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

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# Chapter 1

**General introduction**



## Prenatal anomaly screening

In 1994, the Dutch National Health Council published a report arguing that the aim of prenatal anomaly screening should be to provide future parents with appropriate information about diseases that could potentially be detected and that participation should be strictly voluntary [1]. The Dutch government adopted the Health Council's report and decided on an opt-in approach for the national prenatal anomaly screening programme [2]. The explicit aim of this programme has been to offer future parents the option of an informed reproductive choice, entailing two decisions: 1) whether or not to participate in the screening programme and 2) whether or not to terminate a pregnancy in the event of an anomaly being diagnosed [2]. In the words of the National Health Council's Commission on Genetic Screening, "Genetic screening must enable people to escape fate by giving them the freedom to make an informed choice and adopt a course of action that they regard as acceptable." [1]. The Committee further emphasised access to an appropriate level of care for new-borns and children affected by genetic disorders as a precondition for voluntary participation in the screening programme tests [1]; after all, an inadequate level of care could create an imbalance in the choice between termination of an affected pregnancy and raising a child with a disability. Both arguments – informed choice and voluntary participation – indicate that pregnant women themselves rather than the Dutch government should decide whether or not to have prenatal anomaly screening [1]; an opt-in approach was therefore preferred.

Prenatal screening for congenital anomalies has been offered to all pregnant women in the Netherlands since 2007. The available screening comprises two non-invasive tests: the Combined Test (CT) at twelve weeks' gestation and the Fetal Anomaly Scan (FAS) at twenty weeks' gestation. The CT is a risk assessment for Down's syndrome, Trisomy 21. In 2011, risk assessments for Edwards' syndrome and Patau's syndrome (trisomies 18 and 13 respectively) were added to the CT [3]. The FAS is an ultrasound for detecting structural anomalies. Both CT and FAS potentially require three decisions: 1) to have the screening test, 2) to follow up positive screening results with diagnostic tests that carry an associated 0.5% risk of miscarriage, and 3) when a positive finding is confirmed, to terminate the pregnancy before 24 weeks' gestation or prepare for having a child with an anomaly. The CT is offered free to women aged 36 or above, whereas younger women pay approximately 150 euros. The FAS is offered at no charge to all women.

In the context of prenatal anomaly screening, one important ethical consideration need to be mentioned. Prenatal anomaly screening is covered by the Population Screening Act [2]. A cornerstone of the Population Screening Act is the treatability of a disease. In prenatal anomaly screening, chromosomal disorders such as Down's syndrome are not treatable or curable. Furthermore, population screening is in general aimed at prevention, but prevention

is not the aim of prenatal anomaly screening [4]. After all, the aim of prenatal anomaly screening tests is to offer (future) parents the option of an informed reproductive choice with some possible courses of action in the event of an anomaly being diagnosed [2]. Prenatal anomaly screening therefore has a special status within the Population Screening Act [4,5].

The Dutch opt-in approach to prenatal anomaly screening is not common in European countries. For instance the Down's syndrome screening test is offered free in Denmark to all pregnant women and recommended by the government, which would seem to be an opt-out approach to prenatal anomaly screening [6]. These different approaches result in a big difference in uptake of the CT: around 27% in the Netherlands and 90% in Denmark [6-8]. A recent study comparing Down's syndrome screening policies and programmes among stakeholders in the Netherlands, Denmark and England reveals that the Dutch context of 'the right not to know' and the 'user pays' approach to the CT partly explain the low participation in the CT programme in the Netherlands [6]. Factors such as age, family situation, socio-economic status, ethnicity, personal experiences and religious beliefs also affect the uptake of the CT [9-17]. In the Netherlands, the mean uptake of the FAS is around 91% [7,18], which is a little bit lower than for example in Sweden (99-100%) [19]. No research into factors associated with the uptake of the FAS was available.

## **Counselling for client decision-making on prenatal anomaly screening**

The specific aim of the Dutch policy on prenatal anomaly screening is reflected in the way that counsellors are responsible for providing support for pregnant women in decision-making about prenatal anomaly screening. There is also a strong emphasis on facilitating informed choices by pregnant women or couples about their future child. An informed choice should be "based on relevant knowledge, consistent with the decision-maker's values and beliefs, and behaviourally implemented" [20-22]. In order to facilitate informed choices, client-centred counselling for prenatal screening consequently entails:

- 'health education' (e.g. giving information about prenatal congenital anomaly tests and conditions that could be detected, such as Down's syndrome and spina bifida),
- 'decision-making support' (e.g. exploring the client's personal values and beliefs with regard to disability and termination),
- building a good 'client-counsellor relationship' (e.g. showing "genuine interest" in each individual client) [23-27].

The aim of facilitating informed choices by their clients requires counsellors to be non-directive, not placing even indirect pressure towards one particular choice [1,23,28]. The

counsellors' own views on prenatal anomaly screening and the tests involved should be absent from the counselling process, implying no interference with the clients' decision. The non-directive attitude also implies that counsellors should be respectful to and supportive of their clients' actual decisions [1,6,23,28-30]. Supporting the client's actual decision means helping clients to explore their views on the value of human life, and the value of a life lived with a disability, as well as the value of an unborn life in view of an optional termination of the pregnancy [1,29,30]. This counselling approach, which supports client decision-making in the light of their own values and beliefs, is based on the view that decisions about having prenatal anomaly screening are too private and too overwhelming to be made by anyone other than the client [1,30,31].

## **The role of religion in decision-making on prenatal anomaly screening**

The task of helping clients make decisions in the light of their values and beliefs is the subject matter for this study. As the reasoning behind the decision-making support task indicates, the private nature of the decisions should be respected; however, at the same time, the task of facilitating these decisions using the clients' values and beliefs means that counsellors must be prepared to some extent to be invited into that private domain. A particularly sensitive point in this regard is how counsellors relate to *religious* values and beliefs. The question can be approached from the perspectives of both the clients and their counsellors.

### *Clients' decision-making*

Faced with the option of prenatal anomaly screening, the ultimate question for clients is whether they want to know if their future child will have a congenital anomaly, and if so whether they prefer to raise a child with a disability or to terminate the pregnancy. These are difficult moral questions for which clients can only find answers by digging deeply into their views on life, unborn life and living with a disability. For religious clients, these questions will presumably make them consult their religious values and beliefs [9,11,12,32,33].

Projecting these conjectures onto the Dutch context, the relevant facts are that approximately 50% of the Dutch population have a religious background, and that Christianity and Islam are the two main religions with 44% and 6% adherents respectively among the Dutch population [34,35]. Furthermore, religious beliefs among Christians about the value of human life, unborn life, and living with a disability are generally familiar to healthcare professionals, whereas Islamic views on decisions about prenatal anomaly screening are less well known.

The main issue to be addressed by the present study emerges from that context. In the Netherlands, people with an Islamic background are also a growing proportion of the general population. Most of these families are of Turkish or Moroccan descent, and almost all of them are Muslim [36]. When Muslim women become pregnant and are faced with the option

of participating in prenatal anomaly screening programme, do their religious values and beliefs enter into the decision-making process, and if so how? And what do Muslim women's religious beliefs and their effect on the decision-making process imply for their counsellors? The counsellors are responsible for helping their clients decide, using their values and beliefs: what does that entail? Should counsellors know about Islamic beliefs? Should they ask about Islamic beliefs?

Research has shown that Muslim women's decision to participate in prenatal screening programmes may depend on several factors, of which religion is an important one [9,32]. Pregnant Muslim women generally do not opt for the combined test, often claiming that their faith does not allow termination [32,37]. But the general picture is by no means clear. For example, Lind described a few cases among pregnant Muslim women with a confirmed serious anomaly of the fetus, after which some terminated and some women continued their pregnancy. He suggested that the decisions of these women depended on what their imams said [38]. On the other hand, there are Islamic sources that indicate that under certain conditions termination of pregnancy is officially permitted, as in the case when a fetus is diagnosed with a serious anomaly [39]. Should Muslim women be told about these sources, given the aim of informed decision-making?

#### *Midwives as counsellors*

In the Netherlands, more than 80% of pregnant women start prenatal care in primary care midwifery practices. Primary care midwives are therefore the ones who counsel the majority of pregnant women for prenatal anomaly screening [2,40]. With the implementation of the national prenatal anomaly screening programme in 2007, counselling became a new role that was added to the professional role of midwives. Looking at the three functions of counselling that were distinguished above, midwives have long been familiar with the task of health education, and building good client-midwife relationships has always been part of the profession. But decision-making support was a new function that came with their new role as counsellors for prenatal anomaly screening. Given that they have the task of counselling religious clients, midwives have become familiar with certain religious rituals during pregnancy, birth and the postnatal period (for example whispering a sentence from the Koran right after the birth of the baby). However, exploring clients' religious beliefs and convictions to help their decision-making processes was entirely new for midwives.

A particularly relevant consideration in this connection is the extent of secularisation in the Netherlands. For decades, the prevailing opinion has been that religion is a declining phenomenon that is being driven out of the public domain and into the private domain. This meant among other things that religiously based healthcare organisations have seen their religious identity in decline. Communicating with patients about tests, therapies and treatments against a religious background was no longer self-evidently part of the

interaction between the professional and the client. However, in 2006 the Scientific Council for Government Policy cautiously identified a resurgence of religion in the public domain [34]. Consequently, the experience of being confronted with (unfamiliar) religious beliefs is relatively new for contemporary healthcare professionals. As healthcare professionals in the Netherlands have always worked at the intersection where publicly regulated healthcare services are delivered to private patients, their professional practice is a key location of the resurgence of religious discourse in the public setting. This is particularly true for midwives in their role as counsellors for prenatal anomaly screening and testing.

Although relatively new in the Dutch context, the recognition of religion and religious backgrounds as a potentially important topic in clients' decision-making has been supported in the context of counselling on prenatal anomaly screening. After all, pregnant women's decisions whether or not to participate in the anomaly screening programmes is based on their views on life, unborn life and living with a disability. Several international studies have underlined the role of religion in decision-making in genetic counselling and highlight the importance of having some knowledge of religious beliefs and convictions [41-43]. Reis *et al.* state that "although professionals ought not to assume the role of spiritual advisor, a working knowledge of doctrinal approaches should help counsellors frame the issues, and avoid missteps" [41]. Hasnain *et al.* investigated provision of culturally appropriate and patient-centred care to Muslim women in the US and recommended education for counsellors focused on the basic religious and cultural beliefs of Muslim women [44]. Another study in Australia about prenatal testing services for Muslim women explored miscommunication between pregnant women and the midwives, which was partly due to "a lack of cultural appreciation among healthcare providers" [45]. For example, pregnant women felt that even where they understood the language properly, midwives asked interpreters in simply because the pregnant women were wearing scarves [45]. A qualitative Canadian study of maternity healthcare looking at the needs of immigrant Muslim women found that women perceived insensitivity and lack of knowledge about their religious and cultural daily life [46]. Other studies have confirmed that professional knowledge of religious and cultural backgrounds of the clients is important, but insufficient [37,47-50].

In view of this literature, the present study explores the issue of religious values and beliefs in the context of counselling for prenatal anomaly screening and testing in the Netherlands. The study researches the opinions of both Muslim women and the midwives who act as their counsellors. It also researches how Muslim women understand the role of religion in the decision-making process. Although most couples want to decide together whether or not to take prenatal anomaly screening tests [51,52], in our study we were interested in women's decision-making and preferences for appropriate counselling and we therefore only interviewed Muslim women and not their partners. The findings will extend the knowledge of the use of religious information in the context of prenatal screening, as part of a professional



practice offered in the public domain. This knowledge will contribute to how the notion of informed choice is currently understood within the practice of counselling, and whether providing religious information is regarded as legitimate part of it. The significance of the project for midwifery counselling in the Netherlands is in its focus on what aiming to give Muslim clients at an informed choice demands, in terms of engaging with their views on human life, unborn life and living with a disability. This knowledge will help to further improve of client-centred counselling.

## **Study design**

This research project is part of the DELIVER study, a unique multi-centre prospective dynamic cohort study to evaluate primary care midwifery in the Netherlands [53]. The main focus of this first nationwide study is on quality, organisation and accessibility of primary care midwifery. It aims to contribute to evidence-based practice and improve midwifery care in the Netherlands [53]. Purposive sampling was used to select practices, using three stratification criteria: region (north, east, south, west), level of urbanisation (urban or rural area), and practice type (dual or group practice); in total, 7685 clients and 136 midwives and assistants from 20 primary care midwifery practices participated in the DELIVER study (for detailed information of the study design, see [53]). As part of the contribution to evidence-based practice in midwifery, in addition to this thesis, several sub-studies were embedded in DELIVER. These included pain management during labour, lifestyle during pregnancy and midwives' and clients' preferences about counselling on prenatal anomaly screening. A video observational study that focused on the first prenatal consultation was added to the DELIVER study.

Regarding this thesis, data from the DELIVER to study that has been used concerns questionnaires completed by midwives and by clients from 20 primary care practices across the Netherlands between August 2009 and March 2011. Regarding the qualitative part of the thesis, 22 retrospective open interviews with pregnant Muslim Turkish and Moroccan women were conducted in 2008 and 2011-2012 respectively.

## **Aims of the thesis**

Because of the lack of research into the role of religion in decision-making on prenatal anomaly screening in the Netherlands, the overall aim of this thesis is to gain insights into the role of pregnant women's religious backgrounds in their decisions whether or not to have the prenatal anomaly screening tests (the Combined Test and the Fetal Anomaly Scan). The first aim of the thesis is to determine what factors are associated with the uptake of both prenatal anomaly screening tests. The second aim is to explore pregnant Muslim women's

views on life and the religious beliefs that they state are relevant for their decision-making, and to explore pregnant Muslim women's preferences as to what constitutes appropriate counselling on prenatal anomaly screening, also in the light of their religious beliefs. The third aim is to explore the extent to which counsellors take the religious backgrounds of their clients into account and to explore their knowledge about termination according to Islamic beliefs.

## Outline of the thesis

To understand the differences in uptake, **Chapter 2** describes a nationwide cross-sectional study to assess the uptake of the Combined Test and the Fetal Anomaly Scan and what factors have influenced the uptake of each of the two tests. Background characteristics of pregnant women were used to determine possible associations with the uptake of the tests.

In order to understand the possible influence of religious background and individual perspective on the value of unborn life and disabled life on the decision to have prenatal anomaly screening, **Chapter 3** investigates in depth what role religious beliefs play in decision-making on prenatal anomaly screening among pregnant Muslim women. Because migrants from Turkey are the largest minority with an Islamic background in the Netherlands, pregnant Turkish Muslim women were interviewed.

How Muslim women from different countries of origin and different Islamic schools approach prenatal anomaly screening is discussed in **Chapter 4**, where the research was extended by including Muslim women of Moroccan descent (being the second largest Muslim minority in the Netherlands).

As described in **Chapter 5**, the same pregnant Muslim Moroccan women were also interviewed to determine their preferences for the content and approach to prenatal counselling for anomaly screening and their preferences for the counsellor's knowledge of Islamic beliefs related to decision-making on anomaly screening.

**Chapter 6** explores the ways counsellors include the role of religion in their practice. Their knowledge of Islamic beliefs about termination of pregnancy, the extent to which counsellors think that they should take the client's religious beliefs into account during counselling and the extent to which they actually do so, plus other factors related to taking client's religious beliefs into account are all described in this chapter.

Finally, **Chapter 7** summarises the main results of this thesis, discussing them and placing them in a broader context. This chapter also presents the resulting practical implications and recommendations for future research.

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