

# BMJ Open Role of relatives of ethnic minority patients in patient safety in hospital care: a qualitative study

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## ABSTRACT

**Objective:** Relatives of ethnic minority patients often play an important role in the care process during hospitalisation. Our objective was to analyse the role of these relatives in relation to the safety of patients during hospital care.

**Setting:** Four large urban hospitals with an ethnic diverse patient population.

**Participants:** On hospital admission of ethnic minority patients, 20 cases were purposively sampled in which relatives were observed to play a role in the care process.

**Outcome measures:** We used documents (patient records) and added eight cases with qualitative interviews with healthcare providers, patients and/or their relatives to investigate the relation between the role of relatives and patient safety. An inductive approach followed by selective coding was used to analyse the data.

**Results:** Besides giving social support, family members took on themselves the role of the interpreter, the role of substitutes of the patient and the role of care provider. The taking over of these roles can have positive and negative effects on patient safety.

**Conclusions:** When family members take over various roles during hospitalisation of a relative, this can lead to a safety risk and a safety protection for the patient involved. Although healthcare providers should not hand over their responsibilities to the relatives of patients, optimising collaboration with relatives who are willing to take part in the care process may improve patient safety.

## INTRODUCTION

Patient safety is a critical aspect of the quality of hospital care. Safe hospital care is care without adverse events (AEs), such as misdiagnosis or adverse drug reactions.

Patient safety risks are situations that potentially lead to AEs. When a patient safety risk has been eliminated before harming a patient, this is called a ‘near miss’—for example, a wrong medication dosage that has been noticed and corrected in time.

## Strengths and limitations of this study

- This study adds evidence to the relation between relatives of hospitalised patients and patient safety.
- Triangulation within the study due to the use of different data sources.
- All interviews were conducted in Dutch.
- A rather small number of interviews compared to documents analysed.

We previously showed that ethnic minority patients in the Netherlands are not at increased risk of AEs. However, a hospital admission can be a potential high-risk situation for a patient of ethnic minority origin, if care provision is insufficiently diversity sensitive.<sup>1</sup> Characteristics such as low mastery of the language of the host population, low health literacy and cultural distance to the healthcare system of the host country, which occur more often among ethnic minority patients, may then increase patient safety risk and, thus, the risk for near misses and AEs. For example, language barriers can cause a delay in diagnosis or misinterpretation of medical advice. Several studies outside of Europe have reported an increased patient safety risk among ethnic minority patients.<sup>2 3</sup>

European countries, including the Netherlands, have become increasingly ethnically diverse, as has the hospital population.<sup>4</sup> During data collection for the observational cohort study on ethnic inequalities in patient safety,<sup>1 5</sup> we observed that hospitalised patients of ethnic minority backgrounds were often accompanied by their relatives (mostly adult (grand)children) during their hospital stay. In contrast to most Dutch relatives of adult patients, relatives of ethnic minorities often spent long hours at the patient’s bedside, wanted to stay outside visiting hours and participated in the care

process of their family members. This prompted us to explore the role of family members of ethnic minority patients in patient safety.

International studies have shown that relatives play an important role in the care process of adult ethnic minority patients in end-of-life care and intensive care.<sup>6 7</sup> However, evidence on the relation between patient relatives and patient safety is scarce and has mainly focused on prevention of specific AEs, such as ventilator-associated pneumonia,<sup>8</sup> or on parents of paediatric and neonatal patients in an acute care setting.<sup>9 10</sup>

This qualitative study was conducted to analyse the different roles that relatives play in patient safety. The focus of this study is mainly on patient safety risks and not on patient safety outcomes (AEs). The results are expected to contribute to the knowledge on the causes of unsafe care and on improvement of patient safety.

### Objective

To explore the potential roles that relatives take on themselves and their influence on patient safety of hospitalised ethnic minority patients.

## METHODS

### Design

We combined document analysis (nursing and medical records, and discharge letters), interviews with healthcare providers and (relatives of) patients, and observations. The combination of different data sources allowed triangulation of data and analysis, and served to increase the internal validity of the results. Method triangulation involves the use of multiple methods of data collection about the same phenomenon. The aim of triangulation is to overcome the intrinsic bias that may come from using single methods to study a phenomenon. Multiple data collection methods can increase the possibility that an internally consistent picture of the phenomenon emerges.<sup>11</sup> The COnsolidated criteria for REporting Qualitative research (COREQ) were used as a reporting framework.<sup>12</sup>

This study was embedded in a larger cohort study, hereafter called the umbrella study (box 1).<sup>1 5</sup>

### Box 1 Umbrella study<sup>1 5</sup>

The umbrella study is a prospective cohort study in four Dutch hospitals among nearly 1500 patients with Dutch or non-Western ethnic origin in four urban hospitals at 30 wards. All patients were recruited during their hospital admission and filled out a questionnaire after informed consent. After discharge, their patient records were reviewed by trained nurses and/or medical specialists to quantify unintended patient safety outcomes (adverse events). During the recruitment of these patients and the screening of patient records, we sampled cases for the qualitative analysis described in this paper.

### Ethical aspects

The umbrella study (box 1) was approved by the medical ethical committees of all participating hospitals. All patients participating in the present study were included in the umbrella project and had, therefore, signed a consent form to permit medical record review. Moreover, during the interviews, all interviewees provided informed consent to audiotape the interviews. The confidentiality of the respondents and their data was guaranteed by the use of codes.

### Data collection

Twenty cases were sampled for the present study. A 'case' is a hospital admission of an ethnic minority patient. Table 1 provides an overview of all cases, some general characteristics and details of the data collected.

### Sampling

Cases were purposively sampled during patient inclusion for the umbrella project and complemented with sampled cases after review of the records within the umbrella study.<sup>5</sup> This enabled us to compile a heterogeneous research sample (ie, different hospitals, different wards, nurses and physicians, physicians from different medical specialties and patients/relatives with different ethnic backgrounds) and search for contra-examples. We stopped sampling cases and planning interviews after we had obtained data saturation, that is, no new ideas or roles taken over by the relatives of patients emerged from the data.

### Data

Of all 20 cases, the medical and nursing records were searched for text passages concerning relatives of the patient and their positive or negative involvement in the care process (table 1). Sometimes, these data were so rich that we did not plan an interview. We considered record data rich when they contained text on relative involvement of many care providers, on many different places in the record (eg, nursing record, discharge letter, decursus), when considerations and feelings of care providers and patients were recorded (eg, 'The daughter came to wash [the patient] this morning, the patient was really happy with it').

For eight cases, interviews with patients and/or their relatives and healthcare providers were planned. In total, seven healthcare providers were interviewed, that is, two nurses and five physicians from different medical specialties. Five patients and/or their relatives were interviewed. For three cases, extensive notes on observations of the interaction between healthcare providers, and patients and their relatives, were written down by the researcher (FvR).

### Recruitment for interviews

When a case was selected for an interview, we chose a healthcare provider that had been directly involved in the patient's care process and was likely to remember

**Table 1** Patient characteristics and additional qualitative data per case

Case number	Patient characteristics, and medical ward	Additional qualitative data (apart from analysis of the patient's record) including interview times. <i>Non-response information (in italics)</i>
C1	Moroccan woman. Internal medicine	<ul style="list-style-type: none"> <li>▶ Interview with nurse—30 min (N1)</li> <li>▶ Interview with physician (internist)—45 min (Ph1)</li> <li>▶ Interview with family members (sister, son, daughter in law, granddaughter)—2 h (F1)</li> </ul>
C2	Ghanaian man. Internal medicine/neurology	<ul style="list-style-type: none"> <li>▶ Interview with physician (internist)—1 h (Ph2)</li> <li>▶ <i>Another physician (neurologist) refused participation in interview due to time constraints</i></li> <li>▶ <i>Patient was not reached (was in nursing care home and asleep/busy each time researcher called)</i></li> </ul>
C3	Moroccan man. Surgery	<ul style="list-style-type: none"> <li>▶ Interview with physician (surgeon)—1 h (Ph3)</li> <li>▶ <i>Patient was not reached (did not answer telephone)</i></li> </ul>
C4	Turkish man. Pulmonology	<ul style="list-style-type: none"> <li>▶ Interview with physician (pulmonologist)—45 min (Ph4)</li> <li>▶ Observation outpatient visit—20 min (O4)</li> <li>▶ Interview with patient and his company (partner and interpreter)—30 min (P4)</li> </ul>
C6	Turkish women. Internal medicine	<ul style="list-style-type: none"> <li>▶ Interview son—1 h (F6)</li> <li>▶ Observation during admission—30 min (O6)</li> <li>▶ <i>Nurses did not respond to interview request</i></li> </ul>
C7	Moroccan man. Different wards	<ul style="list-style-type: none"> <li>▶ Interview physician (internist)—45 min (Ph7)</li> <li>▶ Interview daughter (by telephone)—30 min (F7)</li> </ul>
C8	Pakistani man. Internal medicine	<ul style="list-style-type: none"> <li>▶ Interview nurse—20 min (N8)</li> <li>▶ <i>Patient not reached (did not answer telephone)</i></li> </ul>
C9	Moroccan man. Internal medicine	<ul style="list-style-type: none"> <li>▶ Interview patient—45 min (P9)</li> <li>▶ Observation during admission (O9)</li> </ul>
C5, C10–C20	<ul style="list-style-type: none"> <li>▶ 4 women, 8 men</li> <li>▶ 6 Turkish, 3 Surinamese, 2 Moroccan, 1 Algerian</li> <li>▶ 3 Cardiology, 7 internal medicine, 1 pulmonology, 1 surgery</li> </ul>	

In the results, document D1 corresponds with case C1, etc. Non-response to interview invites is italicised.

the patient. Since a patient with multiple diseases and a long hospital stay, as well as his/her relatives, often interacts with many different healthcare providers, we had to choose one healthcare provider per case.

For the present sample, we selected physicians and nurses because they both play different professional roles in the care process and may have different experiences with the relatives of the patients. Healthcare providers were approached by email.

Selected patients and/or their relatives were approached during hospital admission or by telephone afterwards, but always after approval of the treating physician. Table 1 also presents data on non-response and shows that three patients could not be reached by telephone by the researcher to ask them to participate.

### Setting

Interviews with healthcare providers always took place in the hospital, at the healthcare provider's office, or another quiet place. Interviews with healthcare providers took between 30 and 90 min. Interviews with patients and/or relatives took place at the home of the family

members, at the work of a family member, during hospital admission at the bedside of the patient or during an outpatient visit. One interview was conducted by telephone. Interviews took 20 min to 2 h. Interview times per interview are shown in table 1.

All interviews (except two) were audiotaped (one healthcare provider did not consent, and one interview with a patient was spontaneously initiated after inclusion in the umbrella project, when a tape recorder was not available). All other interviews were transcribed. Only one interviewee (a physician) requested to read the transcript afterwards, which did not lead to any changes. All interviews were carried out by FvR. Field notes (eg, on non-verbal communication, 'off the record' texts, impression of atmosphere, etc) made after each interview were also used to interpret our results.

### Interview structure

Interviews were semistructured. We asked all interviewees about the specific role of relatives in the care process, the role of relatives in the quality of hospital care, and the role of relatives in the safety of care.

Different roles emerged from the data and were not specified beforehand.

### Cases

All 20 cases (14 males, 6 females) were ethnic minority patients aged 45–75 years who were admitted to the hospital in 2011 or 2012. All patients were first-generation migrants and had different ethnic backgrounds (Moroccan, Turkish, Pakistani, Surinamese and Ghanaian) and different levels of Dutch language proficiency, varying from adequate Dutch proficiency to no Dutch proficiency at all. Patients were admitted to wards of different medical specialties in different hospitals (internal medicine, surgery, neurology) and, therefore, were admitted for a wide variety of reasons (table 1).

### Data analysis

Our study was informed by the empirical–analytical tradition<sup>13</sup> in which reality is assumed to exist and can be known and analysed in terms of categories and diagrams. Miles and Huberman (1994) suggest that qualitative data analysis consists of different procedures, including data reduction, which refers to the process whereby the transcripts, field notes and observations are reduced and organised, and the process of coding, in which codes preferably are displayed in the form of matrices to facilitate the analysis of themes.<sup>13 14</sup>

Document text passages, transcripts of interviews and field notes of observations and interviews were analysed using Atlas.ti software (Atlas.ti Scientific Software. <http://www.atlasti.com> 2012). The first step in the analysis was an inductive approach of open coding, generating a number of themes. All data were analysed by FvR; also, three transcripts of interviews and all text passages from the patient records concerning family/relatives of patients were independently read by another researcher (JS) to check whether the same themes were derived from the data.

The next step was selective coding of the material, followed by integration. Inter-rater reliability was applied: FvR and JS thoroughly discussed the interpretation of the data and MLEB participated in the discussion on the emerged themes to reduce the possibility of a biased interpretation of the data.

## RESULTS

We identified four roles that relatives of hospitalised ethnic minority patients took over during the care process: (1) the visiting family member ('social support'), (2) 'the interpreter', (3) 'the patient' and (4) 'the care provider'.

All four roles are described below in relation to patient safety, followed by a general discussion on the interaction between healthcare providers and relatives of patients, and conditions to ensure patient safety in hospital admissions of patients with actively participating relatives.

### Role of usual visiting family member

First of all, relatives had the 'usual role' of visitor to socially support their family members who were admitted to the hospital. Social support includes, for example, emotional support and informational support.<sup>15</sup> Relatives in this role did not interfere with the care process. Furthermore, this role was interpreted differently among visiting relatives. Dutch relatives tended to comply with the hospital's visiting rules more than the relatives of ethnic minority patients. Sometimes, relatives visited a patient together with many other family members at the same time and did not always comply with the hospital's visiting hours.

Healthcare providers did not always want large groups of relatives to visit the patient at the same time, especially outside of regular visiting hours. Nurses sometimes experienced a disturbed workflow and had concerns about the recovery of the patient and other patients on the ward.

Q1[Senior nurse: The culture-related large numbers of visitors for a patient often causes a problem. Our rules state a maximum of two visitors, and only during visiting hours. These rules were made to ensure peace and quietness on the ward and to guarantee rest for the other patients]

However, relatives often thought that their presence would enhance the recovery of the patient, and many healthcare providers tended to agree with this. From most of the data, we found that (under certain conditions) the strict visiting rules were often given considerable flexibility by healthcare providers. Relatives were grateful when healthcare providers did this:

Q2[D7: Patient X can stay in a single room as long as it's not needed for another critically ill patient. As long as the patient is in the single room, one family member can stay with him permanently; this family member can also sleep in the room. This decision was taken to keep the patient calm and increase his recovery]

Q3[Ph1: But we have to make very clear arrangements. So we don't say 'It's always permitted to be around', because then they'll come with a group of ten persons at 9 AM, which is just not practical. So we have to make very clear arrangements—and by doing this we can have some flexibility in the visiting rules ...it must be helpful when they are around—and not cause any problems.]

However, the role of 'usual visitor' may increase patient safety risks. For example, relatives often bring food and/or drinks for their hospitalised family member. Many patients had dietary restrictions that were not always followed by the relatives. We found many examples about a family bringing drinks for their relative who had a restriction of fluid intake. Ignoring fluid restriction may have serious medical consequences.

Q4[D16: The family of patient X came to visit. The family were told that they were only allowed to come during visiting hours. They gave him a bottle of Coke (500 ml); this is empty now. The family was told that they should not give this to him because of the restrictions in fluid intake]

Relatives in the role of usual visitor may also decrease patient safety risks when they serve as an extra pair of eyes/ears for the patient; this may decrease the risk of information loss during risk communication, or explanation of medication use to the patient. The quotation below is an example from an interview with a physician about a patient without any relatives around him, illustrating that the presence of relatives can reduce the risk of information loss.

Q5[Ph2: F: I read that this patient is an asylum seeker, do you think this influences his care process? P: Yes, most of the time these people are alone. Some studies show that these people remember only up to 25% of what you told them. These people have no-one around to help them. We have a shortage of time, we do what we have to do, and after 15–30 minutes we have to continue with other tasks. Such a patient is then stuck with a piece of information or a decision—and when there's someone around there is more support]

### Role of interpreter

Relatives competent in the Dutch language were almost always involved in interpreting for patients who did not master Dutch. For the healthcare providers and relatives, it seemed to be a 'common practice' that relatives act as an interpreter. Healthcare providers were often glad that relatives were around to interpret, and relatives sometimes worried when they were not there to interpret.

Q6[F1: I stayed in the hospital permanently when my mother was admitted. From 10 AM until 11 PM because I was afraid that someone would come to ask her things and she would not have been able to respond.]

When relatives were always available to interpret, the incentive for a healthcare provider to involve a professional interpreter was low, even though healthcare providers sometimes felt that relatives did not translate and interpret properly. In Q7, the physician had to discuss some critical treatment options with her patient, and from the patient's facial expression, she had the feeling that the patient's son did not translate correctly. In the same interview, the physician said she had the feeling that the son chose the treatment option that he preferred, rather than the treatment option that the patient preferred.

Q7[Ph1: Ehm..What I found difficult, is that I sometimes doubted the son's translations. I was uncertain whether the things the son told me, were really the things his mother wanted to say]

Relatives acting as an interpreter can increase patient safety risks when medical decisions need to be taken, or during risk communication. When relatives interpret inadequately or not at all, this can adversely affect patient outcomes—for example, when crucial risk information is not adequately interpreted and conveyed to the patient.

In situations in daily hospital care without critical information exchange, relatives acting as interpreter can decrease patient safety risks. For example, during pain measurement (a quick measure which is applied three times a day after surgery), or during mobilisation of patients after surgery, professional interpreters are not feasible and the risk of interpretation errors with severe consequences is smaller.

### Role of the patient

We found that relatives often took over the role of the patient. In some cases, patients were hardly (or not) aware of their own disease and lacked knowledge about their disease management and treatment. Relatives often replaced the 'brains and memory' of the patient. For example, during patient inclusion, FvR observed a son sitting next to his mother who was admitted to the hospital. He was called on his mobile phone. It was the hospital pharmacist who asked him about his mother's allergies. A few weeks later, the son was interviewed and told us that only he and other family members knew about his mother's allergies. His mother did not know herself. Another example is a daughter who interprets her father's pain and asks the doctor for another pain medication.

Q8[F6—Son of a Turkish patient who had did not master the Dutch language]:

F: You received a phone call from the hospital pharmacist, about your mother's allergies

S: Yes yes

F: Does your mother know her allergies herself?

Z: [Only I know. And my brothers and sisters.]

Q9 [D11: Patient called his daughter to tell her that he is in pain and paracetamol does not work. Daughter wants that patient gets pain medication because the pain is on the side where the lung cancer is]

Relatives who are closely engaged in the care process of their family member can have a positive influence in decreasing patient safety risks, as described before. However, when they completely replace the patient in all communication with healthcare providers, as in the example above, this may increase safety risks. When only relatives, and not the patient himself, have the knowledge of the disease and treatment, the patient becomes dependent on these close family members. A risky situation might arise when relatives are not around and when healthcare providers are not aware of this 'replacement'.

### Role of care provider

We found that it was considered ‘normal’ that relatives were often involved in daily professional nursing tasks, such as washing and mobilising patients. Nurses told us that it made a considerable difference to the amount of work they had to do when relatives took over some of these tasks. Relatives stated that the reason for taking over these tasks was mainly cultural, that is, relatives of (most) Turkish and Moroccan patients considered it normal that they should participate in the care provision for their parents or grandparents.

Q10[F6: It’s common sense. They brought us up—we must give back. That’s the way it ought to be, that’s the way it works. [...] F: So, she was never alone during her hospital stay? T: No, she was never alone. That is not allowed. F: So she will never be in a situation of being alone with a care provider? T: Nonononono. Absolutely not! Look, that is why I say: They brought us up, now we care for them. End of discussion.]

Apart from taking over nursing tasks, relatives sometimes also interfered in the clinical process. Relatives often felt that they knew better what was best for their relatives, even though they were not medically trained. For example, a female patient who had had a kidney transplant and suffered from graft failure and the graft kidney had to be removed after a while; the family felt that there had been a delay in the decision to remove the graft kidney.

Q11[F1: N: All my uncles and aunts already noticed this. My grandmother told them what she felt in Arabic and they translated this and told the physicians. Her body was not able to cope, but they left it in her body, the kidney. And then the consequences came, which harmed her body and health. F: So they noticed too late that the kidney had to be removed? N: The doctors did, yes.]

Healthcare providers sometimes felt that their work and therapeutic advice were hindered by relatives of the patients. Sometimes, this was a risk for patient safety. An example was provided in an interview with a nurse about a man with a pressure ulcer who needed to lie on his side because of necrotising tissue on his back. Since this medical advice was not followed, he needed surgery to remove the tissue.

Q12[N8: Some family members said ‘It’s baloney, he doesn’t have to lie on his side when he doesn’t want to.’ Which is absolutely cumbersome]

Relatives often felt that they were not taken seriously by the healthcare providers and did not understand why healthcare providers were not ready to help.

Q13[F1: A: We don’t know the medical stuff. But if we hear a beep—then we call. If we see things happening—

we go to the ward reception counter, where they tell us “Sorry, we are busy”]

All examples described above concern misunderstandings and differences in expectations between healthcare providers and relatives, which may increase patient safety risks.

### Mix of different roles

In most cases, different roles were taken over at the same time during one period of hospitalisation. A representative example was a patient with diabetes admitted to the hospital with renal failure. He had a restriction of intake of salt and liquids. His relatives often visited and brought food/drinks for him in the role of usual visitor. At the same time, the relatives also fulfilled the roles of interpreter and patient. Healthcare providers only communicated the dietary restrictions to the relatives and did not discuss these with the patient. However, the relatives did not adhere to these dietary restrictions and gave lots of water to this patient because he was thirsty. Healthcare providers seemed to struggle with these different roles being taken at the same time. In Q13 and Q14, healthcare providers approach relatives in the role of usual visitor and in the role of ‘interpreter’, and seem to confuse these roles.

Q14[D15: Once again—I explained to the son that his father has a liquid restriction and a salt-free diet—and that they should not bring him litres of water.]

Q15[N8: Often the grandchildren speak perfect Dutch and are empowered to stand up for their grandparents. They often see possibilities and have some knowledge. I make use of that. It can be used against you, but when there is a good understanding it can be advantageous.]

In the example below, a physician explained that she was glad that the son of one of her patients was always available to fulfil a role other than the role of usual visitor.

Q16[Ph1: One son—I don’t know what he was doing the rest of the day—seemed to be available full-time for his mother ... we could always call him, and when we did he came to the hospital immediately]

The following examples illustrate mutual incomprehension between the relatives and healthcare providers. Healthcare providers did not understand the relatives’ willingness to stay around outside visiting hours and thus play a role other than usual visitor, while the relatives did not understand why they were allowed to visit their sick family member only within a strict time frame. This example also illustrates that relatives found it completely normal to fulfil roles other than the role of usual visitor.

Q17[F1: Granddaughter: “First they were acting difficult when my aunt wanted to sleep over. [...] They found it

inconceivable. [...] They said we would disturb other patients, while we were not even talking because talking would take too much energy for my grandmother (=patient) Son: They made a note that we were allowed to stay until 9 pm. They wanted to make a contract that one of us was allowed to stay outside of visiting hours, but sleeping over...they really did not want that. [...] We really had to apply pressure in order to stay. FvR: "So, they finally agreed?" Son: "No, they didn't, if they would have agreed they would have arranged a bed to sleep on. I slept on the floor beside my mother's bed, next to the blood." Granddaughter: "It seems that they did not understand our emotions"

Q18[D10: I took much effort to communicate with the patient [...] Around 10 PM we called the security because her son was still there. He did not want to leave and declared that he was here because of the language barrier of his mother. I told her son that the visiting times were over. Son did not want to listen and got angry. Security came rapidly and sent the man away.]

## DISCUSSION AND CONCLUSION

This study explored the roles by which relatives interact with the safety of hospitalised ethnic minority patients. It was found that, apart from fulfilling their usual role as a visiting family member, relatives often took on the role of the interpreter, the patient and the care provider. All four roles can help optimise quality and decrease safety risks for the hospitalised patient, but can also increase patient safety risks. Good understanding between the healthcare provider(s) and the relatives tended to increase patient safety.

In a large study among 1500 patients, we found no ethnic differences in AEs, while we hypothesised that a hospital admission is a high-risk event for ethnic minority patients.<sup>1</sup> As we observed involvement of relatives, we suggested that those relatives might have played a protective role.

Two international studies examined the link between family members and patient safety in general. Berger *et al* conducted a systematic review on engagement of patients and families to reduce AEs in acute care. Only few studies addressed family engagement, but they studied 'willingness to engage' rather than the different roles that we studied, and they did not relate their findings to patient safety risks.<sup>16</sup> Reid Ponte *et al*<sup>17</sup> discussed the link between family-centred care and patient safety by presenting the design of a project on involvement of family members in patient safety rounds in the Dana-Farber Cancer Institute (DFCI) and speculated that patient safety improves when family and healthcare providers effectively work together as a team. Our study showed that relatives taking the role of interpreter may increase patient safety risk. This finding is in agreement with the findings of international literature—for example, Flores *et al*<sup>18</sup> showed that trained professional interpreters make significantly less translation errors

with clinical consequences than ad hoc interpreters, such as relatives.<sup>19</sup>

Training and empowerment of relatives may contribute to decreasing patient safety risks, as illustrated by three studies on interventions to involve the family to call the rapid response team (RRT), a team of healthcare providers that respond to hospitalised patients with early signs of clinical deterioration to prevent respiratory or cardiac arrest.<sup>9 10 20</sup> Families of patients were educated and empowered to seek help when serious concerns arose and/or when they learnt about the protocol of the RRT. When families know what to do, patient safety risks decrease, while efficiency of care might also be enhanced because family members less often raise a 'false alarm'. The value of training is also apparent for relatives who take over nursing tasks such as washing, because relatives are usually not trained in the clinical inspection of the patient's skin during washing for signs of pressure ulcers. The most recent standards of the Joint Commission International include statements on family involvement like 'The patient's and family's ability to learn and willingness to learn are assessed', showing that family involvement is becoming not merely accepted but is also being seen as 'normal'.<sup>21</sup> However, despite the potential positive aspects of family engagement in hospital care, patient safety remains the responsibility of the healthcare system and its healthcare providers. The responsibility for patient safety can never be handed over to the patient's relatives.

## Strengths and limitations

The major strength of the present study is the use of different data sources, allowing for triangulation which strengthens the internal validity of the results. The fact that our study was carried out in different hospitals, on different wards and among patients with a variety of diseases and ethnic backgrounds adds to the generalisability of the results. Another strength is the use of patient record data, because they are almost 'real time' and longitudinal as they follow the complete patient admission. When patient record data were (too) concise, we always tried to plan an additional interview.

A possible limitation is that all interviews were conducted by an ethnic Dutch researcher. However, all healthcare providers and most of the patients' relatives were fluent in Dutch. An interviewer with the same ethnic background as the interviewees might have achieved more depth in three of the interviews and might have been better understood by ethnic minority patients and their relatives. However, we believe that there may also have been a beneficial effect, as ethnic minorities may have explained more to an 'outsider' interviewer who was unaware of their cultural habits.<sup>22</sup> Only 12 interviews were carried out in addition to the document analysis. Although we had planned to conduct more interviews with patients and families, it proved difficult to reach them for these interviews. However, the data were saturated; it has been shown that

data saturation can be present with a relatively small number of interviews.<sup>23</sup> Owing to the small and heterogeneous sample, we did not focus on the different perceptions between specific ethnic groups on the role of relatives in patient safety.

### Generalisability to the majority population

Although this study focused on ethnic minority patients, the roles of the relatives described may also apply to non-minority patients. The roles of patient and healthcare provider can also be fulfilled by relatives of patients of the majority population. The role of interpreter might be less applicable because Dutch patients have no functional language barrier. However, in case of low health literacy and/or use of difficult medical language by healthcare providers, the role of an interpreter may also apply to relatives of non-minority patients. This phenomenon has been termed a ‘magnifying glass effect’, that is, the results of our study are not caused by the patient’s ethnic backgrounds but by universal determinants that could apply to all patients.<sup>24</sup> However, we did not include hospital admissions of Dutch patients; thus, we did not generate evidence on the roles of ethnic Dutch relatives in this study.

### Practice implications

The main issue emerging from our results is how to optimally engage family members, who are willing to help, in hospital care. Currently, Dutch (adult) hospital care organisation is not optimally suited for family participation, while in certain American hospitals and also in Dutch paediatric hospital care, family involvement is considered to be ‘usual’.<sup>25–26</sup> The hospitals in our sample had strict visiting hours, and single rooms were only used for very ill patients, or for patients who needed isolation. On the one hand, we found that healthcare providers had a positive attitude towards family involvement (eg, because they can serve as interpreters and take over selected tasks) and on the other, we found many examples of the opposite, for example, healthcare providers who did not like relatives to be around all day long. However, not expecting a relative to be in hospital outside visiting hours, but welcoming a relative outside visiting hours to fulfil the role of interpreter, patient or care provider, can be confusing and can cause friction, which can increase safety risks. Therefore, when healthcare providers do allow relatives to participate in the care process, a thorough intake consultation with these relatives should take place, including risk communication. Arrangements made with relatives regarding care must explicitly be written down and must be totally clear for all healthcare providers (eg, ‘Daughter is coming to wash patient X every morning at 9 AM, and is trained to check for pressure ulcers’ or ‘Daughter is coming to wash patient X every morning at 9 AM, please do pressure ulcer check afterwards’). A recent systematic review on patient–companion–provider communication revealed similar recommendations, that is, to encourage/involve

companions, highlight helpful companion behaviours and clarify and agree on the role preferences of the patient/companions.<sup>27</sup> Nevertheless, healthcare providers remain responsible for adequate communication with the patient, for the management of hospitalisation and for patient safety. The challenge for clinical practice is to optimise the role of family members when they are closely involved in the care process.

### CONCLUSION

Family involvement can increase or create patient safety risk during a hospitalisation of their relative, but may also increase patient safety. Although healthcare providers should in no way hand over their responsibility to the relatives of patients, optimising collaboration with relatives who are willing to take part in the care process may improve patient safety.

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