

# VU Research Portal

## Religious beliefs in decision-making and counselling around prenatal anomaly screening

Gitsels-van der Wal, J.T.

2015

### **document version**

Publisher's PDF, also known as Version of record

[Link to publication in VU Research Portal](#)

### **citation for published version (APA)**

Gitsels-van der Wal, J. T. (2015). *Religious beliefs in decision-making and counselling around prenatal anomaly screening: Views of pregnant Muslim Turkish and Moroccan women and midwives*. [PhD-Thesis – Research external, graduation internal, Vrije Universiteit Amsterdam].

### **General rights**

Copyright and moral rights for the publications made accessible in the public portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

- Users may download and print one copy of any publication from the public portal for the purpose of private study or research.
- You may not further distribute the material or use it for any profit-making activity or commercial gain
- You may freely distribute the URL identifying the publication in the public portal

### **Take down policy**

If you believe that this document breaches copyright please contact us providing details, and we will remove access to the work immediately and investigate your claim.

### **E-mail address:**

[vuresearchportal.ub@vu.nl](mailto:vuresearchportal.ub@vu.nl)

# Chapter 4

**A qualitative study on how Muslim women of Moroccan descent  
approach antenatal anomaly screening**

Gitsels-van der Wal JT, Martin L, Manniën J, Verhoeven P, Hutton EK, Reinders HS.

Midwifery 2015;31:43-49.

## Highlights

- Motherhood was the lens through which participants approached anomaly tests
- The Combined Test was perceived as a test and approached with hesitations
- The Fetal Anomaly Scan was mostly perceived as a scan to see and connect with the fetus
- Some Muslim women know the fatwa about termination in case of serious anomalies
- Women underlined the importance of making their own decisions; they felt accountable.

## Abstract

**Objective:** to extend the knowledge on Muslim women's approach of antenatal anomaly screening.

**Design:** qualitative interview study with pregnant Muslim women from Moroccan origin.

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

**Participants:** Twelve pregnant Muslim women 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 analyses:** We conducted open interviews with pregnant Moroccan Muslim women for the purpose of studying how they made decisions about antenatal anomaly screening. We used a thematic analysis approach.

**Findings:** Women experienced the combined test as 'a test' that could identify potentially anomalous infants, and could result in being offered termination of the pregnancy; a fact that resulted in their extensive deliberations and hesitation about the test uptake. Only two women had the Combined Test. Conversely, women opted for the Fetal Anomaly Scan and saw it as 'only an ultrasound to see the baby'. Above all, women emphasized that whether or not to participate in antenatal anomaly tests was their own, individual decision as ultimately they were accountable for their choices. All women, including nulliparous women, viewed becoming pregnant as the point of becoming a mother – and considered prenatal screening through the lens of motherhood.

**Key conclusions:** Motherhood was the lens through which the decision to participate in antenatal anomaly screening was approached. Religious beliefs influenced values on termination and disability and were influential in the deliberations for prenatal testing. Combined Test but not Fetal Anomaly Scan was considered to be a prenatal screening test.

**Implications for practice:** counsellors should have knowledge of the different Islamic beliefs about-the latest possible day for- termination and an awareness that Muslim women make their own conscious choices, also beyond Islamic rulings.

**Keywords:** Islam, immigrants, antenatal diagnosis, congenital anomalies, decision-making, motherhood

## Introduction

The aim of counselling for antenatal anomaly screening is to engage pregnant women or couples in making reproductive, informed choices (RIVM, 2011). Informed choices are based on relevant knowledge, consistent with the decision-maker's values and behaviourally implemented (O'Connor & O'Brien Pallas, 1989; Marteau et al., 2001). Research into the practice of antenatal screening shows that lower rates of informed choice were found among women of non-western ethnic minority groups and socio-economically disadvantaged women; this is partly because of insufficient knowledge, and partly because their choices did not reflect their attitudes towards screening (Dormandy et al., 2005; Fransen et al., 2010a). Women's attitudes and values towards termination are based on their philosophy of life and in particular of disabled life and play a role in their decision-making around antenatal screening and termination of pregnancy. Several studies underline the importance of religion on these decisions (Van den Berg et al., 2005; Neter et al., 2005; Ahmed et al., 2006; Fransen et al., 2007; Garcia et al., 2008a; Fransen et al., 2010b; Gitsels-van der Wal et al., 2014a). For example, Muslim women's view on termination seems to weigh heavily regarding the decision of whether or not to participate in antenatal anomaly screening (Neter et al., 2005; Fransen et al., 2007; Fransen et al., 2010b; Gitsels-van der Wal et al., 2014a). See Appendix for detailed information about antenatal anomaly screening.

Research into the practice of antenatal counselling shows that a substantial proportion of women and partners prefer to get decision-making support during counselling (Dormandy et al., 2005; Garcia et al., 2008b; Fransen et al., 2010a; Ahmed et al., 2012; Aune and Moller, 2012; Martin et al., 2013) and that they do not perceive this to be in conflict with making an autonomous choice (Garcia et al., 2008b; Ahmed et al., 2012; Aune and Moller, 2012; Martin et al., 2013;). However, a recent study showed that clients perceived a lack of decision-making support (Martin et al., 2013). To better enable pregnant women to make informed choices about antenatal screening, counsellors should explore clients' deliberations. Within these deliberations counsellors should explore the role of clients' religion or philosophy of life regarding decision-making (Pivetti et al., 2012; Crombag, 2013). Women with a Muslim background constitute a substantial, growing part of the population of pregnant women in many western countries. A year after antenatal anomaly screening was implemented in the Netherlands, we conducted an exploratory qualitative study among pregnant Muslim women of Turkish origin. This study focussed on the role of religious beliefs in decisions around whether or not to participate in antenatal anomaly screening and demonstrates that women's religious beliefs played an important role in decision-making on the Combined Test (CT), but played a limited role in decision-making on the Fetal Anomaly Screening (FAS). Their views on termination and disability, based on religious convictions, were key in their decision-

making on CT. Most women would not consider termination if an anomaly was diagnosed, and most women were unaware of the possibility of termination within Islamic tradition should their fetus be diagnosed with a serious anomaly (Gitsels-van der Wal et al., 2014a).

In the Netherlands, migrants from Turkey and Morocco are the two largest Islamic minorities (Statline). The Turkish and Moroccan populations belong to different Islamic schools, respectively the Hanifi school and the Maliki school (Atighetchi, 2007; Ghaly, 2008). These two Islamic schools have small differences in opinions about termination; the most important difference is the latest possible day of termination if a fetal anomaly is diagnosed (Atighetchi, 2007). In general, scholars from the Hanifi school permit a termination till 120 days after conception, whereas most scholars of the Maliki school permit a termination till 40 days after conception (Atighetchi, 2007). From the obstetrical perspective, which typically calculates pregnancy duration starting from the first day of the last menstrual period that means two weeks before conception, 120 days after conception is a gestational age of 19 weeks plus one day; 40 days after conception corresponds with seven weeks and five days of gestation. More detailed information about the Islamic schools and Islamic bioethics is provided in our previous work (Gitsels-van der Wal et al., 2014a).

Women have become increasingly familiar with antenatal screening tests in the five years since testing was first implemented. The aim of this study was to extend the knowledge on Muslim women who belong to different Islamic schools in terms of their approach to antenatal anomaly screening. Therefore, we undertook to study the views of Muslim women of Moroccan origin in terms of antenatal screening and to compare our findings with our prior research on Muslim women of Turkish origin.

## **Method and recruitment**

### *Data collection*

We conducted open interviews in Dutch with pregnant Muslim women of Moroccan descent between December 2011 and May 2012 for the purpose of studying how they made decisions about antenatal anomaly screening. Informed (written) consent was obtained from all participants. The Medical Ethics Committee of the VU University Medical Centre, Amsterdam approved the study.

### *Participants*

Participants were recruited using a purposive sample from a population of pregnant women from a medium-sized city near Amsterdam; the participants received antenatal care at a midwifery practice, with a relatively large proportion of clients from ethnic minorities. The

interviewees were selected according to three inclusion criteria: women, who were born in Morocco or whose parents were born there, and who had a reasonable command of Dutch. To ensure that the interviews could not influence the women's decision-making about antenatal screening we only included women who were past the cut-off time for the FAS. We planned to interview until saturation was reached, which in a homogeneous population typically requires a small number of 12 or so (Guest et al., 2006).

#### *Procedure*

Eligible participants were informed about the study by their midwives. Next, one of the researchers called the women to ask whether they agreed to be interviewed on the topic, and when consent was provided an appointment was made. The interviews took place without other family members present, so that the women could speak openly. The interviewer was a midwife in the recruiting practice; independence of the interviewer was ensured because she was on study leave at the time of the interviews and the participants were not her direct clients. With permission of the interviewees, the interviews were digitally recorded and transcribed verbatim.

#### *Instruments*

We used the same topic list as used for our previous study among Turkish pregnant women (Gitsels-van der Wal et al., 2014a) but focused on only three topics on the list:

1. Women's approach to antenatal anomaly screening;
2. The value of life including unborn life and disabled life;
3. Women's views on termination of pregnancy.

#### *Analysis plan*

The transcripts were coded and analysed using Thematic Analysis as described by Braun and Clarke (2006). In order to reach inter-subjectivity of the results, two researchers independently coded text fragments of the first seven interviews and grouped them into categories. This initial coding was discussed by the two researchers to redefine the categories and define the themes. Table 1 shows an example of the initial coding.

**Table 1.** Example of coding; decision-making on the combined test

1 <sup>th</sup> level: Fragment	2 <sup>th</sup> level: Coding	3 <sup>th</sup> level: Category	4 <sup>th</sup> level: Theme
What do I have to do with the result? If it is good then that's fine, but if it isn't, then what can I do then? No, I thought, well, if I don't have that test, I won't have to think about it, but if I have the test, then I might get a bad result and I don't know what I'd do. So, I decided not to have the test.	What to do with the result?  If I don't have the test, then I won't have to think about it  If I have the test and the results are bad, I don't know what to do  Decision	What to do with test results?  I could be faced with a result that I don't know what to do with	<u>Termination</u> : avoid facing the question about termination

Subsequently, the themes arising from the initial coding formed the basis for the next part of the analysis, during which one of the researchers re-analysed the complete set of interviews, trying both to complement and to redefine the specific themes and reach a clear definition of each theme based on all interview data. This led to an initial thematic map. Next, the two researchers analysed the themes and subthemes as well as potential relationships between themes and subthemes and generated a developed thematic map. These themes and subthemes were discussed with a third member of the research team. During the final phase of the analysis, the themes, subthemes, and possible (hierarchical) relationships were analysed, yielding the final thematic map. This final thematic map led to a detailed systematic description and explanation of the findings related to the research question.

## Findings

A total of 19 women were invited to participate in the study, seven women did not want to participate, and the interviewer believed to have reached saturation after interviews were conducted with 12 women. The interviews lasted between 24 and 80 minutes, with an average of 44 minutes. The socio-demographic characteristics of the participants are described in Table 2. All women described themselves as Muslim. The interviewees' gestational age ranged from 21 to 33 weeks. Two of the 12 women had the CT during the current pregnancy; both CT's were negative. All 12 women had the FAS; none of these screening ultrasounds demonstrated structural anomalies.

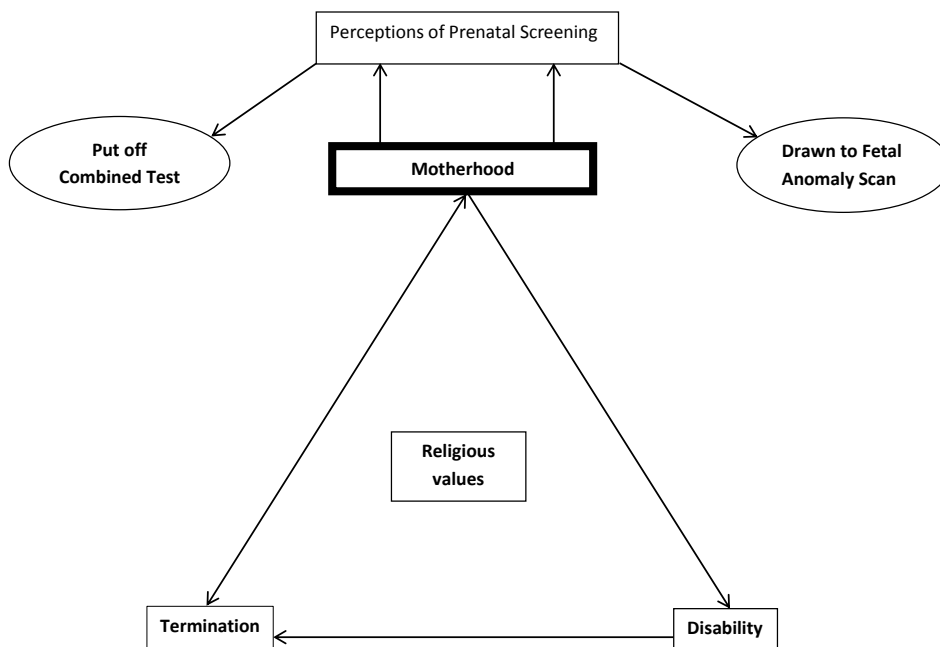


**Table 2.** Characteristics of the participants

Participant	Immigrant Generation	Parity	CT/FAS* Uptake	Age	Education	In Employment
1	First	1	- / +	32	High	Yes
2	First	0	- / +	20	Medium	No
3	Second	2	- / +	33	Low	Yes
4	Second	0	- / +	30	High	Yes
5	Second	2	- / +	31	High	No
6	Second	1	- / +	28	Medium	No
7	Second	1	- / +	20	Medium	No
8	First	1	- / +	26	Medium	Yes
9	First	2	+ / +	33	High	Yes
10	Second	1	- / +	27	Low	Yes
11	First	3	+ / +	36	Medium	Yes
12	First	2	- / +	34	Medium	No

\*CT = Combined test; FAS = Fetal Anomaly Scan

The most important themes that emerged during the analysis regarding decision-making on antenatal congenital anomaly tests are summarized below, illustrated by quotes that were translated by a professional translator into English. We have identified four themes: motherhood, perceptions of antenatal screening tests, termination and disability (figure 1).



**Figure 1:** Final thematic map of decision-making on participation in prenatal anomaly screening

A. *Motherhood: The lens through which decision-making process was made*

Motherhood was perceived to begin with becoming pregnant, not with birth of the child. Thus, although two women were giving birth to their first child, they perceived themselves as mothers, and all women deliberated participation in the anomaly screening program through the lens of motherhood. Women's views on motherhood, termination and disability were inseparably linked and were informed by individual religious beliefs. The value of motherhood as a blessing from God seemed to outweigh the possibility of having a disabled child:

“Sure, you’ve got to consider the parents as well as the [disabled] baby itself. I mean, going to the hospital all the time can’t be much fun. But then on the other hand, you’ve got to be pleased that you were blessed with the gift of motherhood at all.” (P10)

“I thought, ‘What if there is something wrong?’ It would have to be something really major before you’d want a termination, but I think it would be a desperately difficult choice. And, um, I would then go and pray about it and, um, ask God whether I should have it terminated or not. But it really seems like a very awkward choice, because you got pregnant in the first place because you wanted a baby, and then it doesn’t matter whether it’s disabled or not.” (P8)

The value of becoming a mother appears to outweigh any perceived challenges or disadvantages associated with having a disabled child.

B. *Perceptions of antenatal screening tests*

Although CT and FAS are both non-invasive tests within the Dutch antenatal screening program, all women approached the CT as a ‘test’, while they approached the FAS as ‘only an ultrasound’. As one nulliparous woman said:

“Yes, well, the twelve-week ultrasound isn’t so much an ultrasound to see the baby as a test to detect an anomaly. And, um, that does have its risks. I reckon you’re going to want to see your baby so much by the time of the twenty-week ultrasound, even if there is a disability. But, um, in the ultrasound at twelve weeks, you simply don’t want to know. Period.” (P8)

This quote also underlines what all women mentioned as the most important reason to take the FAS: ‘to see your child’. Women perceived the FAS as part of routine antenatal care and did not view it as a screening test that they had a choice to opt for or not. The decision to have the FAS did not appear to be based on any deliberation other than the wish to connect with the baby:

“For me, the 20-week ultrasound was particularly for watching my baby, looking at the gender and seeing the child, because it’s the final ultrasound and after that you won’t have any more ultrasounds and there’s no chance to watch your child again.” (P5)

In contrast to the lack of decision making involved around the FAS, the decision to have or decline the CT seemed to be based on extensive deliberations based on the perception of the CT as being a ‘test’. Women identified deterrents to CT at several levels: physically, financially (this test is not covered by the Dutch insurance system for women younger than 36 years of age) and values regarding termination and disability. Women reported not having the energy to even think of a CT due to early pregnancy nausea, tiredness or weakness. The cost of the CT seemed to influence the decision-making process for some. Although in general women who did not opt for the CT reported that their decision would not have been different had the CT been free, one woman who did not opt for a CT mentioned the cost as a reason, but also added what she saw as the implicit message of the required payment:

“Um, yes, I wouldn’t have minded the nuchal translucency ultrasound if it was free; I’d have gone then. The costs did affect my decision whether or not to do it, partly because of the indirect argument that it would surely be covered by the health insurance if it really mattered.” (P1)

### C. *Terminating Pregnancy*

With a prenatal fetal anomaly screening test, the ultimate question comes down to whether or not to terminate the pregnancy in the case of a confirmed disabled fetus and this question loomed large in women’s deliberations about whether to have or refuse the CT. The test was equated with termination for some. Not wanting to terminate pregnancy in any case, or not wanting to think about termination in the event of confirmed diagnostic testing, were the main reasons not to participate in CT:

“What was the combined test again? Oh, that’s the one about whether you want a termination or whatever. No, I didn’t do the test; I would not terminate the pregnancy.” (P2)

“I can have the test [CT] done- my religion lets me test whatever I want. But what should I then do with the result? It’s fine if the result is good, but what if it isn’t? What can I do then? I thought, well, if I don’t take the test then at least I won’t have to think about it [termination].” (P5)

When asked about permissibility of termination according to the Islam, some of the women stated that a termination is always forbidden. Other women mentioned the following exceptions: when pregnancy endangers the mother's health, when a woman was raped, when a young woman is unmarried, if there are financial problems, or when the fetus has serious congenital anomalies. Some women mentioned 40 days after conception as the last possible date that termination was allowed while others mentioned 120 days. Two women would consider terminating their own pregnancy in the event of a positive diagnostic test. Although the majority of the women would not consider a termination themselves, they underlined that the Islam is a flexible religion that offers the possibility of termination. Most women were of the same opinion with regard to not opting for a termination themselves, as illustrated by this quote:

“I'd never have a termination myself. That's what I'd do; it's just how I am. I'd never be able to live with myself after that- I'd really sort of feel that I'd killed something then. My feeling, something that's just part of you, is- well- you never want to hurt anybody, and that's the way I'd see it. And then I think, because I'm religious, that if I were then to get a child who was sick or whatever, then that's the way it was meant to be, I reckon, and there's a reason why. So that's how things go, then, it's part of life.” (P 3)

One of the pregnancies was unplanned; after using the pill in combination with antibiotics. The woman in question definitely did not want to have a disabled child and therefore she did the CT and would have terminated her pregnancy in the event of a confirmed anomaly even if it had been against Islamic rules. This woman was the only one who thought that Down's syndrome was severe enough to terminate a pregnancy. The other woman who had the CT had many doubts about taking it; a friend's comment had persuaded her to take the first step of the combined test:

“You've got nothing to lose” (P11)

Because of her age (over 36), she was the only participant who was offered the combined test free. Her motivation to take the CT was hoping for reassurance and she had not decided yet whether or not to do an invasive diagnostic test if the combined test showed a high risk of Down's syndrome; nor had she decided whether or not to terminate her pregnancy in that case.

Considering participation in the CT and termination in the event of positive diagnostic testing, some women said they would know immediately what to do, but most said they would discuss the subject with others, like their partner or female relatives. Although the women said they

would consult their Islamic sources and discuss different aspects of the CT with others, they underlined that the decision would be their own, and that a partner's opinion was secondary to their own. Some women did not inform even their partner about the possibility of having the CT:

"In terms of abortion, yes, well, I think he'd never approve of it, no way. I didn't even ask him if he (laughs), if he wanted the test. I think that it's mine, it's in my belly (laughs). ... Yes, that's what I say, and I always say it's my responsibility too. If I have to justify that, then I'll do it before God. I don't have to justify my actions before a man." (P3)

Nearly all women reported that their religious views were important and helpful in decision-making regarding the uptake of the CT. At the same time, women hastened to say that not only their religious views but also their own opinions were part of their deliberations. They also asserted that both perspectives inadvertently coincided. Apparently, they meant to claim an independent position regarding their religious views even when they valued their Islamic belief system in arriving at the right decision.

Some women related terminating pregnancy to accountability during the Judgment on the Last Day; this also underlined the importance of making your own decision.

"Suppose I did decide to have the abortion. Could I forgive myself? Would God forgive me? Or, um, would I always have that hanging over me, whatever I do? How could I make it right? That would be very difficult, because you know that it isn't allowed but you did it even so." (P11)

#### D. *Disability*

The deliberations on disability were partly informed by personal experiences, as many women were familiar with disabled relatives; one of them had previously given birth to a son with a serious heart disease. This made them aware of the possibility of having a disabled child. Nonetheless, they were not interested in the possibility of termination in the case of an anomaly:

"For me, again....a child has a right to live, no matter what condition .... you have to accept what God gives you." P(5)

The interviewees said they believe God decides whether or not they have a disabled child. They did not experience this as punishment by God, but rather as a test or a sign. Views on disability were also strongly intertwined with religious views on the meaning of being disabled, for example, having a disabled child was reported to guarantee access to paradise.

All women believed that in the eyes of God people with a disability are the same as 'healthy' people:

“Someone with a disability is worth just as much, I think... A disabled person doesn't have as much to do as other people. And that's the same as the difference you have between the rich and the poor, for instance. Some people - the rich - have more money than the poor, just like God made us all different... different people. So they're just as human, but they don't have as many things. For instance, there are some things you can't do if you're disabled, and there are some things you can't do if you're not rich. That's how I see it.” (P6)

## Discussion

The aim of this study was to understand how Muslim women of Moroccan origin approaching anomaly screening tests and to compare these findings to prior research on Muslim women of Turkish origin thus extending our knowledge on how pregnant Muslim women from different Islamic schools approach antenatal anomaly screening. We found that among Moroccan Muslim women the privilege of motherhood or becoming a mother appeared to outweigh any perceived burden of bearing a disabled child. Nearly all women thought of the CT as a test that could identify potentially anomalous infants, and could result in being offered termination of the pregnancy; a fact that resulted in their extensive deliberations and hesitation. In contrast, women viewed the FAS as an opportunity to see their child, and the decision to opt for the FAS was not focused on the possibility of pregnancy termination after an adverse outcome. Above all, women underlined that it was their own individual decision to take or refuse both tests as in the end they were accountable for their choices. As in our previous study among pregnant women of Turkish Islamic backgrounds, women's views on termination were most decisive concerning taking the CT; these views were based on their individual religious beliefs and inseparably linked with their views on disability and on the value of life (Gitsels-van der Wal et al., 2014a).

Women's considerations of pregnancy termination in response to fetal anomalies have, among other things, been based on their views on motherhood and reproduction. Motherhood was perceived to begin with pregnancy, even among nulliparous women, and not with birth of the child. In Islam, as well as in other religions, motherhood is regarded as a blessing and reproduction is taken to be a divinely ordained obligation (Stephens et al., 2010; Ivry et al., 2011).

Religious beliefs were an important framework for deliberations, particularly regarding termination. Interestingly, there was diversity of opinions among the interviewees with regard to Islamic teaching on termination in the case of a confirmed anomaly, which reflects the diversity of opinions that exists among Muslim scholars on this topic (Rispler-Chaim, 1993; Atighetchi, 2007). In view of Islamic ruling, in our earlier work we saw that women of Turkish backgrounds were not aware of the fatwa, Islamic ruling, that permits termination in cases of serious anomalies up to 120 days after conception; this is in contrast to some of the Moroccan women in this study, who were aware of it (Gitsels-van der Wal et al., 2014a). An explanation could be, that the fatwa, introduced in 1990, only became relevant for the low risk pregnant population in the Netherlands since 2007 with the introduction of prenatal anomaly screening. Women with Turkish backgrounds were interviewed only one year after the antenatal anomaly screening program was introduced and therefore might not have known this specific fatwa (El-Hashemite, 1995).

Another possible explanation is that Muslims from Turkish and Moroccan origin belong to different Islamic schools (respectively Hanifi school and Mâlikî school) and opinions of timing of termination differs among them (Atighetchi, 2007). In this respect, the Hanifi school permits termination up to 120 days, and the Mâlikî school permits it up to 40 days although the majority of Mâlikî scholars prohibit termination even in the first 40 days (Rispler-Chaim, 1993; Atighetchi, 2007). However, in order to avoid stereotyping based on religion or ethnicity it is important for counsellors to recognize the diversity of opinions within Islamic jurisprudence as well as in the individual choices expressed by women in our study (El-Hazmi, 2007; Hasnain et al., 2011).

Despite Moroccan women's knowledge of the possibility to terminate a pregnancy in the case of a positive diagnostic test result within Islamic ruling, only two women said they would consider a termination. One participant would consider a termination, even if it was against Islamic ruling. Recent studies among Muslim women also observed that, although women's dominant view that termination is forbidden by Islam, Islamic rulings are not the only context for Muslim women's attitude either for or against termination; women would consider also a termination for personal or medical reasons (Ahmed et al., 2006; Shaw, 2012). Finally, other studies have confirmed that women's attitudes to termination were key in deciding whether or not to have the CT (Ahmed et al., 2006; Serror and Ville, 2009; Shaw, 2012; Gitsels-van der Wal, 2014a). Therefore, as Pilnick et al., we recommend counsellors to encourage all women to consider what they might do if the tests confirmed an anomaly (Pilnick et al., 2004).

In contrast to the CT, as in the study among women of Turkish backgrounds, the question whether or not to have the FAS was not related to the issue of termination (Gitsels-van der

Wal et al., 2014a). This is not surprising in light of the fact that the FAS is performed in week 20 of gestation, which is after the 40 or 120 days in which termination could be permitted according to the Islam. In fact, the timing of the FAS in the Netherlands potentially promotes the perception of the FAS as only being a ultrasound to see the baby. Other studies among Muslim and non-Muslim women confirmed our finding that some pregnant women saw the FAS as ‘only an ultrasound to see the baby’, and relatively few women saw it as a screening tool for detecting structural anomalies (Williams et al., 2005; Molander et al., 2010; Skirton and Barr, 2010; Schoonen et al., 2011; Barr and Skirton, 2013; Gitsels-van der Wal et al., 2014a). The wish to see the baby seemed to be a significant determinant in the decision to have the FAS in part because the FAS is the only ultrasound offered in the second trimester in the Netherlands. The fact that women in our study did not understand that the FAS was optional raises questions about how information about this screening test is presented.

Although screening was often discussed with the spouse or (female) relatives, most women stated that it was their individual decision and some did not even inform their spouses about the CT. Pivetti et al. observed a similar decision-making process among Catholic women, namely that it is primarily an individual female choice (Pivetti et al, 2012). This emphasis on autonomy is not exceptional when women are held to be accountable to God for their decisions, as appeared to be true for most of the women in our study.

This study has some limitations. Women who were invited but did not want to participate in the study might have had different opinions and values than the women who took part. All the interviewed women opted for the FAS, so deliberations of Muslim women who decline the FAS could not be explored. Although we looked specifically for such women, we did not find any because the uptake in the study area is nearly 100%. Nevertheless, this study provides additional insights into important values within the decision-making process regarding antenatal anomaly screening by pregnant Muslim women; the results contribute to our understanding of decision-making within Muslim women of different Islamic streams. The inter-subjective approach to the analysis of the data contributes to the reliability of the results (Verhoeven, 2014). The inclusion of Muslim women of Moroccan descent from a variety of ages, parities, and levels of education, as well as those who are first and second generation in the Netherlands adds to the strengths of the study.

In conclusion: As in our previous study among Muslim women from Turkish descent, Moroccan women’s views on termination, disability and life, based on their religious beliefs, were key in decision-making on the CT. Additionally, the current study shows that motherhood was the lens through which Muslim women from Moroccan descent approached decision-making to participate in antenatal anomaly screening; furthermore, women from Moroccan descent



underlined the importance to take their own individual decision because of their experienced accountability for their own choices. Although also observed in Turkish origin women, values on termination and disability dominated the deliberation whether to opt for the CT or not, while looking forward to see the baby led the decision to have a FAS were more strongly emphasised in the current study. The current study demonstrates that women viewed the CT as repellent while they viewed the FAS as attractive. In order to enable informed decision-making about antenatal anomaly screening in Muslim women, counsellors should be aware that women approach pregnancy, including the fetal anomaly screening tests through the lens of motherhood. Counsellors should have knowledge of Islamic beliefs on the value of life, disabled life, and the different beliefs of-of-the latest possible day for- termination. At the same time, counsellors should also be aware that Muslim women make their own conscious choices, sometimes even beyond their Islamic rulings. Research among Muslim women who decline the FAS is needed. Furthermore, recent research studied preferences of antenatal counselling among Dutch pregnant women. Additional research is needed into Muslim women's preferences regarding counselling for antenatal anomaly screening.

## **Appendix**

Antenatal screening for congenital anomalies has been offered to all pregnant women in the Netherlands since 2007, using an opt-in approach. The available screening comprises two non-invasive tests: the Combined Test (CT) and the Fetal Anomaly Scan (FAS). The CT is a risk assessment for Down's syndrome, Edwards syndrome and Patau syndrome (respectively trisomy 21,18 and 13), comprising a blood test for PAPP-A and free  $\beta$  HCG, and an ultrasound to measure the nuchal translucency at around twelve weeks' gestation. The FAS is an ultrasound to detect structural anomalies, carried out around twenty weeks of gestation. The CT is offered free for women aged 36 or older, whereas younger women pay approximately 150 Euros. The FAS is offered without cost to all women. In the event of a confirmed diagnosis of abnormality, two options are available: terminating the pregnancy before 24 weeks' gestation, or health-oriented antenatal and postnatal care for the fetus combined with support for the parents. Both CT and FAS potentially require three decisions: 1) to have antenatal screening, 2) to follow up positive screens with diagnostic tests which carry an associated 0.5% risk of miscarriage, and 3) when a positive finding is confirmed, to terminate the pregnancy or prepare for having a child with an anomaly. In the Netherlands, the mean uptake is around 27% for the CT and 91% for the FAS (Fracheboud et al., 2011). Generally, factors such as age, parity, anxiety, family situation and personal experiences play a role in decision-making on the CT and FAS (Van den Berg et al., 2005; Seror and Ville, 2009; Fransen et al., 2010a; Maxwell et al., 2011; Tischler et al., 2011; Bakker et al., 2012; Crombag et al., 2013; Gitsels-van der Wal et al., 2014b). Since April 2014, in the Netherlands, only

women who are at risk (e.g. the CT results show an increased chance of carrying a child with Down's syndrome) are offered the non-invasive prenatal test (NIPT) in a study setting; the NIPT is a blood test to determine fetus' DNA from mother's blood ([www.niptconsortium.nl](http://www.niptconsortium.nl)).

### **Conflict of interest statement**

The authors declare that they have no competing interests.

### **Ethical approval**

The design and conduct of the study were approved by the Medical Ethics Committee of the VU University Medical Centre Amsterdam.

### **Abbreviations**

Combined Test – CT

Fetal Anomaly Scan- FAS

## References

- Ahmed, S., Atkin, K., Hewison, J., Green, J., 2006. The influence of faith and religion and the role of religious and community leaders in prenatal decisions for sickle cell disorders and thalassaemia major. *Prenatal Diagnosis* 26(9), 801-809.
- Ahmed, S., Bryant, L.D., Tizro, Z., Shickle, D., 2014. Is advice incompatible with autonomous informed choice? Women's perceptions of advice in the context of antenatal screening: a qualitative study. *Health Expectations* 17(4), 555-564.
- Atighetchi, D., 2007: *Islamic bioethics: problems and perspectives*. Springer, Dordrecht.
- Aune, I., Moller, A., 2012. 'I want a choice, but I don't want to decide'. A qualitative study of pregnant women's experiences regarding early ultrasound risk assessment for chromosomal anomalies. *Midwifery* 28(1), 14-23.
- Bakker, M., Birnie, E., Pajkr, E., Bilardo, C.M., Snijders, R.J., 2012. Low uptake of the combined test in The Netherlands - which factors contribute? *Prenatal Diagnosis* 32(13), 1305-1312.
- Barr, O., Skirton, H., 2013. Informed decision making regarding antenatal screening for fetal abnormality in the United Kingdom: A qualitative study of parents and professionals. *Nursing Health Science* 15(3), 318-325.
- Braun, V., Clarke, V., 2006. Using thematic analysis in psychology. *Qualitative Research in Psychology* 3(2), 77-101.
- Crombag, N.M., Bensing, J.M., Iedema-Kuiper, R., Schielen, P.C., Visser, G.H., 2013. Determinants affecting pregnant women's utilization of prenatal screening for Down syndrome: a review of the literature. *Journal Maternal Fetal Neonatal Medicine* 26(17), 1676-1681.
- Dormandy, E., Michie, S., Hooper, R., Marteau, T.M., 2005. Low uptake of prenatal screening for Down syndrome in minority ethnic groups and socially deprived groups: a reflection of women's attitudes or a failure to facilitate informed choices? *International Journal Epidemiology* 2, 346-352.
- El-Hashemite, N., 1995. In: *Genetic malformation in children, its causes, and the Islamic view in preventive procedures*. Dar Al-Hekma, London 105-131. (in Arabic language)
- El-Hazmi, M.A., 2007. Islamic teachings of bioethics in relation to the practice of medical genetics. *Editorial Saudi Medical Journal* 28(12), 1781-1787.
- Fracheboud, J., Agt van, H.M.E., Koning de, H.J., 2011. Monitoring 2009 of prenatal screening for Down's Syndrome and for foetal anomalies in the Netherlands. Eindrapport. RIVM, Bilthoven.
- Fransen, M.P., Essink-Bot, M.L., Oenema, A., Mackenbach, J.P., Steegers, E.A.P., Wildschut, H.I., 2007. Ethnic differences in determinants of participation and non-participation in prenatal screening for Down-syndrome: A theoretical framework. *Prenatal Diagnosis* 27, 938-950.
- Fransen, M.P., Schoonen, M.H., Mackenbach, J.P., Steegers, E.A., de Koning, H.J., Laudy, J.A., Galjaard, R.J., Looman, C.W., Essink-Bot, M.L., Wildschut, H.I., 2010a. Ethnic differences in participation in prenatal screening for Down syndrome: a register-based study. *Prenatal Diagnosis* 30(10), 988-994.
- Fransen, M.P., Essink-Bot, M.L., Vogel, I., Mackenbach, J.P., Steegers, E.A., Wildschut, H.I., 2010b. Ethnic differences in informed decision-making about prenatal screening for Down's syndrome. *Journal Epidemiology Community Health* 64(3), 262-268.
- Garcia, E., Timmermans, D.R., Leeuwen, E. van, 2008a. The impact of ethical beliefs on decisions about prenatal screening tests: searching for justification. *Social Science & Medicine* 66(3), 753-764.
- Garcia, E., Timmermans, D.R., Leeuwen, E. van, 2008b. Rethinking autonomy in the context of prenatal screening decision-making. *Prenatal Diagnosis* 28(2), 115-120.
- Ghaly, M.M., 2008. Physical and spiritual treatment of disability in Islam: perspectives of early and modern jurists. *Journal of Religion, Disability & Health* 12, 106-109.
- Gitsels-van der Wal, J.T., Manniën, J., Ghaly, M.M., Verhoeven, P.S., Hutton, E.K., Reinders, H.S., 2014a. The role of religion in decision-making on antenatal screening of congenital anomalies: A qualitative study amongst Muslim Turkish origin immigrants. *Midwifery* 30, 297-302.
- Gitsels-van der Wal, J.T., Verhoeven, P.S., Manniën, J., Martin, L., Reinders, H.S., Spelten, E., Hutton, E.K., 2014b. Factors affecting the uptake of prenatal screening tests for congenital anomalies; a multicentre prospective cohort study. *BMC Pregnancy and Childbirth* 14, 264.

- Guest, G., Bunce, A., Johnson, L., 2006. How many interviews are enough? An experiment with data saturation and variability. *Field Methods*;18, 59-82.
- Hasnain, M., Conell, K.J., Menon, U., Tranmer, P.A., 2011. Patient-centered care for Muslim women: provider and patient perspectives. *Journal Womens Health* 20(1), 73-83.
- Ivry, T., Teman, E., Frumkin, A., 2011. God-sent ordeals and their discontents: ultra-orthodox Jewish women negotiate prenatal testing. *Social Science Medicine* 72(9),1527-1533.
- Martin, L., Van Dulmen, S., Spelten, E., De Jonge, A., De Cock, P., Hutton, E., 2013. Prenatal counseling for congenital anomaly tests: parental preferences and perceptions of midwife performance. *Prenatal Diagnosis* 33(4), 341-353.
- Marteau, T.M., Dormandy, E., Michie, S., 2001. A measure of informed choice. *Health Expectations* 2, 99-108.
- Maxwell, S., Brameld, K., Bower, C., Dichinson, J.E., Godblatt, J., Hadlow, N., Hewitt, B., Murch, A., Murphy, A., Stock, R., O'Leary, P., 2011. Socio-demographic disparities in the uptake of prenatal screening and diagnosis in Western Australia. *Australian New Zealand Journal Obstetrics Gynaecology* 51(1), 9-16.
- Molander, E., Alehagen, S., Bertero, C.M., Josefsson, A., Molander, E., Selbing, A., 2010. Routine ultrasound examination during pregnancy: a world of possibilities. *Midwifery* 26(1), 18-26.
- Neter, E., Wolowelsky, Y., Borochowitz, Z.U., 2005. Attitudes of Israeli Muslims at Risk of Genetic Disorders towards Pregnancy Termination. *Community Genetics* 8, 88-93.
- O'Connor, A., O'Brien Pallas, L.L., 1989. Decisional conflict. In *Nursing Diagnosis and Intervention*. Edited by Mcfarlane GK, Mcfarlane EA. Mosby: Toronto 486-496.
- Pilnick, A.M., Fraser, D.M., James, D.K., 2004. Presenting and discussing nuchal translucency screening for fetal abnormality in the UK. *Midwifery* 20, 82-93.
- Pivetti, M., Montali, L., Simonetti, G., 2012. The discourse around usefulness, morality, risk and trust: a focus group study on prenatal genetic testing. *Prenatal Diagnosis* 32(12), 1205-1211.
- Rispler-Chaim, V., 1993. *Islamic medical ethics in the twentieth century*. Brill, Leiden.
- Schoonen, H.M., Essink-Bot, M.L., Van Agt, H.M., Wildschut, H.I., Steegers, E.A., de Koning, H.J., 2011. Informed decision-making about the fetal anomaly scan: what knowledge is relevant? *Ultrasound in Obstetrics and Gynecology* 37(6), 649-657.
- Roadmap of prenatal screening [Draaiboek prenatale screening], 2011. RIVM, Bilthoven. (in Dutch)
- Seror, V., Ville, Y., 2009. Prenatal screening for Down syndrome: women's involvement in decision-making and their attitudes to screening. *Prenatal Diagnosis* 29(2), 120-128.
- Shaw, A., 2012. The say Islam has a solution for everything, so why are there no guidelines for this? Ethical dilemmas associated with the births and deaths of infants with fatal abnormalities from a small sample of Pakistani Muslim couples in Britain. *Bioethics* 26(9), 485-492.
- Skirton, H., Barr, O., 2010. Antenatal screening and informed choice: a cross-sectional survey of parents and professionals. *Midwifery* 26(6), 596-602.
- Statline, Statistics Netherlands. Population, Ethnic background, Islam. <http://statline.cbs.nl/Statweb/publication/?DM=SLNL&PA=70086NED&D1=a&D2=0,9,19,29,32-33&VW=T>; retrieved October 1, 2014. (in Dutch)
- Stephens, M., Jordens, C.F.C., Kerridge, I.H., Ankeny, R.A., 2010. Religious perspectives on abortion and a secular response. *Religion Health* 4, 513-535.
- Tischler, R., Hudgins, L., Blumenfeld, Y.J., Greely, H.T., Ormond, K.E., 2011. Noninvasive prenatal diagnosis: Pregnant women's interest and expected uptake. *Prenatal Diagnosis* 31(13), 1292-1299.
- Van den Berg, M., Timmermans, D.R.M., Kleinveld, J.H., Garcia, E., Van Vugt, J.M.G., Van der Wal, G., 2005. Accepting or declining the offer of prenatal screening for congenital defects: test uptake and women's reasons. *Prenatal Diagnosis* 25, 84-90.
- Verhoeven, N., 2014. *Doing research*. Boom Lemma: Den Haag, 331-337. (in Dutch)
- Williams, C., Sandall, J., Lewando-Hundt, G., Heyman, B., Spencer, K., Grellier, R., 2005. Women as moral pioneers. Experiences of first trimester antenatal screening. *Social Science & Medicine* 61, 1983-1992.

