Chapter 3

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: ten 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 ten 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.

Keywords: antenatal diagnosis; combined test; congenital anomalies; Islam.
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 partner 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
Hannifi, the Alevi, part of Shia, is estimated to be the second largest religious group in and
from Turkey. The Alevits are characterized by a moderate humanist philosophy that allows
human beings a place aside of God, and teaches human responsibility in all domains of life.
They emphasize 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 a a a 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 Khitamy, 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 [Sûra 23:12-14] (Koran). Within the process of human
creation “ensoulment” is a decisive moment, when God breathes spirit into the fetus [Sûra
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 emphasize 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, preferably Muslim doctors (Al-Aqueel, 2005; Rispler-Chaim 2007). A hundred and twenty days after conception corresponds to 19 weeks plus one day of gestational age.

With regard to decision-making, in Islam every human being has a free will and is thus responsible for his or her own actions. This means that every believer has a duty to explore the teachings of the Qur’an and the Hadith in order to arrive at practical conclusions with regard to how to live and act, rather than following uncritically what one is told (Bazna and Hatab, 2005).

Research question

Religious background and individual perspective on the value of unborn life and disabled life can influence the decision-making process on antenatal screening of congenital anomalies. Pregnant Muslim women generally do not opt for the combined test, often claiming that their faith does not allow termination (Neter et al., 2005, Fransen et al., 2007). On the other hand, Lind (2008) describes a few cases with and without termination of pregnancy after a confirmed serious anomaly of the fetus. In view of these discrepancies, this study examined in depth what role religious beliefs of pregnant Muslim women play in their decision-making on antenatal screening. Furthermore, we explored how these women interpret their religious
beliefs with regard to participation in antenatal screening and termination of pregnancy and whether their interpretations correspond to the main sources of Islam. Because migrants from Turkey are the largest minority with an Islamic background in the Netherlands, this exploratory study was undertaken with pregnant Muslim women from Turkish descent.

**Method and Recruitment**

*Data collection*

In order to explore the role of religious beliefs with regard to the decision-making process for an uptake of antenatal screening tests, 10 in-depth interviews were held with pregnant Muslim women from Turkish descent. This qualitative pilot study provides insight into opinions and perspectives of pregnant Muslim women regarding their decision-making process. Data were collected in January and February 2008. Informed consent was obtained from all participants. The study was approved by the Medical Ethics Committee of VU University Medical Centre Amsterdam, the Netherlands.

*Participants*

Participants for the study were recruited by means of a convenience sample from a population of pregnant women, visiting the midwifery practice in a medium-sized city near Amsterdam, which has a relatively large proportion of clients from ethnic minorities. First, a purposive subpopulation was selected fulfilling three pre-set criteria. First of all, we focused on pregnant women who themselves were born in Turkey, or were from Turkish descent through (one of) their parents, and who were able to speak Dutch reasonably well. Furthermore, only women who were at least 20 weeks pregnant were included to ensure that the legal period for antenatal testing had passed and that the interviews could not influence the women’s decision-making process. Lastly, only women who were pregnant for the first time since the introduction of the antenatal screening-programme were included, thus this was the first time they had to make a decision on the antenatal screening tests. There was no restriction regarding the women’s age, parity or Islamic stream. Ten women were selected on a first come, first served basis. The sample size of ten was chosen because it was expected to achieve data saturation.

*Procedure*

All interviewees were informed about the study by their midwife and invited to participate. The interviewer, also an expert midwife and researcher, approached the women after consultation in the clinic. The interviewer was also a midwife at the practice but did not provide care to the participants as she was on study leave during the study period. The interviews took place at the women’s homes without other family members being present, so that the women could
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speak openly of their own ideas and opinions. Each interview lasted between half an hour and one hour. With permission of the interviewees, the in-depth interviews were digitally recorded and transcribed verbatim afterwards.

**Instruments**

In accordance with important items of decision-making on antenatal screening derived from literature, a topic list was formulated (Table 1). The two core issues of antenatal screening tests are whether people want to be informed about the possibility of having a disabled child, and if so, whether they would consider a termination of the pregnancy in the case of a child with Down syndrome or a seriously affected child with structural anomalies. With this and the role of religion in mind, the topic list focussed on four points: to what extent the women considered themselves as Muslims; their decision-making process; their view on unborn life and on disabled life; and their view on termination of pregnancy.

**Table 1.** Contents of the topic list used for the interviews

<table>
<thead>
<tr>
<th>Topics</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Was it difficult for you to make a decision whether or not to do the tests?</td>
</tr>
<tr>
<td>2. How do you describe your religious background and its role in your daily life?</td>
</tr>
<tr>
<td>3. Did your faith influence your choices regarding antenatal screening?</td>
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<tr>
<td>4. As a Muslim woman, what is your perspective on termination?</td>
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<tr>
<td>5. Can someone with Down syndrome (or a physical/mental disability) be a good Muslim, or a good person?</td>
</tr>
<tr>
<td>6. Are you satisfied with the decision you made about the combined test and the second trimester ultrasound (STU), or would you have made another decision?</td>
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<tr>
<td>7. Do you think that a midwife or obstetrician must know about the faith of Muslim pregnant women in general when informing them about antenatal screening?</td>
</tr>
</tbody>
</table>

**Analysis plan**

When all interviews were completed, the transcripts were analysed using thematic analysis. This approach is concerned with capturing and interpreting substantive meanings in the interview results, using an iterative process of open and axial coding, whereby the transcripts were read to identify emerging themes, based on the Grounded Theory approach (Glaser and Strauss, 1967). During this process, sensitizing concepts were noted according to the topic list, as being a (practising) Muslim, testing, terminating pregnancy and disability. After this first stage, descriptive and analytical themes were identified and interpreted (Thomas and Harden, 2008).
Findings

Table 2. Characteristics of the interviewees

<table>
<thead>
<tr>
<th>Interviewees</th>
<th>Generation of immigration</th>
<th>Number of children</th>
<th>Religious group</th>
<th>Uptake CT/STU*</th>
<th>Age</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>First</td>
<td>0</td>
<td>Alevit</td>
<td>+/+</td>
<td>25</td>
</tr>
<tr>
<td>2</td>
<td>First</td>
<td>2</td>
<td>Alevit</td>
<td>+/+</td>
<td>37</td>
</tr>
<tr>
<td>3</td>
<td>First</td>
<td>0</td>
<td>Sunni</td>
<td>-/+</td>
<td>20</td>
</tr>
<tr>
<td>4</td>
<td>Second</td>
<td>0</td>
<td>Sunni</td>
<td>-/+</td>
<td>26</td>
</tr>
<tr>
<td>5</td>
<td>First</td>
<td>0</td>
<td>Sunni</td>
<td>-/+</td>
<td>30</td>
</tr>
<tr>
<td>6</td>
<td>Second</td>
<td>1</td>
<td>Alevit</td>
<td>+/+</td>
<td>25</td>
</tr>
<tr>
<td>7</td>
<td>Second</td>
<td>0</td>
<td>Sunni</td>
<td>+/+</td>
<td>22</td>
</tr>
<tr>
<td>8</td>
<td>First</td>
<td>0</td>
<td>Sunni</td>
<td>-/+</td>
<td>22</td>
</tr>
<tr>
<td>9</td>
<td>First</td>
<td>1</td>
<td>Sunni</td>
<td>-/+</td>
<td>30</td>
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<tr>
<td>10</td>
<td>Second</td>
<td>0</td>
<td>Sunni</td>
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</tr>
</tbody>
</table>

*CT=combined test, STU=second trimester ultrasound

The characteristics of the women who were interviewed are described in Table 2. Four of the ten interviewees had done the combined test; one Sunni woman and the three Alevit women. None of the combined tests showed an increased chance of having a child with Down, which meant that none of them had an amniocentesis. All ten interviewees had done the STU. One woman had a serious congenital abnormality herself, a serious form of scoliosis, and the STU revealed that her child would be born with the same condition.

Six themes arose from the interviews: being a (practizing) Muslim, terminating pregnancy, disability, family planning, decision-making and the counsellor’s knowledge of Islam.

A. Being a (practicing) Muslim

All women in the study described themselves as Muslim. Four women described themselves as not practicing Muslims. According to the women, the essence of being a Muslim is to be a good person: You must have a clean heart [woman 7]. Four women stressed that as Muslim, they must judge whether a particular behaviour or act is right or wrong. All women highlighted the importance of their belief, regardless of their parity, their Islamic stream (Sunni or Alevit) or whether they were a first or second-generation immigrant.

“It is very important for me to be a Muslim, my faith has the first priority in my life, it is very important to me.” [woman 7]

“I can rely on my belief if I have a hard time, it gives me strength even if I don’t find the answers.” [woman 5]

“It is important, it is my common lifestyle.” [woman 10]
B. Terminating pregnancy

Both ultrasound-screening tests are non-invasive tests and imply the legal and medical option of a termination in case of a positive test result. The responses from the women suggest that none of them considered terminating the pregnancy. The four women who did the combined test only wanted to be prepared in case of Down syndrome:

“Even if my child would have Down Syndrome, I do not consider a termination, but for me it was better to do the combined test to be prepared in case of Down Syndrome.” (Woman 7, the Sunni who did the combined test)

Regarding termination, eight women stated that Islam forbids termination of a pregnancy, and one of them said that it is a terrible sin:

“Certainly it is a sin. You can do other forbidden things, but this is something about life. Actually, I didn’t want this child, but I never thought about a termination.” [woman 6]

Talking about the reasons for permitting a termination in Islam, the interviewees mentioned the following possibilities: when pregnancy endangers the mother’s health, or when a woman was raped. Two women said that termination is permitted when the fetus is disabled or has Down’s syndrome, but they did not consider a termination themselves; the other women were convinced that, from their religious point of views, it is improper to terminate a pregnancy in case of an affected fetus. Six women said that the Koran forbids termination, and one said that God will punish the one who perpetrates a termination.

Three women made a link between termination and divine destiny. In their views, life follows God’s plan. Terminating a pregnancy means that you take destiny into your own hands.

C. Disability

All of the interviewees believed that people with a disability are the same as ‘healthy’ people in the eyes of God. The women called several possibilities for the wise purpose that God could have for people with disabilities:

“I think, it is given by God as a test for yourself to see how you handle it.” [woman 2]

“Some people are disabled, and we think that it is a test for the parents that you have to go through and at the end there will be a recompense.” [woman 4]

“Am I too good, that God also gives me this?” [woman 5, knowing that her child will have the same abnormality as herself]
D. Family planning

Four women emphasized that it is a woman’s responsibility to prevent pregnancy if she doesn’t want to have a baby, and they suggested or implied the opportunity of family planning. In speaking of contraception, all women used the term ‘protection’ instead of ‘contraception’. The woman with the congenital abnormality went to see her family doctor before she got pregnant to ask about the risk of getting a child with the same abnormality:

“The doctor didn’t answer my question, but asked me: ‘Do you want to abort the child if the child will have the same abnormality?’ I told him ‘no’. ‘In that case it is not necessary to know that chance, because you will not opt for termination anyhow.’” [woman 5]

E. Decision-making

When discussing the option to have the combined test, nine interviewees indicated that their faith contributed explicitly in their decision-making process, while one woman said that her faith played a more implicit role. In case of the STU, six interviewees answered that faith contributed in their decision-making process. Remarkably, three women who did the STU said that at the time of the test they had not been aware of the aim of the STU particularly the detection of congenital abnormalities. One woman thought it was obligatory to take this test. Although both screening tests imply the option of a termination in case of a positive test result, the responses from the women suggest that although they did the test(s) none of them had in mind the option of terminating the pregnancy.

Two young interviewees (20 and 22 years old) experienced the decision-making on antenatal screening as being difficult, especially regarding the combined test, and were anxious during the weeks after the counselling. In retrospect, most interviewed women were still satisfied with the decision they made. Two women were uncertain and one said:

“In fact, I really don’t know, on one hand I would say yes, on the other hand no. Interviewer: ‘is this because of the abnormality of your unborn child?’ Yes, I am constantly worried.” [woman 5]

F. Counsellor’s knowledge of Islam

Five women were of opinion that it is not important for a counsellor to have knowledge of the Islam regarding antenatal screening. One woman had no opinion; the other four found knowledge of the Islam important, as one of them said:

“They have to understand what our faith is about. They have to know what the meaning of life is. What life means to me.” [woman 10]
Discussion

The aim of this study was to explore the role that religious beliefs of pregnant Muslim women play in their decision-making on antenatal screening tests, and how these pregnant women interpret the religious doctrines with regard to termination of pregnancy. All women stated to be a Muslim and six of them stated to be a practicing Muslim. The faith of the ten interviewed Muslim women appeared to be part of their daily life and it played a role in their decision-making concerning their participation in the combined test. Regarding participation in the STU, some of the interviewees indicated that their faith played a role in the decision-making process, although not all interviewees appeared to understand that a primary aim of the STU is screening for congenital anomalies. The interviewees did not act in the same way; the Alevit women and one Sunni woman who all wanted to be prepared in case of Down syndrome participated in the combined test, but none of them considered a termination in case of a disabled child. This indicates that Muslims with the same country of origin can have different perspectives on life and that counsellors of antenatal screening have to approach women as individuals with a personal view on life. Nearly all of the interviewees did not consider having a disabled child to be a problem. These women did not regard terminating the pregnancy as an option if the fetus would be disabled because of their faith and were of opinion that termination is only permitted in case of rape or when the mother’s life is in danger. Islamic literature confirms the latter two reasons, and in addition, some Muslim scholars are of the opinion that terminating pregnancy is allowed if the fetus has serious abnormalities, but only if it is performed before the 120th day after the conception (Rispler-Chaim, 1993; Atighetchi, 2007; Ghaly, 2008). Most of the interviewed women did not demonstrate any awareness of the contents of the fatwa pertaining to termination of pregnancy. An overwhelming majority of Islamic scholars are of opinion that termination is in principal forbidden, unless there is a legal reason; this is possibly the reason why the interviewed women try to avoid a termination as much as possible. It is perhaps not surprising that Muslim pregnant women have little or no knowledge of Islamic jurisprudence; it has been argued that the average Muslim is not familiar with contemporary Islamic rulings on bioethical issues (Daar and Kitamy, 2001). Furthermore, it could be problematic for people to differentiate between their religious and cultural beliefs and the knowledge of what is permissible according to the religion of Islam (El-Hashemite, 1997).

This small exploratory study suggests that religious convictions play a role for Turkish pregnant women in decision-making with regard to antenatal screening. Similar findings were reported by Fransen et al. (2007) based on focus group discussions with pregnant Turkish, Surinamese and Dutch women. Furthermore, De Graaf et al. (2010) observed that 14.8% of pregnant women declined the combined test for religious reasons, and termination of a fetus with
Down’s syndrome was refused significantly more often by non-Western immigrants than by autochthon families (30% versus 10%). Another study showed that women who did not consider termination to be an option in case of an affected child, more often stated that religion was important for them (Seror and Ville, 2009). By using in depth interviews to explore women’s perceptions of the possibility of having a disabled child and their feelings with regards to uptake of antenatal screening we report findings that contradict the conclusion of a study in Lebanon by Usta et al. (2010). They suggested that religion does not play a significant role in decision-making on antenatal screening based on the observation that there was a comparable acceptance rate of antenatal screening among Muslims, Christians and Druze (Usta et al., 2010). The comparable acceptance rate among Muslims, Christians and Druze is perhaps not surprising because these three religions have a quite similar view on terminating a pregnancy as well as the fact that in local culture, different religious groups assimilate to each other.

The official aim of the antenatal screening-programme of the Dutch government is to enable informed choice for people who seek information about the health status of their future child. The fact that the antenatal screening-programme is available for the entire population of pregnant women indicates that the Dutch government encourages people to participate in this programme. When congenital anomalies are detected, antenatal care will focus on the health of the fetus or the pregnancy may be terminated. In the Netherlands, the STU is offered around the 20th week of gestational age and termination is legal if it is before the 24th week. However, as according to Islam, Muslim women are not able to terminate the pregnancy after 19 weeks plus one day gestation. In Canada and the United Kingdom, the STU takes place around the 18th week (SOGC, 2009; NICE, 2010). In order to give Muslim women in the Netherlands the opportunity to choose to terminate pregnancy because of congenital abnormalities, revision of the timing of the STU may be necessary.

There are at least two findings of this study that are relevant to counsellors of antenatal screening. Firstly, the aim of the STU was not clear to all interviewees. This means that there was not really proper informed consent and that counselling on antenatal screening should be improved. Misunderstanding of the aim of STU has serious consequences, as it involves choices regarding termination of pregnancy or bringing up a disabled child. Secondly, two interviewees of 20 and 22 years old were anxious during the weeks after the counselling, which is remarkable because the chance to give birth to a child with Down’s syndrome is very low for young women (RIVM, 2009). Counsellors may need to change the way they provide information to these women.
A limitation of this qualitative set up is the small and selective sample size, limiting the generalizability of the findings. Moreover, one must keep in mind that only Muslim women from Turkish origin were interviewed. Other Islamic women, for example from Moroccan origin who belong to the Maliki, the second largest minority group in the Netherlands might have different views and make other decisions as they adhere to different schools of Islamic jurisprudence. However, this descriptive pilot study provides insight into the decision-making process on antenatal screening of the interviewed Muslim women and this could be the starting point of future studies with other Islamic women and other religions. A strength of the study is the inclusion of Muslim women from a variety of age groups, parity and who are first and second generation in the Netherlands.

This study shows that religious convictions play a role regarding antenatal screening in our study population of pregnant Muslim women of Turkish origin in the Netherlands, especially with regard to the combined test and to a lesser extent to the STU. Women included in our study were unaware that there are statements of Islamic scholars within Islamic tradition that allow terminating pregnancy before 19 weeks plus one day of gestational age if the fetus has a serious congenital abnormality. However, even with that knowledge, the timing of the STU at around 20 weeks of gestation in the Netherlands limits, the option of termination of a congenitally abnormal fetus for these women.

This pilot study resulted in several recommendations for antenatal care and for future research. In jurisdictions that include Muslim women as part of the pregnant population, the STU should be offered prior to the 19th week of pregnancy. Furthermore, it will be interesting to examine whether the test uptake differs between clients from various religious backgrounds. Additionally, future research into the way midwives counsel clients regarding antenatal screening might improve the counselling and with that the understanding of the aim of antenatal screening by pregnant women. Ideally, this is assessed objectively by videotaping the counselling. Finally, as religion seems to play a role in decision-making regarding antenatal screening, the question arises to what extent counsellors actually pay attention to the religious background of clients during counselling.

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None declared.
Chapter 3

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