



Ineke J. van Eechoud, MSc
Mieke Grypdonck, PhD, MSc, RN
Johan Leman, PhD, MSc
Nele J. Van Den Noortgate, PhD, MD
Myriam Deveugele, PhD, MSc
Sofie Verhaeghe, PhD, MSc, RN

Caring for Family Members Older Than 50 Years of Turkish and Northwest African Descent

The Meaning of Caregiving

KEY WORDS

Adult children
Cultural diversity
Family
Family caregivers
Older adult
Oncology

Background: The first generation of immigrants to Belgium from Turkey and Northwest Africa are aging and at risk for developing cancer. Family members play an important role in both illness and old age. **Objective:** The objective of this study was to gain insight into experiences and perceptions of families with Turkish or Northwest African backgrounds who were caring for cancer patients older than 50 years in Flanders, Belgium. **Methods:** A qualitative research design with elements of constructivist grounded theory was used. Twenty-eight loosely structured interviews were conducted. Three researchers were involved in data analysis (researcher triangulation), and 6 conversations took place with experts. **Results:** Cancer appeared to be a family matter. Caregiving had a strong moral meaning for all participants, particularly for children providing care to a parent. Caregiving could be described as "guiding": family members led the patient through, or familiarized the patient with, the healthcare system. There were strong differences in the extent to which family members believed they should provide care, as well as the kind of professional care considered desirable. **Conclusions:** Despite shared values of the importance of family and family caregiving, concrete ideas about caregiving differed considerably. The findings imply that shared cultural or religious normative values do not predict day-to-day care practices. **Implications for Practice:**

Author Affiliations: Department of Public Health, University Centre for Nursing and Midwifery, Ghent University (Ms van Eechoud and Drs Grypdonck and Verhaeghe); Department of Social Sciences, KU Leuven (Dr Leman); Department of Geriatrics, Ghent University Hospital (Dr Van Den Noortgate); and Department of Family Practice and Primary Health Care, Ghent University, Belgium (Dr Deveugele).

This study was funded by a grant from the Flemish League Against Cancer.

The funder had no role in the study design, or in the collection, analysis, interpretation or presentation of the information.

The authors have no conflicts of interest to disclose.

Correspondence: Ineke J. van Eechoud, MSc, Department of Public Health, University Centre of Nursing and Midwifery, Ghent University, UZ - 5K3, De Pintelaan 185, B-9000 Ghent, Belgium (ineke.vaneechoud@ugent.be).

Accepted for publication December 18, 2014.

DOI: 10.1097/NCC.0000000000000239

This study provides new insights into the moral and practical meaning of caregiving, which will help professionals understand the roles adopted by family members. Furthermore, individualized approaches to care appear to be essential, because concrete ideas about informal caregiving differ strongly despite shared values.

Although Belgium is characterized by increasing diversity in its population, little is known about the experiences and perspectives of care users from ethnic minority groups. The Belgian healthcare system has been recognized as 1 of the most equitable in the world¹; however, its commitment to diversity is rather weak.² Among other things, healthcare organizations in Belgium have no official obligation to pay attention to diversity, leading to implicit denial that there may be discrimination in the delivery of healthcare.^{2,3} There are state-funded intercultural mediators, but their practice is limited to hospitals, and few interpreting services exist in outpatient settings.^{1,2}

Moreover, the proportion of people from foreign countries in the aging population of Flanders (the Dutch speaking part of Belgium) is rising, as in other Western European countries.⁴ Given the higher incidence of cancer in older age groups,⁵ it is expected that oncology health professionals will increasingly confront patients of diverse ethnic and cultural origins. The 2 largest non-European immigrant groups of people older than 55 years in Flanders are of Turkish or Northwest African descent.⁴ The ethnic roots of the 2 groups differ, but they share a similar immigrant history, as the majority came to Belgium as young labor immigrants between 1960 and 1975.⁴ Furthermore, both groups live in Belgium as a Muslim minority.

It has widely been acknowledged that cancer affects both the patient and the family.⁶⁻⁸ Family members play an essential role in the cancer trajectory^{9,10} and often provide emotional and practical support.¹¹⁻¹⁵ Many studies have focused on the burdens, needs, and coping strategies of family caregivers; being a caregiver causes many emotional, health-related, social, and financial strains.¹⁶⁻²⁰ On the other hand, caregiving also appears to have positive effects on family members, such as revised life priorities, an improved relationship with the patient, and feelings of fulfillment.^{9,13,18,21-24}

Relatively little research has been undertaken with regard to family members of ethnic minority cancer patients.^{6,25-27} Among the studies about caregiving with specific attention to race, ethnicity, or culture, the 20-year review (1980-2000) of Dilworth-Anderson and colleagues²⁷ provides good insight. Although the included studies mainly concerned caregiving to patients with dementia/Alzheimer disease, and most were conducted in North America, the review makes the point that culture affects caregiving experiences and "cultural groups have values about reciprocity (giving back), filial obligation, and a sense of responsibility for providing care to older family members."^{27(p266)} Similar conclusions about the importance of normative cultural values on family caregiving are also drawn in other studies.^{19,28-30} More recently, an extensive systematic review of family members' care and communication with incurably ill Turkish and Moroccan patients points out that family members are crucial care providers for incurably ill Turkish and Moroccan patients and that many patients expect

their children and their children's partners to care for them.³¹ Two quantitative Dutch studies confirm that adult children and older parents with a Turkish or Moroccan background adhere far more strongly to norms of filial responsibility compared with native Dutch.^{32,33} However, with regard to providing support, the patterns become more complex,³³ and care for older parents is no longer as self-evident as it traditionally was.³⁴

Therefore, it is important to gain insight into the experiences and perspectives of family members, presumably adult children, of older adult cancer patients of Turkish or Northwest African descent who are living in Belgium. Through gaining this insight, this study could enhance the limited knowledge about the experiences of family members of ethnic minority patients in a Western European country. Understanding the experiences and perspectives of family caregivers allows healthcare professionals to tailor interventions and support, thereby improving outcomes.

■ Methods

Design

A qualitative methodology, with elements of the constructivist grounded theory,³⁵ was chosen because it is well suited to gather data on *how* family members experience and perceive the patient's disease and the care situation. Although the study concerns a multicultural context, it is not an anthropological study. The aim is not to enrich anthropological theory but to use insights from several disciplines, including anthropology, to understand as far as possible the lived experience of a vulnerable group in healthcare.

Definition of Culture

Culture is defined here as "a process through which ordinary activities and conditions take on an emotional tone and moral meaning for participants."^{36(p1674)} This means that cultures are not fixed entities or things,³⁷ culture is not static or homogeneous, and "cultural processes frequently differ within the same ethnic or social group because of differences in age cohort, gender, political association, class, ethnicity, and even personality."^{36(p1674)}

Participants

Participants included adult family members of patients who were 50 years or older, diagnosed with cancer or a severe hematologic disease (with increased risk of developing leukaemia), and Turkish or Northwest African (Moroccan, Algerian, or Tunisian) by birth. The sample consisted of family members of patients who were in different stages of the illness trajectory. Participants were recruited from multiple settings and through different

channels in Flanders (Table 1). Because it proved difficult to recruit participants, several attempts were made in new settings and different recruitment channels. Healthcare providers, and in 1 case a participating family member, asked permission for the researcher to contact family members and provide more information on study goals and the nature of the interview. Of 43 potential participants, 5 refused to be contacted when the healthcare providers asked permission, and 6 refused to participate when asked by the researcher. One interview took place unintentionally with 3 family members of a deceased patient whose death appeared to have been caused by kidney failure rather than cancer. The research team decided to include this interview as it enriched the constant comparative method. The differing diagnosis was taken into account in the analysis process.

The study protocol was approved by the ethical committees of the involved hospitals (B670201111438). Written informed consent was obtained for all interviews.

Data Collection

Data were collected via 28 loosely structured interviews with 32 family members. All interviews were conducted by the same researcher. At the request of the participants, 2 interviews took place with 3 family members together. Twenty-three participants were adult children; 3 were daughters-in-law, and 6 were spouses. The mean ages of the family members and the patients were 37 and 64 years, respectively (Table 2).

The interview framework was based on the literature and previous research³⁸⁻⁴⁰ and was discussed with experts in medical and nursing care and intercultural care for older migrants. The interviewer attempted to elicit personal narratives from the interviewees on their experiences with and ideas about the patient's disease, the care situation, and their experiences and ideas about their role in caregiving and their experiences with professional caregivers and the medical care system. Basic demographic information was also collected. To invite participants to speak, each interview started with the following question: "I understand your family member is diagnosed with a severe illness/has died. Can you tell me something more about this?" As the interviews and analyses progressed, the focus of the interviews changed to pursue deeper understanding of central themes emerging from the data.

The interviews had a mean duration of 97 minutes (range, 32-185 minutes). According to participant preference, 20 interviews occurred in homes, 10 in a private room in the hospital, and 2 at

Table 2 • Descriptive Information About Family Members (n = 32 of 27 Patients)

Characteristic	n
Gender of family member	
Male	10
Female	22
Gender of the patient	
Male	16
Female	16
Relationship	
Husband	2
Wife	4
Daughter	15
Son	8
Daughter-in-law	3
Diagnosis	
Cancer	26
Myelodysplastic syndrome/aplastic anaemia	3
Severe kidney failure (deceased)	3
Patients deceased by the time the interview took place	10
Age of the family member, y	
21-30	11
31-40	13
41-50	3
51-60	2
61-70	3
Age of the patient, y	
51-60	15
61-70	8
71-80	7
>80	2
Country of birth of the patient	
Turkey	12
Morocco	16
Tunisia	2
Algeria	2
Origin of family member	
Turkish	11
Moroccan	17
Other: Belgian, Polish, Macedonian, Algerian-Moroccan	4

the workplace. All interviews but 1 were audiotaped and transcribed verbatim. One participant refused tape recording of the interview. The interviewer took notes during that interview and wrote a detailed report the same day. Field notes were made about interactions with all family members, interview settings, and the atmosphere. Although the ability to speak Dutch was not required to participate in the study, all but 1 participant knew enough of the Dutch language for sufficient expression; a professional translator assisted in the interview with the excepted participant.

Data Analysis

Data collection and data analysis alternated in a cyclic process and continued until theoretical saturation.⁴¹ Constant comparative analysis, 1 of the defining components of grounded theory, was conducted.³⁵ The process of analysis in this study is comparable with the Qualitative Analysis Guide of Leuven.⁴² It is important

Table 1 • Recruitment Settings and Channels in Flanders

Settings and Channels
Oncology wards
1 Academic hospital
3 Regional hospitals
General practitioners
Home care nursing organization
Staff member of the Flemish League Against Cancer
Participating family member (snowball method)

to emphasize that the stages were not discrete and linear.⁴² On the contrary, the analysis moved among the different stages, and the process of analyzing started after the first interview and continued until theoretical saturation.⁴² The first stage in the analysis consisted of a thorough reading of the transcribed interviews. To further explore the meaning of the narrative, 2 researchers discussed the interviews together in a second stage of analysis. In addition, a quarter of the interviews were read and discussed with a third researcher who is an anthropologist specializing in interculturalism and Mediterranean cultures. In a third phase, themes were identified, and theoretical notions were developed by continually comparing fragments within and among the transcribed interviews. In stage 4, transcripts were reread, and relevant fragments were linked to appropriate codes⁴² using the qualitative software program NVivo 10 (QSR International, Doncaster, Australia). In the final phase, themes were refined through confrontation with new data. During the analysis, all decisions were made by researcher triangulation, thus contributing to the credibility of the analysis.⁴³

To allow better understanding of specific themes and to consider the field of possible interpretations of the data, 6 experts or privileged witnesses involved in transcultural healthcare or religious matters (Table 3) were consulted. Topics for discussion included illness, healthcare, and family care in the respondent's culture and religion.

Preliminary results were discussed a total of 5 times with 3 different groups of experts: the steering committee of the research project, a group of 15 nurse consultants and clinical nurse specialists in oncology, and a group of experts in diversity and healthcare. The experts were asked to provide alternative interpretations, which were used to confront the data.

■ Results

Two central themes and several subthemes resulted from the analysis of family member narratives. The first central theme, that cancer was a family matter in which the experiences and perceptions of the participants were embedded, enclosed the second central theme: caregiving had a strong meaning, both moral and practical, for all family members. The moral meaning encompassed a deeply felt moral obligation. The practical meaning of caregiving was divided into the following subthemes: a description of caregiving ("being a guide"), division of caregiving tasks, and the use of professional care. The following discussion presents the details of these findings.

 **Table 3 • Information About Experts**

Expertise
Iman
Academic expert in traditional healing methods in Morocco
Traditional healer
Academic expert on Turkish Muslims in Europe
Consultant of an integration service
Turkish intercultural mediator

Characteristics of the Families

Many participants came from families with an average of 6 children. In almost all families, at least some of the adult children lived close to their parents. In most cases, parents came to Belgium as young adults, and the children were either born in Belgium or were brought to Belgium at a young age. A few of the patients had immigrated to Belgium as middle-aged or older adults. In some cases, adult children brought their parents to Belgium because of health problems, or they stayed on after a visit to Belgium. Most of the patients and their spouses had a poor command of the Dutch language, whereas most children spoke Dutch well. All but 1 family member referred to Islam as their religion. However, this varied among participants, some of whom stated religion was paramount in life, whereas others mentioned that they did not really practice their religion. Based on the demographic data collected during the interview and the interviewer's observations about the participants' appearances and their living conditions, the participants represented diverse social classes.

Central Themes—Cancer: A Family Matter

The cancer diagnosis concerned the whole family. Family members described feeling responsible for making sure that what was needed would happen, and they played an active role in bringing it about. The role played by the patient differed. Sometimes the patient acted together with family members, and in other cases, the family members decided what should happen without consulting the patient. In several cases, the patient was left out of the decision making deliberately so that the family could do what they thought necessary.

We [children and children-in-law] dragged him to the hospital, because he doesn't understand it [the Belgian healthcare], he is not familiar with it, and he doesn't want to know about it and about doctors. Not about the disease. It was already difficult for him to go there, he would rather prefer to stay home and die. He doesn't want to know anything about hospitals. He is not familiar with it; he doesn't want to go there.
(Daughter-father with Moroccan background)

The following quote illustrates how in other families the patient participated more fully:

We discussed it [treatment options]. We are one family. We are.... He has 8 children; 7 were still alive. And everyone had his say in it. [...] No one wants to let his father go too early, so... So everybody thought about it and took part in decision making. Useful or not. And at the same time gave him some freedom to make his own decision consciously. (Daughter-father with Moroccan background)

The Meaning of Caregiving: Moral and Practical

THE MORAL MEANING OF CAREGIVING

Taking care of an older adult family member had a strong moral meaning for all the participants, particularly when it pertained

to caring for a parent. The adult children experienced a deeply felt moral obligation (which is not the same as an imposed duty) toward a parent. Participants were both intrinsically and extrinsically motivated to take care of the patient. They mentioned that they felt "in their heart" that caregiving was the right thing to do (intrinsically motivated), as well as that it was something they were "supposed to" or "obliged to" do (extrinsically motivated). Love and fear of losing the patient were intrinsic motivations to take good care of their mothers or fathers. The family members had internalized the idea that a parent needed to be taken care of and that this responsibility devolved first and foremost to the children. They maintained this standard by providing good care. The parent deserved it or had earned the right to it by having borne the burdens of parenthood.

Adult children often mentioned that caring for a parent diagnosed with cancer is the least they could do because "they brought you into the world and raised you."

They [parents] took care of us too, so you need to take care of them in return, you see. That's the way we think about it [...] they took care of you. When they are in need of care, you must take care of them. It's just the way it is. (Daughter-in-law–father-in-law with Moroccan background)

They are still my parents. I won't say, you raised me, and that's it. (Son–mother with Turkish background)

Some family members explained that taking care of a mother had an even stronger moral meaning than taking care of a father, as she is the one who "carried you for 9 months."

Daughter: She took care of you for years. And for us that's how it is, your mother, your father, they are the most important persons in your life. I think for everybody, but for us in our religion, you need to be good to your parents. You need to be good to everyone, but certainly to your parents. [...] Certainly to your mother.

Interviewer: Yes, certainly to your mother?

Daughter: Yes, because it's a saying, you know, your mum carried you 9 months; it doesn't matter what you ever did, you will never be able to give enough in return. A mother, to us, is highly valued in the family. (Daughter–mother with Moroccan background)

The source of the deeply felt moral obligation to take care of family members was most often explained as a cultural or religious matter and sometimes as "natural." The participants often mentioned a difference between "their" way of taking care of older or ill family members and the way of native Belgians.

From Islamic perspective, you need to take care of your father, right, or of your mother [...] I thought it was my duty as a Muslim to do this. (Son–father with Moroccan background)

To us in, in Turkish families, I think so too in Tunisian and Moroccan, if, for example, 1 person in the family is ill, we all must help each other. You should not remain distant from it. (Daughter-in-law–mother-in-law with Turkish background)

In my case, caring for parents is ingrained. It is ingrained in us, we sometimes do not understand, like "come on, why do they [healthcare workers] consider it special what we do?" And then you give it a moment's thought and start to realize, wait a second, I see, here [in Belgium], it is not like that. We do not have old people's homes. (Daughter–mother with Moroccan background)

Although taking care of the patient was often experienced as a difficult task, many family members described a feeling of satisfaction resulting from it or peace of mind, because taking good care of one's older adult family member with cancer was felt to be the right thing to do.

• I think that we psychologically strongly supported her and that she was very satisfied with us emotionally. It made me feel good to be able to achieve this. [...] That I was able to do something after all [...]. The right of mothers is beyond any value to us. And I believe I... to her a little, you see, after everything she did for me, I was able to do something for her of significance and about which she was satisfied. (Son–mother with Turkish background)

I am glad she permitted the assistance. For us it was a way to be there for her. She has always been there for us... And now we were able to give something in return [cries]. (Daughter–mother with Moroccan background)

We didn't let her down; we take care of each other together. My mum and dad, we feel well when we lay our head down on bed, on our pillow, we sleep, we can sleep after all. Some people do not help their parents; I wonder, how can these people sleep? (Daughter–father with Turkish background)

Some family members also referred to a possible benefit for themselves by taking good care of the patient, as they hoped they would be taken care of when needed.

It gives a good feeling, to be able to help someone. And you never know, in case I need help, it will be there too. (Wife–husband with Moroccan background—with translator)

The only thing I can do is to take good care of her, always be polite and respectful. And I hope my children will do the same for me. [...] Allah, God wrote it also down for us that you should respect your parents. If you want respect, you should give respect to your parents first. And your children will do it for you in return. Insha'Allah, I hope so. (Daughter–mother with Turkish background)

The general pattern, in which caregiving carried a strong moral meaning, was not evident in 1 case. This family member was the Belgian wife of a Northwest African man. She was the only participant who explicitly mentioned that she and her husband were not religious at all. She stated that their 2 children played only a minor role in the care for their father. She was the main family caregiver for her husband, and when the interviewer asked about the caregiving tasks of the children, she explained that they had already left the parents' home. Later she stated that

the children "have a life of their own" and that her husband, influenced by the Northwest African mentality, would have liked the children to pay more attention to him, but "he can't compel them."

Family members who reported a loving relationship with the patient perceived caregiving tasks as less burdensome compared with family members who lacked a loving relationship. A few interviews also revealed that the intrinsic motivation for caregiving played a lesser role when there was a negative relationship between the patient and the family member. However, this was not always the situation. In 1 case where a reduced intrinsic motivation was strongly present, the family member, a daughter-in-law who described a sequence of bad experiences with her father-in-law, chose to play a minor part in the caregiving for her father-in-law, even though she attached strong moral meaning to caregiving for older family members.

The Practical Meaning of Caregiving: What Does Caregiving Entail?

Moral obligation in practical terms meant making sure that the older family member received the appropriate care. In most cases, family caregivers ensured that all the patient's needs received attention. Both emotional and practical care were provided, such as physical and domestic caregiving at home, acting as a contact person or a translator for healthcare providers, "being" with the patient, searching for a cure (via alternative treatment), mental support, and sharing the financial burden of illness (such as costs related to transport to and from the hospital or the country of origin, alternative medication, food, and professional care).

SUBTHEME 1: "BEING A GUIDE" THROUGH THE BELGIAN HEALTH CARE SYSTEM

Most participants considered their primary task to be ensuring that the patient received the most beneficial care possible. The role of family members varied, but can best be described as "guiding" the patient through the Belgian healthcare system. They helped the patient to navigate the healthcare system, provided advice on events and choices, and supported the patient in coping with the experiences of diagnosis and treatment. They made sure that, despite the patient's unfamiliarity with the system and limited knowledge of the language, the appropriate care was provided.

The difference, mentioned above, between acting together with the patient or acting on behalf of the patient was also reflected in the "guiding style" of family members: some "guided" the patient by directing events and making choices, and others tried to empower the patient to understand what was happening and which decisions needed to be taken.

The following quote is from a family member who attempted to empower the patient as a "guiding style":

I was raised here, I have my own driver's license, I know the language. [...] My mommy depends on me actually. I go with her, I make the appointments, I talk to the doctors, I go to the emergency department, you know. [...] I said to my mom a couple of times already, try to manage yourself

a little, because I do not work for the moment, as I have a career break. Imagine that I had been working. You need to be able to go your own way a little, you know. Imagine that someday I can't be there, for example. What will happen in case I am ill or I don't know what, you don't know what will happen then, right? (Daughter-mother with Turkish background)

In contrast, family members sometimes took on a "directing guiding style," as previously illustrated by the daughter who explained that she, together with her brothers and sisters, "dragged" their father to the hospital.

SUBTHEME 2: DIVISION OF CAREGIVING TASKS

Caregiving was often coordinated by 1 or a few of the children, who saw to it that all the patient's needs were met to the fullest extent possible and who took responsibility for organizing support. Often, they were assisted by other family members who provided as much practical help as they could.

The participants described the division of care tasks as mainly pragmatic: a particular task is fulfilled by the person most suited or in the best circumstances. Circumstances considered good or bad in terms of caregiving tasks included: being employed (full- or part-time) or not, having a family of one's own (children to take care of) or not, being in good health or not, and the distance between the place of residence and the home of the patient.

Interviewer: What was your main reason to say: "I will do this [taking care of your mother]?"

Daughter: Just because for me it was more easy... I lived at home. And I simply had most time, didn't have children, I didn't have a family. So I was just able to do that, practically. (Daughter-mother with Moroccan background)

I was with her always. But I left in the evening, to my own home, I had 3 children too, my husband had to go to work, and things like that. I had to be at home, right? And my brothers stayed there, with my dad and my mum. (Daughter-mother with Turkish background)

Suitability to task pertained to contact with professional caregivers. Familiarity with the Belgian healthcare system (including general health literacy) and mastery of both the Dutch language and the patient's language were seen as key characteristics.

Interviewer: What is the reason that 1 of the 2 of them [2 of 5 children who are nurses] went along [to consultations with the doctor]?

Wife: Well, because it was the most practical... how can I explain? It is their field, they are nurses. They will more easily understand something in case of terms related to treatment or something or another. (Wife-husband with Algerian background)

Although caregiving tasks were usually divided among family members along pragmatic lines, some participants referred to the position of the "eldest son" or the role of responsibility within the family. When a family member did not fulfill an expected caregiving task, the others took over. In most cases, this

did not seem to cause relational issues between siblings. When others did less than was expected, the obligation to make sure parents received the care to which they were entitled was not diminished; it was increased for other family members.

In contrast, the division of tasks concerning intimate matters, such as personal hygiene and conversations with healthcare providers about issues related to sexuality, was mainly determined by gender. However, when needs could not be met according to these rules, needs prevailed, and rules were bent.

For a male patient, a spouse was preferred for the performance of intimate care tasks. The second preference was for a son, but this was sometimes perceived as unsuitable and emotionally difficult. A daughter was perceived as the most inappropriate choice for intimate caregiving; nevertheless, some daughters did provide care when no one else was available. Similarly, for female patients, a daughter or the husband was perceived as the most suitable choice. Some sons provided this type of care for their mothers, but the experience was emotionally charged. None of the 3 daughters-in-law who participated in this study carried out intimate care tasks.

I have done that, changing diapers and things like that. But doing this for my mother, it was very painful, because I always... my mother, as to say, she was really a kind of father figure at home. (Son-mother with Turkish background)

Daughter: I have 2 other brothers and to the doctor he [father] goes with my brother. I go with my mum, my brother accompanies my dad. [...] helping my father to the toilet, if my brother is in the room, I would rather not go.

Interviewer: In that case, your brother goes?

Daughter: Yes. In our religion, it is like that actually [...] in case my brother is not in, I will go.

But when my brother is in, I won't go. It depends [...] rather girls with the mother. [...] Generally, it is like that; in Turkish culture, it is like that. Without, in case I wouldn't have a brother, I should give them both [mother and father] a bath. I never gave my father a bath [...], my brother always gives my father a bath. [...] once in every 2 days.

Interviewer: Every 2 days, yes. What if your brother wouldn't manage it, would you do it?

Daughter: Yes, we did that, but uhm... I let him keep on his underwear, and afterward I said, take it of yourself, and wash yourself down there. Not naked constantly, with my brother he is naked constantly, right? I did the toilet, but not underneath. Because my brother returned Monday, he returned from Mecca Monday last week [...]. He was away 2 weeks, 18 days and in the meantime, I did the washing. (Daughter-father with Turkish background)

Combining an extensive caring role with full-time employment and dependent children was especially demanding. This was most apparent when family members were unable to share care tasks with relatives.

SUBTHEME 3: USE OF PROFESSIONAL CARE

In general, professional caregivers were engaged only if family members believed they lacked the competencies required and that professional care would be superior. This concerned mostly medical care or technical nursing tasks. However, there was strong disagreement among participants as to how care should be organized and which professional care was desirable. For example, family members differed in their ideas about transport service to and from the hospital. One daughter mentioned that making use of this service was something that no one "among them" would ever do and something she could not think of doing. In contrast, other family members explained how useful this service was and how happy it made them and the patient.

Admission of patients to palliative care elicited similar responses. Two of the participants had chosen to have the patient admitted to a palliative care unit (one with and one without patient involvement). Both family members described very positive experiences with the care provided.

But at the palliative care unit, I thought it was very positive. The commitment of these people, the way they really create an atmosphere in which you are truly able to say goodbye to your loved one, and things like that. (Daughter-mother with Moroccan background)

Some other participants were made aware of palliative care services and decided not to admit the patient, because they (or the patient) preferred the patient to die at home surrounded by relatives. A son and his mother and sister explicitly stated that admitting their father/husband to a palliative care unit went against their principles regarding fulfillment of the moral obligation of caregiving.

Son: We didn't want that [admission to a palliative care unit] [...]. It doesn't suit us, you see yes, it doesn't suit us.

Daughter: In our Islam, it's...

Wife: Islam.

Son: For us, according to our religion and, uhm..., to honor your parents, or whom it may be. You see, it's impossible. It's out of the question.

Interviewer: And what... can you explain it a bit more, what is exactly out of the question?

Son: Uhm... Yes... uhm, in case you have children, for us it is system, culture. If you have children, your children need to take care of you. In bad times. And if you don't do that, it is bad also. As to say, it is a bad example for society too. For us, it's something... yes, it is not allowed. It is not allowed. You have to take care of your parents.

Wife: Yes.

Daughter: Till death.

Son: They took care of you. They took care of you, right, until this moment for example. And it's your turn now. (Daughter, wife, and son—patient with Turkish background)

All Belgian healthcare facilities were considered acceptable by some of the participants. Even admission to a nursing home, seen by most participants as beyond consideration, was still acceptable to some family members, provided the facility respected the religion, language, and culture of the parent.

There were discrepancies between family member and parent perceptions of the desirability of professional support. For example, some family members wanted to hire cleaning people, but as the patient thought this was the children's duty, the children did the chores. Some family members reported doing more for their parents than they expected from their own children. They attributed lower expectations to familiarity with the Belgian health care system and their ability to communicate with healthcare workers. Apparently they believed they would need less support than did their parents.

In summary, the narratives of the family members' experiences revealed that cancer was considered a family matter. Embedded within this context, caregiving had a strong meaning, both moral and practical, for all family members. Particularly, the adult children experienced a deeply felt moral obligation toward caring for the sick parent. Most participants considered their primary task to make certain that the patient got the most beneficial care possible. An important characteristic of caregiving is providing the "guiding" role through the healthcare system. The division of care tasks within the family is pragmatic. However, more intimate care tasks are generally determined by the gendered position of a family member. Although in general, family members are considered to be the most appropriate caregivers, opinions differed as to how care should be organized and which professional care was desirable. While participants have strongly shared principles and values, their concrete ideas about daily care practices differed considerably.

■ Discussion

For the participants in this study, when an older adult relative of Turkish or Northwest African descent had cancer, the disease was considered a family matter, and caregiving held strong moral meaning for all participants. As previously discussed, the importance of family for cancer patients has been widely acknowledged in the literature. However, the emphasis on patient autonomy in contemporary Western biomedicine⁴⁴ was not shared by the participants in this study, who perceived the family as the "principal actor" instead of the patient alone. The strong moral meaning caregiving had for all family members, in particular for adult children taking care of a parent, is in accordance with literature specifically concerned with the ethnic-cultural minority groups we studied.³¹⁻³⁴ Only a few qualitative studies on West-European family caregivers, mainly partners, point out the meaningfulness of supporting or taking responsibility in caregiving.²¹⁻²³ The current study provides further insight into the reasoning behind the value family members attached to caregiving, which they compared with persons of Belgian origin. The intrinsic and extrinsic motivations for caregiving are similar to a Turkish study pointing out motives for caregiving, including responsibility and social obligation, and emotional and personal

connectedness.⁴⁵ In the context of culture as defined in this study, the narratives show that culture is the process through which caregiving takes on an emotional tone and strong moral meaning for the family members.^{36,37}

Despite the shared values of the importance of family and family caregiving in the illness trajectory, concrete ideas about how care should be organized and what type of professional care is desirable differed considerably among the family members. Understanding shared values can help nurses and other healthcare providers accommodate the roles family members adopt, for example, the presence of an adult child with an ill parent. However, the results also illustrate that shared cultural or religious normative values do not predict the daily care practices and preferences of family members. Reducing cultural competency to a list of "do's and don'ts" is useless and may be dangerous.³⁶

The complexity of understanding family roles in caregiving is even more apparent when considering the division of caregiving tasks within these families. Although the division of more intimate tasks was determined by gender,⁴⁶ care tasks were generally assigned to family members on pragmatic grounds such as the life circumstances and capacities of each person. This finding is similar to the study on informal caregivers in Turkey.⁴⁵ The few West-European, mainly Dutch, studies on family caregiving in Turkish and Northwest African minority groups describe a somewhat more static picture of family care as an obligation in which mostly female relatives are heavily burdened.^{31,47} The findings from this study are comparable to the conclusions of the anthropological study of Yerden³⁴ on care expectations and care practice (non-cancer related) among 3 generations of Turkish immigrants in The Netherlands. Family care remains central, but traditional care is subject to change, and care practice has become a combination of traditional and new forms.³⁴ We might well speak of new forms of family care practices within "old" values of family care.

Characteristic of family caregiving is the "guiding" role that family members adopt. Often adult children, who have been raised in Belgium, led the patient through or familiarized the patient with the healthcare system. They made sure that the most beneficial care was provided despite the patient's unfamiliarity with the system and his/her limited knowledge of the language. Understanding the "guiding role" and the high level of responsibility this involves is useful for nurses and other healthcare providers. To our knowledge, this has not been explicitly identified elsewhere, although previous studies on cancer caregiving have shown that family members take on advocating,⁴⁸ sometimes leading,⁴⁹ and other active roles with regard to communication with healthcare providers.^{15,20,50} One other study notes that Turkish family members in The Netherlands act as intermediaries between healthcare professionals and their mostly non-Dutch-speaking parents.⁴⁷

Limitations

This study had several limitations. Because of ethics committee requirements, no information could be obtained about potential participants who had not been approached by healthcare providers or potential participants who refused to be contacted by

the researcher. It was difficult to recruit participants, and some healthcare providers reported reluctance to ask potential candidates permission for the researcher to contact them. This might have caused a less diverse sample compared with the general population of family members of these patient groups. However, of the 43 potential participants who were asked to participate, only 11 refused.

This study provides insight into the experiences and expressed motives of family members involved in caregiving and only to a limited extent into motives for not being involved in caregiving. Hence, the findings might not be generalizable to family members of these immigrant groups in general.

Although the sample consisted of family members of patients in different stages of the illness trajectory, because of the cross-sectional study design, insight into the care experience is limited to the information obtained during a single interview with each family member.

Reflection

The researcher who conducted the interviews was a woman of approximately 30 years of age; therefore, she belonged roughly to the same age group of most participants. As she was of West European origin, the narratives were constructed from an interactive process between a West European researcher and family members of Turkish or Northwest African origin. This may have affected the results in the sense that participants explicitly explained cultural or religious values to the researcher of another cultural, ethnic, and religious group. Because the researcher was employed by the Faculty of Health and Medical Science, she might have been perceived as part of the Belgian healthcare system. In order to obtain valid data, the researcher tried to behave as free from value judgement as possible, by being well aware of her own background, characteristics, and opinions.

Future Research

It would be beneficial to study the family member perspectives within a triad including the patient and professional caregiver perspectives. This would provide insight into perspectives of care users as well as a better understanding of the perspectives of healthcare providers caring for people with culturally diverse backgrounds. The current study provides a useful basis for future research on this subject.

Contrary to the static way culture is often defined in medicine,^{36(p1673)} the current study empirically confirms the dynamic definition of culture as "a process through which ordinary activities and conditions take on an emotional tone and moral meaning for participants."^{36(p1674)} In future studies on diversity in healthcare, researchers should be clear and thoughtful about the definition of culture they use.

Conclusion and Clinical Implications

This study provides insights into the moral and practical meaning of caregiving for older adult cancer patients of Turkish or Northwest African descent, the 2 largest Non-European immi-

grant groups of people older than 55 years in Flanders.⁴ These insights will help nurses and other professional healthcare workers understand the roles family members adopt.

Cancer affects the whole family.⁶⁻⁸ This takes on particular form in Muslim immigrants from Turkey or Northwest African countries. Nurses, who have easy access to patients and their family members in the course of their activities, are well positioned to explore the role family members want to play and especially why they want to play that role. An open dialogue with family members exploring how to best provide care to the patient will best meet the needs of both patient and family members.

Cancer is considered a family matter, and caregiving has a strong moral meaning for all family members, particularly when providing care to a parent. Despite these shared principles and values, concrete ideas about how care should be organized and the type of professional care that is desirable differ considerably. This makes it essential that care is attuned to the individual. In fulfilling this, it can be helpful, to use Kleinman and Benson's words,^{36(p1676)} "to routinely ask patients and (where appropriate) their family members what matters most to them in the experience of illness and treatment."

Family members adopt a "guiding" role to lead the patient through and/or familiarize the patient with the healthcare system. As a nurse or other healthcare provider, it is important to take this into account. Family members should be supported in adopting this role, without limiting the patient in the exercise of his/her rights. In addition, it is important to realize that performing certain intimate care tasks can be perceived as strongly inappropriate within particular (gendered) family relations.

ACKNOWLEDGMENTS

The authors thank the participants who were willing to share their time and thoughts. They also thank the experts for sharing their knowledge with them. The authors are particularly grateful to Patricia Fruyt, head of the Department of Social Work and Intercultural Mediation of the University Hospital Ghent, for sharing her expertise with them.

References

1. Derluyn I, Lorant V, Dauvrin M, Coune I, Verrept H. *Towards an Intercultural Health Care. Recommendations of the ETHEALTH-Group for Equal Health Care for Migrants and Ethnic Minorities*. Brussels, Belgium: Federal Public Service Health, Food Chain Safety and Environment; 2011.
2. Dauvrin M, Derluyn I, Coune I, Verrept H, Lorant V. Towards fair health policies for migrants and ethnic minorities: the case-study of ETHEALTH in Belgium. *BMC Public Health*. 2012;12(1):726.
3. Lorant V, Bhopal RS. Comparing policies to tackle ethnic inequalities in health: Belgium 1 Scotland 4. *Eur J Public Health*. 2010;21(2):235-240.
4. Lodewijckx E. *Older People of Foreign Origin in the Flemish District: Origin, Socio-demographic Characteristics and Composition of Household*. Internal affairs of the Flemish Government, 2007. Internal affairs of the Flemish Government Web site. <http://www.vlaanderen.be/svr>. Accessed February 5, 2010.
5. Anisimov VN, Sikora E, Pawelec G. Relationships between cancer and aging: a multilevel approach. *Biogerontology*. 2009;10(4):323-338.
6. Kristjanson LJ, Ashcroft T. The family's cancer journey: a literature review. *Cancer Nurs*. 1994;17(1):1-17.

7. Nijboer C, Tempelaar R, Sanderman R, Triemstra M, Spruijt RJ, van den Bos GA. Cancer and caregiving: the impact on the caregiver's health. *Psychooncology*. 1998;7(1):3-13.
8. Harden J. Developmental life stage and couples' experiences with prostate cancer: a review of the literature. *Cancer Nurs*. 2005;28(2):85-98.
9. Haley WE. Family caregivers of elderly patients with cancer: understanding and minimizing the burden of care. *J Support Oncol*. 2003;1(4 suppl 2):25-29.
10. Ponto JA, Barton D. Husbands' perspective of living with wives' ovarian cancer. *Psychooncology*. 2008;17(12):1225-1231.
11. Blindheim K, Thorsnes SI, Brataas HV, Dahl BM. The role of next of kin of patients with cancer: learning to navigate unpredictable caregiving situations [published online ahead of print November 2, 2012]. *J Clin Nurs*. 2013;22(5-6):681-689.
12. Röing M, Hirsch JM, Holmström I. Living in a state of suspension—a phenomenological approach to the spouse's experience of oral cancer. *Scand J Caring Sci*. 2008;22(1):40-47.
13. Teschendorf B, Schwartz C, Ferrans CE, O'Mara A, Novotny P, Sloan J. Caregiver role stress: when families become providers. *Cancer Control*. 2007;14(2):183-189.
14. Pusa S, Persson C, Sundin K. Significant others' lived experiences following a lung cancer trajectory—From diagnosis through and after the death of a family member [published online ahead of print March 22, 2011]. *Eur J Oncol Nurs*. 2012;16(1):34-41.
15. McIlpatrick S, Sullivan K, McKenna H. What about the carers?: Exploring the experience of caregivers in a chemotherapy day hospital setting [published online ahead of print January 27, 2006]. *Eur J Oncol Nurs*. 2006;10(4):294-303.
16. Amir Z, Wilson K, Hennings J, Young A. The meaning of cancer: implications for family finances and consequent impact on lifestyle, activities, roles and relationships [published online ahead of print July 18, 2011]. *Psychooncology*. 2012;21(11):1167-1174.
17. Proot IM, Abu-Saad HH, Crebolder HF, Goldsteen M, Luker KA, Widdershoven GA. Vulnerability of family caregivers in terminal palliative care at home; balancing between burden and capacity. *Scand J Caring Sci*. 2003;17(2):113-121.
18. Clemmer SJ, Ward-Griffin C, Forbes D. Family members providing home-based palliative care to older adults: the enactment of multiple roles. *Can J Aging*. 2008;27(03):267-283.
19. Doumit MA, Huijter HAS, Kelley JH, Nassar N. The lived experience of Lebanese family caregivers of cancer patients. *Cancer Nurs*. 2008;31(4):E36-E42.
20. McConigley R, Halkett G, Lobb E, Nowak A. Caring for someone with high-grade glioma: a time of rapid change for caregivers [published online ahead of print February 1, 2010]. *Palliat Med*. 2010;24(5):473-479.
21. Bruun P, Pedersen BD, Osther PJ, Wagner L. The lonely female partner: a central aspect of prostate cancer. *Urol Nurs*. 2011;31(5):294-299.
22. Levesque JV, Maybery D. Parental cancer catalyst for positive growth and change [published online ahead of print September 2, 2011]. *Qual Health Res*. 2012;22(3):397-408.
23. Sand L, Olsson M, Strang P. What are motives of family members who take responsibility in palliative cancer care? *Mortality*. 2010;15(1):64-80.
24. Williams AL, Bakitas M. Cancer family caregivers: a new direction for interventions [published online ahead of print May 21, 2012]. *J Palliat Med*. 2012;15(7):775-783.
25. Mosher CE, Danoff-Burg S. Psychosocial impact of parental cancer in adulthood: a conceptual and empirical review. *Clin Psychol Rev*. 2005;25(3):365-382.
26. Dilworth-Anderson P, Brummett BH, Goodwin P, Williams SW, Williams RB, Siegler IC. Effect of race on cultural justifications for caregiving. *J Gerontol B Psychol Sci Soc Sci*. 2005;60(5):S257-S262.
27. Dilworth-Anderson P, Williams IC, Gibson BE. Issues of race, ethnicity, and culture in caregiving research: a 20-year review (1980-2000). *Gerontologist*. 2002;42(2):237-272.
28. Goodman CR, Zarit SH, Steiner VL. Personal orientation as a predictor of caregiver strain. *Ageing Ment Health*. 1997;1(2):149-157.
29. Knight BG, Sayegh P. Cultural values and caregiving: the updated sociocultural stress and coping model [published online ahead of print November 24, 2009]. *J Gerontol B Psychol Sci Soc Sci*. 2010;65B(1):5-13.
30. Anngela-Cole L, Busch M. Stress and grief among family caregivers of older adults with cancer: a multicultural comparison from Hawai'i. *J Soc Work End Life Palliat Care*. 2011;7(4):318-337.
31. de Graaff F, Mistiaen P, Devillé W, Francke A. Perspectives on care and communication involving incurably ill Turkish and Moroccan patients, relatives and professionals: a systematic literature review. *BMC Palliat Care*. 2012;11(1):17.
32. de Valk HA, Schans D. "They ought to do this for their parents": perceptions of filial obligations among immigrant and Dutch older people. *Ageing Soc*. 2008;28(01):49-66.
33. Schans D, Komter A. Ethnic differences in intergenerational solidarity in The Netherlands. *J Aging Stud*. 2010;24(3):194-203.
34. Yerden I. *Traditions, Care Expectations and Care Practices Among Elderly Turkish Immigrants and Their Children in The Netherlands* [dissertation]. Amsterdam, The Netherlands: University of Amsterdam; 2013.
35. Charmaz K. *Constructing Grounded Theory. A Practical Guide Through Qualitative Analysis*. London, UK: Sage; 2006.
36. Kleinman A, Benson P. Anthropology in the clinic: the problem of cultural competency and how to fix it. *PLoS Med*. 2006;3(10):1673-1676.
37. Kleinman A. Culture and depression. *N Engl J Med*. 2004;2;351(10):951-953.
38. Verhaeghe ST, van Zuuren FJ, Defloor T, Duijnstee MS, Grypdonck MH. How does information influence hope in family members of traumatic coma patients in intensive care unit? *J Clin Nurs*. 2007;16(8):1488-1497.
39. Verhaeghe ST, van Zuuren FJ, Defloor T, Duijnstee MS, Grypdonck MH. The process and the meaning of hope for family members of traumatic coma patients in intensive care. *Qual Health Res*. 2007;17(6):730-743.
40. van Eechoud IJ, Piers RD, van Camp S, et al. Perspectives of family members on planning end-of-life care for terminally ill and frail older people [published online ahead of print September 11, 2013]. *J Pain Symptom Manage*.
41. Boeije H. *Analysing in Qualitative Research. Think and Act*. Amsterdam, The Netherlands: Boom; 2005.
42. Dierckx de Casterlé B, Gastmans C, Bryon E, Denier Y. QUAGOL: a guide for qualitative data analysis. *Int J Nurs Stud*. 2012;49(3):360-371.
43. Côté L, Turgeon J. Appraising qualitative research articles in medicine and medical education. *Med Teach*. 2005;27(1):71-75.
44. Ho A. Relational autonomy or undue pressure? Family's role in medical decision making. *Scand J Caring Sci*. 2008;22(1):128-135.
45. Kuşçu MK, Dural U, Yaşa Y, Kızıltoprak S, Oenen P. Decision pathways and individual motives in informal caregiving during cancer treatment in Turkey [published online ahead of print June 1, 2009]. *Eur J Cancer Care (Engl)*. 2009;18(6):569-576.
46. Yerden I. *Concerns About Care. Traditions, Kinship Relations, Migration and Care for Turkish Older Persons in The Netherlands*. Amsterdam, The Netherlands: Het Spinhuis; 2000.
47. van den Brink Y. Diversity in care values and expressions among Turkish family caregivers and Dutch community nurses in The Netherlands. *J Transcult Nurs*. 2003;14(2):146-154.
48. Balneaves LG, Bortoff JL, Grewal SK, Naidu P, Johnson JL, Howard AF. Family support of immigrant Punjabi women with breast cancer. *Fam Community Health*. 2007;30(1):16-28.
49. Sinfield P, Baker R, Agarwal S, Tarrant C. Patient-centred care: what are the experiences of prostate cancer patients and their partners? [published online ahead of print June 18, 2008]. *Patient Educ Couns*. 2008;73(1):91-96.
50. Hricik A, Donovan H, Bradley SE, et al. Changes in caregiver perceptions over time in response to providing care for a loved one with a primary malignant brain tumor. *Oncol Nurs Forum*. 2011;38(2):149-155.