Partners in palliative care? Perspectives of Turkish and Moroccan Immigrants and Dutch professionals

degraaff, F.M.

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Talking in triads: communication with Turkish and Moroccan immigrants in the palliative phase of cancer

This chapter has been submitted as:
Fuusje M. de Graaff; Anneke L. Francke, Maria E.T.C. Van den Muijsenbergh, S. van der Geest. Talking in triads: communication with Turkish and Moroccan immigrants in the palliative phase of cancer.
Abstract

Aim
The aim of this study is to gain insight into the factors that hamper communication between health professionals and Turkish and Moroccan immigrants in the palliative phase of cancer.

Background
In palliative care communication is crucial. The question, however, is whether Dutch health care providers, on the one hand, and Turkish and Moroccan patients and their family members, on the other, agree on what is constituted by good communication.

Design
A descriptive qualitative method is used.

Method
Data of semi-structured interviews with 83 patients, relatives and professional care providers in 33 cases were analysed to determine perceptual communication differences about care and treatment during the palliative phase.

Results
As many patients with a Turkish or Moroccan background speak little Dutch, conversations often take place in triads, which makes it difficult for the actors to understand and resolve communication problems arising from diverging perceptions of ‘good communication’.

Conclusion
Miscommunication around palliative care cannot solely be explained by the different cultural backgrounds of patients and their care providers. The multilingual communication triangle of patient-family-care provider often also complicates the bridging of differences in care perceptions.

Relevance to clinical practice
Professional care providers should develop adequate strategies to handle triads, explore their own conventions and those of patients and relatives.

Key words
Immigrants; communication; triads; palliative care; cancer
Introduction

Equality between care provider and patient in communication about health care is often seen as the ideal (Van den Brink-Muinen et al., 2006). Care provider and patient mutually engage in an interactive process, sharing with one another information, wishes and decisions (Elwyn et al., 2000; Charles et al., 1999; Whitney 2003). The care provider is knowledgeable about health care, but the patient is the ‘expert’ when it comes to his or her own life history, life style and social environment. However, reality does not always correspond with this ideal of communication. For instance, elderly patients, immigrants, patients with a low level of education and patients with a poor prognosis relatively often prefer the health professional to take the initiative and responsibility during communication (Street et al., 2005; De Haes, 2006; Joosten et al., 2008).

Patients’ socioeconomic and cultural backgrounds also affect communication (Abarshi et al., 2009; Babitsch, 2008; Butow et al., 2007). Communication with immigrants may be influenced by language barriers, differences in values and conflicting ideas about the preferred doctor-patient relationship, as well as by cultural-specific illness explanations (Schouten and Meeuwesen, 2005; Suurmond & Seeleman, 2006; De Graaff & Francke, 2009).

In our study on palliative care for Turkish and Moroccan immigrants in the Netherlands, we found that professionals and patients often had conflicting views on what was constituted by ‘good care’ in the palliative phase; the Turkish and Moroccan families urged for maximum treatment and curative care and stressed the importance of dying with a clear mind, while care providers emphasized quality of life and advanced care planning (De Graaff et al., 2010). Yet these diverging views on care and treatment did not always lead to unbridgeable problems. Other factors - related to characteristics of the communication and decision making process itself – seemed to be relevant for adequate communication with migrants in general. We therefore studied how Dutch professional care providers and Turkish and Moroccan cancer patients managed their communication and decision making. The following questions are addressed in this article:

1. How is communication about care and treatment during the palliative phase realized between cancer patients with a Turkish or Moroccan background, their families and their health care providers?
2. What are the expectations of these actors about their joint communication and to what extent do their expectations conflict?
3. How do the Turkish and Moroccan patients and family on the one hand and their care providers on the other hand react to conflicting expectations about communication?
Methods

Definitions
‘People with a Turkish or Moroccan background’ refers to inhabitants of the Netherlands of whom at least one parent was born in either Turkey or Morocco. Turkish and Moroccan immigrants account for the largest minorities in The Netherlands. Although the Turkish and Moroccan culture and ethnic background differ, the two groups are examined together in this study, as they share a comparable immigration and integration history in the Netherlands. The first generation Turkish and Moroccan immigrants came to the Netherlands in 1970-1980. Working as ‘guest workers’, many of them did not learn the Dutch language. In the communication with care providers, they now depend on their children.

‘Care providers’ refers to nurses, physicians, pastoral and social workers who are directly involved in providing palliative care to cancer patients and their relatives. ‘Communication’ is defined as the exchange of information about issues relating to disease, care or treatment between various parties, and, in this case, more specifically between care providers, patients and their relatives.

‘Palliative care’ refers to the care provided from the time an incurable illness is diagnosed until death occurs.

Design
We opted for a qualitative research design, as, to date, few studies have been conducted in this area and the targeted patient group (migrants of Turkish or Moroccan descent receiving palliative cancer care) is still relatively small. To answer the research questions formulated above, we conducted semi-structured interviews with patients receiving palliative care, and with their immediate family and care providers. The study was approved by the medical ethics committee of Zuidwest Holland (no. 07-113) and by the regulatory committees of the hospitals involved.

Participants and recruitment
This study is based on a convenience sample: care providers were recruited at meetings of regional networks for palliative care and at relevant symposia. Patients and family were, for the most part, recruited indirectly, via general practitioners, hospital care providers and home care organizations. Consent to participate as an interviewee was recorded on audiotape. Oral informed consent was opted for as many patients and family members in these target groups were illiterate and/or distrustful of setting their signatures to documents (Saan & Singels, 2006).

Eighty-three people were interviewed, covering a total of 33 cases. In six cases, the patient could also be interviewed in person, although a family member was present in four cases at the patient’s request. In all other cases, the interviews were conducted with family members and caregivers, as the patient had already died or the care provider or family did not wish to burden the patient with the interview. Five male and 25 female family members were interviewed, as well as 47 care
providers. Of the care providers, 19 were nurses, 17 were general practitioners, five were medical specialists, four were social workers and two were pastoral workers (see Table 5.1).

Interviews
The interview started with questions about the patient’s background, the family situation, the disease process, and the care activities of family members and professionals. Next, questions were asked about important decisions that had needed to be taken since the patient had become seriously ill, followed by an evaluation of the communication surrounding each decision. The interviews varied in length from just half an hour (some care providers were pressed for time) to two hours. The first author conducted the interviews with the healthcare providers at their place of work, and with the patients and families at their homes or the hospital. Interviews were mainly in Dutch, although the interviewer could understand Arabic. In four cases, family members acted as interpreter and in four cases, use was made of a professional interpreter.

Analyses
The interviews were typed out in full, and subsequently analyzed. The first author analyzed all the interviews and systematically coded all data. Among other categories, experiences with and opinions on communication were coded for, using keywords like information transfer, language, opinions on topics (not) to be discussed, opinions about whom and when, triad conversations, who takes the initiative, feelings of exclusion/inclusion, etcetera. Some interview fragments were assigned several keywords. To reinforce the quality of the analyses, the second author also analyzed nearly half of the interviews. The first two authors compared their analyses and discussed disparities until agreement was reached. In addition, peer debriefing was performed (Lincoln & Guba, 1985): interim analyses were discussed intensively with the other authors and with the members of the supervisory committee, consisting of a general practitioner, an oncologist, one Turkish and three Dutch advisors, two researchers and two policy workers specialized in this area.

Results

Multilingual triads
In only seven of the 33 cases the patient mastered the Dutch language well enough to communicate independently with the care providers. In the other cases, communication on care and treatment needed to be translated (see Table 5.1).
<table>
<thead>
<tr>
<th>Case Nr</th>
<th>Back-ground</th>
<th>Diagnosis</th>
<th>Patient interviewed</th>
<th>Family interviewed</th>
<th>Professional interviewed</th>
<th>Language barriers</th>
<th>Quality of triads</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Tu*</td>
<td>mesothelioma cancer (no daughter)</td>
<td>no</td>
<td>daughter</td>
<td>GP</td>
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<td>good</td>
</tr>
<tr>
<td>2</td>
<td>Mo**</td>
<td>bladder cancer (no GP)</td>
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<td>------</td>
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<td>good</td>
</tr>
<tr>
<td>3</td>
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<td>------</td>
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<td>bad</td>
</tr>
<tr>
<td>4</td>
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<td>bronchial cancer</td>
<td>yes</td>
<td>wife brother-in-law</td>
<td>pain specialist nurse home care nurse GP</td>
<td>yes</td>
<td>good</td>
</tr>
<tr>
<td>5</td>
<td>Tu</td>
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<td></td>
<td>no</td>
<td>-</td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>Mo</td>
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<td>GP</td>
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<td>bad</td>
</tr>
<tr>
<td>7</td>
<td>Tu</td>
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<td>------</td>
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<tr>
<td>8</td>
<td>Mo</td>
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<td>wife</td>
<td>GP social worker</td>
<td>no</td>
<td>good</td>
</tr>
<tr>
<td>9</td>
<td>Tu</td>
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<td>------</td>
<td>nurse</td>
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<td>medium</td>
</tr>
<tr>
<td>10</td>
<td>Tu</td>
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<td>------</td>
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<td>medium</td>
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<tr>
<td>11</td>
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<td>------</td>
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</tr>
<tr>
<td>12</td>
<td>Tu</td>
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<td>no</td>
<td>------</td>
<td>hospital nurse</td>
<td>no</td>
<td>-</td>
</tr>
<tr>
<td>13</td>
<td>Tu</td>
<td>breast cancer (no social worker GP)</td>
<td>yes</td>
<td></td>
<td>no</td>
<td>-</td>
<td></td>
</tr>
<tr>
<td>14</td>
<td>Mo</td>
<td>brain tumor (no GP oncologist pastoral worker)</td>
<td>yes</td>
<td>mother 2 sisters brother</td>
<td>GP oncologist pastoral worker</td>
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<td>good</td>
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<tr>
<td>15</td>
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<td>GP</td>
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<td>medium</td>
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<td>16</td>
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<td>GP</td>
<td>yes</td>
<td>medium</td>
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<tr>
<td>17</td>
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<td>wife son</td>
<td>oncology nurse</td>
<td>yes</td>
<td>bad</td>
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<td>sister</td>
<td>home care nurse</td>
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<td>good</td>
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<tr>
<td>19</td>
<td>Mo</td>
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<td>no</td>
<td>daughter</td>
<td>hospital nurse</td>
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<td>medium</td>
</tr>
<tr>
<td>20</td>
<td>Tu</td>
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<td>yes</td>
<td>daughter</td>
<td>hospital nurse</td>
<td>yes</td>
<td>medium</td>
</tr>
</tbody>
</table>

- Table 5.1 to be continued -
### Table 5.1 continued

<table>
<thead>
<tr>
<th>Case Nr</th>
<th>Back-ground</th>
<th>Diagnosis</th>
<th>Patient interviewed</th>
<th>Family interviewed</th>
<th>Professional interviewed</th>
<th>Language barriers</th>
<th>Quality of triads</th>
</tr>
</thead>
<tbody>
<tr>
<td>21</td>
<td>Mo</td>
<td>lung cancer</td>
<td>no</td>
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<td>social worker oncologist pain specialist transfer nurse</td>
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<tr>
<td>22</td>
<td>Tu</td>
<td>bone cancer</td>
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<td></td>
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</tr>
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<td>23</td>
<td>Tu</td>
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<td>no</td>
<td></td>
<td>home care nurse</td>
<td>yes</td>
<td>bad</td>
</tr>
<tr>
<td>24</td>
<td>Tu</td>
<td>lung cancer</td>
<td>no</td>
<td>wife, son</td>
<td>GP</td>
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<td>medium</td>
</tr>
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<td>bowel cancer</td>
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<td>daughter</td>
<td>GP</td>
<td>no</td>
<td>-</td>
</tr>
<tr>
<td>26</td>
<td>Tu</td>
<td>lung cancer</td>
<td>no</td>
<td>wife</td>
<td>GP</td>
<td>yes</td>
<td>bad</td>
</tr>
<tr>
<td>27</td>
<td>Mo</td>
<td>stomach cancer</td>
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<td>daughter</td>
<td>GP home care nurse</td>
<td>yes</td>
<td>medium</td>
</tr>
<tr>
<td>28</td>
<td>Mo</td>
<td>brain tumor</td>
<td>no</td>
<td>daughter</td>
<td>GP</td>
<td>no</td>
<td>-</td>
</tr>
<tr>
<td>29</td>
<td>Mo</td>
<td>bowel cancer</td>
<td>no</td>
<td>husband</td>
<td>medical specialist</td>
<td>yes</td>
<td>bad</td>
</tr>
<tr>
<td>30</td>
<td>Tu</td>
<td>bowel cancer</td>
<td>no</td>
<td>sister-in-law</td>
<td>oncology nurse</td>
<td>no</td>
<td>good</td>
</tr>
<tr>
<td>31</td>
<td>Mo</td>
<td>ovarian cancer</td>
<td>yes</td>
<td>daughter</td>
<td>oncology nurse</td>
<td>yes</td>
<td>good</td>
</tr>
<tr>
<td>32</td>
<td>Mo</td>
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<td>sister</td>
<td>no</td>
<td>medium</td>
<td></td>
</tr>
<tr>
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<td>Mo</td>
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<td>no</td>
<td>daughter</td>
<td>nurse home care nurse</td>
<td>yes</td>
<td>medium</td>
</tr>
</tbody>
</table>

* Tu = Turkish patient; ** Mo = Moroccan patient

However, few care providers made use of professional interpreters, as they considered this a time-consuming practice that needed planning and, moreover, one that most relatives did not appreciate. Relatives often did not consider a
professional interpreter to be an acceptable alternative, as they feared that the
information provided to their beloved sick one would be too direct.

Communication mostly took the form of a ‘triad’, i.e. triangular communication
between the care provider, the patient and a close relative who helped to resolve
language problems. Often, the patient was supported by an appointed member of
the family – usually a daughter who spoke Dutch very well – who geared the
decision-making process to the patient’s own wishes. In other cases, the patient
was accompanied by alternating family members, which could complicate the
communication process. Relatives for the most part viewed the task of acting as
companion and interpreter as a matter of course, although some found it at times
demanding to have to deliver bad news or to translate medical jargon properly.

Some care providers - in the studied cases, usually those with less experience –
viewed the language differences and the involvement of interpreting family
members as an impediment to providing good care.

I think that the GP ran up against the same thing, the communication problem.
I have no experience with interpreters. I did hear later that an interpreters’
phone is very important. In my view it’s better not to work with the children, as
they often say the wrong thing. So I used sign language and didn’t understand
half. I thought it was extremely unsatisfying. I could just as well take care of a
dummy (case 23, district nurse, about a Turkish patient).

Others – especially those who adopted an open, inquiring attitude and who took
plenty of time – were well satisfied with the contact with the patient and his family,
even though they also realized that language differences restricted the
communication.

Different expectations of communication
Both care providers and relatives mentioned examples of subjects that failed to be
discussed (well), because the other party did not want to talk about them. Many
relatives, for example, did not wish to speak openly about the diagnosis of ‘cancer’,
as they immediately associated this with ‘dying’. If a doctor talked about this with a
member of the family (acting as interpreter), he or she generally refused to convey
this to the patient.

A strange doctor comes in, he may be good, technically, but what he’s come to
say is that there are metastases. I told father: they couldn’t find anything (case
21, daughter of a Moroccan patient).

Other subjects that patients and relatives were reluctant to raise, were financial
barriers, social pressure within the family and community and religious beliefs -
resulting in visits to alternative healers or sudden departures for Turkey, Morocco
or Mecca, and thus at times impeding the continuity of care and the
communication process.

There were also subjects that care providers did not discuss with the patient or
family. For example, many care providers saw no need to communicate the reason
for discharge from the hospital. To them, it was self-evident that patients, for whom further curative treatment is unavailable, should be discharged, whether for moral (it is best to die in the intimacy of the home) or for economic reasons (limited hospital capacity). Many patients and family members, however, continued to hope for a cure and hence wished to stay in hospital. The various arguments of the care providers on the one hand, and of the family on the other were almost never shared, which at times could lead to a communication block.

**Different ideas about the role division in communication**

As mentioned above, the communication between care providers and patients of Turkish or Moroccan descent rarely took place on a one-on-one basis. A great deal of communication occurred via relatives. This situation was generally regarded as normal by patients and family, but was troubling to some care providers, as they tended to see the patient as the primary communication partner. In their view, the patient should be the one to decide about treatment or care.

*I tried to talk to him, but he pulled his daughter over and closed himself off by turning his back to me. I was forced to talk with his daughter. He may have had his reasons for doing so, but it was hard for me (case 21, nurse of a Turkish patient).*

Moreover, care providers often had difficulties understanding the wishes and opinions of family and relatives, as they were unable to follow discussions within the family and to gauge the mutual relations. Family members acting as interpreters often held a key position in the triad, as they not only translated in the literal sense, but were also able to furnish patient and health care provider with background information. Despite the appreciation of care providers for the effort made by relatives and family, at times they felt they also formed an obstacle to communication, especially when there were differences in expectations as to who should determine the content of the communication: the physician or the family.

*The lung doctor asked me: does your father know he has lung cancer? I said no, he doesn’t know and I’m not about to tell him. He said: But you have to tell him! I said, so, this will make him better? The doctor said: No, but he should know. It’s his right to decide. I told him: but that’s what I’m for, I know. It’s really horrible, it hurts me bad enough already, so no way I’m going to do that to him (case 15, daughter of a Moroccan patient).*

The family often decided when and to what extent the patient should be involved in the conversation. Care providers sometimes were unpleasantly surprised by changes in the roles played by various family members. Sometimes, a new family representative, who had other ideas, overruled a family member who had hitherto spoken for the patient.
Responses of patients and family to conflicting opinions and wishes regarding communication

Resignation or blaming the care provider
Older patients often responded with resignation. They appeared to accept the fact that they did not determine the agenda, and left the communication to their family. Relatives, however, were less acquiescent. Some grew angry at the care provider, but felt that protests would be to no avail, as they would not be heard, anyway. They projected the cause of the faulty communication mainly onto the Dutch health care providers.

That Belgian doctor was very helpful and supportive, also regarding our wish not to inform my father; he can't handle it. With Dutch doctors I'm stressed out, I have to ask the assistant: would you please not mention the word ‘C’? (case 19, daughter of a Moroccan patient).

Acknowledging differences and searching for a solution
Other relatives acknowledged that expectations about communication could differ. Some accepted that care providers wished to bring up sensitive subjects that the family would rather avoid. They did feel, however, that care providers should convey painful messages gradually.

I notice that they are very theoretically focussed when they’re about to give bad news; it’s what I learn at school, too. I understand that you have to be honest with your patient, but for some people you need to first consider a few things. What’s important is how he conveys the message (case 14, sister of a Moroccan patient).

Moreover, many relatives wanted the doctors to discuss the agenda with them in advance. A few had meetings before and afterwards, in particular with GPs willing to invest the necessary time and energy. Looking back on their experiences, all relatives indicated that what they found most important was that the care providers recognized them as participants in the communication process.

Responses of care providers to conflicting opinions and wishes regarding communication

Resignation or blaming the family
While care providers realized that communication had been difficult in certain cases, some failed to recognize that the root of the problem could lie in differing opinions about what good communication was. Hence they made no attempt to bridge these differences. Some thought the other party was wholly to blame for the faulty communication, closing off all discussion of their own role in the process.

Recognizing differences and complying with the wishes of patient and family
But there were also care providers who acknowledged the differences of opinion about, for example, the extent to which cancer could be discussed, or the different roles of the family members in the communication process. These care providers
made a conscious effort to adjust their choice of words; some made extra time for a talk in connection with the need for interpretation or organized – only once or twice – a conversation in the presence of a professional interpreter. Another strategy involved discussing matters with the various family members separately, preferably at ‘safe times’ and ‘in quiet places’.

The time care providers invested in comprehending the internal family relations and the family’s position within the community, proved beneficial later on.

*It took a few visits to make it clear to them that he really would be dying soon. First, a meeting with the women, then with the men, and then another with everybody together... to make it accessible enough, that everybody was at peace about it. I think you should give everyone the chance to make his/her own choices, without losing face. It seems that this approach was a success (case 2, GP of a Moroccan patient).*

Some acquiesced to the wish of the patient or family to remain silent about the approaching death. They had a variety of reasons for doing so: their own limitations (‘even a doctor can’t be completely sure’), the patient’s limitations (‘not everyone can always handle the whole truth’), the competence of the family and relatives (sometimes they are more capable of judging what is best for this patient) or understanding for different customs regarding illness and dying.

*Acknowledging differences yet proceeding on the basis of their own opinions and wishes*

Other care providers showed that they had heard the family, but also voiced their own wishes, mentioning, for example their feeling of constraint in the contact with the patient if they were not permitted to say anything about the impending end. Or the fact that at certain moments they deemed it essential for the patient to be aware of the diagnosis and prognosis.

*At the family meeting I talked about how hard it was for me, as a doctor, not to be allowed to talk about something. I asked: ‘How do they do that in your culture?’ Because that’s the best way to get the ball rolling. But I also talked about my side of the discussion. ‘How do they do that in your culture’ is one side, and I’m happy to accommodate to some extent, but I also have a problem.’ Then they said: But you can talk about death, you’re the doctor, that’s a different position. They felt that I shouldn’t be stuck with the problem [laughs] (case 14, GP of a female Moroccan patient).*

*Acknowledging differences and jointly seeking the middle ground*

Some of the care providers tried to open up a discussion about the different preferences for communication about incurable illness or the role division in the communication with the family. This could be done, for example, by explicating the reasons for their open communication style. They also asked relatives to explain how communication about severe illnesses was done in their country or within their family. By subsequently dwelling on the similarities in the method or solutions,
they created room for articulating – and sometimes accepting – differences of opinion. Moreover, asking themselves the open question ‘Why do we think that open and direct communication would be a good thing?’ had as result that many health care providers started to view their own communication practices in a more relative light.

Discussion

Care providers of immigrant Turkish or Moroccan patients often find triad conversations (between patient, family, and care provider) strenuous. They dislike their dependence on family members acting as interpreters, and feel insecure because of the – to them – perplexing relations in the family and the migrant community. This study shows that miscommunication around palliative care cannot be explained solely by the difference in cultural background between patients and their care providers. Multilingual triads also complicate communication about, for instance, differences in care perceptions. However, this study also shows that some care providers are able to develop workable strategies: they acknowledge the constraints, and tailor the information provided. Some go along with the wishes of the family, others clarify the need for certain information to be conveyed, elucidate their own questions and customs, and ask both the patient and the relatives about their needs.

This study is an expansion on traditional communication studies, as research literature on triadic communication, particularly with immigrants, is scarce. Various previous studies have focused on triadic communication with young patients and their parents. These studies show that the communicative needs of children and their parents are not the same, and that care providers are often more involved in the parents’ needs – sharing information and making decisions - than in the needs of the patient (Tates et al., 2002; Fisher et al., 2011; Shin & White-Traut, 2004). Furthermore, studies on communication with elderly or Alzheimer patients and their companions, reveal that in these cases, too, care providers find it difficult to communicate with both the patient and the relative (Tsai, 2007; Bourbonnais, 2010), and often fail to consider the communicative needs of relatives (Docherty et al, 2008; Schmidt et al. 2009). However, triads in communication with immigrant patients and their relatives have not yet been studied in depth, as communication research among immigrants tends to concentrate on translation problems and divergent care values.

Conclusion

In conclusion, miscommunication around palliative care involves more than different cultural backgrounds or language problems; it may also be caused by the
triangular form of communication. Nurses, doctors and other care providers should, therefore, learn how to deal with ‘talking in triads’. And communication research should pay more attention to triads and group processes in which the decision making takes place.

Relevance to clinical practice

Based on this study, we would strongly recommend that care providers develop skills in handling professional interpreters, in addition to exploring the different concepts of ‘good care’, in order to avoid non-cooperative strategies and mutual blame. We moreover advise cultivating skills to acknowledge divergent expectations on ‘good communication’ and family role division in intercultural, multilingual triads. A skilful triadic conversation may reward all participants with the feeling of being understood, respected and cared for.

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References


