



Men's involvement in antenatal screening: A qualitative pilot study using e-mail

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ABSTRACT

Objectives: this study aimed to explore and analyse men's involvement in antenatal genetic screening and testing in England, and evaluate the use of e-mail communication as a method of health research with men.

Design: after receiving a favourable ethical opinion, a longitudinal qualitative pilot study was undertaken.

Participants: eight men, whose partners were pregnant, were recruited by purposive sampling.

Findings: findings indicated that the men experienced ambivalence, doubts and uncertainty about medically identified genetic risks, and also experienced an 'emotional rollercoaster', which was associated with their involvement in antenatal genetic screening and testing. Although connectedness with their partners and shared decision making were highly valued, men's involvement was mediated by their partners and health professionals, including midwives.

Conclusions and implications for practice: the implications of findings for medicalisation theory and future research are discussed. Using e-mail was a success in that the strong pilot data produced provides a stimulus for future research. In addition, implications for policy and practice are also considered, specifically the importance of addressing ambivalence and mediation if midwives are to communicate effectively when working with men and women regarding antenatal genetic screening and testing.

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Introduction and background

There have been calls, internationally, for further engagement with men and fathers in healthcare (WHO, 2007). Within the Healthy Child Programme (DH, 2008) and in recent maternity services policy documents (DfCS/DH, 2009) in England, there is high level rhetoric about how men should be engaged during pregnancy, and in the first few months of a child's life, by midwives in order to improve maternal and child health. Improving men's involvement in pregnancy will become more important following the passing of the United Kingdom (UK) Equality Bill (2010) which requires public sector organisations to positively promote gender equity within services.

UK policy is for all pregnant women to be offered screening for a range of genetically related conditions including: Down's syndrome, fetal anomalies, sickle cell anaemia and thalassemia and Tay Sachs (in high-risk populations) (UKNSC, 2009). Postnatally

there is also systematic screening for genetic conditions including phenylketonuria, haemoglobinopathies and a number of congenital diseases. Women have prerogative in law to make decisions about accessing screening during pregnancy, and their views about antenatal screening have been quite widely investigated (Garcia et al., 2008). In contrast, men's (fathers') views and involvement in decision making regarding antenatal genetic screening have not been exclusively examined previously. In existing research, women participants have constantly outnumbered men (Ekelin et al., 2004; Locock and Alexander, 2006; Mullaney, 2006; Skirton and Barr, 2009), making it unclear how involved men currently are, how involved they want to be and what barriers they face. This research gap is important because decisions made by the woman about her pregnancy are likely to affect not only her relationship with the man but also his relationship with the child and their future as a family.

Many men want to be involved in their partner's pregnancy (Draper, 2002). In addition, men's greater involvement at all stages of the pregnancy not only helps them support their partners but also gives the couple the opportunity to conceptualise and adapt to their family transition together (Ekelin et al., 2004). However, how men's involvement in pregnancy is mediated may possibly hold

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some challenges for midwives and other healthcare professionals. Some men perceive that midwives may 'ignore' them (Singh and Newburn, 2003) and other men feel marginalised, perceiving that midwifery services target mothers (Pollock et al., 2005). It is not just midwives; some women partners mediate fathers' involvement with health and welfare services (Doucet, 2006). In addition, male partners of pregnant women receive antenatal and genetic screening information secondhand from women (Green et al., 2004).

In this present study we aim to explore men's views, feelings and experiences regarding antenatal genetic screening, and how these change during the time period of their partner's pregnancy.

One final background issue concerns the novel research methods employed. Research shows that the intimacy of face to face individual or group interviews may be challenging for some men (Robertson, 2007; Williams, 2007). Therefore, this study explored an alternative approach by asking men to record their views via electronic media, specifically using email. Aside from the practical benefits, such as saving time and costs on travelling and transcription, email communication allows time to reflect on and explore views and ideas by both the participant and researcher having access to data. Email interviews also provide anonymity and a longer period in which to build rapport, which can facilitate the disclosure of sensitive discussion topics (Hunt and McHale, 2007; Kazmer and Xie, 2008). It was speculated that this disembodied communication may enable men, within this new study, to feel more comfortable and able to express their views, feelings and experiences with interviewers, and this was also evaluated.

Methods

This was a pilot, longitudinal study, which aimed to explore men's experiences of antenatal genetic screening and their involvement with it. Secondly, the study also examined the efficacy of using electronic media as an alternative method of engaging men in health related research.

Purposive sampling was undertaken to enable us to answer our research questions. A sample of eight men, whose partners were in the first trimester of their pregnancy, was recruited using an advertisement via the National Childbirth Trust (NCT) network throughout the United Kingdom (UK). (The NCT is a national charitable organisation which focusses on supporting parents through antenatal, pregnancy and the postnatal time period). It is important to emphasise that we were not intending to access a representative sample of men but were using a novel form of communication to acquire some valuable data regarding the psycho-social dimensions of men's experiences. Twenty-eight men contacted the research team, had the study explained to them and they were sent copies of participant information leaflets and consent forms. Invitation to participate continued for approximately 1 month, until we had recruited eight participants. No applications to participate were refused.

Participants were requested to identify a personal email address that only they had access to. We did not ask for clinical or demographic information as this was not a priority for a pilot study and as we also wished to ensure the anonymity of participants. Participants were emailed four to six questions at three critical time points, at 16 and 28 weeks during their pregnancy and immediately post partum, in order to ascertain their views on genetic screening. These time points were chosen because the time period between 12 and 16 weeks is when the majority of scan, genetic risk assessments and screening are carried out to determine whether the fetus is affected by a genetic condition. At 24–28 weeks, the pregnancy is viable, and there is limited opportunity for elective termination of the pregnancy. The 1990 Human

Fertilisation and Embryology Act reduced the time limit of 28–24 weeks for most abortions, although if there is a substantial risk to the women's health or if there are fetal abnormalities there is no time limit, (Marie Stopes International, 2010). Post partum involves routine genetic screening of the newborn, for example, haemoglobinopathies and phenylketonuria testing.

The development of questions was supported by the literature review, feedback from the two fathers (non-participants) who contributed to the advisory group, and, for the later questions, by analysis of earlier data. Depending on the replies, specific points raised by the men were explored in more detail by up to two further emails in the proceeding month following their initial reply. The participants were requested to spend no longer than 30 minutes on their replies to prevent the research becoming viewed as too onerous. We had made this decision explicit within the ethical scrutiny process. Data were analysed at each stage of the pregnancy, longitudinally, to ascertain how experiences impacted upon later views or perceptions. Data recorded by participants were read and developed into codes, themes and concepts, which were dialectically and dynamically related, rather than being built in a linear fashion one from the other in order to test theory (Blaikie, 1993). The data analysis generated categories and patterns, which were organised into coherent themes. Furthermore, the diversity of participants' views and experiences are also noted, as are 'outliers' (the small number of views or experiences that contrast with the main patterns in the data) (Silverman, 2000). Each participant's extract is identified by the pseudonym and the phase at which he was interviewed.

The study was favourably reviewed by a UK university ethics committee and was undertaken within university recommended research governance guidelines. All participants were guaranteed confidentiality, with only two researchers having access to the raw data. Any findings potentially identifying individuals are omitted.

Findings

Four interdependent themes were identified in the data, as follows:

- One: Ambivalence, doubt and uncertainty regarding medically identified risk.
- Two: The 'emotional rollercoaster'.
- Three: Men and their partners: mediation and shared decision making.
- Four: Limited engagement with midwives and other health professionals.

Each theme will be presented in turn.

Theme one: Ambivalence, doubt and uncertainty regarding medically identified risk

Men reported that their partners had accessed a range of medical technologies, including genetic tests and screening. The men had sophisticated understandings of the processes involved, although they were not always clear on the specific tests conducted. Findings indicate that, to some extent, genetic screening and testing were associated with some valued experiences for men, including learning more about the pregnancy, the developing fetus and baby, and women's needs. Men were able to gain some reassurance, and with it, some reduction in anxieties and stress, if the outcomes for tests indicated they were less likely to have a baby with a disability. Medical information was described as having the potential to inform decisions about continuing with the pregnancy or thinking about it and preparing for a child with a disability.

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