

ORIGINAL ARTICLE

Neurosurgical input at pre-natal counselling for parents of babies with Spina bifida

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Abstract

Prenatal counselling can be helpful to parents in making a decision with regard to continuation of the pregnancy or to help prepare for the birth and the future life of a child with Spina bifida. We aimed to assess the effectiveness of our specialist neuro counselling sessions and to highlight areas that could be improved upon. This was in the form of a questionnaire given to parents, who had been through the counselling and continued with their pregnancy.

The areas highlighted for improvement were more explicit information about urinary catheterisation, the need for admission to the special care baby unit (SCBU) and the need for an information leaflet on Spina bifida.

Keywords: ante-natal; counselling; myelomeningocele; spina bifida

Introduction

Spina bifida results when there is a failure of normal fusion of the neural plate to form the neural tube. Closure normally occurs during the first 28 days post conception.¹ In 2008, the prevalence of Spina bifida in the UK was 1.3/10,000 births.² The prevalence of Spina bifida is decreasing in the UK, which is largely thought to be due to the recommendation of pre-conceptual folic acid.³ Research has shown that pre-conception folic acid consumption reduces the risk of neural tube defects by 70%.⁴ There are other factors that may contribute to incomplete closure including anti-convulsant medication, diabetes and a positive family history.^{5,6}

Prenatal counselling can be helpful to the parents in making a decision with regard to continuation of the pregnancy or to help prepare for the birth and the future life of a child with Spina bifida. All parents diagnosed with a baby with a neural tube defect are offered to see the Fetal Management team at Cardiff. Our service involves an initial meeting with the specialist Fetal Management team followed by the offer of neurological counselling by a Consultant Paediatric Neurologist

combined with a Consultant Paediatric Neurosurgeon. We aimed to assess the effectiveness of our counselling sessions and to highlight areas that could be improved upon.

Eleven parents of children with myelomeningocele were included in the study and they answered questions either in person or via telephone. Overall, the prenatal counselling service had a very positive effect on parents of babies with Spina bifida and allowed parents to reach decisions regarding termination and preparation for the future with their new baby. The areas highlighted for improvement were more explicit information about urinary catheterisation, the need for admission to the special care baby unit (SCBU) and the need for an information leaflet on Spina bifida.

Method

All fifteen babies that underwent closure of their myelomeningocele by the senior author since his appointment in November 2008 were identified. Two babies were excluded from the study. One baby died soon after myelomeningocele closure due to respiratory disease and it was deemed insensitive to interview these parents. One baby had been adopted and therefore the foster mother had not been at the counselling session. The parents of the thirteen remaining babies were contacted by letter requesting their cooperation in answering questions regarding the counselling. Two sets of parents made no reply and were unable to be contacted, so they were also not included. The remaining 11 parents agreed to take part and were either telephoned or interviewed in person.

Our aim was to learn how beneficial the prenatal counselling sessions were and how they could be improved. With this in mind we generated questions that would allow parents to express their feelings, from receiving the initial diagnosis right through to the post-natal care. The questions aimed to look at how parents felt when first told the diagnosis of Spina bifida, their thoughts and feelings towards possible termination and if and why the counselling sessions were useful to them (see Appendix).

Results and discussion

Pre-counselling experiences

The majority of the diagnoses were made at the 20 week anomaly scan. Only 1 patient was given more information about Spina bifida at this point, the rest had to either perform an internet search or wait to hear from the specialist team. Only 3/11 parents had heard of Spina bifida but said that they had very little knowledge. One couple had worked with disabled children and therefore had some experience of children with Spina bifida.

The majority of parents said that their initial reaction to the diagnosis was shock. Many said 'you just never think it will happen to you' and many said the initial shock was followed by sadness. One father said he felt like it was his fault and was looking for reasons why. One couple's main concern was how other people would react.

Unfortunately 8 parents had bad experiences at their anomaly scan when the diagnosis was first made. Many of the parents remembered having medical staff telling them, that they would have to have a termination and 3 mothers recall being given a time limit to make a decision regarding termination. These 8 couples were unhappy with the lack of information they received at this initial consultation.

Neurological counselling

Aims of the counselling for the parents

Of the 11 couples questioned for this study, only 3 would have considered a termination. The remaining 8 couples had already decided against a termination. The undecided 3 couples therefore entered into the counselling with a view to helping them decide on the continuation of the pregnancy. Therefore, it was important to ascertain the probable extent of the child's disability and the quality of life they would have. One couple had felt pressured into booking a termination at the initial diagnosis and they wanted to know if they would have to go through with it. Another couple were given a similar view at their initial diagnosis and so they entered into the counselling with a very negative mind-set, wanting to know more about Spina bifida and if their baby would have brain damage, as they had previously been told.

In the three cases where a decision on termination had to be made, the counselling session helped the parents make the decision to continue with their pregnancies. They all felt that the sessions gave the honest negative facts about having a child with Spina bifida, but also the positive aspects. They all felt that the counselling session gave them the necessary information to enable them to feel more optimistic and empowered to cope with having a disabled child.

For the remaining 8 parents the main aim was to establish how disabled their child might be. By this point most parents had looked up Spina bifida on the internet and noted only the most severe cases. Therefore the counselling session was an opportunity for them to ask questions about what they had read. The most common concern was the physical disability the child would have and parents wanted to know the extent of their baby's disability. They wanted to know if their child would be wheelchair bound or be able to walk. One mother's main concern was whether her child would be in pain every

day and whether her child would look different. All parents had read about bladder and bowel problems being common but none of the parents mentioned this as something that they were particularly concerned about.

The parents also wanted to use the counselling session as an opportunity to find out about the mode of birth and the surgery required post-partum. One couple said that they wanted to know every detail about what was going to happen so they could feel prepared for it. One father particularly wanted to know how the surgery would affect his baby, why it was needed and how many operations would be required.

Information gained at the counselling session

All the parents reported very positive experiences at the counselling session. Many commented on how reassured they felt and one mother said how 'everything changed for me' after the session. The team took time to explain about Spina bifida and one father recalled positively that they were never bombarded with information; they were told only as much as they could deal with at the time. Many parents were pleased that the neurosurgeon assessed each case individually and took time to answer any questions, no matter how trivial. Each couple were talked through their baby's lesion and the possible implications of this including bladder and bowel problems and physical disabilities. A few parents mentioned wishing that they could have known definite effects on their baby, but all said they appreciated that it was impossible for anyone to know exactly what would happen.

Many parents used the phrase 'worst case scenario' when remembering what they had been told. They knew that the team could not say for definite how severely affected their child would be, but they all said that they preferred to know the worst possible outcomes as everything else would be a bonus. One mother said she was devastated when she was told how disabled her daughter could be, but being told the worst case scenario now makes her extremely proud of everything her daughter achieves. No parents reported being shocked by any disabilities that their children now have, as they felt that they were adequately prepared.

A baby with Spina bifida can be terminated at any point through the pregnancy (England, Wales and Scotland). Two couples had been previously told that they would have to make a decision within a finite amount of time. Knowing they did not have to make a decision immediately and could wait to find out more information proved to be a huge relief and therefore allowed them to feel much more confident that they had made the correct decision.

The counselling session also informed the parents of what would happen after their baby was born. All parents were pleased with how well the surgery was explained to them and how quickly it would be done. Two parents were happy that the sessions involved the neurosurgeon who would be performing the operation. They felt that meeting the surgeon and discussing the operation with him allowed them to feel more confident and prepared for what would happen. Parents were also informed about hydrocephalus and the probabilities of needing a shunt. The parents whose babies needed a shunt all felt more prepared and less anxious about the surgery.

Nine of the parents remember being told that they could be seen again during the pregnancy if required and were given a telephone number for any questions. They all appreciated having this support system should they need it.

SHINE charity

Information on SHINE charity (formally ASBAH- Association for Spina bifida and Hydrocephalus) was given to all parents at the prenatal counselling sessions. All parents remember being given the information and advised that they were a useful resource for parents of children with Spina bifida. Six out of the 11 parents have used the charity and all highly recommended it as a support system. One Mum was very enthusiastic about sharing stories with other parents and others reported using it for help with disability forms and travelling abroad.

Improvements for the future/negative reflections

Overall parents were very positive about their experiences at the prenatal counselling, however, some points for improvement were made. The main issue was being unprepared for urinary catheterisation. They all remembered being told that their baby would have bladder and bowel problems and the need for catheterisation. However, 3 couples were surprised when they realised that their child needed catheterisation straight away and would have liked more information regarding this.

Two parents also recalled being worried and surprised when their baby was taken to SCBU shortly after birth. All parents understood that it was the best place to care for their baby, but for two couples they would have liked more warning. The need for admission to SCBU post delivery needs to be explained and an offer of a pre-natal visit to the unit should be offered to all parents.

Another issue raised was the amount of information that was provided by the counselling team. One mother thought that it would be useful to provide an information leaflet including all the important topics discussed at the counselling session. This mother remembered being in such a state of shock and denial about her baby's diagnosis that she did not entirely take in the information that was being offered.

Discussion

Overall, the findings from this study were in favour of the prenatal counselling with a paediatric neurosurgeon and a paediatric neurologist and many of the negative views expressed were due to experiences prior to meeting with the specialist team. Other studies on this topic have found similar results. Chaplin et al.⁷ found that many parents remembered feeling very distressed at the initial diagnosis, provoked in part by the treatment by medical staff and their attitudes towards Spina bifida. Parents in this study had similar reactions and felt that they were treated insensitively. Chaplin found that parents when first told about the diagnosis had feelings of sadness, disbelief and shock comparable to the feelings of the parents in this study. We are currently discussing with our fetal management colleagues with regard to how we can improve the experience and give information at the time

of initial diagnosis. Chaplin et al. also found that parents appreciated a quick referral to specialist centres as specialist teams were able to provide more accurate information.

One issue that was raised in our study was the amount of information given to parents at sessions, Chaplin found that parents often found it difficult to understand and retain this information. Doherty et al.⁸ had a solution for this in their prenatal counselling which involved a written explanation of the topics that had been covered in the session. This is something that our service provides, however, not consistently and therefore is to be addressed by the authors. Doherty also showed that it was important to have the input of neurosurgeons in the prenatal counselling as they were able to offer more knowledge and predictions on outcomes for each individual case. This allowed parents to make well-informed decisions on continuation of pregnancy.

An information leaflet could be provided which contains all aspects of Spina bifida. Parents in this situation are often shocked and upset and therefore not able to comprehend detailed information and therefore a leaflet could help to overcome this problem faced by the parents. In our department we have designed such a leaflet to be given to parents and are currently discussing the funding of this with SHINE.

The findings from this study have largely been positive but there were limitations which could have affected the outcomes. The number of parents involved in the study was only 11 and therefore the feedback is only from a small cohort; we must be careful not to generalise these findings to all similar parents. Another point to make is that only parents who decided to continue with their pregnancies were included. These parents are all very proud and devoted to their babies and therefore their feelings towards the counselling may be biased because they are grateful for their baby being alive and well. The parents who decided to have terminations after the session were not contacted as it was felt that this could be seen as insensitive. However, the input of these parents would have been interesting as it would be useful to know if the counselling affected their decision or not.

Conclusion

This service evaluation study found that parents who had a prenatal diagnosis of Spina bifida appreciated the input of a paediatric neurosurgeon and a paediatric neurologist at counselling sessions before birth. Parents reported feeling well supported, informed and prepared for the birth and every parent was extremely happy with the care and attention they received. Overall there were only three issues raised that could be improved upon; more information on catheterisation, the need for SCBU admission and a leaflet provided at the counselling session. These will all now be addressed by the authors in our institution. The major negative points were related to the lack of information given at the time of initial diagnosis. The authors hope that having an understanding of the thoughts, concerns and worries of these parents will enable us to improve on the specialist neurological counselling offered in our unit.

Declaration of interest: The authors report no conflicts of interest. The authors alone are responsible for the content and writing of the paper.

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Appendix

Questionnaire

1. Parental age, gestational age at diagnosis, medical professional who first suggested diagnosis (where?), was any initial clinical information given at that time?
2. Have you ever heard of Spina bifida before this? How much did you know? Did you have any previous experience with disabled children/Spina bifida?
3. What was the situation in which you were first told that something might be wrong?
 - a. What was your initial reaction? How did you feel?
 - b. Did you understand what was being said?
 - c. How could this initial consultation have been improved?
 - d. What happened next?
4. When you were referred for counselling with the specialist team what were you most keen to gain? (i.e. decision on continuation of pregnancy, extent of disability etc).
 - a. Did the counselling session affect your decision on whether to continue with the pregnancy or not?
 - b. Do you feel you were persuaded to make a decision either way?
 - c. Were you given enough information to prepare for what lay ahead eg disability, surgery, future problems?
 - d. Do you remember being offered to be seen again if required during the pregnancy?
 - e. In hindsight, is there anything else you would have liked to have known at the time?
5. What extra information were you given at the counselling session? Was this helpful? How did it make you feel with regard to your pregnancy?
6. Did you seek any other information or tests whilst pregnant and with regard to the Spina bifida diagnosis?