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Antenatal counselling for congenital anomaly tests: Pregnant Muslim Moroccan women's preferences

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ABSTRACT

Objective: to gain insight into pregnant Muslim Moroccan women's preferences regarding the content of and approach to antenatal counselling for anomaly screening.

Design: qualitative study using in-depth interviews.

Setting: participants were recruited from one midwifery practice in a medium-sized city near Amsterdam.

Participants: 12 pregnant Muslim Moroccan women who live in an area with a high density of immigrants.

Data collection and data analyses: we conducted open interviews after the cut-off date for the 20 week fetal anomaly scan and used techniques from the thematic analysis approach described by Braun and Clarke (2006).

Findings: pregnant Muslim Moroccan women's preferences towards counselling could be summarised in three main findings. Firstly, pregnant Muslim Moroccan women underlined the importance of accurate and detailed information about the tests procedures and the anomalies that could be detected. Secondly, pregnant Muslim Moroccan women preferred counsellors to initiate discussions about moral topics and its relationship with the women's religious beliefs and values to facilitate an informed choice about whether or not to participate in the screening tests. Thirdly, pregnant Muslim Moroccan women preferred a counsellor who respects and treats them as an individual who has an Islamic background. The counsellor should have practical knowledge of Islamic rulings that are relevant to the anomaly tests.

Key conclusions: pregnant Muslim Moroccan women preferred to be accurately informed about antenatal anomaly tests and to be asked about their individual views on life by a counsellor who has genuine interest in the individual client and applied knowledge of Islamic beliefs regarding the value of life.

Implications for practice: counsellors should explore clients' moral values about quality of life and termination and its relationship with religious beliefs. Counsellors should know about Islamic rulings related to antenatal anomaly screening.

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Abbreviations: CT, combined test; FAS, fetal anomaly scan

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Introduction

Since 2007, the Dutch antenatal anomaly screening programme has consisted of two tests: the combined test (CT) at 12 weeks' gestation, which is a probability test for trisomy 13, 18 and 21 (Patau, Edwards and Down Syndromes respectively), and the fetal anomaly scan (FAS) at 20 weeks' gestation to detect structural anomalies. In the case of a serious anomaly a woman may choose to terminate the pregnancy before 24 weeks of gestation or have antenatal care focussed on the best outcome possible. Recently,

a nationwide study showed overall mean CT and FAS uptakes of respectively 23% and 90% (Gitsels-van der Wal et al., 2014c), but findings among Muslim women indicate somewhat lower rates of uptake for CT and FAS (mean rates 20% and 80% respectively). At the time the current study was conducted, considering early antenatal genetic screening precipitated three potential decisions: (1) opt for the CT or not, (2) follow-up any positive CT result with amniocentesis which is associated with a 0.5% risk of miscarriage and (3) in cases of a trisomy, either to prepare for having a child with a trisomy or to terminate the pregnancy before 24 weeks' gestation. Since April 2014, the non-invasive antenatal test (NIPT) has been added to the national screening programme as part of a nationwide study (<http://www.niptconsortium.nl>). Considering second trimester anomaly screening follows a similar process of four potential decisions (Fig. 1).

The goal of counselling about anomaly screening is to enable a pregnant woman or couple to make informed choices with regard to screening tests (RIVM, 2011). An informed choice must meet three criteria, being 'based on relevant knowledge, consistent with the decision-maker's values and beliefs, and behaviourally implemented' (O'Connor and O'Brien Pallas, 1989; Skirton and Barr, 2010; Vanstone et al., 2012; Dixon and Burton, 2014). To facilitate

informed choices, counselling consists of health education (e.g. giving information about antenatal congenital anomaly tests and about the conditions that could be detected), decision-making support (including exploring the client's personal standards and values) and building a good client–counsellor relationship (e.g. showing genuine interest in each individual client) (Elwyn, 2004; Resta, 2006; Smets et al., 2007; Martin et al., 2013). Decision-making support has been seen as an important function in the theoretical antenatal counselling model (Meiser et al., 2008; Martin et al., 2014a). Previously, Martin et al. (2013) studied what midwifery clients in the Netherlands preferred in terms of counselling for antenatal anomaly screening; almost all participants valued the client–counsellor relationship and health education as important aspects of counselling whereas one-third of the participants valued individual decision-making support as important. As that study did not provide sufficient information about the preferences of pregnant women with non-Dutch, non-Western origins, further research was recommended to assess the counselling preferences for anomaly screening among women of non-Western origin.

An important and growing group of women with non-Western origins in the Netherlands is non-Dutch Muslim women. Recent

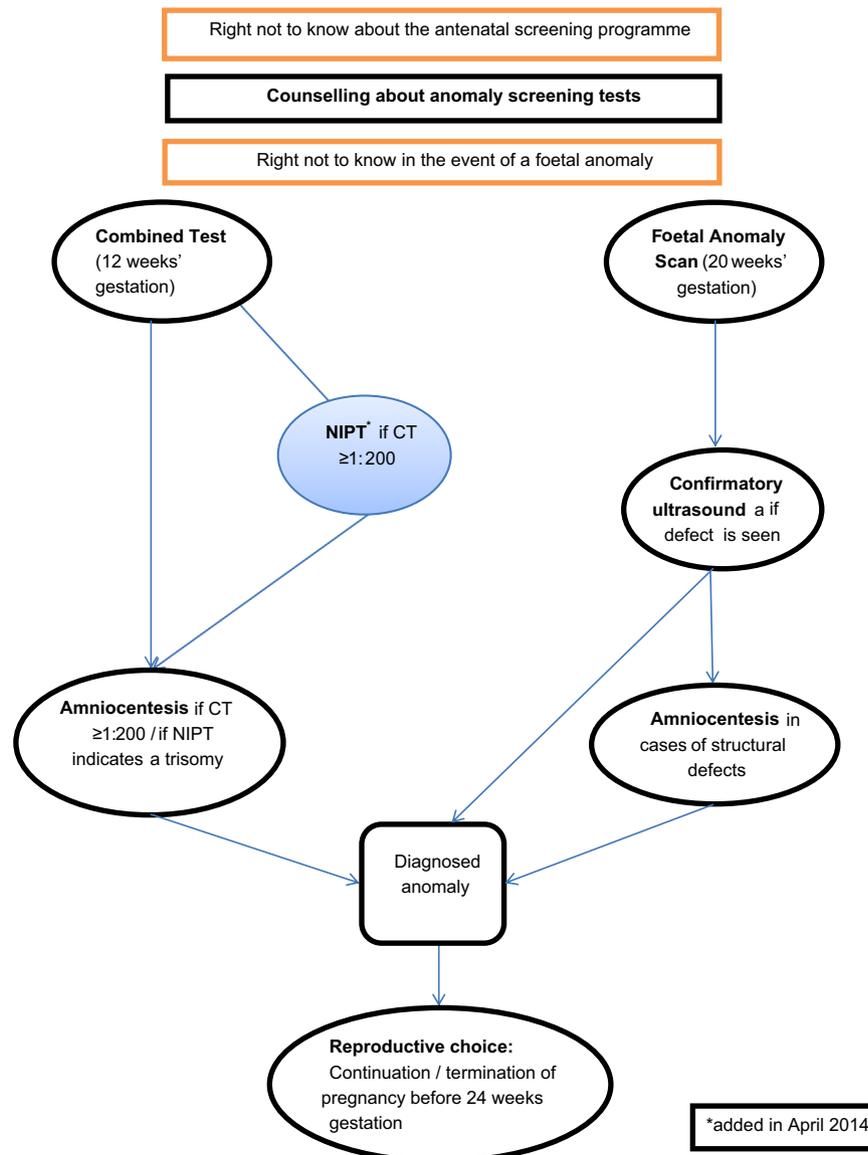


Fig. 1. Flow chart of choices within the Dutch Antenatal Anomaly Screening Programme based on an opt-in procedure.

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