"What do you think I should do?": Understanding intercultural medical communication in general practice

Schinkel, S.

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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.

This chapter is published as:
Introduction

Previous literature suggests that doctors underestimate their patients’ need for information (Fallowfield, Ford, & Lewis, 1995; Waitzkin, 1984; Zemencuk, Feightner, Hayward, Skarupska, & 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; Endo, Kazis, Ash, & Moskowitz, 1989; Nease Jr & Brooks, 1995; Sutherland, Llewellyn-Thomas, Lockwood, Titchler, & Till, 1989; Waitzkin, 1985). Consequently, unfulfilled information needs for different types of patients have been reported (Jones et al., 1999; Kjeken et al., 2006; Koning, Maille, Stevens, & Dekker, 1995; Tsuchiya & Horn, 2009; Turner, Maher, Young, Young, & Vaughan Hudson, 1996; van Weert et al., 2009; Wachters-Kauffman, 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 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 prevention, 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 (Devillé, 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 (71.1% 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.
Based on Harmsen et al.’s (2008) division of three cultural views was measured by subtracting the score on Turkish culture from Dutch culture, resulting in two independent measures of group identification. A self-developed identification score disagree” to “(5) totally agree”. The two items are uncorrelated (they belong to the Dutch and Turkish culture on a 5-point scale, ranging from “(1) totally

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; Coultet, 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.

**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 Pearsons’ 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. 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; $SD = 1.1$).
Company during consultation

<table>
<thead>
<tr>
<th></th>
<th>Dutch (78.6%)</th>
<th>Turkish (21.4%)</th>
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<tbody>
<tr>
<td>Alone</td>
<td>85 (69.4%)</td>
<td>50 (40.6%)</td>
</tr>
<tr>
<td>Partner</td>
<td>14 (12.6%)</td>
<td>7 (9.7%)</td>
</tr>
<tr>
<td>Child</td>
<td>8 (7.2%)</td>
<td>10 (13.9%)</td>
</tr>
<tr>
<td>Parent</td>
<td>4 (3.6%)</td>
<td>2 (2.8%)</td>
</tr>
<tr>
<td>Other</td>
<td>0 (0%)</td>
<td>3 (4.2%)</td>
</tr>
</tbody>
</table>

**Dutch language proficiency**

<table>
<thead>
<tr>
<th>Measure</th>
<th>Mean overall scores (SD)</th>
<th>Mean scores first/second generation</th>
</tr>
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<tbody>
<tr>
<td>Overall scores</td>
<td>3.6 (1.1)</td>
<td>3.3 (1.1) / 4.4 (0.6)</td>
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**Identification Dutch culture**

<table>
<thead>
<tr>
<th>Measure</th>
<th>Mean overall scores (SD)</th>
<th>Mean scores first/second generation</th>
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<tbody>
<tr>
<td>Overall scores</td>
<td>2.9 (1.2)</td>
<td>2.7 (1.2) / 3.5 (1.2)</td>
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**Identification Turkish culture**

<table>
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<tr>
<th>Measure</th>
<th>Mean overall scores (SD)</th>
<th>Mean scores first/second generation</th>
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<tbody>
<tr>
<td>Overall scores</td>
<td>3.7 (1.2)</td>
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**Unfulfilled information needs**

Table 2 shows mean QII s 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), QII s above 0.4 were considered as moderately in need for improvement, and QII s 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 QII s 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 QII s were found. Overall, Dutch patients experienced less unfulfilled information needs than Turkish-Dutch patients. Dutch patients reported lower QII s than for Turkish-Dutch patients on information on prognosis (F[1, 126.21] = 8.04, 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 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).
with medication (procedures at hospital/other caregivers (information provision (see Table 3). Most significant correlations were moderate, ranging but was not reported as being discussed more than the other topics. For around half of the other hand, information on symptoms was the most frequently discussed in all groups, discussed, while in fact these topics were hardly discussed during the consultation. On medicine, consequences for daily life and psychological aspects as rather extensively Table 3 shows that patients in both groups rated information on prognosis, seriousness, treatment with medication, treatment without medication 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 ($r = .49, p < .05$).
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, & Souchek, 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 (Glaberts, 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.