

## ARTICLE

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

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**Aims and objectives.** To gain insight into the factors that influence 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 healthcare 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.

**Methods.** Data of semi-structured interviews with 83 persons (six patients, 30 relatives and 47 professional care providers) were analysed to determine perceptual communication differences about care and treatment during the palliative phase of 33 cases.

**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:** cancer, communication, immigrants, palliative care, triads

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### 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.* 2001, 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, older 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 (Butow *et al.* 2007, Babitsch *et al.*

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2008, Abarshi *et al.* 2009). 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 (Koppenol-van Hooijdonk *et al.* 2002, De Graaff & Francke 2003, Schouten & Meeuwesen 2005, Suurmond & Seelenman 2006), resulting in cultural isolation and alienation of the immigrant patients (Butow *et al.* 2010) and structural inequality in service provision to immigrants (Evans *et al.* 2011).

Although the number of immigrant patients in palliative care is still limited in the Netherlands, it is expected to grow, especially in the largest immigrants groups: the Turkish and Moroccan immigrants, who share a comparable immigration and integration history in the Netherlands (Bevelander & Veenman 2004). The first generation came to the Netherlands in 1970–1980 to work as ‘guest workers’. They often did not learn the Dutch language and even today tend not to be well informed about the Dutch health services (Moree *et al.* 2002), as their dream is ultimately to return to their home country. As in practice this dream is seldom fulfilled, healthcare institutions in the Netherlands have started to realise that adequate end-of-life care must be put in place for these groups, as well.

Some 385,000 Turkish immigrants live in the Netherlands (2·2 per cent of the Dutch population) and some 350,000 Moroccans (2·0 per cent). The Turkish population is slightly older than the Moroccan, but both groups are approaching ages when end-of-life care may become necessary (De Graaff 2012). Moroccan immigrants make significantly less use of older services, such as home care, than Dutch adults and Turkish immigrants rate their health status as worse than Moroccans or Dutch adults. (Devillé *et al.* 2006) Turkish and Moroccan immigrants still have lower cancer rates than the native Dutch population, but the incidence of cancer in ‘non-Western migrants is rising’ (SCK-KWF 2006), as there is a tendency for cancer prevalence rates to converge to the rates of the host country (Stirbu *et al.* 2006).

To gain insight into the factors that influence the joint decision-making between health professionals and Turkish and Moroccan immigrants in the palliative phase of cancer, we investigated several aspects of their relation and encounters. First, we looked at the sometimes 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 emphasised quality of life and advanced care planning (De Graaff *et al.* 2010a). Yet these diverging views on care and treatment did not always lead to unbridgeable problems (De Graaff

*et al.* 2010b). 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 also examined their views on ‘good communication’: How did Dutch professional care providers and Turkish and Moroccan cancer patients and their relatives perceive the communication in the decision-making process? The following questions are addressed in this article:

- 1 How is communication about care and treatment during the palliative phase realised 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?

In this article, ‘people with a Turkish or Moroccan background’ or ‘Turkish or Moroccan immigrants’ refers to inhabitants of the Netherlands of whom at least one parent was born in either Turkey or Morocco, as this is a useful indicator of ethnicity in health research in the Netherlands (Stronks *et al.* 2009). ‘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. And ‘palliative care’ refers to the care aimed at improving the quality of life of patients and their relatives coping with an incurable and ultimately terminal disease.

## Methods

### 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 previously, 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 (GP), hospital care providers and home care organisations. The main inclusion criterion for the professional care providers was that they had actual 'experience' in intercultural palliative care, that is, they were personally involved in the palliative care or treatment of a Turkish or Moroccan patient with incurable cancer and attempted to contact this patient or his relatives to invite them to join in the study. Owing to the patients' health condition and the protective attitude of their relatives, we often had to rely on the information of relatives and professionals only, instead of being able to interview them directly. The main inclusion criterion for the relatives was that they were personally involved in the care for the patient. Most of the relatives we included were women, because we noted that, in most cases, the main care tasks were all performed by women. We purposely tried to recruit cases in major cities and in small towns, in neighbourhoods with a concentration of ethnic minorities and in 'white areas', to avoid overrepresentation of patients from 'ethnically marked places and ethnic communities' (Brubaker 2001). Both patients with long-standing illness and those who had been ill for a short time were included. Family members and care professionals were interviewed when the patient was still alive or within a short time after the patient died. The risk of recall bias was reduced as we spoke in each case with several informants and most of them vividly remembered the chronology of the events.

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 men and 25 women 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 (Table 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 because 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. We stopped recruiting new interviewees after we obtained saturation of categories regarding the main research questions.

## Analyses

The interviews were typed out in full and subsequently analysed. Data analysis started after the initial interviews, as part of a cyclic process of inductive and deductive reasoning (Abbott 2004, Baarda *et al.* 2005). The first author analysed all interviews, while the second author analysed the interviews of the first 13 cases and a third of the remaining 20 cases. Both first thoroughly read all the interviews through in full, to gain an overall sense of the ideas provided by the participants. In the process of identifying units in the texts that described similarities and differences, attention was also paid to aspects of the perception of communication. The coding tree was discussed with all authors, resulting in the use of 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 analysed nearly half of the interviews. The first two authors compared their analyses and discussed disparities until agreement was reached.

To enhance the credibility of our findings, we performed member checking and peer debriefing (Lincoln & Guba 1985): we sent the transcribed interviews to the interviewees and discussed interim analyses intensively with the other authors and with the supervisory committee, consisting of a general practitioner, an oncologist, one Turkish

and three Dutch advisors, two researchers and two policy workers specialised in this area. Triangulation was performed by discussing the results in implementation sessions with in total 200 representatives of Turkish and Moroccan communities (De Graaff *et al.* 2010b).

## Results

### Multilingual triads

In only seven of the 33 cases had 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 (Table 1).

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', that is, 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 of 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 realised that language differences restricted the communication. The general quality of the triadic communication, as perceived by GP, patients and relatives is presented in Table 1.

### 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 earlier, 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

**Table 1** Characteristics of the cases

Case number	Back-ground	Diagnosis	Patient interviewed	Family interviewed	Professional interviewed	Language barriers	Quality of triads
1	Tu	Mesothelioma	No	Daughter	GP	Yes	Good
2	Mo	Bladder cancer	No	-*	GP	Yes	Good
3	Tu	Stomach cancer	No	-*	GP	Yes	Bad
4	Mo	Bronchial cancer	Yes	Wife, Brother-in-law	Pain specialist nurse, Home care nurse, GP	Yes	Good
5	Tu	Breast cancer	Yes	-*	Social worker	No	-†
6	Mo	Lung cancer	No	Wife	GP	Yes	Bad
7	Tu	Lung cancer	No	-*	Pastoral worker	Yes	Medium
8	Mo	Stomach cancer	No	Wife	GP Social worker	No	Good
9	Tu	Brain tumour	No	-*	Nurse GP	Yes	Medium
10	Tu	Lung cancer	No	-*	Oncology nurse	Yes	Medium
11	Mo	Breast cancer	No	-*	Oncology nurse	Yes	Bad
12	Tu	Stomach cancer	No	-*	Hospital nurse	No	-†
13	Tu	Breast cancer	Yes	-*	Social worker	No	-†
14	Mo	Brain tumour	Yes	Mother, 2 Sisters, Brother	GP Oncologist, Pastoral worker	Yes	Good
15	Mo	Lung cancer	No	Daughter	GP	Yes	Medium
16	Mo	Breast cancer	No	Daughter	GP	Yes	Medium
17	Tu	Bowel cancer	No	Wife, Son	Oncology nurse	Yes	Bad
18	Mo	Stomach cancer	No	Sister	Home care nurse	Yes	Good
19	Mo	Bowel cancer	No	Daughter		Yes	Medium
20	Tu	Stomach cancer	Yes	Daughter	Hospital nurse	Yes	Medium
21	Mo	Lung cancer	No	Daughter	Social worker, Oncologist, Pain Specialist, Transfer nurse	Yes	Medium
22	Tu	Bone cancer	No	-*	GP, Home care nurse	Yes	Good
23	Tu	Lung cancer	No	-*	Home care nurse	Yes	Bad
24	Tu	Lung cancer	No	Wife, Son, Daughter	GP	Yes	Medium
25	Mo	Bowel cancer	No	Wife	GP	No	-†
26	Tu	Lung cancer	No	Wife, Daughter	GP	Yes	Bad
27	Mo	Stomach cancer	No	Daughter	GP, Home care nurse	Yes	Medium
28	Mo	Brain tumour	No	Daughter	GP	No	-†
29	Mo	Bowel cancer	No	Husband, Sister-in-law	Medical specialist	Yes	Bad
30	Tu	Bowel cancer	No	-*	Oncology nurse, Specialist	No	Good
31	Mo	Ovarian cancer	Yes	Daughter	Oncology nurse, Home care nurse, GP, Wound nurse	Yes	Good
32	Mo	Breast cancer	No	Sister		No	Medium
33	Mo	Breast cancer	No	Daughter	Nurse, Home care nurse	Yes	Medium

Tu, Turkish patient; Mo, Moroccan patient; GP, general practitioners.

\*Patient has no family members, or family members were not interviewed.

†Patient and care provider communicate directly; triads are not at issue.

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 also were 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 recognised 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 realised that communication had been difficult in certain cases, some failed to recognise 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.

#### *Recognising 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 organised – 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 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 performed, 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:

As I understand it, doctors in Turkey use their knowledge and skills differently. I try to explain everything. In Turkey, the doctor says: you must do this and that. While in the Netherlands, you can make choices as a patient, but then you have to know what the choices are. That is the dilemma. I try to strike a balance between letting people decide and eliciting what it is that people want. (case 1, GP of a male Turkish patient)

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 interpreting family members and feel insecure because of the – to them – perplexing relations in the family. 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 their need for certain information and elucidate their own customs. And some relatives succeeded in playing the multiple roles of interpreter, family member with their own problems and questions and patient representative.

This study revealed no great differences between Moroccans and Turks. Moreover, the communicative obstacles described are not exclusive to Turkish and Moroccan immigrants, as Dutch terminally ill patients and their relatives sometimes face similar triadic communication moments at the end of life. Yet Dutch care providers indicated that they feel more capable of supporting native Dutch patients, as they are better able to recognise and appreciate the family ties and role of certain Dutch relatives. Hence, we might conclude that the combination of

diverging cultural baggage and the complicated communicative structure seems to hamper the palliative care consultations of immigrants. This study has several limitations. We take into account a selection bias: as patients and relatives were approached by their professional health worker, we probably got an overrepresentation of informants with whom the care provider health care worker has a good relationship. However, even in these cases problems and dissatisfaction was mentioned more than once. Another source of bias is the fact that patients and relatives were seldom interviewed in their primary language. By interviewing more than one person around a case, we tried to diminish this bias.

## Conclusion

In conclusion, miscommunication around palliative care involves more than different cultural backgrounds and 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.

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## 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', 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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## Contributions

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