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Perceptions of Barriers to Patient Participation: Are They Due to Language, Culture, or Discrimination?

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ABSTRACT

Previous research has shown that ethnic minority patients participate less during medical encounters than patients from majority populations. Given the positive outcomes of active patient participation, such as higher understanding of information and better treatment adherence, interventions are required to enhance ethnic minority patients' participation levels. However, little is known about what patients perceive as barriers hindering their participation. This study therefore aimed to explore differences in perceptions of barriers to patient participation among ethnic minority and ethnic majority patients in general practice. Eight focus-groups with Turkish-Dutch and indigenous Dutch participants were performed. A semi-structured topic-list concerning patients' enabling and predisposing factors to participate, and physicians' responses guided the interviews. Interviews were recorded, transcribed verbatim, and transcripts were analyzed using the constant comparison method described in Grounded Theory. Regarding Turkish-Dutch patients' enabling factors to participate, two perceptions of barriers were identified: (i) low Dutch language proficiency; (ii) a preference for an indirect communication style. Three perceptions of barriers to Turkish-Dutch patients' predisposition to participate were identified: (i) collectivistic values; (ii) power distance; (iii) uncertainty avoidance. Regarding doctors' responses, discrimination was identified among Turkish-Dutch patients as a perception of barrier to their patients' participation. None of these perceptions of barriers emerged among indigenous Dutch patients. This study contributes to our understanding of which perceptions of barriers might impede ethnic minority patients' level of patient participation. To enhance their participation, a combined intervention is needed, tackling the language barrier, raising awareness about cultural differences in values, and increasing doctors' cultural competencies to communicate adequately with ethnic minority patients.

An important aspect of effective medical communication is patient participation, defined as “the extent to which patients produce verbal responses that have the potential to significantly influence the content and structure of the interaction, as well as the health care provider's beliefs and behaviors” (Street & Millay, 2001, p.62). Previous research has indicated that ethnic minority patients generally participate less actively during medical consultations than patients belonging to the majority population; they ask fewer questions, are less verbally dominant, and display fewer initiatives (Cooper-Patrick et al., 1999; Schouten & Meeuwesen, 2006). This relatively lower participation of ethnic minority patients might be problematic, because actively participating patients better understand and adhere to their treatment (Street, Gordon, Ward, Krupat, & Kravitz, 2005), and are more satisfied with the communication and care they receive (Street, Makoul, Arora, & Epstein, 2009).

It is, however, unclear why ethnic minority patients participate less during medical encounters than the majority population, as no research has addressed underlying mechanisms of these differences yet. More insight is particularly needed in patients' perceptions of barriers to participation, to be able to

design effective future interventions that stimulate their participation. We choose to study perceptions of barriers rather than actual barriers – although the two may overlap – because previous research has indicated that perceptions can be equally if not more predictive of behavior than more objective components of reality (Clarkson, Hirt, Jia, & Alexander, 2010). Hence, the aim of this study was to unravel patients' specific perceptions of barriers to participation during medical encounters in general practice. As consultations in Dutch general practice are fixed to 10 minutes each, this context makes it particularly important that providers shape an environment in which there is sufficient space for patients' voices to be expressed and heard, in order to achieve an adequate doctor–patient communication process.

For this study, Turkish-Dutch patients are chosen as reference group. Migration of Turkish people to the Netherlands started with the recruitment of male workers by the industries in the 1960s for cheap labor. While many Turkish men saw their Dutch labor as temporary and planned to return to Turkey, migration became more permanent with the migration of their wives and children to the Netherlands (years after the migration of the men) for reasons of family reunification.

Nowadays, they are the largest migrant group in the Netherlands with over 400,000 people in 2017 (Central Bureau of Statistics, 2017). The Turkish-Dutch community consists of specific characteristics that might make them particularly vulnerable to experiencing and perceiving barriers to patient participation. That is, Turkish-Dutch migrants are the least proficient in the Dutch language (Huijnk & Dagevos, 2012) and are more likely to adhere to the values of their own community regarding religion, marriage and gender roles than other large migrant groups in the Netherlands (Crul & Doornik, 2003). They also report poorer health status and more health problems, visit their general practitioner (GP) more often, and experience more miscommunication and less mutual understanding in health care (Uitewaal et al., 2004) than Dutch and other non-Western migrant patients. Previous Dutch research has further indicated that Turkish-Dutch patients are less verbally dominant, exhibit fewer initiatives, and are less engaged in dialogues with their GP than Dutch patients (Schinkel, Van Weert, Kester, Smit, & Schouten, 2015).

Theoretical background

Street's *linguistic model of patient participation in care* (2001) suggests that both patients' enabling and predisposing factors, and physicians' responses determine patients' level of participation. Hence, this model suggests a two-way interaction in which both the patient and the doctor affect patients' participation. It emphasizes the crucial role of physicians' communicative behavior and suggests that patients are not passive participants in the encounter, but can actively shape the content of the consultation too. It thus takes an interactional stance toward patient participation. As there is a dearth of research specifically addressing perceptions of barriers to patient participation within the context of culture, below we will review the broader literature on intercultural doctor-patient communication within the confines of this model.

Patients' enabling factors

Patients' enabling factors entail the communicative skills, resources, and routines of patients to participate in the consultation. For instance, patients will be more enabled to discuss medical issues when they share sufficient common ground regarding preferred and enacted communication styles and a common language with their physician. Previous research has indeed indicated that ethnic minority patients who are less proficient in the physicians' language had lower participation levels compared to ethnic minority patients who are more proficient (e.g., Meeuwesen, Harmsen, Bernsen, & Bruijnzeels, 2006). As Turkish-Dutch patients are the least proficient in the Dutch language of all main migrant groups in the Netherlands (Huijnk & Dagevos, 2012), their low Dutch language proficiency might be an important barrier to their participation during medical encounters. It

should be noted, though, that results of a recent study among Turkish-Dutch GP patients indicated that when patients take along informal interpreters¹ with them to the consultation, the interpreters' Dutch language skills are perceived to be sufficiently adequate to enable these patients to communicate properly with their GPs (Zendedel, Schouten, Van Weert, & Van Den Putte, 2016). Hence, the impact of low language proficiency on perceptions of barriers regarding patient participation is not that clear-cut.

In addition to the language barrier, culture-related differences in preferred and enacted communication styles between indigenous Dutch physicians and Turkish-Dutch patients might hinder Turkish-Dutch patients' ability to participate during medical encounters. In general, Western people tend to communicate in a low-context style in which communicators are direct, precise, open, and quickly get to the point (Hall, 1976), while non-Western people tend to communicate more in a high-context style, a more indirect and implicit style in which people do not explicitly come to the point but expect others to infer meaning from the context of the conversation, both verbally and non-verbally (Gudykunst et al., 1996; Korac-Kakabadse, Kouzmin, Korac-Kakabadse, & Savery, 2001). In addition, low-context people are more solution oriented and confrontational, whereas high-context people are less solution oriented and more non-confrontational (Chua & Gudykunst, 1987).

Patients' predisposing factors

Street's *linguistic model* (2001) contains several social, psychological, and cultural variables that predispose a patient to participation during medical encounters, including patients' belief in the appropriateness of participation and their perceptions of rapport with their provider. Results of previous research indicate that ethnic minority patients are less predisposed to participate compared to majority populations (e.g., Johnson, Roter, Powe, & Cooper, 2004; Levinson, Kao, Kuby, & Thisted, 2005; Street et al., 2005), which might partly be explained by having strong collectivistic values, such as being obedient and maintaining harmony in conversations (Gudykunst et al., 1996). Their predisposition to actively participate, which involves being assertive and taking initiatives (and hence being more low-context), might therefore be lower. A study among Chinese patients showed that collectivistic values are indeed related to more negative beliefs about patient participation, such as assertive behavior (Kim et al., 2000). Hence, the more collectivistic values of Turkish-Dutch people compared to indigenous Dutch people (Hofstede, 2001) might be a barrier to active participation during medical encounters.

In addition, in non-Western cultures, such as the Turkish culture, a higher power distance (the degree to which people accept and expect power to be distributed unequally, Hofstede, 2001), can also predispose Turkish-Dutch patients' to participate less actively. In non-Western cultures, medical decision making

¹Turkish-Dutch patients commonly make use of informal interpreters instead of professional interpreters when visiting their GP because the free provision of professional interpreters has ceased to exist in the Netherlands. Turkish-Dutch patients have indicated that they prefer family members to interpret for them instead of professional interpreters (Zendedel, 2017).

is often the responsibility of the doctor and family, instead of the individual patient (Gaston & Mitchell, 2005). Turkish-Dutch patients might expect a large power distance in medical encounters, thereby preferring the doctor to take control and to play a more passive role in the conversation than indigenous Dutch patients. Note that power inequalities, inherent in encounters between dominant and marginalized groups, could also be a reality that Turkish-Dutch patients have to contend with, thereby not so much reflecting an accepted cultural value but a system-level factor which silences these patients' voices and diminishes their quality of care (e.g., Marmot, 2005).

Physicians' responses

Physicians' communicative behavior during the medical encounter exerts a major influence on patients' participation levels. Physicians' communicative behavior seems to have a stronger negative influence on migrant patients' participatory behaviors than patients' individual characteristics (Schouten, Meeuwesen, Tromp, & Harmsen, 2007). Ethnic minority patients, in particular the ones with low language proficiency, receive less information, less empathetic responses, less rapport building and are less likely to be encouraged to be participative than ethnic majority patients (Ferguson & Candib, 2002). In addition, mutual perceptual biases between patients and physicians have been documented by, for instance, Van Ryn and Burke (2000) who found that American physicians perceive African-American patients as less likely to adhere to medication compared to White patients. Also, African-American patients perceive more unfairness in getting the treatment they need, perceive more racism and have more mistrust in the medical system than White patients (LaVeist, Nickerson, & Bowie, 2000). Hence, besides patients' enabling and predisposing factors, patients' perceptions of negative physicians' responses could be an important barrier to Turkish-Dutch patients' participation.

In sum, differences between indigenous Dutch and Turkish-Dutch patients in their enabling and predisposing factors, as well as physicians' responses might explain why Turkish-Dutch patients' participate less during medical encounters than indigenous Dutch patients. Because studies so far focused on barriers of (intercultural) doctor-patient communication in general and no studies yet exist identifying which factors are specifically perceived as a barrier to patient participation, this study explored differences in these perceptions of barriers among indigenous Dutch and Turkish-Dutch patients consulting an indigenous Dutch GP. The central research question was: How do indigenous Dutch and Turkish-Dutch patients differ in their perceptions of barriers concerning patient participation during a GP consultation?

Methods

Participants

Eight focus groups of five to seven participants were conducted between April 2013 and May 2014, four with Turkish-Dutch, and four with indigenous Dutch participants. We used the ethnicity definition of the Dutch Central Bureau of Statistics to

form groups of indigenous Dutch and Turkish-Dutch migrant participants. In the Netherlands, a migrant is defined as a person who is born in another country than the Netherlands or of whom one of his/her parents is born in another country than the Netherlands (Central Bureau of Statistics, 2000). According to this definition, a person who is born in Turkey or has parents born in Turkey, and is now living in the Netherlands, is called a Turkish-Dutch migrant. Participants born in the Netherlands with both parents born in the Netherlands are categorized as indigenous Dutch.

We composed small focus groups to allow for greater contribution of participants (Bender & Ewbank, 1994; Kitzinger, 1995). In total, 46 participants participated: 22 Turkish-Dutch (12 men, 10 women) and 24 indigenous Dutch (12 men, 12 women). All participants met the following inclusion criteria: (1) have a Dutch speaking GP; (2) have had an appointment with their GP in the last six months; (3) be able to read and speak in Dutch or Turkish. All Turkish-Dutch participants were born in Turkey, were migrated at the age of 24.25 on average ($SD = 8.85$, range 14–51) and reported to live in the Netherlands for 32.80 years on average ($SD = 7.32$, range 16–45).

Focus groups were run separately for indigenous Dutch and Turkish-Dutch, male and female, and older and younger participants. We separated older and younger participants because of possible linguistic and cultural differences between the age groups. We excluded participants under the age of 40 because of their higher Dutch language proficiency and better acculturation in Dutch culture than older participants (Huijnk & Dagevos, 2012).

Because patients' level of patient participation is influenced by gender, age, and educational level (Kiesler & Auerbach, 2006; Levinson et al., 2005), indigenous Dutch and Turkish-Dutch participants were matched as far as possible on these characteristics to have comparable groups. As can be seen from Table 1, indigenous Dutch and Turkish-Dutch participants did not differ significantly in age ($t(44) = .71$, $p = .49$), educational level ($\chi^2(4) = 8.45$, $p = .08$), satisfaction with GP ($\chi^2(3) = 6.11$, $p = .11$), and duration of relationship with GP ($\chi^2(2) = .88$, $p = .65$). In each group, the majority of patients had different GPs and participants had male, as well as female GPs.

Recruitment

To enable an in-depth dialogue on perceptions of barriers to patient participation, we recruited participants who would most likely have difficulty with active participation: lower acculturated, less language proficient, and lower educated participants. We recruited Turkish-Dutch migrant participants via key figures at community centers (women) and a mosque (men) by using purposeful sampling. The older indigenous Dutch women were recruited via key figures at the same community center as the older Turkish-Dutch women and the older indigenous Dutch men were recruited at a residence for the elderly. The younger indigenous Dutch participants were recruited via a health center (women) and a soccer club (men). We recruited participants who knew each other because acquaintances discuss topics in a more natural

Table 1. Composition of focus groups.

Focus group	N	Gender	Ethnic background	Age group	Educational level	Duration of stay in the Netherlands
1	5	Female	Turkish-Dutch	Range 53–71 (<i>M</i> = 61; <i>SD</i> = 7.8)	4 Lower, 0 intermediate, 1 higher	Range 16–37 (<i>M</i> = 27.80; <i>SD</i> = 9.2)
2	6	Male	Turkish-Dutch	Range 55–75 (<i>M</i> = 65.67; <i>SD</i> = 7.6)	2 Lower, 3 intermediate, 1 higher	Range 38–45 (<i>M</i> = 40.50; <i>SD</i> = 2.4)
3	5	Female	Turkish-Dutch	Range 43–52 (<i>M</i> = 47.40; <i>SD</i> = 4.3)	1 Lower, 3 intermediate, 1 higher	Range 25–33 (<i>M</i> = 29.40; <i>SD</i> = 3.4)
4	6	Male	Turkish-Dutch	Range 48–56 (<i>M</i> = 51.83; <i>SD</i> = 3.5)	2 Lower, 3 intermediate, 1 higher	Range 25–35 (<i>M</i> = 31.75; <i>SD</i> = 4.6)
5	6	Female	Dutch	Range 66–90 (<i>M</i> = 78; <i>SD</i> = 8.3)	3 Lower, 3 intermediate, 0 higher	
6	5	Male	Dutch	Range 55–74 (<i>M</i> = 64.60; <i>SD</i> = 8.8)	0 Lower, 5 intermediate, 0 higher	
7	6	Female	Dutch	Range 46–53 (<i>M</i> = 50.33; <i>SD</i> = 2.4)	0 Lower, 4 intermediate, 2 higher	
8	7	Male	Dutch	Range 45–49 (<i>M</i> = 46.71; <i>SD</i> = 1.7)	0 Lower, 6 intermediate, 1 higher	

conversational flow and are less inhibited to talk than strangers (Kitzinger, 1994).

Moderator/Observer

A Dutch bilingual researcher of Turkish background (fourth author) led all focus groups to ensure reliability of the data (Lindlof & Taylor, 2011). By using one moderator for all groups, group interviews are more similar and thus more comparable. The moderator was an experienced focus group leader. Because the moderator was familiar with both cultures, she could take into account cultural aspects during the interviews, thereby accounting for cultural context (Bender & Ewbank, 1994). All focus groups were attended by an observer who made notes and dealt with refreshments, informed consent, questionnaire, and recordings.

Materials and procedure

Participants were given three forms prior to the focus groups: an information sheet, an informed consent form, and a short questionnaire to gather background information about the participants. To clarify the concept of patient participation and stimulate discussion, in all groups two film fragments were shown to the participants prior to the discussion, lasting around two to three minutes (Kitzinger, 1994). The first fragment showed an actively participating patient, the second fragment showed a passively participating patient. After watching, a semi-structured topic list was used in all focus groups, based on Street's model (2001). The following main topics were included: perceptions of barriers that enable patients to participate, perceptions of barriers that predispose patients to participate, and perceptions of barriers related to physicians' responses. The list consisted of several general open questions for each topic

and follow-through questions to deepen or stimulate the discussion.

For validity reasons, the moderator summarized statements of participants after each main topic and asked for suggestions or additional remarks. After the interviews, participants and key figures received a ten-euro gift card. The study was approved by the Ethical Committee of our research institute (2013-CW-13).

Data analysis

All focus groups were held in the centers where participants were recruited, lasted 45–90 minutes, were audiotaped, and transcribed verbatim. Three focus groups were led in Turkish and translated into Dutch by a Turkish-Dutch bilingual research assistant. Back-translation into Turkish was performed on 25 percent of the translated transcripts. Turkish translations were compared to the original audiotape by another Turkish-Dutch bilingual research assistant to ensure accuracy (Esposito, 2001). Apart from dialect differences, the content of the back-translation fully represented the Turkish interviews.

Constant comparative method from Grounded Theory was used to analyze the data (Glaser & Strauss, 1967). First, one coder (first author) coded two transcripts (one with indigenous Dutch and one with Turkish-Dutch participants) in Atlas Ti 7.1.6 through open coding for theme identification. Comments related to the main topics were marked with codes describing the themes. An indigenous Dutch research assistant and the bilingual moderator independently repeated this first step for the same transcripts to examine cultural differences in the interpretation of transcripts and increase the reliability of the analysis. Because only small coding differences emerged (for which mutual agreement was achieved), the first author coded the remainder of the transcripts.

Second, the first author compared the content of the codes across the Dutch and Turkish-Dutch groups in total and across the age and gender groups. For example, different discussions emerged between indigenous Dutch and Turkish-Dutch participants about responsibility, autonomy, assertiveness, and decision making, which reflected differences in preferred power distance. The first-order codings (e.g., assertiveness) were therefore summarized into second-order codings (e.g., power distance) and placed into the main themes (e.g., patients' predisposing factors) of Street's model of patient participation to categorize the main perceptions of barriers of patient participation. Differences between the participant groups were discussed extensively with the second and fifth author to identify the most important ones. Quotes are used in the results section to illustrate the findings. All quotes were first translated from Dutch into English by the first author; translations were then checked by the second and fifth authors for accuracy.

Results

Table 2 presents the perceptions of barriers within each main theme that emerged from the focus-group discussions, a description of all perceptions of barriers, and a number of quotes to illustrate these perceptions.

Patients' enabling factors

Two perceptions of barriers emerged regarding Turkish-Dutch patients' enabling factors to participate: Dutch language proficiency and preferred communication style. These perceptions of barriers did not emerge among indigenous Dutch participants.

Language proficiency

Turkish-Dutch participants discussed difficulties with understanding information and expressing themselves due to language problems. Participants feel ashamed and frustrated about their low proficiency in Dutch, and older Turkish-Dutch participants discussed that language problems inhibited them to participate actively. The results implicate that low language proficiency in Dutch is a large perception of barrier for their participation; they are simply not able to communicate effectively, it is hard to communicate at all – “We repeat the things the doctor tells us because we don't understand them. We repeat it and repeat it.” (FG2 (= Focus group 2), participant #1, older Turkish-Dutch man). An older Turkish-Dutch woman illustrates the relation between language problems and patient participation by comparing the participants who can't speak Dutch with a Turkish-Dutch woman who can:

“She can communicate better and she can express herself to a doctor. Because she knows the language... She does not hesitate to discuss her problems with the doctor. We are shy and reluctant. Because we don't know the language.” (FG1, participant #3, older Turkish-Dutch woman)

Older Turkish-Dutch participants expressed more language difficulties than younger ones and discussed their experiences with informal interpreters, mainly their (grand)children. Not

everything is translated, especially when it involves information that can distress the patient – “She [daughter] does not translate everything back to me. She does not want me to get sad about it.” (FG1, participant #1, older Turkish-Dutch woman). Additionally, not everything can be discussed in the presence of an informal interpreter – “Sometimes it involves such problems... which we do not want to share with a third person... [...] Imagine that you get a serious illness and your son is the first one who hears about that from the doctor and has to tell you that.” (FG2, participant #1, older Turkish-Dutch man).

Although Dutch language proficiency is better among younger Turkish-Dutch participants, they also discussed difficulties with expressing themselves in Dutch. They mentioned thinking in Turkish but having to talk in Dutch, which requires more time. Hence, even with better Dutch language proficiency, the language barrier still is perceived to hinder younger Turkish-Dutch patients to participate.

Preferred communication style

Both older and younger Turkish-Dutch participants often perceived communication style differences with their GP as a barrier for their participation. Communication style did not emerge as a perception of barrier among indigenous Dutch participants; they expressed satisfaction with their GP and discussed the importance of being able to be open and to-the-point and to ask and say everything. The conversation is direct and goal oriented; they discuss with the GP what is relevant to their health problem to get good treatment – “...we are quite assertive.” (FG5, participant #3, older Dutch woman).

In contrast, Turkish-Dutch participants reported discomfort with their GP's direct and confrontational communication style; the GP asks too many questions and is too direct and impersonal. When a GP asks direct questions about their health problem, he/she is perceived as careless. They indicated that they prefer a GP who is supportive and caring, and incorporates social talk and emotions. A high-context communication style was also noticeable during the focus groups, in which Turkish-Dutch participants oftentimes used an indirect communication style, for instance by telling anecdotes to illustrate their answers, instead of answering directly to questions (which seldom occurred during the indigenous Dutch focus groups, who answered questions directly and to-the-point). Turkish-Dutch participants indicated to prefer a high-context, indirect way of communicating with their GP:

“As long as the doctor is similar to you [Turkish], then it doesn't matter in what language you speak. Because a doctor... [...] without speaking he should be able to understand you based on your posture, the way you walk or how you look at him. You don't need to explain everything.” (FG4, participant #5, younger Turkish-Dutch man)

As is clear from the above quote, Turkish-Dutch participants stressed the importance of non-verbal communication, such as laughing and touching, to build a positive relationship – “When he sees me he laughs and asks how I am doing. I mean, that is something beautiful.” (FG1, participant #2, older Turkish female)

Table 2. Perceptions of barriers of patient participation among indigenous dutch and Turkish-dutch participants.

Main theme	Perceptions of barriers	Description of barriers	Sample quotes indigenous Dutch patients	Sample quotes Turkish-Dutch patients
1. Enabling factors	Language proficiency	Barrier to participate because of low Dutch language proficiency	Not applicable	"In Dutch, I'm able to point to for instance my kidney or something else and then say that it hurts. But I can't be more specific than that." (Older Turkish female) "I find it difficult [explaining the health problem], because I don't speak the language." (Older Turkish female) "If I would go without an interpreter, then I would only be able to say pain." (Older Turkish male) "When I have a good conversation with my GP, I do not have any worries anymore. Perhaps it is because of the good conversation that we feel better; it diminishes the stress. I have a beautiful day that day." (Older Turkish female) P1: "Some people can, although they do not speak the [other's] language." P2: ".by just gesturing." P1: ".still communicate." (Older Turkish females) "The doctor's assistants are not very kind to us. They ask a lot of questions. Why are you calling? What do you want?" (Older Turkish female) "My doctor laughs a lot. [...] He is very kind." (Older Turkish female) "They [Turkish-Dutch patients] rather choose a female doctor. Why? They look more friendly, and they give you more time." (Older Turkish male) "A Turkish doctor is able to satisfy a patient with words only. A Dutch doctor focuses on stress or pain killers." (Younger Turkish female) "A doctor should not be like a remote control, from a distance asking where does it hurt, I'll write you this or that, and then bye. That's unacceptable." (Younger Turkish male) "He [GP] could have asked his question in a different manner.[...] He could have asked by grabbing his [patient in film fragment] arm and moving it to find out whether it hurts and what kind of pain it was..he could have understood.., but the GP did not bother." (Younger Turkish male) "I am worried about my health, and there is no end to his questions! I think he [doctor's assistant] puts a list before him: do you have this, do you have that?" (Younger Turkish male)
	Communication style	Barrier to participate because of differences in preferred communication style between patient and GP: direct and to the point versus indirect and implicit	"I can ask everything you know. Everything." (Older Dutch female) "When you finish your story and he gives you those pills or whatever, then you're done right?" (Older Dutch female) "I just tell [the GP] what is the matter, and then I start talking." (Older Dutch female). M: "I understand that nobody has problems [with expressing complaints]" P1: "No, I don't." P2: "No." (Older Dutch females) "I can say everything to him [GP]." (Older Dutch female) P1: "Well, the GP appreciates her [other patient] for it. An elderly that is so assertive." P2: "Well, I do forgot things sometimes." P3: "But you have become as assertive as can be!" (Older Dutch females) M: "What is needed to do so? To take up an active role [during doctor-patient communication]" P1: "Well, that you are assertive and take the initiative." (Older Dutch male) M: "So, you can stand up well for yourselves?" P1: " Yes, I uhm..I ehm can do so...at the GP." P2: "Certainly." M: " " " P3: "But we are quite assertive." (Laughs) (Younger Dutch females) P1: "If you are not sufficiently quick-witted, you will receive less quality care than someone who is quick-witted." P2: "Yeah, that's true." P3: "Yes, that's true [...]" (Dutch younger males) "If I don't understand, I will continue to ask questions." (Dutch younger male).	

(Continued)

Table 2. (Continued).

Main theme	Perceptions of barriers	Description of barriers	Sample quotes indigenous Dutch patients	Sample quotes Turkish-Dutch patients
2. Predisposing factors	Individualism/Collectivism	Barrier to participate because of different cultural values: individualistic (Dutch) versus collective goals (Turkish), independence versus strong relationships	"When something needs to be done... Well no problem of course. In most cases, I decide for myself what I prefer anyway." (Older Dutch female) "Being a bit assertive is pretty good." (Older Dutch female). M: "How would you describe the relation with your GP?" P1: "Good." P2: "Business like." P3: "Yes." M: "Business like?" P2: "Yes." P4: "Yes." P1: "Yeah, eh." P2: " And also uhm..not like friends or something." (Older Dutch males).	"Sometimes he [former doctor] said some Turkish words, he let us feel he was close to us. When you left his room, you left it with a smile." (Older Turkish male) "You just feel better [with her Turkish dentist]. How are you? Yeah, how is the little one and your husband, and so on. It is like visiting an acquaintance, something like that...And with my GP, I don't have that." (Younger Turkish female) "I think ten minutes for an appointment is just minimal, it's no good. The doctor cannot really know his patient this way." (Younger Turkish female) M: "How should a GP behave towards you?" P1: "Like family." (Younger Turkish male)
			"But that person is being overruled by her doctor. And, she does not have a good doctor. And I think that.. I think that that is uhm wrong." (Older Dutch female) "I remember that I used to have a tremendous amount of respect for my GP. Yes, that is, of course, a long time ago [laughing]." (Older Dutch female) "Some people think well the doctor knows best. Right, cause I'm sick and that man is going to make me better. Well, I don't have that, that's... no, never had it." (Older Dutch male)	"In the end he is a doctor. He has studied for it. Ultimately uhm...he sees ill people every day. He has more knowledge. How can I say 'no' to the doctor? I accept everything he says." (Older Turkish female) "My daughter was sick and the doctor asked what she wanted and what the doctor should do. Then my daughter answered if I knew what to do and what you should do I wouldn't be here, then I would look for a solution myself" (Older Turkish male) " If there is something the matter with me, he [the doctor] has to find out what it is." (Younger Turkish female) "Go home today and come back tomorrow. When you use this medicine it will disappear, over and over again. Why don't you give me what's really necessary in the first place?" (Younger Turkish male)
	Power distance	Barrier to participate because of different values regarding distance to GP: low (Dutch) versus high (Turkish)		
Uncertainty avoidance	Uncertainty avoidance	Barrier to participate because of different values regarding dealing with tolerance for uncertainty and ambiguity: low (Dutch) versus high (Turkish)		

(Continued)

Table 2. (Continued).

Main theme	Perceptions of barriers	Description of barriers	Sample quotes indigenous Dutch patients	Sample quotes Turkish-Dutch patients
3. Physicians' responses	Perceived discrimination	Barrier because of feelings of being treated differently because of ethnic/linguistic background	"When I visit [the GP] with my [health] complaints, then I am being listened to, I am taken seriously..." (Dutch younger female) "I don't visit [the GP] often, but when I go, I am taken seriously..." (Dutch younger female) "When I am with him or her [GP], I feel that I am being taken seriously." (Younger Dutch male) "He [GP] pays attention." (Younger Dutch male)	"They [GPs] will not refer you to the hospital if you cannot express yourself well enough." (Older Turkish female) "Hidden or open...everywhere in the Netherlands or in other countries, there is discrimination." (Older Turkish male) "I feel betrayed here [in the Netherlands]...that is why I do not trust them [doctors]. They use us as guinea pigs...as guinea pigs...that's how I feel." (Older Turkish male) "Something has to go seriously wrong first, before they start listening. That is my experience." (Younger Turkish female) "And ehm...at a certain moment [...] I started to cry and I said: 'I will not leave until you have referred me [to the hospital].'" (Younger Turkish female) "I do not visit my GP often, but it is always the case that you do not get the answers that you want or uhm...the medication that you want." (Younger Turkish female) "Is it because I cannot explain my problems or because of the indifference of the GP? He did not take me very seriously." (Younger Turkish male) "These people [Dutch doctors] did not take us seriously. Maybe because we are foreigners." (Younger Turkish male)

Patients' predisposing factors

Three perceptions of barriers emerged regarding patients' predisposition to participate, reflecting the following cultural value dimensions: individualism/collectivism, power distance and uncertainty avoidance (i.e., the degree to which people tolerate uncertainty and ambiguity; Hofstede, 2001).

Individualism/Collectivism

Whereas indigenous Dutch participants primarily discussed individualistic values, collectivistic values were most prominent in the discussions among Turkish-Dutch participants. Indigenous Dutch participants valued being autonomous and taking responsibility for their own health. Hence, indigenous Dutch participants believe that patients are responsible for providing their GP with information:

"...when you visit a doctor and uhm you do not tell a doctor anything yourself (participant #1)... and your doctor has to get that out of you. That is not good. [...] That is not up to the doctor... that is mainly up to you..." (FG6, participant #4, older indigenous Dutch men)

Whereas most indigenous Dutch patients do not believe that talking about personal matters is important to establish a good relationship with the GP, except when these are related to the medical problem, Turkish-Dutch participants agreed on the importance of a strong and warm relationship with their GP, and discussed that most indigenous Dutch GPs are too formal and aloof. Turkish-Dutch participants reported to prefer a GP who is like family, who knows the patient's personal situation, which reflects their collectivistic values:

"We see him as family member. [...] When I go to the doctor, he first shakes hands and welcomes us. Walks with you to the door and apologizes when you had to wait... [...]. First he asks how I am doing and how the children are doing. And then he asks about my health problems and does his research. [...] I'm very satisfied." (FG4, participant #1, younger Turkish-Dutch man)

Power distance

From the discussions among indigenous Dutch participants, a smaller power distance between patients and GPs emerged than among Turkish-Dutch participants. Indigenous Dutch participants agreed with each other that as a patient they want to share decisions and discuss treatment options, all reflecting a small power distance between GPs and patients. Disagreeing with their GP was seen as an opportunity to share opinions; it is part of the conversation:

"When I am with the doctor and she says you have to go left and I think well... I could also go right, then you start a discussion, that should be discussable." (FG7, participant #1, younger indigenous Dutch woman)

Turkish-Dutch participants on the other hand indicated that the GP knows best and is responsible for their health and its treatment; therefore, the GP should decide about the diagnosis and treatment. Turkish-Dutch participants agreed on that you accept the advice or treatment a GP prescribes:

"If we would act according to our ideas, why would I go to a doctor? The doctor's thoughts are more important than ours. His thoughts count for 95 percent and ours for five." (FG4, participant #1, younger Turkish-Dutch man)

Turkish-Dutch participants discussed feeling frustrated when their GP actively tries to involve them and asks them what to do. They think such a GP is not capable of doing his work and become silenced by the situation:

"...and then I tell him about my complaint and then he says: 'What do you think I should do about it?' Then I say... well... when I would know that, I wouldn't be sitting here! That's enough for me then, then I've had it with him." (FG3, participant #4, younger Turkish-Dutch woman)

Despite the fact that all Turkish-Dutch participants agreed on a large power distance between GPs and patients, no consensus was reached among younger Turkish-Dutch participants in which behaviors they valued when disagreeing with the GP. While older participants thought it would be rude to disagree with the GP because the patient is subordinate to the GP, some younger participants indicated that they do discuss disagreements with the GP:

"When I'm not satisfied then I tell him that it's not possible. It happens that I tell the doctor like, you are the doctor but on this topic you're wrong. We have this kind of dialogue. Sometimes he is right of course, at the end he is the doctor." (FG4, participant #2, younger Turkish-Dutch man)

Uncertainty avoidance

The positive attitude among indigenous Dutch participants towards how treatments are organized in the Dutch health care system reflects lower uncertainty avoidance than among the Turkish-Dutch participants, who expressed frustration about how the Dutch health care system is organized. Turkish-Dutch participants were well aware of the protocols in the system, but criticized them, such as making a double appointment with the GP when you have more than one health issue, and the obligation to get a referral before you are allowed to visit the hospital. Indigenous Dutch participants only expressed frustration about the new setup of larger general practices in which you don't have a regular GP anymore. The health system itself seems to suit them. In addition, they discussed treatment in which you try different things or a wait-and-see approach as good practice.

In contrast, among Turkish-Dutch participants, treatment is not accepted when it involves trying different options or a wait-and-see approach. The general consensus among Turkish-Dutch participants was that only one right treatment exists and that one should be immediately prescribed. One participant indicated that he feels he has not been treated when the GP wants to wait for the medication to work:

"Our GP also rarely treats us. [...] He prescribes some pills and says come back in about three weeks if the pain is still there." (FG4, participant #3, younger Turkish-Dutch man)

Additionally, the need for physical research instead of talking is discussed in all Turkish-Dutch groups; they expressed concern when a GP only asks questions and does not research their body. "Sometimes I think: what kind of question is this? All these stupid questions. Do some research!" (FG3, participant #3, younger Turkish-Dutch woman)

Physicians' responses

Perceived discrimination

The main barrier that emerged regarding physicians' responses among Turkish-Dutch patients was perceived discrimination, ranging from participants reporting being treated indifferently and neglectful, to being openly discriminated by their GPs and other physicians. They commonly discussed feelings of being treated differently because of their ethnic, cultural and/or linguistic backgrounds, resulting in frustration and anger, which might lead to inhibition to participate actively. This barrier perception was not mentioned by indigenous Dutch patients, who were generally quite satisfied with their GP, and felt they were taken seriously and treated with respect by their GP.

The older Turkish-Dutch participants often attributed their feelings of being discriminated to their low Dutch language proficiency. For instance, a highly educated older Turkish-Dutch woman discussed that her GP did not want to speak in English with her but only in Dutch. She illustrates her feelings as follows:

"Because of the language they don't care about us. They want to speak in their own language. [...] He did not pay attention to my disease because I wanted to speak in English. [...] When you speak Dutch, then you will be treated carefully." (FG1, participant #2, older Turkish-Dutch woman)

Hence, due to their low Dutch language proficiency, Turkish-Dutch patients perceive that they are not being taken seriously and get worse treatment than indigenous Dutch patients. One of the older men discusses that he thinks Dutch doctors treat them differently because of their worse Dutch language proficiency as follows:

"I think there is hidden or open discrimination... When you are more proficient in Dutch language, the doctor will treat you more carefully. The doctor will be more humble and careful, because that patient can speak up for himself and can act on his rights." (FG2, participant # 3, older Turkish male)

Another aspect related to participants' feelings of being discriminated has to do with their religious background. They feel they are being forced to act in ways that go against Islamic rules and traditions, such as, for instance, showing their selves to another man than their husband or children. One participant recalled being asked by a male physician to take off her clothes because of an X-ray, which was later on revoked by a female physician:

"Undress, he [physician] said to me. I won't undress, I replied, I am wearing a headscarf. [...] He said, why don't you undress, I told you to undress. Everyone that comes here takes off their headscarves and undresses. [...] I went to see another physician. [...] It was a female physician. I asked her if I should undress. No, she replied, that is not necessary." (FG1, participant #2, older Turkish female).

The younger participants, having less difficulty with Dutch language, do not relate feelings of discrimination to their Dutch language proficiency, but feel they are discriminated because of their ethnic and cultural backgrounds:

"Then the doctor talked [to another doctor] like: here's a Turkish child crying, sick and his dad is panicking. I got angry and asked

him what kind of doctor he was. Is it about a nationality or a health complaint? [...] I dropped his phone in his face and left. Such things happen, racism, treatment on nationality." (FG4, participant #1, younger Turkish-Dutch man).

Discussion

The results of our study show that Turkish-Dutch patients perceive many different barriers regarding enabling and predisposing factors to participate, and because of physicians' responses. Within these three broader themes, the main perceptions of barriers that emerged were having a low Dutch language proficiency, a preference for an indirect communication style, having different cultural values than their GPs, and perceiving discrimination because of their linguistic, cultural and/or ethnic background. Indigenous Dutch patients, who are generally satisfied with the communication process with their GPs and their level of participation during medical encounters, report none of these barriers. Hence, our results confirm the basic tenets of Street's linguistic model of patient participation in care (2001), by showing that both patient-related factors and physician-related factors can either hinder or stimulate patient participation during medical encounters and tend to interact with each other.

The low Dutch language proficiency reported by, in particular older, Turkish-Dutch patients, points to a host of difficulties in enabling them to participate during medical encounters, because, for instance, they do not understand their GP well enough and cannot express their health problems properly. Although this barrier perception was less present among younger Turkish-Dutch patients, they too indicated that due to thinking in the Turkish language they had difficulty to express themselves clearly. This result is in concordance with previous studies (e.g., Sudore et al., 2009), indicating that language barriers negatively impact the quality of doctor-patient communication. Although older Turkish-Dutch participants try to overcome this language barrier with their GP by taking along family members to interpret for them, this is often not perceived as being an adequate solution. Their presence inhibits them from being entirely open to the GP and because the interpreter does not translate everything they say. These findings are consistent with previous research suggesting that informal interpreters omit information, inhibit patients, make errors in translation and even tend to exclude the patient from participating during medical conversations (Aranguri, Davidson, & Ramirez, 2006; Leanza, Boivin, & Rosenberg, 2010; Schouten & Schinkel, 2014), but contradict recent Dutch research on family interpreters among Turkish-Dutch women, who did not perceive difficulties with family interpreters (Zendedel, 2017). Hence, the seemingly obvious solution to make use of professional interpreting services, which is hindered by financial barriers nowadays in the Netherlands, might not be preferred or even necessary for all Turkish-Dutch patients. Therefore, GPs should take into account each individual patient's needs regarding interpreting services and guidelines should be developed that help GPs decide about which type of interpreter to use in which situation (for a similar perspective, see Gray, Hilder, & Stubbe, 2012).

Bridging the language gap is a first, necessary step to improve migrant patients' ability to participate, but, as our results indicate, there are many other perceptions of barriers hindering their participation during medical encounters. In line with earlier research indicating that Turkish-Dutch people prefer a more indirect communication style (Schouten, 2008), the direct, low-context, communication style of Dutch GPs is perceived as a hindrance to Turkish-Dutch patients' ability to participate in medical conversations. While indigenous Dutch patients stress the benefits and importance of being open and to the point, Turkish-Dutch patients are dissatisfied when their GP directly asks them what they want or think, feel discomfort with their GPs' direct and distant communication style and, as a consequence, become silent. They repeatedly indicated to prefer communicating in a high-context style, as has been found in previous research (e.g., Gudykunst et al., 1996; Korac-Kakabadse et al., 2001), in which there is space to share their illness stories and express emotions (non-verbally). The instrumental manner in which GPs tend to communicate with them, is thus not in concordance with their preferences, and consequently lowers their ability to participate during the doctor-patient communication process.

Regarding perceptions of barriers concerning patients' predisposing factors, cultural values emerged as an important factor underlying perceptions of difficulties in Turkish-Dutch patients' participation. In concordance with their collectivistic values (Hofstede, 2001), Turkish-Dutch participants value a GP who acts like family and stress the importance of having a warm and strong relationship for good communication. In contrast, indigenous Dutch participants prefer a more formal, individualistic relationship, in which personal matters are not that important. The perceived impersonal relation with their GPs causes Turkish-Dutch patients to withdraw from the interaction and lowers their willingness to participate actively. As people from predominantly collectivistic cultures attach much value to relationship building based on trust and tight personal networks (e.g., Korac-Kakabadse et al., 2001), the distant relation with their GP might effectuate negative emotions toward their GP during the medical encounter, causing these patients to shut down. Alternatively, as previous research has indicated that GPs themselves are less affective toward ethnic minority patients than towards patients having the same ethnic background as themselves (Schouten & Meeuwesen, 2006), Turkish-Dutch patients might simply mirror this cold, impersonal attitude of their GPs, by becoming withdrawn themselves. Hence, more research is needed to be able to better understand the underlying processes explaining the relation between having collectivistic values, the doctor-migrant patient relation, and patients' predisposition to participate during medical encounters.

Another culture-related difference in values is reflected in the finding that disagreeing with the GP is considered to be rude, inappropriate and embarrassing to Turkish-Dutch patients. Turkish-Dutch participants feel their GP is responsible for their health and should know what to do, in contrast to indigenous Dutch participants who want to share responsibility and decision-making, and prefer to be autonomous

and assertive. This difference in power distance is in line with findings indicating that non-Western patients prefer the doctor to make their health decisions (Levinson et al., 2005). In addition, the concept of *face* as explained in face-negotiation theory (Ting-Toomey, 1988) might explain why Turkish-Dutch patients feel disagreeing with their GP is rude and embarrassing, as this poses a threat to maintaining face in a potential conflict situation. As cultural collectivism is associated with avoidant conflict styles (Oetzel & Ting-Toomey, 2003), face-saving motives might explain why Turkish-Dutch patients prefer not to disagree with their GPs.

Regarding perceptions of barriers concerning GPs' responses, our results show that Turkish-Dutch patients perceive discrimination on the part of their Dutch GPs to be a main barrier to active participation, and to contribute to the often-noted ethnic inequalities in health care (Marmot, 2005). The negative experiences reported by Turkish-Dutch patients might cause them to have a profound mistrust in the medical system and quality of treatment they receive (e.g., LaVeist et al., 2000; Lillie-Blanton, Brodie, Rowland, Altman, & McIntosh, 2000). The fact that in the Netherlands migrant patients in general and Turkish-Dutch patients specifically overuse general practice care, while at the same time underusing specialized care (Uiters, Devillé, Foets, & Groenewegen, 2006), points to the possibility that, in some instances, they indeed receive differential and worse treatment than indigenous Dutch patients. The Turkish-Dutch patients in our study told an abundance of stories about not getting needed referrals and being treated inadequately by their GPs, leading to diminished access to specialized care. Further research is urgently needed to assess the extent to which these differential treatments take place in Dutch health care and which factors explain this phenomenon. According to the patients in our study themselves, their low Dutch language proficiency, having an Islamic religious background, and being from Turkish descent, might all contribute to not being taken sufficiently seriously by GPs and other health providers with not only decreased patient participation, but detrimental health outcomes as a consequence. Hence, the inherent power inequality between Turkish-Dutch patients and their health providers, caused by inequalities in having access to much needed economic, social and other forms of capital (see Bourdieu, 1986), place these patients at increased risk of being marginalized and treated unfairly by the Dutch health care system.

Study limitations and suggestions for further research

Our results indicate that several types of perceptions of barriers exist that hinder migrant patients' participation levels during consultations with their GP. Due to the qualitative approach of the current study, the extent to which each of these perceptions of barriers influences actual patient participation remains open to further quantitative research. Furthermore, because our sample consisted of mainly lower-educated patients, who participate less regardless of ethnic background (e.g., Levinson et al., 2005), further research on perceptions of barriers to patient participation among higher educated migrant patients is needed. Finally, the possible interrelationships and hierarchies between the perceptions of

barriers needs to be further investigated. For instance, having sufficient common language between GPs and patients is a precondition of being able to have an adequate conversation in the first place. As previous research has shown that not being able to make yourself properly heard as a patient leads to feelings of anxiety and despair (Ramirez, 2003), the lack of a common language might, in turn, increase perceptions of discrimination which, in turn, might strengthen the salience of cultural values, such as being able or willing to tolerate uncertain situations, thereby negatively impacting patient participation.

Some caution is advised in using the concept of patient participation by taking a predominantly Western-biased approach. Defining patient participation in terms of patients' asking more questions, expressing more concerns and being more assertive (Street, 2001) presupposes that all patients should behave as individualistic-oriented partners in the health care encounter. Considering the perceptions of barriers identified in this study, it is questionable whether this approach is always applicable or even desirable for all patients and whether it is always necessary to stimulate such behaviors. Hence, when developing interventions to stimulate participative behavior, a culture-centered approach is propagated (e.g., Dutta, 2007) that includes patients from the bottom-up in its development, ensuring that such an intervention will indeed decrease barriers to patient participation from the perspective of patients themselves. Based on the results of our study, tackling the language barrier, raising awareness about cultural values differences, and increasing doctors' cultural competencies to communicate adequately and respectfully with migrant patients, might be good starting points to raise participation levels, improve health outcomes, and reduce ethnic health inequalities in medicine.

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