

# Balancing truth-telling: relatives acting as translators for older adult cancer patients of Turkish or northwest African origin in Belgium

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VAN EECHOUD I., GRYPDONCK M., LEMAN J., VAN DEN NOORTGATE N., DEVEUGELE M. & VERHAEGHE S. (2016) *European Journal of Cancer Care*

**Balancing truth-telling: relatives acting as translators for older adult cancer patients of Turkish or northwest African origin in Belgium**

The first generation of Turkish and Northwest African immigrants in Belgium are ageing and at risk for developing cancer. Relatives play an important role and provide both emotional and practical care, including mental support and acting as a contact person and/or a translator for improving access to healthcare, as most patients and their spouses have only a limited command of the language. Although access to professional interpreters has shown to be the best guarantee for qualitative healthcare, oncology health providers working with relatives as interpreters is much more common than professional interpreters. The aim of this study was to provide insight into the process wherein relatives balance truth-telling in translating for an older family member diagnosed with cancer. This was a qualitative research study, with elements of constructivist grounded theory. Twenty-eight loosely structured interviews were conducted. Most relatives consider it their responsibility to contribute to a positive attitude of the patient. Relatives decided to what extent they inform the patient, based on several motives and embedded in their assessment of the patient's emotional strength, understanding and need to be informed. What they decide influences the way they act as a translator and/or a contact person between the patient and health professional(s). Some considered it best to omit medical information while others considered it best to inform the patient fully. The results emphasise the importance for healthcare providers to take into account the complexity and unpredictable character of the process of balancing truth-telling when family members translate for their ill older relative.

**Keywords:** family, ethnic and cultural diversity, oncology, older adult, truth-telling.

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Accepted 10 March 2016

DOI: 10.1111/ecc.12498

*European Journal of Cancer Care*, 2016

## INTRODUCTION

As in other West-European countries, Belgium is realising increasing ethnic diversity in its population. More than 18% of the population in the Flemish region, the Dutch speaking part of Belgium, is of foreign descent (Noppe

2015). About half of these inhabitants of foreign descent, or one of their parents, are born in a country outside of the European Union (SVR 2014). Furthermore, the proportion of people from abroad is rising in the ageing population (Lodewijckx 2007). As the incidence of cancer is higher in older age groups (Anisimov *et al.* 2009), it is expected that oncology healthcare providers will increasingly confront patients of foreign descent. Five per cent of all people older than 55 years in the Flemish region are of foreign descent; this share, as well as the number, will rise in the near future (Lodewijckx 2007). People from Turkey or North-west Africa account for the two largest non-European immigrant groups of this age and account for about 20% of all, European and non-European, older immigrant groups (Lodewijckx 2007). The majority of both groups came to Belgium as young labour immigrants between 1960 and 1975 and live in Belgium as a Muslim minority (Lodewijckx 2007). Literature shows that respectively 19% and 16% of immigrants of Moroccan and Turkish descent in Flanders reported (very) little understanding of what people say in Dutch – the official language of Flanders (Vancluysen *et al.* 2008). Furthermore, Dutch language proficiency within these ethnic groups is lower in older age groups (Vancluysen *et al.* 2008).

It has been widely acknowledged that family members play a crucial role in the patient's cancer trajectory (Haley 2003; Ponto & Barton 2008). Although much qualitative research has been undertaken exclusively with regard to family members of western origin, relatively few studies have focused on relatives of ethnic minority patients (Kristjanson & Ashcroft 1994; Dilworth-Anderson *et al.* 2002, 2005).

Family members of cancer patients often provide practical as well as emotional support (McIlpatrick *et al.* 2006; Teschendorf *et al.* 2007; Röing *et al.* 2008; Pusa *et al.* 2012; Blindheim *et al.* 2013). Some studies explicitly point out that family members try to protect the patient from unpleasant information (Steinvall *et al.* 2011), keep peace and maintain an upbeat atmosphere (Teschendorf *et al.* 2007), and try to keep hope alive (Sand *et al.* 2010). In addition, a few studies, mostly concerning non-western countries or populations, found that family members sometimes played a role in non-disclosure of the cancer diagnosis or prognosis (Balneaves *et al.* 2007; Teschendorf *et al.* 2007; Doumit *et al.* 2008). A systematic review specifically focussing on incurably ill Turkish and Moroccan patients reported that 'relatives often prevented disclosure as they felt this might upset their patient' (De Graaff *et al.* 2012). Studies concerning the perspective of oncology healthcare providers in caring for ethnic minority patients found that professionals experienced ethical

dilemmas when the family asked not to tell the truth or to omit information when speaking to the patient (Pergert *et al.* 2007; Huang *et al.* 2009). Professionals believe it is important that their patients have full understanding of the diagnosis and prognosis (Richardson *et al.* 2006; Pergert *et al.* 2007; Graaff *et al.* 2012; Butow *et al.* 2013). Furthermore, it is common for oncology healthcare providers to work with relatives as interpreters rather than with professional interpreter services (Owens & Randhawa 2004; Elkan *et al.* 2007; Kai *et al.* 2011; Graaff *et al.* 2012).

Oncology healthcare professionals experience several difficulties when working with professional interpreters, including being time-consuming, practical issues, sense of less control, not knowing what is translated and relatives not willing to have a professional interpreter (van Eechoud *et al.* 2016a). Other literature shows, however, that access to trained professional interpreters or bilingual providers are the best guarantee for qualitative healthcare for patients where shared language is lacking (Flores 2005; Verrept 2012).

According to the Belgian Law on Patient's Rights (2002), a patient has the right to be informed about his/her health condition, as well as the right not to be informed. This has an impact on patients who do not speak the same language as the health professional. For them, someone else has to interpret/translate and this person is then in a position to decide what to tell/not to tell the patient. Although the Belgian healthcare system has been recognised as one of the most equitable in the world, Belgian healthcare organisations have no official obligation to pay attention to diversity (Lorant & Bhopal 2010; Derluyn *et al.* 2011). There are state-funded intercultural mediators in Belgium within hospitals – 81 intercultural mediators in 62 (out of 215) hospitals (Verrept, 2009 in Lorant & Bhopal 2010), but few interpreting services exist outside the hospital setting (Lorant & Bhopal 2010; Derluyn *et al.* 2011).

We conducted a study to gain insight in the experiences and perspectives of family members of older adult cancer patients of Turkish or Northwest African descent who are living in Belgium. The current article is part of this larger study. In an earlier paper, concerning the meaning of caregiving, we reported that cancer is considered a family matter and caregiving had a strong meaning, both moral and practical, for all participants (van Eechoud *et al.* 2016b). In particular, adult children felt a deeply moral obligation towards caring for the sick parent. Moral obligation in practical terms meant making sure that older family members received the most beneficial care possible. Most participants ensured that all the patient's needs received attention. Characteristic of caregiving was the 'guiding'

role that participants took on to help older family members navigate the healthcare system. Both emotional and practical care was provided, including mental support and acting as a contact person or a translator. The analysis of the family member narratives in the larger study also yielded in-depth understanding of a process wherein family members attempted to balance truth-telling in the role of translator. Following research questions will be answered in the current article: What role do family members play when their older ill relative does not speak the same language as the health professional? Furthermore, how do family members balance truth-telling when they act as translator and which interrelated motives are of influence?

## METHODS

### Design

A qualitative methodology, with elements of the constructivist grounded theory (Charmaz 2006), was used as it is well suited to gain an in-depth understanding of experiences and perceptions of participants. The technique of constant comparison analysis was used to analyse the data from the interviews, because it is one of the defining components of grounded theory (Charmaz 2006).

### Participants

Twenty-eight loosely structured interviews were conducted by the first author with 32 family members (of 27 patients). Two interviews took place with three relatives together at their request, and two interviews were conducted separately with a daughter and a son of the same patient. Twenty-three participants were adult children, six were spouses, and three were daughters-in-law. The mean age of the patients and the family members was 64 and 37 years respectively. More demographic information is presented in Table 1.

We intended to include family members of patients who were diagnosed with cancer or severe haematological disease, aged 50 years and older, who were Turkish or Northwest African (Moroccan, Tunisian or Algerian) by birth. Participants were recruited from multiple settings and through several channels in Flanders (Table 2). Because it proved difficult to recruit relatives, several attempts were made in different recruitment channels and new settings. Permission for the researcher to contact family members and to provide more information on the study was sought by healthcare providers, and in one case a participating family member. One interview was conducted unintentionally with three family members of a

**Table 1.** Descriptive information about family members ( $N = 32$  of 27 patients)

Characteristic	<i>N</i>
Gender family member	
Male	10
Female	22
Gender 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
<i>Patients deceased by the time the interview took place</i>	10
Age family member	
21–30	11
31–40	13
41–50	3
51–60	2
61–70	3
Age patient	
51–60	15
61–70	8
71–80	7
>80	2
Country of birth patient	
Turkey	12
Morocco	16
Tunisia	2
Algeria	2
Origin of family member	
Turkish	11
Moroccan	17
Other: Belgian, Polish, Macedonian, Algerian-Moroccan	4

**Table 2.** Recruitment settings and channels in Flanders

Settings and channels
Oncology wards
One academic hospital
Three regional hospitals
General practitioners
Home care nursing organisation
Staff member of the Flemish League against Cancer
Participating family member (snowball method)

deceased patient whose death was caused by kidney failure rather than cancer. The authors decided to include the interview as it enriched the technique of constant comparison analysis. The differing disease was taken into account during the analysis.

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

## Data collection

Literature and previous research was used in developing the interview guide (Verhaeghe *et al.* 2007a,b; Van Eechooud *et al.* 2014), which was evaluated by experts in nursing and medical care and intercultural care for older migrants. During interviews, personal narratives on the following subjects were recorded: participant experiences with and perspectives on the patient's disease; the care situation, and their experiences and perspectives on their role in caregiving; and their experiences with the medical care system and professional care providers. Basic demographic information also was collected. To seek deeper understanding of the process of balancing truth-telling, the focus of the interviews changed slightly as the data collection and analyses progressed.

The interview recordings had a mean duration of 97 min (range 32–185 min). According to participant preference, 10 interviews were held in a private room in the hospital, 20 in the homes of family members and two at the workplace. All interviews except one were audio-taped and fully transcribed; for the single participant who refused tape recording, the interviewer took notes during the interview and made a detailed report the same day. Field notes described interactions with the participants, the atmosphere and interview settings. All but one participant had enough knowledge of the Dutch language for sufficient expression; a professional interpreter assisted in the interview with the excepted family member.

## Data analysis

A cyclic process, alternating data collection and data analysis, occurred until theoretical saturation was reached. The analysis process was comparable with the Qualitative Analysis Guide of Leuven (QUAGOL) (Dierckx De Casterlé *et al.* 2012). The analysis moved among different stages, and the process started after the first interview was conducted and continued until theoretical saturation was reached (Dierckx De Casterlé *et al.* 2012). In the first stage, transcribed interviews were thoroughly read. In a second phase in the analysis, two researchers discussed all the interviews to further explore narrative meaning. In addition, a quarter of the transcripts were discussed with a third researcher who is an expert in Mediterranean cultures and intercultural issues. By continually comparing fragments within and among the interviews in a third stage, the process of truth-telling and interrelated motives were identified as a major theme. In stage four, interviews were reread and relevant parts were linked to applicable codes using the qualitative software program Nvivo 10

(QSR International, Australia). In the final phase, the process of balancing truth-telling and interrelated themes were further refined through confrontation with new data. All decisions during the analysis were made by researcher triangulation, which contributed to the credibility of the analysis (Côté & Turgeon 2005).

To consider the field of possible interpretations of the data and to allow better understanding of the process of balancing truth-telling, six experts or privileged witnesses were consulted (Table 3). In addition, preliminary results were presented for comments a total of five times to three different expert groups: a group of experts in diversity and healthcare; a group of 15 clinical nurse specialists and nurse consultants in oncology; and the steering committee of the research project. Alternative interpretations provided by these experts were used in testing the interpretations with the data.

## RESULTS

The narratives of participating relatives provided insight into the process of balancing truth-telling (see Fig. 1). Following from their self-perceived responsibility for ensuring that all of the patient's needs received attention, family members felt that it was important to contribute to a positive attitude in the patient (Fig. 1, second text box). Their decision about truth-telling was based on several motives (Fig. 1, inner circle) and embedded in their assessment of the patient's emotional strength, understanding and need to be informed (Fig. 1, outer circle). What relatives decided about truth-telling influenced the way they acted as a translator and/or a contact person (Fig. 1, text box at the foot of the figure). Some participants considered it best to omit medical information while others considered it best to transmit all information to their ill older relatives. Details of this process are described in the following section.

### Contributing to a positive attitude

Since most relatives felt a deeply moral obligation to take good care of their ill family members, many of them also considered it their responsibility to provide mental support to the patient. Contributing to a posi-

**Table 3.** Information about experts/privileged witnesses

Expertise
Imam
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

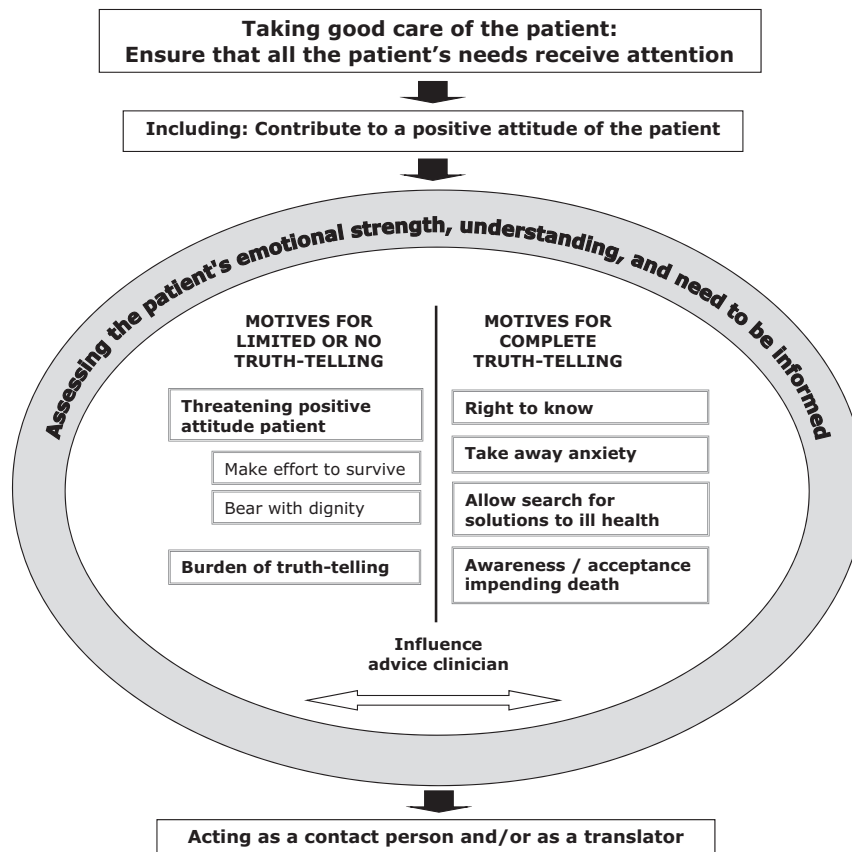


Figure 1. Process of balancing truth-telling.

tive attitude was perceived as an important aspect of mental support. Some relatives imparted a psychological interpretation to the concept of positive attitude. They feared that patients would no longer do what was necessary to remain alive if they lost hope. Some could not face the fact that they might lose their loved ones and therefore wanted the patients to do anything that might extend life.

I tried to keep her as strong as possible on a psychological level. Because my mother, pardon me, didn't get that mental support from my father, I really tried to keep her spirits up [...] She really thought she was going to get better, and you know, I think that we were of real mental support to her and that she was very happy with us emotionally. I'm happy that I've been able to do that for her.

(Son – woman of Turkish origin)

My mom stayed positive. Whereas if you start to think in a negative way, this won't be alright, this and that, then it really won't get right because you stop fighting.

(Daughter – woman of Moroccan origin)

Daughter: [...] her psychological attitude is important as well. You know, she always has positive thoughts. I can do this, I am going to get my health back, by the doctors too, I mean the treatments they've given her [...]

Interviewer Because if you don't, if you don't think positively, how do you think...?

Daughter: Well then you don't feel like doing anything and she won't be taking her drugs on time, she won't be going to her check-ups. Basically, she wouldn't put in any effort, and if you don't put in an effort, you're not going to get very far either.

(Daughter – woman of Turkish origin)

For other family members, the need for the patient to stay positive was rooted in religious convictions. According to these participants, a patient needed a positive attitude in order to behave in a 'dignified' way and thus show submission to God and the fate to which they were destined. To express this attitude, they used phrases such as 'behaving in a dignified way', 'calmness', 'gratitude', 'acceptance' and 'patience'. Some relatives explicitly



voiced the belief that the patients could be forgiven for sins if they expressed submission and gratitude towards the fate willed by God, and they wanted to contribute what they could to make sure the patients did not miss this forgiveness.

Daughter: It is important to know that in our religion, that the perception of being ill, of illness, is, you know, different, it is perceived differently [...] If you are grateful. In fact, you should, you know, you have to be grateful every day. For everything you receive and carry with you. But being ill is actually, is actually a, not everybody becomes ill. Not everybody has the opportunity to experience that. And if you carry your illness with dignity and still remain thankful to God, that erases your sins. To put it like that.

(Daughter – woman of Moroccan origin)

### Balancing truth-telling

The interviews revealed that relatives held diverse views of what they did and did not tell the patient concerning the illness – which they had been told by the healthcare professional but which their patient had not heard directly due to the lack of a shared language – varying from keeping silent about all bad news (and twisting information) to sharing all they knew. The extent to which relatives communicated information to the patient was embedded in their assessment of the patient's emotional strength, how much he/she could understand medical care in Belgium and of what he/she wanted to know about the illness. Reasons for the relatives to assess the patient's emotional strength as limited include advanced age, a vulnerable personality, and having gone through many difficult experiences. Some children indicated that the ill parent viewed cancer differently because he or she did not know that it could be treated, and did not know and possibly could not understand the possibilities offered by the Belgian healthcare system.

#### *Motives for limited or no truth-telling*

Taking into account the patient's emotional strength and his/her need to be informed, many relatives considered the extent to which they should be open about the information provided by the healthcare professional, about the diagnosis, prognosis and treatment.

One daughter informed her mother about the diagnosis, but did not tell her about the metastases and the terminal prognosis:

It is also our job to make sure that that message comes across as well as possible. Because doctors are not always the most communicative people. So actually, we are making it easier for them too. Because you can omit, not say certain things. For instance, in my case, I told her "look, this chemo, it's all in God's hands. The doctor is not God".

(Daughter – mother of Moroccan origin)

The majority of relatives opted not to inform the patient fully, but for varying reasons. In an extreme case, a son made his mother believe that she was treated only for diabetes while in fact she received treatment for malignant liver tumours. Usually, however, cases were less extreme and only part of the information was withheld. This was the case, for instance, for a daughter who told her mother that she had 'the bad disease', but did not communicate her prognosis and the number of metastases.

The relatives who opted not to inform the patient fully were convinced that a positive attitude could be maintained only with partial, or no, information about the diagnosis, prognosis or treatment. As mentioned earlier, some relatives thought it necessary for the patient to have a positive attitude to continue with the treatment, or in other words to make an effort to stay alive. Others believed that partial or no information was necessary so that the patient continued to behave in a dignified way and thus demonstrated submission to the fate willed by God. Relatives had various reasons for wanting the patient to continue with the treatment; some expressed the hope that the patient would 'be able to stay with them [to stay alive] for a longer time' by continuing with the treatment. Other relatives, however, indicated that it was of the utmost importance for the patient to 'remain in good shape' because otherwise, care would become too difficult. Finally, some stated that it was important to continue treatment from an Islamic point of view. It was the patient's duty to God to do everything in his/her power to heal, and they would not want to contribute to failure to conform to the requirements of religion.

Interviewer: "Who decided to say "we are not going to tell"?"

Daughter: "All of us, actually. All brothers and sisters [...] All of us together said "no, no we're not going to tell him that, he doesn't understand that and he won't understand, and he'll panic and you know he doesn't like hospitals, it's hard enough as it is, we're glad he agreed to come in the first place, we've been able to bring him there." So you know."

(Daughter – father of Moroccan origin)

It hurts to know that you're going to lose someone, doesn't it... But you know, it did give us a bit of strength. The fact that we, well ... that she carried the burden of her disease with so much dignity. She never actually, this might be important, she never heard the actual diagnosis [...] That was difficult for me, at first. Because that's not how I am, because I think that, you know, you should know what's going on inside your body, you know, you're entitled to that, you know, you should know. [...] And then we [brothers and sisters] really started thinking, look, does our mother need that? Who is our mother? And then we really started talking in those terms. And then I thought, no, we shouldn't do that [...] I'm happy now that I didn't.  
(Daughter – woman of Moroccan origin)

It was also apparent from the interviews that apart from wanting to prevent the patient from losing his/her positive attitude, some relatives did not inform the patient of the full seriousness of the illness because of the emotional burden of telling the truth.

Of course, none of the reasons above can be disconnected from the relatives' ability to cope with the illness and the negative prognosis, the hope they attempted to maintain, their ability to let go or their need to control the situation. It might be easier for the relative to deal with the situation by not confronting the patient with the seriousness of the illness.

#### *Motives for complete truth-telling*

Although a majority of the participants were not completely open about how seriously ill the patient was in the hope of preserving a positive attitude, there were also family members who believed that information should be fully shared, even though they too considered it their duty to contribute to a positive attitude for the patient. These family members did not think that complete truth-telling would undermine the preservation of a positive attitude.

Approximately, one-third of the family members interviewed believed that the patient should be fully informed. They felt that the patient was entitled to know, or that they did not have the right to omit certain things or lie, and that the patient's anxiety would be relieved by full information. Relatives who expected that the illness might be beyond cure also described a search for solutions, such as alternative treatments, and awareness or acceptance of an impending death as reasons why patients should know. Awareness or acceptance of the possibility that the end of a person's life is near enables one to prepare

one for death, for instance by saying goodbye, forgiving and asking for forgiveness, and taking care of practical matters.

Well I know that he always wants to be informed of everything. I can tell [...] When you're ill, you just want to know everything. So I don't think it's nice not to be informed of anything, so [...] Because at the beginning, my mother was like "we're not going to say that". But I said no I'm sorry, I mean, we don't have the right to do that, we don't have the right to hide things like that from him. It's about his life and he needs to know everything [...] So I tell him everything. How hard it may be, because you know, it is hard. But it has to be said, hasn't it  
(Daughter – father of Northwest African origin)

Interviewer: What mattered most to you during this period, within the period of illness? What was important?

Daughter: Well that he actually, that he knew. And that he, if possible, could say goodbye to people. That I thought, was most important. You know, my brothers thought it didn't matter, but I believe if my time has come and you realize in advance, you want to straighten things out. That's the way I saw it.  
(Daughter – father of Moroccan origin)

Most family members tried other ways of providing mental support to the patient in order to contribute to a positive attitude. The belief that, in the end, the decision of life or death is in God's hands could give them the strength to maintain a positive attitude. However, this strength could also be found through trust in medical treatment or a search for alternative treatments.

As the narratives of these relatives show, there are often various opinions within a single family, and individual members who do not want the patient to be fully informed of the illness. The above also reveals that the same religious views can lead to varying conclusions, as the same religion-based arguments were made both by those who wished to tell the complete truth and those who wished to divulge part of the truth.

#### *Influence of healthcare providers*

The stories of some relatives show that their 'choice' to inform the patient of the illness was influenced by a physician's advice. One daughter, for instance, reported that she and her brothers chose not to inform their father of his diagnosis of lung cancer partly on the physician's advice.

In other situations, advice from a physician led to increased openness concerning the illness. In these cases, the relatives perceived the physician as sharing the same concerns. The following quote, for instance, is from a daughter who was advised by physicians to tell her mother that she would undergo a stem cell transplant, even though she (and her father) did not want to do that. The physicians explained that her mother would be 'really scared' if she is not told the truth, and the daughter, who wanted to prevent that, assumed the physicians were right. She believed that they had the experience and thus the knowledge to make a person less anxious and fully accept the advice.

We always said, well my father said 'we're not going to tell her anything'. Not even about the transplant but the doctors said, if you're not going to tell her, she's going to be really scared about what we're going to do [...] she'll be even more frightened so the best way is to tell her, look this is what you've got, this is what they're going to do, and she'll be more at ease. So we just, you know, explained it to her [...] They're seeing so many patients so we thought, you know, the doctor knows better than we do. (Daughter – woman of Turkish origin)

### **Taking on the role of translator and/or contact person**

The flow of medical information from healthcare providers to patients is often in the hands of relatives, since they, either voluntarily or without an alternative available, take on the role of translator and/or contact person. The adult children, who are second-generation immigrants, predominantly take on this role. They often have a good command of Dutch, while most patients and their spouses have only a limited command of the language. Only a few relatives reported that conversations occurred with the help of a professional interpreter or intercultural mediator.

Family members who acted as translators held the key to the degree of disclosure, and healthcare providers had little or no control. As previously discussed, complex considerations guided their decisions, and similar considerations appear to lead to very different decisions. In some situations, family members provided only translation between the patient and the healthcare providers, while in other cases the patient was practically excluded from the conversation. Some participants considered it best to omit medical information while others considered it best to fully inform their ill older relatives.

In addition, preferences as to how to solve the language issue were divergent. Some relatives preferred the presence of an interpreter or an intercultural mediator, or a healthcare provider who spoke the same language. Other participants felt that they, as a member of the patient's family, were the best choice of translator, because it prevented a 'stranger' being involved in the situation, and/or because it provided them with control over the information reaching the patient.

But that doesn't make sense to us, a complete stranger [translator]. (...) I mean come on, it's the least you can do if you have the time of course, and possibility to take your mum to the doctor's, to tell the doctor about your mum's issues, problems or complaints. I don't want a third party to do that, to be honest.

(Daughter – woman of Turkish origin)

I didn't need an interpreter. And that wouldn't have been okay for my mother either. No, she wouldn't like to hear that from a stranger, or she wouldn't like a stranger to know about her current medical situation.

(Daughter – woman of Moroccan origin)

Being asked or assumed by healthcare providers to act as a translator gave them the responsibility to decide what to tell and how. Relatives experienced this process of translating differently; some thought it normal to do that if you care for your parent, while others felt that it was too difficult and burdensome to deliver such news to your parent. Regarding diagnosis and bad prognosis it was often very difficult for family members to decide what to tell and what not to tell the patient.

Daughter: You know, you stay positive until they say that there is absolutely nothing left to do, and then you have to start explaining that, don't you.

Interviewer: What was it like for you to explain that?

Daughter: It was very hard. I said 'father there isn't anything they can do for you, chemo isn't going to help, radiation isn't going to help'. [...] And that is a shame, it all becomes the family's burden.

Interviewer: What do you mean, it all becomes the family's burden?

Daughter: Well, the nurses, the doctors, they all come to you: 'Can you tell your father this? Can you tell your father that? We are going to do this or we are no longer going to be able to do that'. Maybe



I didn't want to do that. I had had it too, you know.  
 I need to pour my heart out too.  
 (Daughter – man of Moroccan origin)

## DISCUSSION

As part of relatives' self-perceived responsibility to ensure that all the patient's needs received attention, they wanted to contribute to a positive attitude in the patient. Based on several motives and embedded in their assessment of the patient's emotional strength, understanding, and need to be informed, relatives decided how much information to give the patient about his or her medical situation. What relatives decided about truth-telling influenced the way they acted as a translator and/or a contact person. A majority of the participants considered it best to omit some medical information, while others decided to fully inform their ill older relatives about the illness, diagnosis and prognosis. Although many previous studies have discussed the more general topic of truth-telling or disclosure of cancer diagnosis (Shahidi 2010), to our knowledge this is one of the first studies providing an understanding of this process from the perspective of relatives of first-generation immigrants, from Turkey and northwest Africa, of whom many are not proficient in the language of the host country.

Although the current study provides insight into a complex process of balancing truth-telling – ultimately resulting in a majority of these relatives not fully informing the patient – previous literature often focuses on the non-disclosure itself, thus often ignoring the decision-making process. A quantitative study conducted in Turkey showed, similar to our findings, that two-thirds of family members did not want the cancer diagnosis to be disclosed (Ozdogan *et al.* 2004). The authors of the extensive systematic review 'Perspectives on care and communication involving incurably ill Turkish and Moroccan patients, relatives and professionals' concluded that 'relatives often prevented disclosure as they felt this might upset their patient' (De Graaff *et al.* 2012, p. 34). The current study provides insight into the process behind this reasoning. In addition, trying to contribute to a positive attitude of the patient has also been shown by research concerning 'western' populations (McIlfatrick *et al.* 2006; Röing *et al.* 2008; Sand *et al.* 2010; Steinvall *et al.* 2011; Pusa *et al.* 2012; Blindheim *et al.* 2013). The current study shows that the same intention can lead to differing actions. While participants shared their desire to contribute to a positive attitude in the patient, some considered it necessary, in this respect, to omit medical information, while

others believed it best to provide full information to their ill older relatives. To this end, the same religious arguments are made both by those who wished to tell the complete truth and by those who wished to divulge only part of the truth.

Few studies have been conducted on the perspective of family members of first-generation immigrants who have cancer and who may not speak the language of the country where they live, and little has been written about family members acting as translator and/or contact person for them. Nevertheless, the topic is of importance to oncology care professionals in western societies, as language issues lie at the heart of their concern in caring for ethnic minority patients (Owens & Randhawa 2004; Pergert *et al.* 2007) and the use of family interpreters is much more common than professionals interpreting (Owens & Randhawa 2004; Kai *et al.* 2011; Graaff *et al.* 2012).

Finally, the findings of this study demonstrate that about a third of the relatives decide to fully inform the patient about his/her medical situation and many others divulge parts of the information. Only in extreme cases did family members decide to hide all information about the illness, diagnosis and prognosis. This is an important finding in the light of the risk for an oversimplified expectation that people of non-western descent all prevent disclosure to their ill relatives. The study of Van den Brink, for example, points out that 'Among Turkish families, it is not acceptable for adult family members to inform their elders about their negative physical state. This is contrary to the religious tenet of showing respect for the elder and acceptance of the will of Allah' (van den Brink 2003, p. 152). Apart from the value judgement based on simplistic interpretations such as these, stereotypes are counterproductive to provision of healthcare to patients with diverse backgrounds. As Knight & Sayegh (2010) point out: 'To date, theory development and empirical research indicate that the role of culture in influencing caregiving outcomes is more nuanced and complex than imagined a decade ago. Cross-cultural research and evidence-based practice should meet this complexity head on rather than retreating to the use of stereotypes and simplistic categorical assumptions' (Knight & Sayegh 2010, p. 7).

## Limitations

Because of ethics committee requirements, no information could be obtained about potential candidates who had not been approached by healthcare workers or potential candidates who refused to be contacted by the researcher. It was difficult to recruit participants, and some healthcare workers reported they were reluctant to

ask potential participants for permission for the researcher to contact them. This might have resulted in a less diverse sample compared with the general population of relatives of these patient groups. This limitation is inevitable in qualitative research, which faces higher barriers in recruitment compared with survey methods. However, only 11 of 43 potential participants who were asked to participate refused.

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

### Future research

It would be beneficial to study both patient and health provider perspectives on the role of family members who act as interpreters, and the process of truth-telling. Besides, also research from the perspective of professional translators and intercultural mediators is of relevance, as they are the third party in this language triangle. It might be interesting to approach this topic from a legal perspective on patient rights as well as from an ethical care perspective. Such research might also provide further understanding of the experience of family members in taking on a role as translator. The current study can be used as a starting point for future research on these topics.

This study shows that differing approaches of family members in balancing truth-telling stem from the same intention and from the same religious arguments. This is in line with the contemporary dynamic definition of culture in social sciences, but contrary to the static way culture is often defined in medicine (Kleinman & Benson 2006). In future research on diversity in healthcare, researchers should be thoughtful about the way they, implicitly and/or explicitly, define culture.

### CONCLUSIONS AND CLINICAL IMPLICATIONS

This study provides insight into a complex process of balancing truth-telling by relatives, mostly adult children, of older adult cancer patients of Turkish or Northwest African descent of whom most immigrated to Belgium in the 1960s and 1970s and have aged there. These relatives attach great value to taking good care of the patient, and from that point of view they want to contribute to a positive attitude of the patient. Based on several motives and embedded in their assessment of the patient's emotional

strength, understanding and need to be informed, relatives decide to what extent they provided information to the patient about his/her medical situation. Motives for no or little truth-telling include maintaining a positive attitude and the burden of truth-telling. The right to know, relieving anxiety, finding solutions and being aware or accepting an impending death are reasons for relatives to be completely open towards the patient regarding the seriousness of his/her illness. This complicated and unpredictable complex of considerations often leads to family members making different decisions in taking on a role as translator and/or a contact person, even when family members have the same considerations. In some situations, the relatives' role is mainly limited to providing translation between the patient and the healthcare providers, while in other cases the patient is practically excluded from the conversation. Some relatives considered it best to omit medical information while others considered it best to fully inform their ill older relatives. Subsequently, it is important for healthcare providers to take into account the complexity and the unpredictable character of this process. Furthermore, it is essential for healthcare providers to be aware of the influence they might have in this process, most certainly when they share and recognise the concerns of the relatives. Routinely asking what matters most to them in the experience of illness and treatment, can be helpful in achieving this (Kleinman & Benson 2006).

Healthcare providers must try to have conversations with the patient, together with immediate family, about designating the most appropriate person(s) with whom to discuss diagnosis, prognosis and treatment information. Discussions should occur as soon as possible and repeatedly, and this is of course only possible with the help of a professional interpreter – as otherwise the family member can answer as he/she wants – so that everyone involved can be clear how the conversational/language issues are to be handled. After all, according to the Belgian Law on Patient's Rights (2002), a patient has the right to be informed about his/her health condition, as well as the right not to be informed.

### ACKNOWLEDGEMENTS

The authors thank the participants who were willing to share their time and thoughts. They also thank the experts for sharing their knowledge with us. They are in particular 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.

## CONFLICTS OF INTEREST AND SOURCE OF FUNDING

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.

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