Relatives' negotiation power in relation to older people's acute hospital admission

A qualitative interview study

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1111Title page

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The authors certify that they have participated in designing the study, analysing the data and drafting and final acceptance of the submitted article.

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Ethical approval

According to the current Danish legislation, the study did not need formal ethical approval from the Regional Scientific Ethical Committees. The storage and management of data are registered with the Danish Data Protection Agency. The study complied with the Helsinki Declaration and the Ethical Guidelines for Nursing Research in the Nordic Countries.

Keywords Older people, Elderly, Acute admission, Emergency department, Relatives, Caregiver, Family, Next of kin, Negotiation, Health literacy.

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BACKGROUND

Changes in the current welfare models, demographic challenges, increasing organisational complexity and the limited healthcare system resources all require citizens to be active and take personal responsibility for their health (1, 2). The policies and strategies of the modern healthcare system assume that patients are well informed and are able to take care of themselves (3-5).

In this regard, according to Katrin Hjort's theory, citizens must have strong client competencies to obtain access to welfare benefits, including quality care and treatment from the healthcare system (3). Hjort's theory is inspired by the French sociologist and philosopher Pierre Bourdieu's perspectives on human access—to economic, cultural and social resources and to different fields—with several forms of practice and power relations (3). Hjort's definition of the concept of 'client competencies' is based on four types of resources: affective (e.g. how to position oneself), cognitive (e.g. how to navigate in relation to organisational procedures), social (e.g. how to create a network) and economic (e.g. how to prejudge potential financial needs for help and support) (3). Thus, Hjort's theory about 'client competencies' and perspectives on citizens' access to welfare benefits inspired the present study (3).

In particular, older people acutely admitted to hospital pose a clinically complex challenge. They may be vulnerable and dependent on resourceful relatives to support them and plead their case

(6, 7). Qualitative studies show that older hospitalised patients often delegate responsibility by authorising relatives to act on their behalf and involve them in decision-making concerning the acute hospital admission (8, 9). Often, relatives, as surrogate decision-makers, feel the need to act as advocates, watchdogs, case managers or intermediaries for an older patient during and after a hospital stay—an experience that they can find frustrating (10-20).

Scandinavian and international studies find that their relatives' actions can affect citizens' access to welfare services (11-13, 15, 18, 21-31). During an older person's acute hospitalisation, some relatives experience exclusion from care and treatment and find participation difficult (32-35). In this context, they can consider their interaction with healthcare professionals (HCPs) a burden that affects their experience of being a relative (18, 19, 32, 35, 36). These experiences relate to conflicts caused by the quality of communication between HCPs and relatives (19, 32, 36, 37).

Relatives' feelings of limited influence may be related to the HCP's perception of them as an obstacle or a demanding resource, judged as an extra burden because they take up the HCP's time and resources (38-40). In contrast, an HCP may perceive some relatives as an asset since they contribute to, and optimise, the HCP's work (31, 38). Therefore, some relatives may experience that the complicated access to an HCP affects the outcomes of their negotiations with the HCP. Further, relatives with HCP background are more likely than other relatives are to have their demands met since their HCP background can make it easier for the former to navigate the healthcare system (24, 41, 42). Thus, different aspects may affect relatives' negotiations with HCPs.

In addition, 'negotiation' is a complex social process influenced by many elements unique to the specific context (43). It is commonly assumed that negotiation is part of social interactions and occurs in all aspects of life since it is a form of decision-making aimed at resolving conflicting interests (43). However, in general, knowledge about relatives' role in relation to older people in an acute admission remains limited. Therefore, relatives' experiences need to be investigated for HCPs to understand the way relatives may negotiate and influence older people's access to quality care and treatment.

Aim

This study aimed to explore relatives' experiences of their interactions with HCPs during acute hospital admission of older people to derive themes of importance for relatives' negotiations with these professionals.

METHODS

Research design

We conducted a qualitative interview study, focusing on the time leading up to an acute admission and the actual admission in the somatic area of the Danish healthcare system.

Participants and setting

We invited relatives who had experience dealing with the acute admission of older relatives for an individual interview (44). The participation criteria were as follows: relatives of patients aged at least 75 years who were acutely admitted to one of two emergency departments (EDs) between September 2018 and April 2019.

The older people were admitted by their general practitioner (GP) or the medical emergency service. In the EDs, they were triaged and treated for a wide range of somatic diseases and were then discharged or transferred to another hospital ward. We aimed to include a broad sample of relatives, encompassing family members as well as other persons significant to the older person, acknowledging a broad definition of relatives based on modern family structures. All relatives included in the study considered themselves close relatives to the older person. Not all relatives were informal caregivers, given that some only supported the older person in performing minor tasks.

We performed purposeful sampling to ensure that the participants suited the study's aim and were able to provide rich information. Physicians and nurses from the two EDs played the role of gatekeepers; they approached potential participants face-to-face and offered oral and written information about the study. Based on reflections on the concept 'Information power', we aimed to recruit approximately 10–15 relatives of older acutely hospitalised patients (45). The reflections encompassed: (a) the aim of the study, (b) the sample specificity, (c) the use of established theory, (d) the quality of dialogue and (e) the analytic strategy (45).

Data collection

We generated data through individual semi-structured interviews (see Table 1), to give the participants the opportunity to describe their experiences (46). We developed an interview guide, inspired by recent research on client competencies and citizens access to welfare benefits' (3, 10-15, 19, 32, 33, 41, 42, 47). In line with the study's aim, the focus was primarily to have relatives describe their experiences: *what* they did concerning the older person's admission, *how* they did it and, maybe, *why* they did it. Clarifying and probing questions were asked (46). The first author, who is an experienced interviewer, conducted all the interviews, which lasted 22–53 minutes. After each interview, the first author noted immediate thoughts about the interview in a logbook. The first author recorded and transcribed verbatim all the interviews.

Please insert Table 1.

Data analysis

The analysis was inspired by Graneheim and Lundman's description of qualitative content analysis (48). This systematic method allowed us to work both with the manifest and the latent dimensions of the material and thereby sufficiently fulfil the study's aim. The manifest content dealt with the obvious components, whereas the latent level involved interpreting the underlying meaning of the text (48), as shown in Tables 2 and 3.

Please insert Table 2.

Please insert Table 3.

The main author is a female nurse, and the four co-authors are male and female researchers with professional backgrounds as a physician, a sociologist, a midwife and a nurse. All authors have relevant experience as a relative of older family members admitted to hospital. Reflections on preconceptions and discussions among the authors and other relevant peers were important parts of the analysis process (44). Throughout the analysis, the main author noted the emerging reflections. The main author participated in steps 1, 2 and 3 (Table 2). All authors worked together to interpret categories and condense them into themes. This analysis occurred through ongoing dialogue and four face-to-face meetings (analysis steps 4 and 5, Table 2). The participants were not involved in the analysis and were not requested to validate the transcript material.

Ethical considerations

In accordance with the Helsinki Declaration, the participants consented both verbally and in writing to participate in this study (49). This study explicitly focused on relatives' experiences of acute admission and did not include demographic information about the patients. Therefore, these patients were not required to provide verbal or written consent for the researchers to approach their relatives.

Some interviews were conducted within a few hours of the admission. Owing to the acute nature of the situation, the interviewer had to keep in mind the extent to which the decision about participation was made quickly, during a potentially emotionally challenging moment. The participants were free to ask questions before and after the interviews. They were informed about the right to withdraw from the study at any time up to the point at which the material had been analysed. Rules of confidentiality were observed, and no names or other sensitive personal information are provided in the findings. Pseudonyms are used to refer to the participants. The Regional Committee on Health Research Ethics for Southern Denmark waived formal permission (Ref. ID 20182000-88), in accordance with Danish legislation. Data storage and management were registered with the Danish Data Protection Agency (Journal number 18/33143). Data were managed in accordance with the European General Data Protection Rules and were stored and analysed in OPEN Analysis, which complies with current data protection requirements (50).

FINDINGS

A total of 17 relatives accepted the invitation to participate (see Table 4).

Please insert Table 4.

The interviews were held in a quiet room in the ED. Apart from one interview that was conducted with two participants since two relatives (sisters) wanted to be interviewed together, all interviews were conducted with one relative and the older person was not present. The analysis derived four themes: (a) *Mandate*, (b) *Incentive*, (c) *Capability* and (d) *Attitude to taking action*. These themes are presented in the next section and are illustrated by selected excerpts from the interviews.

<u>Mandate</u>

An essential element of a relative's negotiation was whether the older person, and other relatives, allowed the relative to speak and act on the older person's behalf. Some relatives seemed to have carte blanche to speak and act on behalf of the older person. Other relatives described the older person as stubborn and found it frustrating to manage their admitted relative's self-determination and still make the right decisions in relation to this person's care, treatment and daily life.

> *Well, because we have not been able to get our father to go to the doctor. 'Dad, we need you to be examined, so you have to go to the hospital', and he didn't want to.* (Ellie, 46-year-old daughter).

Relatives seemed to spend energy to obtain the older person's permission to negotiate and navigate on their behalf. Some relatives eventually achieved the mandate, and they described this as an important change in their relationship with the older person and their role as a relative because of the older person's reduced physical and cognitive condition. To have a mandate to negotiate and act on the older person's behalf made the relatives feel less frustrated and allowed them to do what they felt was right.

Other relatives apparently acted on behalf of the older person without having full permission or the mandate to do so. Felicia and Fiona negotiated with the HCPs to obtain admission to a temporary nursing home for their mother, who (according to the relatives) had dementia. They did not involve their mother in deciding on these arrangements despite her ambivalent feelings about moving to a retirement home. Felicia explained that she still hinted to her mother that if her mother recovered, she would be able to go back to her own home after discharge. This approach calmed her mother and avoided problems during the hospital stay.

When family members disagreed, it was problematic for only one family member to negotiate on behalf of the older person. Before Béatrice chose to call her brother's GP for assistance in an acute situation, she called her brother's daughter to ask for permission:

> *So that I wouldn't have to get into a tangle with anyone, I called her before anyone else, before the emergency team and the doctor or whoever got mixed up in it.* (Béatrice, 70-year-old sister).

Incentive

Relatives' incentive appeared to stem from fundamental values. Some relatives experienced a fundamental obligation and urge to protect the older person by taking care of this person. Further, the relationship between the older person and the relative appeared to be an important driver of the relatives' feeling of obligation to help the older person. For instance, others underlined the older person's independence and downplayed their responsibility. Relatives who focused on protecting the older person were keen to communicate wishes and needs to the HCPs. A daughter to a female patient termed herself as her mother's advocate and described the admission to the ED as a game: *'I am her advocate in this game here'* (Gabriella, 55-year-old daughter).

Moreover, the relatives' trust or distrust of the HCPs and the healthcare system seemed to affect their experience of responsibility and their incentive to act on behalf of the older person. Relatives who did not feel trust in the HCPs and the system seemed more alert and compared their experiences in the healthcare system to those on a battlefield. These relatives negotiated the quality of care and treatment with a very proactive, assertive approach. Their feeling of trust or distrust as regards the HCPs and the healthcare system seemed to be based on previous experiences from their own or other peoples' lives. Hector, a 49-year-old son, referred to several negative experiences with the healthcare system. He was dissatisfied with the information about the diagnosis and the medical treatment related to his father's acute admission and confronted the HCPs:

> *Even I (emphasis on the 'I') had a hard time understanding her (the doctor), and I usually understand most people (…) But, I said it directly to the nurse: 'This is damned useless' (…) It may well be that where she (the doctor) comes from, you do not question the doctor, but she (the doctor) should be aware that we do that here in Denmark* (Hector, 49 year-old son).

Conversely, relatives who expressed trust in the HCPs and the healthcare system seemed less motivated to question the HCPs' decisions:

> *So, I have to get used to it because he is a doctor and I am a relative, and he probably knows more about the disease than I do, right?* (Carl, 65-year-old son).

Capability

If relatives had knowledge about health-related issues, such as symptoms and medication, and about the organisation of the healthcare system and had specific knowledge about the older person's everyday life, it seemed to help them feel more confident in their contact and negotiations with the HCPs. Relatives with a HCP background or with experience of previous admissions described this as an advantage, whereas those who felt they lacked knowledge or were inexperienced felt frustrated and powerless. Some relatives searched online for information in relation to the older person's disease:

> *'For someone like me, who doesn't know a damn thing, maybe they (HCPs) should spell it out to me'* (Isabel, 48-year-old daughter).

In addition, relatives who were able to think ahead and calculate consequences seemed to be able to negotiate in a more effective way than relatives who were incapable of doing so. Because of the first group's ability to anticipate potential problems related to the older person's condition, they were able to draw the HCPs' attention and potentially influence decisions related to the older person's care and treatment. Gilbert (50-year-old son) described his mother's situation as a project and explicitly named it *'mother project'*. He seemed well informed about how the healthcare system is organised and how to become involved in decision-making, and he explained how he acted very systematically and proactively in his contact with the HCPs:

> *I like to be structured and to plan; also, I have worked with this (project) for a long time. Yes, so now it's my 'mother project'* (Gilbert, 50 year-old son).

Physical, mental and social resources appeared to affect the relatives' capability to negotiate. Some relatives described how their family or professional background strengthened their capability to negotiate on behalf of the older person. In contrast, others described themselves as powerless or weakened because of psychological or social issues in their own lives, including stress and frustrations related to their role as a relative:

> *And at the same time, you need to make your family happy and your child. And you also have to manage your job. I am a person with a lot of international contact in my job. And it is damn hard work to keep smiling.* (Isabel, 48-year-old-daughter).

Attitude to taking action

The relatives interacted and negotiated with the HCPs. Some relatives acted passively and hesitantly and did not plan ahead or initiate contact with the HCPs. When dissatisfied, they did not ask questions or discuss issues with the HCPs. Other relatives took a more active position. They asked critical questions and addressed problems when unhappy with the quality of care and treatment. Relatives who took action were eager to be present in the ED during rounds or close to the older person during clinical examinations. According to Diana, a 58-year-old daughter-in-law, her mother-in-law was admitted because of neglect by the homecare service. Diana wanted the municipality to allow her mother-in-law to move to a retirement home, but the municipality repeatedly rejected the request. During the admission, Diana proactively tried to use the acute admission as leverage to negotiate with the municipality. She had a healthcare-related background and knowledge about aspects such as legal rights, and she felt the organisation of the healthcare system made it easier for her to navigate this system and to present her case to the HCPs. Diana initiated contact with the GP to encourage him to admit her mother-in-law to hospital. The GP offered Diana two options for her mother-in-law: fluid therapy at home and acute admission. As Diana said:

> *I wanted her to be admitted because then I knew that she would get a temporary stay at a nursing home* (Diana, 58 year-old daughter-in-law).

Some relatives deliberately used negotiation strategies in their contact with the HCPs. Felicia and Fiona, two 57- and 54-year-old sisters, formed an alliance with their mother's GP, who was very supportive in trying to help them secure a temporary stay at a retirement home. They showed the interviewer a handwritten note from the GP on which the GP had written 'causa socialis' (Latin for 'social cause of admission'). Felicia and Fiona had obtained the note from the GP, who advised them to use those particular words when negotiating with the HCPs at the ED and in the municipality.

DISCUSSION

We found that relatives' possibilities to negotiate involved four themes: mandate, incentive, capability and attitude to taking action. The themes appeared in different combinations and strengths depending on the specific situation. Our findings showed that relatives' possibilities to

negotiate were weakened or strengthened in relation to these themes. Therefore, these themes can be defined as the sources of the relatives' negotiation power.

Further, our findings showed that these sources of power are related to the specific context and can thereby change according to the situation. Changeability is also embedded in Hjort's theory: Hjort asserts that a client's affective and cognitive competencies are weakened by, for example, fear, crisis or pain (3). Other studies have shown that older hospitalised patients often authorise family members to act on their behalf (8, 9). In contrast, some relatives did not feel that the older person had given them a mandate to act on their behalf. Several felt trapped between their own incentive and capability to help and act on behalf of the older person and a weak mandate.

Relatives' mandate for negotiations can be related to the concept of 'the paradox of care', as Kari Martinsen (51) describes. Martinsen describes the connection between nurse and patient as an asymmetric power relation—a paradox between two opposites: negligence and paternalism (51). If the caregiver is too focused on respecting a patient's autonomy, the caregiver may act in a way that is too complicit with the patient's wishes and may be negligent and harm the patient. Conversely, if a nurse is too protective, the patient's autonomy may be violated by paternalistic actions. Both positions result in a disregard of the patients' interests (51). Through the lens of Kari Martinsen's polarised concepts of negligence and paternalism, similar frustrations were observed among relatives in this study when they tried to balance between making competent decisions and respecting the older person's right to autonomy. This situation may lead to frustrations since relatives feel they cannot change the situation and may fear being negligent. We observed this frustration among the participants in the current study in that the relatives who intended to negotiate on behalf of the older person but did not hold a mandate described the situation as frustrating and stressful.

The theme 'incentive' encompasses relatives' experiences of their caring responsibility and motivation for negotiating on behalf of the older person. Relatives' trust or distrust of the healthcare system and the HCP seemed to influence their incentive to act on behalf of the older person. A strong incentive seemed to strengthen their negotiation power by making them act persistently and by making them persevere. Andersen et al. defined caring responsibility as the balancing of a relative's different roles vis-á-vis the older person, their own life and the healthcare

system (52), which our findings also reflect. Other studies have also widely documented that relatives' caring responsibility can enhance their proactivity on the older person's behalf and give them the incentive to assume the role of advocate or case manager (12-15, 17-18).

Relatives' ability to access, understand, appraise and apply information provided by the HCP influences their capability to negotiate and navigate on behalf of the older person. Further, personal characteristics and social resources influenced relatives' capability to negotiate in a specific situation. Their specific knowledge about the older person was important, and their knowledge about the healthcare system or from a health professional background were important aspects of this capability.

Relatives' capabilities to act on behalf of the older person can be associated with the concept of 'health literacy', which is defined by the personal characteristics and social resources that enable an individual to access, understand, appraise and apply information and services to participate in decisions related to their health (53). Positive associations between relatives' resources and patients' health outcomes are echoed in Hjort's definition of 'client competencies' (3).

Strong 'capability' (e.g. knowledge) is not necessarily the same as 'strong negotiation power' in a specific situation, because their mandate, incentive and attitude to taking action are also important sources for relatives' negotiation power. Further, relatives who present an initial impression of being resourceful and who hold the affective, cognitive, social and, perhaps, economic resources, cannot necessarily always fill the role of a 'strong relative' in all situations because their mandate, incentive, capability or attitude to taking action in the specific situation can differ. Thus, the findings of the present study refine, and present a nuanced view of, the complexity of negotiations, the results from similar studies describing various 'types' of relatives and Hjort's theory on client competencies (3, 20, 29).

The four sources of power can also be linked to Bourdieu´s interrelated concepts: habitus, capital and field (54, 55). An ED can be described as a field defined by power relations between patients, relatives and HCPs. The four sources of power can be considered a reflection of relatives' habitus and as part of their symbolic capital in the field. This capital seems to optimise their position in the ED by facilitating their access to the HCP and their possibilities to negotiate quality of care and treatment.

STRENGTHS AND LIMITATIONS

In-depth interviews were a suitable method to achieve the study's aim. We were inspired, but not limited by, Hjort's concept of 'client competencies', and this study added important aspects to the concept (3). The transparent process improved the reliability and trustworthiness of the study (56). Discussions between the authors, in relation to the analysis and interpretation of the empirical material, ensured a reflexive stance throughout the analysis process. Based on reflections of the concept 'information power' we continuously assessed whether the planned sample size was adequate (45). Consequently, we chose to increase the number of participants from an initial 10–15 participants to 17 participants because the interviews were shorter than expected and yielded less data (45).

Further research is needed to explore (a) whether HCP-related knowledge is more powerful than specific knowledge about the older person in negotiations between relatives and the HCP, (b) how different relatives act and interact with the HCP in relation to older people's acute admission to an ED and (c) how their negotiation power is affected by the local setting and their relationship with the HCP in a specific situation.

In future studies, it would be interesting to narrow the selection criteria to gain specific knowledge about relatives of a particular group of older people. In addition, it could also be relevant to explore whether gender, age and ethnicity influence relatives' negotiation power. Moreover, whether they are 'caregivers' or 'significant others' to the older person may significantly influence relatives' negotiation power, since 'caregivers' may have more knowledge on aspects such as the older person's needs and habits.

IMPLICATIONS

The initial letters of each of the four sources of importance for relatives' negotiation power can be combined to form an acronym: MICA (mandate, incentive, capability and attitude to taking action). MICA can be illustrated in a model, the MICA model (Figures 1 and 2).

Please insert Figure 1.

Please insert Figure 2.

The MICA model is regarded as a reflection tool and can be used for reflection on the four sources of power related to relatives' negotiation power in a specific situation. Each source of power has its own axis; each can be assessed from low to high and can be connected to illustrate the shape of a square. Thus, the MICA model can lead to a visual illustration of relatives' negotiation power in a specific situation.

It is not possible to reflect on relatives' 'negotiation power' without having a dialogue with the relative. The goal of this dialogue is to increase the HCP's understanding of the relative's negotiation power. The themes included in the MICA model can be related to the specific context and are potentially modifiable. By gaining a nuanced understanding of the motives behind the relative's behaviour in a specific situation, the HCPs can increase the opportunity to meet the relatives on their own terms and provide the best support for both the relatives and the older persons.

HCPs can use the MICA model as a reflection tool to strengthen their understanding of relatives' behaviour and 'negotiation power'. The reflections can guide the HCPs' support of relatives. Some relatives may need knowledge, whereas others may need psychological support, such as support to handle the paradox of care. The model may also be applicable as a reflection model in health education.

CONCLUSION

Four themes were identified as important sources of relatives' negotiation power: mandate, incentive, capability and attitude to taking action. Relatives' negotiation power seems to be strengthened if they hold a strong mandate, have an incentive to act, hold the necessary capabilities and are active or even act proactively in their contacts with the HCPs. Since the four sources of power may change from situation-to-situation, relatives' negotiation power seems to be context dependent. This means that relatives who appear to be resourceful in one situation may lack certain sources of power, such as a mandate or the necessary knowledge, in other situations.

Our findings offer a nuanced view of Hjort's description of the resources related to her definition of 'client competencies'. Further research is needed to provide knowledge on the interrelationship

between the four sources of relatives' negotiation power and on the ways in which the context and the human relationships in the specific situation affect this power.

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Table 1. Examples of questions included in the interview guide

Questions
What happened the day X was admitted to the hospital?
Who was involved in decision-making regarding the admission?
Tell me about how X was transported to the hospital.
Tell me about the arrival at the emergency department (ED).
What was your role in relation to the healthcare professionals' (HCPs') clinical examination of X?
How do you perceive your experience regarding your contact with the HCPs?
How do you perceive the significance of your presence at the time of arrival at the ED?
What was your experience related to your responsibility in this part of the trajectory?
The focus for answering these questions is as follows: What did you do? How did you do it? If possible, tell us why you did it.

Table 2: Steps in the inductive content analysis

Step no.	Description
Step 1	All interview transcripts were read several times to capture a sense of the whole meaning.
Step 2	Meaning units of importance were identified to fulfil the study's aim.
Step 3	Meaning units were condensed and coded according to the *manifest* content.
Step 4	Codes were compared based on similarities and differences and were sorted into 22 categories describing the *manifest* content across the transcribed material.
Step 5	Based on our interpretation of the categories, they were condensed into four themes. These themes express the underlying meaning of the material on an interpretative level and, thus, the themes represent the *latent* content of the material.

Table 3. Examples of the analysis process

Meaning unit	Condensed meaning unit	Code	Category	Theme
There is no one to come and help, and it is no use that we try to explain to her that now she is going to a nursing home or whatever, because we can't get her to do it.	The older person will not accept help, or agree to move to a nursing home, and the relatives cannot persuade her.	The older person's challenge of self-determination	Permission to act	Mandate
If there is something I am not satisfied with, I call immediately.	The relative reacts when she is unsatisfied.	Dissatisfaction leads to action	Active in doing something	Attitude to taking action

aTable 4. Participant characteristics

Characteristic	Description
Gender	Female (12) Male (5)
Age	41–83 years
Relationship with the older person	Daughters-in-law (2), Sister (1), Daughters (8), Sons (4), Husband (1), Wife (1)
Employment status	Retired (5), Sick leave (1), Unemployed (1), Early retirement (1), Employed (9) Participants with health-related background: 3
Distance to the older person's residence	*Same land register (2), Cohabiting (2), 1–10 km (6), 10–20 km (1), 20+ km (6)

* Does not live in the same house as the relatives but in a small flat or annex.

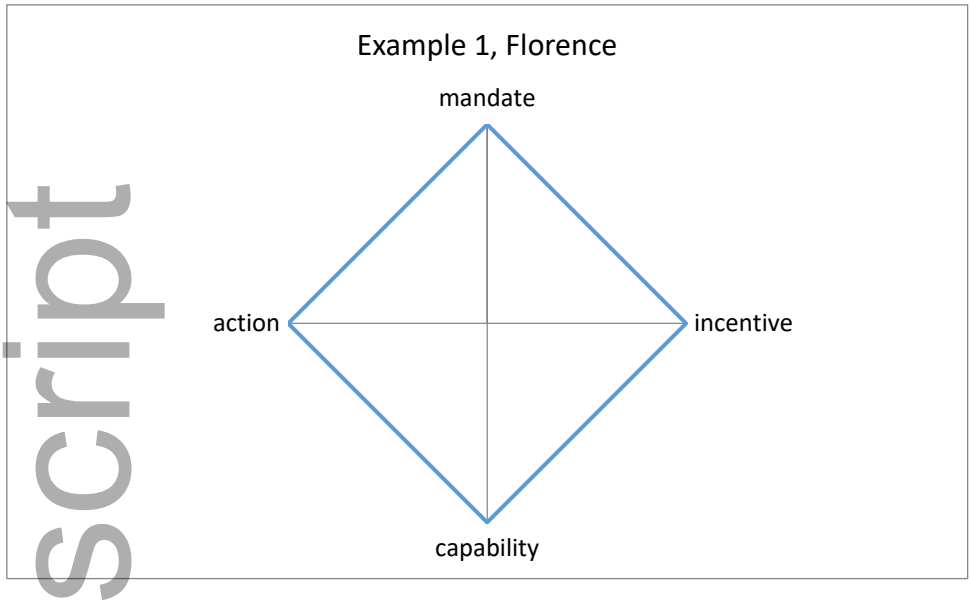

Figure 1. The MICA model: An example of a relative's negotiation power.

Graphic illustration of a strong, symmetric structure of relatives' negotiation power.

Florence, 72-year-old daughter with a health professional background. *Mandate:* Had her mother's mandate to speak and act on her behalf: *'She actually says "yes" to most of what I say.' Incentive:* Very determined to help her mother and to take good care of her: '*She only has me, after all.'* Critical of the health care system: *'You have to be a little more forward. My boss always said, "Oh boy, it gets worse when we get older" (laughs). (...) I don't know ... but I carry on, at least. They will have to hear what we say.' Capability:* Health-related background. *Attitude to taking action:* Takes a great deal of action: *'You have to have a plan for what is going to happen.'*

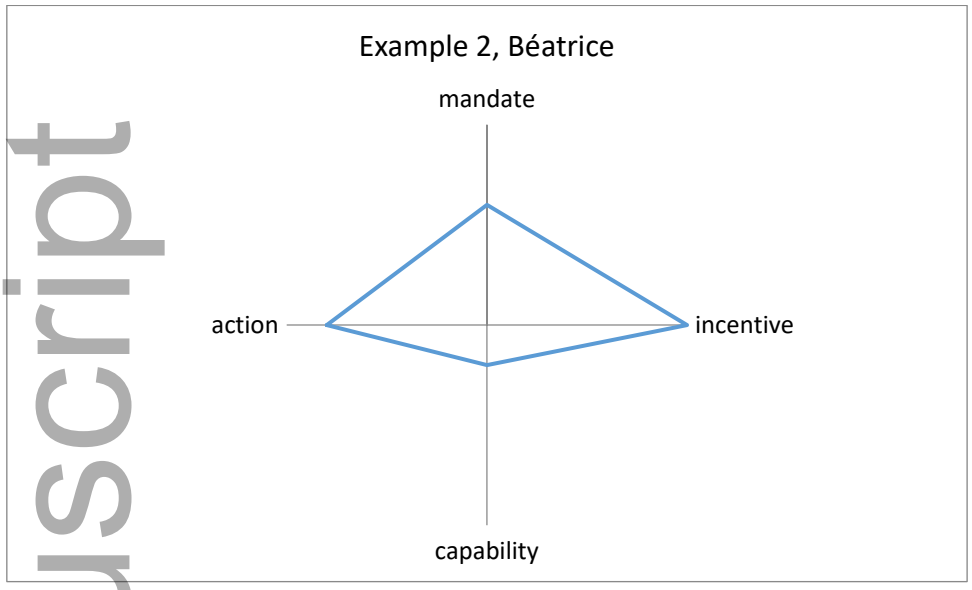

Figure 2. The MICA model: An example of a relative's negotiation power.

Graphic illustration of an *asymmetric* structure of *relatives' negotiation power.*

Béatrice, 70-year-old sister. *Mandate:* Most of the time, her brother gave her a mandate to speak and act on his behalf: *'And then I said, "Well, you know, I need an answer from you, of course". And then I said, "What do you say?". "You can call the doctor" (the brother replied). And so, I called the doctor and then everything was actually in motion. And so, we came up here to the emergency ward.' Incentive:* Determined to take care of her brother, to protect him and not let him down: *'You know what, you can't let someone down' (looking at the interviewer intently). Capability:* Limited health-related and illness-related knowledge. Did not search for knowledge. *Attitude to taking action:* Acted actively and if dissatisfied with the decisions of the healthcare professionals (HCPs) or the care and treatment they offered, she confronted them and tried to make them change it: *'You know what, she (the HCP) called back and then she said, "Yes, there is someone from the emergency team, but it can take up to 2–3 hours". Then I said, "You know what, I just won't wait for that. I am going to call 112". Well, then she said that I could do that, so …'*