immediately offered termination of pregnancy (TOP) even though they knew little about the condition. Positive and negative aspects of care were found. Teams that were gentle, kind, and empathetic, who did not use jargon, and highlighted positive and negative aspects of the baby's life were seen favourably. Callous language, and overly negative or incorrect counselling was not, particularly if there was pressure to agree TOP. Families based their decisions on how they would cope, the effect on siblings, and the baby's likely quality of life. Prenatal surgery was viewed positively. The views of families who chose TOP, were happy with their care, partners, families, and the LGBTQ+ community were under-represented in the literature.

Conclusions: Unlike other conditions where limited data on outcome exists or the spectrum is genuinely broad, the outcomes of children with spina bifida is well described. Poor aspects of antenatal counselling were described frequently by families, and further work is needed to capture the full spectrum of views on antenatal counselling, how it can be improved, and what training and resources health care professionals need to perform it better.

WHAT IS ALREADY KNOWN ON THIS TOPIC

- Spina bifida can be diagnosed during routine pregnancy screening
- Around 2/3 of pregnancies with spina bifida are terminated in the UK
- Antenatal counselling is important to ensure parents have health literacy and make informed choices about pregnancy management

WHAT THIS STUDY ADDS

- The literature predominately represents families who had negative experiences and decided to continue their pregnancy.
- Families described some concerns with attitudes of staff and the timing, manner, content and accuracy of counselling along with pressure to choose a termination.
- Compassionate staff who listened, clear explanations, accepting families' decisions, and written information were some aspects of good care.
- Previous dissatisfaction about antenatal care has been attributed to the fact it is hard to predict developmental outcome in many fetal brain anomalies. However outcomes are well described and predictable in spina bifida, so this work highlights there are inherent problems with the way antenatal counselling is currently being delivered.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE, OR POLICY

- Further data is needed on experiences of care from families who were satisfied and those who chose termination of pregnancy
- Advice from parents and people with spina bifida on how and when information should be provided on spina bifida could be incorporated into care

- To improve antenatal counselling, we need to look at who provides the counselling, what training they have in communication and predicting developmental outcome if services are to be delivered in a more patient-directed fashion.

INTRODUCTION

Spina bifida can be diagnosed during pregnancy on routine ultrasound screening at 18-20weeks gestation. Its prevalence in Europe is 5.05/10,000 births,(1) although differences in rates exist in the UK between ethnicities.(2) In England and Wales, around 68.5% of pregnancies over 20 weeks gestation with spina bifida are terminated.(3) The communication of accurate information about spina bifida to families is important to help them make informed choices about pregnancy management;(4, 5) however, families in a recent UK survey reported the information they were given antenatally was often low quality and inaccurate,(6) despite outcomes and quality of life (QOL) being well described in the literature.(4, 7-13) Participants also reported frequently feeling pressure from health care professionals to terminate their pregnancy.(6)

The aim of this project was to perform a systematic review of the published data on prospective parents' experiences of antenatal counselling for spina bifida and use it to make recommendations on how care could be improved.

METHODS

Search Strategy

No protocol was published in advance of this systematic review. The project was not registered on PROSPERO because it was a student project performed within a limited time, and this was an oversight of the team. MEDLINE, CINAHL, PsycInfo and Embase databases were searched on 27 May 2022. Medical Subject Headings (MeSH) were used, along with text and abstract terms (supplementary table 1). Google scholar was used to search for additional references, including grey literature, and the reference lists of relevant papers were also reviewed. The inclusion criteria were papers reporting families' experiences of antenatal diagnosis and counselling of spina bifida, including case report(s) / published personal accounts, qualitative interviews, and questionnaires published in English. No limitation was applied on publication date.

Data collection and analysis

Duplicates were removed, SA and ARH screened the titles and abstracts to identify relevant papers, then the authors independently performed a full text review to determine which articles met the inclusion criteria. Disagreement was resolved by consensus. The authors reviewed the papers and summarised the main findings. Two authors (SA and EH) reviewed the quality of the identified articles using the Critical Appraisal Skills Programme (CASP) Checklist, 2022. The CASP checklist is a standardised scoring system for qualitative and mix methods studies and involves 10 questions relating to whether the aims of the study were clear, methodology sound, the results valid, and the findings applicable locally. Each of the the questions is scored out of 2, with a maxiumum score being 20.(14) Disagreement between scores was resolved by the third author (ARH).

Data synthesis

A narrative synthesis was used. The preliminary synthesis included arranging extracted data into the stages of antenatal care from diagnosis through to birth, including prenatal surgery. Relationships between the data were explored between stages and family experiences. The synthesis and theories were reviewed and refined by the research team. Robustness of the data was considered via our quality scoring.

RESULTS

Eight papers met our inclusion criteria (Figure 1).(6, 15-21) Three were personal accounts (two were commentaries written by parents, and one a reflection by a health care professional on what a parent said in an interview), three qualitative interview studies (one exploring the role of paediatric staff in counselling, one about a fetal surgery programme, and one on communicating the diagnosis antenatally), and two questionnaire studies (one about diagnosis / counselling, and one on prenatal surgery). The main results of the included articles are summarised in table 1. Table 2 outlines the result of the quality assessment. We grouped the findings into natural categories based on the antenatal experience:

1. Reaction to the diagnosis
2. Information gathering
3. Making and living with a decision about the management of pregnancy
4. Prenatal surgery.

Reaction to the initial diagnosis

Families' initial responses to a diagnosis of spina bifida was shock.(16-19, 21) Families had expected a “normal” child, one noting “no one desires, earns, or asks for a child with a disability”.(17, 19) The diagnosis was described as life changing, devastating, and associated with feelings of hopelessness and sadness.(17-19, 21) Families wondered if it was their fault, questioning why this happened and whether it could have been avoided.(17, 19) Sleepless nights followed.(19) Families felt sorry for their baby and worried about their baby's future.(16, 19) The duration of shock and grief varied, but the first week was felt to be the worst.(16) If further diagnostic tests were needed, families found the wait anxiety-provoking.(16)

Information gathering

The consultations at which diagnoses were made were often perceived negatively.(6, 16, 17, 20) Some families reported health care professionals refused to give them information, particularly if the doctor was a trainee.(16) Language used was often perceived to be insensitive, callous, or overly negative. Words used included “brain damaged”, “vegetable”, “cabbaged”, “mentally retarded”, or a repeated insistence that “things look bad”.(6, 17, 20) Fruit-based terminology, such as the lemon shaped head and banana shaped cerebellum, was recalled, and over half found it unhelpful or distressing.(6) Discussions focussed on things a child would not do, with limited discussion on what they would achieve,(19) the financial burden to the family, potential changes to family lifestyle, the child’s dependency on their parents, and the burden to society as a whole. QOL was described as low.(6, 18-20) Overall, families felt the amount of information they were given was inadequate, some reported family questions were answered with simple “yes” or “no’s”, and requests for second opinions were met with hostility.(6, 16, 17, 19-21) Professionals could appear uncaring or unempathetic.(6, 16, 17)

At times, the quality of information provided was felt to be inaccurate. Families who did further research or continued their pregnancy found the information they had been given was sometimes wrong and overly negative, particularly the risk of cognitive impairment.(16, 18) Yaz et al found 25% of responders had been told that their child would have severe cognitive impairment(6) when most children have learning abilities within the normal range.(9-13) 73% found their child was less severely affected than they were told.(6) Faced with a lack of information or negative perspectives, families sought out information from other sources, such as the internet, particularly focussing on hope, personal stories, and opportunity.(6, 16, 17, 19, 20) Once further information had been found, especially if it was more positive than the health care professionals had provided, some parents felt guilty for considering a termination of pregnancy (TOP) or were angry the counselling was wrong.(18)

Families commonly reported pressure to have a termination.(6, 15-20). Yaz et al found 76% of responders were offered a TOP at the same discussion as spina bifida was first diagnosed, i.e., before seeing a specialist in spina bifida, half felt highly or extremely pressured and to decide about TOP quickly, and 14% felt no pressure.(6) Some families were led to believe they have to make a decision in a shorter timeframe than the law allowed.(17)

There were many positive aspects of care.(6, 16-19, 21) When presented well, the information helped families make “the right decision for our family with confidence and peace of mind”.(21) Good counselling took place in comfortable rooms,(21) with health care professionals empathising with families’ emotional and physical states,(19) and demonstrating sincerity, gentleness, and genuine emotion.(6, 16, 19, 21) Families valued health care professionals who listened to and accepted their circumstances, lifestyles, religious beliefs, and views about TOP.(6, 16, 19, 21) They wanted their baby talked about as a human being, with love, respect, and dignity, rather than a medical problem to be fixed.(16, 19, 21) When scans were performed, the families wanted to see normal parts of the baby and for professionals to discuss the baby with the same excitement that other families experienced, rather than silence.(19)

Open and honest information without jargon was most helpful,(17, 19, 21) including best- and worst-case scenarios, realistic estimations of the likely severity of any difficulties,(16, 17, 19, 20) and information on the positive things a child would do as well as the negatives.(16, 17, 21) Information on QOL and participation were valued,(16-18) along with how their child’s problems would be managed after birth.(20) Time alone was valued.(16, 17, 19, 21) Families liked written information, although few received this.(6, 17) Meeting a neurosurgeon and trips to the neonatal unit were helpful.(17, 19) Although families knew urinary and bowel problems would be a feature antenatally, they were not concerned about them; however, after their child was born, they wished they had been given more information on catheterisation during antenatal counselling.(17)

Making and living with a decision about the management of pregnancy

Some families made quick decisions; others took longer to absorb information and agonised over what was right.(16) The factors that influenced families decisions most were the severity of disability and QOL, with physical disability less important than cognitive difficulties.(16-18) The data on families' experiences of support after making decisions was biased towards those continuing the pregnancy. Only one paper interviewed families who chose TOP, and included five participants.(18) Families choosing TOP balanced the desire to be a parent with the burden of disability for their child and the effect on any siblings. They felt continuing the pregnancy would be selfish on their child. Following TOP, families reported intense grief but protected themselves by detaching themselves from their baby.(18) Validation of families' decisions was important, even if families felt their health care professional disagreed with their choice.(16, 19-21)

Families who decided to continue their pregnancy sometimes felt their decision was not respected.(20) Such disagreement caused families to feel isolated, particularly if requests for referrals were not acted upon or followed up.(16) Families could face repeated offers of TOP: (6, 19), Yaz et al found 34% of their responders had been offered TOP multiple times during the pregnancy, 28% four times, and 17% more than six times.(6) Repeated offers of TOP made families feel unheard and set a negative tone for the rest of pregnancy.(19, 21)

In a qualitative study, partners were described as supportive when they were calm, positive and optimistic. They increased feelings of hurt and isolation when they were distant.(16) If partners were not present when the diagnosis was explained, mothers found explaining the news to them later traumatic.(16) Friends, family, and church members varied in their helpfulness,(16, 19, 21) so families became strategic on whom they relied. Disability support groups were helpful so families could see a children with spina bifida rather than 'a medical condition'.(16)

Prenatal surgery for spina bifida

Families heard about prenatal surgery from a variety of sources: 71% were counselled about prenatal surgery by their obstetric team. Families gained additional information from the internet, family, magazines / newspapers, and television.(15) The motivation for exploring prenatal surgery was a sense of parental responsibility to explore all options for their child and find hope.(18, 19) In particular, they wanted to preserve cognitive, rather than motor function, and improve QOL.(18) Families reported that local Feto-Maternal Units did not know much about prenatal surgery, but valued referrals to specialist units.(19, 21) Although maternal risks, such as uterine rupture and death, were discussed,(21) families' fears were more related to the complications for their baby and the risk to future pregnancies.(18) The practicalities of the process were also important, including the stress of organising travel and accommodation, the time away from work and family, childcare, and financial implications.(18) Families who were exploring prenatal surgery as part of a research study felt it was important they were not solely valued because they were considering enrolment in the study.(19)

Families who chose not to have prenatal surgery thought there were too few certainties about the improvements in QOL for their child.(18) Families who chose surgery worried about maternal death during the operation, and their other children being left without one parent. The end of surgery was characterised by relief.(18) The ease of post-operative recovery varied, with pain the biggest issue. Outcomes for the babies after prenatal surgery were often better than parents expected, and 49% of families reported their child had only a positive effect on the family, 51% positive and negative and effects, and no one reported only negative effects from having a child with spina bifida.(15) The majority of families would have chosen prenatal surgery again,(15) although some were still surprised when unexpected issues arose, such as hip dislocation.(18)

DISCUSSION

Health literacy is defined as "the personal characteristics and social resources needed for individuals and communities to access, understand, appraise, and use information and services to make decisions about health”.(22) Antenatal counselling is an area in which high health literacy is important to enable families to make informed decisions about TOP.(5) Decisions cannot be truly informed where poor health literacy exists, and there have been wrongful life and death law suits in the UK. These are medicolegal terms for cases in which families would have made a different decision if they had been given correct antenatal information. Wrongful life cases occur when incorrect information is given to families on the nature of the anomaly or prognosis, so termination of pregnancy is either not offered or is rejected by the family based on the substandard counselling, and their child develops a significant disability. Wrongful death cases are less common, and include cases where a procedure causes injury and death to the fetus, or where an incorrectly negative prognosis led the family to choose a termination when their child had a greater chance of being neurotypical.

Predicting outcome antenatally is difficult because the range of possible outcomes for many neurological or genetic conditions is wide, or the published developmental data limited.(4) This is reflected in the wide variations of risk for atypical outcomes offered by health care professionals in Feto-Maternal units for the same condition.(23) However, outcomes in spina bifida can be predicted relatively accurately, even though the functional level of lesions may be slightly different to antenatal imaging.(4, 8-10, 24-28) Therefore, we should expect families to report antenatal counselling of spina bifida to be more positive than for other conditions.

This was not what we found in the published literature. The survey data by Yaz et al, in particularly, highlighted that families were given wrong prognostic information, felt pressurised to have a termination of pregnancy, and experienced perjorative language and dismissive attitudes from health care professionals.(6) Parental descriptions of their antenatal counselling highlighted similar findings, and not just in the UK.(16-20) This suggests a more systemic problem with antenatal counselling across many countries.

The possible reasons why families have bad experiences of antenatal counselling are wide. It is too simplistic to argue that the diagnosis of a fetal neurological anomaly is stressful and traumatic, so all counselling would be percieved negatively. Some families report good antenatal counselling, characterised by empathetic and caring health care professionals, where the baby was discussed as a human and not a medical problem to be fixed, in which clear language was offered, accurate pictures of outcomes were given in functional terms, and families' decisions and beliefs were respected.(16, 17, 19-21) These findings should form the basis of any antenatal counselling, not just in spinal bifida. However, the literature frequently describes family experiences in which some professionals manifest negative views on childhood disability using inappropriate language. This may result from poor knowledge on childhood outcomes, societal or personal prejudice towards disability, or poor training on basic communication skills. It may also reflect the fact that those providing antenatal counselling may not provide long-term follow-up for children with disabilies to understand what it is like "in real life". Certainly, one study showed involvement of paediatric teams was helpful.(17)

However, the extent to which care is good or not cannot be quantified from our review, and the findings are not generalisable to the whole of the UK. There has been considerable discussion about how to assess the quality of qualitative research, and which studies should be included when data is synthesised.(29) The Cochrane Qualitative and Implementation Methods Group endorse the CASP questionnaire to rate study quality,(14) although there are concerns about whether it scores reporting rather than actual methodology.(29) Notwithstanding these concerns, of the 8 papers included in our review, only 3 score above 50% (10/20) and 2 over

75% (15/20). Some articles, particularly the reflections from individual families, score very low. It is also highly likely that the data is biased, being heavily skewed towards families who continued their pregnancy and were dissatisfied with care, often because of Christian beliefs around the appropriateness of termination of pregnancy. It is possible that families who feel aggrieved, traumatised, or disappointed with medical care are more likely to recruit to surveys and interview studies than those who thought their care was good. For example, families who chose TOP were only included specifically in one study.(18) There is also little data specifically from families with other or no faiths, or LGBTQ+ families, and these families may have different experiences and views. Nevertheless, it is important to hear and validate all patients' experiences, which is why we included all of the articles in our review, despite their low quality.

It is well known that increasing contact with people who have learning disabilities reduces prejudice,(30) and this may be why families found contacting support groups and other affected families helpful to see first-hand the reality of spina bifida and challenge a priori assumptions and prejudices about disability and QOL. It is possible that, if health care professionals who provide antenatal counselling are in touch with people who have disabilities, any prejudice may be reduced and this could form a part of training. There may also be other, service specific reasons why antenatal counselling is problematic, such as the environment it is given in and the time available to health care professionals. Understanding the health care professionals' experiences and the barriers they face could help us understand this phenomenon.

Ultimately, more data is needed on the full spectrum of views on antenatal counselling in spina bifida and other fetal neurological conditions. Once this is collected, recommendations can be made for service deisgn and training.It is important, however, that we do not aim to move from pressurising families to have TOP to pressuring them to accepting a disabled child they do not want. We need to ensure the focus of antenatal care is not an arbitrary reduction in termination rates, but improving health literacy and supporting families to make “the right decision for our family with confidence and peace of mind”.(21)

TABLE 1: Summary of papers included

AUTHORS / REFERENCE	YEAR	TITLE	STUDY DESIGN	NUMBER OF PARTICIPANTS	KEY FINDINGS
Kennedy and Kennedy, 2005(19)	2005	*Parental voices: Our Journey of Grace*	Reflection of two parents' experiences after their child was diagnosed with spina bifida antenatally and they were considering fetal surgery	2	• Initially felt unheard, and overwhelmed • Had a positive experience with medical professionals at the fetal surgery hospital • Felt the clinicians were genuinely interested and supportive
Williamson and Williamson, 2005(21)	2005	*Parental Voices: The Positive Impact of Medical Professionals*	Reflection of two parents' experiences after their child was diagnosed with spina bifida antenatally and they were considering fetal surgery	2	• Positive impact with medical professionals at a fetal surgery centre • Felt respected, valued, with no pressure • They were allowed to make the right choice for them peacefully and confidently
Chaplin, Schweitzer and Perkoulidis, 2005(16)	2005	*Experiences of prenatal diagnosis of spina bifida or hydrocephalus in parents who decide to continue with their pregnancy*	Qualitative semi-structured interviews conducted in Queensland, Australia, with parents who learned of the spina bifida diagnosis prenatally	15	• Parents experience shock and distress when they learned about the diagnosis • Significant lack of clarity about the diagnosis and information • Parents either experienced honest and sensitive health care staff, or callous and cruel • Parents looked to partners for support at first
Pickering, 2011(20)	2011	*A fight for the right to life*	A parent of a child with spina bifida telling her story through an informal interview	1	• Unsupportive staff and made to feel as though she made the wrong decision to continue the pregnancy • Negative attitudes and inappropriate language used towards her baby
Cockayne, Gibbon and Leach, 2013(17)	2013	*Neurosurgical input at pre-natal counselling for parents of babies with Spina bifida*	Interviews of parents of children with MMC who previously received antenatal counselling	11	• Parents were unhappy of the information provided at the initial diagnosis • They felt that the counselling sessions with paediatric staff gave both the negative and positive aspects honestly

					- Parents felt reassured and reported overall positive experiences of the counselling with paediatric staff - Parents would have liked more information about care after birth, particularly urological
Antiel *et al.*, 2018(15)	2018	*The experience of parents with children with myelomeningocele who underwent prenatal surgery*	Parents of children with MMC who did not participate in the MOMs trial completed questionnaires but had prenatal surgery	109	- 84% of families were spoken to about surgery after birth; 80% were spoken to about TOP - 29% of patients were not given the option of fetal surgery - 25% of patients felt pressure to take 1 option - Families experienced both negative and positive impacts on having a child with MMC
Yaz and Smith-Wymant, 2021(6)	2021	*Antenatal experiences of expectant parents in pregnancies affected by spina bifida*	A survey to assess the antenatal care experiences of parents to children with spina bifida. Families were recruited from the UK via social media	71	- 70% made TOP decision at diagnosis without consultation of a clinician with experience of spina bifida care - 76% of parents were offered TOP in the same appointment that the spina bifida diagnosis was made - 53% of parents were offered no written information to take away - 73% of respondents said their child’s condition was less severe than they were told to expect - 52% of parents found ‘‘lemon-shaped head’ and/or ‘banana-shaped cerebellum’ or other language distressing
Crombag *et al.*, 2021(18)	2021	*We did everything we could*	Interviews of parents during different time points who underwent fetal surgery (n=24), and interviews of those who terminated the pregnancy (n=5)	29	- Parents felt that the surgery was an opportunity that needed to be taken - Parents felt the surgery was an ‘emotional roller coaster’ reporting both stress and relief - All parents were happy with the outcome after the surgery - Those who decided to terminate felt grief and felt the risks of the surgery on the mother and child were too great

TABLE 2: Summary of quality assessment of included papers

CRITERIA	Kennedy and Kennedy, 2005*	Williamson and Williamson, 2005*	Chaplin, Schweitzer and Perkoulidis, 2005	Pickering, 2011	Cockayne, Gibbon and Leach, 2013	Antiel et al., 2018**	Yaz and Smith-Wymant, 2021**	Crombag *et al.*, 2021
Clear aims?	N	N	Y	N	Y	Y	S	Y
Qualitative methodology appropriate?	N	N	Y	N	Y	Y	Y	Y
Research design appropriate to address aims?	N	N	Y	U	S	S	U	Y
Appropriate recruitment strategy?	N	N	S	N	Y	Y	S	Y
Data collection appropriate?	N	N	Y	N	S	Y	N	Y
Relationship between researcher and participants considered?	N	N	N	N	N	S	N	Y
Ethic issues into consideration?	N	N	N	N	N	N	N	Y
Data analysis sufficiently rigorous?	N	N	S	N	N	Y	N	Y
Clear statement of findings?	S	S	Y	S	Y	Y	S	Y
Valuable research?	Y	Y	Y	Y	Y	Y	Y	Y
Total score	3	3	14	3	12	16	7	20

Y: Yes (2 points); S: Somewhat (1 point); N/U: No/unclear (0 point) (Highest possible score = 20)

FIGURE LEGENDS

Figure 1: PRISMA flow chart for the search process

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Supplementary table 1: Search terms used in this systematic review

MEDLINE		
	NUMBER	**TERM**
COUNSELLING OPTIONS	#1	Prenatal care.mp. or Prenatal Care/
	#2	prenatal education.mp. or Prenatal Education/
	#3	prenatal diagnosis.mp. or Prenatal diagnosis/
	#4	Counseling/ or counseling.mp.
	#5	antenatal counsel*.af.
	#6	prenatal counsel*.af.
	#7	pregnancy counsel*.af.
	#8	antenatal communic*.af.
	#9	prenatal communic*.af.
	#10	pregnancy communic*.af.
	#11	#1 OR #2 OR #3 OR #4 OR #5 OR #6 OR #7 OR #8 OR #9 OR #10
DISEASE NAME	#12	Spina Bifida Occulta/ or spina bifida occulta.mp.
	#13	spinal dysraphism.mp. or Spinal Dysraphism/
	#14	myelomeningocele.mp. or Meningomyelocele/
	#15	spina bifida.af.
	#16	myelomeningocele.af
	#17	#11 OR #12 OR #13 OR #14 OR #15 OR #16
POPULATION	#18	Parents/ or prospective parents.mp.
OVERALL SEARCH	#19	#11 AND #17 AND #18
CINAHL		
COUNSELLING OPTIONS	#1	MH prenatal care
	#2	prenatal care
	#3	MH prenatal education
	#4	prenatal education
	#5	MH prenatal diagnosis
	#6	prenatal diagnosis
	#7	MH counseling
	#8	counseling
	#9	antental counsel*
	#10	prenatal counsel*
	#11	pregnancy counsel*
	#12	antenatal communic*
	#13	prenatal communic*
	#14	pregnancy communic*
	#15	#1 OR #2 OR #3 OR #4 OR #5 OR #6 OR #7 OR #8 OR #9 OR #10 OR #11 OR #12 OR #13 OR #14
DISEASE NAME	#16	MH spina bifida occulta
	#17	MH spina bifida
	#18	spina bifida
	#19	MH spinal dysraphism
	#20	spinal dysraphism
	#21	myelomeningocele
	#22	MH myelomeningocele
	#23	#16 OR #17 OR #18 OR #19 OR #20 OR #21 OR #22
POPULATION	#24	Prospective parent
	#25	parent*
	#26	MW parent

	#27	#24 OR #25 OR #26
OVERALL SEARCH	#28	#15 AND #23 AND #27
PSYCINFO		
COUNSELLING OPTIONS	#1	mainsubject(Prenatal care)
	#2	mainsubject(prenatal education)
	#3	mainsubject(prenatal diagnosis)
	#4	mainsubject(counseling)
	#5	Prenatal care
	#6	Prenatal education
	#7	Prenatal diagnosis
	#8	Counseling
	#9	#1 OR #2 OR #3 OR #4 OR #5 OR #6 OR #7 OR #8
	#10	(antenatal counsel*) OR (prenatal counsel*) OR (pregnancy counsel*) OR (antenatal communic*) OR (prenatal communic*) OR (pregnancy communic*)
	#11	#9 OR #10
DISEASE NAME	#12	mainsubject(SPINA BIFIDA)
	#13	mainsubject(SPINA BIFIDA OCCULTA)
	#14	SPINA BIFIDA OCCULTA
	#15	SPINA BIFIDA
	#16	mainsubject(SPINAL DYSRAPHISM)
	#17	SPINAL DYSRAPHISM
	#18	SU.exact(“MENINGOMYELOCELE”)
	#19	myelomeningocele
	#20	(spina bifida) OR myelomeningocele
	#21	#12 OR #13 # OR #14 OR #15 OR #16 OR #17 OR #18 OR #19 OR #20
POPULATION	#22	mainsubject(prospective parents)
	#23	prospective parents
	#24	parents
	#25	mainsubject(parents)
	#26	#22 OR #23 OR #24 OR #25
OVERALL SEARCH	#27	#11 AND #21 AND #26
EMBASE		
COUNSELLING OPTIONS	#1	Prenatal care.mp. or Prenatal Care/
	#2	prenatal education.mp. or childbirth Education/
	#3	prenatal diagnosis.mp. or Prenatal diagnosis/
	#4	genetic counseling/ or counseling/ or parent counseling/ or counseling.mp.
	#5	antenatal counsel*.af.
	#6	prenatal counsel*.af.
	#7	pregnancy counsel*.af.
	#8	antenatal communic*.af.
	#9	pregnancy communic*.af.
	#10	prenatal communic*.af.
	#11	#1 OR #2 OR #3 OR #4 OR #5 OR #6 OR #7 OR #8 OR #9 OR #10
DISEASE NAME	#12	spina bifida.mp. or spinal dysraphism/
	#13	spina bifida occulta.mp. or occult spinal dysraphism/
	#14	myelomeningocele.mp. or meningomyelocele/
	#15	#12 OR #13 OR #14
POPULATION	#16	parent/ or prospective parents.mp.
OVERALL SEARCH	#17	#11 AND #15 AND #16