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

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Introduction

Caring for the incurably ill is of all times, but palliative care in its current guise is a relatively new phenomenon. Since 1990 palliative care has been an explicit focus of attention in many countries. Specific care facilities and clinical guidelines have been developed for patients needing palliative care, inspired by the pioneers in the hospice movement, such as the English Cicely Saunders and the Swiss-American Elisabeth Kübler-Ross. The World Health Organisation has recognized palliative care as a specific form of care and defines this as: “an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness.” (WHO, 2002).

In the Netherlands, palliative care is provided by a wide range of institutions and professionals. Hospices and volunteer institutions have sprung up, while generic care providers such as physicians, home care organizations, nursing homes and hospitals, too, also offer palliative care (see www.palliatief.nl). As the majority of Dutch patients at the end of life prefer to be cared for in their own familiar surroundings, general practitioners and home care providers often play a central role in the provision of palliative care (Van den Muijzenbergh, 2001; De Korte-Verhoef & Teunissen, 2009), with the support of specialized palliative care consultants (Klinkenberg & Middelburg-Hebly, 2010).

Palliative care emphasizes a holistic approach aimed at patients and their families, their physical wants and their social, psychological and spiritual needs. Meeting these needs demands interdisciplinary cooperation between care providers and good communication with the patient and the patient’s family on a plethora of subjects (Osse et al., 2002). Often, many problems can be avoided with timely consultations and proactive approach (Francke & Willems, 2005). Not for all patients, however: elderly people often find it difficult to process all the information they receive and sometimes prefer to leave the decision making to a trusted caregiver (Posma et al., 2009). This trust is lacking in some cases, as, for example, when resentment against a caregiver had already developed during the curative phase (Osse et al., 2001), or, as is the case among certain migrants, the gatekeeper role of the general practitioner in health care is an unknown and unwanted phenomenon (Feldman et al., 2007).

Although The Netherlands is home to many immigrants, until a few years ago remarkably little was known about the palliative care given to them. In the first instance, neither the Dutch care providers nor the immigrants themselves felt that insight into the palliative care needs of people from Turkey and Morocco, currently the largest immigration population groups, was particularly relevant, as they were expected to remigrate to their country of origin. The dream of returning home, however, often failed to become reality: Turkish and Moroccan first-generation immigrants are aging in the Netherlands, and more and more need to make use of
palliative care. It is therefore essential to examine how palliative care can be attuned to this group of patients. This thesis is the result of a study of the palliative care delivered to patients with a Turkish or Moroccan background, of the factors that determine their use of these services, of the communication between them, their families and their Dutch care providers, and of their specific care needs and opinions.

The results of the study are presented in chapters 2 through 7. First, however, this introductory chapter will address a number of developments and signals that underscore the importance of this research, such as the expected changes in population demographics, in incidence of illnesses requiring palliative care, and the known specific care needs of Turkish and Moroccan patients and their families.

Demographic and epidemiological developments

In the Netherlands, the origins of the immigrant population are registered in the population registers up through the second generation. A person with a Moroccan or Turkish background is defined as a person who is either born in Turkey or Morocco himself or of whom at least one of the parents is born there. In 2010, the approximately 385,000 persons with a Turkish background made up 2.2 percent of the Dutch population, while the approximately 350,000 persons with a Moroccan background accounted for 2.0 percent of the total population (http://statline.cba.nl/StatWeb/publication). Population data further show that – unlike the native Dutch elderly population group – the group of men between the ages of 60 and 80 is relatively large (see Table 1.1). The high number of older men especially among Moroccan migrants – is related to their migration history. The Turks and Moroccans came to the Netherlands in response to shortages in the labour market in this country. The new arrivals were mainly young men who initially left their families in their country of origin. Their wives, who arrived later, tended to be younger.

Table 1.1 Number of people of 50 years or older with a Turkish or Moroccan background in the Netherlands

<table>
<thead>
<tr>
<th>Age</th>
<th>Total Turks in 2010</th>
<th>Of whom men</th>
<th>Total Moroccans in 2010</th>
<th>Of whom men</th>
</tr>
</thead>
<tbody>
<tr>
<td>50-59</td>
<td>23,430</td>
<td>12,016</td>
<td>2,151</td>
<td>10,094</td>
</tr>
<tr>
<td>60-69</td>
<td>17,499</td>
<td>8,915</td>
<td>15,469</td>
<td>9,819</td>
</tr>
<tr>
<td>70-79</td>
<td>7,402</td>
<td>4,275</td>
<td>7,347</td>
<td>4,768</td>
</tr>
<tr>
<td>80-89</td>
<td>666</td>
<td>217</td>
<td>487</td>
<td>321</td>
</tr>
<tr>
<td>90+</td>
<td>41</td>
<td>5</td>
<td>18</td>
<td>7</td>
</tr>
<tr>
<td>50+</td>
<td>49,048</td>
<td>25,228</td>
<td>44,472</td>
<td>25,009</td>
</tr>
<tr>
<td>80+</td>
<td>717</td>
<td>220</td>
<td>505</td>
<td>328</td>
</tr>
</tbody>
</table>

Source: http://statline.cba.nl/StatWeb/publication/ 2-8-2010
Earlier research has shown that many older Turks and Moroccans feel less healthy than does the elderly Dutch population (Meyboom & Van Eekele, 1999; Stronks, 2001; Devillé et al., 2006; Lamkaddem et al., 2008). Turkish and Moroccan patients have also been observed to make more frequent use of the general practitioner, who in the Netherlands acts as a gatekeeper to secondary care facilities (Stronks, 2001; Uiters et al., 2006). However, older Turks and Moroccans do not make more frequent use of specialised care in hospitals (Uiters et al., 2006), and actually make less use of professional home care (Denktaş, 2009). The relatively high GP use by these groups may partly be explained by the fact of their poorer perceived health. Their often low socioeconomic position and limited acculturation may pose obstacles to finding the way to home care services. However, comparative research shows that the differences in health care consumption are not due to such factors alone, rendering the search for specifically culture-bound health care needs more than justified (Uiters et al., 2006; Denktaş, 2009).

People with cancer make up the largest target group in palliative care (Van der Velden et al., 2008). The Dutch Cancer Society has carried out research into the epidemiological characteristics of migrant patients with cancer. This revealed that, for now, migrants from Turkey and Morocco have lower cancer rates than found for the native Dutch population (SCK-KWF, 2006). In the period 1995-2000, the relative risk of dying from cancer (relative to the native Dutch mortality rate, with a confidence interval of 5%) was estimated at 0.95 for Turkish migrants and 0.44 for migrants from Morocco. However, the incidence of cancer among ‘non-Western allochtones’ in the major Dutch cities is expected to rise from 6% in 2005 to 19% in 2030 (SCK-KWF, 2006). Mortality from cancer and other chronic diseases among non-Western allochtones – including people of Turkish or Moroccan descent – will also grow throughout the coming years (Van der Velden et al., 2008; SCK-KWF, 2006). This increase in non-acute mortality is attributable not only to the growth in number of elderly migrants, but also to the fact that younger generations are adopting bad Western lifestyle habits, such as smoking and an unhealthy diet (Pacemaker, 2008). Addressing cultural diversity issues is therefore an increasingly important factor in palliative health care.

**Specific care needs of Turkish and Moroccan immigrants**

Various studies have been conducted on the general care needs of elderly Turkish and/or Moroccan migrants and their informal caregivers (e.g. Moree et al., 2002; Yerden, 2000; Van den Brink, 2003). The care needs of elderly Turks and Moroccans have been found to correspond in part with those of needy Dutch elderly: their deteriorating physical condition interferes with their daily functioning, which means they must more and more turn to family members and professional care services for help with the shopping, domestic and personal care. In general, elderly Turkish and Moroccan migrants have only a patchy command of Dutch and
therefore require help from the family with correspondence, telephone conversations and consultations with Dutch care providers. Hence Turkish and Moroccan family members are expected to provide support over a broader range of areas than Dutch informal caregivers. Moreover, the duty of care in Turkish and Moroccan families is far greater than in Dutch families (Yerden, 2000; De Graaff and Francke, 2002). Earlier research revealed that the care roles are often gender based: Turkish and Moroccan sons have a duty of maintenance towards their parents (‘bakim’ in Turkish), but care is mainly provided by the daughters (-in-law) (‘yardım’ in Turkish). This duty of care is so taken for granted in many Turkish and Moroccan families that the often heavily burdened daughters or daughters-in-law find it very difficult to hand over to or share this care with professional care providers (Frederiks & Korstanje, 2007; Yerden 2003; Van den Brink, 2003; Van Buuren et al., 2005).

Turkish and Moroccan families tend not to be well informed about the various Dutch care services, such as home care, that are available. Moreover, many Turkish and Moroccan family members find the application procedures they need to go through to make use of these services difficult to understand (Moree et al., 2002). Recent studies have also shown differences between Moroccan and Turkish patients. Turkish patients in general seem to present the poorest health situation (Denktaş, 2006; Devillé at al., 2006) and Moroccans to make less use of Dutch healthcare facilities (Denktaş, 2011; Uters, 2006).

We examined these two groups together, as, in the Netherlands, they share a similar minority position and immigration history. We also thought that it would be interesting to include both groups, as we expected to find some variation between the two. For example, there are indications that Turkish women more often have jobs outside the home (Keizer & Keuzenkamp, 2011). They may consequently more often be ‘doubly’ burdened, but are also better informed about the available facilities in the Netherlands.

The above-mentioned studies examined the care needs of elderly Turkish and Moroccan patients and/or their families. At the start of the study less was known about the specific care needs of incurable ill Turkish and Moroccan patients and their family members in the Netherlands. Research elsewhere has shown, however, that the cognitions and attributions pertaining to incurable illness and dying are strongly culturally determined (Dogan & Deger, 2001; Vincent, 2001; Cetingoz et al., 2002). Previous research indicated that Turkish and Moroccan migrants view cancer as being caused by physical processes, but also by supernatural powers. The disease is preferably not talked about and should the physicians have given up on recovery, people with cancer and their families focus their hopes on Allah. This may be part of the reason Turks and Moroccans are less likely to make use of professional services such as home care (De Meyere, 2004; Koppenol-van Hooijdonk et al., 2007).
Structure and content of the book

This book has a loosely chronological structure that illustrates how in each case the questions in the sub studies are a logical consequence of previous sub studies. As there were indications that Turkish and Moroccan immigrants made little use of home care during the terminal stage (the final part of the palliative stage), initially a qualitative study (see Chapter 2) on the use of home care for terminal Turkish and Moroccan patients was conducted. Based on interviews with family members, the following questions were to be answered:
1. What experiences do the Turkish and Moroccan families of terminally ill patients have of Dutch home care in the terminal phase?
2. What factors influence the access to and use of home care in the terminal phase according to these family members?

The perspective of family members appeared to be different from that of professional care providers, and hence a survey was conducted among Dutch general practitioners and home care nurses. The central questions of this survey study were:
3. What experiences and perceptions do general practitioners and home care nurses have with regard to home care for terminally ill Turkish and Moroccan migrants and their families in the Netherlands?
4. What factors, according to them, influence the access to and use of home care in the terminal phase?

The answers to these questions are presented and discussed in Chapter 3.

Exploring the perceptions of Turkish and Moroccan family members (Chapter 2) and Dutch care providers (Chapter 3) yielded relevant insights, yet was at the same time encumbered by the methodological constraint that interviewees and respondents based their experiences on different case histories. Further qualitative research was therefore conducted on a specific target group, namely that of 33 patients with incurable cancer, in which per case several perspectives – of patients, family members and/or professionals - were explored. The focus of the interviews was mainly on communication and decision making during the palliative phase. This topic was addressed, as the previous sub studies had shown that patients, family members and care providers all felt that communication and decision making concerning palliative care management was often inadequate.

The various research questions arising in this study of 33 cases may be summarized as follows:
* How does communication and decision making about the care and treatment of Turkish and Moroccan patients with cancer function during the palliative stage?
* To what extent do ideas and expectations of patients, family members and care providers differ with regard to communication and decision making, and how do they handle possible differences?
The results are presented in Chapters 4, 5 and 6. Chapter 4 looks at the differences in opinion about the desired communication and decision making. Dutch care providers often consider a timely discussion with the patient about the options for care and treatment when no cure is possible a matter of course. In many cases, this does not correspond with the notions of Turkish and Moroccan patients about what constitutes ‘good care’.

Chapter 5 describes, on the basis of interviews with patients, family, physicians, nurses, pastoral care and social workers the way in which often complicated triad conversations take place between the patient, relative and care provider during the palliative stage.

In Chapter 6, the communication process of the patients, their family and their care providers are discussed and related to their divergent care management styles. Various communication variants occur, ranging from smooth communication and shared decision making amongst all actors to situations where both the communication within families and between care providers is fraught with difficulties.

Lastly, the final sub study, a systematic literature study, was conducted to investigate the status quo of the research into palliative care for Turkish and/or Moroccan patients in 2010. When we started out in 2001/2002, little other relevant research had been carried out on palliative care for these target groups (De Graaff & Francke, 2002). But was this still the case? To find out, the Dutch and international literature databases and websites were searched. The questions posed in the systematic literature study are:

What is known from previous research about
1. care experiences and care perceptions of incurable ill Turkish and Moroccan patients, their relatives and care professionals?

2. communication between these patients, relatives and care professionals regarding care and treatment in the palliative phase?

The results of the systematic review are presented in Chapter 7, providing insight into the extent to which the findings of the sub studies presented in earlier chapters are corroborated by other academic studies.

Chapter 8 discusses the results of the sub studies and reflects on the research process. The chapter closes with conclusions and recommendations for researchers, care providers and Turkish and Moroccan concerned parties.

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