Dutch Moroccan and Turkish consanguineously married women and their perspectives on preconception carrier screening and reproductive choices
7.1 Introduction

In the Netherlands, preconception screening (PCS) is offered and studies are conducted to assess preferences for targeted carrier screening among Jewish groups and, more recently, among genetically isolated communities (Holtkamp, Van Maarle, Schouten, Dondorp, Lakeman and Henneman, 2016; Mathijssen, Henneman, Van Eeten-Nijman, Lakeman, Ottenheim, Redeker, Ottenhof, Meijers-Heijboer and Van Maarle, 2015). When partners carry a same genetic mutation for autosomal recessive disorders they have a 1 in 4 chance of having an affected child. Consanguineous couples (e.g. 1st or 2nd cousins) more often have identical DNA inherited from a common ancestor. Hence, they are a target group for preconception carrier screening (PCS) also for rare diseases beyond already identified and highly prevalent recessive disorders such as thalassemia (Teeuw, 2015; Hamamy). In the Netherlands, where this most frequently concerns couples of Moroccan and Turkish descent, consanguinity is a sufficient indication for genetic counseling (Teeuw, 2015). Disseminating genome-based information to an ethnically diverse audience demands reflection on intercultural communication and ethical questions. Besides, genetic technology can affect women differently than men as women feel, and are held, more responsible for the well-being and health of children than their partners (Van Berkel and Klinge 1997). Not much is known about the perspectives of consanguineously married Turkish or Moroccan women on screening, counseling and the reproductive options that are available to them. Currently, improved risk assessment tools are being developed to identify larger numbers of pathogenic mutations (including rare mutations) and differentiate between high-risk and low-risk couples (Teeuw, 2015). For this study, we have considered the most common reproductive options that follow upon an unfavorable outcome of PCS: (1) refraining from having children; (2) termination of pregnancy (TOP) after prenatal genetic diagnosis (PND); (3) in vitro fertilization (IVF) combined with Pre-Implantation Genetic Diagnosis (PGD); (4) in vitro fertilization with a donor egg cell; (5) artificial insemination with donor sperm (AID); (6) adoption, or (7) not taking any special measures and/or preparing for the possibility of having a disabled child.

Turkey and Morocco are both populated by Islamic majorities (Storms and Bartels 2013). An important perceived advantage of such marriages is the security for women and children by strengthening of family ties (Bittles and Black 2010; Storms and Bartels 2015; Kilshaw, Al Raisi and Alshaban, 2015). Although the discussion on medical risk for offspring in the case of marrying within the family is widespread, genetic literacy is low (Giordano, Dihal and Hartevelt 2005; Van der Pal, Van Kesteren, Van Dommelen, Detmar 2009; Storms and Bartels 2013). Besides, these groups hardly perceive or accept a medical risk, or do not consider that risk a reason to refrain from family marriages. Medical risk is not prioritized, as it is often considered just one of many risks in life or it is framed in terms of fate (Storms and Bartels 2015).

In the Netherlands, 80% of Turkish and Moroccan migrants (who make up about 11% of the Dutch population) marry a within-ethnic group partner (Statistics Netherlands 2010; Van Agtmaal-Wobma 2009). The prevalence of consanguineous marriages among these groups is about 20-25% (Waelput and Achterberg 2007). In the general population, a couple’s statistic risk of having offspring with a hereditary/congenital disorder is 2-3%, whereas on average first cousin couples have an additional 2-3% risk, thus 4-6%. However, only a minority (10-
12%) of consanguineous couples have an increased risk of 25% or higher and thus the other 80% has a similar risk as non-consanguineous couples (Teeuw 2015; Hamamy 2011). This is related to the possibility that both parents are carriers which is higher for consanguineous couples. The most common autosomal recessive (AR) hereditary disorders among Dutch ethnic minorities are haemoglobinopathies (HBp), such as thalassaemia and sicklecell disease (Jans, van EI, Houwaart, Westerman, Janssens, Lagro-Janssen, Plass, and Cornel 2012).

In many Middle Eastern and Mediterranean countries, PCS is offered premaritally on a large scale, especially where both the prevalence of these AR disorders and consanguinity are relatively high (Cousens, Gaff, Metcalfe, and Delatycki 2010; Kilshaw et al. 2015). Although new, mostly rare, AR diseases are identified continuously, screening programmes focus on a number of diseases which are highly prevalent among the population. They offer people the possibility of considering the risks of consanguinity for offspring and, to a lesser degree, making informed choices, such as taking preventive measures (De Wert, Dondorp, and Knoppers 2012). Some forms of screening are mandatory, for instance the test for HIV, hepatitis and thalassaemia before civil marriage in Turkey. However, rather than providing the results of these tests, providing proof of being tested is obliged. Besides, religious marriages without having a civil marriage are still practiced frequently. In Morocco genetic tests are hardly available. Nevertheless, in an anthropological field study in Morocco and Turkey (Storms and Bartels 2013), all people were very well aware of the discussion on family marriages and the genetic risk for offspring but part of them did not accept the medical risk.

Earlier research shows that in the Netherlands, Dutch Turks and Moroccans find PCS acceptable for severe disorders because it is perceived to provide information about the health of future children (Giordano et al. 2005; Van der Pal et al. 2009). Van Elderen et al. explored the acceptability of PCS in general for Dutch Moroccans, Turks and Surinamese and they did not find an association with education, religion, or consanguinity (Van Elderen, Mutlu, Karstanje, Passchier, Tibben, and Duivenvoorden 2010). Thus, in general, primary prevention of diseases in the form of PCS seems welcomed. Less is known, however, about how this prevention is perceived by Dutch Moroccan and Turkish women and more specifically, consanguineously married women, and how they welcome reproductive choices. To our knowledge, there are no studies that focused on consanguineously married women’s preferences with regard to PCS and several reproductive choices, even though more technologies are going to be available to estimate risk. Little is known about how to deliver health care to particular migrant groups and how to accommodate to their needs, but good preconception care requires insight into target groups’ perspectives and preferences. Beyond diseases with a high prevalence, PCS technologies are also expected to identify carrier couples for rare AR diseases. With this study we aimed to gain a better understanding of the perspectives Dutch Moroccan and Turkish women and, more specifically, consanguineously married women among them, on what PCS is expected to offer even when they do not perceive or accept a medical discourse on risk. Therefore, exploring the possible future implications of PCS in terms of reproductive and related choices is relevant especially for these women.

Therefore, a key concept in our study is frameworks of choice. It indicates how people perceive choice, how choices are embedded in broader contexts, and how they are
influenced by individuals, families and communities and are related to socio-economic circumstances, opportunities, belief systems and social networks (Sleeboom-Faulkner 2011,13). Framing refers to the selection of aspects of reality which are important in the interpretation, communication, and reception of (social) knowledge. A process of framing takes place to bridge the ‘know-do’ gap, the gap between what is known and what is done (Verdonk and Klinge, 2013). Frameworks of choice is not opposed to the concept of individual choice but it “puts into perspective approaches that regard ‘individual’ or ‘autonomous choice’ [main concepts in classical bioethics] as the basis of predictive and reproductive decision-making.” (Sleeboom-Faulkner 2011,14). Understanding the frameworks of choice of individuals makes it possible to contextualize their choices. Such an approach takes into account the women’s individual agency, their social interdependency or ‘relational autonomy’ (Mackenzie’s, 2008), and the structural gendered cultural and religious contexts in which the women’s choices are embedded. In this study we explore Dutch Moroccan and Turkish women’s perspectives on partner choice, marriage, having children, PCS and reproductive choices as embedded within these larger frameworks.

7.2 Methods

Despite differences such as societal and ethnic background and differing interpretations of Islam, Dutch Turkish and Moroccan women have similar characteristics such as simultaneous arrival in the Netherlands, class background, and patterns of partner choice (Storms and Bartels, 2008). Both groups have a relatively high rate of consanguineous marriage and in both groups, women are considered responsible for procreation and care for children. Besides, women compared with men in general have more contact with their doctors because of reproductive care. Hence, we drew together from both groups and interviewed women only. Ten in-depth interviews were conducted in Dutch to explore consanguineously married women’s perspective(s) towards (a) the possibility of screening, and (b) the reproductive options available afterwards, and (c) the contexts and embeddedness of their choices. We used purposive sampling to maximize the richness, depth and variability of the data and selected a variety of individual interviewees, based on a marriage with a cousin, having children or not, disabled children or healthy, age, and Turkish and Moroccan background (table 7.1, pseudonyms used) (Green and Thorogood 2014). Women were recruited through Turkish and Moroccan women’s organizations, a self-support group for mothers with a disabled child via a care organization, and through students. During one interview the husband was present.

Table 7.1. Overview of Individual Interviewees’ Characteristics

<table>
<thead>
<tr>
<th>No.</th>
<th>Name*</th>
<th>Education</th>
<th>Ethnic background</th>
<th>Migrant status (1st or 2nd generation, age of migration)</th>
<th>Age</th>
<th>Children</th>
<th>Disability/disease**</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Nawel</td>
<td>Highly educated (MSc, chemist)</td>
<td>Moroccan</td>
<td>1st generation,</td>
<td>39</td>
<td>2 (son and daughter)</td>
<td>Both children diseased</td>
</tr>
</tbody>
</table>
Methods

To examine the reproductive experiences and perspectives of consanguineous families, we conducted natural group discussions and individual interviews in both Dutch and Turkish settings. The goal was to bridge the ‘know-do’ gap and understand the health care knowledge and choices in this context. Participants included individuals from different socio-economic backgrounds, including Turkish and Moroccan women, and their family members. The study was approved by the ethical committee of the university (2011/0015).

The context of the study is influenced by the socio-cultural background and the family structure. In this study, we explore the perspectives of individuals in consanguineous marriages and the reproductive choices they make. We used a qualitative approach to understand the individuals’ perspectives and the factors that influence their choices.

We were interested in the possible choices and the contexts in which meaning making on PCS and reproductive choices is produced. Starting point is the notion that health care decisions are made and embedded in daily life. Discussions in ‘natural’ groups of people, people who know each other already, is useful to gain insight in the content of social knowledge about topics such as consanguineous marriage, PCS, and reproductive choices, and to access how that knowledge is generated, framed, and embedded within possible choices. These discussions help to gain insight in an agreed upon perspective on consanguineous marriage, PCS, and reproductive options shared group culture (Green and Thorogood 2014). So prior, and running parallel (April 2011-January 2012) to the individual interviews (December 2011-September 2012), 7 natural group discussions with in total 86 participants, were organized by women’s organizations (2 Turkish, 3 Moroccan, and 2 mixed groups). Not all participants of these group discussions were consanguineously married and 2 participants had other ethnic backgrounds. A translator was present. In the group discussions and interviews the same topic list was used which was based on the literature. Minutes were taken during the sessions as not all women would permit recordings.

We were interested in the possible choices and the contexts in which meaning making on PCS and reproductive choices is produced. Starting point is the notion that health care decisions are made and embedded in daily life. Discussions in ‘natural’ groups of people, people who know each other already, is useful to gain insight in the content of social knowledge about topics such as consanguineous marriage, PCS, and reproductive choices, and to access how that knowledge is generated, framed, and embedded within possible choices. These discussions help to gain insight in an agreed upon perspective on consanguineous marriage, PCS, and reproductive options shared group culture (Green and Thorogood 2014). So prior, and running parallel (April 2011-January 2012) to the individual interviews (December 2011-September 2012), 7 natural group discussions with in total 86 participants, were organized by women’s organizations (2 Turkish, 3 Moroccan, and 2 mixed groups). Not all participants of these group discussions were consanguineously married and 2 participants had other ethnic backgrounds. A translator was present. In the group discussions and interviews the same topic list was used which was based on the literature. Minutes were taken during the sessions as not all women would permit recordings.

<table>
<thead>
<tr>
<th>No.</th>
<th>Name*</th>
<th>Education</th>
<th>Ethnic</th>
<th>Age</th>
<th>Genetic Risk</th>
<th>Disability/disease**</th>
</tr>
</thead>
<tbody>
<tr>
<td>2</td>
<td>Kaoutar</td>
<td>Intermediate (secondary)</td>
<td>Moroccan</td>
<td>1st generation, age 21</td>
<td>32</td>
<td>1 (son)</td>
</tr>
<tr>
<td>3</td>
<td>Nesrin</td>
<td>Highly educated (BA, teacher)</td>
<td>Turkish</td>
<td>2nd generation</td>
<td>26</td>
<td>1 (daughter)</td>
</tr>
<tr>
<td>4</td>
<td>Meryem (&amp; Kerem)</td>
<td>Intermediate (secretary)</td>
<td>Turkish</td>
<td>2nd generation</td>
<td>30</td>
<td>2 sons deceased 2 (daughters)</td>
</tr>
<tr>
<td>5</td>
<td>Aysel</td>
<td>Intermediate (administration)</td>
<td>Turkish</td>
<td>2nd generation</td>
<td>26</td>
<td>No children (yet)</td>
</tr>
<tr>
<td>6</td>
<td>Gülşen</td>
<td>Intermediate (now in 1st year of bachelor programme)</td>
<td>Turkish</td>
<td>2nd generation</td>
<td>25</td>
<td>2 (son and daughter)</td>
</tr>
<tr>
<td>7</td>
<td>Farida</td>
<td>Low (chairwoman Moroccan women’s organization)</td>
<td>Moroccan</td>
<td>1st generation</td>
<td>50</td>
<td>4</td>
</tr>
<tr>
<td>8</td>
<td>Malika</td>
<td>Low (volunteer for women’s organization)</td>
<td>Moroccan</td>
<td>1st generation</td>
<td>41</td>
<td>4 (2 sons 2 daughters)</td>
</tr>
<tr>
<td>9</td>
<td>Amade</td>
<td>Intermediate</td>
<td>Turkish</td>
<td>1st generation</td>
<td>37</td>
<td>4</td>
</tr>
<tr>
<td>10</td>
<td>Sarah</td>
<td>Intermediate</td>
<td>Moroccan</td>
<td>2nd generation</td>
<td>24</td>
<td>1 (daughter)</td>
</tr>
</tbody>
</table>

* Pseudonyms

** Disability/disease not specified; the information is based on mothers’ evaluation of the disease and its genetic risk
Participant observation was partly possible for instance during dinners with the respondents and at meetings in mosques. This offered the opportunity to learn about the background of the women and seek their views in the discussions between them. Validity was reached by triangulation of research methods, discussions among the researchers (researcher triangulation), in-depth interviews, and minutes of the group discussions (data triangulation). Fieldwork was carried out by the two anthropologists in the research team.39

Interviews were tape-recorded, and notes were taken at group discussions. New topics raised during group discussions were checked in interviews and vice versa and no more interviews were conducted when no new information emerged (data saturation). Researcher triangulation was applied to base coding and analytic decisions on convergent validation: discussions on coding, clustering, and analyzing were held among the researchers. All the interviews were transcribed verbatim and read several times to get a feeling for the depth of the data, and to collate and discuss ideas that came up during its reading. We identified key themes relating to PCS and reproductive options and clustered thematically to identify and report patterns and categories in the data (Green and Thorogood 2014). For instance, we identified 19 characteristics of a good husband (code), such as trustworthiness, education, and parents’ approval. Focusing on the research question, frameworks of choice helped to contextualize preferences for and ambivalences towards PCS and reproductive options. Quotes presented are mainly derived from the individual interviews as they give an insight not only in what was said, but also in ‘who the women were’ and how they expressed themselves.

### 7.3 Results

We identified four major themes in the women’s perspectives which we will subsequently describe: (1) partner choice; (2) marriage and having children; (3) healthy children, and; (4) having your own child.

#### 7.3.1 Partner choice

Perspectives on PCS and the options which ensue are framed and embedded within the contexts of family, religion, and gendered norms. These aspects were seen as mutually constituting and influencing each other. For a part of the women consent with the rules set within these contexts is expressed in how consanguineous marriage is ‘normal’ or even preferable and how they ‘just’ stopped working after marriage. Other (especially younger) women express ambivalence towards consanguineous marriages and gender roles. Aysel (26 years), grew up in the Netherlands. Originally she opposed to cousin marriage, but then developed feelings for her cousin although she was not in love. But he just seemed ‘perfect’, and she accepted his marriage proposal. Soon she considered breaking up the relationship, continued on however, and a difficult time awaited them. After a holiday and spending time together they started getting along again. Her Turkey-raised husband got an education in the Netherlands, started his own business, and let go of his rules for her:

---

39 Under Dutch legislation ethics consent is not required for this type of study, but the women gave their oral consent and could withdraw at any time (http://www.ccmo.nl/nl/medisch-wetenschappelijk-onderzoek-en-de-wmo).
“And since, about four years, everything is perfectly happy. Because otherwise I would get a divorce. When it doesn’t work, it was just a black life that I see before me. Just, one and a half year, a black life. I could not live like that my entire life. And he says the same thing. He gave me time. He says Aysel, look, when you say ‘this does not work’ then it does not work.” (Aysel)

The ideal for all of them seems that a couple should be ‘able to live a life together’ or compatible and husbands should meet criteria such as an education, work, parents’ consent, or not using drugs. Most important and always mentioned was being a Muslim as a precondition for a successful marriage: “If all men follow the Prophet’s example, everything goes well” (Group discussion). In case of an arranged marriage, most women hoped to fall in love with their partners but other women, fell in love with their cousins first before entering marriage. Partner choice based primarily on love seems more important for the second generation migrant women than for the first generation. For all women, in arranged or love marriages, cousins are only eligible if they are men with whom the women had little contact before marriage, often because they live far away in the country of origin. ‘Real cousins’, i.e. kin that you actually grew up with and who ‘feel like a brother’, are not eligible to marry (Storms and Bartels 2015), and the Moroccan group leader of one of the group discussions expresses this widely held belief as follows: “How to marry someone with whom you played in the sandpit?”

Forced marriage was rejected by all women. But in practice some women had either experienced or witnessed both covert and overt coercion. In any case, family and parents are heavily involved in partner choice, either by arranging or consenting to a marriage.

Most women felt they could have refused a proposed spouse and, therefore, believe they have individual autonomy in partner choice. The women perceive that men are granted more freedom than women, but the younger generation seems to claim and gain more and more ground for individual partner choice. Nevertheless, approval of parents remains highly important for most women (Storms and Bartels, 2015).

### 7.3.2 Marriage and having children

Malika finds PCS unnecessary ‘because everything is God’s will’, but all the other women were positive about PCS, mainly to have certainty about the child’s health. Kaoutar, (divorced) who has a child with a severe disability, favours PCS for a possible next child with a possible next husband:

‘To have a clear picture. With him [ex-husband, cousin], I do not know what caused it. Yes, I’d just want to know.’ (Kaoutar)

Furthermore, although the women desire healthy children and intend to participate in PCS, they consider the genetic risk related to consanguinity to be low. Consanguineous couples can have healthy children and non-consanguineous couples can have disabled children, they argue; other factors cause health problems too. Genetic risk does not seem to play a role in consanguineous partner choice, and may even be denied. This does not conflict with their...
interest in PCS. PCS offers the possibility to get information on the health of the child, about compatibility with the partner, or about reproductive potential (as also found by e.g. Kilshaw 2015, 5). Children are considered to be central to a marriage; refraining from having them is out of the question because ‘you want to feel like you are a family’ (Gülşen). Aysel literally does not want to think about the question: ‘All those strange questions that I cannot answer! I really do want a child.’ Farida, who chairs a women’s organization and hears of illegal polygamy cases in the Netherlands, explains how actively refraining from having children for carrier couples can be risky for women:

‘You have to know for sure that this man can be trusted, that he remains faithful. Generally, when you are in love, everything is okay, but after that period, there might be a second wife, as he has a right to take a second wife if he wants children.’ (Farida)

Therefore, not marrying a carrier partner is a viable option and for some divorce is preferable to refraining from having children. Aysel, hoping to get pregnant for several years now, would not have married her cousin if they were a carrier couple. For women in love marriages, breaking up the relationship is not an option. Gülşen (25 years, arranged marriage) balances avoiding and accepting the risk of having a child with a disease while embracing PCS itself:

‘I do not think that someone, when she hears that she has 25% chance to have a baby with a genetic disease, will say no, when she wants to marry. When they really love each other. But when that woman says no, the risk is too large so I will not marry, that is possible too. It can work in both ways. It is about risk assessment.’ (Gülşen)

Being in love with your partner is considered a disadvantage for a carrier couple, but an arranged couple should stop seeing each other, which is what Gülşen would do because:

‘When a child is ill during the night, as a mother you are completely stressed out. Measuring their temperature, when they have diarrhoea you have to take care of them. And when a child will have a disease it is really not worth it to marry someone, I would not do it. (...) They think let’s do it because it is a small risk. But later when they realize it when they have it [the child] they regret it, because it is not worth it. It will destroy your marriage.’

However for Gülşen, a genetic risk up to 25% is not high enough to worry about, because it does not provide enough certainty about the child’s health. Rather than having PCS after marriage, the women do prefer premarital screening and carrier status to be added to the long list of criteria for eligible husbands.

7.3.3 Healthy children

If a carrier couple wants to have (more) children together, termination after PND or IVF with PGD are possible options. Both technologies put a heavy burden on women, but with PND/termination, the women perceive loss, such as transgressing religious rules, the difficulty of letting go of a pregnancy, and uncertainty about the future. With IVF/PGD, they perceive only gain, i.e. certainty about the child’s health. For some women, termination is taboo and forbidden (‘haram’), for others, it is acceptable if the mother’s life is endangered.
or the child’s diagnosis is severe. Religious permission is decisive but the women seem uncertain about what is allowed:

‘Abortion is the last option I would consider. I try to live by my faith. [...] I heard that before the child is one and a half month you can have an abortion when something is wrong. After that period, not anymore. But I have only heard this, I do not know for sure now. First, I would check whether that is allowed by my faith. If it is allowed, I would do it.’ (Aysel)

Meryem and Kerem are a carrier couple, and after their first baby died from an AR disease they opted for PND and possibly, termination, in the second pregnancy. Tragically, Meryem’s second baby also died but from yet another AR disorder which had not been tested during pregnancy. They went to Turkey for IVF after PGD. Rather than a burden, it felt a bit like a holiday to her, in-between the treatments. Now, she has healthy twins and states that IVF/PGD provides ‘certainty’:

‘Suppose you get pregnant, and you want to terminate it, that is really hard. So you’d rather have a selection at the start, and then have it placed back. Then you know that it all goes well. It is just 98, 99% certain that everything goes well.’ (Meryem and Kerem)

In contrast to abortion, the women are certain that Islam allows IVF/PGD, although Islam offers no precise definition of the beginning of life, the moment of conception, and the onset of ensoulment. When couples do not wish to separate, IVF/PGD as a preventive measure seems acceptable because an actual pregnancy is not yet established as Gülşen explains:

‘No, then it is not yet a child, only when the brain is developed and so on. Actually, from the moment of conception it is a child. But the organs are not developed yet.’

When a woman is pregnant, the child is accepted. Having an affected child is an assignment from God, not a punishment, but rather the contrary, according to Kaoutar: an affected child is for selected people exclusively, for those with sabr, patience, energy, and power. In the end, most women agree: ‘How we are made is God’s will’.

7.3.4 Having your ‘own’ child: biological and social parenthood

For most women, a child should be genetically one’s own and born within marriage. A donor gamete is ‘not your own child’. Despite the flexibility she perceives in her faith, Farida stressed that:

‘I do not think that anyone will do that. It is not your real child. And it is not allowed by our faith. Whether it is a man’s or a woman’s gamete, it does not matter. You must be married to have children.’ (Farida)

Nesrin, however, assumes that couples would differentiate between egg cells and sperm. Her remark exemplifies how the women perceive double standards for men and women, not as large inequalities, but small and sensible, ‘just the way it is’: 
Like donor gametes, adopted children are ‘not your own’. Although adoption is preferred over donor gametes, complications may arise as the adopted child grows up:

'I think that for mothers, they will be less difficult, because the fathers’ sperm is more important. Because he is the namegiver. So yeah, it doesn’t matter which mother. If only the name of the father is continued. [I: And what do you think yourself?] No, I do not think so. [I: For the same reasons?] No, I would not...no. I would not like it. Even when I know it is for medical reasons, it almost sounds like adultery.' (Nesrin)

Both the use of a donor gamete and adoption do not result in having ‘your own child’, but whereas ambivalence exists towards adoption, the use of donor gametes is clearly refuted.

7.4 Discussion

A complex mix of religious, secular, cultural and gender logics frames the women’s perspectives on PCS and their reproductive options. In line with earlier reports, the Dutch Turkish and Moroccan women in our study welcome PCS (Giordano et al. 2005; Van der Pal et al. 2009). Above all, they prefer information about their future child’s health. A Dutch anthropological study concluded that, according to Dutch Muslim theologians, imams and physicians, couples would not be interested in PCS because they either consider the genetic risk to be low or have religious reasons to refrain from screening (Bartels and Loukili 2012). But in close agreement with Dutch Muslim theological expert opinions that in Islam, pursuing health and gaining knowledge through science are important, our study reveals that the women do want to know.

Second, the women’s outspokenness about not marrying or even divorcing when both partners are carriers is striking, as is their preference for PCS for premarital screening. Marriage should not endanger the health of future children (Bartels and Loukili, 2012).

Third, the difference in attitude towards PND/termination and IVF/PGD is remarkable. For some women PND/termination is taboo and forbidden (‘haram’). For others, it is a serious option to consider under rare conditions. In any case, religious permission is decisive. Women’s insecurity about Islamic perspectives towards termination has been reported earlier (Ahmed, Green and Hewison 2006; Shaw 2012). Other studies also show that termination is hardly acceptable to migrant Muslim women (Giordano et al. 2005; Ahmed et al. 2006; Van der Pal et al. 2009), although reproductive choices including termination, may be highly dependent upon the particular diagnoses (Sandelowski and Corson-Jones 1996). The women were very positive about IVF/PGD, because they expect it to provide certainty about a future child’s health. Interestingly, they did not mention the burden for the mother, the artificiality of conception, or the health risks. Rather, they stressed the fact that these procedures take place outside of the womb, and are therefore acceptable interventions and in line with supposed religious prescriptions.
Fourth, reproductive technologies such as PCS, IVF and PGD, are considered to be valuable particularly because they are regarded by the interviewees as interventions that provide certainty about the health of a future child. For our interviewees, refraining from or avoiding future procreation is not an option. Especially since having children is socially required; it is grounded in family values and gender norms (Stephens et al. 2011).

Finally, gamete donation and adoption, are considered less acceptable because the women want to have ‘their own child’. Not doing anything or preparing for a diseased child are hardly discussed, since they seem to be the default option: when a woman is pregnant, a child is accepted as it is.

Our findings raise several concerns. Most of our interviewees had no individual experiences with PCS and its consequences. They emphasized their own agency but also explained how their decisions are and would be embedded and framed within gender roles, religious and cultural factors. Our interviewees, for instance, did mention faith, gender inequalities such as polygyny or the greater freedom that men have in choosing a partner. The concept of frameworks of choice is relevant here. On the other hand, from a health care perspective, respecting the women’s autonomy, means that one is obliged to promote it (Mackenzie 2008). Women are confronted with different reproductive choices than men and face different consequences (Van Berkel and Klinge 1997). Our interviewees did not mention the possibility of being refused as marriage partners; they only considered the possibility of refusing; conceptions that genetic or biological ancestry is ‘stronger’ through paternal than maternal lines, may explain their views (Shaw and Hurst 2008, 2009). But carrier status may stigmatize women in particular, labelling them as non-eligible wedding partners within their communities (Jans et al. 2012). When screening and the disclosure of the results causes problems for women with positive carrier status, they face either the risk of having a child with a disability, or of being an unmarried outsider. The women we interviewed do not expect problems, possibly because healthy children are so important to the family. But not marrying or divorcing means that the women have to share their genetic information with their families. Pakistani adults in the UK would not readily share genetic information within the family as Shaw and Hurst (2009) explain; information was kept private for reasons related to disruptive effects. In our study, the women did not refer to these consequences of disclosing genetic information. And besides the possible stigmatization, people also individually need to come to terms with being a carrier (Frumkin et al. 2011). New reproductive technologies may change the women’s social interdependency and their social embeddedness as is already known from other technologies. In particular contraceptive measures have been revolutionary in changing women’s and men’s lives before.

There are several limitations to our study which requires further research. First, the findings must be further verified in larger studies. We spoke with only ten individual women and seven groups; partners, families, and unmarried individuals were not included. Second, as found in other studies, in reality the women may be more positive towards abortion (Giordano 2005) and more negative towards IVF/PGD (Frumkin et al. 2011). Third, effectively conveying information about genetic technologies during the interview may have been problematic because genetic literacy is low (Shaw and Hurst 2008; Van Elderen et al. 2010). Besides, the costs of technologies in the interviews has not been discussed. Fourth, all the
women spoke Dutch and were prepared to speak with us about this subject, although we involved a translator in our group discussion.

Our study has several implications. In general, more awareness seems useful about consanguinity, genetic risk, and counseling. Misunderstanding occurs because on the one hand consanguineous couples underestimate their genetic risks, although they do want to know what these risks are, while on the other hand, primary health care providers in the Netherlands think that consanguineous couples do not wish to discuss these issues. In addition, many primary health care providers disapprove of consanguineous marriage (Teeuw 2015).

Second, information can be provided about PCS and IVF/PGD, and about the limitations that these technologies have. The genetic variants that are found may have unknown effects and not all possible disorders are tested for, but people may feel reassured of having a healthy baby after PCS and/or IVF/PGD.

Third, PND/termination was mostly refuted because of religious beliefs, but health care providers should still discuss it (Neter, Wolowelsky and Borochwitz 2005; Ahmed et al. 2006). Different Islamic viewpoints do exist about termination of pregnancy, which may be mentioned by family physicians or theological experts (Neter et al. 2005). For instance, according to some Islamic scholars termination is permissible in case the child has a severe condition.

Finally, our study has shown that PCS seems welcomed in particular before marriage. Health services can help individuals to make choices in the view of their specific risks and frames of choices as related to family goals, ethical and religious values, and to act in a manner which supports and confirms their choices (Shaw and Hurst 2008; Khan, Benson, MacLeod, and Kingston 2010; Hamamy 2011).

However, implementing premarital screening is challenging. Generally, couples-to-be do not present themselves as such to health care providers. Both, health care providers and consanguineous couples themselves consider the genetic risk to be low. Moreover, offering premarital screening largely relies on the subjects identifying their own ethnicity and consanguinity, which does not necessarily correspond to genetic risk (Hinton, Grant and Grosse 2011). Finally, at this moment, the stigmatization of consanguineous couples is a realistic negative side-effect of the ethnically-targeted implementation of screening (Shaw and Hurst 2008; Hamamy 2011; Raz and Vizner, 2008). Currently, Dutch politicians overestimate the risk and negatively frame consanguinity, genetic risk, migration, and relate these issues to forced marriages (De Koning, Storms and Bartels 2014). A realistic understanding of the risks and perceived benefits of consanguinity should therefore be encouraged among politicians and policymakers.

7.5 Conclusion

New technologies for PCS are welcomed by consanguineously married women regardless of possible reproductive options because it provides information about the future child’s
health. Their preference for PCS for premarital screening as well as their outspokenness about not marrying or even divorcing when both partners appear to be carriers is striking. Raising awareness (of both risks and options), and providing information, screening and counseling sensitive to this target group and their preferences are important.

References


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 Fatal Abnormalities from a Small sample of Pakistani Muslim Couples in Britain.” *Bioethics*. 26 (9): 485-492.


