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2015

document version

Publisher's PDF, also known as Version of record

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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].

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Chapter 8

Summary & Samenvatting

Chapter 1 *General introduction*

The general introduction describes the rationale and aims of the present study. Prenatal anomaly screening has been offered to all pregnant women in the Netherlands since 2007. The 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, Edwards's syndrome and Patau's syndrome (trisomies 21, 18 and 13 respectively). The FAS is an ultrasound for detecting structural anomalies. The aim of a prenatal anomaly screening programme is to offer future parents the option of an informed reproductive choice. Whether or not to participate in prenatal anomaly screening tests, the Combined Test (CT) around 12 weeks' gestation and Fetal Anomaly Screening (FAS) around twenty weeks' gestation, will partly be based on pregnant women's or couples' values and beliefs about life, unborn and disabled life, and termination. After all, the ultimate question for pregnant women or couples is whether they want to know if their future child will have a congenital anomaly, and if so whether they would prefer to raise a child with a disability or to terminate the pregnancy. Religious women's values are grounded in their religious beliefs. Dutch counsellors' can be presumed to know about Christian and Jewish perspectives on life, disabled life and termination, but knowledge of Islamic perspectives on issues about deciding whether or not to participate in anomaly screening is not a given. Although midwives are familiar with discussing ritual religious topics such as circumcision with their clients, they are not familiar with discussing moral religious issues and it was not known if midwives take clients' religion into account in their role as counsellors. Furthermore, the prevailing opinion for decades 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 communication about tests, therapies and treatments in the light of a religious background was no longer self-evidently part of the interaction between the professional and the client.

The overall aim of this thesis is therefore 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 CT and the FAS. The first aim of the thesis is to determine which 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 religious beliefs that are relevant to deciding whether or not to participate in prenatal anomaly screening tests, and to explore pregnant Muslim women's preferences for appropriate counselling on prenatal anomaly screening. 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.

Chapter 2 *Factors affecting the uptake of prenatal screening tests for congenital anomalies; a multicentre prospective cohort study*

We performed a nationwide cross-sectional study to assess factors associated with the combined test (CT) and fetal anomaly scan (FAS) uptake. This study among 5216 pregnant women in twenty midwifery practices in all regions in the Netherlands, part of the DELIVER study, demonstrated a mean uptake for the CT and FAS of respectively 23% and 90%. Factors independently associated with the CT uptake were age, religious background, ethnicity, income, parity and region. Women were less likely to have the CT if they identified themselves as Protestant, were multiparous and living in the Eastern part of the Netherlands. Women were more likely to have the CT if they were older, had a non-Dutch ethnic background and had above average income. Independent factors associated with the FAS uptake were religion, income, education and parity. Women were less likely to have the FAS if they identified themselves as Protestant or Muslim and were multiparous, whereas women were more likely to have the FAS if they had higher incomes and were more highly educated. Because the two tests have the same aim, i.e. detecting anomalies, and offer the same possibilities after a diagnosed affected fetus, i.e. termination of pregnancy or preparing to have a disabled child, we expected that similar factors would be associated with both the CT and FAS. However, age, ethnicity and living in the eastern part of the country were associated with the CT uptake but not with the FAS uptake, and education and being Muslim were associated with the FAS uptake and not with the CT uptake. One striking element was the large differences in CT and FAS uptake among the twenty practices, with a range of 4% to 48% for the CT uptake and a range of 62% to 98% for the FAS uptake. The three practices with the lowest CT and FAS uptake were in the Dutch Bible Belt. 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.

Furthermore, we examined factors associated with uptake of the tests among women with non-Dutch ethnic backgrounds, dividing this subgroup into women with western and women with a non-western non-Dutch ethnic backgrounds. The mean uptake for the CT and FAS among women with a *western* non-Dutch background was 35% and 94% respectively, and for women with a *non-western* non-Dutch background 24% and 84% respectively. We found that factors associated with the uptake of the tests differed between these subgroups. For instance, limited proficiency in Dutch was associated with a higher uptake of the CT test among women with a *non-western* non-Dutch background but did not play a role in the uptake of the CT test among women with a *western* non-Dutch background.

Chapter 3 *The role of religion in decision-making on antenatal screening of congenital anomalies: a qualitative study among Muslim Turkish origin immigrants*

Religious beliefs and individual perspectives on life, unborn life, disabled life and termination are values that can influence women's decision-making whether or not to participate in prenatal anomaly tests. One year after the implementation of the screening programme in the Netherlands, ten in-depth interviews with pregnant Muslim women of Turkish origin aimed to explore the role of religious beliefs and individual values whether or not to have the CT and FAS. Views on life, disability and termination based on women's religious beliefs were key in decision-making on prenatal anomaly screening. Women viewed life – including disabled life – as sacred and 'God-given' and therefore they did not consider termination as an option in case of an affected child. Women mentioned contraception as the way to prevent the birth of a disabled child. At the time of the interviews, the women were unaware of Islamic jurisprudence regarding permissibility of termination in cases of serious anomalies being diagnosed. Religious convictions played a role in women's decision-making whether or not to participate in the CT, but the women did not all act in the same way. Although none of the women considered a termination in case of a disabled child, some (four) women had the CT because they wanted to be prepared in the case of Down's syndrome. All women had the FAS, but hardly anyone knew the aim of the FAS.

Chapter 4 *A qualitative study on how Muslim women of Moroccan descent approach antenatal anomaly screening*

Five years after the implementation screening programme and four years after the aforementioned study among pregnant Turkish women, twelve open interviews were held with pregnant Moroccan women, aiming to understand how these Muslim women approach prenatal anomaly screening. Two women had the CT and all women had the FAS. As in our study among pregnant women of Turkish origin, pregnant Muslim Moroccan women's views on termination were more decisive regarding opting for the CT. These views on termination were based on their individual religious beliefs and inseparably linked with their views on disability and on the value of life. Additionally, the privilege of motherhood or becoming a mother appeared to outweigh any perceived burden of bearing a disabled child. Motherhood was the lens through which women approached decision-making on whether or not to participate in the screening tests. Women approached the CT and the FAS entirely differently. The women seemed to view the CT as a deterrent test and the FAS as an attractive ultrasound examination. Nearly all the women thought of the CT as a test that could potentially detect Down's syndrome, and could result in them being offered termination of the pregnancy; a fact that resulted in their extensive deliberations and hesitation. And although some women were aware of the Islamic ruling that permits termination in cases of serious anomalies before the *ensoulment*, this ruling did not appear to play a role in the extensive deliberations on

whether or not to take the CT. In contrast to the CT, women viewed the FAS as an opportunity to see their child, and the decision to take the FAS was not at all focused on the possibility of pregnancy termination after an adverse outcome. Most of all, in deciding whether or not to participate in the CT, women stressed the importance of taking their own individual decision as in the end they were accountable for their choices.

Chapter 5 *Antenatal counselling for congenital anomaly tests: pregnant Muslim Moroccan women's preferences*

The same Moroccan women as in the aforementioned study were interviewed to obtain insights into the preferences of Muslim women regarding the content and approach to prenatal counselling for anomaly screening tests and to define women's preferences for the counsellor's knowledge of Islamic convictions. The interviewed Muslim Moroccan women preferred a counsellor who would accurately inform them about the test procedures and the anomalies that could be detected, and who put moral topics on the counselling agenda in order to facilitate a deliberate, consciously made and informed choice about prenatal anomaly screening. The interviewees preferred a non-directive approach in the counselling, not wanting to be advised whether or not to take the tests. The women interviewed also preferred a counsellor to initiate discussions about moral topics, such as disability and termination, and their relationships with their own individual values and beliefs, with the aim of empowering them make their own autonomous decision. Women therefore preferred a counsellor who knows Islamic beliefs regarding the value of life, disabled life and termination. The interviewees also preferred to be treated respectfully and as individuals and not as stereotyped Muslim women. Because some women perceived the content of the counselling as somewhat threatening, women also preferred the counsellor to speak clearly and calmly and take plenty of time to reduce anxiety.

Chapter 6 *Prenatal screening for congenital anomalies: exploring midwives' perceptions of counselling clients with religious backgrounds*

A quantitative exploring study among primary care midwife counsellors in the twenty participating DELIVER study practices aimed firstly to assess counsellors' perceptions and practices about taking clients' religious backgrounds into account during counselling on anomaly screening and secondly to assess counsellors' knowledge of whether termination of pregnancy is allowed in Islam. Of the 98 participants, 75% said that midwives should take clients' religious views into account during counselling, and 68% stated that they did actually pay attention to the client's religious background. The three main reasons for not taking the client's religious background into account were that religion was seen as unrelated to client's decision-making process, that the onus is on the client to bring her religion up in the counselling dialogue and that taking client's religious background into account is not

necessary because of client's decision whether or not to participate in the screening tests is autonomous. The participants had some knowledge about the termination of pregnancy according to Islam doctrines. Although the midwives with a higher percentage of Muslim clients (more than 9%) had more knowledge of Islamic attitudes to terminating pregnancy in general than midwives with a lower percentage of Muslim clients, the specific knowledge of termination with regard to Down's syndrome and other congenital anomalies was limited in both groups. Finally, the majority of midwives (65%) needed additional education about religious beliefs with respect to counselling on prenatal anomaly screening tests.

Chapter 7 *General Discussion*

Finally, the general discussion of this thesis offers a brief overview of the main findings, discusses a number of higher-level topics related to the main findings and ends with recommendations for practice and further research.

As far as we are aware, our study into the actual uptake of the CT and FAS in the Netherlands is the first *nationwide* study as well as the first study into factors associated with the FAS uptake. We would like to make the case for a reliable method that represents the actual uptake of both tests nationwide, e.g. properly functioning national registration of the uptake. The Muslim women interviewed showed significant differences between the deliberations and decision-making for the CT and those for the FAS which translates not only into a relatively low CT uptake and a relatively high FAS uptake, but also into questionably informed choices about participating in the FAS. It seems that having the CT is on an opt-in basis whereas having the FAS uses an opt-out approach.

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 the exploration and discussion of women's values and beliefs about participation in anomaly screening programme, thereby aiming to facilitate informed reproductive choice. While many midwives in their role as counsellors said that they do take the client's religion into account, counsellors need to know more about religious views related to decision-making on anomaly screening and need the skills to approach religious issues with clients. As women's religious values and beliefs are relevant in their decisions about 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.