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

de Graaff, F.M.

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General Discussion
Introduction

This book explored the palliative care provided to immigrants with a Turkish or Moroccan background, in the Netherlands. The choice to explore this theme was motivated by observations that these two groups used home care services at a disproportionately low rate (Yerden, 2000; Van den Brink, 2000) and that palliative care is intended for all incurably ill patients and their families. Before the current study, no work had investigated the possible palliative care needs of these groups nor was it clear to what extent specific needs remained unrecognized due to communication problems (Boevink et al., 2001; RVZ, 2000).

This study was comprised of two empirical qualitative sub-studies, a survey and a systematic literature review. In this final chapter, the most important conclusions are presented followed by reflections on the study population, the focus on palliative care and the research methods. On the basis of these conclusions and reflections, recommendations are provided for representatives of the Turkish and Moroccan communities, care providers and for further research.

Significant conclusions

The first qualitative sub-study was based on interviews with close relatives of terminal or recently deceased Turkish and Moroccan patients to elicit their views and experiences regarding professional home care. The fact that these terminal patients and their families make relatively little use of home care was related to factors on four levels. At the individual level, in many cases, the patient’s limited knowledge of their disease and its expected course played a role. At the family level, it was described that the family often did not acknowledge that the patient was near the end. Close female relatives in Turkish and Moroccan families usually bore the heavy burden of caring for the patient. They recognized the need for professional help, however, male family members were rarely sensitive to this need. When physicians only communicated with the male relatives, the family’s message was frequently: no outsiders wanted. The third level was that making use of professional help may be seen by the community as shameful for the family, as if the family members are shirking their duty to care for one of their own. Finally, at the institutional level it was found that available care services did not always correspond with the care needs of these two groups. In addition ‘preferences regarding family care’ influenced all factors.

In a second sub-study, general practitioners and home care nurses completed a questionnaire about their experiences with home care for Turkish and Moroccan patients with an incurable illness: what factors did they see as important in the delivery of care to these patients? The care providers cited the same barriers for making use of home care as the family members did. However, they were far less likely to recognize the influence of the community on the family’s readiness to make use of home care and the strength of the core value that the sick are to be cared for by their own kin. The greatest problems for the care providers were
communication problems. They often found communication complex. Family members, acting as interpreters, sometimes had their own ideas or support needs, which the care providers were unable to distinguish from the needs of the patient. As a result, general practitioners made relatively few referrals to home care, thus addressing neither the problem of the caregivers’ burden nor the quality of the care provided.

The theme of communication was explored in depth in a third sub-study conducting qualitative interviews with cancer patients in the palliative phase, their families and the care providers involved. The decision to focus on cancer patients in this study was made because in supporting cancer patients, it is often relatively clear to care providers when the palliative phase starts compared to patients with other chronic diseases. This sub-study has clarified in more detail how the various perspectives on use of home care during the palliative phase described above relate to one another. The communication issues experienced by the care providers and the ‘other’ care values experienced by the families were found to be mutually reinforcing.

The interviewed study participants did not always concur on what constitutes ‘good care’ during the final phase of life. Differences of opinion arose in regard to the preferred goals of care. The interviewed care providers strove for palliation, giving the quality of life the priority for care. To this end, they aimed to provide timely information about the possibilities for care and to plan the necessary care together with the family. However, patients and their family members often continued to strive for treatment and a cure until the end. In addition, care providers often attached great importance to a peaceful and painless death, while for patients and their families it was often far more important to have a clear mind when entering the afterlife. Differences of opinion also arose regarding communication: to what extent and in what way should patients be told of their diagnosis and prognosis? The family often asked the care providers not to inform the patient that he or she was incurably ill, while physicians thought patients should be informed. Since family members frequently functioned as informal interpreters, they tended to play multiple roles: interpreter, family member with their own problems and questions, and patient representative.

Furthermore, the family was often found to function as a ‘care management group’. Joint decision-making could only be realized if the relatives and the patient reached agreement and depended on the care providers willingness to recognize the family as (part of) a ‘care management group’. Decisions about care and treatment were made within the family group. This went against the grain for many care providers, who often preferred to regard the patient as an autonomous decision maker. At the same time, this sub-study revealed limited coordination between the care providers, be it the various care providers in the Netherlands, or those in the patient’s country of origin. Communication problems and conflicting expectations about the care to be provided were especially likely, as patients and their families continued to demand curative treatments until the very end.
Finally, a systematic review was performed to investigate international literature on the views of Turkish and Moroccan patients and their families on end-of-life care and the communication with care providers. A previous literature study (De Graaff & Francke, 2002) had been conducted prior to the first sub-study, but little relevant research literature about palliative care for these target groups was found at that time. In 2010/2011, at the end of the entire research trajectory, a new systematic literature study was performed, based on the expectation that this research area would now have opened up. This proved to be the case: 33 studies were found from Turkey, 18 from the Netherlands, 4 from Morocco, 1 from Germany and 1 from Belgium. The review confirmed that the care perceptions of incurably ill Turkish and Moroccan patients are mainly characterized by the expectation that the family will care for them and their hope of recovery not be taken away. From a patient or family perspective, there should preferably be no open conversations about negative diagnoses and prognoses, no termination of life-prolonging treatments and no offer of pain medication if this would make the patient drowsy or hasten death. Moreover, the systematic review confirmed that the families of incurably ill Turkish and Moroccan patients are important in any communication about the care to be provided. This is partly true because care is considered a family matter, and partly because there are often language barriers, thus family members, as interpreters, are a vital link in patient communication with care providers.

**Why ‘immigrants’?**

The study was conducted since, in both practice and research, Turkish and Moroccan patients in the Netherlands enter the healthcare system in small numbers or at a late stage of their disease, and care providers encounter bottlenecks in the care system (Yerden, 2000). Attention to these immigrants and their palliative care in this research was therefore warranted. However, devoting separate attention to immigrants because of their origin could foster unwanted stereotyping and mask the diversity within these two groups (Van Asperen, 2003). This was one reason for investigating two immigrant groups in this study, namely Turkish and Moroccan patients and their families and care providers. However, the informants in this study were not able to draw comparisons between the Turkish and Moroccan groups. Either an informant was a Turk or Moroccan, or if they were a care provider they could only comment on the population in their own district or neighbourhood. The study did show that variation occurred within the groups studied, for example, regarding the division of labour within the family (differences in hierarchy and divergent patterns in case decisions are made by male or female family members) or the ties with their own ethnic community (families with tight ties could experience social control by their community thus curtailing requests for professional care).
Moreover, the interviews with care providers indicated that there were differences, as well as similarities in the way they managed Turkish and Moroccan patients compared to their native Dutch patients. Culturally divergent values were influential, but a lack of consensus was also caused by language barriers resulting in triadic consultations and the care givers’ insufficient recognition of the function of the family as a care management group. For care givers in the Netherlands, supporting native Dutch patients, family relations and their substantial role in communication and decision making are more easily recognized and appreciated as the composition of the care management group is often less complex. But triadic consultations and complex family ties are not exclusive to the culture or ethnicity of the Turkish and Moroccan immigrants. Therefore, this study calls for attention to cultural features, as Leininger (2002), Williams (1999), Stronks (2001) and Gutnaram (2007) have advocated, and for taking into account the whole context of each patient, considering cultural competent care as one of the non-negligible aspects of patient-centred care (Saha, 2008).

Focus on palliative care

In 2000, when the first research questions for this study were formulated, the focus was on home care for terminal patients with, at the most, only a few months to live. In a later sub-study on communication and decision making during the palliative phase, the terminal-illness criterion was relinquished, as the Dutch healthcare services recognized that the Turkish and Moroccan patients’ needs arose earlier in the palliative phase. According to the WHO (2002) definition, palliative care commences at the time of diagnosis of a disorder that is expected to lead to death. Although life-prolonging treatments may be given at first (such as palliative chemotherapy), as death approaches it is the quality of life that increasingly determines the care that is provided (Lynn & Adamson, 2003; Vissers, 2006; Francke, 2010). Palliative care in the Netherlands is offered in various settings, so the exclusive focus on home care was also abandoned in the sub-study on communication and decision making.

In palliative care, attention is paid mainly to somatic, psychosocial and spiritual problems. Good communication and decision making is essential, because of the grave and often complex nature of the problems. However, many of the bottlenecks and patterns unveiled by this study are likely to be just as prevalent in curative and preventive care situations. As a result, the conclusions of this study can extend beyond patients in the palliative phase alone.
A mixed methods and ‘multiperspective’ approach

This study is exploratory, characterized by theory development on the basis of unique situations and the active involvement of the researcher. As a result, descriptions of care situations are not objective accounts; after all, the qualitative researcher is continuously interpreting and selecting data (Reis et al., 2007). In anthropology, a narrative from the perspective of the group under study is called the ‘emic view’. The opposite is called the ‘etic view’: the view of an outsider, for example, the researcher. In this study various perspectives are presented: the Turkish and the Moroccan patients and their families, Dutch care providers and the researcher. Personal experiences and multiple contacts with Turkish and Moroccan families enabled the researcher to place herself in the shoes of migrant patients and their families. Thanks to her other activities (trainer/teacher in health care) she was also able to empathize with the professional care providers. The researcher used her personal knowledge to describe the care and communication processes, recognizing and acknowledging both the immigrants’ and the professionals’ perspectives. In the analyses she looked at the actual care provided and the decisions that had been made, as well as the way the people involved experienced the care and felt that decisions made were in line with their interests. Conflicts can arise due to diverging conceptions of realities, standards and values, or experiences since life can be viewed from several angles (Frijda, 1993; Habermas, 1987). This also applies to the care use and communication during the palliative phase. Joint decision making may be achieved if agreement is reached on realities, norms and terms of references (Cohen-Emerique, 2003; Schwarwächter, 2002; De Graaff, 2006). It is characteristic of researchers in medical anthropology to describe the realities of the study context with empathy (Reis, 2010).

Complementary research methods were also used including a survey study and a systematic review. These supplement the qualitative sub-studies and enhance the generalizability of the findings.

This study contributed to a research area that is under development—patient-provider communication (Bensing et al., 2008; Haes & Bensing, 2009). To date, much comparative research has been performed on Dutch general practitioners communication with immigrants and with native Dutch patients in specific and limited care scenarios (Harmsen et al., 2003; Harmsen et al., 2008; Meeuwesen, 2007; Schouten et al., 2007). It has been established that the length of the consultation and behaviour of the care provider and the patient are affected by the patient’s ethnicity (Johnson et al., 2004). However, the possibility of culturally related sensitivity to certain topics has received little or no attention in these comparative studies. Another characteristic of the existing studies is that that they mainly focused on two-way dialogs (Van Wieringen et al., 2002; Schouten & Meeuwesen, 2006; Suurmondt et al., 2007) rather than on the communication between patient, family, and care provider.

In this study, a qualitative and multiperspective approach was chosen, to shed light on underexposed aspects in communication research. This study’s method made it
possible to devote attention to sensitive topics and the experiences and interactions of all parties involved: patients, family members and a host of care providers. The results demonstrated that communication problems are partly associated with the cultural baggage of the discussion partners, but also that culture is not an all-decisive factor, as Van Dijk (1998) and Reis et al. (2007) have stipulated. To prevent or reduce problems in care services, communication and decision making, various constructive strategies may be employed both by Turkish and Moroccan patients and families and Dutch care providers. These strategies are examined in the following two paragraphs.

**Recommendations for members of the Turkish and Moroccan communities**

First generation immigrant patients and family members are pioneers in their communities in the search for relevant palliative care services. They often lack role models, partly because they have relinquished the care of their parents and elderly family members to relatives remaining with them in their country of origin. For many patients and their families, the general practitioner is their mentor, supporting them through the process of decision making for care at the end of life; for others, the hospital is the first point of entry to the health care system. However, for nursing care, some patients and their families simply miss out completely, or find their way to professional care services far too late. Others, who do make use of available professional care, are not always content with the services offered. Severely ill patients and their families should investigate available professional care options in a timely manner (in addition to the care provided by the family). The general practitioner can advise the family and patient on this. It is wise to clearly and fully apprise the general practitioner of the patient’s care needs and if necessary, to arrange for an interpreter to be present so that all questions and wishes can be adequately expressed.

In this study, we also noted that female family members, in particular, often cared for incurably ill family members intensively and for prolonged periods of time, which sometimes led to enormous strain. Based on this finding, we recommend that the wife or daughter (-in-law) not assume all care-related duties until the end as a matter of course, but that care is more evenly shared among all family members. Professional home care services are available to provide support. If this is not easily discussed within the family, it may be wise to enlist the help of the general practitioner or another care provider whom the family trusts. They are generally aware of what to expect as the illness advances, and the care demands that will arise. The patient and his or her family could also consult separately with the relevant care provider in order to avoid a situation in which the wish to protect each other hinders relatives’ ability to solve problems and leads to unsatisfactory care for the patient (De Graaff et al., 2010).
Recommendations for care providers

When caring for incurably ill patients, Turkish and Moroccan families in many cases did not make use of the home care services available, even though this primarily placed a heavy burden on the female members of the family. This limited use of home care facilities was due both to the conviction that a family should care for its own and that these groups were largely unaware of the available care services. A personal referral from a trusted care provider—for example, the general practitioner—often proved quite effective. Therefore, it is vital that care providers who know the patient identify the patient’s and family’s expectations and wishes. In order to fulfil the ideal of the caring family, it may be necessary for the professional care provider to first focus on the medical care aspects such as pain relief, medication, etc. Later, after initial contact has been established and a foundation for mutual trust has been laid, the professional can offer psychosocial support or personalized care.

This study also showed that communication with first-generation immigrant patients is often conducted via the family, as the family acts not only as interpreter but also as the patient’s representative. Care providers should acquire the necessary skills to make use of formal interpreters (either via the interpreters’ telephone or otherwise) and informal interpreters (i.e. relatives), to ensure effective communication with the patient and family. In both cases, triad communication is used, although the two approaches are distinct. A formal interpreter is an instrument employed to improve and facilitate the care relationship with the patient. The use of an informal interpreter (relative) involves two care relationships: one with the patient and one with the relative. This implies that when using a formal interpreter the care provider focuses on the patient, even if the message is conveyed by the interpreter or the interpreters’ telephone. If a member of the family is acting as interpreter, the care provider should make eye contact with the patient and the relative, indicating that the information and care needs of both are being addressed. After all, a relative acting as an interpreter fulfils three roles: interpreter, patient representative and person in need of care. The care provider therefore has to first explore who the patient feels should be the conversation partner: what does the patient want to know and what does the patient wish to delegate to the family? In the case of bad news, it may be wise to ask the patient and family separately how much they already know and what else they want to know. According to the answers given, the care provider can gauge how much information to provide and how to formulate the information.

We explored the circumstances when patients and families do not wish to speak openly about the poor prognosis, while care providers would like to communicate openly because they attach importance to advance care planning. It is recommended that care providers learn to make proactive care proposals, even in situations where the unfavourable prognosis is difficult to address and the patient
and family continue to hope for a cure, or at least for a prolongation of life. This approach requires care providers to demonstrate empathy and engagement and an understanding that for some patients and families, more ‘quantity of life’ may also mean experiencing more ‘quality of life’.

It was also found that patients and families sometimes refuse medication to relieve pain or other symptoms so that the patient will appear before Allah with a clear mind. This can clash with the care providers’ target of effective pain control, precisely from the point of view of quality of life. The challenge for care providers is to learn to cope with a range of health care beliefs, instead of blindly holding on to the prevailing Dutch ideal of the autonomous individual decision-making patient. This implies that care providers must acquire some knowledge of the relevant culture and traditions to take the necessary proactive steps to build a relationship with the patient, the family and relatives. This relationship should be characterised by personal attention, mutual exchange of information and respect for the patient and family’s wishes, but also for the care provider’s personal limits. This study shows that care providers can acquire these skills, since several of the more experienced care providers taking part in this study had already adopted this approach on the basis of their own experience and targeted training programmes (De Graaff et al., 2009).

Moreover, the study revealed that some families attempt to obtain maximum care by working with several care providers at the same time: the general practitioner, various specialists or alternative healers, both in the Netherlands and in their country of origin. In this case, careful coordination is needed with the patient and family and among the various care providers to ensure that decisions are shared by all members of the care management group and that adequate care is delivered jointly.

Finally, we found that despite the diverging beliefs and positions of the care providers, patients and family, there are nonetheless similarities, too. All the parties concerned strive to provide the patient with good care, and all parties wish to be heard. Should communication problems arise, it is wise not only to be aware of differences, but also of the shared values and needs.

**Research recommendations**

This study is concerned with the palliative care for Turkish and Moroccan patients and their close family members. The question that subsequently arises is whether the findings can also be applied to other immigrant groups in the Netherlands, such as Moluccans, the Chinese, Surinamese and Antilleans, and refugees from various countries. No unequivocal conclusions can be drawn on the basis of this study as the listed immigrant groups differ from the Turkish and Moroccan immigrants in regard to origin, time period and motivation for immigration, their reception in the Netherlands and language skills. However, studies performed among refugees point to similar dilemmas for palliative care providers and incurably ill refugees.
(Van den Muijsenberg et al., 2010). Future research of care beliefs, needs and communication processes in the palliative care phase for other immigrant groups in the Netherlands could bolster the current insights. This study mainly targeted the experiences with and beliefs about care, and the communication of care needs during the palliative phase. The socioeconomic and policy-related factors affecting the palliative care provided to Turkish and Moroccan immigrant patients remained relatively unexplored. Further research is advisable in these areas, as well as problems of housing, income and legal status, all of which can sometimes impede palliative care.

Another characteristic of this study is the way sources (patients, family members, various care providers) and methods (qualitative and quantitative research, literature research) have been triangulated. This proved to be a workable means to gain insight into the various perspectives on palliative care and the accompanying communication problems. We recommend employing this multi-perspective approach more frequently in healthcare research, in particular if studying circumstances when care providers and care consumers operate from divergent perspectives, with influential factors playing a role on the individual, cultural and social level.

To ensure that these distinct perspectives on healthcare and related communication are taken into account in the practice of palliative care, it would be wise to investigate the adequacy of a wide range of measuring instruments (e.g. Albers et al., 2010), quality indicators (e.g. Pasman et al., 2009) and clinical guidelines for palliative care (e.g. De Graeff et al., 2010; Gootjes et al., 2010) to serve cultural diversity. Not only should attention be paid to language barriers and specific ideas of what constitutes ‘good care’ and ‘good communication’, but there may also be a difference in the way illness and symptoms are perceived and expressed. Assessment, for example, of pain and physical functioning in immigrants is not always easy, since the questions formulated in the measuring instruments are not attuned to the experience of those involved (Driessen, 2002; Hoopman, 2010).

Finally, we found that the only persons studied in much of the research on healthcare and communication were adults of the native population. Too often, specific target groups are not included because of challenges to recruit study participants or a lack of translated questionnaires or topic lists. Solving these practical problems is important in order to gain a comprehensive overview of the course of affairs in health research and the available solutions for all inhabitants. Insights and tools are needed in current healthcare practice in order to ensure that good care is provided in multicultural settings, as well.
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