

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

Chapter 5

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

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

Midwifery 2015;31:50-57.

Highlights

Pregnant Muslim Moroccan women prefer:

- to be counselled as individuals and religion is part of their individuality.
- counsellors to initiate questions about women's values and religious beliefs regarding decision-making on anomaly screening.
- to be adequately and accurately informed about screening options.

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: Twelve 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.

Keywords: genetic counselling, antenatal diagnosis, Islam, needs assessment, Down Syndrome, personal autonomy.

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.

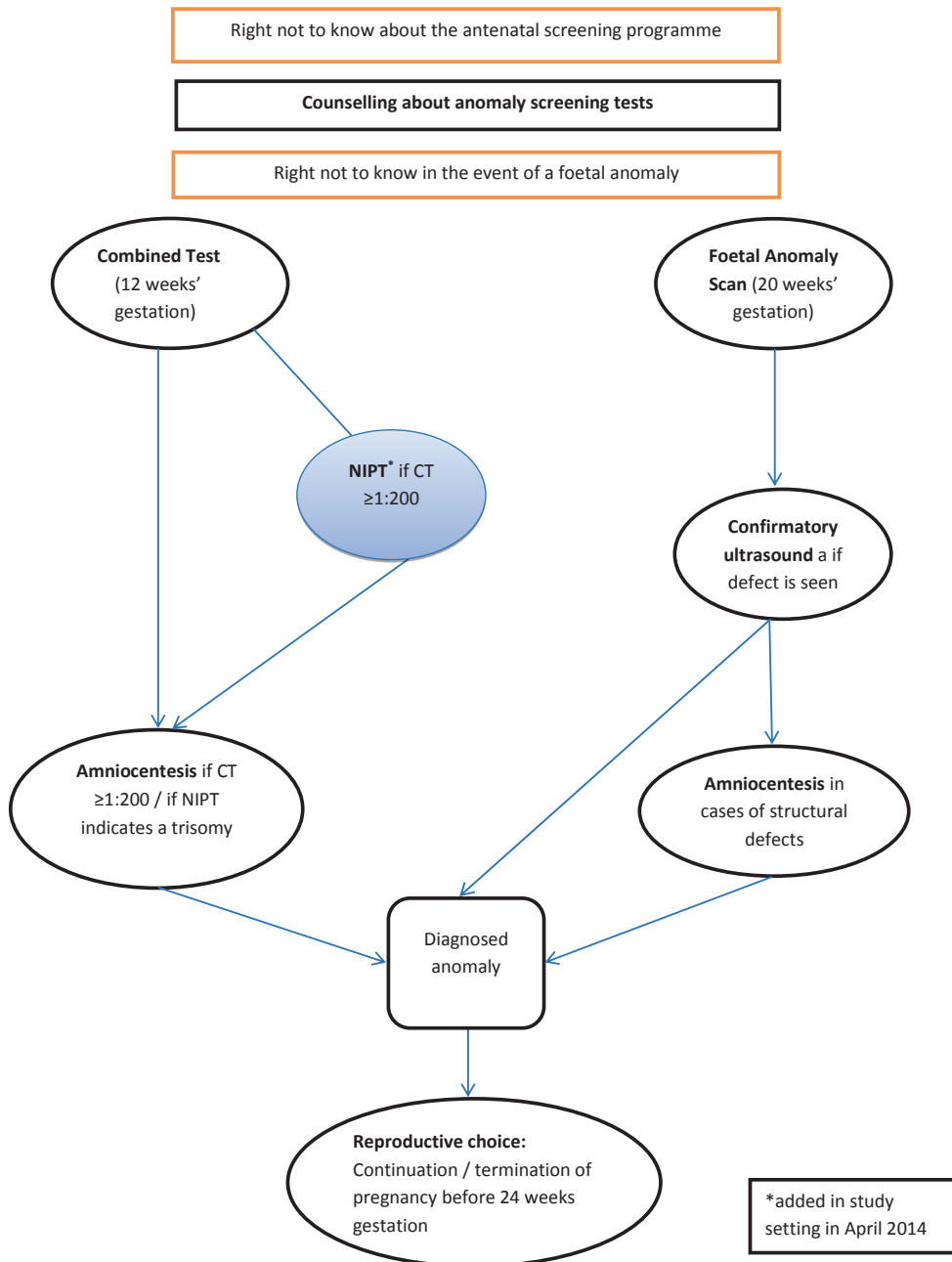


Figure 1. Flow chart of choices within the Dutch Antenatal Anomaly Screening Programme based on an opt-in procedure

An important and growing group of women with non-Western origins in the Netherlands is non-Dutch Muslim women. Recent studies have shown that Muslim women are less likely to choose to have fetal anomaly screening tests and that their views on life, disabled life and termination based on their religious beliefs are a key factor in their decision-making on whether or not to have anomaly screening done (Neter et al., 2005, Fransen et al., 2010, de Vlemminck et al., 2012, Gitsels-van der Wal et al., 2014a, Gitsels-van der Wal et al., 2014c, Gitsels-van der Wal et al., 2015). Islamic rulings permit termination in cases of serious anomalies, but only before the *ensoulment*, the moment when an angel of God breathes the spirit in (Rispler-Chaim, 1993, Albar, 1996). There are different views on the moment of *ensoulment*, but the majority of Islamic scholars believe that *ensoulment* takes place at the 120th day after conception or 19 weeks plus one day of clinical gestation (Albar, 1996, Kithamy, 2013). Allowing termination in case of a serious anomaly before the *ensoulment* reflects Islamic views on the principle of respecting women's autonomy in their reproductive choices (Kithamy, 2013).

The first aim of the current study is to explore the preferences among pregnant Muslim Moroccan women, who are of non-Western origin, regarding content of and approach to antenatal counselling for anomaly screening and the second is to determine their preferences as regards the counsellor's knowledge of Islamic beliefs.

Method and recruitment

Data collection

We conducted open interviews in Dutch with pregnant Muslim women of Moroccan descent, who belong to the group of non-Western non-Dutch women, between December 2011 and May 2012. People from Morocco are a large minority group in the Netherlands (Statline, 2014). The study was designed to explore a) pregnant Muslim Moroccan women's attitudes towards *participation* in anomaly screening (Gitsels-van der Wal et al, 2014d), and b) pregnant Muslim Moroccan women's preferences regarding the *approach taken to counselling* for anomaly screening as well as pregnant Muslim Moroccan women's opinions about the counsellor's knowledge of Islamic beliefs, which is reported here. The qualitative set-up of the study was built on a large quantitative study focusing on clients' preferences on appropriate counselling in general (Martin et al., 2013). The Medical Ethics Committee of the VU University Medical Centre in Amsterdam approved the study. Informed consent was obtained in writing from all participants.

Participants

In the Netherlands, around 80% of pregnant women start antenatal care in primary midwifery practices. Midwives counsel these pregnant women about antenatal anomaly screening (Wiegers, 2009). We recruited participants from a population of pregnant women at a primary care midwifery practice situated in a medium-sized city; this was done by purposive sampling. The practice in question has a relatively large proportion of clients from ethnic minorities. We only included pregnant Muslim Moroccan women who were born in Morocco or whose parents were born there, who had a reasonable command of Dutch, and who were past the cut-off date for antenatal anomaly testing. In a homogeneous population, ten to twelve interviews will typically reach data saturation, so we planned twelve interviews (Guest et al., 2006).

Procedure

First, midwives gave information about the study to women who were eligible to participate. Next, one of the researchers asked the pregnant Muslim Moroccan women whether they would agree to be interviewed on the topic. If consent was given, an interview-appointment was made. Pregnant Muslim Moroccan women who did not agree were asked about their reasons for not participating. The interviewer was a midwife from the practice where the recruitment was done. However, she was not the care-provider of any participants. The interviews were recorded digitally and transcribed verbatim with permission of the participants.

Instruments

To examine pregnant Muslim Moroccan women's preferences regarding antenatal counselling for anomaly screening, we asked the participants two questions:

1. What topics should be addressed during counselling on anomaly screening?
2. What do you think that a counsellor should know about the faith of Muslim pregnant women when counselling them about antenatal anomaly screening?

Analysis plan

We coded and analysed the transcripts using techniques from the Thematic Analysis, an inductive approach described by Braun and Clarke (2006). To obtain inter-subjectivity of the results, two researchers individually coded text fragments of the first seven interviews and grouped them into categories. The two researchers discussed the initial coding and then redefined the categories and defined the themes. Table 1 gives an example of the initial coding. One of the researchers then examined the remaining interviews, trying both to complement and to redefine the themes raised by the initial coding. Finally, the two researchers analysed the themes and subthemes, plus possible connections between themes and subthemes.

Table 1. Example of coding; preferences regarding the counsellor's agenda setting

1 st level: Fragment	2 nd level: Coding	3 rd level: Category	4 th level: Theme
(Interviewer): Do you think that a counsellor ought to know something about how Islam thinks about being handicapped or about terminating the pregnancy? (Participant): Maybe, in the sense that Muslim women may say that I won't have a termination, and then you'll know why. That's really the only thing. The rest doesn't matter. But I do reckon that you don't all say "Uh-oh, here comes a Muslim so we won't ask her." So do keep it all the same. You have to ask, because you never know! Muslim women can also... within a religion, there's also (how should I put it?), uh, one woman may believe very strongly and stick to all the rules, but for others it doesn't involve much more than praying and they might choose a termination, you know? And they haven't been given the chance to make that choice.	Understand why Muslim women might not have a test done	Knowledge of Islam focused on the views on life and termination	<u>Counsellor</u> : applied knowledge
	No other knowledge of Islam required Do ask whether Muslim women would want to have the test done	Muslim women should be informed	
	Keep it the same as for non-Muslims	Do not put Muslim women into a separate conceptual group	<u>Counsellor</u> : unbiased attitude, individual approach, and 'obligation' to inform each Muslim woman
	Do ask about this, as Muslim women may have differing perceptions or interpretations of their religion, and there could be some who would choose to terminate the pregnancy but who are then not given the opportunity	Treat Muslim women as individuals, so that each woman can make an informed choice	

Findings

A total of 19 pregnant Muslim Moroccan women were invited to participate in the study. For the clarity of the paper, 'interviewed women' or 'interviewees' will be used to refer to the interviewed pregnant Muslim Moroccan women, i.e. the study sample. Seven invited women did not want to participate, mainly because they were busy or lacked confidence that their views would be in line with Islamic rulings on antenatal anomaly screening. The ages of the twelve interviewed women ranged from 20 to 36 years (see Table 2). Six interviewed women were first generation immigrants and six interviewed women were second generation non-Dutch; the latter means that they are born in the Netherlands and that (one of) their parents were born in Morocco. All participants described themselves as Muslim. All interviewed

women started antenatal care before twelve weeks' gestation and were therefore in time for counselling for both tests. Two interviewed women took the CT and all twelve interviewed women opted for a FAS.

Table 2. Characteristics of the participants

Participant	Immigrant Generation	Age	CT/FAS* Uptake	Parity	Education
1	First	32	- / +	1	High
2	First	20	- / +	0	Medium
3	Second	33	- / +	2	Low
4	Second	30	- / +	0	High
5	Second	31	- / +	2	High
6	Second	28	- / +	1	Medium
7	Second	20	- / +	1	Medium
8	First	26	- / +	1	Medium
9	First	33	+ / +	2	High
10	Second	27	- / +	1	Low
11	First	36	+ / +	3	Medium
12	First	34	- / +	2	Medium

*CT = Combined test; FAS = Fetal Anomaly Scan

Analysis of the interviewed women's preferences for antenatal counselling about anomaly screening yielded in three themes: 1) provision of accurate and detailed information, 2) exploring the client's values, and 3) the counsellor's knowledge and attitude.

Analysis also produced an overarching finding. Interviewed women indicated that they needed sufficient time during the counselling consultation and would like an opportunity for a follow-up discussion at a later date; sufficient time was also needed to read the leaflet about the screening.

Theme 1. Accurate and detailed information

Interviewed women wanted accurate and detailed medical information about the anomalies that could be detected. Interviewed women indicated that one factor that considering a termination would depend on was the seriousness of an anomaly.

"If it's a really bad abnormality and the baby's life would be, well, ruined... then I think that I would, eh, terminate it." (P6)

Interviewed women also preferred detailed information about the process and the pros and cons of the tests that are available. Several interviewed women reported not wanting a test with a risk of a spontaneous miscarriage, as explicitly stated by one interviewee:

"Muslim women do not want a test with a risk of a spontaneous miscarriage". (P11)

Many interviewed women in this study also wanted to receive written information; on the other hand, some women experienced difficulties in understanding the written information and preferred a clear verbal explanation. Furthermore, because of the density of the information, some interviewed women suggested discussing the antenatal screening tests during two consultations instead of one; others suggested reading the brochure at home before counselling so that they could ask specific questions during the counselling session.

Some of the interviewed women were familiar with the information about anomaly testing, because they had been counselled on anomaly screening tests during a previous pregnancy. These women suggested that counselling a multiparous pregnant woman should start by asking her what she already knows about the tests.

Theme 2. Exploring client's values

Interviewed women in this study indicated a number of topics that a counsellor should address in order to help them make their own decisions. Firstly, they suggested for instance that counsellors should ask clients what kinds of anomalies would be acceptable and would result in them keeping the baby. For most interviewed women in this study, Down Syndrome was not severe enough to terminate the pregnancy. In addition to the seriousness of an anomaly, some interviewed women explained that the decision whether or not to terminate a pregnancy if an anomaly was diagnosed could depend on the physical and mental strength of a mother or the strength of her faith:

“For me, personally, well... yes, because like I just said [my body has a lot of weaknesses] I know that I myself simply couldn't handle it. I couldn't do that and I wouldn't want to do that to the child. ...so yes, for me that would be a reason to have a termination.” (P7)

“One woman may believe very strongly and stick to absolutely all the rules, but there are others who don't go much further than saying a few prayers, and maybe they would choose to terminate a pregnancy, you know?” (P6)

Secondly, the counsellor tends to set the agenda during the consultation, in terms of questioning moral issues such as what women think constitutes a healthy child: interviewed women seem to prefer using that agenda as a stepping-stone towards doing research at home using their own religious sources, after the consultation. In the case of moral issues, interviewed women were familiar with doing research using their own (religious) resources and indicated that decision-making about antenatal anomaly screening is not so easy and could take quite some time:

“Yes, it's so complicated – the various rules and the nuances within them and so forth. If there's some kind of delicate question that you can't simply give a yes-and-no answer to, that you have to ask or read about carefully and see exactly what's been said about it... and then there can be contradictions too. So yes, it's quite an issue. You do have to be able to make a carefully considered choice.” (P4)

Therefore, as religious beliefs play a role in interviewed women's decision-making about whether or not to participate in anomaly screening, one interviewee suggested that it would be helpful for Muslims if counsellors were to ask the following questions:

“Are you religious? What does it mean to you? And what could it mean in this case?” (P1)

Thirdly, interviewed women in this study emphasised that they did not want the counsellor's advice about whether or not to take the anomaly tests. However, interviewed women found it difficult to speak and think about the tests, so most of them preferred to get advice about how to discuss the tests with their spouse at home, and about how to think and decide about having the tests.

In summary, interviewed women wanted to be questioned about the moral issues of anomaly screening and to be challenged to make an autonomous and carefully considered decision. As an interviewee expressed it:

“Make sure that I think about it very carefully!” (P1)

Theme 3. The counsellor's knowledge and attitude

Interviewed women in this study preferred a counsellor who has practical knowledge of Islamic views on life and who respects every single woman and her decision. The counsellor's knowledge of Islamic views and a respectful attitude seem to be a necessary condition for meeting these two criteria. Applied knowledge of the Islam and a respectful attitude should on the one hand guarantee that the counsellor informs a Muslim client appropriately about e.g. the details of the antenatal tests and the medical conditions that could be detected; on the other hand, this knowledge should help them support active decision-making.

Applied knowledge of Islamic beliefs

When discussing counselling about anomaly screening, there were some interviewed women who did not think that counsellors should necessarily know about Islam. However, the majority of the interviewees preferred counsellors who have some knowledge of Islam or Islamic rulings (relevant to antenatal anomaly tests in particular), e.g. knowledge about

different Islamic views on life, disabled life, termination and *ensoulment*, and the variability within Islam. Knowledge of Islamic rulings would be a helpful tool for the counsellor when asking exploratory questions intended to help women make their own decisions; it ought also to make the conversation during counselling easier, because the counsellor could then communicate more consistently with Muslims women's frame of reference. As an interviewee said:

"It would be useful [for the counsellor] to know about, uh, what the religion [Islam] is all about... it makes it easier to talk..." (P10)

On the other hand, interviewed women emphasised the importance of making their own decisions and the counsellor's knowledge about Islamic rulings should therefore not be used with the aim of telling pregnant Muslim women what to decide or what is allowed within Islam. As an interviewee put it:

"If you live in Saudi Arabia, where Islam is – well very, uh, strictly according to their interpretation – then I think, yes, you can say that this is allowed and that isn't and so forth. But I don't think that's necessary here in the Netherlands. I mean, it's my decision whether I want an abortion or to have a test done – not the midwife's or anybody else's. I don't think that's necessary. Nope. I think 'No, this is really up to me' – because I'm the Muslim, aren't I?!" (P4)

The preceding quote also shows how important it is to ask about a woman's religious beliefs regarding decision-making on anomaly screening.

Respectful attitude

Although we did not ask the interviewed women about their preferences regarding the professional's attitude during counselling, they did bring up a number of attitudinal aspects. Interviewed women preferred to be approached respectfully, not as a generic Muslim woman but as an individual who has an Islamic background. Furthermore, based on relatives' experiences, an interviewee underlined the counsellor's duty to put antenatal anomaly screening on the agenda during consultations with Muslim women:

"But I do reckon that you all don't think 'Uh-oh, here come a Muslim woman so we'd better not ask.' So do keep doing the same things. You do have to ask, because you never know!" (P6)

Interviewed women in this study also felt that the content of the counselling conversation was rather heavy and scary; interviewees therefore also wanted the counsellor to speak calmly and clearly, taking plenty of time and using understandable words to reduce the anxiety. The aspects of counsellor's attitude listed above plus practical knowledge of Islamic rulings seemed to be the basis for antenatal counselling about anomaly screening that would be better tailored to suit Muslim women's preferences.

Discussion

This study aimed to obtain insights into the preferences of pregnant Muslim women of Moroccan descent regarding content of and approach to antenatal counselling for anomaly tests and to determine women's preferences towards counsellor's knowledge of Islamic beliefs. Consistent with the criteria of informed choice, our findings show that interviewed women prefer a counsellor who accurately informs them about the tests and the anomalies that could be detected, and who put moral topics on the counselling agenda in order to facilitate a deliberate, consciously made informed choice about whether or not to participate in the screening programme (O'Connor and O'Brien Pallas, 1989, Skirton and Barr, 2010, Vanstone et al., 2012, Dixon and Burton, 2014). Furthermore, interviewed women preferred a counsellor who not only respects client's cultural and religious background but also knows about Islamic rulings that are relevant to antenatal anomaly screening.

The preferences of the study participants are in clear alignment with the three functions of the theoretical antenatal counselling model: (1) the need for accurate and detailed information as part of the health education function; (2) informed choice based on the client's values and counselling that is tailored to the individual as part of decision-making support; and (3) the need for a reliable counsellor as part of the client-counsellor relationship (Martin et al., 2013). However, the aforementioned study also demonstrated that only one-third of the clients consider counsellor's decision-making support as important (Martin et al., 2013). Another study among midwife counsellors showed that only half of these counsellors value decision-making support as important (Martin et al., 2014a). To meet the needs of Muslim Moroccan pregnant women, further research is needed as to why some midwife counsellors do not value decision-making support as an important component of antenatal counselling.

Furthermore, our findings indicate that pregnant Muslim Moroccan women prefer counsellors to initiate discussions about issues that help decision-making, such as perceptions of the seriousness of anomalies that the tests may uncover and how that relates to women's values and religious beliefs. These preferences suggest that counsellors should use an active counselling approach (e.g. asking exploring questions about moral topics) particularly because

of the strong relationship between individuals' values regarding disability and termination and the decision whether to opt for antenatal screening or not, and making an autonomous informed choice. Such an active counselling approach was also recommended by other studies (Van Zwieten, 2008, Pennacchini and Pensieri, 2011, Vanstone et al., 2012). Vanstone et al. (2012)) suggest a model for counselling in which (1) the counsellor supports the woman to fully understand the information about the tests and the anomalies that could be detected and its consequences, such as the possibility to terminate a pregnancy in the event of a diagnosed serious anomaly; (2) the counsellor and the women discuss woman's individual values related to the tests and the possible tests outcomes; and (3) the woman makes her autonomous informed decision on her own. The model as suggested by Vanstone et al. also corresponds to our study participants' preferences towards counselling for antenatal anomaly screening: receiving accurate and detailed information about anomaly screening, discussion of moral topics in relationship with client's view on life and religious beliefs. This model is also consistent with our earlier findings that pregnant Muslim Moroccan women underline the importance of making their own autonomous decision (Gitsels-van der Wal et al., 2015).

A recent study revealed that relatively many clients preferred the counsellor to give advice using a directive approach of counselling, about whether or not to take the antenatal tests as part of decision-making support (Martin et al., 2013). In contrast, the interviewed women in our study strongly preferred not to be advised whether or not to take the tests; they preferred a counsellor to empower them make their own, carefully deliberated decision whether or not to take the tests. This is perhaps not so surprising in an Islamic context, as individuals are held accountable for their own decisions and they are therefore familiar with doing research into reliable authoritative sources such as the Qur'an and the Hadith with the aim of making the right decisions (Bazna and Hatab, 2005, Mustafa, 2014). Although pregnant Muslim Moroccan women did sometimes stress the importance of making their own, individual decisions (Gitsels-van der Wal et al., 2015), Muslims will in general discuss anomaly screening with family members prior to taking the autonomous decision, and if necessary with religious scholars (El-Hazmi, 2007).

Previous studies showed that pregnant women prefer counsellors to have a basic knowledge of women's religious and cultural beliefs so that they can help women explore their own values about the issues for which decisions have to be made (Stephens et al., 2010, Skirton and Barr, 2010, Hasnain et al., 2011, Gitsels-van der Wal et al., 2014a). Our findings help to define counsellor's knowledge of Islam that Muslim women feel is necessary for adequate counselling, namely practical knowledge of Islamic rulings that are relevant to various aspects of antenatal anomaly screening, such as views on disabled life and on termination. However, a recent Dutch study revealed that knowledge of Islamic rulings relevant to anomaly

screening among midwifery counsellors was poor and that the counsellors needed additional knowledge about religious beliefs relevant to counselling for antenatal anomaly screening (Gitsels-van der Wal et al., 2014b). In order to take client's cultural and religious background into account, it is also important to recognise the diversity in individuals' experience of faith and individual choices (Tsianakas and Liamputtong, 2002, El-Hazmi, 2007, Hasnain et al., 2011). In this context, as one of the pregnant Muslim Moroccan women suggested, questions such as '*Are you a believer?*' followed by '*What would religion mean to you in relation to antenatal screening tests?*' can help to facilitate informed choice in line with the decision-maker's values; because every single person has a philosophy of life, religious or non-religious, these questions might be raised regardless of the client's religious background. Interviewed women in our study preferred counsellors to initiate discussion of the role of the religious background during antenatal counselling for anomaly screening. In contrast, our earlier work exploring midwives' experience with counselling revealed that some counsellors believe that the responsibility to raise issues of religious background rests with the client and that religious beliefs are irrelevant (Gitsels-van der Wal et al., 2014b). These findings are perhaps not surprising in the Dutch context, since for decades Dutch society has shifted towards a secular perspective in which religion should be placed in private domain and not in public domain (Van der Donk et al., 2006). As professional health care, e.g. midwifery care and counselling for anomaly screening, is seen as part of the public domain, the moral aspects of counselling are commonly addressed from a secular rather than a religious perspective. This practice fails to respond to the preferences of our participants, who prefer to be counselled as individuals and whose religion is part of their individuality. As we recognise that religious background of clients plays an important role in decisions about antenatal anomaly screening the importance for counsellors to invite women to discuss the role of faith must be emphasised (Anderson, 2009). Discussing the role of faith and exploring values focused on decision-making about anomaly screening requires additional emphasis in counselling training programs.

The pregnant Muslim Moroccan women in our study emphasised the importance of receiving accurate and factual information about anomaly screening test characteristics including detailed information about which anomalies can be detected. One of the reasons for the latter could be that some Muslim Moroccan women would consider termination if an anomaly is diagnosed (El-Beshlawy et al., 2012, Shaw, 2012, Belahcen et al., 2014, Gitsels-van der Wal et al., 2015). Informing pregnant Muslim women of Moroccan descent is all the more important because there is as yet no antenatal screening for Down Syndrome in Morocco and termination of an affected fetus with for example Down Syndrome is forbidden (Belahcen et al., 2014). Muslim women of Moroccan descent might therefore not know anything at all about antenatal screening for Down Syndrome and the possibility of a decision about whether

or not to terminate the pregnancy. Some other Muslim countries such as Iran and Saudi Arabia do have antenatal anomaly screening programmes and have lists of specific serious anomalies for which termination of pregnancy is allowed before the *ensoulment* (Hedayat et al., 2006, Al-Alaiyan and Alfaleh, 2012).

To the best of our knowledge, little qualitative research has been done into pregnant women's preferences regarding appropriate counselling for anomaly screening. The current study provides insights into pregnant Muslim Moroccan women's preferences and the results therefore (1) contribute to the conceptualisation of women's preferences about anomaly screening counselling; and (2) strengthen the theoretical three function antenatal counselling model. These interviews were with women in daily life situations and therefore generated findings that give a good picture of reality, which helps ensure that the content can be generalised (Verhoeven, 2014). Another strength is the thematic approach to the analysis, which improves the validity of the outcomes. The systematic and inter-subjective set-up of the analysis adds to the reliability of the study (Verhoeven, 2014). Furthermore, our study included pregnant Muslim Moroccan women of both the first and second generations, representing a variety of parities, ages and levels of education. However, pregnant Muslim Moroccan women in our study all had low-risk pregnancies, spoke Dutch and were recruited in a single midwifery practice in the Netherlands. We would therefore recommend future research to verify and quantify our findings. We also recommend future research into the midwife counsellors' arguments not to consider decision-making support as an important part of the theoretical three function antenatal counselling model.

Key conclusion:

In line with the theoretical three function counselling model, pregnant Muslim Moroccan women preferred to be given accurate and detailed information about antenatal anomaly tests and to be asked about their individual views on life by a counsellor who has a genuine interest in the individual client and practical knowledge of Islamic beliefs about the value of life, disabled life and termination. In addition to the theoretical model, counselling on anomaly screening should include an *explicit* exploration of the role of religion in decision making for each woman.

As a result of our findings we produced a set of recommendations for the counselling practice.

We recommend that counsellors:

- Counsel according the theoretical three functions counselling model: 1) health education; 2) decision-making support; and 3) client-counsellor relationship
- Personalise the counselling and tailor it to the needs and knowledge of the client
- Take sufficient time to share information about the tests' possibilities and procedures, and give information about the anomalies that could be detected

- Put moral topics on the agenda and its relationship with clients' religious beliefs
- Know about Islamic rulings that are relevant to antenatal anomaly screening

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.

References

- Al-Alaiyan, S., Alfaleh, K.M., 2012. Aborting a malformed fetus: a debatable issue in Saudi Arabia. *Journal of Clinical Neonatology* 1(1), 6-11.
- Albar, M., 1996. Human development as revealed in the Qur'an and Hadith: The creation of man between medicine and the Qur'an. 4th ed. Saudi Publishing House, Jeddah.
- Anderson, R.R., 2009. Religious traditions and prenatal genetic counselling. *American Journal of Medical Genetics* 151C(1), 52-61.
- Bazna, M.S., Hatab, T.A., 2005. Disability in the Qu'ran: The Islamic Alternative to Defining, Viewing, and Relating to Disability. *Journal of Religion, Disability & Health* 9(1), 5-24.
- Belahcen, A., Taloubi, M., Chala, S., Thimou Izgua, A., Mdaghri Alaoui, A., 2014. Mother's awareness and attitudes towards prenatal screening for Down syndrome in Muslim Moroccans. *Prenatal Diagnosis* 34, 1-10.
- Braun, V., Clarke, V., 2006. Using thematic analysis in psychology. *Qualitative Research in Psychology* 3(2), 77-101.
- Dixon V., Burton N., 2014. Are midwifery clients in Ontario making informed choices about prenatal screening? *Women and Birth* 27, 86-90.
- Van der Donk, W.B.H.J., Jonkers, A.P., Kronjee, G.J., Plum, R.J.J.M. (red), 2006. Beliefs in public domain. WRR/Amsterdam University Press, Den Haag/Amsterdam. (in Dutch)
- El-Beshlawy, A., El-Shekha, A., Mamtaz, M., Said, F., Hamdy, M., Osman, O., Meshaal, S., Gafaar, T., Petrou, M., 2012. Prenatal diagnosis for thalassemia in Egypt: what changed parents' attitude? *Prenatal Diagnosis* 32, 777-782.
- 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.
- Elwyn G., 2004. Arriving at the postmodern medical consultation. *European Journal of General Practice* 10, 93-97.
- Fransen, M.P., Essink-Bot, M.L., Vogel, I., Mackenbach, J.P., Steegers, E.A., Wildschut, H.I., 2010. Ethnic differences in informed decision-making about prenatal screening for Down's syndrome. *Journal Epidemiology Community Health* 64(3), 262-268.
- 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 among Muslim Turkish origin immigrants. *Midwifery* 30, 297-302.
- Gitsels-van der Wal, J.T., Manniën, J., Gitsels, L.A., Reinders, H.S., Verhoeven, P.S., Ghaly, M.M., Klomp, T., Hutton, E.K., 2014b. Prenatal screening for congenital anomalies: exploring midwives' perceptions of counselling clients with religious backgrounds. *BMC Pregnancy and Childbirth* 14, 237.
- Gitsels-van der Wal, J.T., Verhoeven, P.S., Manniën, J., Martin, L., Reinders, H.S., Spelten, E., Hutton, E.K., 2014c. Factors affecting the uptake of prenatal screening tests for congenital anomalies; a multicentre prospective cohort study. *BMC Pregnancy and Childbirth* 14, 264.
- Gitsels-van der Wal, J.T., Martin, L., Manniën, J., Verhoeven, P., Hutton, E.K., Reinders, H.S., 2015. A qualitative study on how Muslim women of Moroccan descent approach antenatal anomaly screening. *Midwifery*, 31, 43-49.
- 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 of Women's Health* 20(1), 73-83.
- Hedayat, K.M., Shooshtarizadeh, P., Raza, M., 2006. Therapeutic abortion in Islam: contemporary views of Muslim Shiite scholars and effect of recent Iranian legislation. *Journal of Medical Ethics* 32(11), 652-657.
- Kithamy, B.A.B., 2013. Divergent views on abortion and the period of ensoulment. *Sultan Qaboos University Medical Journal* 13(1), 26-31.

- 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.
- Martin, L., Hutton, E.K., Spelten, E.R., Gitsels-van der Wal, J.T., van Dulmen, S., 2014a. Midwives' views on appropriate antenatal counselling for congenital anomaly tests: Do they match clients' preferences? *Midwifery* 30(6), 600-609.
- Meiser, B., Irle, J., Lobb, E., Barlow-Stewart, K., 2008. Assessment of the content and process of genetic counselling: a critical review of empirical studies. *Journal of Genetic Counseling* 17, 434-451.
- Mustafa, Y., 2014. Islam and the four principles of medical ethics. *Journal of Medical Ethics* 40, 479-483.
- 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.
- NIPT (non-invasive prenatal test) (in Dutch): www.niptconsortium.nl
- 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.
- Pennacchini, M., Pensieri, C., 2011. Is non-directive communication in genetic counseling possible? *La Clinica Terapeutica* 162(5), 141-144.
- Resta, R.G., 2006. Defining and Redefining the scope and goals of genetic counseling. *American Journal of Medical Genetics* 142C, 269-275.
- RIVM, 2011. Roadmap of prenatal screening [Draaiboek prenatale screening]. RIVM, Bilthoven. (in Dutch)
- Rispler-Chaim, V., 1993. *Islamic Medical Ethics in the Twentieth Century*. Brill, Leiden.
- Shaw, A., 2012. They 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 fetal 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.
- Smets, E., van Zwieten, M., Michie, S., 2007. Comparing genetic counselling with non-genetic health care interactions: two of a kind? Review article. *Patient Education and Counseling* 68, 225-234.
- 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.
- 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)
- Tsianakas, V., Liamputtong, P., 2002. What women from an Islamic background in Australia say about care in pregnancy and prenatal testing. *Midwifery* 18(1), 25-34.
- Vanstone, M., Kinsella, E.A., Nisker, J., 2012. Information-sharing to promote informed choice in prenatal screening in the spirit of the SOGC clinical practice guideline: a proposal for an alternative model. *Journal of Obstetrics and Gynaecology Canada* 34(3), 269-275.
- Verhoeven, N., 2014. Doing research. Den Haag: Boom Lemma p331-337. (in Dutch)
- Vlemminck de, A., Deschepper, R., Foulon, W, Louckx, F., 2012. Experiences and perceptions of Muslim and non-Muslim women during prenatal screening: a comparative study in Flanders and Brussels, Belgium. *Journal of Family Planning and Reproductive Health Care* 38(2), 142-143.
- Wiegiers, T.A., 2009. The quality of maternity care services as experienced by women in the Netherlands. *BMC Pregnancy and Childbirth* 9, 18-22.
- Zwieten van, M.C.B., 2008. The importance of an informed choice, but what concerns the choice? The complex decision-making in prenatal screening. *De Psycholoog* 43, 20-25. (in Dutch)

