

Antenatal screening: Informed choice and parental consent

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Background to the study

Antenatal screening of the fetus can be performed for a range of conditions, including Down syndrome, spina bifida or congenital heart disease. Screening may be offered using either blood tests or ultrasound, or a combination of both.

The UK National Screening Committee (2003) is very clear about the information that should be provided to women considering antenatal screening. However, a review of other published literature (Skirton and Barr, 2007) indicated that parents were not always making informed choices about screening. The aim of this study was to identify how prospective parents could be supported to make informed decisions about antenatal screening of the fetus.

Study method

In Phase 1 we held four focus groups with prospective parents and four focus groups with professionals involved in antenatal screening in different regions of England (South East, South West, North East and West Midlands). Two questionnaires were developed, based on the data collected in Phase 1. These were used in Phase 2 to investigate the knowledge and opinions of both prospective parents and health professionals. Questionnaires were completed by 111 prospective parents and 78 midwives from across the UK.

Main findings

1. Parents appear to appreciate the offer of screening, with uniform approval from respondents in both phases that choice was 'a good thing'. However, many parents expressed the view that they did not have enough time to consider their decisions and there were some instances where screening was not discussed with them until the second trimester. While some midwives talked about encouraging parents to think about the screening decision in terms of their values and beliefs, many simply said they did not have enough time to spend on the issue of screening.
2. Pregnant women are given a great deal of information about many aspects of pregnancy, birth and even postnatal care at the first booking consultation with the midwife. This was seen by both parents and midwives as counter-productive to achieving informed decision making about screening tests.
3. There is recognition amongst parents and some, but not all, professionals that screening could be used to prepare for the birth of a child with Down syndrome and this is a valuable role for it.

4. The printed material provided about screening is appreciated by parents, but this is not generally supported by adequate personal discussion with the health professional offering screening. While the majority of our participants could write and read English, there are serious concerns about those parents who cannot read well or who do not have material in their languages.
5. Both parents and professionals overestimated the ability of the screening tests to detect a range of problems. This causes difficult issues for both parents and professionals when a child is born with Down syndrome and this had not been expected. Indeed, through the study we found examples of the birth of an affected child being viewed as a failure of the system and a 'critical incident'.
6. Pregnant women and their partners felt that the decision about screening should be made by both parents. However, in the majority of cases midwives reported that they only involved fathers in the discussion if they 'happened to be present'.
7. Midwives were concerned that parents were not well-prepared for the possibility that problems might be detected via an ultrasound scan, believing it was viewed more as a social experience than a screening test. However, some parents had come to a realisation as they were waiting for the scan that problems might be detected. There appear to be insufficient information resources about the use of scans to detect problems in the fetus. There was little evidence that parents were being asked to consent to scans in the same way as they were asked to consent to other screening tests.
8. The majority of parents and professionals recognised that knowledge of the lives of people with Down syndrome is relevant to the decision about screening. However, there were concerns expressed by many parents and some professionals about the way in which having a child with Down syndrome is presented in a medical context and is often a negative rather than a balanced view.
9. A number of parents and professionals supported the provision of information that gives a balanced account of the lives of people with Down syndrome and moves beyond the clinical condition and childhood images. Both groups stressed the need for information to be recommended by health professionals. The two methods of providing information thought to be most useful by both parents and professionals were via books and leaflets or via a website recommended by a professional.

Recommendations

It is clear that, while provision of information about antenatal screening is available to the majority of parents in the population, there are significant groups of parents who are being given insufficient opportunity to consider the options. Our findings are consistent with data generated by the 2007 Health Commission Report on Maternity Services. These findings, viewed in conjunction with the recent BBC report that focuses on the increasing use of maternity services by immigrants (BBC, 2008), highlight the need for information in a format that is not dependent on written text.

Our recommendations are:

1. At the initial consultation between midwife and prospective parents, a high priority should be given to discussion of issues specific to the antenatal period, with discussion on labour, birth and postnatal issues left to a later time when it is more relevant. These discussions should take place *in addition* to written information.
2. Information about antenatal screening should be produced in a format that is easily understandable, regardless of ability to read. For example, this could be in a book or DVD that relies upon visual images to communicate the key points. This could be presented in the form of a decision tool.
3. Information about the detailed ultrasound scan is provided to prepare parents for the possibility of a problem being detected.
4. Information about the lives of people with Down syndrome is available to parents and professionals, with an emphasis on the social (rather than the purely medical) aspects of life. This material should provide a balanced view of the range of potential issues faced by both the affected person and his or her family. This material should be available in booklet form and via a website.

References

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More information about the study

The final report from the study is available to download free at:

<http://www.learningdisabilities.org.uk/antenatal-screening>

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