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Decision-making, barriers, and facilitators regarding cervical cancer screening participation among Turkish and Moroccan women in the Netherlands: a focus group study

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ABSTRACT

OBJECTIVES: Whether the lower Dutch cervical cancer (CC) screening participation of Turkish- and Moroccan-Dutch women is based on informed decision-making is unknown. Our aim was to explore how and why Turkish- and Moroccan-Dutch women decide to participate or not in the current Dutch CC screening programme as well as to learn their perceptions on self-sampling.

DESIGN: Six focus group discussions were conducted between March and April 2019 with Turkish ($n = 24$) and Moroccan ($n = 20$) women in the Netherlands, aged 30–60 years. Questions were based on an extended version of the Health Belief Model. Discussions were transcribed verbatim and thematically analysed.

RESULTS: Participants lacked knowledge about CC and its screening, and seemed to be unaware of the cons of CC screening. Perceived barriers for screening were lack of a good command of the Dutch language, having a male general practitioner, fatalism, shame and taboo, and associations of CC with lack of femininity and infertility. Other barriers were fear of the test result, cancer, suffering, death, and leaving their children behind after death. Perceived facilitators were a high perceived severity of disease, social support, and short procedure time. An additional religious facilitator included the responsibility to take care of one's own health using medical options that God provided. Participants had low self-efficacy expectations towards performing correct self-sampling.


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CONCLUSIONS: Although participants' informed-decision making seems to be limited, this study showed that women do not only consider factual medical information, but also practical, emotional, cultural, and religious aspects prior to deciding to screen or not. Information materials should be tailored to these aspects, as well as translated to appropriate languages due to lack of a good command of the Dutch language. Self-efficacy expectations towards performing correct self-sampling should be enhanced to promote informed CC screening participation among Turkish- and Moroccan-Dutch women.

Introduction

Cervical cancer (CC) is ranked as the fourth most frequently diagnosed cancer in women worldwide (Bray et al. 2018). The most important co-factor for CC is the sexually transmitted Human Papilloma Virus (HPV), which is estimated to be contracted by 70% of all sexually active individuals worldwide (RIVM 2018). As the majority of HPV infections resolve within one or two years, a HPV infection does not necessarily lead to cancer development (Muñoz 2016). A long-term infection with high-risk HPV (hrHPV), however, may develop to invasive CC, which can take up to 20–30 years (Steenbergen et al. 2014). Because of this, there is a window of opportunity for screening programmes to target precancerous cervical lesions and prevent invasive cancer.

In 1996, the Dutch national CC screening programme was implemented to detect CC in an early treatable stage. Since then, women aged 30–60 years are invited to participate every five years via a Dutch invitation letter. Since 2017, the Netherlands switched from cytology-based to HPV-based screening because of substantial evidence that the latter is more effective in reducing the incidence of cervical (pre)cancer (Arbyn et al. 2012). An important advantage of HPV-based screening is that HPV testing can be done on a sample collected by women themselves (i.e. 'self-sampling').

Despite the availability of a national free of charge CC screening programme, especially Turkish- and Moroccan-Dutch women, who account for the two largest ethnic minority groups in the Netherlands, show low screening participation. Although recent screening participation rates among these populations are lacking, Steens et al. combined data from different sources and at different levels of aggregation with screening data of 2005–2010. Based on this dataset, Steens et al. estimated considerably lower screening participation rates for women born in Turkey or Morocco (64% and 53%, respectively) compared to native Dutch women (79%) (Steens et al. 2013). This is especially worrying as these populations are found to have an increased risk for CC compared to native Dutch women (Arnold et al. 2013) and more than half of the diagnosed CC cases occur in women who have not participated in screening (Bulk et al. 2003; van der Aa et al. 2008).

Traditionally, cancer screening programmes are aimed to reach a maximum uptake level and thus effectiveness (i.e. reduction of incidence and mortality) at a population level. From the perspective of the individual, however, deciding to participate in screening involves careful consideration between uncertain benefits (e.g. longer duration of life, if a precursor of cancer is successfully detected and treated) and risks of adverse effects (e.g. false-positive and – negative test results, overdiagnosis and – treatment, and

discomfort or pain). With informed decision-making (IDM) individuals are entitled to individually consider these pros and cons, and make an autonomous decision regarding their participation. Thus, nonparticipation can be an acceptable outcome whenever it is the result of IDM. Therefore, an informed decision is defined as one that is based on decision-relevant knowledge while the decision-maker's attitude is consistent with (intended) screen behaviour (Marteau, Dormandy, and Michie 2001).

There is a limited IDM regarding CC screening among the native Dutch population due to insufficient decision-relevant knowledge (Korfage et al. 2011). For Turkish- and Moroccan-Dutch women specifically, no data are available regarding IDM. There is also a lack of recent information regarding their perceived barriers and facilitators for participation in CC screening. Furthermore, (non)participation in CC screening might also be influenced by the possibility of self-sampling, introduced in 2017. Previous studies among Dutch and Australian general populations show that CC screening participation increased when never- and under-screened women were offered self-sample HPV tests (Sultana et al. 2016; Verdoodt et al. 2015). Dutch women reported self-sampling as more convenient, since they could do it in their own time and it was less time consuming (Bosgraaf et al. 2015). Additionally, previously screened Dutch women reported self-sampling as less embarrassing, less uncomfortable, and less painful than clinician-based sampling (Bosgraaf et al. 2015; Ketelaars et al. 2017). A qualitative study among women in Turkey did, however, show that women thought that only a general practitioner (GP) should take a smear, and that they would be unable to use the self-sampling device themselves (Sahin et al. 2014). As self-sampling has only been implemented as a possible screening method in the Netherlands in 2017, it is unknown what influence it might have on the CC screening participation rates among Turkish and Moroccan women in the Netherlands.

Therefore, our aim was to explore how and why Turkish- and Moroccan-Dutch women decide to participate or not in the current Dutch national CC screening programme as well as to learn their perceptions on self-sampling.

Materials and methods

Study design

A qualitative study was conducted using focus group discussions (FGDs) to elicit information regarding the decision-making process and the perceived barriers and facilitators regarding CC screening participation among Turkish- and Moroccan-Dutch women (Green and Thorogood 2018). This design was chosen, since FGDs facilitate participants exploring and clarifying their knowledge, attitudes, feelings, beliefs, and experiences in ways that would be less easily accessible in individual interviews because of the interaction between participants. A focus group design enables researchers to identify group norms and shared cultural understandings and values among participants (Gibbs 1997; Kitinger 1995). Focus groups were held between March and April 2019. The reporting of this study was based on the Consolidated criteria for reporting qualitative research (COREQ) checklist (Tong, Sainsbury, and Craig 2007).

To avoid cultural differences to emerge and affect discussions, FGDs with Turkish and Moroccan women were conducted separately. Through telephone and email, contact

persons of community organisations (e.g. community centres, mosques, and civil support foundations) were recruited and asked in which language they would like to have the FGD be conducted. Based on their reported language preference, five FGDs were conducted in Dutch and one in Turkish (for which an extra Turkish-speaking moderator was arranged). Moroccan participants may speak Moroccan-Arabic, -Berber, or both. Since the majority of Moroccans in the Netherlands speak Moroccan-Berber or both Moroccan-Berber and -Arabic, a Moroccan-Berber speaking moderator (NH) was available to translate for Moroccan-Berber speaking participants in case they had difficulties with ‘finding the words’ in the Dutch language.

Study population and recruitment

Dutch women aged 30–60 years old (the target age groups for CC screening), born in Turkey or Morocco, were included (first generation migrants, FGM), as well as those born in the Netherlands with at least one parent born in Turkey or Morocco (second generation migrants, SGM). SGM often act as brokers for their parents in communicating with Dutch health care professionals. They act as instructors, models, and interpreters, and provide financial, social, and/or emotional support to their parents. Therefore, SGM are important to consider when studying the thoughts and perceptions of FGM (Hamdiui et al. 2018; Katz 2014). Participants were recruited through purposive and snowball sampling, aimed at diversity in age, educational level, geography, marital status, number of children, number of years residing in the Netherlands, and command of the Dutch language (both participants and non-participants in CC screening). Through telephone and email, contact persons of community organisations (e.g. community centres, mosques, and civil support foundations) in various cities in the Netherlands were recruited (Amsterdam, Arnhem, Utrecht, The Hague, and Hoofddorp). These contact persons then invited women who were actively involved within the community organisations, or who frequently visited these organisations, and/or women in their social network.

Participants received information about the study and were asked to participate in the FGD. FGDs took place at community centres or mosques where participants held weekly meetings. Recruitment for the FGDs went on until data saturation was reached for both Turkish and Moroccan woman, i.e. no new information was found during the last FGD.

Focus group topics

The topic list was constructed based on previous literature (Acar and Pinar 2015; Bosgraaf et al. 2015; Duran 2011; Gok et al. 2012; Jong 2005; Ketelaars et al. 2017; Lale, Ory, and Detmar 2003; Reis et al. 2012; Sahin et al. 2014; Selmouni et al. 2015; Sultana et al. 2016; Verdoodt et al. 2015; Yanikkerem et al. 2013) and a conceptual model primarily based on the Health Belief Model (HBM) (see Figure S1 in the Appendices) and pilot tested in the first FGD. The HBM contains the following constructs: perceived susceptibility, perceived severity, perceived benefits, perceived barriers, perceived self-efficacy, and cues to action. This model assumes that individuals are likely to engage in a ‘health action’ if they perceive (1) themselves susceptible to the disease in question, (2) that the disease has serious consequences, (3) that taking a ‘health action’ could be

beneficial in reducing the susceptibility to or severity of disease, (4) that the benefits of the 'health action' outweigh the barriers, (5) that they are self-efficient in relation to performing the 'health action', and (6) that one receives cues to take the 'health action' (Champion and Skinner 2008; Rosenstock, Strecher, and Becker 1988). Furthermore, descriptive and injunctive norm (further referred to as 'subjective norm') of the Reasoned Action Approach (RAA) was included in our conceptual model (Fishbein and Ajzen 2011), since previous literature showed that the decision to participate in CC screening could be influenced by others (Acar and Pinar 2015; Duran 2011; Ersin and Bahar 2013; Gol and Erkin 2016; Reis et al. 2012; Savas and Taskin 2011; Selmouni et al. 2015; Yanikkerem et al. 2013). Betancourt's Model of Culture and Behaviour assumes that health behaviour is also associated with aspects of culture, such as value orientation, beliefs, and expectations, which can either influence behaviour directly or indirectly through psychological processes (Betancourt and Flynn 2009). We incorporated 'cultural factors' to our conceptual model, since this compilation of constructs has previously been used in studies regarding screening intention among Turkish- and/or Moroccan-Dutch population(s), which resulted in valuable insights in important cultural values affecting screening intention (Hamdiui et al. 2018; van der Veen et al. 2014). Furthermore, literature shows that religious beliefs and values may influence screening intentions and were, therefore, included as well (Duran 2011). At the start of each FGD, socio-demographic characteristics of the participants were collected using a short Dutch questionnaire. Educational level was categorised according to the Dutch Standard Education Format by Statistics Netherlands: (1) low when participants had no education, primary education, or had not finished secondary education, (2) medium when participants were secondary school graduates or had finished vocational education, (3) and high when participants were university or applied sciences graduates (CBS 2016).

Two main subjects were discussed during the FGDs: (1) decision-making process with perceived barriers and facilitators of CC screening (non)participation and (2) perceptions on self-sampling. This was done following the conceptual model's constructs: modifying factors, cultural and religious beliefs and values, perceived susceptibility to and severity of disease, perceived benefits and barriers, perceived self-efficacy, subjective norm, and cues to action. See Table S1 in the Appendices for an overview of the complete topic list.

Data collection

Each FGD contained five to eleven participants each. A female moderator and a female assistant (NH, EM) facilitated all five Dutch-spoken FGDs. NH is a bilingual Moroccan-Dutch PhD candidate, who speaks both Moroccan-Berber and Dutch, and has a background in qualitative research including conducting and analysing interviews and FGDs. A bilingual Turkish-Dutch female GP (fluent in Turkish and Dutch) and a female assistant (NH) facilitated one Turkish-spoken FGD.

Each FGD took approximately two hours. Prior to the start of the FGDs, participants were explained again the nature of the study through a short introduction, and were then given the time to ask questions. After the introduction, open questions based on the topic list were discussed. After the discussions, participants received a gift voucher of twenty

euros as a token of appreciation for their participation. All FGDs were audio-recorded and the assistant took field notes during the FGDs.

Data analysis

All FGDs were transcribed verbatim. The Turkish- and Moroccan-Berber spoken (parts of the) discussions were directly transcribed into Dutch by a bilingual Turkish-Dutch research assistant and NH (who also moderated all Dutch-spoken FGDs), respectively. Because of the involvement of bilingual researchers, audio recordings could be directly transcribed into Dutch, taking the meaning of what was said (in another language) into account (Choi et al. 2012). Transcripts were analysed inductively for grouping perceived barriers and facilitators using the qualitative software programme MAXQDA (version 18.0.5), based on the principles of thematic analysis (Braun and Clarke 2006). We used open coding, where transcripts were coded by labelling meaningful fragments of text with concepts abstracted from this text. Through systematic comparison of coded text (also called axial coding), we identified emerging themes and subthemes. These themes and subthemes were compared for several collected socio-demographic characteristics (such as being Turkish or Moroccan). To ensure reliability of the data interpretation, two researchers (EM, NH) carried out the analysis of a random sample of 40% independently. Discrepancies were discussed until consensus was reached on the labelling criteria and the coding scheme. The remaining 60% of the analysis was conducted by EM.

Ethics approval and consent to participate

Ethical clearance was obtained from the Medical Ethics Review Committee of the University Medical Centre Utrecht. The Committee confirmed that the Medical Research Involving Human Subjects Act (WMO) does not apply to this study (nr. 19-251). Written informed consent was obtained prior to the discussions. All transcripts were processed and stored anonymised.

Results

Study participants

A total of 24 Turkish and 20 Moroccan women were included in six FGDs (see Table 1). One participant was born in Bulgaria and two participants did not meet the age criteria. These participants were excluded from Table 1. Most Turkish and Moroccan participants were FGM (85% and 95%, respectively) and had a family history of cancer (79% and 80%, respectively). Furthermore, 75% of Turkish participants reported to participate every five years in the CC screening programme compared to 30% of Moroccan participants.

We identified seven main themes in relation to CC screening participation from our thematic analysis, including one theme regarding self-sampling. For a schematic overview of the subthemes and coding tree, see Figure S2 in the Appendices. There were no distinct differences in identified themes between Turkish and Moroccan women. Also, no distinct differences were observed among the two groups related to other socio-demographic characteristics (such as age and educational level).

Table 1. Characteristics of the participants ($n = 44$).

		Turkish participants ($n = 24$)	Moroccan participants ($n = 20$)
Migrant generation (%)	First	21 (88)	19 (95)
	Second	3 (13)	1 (5)
Age group (%)	30–45 years	6 (25)	10 (50)
	46–60 years	18 (75)	10 (50)
Mean age, in years (SD)		49 (6)	46 (6)
Marital status (%)	Married	18 (75)	17 (85)
	Divorced	4 (17)	3 (15)
	Widowed	2 (8)	0 (0)
Mean number of children (SD)		3 (1)	4 (1)
Educational level (%)	Low	16 (70)	9 (45)
	Medium	4 (17)	10 (50)
	High	3 (13) ^a	1 (5)
Employed (%)	Yes	8 (33)	6 (30)
	No	16 (67)	14 (70)
Self-reported family history of cancer (%)	Yes	19 (79)	16 (80)
	No	5 (21)	4 (20)
Self-reported command of the Dutch language: speaking (%)	Insufficient	8 (33)	3 (15)
	Sufficient	10 (42)	9 (45)
	Good	6 (25)	7 (35) ^a
Self-reported command of the Dutch language: reading (%)	Insufficient	8 (33)	3 (15)
	Sufficient	9 (38)	6 (30)
Self-reported CC screening participation (%)	Good	7 (29)	9 (45) ^b
	Every 5 years	18 (75)	6 (30)
	Not every 5 years	4 (17)	7 (35)
	Not sure how often	0 (0)	3 (15)
	Never	2 (8)	4 (20)

^aOne participant did not respond to this question. ^b Two participants did not respond to this question.

(Informed) decision-making and information need

(Informed) decision-making

Some participants expressed having difficulties with making the decision to screen or not, while others indicated it as easy and not perceiving it as a choice, but as self-evident: *It [decision to screen or not] is easy, not difficult. It is not a choice* (Turkish participant). Some thought that it does not hurt to participate in screening and it would rather improve their health:

I think it [decision to screen or not] is easy, because when I get a letter at home, I think: I will go for it. [...] For me, it really is better. Why not? It can't hurt. It can only make matters better. [...] To take the matters into one's own hands. (Moroccan participant)

Participants thought that it is important and useful to participate in the CC screening programme, as it concerned their health. Many participants mentioned the saying *prevention is better than cure* and thought that timely detection of CC is a benefit of the programme. Participants often mentioned that screening meant five years of guaranteed health. However, some participants did not share this view, as they were convinced that cancer development could potentially start right after you have just been screened.

Many participants did not seem to know the cause of CC (i.e. HPV), especially not the fact that HPV is sexually transmittable: *People think that it is a cough, a virus, they think you can get cancer from everything, and not from sexual intercourse.* (Moroccan

participant). This revelation caused some anger towards men in several FGDs, blaming them for CC. Although most participants knew the symptoms of CC, they often did not know that having these symptoms meant that the cancer is already in a late stage. Some participants thought CC is not preventable, as they had a fatalistic approach, but they did think that it can be detected in time to be treated. Few participants knew the eligible screening age range for participation. We also observed that participants lacked knowledge about the procedure, which resulted in fear for the procedure and distrust towards health care professionals and the screening programme: *Ignorance creates fear, because they do not know what will happen (i.e. the screening procedure). If they knew, they wouldn't be afraid.* (Turkish participant).

Need for information

Participants mentioned that there is a lack of information regarding CC. Some participants mentioned that taboo around CC contributed to this. A need for information was emphasised, especially about the cause of CC, how to prevent it, and how the procedure is performed. Participants suggested that information meetings at mosques or community centres would facilitate screening participation. These meetings would need to be provided by a female health care professional, in their own language (i.e. Turkish, Moroccan-Berber, or -Arabic), and need to incorporate Islamic beliefs and values.

Religious beliefs and values

Norms regarding health and illness in the Islam and fatalism

Most participants expressed their belief that health plays an important role in the Islam. Participants mentioned that according to the Quran, it is important to take care of one's body using all available medical options, therefore facilitating CC screening participation. Participants also explained that they believe in fate and would accept whatever is God-given, including CC. Yet, for most participants this did not mean that they would not have to try to prevent it:

God has also said, if you have something, go after it. Help exists, doctors exist, there are medicines. And if your day has arrived, correct, your day has arrived, but this doesn't mean that you don't need to do anything about it. (Moroccan participant)

However, some participants reported cancer screening as pointless. They believed that if they would get cancer, screening would not have prevented this, and thus regarded screening as unbeneficial (i.e. fatalism). Therefore, for some, fatalism seemed to function as a barrier for screening participation: *Even if you go every year to the cervical cancer screening programme, or every month, if it's meant to be, you will get it.* (Moroccan participant).

Cultural beliefs and values

Shame and taboo around cervical cancer

Participants mentioned frequently that Turkish and Moroccan people do not talk about CC or screening with each other. They only discussed it with very close friends or with

their husbands at home, and merely when someone in the surroundings had been diagnosed with cancer, or had died from it. When asked why women did not talk about it, several reasons surfaced. First, participants explained that people in their environment believe that if you do not talk about cancer, it does not exist. Second, participants mentioned that it is not custom to talk about negative subjects, such as disease or death. Third, participants expressed that if people would know that they have a disease, they would receive pity, which was perceived as unwelcome. Another issue that frequently arose, when the cause (i.e. HPV) and transmission route of HPV was explained, was the belief that having CC meant that a woman or her partner had sexual relationships with multiple partners which would not be acceptable according to the Islam. Because of this, participants often mentioned that they would be afraid of the judgement of others, would they go to the screening programme or be diagnosed with CC, thus keeping the subject undiscussed:

It is more like, what will they think? How did I get it, which of course is also an issue. It is an intimate piece of you. How did I get it then? And people are going to think, where did she catch that? (Turkish participant)

Furthermore, participants perceived CC and screening as an intimate and private matter. Talking about feminine issues at home, such as menstruation, was reportedly not customary while growing up, not even among the women in the family. Other participants supported this, claiming that there is shame around CC. The uterus was deemed the most intimate part of a woman's body, making them feel ashamed with *spreading their legs* during the procedure: *It is shame. I remember the first time I went, I was thirty. I didn't know what was going to happen to me. [...] I wasn't afraid, I was ashamed to show the 'stuff'.* (Moroccan participant).

Since participants associated the uterus with fertility and CC with infertility, and procreation is perceived important, participants feared that participating in screening might negatively affect their chances of a successful future (i.e. husband and children). Besides, they would feel ashamed in participating in screening, as people around them would think that they might be infertile: *It is a very sensitive subject for women. It is something feminine. It feels as if when you have no uterus anymore, you are not a woman anymore.* (Moroccan participant).

Perceived threat of disease and fear of cancer and death

Perceived susceptibility to and severity of disease

Participants perceived their overall susceptibility to developing CC as very low. This was mostly due to the belief that Muslims are not supposed to have sexual intercourse before marriage, therefore, having much fewer sexual partners compared to non-Muslims: *I think that in our culture it [CC] is less frequent, because I think men have less often sex with several women. A woman idem ditto.* (Moroccan participant). Participants believed that this is a reason for nonparticipation in the CC screening programme among Turkish and Moroccan women. However, others perceived that everybody is susceptible to CC, especially women with cancer in their family, as participants believed it to be hereditary, which facilitated screening participation. All participants believed CC is a very severe disease.

Fear of cancer and death

It was often mentioned that the word *cancer* itself is frightening due to the frequency of people having cancer in their surroundings and due to the association of cancer with death. As CC was perceived as very severe and was associated with death, participants mentioned that they were scared of hearing the results of the screening. Many participants explained that they were very stressed and nervous until the test results would come back, especially as they experienced the waiting period as far too long. Participants explained that they did not fear death itself, but they were afraid for their children being left behind after their death:

We all know that we are going to die. [...] But if you still have small children, it's more about your children than yourself. Even if I'm not here right now, who is going to take care of my children? (Moroccan participant)

Some participants expressed that they did not attend the screening because of this fear of cancer and the psychological stress they would have to endure if they knew they had the disease. On the opposite, for others the fear of leaving their children behind, made them participate in the screening programme.

Subjective norm and social support

Participants believed that the ultimate decision about participation is made by them and not by others. There were, however, several influences reported. First, participants mentioned that because of the taboo, women felt ashamed to participate in the screening programme, mostly because they were afraid of what others would think (i.e. multiple partners, infertile). However, they mostly expressed that others would provide support in participating. Their doctors and husbands acted as advisors or supporters, but did not influence their decision-making. Furthermore, close friends acted as emotional support in pushing someone to take the last steps in going to the GP when the procedure was regarded as scary. Close friends were also indicated as verbal support when women lacked a good command of the Dutch language, and were not able to make an appointment. Additionally, participants mentioned that they made sure their mothers would participate, who did not always understand that they were being invited due to the lack of a good command of the Dutch language. Overall, participants did not feel pressure from others to (not) participate in screening, but instead, tried to influence and support others to screen themselves:

But if someone comes to me who has to go for the first time. You go like: You have to do it, it's done very quickly, just do it. It means certainty for yourself, it's your health and you shouldn't think easily about that. That can be, especially for someone going for the first time, that last push. (Turkish participant)

Practical factors

Practical barriers and facilitators

The (expected) pain of the procedure was a barrier for some, but most participants expressed that it did not impede them to participate in screening. However, menstruation and bodily (un)cleanliness did defer participants from screening. Having a male GP

contributed to nonparticipation, especially since many participants did not know it was possible to request a female doctor or assistant for the procedure. Furthermore, participants experienced difficulties with scheduling appointments due to their working schedule or because of having been pregnant:

You can't go right after your pregnancy and around the age of thirty, many women are pregnant and having children. So it is for sure a difficult target population to contact. And then I was breastfeeding, and then I thought it was scary, and then I was pregnant again. You have to be fast. (Moroccan participant)

Observed facilitators for participation were that the screening is free of charge and that the procedure is quickly performed.

Invitation letter and information brochure

Participants expressed that they feel screening participation is important because the invitation letter is sent to their homes. This created a feeling of obligation to respond to the letter and participate. Other participants expressed that the letter functioned as a reminder to make an appointment, therefore facilitating screening participation: *If you get such a brochure, such information, you just know that it's important* (Moroccan participant).

Participants expressed that the invitation letter and information brochure were often not (thoroughly) read or they were unable to understand it due to the lack of a good command of the Dutch language: *I have never read it completely. I know it is an option. Then I decide whether I go or not.* (Moroccan participant). When women did not understand that the letter was an invitation to attend the screening, they were not able to react and participate. Participants mentioned that this applied to their mothers, unless they made an appointment to make sure that their mothers would go to the screening.

Furthermore, few participants knew of the existence of the online available Arabic and Turkish information brochures. Being available online was a barrier, especially for older Turkish and Moroccan women, who often do not know how to use the Internet. Those who had read these brochures mentioned that they are badly translated and that the language level is too complicated making them difficult to understand: *Sometimes the translations are not even done properly. I ask myself, is it just Google Translate or something?* (Turkish participant). Some participants were positive towards the Arabic and Turkish information brochures, as they used them in addition to the Dutch brochure in case they could not understand everything stated.

Self-sampling

Practical pros and cons

The majority of the participants had not heard about self-sampling before. However, participants, who had heard of it, expressed difficulties in performing it, since instructions were complicated and difficult to understand. After explanation of the self-sampling procedure, most participants had a positive attitude towards it. Not needing to go to the GP's office and not having to *spread their legs* for the GP were perceived benefits. Another positive aspect was the possibility to perform it in their own time without someone

else around. However, participants mentioned that there is no visual inspection of the cervix, such as at the GP's office, and that they would need to go to the GP anyway would the test result be HPV positive:

I had received such a letter, like you said. But it also said, if it's not good, you have to go to the GP again. I thought, then I'll just go to the GP right away. I did not ask for it. (Turkish participant)

Self-efficacy

Participants regarded their ability to correctly perform self-sampling as low. Because of this low self-efficacy, they were hesitant on whether the results of the test could be trusted: *Especially when the results are good, then you think, hmm, but what if I haven't done it properly. Then I am going to be hesitant.* (Moroccan participant). This led to the majority of participants being hesitant towards self-sampling, preferring to go to the GP. However, participants suggested that they would be interested in self-sampling if their GP showed them how to do it or had video tutorials instead of written tutorials with pictures: *It is written down with pictures, but it would be easy as well if you could watch a video. For example, you could go to this website and look how it should be done. [...] I find that important.* (Moroccan participant). Participants would suggest self-sampling to others if women were determined not to go to the GP. Overall, a few participants seemed open to try self-sampling.

Discussion

Main findings

We explored how and why Turkish- and Moroccan-Dutch women between 30 and 60 years old decide to participate or not in the current Dutch national CC screening programme including their perceptions on the newly implemented self-sampling method.

Regarding informed decision-making (IDM), we found that many participants reported making their decision without neither being fully informed nor deliberately weighing all aspects involved. Overall, the decision was either experienced as difficult due to considering pros and cons, or as easy due to the perception that it is self-evident to participate. Prior to explaining the role and transmission route of HPV (either by the moderator or by one of the participants), many participants were not aware of HPV and did not know about its sexual transmission route. CC was thought to be hereditary and although most participants knew the symptoms of CC, they often did not know that having these symptoms meant that the cancer is already in a late stage. We also observed that participants lacked knowledge about the screening and thought that it only had advantages and could not hurt. Participants also often mentioned that screening meant five years of guaranteed health, indicating ignorance about the possibility of false-negative test results. A need for information was observed amongst participants, especially about the cause and prevention of CC. We found that having a male GP was a barrier, while women were often oblivious to the fact that it is possible to ask for a female GP or assistant. This suggests that the decision to participate (or not) is based on insufficient knowledge about CC screening.

We found several barriers to participate in CC screening, such as shame and taboo around CC, which contributed to a lack of knowledge and a low perceived susceptibility to CC, having a male GP, extra effort to schedule an appointment due to menstruation, pregnancies, and (un)cleanliness, scheduling difficulties, and lack of a good command of the Dutch language. Religion seemed to function as a barrier if people had a fatalistic approach, seeing the disease as something out of their control and God-given, and as a facilitator in regard to taking responsibility of one's own health, and using all medical options given by God. Fear of the test result, cancer, and death were also observed as both facilitating and hindering screening participation. Practical facilitators were the invitation letter, a short procedure time, and that screening is free of charge. Subjective norm was often not perceived to be influential on decision-making, but others could facilitate screening participation through emotional or verbal support.

Most participants had not heard about self-sampling before, but expressed a positive attitude towards it, especially for those who did not want to visit the GP. However, a lack of self-efficacy towards performing self-sampling correctly was observed when self-sampling was explained. As a result, women were concerned about whether the test results could be trusted. Consequently, participants hesitated about performing self-sampling and preferred clinician-based sampling.

Comparison with other studies

We showed that taking a fully informed and well-considered screening decision does not appear to be entirely reflective of the decision-making process in practice. Most participants reported considering not only factual medical information (i.e. detection of CC in an early treatable stage), but also practical, emotional, cultural, and religious aspects. This is in line with previous research regarding colorectal screening among the general Dutch population (Douma 2019). A study of Korfage et al. reported a limited IDM among native Dutch women regarding CC screening and also showed their unawareness of the possibility of false-negative and -positive test results (Korfage et al. 2011).

Many barriers and facilitators reported by this study are in line with previous research (Duran 2011; Lale, Ory, and Detmar 2003; Reis et al. 2012; Sahin et al. 2014; Yanikkerem et al. 2013). A previous study also found that participants associated CC with being infertile (Duran 2011). Participants in our study believed that others would think that they had multiple partners if they participated in CC screening. Studies that support this among Turkish and Moroccan women are lacking. However, two studies observed similar shame and stigma around Hepatitis B due to sexual transmission being one of the possible transmission routes (Hamdiui et al. 2018; van der Veen et al. 2014). Religion acting as both a barrier and facilitator had previously been reported by Duran (2011) in a study regarding CC screening participation among Turkish women, but was until now unknown to play a role among Moroccan-Dutch women as well (Duran 2011). In contrast to previous studies, we observed that fear of cancer and death functioned as a facilitator, since women wanted to use the chance to cure the disease would they fall ill, in order to prevent leaving their children behind after death. The fear of their children being left behind appeared to overthrow the fear of the test result, cancer, and death itself, and ultimately appeared as a key reason why women would participate in screening. Although many participants reported inability to understand the invitation letter and

information brochure, which is in line with other studies among Turkish-Dutch women (Jong 2005; Lale, Ory, and Detmar 2003; Zander 2008), we found that daughters play an important role in the decision-making process of their mothers by translating the letter and brochure, and ensuring that screening appointments were made. This finding is in line with SGM frequently acting as brokers for their parents in communicating with Dutch health care professionals (Katz 2014).

Previous literature showed that screening participation increased when never- and under-screened women were offered self-sampling (Sultana et al. 2016; Verdoodt et al. 2015). In line with previous studies among the general Dutch population, we found that women lacked trust in their correct performance of self-sampling and, consequently, lacked trust in the test result (Duran 2011; Polman et al. 2019; Sultana et al. 2016). However, in contrast to these studies where self-sampling was nonetheless preferred, Turkish- and Moroccan-Dutch women in our study were hesitant towards self-sampling and, thus, preferred clinician-based sampling. A possible reason for this discrepancy is that self-sampling instructions were deemed complicated by our populations, whereas Polman et al. (2019) showed in their study among the general Dutch population that the intelligibility of the self-sampling instructions were perceived very to extremely good (Polman et al. 2019).

Strengths and limitations

A strength of our study is that FGDs were held at community organisations and mosques that participants frequently visited. This provided a comfortable setting for participants. Additionally, one moderator was of Moroccan origin and another of Turkish origin, which also might have contributed to participants feeling more comfortable in participating in the discussions (Krueger and Casey 2002). Second, our sample shows a considerably even distribution between and within the groups of Turkish and Moroccan women regarding migrant generation status, age, educational level, and employment status, which indicates that we reached a diverse sample of Turkish and Moroccan women in the Netherlands.

A possible limitation of our study was that we only arranged an extra Turkish-speaking moderator for one FGD based on what contact persons of community organisations indicated as preferred language for the FGD. In some cases, contact persons indicated that participants could participate in the discussion in Dutch. However, during the discussion itself, some Turkish participants lacked a good command of the Dutch language. Because of this, other participants in the group translated the discussion. The accuracy of these translations could not be verified, as participants could translate according to their own beliefs. Participants might also have been unable to express themselves fully during these FGDs due to this lack of a good command of the Dutch language, therefore, reducing interaction in the group and causing possible loss of information. In the future, to avoid these situations, it would be better to ask every participant what her preferred language is beforehand instead of the contact persons of the community organisations only.

Recommendations and implications for future research

The majority of the participants lacked knowledge regarding CC and screening, which was partially caused by a lack of a good command of the Dutch language. We also

found that the need for information about HPV infection, developmental stages of (pre)-cancerous lesions, and prevention of CC is high. In order to increase knowledge and, therefore, IDM regarding screening participation, we suggest that female health care professionals deliver information at community-organised meetings in Turkish, Moroccan-Berber, and -Arabic. We also recommend including discussions about religious values in relation to health (care) and addressing the fear of leaving children behind whenever the mother dies due to the consequences of CC, which could be facilitated by respected female mosque members. Furthermore, as Turkish and Arabic brochures were difficult to understand due to the advanced language level or incorrect translations, we recommend to revise these. As the online availability was also a barrier for older women in particular, we suggest to let these brochures be brought under attention by women's GPs. Our findings also suggest that when addressing self-sampling uptake among Turkish- and Moroccan-Dutch women, tailored video or face-to-face instructions are needed, which need to focus on increasing self-efficacy towards correctly performing self-sampling, and emphasise the accuracy of this sampling method. These instructions need to take the lack of a good command of the Dutch language among FGM into account. As was suggested by our sample, face-to-face instructions could possibly be provided by the GP with a translator and video instructions need to be available in several languages (Dutch, Turkish, Moroccan-Berber, and -Arabic). Furthermore, our findings reflect that by extending the traditional HBM with the RAA construct 'descriptive and injunctive norm' and 'cultural factors' from Betancourt's model of Culture and Behaviour, this model proved itself valuable in conceptualising the plausible relationships between culture and religion, psychological processes, and behaviour, and we, therefore, recommend using this model in future research among these populations. In addition, an IDM measure that is reflective of the decision-making process in practice is urgently needed. Moreover, since this study is part of a larger project, we will focus on two main interventions in the coming years. First, a blended learning approach will be developed. Part of this approach is organising several community-organised meetings in Turkish, Moroccan-Berber, and -Arabic regarding CC and screening. Second, found determinants should be selected on relevance (through a quantitative study) and targeted by using tailored communication strategies (e.g. culturally sensitive educational films) to improve IDM regarding CC screening participation among Turkish- and Moroccan-Dutch women.

Conclusions

Turkish- and Moroccan-Dutch women lacked knowledge about CC and its screening, and seemed to be unaware of the cons of the CC screening programme. Although their IDM seems to be limited, this study showed that women do not only consider factual medical information, but also practical, emotional, cultural, and religious aspects prior to deciding to screen or not. Important barriers and facilitators for CC screening participation were identified among Turkish- and Moroccan-Dutch women. These factors need to be considered in designing tailored information materials and educational meetings. Self-efficacy about conducting self-sampling correctly should also be taken into account when addressing informed CC screening participation among Turkish- and Moroccan-Dutch women.

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Data availability

The authors confirm that the data supporting the findings of this study are available within the article.

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