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“What do you
think I should do?”

Understanding intercultural
medical communication
in general practice

Sanne Schinkel

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ACADEMISCH PROEFSCHRIFT

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op gezag van de Rector Magnificus
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ten overstaan van een door het College voor Promoties
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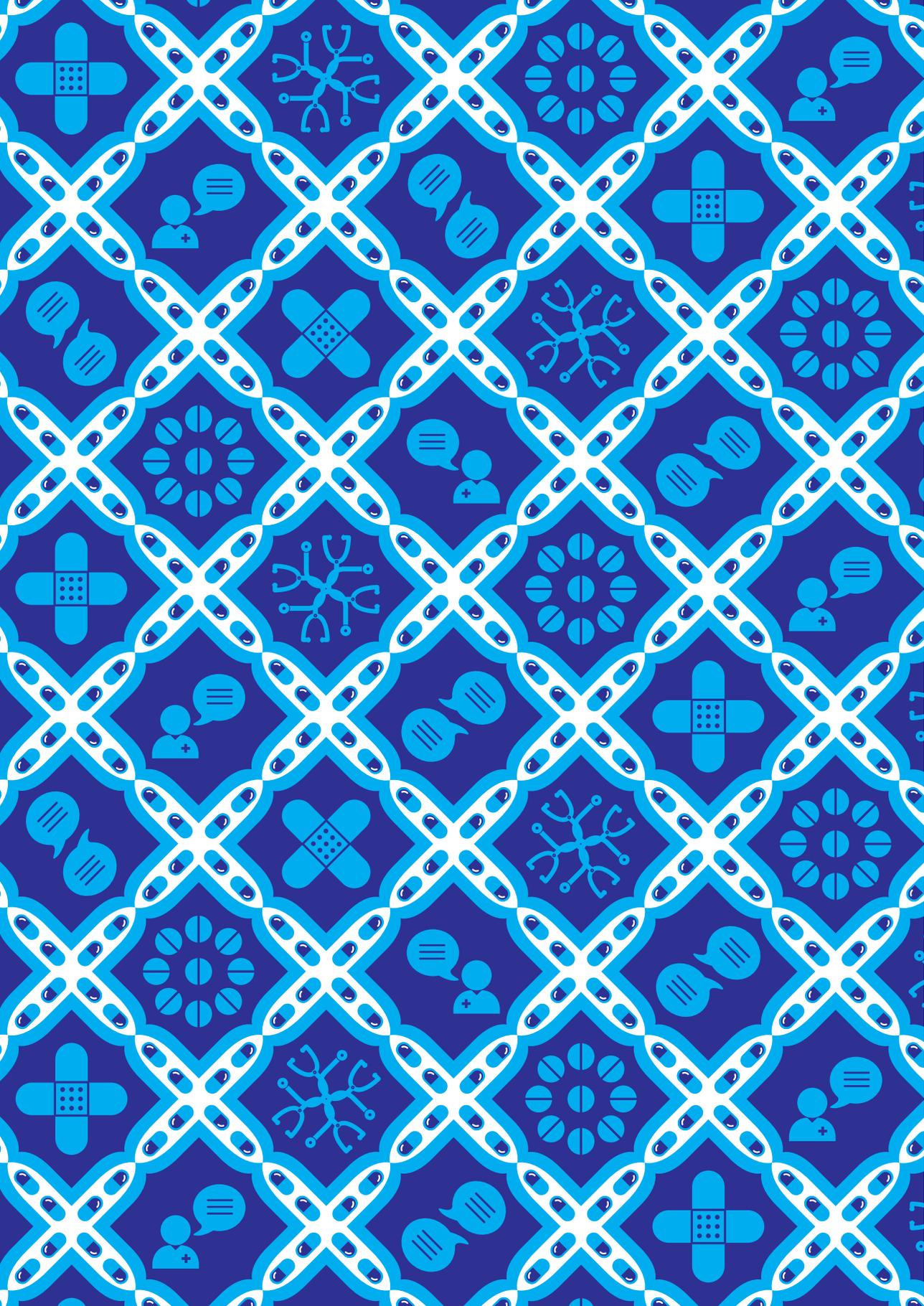
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CHAPTER 1

Introduction

Communication between doctors and patients is a crucial aspect of effective health care (Bensing & Verhaak, 2004; van den Brink-Muinen et al., 2000). Through communication, doctors and patients exchange information which is necessary for understanding health problems, creating a therapeutic relationship and managing diseases (Roter & Hall, 2006). In today's multicultural society, medical communication increasingly involves intercultural medical communication, with doctors and patients from different ethnic backgrounds. In the Netherlands, almost two million non-Western migrants take up around twelve per cent of the total population (Central Bureau of Statistics, 2014). This percentage is expected to increase to 18 per cent in 2050 (Central Bureau of Statistics, 2014). Dutch doctors in the Netherlands will thus increasingly be confronted with intercultural medical communication.

Research has shown that intercultural medical communication is less effective than intracultural medical communication: it is characterized by more miscommunication and less mutual understanding between doctors and patients, lower satisfaction among patients and lower understanding of the information provided by the doctor, leading to undesired health outcomes such as non-compliance and different and often even incorrect health care usage (Harmsen, Bernsen, Bruijnzeels, & Meeuwesen, 2008; Schouten & Meeuwesen, 2006; Seeleman, Suurmond, & Stronks, 2009; van Wieringen, Harmsen, & Bruijnzeels, 2002). Among ethnic minority patients in the Netherlands, more prescribed medication use, higher use of the general practitioner (GP), and less usage of specialized care are found compared to the majority group (Stronks, Ravelli, & Reijneveld, 2001; Uiters, Devillé, Foets, & Groenewegen, 2006). These health disparities among ethnic minority patients do not seem to be explained by socio-economic factors but by a lower accommodation of their needs in health care (Yilmaz-Aslan, Brzoska, Bluhm, Aslan, & Razum, 2014), due to less adequate communication (Nierkens, Krumeich, de Ridder, & van Dongen, 2002). Improving intercultural medical communication thus seems crucial for enhancing communication outcomes and health care delivery to ethnic minority patients.

So far, the few interventions that are implemented to improve intercultural communication in GP practices have led to no or only small changes due to a lack of knowledge on explanatory factors of miscommunication between GPs and migrant patients (Schouten, Meeuwesen, & Harmsen, 2005; Schouten & Meeuwesen, 2006). Thus, before effective interventions can be designed, more knowledge is needed on factors underlying intercultural medical (mis)communication. Because intercultural medical communication is hindered by language barriers and differences between patients and doctors in values, preferences and expectations (Schouten & Meeuwesen, 2006; Suurmond & Seeleman, 2006), research is needed to understand how these differences affect medical communication and its outcomes in order to understand how intercultural medical communication can be improved.

Given the possible differences between ethnic minority patients and patients from the ethnic majority population, it is unclear whether existing models of medical communication can be applied to ethnic minority patients. Without more knowledge on the differences between ethnic minority patients and patients from majority groups, and on how these differences affect the communication and its outcomes, interventions to improve intercultural communication lack sufficient theoretical ground to be effective.

Given the importance of effective communication in intercultural medical encounters and the lack of knowledge on factors underlying intercultural medical communication, this dissertation aims to investigate differences between ethnic minority (non-Western) and ethnic majority (Western) patients in factors underlying medical communication to be able to better understand intercultural medical communication and understand how it can be improved.

Target population

The majority of non-Western migrants in the Netherlands are from Turkish and Moroccan origin. For both migrant groups, male workers were first recruited by the industries in the 1960s for cheap labor, their families followed later. Although Turkish and Moroccan migrants share their migration tradition, religious backgrounds and socioeconomic status, Dutch people with Turkish origin were the subject for this dissertation. They are the largest non-Western migrant group in the Netherlands, with almost 400,000 people in 2014 (Central Bureau of Statistics, 2014) and differ from Moroccan-Dutch people in terms of integration into Dutch society (Crul & Doomernik, 2003). Turkish-Dutch people (first- and second-generation) are more likely to adhere to the norms and values of their own ethnic community (regarding religion, marriage and gender roles) than Moroccan-Dutch people. Tightly knit social networks play an essential role in the Turkish community; people keep up with Turkish family in Turkey, watch Turkish news more often than Dutch news, and the majority regard themselves primarily as Turkish (Crul & Doomernik, 2003), even the second-generation Turks (Central Bureau of Statistics, 2013). Whereas adaptation to Dutch culture is more prominent in the public domain than in the private domain, Turkish-Dutch people prefer cultural maintenance in both domains (Arends-Tóth & van de Vijver, 2004). They also tend to have contacts with only Turkish people rather than with both Turkish and Dutch or only Dutch people (Central Bureau of Statistics, 2013). Moreover, they report poorer health status and more health problems (Lindert, Droomers, & Westert, 2004), visit their GP more often, and experience more miscommunication and less mutual understanding in health care (Uitewaal et al., 2004) than Dutch and other non-Western patients. Turkish-Dutch patients are thus found to be the most eligible group for this dissertation, because of its size and higher adherence to their culture of origin, which places a large cultural distance between themselves and their Dutch doctors.

Focus of this dissertation

Medical communication and its outcomes are suggested to improve when patients are stimulated to be more actively involved during the medical encounter. This active patient behavior during the medical communication process is also known as *patient participation* and is considered to form a key component of good medical communication (Street, 2001). Despite wide attention in the literature, patient participation is still ill-defined. The term is used for participation in decision-making and information-seeking, for actively adhering to treatment decisions and being involved in the management of care and in health care in general. The term is used interchangeably with *patient involvement*, *patient collaboration*, and *patient partnership* (Cahill, 1998), and is often operationalized in relation to *patient-centered care* and *patient empowerment* (Longtin et al., 2010). The focus of this dissertation is on patient participation in the communication during the medical encounter. Street's definition of patient participation is central to this focus: "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). Patient participation in this dissertation thus involves the patient's verbal contribution during the medical encounter.

The most important elements of patient participation are asking questions, expressing concerns, and being assertive (Street, 2001). The more a patient displays these behaviors, the more active that patient communicates. Many beneficial outcomes of active patient participation have been found: actively participating patients receive more information from their doctor, experience more support from their doctor, understand the information better, and report more satisfaction with care and the communication process (Street, Voigt, Geyer, Manning, & Swanson, 1995; van den Brink-Muinen et al., 2006). More active patient participation might even have the potential to reduce medical errors and health care costs (Mavis et al., 2014).

The concept stems from the consumer movement in the 1960s, in which consumer's rights were stressed and people got the right to be heard and informed before making choices (Longtin et al., 2010). The health care changed from employing a paternalistic approach, in which the patient passively received care from the doctor, to a more patient-centered approach (Cahill, 1998), in which a patient is regarded as active consumer. As a consequence of this movement, health care policy in the Netherlands changed with, for instance, the introduction of the Medical Treatment Act in 1995. Patient's rights to be both informed and heard about his/her health were explicitly addressed in this act. The introduction of "informed consent" obligated doctors to obtain patients' consent on the treatment, and to provide patients with understandable and relevant information about the treatment to be able to give their consent (Berg, Appelbaum, Lidz, & Parker, 2001). Treatment decisions were no longer made for a patient, but with a patient. These changes in health care imply a large responsibility on the doctor to adequately inform the patient, for which patients' preferences need to be elicited and addressed, but also on the patient to share decision-making about treatment options.

Simultaneously, the introduction of the Internet has given patients the opportunity to become more knowledgeable about their health. Using the web for health information-seeking by patients has the potential to enhance medical communication, because patients are able to acquire more knowledge and be better prepared for participation during the communication process (Wald, Dube, & Anthony, 2007). Both changes in health care policy and the introduction of the Internet led to a power-shift between patients and doctors (Goodyear-Smith & Buetow, 2001; Powell, Darvell, & Gray, 2003), underlining the importance of patient participation for effective communication. Although a shift towards more patient participation of Dutch patients was indeed found in current medical encounters in the Netherlands (van den Brink-Muinen et al., 2006), ethnic minority patients are generally found to display lower participation levels during the medical encounter; they ask fewer questions and give less information to the doctor than Dutch patients (Meeuwesen, Harmsen, Bernsen, & Bruijnzeels, 2006; Schouten, Meeuwesen, Tromp, & Harmsen, 2007).

This difference in communicative behavior between ethnic minority and majority patients is unfortunate, given the beneficial outcomes of active patient participation. By actively participating, patients can enhance the information provision they receive during the encounter, which results in better fulfillment of information needs, more satisfaction and better understanding of the information and, consequently, of their health (Street, 2001). In order to improve these communication outcomes, patients thus need to participate in the conversation with the doctor, reflecting the importance of patients' active participation. Increasing patients' participation—to be able to achieve better fulfillment of information

needs, higher satisfaction and better understanding of the information—thus seems crucial for enhancing medical communication. Because of the lower participation levels among ethnic minority patients, increasing their participation seems even more necessary to enhance their communication outcomes. Given the importance of patient participation during the consultation to increase the communication outcomes and the lower participation levels found among other ethnic minority patients, this dissertation focuses on two specific research questions underlying the general aim of the dissertation: (1) to what extent do Turkish-Dutch and Dutch patients differ in the factors underlying patient participation and (2) how is patient participation related to communication outcomes such as fulfillment of information needs, patient satisfaction and understanding of information among these patient groups?

Dissertation outline

Figure 1 illustrates the relationships that represent the research questions and shows in which chapter the relationship is investigated. As discussed before, patient participation is central in this dissertation, with the potential to improve the communication outcomes of intercultural medical communication. The extent to which a patient participates is, according to Street's linguistic model of patient participation (Street, 2001), dependent on predisposing factors, enabling factors and doctor's responses. Predisposing factors are patient demographic characteristics such as ethnicity, gender, age and education, but also involve patients' willingness to participate. Generally, ethnic minority patients, male patients, older patients and lower educated patients are found to be more passive communicators compared to ethnic majority, female, younger and better educated patients (Kiesler & Auerbach, 2006; Levinson, Kao, Kuby, & Thisted, 2005). According to the model, higher willingness to participate is said to increase a patient's participation. Enabling factors are those factors related to a patients' ability to participate, such as having knowledge about the health issue(s) and sufficient communication skills. Less health knowledge and insufficient communication skills are said to decrease a patient's ability to participate with lower participation as a result. The doctor's responses refer to a climate in which a patient is enabled and stimulated by the doctor to be participative.

In short, patients need to be able and willing to become active communicators and their doctors need to stimulate participation among their patients. Based on Street's model, this dissertation focuses on the influence of patient's willingness and ability to participate on their participation levels and consequent communication outcomes. In addition, it is investigated how patients' match between their preferred and perceived participation during the encounter and doctor-patient concordance (i.e. level of similarity) in preferred doctor-patient relationship influences the communication outcomes. The different relationships and aims of the chapters will be discussed below in more detail.

A patient's willingness to participate is determined by their information needs and participation needs (Street, Krupat, Bell, Kravitz, & Haidet, 2003), with higher needs generally associated with higher patient participation. Because those needs are determined by a patient's cultural background (Helman, 2001), lower participation levels of ethnic minority patients could be explained by lower needs among these patients. Scarce evidence showed lower information (Kumar et al., 2004) and participation needs (Levinson et al., 2005) among ethnic minority patients compared to the majority population. In the Netherlands, no differences were found in participation needs between Turkish-Dutch and Dutch patients, but the groups reported different information topics as important to discuss with their GP (Schinkel, Schouten, & van Weert, 2010). The question is thus

whether during encounters with Turkish-Dutch and Dutch patients, in which patients prefer to discuss different topics with their GP, the information provision by the GP fulfills the information needs of both patient groups to the same extent. To answer this question, **Chapter 2** aims to examine the differences in information needs, information provision and fulfillment of information needs between Dutch and Turkish-Dutch patients.

The results of Chapter 2 revealed that GPs' information provision during the encounters better fulfilled Dutch patients' information needs than those of Turkish-Dutch patients. Because it was assumed that this result could partly be explained by Turkish-Dutch patients' lower levels of participation during the consultation compared to Dutch patients, the aim of **Chapter 3** was to investigate differences between Turkish-Dutch and Dutch patients in their health information-seeking behaviour prior to their consultation and how this information-seeking behavior is related to their participative behavior during the encounter and communication outcomes. The rationale behind this aim is that previous research has indicated that patient participation can be increased by obtaining health knowledge prior to the medical appointment (Cahill, 1998; Henwood, Wyatt, Hart, & Smith, 2003; Street, 2001). Patients' information-seeking behavior is dependent on health-related factors, such as their experience with diseases, their beliefs about control and information-carrier factors, such as the utility of media (Johnson & Meischke, 1993). Because ethnic minority patients differ in their beliefs about diseases (Helman, 2001) and control (Levinson et al., 2005), often report lower health literacy (Sudore et al., 2009), and are less active searchers for information (Dickerson et al., 2004) than ethnic majority patients, it was assumed that Turkish-Dutch and Dutch patients differ in their information-seeking behavior before the consultation, which might explain differences in their participation.

The results of Chapters 2 and 3 suggested that Turkish-Dutch patients' ability and willingness to participate does not seem to be hindered by their health information-seeking behavior and information needs. Considering the research model of intercultural medical communication (Schouten & Meeuwesen, 2006), cultural values might explain their lower patient participation better. As discussed before, the ability to participate is partly dependent on patients' communication skills (Street, 2001). Due to different cultural values among ethnic minority patients, the communicative repertoire of ethnic minority patients could be different from that of ethnic majority patients. That is, cultural values (such as individualism versus collectivism; Hofstede, 2001) and patients' self-construal (independent versus dependent; Markus & Kitayama, 1991) affect people's (preferred) communication styles (Schouten, 2008). As Western doctors are generally more individualistic oriented than their more collectivistic non-Western patients, adequate communication might be hard to achieve. When doctors and patients do not share similar communication styles, the ability of the patient to participate could be hindered. In addition, due to different cultural values such as higher power distance and more identification with collectivistic values than with individualistic values (Hofstede, 2001), ethnic minority patients' willingness to participate can be affected too. A study among Chinese patients showed that higher identification with collectivistic values is indeed related to more negative beliefs about patient participation (Kim et al., 2000). **Chapter 4** therefore aims to understand differences between Dutch and Turkish-Dutch patients in their perceived barriers regarding their willingness and ability to participate, specifically regarding cultural values between the groups.

The results of Chapter 4 indicated differences between Turkish-Dutch patients and their Dutch doctors in their preferences for the way doctors and patients are oriented towards each other. Research has shown that concordance between doctors and patients in their preferences for the doctor-patient relationship results in more positive

communication outcomes and better health outcomes than discordance (Cousin, Mast, Roter, & Hall, 2012; Krupat, Bell, Kravitz, Thom, & Azari, 2001; Street Jr, Makoul, Arora, & Epstein, 2009). Because Turkish-Dutch patients value a good doctor-patient relationship more than Dutch patients, doctor-patient concordance in preferred doctor-patient relationship seems to be more important for Turkish-Dutch patients than Dutch patients for establishing positive communication outcomes. In addition, when doctors stimulate patients to participate in the conversation, patients can more easily participate to the level they desire. This consequent match between patients' preferred and perceived participation is suggested to positively influence communication outcomes (Heyland et al., 2003; Kiesler & Auerbach, 2006). Because Turkish-Dutch patients seem to experience more unfulfilled information needs and display lower participation levels, it is unknown whether this match between preferred and perceived participation can be achieved by Turkish-Dutch patients and how it influences the communication outcomes. **Chapter 5** therefore aims to study the effects of doctor-patient concordance in preferred doctor-patient relationship and the match between patients' preferred and perceived participation on communication outcomes among both Turkish-Dutch and Dutch patients.

In addition, medical communication with migrant patients is also influenced by their language proficiency in the GP's language and acculturation levels. Patients can be willing and have sufficient health knowledge to participate, but if their language proficiency is insufficient their ability to participate will still be low. A study among ethnic minority patients indeed found that patients who reported poor language proficiency were less participative than patients with better language proficiency (Meeuwesen et al., 2006). Moreover, patients with sufficient language proficiency might still be hindered to be participative due to having lower acculturation levels in Western society. Higher acculturation levels among ethnic minority patients might be related to better adoption of values and preferences of the country of residence concerning patient participation (Tortolero-Luna et al., 2006), suggesting lower willingness to participate for lower acculturated migrant patients. Because it is unclear how language proficiency and acculturation are related to the factors underlying patient participation and its outcomes for Turkish-Dutch patients, both concepts are taken into account in every chapter.

As illustrated in Figure 1, ethnicity was assumed to influence the determinants of patient participation and higher patient participation was assumed to result in more positive communication outcomes. For Turkish-Dutch patients, language proficiency and acculturation were assumed to influence the determinants of patient participation as well. In Chapters 2 to 5, the studies addressing the assumed relationships are described. In **Chapter 6**, the research questions are answered by elaborating on the findings. In addition, the concept of patient participation in intercultural context as well as methodological and clinical implications are discussed.

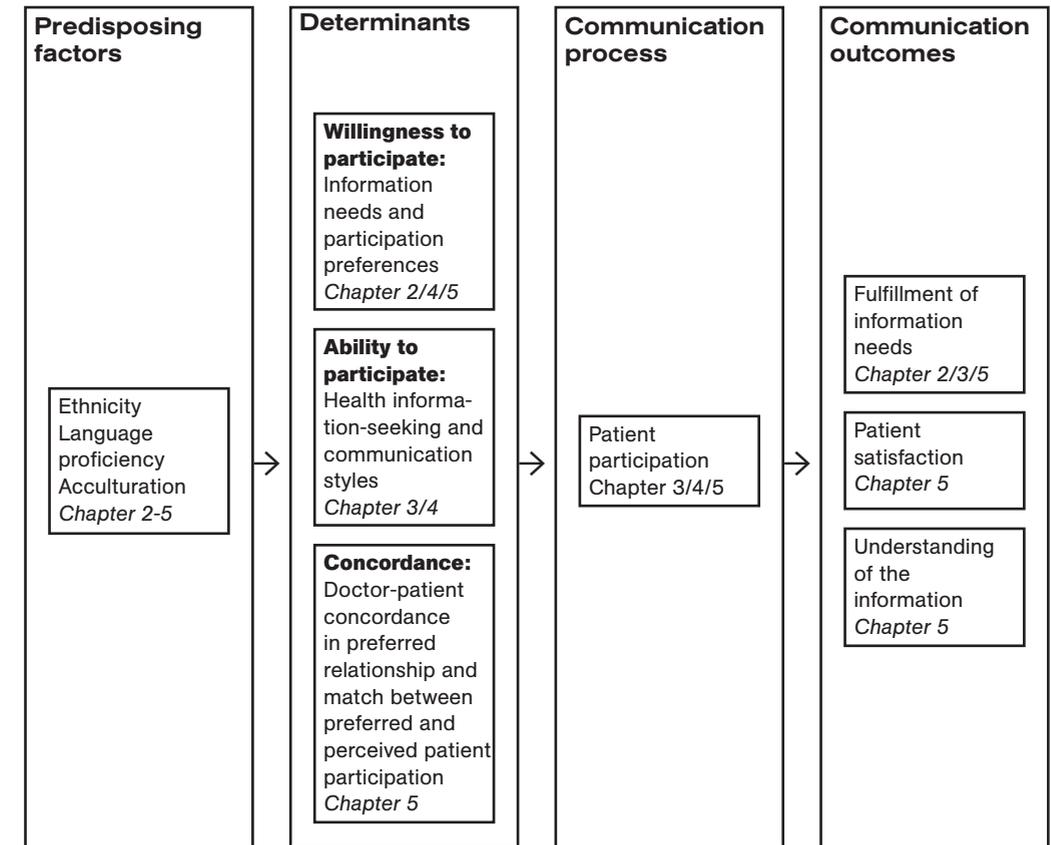


Figure 1. The conceptual framework of this dissertation



CHAPTER 2

Information needs and communication outcomes

Abstract

This study aimed to assess differences in (fulfillment of) information needs between Dutch and Turkish-Dutch GP patients in the Netherlands. In addition, the relation between recorded information provision by GPs and patients' perceived information provision is studied. Information needs of Dutch ($N=117$) and Turkish-Dutch patients ($N=74$) were assessed through a pre-consultation questionnaire and the fulfillment of these needs was assessed combining pre- and post-consultation questionnaires. Audiotapes of 120 GP consultations were used to code GPs' information provision. Results show that Turkish-Dutch patients have higher information needs concerning information on prognosis, prevalence, physical examination, medical terms, alternative medicine and procedures at other hospital/other caregivers than Dutch patients. They also experience more unfulfilled information needs than Dutch patients, in particular those who identify equally with Dutch and Turkish culture. Overall, patients' perceived information provision is hardly related to the recorded information provision. GPs insufficiently provide Turkish-Dutch patients and, to a lesser extent, Dutch patients as well, the information they need. GPs should be trained in giving adequate, tailored information to patients with various ethnic and cultural backgrounds.

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Introduction

Previous literature suggests that doctors underestimate their patients' need for information (Fallowfield, Ford, & Lewis, 1995; Waitzkin, 1984; Zemencuk, Feightner, Hayward, Skarupski, & Katz, 1998) while patients generally desire as much information about their condition as possible (Beisecker & Beisecker, 1990; Blanchard, Labrecque, Ruckdeschel, & Blanchard, 1988; Davis, Hoffman, & Hsu, 1999; Ende, Kazis, Ash, & Moskowitz, 1989; Nease Jr & Brooks, 1995; Sutherland, Llewellyn-Thomas, Lockwood, Tritchler, & Till, 1989; Waitzkin, 1985). Consequently, unfulfilled information needs for different types of patients have been reported (Jones et al., 1999; Kjekken et al., 2006; Koning, Maille, Stevens, & Dekker, 1995; Tsuchiya & Horn, 2009; Turner, Maher, Young, Young, & Vaughan Hudson, 1996; van Weert et al., 2009; Wachters-Kaufmann, Schuling, The, & Meyboom-de Jong, 2005). For example, cancer patients report unmet information needs on severity of the disease, prognosis and treatment alternatives (Hack, Degner, & Parker, 2005) and GP patients report unmet needs on risks and benefits of treatments (Ford, Schofield, & Hope, 2003). Thus, it seems that physicians should provide their patients with more or different information than they, on average, do, to meet their patients' information needs.

Up till now, research is lacking regarding ethnic minority patients' information needs. Therefore, it is unclear whether previous study findings can be generalized to ethnic minority patients. The scarce research on this topic is unfortunate given the fact that in today's multicultural society, medical encounters between GPs and patients from different ethnic backgrounds are not only common, but also less adequate than encounters between doctors and patients from the same background (Schouten & Meeuwesen, 2006).

A few studies suggest that ethnic minority patients might prefer less information than ethnic majority patients. For instance, cancer-diagnosed Asian-British patients reported lower information needs than British patients (Kumar et al., 2004) and non-Swiss patients reported lower information needs when the news was bad (Langewitz, Nubling, & Weber, 2006). However, since these studies measured information needs with a single item, it is unknown what specific information needs ethnic minority patients have. A Dutch qualitative study indicates that Turkish-Dutch GP patients feel they receive too little explanation on the diagnosis, further research and medication (Vink, van der Heijden, Wiese, & van Eerd, 2002). Another Dutch study revealed that Dutch patients primarily want information on the diagnosis, while Turkish-Dutch patients report higher need for information on prevalence, physical examination, medical terms and procedures at other care givers (Schinkel, Schouten, & van Weert, 2010). However, since both Dutch studies involved quite small samples, it is unknown whether these findings can be generalized.

Given the scarcity of findings on ethnic minority patients' information needs, this study aims to provide more insight into differences in information needs between Dutch and Turkish-Dutch patients and to examine to what extent their needs are being met during GP consultations. Additionally, the relationship between perceived and recorded information provision is examined, in order to gain insight into the extent to which unfulfilled needs are due to deficiencies in GPs' information provision. Turkish-Dutch patients are compared to Dutch patients because they are the largest minority group in the Netherlands (Central Bureau of Statistics, 2012) and are the least oriented towards Dutch society compared to other large minority groups (Dagevos, 2001). Additionally, more Turkish-Dutch patients visit the GP than Dutch patients and they also visit the GP more often, even patients who rate their health as good (Deville, Uiters, Westert, & Groenewegen, 2006; Uiters et al., 2006). Thus, it is particularly relevant to study whether information needs of Turkish-Dutch patients are being met.

Lower language proficiency is found to correlate with negative experiences and less satisfaction with primary care among ethnic minority patients (Jacobs, Chen, Karliner, Agger-Gupta, & Mutha, 2006; Pippins, Alegria, & Haas, 2007). Therefore, language proficiency might confound their (perceived) unfulfilled information needs. As previous literature suggests that language proficiency and cultural views are stronger predictors of patient satisfaction than ethnic background per se (Harmsen et al., 2008), this study includes acculturation levels (i.e. language proficiency and cultural identification) of Turkish-Dutch patients.

In sum, the aim of this study is twofold: 1) to assess (unfulfilled) information needs of Dutch and Turkish-Dutch patients, and 2) to assess the relationship between perceived information provision and recorded information provision.

Methods

Procedure

Eleven GPs (seven men, four women) working in six practices in three multicultural cities in the Netherlands participated. All patients in the waiting room were asked to participate by research assistants during three to ten days per practice. To be included patients should have an appointment with the GP for themselves and be able to read in Dutch or Turkish or be accompanied by someone who could read in these languages. After signing the informed consent form in the waiting room, participants were given a pre- and post-consultation questionnaire (available in Dutch and Turkish). When patients had too little time to finish the post-questionnaire, they were allowed to fill out the questionnaire at home. Consultations of participating patients were audiotaped by the GP. The study was approved by the ethical committee of the Amsterdam School for Communication Research (ASCoR).

Participants

For this study two samples were used: sample one with pre- and post-consultation questionnaires, and sample two with pre- and post-consultation questionnaires and audiotapes. Of all 476 eligible patients (sample 1: 130; sample 2: 346), 338 consented to participate (71% total; sample 1: 87.8%; sample 2: 63.8%). Of the 338 patients who consented, 82 did not return the post-consultation questionnaire and 21 questionnaires contained too many missing values. Moreover, in the second sample 41 audiotapes were not applicable for analyses, because the consultations were only partly audiotaped by the GP or contained too much noise. In total, sample one consisted of 62 patients (35 Dutch, 27 Turkish-Dutch) and sample two of 129 patients (82 Dutch, 47 Turkish-Dutch). Nine Turkish-Dutch patients in sample 2 wanted to participate with the questionnaires but without audiotape. These patients were included in sample one. Thus, total sample to analyze unfulfilled information needs (study aim 1) consisted of 117 Dutch and 74 Turkish-Dutch patients ($n = 191$). Of these patients, 11 (9,4%) Dutch and 9 (12,2%) Turkish-Dutch patients filled out the post-questionnaire at home. Since these patients did not differ from the patients that filled out the questionnaire at the GPs' office, all patients are taken together in the analyses. Total sample size to investigate the relationship between self-reported and recorded information provision (study aim 2) consisted of 82 Dutch and 38 Turkish-Dutch patients ($n = 120$). Figure 1 shows the flow chart for both samples.

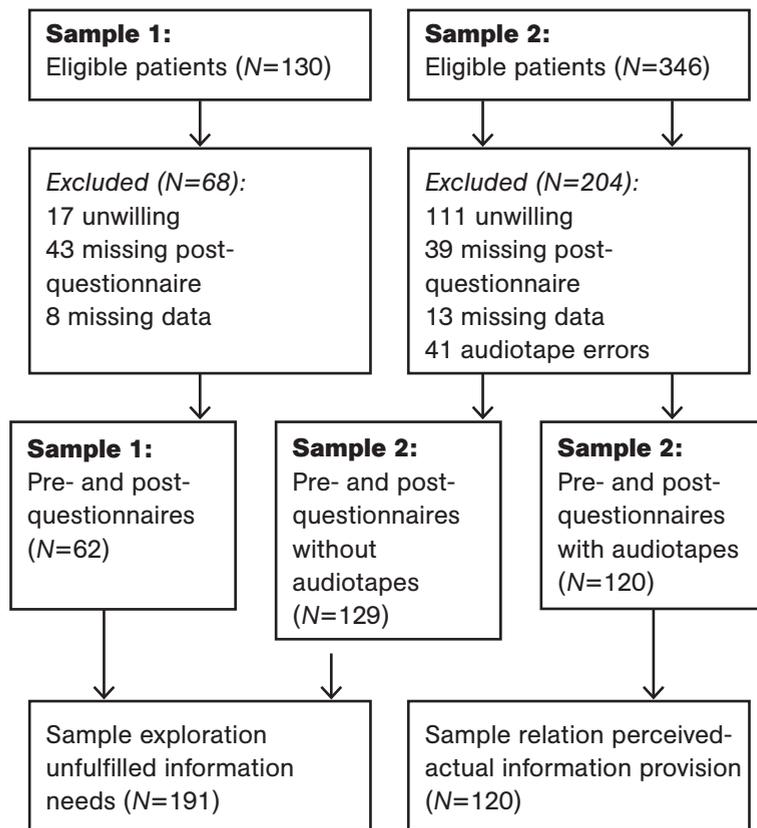


Figure 1. Response diagram for the two samples

Measures

Pre-consultation questionnaire

Socio-demographic variables

To establish the ethnicity of respondents, the ethnicity definition of the Dutch Central Bureau of Statistics was used (Central Bureau of Statistics, 2000). Respondents with both parents born in the Netherlands were categorized as Dutch; respondents who are born in Turkey and/or have at least one parent born in Turkey were categorized as Turkish-Dutch. Other variables assessed were gender, age, educational level and health status, the latter being measured with a single item assessing how patients perceive their health, with a 5-point scale, ranging from “(1) poor” to “(5) excellent”.

Acculturation

For Turkish-Dutch patients, group identification and language proficiency were assessed. Group identification was measured by Stevens et al.’s ethnic identity measure (Stevens, Pels, Vollebergh, & Crijnen, 2004). Patients could indicate the extent to which they feel they belong to the Dutch and Turkish culture on a 5-point scale, ranging from “(1) totally disagree” to “(5) totally agree”. The two items are uncorrelated ($r = -.02$, ns), indicating two independent measures of group identification. A self-developed identification score was measured by subtracting the score on Turkish culture from Dutch culture, resulting in scores between -4 to 4. Based on Harmsen et al.’s (2008) division of three cultural views groups (traditional, partly traditional/modern, modern), three groups were formed: patients

with equal (-1 to 1), more Dutch (2 to 4) and more Turkish (-2 to -4) identification.

As previous research has indicated high correlations between patients’ self-report, interviewers’ assessment and GPs’ assessment of ethnic minority patients’ language proficiency (Schouten et al., 2007), language proficiency of the Dutch language was measured by a single self-report item assessing the extent to which patients think they have command of the Dutch language (5-point scale, ranging from “(1) not at all” to “(5) excellent”).

Information needs

Based on the importance questionnaire of the QUOTE^{communication} (van den Brink-Muinen et al., 2000), and various information needs scales (Beisecker & Beisecker, 1990; Coulter, Entwistle, & Gilbert, 1999; Rüdell, Myers, & Newman, 2006), patients rated the importance of nineteen different information topics for their health problem on a 5-point scale, ranging from “(1) not at all important” to “(5) extremely important”. Items covered basic medical information such as the diagnosis, symptoms and cause as well as more specific information such as consequences for daily life, psychological aspects and medication use. Principal component analyses showed different patterns across the groups. For Dutch patients two components were found, for Turkish-Dutch patients three were found. Scree plots for both groups showed that a single factor matches best, but regarding the different patterns analyses are conducted on item level.

Post-consultation questionnaire

Information provision

The information provision was measured on the same nineteen items as for information needs in the pre-consultation questionnaire. Patients had to indicate the extent to which the issue was discussed during the consultation on a 5-point scale ranging from “(1) not at all discussed” to “(5) extensively discussed”.

Observational measures

Information provision during consultation

The frequency of which seventeen out of the nineteen information items of the questionnaires were addressed during the consultation, were coded. Since the questionnaire items “information on all possible treatments” and “self-treatment” could both concern “treatment without medication” and “treatment with medication”, only the last two information topics were coded from the audiotapes. Coding was done directly from audiotape. Only utterances in which the information topics were addressed were coded. When utterances addressed more than one topic, utterances were split into parts and coded for the topics that were addressed. For each utterance it was coded which person addressed the information, either the GP, patient or another person. Total amount of utterances addressing one of the information items was counted per consultation for all parties together. The first author (SS) coded all 120 consultations and recoded 23 randomly selected consultations (19%) one month after the first round. Additionally, the second author (BS) coded the same 23 consultations. Intracoder and intercoder reliability were measured for the categories that took up more than 2% of all coded utterances (van Weert, van Dulmen, Bär, & Venus, 2003). Intracoder reliability (Mean Pearson’s r .96; range .93-.98) and intercoder reliability (Mean Pearson’s r .78; range .56-.93) were sufficient to good.

Analyses

To measure unfulfilled information needs, Quality Impact Indices (QIIs) were calculated based on studies using QUOTE questionnaires (Brouwer, Sixma, Triemstra, & Delnoij, 2006; van Weert et al., 2009). Categories 1 and 2 (“not at all discussed” and “a bit discussed”) of the perceived information provision scale were recoded as low information provision, and category 3, 4 and 5 (“fairly discussed” to “extensively discussed”) as high information provision. The fraction (%/100) of patients who reported low information provision was multiplied by the mean importance score on the information item (mean importance score * proportion low information provision) to calculate QIIs.

Differences in background characteristics were assessed with chi-square tests or independent samples t-tests, where appropriate. Differences between patient groups on information needs and unfulfilled information needs were assessed with multilevel analyses (ANCOVAs) using linear mixed models with group as fixed effect and GP as random effect. Patients’ age, gender and health status were taken as covariates, testing main effects and interactions between group and these background characteristics. The intercept of the information item was allowed to vary over GPs, taking into account the hierarchical structure of the data. One-way ANOVAs were performed to assess within-group differences for identification among Turkish-Dutch patients. The relation between self-reported and recorded information provision was assessed with Pearson correlation coefficients. Bivariate correlations were performed since the sample size was too small to perform multivariate analyses.

Results

Patient sample

Table 1 gives an overview of the total sample. 57 out of 74 Turkish-Dutch patients are born in Turkey, 16 in the Netherlands and have at least one parent born in Turkey (one patient did not report own country of birth). Since no significant differences were found between these patients in their needs the group is taken as one.

The Dutch group consisted of more women than men, while the Turkish-Dutch group was equally distributed. Moreover, Turkish-Dutch patients were younger and reported poorer health status than Dutch patients. The groups did not differ significantly in their educational level and health problems, classified with ICPC classification (Bentsen, 1986). In both groups the majority reported problems with the locomotor system and general complaints such as flu and common cold. In addition, Turkish-Dutch patients reported to go to the GP for psychological problems five times more often than Dutch patients. Table 1 gives an overview of the health problems per patient group. In terms of acculturation, Turkish-Dutch patients reported more identification with Turkish culture than with Dutch culture (see Table 1) and reported relatively high Dutch language proficiency ($M = 3.6$ on a 1-5 scale; $SD = 1.1$).

Table 1
Sample characteristics

Patients' characteristics	Dutch (N=117)	Turkish-Dutch (N=74)
<i>Sex**</i>		
Men	33 (28.2%)	36 (48.6%)
Women	84 (71.8%)	38 (51.4%)
<i>Age***</i>		
Mean age in years (<i>SD</i>)	48.2 (17) ^a	37.4 (13.5)
<i>Education</i>		
Low	43 (36.8%)	23 (31.5%)
Intermediate	51 (43.6%)	41 (56.2%)
High	23 (19.7%)	9 (12.3%)
<i>Health status*</i>		
Poor	29 (26.1%)	27 (38.0%)
Moderate	55 (49.5%)	35 (49.3%)
Good	27 (24.3%)	9 (12.7%)
<i>Self-reported health problems</i>		
General problems	17 (14.5%)	9 (13.8%)
Tractus digestivus	10 (8.5%)	6 (9.2%)
Eye	4 (3.4%)	2 (3.1%)
Ear	2 (1.7%)	1 (1.5%)
Tractus circulatorius	11 (9.4%)	1 (1.5%)
Locomotor system	28 (23.9%)	13 (20%)
Nervous system	1 (0.9%)	2 (3.1%)
Psychological problems	2 (1.7%)	6 (9.2%)
Tractus respiratorius	13 (11.1%)	3 (4.6%)
Skin	10 (8.5%)	8 (12.3%)
Endocrine problems/metabolism/nutrition	1 (0.9%)	0 (0%)
Urine	0 (0%)	1 (1.5%)
Genitals women	7 (6%)	1 (1.5%)
Genitals men	1 (0.9%)	0 (0%)
Unknown	8 (6.8%)	6 (9.2%)

Company during consultation

Alone	85 (76.6%)	50 (69.4%)
Partner	14 (12.6%)	7 (9.7%)
Child	8 (7.2%)	10 (13.9%)
Parent	4 (3.6%)	2 (2.8%)
Other	0 (0%)	3 (4.2%)

Dutch language proficiency

Mean overall scores (SD)	3.6 (1.1)
Mean scores first/second generation	3.3 (1.1) / 4.4 (0.6)

Identification Dutch culture

Mean overall scores (SD)	2.9 (1.2)
Mean scores first/second generation	2.7 (1.2) / 3.5 (1.2)

Identification Turkish culture

Mean overall scores (SD)	3.7 (1.2)
Mean scores first/second generation	3.8 (1.0) / 3.5 (1.6)

* $p < .05$ ** $p < .01$ *** $p < .001$

Note. Language proficiency and identification are measured with a 1-5 scale, with 5 as highest score

Consultation characteristics

No significant differences between consultations with Dutch and Turkish-Dutch patients were found in consultation length, amount of talk of GPs and patients and frequency in which patients brought company with them. Dutch patients were generally accompanied by their partner, while Turkish-Dutch patients were generally accompanied by a child or another person than their partner.

Information needs

Turkish-Dutch patients reported higher information need than Dutch patients on prognosis ($F(1,126.21) = 6.04, p < .05$), prevalence ($F(1,139) = 5.03, p < .05$), physical examination ($F(1,133.78) = 6.55, p < .05$), explanation of medical terms ($F(1,133.66) = 8.59, p < .01$), alternative medicine ($F(1,130.61) = 6.54, p < .05$) and procedures at other hospital/other caregivers ($F(1,130) = 4.45, p < .05$). No significant interaction effects were found between group and background characteristics on information needs.

When dividing Turkish-Dutch patients into three groups (more Dutch, equal and more Turkish identification), significant differences were found on causes ($F(2,51) = 5.51, p < .01$), prognoses ($F(2,49) = 3.47, p < .05$), physical examination ($F(2,51) = 3.23, p < .05$), treatment with medication ($F(2,52) = 3.61, p < .05$), medication use ($F(2,52) = 4.53, p < .05$) and self-treatment ($F(2,52) = 4.05, p < .05$). Patients with more Dutch identification reported the lowest information needs on all topics. Patients with equal identification reported the highest information needs on all topics, except for medication use for which patients with more Turkish identification reported higher information needs (see figure 2). Language proficiency was weakly associated with information needs, i.e. better Dutch proficiency was related to higher need for information on prognoses ($r = .3, p < .05$) and risks of no treatment ($r = .3, p < .05$).

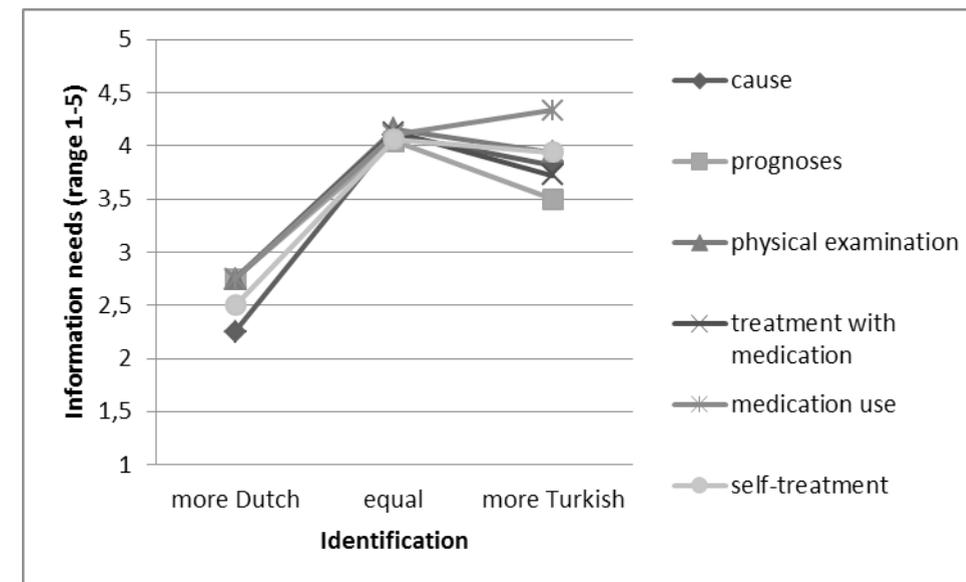


Figure 2. Information needs per identification group for Turkish-Dutch patients

Unfulfilled information needs

Table 2 shows mean QIIs per information item per group. Based on the criteria used in the QUOTE system (with 4-item scale) (Brouwer et al., 2006; van Weert et al., 2009), QIIs above 0.4 were considered as moderately in need for improvement, and QIIs above 1.2 as importantly in need for improvement (one third of the patients reporting low information provision on an important item). Table 2 shows that QIIs are moderate for typical biomedical information such as diagnosis, symptoms and seriousness. These information needs were reasonably fulfilled during the consultation according to both patient groups. However, for most other types of information relatively large QIIs were found. Overall, Dutch patients experienced less unfulfilled information needs than Turkish-Dutch patients. For Dutch patients lower QIIs were found than for Turkish-Dutch patients on information on prognosis ($F(1,126.21) = 6.04, p < .05$), prevalence ($F(1,139) = 5.03, p < .05$), physical examination ($F(1,133.78) = 6.55, p < .05$), medical terms ($F(1,133.66) = 8.59, p < .01$), alternative medicine ($F(1,130.61) = 6.54, p < .05$) and procedures at hospital/others ($F(1,130) = 4.45, p < .05$). No significant interaction effects were found between group and background characteristics on information needs.

When dividing Turkish-Dutch patients in identification groups, significant differences were found on causes ($F(2,51) = 5.51, p < .01$), prognoses ($F(2,49) = 3.47, p < .05$), physical examination ($F(2,51) = 3.23, p < .05$), treatment with medication ($F(2,52) = 3.61, p < .05$), medication use ($F(2,52) = 4.53, p < .05$), and self-treatment ($F(2,52) = 4.05, p < .05$). Patients with equal identification reported the highest unfulfilled information needs while patients with more Dutch identification reported the lowest unfulfilled information needs. Information needs were best met for patients who feel they belong to either the Dutch or Turkish culture. It should be noted though that these differences are based on small numbers of patients per group. Dutch language proficiency was related to unfulfilled information needs on prognoses ($r = .3, p < .05$) and risks of no treatment ($r = .3, p < .05$).

Table 2
Mean Quality Impact Indices (QIIs) per information topic

Category (scale 0-5)	Dutch (N=117)	Turkish-Dutch (N=74)
Diagnosis	.38	.35
Cause	.65	.67
Symptoms	.42	.46*
Seriousness	.55	.54
Prognosis	.72	.68
Prevalence	1.08	1.36***
Physical examination	1.07	1.22***
Treatment options	1.03	1.07
Treatment risks	1.97	2.10
Consequences of no treatment	2.26	2.37
Treatment with medication	1.21	1.21
Medication use	1.65	1.73
Treatment without medication	2.18	2.10
Explanation medical terms	1.98	2.29*
Alternative medicine	2.00	2.49**
Further research	1.52	1.56
Procedures at hospital/others	2.16	2.53*
Consequences for daily life	1.94	1.98
Self-treatment	1.45	1.42

* $p < .05$ ** $p < .01$ *** $p < .001$

Note. Higher Quality Impact Indices mean more unfulfilled information needs. QIIs above 0.4 are considered as moderately in need for improvement; QIIs above 1.2 are considered as importantly in need for improvement

Self-reported information provision versus recorded information provision

In both groups, symptoms, diagnosis, treatment with medication, treatment without medication and cause of the health problem were most frequently addressed during the consultation. Prevalence, consequences of no treatment, explanation of medical terms and alternative medicine were the least addressed. Except for medication use no differences were found in the recorded information provision. In consultations with Turkish-Dutch patients medication use was significantly more addressed than with Dutch patients ($t(118) = -2.1, p < .05$).

Table 3 shows that patients in both groups rated information on prognosis, seriousness, prevalence, treatment risks, consequences of no treatment, medical terms, alternative medicine, consequences for daily life and psychological aspects as rather extensively discussed, while in fact these topics were hardly discussed during the consultation. On the other hand, information on symptoms was the most frequently discussed in all groups, but was not reported as being discussed more than the other topics. For around half of the information items hardly any correlation was found between self-reported and recorded information provision (see Table 3). Most significant correlations were moderate, ranging from around .3 to .5. Two strong correlations were found: for Turkish-Dutch patients on procedures at hospital/other caregivers ($r = .57, p < .05$), for Dutch patients for treatment with medication ($r = .49, p < .05$).

Table 3
Correlation between self-reported and coded information provision

Category	Dutch (N=82)		r	Turkish-Dutch (N=38)		r
	self-reported info provision M (SD)	actual info provision M (SD)		self-reported info provision M (SD)	actual info provision M (SD)	
Diagnosis	4,0 (1,0)	2,8 (1,9)	.08	3,7 (1,1)	2,1 (2,1)	.39*
Cause	3,7 (1,0)	2,5 (2,3)	.13	3,2 (1,2)	1,8 (1,9)	.07
Symptoms	3,9 (1,0)	7,4 (3,9)	.24*	3,2 (1,2)	7,5 (4,4)	.22
Seriousness	3,8 (1,0)	0,4 (1,0)	.18	3,1 (1,1)	0,4 (0,9)	.24
Prognosis	3,7 (1,2)	0,4 (0,8)	-.01	3,4 (1,3)	0,4 (0,9)	.05
Prevalence	2,9 (1,4)	0,1 (0,4)	.08	3,0 (1,4)	0,2 (0,4)	.43*
Physical examination	3,0 (1,5)	1,5 (1,5)	.28*	3,2 (1,5)	1,4 (1,7)	.29
Treatment risks	2,3 (1,5)	0,5 (0,8)	.12	2,1 (1,4)	0,4 (0,8)	.03
Consequences of no treatment	2,1 (1,5)	0,2 (0,6)	-.05	2,2 (1,5)	0,2 (0,5)	.01
Treatment with medication	2,8 (1,5)	2,8 (3,0)	.49*	2,6 (1,4)	3,6 (3,5)	.43*
Medication use	2,5 (1,6)	0,5 (1,1)	.39*	2,2 (1,4)	1,0 (1,4)	.33*
Treatment without medication	2,2 (1,6)	2,2 (2,4)	.18	1,8 (1,3)	1,9 (2,2)	.15
Explanation medical terms	1,9 (1,4)	0,0 (0,2)	.06	2,0 (1,3)	0,0 (0,2)	.15
Alternative medicine	1,4 (0,9)	0,0 (0,1)	-.05	1,9 (1,3)	0,0 (0,0)	-**
Further research	2,6 (1,5)	1,5 (1,9)	.28*	3,1 (1,5)	1,5 (1,9)	.25
Procedures at hospital/others	1,5 (1,1)	0,7 (1,2)	-.05	1,4 (1,0)	1,3 (1,9)	.57*
Consequences for daily life	2,1 (1,4)	0,4 (0,8)	.23*	2,4 (1,5)	0,6 (1,0)	-.09

* $p < .05$

** no cases to perform correlation

Note. Scales are different; self-reported information provision is measured on a scale from 1-5, amount of utterances is measured as frequency

Discussion and Conclusion

Discussion

In line with previous research (Schinkel et al., 2010), results of this study show that Turkish-Dutch patients report higher needs for information on prognosis, prevalence, physical examination, medical terms, alternative medicine and procedures at other hospital/other caregivers than Dutch patients. Turkish-Dutch patients also experience more unfulfilled information needs. This might be explained by the fact that the recorded information provision by the GP is similar among the two groups, while Turkish-Dutch patients have higher (and other) information needs than their Dutch counterparts. Thus, despite the increasing attention that is given to tailoring doctor-patient communication to the specific needs of patients (van den Brink-Muinen et al., 2000), GPs do not adjust the information provision to specific characteristics and needs of the patients. This finding corresponds with results of previous research (Rosenberg, Richard, Lussier, & Abdool, 2006; Wachtler, Brorsson, & Troein, 2006). In addition, Dutch patients also experience some unfulfilled information needs. In both groups, information needs that are insufficiently met are needs that go beyond purely biomedical information, such as treatment options without medication, explanation of medical terms and procedures at other caregivers.

A noticeable result concerns the information provision on medication use, which is discussed more often with Turkish-Dutch than with Dutch patients, while Turkish-Dutch patients, in particular those with equal identification, still express a large unmet need for information about treatment with medication and medication use after the consultation. This result might be related to study findings, showing that clinicians more frequently prescribe medication to non-Western patients than to Dutch patients (Hogenhuis, Grigoryan, Me Numans, & Verheij, 2010; Uiters et al., 2006). The commonly noted higher demand for drug treatment by non-Western patients, might explain why this topic is more frequently discussed during GP consultations. Future research should be conducted to gain more insight into this topic and on which initiative (i.e. the GP or the patient) medication use is discussed.

Most correlations between self-reported and recorded information provision are not significant. It is known that accurately recalling information after a consultation is difficult for patients (Roter & Hall, 2006) and that asking patients to report what has been said during the consultation is not always a reliable method for finding out what has actually been said. Therefore, we included observational data in our study. Future research is recommended to investigate whether other communication measures besides frequency of utterances will yield the same pattern of low correlations or will yield different results.

Turkish-Dutch patients with equal identification with Dutch and Turkish culture report the highest information needs and consequently, the highest unfulfilled needs. This finding is in line with Harmsen et al. (Harmsen et al., 2008), who found that ethnic minority patients with partly modern/traditional cultural views report more negative experiences with their GP than patients with either more traditional or more modern cultural views. Possibly, better language proficiency affects patients' experiences negatively when patients have equal identification with both their country of origin and their host country. Future research should study these relationships in more detail.

Study limitations

The number of rejected audiotapes is unfortunate, but among the same range as in other studies among ethnic minority patients using observational data (Cooper et al., 2003; Gordon, Street, Sharf, & Soucek, 2006; Johnson, Roter, Powe, & Cooper, 2004). As the

patients with unusable audiotapes did not differ from patients with adequate audiotapes on age, gender or race in these studies, there is no reason to assume differences in this sample. However, to increase the sample size of this study, we deemed it necessary to collect data on a second occasion. As it is difficult to reach Turkish-Dutch patients, the sample size remains somewhat small and therefore, caution should be employed in generalizing our results to other Turkish-Dutch patients. Despite the small sample sizes, significant differences are found. Since findings correspond with other research on unfulfilled information needs (see discussion earlier), it is reasonable to assume that these differences do actually exist in the population. It must be noted, however, that the possibility of a type 1 error exists. Therefore, it is advised to replicate the study with larger samples of Turkish-Dutch patients in future research.

Since the groups could not be randomly assigned and the patient groups differ on age, gender and health status, ANCOVAs might be problematic (Miller & Chapman, 2001) because group differences in (unfulfilled) information needs can be partly affected by these background variables. According to Miller and Chapman (Miller & Chapman, 2001), ANCOVAs can be appropriate with non-random groups when the independent variable and covariates are unrelated. As the proportion of men and women is currently equal among non-Western migrants in the Netherlands (Gijssberts, Huijnk, & Dagevos, 2012), it is unlikely that differences between Dutch and Turkish-Dutch patients could be due to gender. However, non-Western migrants are younger than the majority Dutch population (Central Bureau of Statistics, 2010) and they also report lower health status. Therefore, future research in which Turkish-Dutch patients and Dutch patients are matched on age and health status should be carried out.

Additionally, more Turkish-Dutch patients reported psychological problems than Dutch patients. Since previous studies in for instance oncology indicate that psychological functioning influences the amount and type of desired information (van Weert et al., 2009; Wong et al., 2000), GP patients dealing with psychological problems may have different information needs than patients with non-psychological problems. Also, it is found that ethnic minority patients have trouble expressing emotional distress during medical interactions (De Maesschalck, Deveugele, & Willems, 2011) and at the same time, health care providers tend to ignore a high percentage of their patients' emotional cues and concerns (Butow et al., 2011). As a consequence, psychosocial encounters between GPs and Turkish-Dutch patients may lead to more unfulfilled information needs. As no research has yet been done on comparing ethnic minority patients' expression of psychosocial concerns with ethnic majority patients in relation to fulfillment of information needs, future studies should investigate this topic with larger samples.

Finally, patients who were willing to participate could have had less concerns with communicating with their GP, and GPs who participated could have been more interested in and aware of ethnic differences in the communication process, resulting in a biased sample. Thus, results of this study might paint a more positive picture than will be found among a more representative sample and, possibly, unfulfilled information needs might be even larger in reality.

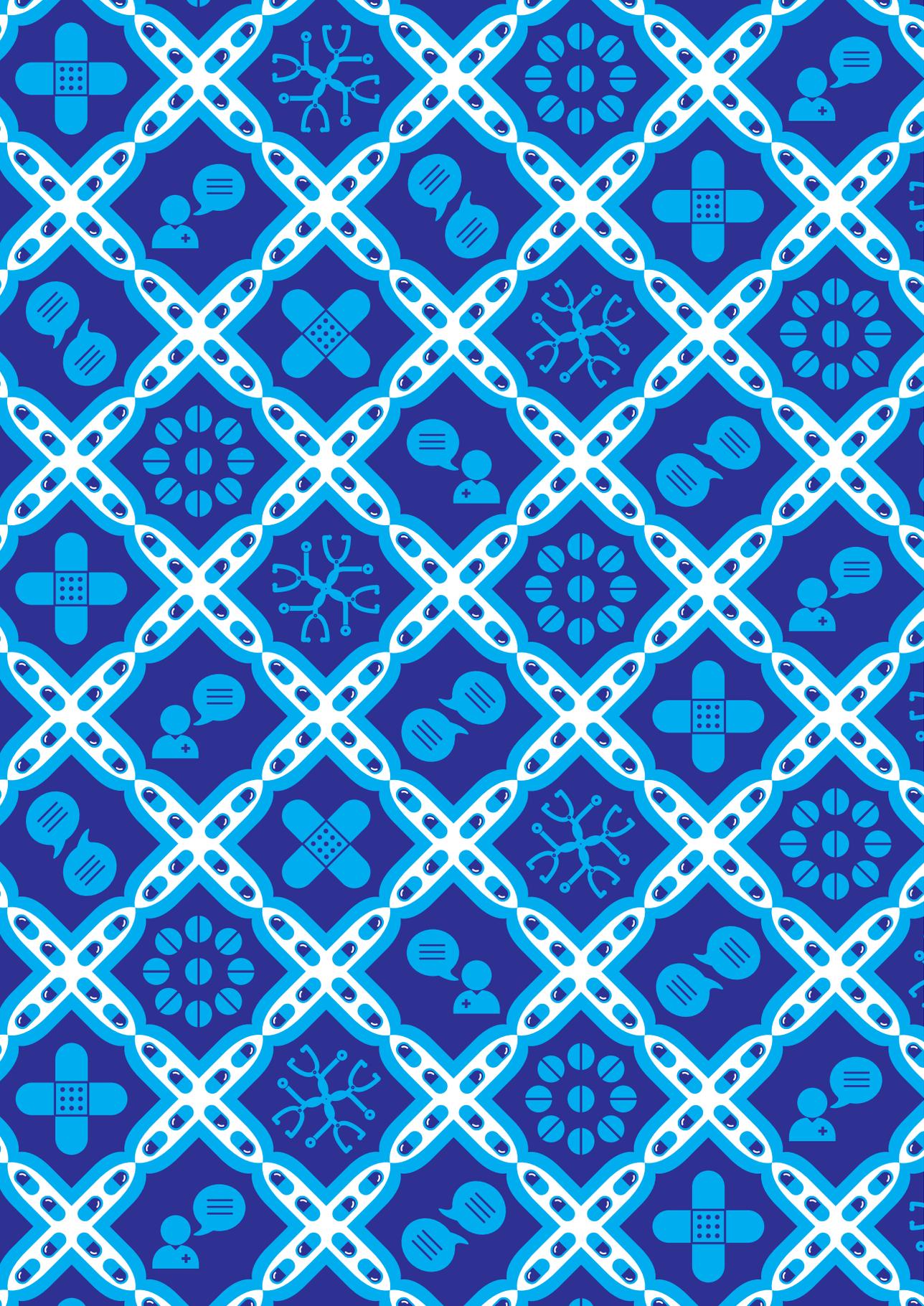
Conclusion

Several studies have found that ethnic minority patients report lower mutual understanding and lower satisfaction with medical communication than ethnic majority patients (Harmsen, Meeuwesen, van Wieringen, Bernsen, & Bruijnzeels, 2003; Stronks et al., 2001; van Wieringen et al., 2002). In line with this, the current study shows that Turkish-Dutch

patients experience more unfulfilled information needs than Dutch patients, indicating that GPs do not sufficiently tailor the consultation to the information needs of these patients.

Practice implications

As unfulfilled information needs can hinder informed decisions, GPs should be trained in tailoring information to the specific needs of their patients. Considering the results of this study, interventions aimed at tailoring the information provision may be most effective when they are designed to educate GPs in cultural differences in information needs and in the extent to which different types of information should be addressed.



CHAPTER 3

Health-information seeking, patient participation and communication outcomes

Abstract

This study investigated differences between Dutch and Turkish-Dutch patients with respect to media usage before and patient participation during medical consultations with GPs. In addition, the relationship between patient participation and communication outcomes was assessed. The patients were recruited in GP waiting rooms, and 191 patients (117 Dutch, 74 Turkish-Dutch) completed pre- and post-consultation questionnaires. 120 patients (62.8%; 82 Dutch, 38 Turkish-Dutch) agreed to have their consultations recorded. The 38 consultations with Turkish-Dutch patients were matched on age and gender with Dutch patients, resulting in 34 Dutch and 34 Turkish-Dutch consultations to assess patient participation. Compared with Turkish-Dutch patients of similar educational levels, the results showed that Dutch patients used different media to search for information, participated to a greater extent during their consultations and were more responsive to their GP. With respect to the Turkish-Dutch patients, media usage was related to increased patient participation, which was correlated with having fewer unfulfilled information needs; however, these relations were not found in the Dutch patient sample. In conclusion, interventions that enhance participation among ethnic minority patients will better fulfill informational needs when such interventions stimulate information-seeking behavior in that group prior to a medical consultation.

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Introduction

In the US, the analysis of healthcare inequality comparing ethnic minority and ethnic majority patients generally focuses on ethnic minorities' lower rate of healthcare usage. This lower usage rate may be the result of the weaker US primary care system compared with that of other developed nations, and because of the high rates of uninsured ethnic minorities in the US (Uiters, Devillé, Foets, Spreeuwenberg, & Groenewegen, 2009). The opposite pattern prevails in the Netherlands, where health insurance is mandatory. In the Netherlands, the Turkish-Dutch population comprises the largest ethnic minority group (i.e., approximately 400,000 people or 2.4% of the Dutch population, Central Bureau of Statistics, 2012), and members of this population perceive their health as poorer, report more health problems (Lindert et al., 2004), and visit their general practitioner (GP) significantly more often than the Dutch population (Deville et al., 2006; Uiters et al., 2006). Therefore, Dutch GPs regularly encounter Turkish-Dutch patients in consultations. Previous research has indicated that these consultations frequently result in suboptimal levels of patient satisfaction and lower perceived quality of care because of inadequate communication processes (Harmsen et al., 2008; Schouten & Meeuwesen, 2006; van Wieringen et al., 2002). Thus, to alleviate these problems, interventions should be designed to improve intercultural communication with GPs.

One widely recognized method of improving medical communication involves encouraging patients to actively participate in consultations (Street, 2001). Compared with less actively involved patients, the previous literature has shown that patients who more actively participate in medical encounters receive more information and support from their doctor, have a better understanding of their treatment (Street et al., 1995), are better equipped to make appropriate decisions (Dickerson et al., 2004; Gerber & Eiser, 2001), experience more satisfaction with their care and are more compliant (Ong, De Haes, Hoos, & Lammes, 1995; Street Jr, Gordon, Ward, Krupat, & Kravitz, 2005; van den Brink-Muinen et al., 2006). Patient participation during medical encounters is thus an important factor both for establishing an effective doctor-patient relationship and for achieving positive health-related outcomes (Street, 2001). However, in the US, ethnic minority patients exhibit patterns of lower participation during medical consultations than patients from the ethnic majority population (Cooper-Patrick et al., 1999; Johnson et al., 2004; Street Jr et al., 2005; Young & Klinge, 1996); notably, a similar pattern holds for the Netherlands (Meeuwesen, Tromp, Schouten, & Harmsen, 2007). For example, ethnic minority patients in the Netherlands ask fewer questions (Schouten et al., 2007) and provide less information and clarification (Meeuwesen et al., 2006) than Dutch patients. Given the dearth of research on the reasons for ethnic minority patients' lower participation levels, this study aims to provide insight into this topic by exploring the differences between Turkish-Dutch and Dutch patients during GP consultations in terms of possible determinants of patient participation, actual patient participation during GP consultations and communication outcomes.

Theoretical Background

This study is based on Street's model of patient participation (2001), which posits several determinants and presents several outcomes of patient participation. Overall, Street's model (2001) indicates that increased patient participation leads to better quality of care, including improvements in the quality of the information provided. Patient participation is 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); thus, patient participation refers to the communication during medical consultations in terms of the patient's contribution to the discussion. According to Street's model, patient participation is determined by predisposing factors, enabling factors and provider responses. Predisposing factors refer to background variables and motivational factors. Previous research examining such predisposing factors indicates that ethnic minority patients are less willing to participate than ethnic majority populations (Levinson et al., 2005). Enabling factors refer to patients' abilities to participate, including their knowledge about the health issue(s) and their communication skills and routines; the 'informed patient' is widely understood as an empowered patient (Henwood et al., 2003). Provider responses are beyond the scope of the current study because our focus is on determinants regarding only the patient. Because scarce attention has been given to the influence of enabling factors among ethnic minority patients, the focus of this study is on the enabling factors of patient participation and communication outcomes.

For ethnic minority patients, the ability to participate in medical consultations can be hindered by insufficient language proficiency (Street, 2001). Previous research in the US indicates that ethnic minority patients who report poor language proficiency participate less than patients with better language proficiency (Schenker et al., 2010). In addition to language proficiency, obtaining health knowledge before a medical appointment can increase patient participation during the consultation (Cahill, 1998; Street, 2001). According to Johnson's model of health information-seeking behavior (Johnson & Meischke, 1993), patients' information-seeking behavior—and consequentially, the amount of health knowledge—is dependent on health-related factors, such as their experience with diseases, their beliefs about control and information-carrier factors, such as the utility of media. This model, which combines the *uses and gratifications approach* (Katz, Blumler, & Gurevitch, 1973) and models regarding health-related behaviors and media exposure, posits that these factors will determine which medium is used to fulfill health information needs. According to this model, ethnic minority patients' media usage will most likely differ from that of the ethnic majority population because previous research has shown that ethnic minority patients generally experience health and sickness differently (Helman, 2001; Kleinman, 1980), are less active searchers for information (Dickerson et al., 2004) and have lower health literacy levels (Sudore et al., 2009) than ethnic majority patients. Indeed, research has shown that white Americans prefer books as their source of health information, whereas African Americans prefer newspapers, television and radio (Guidry, Aday, Zhang, & Winn, 1998). Furthermore, white patients prefer to use scientific and objective sources for their health information (e.g., telephone services and medical journals), whereas Japanese patients prefer commercial and media sources (e.g., television and print media; Kakai, Maskarinec, Shumay, Tatsumura, & Tasaki, 2003).

Health information can be obtained either actively or passively (Longo, 2005). Patients who obtain information passively (i.e., indirectly or accidentally) are less participative during a consultation than patients who obtain information actively (i.e., purposefully and consciously) before the consultation (Czaja, Manfredi, & Price, 2003; Radina, Ginter, Brandt, Swaney, & Longo, 2011). Because patients' pre-consultation information-seeking media usage that aims to learn information regarding their health issue can be considered as a form of actively obtaining information, these patients are more likely to actively participate during the consultation than those who did not use media (or who did so to a lesser extent).

Both Street (2001) and Longo (2005) suggest that higher participation leads to higher patient empowerment. More active patients inform their doctors more clearly

(e.g., by asking questions and asking for clarification) about what matters to them than passive patients (Cegala, Street Jr, & Clinch, 2007). As a consequence, active patients receive better information from their doctors (Street et al., 1995). These patients align the information provision from their GPs with their own needs, suggesting that more active patients have their information needs better fulfilled during consultations than less active patients.

Although a number of studies have found differences between ethnic minority patients and the ethnic majority population, these studies have primarily examined US minorities. It is unclear whether these results will be consistent with results for Turkish-Dutch patients in the Netherlands. Because Turkish-Dutch people are more likely to engage in face-saving (i.e., indirect) communication rather than engaging in direct communication (Ting-Toomey & Kurogi, 1998), it seems likely that Turkish-Dutch patients will be less assertive with their GPs than Dutch patients, which may lead to lower participation levels. Moreover, Turkish-Dutch patients have different information needs than the Dutch population (Schinkel, Schouten, & van Weert, 2013), and tend to watch television and read newspapers and magazines (i.e., consume media) from their country of origin more often than other ethnic minority groups in the Netherlands (Central Bureau of Statistics, 2012), which suggests that Turkish-Dutch patients will use different media than Dutch patients when searching for health information. In addition, because Turkish-Dutch patients have lower Dutch language proficiency than Dutch patients (Meeuwesen et al., 2006), language proficiency is likely a relevant factor for patient participation for Turkish-Dutch patients. Thus, the results found in the US may also apply to Turkish-Dutch patients. For both patient groups, media use aiming at obtaining health information will increase patient participation levels, which will enable patients to fulfill their information needs. Based on our literature review, the following hypotheses are proposed in the current study:

H1: Turkish-Dutch patients will demonstrate lower participation than Dutch patients during GP consultations.

H2: Turkish-Dutch patients will use different media sources to search for health information than Dutch patients.

H3: Turkish-Dutch patients with higher Dutch language proficiency will participate more than those with lower Dutch language proficiency.

H4: Patients who use media before their consultations will participate more than patients who do not use media.

H5: A higher level of patient participation will be related to a decrease in unfulfilled information needs.

Methods

Procedure

A total of eleven GPs (seven men and four women) from six GP practices located in three multicultural cities in the Netherlands (Rotterdam, Utrecht, Zaandam) participated in the current study. A research assistant asked all the patients in the waiting room of each practice to participate. The inclusion criteria stipulated that patients must have an appointment with the GP for themselves and must be able to read in Dutch or Turkish or be accompanied by someone who could read in Dutch or Turkish. After signing the informed consent form in the waiting room, participants were asked to complete pre- and post-consultation questionnaires. Questionnaires were available in Dutch and Turkish. Participating patient consultations were recorded on audiotape by the GP and were later transcribed verbatim. The study was approved by the ethical committee of the Amsterdam School for Communication Research (ASCoR).

Participants

In total, 191 patients (117 Dutch, 74 Turkish-Dutch) completed the pre- and post-consultation questionnaires assessing their information-seeking behavior. Of the 191 patients, 120 patients (82 Dutch, 38 Turkish-Dutch) consented to have their GP consultation recorded (see Schinkel et al., 2013 for a detailed description of the sample and non-responses). Given that the Dutch and Turkish-Dutch patients differed significantly in age and gender and that differences in information-seeking behavior and participation might be the result of these factors (Eheman et al., 2009; Mayer et al., 2007; Street Jr et al., 2005), the 38 Turkish-Dutch patients for whom audiotapes were available were matched with Dutch patients with respect to age and gender. This result led to two comparable groups of 34 Dutch and 34 Turkish-Dutch patients to assess patient participation (four Turkish-Dutch patients could not be matched by age).

Measures

Pre-consultation questionnaire measures

Socio-demographic variables

Based on the ethnicity definitions used by the Dutch Central Bureau of Statistics, respondents born in the Netherlands with both parents born in the Netherlands were categorized as Dutch, and respondents born in Turkey and/or with at least one parent who was born in Turkey were categorized as Turkish-Dutch. Other variables measured included gender, age, educational level, companion during the encounter, health problem for which the patient had an appointment (according to ICPC classification; Bentsen, 1986) and the GP's perception of the seriousness of the health problem. The latter was measured with a single item on a 5-point Likert scale, ranging from 1 (*not at all serious*) to 5 (*very serious*). For Turkish-Dutch patients, Dutch language proficiency was measured with a single self-reported item assessing the extent to which the patients believed that they were proficient in the Dutch language on a 5-point scale, ranging from 1 (*not at all*) to 5 (*excellent*).

Pre-consultation media usage

Patients reported their media usage for searching for information about their health problem using the following options: Internet, books, leaflets, magazines/newspapers, television/radio and other sources (Guidry et al., 1998; Kakai et al., 2003). Multiple answers could be provided, and answers were analyzed at the item level to assess differences in media usage between the groups. A dummy variable of 1 (*media use*) or 0 (*no media use*) was used to measure the influence of this factor on patient participation.

Pre- and post-consultation questionnaire measures

Unfulfilled information needs

For the pre-consultation questionnaire, patients rated the importance of twenty information topics to discuss with their GP on a 5-point scale, ranging from 1 (*not at all important*) to 5 (*extremely important*). For the post-consultation questionnaire, patients rated the extent to which identical information topics had been discussed during the consultation on a 5-point scale, ranging from 1 (*not at all discussed*) to 5 (*extensively discussed*). To measure unfulfilled information needs, Quality Impact Indices (QIIs) were calculated for each information item by multiplying the proportion of patients reporting low levels of information provision (< 3) with the mean importance scores for that information item, a calculation based on studies using QUOTE questionnaires (van Weert et al., 2009). For a full description of this measurement, see Schinkel et al. (2013). The QIIs were divided into the following two subscales (see Table 1): (a) unfulfilled information needs concerning primary

biomedical information (i.e., information that is necessary for diagnosis and treatment, such as diagnosis, causes and prevalence; $\alpha = .87$ for Dutch and $\alpha = .92$ for Turkish-Dutch group) and (b) unfulfilled information needs concerning secondary information (i.e., additional information that extends beyond purely biomedical information, such as psychosocial information, procedures at the hospital and alternative medicine; $\alpha = .89$ and $\alpha = .93$, respectively).

Table 1

Two subscales for the (unfulfilled) patients' information needs

Primary biomedical information	Secondary information
1. Diagnosis	1. Consequences of no treatment
2. Cause	2. Treatment without medication
3. Symptoms	3. Explanation of medical terms
4. Seriousness	4. Alternative medicine
5. Prognosis	5. Further research
6. Prevalence	6. Procedures at a hospital/other
7. Physical examination	7. Consequences for daily life
8. All possible treatment options	8. Self-treatment
9. Treatment with medication	9. Psychological aspects
10. Medication use	
11. Risks of treatment	

Observational measures

Patient participation was measured with the following measures: (a) relative talk, (b) proportion of dialogues/monologues, (c) number of questions asked by patients and (d) referrals to searched information by patients during the consultations. For the first two measurements, all the consultations were divided into two major segments: (1) medical background and (2) the discussion of diagnosis and decision-making (based on Tates & Meeuwesen, 2000). The physical examination segment of the consultation was excluded from the analysis because it involves less communication. Interrater reliability checks regarding the observational measures were conducted during observer training. The final interobserver reliability was calculated for 17 of the 68 transcripts (25%).

Relative talk

All utterances were counted and coded regarding who initiated the utterance (GP, patient or companion of the patient). An utterance is defined as the smallest part of an utterance that has a specific function, such as a question, concern or assertive act (Street, 2001; Tates & Meeuwesen, 2000). Intraclass correlation coefficients (with a two-way random model, single measures) showed almost perfect agreement ($M = .98$, ICC range .94-1.0) (Altman, 1991). The relative talk per person was calculated by subtracting the amount of utterances from one person during a consultation relative to the total amount of utterances for that consultation.

Proportion of dialogues/monologues

Based on the MEDICODE instrument (Richard & Lussier, 2007), coding included whether an utterance was related to a dialogue or a monologue and who initiated the dialogue

or monologue (GP, patient or companion). Dyads between doctor and patient or doctor and companion were coded, whereas dyads between the patient and the companion were excluded. A dialogue refers to an utterance followed by a reaction from another party (Richard & Lussier, 2007). All types of explanations, answers and short remarks to support the utterance of the initiator were coded as reactions. A monologue code was implemented when the other party began an utterance on a different topic that was not a reaction to the preceding utterance. Intraclass correlation coefficients (with two-way random model, single measures) showed almost perfect agreement on the dialogue scores ($M = .99$, ICC range .97-.99) and good agreement on the monologue scores ($M = .77$, ICC range .67-.93) (Altman, 1991). The proportion of dialogues and monologues were calculated by subtracting the frequency of a code being present from the total frequency of all of the codes.

Number of questions asked

All questions asked by the patients were coded. Intraclass correlation coefficient showed almost perfect agreement (ICC = .97) between the coders (Altman, 1991).

Referrals to searched information during the consultation

Finally, the coding included whether patients referred to information that they searched for before the consultation. Cohen's Kappa showed good agreement ($\kappa = .77$) between the coders (Altman, 1991).

Analyses

Differences between the groups in their media usage and in the referrals to searched information by the patients prior to the consultation were measured using chi-square tests. Differences between the groups in relative talk, questions asked and the proportion of dialogues/monologues were measured with independent samples t-tests. Stepwise multiple regression models were used to measure the relationship between media use, Dutch language proficiency and patient participation (with relative talk, question asking and proportion of dialogues/monologues entered separately as dependent variables). As independent variables, step 1 included media use, and step 2 included media use and Dutch language proficiency. The relationships between patient participation and unfulfilled information needs were assessed with separate regression models for unfulfilled information needs regarding primary and secondary information as dependent variables. As independent variables, the patients' relative talk during both segments was included in one model. In the other models, the proportion of dialogues/monologues were included per consultation segment for both doctor and patient initiations.

Results

Patient sample

Table 2 provides an overview of the total sample. Turkish-Dutch patients were younger than Dutch patients, and there were more males in the Turkish-Dutch sample. Educational level, the seriousness of the problem, the health problem according to ICPC classification and the patients' companion during the consultation did not differ between the groups. The matched groups for analyzing patient participation were similar across all the background variables. No correlations between gender and the dependent variables were found; therefore, only age was taken into account in subsequent analyses.

Table 2
Sample characteristics

Patient characteristics	Dutch (N=117)	Turkish-Dutch (N=74)
<i>Gender*</i>		
Men	33 (28.2%)	36 (48.6%)
Women	84 (71.8%)	38 (51.4%)
<i>Age</i>		
Mean age in years (SD)**	48.20 (17)	37.38 (13.5)
<i>Educational level</i>		
Low	43 (36.8%)	23 (31.5%)
Intermediate	51 (43.6%)	41 (56.2%)
High	23 (19.7%)	9 (12.3%)
<i>Seriousness of problem according to GP</i>		
Minor	68 (77.3%)	48 (81.4%)
Moderate	16 (18.2%)	8 (13.6%)
Major	4 (4.5%)	3 (5.1%)
<i>Health problem (ICPC classification)</i>		
General problems	17 (14.5%)	9 (13.8%)
Tractus digestivus	10 (8.5%)	6 (9.2%)
Eye	4 (3.4%)	2 (3.1%)
Ear	2 (1.7%)	1 (1.5%)
Tractus circulatorius	11 (9.4%)	1 (1.5%)
Locomotor system	28 (23.9%)	13 (20%)
Nervous system	1 (0.9%)	2 (3.1%)
Psychological problems	2 (1.7%)	6 (9.2%)
Tractus respiratorius	13 (11.1%)	3 (4.6%)
Skin	10 (8.5%)	8 (12.3%)
Endocrine problems	1 (0.9%)	0 (0%)
Urine	0 (0%)	1 (1.5%)
Genitals women	7 (6%)	1 (1.5%)
Genitals men	1 (0.9%)	0 (0%)
Unknown	8 (6.8%)	6 (9.2%)

Companion during consultation

No companion (alone)	85 (76.6%)	50 (69.4%)
Partner	14 (12.6%)	7 (9.7%)
Child	8 (7.2%)	10 (13.9%)
Parent	4 (3.6%)	2 (2.8%)
Other	0 (0%)	3 (4.2%)

Dutch language proficiency

Mean proficiency (SD)	3.55 (1.1)
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* $p < .01$; ** $p < .001$

Differences in patient participation

Dutch patients had a significantly higher proportion of talk ($M = 24.6\%$; $SD = 9.2$) during the diagnosis and decision-making segment of the consultation ($M = 17.7\%$; $SD = 10.9$; $t(66) = 2.8$; $p < .01$; see Figure 1) and asked significantly more questions ($M = 4.1$; $SD = 3.4$, range 0-14 questions) during the consultation than the Turkish-Dutch patients ($M = 2.3$; $SD = 2.2$, range 1-9 questions; $t(56.6) = 2.6$; $p < .05$). Additionally, consultations with Dutch patients were more often characterized as dialogues, particularly during the diagnosis and decision-making segment (see Figures 2 and 3). Both doctors ($t(64) = 2.20$, $p < .05$) and patients ($t(64) = 3.45$, $p < .01$) initiated more dialogues with one another during consultations when the patient was Dutch than when the patient was Turkish-Dutch. More monologues were evident during both consultation segments with Turkish-Dutch patients ($t(53.02) = -3.38$, $p < .01$; $t(53.19) = -4.19$, $p < .001$), which indicates that the parties reacted less frequently to one another during consultations when the patient was Turkish-Dutch. In addition, the individuals who accompanied the Turkish-Dutch patients had a higher proportion of talk and initiated more dialogues during the medical background segment ($p < .05$) than the individuals who accompanied Dutch patients. More than one-third of the patients referred to information that they had previously found during the consultation (Dutch: 41.2%, Turkish-Dutch: 32.4%, ns). Although this was not significant, more Dutch patients (66.7%) who reported searching for information before the consultation referred to that information during the consultation than Turkish-Dutch patients (37.5%). Taken together, Turkish-Dutch patients participated less during the medical consultation than Dutch patients, thereby supporting our first hypothesis.

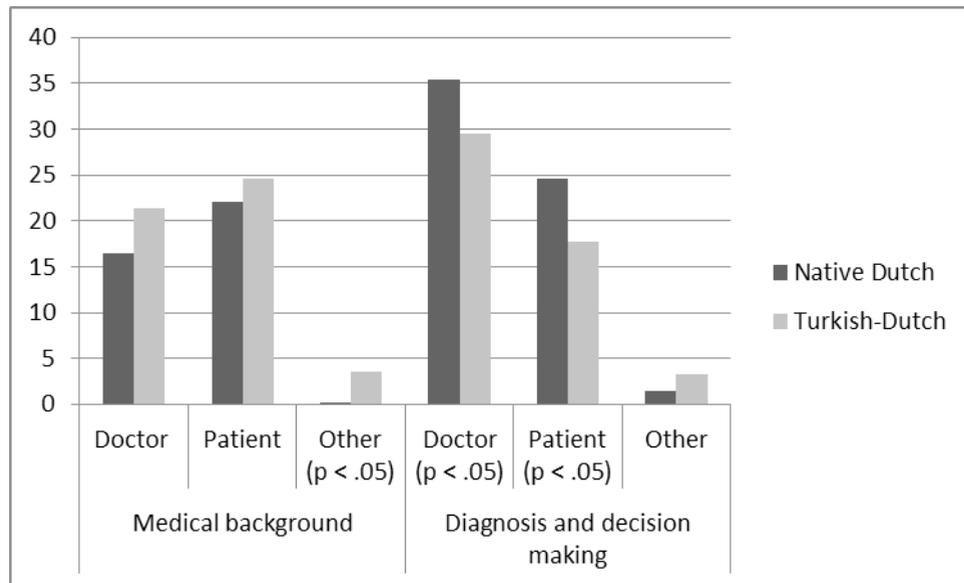


Figure 1. Relative talk per segment, group and person (%), n=68

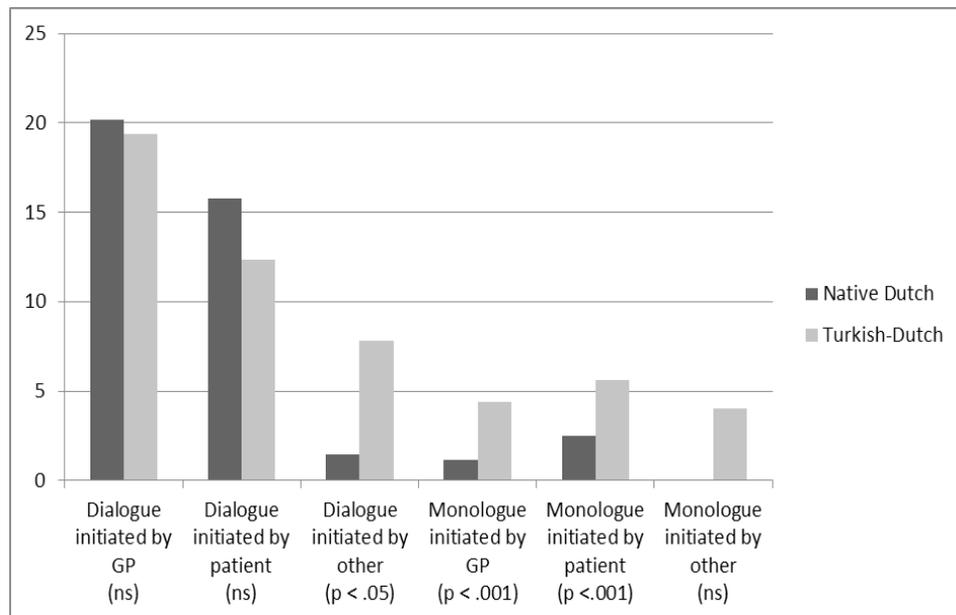


Figure 2. Proportion of dialogues/monologues per group for medical background segment (%), n=68

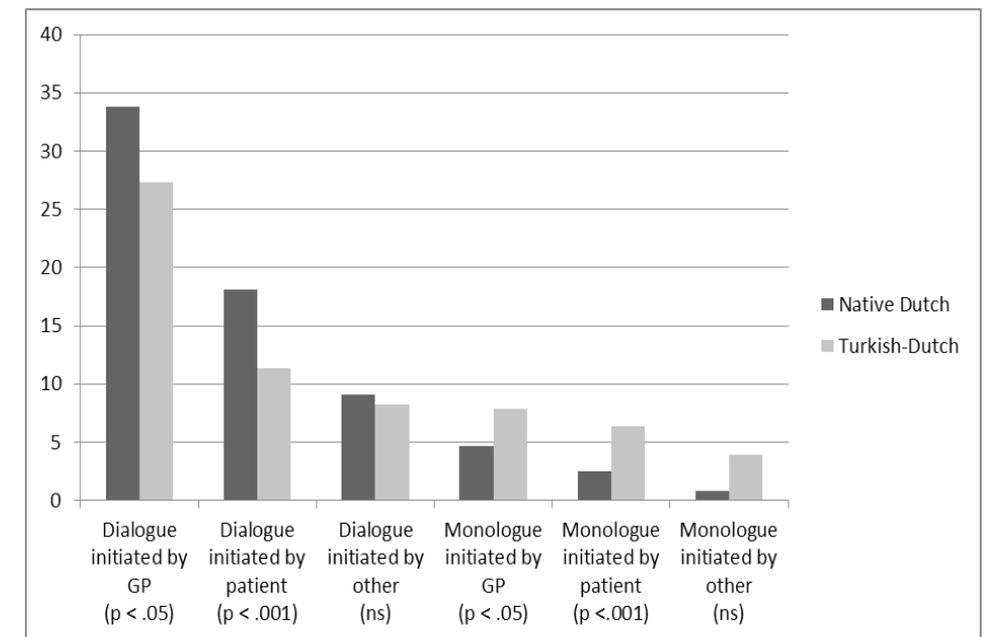


Figure 3. Proportion of dialogues/monologues per group for diagnosis and decision making segment (%), n=68

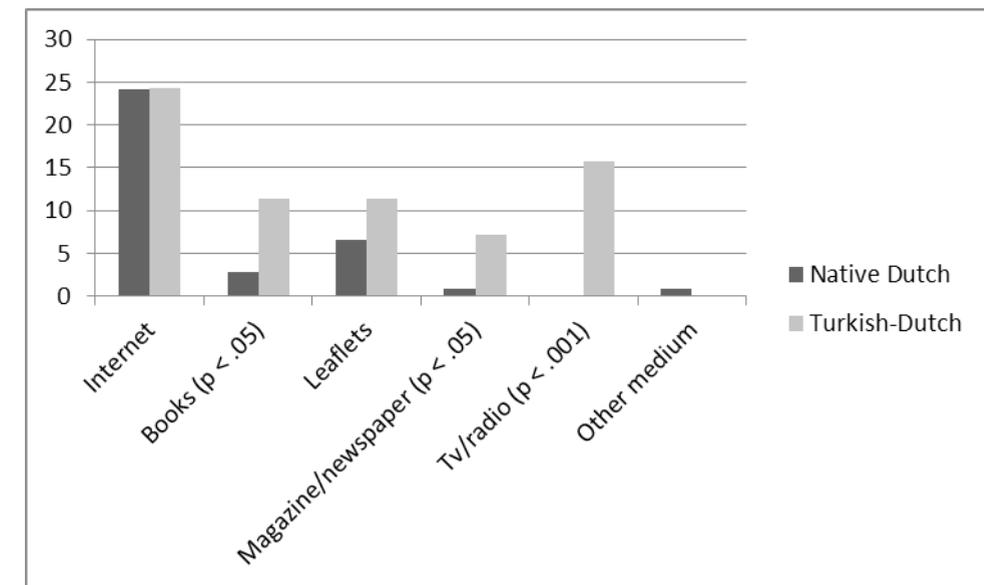


Figure 4. Media use per group (%), N=191

Differences in media use

Figure 4 presents the differences in media usage between the Dutch and Turkish-Dutch patients. Approximately half of the Turkish-Dutch patients reported that they consulted a media source (45.7%), whereas the Dutch patients were less likely to have done so (27.8%) ($\chi^2(1) = 6.0, p < .05$). The Internet was the most popular media source to search for health information (Dutch: 24.1%, Turkish-Dutch: 24.3%). Turkish-Dutch patients consulted books ($\chi^2(1) = 5.5, p < .05$), magazines and newspapers ($\chi^2(1) = 5, p < .05$) and television and radio more often than Dutch patients ($\chi^2(1) = 18.1, p < .001$). Younger Dutch patients reported using the Internet more often than older Dutch patients ($r = -.27, p < .05$), and younger Turkish-Dutch patients reported using leaflets ($r = .31, p < .01$) and TV/radio ($r = .23, p < .07$) less often than their older counterparts. Thus, H2 was supported in that Turkish-Dutch patients used different media for health information-seeking purposes before their consultations than Dutch patients.

Enabling factors and patient participation

A relationship between enabling factors and relative talk was only evident for the Turkish-Dutch patients, and those who reported using media engaged in more relative talk regarding patients' medical background ($b = .39, t = 2.39, p < .05$). The patient's relative talk was not related to Dutch language proficiency ($b = .12, t = 0.74, ns$) (model 1: $R^2 = .15; F(1, 32) = 5.71, p < .05$; model 2: $R^2 = .16; F(2, 31) = 3.09, p < .07$). Media use prior to the consultation and Dutch language proficiency were not related to the other three dimensions of patient participation, namely, the proportion of dialogues/monologues, the amount of question-asking and referrals regarding information search, in either group. Thus, H3 was not supported: Dutch language proficiency was not related to patient participation. H4 was partly supported by the findings that the relationship was only evident for the Turkish-Dutch patients and that media use was only related to the patients' relative talk.

Patient participation and unfulfilled information needs

Table 3 presents the relationship between patient participation and each subscale for unfulfilled information needs. For the Turkish-Dutch patients, better fulfillment of information needs regarding primary biomedical information was related to more relative talk of the patient ($b = -.30, t = -2.25, p < .05$), fewer doctor dialogues ($b = .33, t = 2.10, p < .05$) and more patient monologues ($b = -.48, t = -2.88, p < .01$) during the decision-making segment.

For the Turkish-Dutch patients, better fulfillment of information needs with respect to secondary information was related to more patient dialogues during the medical background segment ($b = -.35, t = -2.21, p < .05$) and more patient monologues during the decision-making segment ($b = -.37, t = -2.11, p < .05$). These relationships were not evident for the Dutch patients. These results partly support H5 in that the relationship between patient participation and unfulfilled information needs was only evident for relative talk and the proportion of dialogues/monologues, and that this finding was only evident for Turkish-Dutch patients and not for Dutch patients.

Table 3

Regression models with effects of patient participation on unfulfilled information needs for Turkish-Dutch patients

	Unfulfilled info needs primary info		Unfulfilled info needs secondary info	
	β	t	β	t
Relative talk MB	-.25 #	-1.88	-.12	-.89
Relative talk DDM	-.30*	-2.25	-.17	-1.26
R^2		.09		.03
Patient dialogues MB	-.31#	-1.95	-.35*	-2.21
Doctor dialogues MB	.33*	2.10	.28 #	1.76
R^2		.21		.21
Patient monologues MB	-.01	-.03	-.02	.10
Doctor monologues MB	-.11	-.45	-.21	-.83
R^2		.01		.04
Patient dialogues DDM	-.32	-1.80	-.16	-.88
Doctor dialogues DDM	.11	.60	.13	.71
R^2		.10		.03
Patient monologues DDM	-.48**	-2.88	-.37*	-2.11
Doctor monologues DDM	.11	.65	.08	.47
R^2		.21		.13

Note. MB = medical background segment; DDM = diagnosis and decision making segment
* $p < .05$. ** $p < .01$. # $p < .09$

Discussion

This study is the first to explore the relationships between pre-consultation media usage, patient participation and unfulfilled information needs with ethnic minority patients, in this case, Turkish-Dutch patients. The importance of obtaining health information (Street, 2001) is clearly reflected in the finding that the Turkish-Dutch patients who reported using media to search for information participated more in their consultations. In addition, consistent with Street's model, the Turkish-Dutch patients who were more participative experienced lower unfulfilled information needs. Thus, encouraging Turkish-Dutch patients to seek information about their health problems may make them more active communicators during consultations and may lead to greater fulfillment of their information needs.

The results clearly showed that the Turkish-Dutch and Dutch patients differed regarding their information-seeking behavior. The Turkish-Dutch patients used a wider variety of media sources in their search for health information and used these media sources more frequently than Dutch patients. With respect to the variety of sources, this result is consistent with research that suggests that ethnic minority patients tend to rely more on traditional media—such as television and leaflets—compared with ethnic majority populations (Talosig-Garcia & Davis, 2005). The high level of Internet usage among Turkish-Dutch patients contrasts with previous findings suggesting lower levels of Internet usage among minority patients (Monnier, Laken, & Carter, 2002), but this might be explained by

the high penetration of Internet access in the Netherlands. Approximately 96% of Dutch citizens currently have access to the Internet (Central Bureau of Statistics, 2012), which suggests a high rate of Internet access among Turkish-Dutch people as well.

Although the Turkish-Dutch patients used various media sources more often, the Dutch patients were generally more participative during their consultations. Dutch patients had more relative talk during their consultations, and they interacted more effectively with their GPs than the Turkish-Dutch patients. These findings are consistent with previous findings regarding ethnic minority patients in the US (Cooper-Patrick et al., 1999; Johnson et al., 2004; Street Jr et al., 2005) and with findings regarding Dutch minority patients (Meeuwesen et al., 2007) showing less patient participation and different interaction patterns (Meeuwesen et al., 2006) among ethnic minority populations compared with the ethnic majority population. Although education is generally understood as an important predictor of patient participation (Street Jr et al., 2005), the results of the current study show that other factors play a role—such as cultural factors—because the Turkish-Dutch and the Dutch patient groups had similar educational levels. Our results indicate that Turkish-Dutch patients had higher relative talk during the medical background segment and lower relative talk during the diagnosis and decision-making segment of the consultation, which suggests that these patients may be less critical and involved during these segments of the medical consultation, perhaps because they believe that this is the doctor's responsibility. The greater power distance among the Turkish population compared with the Dutch population (Hofstede, 2001) may lead Turkish-Dutch patients to place more responsibility on their doctors than on themselves. To explore these differences, future qualitative research should investigate patients' willingness to be involved in the consultation process.

A relationship between high levels of Dutch language proficiency and greater patient participation was expected, because previous research has indicated that patients must be comfortable with the language used to actively engage in a discussion with their doctors (Meeuwesen et al., 2006; Schenker et al., 2010). This hypothesis was not supported, perhaps because the language in which the information is sought is more important than the patients' Dutch language proficiency. When patients read and think in Turkish about their health problems, they may experience difficulty explaining that information in Dutch to their GP, even when their general language proficiency in Dutch is adequate. Further research should explore these relationships. A second possibility is that the companions in the Turkish-Dutch consultations—who contributed more to the conversation than those in the Dutch consultations—might have acted as informal interpreters, thereby decreasing the level of patient participation. Previous research has shown that patients in interpreter-mediated medical consultations talk less compared with dyadic conversations with migrant patients (Aranguri, Davidson, & Ramirez, 2006). However, because of the small sample size of the accompanied consultations in this study, we were not able to statistically test this interaction. Future research should explore the influence of an informal interpreter on migrant patients' level of participation.

For the Turkish-Dutch patients, unfulfilled information needs were related to patient participation. Specifically, more relative talk from the patient and more dialogues initiated by the patient were related to lower unfulfilled information needs regarding both primary and secondary information. Given that more dialogues initiated by the doctor were related to more unfulfilled information needs, fulfilling information needs may depend more on the patient's contributions and initiations than on the interaction between doctor and patient. Thus, consistent with Street's model (2001), encouraging Turkish-Dutch patients to more actively participate in consultations may be important for improving communication

outcomes. It is important to note that medical communication is a two-way interaction with the GP as the lead party. Therefore, GPs should encourage Turkish-Dutch patients to be more open and participate in the communication process and to express their misunderstandings and disagreements about diagnoses and decisions (Harmsen et al., 2003). Further research is required to investigate techniques to encourage communication through interventions at the level of the GP practice and outside the consultation room to empower Turkish-Dutch patients in consultations.

Notably, media use was only related to the relative contribution of the patients, whereas the patients' relative contribution and interactions during consultations were related to unfulfilled information needs. Thus, enabling factors may influence certain aspects of patient participation, which may lead to certain communication outcomes. Future research should examine the different aspects of patient participation to explore the relationships between enabling factors, patient participation and communication outcomes.

Dutch patients did not exhibit relationships between media use and patient participation and between patient participation and unfulfilled information needs, which may be the result of different motivational factors. According to the model of information-seeking behavior (Johnson & Meischke, 1993), specific motivations to search for information may be related to certain types of media usage. Additionally, Longo's model (2005) posits that how health information is used during consultations depends on a combination of contextual and personal factors, including cultures, attitudes and motives. Specific motivations and attitudes might lead to particular usage of the information that is learned. Future research should explore the influences of motivations and attitudes toward media usage when searching for health information prior to a consultation.

A strength of the current study is that patients reported their actual searching behavior before their consultations, not their intended behavior. Therefore, these findings reflect real rather than hypothesized settings. Additionally, this study coded the patients' behavior during their consultations, which made it possible to draw conclusions about their actual participation rather than their intended or preferred participation. However, a number of limitations should be discussed. First, although participation was measured via consultation audiotapes that were recorded after patients completed the pre-consultation questionnaire, the causality of the relationship between information-seeking behavior and patient participation cannot be fully established. Whether patients searched for information because they want to be involved or they became more involved because of their information-seeking behavior should be further explored using experimental methods.

Second, this study's small sample size for measuring patient participation makes it difficult to generalize the findings to a larger population. Despite the fact that the groups, which were similar in age, gender and educational level, still exhibited certain differences, follow-up studies with larger samples are advised to replicate our results. The small sample size was due to the relatively high non-response rate from Turkish-Dutch patients, which is a common issue in cross-cultural health research (Hussain-Gambles, Atkin, & Leese, 2004). Given that most Turkish-Dutch patients refused to participate in this study because of audiotaping, more efforts must be made to encourage these patients to participate in observational research, for instance, by using research assistants who belong to the same ethnic community as the migrant patients.

Third, the pre-consultation questionnaire inquired about the importance of information needs, which may have prompted patients to be more participative than they might normally be because it stimulated more awareness of patients' preferences, which might have led to increased participation. Additionally, although patients' information-

seeking behavior was measured in relation to their current health issues, they could have been reporting on a more general health information search. Follow-up studies with designs that include and exclude a pre-consultation questionnaire are recommended.

To conclude, the findings of the current study suggest that motivating patients to search for health information may help empower them. To encourage Turkish-Dutch patients to be more open and participative, GPs should explicitly inquire about whether patients sought information prior to the consultation and whether the patients have any questions. One way to accomplish this is to implement question prompt lists, which can positively affect communication outcomes (Brandes, Linn, Butow, & van Weert, 2015). By using such lists, patients may become more actively involved in the medical consultation, which may lead to increased fulfillment of their information needs. Health care for migrant patients can be enhanced by empowering ethnic minority patients to become more actively involved in their own health both before and during medical consultations.



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.

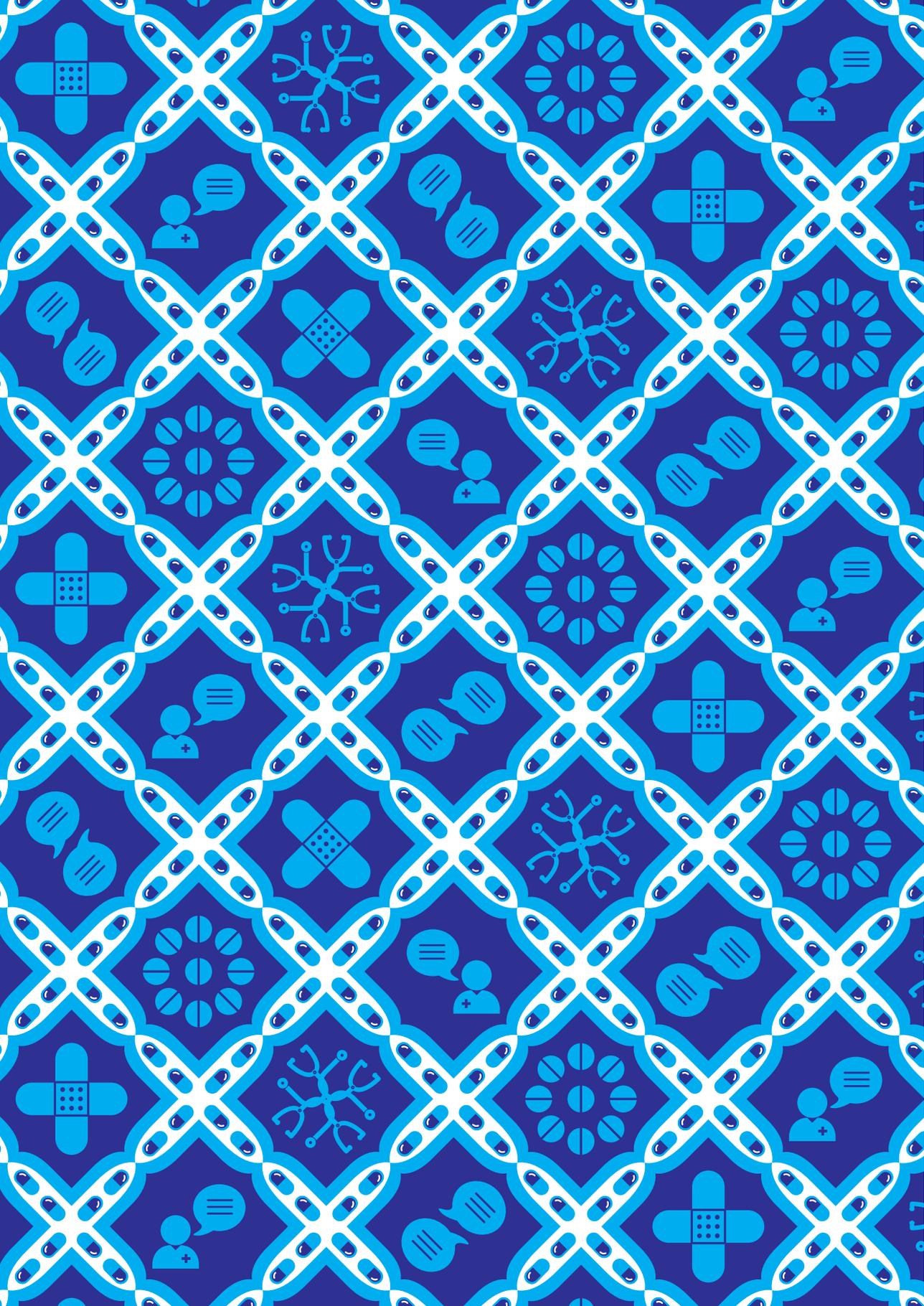
Furthermore, Turkish-Dutch participants feel their GP is responsible for their health and should know what to do, while Dutch participants want to share responsibility, and prefer to be autonomous and assertive, reflecting differences in power distance. This result is in line with previous findings indicating 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.



CHAPTER 5

The match between preferred and perceived patient participation and the role of the doctor-patient relationship

Abstract

The aim of the study was to investigate differences between Turkish-Dutch and Dutch patients in the effects of the match between patient's preferred and perceived participation and doctor-patient concordance in preferred doctor-patient relationship (doctor-centered versus patient-centered) on communication outcomes. Pre- and post-consultation questionnaires were filled out by 136 Dutch and 100 Turkish-Dutch patients in the waiting room of 32 GPs, who also filled out a questionnaire. Outcome variables were patient satisfaction, fulfillment of information needs and understanding of information. Results show that a match between patients' preferred and perceived participation predicted more positive communication outcomes among both Dutch and Turkish-Dutch patients than a mismatch. Discordance in preferred doctor-patient relationship was related to worse outcomes, but only for Turkish-Dutch patients' who perceived themselves as highly participative during the consultation. Among Dutch patients, no effects were found on doctor-patient concordance. In conclusion, doctor-patient concordance in preferred doctor-patient relationship seems important for Turkish-Dutch only and the effect is moderated by perceived patient participation. The match between preferred and perceived patient participation seems important for all patients. In order to improve both intracultural and intercultural medical communication GPs should be trained to communicate in such a way that a good match between patients' preferred and perceived participation is created.

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Introduction

In intercultural medical communication, more miscommunication and less mutual understanding have been found than in intracultural medical communication (Schouten & Meeuwesen, 2006). Ethnic minority patients are also less satisfied with their care, have more unmet information needs and lower understanding of the information given by their doctors than patients from majority populations (Mead & Roland, 2009; Schinkel et al., 2010; Schinkel et al., 2013). Several explanations have been offered for these findings, among which language barriers and culture-related differences in health and illness beliefs, and different preferences and expectations for information and participation (Helman, 2001; Levinson et al., 2005; Schenker et al., 2010; Scheppers, van Dongen, Dekker, Geertzen, & Dekker, 2006; Suurmond & Seeleman, 2006; Suurmond, Uiters, de Bruijne, Stronks, & Essink-Bot, 2011).

Because of these cultural differences, a recent trend in research on intercultural medical communication is to investigate whether doctor-patient concordance on certain attributes has a positive influence on the medical communication process and its outcomes. The majority of studies on concordance in this context involve race-concordance, referring to medical consultations with patients and doctors belonging to a (dis)similar ethnic/racial group. Although some studies have suggested that race-concordance leads to higher patient satisfaction compared to race-discordance (Cooper, Powe, & Fund, 2004; LaVeist, Nuru-Jeter, & Jones, 2003), a review on the effects of race-concordance has yielded inconclusive results. Only a third of the reviewed studies showed evidence of positive health outcomes; the remaining studies either found mixed effects or no effects at all (Meghani et al., 2009).

A more fruitful approach might therefore be to research the effects of other types of doctor-patient concordance, such as concordance in preferred doctor-patient relationship. Doctor-patient concordance in preferred doctor-patient relationship refers to the similarity between doctors' and patients' respective preferences for a more doctor-centered (e.g., physician in control, setting the agenda for the consultation, making decisions) or a more patient-centered relationship (e.g., participatory patient, patient and doctor setting the agenda together and engage in shared decision-making) (Kiesler & Auerbach, 2006; Krupat et al., 2000). Previous studies have shown that doctor-patient concordance in preferred doctor-patient relationship positively affected patient satisfaction and treatment adherence (Chan & Azman, 2012; Cousin et al., 2012; Jahng, Martin, Golin, & DiMatteo, 2005; Krupat et al., 2000; Krupat et al., 2001; Street Jr et al., 2009b; Williams & Ogden, 2004). However, ethnic minority patients value the doctor-patient relationship more than ethnic majority patients, while at the same time perceiving lower quality of the doctor-patient relationship in comparison to ethnic majority patients (Saha, Arbelaez, & Cooper, 2003; Schinkel, Schouten, van den Putte, Kerpiclik, & van Weert, under review). Doctor-patient concordance in preferred doctor-patient relationship could be more effective for ethnic minority patients than for ethnic majority patients in establishing positive communication outcomes such as patient satisfaction, fulfillment of information needs and understanding of information. As this has not been studied so far, the first aim of this study is to investigate possible differences between ethnic minority and majority patients in the effects of doctor-patient concordance in preferred relationship on medical communication outcomes.

A second goal of this study involves investigating the effects of the degree of match between patients' preferred participation and the level of their perceived participation during the medical encounter on communication outcomes. Although a good match can positively affect communication outcomes (Heyland et al., 2003), a review by Kiesler

and Auerbach (2006) showed that positive effects do not always emerge when there is a match between patients' preferred and perceived participation levels. More recent studies found support for positive effects of a mismatch between preferred and perceived participation. That is, patients who were more involved during the medical encounter than they preferred beforehand, were more satisfied with the consultation than patients whose perceived levels of participation matched or were lower than their preferred levels of participation (Brown et al., 2012; Cvengros, Christensen, Cunningham, Hillis, & Kaboli, 2009). Some research indicates that ethnic minority patients prefer less participation during the medical encounter and display less participation during the encounter than majority patients (Gordon, Street, Sharf, & Soucek, 2006; Schouten et al., 2007). Yet, it is unclear whether the effects of a match or a mismatch between preferred and perceived participation operate similarly for ethnic minority compared to ethnic majority patients on communication outcomes. The second aim of our study was thus to investigate possible differences between ethnic minority and majority patients in the effects of the match between patients' preferred and perceived participation on patient satisfaction, fulfillment of information needs and understanding of information.

In sum, our study aims to explore how doctor-patient concordance in preferred doctor-patient relationship and the match between patients' preferred and perceived participation are related to communication outcomes among ethnic minority and majority patients. In addition, a possible interaction effect between doctor-patient concordance and patients' perceived participation on communication outcomes will be studied. Patient participation during the encounter can influence communication outcomes (Street, 2001), which might interact with doctor's and patients' preferences beforehand. We focused on Turkish-Dutch general practice patients as ethnic minority group, because they form the largest migrant group in the Netherlands (Central Bureau of Statistics, 2014) and visit their GP more frequently compared to ethnic majority patients and other migrant groups (Uiters et al., 2006).

Methods

Procedure

Between September and December 2014, Turkish-Dutch and Dutch patients were recruited to participate in GP waiting rooms. Inclusion criteria for patients were: (1) having an appointment with the GP for themselves, (2) being at least 18 years old and (3) being able to read in Dutch or Turkish or being accompanied by someone who could read in these languages. We recruited both Dutch and bilingual Turkish-Dutch assistants for the data collection. The Turkish-Dutch patients were primarily recruited by the Turkish-Dutch assistants because they are known to lessen concerns among these patients about immigration status, mistrust of institutions, and lack of familiarity and distrust of research, leading to easier data collection (Hoopman, Terwee, Muller, Öry, & Aaronson, 2009). After signing the informed consent form in the waiting room, participants were given a pre-consultation questionnaire (available in Dutch and Turkish). Following the consultation, they were given the post-consultation questionnaire. GPs were given their questionnaire during data collection days and could return it to the assistants or email a copy to the first author.

The patient questionnaires were pilot tested twice among low-educated and low-literate Dutch and Turkish-Dutch people to ensure that all items were understood by the targeted population. The questionnaire was translated into Turkish by a professional translation service and the translation was checked on grammar and understandability by two Turkish-Dutch assistants. The study was approved by the Ethical Committee of the Amsterdam School of Communication Research (ASCoR), no. 2014-CW-68.

Participants

In total, 32 GPs (18 men, 14 women) from ten different practices in multicultural cities in the Netherlands participated in the study. 107 GP practices (with multiple GPs) were asked to participate (response rate of 9.3%). Most common reasons for not participating concerned too little time to participate, a too busy practice, too many research projects during the year, or currently ongoing research projects in the practice. GPs were recruited based on their relatively large Turkish patient population: six practices consisted of a population of around thirty per cent Turkish patients, two practices of around fifteen per cent and two other practices of around ninety per cent. GPs participated with seven patients on average (range 1-14).

In total, 236 patients (136 Dutch and 100 Turkish-Dutch patients) out of 366 eligible patients participated (64% response). Figure 1 shows the flow diagram. Patients who were unwilling to participate had similar distribution of ethnicity as the participating patients ($\chi^2(1) = .99; p = .320$).

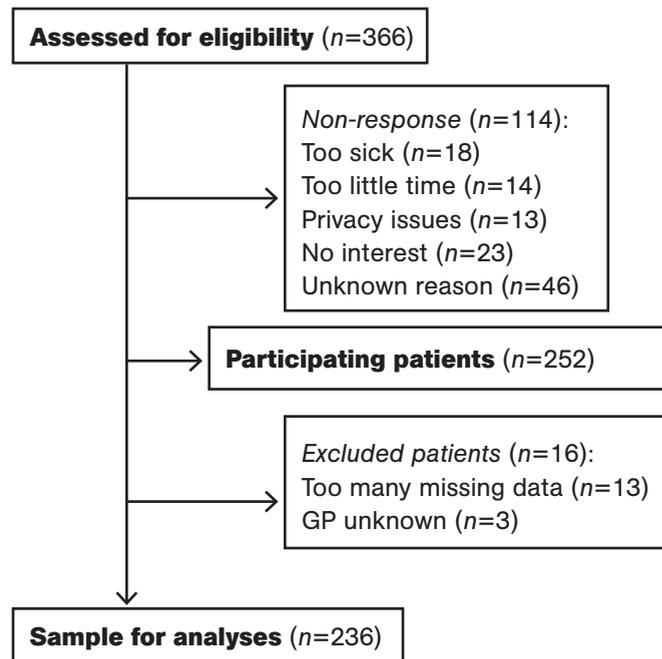


Figure 1. Flow diagram of the patient sample

Measures

Pre-consultation patient questionnaire measures

Socio-demographic variables

The ethnicity definition of the Dutch Central Bureau of Statistics was used to assess the respondents' ethnicity. Respondents born in the Netherlands and with both parents born in the Netherlands were categorized as Dutch; respondents born in the Netherlands or Turkey and having at least one parent born in Turkey were categorized as Turkish-Dutch. For Turkish-Dutch patients, group identification and language proficiency were assessed. Group identification was measured by Stevens et al.'s ethnic identity measure (Stevens et al., 2004). Patients could indicate their group identification answering two questions on the extent to which they felt they belong to either the Dutch and Turkish culture on a 5-point

scale, ranging from (1) *totally disagree* to (5) *totally agree*. Dutch and Turkish language proficiency was assessed by patients' self-reports on a 5-point scale, ranging from (1) *not at all* to (5) *excellent*. For both the group identification and language proficiency measure, first the score on Turkish culture and Turkish language was subtracted from that of Dutch culture and Dutch language, respectively. Second, both scores were divided into three subgroups (Harmsen et al., 2008; Schinkel et al., 2013): (1) more Turkish identification/Turkish language proficiency than Dutch identification/Dutch language proficiency (-4 to -2), (2) equal Turkish and Dutch identification/language proficiency (-1 to 1) and (3) more Dutch identification/Dutch language proficiency than Turkish identification/Turkish language proficiency (2 to 4). Because only three patients were present in the third group, these patients were excluded from the regression analyses and dummy variables for both group identification and language proficiency were included (i.e. more Turkish versus equal) in the regression models. For the total sample, gender, age, educational level and health status were assessed, the latter being measured with a single item assessing how patients perceived their health, with a 5-point scale, ranging from (1) *poor* to (5) *excellent*.

Preferred patient participation

To measure patients' preference for patient participation, we used the eight items of the *Patient information scale* and *Patient decision making scale* of the *Patients' perceived involvement in care measure* (Lerman et al., 1990). Patients could indicate the importance of the items for the upcoming consultation on a 4-point scale, ranging from (1) *not important* to (4) *very important* (with a *not applicable* option for items not relevant to that consultation). Items were simplified for low-literate patients to statements such as "I find it important to ask the GP many questions", "...propose a certain treatment" or "...express concerns about the GP's advice". The scale had good reliability: $\alpha = .83$ (Dutch group .80; Turkish-Dutch group .84).

The preferences scores were divided into high (3 and 4=1) or low (1 and 2=0) preference for participation. To take into account the applicability of the preferences in that consultation, we first determined the number of answers that were applicable. Next, the number of highly important items was divided by the number of applicable items and this was multiplied by the total number of items of the scale (8). By performing this imputation, patients who reported to highly prefer six of the eight behaviors and scored two items as non-applicable received the same participation preferences score as patients who reported to highly prefer all eight behaviors. Preferred patient participation thus ranged from 0 to 8, with higher scores reflecting higher participation preferences.

Preferred doctor-patient relationship

To measure the extent to which patients preferred a patient- versus doctor-centered consultation, we used nine items from the *Patient-Practitioner Orientation Scale* (Krupat et al., 2000). We used only those items that reflected previous findings on communication barriers among Turkish-Dutch patients, concerning how doctors and patients should treat each other and the importance of taking into account patients' cultural background, based on Schinkel et al. (under review). Items were simplified for low-literate patients to statements such as "The GP should decide what is being said", and "It is disrespectful to disagree with the GP". Higher scores represented a higher preference for doctor-centered consultations (with two reversed items). Patients could indicate their agreement with the statements on a 5-point scale, ranging from (1) *totally disagree* to (5) *totally agree*. Reliability analyses suggested to remove two items, "Patients should be treated as equals" and "Warm and

open GPs are better than distant GPs”, from the scale. The remaining seven items had satisfactory reliability: $\alpha = .73$ (Dutch group: .75; Turkish-Dutch group: .65).

Post-consultation patient questionnaire measures

Perceived patient participation

To measure the perceived participation of patients, we used the items of the preferred patient participation scale in the pre-consultation questionnaire. Patients could indicate on the same 8-item scale whether they (0) *did not perform* or (1) *did perform* the behavior during their consultation, with a *non-applicable* option for every item. To calculate patients' perceived participation, we used the same procedure as was done for preferred patient participation. Perceived participation also ranged from 0 to 8, with higher scores reflecting higher perceived participation.

Satisfaction

To assess how satisfied patients were with the communication and their doctor, we used five items of the *Patient Satisfaction Scale* (Poulton, 1996). Patients could indicate their agreement on items such as “I am satisfied with the conversation I just had with the GP” and “There was enough time to discuss everything” on a 5-point scale ranging from (1) *totally disagree* to (5) *totally agree*. Reliability was high: $\alpha = .93$ (Dutch group .96; Turkish-Dutch group .88).

Fulfillment of information needs

Fulfillment of information needs was measured by a single item on which patients could indicate their agreement with: “I have discussed everything I wanted to discuss”, on a 5-point scale ranging from (1) *totally disagree* to (5) *totally agree*.

Understanding of information

Patients could indicate to what extent they had understood the information discussed during the consultation with a single item, measured on a 5-point scale ranging from (1) *totally disagree* to (5) *totally agree*.

GP questionnaire measures

Besides background characteristics such as age, gender, practice experience and having received intercultural training, GPs were asked to report their preferred doctor-patient relationship using the same scale as in the pre-consultation patient questionnaire. The scale score was computed similarly to the patient's score. In addition, GPs' intercultural orientation was measured by combining items from the *Cultural Sensitivity Scale* and *Intercultural Communication Effectiveness Scale* (Ulrey & Amason, 2001). GPs could indicate to what extent they agreed on eight items regarding intercultural orientation, ranging from (1) *totally disagree* to (5) *totally agree*. Reliability of the scale was good: $\alpha = .81$.

Calculation of doctor-patient concordance scores

Concordance between patients and GPs in their preferred doctor-patient relationship was calculated by first subtracting standardized GP scores from standardized patient scores. The doctor-patient concordance in preferred doctor-patient relationship ranged from -3.89 to 3.68. Higher positive or negative discrepancy scores represented lower concordance between GPs and patients. Patients were then divided into two groups: concordant or discordant with their GP, with a cut point of 1.5, resulting in around 25 per cent of patients in the discordant group.

Calculation of the match between patients' preferred and perceived participation

To calculate the match between patient's preferred and perceived patient participation, the perceived participation scores were subtracted from the preferred participation scores. These discrepancy scores ranged from -7 to 8. To take into account that patients' participation never exactly matches their preferences (Kiesler & Auerbach, 2006), we used half of the items as cut off point for discrepancy scores; patients with discrepancies of lower than -4 or higher than 4 had unmatched preferences (score 1), patients with discrepancy scores between -4 and 4 had matched preferences (score 0).

Analyses

Differences between the groups in socio-demographic characteristics and pre- and post-consultation scores were assessed with chi-square tests and t-tests. Relationships between communication outcomes and, respectively, doctor-patient concordance, perceived patient participation and match between patient's preferred and perceived participation were assessed by separate multilevel regression models for Turkish-Dutch and Dutch patients, with the GP as random effect to account for the nested nature of patient data. In addition, an interaction term between perceived patient participation (continuous scale) and doctor-patient concordance (dummy variables) was included. All models were controlled for health status, age and education. For Turkish-Dutch patients, we also controlled for language proficiency and group identification.

Results

GP sample

As shown in Table 1, the majority of participating GPs was male, they varied in their age and years of working as GP, and reported a relatively high intercultural orientation ($M = 3.56$ on a 5-point scale, $SD = .42$). In addition, a majority of GPs reported to be trained in intercultural communication (68.8%). 29 GPs were Dutch, one GP was from Turkish and two were from European origin (Germany and Slovenia).

Patient sample

Table 2 provides an overview of the patient sample. Dutch patients were significantly older ($t(227.62) = 5.24$; $p < .001$; range 18-89), higher educated ($\chi^2(2)=6.41$; $p = .041$), and perceived their health status as better ($\chi^2(2) = 17.67$; $p < .001$) than Turkish-Dutch patients. The groups did not differ in gender and having company during the consultation. The Turkish-Dutch patients reported significantly higher Turkish language proficiency than Dutch language proficiency ($t(89) = -9.29$; $p < .001$) and higher identification with Turkish culture than with Dutch culture ($t(94) = -8.07$; $p < .001$). As shown in Table 3, Turkish-Dutch patients reported a preference for a more doctor-centered relationship ($t(232) = -2.27$; $p = .024$), higher preference for patient participation ($t(232.56) = -3.88$; $p < .001$), higher perceived participation ($t(223.54) = -3.37$; $p < .001$), lower satisfaction ($t(225) = 2.55$; $p = .011$), lower fulfillment of information needs ($t(224) = 1.87$; $p = .063$), and lower understanding of the information ($t(223) = 2.83$; $p = .005$) than Dutch patients.

Table 1
GP Sample

GP characteristics	(N=32)
<i>Gender</i>	
Men	18 (56.3%)
Women	14 (43.7%)
<i>Age</i>	
Mean age (SD, range)	47.78 (11.65, 31-65)
<i>Practice experience</i>	
Mean years working as GP (SD, range)	15.80 (11.88, 2-37)
Having own practice	23 (71.9%)
<i>Intercultural experience</i>	
Intercultural orientation, 5-point scale (SD)	3.56 (.42)
Received intercultural communication training	22 (68.8%)

Table 2
Patient Sample

Patient characteristics	Dutch (N=136)	Turkish-Dutch (N=100)
<i>Gender</i>		
Men	49 (36.0%)	35 (35.0%)
Women	87 (64.0%)	65 (65.0%)
<i>Age**</i>		
Mean age in years (SD)	53.46 (19.85)	41.90 (13.62)
<i>Educational level*</i>		
Low	42 (31.3%)	43 (43.9%)
Intermediate	66 (49.3%)	46 (46.9%)
High	26 (19.4%)	9 (9.2%)
<i>Perceived health status**</i>		
Bad/very bad	43 (31.6%)	59 (59.0%)
Moderate	81 (59.6%)	35 (35.0%)
Good/excellent	12 (8.8%)	6 (6.0%)
<i>Company during consultation</i>		
No companion (alone)	108 (80.6%)	66 (66.0%)
Partner	13 (9.7%)	12 (12.0%)
Child	7 (5.2%)	14 (14.0%)
Parent(s)	2 (1.5%)	3 (3.0%)
Other	4 (3.0%)	5 (5.0%)
<i>Mean language proficiency</i>		
Dutch language (SD)		3.34 (1.33)
Turkish language (SD)		4.57 (0.69)
<i>Mean identification</i>		
Dutch culture (SD)		2.65 (1.39)
Turkish culture (SD)		4.39 (1.06)

* $p < .05$; ** $p < .001$

Table 3
Patient Scores on Pre- and Post-Consultations Measures per Group

Patient means (SD)	Dutch (N=136)	Turkish-Dutch (N=100)
Pre-consultation:		
Preferred patient involvement (0-8 scale)	5.63 (2.45)	6.72 (1.89)***
Preferred doctor-centered relationship (versus patient-centered, 1-5 scale)	3.01 (0.74)	3.24 (0.82)**
Post-consultation:		
Perceived patient involvement (0-8 scale)	5.37 (2.12)	6.26 (1.89)***
Satisfaction with communication (1-5 scale)	4.43 (0.68)	4.21 (0.61)*
Discussed everything as wanted (1-5 scale)	4.34 (0.72)	4.15 (0.74)†
Understanding information (1-5 scale)	4.41 (0.65)	4.13 (0.80)**

* $p < .05$; ** $p < .01$; *** $p < .001$; † $p < .10$

Predictors of communication outcomes: Dutch patients

Among Dutch patients, matched preferred and perceived participation was found to positively affect all communication outcomes (see Table 4). Dutch patients with matched preferences regarding patient participation reported higher satisfaction ($M_{\text{matched}} = 4.47$, $M_{\text{unmatched}} = 3.92$; $p = .021$), better fulfillment of information needs ($M_{\text{matched}} = 4.34$, $M_{\text{unmatched}} = 3.69$; $p = .009$) and better understanding of the information than patients with unmatched preferences ($M_{\text{matched}} = 4.42$, $M_{\text{unmatched}} = 3.79$; $p = .007$). No main or interaction effects on any of the communication outcomes were found for the other predictors.

Table 4
Effects of Matched Preferences, Concordance, and Perceived Participation on Communication Outcomes among Dutch Patients

Predictor	Dutch (N=136)					
	Satisfaction		Fulfillment information needs		Understanding	
	Estimate (SE)	P	Estimate (SE)	P	Estimate (SE)	P
Match patient's preferred-perceived participation (ref=matched)	.55 (.23)	.021	.65 (.24)	.009	.63 (.23)	.007
Doctor-patient concordance in preferred relationship (ref=concordant)	.71 (.47)	.131	.62 (.49)	.207	.54 (.46)	.237
Perceived patient participation	.07 (.07)	.355	.05 (.08)	.541	.06 (.07)	.364
Perceived patient participation x concordance in preferred relationship	-.12 (.08)	.155	-.08 (.08)	.335	-.08 (.08)	.328

Note. Model controlled for age, health status and education, which not significantly influenced any communication outcomes.

Predictors of communication outcomes: Turkish-Dutch patients

Among Turkish-Dutch patients, matched preferred and perceived participation positively affected all communication outcomes (see Table 5). Turkish-Dutch patients with matched preferences regarding patient participation reported higher satisfaction ($M_{\text{matched}} = 4.21$, $M_{\text{unmatched}} = 3.65$; $p = .052$), higher fulfillment of information needs ($M_{\text{matched}} = 4.30$, $M_{\text{unmatched}} = 2.07$; $p < .001$) and higher understanding of information ($M_{\text{matched}} = 4.30$, $M_{\text{unmatched}} = 2.41$; $p < .001$) than patients with unmatched preferences. In addition, Turkish-Dutch patients reporting better health status were more satisfied ($p = .030$) and reported better understanding of the information ($p = .012$), and those with equal language proficiency in Turkish and Dutch language were more satisfied ($M_{\text{equal}} = 4.16$, $M_{\text{moreTurkish}} = 3.71$; $p = .005$) and reported better fulfillment of information needs ($M_{\text{equal}} = 3.38$, $M_{\text{moreTurkish}} = 2.99$; $p = .040$) than patients who reported more Turkish language proficiency than Dutch language proficiency. Cultural identification did not affect any of the communication outcomes.

For Turkish-Dutch patients, an interaction effect between perceived patient participation and doctor-patient concordance in preferred doctor-patient relationship was found on all three outcomes (although marginally significant on understanding of the information). For Turkish-Dutch patients who were concordant with their GP in the doctor-patient relationship, perceived patient participation was not related to the communication outcomes. However, for patients who were discordant with their GP in the preferred doctor-patient relationship, higher perceived participation was related to lower satisfaction, worse fulfillment of information needs and worse understanding of the information. Subsequent analyses among patients who were discordant with their doctor regarding their preferred doctor-patient relationship revealed that the Turkish-Dutch patients were discordant on both sides: 16% of patients scored higher than their doctor, 13% of patients scored lower than their doctor. In both discordant groups higher perceived patient participation was related to worse communication outcomes (sample sizes were too small to test for significance).

Table 5

Effects of Matched Preferences, Concordance, and Perceived Participation on Communication Outcomes among Turkish-Dutch Patients

Predictor	Turkish-Dutch (N=97)					
	Satisfaction		Fulfillment information needs		Understanding	
	Estimate (SE)	P	Estimate (SE)	P	Estimate (SE)	P
Match patient's preferred-perceived participation (ref=matched)	.57 (.29)	.052	2.23 (.35)	.000	1.88 (.37)	.000
Doctor-patient concordance in preferred relationship (ref=concordant)	-1.66 (.54)	.003	-1.60 (.66)	.018	-1.32 (.69)	.059
Perceived patient participation	-.24 (.07)	.002	-.19 (.09)	.040	-.06 (.09)	.519
Perceived patient participation x concordance in preferred relationship	.23 (.08)	.005	.22 (.10)	.027	.17 (.10)	.088
Language proficiency (ref=more Turkish)	-.45 (.15)	.005	-.39 (.19)	.040	-.27 (.19)	.176
Identification culture (ref=more Turkish)	-.02 (.12)	.874	-.07 (.15)	.664	.02 (.16)	.883

Note. Model controlled for age, health status and education. Health status significantly influenced satisfaction and understanding of information (estimates: .17 [.08], $p = .030$; .26 [.10], $p = .012$, respectively). The main effects of doctor-patient concordance in preferred relationship are only present after including the interaction term with perceived patient participation.

Discussion

The first aim of this study was to investigate differences between Turkish-Dutch and Dutch patients in the effects of doctor-patient concordance in preferred doctor-patient relationship on patient satisfaction, fulfillment of information needs and understanding of information independently and in relation to perceived patient participation. The second aim was to investigate how the match between patients' preferred and perceived participation affect those communication outcomes among Turkish-Dutch and Dutch patients. To our knowledge, this is the first study that combines effects of doctor-patient concordance with perceived patient participation, and the match between patient's preferred and perceived participation. In line with other research suggesting more negative communication outcomes among ethnic minority patients (Mead & Roland, 2009), the results overall show that Turkish-Dutch patients reported lower satisfaction, worse fulfillment of information needs and worse understanding of information than Dutch patients. The findings further indicate that the match between preferred and perceived patient participation relates more strongly to communication outcomes than doctor-patient concordance, which only showed an interaction effect with perceived patient participation on the communication outcomes among Turkish-Dutch patients (see below for a discussion of these results).

The match between patients' preferred and perceived participation was found to positively affect all communication outcomes among both Dutch and Turkish-Dutch patients. A match between patients' preferred and perceived patient participation enhanced patients' satisfaction, fulfillment of information needs and understanding of information. Hence, by accommodating patients' preferences for participation, GPs can improve crucial communication outcomes for both ethnic majority and ethnic minority patients, thereby enhancing the quality of care (Carlson & Aakvik, 2006). By accommodating migrant patients' preferences for participation—i.e. low or high level of patient participation during the consultation—GPs can overcome the differences between doctors and patients in intercultural encounters and improve the communication process and its' outcomes (Flocke, Miller, & Crabtree, 2002).

Although doctor-patient concordance did not independently affect the outcomes in our study, there was an interaction effect between doctor-patient concordance in preferred doctor-patient relationship and perceived patient participation among Turkish-Dutch patients. This interaction effect is in line with other findings indicating that patients' communicative behavior during the encounter moderates the effect of patient preferences on communication outcomes (Golin, Matteo, Duan, Leake, & Gelberg, 2002; Kiesler & Auerbach, 2006; Lee & Lin, 2010). The more negative communication outcomes among Turkish-Dutch patients who are discordant with their doctor in preferred relationship when perceived participation is high are in line with the results from a qualitative study that revealed that Turkish-Dutch patients felt discomfort with being highly involved when their preferred relationship was not met by the GP (Schinkel et al., under review). In this previous study, Turkish-Dutch patients explicitly mentioned frustration when their GP stimulated them in a direct manner to become more involved (with questions such as: What do you think I should do?). Thus, when a GP prefers patient-centered consultations more than the patient, that GP might stimulate the patient to become more involved than Turkish-Dutch patients actually prefer, leading to higher perceived patient participation, but worse communication outcomes. In case a Turkish-Dutch patient prefers patient-centered consultations more than their GP, that patient will be more involved than the doctor prefers, also leading to high perceived patient participation but worse communication outcomes. Future studies should investigate the effects of doctor-patient concordance in preferred relationship among ethnic minority patients further in relation to perceived

patient participation. In addition, investigating the actual communication process between GPs and ethnic minority patients, using observational data, will give more insight in what happens during the encounter and might explain the interaction effect of doctor-patient concordance in this sample.

Doctor-patient concordance in preferred doctor-patient relationship is calculated with doctor scores that were reported once, not for every patient, following the procedure of Krupat et al. (2000). Because there is a possibility that there is some variation in GPs' preferences depending on the individual patient, future research could measure concordance by means of separate doctor scores per patient. In addition, measuring patients' perceived concordance with the GP (Street Jr et al., 2008), instead of measuring concordance using doctor and patient scores, might be an interesting avenue for future research too.

Although Turkish-Dutch patients report relatively positive communication outcomes, they still experienced worse communication outcomes than Dutch patients. Considering that GPs in our study were relatively high interculturally orientated and trained in intercultural communication, communication outcomes among patients consulting GPs who are less aware of or trained in cultural differences will probably be worse. Therefore, our findings are hard to generalize to all GPs. We expect that future studies will have similar samples because GPs who are less aware of cultural differences will less likely take part in intercultural communication studies. It could therefore be interesting to develop a more experimental study that uses video vignettes in which GPs' behavior is simulated to be more doctor- or patient-centered and investigate how those behaviors impact communication outcomes among migrant patients.

The higher preference for patient participation and higher perceived participation among Turkish-Dutch patients were surprising findings, because most studies report lower preference for participation and lower participation levels among ethnic minority patients (e.g., Johnson et al., 2004; Levinson, Kao, Kuby, & Thisted, 2005; Meeuwesen et al., 2007; Street Jr et al., 2005). The higher scores in our sample could be explained by measurement differences (Say, Murtagh, & Thomson, 2006). We asked patients to indicate (the importance of) their communicative contribution during the encounter, whereas most other studies focused on different aspects of patient participation, such as shared-decision making or communication symmetry. Ethnic minority patients might more strongly prefer to participate in the discussion rather than the decision-making itself. Ethnic minority patients' preferences for participation in both the communication and decision-making should therefore be investigated further as separate concepts.

In conclusion, the match between preferred and perceived patient participation was a stronger predictor of communication outcomes than doctor-patient concordance. Doctor-patient concordance in preferred doctor-patient relationship was found to influence the communication outcomes among Turkish-Dutch patients but only for patients with high perceived patient participation. Future research should thus include perceived patient participation in models investigating doctor-patient concordance among migrant patients. Doctors need to become more aware of cultural differences in patients' preferences and trained in overcoming these differences in order to enhance the communication process and its outcomes for migrant patients. Stimulating more patient participation will not automatically enhance communication outcomes among Turkish-Dutch patients. These patients need to be stimulated to be as participative as they prefer. Training doctors to elicit patient's preferences and accommodate them, will shape an environment for ethnic minority patients in which matched preferred and perceived preferences will be established, leading to more positive communication outcomes.



CHAPTER 6

Summary and discussion

The aims of this dissertation were to unravel the differences between Dutch and Turkish-Dutch patients in the determinants of patient participation (willingness to participate, ability to participate and concordance) and the relationship between patient participation and communication outcomes (fulfillment of information needs, patient satisfaction and understanding of information) among these patient groups. Investigating the differences gains knowledge on why intercultural communication is less effective and less adequate than intracultural communication. The knowledge derived from this dissertation provides more understanding of intercultural medical communication and can be used to design effective interventions to improve the communication between Turkish-Dutch patients and Dutch doctors. The main findings of the four empirical studies in this dissertation will be summarized below, followed by a discussion of the findings.

Information needs and communication outcomes

Chapter 2 aimed to assess information needs and fulfillment of information needs among Dutch and Turkish-Dutch GP patients in the Netherlands. In addition, the relation between perceived and recorded information provision by GPs was studied. Unfulfilled information needs of Dutch ($N=117$) and Turkish-Dutch patients ($N=74$) were measured using pre- and post-consultation questionnaires. GPs' information provision was coded using the transcripts of 120 audiotapes of the consultations. The results showed that both Turkish-Dutch and Dutch patients reported high information needs. However, Turkish-Dutch patients preferred to discuss prognosis, prevalence, physical examination, medical terms, alternative medicines and procedures at other hospital/other caregivers more than Dutch patients. Turkish-Dutch patients also experienced more unfulfilled information needs than Dutch patients. Fulfillment of information needs among Turkish-Dutch patients was also affected by their acculturation levels. Turkish-Dutch patients who reported intermediate acculturation levels experienced worse fulfillment of information needs compared to patients who had lower or higher acculturation levels. Moreover, the results showed that perceived information provision was hardly related to the recorded information provision, suggesting that patients' perceived information provision during the encounter seems to be affected by something else than the actual provision by the GP. The overall conclusion of Chapter 2 was that Turkish-Dutch patients and, to a lesser extent, Dutch patients as well, are insufficiently provided with the information they prefer by their GP.

Health-information seeking, patient participation and communication outcomes

In Chapter 3 it was investigated how Dutch and Turkish-Dutch GP patients use media to prepare themselves for the consultation and how the groups differ in their participation during medical consultations with GPs. In addition, the relationships between media use and patient participation and between patient participation and fulfillment of information needs were assessed. Patients were recruited in the waiting rooms of their GP. In total, 191 patients (117 Dutch, 74 Turkish-Dutch) completed pre- and post-consultation questionnaires, from which 120 patients (62.8%; 82 Dutch, 38 Turkish-Dutch) agreed to have their consultations recorded. The 38 Turkish-Dutch patients were matched on age and gender with Dutch patients, resulting in 34 Dutch and 34 Turkish-Dutch consultations

to assess patient participation. Despite the fact that patients had similar educational level, the results showed that Turkish-Dutch patients used a wider variety of media to search for information. Dutch patients primarily reported to use the Internet, whereas Turkish-Dutch patients reported to also use books, magazines and newspapers, and television and radio. Turkish-Dutch patients also asked fewer questions, initiated fewer topics and responded to their GP to a lower extent during the consultations than Dutch patients. Among Turkish-Dutch patients, media usage was related to increased patient participation, and higher patient participation was related to better fulfillment of information needs. These relationships were not found among Dutch patients. The overall conclusion of Chapter 3 was that through interventions that stimulate ethnic minority patients in information-seeking behavior using media prior to their medical consultation, patients will enhance their participation resulting in better fulfillment of informational needs.

Communication and cultural barriers for patient participation

Chapter 4 was aimed at better understanding why Turkish-Dutch GP patients participate less actively during a medical consultation than Dutch GP patients. Four focus groups were conducted with Turkish-Dutch and four with Dutch participants ($N=46$) assessing their perceived barriers to participate during an encounter with their GP. Separate focus groups were run for male and female participants, and Dutch and Turkish-Dutch participants were matched to each other on age, education and neighbourhood. Findings showed that, due to language barriers, Turkish-Dutch patients have difficulties understanding the information of the GP and were less able to participate and to express their health problems. Turkish-Dutch participants further reported stronger feelings of hierarchy with their doctor (more distance with the doctor, doctor having larger responsibility), higher uncertainty avoidance (struggling with the Dutch treatment approach in which several options are tried), and a more high-context, indirect communication style (more implicit style in which the message is picked up from the context) than Dutch participants. Turkish-Dutch participants also preferred a more personal doctor-patient relationship compared to Dutch participants; the doctor should be like a family member or friend. Language and communication style barriers seem to influence Turkish-Dutch patients' ability to participate, while cultural barriers seem to affect their willingness to participate. To conclude, cultural and communication differences hinder Turkish-Dutch patients to be active communicators during the conversation with their GP.

The match between preferred and perceived patient participation and the role of the doctor-patient relationship

In Chapter 5 it was investigated how doctor-patient concordance in preferred doctor-patient relationship and the match between preferred and perceived patient participation were related to communication outcomes among Turkish-Dutch and Dutch GP patients. 32 GPs (9.3% response) participated with questionnaires. 136 Dutch and 100 Turkish-Dutch patients (64% response) participated with pre- and post-consultation questionnaires, which were filled out in their GP's waiting room. GPs and patients answered the same items to measure their concordance in preferred doctor-patient relationship. The match between patients' preferred and perceived participation was calculated using pre- and post-consultation patient scores. The results showed that a match between preferred and perceived patient participation resulted in more positive communication outcomes among both Dutch and Turkish-Dutch patients. In addition, Turkish-Dutch patients who were discordant with their GP in preferred relationship and perceived high participation during

the medical encounter reported worse satisfaction, fulfillment of information needs and understanding of the information than those with lower perceived patient participation. Among Dutch patients, no effects were found for doctor-patient concordance. For Turkish-Dutch patients, better Dutch language proficiency also accounted for more satisfaction and better fulfillment of information needs compared to patients with lower Dutch language proficiency. Because concordance effects seem to be moderated by perceived patient participation among Turkish-Dutch patients, concordance studies should include perceived patient participation and should separate ethnic groups in the analyses to investigate the relationships between doctor-patient concordance and communication outcomes. For improvement of the intercultural medical communication, GPs should be trained to communicate in such a way that a match is established between a migrant patients' preferred and perceived participation during the encounter.

Discussion and suggestions for future research

The objective of this dissertation was to examine differences between Dutch and Turkish-Dutch patients in the factors determining patient participation and its relationship with communication outcomes in order to better understand intercultural medical communication. Specifically, the dissertation was aimed at answering the questions: (1) to what extent do Dutch and Turkish-Dutch patients differ in the factors underlying patient participation, and (2) how is patient participation related to the communication outcomes among Turkish-Dutch and Dutch patients? By examining differences between Dutch and Turkish-Dutch patients, inadequacies in intercultural medical communication can be better understood and more effective interventions to improve intercultural communication can be designed.

In the framework that was central to this dissertation (see Figure 1 in the Introduction) it was postulated that ethnicity influences the determinants of patient participation and that higher patient participation will result in better communication outcomes. The results of the studies provide clear evidence that differences exist between Turkish-Dutch and Dutch patients in the determinants of patient participation, in patient participation itself and in how patient participation is related to communication outcomes. The studies revealed new insights into the factors underlying patient participation and how participation affects the communication outcomes among Turkish-Dutch patients, which have important research and clinical implications and help to better understand the intercultural medical communication. First, the differences between the patient groups in the determinants of patient participation and their participation will be described, followed by the differences in how patient participation affects communication outcomes.

Differences in willingness to participate

The results of this dissertation showed differences between Turkish-Dutch and Dutch patients in their willingness to participate. Turkish-Dutch patients' willingness to participate is determined by an interplay of (1) information needs and (2) participation preferences, and (3) differences in cultural values compared to their Dutch doctor. As described in Chapter 2, Turkish-Dutch patients had similarly high levels of information needs as Dutch patients, but reported a higher need to discuss prognosis, prevalence, physical examination, medical terms, alternative medicine and procedures at the hospital/other caregivers. In Chapter 5, higher participation preferences were found among Turkish-Dutch patients compared to Dutch patients. Because higher information needs and participation preferences are considered to stimulate patients to become more participative (Street

et al., 2003), the high information needs and participation preferences among Turkish-Dutch patients cannot account for their lower participation levels compared to Dutch patients. For Turkish-Dutch patients, the willingness to express information needs and act on participation preferences—resulting in higher participation—seems to be hindered by cultural differences in power distance, preferences for a more personal relationship and a different preferred treatment approach than is common practice in the Netherlands. Turkish-Dutch patients who experience difficulties with their relationship with their GP and with the treatment approach offered by their GP, will have lower willingness to participate and will be less participative than would be expected by their information needs and participation preferences.

As was found in Chapter 5, Turkish-Dutch patients with matched preferred and perceived participation preferences reported more satisfaction, better fulfillment of information needs and better understanding of the information. Given the different preferences found among Turkish-Dutch and Dutch patients for information topics (Chapter 2), for the doctor-patient relationship and the treatment approach (Chapter 4), and for patient participation (Chapter 5), it seems plausible that not the level of preference (either high or low) determines their level of participation, but how well their preferences are met by their doctor. Future research studying patient preferences in intercultural communication should thus take into account the level of preference-matching instead of, or combined with, how much a patient prefers certain topics or certain behaviors in order to understand ethnic minorities' participative behavior and communication outcomes.

Turkish-Dutch patients with intermediate levels of acculturation reported the highest information needs and worse fulfillment of information needs. Hence, better integration into Dutch society will not automatically enhance their willingness to participate. More research is needed to understand the role of acculturation on patient participation and communication outcomes, especially among Turkish-Dutch patients with equal identification.

In addition, it could be important to include previous experiences with the doctor and the health care system when explaining ethnic minority patients' willingness to participate (Harrington, Noble, & Newman, 2004). Considering the higher unmet information needs, lower understanding of the information and lower satisfaction found among Turkish-Dutch patients, previous negative experiences with Dutch GPs might negatively affect Turkish-Dutch patients' willingness to participate in future consultations. Moreover, as Turkish-Dutch patients often compare experiences with the Dutch health care system with the Turkish one (Bäärnhielm & Ekblad, 2000), the possibly more positive previous experiences with Turkish doctors and the health care system in Turkey might negatively affect their willingness to participate in a Dutch encounter. Research in which experiences with a Turkish-Dutch doctor in the Netherlands and a Turkish doctor in Turkey are compared, will give more insight into the effects of cultural differences in communication style, doctor-patient relationship and the treatment approach among Turkish-Dutch patients. Because Turkish-Dutch doctors will probably adopt the Dutch treatment approach and might also adopt the doctor-patient relationship common in Dutch encounters, it can be investigated which effect accounts for positive communication outcomes more: communication styles, treatment approach or the doctor-patient relationship.

Differences in ability to participate

The results of the dissertation also revealed differences between Turkish-Dutch and Dutch patients in their ability to participate. The ability to participate among Turkish-Dutch patients is affected by an interplay of (1) insufficient Dutch language proficiency, (2) different

health information-seeking behavior than Dutch patients and (3) different communication styles compared to their Dutch doctors'. As described in Chapter 4, better Dutch language proficiency enhances Turkish-Dutch patients' ability to understand the GP and to express and explain their health problem, making it easier for patients to participate actively during the discussion with their doctor. In Chapter 5 it was found that Turkish-Dutch patients with lower Dutch language proficiency were less satisfied and reported worse fulfillment of information needs than patients with better Dutch language proficiency, suggesting that better Dutch language proficiency improves communication outcomes through enhanced ability to participate.

Regarding their health information-seeking behavior, Dutch and Turkish-Dutch patients differed in their media usage prior to the consultation. Chapter 3 revealed that Dutch patients primarily report to use the Internet to search for health information, while Turkish-Dutch patients reported the Internet, books, magazines/newspapers and TV/radio as important sources for searching health information as preparation for the consultation. The different media usage between the patient groups could be related to the level of satisfaction of patients, because patients' tendency to use media for information is higher when their level of satisfaction with the doctor is lower (Tustin, 2010). The wider variety of media usage found in Chapter 3 might thus also be related to more unmet information needs among Turkish-Dutch patients found in Chapter 2 and the lower satisfaction levels found in Chapter 5.

Another explanatory factor for the difference in media usage might be patients' motivation to use these media. Health information can be searched for actively, by deliberately seeking for information, or through passively receiving health information (Longo, 2005). The Internet will primarily be used when patients have an active need for information, while media such as TV and radio will provide patients with information in a more passive manner. Considering the wide variation of media used among Turkish-Dutch patients, these patients might have other motivations or a wider variation of motivations for health information-seeking than Dutch patients. Preliminary analysis on qualitative data—not described in this dissertation but based on the same data used in Chapter 4 (Schinkel, Schouten, van Weert, Kerpiclik, & van den Putte, 2014)—revealed that Dutch patients expressed their information-seeking behavior as a way to prepare to communicate better with their doctor (to express themselves better, to discuss the information with the doctor, to be more assertive), while Turkish-Dutch patients' motivations to seek for information were associated with wanting to know more about their problem and to prepare for how to explain it in Dutch during the encounter. Although sufficient Dutch language proficiency is a prerequisite for Turkish-Dutch patients to be able to use the information effectively during the encounter, their participation can be enhanced by stimulating them to search for information to use it in their discussion with the GP—with or without an interpreter. Future research should incorporate the motivations patients might have to prepare for the consultation in order to understand their behavior during the consultation and their communication outcomes afterwards.

The focus group study described in Chapter 4 revealed important barriers concerning the different communication styles of Dutch and Turkish-Dutch patients. For Turkish-Dutch patients, the direct and to-the-point communication style of their Dutch doctor is uncomfortable. Turkish-Dutch patients expressed a preference for a more indirect way of communicating, reflecting the high-context style often found in non-Western populations (Hall, 1976). This communication style is more indirect and implicit, in which subtle details should be picked up from the context in order to understand what is being said

(Gudykunst et al., 1996; Gudykunst, 1997). Given that sufficient communication skills are needed in order to participate actively, Turkish-Dutch patients' struggle with the Dutch communication style decreases their ability to participate. The different communication styles between Turkish-Dutch patients and Dutch doctors seem to result in more passive patients. It could therefore be interesting to investigate the effects of patients' and doctors' preferred communication style on the level of patient participation during the encounter further in future research.

Turkish-Dutch patients who lack Dutch language proficiency will have the lowest ability to participate in an encounter with their Dutch GP. When Turkish-Dutch patients have sufficient Dutch language proficiency, they could go beyond preparing for the consultation in language terms and might be able to seek for health information to prepare for a more active role during the consultation. When Turkish-Dutch patients reach this level of ability to participate, they still need to be comfortable with the communication style of their doctor to be able to use the health information during the consultation, and consequently become more participative. More research is needed on the interplay between these factors among ethnic minority patients and how interventions can get ethnic minority patients to the third level of the ability to participate, thereby enhancing their participation.

Differences in concordance

Contrary to previous research which found that doctor-patient concordance positively influenced communication outcomes (Kiesler & Auerbach, 2006; Krupat et al., 2001; Street Jr et al., 2008), the results of Chapter 5 showed that doctor-patient concordance did not affect communication outcomes per se. However, perceived patient participation moderated the concordance effects for Turkish-Dutch patients who were discordant with their doctor in preferred doctor-patient relationship. Given that a discordant patient's perception of higher patient participation decreased communication outcomes among Turkish-Dutch patients, communication outcomes might not be affected by the level of agreement between patients and doctors in their preferences but by the perceived concordance by the patient or by how well the patients' preferred and perceived participation are matched. The negative effect of patient participation for discordant Turkish-Dutch patients found in Chapter 5 could be explained by a lack of flow in the conversation. Chapter 3 revealed more monologues and fewer dialogues during encounters with Turkish-Dutch patients compared to Dutch patients, suggesting a worse flow of the conversation. Thus, Turkish-Dutch patients might think they participated highly when they asked some questions or expressed a few concerns, while the actual conversation between patients and GPs does not go well at all.

Given the positive effect of the match between patients' preferred and perceived participation, accommodating patient preferences in order to reach a match between preferred and perceived participation behavior for the patient might be a more important predictor of communication outcomes than doctor-patient concordance (Campbell, Auerbach, & Kiesler, 2007). A match between what patients prefer and perceive to get during the consultation regarding the communication style, doctor-patient relationship and treatment approach could have similar positive effects. To be more specific, a match between preferred and perceived communication style might be an important predictor of Turkish-Dutch patients' ability to participate, resulting in higher patient participation. Matches in preferred and perceived doctor-patient relationship and treatment approach might be important predictors of patients' willingness to participate as well. Given the results of all chapters together, these matches might not be independent determinants of

patient participation, but might function as prerequisites of the ability and willingness to participate among ethnic minority patients. Further research is needed to investigate the relationships between different kinds of preference-matches and a patient's ability and willingness to participate.

Patient participation and communication outcomes

Considering the differences between Dutch and Turkish-Dutch patients in the determinants of patient participation, it seems logical that the groups also differ in their level of patient participation. In Chapter 3, lower *observed* patient participation was indeed found among Turkish-Dutch patients than among Dutch patients. Turkish-Dutch patients asked fewer questions, contributed and responded to a lower extent during the encounter than their Dutch counterparts. The opposite was found though for *perceived* patient participation in Chapter 5. When asked about the perception of their participation during the discussion with the doctor, Turkish-Dutch patients reported a higher perceived participation than Dutch patients. The discrepancy between observed and perceived participation among Turkish-Dutch patients is interesting, suggesting that patients perceive high participation while the observations indicate otherwise. The discrepancy might reflect differences in frame of reference regarding communicative behavior such as patient participation. Given that Turkish-Dutch patients reported a higher preference for doctor-centered consultations in Chapter 5 and a higher power distance with the doctor combined with a preference for a more indirect communication style in Chapter 4, Turkish-Dutch patients are less likely to display higher participation levels than Dutch patients, as was found in Chapter 3. Their perceived participation might thus be related to other factors than their actual behavior, such as problems in the relationship with the doctor, misunderstandings during the encounter or not getting their preferred treatment approach. Further research is needed to investigate whether the discrepancy can be replicated among research in which both the perceived and observed participation of patients is measured.

Regarding the relationships between patient participation and communication outcomes, the results of Chapter 3 showed that higher observed participation among Turkish-Dutch patients was related to better fulfillment of information needs. A higher contribution to the conversation thus seems to enhance Turkish-Dutch patients' communication outcomes. In Chapter 5, a match between patients' preferred and perceived participation was found to improve the communication outcomes and higher perceived participation resulted in worse communication outcomes among Turkish-Dutch patients who were discordant with their doctor in preferred doctor-patient relationship. Thus, the positive relationship between observed patient participation and communication outcomes in Chapter 3 might indicate that these Turkish-Dutch patients matched their preferred higher participation. More research is needed to disentangle the effects of preferred and perceived patient participation on different levels to know what kind of match results in most optimal communication outcomes.

Implications for patient participation theory in an intercultural context

This dissertation contributes to the literature on intercultural medical communication by investigating the factors underlying patient participation and its effects on communication outcomes. First, Street's model on patient participation could be applied to ethnic minority patients in intercultural settings, but the model should be extended with variables relevant for intercultural medical communication, and needs to take into account the differences between migrant patients and their doctors more strongly. It is suggested to include the

cultural and communication differences found among Turkish-Dutch patients compared to Dutch patients. In addition to language proficiency and acculturation, specific preferences regarding information provision and patient participation need to be addressed, not in terms of the level of information needs and participation preferences but in terms of the match between a patient's preference and what they perceive to get from their GP during the encounter. Furthermore, motivations to search for health information should be incorporated too.

Second, the findings of this dissertation suggest that the concept of patient participation needs to be operationalized differently in intercultural settings. In the literature, patient participation is defined in terms of asking questions, expressing concerns and assertive utterances, and the more a patient behaves as such, the better the communication and health outcomes will be (Street, 2001). However, this notion of patient participation seems to be a Western view on patient participation; it assumes that migrant patients act as individualistic-oriented partners in medical communication, preferring assertive behavior and communicating directly. Considering the cultural and communication differences between Turkish-Dutch and Dutch patients, it is questionable whether this approach is most optimal for these patients and whether it is necessary to stimulate such behaviors. Patient participation needs more diverse aspects to take into account the variety in patient preferences. In this context, it might be particularly important to clearly distinguish patients' preferences for participation regarding information provision and their preferences for participation in the medical decision making process. Patients' preferences for participation in the information provision are generally higher and more stable than their preferences for participation in the decision-making process (Gaston & Mitchell, 2005; Kiesler & Auerbach, 2006). This distinction between information provision and decision-making is widely known in the literature, but the concepts are often used interchangeably, both considered as patient participation. Making this distinction seems even more relevant for non-Western cultures, for which medical decision-making is often the responsibility of the doctor and family, instead of the individual patient (Gaston & Mitchell, 2005). Because Chapter 3 revealed that Turkish-Dutch patients were the least participative in the decision-making part of the consultation, Turkish-Dutch patients might be more willing to participate in the information provision, but less willing to participate in the decision-making. More research is needed to investigate preference differences in these different aspects of patient participation among ethnic majority and ethnic minority patients to gain more insight into cultural differences in the level of patient participation. For future research it is recommended to simultaneously measure both aspects of participation but separate them for analyses.

In addition, a division in instrumental and affective participation is suggested. Although this dissertation found lower participation levels among Turkish-Dutch patients, observed with instrumental parts of the conversation such as question asking, taking initiative and responding to the doctor, another study found higher expression of emotional cues and concerns among Turkish-Dutch patients compared to Dutch patients (Schouten & Schinkel, 2015). Given that in intercultural encounters doctors tend to demonstrate less affective behavior (Ferguson & Candib, 2002; Schouten & Meeuwesen, 2006), this affective behavior should be taken into account more specifically regarding patient participation and its communication outcomes. Given the different communication styles and different participation preferences found in this dissertation between Dutch and Turkish-Dutch patients, their preferences to display affective behavior might be different than their preferences to display instrumental behavior. More research is needed to investigate how

patients' preferences for either instrumental or affective participative behavior affect the communication and its outcomes.

In medical communication, especially in intercultural context, patient participation needs to be interpreted as a behavior in which a patient expresses its preferences. This could be either a preference for assertive behavior or for more passive behavior. Higher patient participation should not involve more assertive behaviors as such, but should be an interplay of different aspects of participation and should concern the expression of preferences for all these aspects. Higher patient participation might involve expressing a preference for assertiveness in one aspect of participation but preferring passiveness in the other. To enable more nuance around the concept of patient participation in intercultural context, future research should explore the effects of ethnic minority patients' preferences for these different kinds of patient participation on their communication and communication outcomes.

Finally, it should be noted that when Turkish-Dutch patients are discussed in this dissertation, it explicitly refers to intercultural medical communication with migrant patients. These patients might be as participative in Turkey as Dutch patients are in the Netherlands. The lower ability and willingness to participate among these patients in an intercultural encounter could be more strongly related to migration problems rather than ethnic background as such, leading to barriers and discordances with their Dutch doctors, which might not be present when they consult a Turkish doctor in Turkey. It should therefore not be assumed that Turkish-Dutch patients' preferences and participative behavior in encounters in the Netherlands could be generalized to their preferences and behaviors in Turkey. Future cross-national research is suggested to investigate differences in preferences and participative behavior among Turkish-Dutch patients visiting a doctor in the Netherlands and a doctor in Turkey.

Methodological considerations

The findings of this dissertation suggest some methodological considerations for the research field of intercultural medical communication. Although the quantitative chapters (2, 3 and 5) gave important insights into differences between Dutch and Turkish-Dutch patients in their needs, behaviors and communication outcomes, the qualitative chapter (4) revealed more barriers among Turkish-Dutch patients and new and more detailed insight into the barriers of intercultural medical communication. Given that intercultural medical communication research is still quite nascent, combining qualitative and quantitative methods is recommended to be able to better understand the differences found between ethnic minority and majority patients. Qualitative research methods might also be more suitable among people with a more high-context communication style such as Turkish-Dutch patients. Given their struggle with direct questions of the doctor, more research is needed to assess whether Turkish-Dutch patients also struggle with direct questions in questionnaires. Although the questionnaire used in Chapter 5 was pilot tested among Turkish-Dutch patients, the higher participation preferences and higher perceived participation might indicate interpretation differences between Dutch and Turkish-Dutch patients of the items or the response scale.

Data collection among ethnic minority patients was especially hard to accomplish for questionnaire research. For the focus group study, finding existing Turkish groups was relatively easy and participants were very willing to discuss the issues with each other. For the focus group study, the Dutch participants were much harder to recruit, because existing groups were harder to find and if found, they were less willing to participate

together. Given the collectivistic nature of the Turkish-Dutch culture, research in which the collective is addressed, such as in focus groups, seems more suitable for Turkish-Dutch patients than for the more individualistic Dutch patients.

Moreover, questionnaire research in medical settings faces a lot of obstacles. First, finding GPs to participate was a major obstacle. Second, patients were reluctant to take part in the questionnaire research, especially Turkish-Dutch, low-educated and low-literate patients. These people have a hard time understanding questionnaires and seem to have distrust in research, partly due to a lack of knowledge on research practice. Low-educated and low-literate Dutch patients often expressed worries about the GP receiving their answers, or about receiving different care after filling out the questionnaire. Turkish-Dutch patients also worried that their GP received their answers, but also expressed worries about the government receiving their signature or that the recording of the consultation will be shared through the Internet and become known in the Turkish community. Although distrust in research is hard to overcome, different kinds of consent could be considered to overcome the barriers among Turkish-Dutch patients. For instance, oral consent might suit this patient group better, but privacy and integrity issues have to be considered then. To overcome the difficulty in understanding questionnaires among low-educated and low-literate Dutch patients and Turkish-Dutch patients, different methods of collecting questionnaire data among these patient groups should be considered. Ideally, assistants could interview all patients. This way, patients do not require the cognitive skills of filling out questionnaires and the interviewer can explain things when necessary. However, this is more time-consuming and thus more expensive. A second option is using visual answer responses and/or recorded questions to which respondents could listen. With these methods however, practical issues such as lack of privacy in the waiting rooms leaves all kinds of logistic obstacles.

Furthermore, the studies in this dissertation involve GP patients, with a wide variety of health complaints and diseases. For Chapters 2 and 3 (using the same data set), we categorized the health complaints into the ICPC classification. Although there were no significant differences between the patient groups in health complaints, psychological problems seemed to be more prevalent among Turkish-Dutch patients. Differences between Western and non-Western patients in health issues are well known, such as a higher prevalence of type 2 diabetes mellitus (Uitewaal, Manna, Bruijnzeels, Hoes, & Thomas, 2004) and depression among Turkish-Dutch patients than Dutch patients (van der Wurff et al., 2004). Because a patient's needs and communicative behavior could be related to the health complaint, future research should take into account the complaint more precisely or setup the research around patients with a certain disease to investigate differences between patients with different health complaints in their needs and behavior.

Although this dissertation was primarily aimed at investigating differences between Dutch and Turkish-Dutch patients in their needs, behaviors and communication outcomes, the similarities between the patient groups as well as the differences within the patient groups should not be neglected. Among Turkish-Dutch patients, variation existed between people with high and low language proficiency or with certain acculturation levels. More research is needed with larger samples to investigate differences between first-, second- and third-generation Turkish-Dutch patients.

Finally, the different measurements used in this dissertation for preferred, perceived and observed participation illustrate the difficulty of measuring patient participation and the necessity of clear definitions and measurements. In a previous study (Schinkel et al., 2010)—not described in this dissertation—Turkish-Dutch and Dutch patients did not differ

in their preferences in decision-making when using the *Problem-Solving Decision-Making scale* (Deber, Kraetschmer, & Irvine, 1996). In Chapter 3, observed patient participation was measured, which revealed lower participation levels of Turkish-Dutch patients than Dutch patients. In Chapter 5, preferred and perceived participation in the communication was measured, using another scale (Lerman et al., 1990). In that study, Turkish-Dutch patients reported higher preferred and perceived participation than Dutch patients. These different findings might be due to the different measurements used for patient participation (Say et al., 2006) and imply that the research field needs to be aware of measurement bias. In order to compare research findings regarding patient participation, researchers should be more precise in their definitions of patient participation and in the measurement that is used.

Clinical implications

The results of this dissertation give insight into potential elements that help to design effective interventions to enhance intercultural medical communication. Given the many barriers that Turkish-Dutch patients encounter during their medical communication, interventions in an intercultural context need to address all these barriers. Turkish-Dutch patients reported high information needs and participation preferences but seem to be hindered to act on these needs and preferences due to cultural and communication barriers. Although stimulating to prepare for the consultation could enhance Turkish-Dutch patients' participation, they need to be educated in the Dutch health care system to be able to use the information during the encounter effectively. When Turkish-Dutch patients are more aware of common practice in the Netherlands, frustration about the communication and anxiety that they are not treated similarly as Dutch patients might decrease.

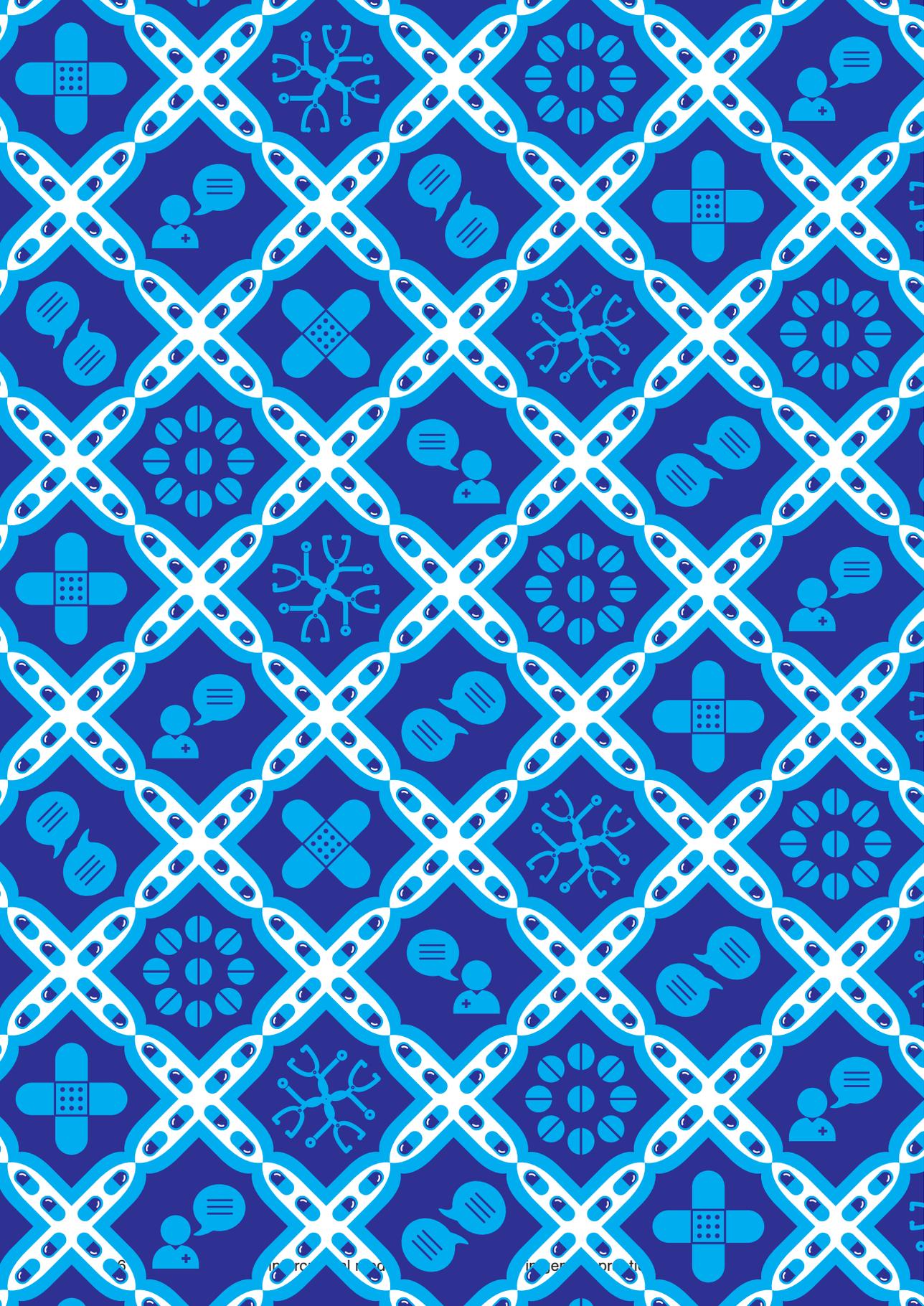
More importantly, when Turkish-Dutch patients learn how to express their preferences during the encounter, a better match might be achieved concerning their preferred communication style, doctor-patient relationship, treatment approach and patient participation, leading to more positive communication outcomes. To enhance patients in expressing their preferences, tools can be helpful. An interesting tool is the "Health Communicator", developed by a GP in order to improve the intercultural communication. The tool is designed in such a way that the patient is able to answer questions about their health problem that are normally asked by the GP during the consultation at home, in the language the patient prefers. The GP receives the answers in Dutch before the consultation, which helps the GP to prepare for the consultation based on more accurate information from the patient himself. For low-literate patients, the questions and answers can be listened to. The importance of such tools is that they can partly overcome the language barriers of the patient. Although Turkish-Dutch patient with large language barriers will still need an interpreter during the consultation, the GP receives the answers of the patient instead of an interpreter. Such tools also have the potential to educate patients in the Dutch health care system by incorporating information about the GP's communication style, treatment approach and doctor-patient relationship into the tool. Research is needed to evaluate such tools and investigate its effects on patients' participation and the communication outcomes.

Stimulating patient participation should not involve stimulating initiative and assertive behavior per se. Turkish-Dutch patients need to be stimulated to express their information needs and participation preferences and to discuss their desired relationship with the doctor, treatment approach and communication style. When they are trained in expressing their preferences, the chance that GPs can better meet their patients' preferences increases. That kind of patient participation should be stimulated in order to strengthen the relationship and consequently enhance the communication and its outcomes.

Training and educating patients in expressing their preferences to be able to meet these preferences does not work without educating and training doctors as well. This dissertation suggests that doctors need to be trained in accommodating the preferences of their migrant patients better. Given that intercultural medical communication is often less affective and informative, both aspects need to be addressed in intercultural training for doctors. Given the results of Chapter 4, doctors should try to avoid direct questions to stimulate Turkish-Dutch patients to think or decide about the diagnosis and treatment on their own. Questions such as “What do you think I should do?” will lead to uncomfortable situations in which Turkish-Dutch patients will not be as participative as they prefer, leading to more negative communication outcomes. Instead, doctors need to communicate in a more indirect way to elicit their patients’ preferences. Adopting a patient-centered approach in which patient preferences are taken into account and accommodated, and in which patients are seen as unique individuals, seems crucial for improving intercultural medical communication (Mead & Bower, 2000). Combining patient-centered care with cultural competence will build health care systems in which the preferences of all patients are effectively addressed, also those of ethnic minority patients (Saha, Beach, & Cooper, 2008). Patient-centered communication should not be a luxury for Western patients, as it also improves ethnic minority patients’ communication outcomes (Henbest & Fehrsen, 1992). However, despite the benefits that are ascribed to both patient-centeredness and cultural competence, adopting either style is hard to achieve and hard to train in practice (Bombeke et al., 2010; Seeleman et al., 2009). Training cultural competence requires a complex set of knowledge, attitudes and skills for doctors to obtain and be aware of and need to be addressed in medical training (Seeleman et al., 2009). This dissertation contributes to this literature by providing insight into cultural differences between doctors and patients and the necessity of eliciting and accommodating patients’ preferences. Training in patient-centeredness and cultural competence should be incorporated in medical curricula to educate young doctors and intercultural communication should not be an optional course for practicing doctors but should be embedded in continuing medical education. While the research field of intercultural communication is still challenging, its necessity is clear, and researchers should continue to investigate how doctors can be adequately trained in strategies to improve intercultural communication.

Concluding remarks

Intercultural medical communication is less effective than intracultural medical communication and needs to be improved in order to enhance communication outcomes and help diminish health disparities. This dissertation shows that language barriers are one of the many barriers Turkish-Dutch patients encounter during their medical communication and that these barriers hinder them to be effective partners in communication. In order to improve their communication, patients and doctors need to be more aware of the cultural and communication barriers in intercultural communication. Turkish-Dutch patients need to be educated in common practice within the Dutch health care system in terms of communication style, doctor-patient relationship and treatment approach and need to be stimulated to actively prepare for the consultation and to express their needs and preferences to increase the chance these needs will be fulfilled. Doctors need to be educated in the expectations and preferences of migrant patients and need to be trained in eliciting and accommodating their migrant patients’ expectations and preferences better. With more awareness and empowerment on both sides of the table, intercultural medical communication will improve, ultimately resulting in better health care for migrant patients.



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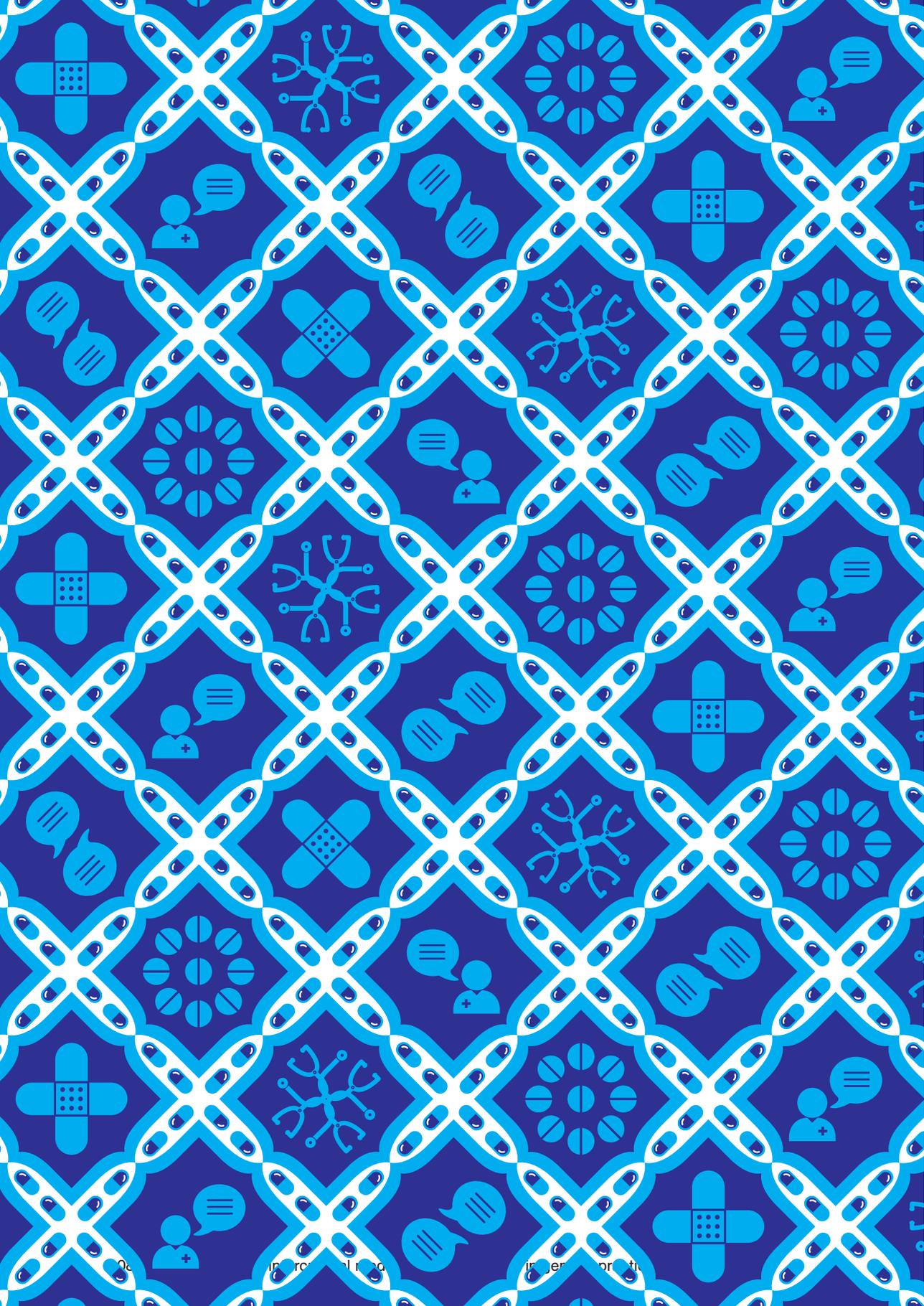
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Chapter 2: Information needs and communication outcomes
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Study concept and design: all authors. Data collection and analysis of the data (dataset 1): SS. Interpretation of the results: all authors. Drafting of the manuscript: SS. Critical revision of the manuscript for important intellectual content: all authors.

Chapter 3: Health-information seeking, patient participation and communication outcomes
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Study concept and design: SS, JvW, ES, BS. Data collection and analysis of the data (dataset 1): SS and JK. Interpretation of the results: all authors. Drafting of the manuscript: SS. Critical revision of the manuscript for important intellectual content: all authors.

Chapter 4: Cultural and communication barriers of patient participation
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Study concept and design: SS, BS, BvdP, JvW. Data collection and analyses of the data (dataset 2): SS and FK. Interpretation of the results: all authors. Drafting of the manuscript: SS. Critical revision of the manuscript for important intellectual content: all authors.

Chapter 5: The match between preferred and perceived patient participation and the role of the doctor-patient relationship
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Study concept and design: SS, BS, BvdP, JvW. Data collection: SS. Analysis of the data (dataset 3): SS and RS. Interpretation of results: all authors. Drafting of the manuscript: SS. Critical revision of the manuscript for important intellectual content: all authors.



Nederlandse samenvatting

Communicatie tussen artsen en patiënten is een essentieel onderdeel van de gezondheidszorg. Door met elkaar te communiceren wisselen artsen en patiënten relevante informatie met elkaar uit, waardoor het probleem of de klacht van de patiënt beter begrepen kan worden, een goede relatie tussen arts en patiënt kan ontstaan en een juiste behandeling kan worden ingezet. In de huidige multiculturele samenleving komen artsen steeds vaker tegenover patiënten te zitten met een andere culturele of etnische achtergrond. In Nederland is momenteel circa twaalf procent van de samenleving van niet-Westerse afkomst en dit aantal zal alleen maar toenemen. Interculturele medische communicatie – communicatie tussen artsen en patiënten met verschillende etnische achtergronden – komt dus steeds vaker voor. Onderzoek wijst echter uit dat deze vorm van communicatie minder goed verloopt dan communicatie tussen artsen en patiënten met dezelfde etnische achtergrond: er is meer miscommunicatie, minder wederzijds begrip, lagere tevredenheid en patiënten begrijpen de informatie die wordt besproken minder goed. Dit resulteert in slechtere gezondheidsuitkomsten onder niet-Westerse patiënten, bijvoorbeeld vanwege lagere therapietrouw.

Interventies om de interculturele medische communicatie te verbeteren zijn daarom hard nodig. De weinige interventies die met dit doel zijn opgezet in de huisartspraktijk leverden echter weinig tot geen effect op, vermoedelijk vanwege te weinig kennis over wat er precies misgaat. Er is dus eerst meer kennis nodig van de factoren die van invloed zijn op de interculturele medische communicatie. Het is bekend dat de communicatie wordt belemmerd door bijvoorbeeld taalproblemen en verschillen in behoeftes en verwachtingen tussen artsen en patiënten. Meer onderzoek is nodig om deze verschillen beter te begrijpen. Gezien het belang van goede communicatie tussen artsen en patiënten en het gebrek aan kennis over de factoren die van invloed zijn op de interculturele medische communicatie, was het doel van dit proefschrift om verschillen tussen Nederlandse en niet-Westerse patiënten in kaart te brengen wat betreft de factoren die van invloed zijn op de communicatie, de communicatie zelf en de uitkomsten van de communicatie.

Doelgroep

Hoewel Turkse en Marokkaanse migranten de grootste groepen niet-Westerse migranten vormen in Nederland en een vergelijkbare migrantengeschiedenis, religieuze achtergrond en socio-economische status hebben, is voor dit proefschrift gekozen om het onderzoek te houden onder Turks-Nederlandse migranten. De Turkse gemeenschap is de grootste niet-Westerse gemeenschap in Nederland en is minder goed geïntegreerd in de Nederlandse samenleving dan de Marokkaanse gemeenschap. Turkse Nederlanders (zowel eerste als tweede generatie) houden over het algemeen sterk vast aan de normen en waarden van hun land van oorsprong, hebben hechte Turkse netwerken, houden vaak contact met familie in Turkije, volgen het nieuws uit Turkije meer dan het Nederlandse nieuws en de meerderheid beschouwt zichzelf vooral als Turks. Daarbij kennen Turkse Nederlanders zichzelf een slechtere gezondheid en meer gezondheidsproblemen toe, gaan ze vaker naar de huisarts dan Nederlandse en andere niet-Westerse patiënten en ervaren ze meer miscommunicatie en minder wederzijds begrip met hun arts. De Turks-Nederlandse populatie in Nederland is dus niet alleen relevant voor dit proefschrift vanwege de grootte van de gemeenschap maar ook vanwege de sterkere identificatie met de Turkse cultuur. Dit creëert een grote culturele afstand tussen Turks-Nederlandse patiënten en hun Nederlandse huisartsen.

Belang van patiëntparticipatie

Een van de manieren om de communicatie tussen arts en patiënt te verbeteren is door de patiënt te stimuleren actief deel te nemen aan het gesprek. Dit actief meepraten van de patiënt tijdens het gesprek met de arts wordt *patiëntparticipatie* genoemd in de onderzoeksliteratuur. Hiermee wordt bedoeld: de verbale bijdrage van de patiënt in de communicatie tijdens het gesprek met de arts. Elementen van patiëntparticipatie zijn vragen stellen, het uiten van zorgen en assertief zijn. Hoe meer de patiënt deze gedragingen laat zien tijdens het gesprek, hoe hoger de patiëntparticipatie van die patiënt. Hoewel er veel positieve uitkomsten gevonden zijn van meer patiëntparticipatie – actieve patiënten krijgen bijvoorbeeld meer informatie en ondersteuning van de arts, begrijpen de informatie beter en zijn over het algemeen meer tevreden – blijken patiënten van niet-Westerse afkomst passiever tijdens het gesprek met hun arts dan Westerse patiënten. Ze stellen over het algemeen minder vragen en geven minder informatie aan de arts dan mensen van Westerse afkomst. Dit meer passieve gedrag van niet-Westerse patiënten is ongewenst, en daarom moet inzicht komen in de vraag waarom deze patiënten passiever zijn en wat hieraan te doen is.

Door actief deel te nemen aan het gesprek, kunnen patiënten de informatie die ze ontvangen sturen, wat leidt tot betere vervulling van hun informatiebehoeften, meer tevredenheid en meer begrip van de informatie. Om deze positieve communicatie-uitkomsten te bewerkstelligen, moeten patiënten dus actiever deelnemen aan het gesprek met hun arts. Het vergroten van patiëntparticipatie onder Turks-Nederlandse patiënten heeft daarom de potentie niet alleen de interculturele medische communicatie maar ook de uitkomsten van die communicatie te verbeteren. Gezien het belang van actieve patiëntparticipatie en de lagere participatie van niet-Westerse patiënten ten opzichte van Westerse patiënten, is in dit proefschrift antwoord gezocht op twee specifieke vragen die onder het doel vallen om de interculturele communicatie beter te begrijpen: (1) in hoeverre verschillen Turks-Nederlandse van Nederlandse patiënten in de factoren die van invloed zijn op patiëntparticipatie en (2) in hoeverre is onder deze patiëntgroepen patiëntparticipatie gerelateerd aan communicatie-uitkomsten als vervulling van informatiebehoeften, tevredenheid over het gesprek en begrip van de informatie?

Inhoud van dit proefschrift

De mate waarin iemand actief participeert is afhankelijk van veel factoren, vooral van (1) factoren die iemands bereidheid om te participeren beïnvloeden, (2) factoren die iemands vaardigheid om te participeren beïnvloeden en (3) hoe de arts reageert (zie figuur 1 in de *Introduction*). De bereidheid is afhankelijk van persoonlijke factoren en aan de behoefte aan informatie en participatie. Over het algemeen zijn jonge, hoogopgeleide, vrouwelijke en Westerse patiënten en patiënten met een grote behoefte aan informatie en participatie het meest actief. De vaardigheid om te participeren wordt bepaald door de kennis die patiënten hebben over hun gezondheid en de communicatieve vaardigheden die nodig zijn om deel te nemen aan het gesprek. Meer kennis en betere communicatieve vaardigheden zullen leiden tot een meer actieve patiënt. Daarnaast is het van belang dat de arts ook bereid is een patiënt actief deel te laten nemen aan het gesprek en dit stimuleert. In het kort moeten patiënten dus willen en kunnen participeren en moet de arts dit gedrag stimuleren. In dit proefschrift staan daarom zowel het willen en kunnen van patiënten centraal als ook de rol van de arts. Er zijn vier studies opgezet waarvan hieronder de belangrijkste bevindingen worden besproken.

In **hoofdstuk 2** zijn de verschillen tussen Nederlandse en Turks-Nederlandse huisartspatiënten in wat ze willen bespreken (vragenlijst voorafgaand aan het gesprek) en wat ze volgens eigen zeggen hebben besproken tijdens het gesprek (vragenlijst na afloop van het gesprek) onderzocht. Hierbij is gevraagd naar verschillende onderwerpen die tijdens een huisarts gesprek aan bod kunnen komen. Daarnaast is de relatie tussen wat patiënten zeggen dat is besproken (vragenlijst) en dat wat daadwerkelijk is besproken (analyse van geluidsopnames) bekeken. Er namen 117 Nederlandse en 74 Turks-Nederlandse patiënten deel aan dit onderzoek met vragenlijsten die ze invulden voor en na het consult. Om te weten wat er tijdens het gesprek werd besproken, zijn er geluidsopnames van 120 consulten gemaakt. De resultaten wijzen uit dat zowel Turks-Nederlandse als Nederlandse patiënten een hoge behoefte aan informatie hebben. Turks-Nederlandse patiënten gaven een hogere behoefte aan om de prognose, prevalentie, het lichamelijk onderzoek, medische termen, alternatieve geneeswijzen en procedure bij andere hulpverleners te bespreken. De informatiebehoeften werden onder Turks-Nederlandse patiënten minder goed vervuld dan onder Nederlandse patiënten. Het acculturatieniveau van Turks-Nederlandse patiënten bleek van invloed te zijn op de informatiebehoeften en hoe goed die behoeften worden vervuld: patiënten die zich evenveel Nederlands als Turks voelden, gaven hogere informatiebehoeften aan en ook een slechtere vervulling van die behoeften dan patiënten die zich meer identificeerden met de Turkse of Nederlandse cultuur. Verder bleek de perceptie van de patiënt over de informatievoorziening slecht te correleren met de informatievoorziening die wij codeerden op basis van de geluidsopnames. Patiënten lijken hun perceptie op andere factoren te baseren dan op de werkelijke informatievoorziening. Huisartsen lijken vooral Turks-Nederlandse patiënten, maar voor een deel ook Nederlandse patiënten, niet de informatie te verstrekken die patiënten willen ontvangen.

Hoofdstuk 3 had tot doel om verschillen tussen Nederlandse en Turks-Nederlandse huisartspatiënten te onderzoeken in hun zoekgedrag naar gezondheidsinformatie voorafgaand aan het consult. Daarbij werd gekeken of dit zoekgedrag leidt tot een hogere patiëntparticipatie en betere vervulling van informatiebehoeften. Van dezelfde 117 Nederlandse en 74 Turks-Nederlandse huisartspatiënten als in hoofdstuk 2 zijn de vragenlijsten gebruikt om het zoekgedrag en vervulling van informatiebehoeften te meten. Uit de opnames van de 120 consulten hebben we voor deze studie de mate van participatie van de patiënt gecodeerd door te meten hoeveel vragen er werden gesteld door de patiënt, hoeveel de patiënt aan het woord was in verhouding tot de huisarts en hoe de patiënt en arts op elkaar reageerden. Uit de resultaten bleek dat Turks-Nederlandse patiënten vaker en meer verschillende media gebruikten als voorbereiding op het consult om informatie te zoeken dan Nederlandse patiënten. Nederlandse patiënten gaven aan vooral internet te gebruiken, terwijl Turks-Nederlandse patiënten naast het internet ook tv, radio, tijdschriften, boeken en kranten raadpleegden. De patiëntgroepen verschilden niet in opleidingsniveau. Daarnaast bleken Turks-Nederlandse patiënten minder vragen te stellen, minder aan het woord te zijn in verhouding met de huisarts en minder vaak te reageren op de huisarts dan Nederlandse patiënten. Onder Turks-Nederlandse patiënten was mediagebruik gerelateerd aan meer participatie en meer participatie aan betere vervulling van informatiebehoeften. Onder Nederlandse patiënten werden deze relaties niet gevonden. Interventies om de participatie van Turks-Nederlandse patiënten te vergroten, zouden daarom effectief kunnen zijn als deze patiënten worden gestimuleerd informatie te zoeken als voorbereiding op het gesprek. Dit zal leiden tot meer actieve patiënten en betere vervulling van de informatiebehoeften van de patiënt.

In **hoofdstuk 4** zijn verschillen onderzocht tussen Nederlandse en Turks-Nederlandse huisartspatiënten in de barrières die ze ervaren ten opzichte van de vaardigheid en bereidheid om te participeren tijdens een gesprek met de huisarts. Hiervoor zijn vier groepsinterviews gehouden met Turks-Nederlandse patiënten en vier met Nederlandse huisartspatiënten (N=46). Voor de interviews deden mannen en vrouwen apart van elkaar mee en zijn de Turks-Nederlandse en Nederlandse deelnemers gelijk gehouden wat betreft hun leeftijd, opleiding en woongebied. Uit de groepsinterviews kwam naar voren dat Turks-Nederlandse patiënten door taalproblemen moeite hebben met de informatie begrijpen en daardoor minder goed in staat zijn het probleem uit te leggen en te participeren in het gesprek. Verder bleek dat Turks-Nederlandse patiënten meer afstand voelden ten opzichte van de huisarts (huisarts heeft grotere verantwoordelijkheid), meer worstelden met de Nederlandse behandelaanpak (waarbij te lang wordt afgewacht en te veel behandelingen worden geprobeerd) en een meer indirecte, zogenoemde *high-context* communicatiestijl hanteerden dan Nederlandse patiënten. Turks-Nederlandse patiënten gaven ook aan een meer persoonlijke relatie te willen met hun huisarts dan Nederlandse patiënten, dat wil zeggen vergelijkbaar met een familielid of vriend. Voor Turks-Nederlandse patiënten lijken taalproblemen en de worsteling met een andere communicatiestijl de vaardigheid om te participeren te beïnvloeden, terwijl de culturele barrières de bereidheid om te participeren lijken te beïnvloeden. Deze communicatie- en culturele barrières maken het voor Turks-Nederlandse patiënten moeilijk om actief mee te communiceren met de huisarts.

In **hoofdstuk 5** is voor zowel Nederlandse als Turks-Nederlandse huisartspatiënten onderzocht hoe gelijkenissen tussen huisarts en patiënt in de gewenste arts-patiëntrelatie en de *match* tussen wat patiënten willen en wat ze volgens eigen zeggen hebben gedaan wat betreft patiëntparticipatie de communicatie-uitkomsten beïnvloeden. Daarbij is gekeken in hoeverre de gelijkenis met de huisarts in de gewenste arts-patiëntrelatie is gerelateerd aan de mate van participatie die patiënten zichzelf toekennen. In totaal namen 32 huisartsen, 136 Nederlandse en 100 Turks-Nederlandse patiënten deel aan het onderzoek met vragenlijsten. Huisartsen vulden dezelfde vragen als de patiënten in over de arts-patiëntrelatie om de mate van gelijkenis met de patiënt vast te stellen. Patiënten vulden voor en na het consult een vragenlijst in waarmee de *match* is gemeten tussen wat patiënten willen (voor) en wat ze naar eigen zeggen hebben gedaan (na) wat betreft participatie. Uit de resultaten bleek dat de *match* tussen wat patiënten willen en wat ze zeggen te hebben gedaan wat betreft hun participatie voor beide patiëntgroepen resulteerde in positievere communicatie-uitkomsten. Die patiënten rapporteerden een betere vervulling van informatiebehoeften, meer tevredenheid en meer begrip van de informatie. Daarnaast werden voor Turks-Nederlandse patiënten die een andere arts-patiëntrelatie wilden dan hun huisarts lagere communicatie-uitkomsten gevonden als ze zichzelf een actievere rol toebedeelden tijdens het gesprek. Onder Nederlandse patiënten werden geen effecten gevonden wat betreft hun gelijkenis met de huisarts. Verder bleek voor Turks-Nederlandse patiënten een betere taalvaardigheid in de Nederlandse taal tot meer tevredenheid en betere vervulling van informatiebehoeften te leiden. Om de interculturele communicatie te verbeteren lijkt een gelijkenis tussen huisarts en patiënt dus niet van belang, maar moeten huisartsen getraind worden om op zo'n manier te communiceren dat de mate waarin Turks-Nederlandse patiënten participeren tijdens het gesprek overeenkomt met de mate waarin ze willen participeren.

Discussie van de bevindingen

Willen participeren

Allereerst verschillen Turks-Nederlandse en Nederlandse huisartspatiënten in hun bereidheid om te participeren. Voor Turks-Nederlandse patiënten wordt deze bereidheid bepaald door een samenspel van (1) informatie- en, (2) participatievoorkeuren en (3) verschillen in culturele waarden ten opzichte van hun huisarts. De hoge informatie- en participatiebehoeften onder Turks-Nederlandse patiënten lijken niet direct te leiden tot meer participatie door de culturele verschillen die ze ervaren ten opzichte van hun huisarts. Voor Turks-Nederlandse patiënten is het ten eerste van belang dat ze de gewenste relatie met hun huisarts en de gewenste behandelaanpak ervaren. Ervaren zij dit niet, dan zal hun behoefte aan informatie en participatie niet direct leiden tot een hogere participatie.

Een betere acculturatie onder Turks-Nederlandse patiënten lijkt niet per se te leiden tot meer bereidheid om te participeren. De bereidheid lijkt het hoogst onder patiënten die zich sterker met de Nederlandse cultuur identificeren dan met de Turkse, maar gezien de kleine steekproeven in dit proefschrift is hiernaar meer onderzoek nodig om te kijken hoe acculturatie zich verhoudt tot de bereidheid om te participeren.

Voor de bereidheid om te participeren kan het ook van belang zijn om eerdere ervaringen die patiënten hebben met de huisarts en het gezondheidssysteem mee te nemen onder migrantenpatiënten. De slechtere communicatie-uitkomsten onder Turks-Nederlandse patiënten ten opzichte van Nederlandse patiënten, kunnen een rol spelen in de toekomstige bereidheid om te participeren. Omdat Turks-Nederlandse patiënten ook ervaringen hebben met de zorg in Turkije, kan het interessant zijn om in toekomstig onderzoek ook de invloed van deze ervaringen mee te nemen.

Kunnen participeren

Naast verschillen in de bereidheid om te participeren, bleken Turks-Nederlandse en Nederlandse huisartspatiënten ook te verschillen in hun vaardigheid om te participeren. De vaardigheid wordt voor Turks-Nederlandse patiënten beïnvloed door een samenspel van (1) gebrek aan taalvaardigheid in de Nederlandse taal, (2) ander zoekgedrag naar gezondheidsinformatie en (3) een andere communicatiestijl dan hun Nederlandse arts. Terwijl taalvaardigheid vaak wordt gezien als belangrijke voorspeller van goede communicatie, laat dit proefschrift zien dat taalvaardigheid slechts een onderdeel van de oplossing is; het verhoogt deels de vaardigheid om te participeren. Omdat een patiënt de juiste communicatieve vaardigheden nodig heeft om te kunnen participeren, leidt het verschil in communicatiestijl tussen Turks-Nederlandse patiënten en Nederlandse artsen tot een lagere vaardigheid om te kunnen participeren onder Turks-Nederlandse patiënten.

De verschillen in mediagebruik kunnen te maken hebben met de motivatie om informatie te zoeken. Gezondheidsinformatie kan actief worden gezocht, door bewust op zoek te gaan naar informatie, of kan meer passief worden verkregen. Het internet kan bijvoorbeeld alleen worden gebruikt als een patiënt bewust op zoek gaat naar informatie, terwijl andere media zoals tv en radio meer passieve media zijn om informatie mee te ontvangen. Gezien de grotere variatie aan media die gebruikt worden onder Turks-Nederlandse patiënten, zouden deze patiënten ook een grotere variatie aan motieven of andere motieven kunnen hebben voor hun zoekstrategie. Verder onderzoek naar de motieven om informatie te zoeken is aan te bevelen om de participatie van de patiënt en de communicatie-uitkomsten beter te begrijpen.

Turks-Nederlandse patiënten die de Nederlandse taal niet voldoende machtig zijn, zullen de laagste vaardigheid om te participeren hebben. Als Turks-Nederlandse patiënten

de Nederlandse taal meer machtig zijn, kunnen ze zich voorbereiden in het Nederlands om zich zo beter voor te bereiden op het gesprek. Maar alleen wanneer ze genoeg machtig zijn om te communiceren in de Nederlandse communicatiestijl, zullen ze hun gevonden informatie ook daadwerkelijk kunnen inzetten in het gesprek, wat leidt tot een hogere participatie.

Het effect van gelijkheid

Uit hoofdstuk 5 bleek dat een huisarts niet per se gelijke ideeën hoeft te hebben wat betreft de arts-patiëntrelatie voor positieve communicatie-uitkomsten. De gelijkheid tussen arts en patiënt in gewenste relatie bleek gemodereerd door wat patiënten naar eigen zeggen hadden gedaan wat betreft patiëntparticipatie. Turks-Nederlandse patiënten die van hun huisarts verschilden in de gewenste relatie waren meer tevreden, hadden een betere vervulling van informatiebehoeften en een beter begrip van de informatie als ze zichzelf minder participatie tijdens het gesprek hadden toegekend. De Turks-Nederlandse patiënten die ongelijk waren met hun huisarts in gewenste relatie en zichzelf meer participatie hadden toegekend bleken juist meer negatieve communicatie-uitkomsten te rapporteren. Dit zou te maken kunnen hebben met de flow van het gesprek. Uit hoofdstuk 3 bleek dat in gesprekken met Turks-Nederlandse patiënten minder op elkaar gereageerd werd en de partijen dus meer langs elkaar heen praatten. Patiënten zouden kunnen denken dat ze meer actief waren tijdens het gesprek of daadwerkelijk meer actief kunnen zijn geweest, maar gezien de slechtere reacties van de arts toch niet positief zijn over het gesprek. Wellicht komen de reacties van de arts niet overeen met hun verwachtingen. Gelijke ideeën tussen huisartsen en migrantenpatiënten lijken dus niet tot meer positieve communicatie-uitkomsten te leiden, maar gelijkheid wat betreft de match tussen wat patiënten willen en denken te doen tijdens het gesprek. Daarom zou een match tussen wat patiënten willen en denken te krijgen tijdens het gesprek wat betreft communicatiestijl, behandelaanpak en relatie met de arts – verschillen gevonden in hoofdstuk 4 – meer invloed kunnen hebben op de communicatie-uitkomsten dan de gelijkheid tussen arts en patiënt. Deze match tussen wat patiënten willen en denken te krijgen zou wel eens de vaardigheid en bereidheid om te participeren kunnen beïnvloeden, waarbij geldt dat hoe beter de match, hoe hoger de vaardigheid en bereidheid om te participeren zal zijn.

De rol van participatie in communicatie-uitkomsten

Gezien de verschillen in de factoren die van invloed zijn op patiëntparticipatie, is het niet verrassend dat Turks-Nederlandse en Nederlandse patiënten ook verschilden in hun mate van participatie. In hoofdstuk 3 werd gevonden dat Turks-Nederlandse patiënten minder vragen stelden, minder initiatief namen en minder reageerden op hun arts dan Nederlandse patiënten. Het tegenovergestelde werd gevonden in hoofdstuk 5 wat betreft de perceptie van de patiënten over hun participatiegedrag. Turks-Nederlandse patiënten bleken zichzelf als meer actieve deelnemers aan het gesprek te zien dan Nederlandse patiënten. Dit verschil tussen geobserveerd gedrag en perceptie van de patiënt is interessant, en suggereert dat Turks-Nederlandse patiënten zichzelf als actiever deelnemers zien dan de observaties laten zien. Het verschil zou verklaard kunnen worden doordat de twee patiëntgroepen een ander referentiekader hanteren over actief, individueel gedrag zoals patiëntparticipatie. Omdat Turks-Nederlandse patiënten meer verantwoordelijkheid bij de arts leggen, een grotere afstand met hun arts ervaren en een meer indirecte communicatiestijl lijken te hanteren, lijkt hun perceptie van hun gedrag gerelateerd aan andere zaken dan hun werkelijke gedrag, zoals de relatie met de arts, miscommunicatie of het al dan niet ervaren van de gewenste behandelaanpak. Als Turks-Nederlandse patiënten denken dat

ze actieve deelnemers zijn tijdens het gesprek met de huisarts, maar – vergeleken met Nederlandse patiënten – minder actief deelnemen dan ze denken, kan het stimuleren van patiëntparticipatie als actief, assertief gedrag ineffectief worden. Hoewel de geobserveerde participatie van Turks-Nederlandse patiënten tot meer vervulling van informatiebehoeften bleek te leiden, bleek de gepercipiëerde participatie van patiënten geen positief effect te hebben op de uitkomsten, alleen als deze perceptie overeenkwam met de gewenste mate van participatie. De mate van participatie lijkt dus niet tot positieve communicatie-uitkomsten te leiden, maar de mate waarin de gewenste participatie tot uiting komt tijdens het gesprek. De positieve relatie voor geobserveerde participatie zal dus gelden voor de patiënten die ook meer participatie wensten.

Aanbevelingen voor onderzoek naar patiëntparticipatie in interculturele context

Allereerst kan worden geconcludeerd dat modellen voor patiëntparticipatie moeten worden uitgebreid met variabelen die relevant zijn in interculturele communicatie, rekening houdend met de verschillen tussen migrantenpatiënten en hun artsen. Naast taalvaardigheid en acculturatie is het van belang om de culturele en communicatieverschillen tussen Turks-Nederlandse patiënten en Nederlandse artsen toe te voegen aan het model en om specifieke wensen ten opzichte van informatie en participatie mee te nemen. Er moet daarbij niet zozeer gekeken worden hoe hoog of laag die wens is, maar of de wens in vervulling gaat tijdens het gesprek. Tot slot is het aan te bevelen om niet alleen zoekgedrag naar gezondheidsinformatie of het hebben van gezondheidskennis mee te nemen, maar vooral ook de motivatie om die kennis te vergaren.

De resultaten van dit proefschrift impliceren dat het concept patiëntparticipatie op een andere manier gedefinieerd moet worden als het in een interculturele context wordt gebruikt. De huidige definitie van patiëntparticipatie lijkt een Westerse gedachte, en veronderstelt dat patiënten assertief gedrag wensen en een directe communicatiestijl hebben. Gezien de culturele en communicatiebarrières voor Turks-Nederlandse patiënten, is het de vraag of een dergelijke assertiviteit optimaal is voor Turks-Nederlandse patiënten en of het nodig is dergelijk gedrag te stimuleren. Omdat interculturele gesprekken vaak gekenmerkt worden door zowel minder instrumenteel als affectief gedrag, is het interessant patiëntparticipatie op te delen in een instrumenteel en een affectief deel. Daarnaast lijkt een onderscheid tussen de belangrijkste communicatieonderdelen van het gesprek – de informatievoorziening en de medische beslissing – van belang voor de definitie van patiëntparticipatie. Turks-Nederlandse patiënten zien de arts als gezaghebbende die de beslissing moet nemen, samen met de familie in plaats van de individuele patiënt. De bereidheid om actief deel te nemen aan het gesprek zou voor hen dus heel anders kunnen liggen als er rekening wordt gehouden met het specifieke onderdeel van het gesprek.

Als laatste moet hier worden opgemerkt dat er in dit proefschrift wordt gesproken over interculturele medische communicatie met migrantenpatiënten. Deze patiënten kunnen even participatief zijn in Turkije als Nederlandse patiënten in Nederland. De lagere vaardigheid en bereidheid om te participeren onder deze groep patiënten lijkt vooral te maken te hebben met hun migratie, niet zozeer met hun etnische achtergrond. Doordat ze naar een cultuur zijn geëmigreerd waar ze taalproblemen en verschillen met hun arts tegenkomen, worden ze belemmerd in hun communicatie, wat niet zo hoeft te zijn als ze naar een arts in Turkije gaan. De resultaten in dit proefschrift kunnen daarom niet worden gegeneraliseerd naar Turks-Nederlandse patiënten in Turkije en al helemaal niet naar Turkse patiënten in Turkije.

Methodologische aanbevelingen

In dit proefschrift zijn kwantitatieve en kwalitatieve methoden gebruikt, waarbij de kwalitatieve studie veel nieuwe inzichten gaf in barrières onder Turks-Nederlandse patiënten. Omdat onderzoek naar interculturele medische communicatie nog in de kinderschoenen staat, wordt geadviseerd onderzoeksmethoden te combineren om meer inzicht te krijgen in hoe de communicatie verloopt en waar het misgaat.

Voor kwantitatief onderzoek is het verzamelen van data onder Turks-Nederlandse patiënten niet gemakkelijk. Voor de groepsinterviews waren Turks-Nederlandse patiënten relatief snel gevonden en waren mensen snel bereid mee te werken. Voor de groepsinterviews waren juist de Nederlandse deelnemers moeilijker te vinden, vanwege het feit dat er in dezelfde leeftijds- en opleidingscategorie minder mensen bereid waren mee te werken. Gezien de meer collectivistische waarden onder Turks-Nederlandse patiënten lijkt onderzoek waarbij het collectief wordt aangesproken – zoals bij de groepsinterviews het geval was – meer te passen dan onderzoek waar het individu wordt aangesproken – zoals bij vragenlijstonderzoek.

Verder moet er bij dataverzameling in huisartspraktijken rekening gehouden worden met veel andere obstakels. Ten eerste is het werven van huisartsen in multiculturele praktijken moeilijk, zij geven vaak aan te druk te zijn voor deelname of al bezig te zijn met een onderzoek of interventie. Ten tweede is het werven van patiënten in de huisartspraktijk niet gemakkelijk, zeker onder Turks-Nederlandse, lager opgeleide of laaggeletterde patiënten. Deze patiënten hebben moeite een vragenlijst te begrijpen en lijken een groot wantrouwen ten opzichte van onderzoek te hebben. Andere manieren om deze patiënten aan te spreken en vragen te stellen moeten overwogen worden om een hogere respons en accuratere antwoorden te verkrijgen. Mondeling afnemen van de vragenlijsten zou mensen beter in staat stellen te antwoorden, maar dit is tijdrovend en duur. Visuele antwoordmogelijkheden en/of ingesproken vragenlijsten zouden dit (goedkoop) kunnen verhelpen, maar hier kleven weer praktische issues aan.

Als laatste moet het belang van heldere definities en metingen van participatie binnen het veld benadrukt worden. In een eerdere studie – niet beschreven in dit proefschrift – verschilden Turks-Nederlandse en Nederlandse patiënten niet van elkaar in participatievoorkeur. In hoofdstuk 5 bleken Turks-Nederlandse patiënten een hogere participatiebehoefte te hebben terwijl in hoofdstuk 3 juist de Nederlandse patiënten de hoogste participatie bleken te hebben tijdens het gesprek. Deze verschillen kunnen verklaard worden doordat de resultaten gebaseerd zijn op verschillende meetinstrumenten. Om resultaten te kunnen vergelijken moeten onderzoekers preciezer hun definities geven van patiëntparticipatie en preciezer beschrijven hoe en wat er gemeten is.

Klinische aanbevelingen

Om de interculturele medische communicatie te verbeteren, moeten interventies opgezet worden waarbij rekening wordt gehouden met de vele barrières die migrantenpatiënten ervaren tijdens het gesprek met hun Nederlandse arts. Hoewel Turks-Nederlandse patiënten een hoge behoefte aan informatie en participatie lijken te hebben, worden ze gehinderd om actief deel te nemen aan het gesprek vanwege culturele en communicatiebarrières. Om de participatie van migrantenpatiënten te vergroten lijkt het stimuleren van informatie zoeken ter voorbereiding op het gesprek nuttig. Om te bewerkstelligen dat patiënten de gevonden informatie daadwerkelijk gebruiken tijdens het gesprek, is voorlichting en training nodig in de communicatiestijl, behandelaanpak en arts-patiëntrelatie die gebruikelijk is in Nederland. Als migrantenpatiënten zich meer bewust zijn van hoe het er

“normaal gesproken” aan toe gaat, kan de frustratie en angst om een andere behandeling te krijgen dan een Nederlandse patiënt weggenomen worden. Daarbij is het stimuleren van de patiënt om zijn/haar wensen en behoeften kenbaar te maken tijdens het gesprek en te proberen te vervullen van groot belang. Ook als patiënten passief willen zijn in bepaalde aspecten, is het belangrijk dat ze dit aangeven. Vergroten van assertiviteit is dus niet per se het vergroten van de verbale bijdrage van de patiënt als wel het stimuleren om behoeften kenbaar te maken en in vervulling te laten gaan. Als de communicatie zo verloopt dat patiënten hun behoeften kunnen vervullen, zal de patiënt het gesprek positiever en beter geïnformeerd verlaten.

Naast het voorlichten en trainen van patiënten moeten ook de artsen worden voorgelicht en getraind. Huisartsen hoeven geen gelijke verwachtingen te hebben of een gelijke relatie te wensen, maar moeten getraind worden in het achterhalen en tegemoetkomen van de wensen en behoeften van hun migrantenpatiënten. Directe vragen als “Wat denk jij wat ik moet doen?” lijken een manier om de behoeften van de patiënt te achterhalen, maar blijken te confronterend voor Turks-Nederlandse patiënten. Er moeten nieuwe manieren worden gevonden om deze patiënten tegemoet te komen. Hoewel patiëntgerichte communicatie en meer culturele competenties worden gezien als cruciale aspecten om artsen te trainen, blijkt het voor hen moeilijk om dit in praktijk te brengen. Dit proefschrift geeft meer duidelijkheid in culturele verschillen en barrières die spelen bij interculturele communicatie. Trainen van artsen in meer bewustzijn van deze zaken en hoe ermee om te gaan, zou een vast onderdeel van het medisch curriculum moeten zijn om jonge artsen erin te trainen en zou een verplicht onderdeel moeten zijn van nascholing van artsen. Het onderzoeksveld van interculturele medische communicatie heeft nog een lange weg te gaan, maar is nodig en door hiermee door te gaan, kunnen steeds effectievere trainingen voor artsen en patiënten worden opgezet om de communicatie te verbeteren.

Algemene conclusie

Interculturele medische communicatie moet worden verbeterd om de gezondheidszorg voor migrantenpatiënten te verbeteren. Dit proefschrift laat zien dat taalbarrières een van de vele barrières zijn die Turks-Nederlandse patiënten ervaren tijdens een gesprek met hun huisarts. Deze vele barrières maken hen minder actief en maken hen minder goede gesprekspartners. Om de communicatie te verbeteren moeten zowel patiënten als artsen zich meer bewust zijn van de barrières die spelen. Turks-Nederlandse patiënten moeten voorgelicht worden in de communicatiestijl, behandelaanpak en arts-patiëntrelatie die in Nederland gebruikelijk is en moeten gestimuleerd worden zich actief voor te bereiden op het gesprek en hun behoeften kenbaar te maken en te proberen die te vervullen. Artsen moeten voorgelicht worden in de verschillen die spelen en moeten getraind worden in het achterhalen en tegemoetkomen van de behoeften van hun migrantenpatiënt. Als beide partijen zich meer bewust zijn van verschillen en beter weten ermee om te gaan, zal de interculturele medische communicatie verbeteren en zal uiteindelijk de zorg voor migranten verbeteren.

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Curriculum vitae

After obtaining her BSc in Media and Information Management at the Hogeschool of Amsterdam, Sanne Schinkel continued with studying Communication Science at the University of Amsterdam, where she became inspired for conducting research. During the Research Master Communication Science, her interest in intercultural medical communication arose. While writing her Master's thesis, she started teaching courses at the Department of Communication Science. After graduating in 2010, she continued working as a lecturer and combined her teaching duties with this PhD project in her spare time. From early 2014, funding from ASCoR allowed her to finish her PhD project as a halftime PhD student. Sanne will continue her work as lecturer and researcher in Health Communication at the Department of Communication Science.

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