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Chapter 7

General discussion

The overall aim of this thesis was to gain insights into the role that pregnant women's religious backgrounds have in their decision whether or not to have the prenatal anomaly screening tests, the combined test (CT) and the fetal anomaly scan (FAS). 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 aspects of pregnant Muslim women's views on life and religious beliefs that they say are relevant for their decision-making, and to explore what pregnant Muslim women see as 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 background of their clients into account and to explore their knowledge about termination according to Islamic beliefs.

Brief summary of the findings

The mean uptake figures for the CT and FAS among the study population were 23% and 90% respectively (**Chapter 2**). Factors independently associated with the CT uptake were age, religious (Protestant) background, ethnicity, income, parity and region. Factors independently associated with the FAS uptake were religious (Islamic or Protestant) background, income, education and parity. Significant differences between CT and FAS uptakes amongst the twenty midwifery practices can be seen in the range of 4% to 48% for the CT uptake and 62% to 98% for the FAS uptake.

One year after the implementation of the screening programme in the Netherlands, interviews among pregnant Muslim Turkish women demonstrated that women's views on life, disability and termination were key in decision-making on prenatal anomaly screening (**Chapter 3**). Women viewed life, including disabled life, as sacred and 'God-given', and did not consider termination as an option in the case of a congenitally affected child. Women mentioned contraception as the way of preventing the birth of a disabled child. Hardly any of the women knew the aim of the FAS. Five years after the implementation of the screening programme, interviews among pregnant Muslim Moroccan women demonstrated that their views on termination were more clear-cut regarding opting for the CT (**Chapter 4**). These views on termination were based on their individual religious beliefs, and were inseparably linked with their views on disability and on the value of life. Additionally, motherhood was the lens through which women looked at the decision whether or not to have the screening tests. Women approached the CT and the FAS entirely differently. Less than half the women knew the aim of the FAS. Women stressed the importance of taking their own individual decision as in the end they were accountable for their choices.

Pregnant Muslim Moroccan women preferred counsellors who: 1) accurately inform them about the test procedures and the anomalies that could be detected; 2) initiate discussions about moral topics, such as disability and termination, and their relationships with their individual values and beliefs with the aim of helping them to make their own autonomous decision; 3) know about Islamic beliefs regarding the value of life, disabled life and termination (**Chapter 5**). Furthermore, women also wanted to be treated respectfully as individuals and not as *the* clichéd submissive Muslim woman.

Two thirds of the participating counsellors stated that they did actually pay attention to the client's religious background (**Chapter 6**). The two main reasons for not doing so were that religion was seen as unrelated to client's decision-making process, and that the onus was on the client to bring her religion into the counselling dialogue. The participating midwives had limited knowledge about the termination of pregnancy according to Islamic doctrines.

General discussion

For a general discussion we will take a broader look at the findings and conclusions of the five studies together regarding decision-making on and counselling for prenatal anomaly screening. Five subjects will be discussed: 1) registration of CT and FAS uptake, 2) 'escaping your fate', 3) different approaches to decision-making between the CT and the FAS, 4) religion in the public domain, and 5) new developments in prenatal anomaly screening.

1. Uptake of the CT and FAS: importance of national registration

We examined which socio-demographic factors were associated with the uptake of prenatal congenital anomaly screening tests in a low-risk population. This provided a unique insight into the similarities and differences between the uptakes of the two tests in the study. The results demonstrated that religion is one of the independently significant factors associated with CT and FAS uptake (Chapter 2); later in the discussion, the differences in CT and FAS uptake will be explained by differences in the decision-making approaches used by Muslim women. The added value of our study compared to other Dutch studies in prenatal anomaly screening is twofold [1-4]. Firstly, our study is the first that gained insights into factors associated with the FAS uptake and compared the outcomes to factors associated with the CT uptake. Secondly, our study is the first study that examined the uptake of the CT and FAS *nationwide* [5]. Our study among primary care midwifery practices reveals differences in CT and FAS uptake among the four regions in the country; furthermore, our study reveals huge differences in the CT and FAS uptake among the midwifery practices involved in the study. So, in addition to client-related socio-demographic factors associated with the CT and FAS uptake, midwifery practices also influenced clients' participation in the CT and FAS. The latter

could imply an inequality of access to the tests. After all, clients' decisions whether or not to have the tests may be related to how they are offered, which makes our findings relevant for policy development. Moreover, in a video observational study of counselling for prenatal anomaly screening, Martin *et al.* found clustering of data among counsellors; it is therefore likely that the CT and FAS uptake is more dependent on particular counsellors than on the particular midwifery practices that offer the tests [6]. Further research is needed to examine this hypothesis and the underlying causes, and nationwide registration of the actual CT and FAS uptake could be a helpful tool. In this regard, it is important to note that self-reported uptake by pregnant women is probably not the most reliable method for collecting data. We therefore plead for a reliable method that represents the actual uptake of the CT and FAS nationwide. Since 2011, Peridos has registered all CT and FAS examinations performed nationwide in the Netherlands. However, this system is not yet functioning as well as it could; the latest report showed that Peridos covered less than 10% of all pregnancies and is thus not a reliable representation of the uptake practice in the Netherlands [7].

2. Different approaches to decision-making between the CT and the FAS

The significant differences in the deliberations and decision-making of the Muslim women interviewed between having the CT and the FAS translates not only into a relatively low CT uptake and a relatively high FAS uptake, but also into questionably informed choices about the FAS. It seems that having the CT is on an opt-in basis whereas having the FAS uses an opt-out approach.

The Muslim women interviewed saw the CT as a deterrent test and they deliberated extensively about whether or not to have it. Being able to terminate a pregnancy in the case of a child with Down's syndrome resulted in deliberations about disability and termination linked to women's religious beliefs, and seemed to be the reference point for whether or not to participate in the CT programme. As in other Dutch studies, hardly any of the women interviewed thought Down's syndrome was severe enough to terminate and these views on Down's syndrome were reflected in a low CT uptake [4,8]. Conversely, the women interviewed hardly deliberated whether or not to have the FAS and saw it as "*a nice opportunity to see the baby*". This was reflected in the high uptake of the test. And the option to terminate an affected pregnancy was not considered at all in decision-making about participation in the FAS programme. The result that one of the main reasons for pregnant women taking the FAS is the opportunity to see their child is confirmed by several other studies [9-13]. Additionally, in the Netherlands the FAS is generally the only second trimester scan and the last scan in prenatal care, which makes the FAS particularly attractive. The fact that women mainly participate in the FAS because they want to see the baby does not necessarily have to be problematic. What should be regarded as problematic, however, is that clients' knowledge of

the aim and voluntary nature of the FAS and the options after diagnostic tests is insufficient [14-18]. In that case the decision-making is arguably not based upon an informed choice. A striking point was our finding that hardly any of the women interviewed knew the purpose of the FAS, even five years after the implementation of the screening programme. Therefore, to enable clients to make informed reproductive choices, counsellors should ensure that their clients fully understand the aim and possible consequences of the tests [19]. Taken as a whole, all the findings listed above give the impression that participation in the CT appears to be the result of an opt-in approach. Conversely, participation in the FAS programme appears to be the result of an opt-out approach, which contradicts the policy on prenatal anomaly screening (aiming for an opt-in approach) [14,15]. An explanation of the opt-out approach for the FAS may probably be found in the counsellors, who give pointers as to whether or not to take the FAS. Although the FAS was offered during the study period only as a scan to detect structural anomalies, fetal and placental measurements happened to be recorded at the same time. Fetal growth measurements and placenta evaluation during the second trimester ultrasound can detect fetal growth restrictions that may cause preterm birth and perinatal death; abnormalities of the placenta may cause serious complications such as fetal growth restriction, preterm birth and preeclampsia [20-23]. Because of this obstetric importance, it is conceivable that midwives in their role as care-givers encourage clients to take the FAS. The daily practice in counselling about the FAS in the Netherlands, in which midwives are the counsellors, reveals a dilemma. On the one hand, counsellors in their role as midwives benefit from their clients participating in the FAS programme in the context of quality of care, because of the obstetric importance prenatally and during labour; therefore, counsellors could be encouraging the FAS in an opt-out approach. On the other hand, those same counsellors have to offer the FAS following an opt-in option and should refrain from giving advice as they should be adopting a non-directive attitude.

3. **Decision-making to escape your fate: post-conception or pre-conception**

The aim of counselling in prenatal anomaly screening as expressed by the Dutch Health Council's Committee on Genetic Screening is to "enable people to escape their fate by giving them the freedom to make an informed choice and adopt a course of action which they regard as acceptable." [14]. The word 'fate' as used by the Committee (in Dutch: *noodlot*) has negative connotations and should be read here as a blind, random force of nature that human beings have a natural tendency to want to escape. In contrast, the word 'fate' or 'destiny' as used by the Muslim interviewees has a religious connotation (in Dutch: *lot*). The basic profile of the Muslim identifies six official tenets: believe in the One God, angels, the holy books, the prophets, the afterlife and providence [24]. The Islamic image of God is based on these six tenets of faith, part of which is that God is the creator of Man and the universe; God creates, supervises and intervenes in human life, from the foetus through to passing

away, and creates the human responsibility for dealing with this life [24]. The Islamic meaning of 'fate' is usually interpreted as God's plan for your life, and may entail both 'good' things as a blessing and 'bad' things as a test [25]. From an Islamic perspective, the task of raising a child with an anomaly is part of your destiny and disabilities or anomalies are viewed as part of the human condition that some people have to face. At any rate, it is not seen either as a curse or as a divine punishment for the sins of the parents [25-27]. Finally, in monotheistic religions such as Islam motherhood *per se* is viewed as a blessing and reproduction is taken to be a divinely designed duty [28,29], which is just as valid if the child you are carrying has a disability.

The background of Islamic beliefs outlined above is linked to the ethical notion that decision-making on prenatal anomaly screening during pregnancy and avoiding the births of disabled children is problematic [30]. Prevention of an affected fetus is impossible, which leaves preventing the birth of an affected child by termination of pregnancy as the only option. From the perspective of motherhood, Islamic women generally view termination of pregnancy as illegitimate killing of their child; the same view is held by many orthodox Jewish and Christian women. On the other hand, preventing disabled children being born is not considered as problematic in the pre-conception phase; the use of contraception can be a legitimate way of preventing the conception of a congenitally affected child. The women interviewed emphasised that it is a woman's responsibility to prevent pregnancy if she doesn't want to have a (disabled) child, and they proposed the opportunity of family planning. Remarkably, when speaking of contraception, women used the word 'protection' instead of 'contraception'. 'Protection' is a term that indicates one side of the religious ambiguity of carrying a child with a disability. It is a bad thing that can happen, and protecting yourself against it at the pre-conception stage is not a religious offence. Should it nonetheless happen, however, it will be regarded at the post-conception stage - at least among Muslims - as a divinely ordained task. To enable people in their fertile phase of life to make informed choices in this regard, it is important to inform and educate young people at an early stage about genetic diseases, genetic screening and prenatal anomaly screening [14,31].

In the context of carrying a child with a disability, two important footnotes have to be mentioned about Muslim women's predominant view that termination is forbidden by Islam. Firstly, Islamic rulings permit termination of pregnancy in cases of confirmed serious anomalies before 19 weeks plus one day of gestation [32]. Recently Muslim scholars in embryology and neonatology recommend that affected fetuses should be detected at the earliest possible point in pregnancy to enable Muslim women to terminate pregnancy before 19 weeks' gestation [33]. To enable Muslim women in the Netherlands to make informed choices, the timing of the FAS should be reconsidered. If it is performed around 17 weeks' gestation, the option of termination may only be open for two more weeks.

Secondly, Muslim women can also consider a termination for personal or medical reasons, i.e. aside from religious beliefs [34,35]. Our findings therefore lead to a recommendation that, in order to facilitate decision-making based upon informed choices, counsellors should at least have some elementary knowledge of Islamic beliefs about moral issues regarding decisions on prenatal anomaly screening.

4. **Counselling: religious beliefs in the public domain**

As values and beliefs are the key components when clients decide whether or not to participate in prenatal anomaly screening programmes, this implies – in the case of religious values and beliefs – that counselling for prenatal anomaly screening constitutes an example of how religion impinges upon prenatal care services within the public domain. As this study has shown, exploring clients' values and beliefs is officially acknowledged in this context as one of the three counselling functions when offering decision-making support [17,19,36]. For client-centred counselling of religious women or couples, this means that taking clients' religious background into account is not optional for the counsellors.

About one third of the counsellors in our study did not take the client's religious background into account during counselling. There were two main reasons for this (Chapter 6). The participating midwives felt firstly that religion is irrelevant in decision-making about anomaly screening and secondly that if clients think their religious values and beliefs are relevant, it is their own responsibility to make them known and they can then be taken into account. One rationale for counsellors' opinion that women should initiate the discussion on religious beliefs could be that they viewed discussions related to religious beliefs as inappropriate in midwifery care. For decades the prevailing opinion in Dutch society has been that the role of religion is being pushed back from the public domain into the private domain [37]. However, at the time of the implementation of the prenatal anomaly screening programme, a resurgence of religion in the public domain was identified; it was therefore not surprising that counsellors in our study who take clients' religious background into account were younger than those who did not pay attention to it [37].

Another rationale for the older generation of counsellors maintaining that the onus is on the woman to bring religion into the discussion could be that they felt unfamiliar or uncomfortable discussing topics related to religious beliefs because they lacked the relevant knowledge about Islamic beliefs. While questions such as *"Are you a believer?"* followed by *"What would religion mean to you in the context of prenatal screening tests?"* may not feel familiar to these counsellors, they could be helpful to start the discussion on the role of religious beliefs in decision-making on prenatal anomaly screening.

At the very least, this thesis demonstrates the important role of religious beliefs in Muslim women's decision-making about prenatal anomaly screening. In view of this finding, the secular opinion of a substantial proportion of the counsellors involved in the study – saying that religious beliefs are irrelevant to decisions on prenatal anomaly tests – is debatable, given the fact that 50% of the Dutch population have a religious background [38]. Greater reason for concern, however, is the recent finding by Martin *et al.* that of 1416 Dutch midwives, only half felt clients' standards, values and views to be important [6]. Because addressing their values and beliefs is acknowledged to be inherent to clients being able to make decisions based on informed reproductive choice, this task should not be subject to counsellors' personal convictions, but is part of their professional task. In order to facilitate informed reproductive choice in a client-centred approach, it therefore follows that counsellors cannot dismiss the question of how to initiate discussion of religious beliefs, as this turns out to be part of exploring clients' values and beliefs.

The study described in this thesis explored whether counsellors said that they take clients' religious backgrounds into account, as well as exploring the reasons for not doing so. Because it was based on a questionnaire, the study did not involve direct observations of whether and how counsellors take the client's religious background into account in daily practice. As part of the DELIVER study, however, over 300 counselling consultations were videotaped in six primary care midwifery practices distributed throughout the country [39]. Preliminary results of the video observational study show that counsellors took clients' religious backgrounds into account in only 5% of the videotaped counselling sessions, whereas approximately 50% of the clients had a religious background. These preliminary results suggest that counsellors probably take the client's religious background into account much less in daily practice than the self-reported figure for paying attention to the client's religion during counselling, i.e. approximately two thirds in our exploratory study.

5. Recent developments in the practice of prenatal anomaly screening

In April 2014, the Non-Invasive Prenatal Test (NIPT) was added to the prenatal anomaly screening programme in a nationwide study setting [40]. During the study, pregnant women can only choose to have the NIPT when the result of the CT has shown a risk of 1 in 200 or higher for trisomy 13, 18 or 21 (see Chapter 5, Figure 1). Another change in the Dutch prenatal anomaly screening programme is that from January 2015 onwards, all pregnant women (irrespective of age), who choose to have the CT will have to pay 160 euros for the CT out of their own pockets [41]. The implicit message of all women having to contribute seems to be that current thinking – that women under 36 are hardly at risk of becoming pregnant with a child with Down's syndrome – has become obsolete. On the other hand, this co-payment could create a barrier to *all* women against having a CT (Chapter 2). The rate of

CT uptake will then be influenced by women's social economic status, which might result in inequality of access to the CT (Chapter 2). Research has shown that women will be more likely to choose the NIPT than the CT [42], but at present women must take the CT first before they can opt to take the NIPT. If it turns out that the rate of CT uptake decreases among older women because of the co-payment, the number of children born with Down's syndrome might be expected to increase. Whether or not this effect will actually occur remains to be seen however. After all, whether or not to terminate a congenitally affected pregnancy will remain the most important question to future parents, both religious and non-religious.

To conclude

Values and beliefs based on women's religious backgrounds play a role in deciding whether or not to have the CT, but they do not play a role in the FAS. Pregnant Muslim women of Turkish and Moroccan origin prefer counsellors to initiate exploring and discussing women's values and beliefs about participation in anomaly screening programme, thereby aiming to facilitate informed reproductive choice. While many midwives said that they do take the client's religion into account, counsellors need more knowledge of religious views related to decision-making on anomaly screening and the skills to approach religious issues with clients. As women's religious values and beliefs are relevant in their decisions on participation in anomaly screening programmes, and because women prefer counsellors who address their values and beliefs, religion has a place not only in the private domain, but also in the public domain, such as counselling for prenatal anomaly screening in healthcare.

Recommendations

As a result of our findings, we propose a set of recommendations for counselling practice. We recommend that counsellors:

- ensure that their clients fully understand the aim of the test and the test procedures;
- initiate discussion on clients' religious beliefs during decision-making support;
- avoid stereotyping based on religion or ethnicity and are aware of individual choices, and thus tailor counselling to the individual client.

Recommendations for midwifery training are education about religious beliefs regarding the value of life, unborn life, disabled life and termination. These are needed for a meaningful implementation of the client-centred approach to counselling for prenatal anomaly screening. We also recommend training to explore clients' values and (religious) beliefs relating to making decisions about anomaly screening. To let Muslim women make informed choices, we recommend a revision at the policy-making level of the timing of the FAS, prior to 19 weeks of gestation.

Future research

Our nationwide study revealed a large range in the CT and FAS uptakes among the practices; to ensure that every woman has equal access to prenatal anomaly screening, future research is needed to uncover the underlying causes. Research among Muslim women who decline the FAS is needed in order to understand their reasons for not having the FAS. To meet the needs of religious women, further research is needed as to why some midwife counsellors do not see religious beliefs as a relevant component in clients' decision-making during antenatal counselling.

We hope that the present thesis will contribute to the discussion about offering prenatal anomaly screening tests in a multicultural but secular society in which people of different religions participate. The thesis could also contribute to rethinking the role of professionals in client-centred healthcare with regard to the recognition of religious and ethnic diversity.

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