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

de Graaff, F.M.

Citation for published version (APA):
de Graaff, F. M. (2012). Partners in palliative care? Perspectives of Turkish and Moroccan immigrants and Dutch professionals.

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Summary

This study explores palliative care provided to immigrants with a Turkish or Moroccan background in the Netherlands. It is known that these two populations make little use of home care services. Considering the fact that palliative care is intended for incurably ill patients and their families and that specific needs may remain unrecognized due to communication problems, we decided to explore the experiences and perceptions of these patients and their relatives as well as the experiences of their professional care providers.

The introduction, Chapter 1, provides background information about the study. It describes the demographic and epidemiological developments of the Turkish and Moroccan immigrant populations in the Netherlands and their specific care needs. It also gives an overview of the structure and content of this study, explaining why we present the findings of the two empirical qualitative studies, the survey and the review in chronological order.

In Chapter 2 we present the results of the first qualitative sub-study of the experiences of nineteen Turkish and Moroccan families who recently cared for an incurably ill patient in the Netherlands. Most information came from the – female - central carers of the patient. No uniform pattern of use of home care was discerned, but several factors influencing access were highlighted. At the individual level, patients’ limited knowledge of their disease played an important role. At the family level, it was mostly female relatives who bore the heavy burden of caring for the patient. They often recognized the need for professional help, but male family members were less convinced. When communication is coordinated by male relatives, the family often refuses outsiders’ help. At the community level this attitude is reinforced as family care is seen as a duty. Finally, at the institutional level, care services did not always correspond with the care needs of the families. Overall, the preference for family care influenced all factors.

Chapter 3 presents the results of the next sub-study, which focused on the perceptions of GPs and nurses regarding home care for incurably ill Turkish and Moroccan patients. We sent questionnaires to home care organizations and GPs working in areas with many immigrants, and analyzed the data of 93 home care nurses and 78 GPs using descriptive statistics. The care providers cited the same barriers for the use of home care as relatives did. However, they often did not recognize the influence of the community on the family’s readiness to make use of home care, nor the strength of the core value that the sick should be cared for by their own kin. The greatest problems for care providers were communication problems.

As the views on the reasons why the Turkish and Moroccan elderly seldom use home care differed, we were interested in the details of these divergent views and
started another qualitative study looking for the personal views of ‘very ill’ cancer patients with a Turkish or Moroccan background, their family members and their Dutch care providers.

In Chapter 4 we present our first conclusions about the diverging ideas on ‘good care’ at the end of life, derived from interviews with 83 patients, relatives and care providers involved in the care of 33 patients with a Turkish or Moroccan background. It appeared that palliative care may be a contradiction in terms for patients and relatives who see ‘care’ as treatment towards recovery. Another contradictory value regarded patient information: Dutch care providers prefer complete openness to the patient to attain shared decision making, while relatives oppose this as they feel that the patient should never lose hope. Relatives also reject pain relief that diminishes the patient’s consciousness as they insist that the patient should enter the hereafter with a clear mind.

Chapter 5 focuses on other findings of the research, concerning the practical problems of talking in triads. We show that miscommunication around palliative care is not solely caused by diverging care values, but can also be the result of translation barriers, different expectations of communication and conflicting ideas about the role division in consultations. Relatives often hold a key position in triadic conversations, while many (particularly young) Dutch care providers prefer the patient to be the primary communication partner. They are often not accustomed to dealing with lay intermediaries whose roles are threefold: interpreter, spokesperson and someone personally affected. Other GPs acknowledged the difficulties faced by the relatives and created a common ground to share diverging wishes and opinions.

Chapter 6 shows the results of a more holistic analysis of the cases in the qualitative sub-study, using the concept of ‘care management group’. We argue that decisions in palliative care are often the outcome of arduous discussions, not only within the patient’s family but also among professionals. Joint decision making requires attention to be given to the diverse tasks and interests of all those involved in care activities. To illustrate this concept we present four anonymized cases illustrating the four typologies we found. In some cases synergy was absent as care providers denied the functioning of the care management group. In some other cases, patient and relatives did not reach social and cognitive consensus on care management, nor did they trust the proposals of professional care providers. In the third typology, lack of cooperation among care providers hampered joint decision making. But we also found cases with a well-functioning care management group of care providers and family members. This chapter shows that problems in decision making with immigrants in palliative care may have different causes: in addition to diverging care values and the barriers of triadic communication, the broker function of the family in the care management group and the professionals’ own involvement in that group need more attention.
In Chapter 7 the findings of a systematic literature review are presented. We examined what is known in the international literature about the care experiences and care perceptions of incurably ill Turkish and Moroccan patients, their relatives and care professionals, and about the communication between them. Fifty-seven studies were found, mainly from Turkey and the Netherlands, plus some from Morocco, Germany and Belgium. The studies reported in particular on experiences and perceptions regarding family care, professional care, end-of-life care, and decision making and communication. The findings emerging from the literature largely confirm the observations of our study. Family care for incurably ill Turkish and Moroccan patients is considered a duty, even when this care becomes a heavy burden for the usually female family caregiver. Hospital care is often preferred as patients and relatives usually strive for curative care until the end. Decisions on withdrawing or withholding treatment are seldom discussed with the patient, and relatives often withhold information about the diagnosis. Communication about pain and mental problems is limited. Language barriers and family dominance may amplify communication problems.

Chapter 8, the general discussion, provides a summary of the main findings and a reflection on the most pertinent conclusions. We also reflect on our decision to study immigrants, in particular our focus on Turkish and Moroccan immigrants. The data do not allow us to compare the perceptions of the two groups, nor to contrast these with those of Dutch incurably ill patients. We could, however, identify variations within these groups and establish that every ill person goes through a unique process. This applies to patients of minorities and majorities alike. The emphasis on palliative care led us to focus on communication rather than on medical issues, but it seems that our findings extend beyond patients in the palliative phase. We also reflect on the ‘multi-perspective’ approach, which has proved fruitful and complementary to existing designs and theories of patient-providers communication. The study ends with recommendations to members of the Turkish and Moroccan communities, to care providers and for follow-up research.