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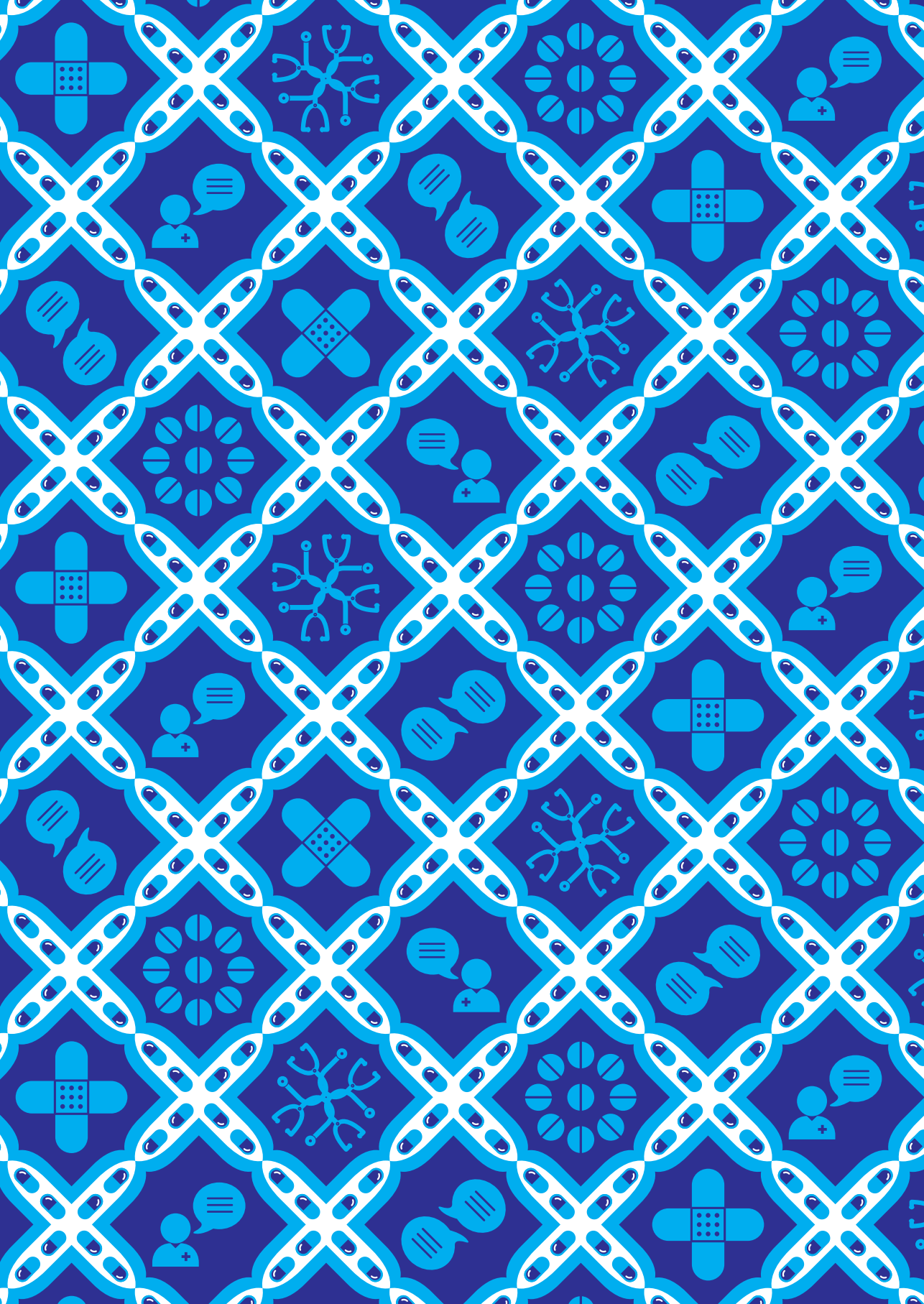
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CHAPTER 4

Cultural and communication barriers of patient participation

Abstract

Previous research has shown that migrant patients participate less actively during medical encounters than patients from the majority population. However, little is known about the underlying barriers hindering migrant patients' participation. Hence, the aim of this theory-based focus group study ($N=46$) was to explore possible barriers to patient participation among Turkish-Dutch and Dutch participants. Results show that both differences in communication styles and cultural values hinder Turkish-Dutch participants to be active communicators during medical encounters. They reported more collectivistic values, higher power distance, higher uncertainty avoidance and a more indirect communication style than Dutch participants. Differences in cultural values and communication styles should be taken into account in both medical practice and theories on intercultural health communication.

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Introduction

An important factor 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, 2001, p.62). Actively participating patients better understand and adhere to their treatment (Ong et al., 1995; Street Jr et al., 2005) and are more satisfied with the communication process and care they receive (Street Jr, Makoul, Arora, & Epstein, 2009; van den Brink-Muinen et al., 2006). Previous research has indicated that ethnic minority patients in the US participate less during medical consultations than patients belonging to the majority population (Cooper-Patrick et al., 1999; Johnson et al., 2004). A Dutch study corroborated these findings among Turkish-Dutch patients (Schinkel, van Weert, Kester, Smit, & Schouten, in press), the largest minority group in the Netherlands. The less active participation of migrant patients is problematic because of its relation with worse health outcomes. Stimulating active participation among migrant general practitioner (GP) patients thus seems necessary for improved communication and health outcomes.

It is, however, unclear why migrant patients participate less than the majority population. More insight is particularly needed in the barriers that these patients encounter regarding patient participation. Street’s *linguistic model of patient participation in care* (2001) suggests that both enabling and predisposing factors determine patients’ level of participation. That is, patients need to be both able and willing to participate. The model proposes that the ability to participate depends on the patients’ knowledge about the health issue as well as their communicative skills and routines. Thus, to discuss medical issues patients need to have sufficient communicative skills and to be proficient in the physicians’ language. Differences in communication styles between Western doctors and non-Western patients could thus form a barrier for Turkish-Dutch patients’ ability to participate. 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 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 pick up 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 solution oriented and confrontational, whereas high-context people are less solution oriented and more non-confrontational (Chua & Gudykunst, 1987). Hence, cultural differences in communication styles between Dutch GPs and Turkish-Dutch patients might possibly hinder Turkish-Dutch patients’ ability to participate because they do not have the same communicative repertoire.

Although Street’s model (2001) has hardly been used for intercultural encounters, language proficiency in the dominant language is proposed to affect patients’ ability to participate. Studies have indicated that ethnic minority patients who were less proficient in the physicians’ language had lower participation levels compared to ethnic minority patients who were more proficient (Meeuwesen et al., 2006; Schenker et al., 2010). Regarding Turkish-Dutch patients, low Dutch language proficiency might thus be an important barrier for their participation during medical encounters, especially because they are the least proficient in the Dutch language of all main ethnic minority groups in the Netherlands (Huijnk & Dagevos, 2012).

Besides barriers concerning patients’ ability to participate, Turkish-Dutch patients’ willingness to participate might be affected by differences in cultural values between

Western doctors and non-Western patients. Most studies have found lower willingness to participate among ethnic minority patients as compared to the majority population (Johnson et al., 2004; Levinson et al., 2005; Meeuwesen et al., 2007; Street Jr et al., 2005). Migrant patients’ lower willingness to participate might be explained by a stronger identification with collectivistic values, which entails being obedient and maintaining harmony in conversations (Gudykunst et al., 1996). Their willingness to actively participate, an individual behavior which involves being assertive and taking initiatives, 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). The more collectivistic views of Turkish-Dutch people (Hofstede, 2001) might thus be an important barrier for their willingness to actively participate during medical encounters.

In addition, a higher power distance in non-Western cultures such as the Turkish culture (Hofstede, 2001) can also form a barrier to patients’ willingness to participate. Power distance is the degree to which people accept and expect power to be distributed unequally (Hofstede, 2001). Turkish-Dutch patients might expect a larger power distance in medical encounters, thereby preferring the doctor to take control and to play a more passive role in the conversation, than Dutch patients.

Taken together, differences in cultural values and communication styles between Dutch GPs and Turkish-Dutch patients might negatively affect Turkish-Dutch patients’ ability and willingness to participate, presumably resulting in lower patient participation. Although it has been found that Turkish-Dutch patients are less participative than Dutch patients (Schinkel, et al., 2015), the mechanisms underlying these differences are not clear. Because empirical research is lacking on the abovementioned barriers in intercultural encounters, the aim of our study is to explore these differences among Dutch and Turkish-Dutch patients consulting a Dutch GP by comparing their perceived barriers concerning the ability and willingness to participate. The central research question is: How do Dutch and Turkish-Dutch patients differ in their perceived 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 Dutch participants. We composed small focus groups to allow for greater contribution of the participants (Bender & Ewbank, 1994; Kitzinger, 1995). In total, 46 participants participated: 22 Turkish-Dutch (12 men, 10 women) and 24 Dutch (12 men, 12 women), $M_{\text{ageDutch}} = 59.17$ ($SD = 14.04$), $M_{\text{ageTurkish}} = 56.68$ ($SD = 9.31$). Purposeful sampling was used to ensure that 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.

Focus groups were run separately for Dutch and Turkish-Dutch participants, men and women, and older and younger participants. We separated older (> 55 years) and younger (40-55 years) Turkish-Dutch participants, representing first- and second-generation migrants, because of possible linguistic and cultural differences between these groups. We excluded younger participants in our study, representing third-generation migrants, because of their higher Dutch language proficiency and better acculturation in Dutch culture than first- and second-generation participants (Huijnk & Dagevos, 2012).

Table 1 shows the composition of the focus groups. In all groups, most participants

had lower or intermediate educational level. Dutch participants were matched with the Turkish-Dutch participants on age, educational level and neighborhood to have comparable groups. As can be seen from Table 1, the 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 ($\chi^2(2) = .88, p = .65$). Almost all participants reported to be satisfied with their GP and to know their GP for more than three years. In each group, the majority of patients had different GPs, and in all groups participants had male as well as female GPs. Participants of three Dutch groups lived in similar neighborhoods as the Turkish-Dutch groups, one Dutch group lived in a comparable neighborhood in another city as their Turkish-Dutch counterpart.

Table 1
Composition of focus groups

Focus group	N	Gender	Ethnic background	Age group	Educational level	Recruitment area
1	5	Female	Turkish-Dutch	range 53-71 ($M=61$; $SD=7.8$)	4 lower, 0 intermediate, 1 higher	Amsterdam, community center
2	6	Male	Turkish-Dutch	range 55-75 ($M=65.67$; $SD=7.6$)	2 lower, 3 intermediate, 1 higher	Zaandam, mosque
3	5	Female	Turkish-Dutch	range 43-52 ($M=47.40$; $SD=4.3$)	1 lower, 3 intermediate, 1 higher	Zaandam, community center
4	6	Male	Turkish-Dutch	range 48-56 ($M=51.83$; $SD=3.5$)	2 lower, 3 intermediate, 1 higher	Zaandam, mosque
5	7	Female	Dutch	range 66-90 ($M=78$; $SD=8.3$)	3 lower, 3 intermediate, 0 higher	Amsterdam, community center
6	6	Male	Dutch	range 55-74 ($M=64.60$; $SD=8.8$)	0 lower, 5 intermediate, 0 higher	Zaandam, residence
7	6	Female	Dutch	range 46-53 ($M=50.33$; $SD=2.4$)	0 lower, 4 intermediate, 2 higher	Almere, health center
8	6	Male	Dutch	range 45-49 ($M=46.71$; $SD=1.7$)	0 lower, 6 intermediate, 1 higher	Zaandam, soccer club

Recruitment

Turkish-Dutch participants were recruited via key figures at community centers (women) and a mosque (men). The older Dutch women were recruited via key figures at the same community center as the older Turkish-Dutch women and the older Dutch men at a residence for the elderly. The younger Dutch participants were recruited via a health center (women) and a soccer club (men). Finally, we recruited participants who knew each other because acquaintances discuss topics in a more natural conversational flow and are less inhibited to talk than strangers (Kitzinger, 1994).

Moderator/observer

A Dutch bilingual researcher of Turkish background (FK) 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 to each other. The moderator was an experienced focus group leader in Dutch and Turkish, and was familiar with the research focus of the study. 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 with background questions. Turkish-Dutch participants received additional questions on their country of birth, years of residence in the Netherlands, and Dutch language proficiency.

To clarify the concept of patient participation and stimulate discussion, two film fragments were shown to the participants prior to the focus group discussion (around two to three minutes in total). The first fragment showed a passively participating patient, the second one an actively participating patient. After watching, a semi-structured topic list was used in all focus groups, based on Street's model of patient participation (2001), including the following main themes: level of patient participation (own behavior), ability to participate, and willingness to participate. Level of participation was discussed through topics such as what participants recognized in the film fragments and which fragment best matched their own behavior and experiences. Ability to participate was discussed by asking about barriers for being assertive. Patients' willingness to participate was discussed through topics such as preferred participation behavior, perceptions about being assertive and disagreeing with the GP. Among Turkish-Dutch patients language and cultural issues were explicitly discussed. The list consisted of several general questions for each topic as well as follow-through questions to deepen or stimulate the conversation.

For validity reasons, the moderator summarized statements of participants and asked for suggestions or additional remarks after each topic. After the interviews, participants and key figures received a ten-euro gift card. The study was approved by the Ethical Committee of the Amsterdam School of Communication Research (ASCoR), no. 2013-CW-13.

Data collection

All focus groups were held in the centers where participants were recruited, lasted forty-five to ninety minutes, were audiotaped, and transcribed verbatim. Three focus groups with Turkish-Dutch participants were led in Turkish and translated into Dutch. Back-translation into Turkish was performed on 25 percent of the translated transcripts, and the Turkish translations were compared to the original audiotape. Apart from dialect differences, the content of the back-translation fully represented the Turkish interviews.

Analyses

Constant comparative method from grounded theory perspective was used to analyse the data (Glaser & Strauss, 1967). First, one coder (SS) coded two transcripts (one with 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 a code to describe the theme. Themes from the topic list as well as new themes were identified. A Dutch

assistant and the bilingual moderator (FK) independently repeated this first step for the same transcripts to examine cultural differences in the interpretation of the researchers and to increase the reliability of the study. Because only small coding differences emerged, which were discussed to achieve mutual agreement, the first author coded the remainder of the transcripts. Second, the first author grouped all codes into higher-level categories, compared the groups on these categories and discussed the findings with the other coders to reach consensus. Finally, 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 are translated from Dutch into English. Quotes are presented with the focus group number (corresponding with Table 1), participant number within that focus group and a description of that participant in terms of age, gender and ethnicity.

Results

Lower levels of patient participation emerged from the discussions among Turkish-Dutch participants compared to the Dutch participants. Apart from two older women, all Dutch participants recognized themselves in the active patient of the film fragments. They criticized the passiveness of the patient in the other film fragment for not asking questions and giving information:

“Well, I... I should... I think the doctor fails a bit in that he does not explain it [medication], but also the patient fails by not asking. I would ask why I need it.” (FG6, participant #3, older Dutch man)

In contrast, the older Turkish-Dutch participants mainly recognized the conversation of the passive patient and the language struggle and miscommunication in that conversation – “The first was not able to express himself; he did not understand the doctor. We feel the same; we behave similarly.” (FG1, participant #3, older Turkish-Dutch woman) Younger Turkish-Dutch participants were more likely to recognize themselves in the active patient and some younger participants criticized the passive patient’s role during the conversation.

As for the barriers of patient participation, themes known from the literature as well as new themes emerged from the transcripts. Differences in communication styles and cultural values between Dutch and Turkish-Dutch participants emerged as overarching barriers for their level of patient participation. Below, we describe how participants differ from each other on these barriers within the context of Street’s model of patient participation. First, we elaborate on the communication styles differences between the groups, then we describe differences in cultural values between the groups. If relevant, we also discuss differences between older and younger Turkish-Dutch participants.

Communication barriers

Differences between Dutch and Turkish-Dutch participants emerged on two factors regarding their ability to participate: communication style and language proficiency.

Communication style

While communication style did not emerge as a barrier among Dutch participants, Turkish-Dutch participants often discussed communication style difficulties as a barrier for their participation. Dutch participants were positive about the communication with their GP, expressed satisfaction with communicating with their GP, who was mostly described as friendly and empathetic. Especially important among Dutch participants was being able to be open and to-the-point to each other and ask and say everything. On the contrary, Turkish-

Dutch participants reported discomfort with their GP’s direct, distant and confrontational communication style; the GP asks too many questions, and is not listening sufficiently. They indicated that they prefer a GP who is supportive and caring, and incorporates social talk. When a GP asks direct questions about their health problem, that GP is seen as careless. One participant explains how the GP in the film fragment should have communicated with the patient instead:

“He could have asked it differently but he didn’t care. He could have asked or by holding the man’s arm and turn it to discover whether it hurts and what kind of pain it is. In that way he could understand it, but the doctor did not care.” (FG4, participant #6, younger Turkish-Dutch man)

The implicit, indirect way of communicating, reflecting a high-context communication style, is preferred among Turkish-Dutch patients:

“As long as the doctor is similar to you, 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 woman)

In addition to the importance of taking context into account during communication, Turkish-Dutch participants discussed their difficulty with being as specific as a Dutch GP wants them to be:

“So when she asks what kind of pain you have... well then I have to think... it’s just pain. [...] When you give me three choices like such a pain, such a pain or such a pain I still have to think hard. It’s pain.” (FG3, participant #4, younger Turkish-Dutch woman)

Language proficiency

Turkish-Dutch participants discussed difficulties with understanding information and expressing themselves due to language problems. This topic did not emerge in the discussions among Dutch participants. The discussions concerning the language struggle among Turkish-Dutch participants implicate that low language proficiency is a large barrier for their ability to participate. 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, participant #1, older Turkish-Dutch man)

Participants feel ashamed and frustrated about their low proficiency in the Dutch language, and feel that language problems negatively affect the relationship with the GP and the treatment they receive:

“...a doctor has ten minutes for every patient... within those ten minutes you [moderator] could explain your problems with hundred words... you can explain better... and I have to try to explain it with ten words... then the doctor will understand me much worse than he will understand you... and finally we both get ten minutes... then you will be treated better than I will.” (FG2, participant #3, older Turkish-Dutch man)

In the older Turkish-Dutch groups, participants discussed that language problems inhibited them to participate actively. One woman illustrates the relation between language problems and patient participation by comparing the participants who can’t speak Dutch with one 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 and difficulties with informal interpreters, mainly their (grand)children. Not everything is translated by these interpreters, especially when it involves information that can distress or frighten the patient – “She [daughter] does not translate everything back to me. She does not want me to get sad about it. She just thinks... well I should know it.” (FG1, participant #1, older Turkish-Dutch woman) In addition, not everything can be discussed in the presence of an informal interpreter or it is hard for an interpreter to deal with the information – “We know each other [interpreter] for years... but um... 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) Thus, participation is hindered due to inefficient conversation patterns through informal interpreters.

Although language proficiency is better among younger Turkish-Dutch participants, they also discussed difficulties with expressing themselves in Dutch. They mentioned to think in Turkish but to have to talk in Dutch, which requires more time. So even with better Dutch language proficiency, the language barrier still hinders younger Turkish-Dutch patients to effectively participate.

Cultural value barriers

Barriers emerged on three cultural values explaining differences in the willingness to participate: power distance, individualism/collectivism and uncertainty avoidance (i.e., the degree to which people tolerate uncertainty and ambiguity, Hofstede, 2001).

Individualism/collectivism

Whereas Dutch participants primarily discussed individualistic values, collectivistic values were most prominent in the discussions among Turkish-Dutch participants. Dutch participants discussed values such as being assertive, autonomous and responsible. Although some participants indicated having trouble being sufficiently assertive, most participants indicated the importance of being assertive – “When you are assertive... that's what counts... then you will accomplish more” (FG8, participant #4, younger Dutch man). According to the Dutch participants, patients are responsible for providing their GP with information:

“...when you visit a doctor and um you do not tell a doctor anything yourself (participant #1)... while you have several problems 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...” (participant #4, FG6, older Dutch men)

For a good relationship with the GP, personal matters are not that important, except for when they relate to the medical problem. The conversation is goal-oriented; they discuss with the GP what is relevant to their health problem to get good treatment:

“He also asks um... private matters, because these are related to um... your... your medical background. Then he asks private matters and medical matters. He asks both and that will be important then right? Well regarding to your problems... I am not asking you um what are you eating tonight or well um... that... or you have to have problems with your stomach or so.” (FG6, participant #4, older Dutch man)

In contrast, Turkish-Dutch participants reported to prefer a GP who is like a friend or family, who knows the personal situation of the patient, 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)

Turkish-Dutch participants agreed on the importance of a strong and warm relationship with their GP, and discussed that most Dutch GPs are too formal and aloof. One participant compared her Dutch GP with her Turkish dentist as follows:

“With him [the dentist] you just feel better. How are you? Yes... how is the little one and how is your husband and so on. It's like you visit a friend or something. That kind of relationship is possible with your dentist. I don't have that with my GP.” (FG3, participant #2, younger Turkish-Dutch woman)

Power distance

From the discussions among Dutch participants a smaller power distance between patients and GPs emerged than among Turkish-Dutch participants. Dutch participants agreed with other that a patient is responsible for his/her own health, primarily because it is his/her own body. They want to share decisions, discuss treatment options and decide on treatments, all reflecting a small power distance between GPs and patients – “I know a person... [...] that person is being um kind of overruled by her GP. That is not a good doctor. I think... well I think that's wrong.” (FG5, participant #6, older Dutch woman)

Disagreeing with their GP was seen as an opportunity to share opinions; it is part of the conversation. When patients preferred a different treatment they discussed it with their GP:

“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 Dutch woman)

Another participant described a situation in which he read about his medications and wanted to discuss it with his GP:

“So he prescribes me the prednisone, but that was um... I got home and I read the Telegraaf [newspaper] and it was about that nasty beast that bit me.... Well... then I called him [the doctor] and said: right, well, this and that... and he said: well then you should not take the prednisone. So that is an interplay between the doctor and me.” (FG6, participant #2, older Dutch man)

Turkish-Dutch participants on the other hand indicated that the GP knows best and is responsible for the 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)

In contrast to the preference of Dutch participants for involvement in the conversation and decision-making, 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 and the fact that the GP should have control, no consensus was reached among younger Turkish-Dutch participants in their behavior 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 Dutch participants towards the Dutch health care system reflects lower uncertainty avoidance than among the Turkish-Dutch participants, who expressed frustration about the way they are treated in the Dutch health care system. Without being asked for by the moderator, Turkish-Dutch participants criticized the protocols in the system, such as making a double appointment with the GP when you have more than one health issue, and the obligation to get a referral from the GP before you are allowed to visit the hospital. Participants were well aware of the protocols but the treatment approach in the Netherlands frustrated them. 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 a treatment in which you try different things or a wait-and-see approach as good practice:

“Before I call the doctor... Then I have the problem for two to three weeks already. And so it did not go away. So then... then I think I should visit the GP.” (FG8, participant #3, younger Dutch man)

In contrast, among Turkish-Dutch participants a 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 prescribed. One participant indicated that he feels he has not been treated when the GP wants to wait and see for the medication to work:

“Our GP also rarely treats us. [...] He does not feel the need. He prescribes some pills and says come back in about three weeks when the pain is still there.” (FG4, participant #3, younger Turkish-Dutch man)

Another participant reported that he does not trust the system when such an approach is used:

“But in the Netherlands, [...] doctors seek for the easiest solution for the patient. First, what do you get? Paracetamol they tell you. It does not work. Then something else is tried on you. It still does not work. Then something different is tried, which is not working. Only at the end they use an important medicine.” (FG4, participant #6, younger Turkish-Dutch man)

In addition, 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. Such a GP does not adequately treat that patient and makes them frustrated – “They ask things they should not ask, I think. Sometimes I think: what kind of question is this? All these stupid questions. Do some research!” (FG3, participant #3, younger Turkish-Dutch woman)

Discussion

The aim of this study was to explore differences between Dutch and Turkish-Dutch patients in the barriers they encounter regarding patient participation, in order to explain why Turkish-Dutch patients are less participative than Dutch patients. Results show that both differences in communication styles and cultural values, as well as insufficient Dutch language proficiency emerged as main barriers among Turkish-Dutch patients. These barriers did not emerge among Dutch patients.

In concordance with both Street’s model on patient participation (2001) and studies on language proficiency and communication (Sudore et al., 2009), Turkish-Dutch patients are less able to effectively contribute to the conversation than Dutch patients, due to language difficulties. They reported difficulties understanding the GP and expressing their problems and feel that their insufficient Dutch language proficiency affects the communication process and treatment they receive. Even second-generation Turkish-Dutch participants, who are more proficient in the Dutch language, struggle with expressing themselves in Dutch. Although most older Turkish-Dutch participants visit a GP accompanied by an informal interpreter to bridge the language barrier, these conversations are often problematic because of inhibition to be entirely open and because the interpreter does not translate all information back to the patient. This is consistent with findings from observational research suggesting that informal interpreters omit information (Aranguri et al., 2006; Schouten & Schinkel, 2014), possibly leading to less social talk and more formal conversations, which hinder good communication.

While language proficiency is an important tool for enhancing patient participation (Street, 2001), this study clearly shows that merely increasing language proficiency will be insufficient to enhance participation among ethnic minority patients. In line with earlier findings suggesting that Turkish-Dutch people prefer a more high-context communication style (Schouten, 2008), the direct, impersonal communication style (i.e., low-context communication style) common in Dutch conversations, is being criticized by Turkish-Dutch participants. While Dutch participants stress the benefits and importance of being open and to-the-point, of asking questions and saying everything, Turkish-Dutch participants are dissatisfied with a GP who directly asks them what they want or think and who expects them to be precise and explicit. They are not able to communicate in the same style as their Dutch GP and, as a consequence, become silenced. Thus, our results suggest that Turkish-Dutch patients’ ability to participate is hindered by both language difficulties as well as cultural differences in communication styles.

While communication style barriers and insufficient Dutch language proficiency affect patients’ ability to participate, differences in cultural values decrease Turkish-Dutch patients’ willingness to be participative. In concordance with their collectivistic values, Turkish-Dutch participants prefer a GP to be like family and stress the importance of a warm and strong relationship for good communication. In contrast, Dutch participants prefer a more formal, individualistic relationship, in which personal matters are not that important for good communication, because the health issue matters. Because Turkish-Dutch patients experience difficulties with the impersonal relationship with their Dutch GP they become reluctant to participate actively. These cultural differences are consistent with research suggesting that more collectivistic views are related to more negative attitudes towards patient participation (Kim et al., 2000). In collectivistic, high-context cultures, people are involved with others and relationships are built on trust and personal networks (Korac-Kakabadse et al., 2001). Disagreeing and mentioning unpleasantness are considered to be rude and embarrassing to these patients.

Furthermore, Turkish-Dutch participants feel their GP is responsible for their health and should know what to do, while Dutch participants want to share responsibility, and prefer to be autonomous and assertive, reflecting differences in power distance. This result is in line with previous findings indicating that non-Western patients prefer the doctor to make the health decisions (Levinson et al., 2005). Hence, for Turkish-Dutch patients, both collectivistic values and higher levels of power distance seem to be related to their passive participation during the medical encounter, because they negatively affect their willingness to be involved in both the communication and the decision making process.

An unexpected barrier that emerged from our data concerns cultural differences in uncertainty avoidance. Dutch participants revealed a higher tolerance for uncertainty, reflected in their wait-and-see approach to health problems, than Turkish-Dutch participants, who were highly dissatisfied with GPs using that approach or trying several options. This difference in treatment approach frustrates and worries Turkish-Dutch patients and hinders them to actively participate. Combined with their reluctance to disagree with their GP and their preference for the GP to have control, our results indicate that Turkish-Dutch patients fall silent because of their frustration about the way they are treated. Further quantitative research is needed to explore the relationships between these differences in cultural values and patients' willingness for participation during medical encounters.

Taken all barriers together, it is clear that it is not ethnic background or race per se which hinders migrant patients to be participative, but the mismatch in communication styles and cultural values between Western GPs and non-Western patients. These mismatches lead to opposite attitudes and expectations towards patient participation, which hinder non-Western patients' participation. The importance of communication style and cultural value concordance between patients and GPs to enhance patient participation is in line with findings suggesting that ethnic similarity is less important for the doctor-patient relationship than perceived similarity in values and beliefs (Street Jr, O'Malley, Cooper, & Haidet, 2008). Because migrants with collectivistic views tend to hold on strongly to their culture of origin (Phalet & Hagendoorn, 1996), mismatches will easily occur among Turkish-Dutch patients visiting their Dutch GP. Thus, more research is needed among migrant patients on how concordance with their GP affects their level of patient participation.

This study contributes to the theoretical literature by providing more insight into the barriers to patient participation among ethnic minority patients. Our results clearly indicate that both the constructs of cultural values and communication styles should be incorporated in existing models on health communication (e.g. Street's model of patient participation), to explain more fully why ethnic minority patients display lower levels of patient participation. To be able to do so, further quantitative research on patient participation among migrant patients is needed.

To conclude, this study reveals that patient participation among ethnic minority patients is hindered by barriers concerning differences in communication styles and cultural values. To stimulate participative behavior, both patients and doctors need to be educated in these differences. When migrant patients are more aware of the cultural values, communication style and treatment approaches of their doctor, they can overcome frustration and anxiety about the communication and treatment. In the same vein, when doctors understand cultural differences and try to acknowledge these during the conversation, the relationship with their patient will become stronger. Providing education to both ethnic minority patients and their doctors will/might enhance these patients' participation level and thereby, ensuring higher quality of care for ethnic minority patients.