

Down's syndrome screening: the perspective of women and midwives in Northern Ireland

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Abstract

The use of maternal serum screening to assess individual risk for Down's syndrome is now standard in many countries and new techniques such as detailed ultrasound screening for nuchal translucency and DNA based tests are rapidly becoming available for mass screening. The increased uptake of these screening and diagnostic tests has provoked concerns about their potential impact on individuals and societal attitudes. The decision to accept or decline screening for Down's syndrome may present ethical or moral dilemmas for women and their partners in early pregnancy. As a serum screening test result indicates the level of risk rather than a diagnosis, the test may be more difficult to explain to women. Under the current law in NI women are not given the option to terminate if they have a positive diagnostic test unless it is in the interests of the mother's mental or physical well being which may affect the provision of universal screening for Down's syndrome and introduce decisional conflict for both women and professionals. As the first point of contact for antenatal care, midwives are ideally positioned to counsel women regarding antenatal screening, but the extent of their influence on women and their decision-making about screening is not clear and may be complex. Questions have also been raised regarding the knowledge and attitude of health professionals about Down's syndrome screening tests and the extent to which they facilitate informed choice for women.

The aim of the study was to explore the reasons why women accept or decline screening for Down's syndrome and the perspective of midwives who are involved in offering screening tests to pregnant women. The first phase of the study used survey methodology where women were interviewed at two stages in their pregnancy: at the booking interview and secondly after all screening had taken place. A total of 317 women who were offered screening were interviewed twice using semi structured interviews. A focused ethnographic approach was used in the second phase of the study and in-depth interviews with fifteen midwives were completed. Women identified several themes which influenced their decision to accept or decline screening but the key theme which emerged was the influence of health professionals on their decision making process. The findings from the midwifery interviews revealed the offer of screening is a difficult discussion with women where underlying negative perceptions of the test and a reluctance to discuss termination of pregnancy were influential. Midwives also experienced personal and professional conflict regarding their opinion of the test, their position in the organisational structure of antenatal care and ultimately their desire to care for women.

References

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