

## Understanding and improving communication and decision-making in palliative care for Turkish and Moroccan immigrants: a multiperspective study

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**Objective.** The aim of this study is to explore how communication and decision-making in palliative care among Turkish and Moroccan patients is influenced by different styles of care management between Turkish and Moroccan families and Dutch professional care providers. Problems as well as solutions for these problems are highlighted.

**Design.** A qualitative design was used, totally interviewing 83 people (6 patients, 30 relatives and 47 care providers) covering 33 cases of incurable cancer patients receiving palliative care. Data were analysed thematically and contextually.

**Results.** The analysis reveals that problems in decision-making are partly related to differences in ethnic-cultural views on ‘good care’ at the end of life: Dutch palliative care providers prefer to focus on quality of life rather than on prolonging life, while Turkish and Moroccan families tend to insist on cure. Another barrier is caused by conflicting views on the role of the ‘care management group’: Dutch care providers see the patient as their primary discussion partner, while in Turkish and Moroccan families, relatives play a major part in the communication and decision-making. Moreover, the family’s insistence on cure often leads to the inclusion of additional care providers in communication, thus complicating joint decision-making.

**Conclusion.** Care providers need to understand that for Turkish and Moroccan patients, decision-making is seldom a matter of one-to-one communication. Next to acknowledging these patients’ different cultural backgrounds, they must also recognise that the families of these patients often function as care management groups, with an ‘equal’ say in communication and decision-making. In addition, professionals should optimise communication within their own professional care management group.

**Keywords:** palliative care; communication; decision-making; care management group; cancer; immigrants; ethnicity; The Netherlands

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## Introduction

*Palliative care* refers to care aimed at improving the quality of life of patients and their relatives coping with an incurable and ultimately terminal disease. Palliative care focuses on the prevention and relief of suffering by means of early identification and careful assessment, as well as on the treatment of problems of a physical, psychosocial or spiritual nature. Palliative care providers support the patient and family using an interdisciplinary approach. Good communication, therefore, is critical, not only between care providers and the patient and family, but also within the team of various care providers, and between patient and relatives.

Patients from an immigrant background have been documented to have specific needs with regard to care or communication in the field of palliative care (Lapine *et al.* 2001, Hanssen 2004, Hagerty *et al.* 2005, Hancock *et al.* 2007, Parker *et al.* 2007, Phelps *et al.* 2009, Worth *et al.* 2009). Earlier research in the Netherlands has shown that elderly people from a Turkish or Moroccan background who need care generally prefer to be cared for by their family. Sometimes, however, this burden is too much for the mainly female family carers (De Graaff and Francke 2003, Van den Brink 2003). Moreover, professionals often have difficulty defining the care needs of immigrant groups; the sometimes laborious communication and decision-making between care providers and their patients and relatives is perceived as an obstacle to good care (De Graaff and Francke 2009). In addition, it is known that a relatively large number of patients from a Turkish or Moroccan background die in hospital rather than at home (Buiting *et al.* 2008). To gain information which can be used to improve communication in the palliative care for these immigrant patients, we studied all relevant perspectives on the mutual communication of cancer patients: the perspectives of Dutch professional care providers, of Turkish and Moroccan patients and of their relatives. Obviously, problems in communication and decision-making about care between migrants and local care providers are a wide spread phenomenon in today's multicultural world. This Dutch case study will also shed light on obstacles and policies in other countries.

## Conceptual framework

The concept of 'therapy management group' seems particularly apt to analyse the complexities of communication and decision-making about care for sick people because it makes visible the diversity of tasks and interests among those involved in care activities. The concept was introduced by the anthropologist Janzen (1978) in a study on health seeking behaviour in the African Democratic Republic of Congo. He observed that treatment decisions were not only made by the medical practitioner and the patient but also by a group of relatives of the patient. The therapy management group functioned as a broker between patient and practitioner.

Janzen (1987) later elaborated the concept, stating that therapy management in both Africa and in Western societies is a process that involves diagnosis and negotiation of illness identities, the selection and evaluation of therapeutic options and the lending of support to the patient. Comparing cases in Zaire and Quebec, he wrote that in both contexts 'it became clear that consensus within the group surrounding the patient was required for a decision to be reached and action to occur' (p. 75). 'Therapy management' offers a 'contextually sensitive framework

within which to test hypothesis concerning medical decision making' (p. 80). Interestingly, he pointed out that a care management group may also include professionals: referring to a case study of an American Leukemia treatment centre he pointed to 'the utility of including healers within the therapy management group, even in societies with a highly professionalized and technologically sophisticated medical institution' (Janzen 1987, p. 82). We will return to this extension of the therapy management group later on in this article.

Nichter (2002), Bossart (2003) and others demonstrate that a focus on the therapy management group illuminates the logic of patient behaviour more clearly than an approach that focuses only on the individual. Janzen's concept, therefore, can also be applied to treatment and care decisions in the 'Western' world and seems particularly useful in reflecting on communication and decision-making in palliative care in immigrant groups. Indeed, the heteronomy of the migrant patient seems to conflict sharply with the western ideal of patient autonomy. Janzen's concept, here renamed 'care management group' will be used as the key analytic tool to unravel the complexities of communication and decision-making during palliative care in Turkish and Moroccan families.

Turkish and Moroccan families generally trust the Dutch medical system as long as cure is pursued, but become more critical when palliative care is offered. We found that there was often little cognitive consensus on 'good care' in this stage. The main concerns about 'good care' expressed by Turkish and Moroccan families included the following: maximum treatment and curative care until the end of life, never giving up hope, devoted care by the family, avoiding 'shameful' situations and dying with a clear mind. Their views conflicted with those of professional care providers who emphasised comfort care, quality of life and advanced care planning, including discussing the diagnosis and prognosis with the patient (De Graaff *et al.* 2010a, b).

Turkish and Moroccan patients and their relatives do not generally distinguish between palliative and curative care. In addition, they often have a strong preference for hospital care, while Dutch care providers regard the patient's own home as the best place for patients in the terminal phase. Furthermore, family members want to 'protect' their seriously ill relative and often expect care professionals to communicate with the family, instead of directly with the patient. This may be at odds with the professionals' principle that informed consent should be obtained directly from the patients.

Yet these differing ethnic-cultural views did not always lead to unbridgeable problems. We therefore analysed the material using the concept of 'care management group', in order to see to what extent problems in decision-making concerning palliative care were related to communication *with* and *within* the family and the wider environment of the patient.

The questions addressed in this article are:

- (1) To what extent are communication and decision-making in palliative care among Turkish and Moroccan patients influenced by differences in styles of care management between Turkish and Moroccan families and Dutch professional care providers?
- (2) What other factors hamper decision-making on palliative care for Turkish and Moroccan patients?

'*Turkish or Moroccan people*' in this article refers to all residents of the Netherlands who have at least one parent born in Turkey or Morocco, as this criterion is a useful indicator of ethnicity in the Netherlands (Stronks *et al.* 2009). We chose to study Turkish and Moroccan immigrants because they have experienced a similar process of socialisation in the Netherlands due to their arrival between 1970 and 1980 as immigrant workers or, later, as relatives of those workers. Although in the Netherlands the Turkish population is relatively older than the Moroccan, both groups are approaching ages when end-of-life care may be more likely. Recent studies showed that Moroccans (aged 18 and older) make significantly less use of home care than Dutch adults and that the Turks rated their health worse than Moroccans or Dutch adults (Devillé *et al.* 2006). But patterns of utilisation of healthcare facilities were also found to be dependent on the general practitioner (GP) (Uiters *et al.* 2006) and on the immigrant patients' mastery of the Dutch language (Denktaş *et al.* 2009).

'*Decision-making*' is understood in this article to mean the process whereby choices can be made between various forms of care or treatment. The term *joint* decision-making is used when those involved keep one another informed and take into account each other's preferences, needs, activities and plans.

'*Communication*' refers to the exchange of ideas and information between two or more parties. In this case, we refer to care providers, patients and their relatives on subjects relating to the disease, its care and treatment.

## Methods

The research was formally approved by the Medical Ethical Committee of Zuidwest Holland (nr 07-113, 2008) and by the ethical committees of the hospitals involved. A qualitative research design was chosen to reach an in-depth understanding of the intricacies of (mis)communication and the personal views and experiences of all subjects involved in care (Abbott 2004, Reis *et al.* 2007). Thanks to private and professional experiences, the first author could empathise with both immigrants and professional care providers, which is a crucial advantage for qualitative fieldwork (Reis 2010).

She carried out semi-structured in-depth interviews with 83 people (6 patients, 30 relatives and 47 care providers) and recorded the interviews on tape. We used a convenience sample. Professional care providers were recruited at regional network meetings on palliative care in the Netherlands while Turkish and Moroccan patients were selected through their care providers. The main inclusion criterion for the care providers was that they had actual experience in intercultural palliative care, i.e., that they were personally involved in the care or treatment of a Turkish or Moroccan patient with an inoperable primary carcinoma or metastasized incurable cancer. We tried to interview all patients, but due to their health situation we often had to rely on the information of their relatives. The main inclusion criterion for these family members was that they were personally involved in the care of their patient. Although we hoped to interview both female and male relatives, we noted that in most cases the care was given only by women. Agreement from patients and their relatives to participate in the study was recorded on tape. A professional interpreter was used in four interviews; relatives acted as interpreters in four other interviews. Translation by professional interpreters is strongly recommendable in medical practice as well as in medical research (Bot 2005, Seeleman *et al.* 2008, Hoopman 2009). In our study we

were not only challenged by translation of patients' statements in terms of linguistic 'correctness', but also by culturally diverging views on 'good' communication regarding the end of life. But the first author is quite sensitive to these diverging views, since she has been working with Turkish and Moroccan people for years in the Netherlands as well as in their home countries and understands Moroccan Arabic. In addition, her age (55+), own experiences with incurable ill relatives and her readiness to invest enough time in the interviews were helpful. In two cases she visited the family twice to get a full report. In the other cases one interview was sufficient.

The list of interview topics included questions about the patient's background, illness, relatives, tasks and contributions of the professionals involved, how decisions were made during the palliative phase and how the interviewees rated treatments and care as well as communication between patient/family/care providers. We stopped recruiting new interviewees after we had obtained theoretical saturation (Glaser and Strauss 1966) on their diverging perceptions on 'good care' and 'good communication'.

We conducted interviews with 83 people (6 patients, 30 relatives and 47 professional caregivers) involved in 33 cases of incurably ill cancer patients. As Table 1 shows, nine patients had lung/bronchial cancer, seven had cancer of the bowel, bladder, or stomach, six had breast cancer, three had a brain tumour, one mesothelioma, one bone cancer and one ovarian cancer. More cases of male than female patients were studied, which is congruent with the demographic situation; of the 10,000 people who died in the Netherlands between 2002 and 2006, 19 were Turkish men and 13 were Turkish women; 15 were Moroccan men and 13 were Moroccan women (Garssen and Van der Meulen 2008). The age of the patients in our study ranged from younger than 20 years (one patient), 30–39 (13 patients), 40–59 (14 patients) and 60–79 (11 patients) to older than 80 (two patients). Distribution over the Netherlands was as follows: 17 patients lived in big cities in the western or middle part of the country (Amsterdam, Rotterdam, The Hague, Utrecht); the others lived in small towns or villages often situated in the eastern or the southern part of the country. Seven patients had died in hospital, 2 in a hospice, 17 at home, 3 in Turkey and 4 were still alive at the time we completed collecting the data. In addition we interviewed 5 male and 25 female family members, as well as 47 care providers. Of the care providers, 19 were nurses, 17 were general practitioners, 5 were medical specialists, 4 were social workers and 2 were pastoral workers.

We asked the same questions to patients, relatives and care providers. Firstly we asked relevant background information. Secondly we asked how the first encounter was perceived and what care decisions had been made since. Finally we asked to evaluate the perceived communication about each decision. Informants narrated how they perceived the process and their own contribution in the decision-making, for example about bad news telling, shifting from curative to palliative care, continuing or abstaining medical treatment, use of alternative care provisions and communication conflicts.

The typed texts from the interviews were analysed in multiple ways. The first author analysed all interviews, while the second analysed the interviews of the first 13 cases and one-third of the remaining 20 cases. After reading and re-reading an interview, they independently wrote a short memo describing the most striking and informative findings in relation to the research questions. They subsequently compared their memos to discuss similarities and differences in the analysis.

Table 1. Characteristics of the cases.

Case number	Background	Illness	Patient interviewed	Family interviewed	Professionals interviewed	Case characterised as
1	Tu <sup>a</sup>	Mesothelioma	–	Daughter	GP	Joint decision-making
2	Mo <sup>b</sup>	Bladder cancer	–	–	GP	Joint decision-Making
3	Tu	Stomach cancer	–	–	GP	No agreement between family and care providers
4	Mo	Bronchial cancer	Patient	Wife Brother-in-law	Pain specialist Nurse Home care nurse GP	Joint decision-making
5	Tu	Breast cancer	Patient	–	Social worker	Joint decision-making
6	Mo	Lung cancer	–	Wife	GP	Miscommunication within the family
7	Tu	Lung cancer	–	–	Pastoral worker	Miscommunication within the family
8	Mo	Stomach cancer	–	Wife	GP Social worker	Joint decision-making
9	Tu	Brain tumour	–	–	Nurse GP	Miscommunication within the family
10	Tu	Lung cancer	–	–	Oncology nurse	Miscommunication within the family
11	Mo	Breast cancer	–	–	Oncology nurse	No agreement between family and care providers
12	Tu	Stomach cancer	–	–	Hospital nurse	Miscommunication within the family
13	Tu	Breast cancer	Patient	–	Social worker	Joint decision-making
14	Mo	Brain tumour	Patient	Mother Two sisters Brother	GP Oncologist Pastoral worker	Joint decision-making
15	Mo	Lung cancer	–	Daughter	GP	Miscommunication among professionals
16	Mo	Breast cancer	–	Daughter	GP	Miscommunication among professionals

Table 1 (Continued)

Case number	Background	Illness	Patient interviewed	Family interviewed	Professionals interviewed	Case characterised as
17	Tu	Bowel cancer	–	Wife son	Oncology nurse	No agreement between family and care providers
18	Mo	Stomach cancer	–	Sister	Home care nurse	Joint decision-making
19	Mo	Bowel cancer	–	Daughter	–	No agreement between family and care providers
20	Tu	Stomach cancer	Patient	Daughter	Hospital nurse	No agreement between family and care providers
21	Mo	Lung cancer	–	Daughter	Social worker Oncologist Pain specialist Transfer nurse	Miscommunication among professionals
22	Tu	Bone cancer	–	–	GP Home care nurse	Joint decision-making
23	Tu	lung cancer	–	–	Home care nurse	Miscommunication within the family
24	Tu	Lung cancer	–	Wife Son daughter	GP	Miscommunication among professionals
25	Mo	Bowel cancer	–	wife	GP	Miscommunication among professionals
26	Tu	Lung cancer	–	Wife daughter	GP	No agreement between family and care providers
27	Mo	Stomach cancer	–	Daughter	GP Home care nurse	Miscommunication among professionals
28	Mo	Brain tumour	–	Daughter	GP	Joint decision-making
29	Mo	Bowel cancer	–	Husband sister-in-law	Medical specialist	Miscommunication within the family
30	Tu	Bowel cancer	–	–	Oncology nurse	Miscommunication within the family

Table 1 (Continued)

Case number	Background	Illness	Patient interviewed	Family interviewed	Professionals interviewed	Case characterised as
31	Mo	Ovarian cancer	Patient	Daughter	Specialist Oncology nurse home care nurse GP wound nurse	Joint decision-making
32	Mo	Breast cancer	–	Sister	–	No agreement between family and care providers
33	Mo	Breast cancer	–	Daughter	Nurse Home care nurse	Joint decision-making

<sup>a</sup>Tu = Turkish patient.<sup>b</sup>Mo = Moroccan patient.



In addition, the first author systematically coded all interviews, supported by the computer programme MaxQda. Some codes referred to perceptions of ‘good care’ (e.g., keeping patients’ hope alive, or keeping patients well informed), some codes referred to perceptions of ‘good communication’ (e.g., perceptions of formal or informal interpreters). But we also distinguished codes referring to different contextual factors (e.g., who takes the initiative, topics (not) to be discussed, feelings of exclusion/exclusion, opinions about whom and when). We synthesised the findings in different ways. The analyses of congruent and divergent perceptions of ‘good care’ and ‘good communication’ according to care providers and patients and their families are presented elsewhere (De Graaff *et al.* 2010a). But we also compared the data at case-level and found that the perceptions and actions of all involved were vital for the functioning of the care management groups.

Interim and final analyses were discussed intensively with the other authors and with the members of the steering committee, consisting of both scientific experts and care professionals in the field of palliative care. In addition, the results were discussed with over 200 representatives of Turkish and Moroccan communities in the Netherlands in a total of 18 group sessions, to verify and disseminate the findings. The discussions of these implementation meetings have been recorded and transcribed. Meetings usually comprised four elements: presentation of the findings by the researcher, followed by reactions and questions of Turkish and Moroccan participants and finally suggestions and advice by participants to professionals and fellow patients and relatives in their community (De Graaff *et al.* 2010a, b).

## Results

The decision-making process in the 33 cases varied. Communication was shown to be hampered by several factors. The earlier presented difference between Turkish and Moroccan immigrants’ care values and those of Dutch care providers, would, at first glance, appear to be the major source of miscommunication in seven cases. However, we will demonstrate that this kind of miscommunication, for example in the situation of Mrs Said (pseudonym), is also rooted in the Dutch care providers’ denial of the existence of the care management group around the patient.

In other cases we observed that decision-making was mainly hampered by communication problems within the family. In the words of Janzen, the care management group did not function effectively. In eight cases, we discovered that the family could not reach *social and cognitive consensus* on the care management, which resulted in *distrust* on the part of the patient and relatives of the proposals of care providers. The patient did not feel supported by his/her family and ‘new’ relatives overruled decisions of other relatives. The result was partial consensus in the care management group and fragmented care for the patient. An example is presented by the case of Mr Osman.

Further analyses showed that care decisions not only postulated consensus between patient and relatives but also among the Dutch care providers. We found six cases where the lack of joint decision-making was clearly related to poor communication among professionals. One of these – the case of the Nur family (a pseudonym) – is presented and discussed.

We concluded that joint decision-making by all participants took place in 12 cases. The case of Mr Sahin is presented as an example.

These four illustrative cases strongly suggest that joint decision-making can only be realised if the care management group of patient and relatives functions well and is accepted as indispensable for decision-making in palliative care. The findings also show that the concept of care management group helps to trace yet another factor in the decision-making process, namely the dynamics in the group of professionals. Although an interdisciplinary approach forms the core of palliative care, full cooperation between specialists, GPs, nurses and other professionals is not always achieved.

***Communication problems and lack of joint decision-making between relatives and professional care providers***

Seven cases revealed communication problems between relatives and professional care providers, related to differing cultural views on 'good care'. Two families chose to go back to their country of origin; the relatives in five families decided that the care of the patient was a family matter and they only called on the Dutch care providers for help with technical medical matters. The care providers involved felt that they had no access to the family and were unable to make meaningful contact with the patient. As a consequence, decisions were made either by the care providers or the relatives, with no explicit agreement between the two parties. A typical example was the case of a Moroccan patient with breast cancer, Mrs Said.

Mrs Said was just over 40 years when she became ill. She had lived in Northern Morocco with her parents till the age of 36 and during that time she had cared for several elderly people until they died. When her uncle's first wife died, she married him and came to the Netherlands to look after him and his teenage sons; his daughters had already left home. She was extremely happy when she became pregnant. But immediately after the birth, she began to suffer pain in one of her breasts, which turned out to be caused by breast cancer. She underwent surgery and chemotherapy. As Mrs Said did not speak Dutch, her husband went with her to the hospital, where she was usually helped by an oncology nurse named Dionne, who had extensive experience with palliative care. The language barrier with Mrs Said was difficult for Dionne, although Mr Said was prepared to interpret. Dionne found Mr Said's behaviour frustrating as in her opinion he not only acted as an interpreter but also as the patient's spokesperson.

What I remember was that the husband did the talking. I did not really have any contact with her [the patient]. She did not understand his explanation about chemo. Oh, the husband came on his own once for information. His wife would go bald and the husband decided for her, she did not need a wig, she could wear a headscarf. They did not want an interpreter. The husband decided that, too, of course. [Nurse]

Mrs Said was given palliative chemotherapy, as there was no possibility of cure. The family refused to translate the bad news to her. The medical specialist decided that a discussion should be organised, under his direction, attended by the whole family and a professional interpreter. Dionne appreciated the specialist's approach to the problem. Thanks to his (unilateral) decision, the family was forced to inform Mrs Said of her prognosis.

During the discussion, the medical specialist indicated that her life expectation would be very short; that she would die of the disease and what the problems were that might occur. He also asked her: “tell me what is the matter, what do you know about it?” She had to tell him in her own words. Then she said that she knew that she could not be cured. She was worried about the future of her daughter. [nursing file]

After the talk with the medical specialist the family wanted to return to Morocco, but this proved to be medically and financially impossible. The choice then became either home or a hospice. The family preferred to care for her at home, but soon ran into problems. Mrs Said vomited frequently and, because of brain metastasis, thrashed about with her arms and legs. Her stepchildren could not cope with her seizures. The family did not want professional home care because they were afraid that it would be expensive and difficult to afford.

They had heard from other people who had had help in the house that, afterwards, they had had to pay a lot of money. That was why they could not accept any help. [nursing file]

Nevertheless, Dionne arranged for home care during the night and morning. The seizure medication was adjusted. With the help of a financial fund, Mrs Said's sister was brought from Morocco to help tend to her during the last phase of her illness. The family was happy with her coming to the Netherlands, but not with the fact that they had been left out of the arrangements. They felt that things had been taken out of their hands, even family matters. During her last few months, Mrs Said was well cared for at home, although coordinating family and professional care remained a problem. Misunderstandings occurred and both sides failed to live up to each other's expectations. Looking back on her part in the care arrangements, Dionne described the situation as 'difficult'. The family actually gave Mrs Said good care, but Dionne was sceptical about the part she had played. She often found that it is hard to decide when to leave decisions to the patient and the family, and frequently felt ignored because the family only half-heartedly supported her decisions and actions.

Very little joint decision-making actually took place in this case. There was a language barrier and professional care providers and relatives disagreed on what constituted 'good care' and 'proper communication'. The efforts of the nurse to arrange a care allowance were appreciated by the family, but her attempts to arrange for home care providers and – later – a bed in a hospice seemed to fly into the face of the family. The professional care providers considered it unacceptable that the husband spoke for his wife, and they ignored the family's request not to inform the patient about her approaching death. In short, the professionals did not accept the family as a 'care management group' in search of appropriate care. In other cases, joint decision-making seems to have been hindered by a similar entanglement of factors.

### ***Communication problems within the family with negative effects on decision-making***

In eight of the 33 cases studied, communication within the family halted, which led to problems in joint decision-making with the professional care providers. In the eyes of both the professional care providers and the relatives, male patients were often (in five cases) considered to be 'difficult', provoking clashes with the women in the family. After arguments at home, the men wanted to be admitted to the hospital, and after

arguments in the hospital, they were sent home again. Sometimes the relationship between the patient and the doctor was reasonable, while the rest of the family was excluded. A typical example was Mr Osman.

Mr Osman was 45 years old when he was diagnosed with colon cancer while on holiday in Turkey. The cancer had already spread to the peritoneum, news which came as a great shock. Mr Osman was angry with the general practitioner who had refused to send him to the hospital in the months before his holidays. For this reason, Mr Osman only wanted to be treated by a medical specialist. His specialist had respect for Mr Osman, who spoke fluent Dutch. During the first consultation, he assessed Mr Osman's expectations and made it clear that he recommended palliative treatment. He spoke directly to Mr Osman. At times Osman's wife attempted to speak to the specialist alone, but he ignored her; in his view, the patient should be the one in control. Unlike the specialist, the nurses found dealing with Mr Osman difficult. It seemed he did not want to have any contact with them. They saw him as an intelligent, but grumpy and moody person, not just towards them but also towards his wife. Mrs Osman had a hard time. Her mother-in-law came over to help her care for her sick husband, but the women had different ideas on how this should be done. The older children were aware that their father was ill, but not how serious it was; they could feel the tension as the situation slipped out of control. Mr Osman was annoyed at his wife and his children and preferred to be in the hospital.

The couple cannot talk to one another about their situation. He said, literally, that he had his own worries and that she must solve hers. Of course, that made her very unhappy. He is frustrated with the general practitioner who let him go on for seven months without referring him for an examination and he is not satisfied with the medical care in the hospital. He seems to be completely unable to cope with his illness. It has been suggested that social workers should be called in, but the patient will only talk to the specialist. [nursing file]

After he had been transferred home, Mr Osman kept all contact with the general practitioner and home care services to a minimum. He felt that his wife and mother should take care of him. Mrs Osman called the home care provider and the general practitioner a number of times because she could not cope with the situation. The home care provider and the general practitioner arranged for a meeting between Mr and Mrs Osman, but the agreements they made failed to be honoured.

It was a very complex situation, in my opinion. I have the idea that, because they could not deal with it together, they could not talk about it either. And that the mother was a determining factor here. Mrs. Osman did not have a place in her house for herself. Her husband could not stand the smell of cooking, so she set up a stove in the shed and ate there with the children. There were two parallel worlds without connection between them. His mother went round with a grim expression on her face. He said: "what I need is positive people around me, but my mother's not like that and I do not like it". [District nurse]

The medical specialist was vaguely aware that there were problems at home, but did not think that he was the right person to address these issues. He did help Mr Osman visit his father in Turkey by arranging for a transfer nurse to organise the necessary medical equipment in the aircraft. But what the specialist saw as a simple organisational procedure was a source of annoyance to the nurses, as Mr Osman would not accept

their role in his care. When, for example, the nurses asked him to complete the necessary papers for his insurance, he refused. Mr Osman finally died in the hospital, withdrawn, angry and alone.

The case shows how dissension within the family can negatively impact on joint decision-making; the broker's function of the care management group fails because of internal conflicts. The contact between the patient and the specialist was good; they respected one another. The specialist treated the patient as someone able to make autonomous decisions, but he confined himself to the medical treatment and had no insight into the nursing care on the ward or at home. The patient was unable to direct his own care, and the result was inadequate care and a shuttling between home and hospital.

Other cases with male patients showed a similar failure of communication within the family. Because of these domestic problems, there was no joint decision-making between patient, relatives and care providers, resulting in inadequate care.

***Lack of communication among care providers with negative effects on joint decision-making by care providers, relatives and patients***

Six of the 33 cases demonstrated good communication between the family and a central professional care provider, usually the general practitioner. They were able to reach agreement on what kind of care was necessary or how to communicate with the patient about the incurable nature of his or her cancer. But this did not always lead to joint decision-making and satisfactory care arrangements, since numerous professional care providers were involved in the patient's care (e.g., GP, home care, specialists and emergency personnel) as the family continued to seek curative treatment. The communication between the multiple care providers was problematic; a typical example of this variant was the care provided for the Nurs, a Moroccan family.

Mrs Nur was approximately 50 years old when she became ill. When her grandson accidentally kicked her and her wound ripped open, she went to the hospital with her daughter Nadia. Dr Maarsen had known Mrs Nur for 20 years, so when he heard that she had cancer, he immediately contacted the family and the hospital. However, he consistently received information from her oncologist about her treatment too late; thus he was unable to co-ordinate his own care for Mrs Nur with the care she received during her hospitalisations.

Every time she came home after a session of chemo, I went to see her. At first, she kept getting infections, because the chemo affected her resistance. So she had a bladder infection, she had a throat infection, she had nosebleeds. Communication with the hospital was rather poor; they treated her and sent her home. I rang the oncologist and only then did I receive a detailed letter with apologies, saying sorry that it had not been done before and telling me what had happened and what the effects of all the treatments were. [General practitioner]

Dr Maarsen was also not satisfied with Mrs Nur's home care. The home care organisation could not arrange for a team of regular care providers and instead sent a different person every time. The wound in her breast frightened the home care providers and they had no authority in the family. The home care organisation subsequently offered a contract for the daily care of Mrs Nur to her daughter Nadia. Nadia cared for her mother with love, but had no professional experience and,

according to the general practitioner, was unable to accurately assess when extra help was necessary. Nadia appeared not to realise that her family was being paid for the care provided by her to her mother, remarking that the home care provider did not come very often.

I've got my jobs, I do the nursing and care, I go to school and my work and then I prepare the food. I would have liked someone to help me. Just to get her out of bed so she can walk a bit, she does not see anything but the four walls of her room. But I cannot ask the home care people to do that. They do come and take her blood pressure, her temperature and so on. I look after the wound, I wash her. I do everything for her. I cannot do anything more.  
[Daughter]

In addition, Nadia maintained contact with the hospital and, although an interpreter's telephone line had been arranged, Nadia acted as interpreter for her mother. She preferred this strategy because she thought that she would be better able to pass on the medical reports than a stranger. However, Nadia found it difficult to interpret the information given by the various doctors at the hospital. Moreover, that information did not always correspond with the information from the last phone call. Nadia therefore went to Dr Maarsen, who asked the various specialists for more detailed information, in order to be able to explain to Nadia and her mother what was going on.

In the hospital they often only think from a hospital point of view and forget that the care has to go on back home. I see that as a bad thing. And so does the head of the department, apparently, because he apologized. I organized a family discussion. They knew that Mother had cancer but were hoping for a miracle. That the chemo was working and that it would all be all right again. And then they said that they wanted to go to Morocco after the chemo to see a traditional healer. I said that I would help them to do this. There was no opportunity at that moment to say what the prognosis really was. [General practitioner]

In retrospect, Dr Maarsen believes he was powerless. The medical specialists failed to inform him regularly and the home care organisation had a far too commercial outlook. He felt Nadia was overburdened, but he was unable to do anything about it from his position. Finally, Mrs Nur died in the hospital.

This case would appear to be a good example of lack of communication and joint decision-making among care providers. The general practitioner is the central point of contact for the patient and the family. Language problems are solved by the daughter who speaks fluent Dutch. She is well able to communicate her mother's care needs and to ask for whatever information she requires as a relative. The contact between the patient, her daughter and the general practitioner is excellent; nevertheless, there is no pattern of joint decision-making due to a chaotic situation around care activities. Other, similar cases also show a lack of joint decision-making caused by communication problems among the many care providers involved in the case, resulting in both family and care providers being dissatisfied with the care.

### ***Joint decision-making between all parties and adequate strategies for dealing with communication problems***

In 12 of the 33 cases explored, some form of joint decision-making occurred. In these cases, the family was often able to count on the help of a daughter with

organisational skills, who was able to establish a working relationship with the general practitioner, an active home care provider or both. A typical example of agreement between all those involved was Mr Sahin, a man with a Turkish background.

Mr Sahin was nearly 60 years old when he became ill. His wife and daughter insisted that he consult the general practitioner. Dr Willems was an experienced general practitioner with many immigrants in his practice. He had known the Sahin family for a long time and was impressed by the patient and his ability to remain calm in spite of his serious illness. At the request of the family, Mr Sahin's approaching death was never explicitly discussed with him. Dr Willems' years of experience with Turkish immigrants had taught him that, although no one actually said out loud that there was no hope, generally speaking everyone nonetheless understood perfectly well what the situation was, but attempted to spare one another. He would never give people false hope, but in his view, if someone can bear only a certain amount of truth, they need know no more. According to Dr Willems, the message should be tailored to the recipient, and bad news be delivered in small doses and in phases.

You start with talking about possibilities. In this way, you can prepare people for the fact that the cancer can indeed spread. If they know that, you can also tell them that it is obvious that chemo is pointless. This is not something which you can do all at once; it is something which you grow towards. The discussion was through the children; they spoke good Dutch, were all well-educated and communicated well with one another.  
[General practitioner]

At first, Mr Sahin's care was mainly organised by the hospital. When his daughter heard the diagnosis, she asked a second opinion. She wanted to go with her parents to Turkey to visit several hospitals there. After their return to the Netherlands, an exploratory operation was performed and the tumour proved to be malignant. Mr Sahin's sole option was radiotherapy to slow down the disease process. From then on, he was cared for at home by his wife, daughters and sons. Dr Willems found the children to be very caring, but noticed that at times, they were at cross purposes. He suggested that they write down in an exercise book everything they did and the medicines they gave. Dr Willems was the central figure, in whom the family trusted. He wrote letters for the housing association and for the doctors in Turkey, was on good terms with the lung specialist at the hospital and knew the family relationships. The bond of trust appeared crucial to the family accepting the news that the chemotherapy was no longer effective.

Then they told us (in the hospital): there's nothing more we can do. It's a question of time, painkillers, but there's no chance of a cure. They gave him the best painkillers, but that did not help, he was still in pain. But we could always go for help to Dr. Willems.  
[Daughter]

Our data contained other cases where patients, relatives and care providers made joint decisions: communication problems between the central professional care provider and the main family representative were solved, and views on care and the wishes of those involved with regard to dialogue were articulated and honoured. In such cases, the family spokesperson consulted with the other family members, and

the central professional care provider maintained contact with the family representative and any other professionals involved. Questions and problems were addressed during various discussions and solutions were reached, increasing both the trust and the self-confidence of everyone involved.

## Discussion

The 33 cases in this study show that the experiences of Turkish and Moroccan patients, their relatives and their professional care providers differ considerably with regard to communication and decision-making. Four different variants were identified: no agreement between family and care providers; communication problems within the family; lack of satisfactory communication and agreement among the professional care providers; and good communication both within the family and with the care providers satisfying all parties. These four 'typologies' of communication and decision-making should not be regarded as a static classification, however. They are snapshots, 'stills' from the ongoing 'film' that is the hallmark of decision-making. The authors looked for ethnic-cultural and other factors in these 33 'films' that could explain the variants in the area of communication and decision-making.

The cases that we presented showed that problems in communication and decision-making were intertwined with, but not limited to, ethnic-cultural differences between the Moroccan/Turkish families and the Dutch professionals; internal conflicts within families as well as professional teams and gender issues were also responsible for problems in mutual understanding and decision-making around palliative care. The crux of our in-depth analysis of these multicultural communication and decision-making patterns is that the complexity of these encounters can only be understood if we look at processes of interaction and social relationships (De Graaff and Francke 2009). The concept of 'care management group', derived from Janzen (1978, 1987), enabled us to grasp these processes more effectively. The concept rejects the assumption that treatment is the outcome of a simple one-to-one communication between an autonomous patient and an all-knowing professional. It emphasises the 'broker' role of the patient's social environment and it relativises the control of professionals over treatment (and care) decisions. Janzen writes:

The control of therapeutic knowledge and resources. . . is often assessed in terms of 'lay' versus 'professional' realms of discourse and understanding, or in terms of the 'doctor-patient' relationship. However, there are many examples of medical decision making, even in highly technical care, where information and crucial symbols are embedded in a total constellation of social relationships that is dominated neither by professionals nor by laity. A focus on therapy management yields understanding of the dynamic qualities of this negotiation, rather than type-casting knowledge and information control as 'lay' or 'professional'. (Janzen 1987, p. 81)

An important feature of the dynamics in these interactions is indeed that they challenge the principle of autonomy, not only for patients, but also for professionals. As early as 1980, Fox described the uncertainty of doctors in making therapeutic decisions. Recent studies that focus on negotiations between professionals and 'lay' persons underscore this. Vermeulen (2001, 2004) studied decision-making about the treatment of extremely premature children in two neonatal intensive care units



(Belgium and the Netherlands). In these situations, professionals and parents alike are uncertain about the child's future, if it is kept alive. Medical success (keeping the child alive) may lead to deep suffering for parents and child. Weighing medical, social and emotional considerations takes place in intense deliberation between parents, nurses and doctors. In fact, doctors hand over much of their responsibility to the parents. Rightly, because, as Vermeulen (2004, p. 2083) remarks, '... the decisions are primarily social, not medical'. Similar examples of shared social-medical decision-making can be found in a study about in vitro fertilisation (IVF) in a Dutch fertility clinic (Gerrits 2008) and in Kaufman's (2005) account of dying in three American hospitals. Death, which used to be a natural part of human life, has become a technical event that one must choose or not choose. Most people in Kaufman's study prefer not to choose death, a decision that is often reached after protracted and difficult meetings between patient, relatives and doctor. Gerrits' research in the fertility clinic raises the question of what makes couples with fertility problems so persistent in their use of IVF treatment. Again, these decisions are the outcome of exhaustive encounters between 'lay' people and professionals. In all three studies, the limitations of professional medical knowledge are highlighted, with 'lay' people emerging as experts in their own (social) field. If such a shift in recognition of expertise and need of communication is noticed in institutional (curative) medicine, how much more will – or should – this be recognised in situations of home-based care, as described in our study?

In other words, the increasing amount of negotiation between professionals and patients/relatives in matters of treatment and care would seem to indicate a trend that is particularly relevant in palliative care, where social and cultural concerns are likely to outweigh the medical ones. Professionals should take this into consideration and pay more attention to the social and cultural competence of those most directly involved in daily care activities. It is not surprising, however, that the communication between Dutch healthcare professionals on the one hand, and patients and the relatives of patients from a different ethnic background on the other, can break down entirely. Professionals underestimate the usefulness of ideas and styles of caring that seem to clash with *their* (cultural) biomedical protocols. Conversely, immigrants tend to distrust or outright reject Dutch culture in the field of medicine. These obstacles became clear in the 33 cases that were followed in our study: only 12 cases showed true communication and shared discussion making between doctors and their patients plus relatives. In 14 cases, overall communication halted because of disagreement or lack of mutual consultation within either the professional group or the family. We may therefore conclude that most problems in communication and joint decision-making derived from 'normal' group dynamics that are not necessarily culture related.

Joint decision-making was only possible when relatives were able to reach agreement among themselves and with the patient, and if the care providers were prepared to recognise the family as a 'care management group'. Medical decisions are often the outcome of arduous discussions, not only within the close family but also among professionals.

One limitation of the study is that in 7 of the 33 cases, the information provided is derived solely from professionals. However, in the remaining 26 cases, we were able to gather the views of both family members and professionals.

Another limitation is the lack of a comparison group of Dutch patients. However, previous research suggests that the presented findings are not unique to these immigrant groups. Until a few decades ago, it was also common in Western cultures not to talk openly about approaching death (Glaser and Strauss 1966, Elias 1985, Wouters 1990). It should be noted further that today some native Dutch patients may also refuse to face death until the very end (The 2002, Francke and Willems 2005). However, the unwillingness to speak openly about poor prognoses tends to occur more frequently among people from a Turkish or Moroccan background than among non-immigrants. The same trend can be observed among other ethnic minorities in other European countries (Bullock 2006, Balboni *et al.* 2007, Braun *et al.* 2007, Cartwright *et al.* 2007, Brunnhuber *et al.* 2008, Phelps *et al.* 2009).

All the same, we have to realise that the prominent role played by family members in communication and decision-making is not specific to Turkish and Moroccan families, Dutch families, too – albeit less frequently – may be deeply involved in decision-making and actual caring for terminally sick family members (De Boer *et al.* 2009, Tonkens *et al.* 2009).

This study not only calls for more sensitivity to the care beliefs and demands of ethnic minorities; it also nuances the use of ‘ethnicity’ in health care and health policy. It contributes to the ongoing debates on culture and care that started in the mid-1950s with the introduction of the concept of transcultural nursing (Leininger 2002), which urged nurses to uncover factors influencing care, such as religion, politics, economics, cultural values, history, language, gender and the like.

Acknowledging such multiple influences is, however, not enough to guarantee the delivery of culturally congruent care. According to Gutnaram (2007), too much attention is given to acquiring information on the beliefs and rituals of different cultural and religious groups. Relying on a standard knowledge of cultures carries the risk of stereotyping. Gutnaram advocated the development of cultural competency, through which care providers acquire cultural sensitivity, leading to empathy and the establishment of a partnership relationship between patient and care provider. Partnership can only be built if minorities are empowered and care providers belonging to the cultural majority evaluate their service delivery in a critical way. Williams (1999) and others emphasised the need for cultural safety in care: care should be embedded in a social environment which is safe for people, where there is no assault, challenge or denial of their identity (Van Dijk 1998). Although the need for cultural competence of care providers and cultural safety for minority patients is well accepted in many Western countries, to acquire equal access for equal needs, the concepts do not indicate how and when the right balance between attitudes, knowledge and skills can be achieved (Stronks *et al.* 2001). A practical framework was therefore developed, transforming the general requirements mentioned by Leininger, Gutnaram and Williams into measurable clinical terms, such as a knowledge of epidemiology and the differential effects of treatment in various ethnic groups, awareness of how culture shapes individual behaviour, social contexts and one’s own prejudices, and skills to transfer information and adapt to new situations (Seeleman *et al.* 2009).

Our study contributes to this debate in several respects. Firstly, it is important in our opinion for this debate to be rooted in practice, and hence our descriptions of actual encounters between Dutch care providers and Turkish and Moroccan palliative care patients and their relatives. Secondly, we argue that the interference

of, on the one hand, culturally diverging values and, on the other hand, the complexity of the care management in non-connected groups logically lead to a lack of consensus in decision-making. Thirdly, our study has pointed out that concepts like 'culture' and 'ethnicity' should not be taken as static and essentialist attributes of people. For too long these two terms have been employed as stereotypical 'excuses' for failing health care among migrants (Van Dijk 1998). Different ideas and values which migrants had brought along in their 'baggage' were blamed for miscommunication and other problems. Our study has shown that that we need a more dynamic perspective on ethnicity and culture and more focus on social, political and economic factors to understand when and why communication between Dutch health care providers and Turkish/Moroccan patients and families succeeds or fails. This relativisation of ethnicity refers both to the growing diversity within ethnic groups (cf. Pickett 2010) and to the overall position of migrants in Dutch society. Paradoxically, migrants stand apart more as a mirror of social interaction patterns than as cultural or ethnic groups. Using the analytical concept of the care management group reveals the influence of characteristics like gender, social class, and communication skills of patients, relatives, and professionals on social relationships within groups, facilitating reflections on the perceptions of all involved and the construction of their partnership in daily practices.

Thanks to the use of a multiperspective design and our focus on interactions and variances, instead of on ethnical group characteristics, we could not only highlight the causes of problems in communication and decision-making, but also examine the possible solutions that care providers, patients and relatives favoured. This multiperspective design is a new way to explore and improve communication and decision-making about palliative care among immigrants. It will also help to prevent stereotyping ethnicity in health care among migrant groups.

### **Key messages**

Communication and decision-making in the palliative phase of cancer may create challenges for immigrant patients, their relatives and professional care providers. Care professionals should keep in mind that the problems in decision-making with immigrants in palliative care may have different causes. One such cause could be the fact that dominant principles in palliative care such as emphasis on quality of life and advanced care planning are not acceptable to immigrant patients and their relatives. Another reason might be that the broker function of the family care group and the professionals' own involvement in that care management group is insufficiently recognised by the professionals. Finally, lack of good communication among professional care providers may further complicate the immigrants' quest for cure, which often results in the inclusion of 'too many' professionals in the decision-making.

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