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'Give us the full story': Overcoming the challenges to achieving informed choice about fetal anomaly screening in Australian Aboriginal communities

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ABSTRACT

This cross-cultural qualitative study examined the ethical, language and cultural complexities around offering fetal anomaly screening in Australian Aboriginal communities. There were five study sites across the Northern Territory (NT), including urban and remote Aboriginal communities. In-depth interviews were conducted between October 2009 and August 2010, and included 35 interviews with 59 health providers and 33 interviews with 62 Aboriginal women. The findings show that while many providers espoused the importance of achieving equity in access to fetal anomaly screening, their actions were inconsistent with this ideal. Providers reported they often modified their practice depending on the characteristics of their client, including their English skills, the perception of the woman's interest in the tests and assumptions based on their risk profile and cultural background. Health providers were unsure whether it was better to tailor information to the specific needs of their client or to provide the same level of information to all clients. Very few Aboriginal women were aware of fetal anomaly screening. The research revealed they did want to be offered screening and wanted the 'full story' about all aspects of the tests. The communication processes advocated by Aboriginal women to improve understanding about screening included community discussions led by elders and educators. These processes promote culturally defined ways of sharing information, rather than the individualised, biomedical approaches to information-giving in the clinical setting. A different and arguably more ethical approach to introducing fetal anomaly screening would be to initiate dialogue with appropriate groups of women in the community, particularly young women, build relationships and utilise Aboriginal health workers. This could accommodate individual choice and broader cultural values and allow women to discuss the moral and philosophical debates surrounding fetal anomaly screening prior to the clinical encounter and within their own cultural space.

Introduction

In recent decades there has been a rapid expansion of antenatal screening programs for fetal anomalies, with a move towards offering testing to all pregnant women, rather than only women at higher risk (ACOG Committee on Practice Bulletins, 2007; Department of Health and Ageing, 2011; National Institute for Health and Clinical Excellence, 2008; Three Centres Consensus Guidelines on Antenatal Care Project, Mercy Hospital for Women, Southern Health and Women and Children's Health, 2001). Testing usually involves an initial screening test (a blood test and/or ultrasound) which gives an individual estimate of risk of fetal anomaly. When there is an increased risk result (for example a probability of Down syndrome higher than 1 in 250) (SAMSAS, 2009) an invasive diagnostic test, such as amniocentesis is

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typically offered. This provides a definite result but carries a small risk (0.5–2.0%) of miscarriage (Mujezinovic & Alfirevic, 2007). As the vast majority (96–98%) of women who receive an increased risk result will not have a baby with the abnormality (SAMSAS, 2009; Three Centres Consensus Guidelines on Antenatal Care Project et al., 2001), the decision to embark on screening often involves the difficult task of weighing the risk of having a baby with an anomaly with that of losing an otherwise healthy baby. If a diagnosis is made a termination of pregnancy may be offered, as the majority of abnormalities identified are untreatable.

Current guidelines advocating universal offering of fetal anomaly screening have been driven by a focus on equity in access to information and health care, and the premise that providing information about the health of the foetus promotes reproductive autonomy. There is consensus that providers should explain all aspects of the testing, including the detectable conditions, procedures involved, test accuracy, meaning of screening results, options following a positive screening result, options following a diagnosis, and where to access further information (Murray, Cuckle, Sehmi, Wilson, & Ellis, 2001). The bioethical principles underpinning discussion of these issues include the provision of information from health provider to client in a non-directive manner where the client makes their own decision, and an emphasis on informed consent.

While non-directiveness has been the prevailing philosophy in genetic counselling since the 1970s (Kessler, 1997), many have questioned its relevance to this context (Kessler, 1992; Weil, 2003) and there is evidence that it is not always achieved in clinical practice (Michie, Bron, Bobrow, & Marteau, 1997). Others (Clarke, 1991; Press & Browner, 1993) argue that the mere presentation of information about antenatal diagnosis promotes acceptance of testing, and therefore non-directive counselling is unachievable. The focus of non-directiveness on promoting autonomy assumes that decisions are made in a rational way, and ignores the social context in which they occur. However, participation in screening requires women and their partners to deliberate not only biomedical interventions into pregnancy but on their moral philosophies in relation to disability and pregnancy termination, which have wider social consequences.

When non-directiveness was first embedded in genetic counselling practice, the main clients of antenatal counselling were women at higher risk of an abnormality, typically based on advanced maternal age, the majority of whom were white, middle class and often highly informed about fetal anomalies (Browner, Preloran, & Cox, 1999). However, the implementation of universal screening programs has resulted in women from a diverse range of socio-cultural backgrounds being introduced to testing and the more invasive diagnostic procedures. Consequently, the relevance of the non-directive approach to ethnic minorities has also been questioned (Browner et al., 1999), as it not only overlooks social contextual factors but the cultural framework underlying decision-making processes. For providers caring for pregnant women, the heterogeneous clientele now accessing screening presents additional challenges to communication. Furthermore, the incorporation of screening into routine antenatal care has shifted the responsibility for counselling beyond clinical geneticists to professionals working across obstetrics and primary health care, who may have had limited training in communication of this highly complex, medicalised and ethically fraught information.

In Australia, fetal anomaly screening is available in the first trimester of pregnancy, which involves a blood test and ultrasound to estimate the risk of Down syndrome (trisomy 21) and Edwards syndrome (trisomy 18), and in the second trimester which entails a blood test that assesses these syndromes and neural tube defects. Although current Australian guidelines (Department of Health and Ageing, 2011; Three Centres Consensus Guidelines on Antenatal Care Project et al., 2001) advocate that all women be offered screening, this is not reflected in uptake. Considerable variation exists between jurisdictions, for example, in 2004 the proportion of pregnant women receiving screening (either first or second trimester) ranged from 17% in the Northern Territory (NT) to 80% in South Australia (O'Leary, Breheny, Reid, Charles, & Emery, 2006). These geographic differences may mask variations in who receives screening by ethnicity. An analysis of state-wide data from ultrasound and pathology providers in Western Australia found uptake of fetal anomaly screening was lowest among women who identified as Aboriginal (Indigenous), lived in remote areas and were socio-economically disadvantaged (Maxwell et al., 2011). The greatest disparity in uptake occurred between Aboriginal and Caucasian women (15% versus 64%) (Maxwell et al., 2011).

Whether this observed variation in screening uptake by ethnicity reflects the quality of available services, attitudinal differences or barriers to access is unclear. A review of studies of screening provision in the United Kingdom found that Asian women were less likely than Caucasian women to be offered and take up screening (Rowe, Garcia, & Davidson, 2004), suggesting both poor access and culturally-determined values contribute to ethnic disparities in screening uptake. However, when studies have assessed the degree to which women act in line with their views about screening, lower uptake of screening in certain ethnic groups has been linked to a lower rate of informed choice rather than negative attitudes. For example, lower uptake has been reported even for women from ethnic minorities who hold positive attitudes about screening when compared with Caucasian women with similar views (Dormandy, Michie, Hooper, & Marteau, 2005; Fransen et al., 2010). In one of these studies (Fransen et al., 2010), women's language difficulties were identified as a major barrier to achieving informed decision-making.

There has been limited examination of Australian practices regarding the provision of fetal anomaly screening, and how they impact on uptake of screening among different ethnic groups. However, data from a recent medical record audit undertaken in Australian Indigenous primary health centres provides some evidence that limited access contributes to low uptake of screening among Aboriginal women. In this study, across the participating services in the NT, Western Australia and Queensland, only 15% of clients were offered fetal anomaly screening (range 6–33% across services) and a similar proportion agreed to screening (11% of the total client population) (Rumbold et al., 2011). The study could not determine the reasons why screening was or was not offered. As the data reflect documented care only, it is possible screening was discussed but not recorded in the medical file. Another explanation is that clients did not present to care early enough in the pregnancy, as Aboriginal women are less likely than other Australian women to present for care in the first trimester (Zhang, Dempsey, Johnstone, & Guthridge, 2010). However, across the participating services, the mean gestational age at first presentation was 16 weeks, which is within the timeframe for second trimester screening.

It is likely there are a number of issues which make communication about fetal anomaly screening particularly challenging in this setting. Language differences may impede discussions, as many of the clients of Indigenous health services, particularly in remote areas, speak an Indigenous first language. Understanding health information is also influenced by beliefs about health, and traditional and contemporary Indigenous beliefs about health and wellbeing can be markedly different from biomedical understandings (Vass, Mitchell, & Dhurrkay, 2011). There may be cultural sensitivities that interfere with communication, which are either real or perceived by the provider. For example, Browner, Preloran, Casado, Bass, and Walker (2003) found that views about cultural appropriateness contributed to miscommunication about