

Antenatal Experiences of Expectant Parents in Pregnancies Affected by Spina Bifida

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Spina bifida develops early in the embryonic stage of pregnancy but is not usually detected until the midterm (20 week) ultrasound scan. This is an important screen for fetal anomalies, but parents more commonly think of it as an opportunity to bond with and celebrate their developing baby. Even expectant parents who understand that the scan's purpose is diagnostic/screening are usually shocked by the discovery of a congenital condition. Parents are then faced with hard choice about whether to continue or to end the pregnancy.

We conducted a survey to assess the antenatal care experiences of parents to children with spina bifida. Volunteers were recruited via social media and 71 eligible (UK-based) responses were received, revealing numerous elements of antenatal care in need of significant improvement.

Figure 1 shows that experiences were shared from across the UK and over a range of timescales but most responses were from England (76%) and most related to births within the last 5 years (64%).

When did you have your baby with spina bifida?

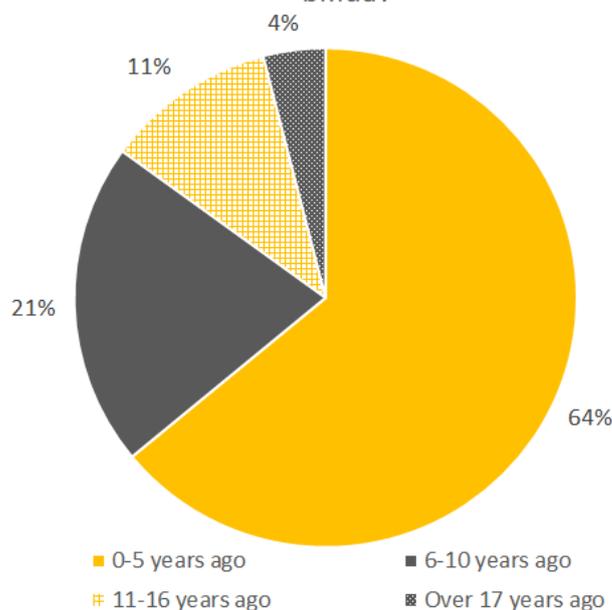
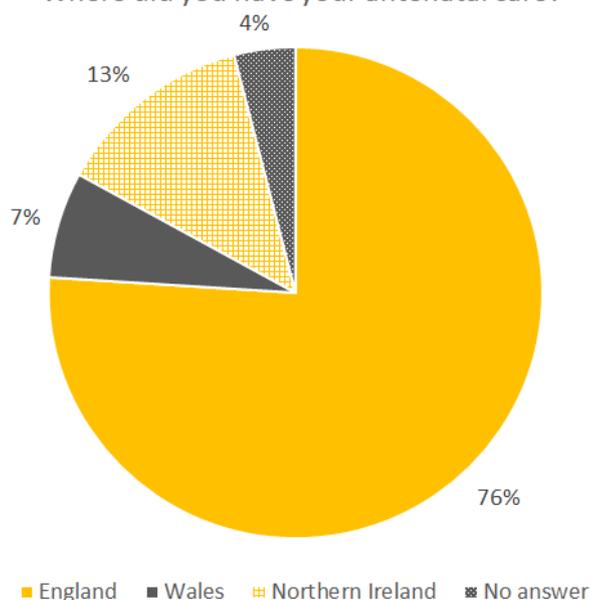


Figure 1: Where and when parents had their babies with spina bifida

Many parents have reported to Shine that termination offers were made at the diagnostic appointment and quick decisions were expected with inadequate support and information. Few parents report being given the opportunity to first consult a clinician with first-hand experience of spina bifida care. A tremendous decision-making weight is therefore placed on diagnosis, so the information and support provided must be of the highest quality. Our survey showed that 53% of parents were offered no written information to take away, only 19% were offered Shine's information, and 18% the NHS spina bifida information (Figure 2).

Where did you have your antenatal care?



What written information/leaflets were you offered at the time of diagnosis?

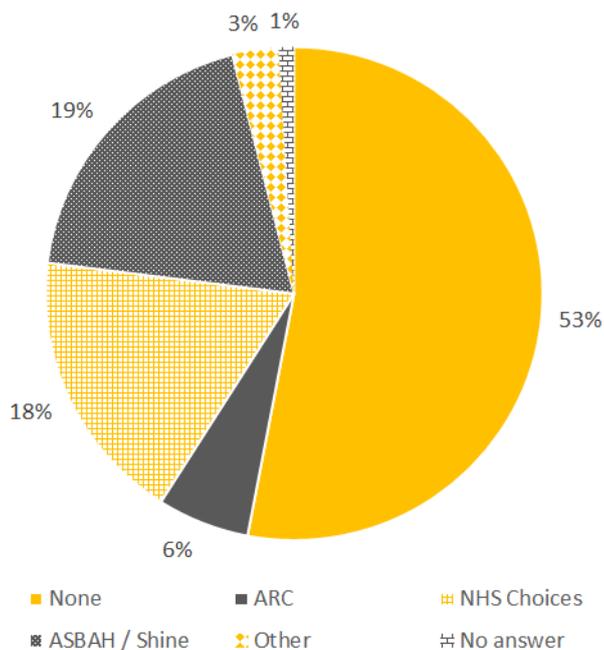
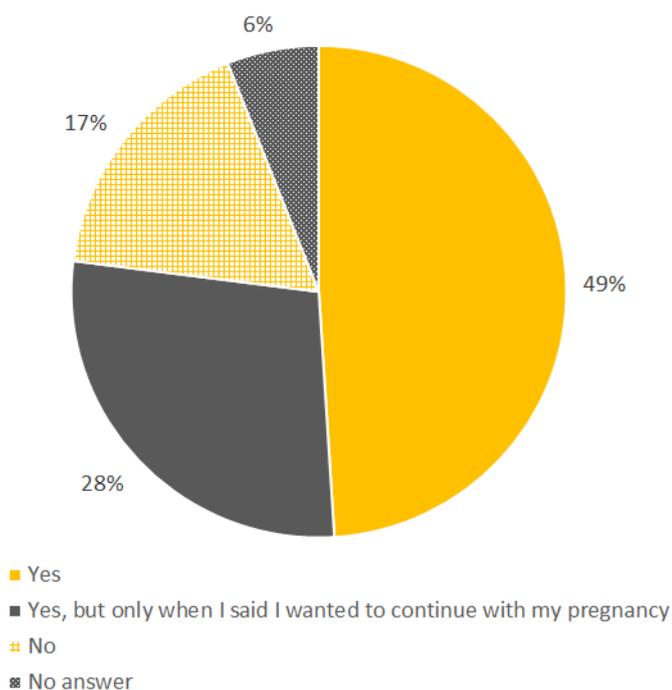


Figure 2: Written information offered to parents at diagnosis

Figure 3 shows that referrals to Fetal Medicine for specialist evaluation were not offered to 17% of parents, and 28% were only referred after deciding to continue their pregnancy. Of the parents not automatically offered referral: 50% had not been offered written material, and 8% had only been offered termination information.

Were you offered a referral to a Fetal Medicine Unit?



Written information offered to parents not automatically given a Fetal Medicine Referral

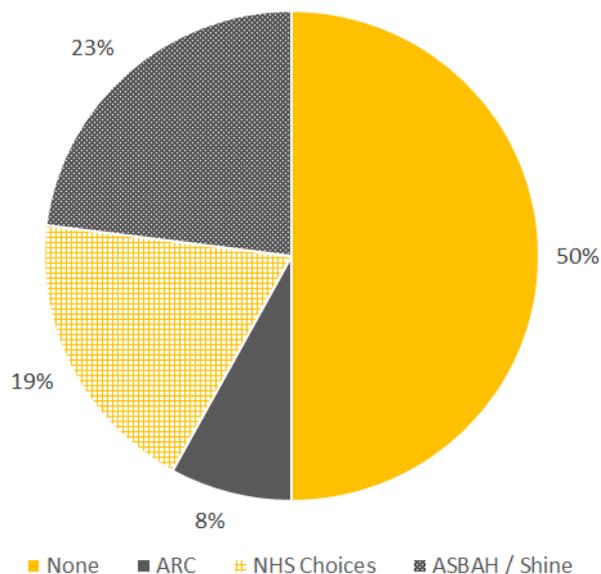


Figure 3: Fetal medicine referrals and written information offered to parents

The spectrum of spina bifida outcomes is broad and it can be a challenge to predict the precise ways, and extent to which, an individual will be affected. However, we do know that generally lesions lower on the spine are associated with fewer/less severe physical and cognitive impairments and a reduced likelihood of needing shunt placement. Our survey results suggest that a misleading and negatively biased impression of the condition is often presented to expectant parents. More than a quarter of the respondents were told at diagnosis that their child would be severely cognitively affected. Excessively negative, emotive and sometimes extremely derogatory language was often encountered e.g. ‘Mentally retarded’, ‘brain damaged’, ‘cabbage’ and ‘vegetable’. Parents have repeatedly told Shine that the descriptions they were given suggested a disability so extreme that the affected child would never communicate or have any independence. This is not an accurate picture of spina bifida: the typical cognitive profile is areas of strength with areas of weakness (Barnes 2010); 60-70% of children with spina bifida have an IQ in the average range; many will be able to walk, potentially with assistive devices or orthoses; and almost all will be independently mobile, able to achieve social continence with support, and able to live rich, fulfilling lives (Bruner and Tulipan 2004).

When asked about the way their baby’s diagnosis was given to them only 7% shared positive examples e.g.

“ We were told the extent, type, location and most likely outcome of her condition, in terms of physical, mental and continence in a very sympathetic but very thorough manner. ”

“ We were told about the myelomeningocele, where it was located on our daughter’s spine and that this meant it was likely that she wouldn’t be able to walk and would have some level of incontinence. The differences in her brain were explained to us and that she would likely develop hydrocephalus and need a shunt. We were given a detailed information sheet to take home. ”

However, the majority (66%) experienced consultations in which pessimistic prognoses were given and their child was described with inappropriate language:

“ Basically we were told the baby would be paraplegic, no supportive information and then told to come in for a termination the next day. When we asked questions and for a second opinion this was met by hostility. ”

“ taken to a room where a consultant came and gave me little to no information other than it looked very bad and they were sorry but I could always try again. Any question I asked was met with a short yes or no answer followed by ‘ but it looks very bad’. No detailed information was given. ”

“ I was told my child would be a vegetable and have no quality of life. That they would be in a wheelchair and be mentally retarded. It was in my best interests to terminate. ”

“ I was told my baby would probably die and encouraged to terminate. Told my son would be severely mentally disabled and completely incontinent. Told half my sons brain was missing! All nonsense and trying to scare me to terminate ”

“ basically told that she was going to be cabbaged and we might not be able to have a relationship with her, everything was so negative. ”

“ I was told by the sonographer [sic] that my son was a complete vegetable and that nothing was working ”

At the midterm ultrasound scan, distinctive alterations in the shape of the head and cerebellum can indicate the presence of spina bifida, even if the spinal lesion itself is not visible. Prof. Nicolaides termed the characteristic scalloping of the frontal bones of the skull as the ‘lemon sign’ and the elongation of the cerebellum as the ‘banana sign’. These descriptions are helpful to sonographers for spotting key spina bifida indicators, prompting closer examination of the spine and accurate diagnosis. However, the terms are often used when talking to parents and can cause distress. Figure 4 shows that 67% of our surveyed parents reported hearing ‘lemon-shaped head’ and/or ‘banana-shaped cerebellum’ used to describe their baby. Although 10% of parents said the terms helped them understand the condition, and a further 38% thought the terminology was unimportant, over half (52%) found these descriptions distressing to some degree. Parents have told Shine how upsetting and dehumanising it was to hear their unborn child described as a piece of fruit. ‘Lemon’ is used in some parts of the UK as a slang term for an unintelligent person, or a defective piece of equipment.

Were you told your baby had a "lemon-shaped head" and/or a "banana-shaped cerebellum"?

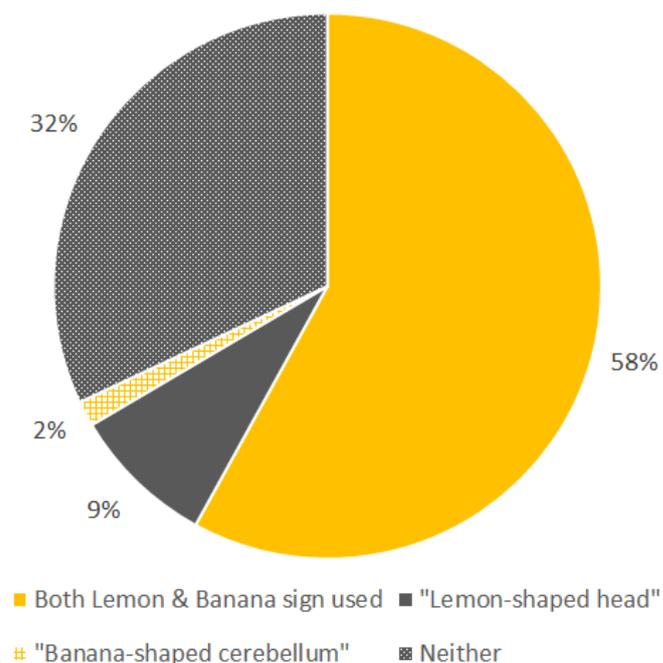


Figure 4 (above and overleaf): Use of ‘Lemon’ & ‘Banana’ sign terminology with parents

If the terms lemon and/or banana sign were used, how did they make you feel?

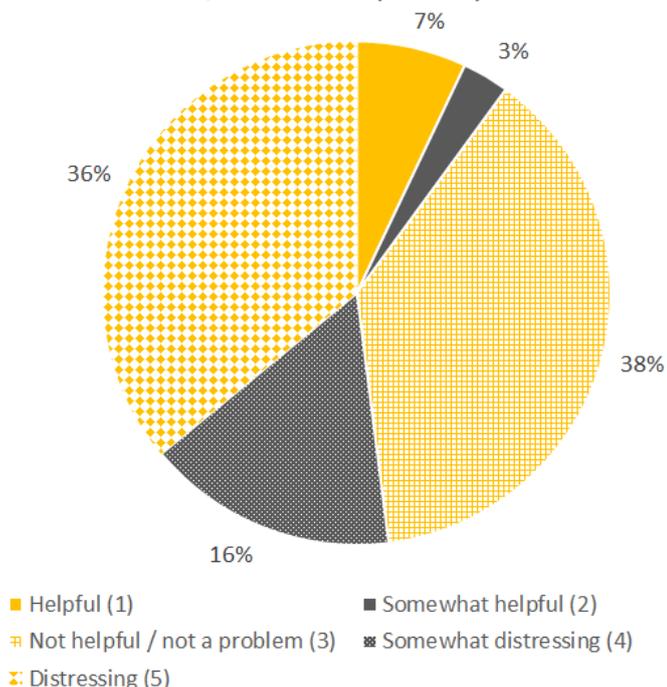


Figure 4: Use of 'Lemon' & 'Banana' sign terminology with parents

The parents were asked 'How does the information first given about your child's condition compare to your child's condition now?'. 73% of respondents said their child's condition was less severe than they were told to expect. Only 9% reported that the condition was more severe (Figure 5). The high percentage of children with conditions less severe than their parents had been led to expect implies that spina bifida is being inaccurately presented on a routine basis.

Parents have frequently raised issues with feeling 'pushed towards' having a termination and being put under pressure to decide quickly so we set out to explore this in the survey. When deciding whether to continue or end their pregnancy parents rely heavily on the early information they receive. In the NHS's own words "for consent to be valid it must be voluntary and informed". This means decisions must be based on the most accurate possible clinical information (informed) and they must be "made by the person and must not be influenced by pressure from medical staff" (voluntary).

On a scale of 0-10, how does the information you were first given compare with your child's condition now?

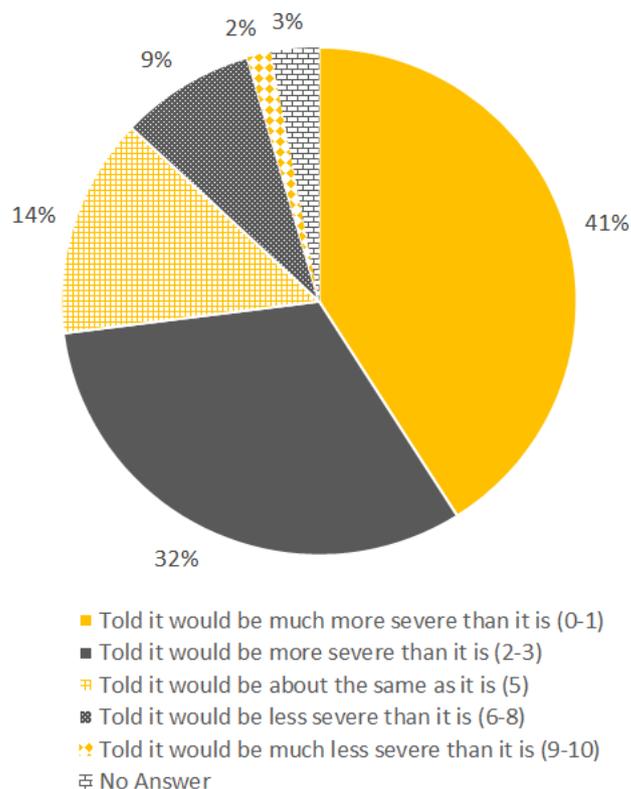
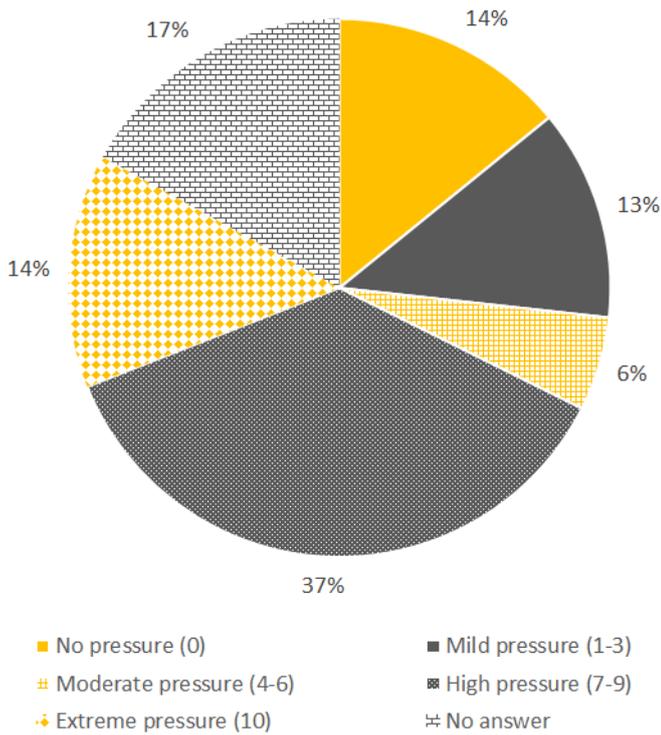


Figure 5: Comparing the severity of a child's condition with what was predicted at diagnosis

Our survey results suggest that antenatal services are often failing to meet the NHS requirements for consent. The responses suggest a termination bias exists in the clinical setting: 51% of parents felt highly or extremely pressured to terminate their pregnancy and 42% felt under high/extreme pressure to decide quickly (Figure 6). Troublingly, 25% of parents said they felt under severe pressure to terminate **and** chose quickly, and more worryingly almost all of these were offered either no information, or information on termination alone.

If you were offered a termination, how pressurised did you feel to end your pregnancy?



If you were offered a termination, how pressurised did you feel to decide quickly?

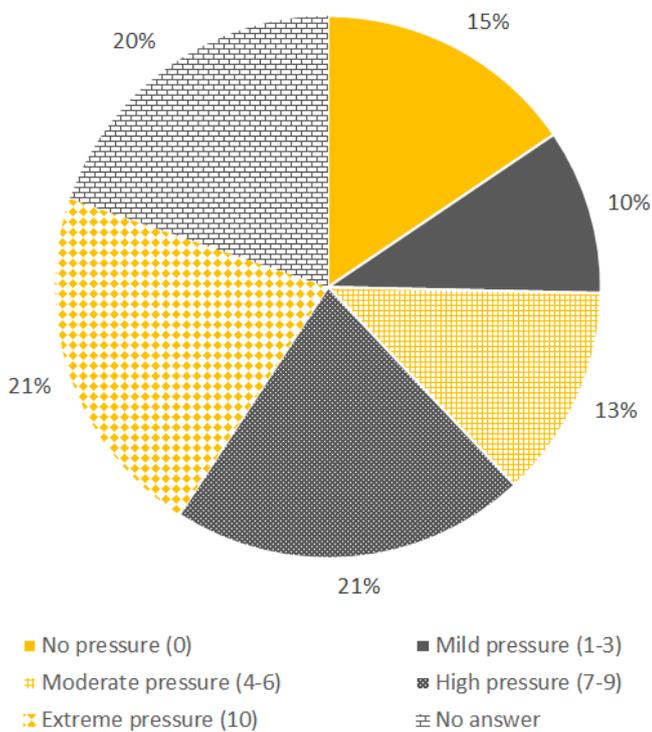


Figure 6: Pressure to terminate & to decide quickly

Some respondents did describe positive experiences:

“ It was given as one of the options but once we said that wasn’t an option for us it wasn’t mentioned again ”

“ Told termination was an option but also that defect didn't look to be too severe so it was 50/50 and up to us. There was no pressure ”

“ offered by my local hospital and the specialist hospital, but they respected our wishes ”

“ Our Obstetrician was extremely sympathetic and said that he had to offer but could absolutely understand our decision either way ”

Sadly however, these were not typical of the parents’ experiences and most reported that the discussions and offers of termination were particularly upsetting elements of their antenatal care. Termination was often offered in the same appointment that the spina bifida diagnosis was made. Figure 7 shows that this was the case for 76% of parents overall and varied between countries: 81% of respondents across England and Wales were offered termination at diagnosis as were 29% in Northern Ireland, where termination law until late 2019 has differed from the rest of the UK.

Were you offered termination the first time you heard that your child had spina bifida?

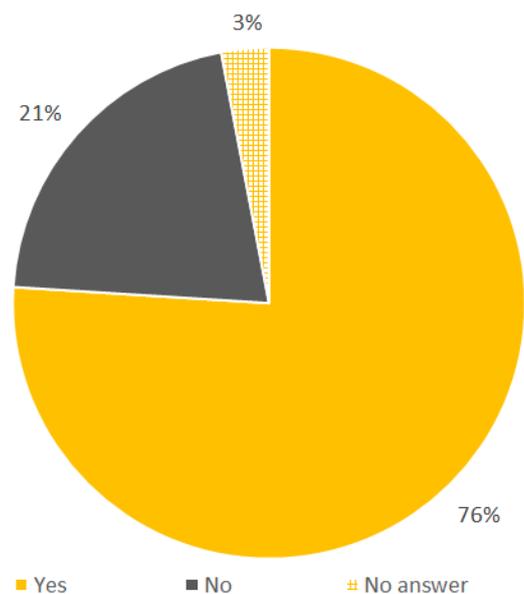
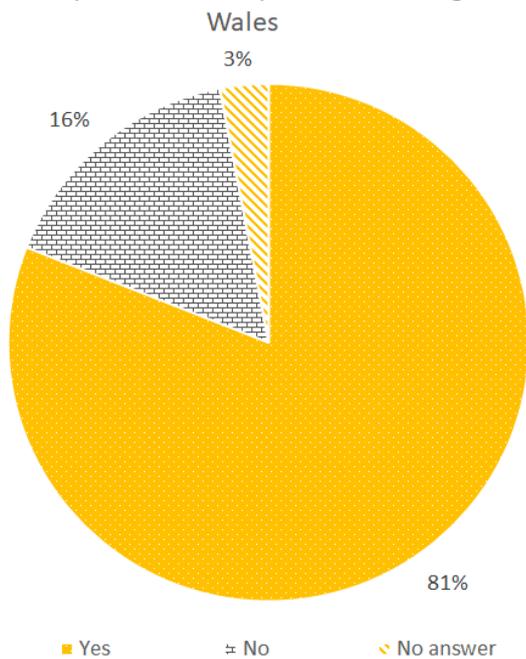


Figure 7 (above and overleaf): Termination offers to parents at diagnosis

Were you offered termination the first time you heard that your child had spina bifida? - England & Wales



Were you offered termination the first time you heard that your child had spina bifida? - Northern Ireland

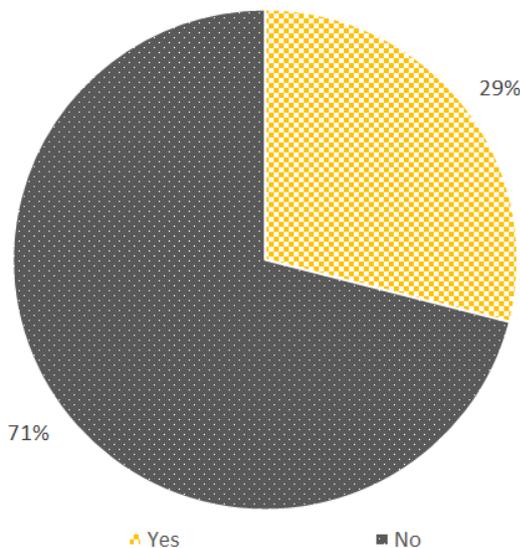


Figure 7: Termination offers to parents at diagnosis

The speed with which termination offers were made was upsetting for many parents:

“During the diagnosis we were told we had the decision and were put in a small side room where we had to make a decision. We were still trying to process everything at such a hard time”

[Termination offered] “within the same breath as the diagnosis was given (badly). Paperwork was given at the same time.”

“Within two minutes of diagnosis I was offered termination. I refused and was given the weekend to think about it.”

“We were told we could be offered a termination as quickly as on the same day.”

As was the pressure to decide quickly and/or to terminate:

“I was told to not bother about continuing with the pregnancy as the baby will have a poor life and a drain on society. I was scanned at 24 weeks and was told he was ill, I had just hours to decide what option to take ! HOURS !!!!”

“Told my baby would not survive and if he did, he would be severely mentally disabled and incontinent. Encouraged to terminate”

“I was constantly offered termination until 26 weeks! I eventually put in a formal complaint and wrote a note on the front of my maternity notes not to be asked again. I was asked questions like "are you sure you don't just want to terminate" "are you really committed to this pregnancy" "it's a big commitment are you sure”

“I was told if I wanted a termination I had to decide by the next day, I didn't want one so never asked anymore details”

“I was told my daughter wouldn't survive birth, and to have a termination would be for the best”

Many parents described hearing ‘most parents in your situation end their pregnancy’ which is unfairly leading and biased because it suggests ‘this is the right thing to do’. It is also problematic because it's self-perpetuating: parents are persuaded to end their pregnancies because they are told other parents have terminated. Figure 8 shows responses to questions about termination: when asked how many times it was offered, 28% stated more than four times and 34% reported that offers continued despite clearly stating their intention to continue their pregnancy. For 22% of the parents to be, offers were repeated beyond the 30th week of pregnancy, until full term for some.

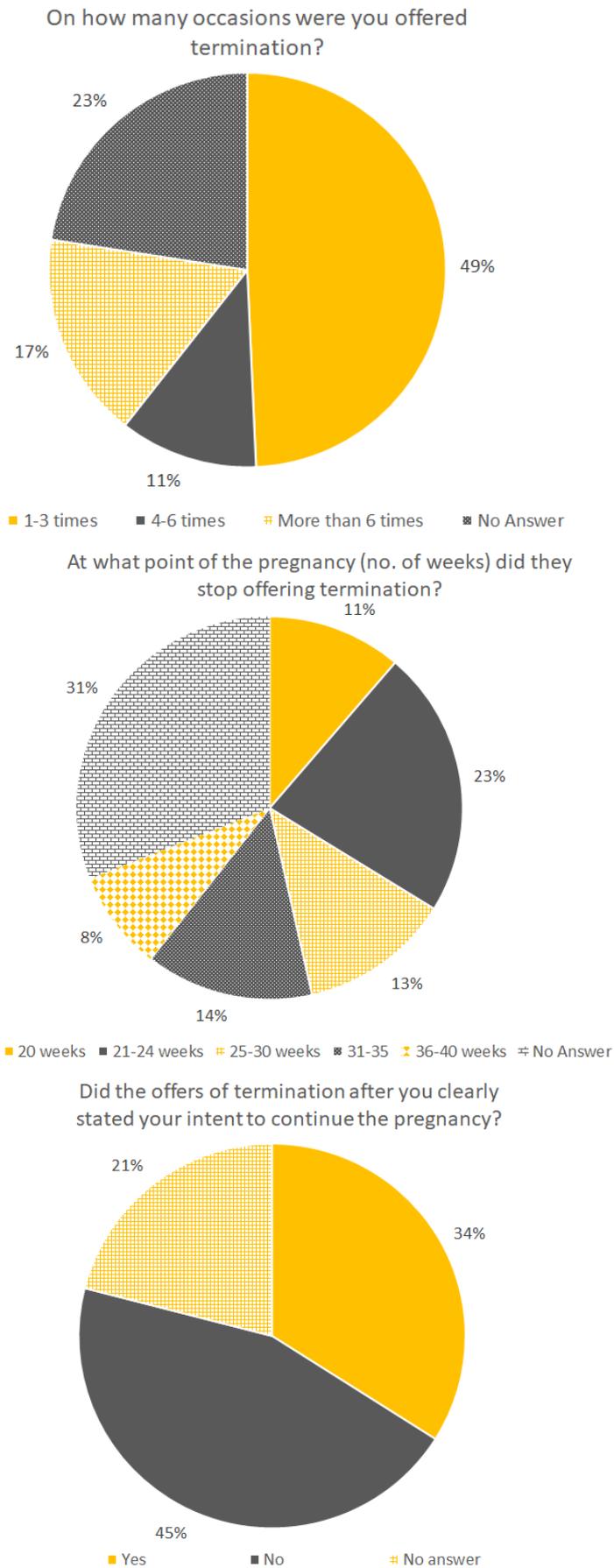


Figure 8: Termination offers at diagnosis

The data raise the question as to why so much pressure is applied for parents to decide quickly if they are in fact able to choose termination so late. Such pressure is

particularly worrying as it was frequently experienced by the parents who were offered no written information or referral. The parents who had reported being made a single termination offer, without pressure, and with time to consider away from the hospital, remembered that the offer had been made. One offer is clearly enough.

For consent to termination to be considered 'informed' the information provided must be of the highest possible quality. The prognosis shared with parents should they continue their pregnancy must be complete, accurate and understandable. Generic written information about the condition/s should be offered but the prognosis must be personalised. The likely outcome discussed with patients must be based on their specific findings with consideration of the latest research and understanding about the conditions. Where this is beyond the experience/expertise of the diagnosing clinician they must then offer to refer parents to a more experienced professional.

Since antenatal screening began around 30 years ago and termination started being routinely offered, relatively few babies are now born each year in the UK, on average 190 were born each year from 1980-2017 (EUROCAT). Fewer born with the condition means that first-hand experience of spina bifida among clinical professionals has waned. As a result those diagnosing spina bifida and discussing prognosis may struggle to accurately counsel parents due to limited exposure to the huge variety of possible outcomes with the condition.

Our results indicate that parents responding about recent pregnancies were just as likely as those from 15 years ago to have had a poor antenatal experience. Unfortunately, this indicates few improvements in care have been made over several years. Since we conducted the survey, a spina bifida information leaflet has been created by Public Health England; the leaflet will be offered at diagnosis and this will be audited. The leaflet marks significant progress, however further reforms must be implemented to improve care standards so that all parents are equally supported and informed throughout their pregnancy and beyond.

“ They went through everything with us and showed us the real hope that is living with spina bifida ”

When we asked parents to share aspects of diagnosis that they found particularly difficult their responses could be broadly categorised into seven recurring issues (Figure 9).

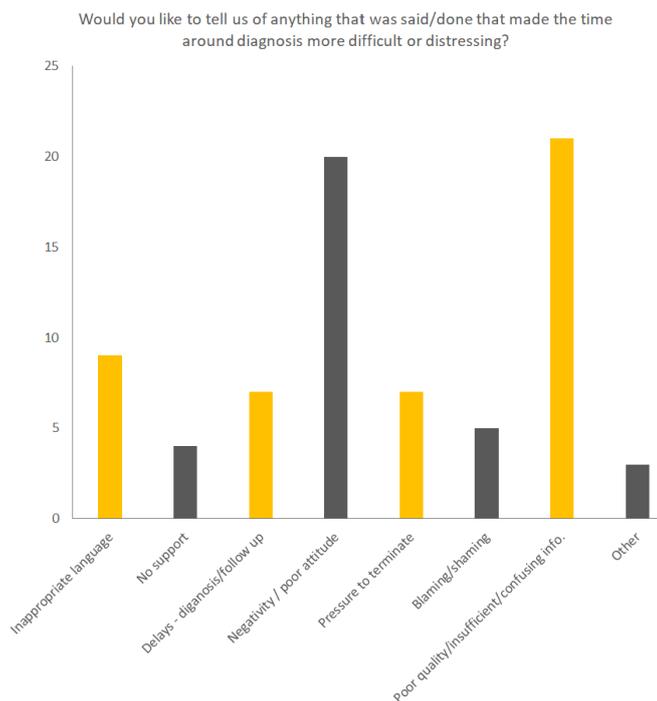


Figure 9: Distressing aspects of antenatal care experiences

Negativity and poor attitude of professionals and poor quality, insufficient or confusing information were highlighted as the most common problems. We aim address these issues by developing guidelines and training to help clinical professionals to improve knowledge and understanding of spina bifida, we aim to collaborate with NICE and the NHS to achieve this. We also want to improve professional communication about the condition such that information and attitudes are more positive, appropriate, and based on an accurate picture of spina bifida.



Shine believes that every parent has the right to expect:

- To hear the diagnosis and prognosis from a clinician who understands the complexity and variation in severity of spina bifida.
- The offer of information on spina bifida and Shine to take home at every appointment.
- To hear their baby described in a respectful manner.
- The opportunity to discuss their child with teams of clinicians experienced in the care of people with spina bifida.
- The offer of termination to be made without bias
- Time at home to consider their options
- The offer of termination to be made twice at the most, and for it to be clearly recorded on the notes that the parents-to-be are committed to the pregnancy.

References

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Acknowledgements

Shine would like to thank all our parent-members who took the time to complete the antenatal survey. Taking part meant revisiting extremely difficult times in their lives and we are incredibly grateful that they chose to share their experiences to help improve the antenatal experience for future parents. We would also like to thank Jane Fisher from Antenatal Results and Choices for her feedback and input.