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'Just a bystander'? Men's place in the process of fetal screening and diagnosis

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Abstract

Despite increasing research into men's experience of pregnancy and fatherhood, experiences of men whose partner is undergoing fetal screening and diagnosis have been less well-studied. This paper begins to fill a gap in the literature by identifying several potentially conflicting male roles in screening, diagnosis and subsequent decision-making. Drawing on a wider qualitative study in the UK of experiences of antenatal screening, it is suggested men may play inter-linked roles: as parents, bystanders, protectors/supporters, gatherers and guardians of fact, and deciders or enforcers. These may be roles they have chosen, or which are assigned to them intentionally or unintentionally by others (their female partner, health professionals). Men's status and feelings as fathers are sometimes overlooked or suppressed, or may conflict with their other roles, particularly when screening detects possible problems with the baby. The paper concludes by discussing these findings in the context of the wider literature on men and pregnancy.

Keywords: Antenatal screening; Antenatal diagnosis; Men; Parents; Fathers; Abortion, induced

Introduction—men's experience of pregnancy, fatherhood and fetal screening

For many years, research into pregnancy focussed primarily (and perhaps unsurprisingly) on women's experiences. As the discourse of 'new fatherhood' became established, research into men's experiences became more common. However, fatherhood has sometimes been characterised as potentially pathological or as a series of problems requiring solutions (Barclay & Lupton, 1999). Several critics note that both service provision and research have too often focussed on men's role as supporters rather than on their own feelings (Barclay & Lupton, 1999; Daly, 1995; Donovan, 1995; Finnbogadóttir, Crang–Svalenius, & Persson, 2003; Hildingsson & Häggström, 1999; Kaila-Behm & Vehviläinen-Julkunen, 2000; Mander, 2004).

From her ethnographic study of 18 middle class men, Draper found the 'inability to directly experience the embodied nature of pregnancy' to be a key factor (Draper, 2002a, p. 565). Seeing men as supporters rather than direct participants reinforces their sense of exclusion. Shapiro (1987, p. 38) notes:

> Men are encouraged to participate fully in the pregnancy and birth of their children but are simultaneously given to understand, in a multitude of ways, that they are outsiders. Most of all, it is made clear that while their presence is requested, their feelings are not, if those feelings might upset their wives. Anxiety, anger, sadness and fear are unwelcome.

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Men's role as supporters and protectors is part of the socially dominant or hegemonic conception of masculinity in contemporary western society. Whilst understandings of masculinity are constantly renegotiated to incorporate changing expectations such as 'new fatherhood' (Brandth & Kvande, 1998), men themselves and those around them continue to see support and protection as a legitimate and desirable part of their identity (Smith, 1999a, b; Moran-Ellis, 1989). These themes of men as fathers, as outsiders and as supporters resonate strongly with our own findings, and we return to this wider literature in our discussion.

Despite increased academic interest in men's experiences of pregnancy, birth and fatherhood, there has been little research into the experiences of men whose partners are undergoing fetal screening and diagnosis (Green, Hewison, Bekker, Bryant, & Cuckle, 2004). Fetal screening has become routine in most developed countries (Geneva Foundation for Medical Education and Research, 2005). Screening can take several forms. Blood tests for biochemical markers of conditions such as Down's syndrome or spina bifida have been available for some time, although the specificity of such tests has increased and their use has become more routine (Green, 1994). Ultrasound scans have also moved from being an optional extra to an expected part of care and a culturally significant point in pregnancy (Green & Statham, 1996; Clement, Wilson, & Sikorski, 1998). A more recent development has been the use of nuchal translucency scans to assess the risk of chromosomal conditions such as Down's syndrome in the first trimester of pregnancy. Earlier and more accurate risk assessment will mean diagnostic tests such as chorionic villus sampling (CVS) and amniocentesis can be targeted more effectively (Wald et al., 2003).

Women are generally the primary recipients of information about screening tests, either when they first contact a healthcare provider to report or confirm their pregnancy or at a more in-depth visit with a midwife or doctor to plan their antenatal care. Male partners are less likely to be present at these contacts than at scan visits. Although the couple may discuss screening together, men are less likely to discuss it directly with a healthcare professional. Trends towards screening earlier in pregnancy also have implications. Making early screening a standard component of routine antenatal care can mean parents embark on this process without adequate discussion and information about where it may lead—including ultimately the decision about whether to terminate an affected pregnancy (Sandall, Williams, Pitson, Lewando-Hundt, Spencer, and Heyman, submitted; Wieser, 2004).

There is little evidence concerning men's experience of serum screening tests. One exception is a study by Burton, Dillard, and Clark (1985) of the psychological impact of false positive results from alpha-fetoprotein tests (assessing the risk of neural tube defects such as spina bifida), which found both women and male partners showed significantly raised anxiety, but only until normal results were obtained.

One of the better-researched areas is men's presence at normal ultrasound scans. In her UK-based study, Draper (2002b) notes the importance of ultrasound for helping men visualise the baby and realise their transition to fatherhood (Draper, 2002b). Sandelowski (1994, p. 230) suggests ultrasound makes parents' relationship to the fetus more equal, offering men 'an enabling mechanism that permits them access to a female world from which they have been excluded.' Ekelin, Crang-Svalenius, and Dykes (2004) note ultrasound's power in confirming the existence of new life for both men and women, but their study of 22 Swedish women and their partners finds few differences between mothers' and fathers' experiences of normal scans.

There is less evidence of men's reactions to ultrasound diagnosis of fetal malformation. One study of 56 women and 24 male partners in Germany observed that women expressed shock and disorientation more strongly than men (Schuth, Karck, Wilhelm, & Reisch, 1994). The authors recommend that if the partner is present he should be included equally with the woman during the examination, communication of the diagnosis and explanation. However, they see his role primarily as supporter and do not address his own feelings, except to imply that he might blame his partner.

By contrast, Statham, Solomou, and Green (2001) note that men 'need to be informed, and supported both in their own right and in order to be supportive to their partners.' Their study of parents' reactions to a diagnosis of fetal abnormality and subsequent decision-making is unusual in including 190 men as well as 247 women; it is emphasised that parents of both genders need sensitive recognition of their needs as individuals and as a couple.

As with watching a painful labour, the experience of watching their partner having fetal diagnostic tests such as amniocentesis or CVS can be difficult for men, but again their expected role may be to act as a supporter to their partner. Sjögren (1992) interviewed 20 men whose partners had CVS or amniocentesis (all with normal results) and reports men themselves may want to take on this supportive role, but also experience considerable psychological distress. However, she finds that men were 'remarkably uninformed about prenatal diagnosis, weakly involved in decision-making and weakly attached to the future child' compared to women (p. 197). Half spontaneously stated the final decision about testing rested with their female partner.

With the exception of Statham et al. (2001), little is known about women's decision-making following a definite diagnosis of fetal abnormality (Marteau &