



## The role of religion in decision-making on antenatal screening of congenital anomalies: A qualitative study amongst Muslim Turkish origin immigrants

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### ABSTRACT

**Objective:** to explore what role religious beliefs of pregnant Muslim women play in their decision-making on antenatal screening, particularly regarding congenital abnormalities and termination, and whether their interpretations of the religious doctrines correspond to the main sources of Islam.

**Design:** qualitative pilot study using in-depth interviews with pregnant Muslim women.

**Setting:** one midwifery practice in a medium-sized city near Amsterdam participated in the study.

**Participants:** 10 pregnant Muslim women of Turkish origin who live in a high density immigrant area and who attended primary midwives for antenatal care were included in the study.

**Data collection and data analysis:** to explore the role of religion in decision-making on antenatal screening tests, a topic list was constructed, including four subjects: being a (practising) Muslim, the view on unborn life, the view on disabled life and the view on termination. To analyse the interviews, open and axial coding based on the Grounded Theory was used and descriptive and analytical themes were identified and interpreted.

**Findings:** all 10 interviewees stated that their faith played a role in their decision-making on antenatal screening, specific to the combined test. They did not consider congenital anomalies as a problem and did not consider termination to be an option in case of a disabled fetus. However, the Islamic jurisprudence considers that termination is allowed if the fetus has serious abnormalities, but only before 19 weeks plus one day of gestation.

**Key conclusions:** religious convictions play a role regarding antenatal screening in pregnant Muslim women of Turkish origin. The interviewees did not consider a termination in case of an affected child. Women were unaware that within Islamic tradition there is the possibility of termination if a fetus has serious anomalies. Incomplete knowledge of religious doctrines may be influencing both decisions of antenatal screening and diagnostic tests uptake and of terminating a pregnancy for fetuses with serious anomalies.

**Implications for practise:** counsellors should be aware of the role of religious beliefs in the decision-making process on antenatal screening tests.

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### Introduction

#### Antenatal screening

Since 2007, antenatal screening of congenital anomalies has been offered to all pregnant women in the Netherlands. Antenatal screening follows an opting in system and therefore the intended aim is to offer the option of informed choice to pregnant women

who want to become informed about the health of their future child (RIVM, 2007; Oepkes and Wieringa, 2008). The aim of the antenatal screening tests is to detect possible congenital abnormalities. If anomalies are detected, there are two options: focusing antenatal care on the health of the fetus, or terminating the pregnancy before 24 weeks of gestation. In the Netherlands, antenatal screening includes two non-invasive tests: the combined test for determining the possibility of Down syndrome at 12 weeks of gestation, and the second trimester ultrasound (STU) for detecting fetal abnormalities at 20 weeks. Although both tests are part of a population-screening programme, they are not offered on the same basis. The STU is free for all women; the combined test is only free for women aged 36 years or older. In the Netherlands, more than 80% of the women start antenatal care in primary care midwifery practices and these pregnant women are informed and counselled by midwives (Wiegers, 2009).

Several factors such as age, family life, personal experience, socio-economic status, ethnicity and religion, may influence the decision whether or not to participate in the antenatal screening-programme (van den Berg et al., 2005; Fransen et al., 2007; Fransen et al., 2010; Maxwell et al., 2011; Tischler et al., 2011; Bakker et al., 2012; Yu, 2012). For pregnant women and their partners implicit moral questions regarding antenatal screening tests include: what is your personal view on the value of life, of unborn life and of disabled life and what is your view on termination in case of an affected fetus? People's responses to these questions will to an extent be influenced by their religion (van den Berg et al., 2005; Fransen et al., 2007; Seror and Ville, 2009). This paper aims to provide in depth information about influence of religion in decision-making on antenatal screening tests according to pregnant Turkish Muslim women living in the Netherlands.

#### *Islam in general*

Migrants with an Islamic background are a growing part of the population in the Netherlands as well as in many other Western countries. Worldwide, Islam has two main streams: Sunni (87–90%) and Shia (10–13%) (Miller, 2009). There are four major directions, the so-called law schools, within the Sunni stream: Hanifi, Maliki, Hanbali and Shafi. These four law schools have no fundamental differences, but evidence of small difference exists (Shadid and Koningsveld, 2008). The Hanifi school of law predominate in Turkey, Pakistan and India (Atighetchi, 2007; Ghaly, 2008, JRDH). Migrants from Turkey are the largest minority with an Islamic background in the Netherlands; 95% stated to be a Muslim (Dutch Statistics, www.cbs.nl). After the Hanifi, the Alevi, part of Shia, is estimated to be the second largest religious group in and from Turkey. The Alevites are characterised by a moderate humanist philosophy that allows human beings a place aside of God, and teaches human responsibility in all domains of life. They emphasise religious tolerance and support the separation between religion and the state (White and Jongerden, 2003). There are different parameters to describe a Muslim. On the theological level, a Muslim is someone who witnesses that there is no other god than God and that Mohammed is Allah's prophet. Being a practicing Muslim can be described on many different juridical levels, of which the best known is that someone keeps the devotional rules of the Shari'a as praying five times a day, fasting during Ramadan, charitable giving and a pilgrimage to Mecca at least once in a lifetime. Because of the methodology of our study, in this paper we choose the anthropological level of being a practicing Muslim: a practicing Muslim is someone who described himself or herself as a practicing Muslim.

The Qur'an and the Hadith, a collection of sayings, acts, tacit approvals or disapprovals ascribed to the prophet Mohammed,

hardly give definitive instructions with direct relevance to bioethical issues in the context of antenatal screening tests. The relevant sources emerged from the contemporary Councils of Islamic Law (*Fiqh*) whose judgments are based on the main sources (Qur'an and Hadith), and the early schools of law (Ghaly, 2008). These Councils of *Fiqh* issue counsel for daily life in the form of non-binding ethical advice (*fatwas*) (Beck and Wiegers, 2008). Bioethical issues like termination of pregnancy have been elaborated by for example the Islamic Organization for Medical Science (IOMS) and the European Council for Fatwa and Research (ECFR). Because they are grounded in the classic sources, the statements of the Councils of *Fiqh* have authority and respectability for the average Muslim (Ghaly, 2007).

The Islamic concept of a human being is important in the context of the value of living with the congenital abnormalities targeted by antenatal screening. Central to the Islamic concept of the human being is the notion that all humans are born as Muslims, but they are raised according to the faith of their parents (Driesen, 2004). With regard to human differences, Islam teaches that all people are equal in the eyes of God, regardless of faith, skin colour, or social class (Sardar, 2007), and that life is sacred even when it is of 'poor' quality (Daar and Khitam, 2001). Every person is born pure and blameless and, as such, every person is perfect in his/her initial conception (Bazna and Hatab, 2005). It is important to know that God creates unborn life stage after stage, and so human life includes the time before birth as part of the creation process [Sūra 23:12–14] (Koran). Within the process of human creation "ensoulment" is a decisive moment, when God breathes spirit into the fetus [Sūra 38:71,72] (Koran). According to the Shari'a, the fetus becomes a person from the moment of ensoulment (Rispler-Chaim, 1993). The most common understanding is that the moment of ensoulment takes place 120 days after the conception, whereas a minority of leading Islamic scholars teaches that ensoulment occurs after 40 days (Atighetchi, 2007).

#### *Islam and aspects of antenatal screening*

With regard to congenital anomalies, Islamic sources emphasise that disabled individuals have to be comforted by love and care (Ghaly, 2007). Disabilities or anomalies viewed in the Quran are neither a curse nor a blessing; they are simply part of the human condition (Bazna and Hatab, 2005). Islamic sources do not teach that congenital abnormalities represent a divine punishment for the sin of one's parents (Ghaly, 2007; Beck and Wiegers, 2008). Besides, Sunni Islamic scholars (*muftis*) rather give advice about family planning and contraception than about fetuses with anomalies (Rispler-Chaim, 1999).

Within the Islamic beliefs, there are a few valid legal reasons for terminating a pregnancy. The most important reason, and for some Muslim jurists the only reason, is when the health of the mother is in serious danger and that continued pregnancy may even incur maternal death (Rispler-Chaim, 1993). A majority of modern Islamic jurists also allow the option of termination when the fetus has serious congenital abnormalities (Rispler-Chaim, 1993; Atighetchi, 2007; Ghaly, 2008). However, in these cases termination is permitted only before the moment of ensoulment (El-Hashemite, 1995; El-Hashemite, 1997). After that moment, it is seen as a crime against a living person with the exception of the situation where the mother's health is in danger (Rispler-Chaim, 1993).

In 1990, the approval of termination before the 120th day in case of congenital abnormalities was officially confirmed in Fatwa number 4 of the Islamic jurisprudence council of Mekkah Al Mukaramah (Albar, 2002). This fatwa gives permission and is not a recommendation. Before termination, the anomalies have to be confirmed by a couple of specialised and competent doctors,

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