

Reframing Patient's Autonomy in End-of-Life Care Decision-Making: Constructions of Agency in Interviews with Physicians

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Abstract: In the research literature, critical viewpoints question the idea of patient autonomy as a robust basis for approaching end-of-life treatments. Yet physicians express distinctly positive attitudes towards patient autonomy and advance directives in questionnaire studies. In this article, we unravel taken-for-granted assumptions about the agency that physicians use when evaluating patient autonomy in end-of-life care. We use Goffmanian frame analysis to analyze semi-structured interviews with eight Finnish physicians. Instead of measuring standardized responses, we explore in detail how distinct evaluations of patient autonomy are made through approving or reserved stand-taking. The results show that the interviewees reframed patient autonomy with the help of biological, medical, ethical, and interaction frames. Through such reframing, the patient's agency was constructed as vulnerable and weak in contrast to the medical expert with the legitimated capacity to act as an agent for the patient. Further, end-of-life treatment decisions by the patient, as well as the patient's interests appeared as relationally defined in interactions and negotiations managed by the physician, instead of attesting the sovereign agency of an autonomous actor.

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Proponents of the right-to-die movement argue that in certain scenarios, providing dying patients with more treatment would increase their suffering (Andorno, Biller-Andorno, and Brauer 2009). Given the difficulties in objectively determining when providing more treatment becomes harmful, the principle of patient autonomy gained a central role in end-of-life care discussions. It follows the assumption that one's best interests for medical treatment are the product of personal values instead of medically determined concepts (Lidz and Arnold 1993). This notion also extends to individuals who had their decision-making capacities circumscribed by illness or injury. The use of advance healthcare directives (or living wills) allows healthy individuals to express their preferences for different medical treatments, providing future instructions in case they become unable to communicate and make decisions for themselves (Dresser 2003).

A literature review of 15 empirical studies crossing 10 countries (from Europe, Asia, North America, and the Middle East) found that physicians, in general, hold positive attitudes towards advance directives, praising their use in promoting patient autonomy. Diverse factors, however, had negative impacts on their attitudes, including religious and cultural background, potential legal problems, family opposition, and fear of increased euthanasia (Coleman 2013). In Finland, a survey found that 92% of physicians had a positive attitude towards advance directives (Hildén, Louhiala, and Palo 2004). The most common advantages include: *promotes patient autonomy* and *acts as an ice breaker for discussing the end of life treatment*.

Despite the overwhelming support from physicians, the prevalence of advance directives varies significantly across countries. In the US, where these documents were originally introduced, very

few individuals have actually signed an advance directive, which suggests a gap between the autonomy-centered model of advance care planning and the patient's desires for end-of-life communication (Hawkins et al. 2005). The legal aspects of advance directives favor the convergence of specific medical treatment preferences in written format; however, it can be daunting for patients to gather all the necessary information to make accurate predictions (Fagerlin and Schneider 2004). Consequently, a substantial minority of patients change their treatment preferences over time (Auriemma et al. 2014), often without realizing they did so (Sharman et al. 2008). Moreover, ethnographic studies (Shapiro 2015; Shapiro 2018) have shown that instead of relying on written guidance, surrogates often refer to one's personality, values, and previously expressed preferences to construct the patient's best interests for end-of-life treatment (Shapiro 2018), thus undermining the importance of advance directives for the decision-making process. In European countries, on the other hand, Andreassen and colleagues (2019) found that the prevalence of advance directives ranges from 0.1% (Italy) to 76.9% (UK)—in Finland, the same study found that 40.1% of the individuals in long-term care facilities have signed an advance directive. Despite these differences, Finnish physicians have expressed similar concerns, such as the possibility of patients making a will for the wrong reasons (e.g., depression) or changing their mind after signing the document (Hildén et al. 2004).

Ditto, Hawkins, and Pizarro (2006) reviewed the key psychological assumptions supporting the legal and ethical arguments for the use of advance directives. The authors concluded that people will often fail to predict future treatment preferences because they:

- (a) have inaccurate beliefs about life-sustaining medical treatments, (b) fail to appreciate how their current

physical and emotional state affects their predictions about future states, (c) under-appreciate how well they will cope with serious illness, and (d) weigh certain aspects of information differently when making decisions about immediate and more distant futures. [Ditto et al. 2006:493-494]

All these critical viewpoints question the idea of patient autonomy as a robust basis for approaching end-of-life treatments. They cast doubt on patients' agency in taking advantage of the autonomy offered to them, as well as their ability to assess and decide on the treatments in an adequate and proper way. Such views may account for physicians' reservations about the use of advance directives that have been reported in the literature. Perhaps the generally positive attitudes stem from abstract values underlying the creation of these documents, whereas reservations are associated with practical concerns surrounding their use. Physicians could also share these critical views due to their institutionally legitimated position in doctor-patient relationships.

According to Laine and Davidoff (1996), different facets of patient-centered decision-making models have developed at different paces. More specifically, whereas medical law and bioethics have advanced the notion of informed consent, their universalistic and disembodied way of dealing with ethical problems fails to address in situ issues surrounding doctor-patient relationships (Lopéz 2004). For instance, physicians are responsible for evaluating which interactional strategies best fit each patient's preferences in terms of information disclosure and decision-making participation (Kiesler and Auerbach 2006). As such, despite the advance of bioethics, certain levels of medical paternalism seem to persist (see, e.g., Légaré et al. 2010; Pollard et al. 2014). If, on the one hand, the emergence of informed consent

ideology has imposed limits to medical authority; on the other, *medicalization* (i.e., the process whereby non-medical problems become defined in terms of illnesses) has increased the role of medicine as a mechanism of social control (Conrad 1992). According to Conrad (1979), physicians remain the sole gatekeepers of medical technologies through which they can secure their role of "experts" during medical decision-making (Freidson 1970). Furthermore, the current biomedicalization process has intensified this tension. On the one hand, innovation in medical technologies has the potential to advance physicians' authority (Clarke et al. 2003); on the other, patients are increasingly regarded as autonomous consumer-citizens (Rose 2013).

Contrary to these speculations, however, physicians express distinctly positive attitudes towards patient autonomy and advance directives in questionnaire studies (Hildén et al. 2004; Coleman 2013). How should we interpret these results in the face of critical views questioning the patient's agency? How do physicians actually construct patient autonomy when they present evaluating comments about it?

In this article, we aim to unravel unspoken assumptions about agency underlying physicians' talk about patient autonomy. According to Kuczewski (1996:30), the notion of informed consent presupposes that individuals possess a "sphere of protected activity or privacy, free from unwanted interference"; patient's autonomy is only possible to the extent this sphere of privacy is respected. Such a notion resonates with what Emirbayer (1997:284) identifies as a substantialist approach to agency, which regards the individual as a "rational, calculating actor" or "rule-follower" driven by "vital inner forces." Drawing from a relational approach (Emirbayer 1997; Emirbayer and Mische 1998), we propose in-

stead that agency is indissoluble from the spatio-temporal contexts of action. Actions are not guided by internalized goals abstracted from concrete situations, instead, ends and means are developed within different ever-changing contexts subjected to constant reevaluation as events unfold.

We utilize Goffman's (1986) frame analytical perspective to discuss how patient autonomy can be constructed not only with an emphasis on agency understood as a property of individual actors, but also on agency seen to be embedded and defined in social relations and interactions at the level of everyday medical practice. We also draw from Meyer and Jepperson's (2000) theory on the cultural construction of agency to distinguish two modalities of agency: *agency over* and *agency for*.

Empirically, we analyze interview talk in which physicians comment on patient autonomy. Instead of measuring standardized responses, we explore in detail the physicians' arguments and show how the expression of positive and negative evaluations of patient autonomy is done through approving or reserved stand-taking. Adding a frame analytical reading, we unpack the contextual assumptions of agency the physicians use when evaluating patient autonomy in end-of-life care.

Agency and Framing

In social sciences, the agency has often been approached as agency towards or over something; for example, an ability to influence one's actions and life circumstances (Bandura 2006). Meyer and Jepperson (2000) argue that in modern society, the efficient agency is highly valued and modern actors are expected to enact and cultivate it. "Helplessness, ignorance, and passivity may be very natural hu-

man properties, but they are not the properties of the proper effective agent. Modern agentic actors involve themselves in all sorts of efforts elaborating their agentic capabilities, efforts that often have only the most distant relation to their raw interests" (Meyer and Jepperson 2000:107). Instead of (more and more standardized) forms of efficient agency, however, they draw attention to the contextual and structural embedding of agency by highlighting that modern agents enact agency for something or somebody ("a principal"). According to Meyer and Jepperson (2000), a unique aspect of modern actorhood is the construction of actors as authorized agents for various types of principals, including themselves, but as well other social actors, society, or abstract ideas and values such as equity, truth, or economic growth.

Actors can enact agency for their self-interests insofar as they are also agents for and under the modern cultural system. Meyer and Jepperson (2000) reject the notion that one's interests stem solely from biological or psychological variables; instead, actors adopt interests legitimated by the cultural system and institutional practices (i.e., the Hippocratic Oath aims to ensure that physicians address a patient's best interests over possible competing interests). Additionally, modern agents can take and shift the principles they serve. "A striking feature of the modern system is the extreme readiness with which its actor participants can act as agents for other actors. They can do this, with rapidity and facility, as employees and consultants, as friends and advisors, as voters and citizen" (Meyer and Jepperson 2000:107).

Physicians, too, can act as agents for different types of principals including patients, the hospital as an organization, society, ethical and legal principles

guiding their professional conduct, and, obviously, the physician's personal interests. In what concerns end-of-life care discussions, physicians act as "death brokers." They rely on different interactional strategies to render the dying process culturally appropriate (Timmermans 2005), which presupposes a scope of action embedded in complex agent-principal relationships that transcend the doctor-patient relationship on its own.

Meyer and Jepperson's paper represents one way to elaborate on a relational view to agency and analyze how the agency is embedded in a social context. A special feature in their relational theorizing is the central role given to the agency in the meaning of agency for somebody. This aspect of agency concerns agents enacting their agency on behalf, or for, somebody or something. It is conceptually different yet intimately connected with the other side of the agency, *agency over or towards something*, which concerns the agent's ability to self-regulate and make things happen (see also: Niska 2015).

The very concept of autonomy can be understood from the perspective of these two aspects of agency: first, autonomy as agency towards or over, as the ability to execute acts, and second, autonomy as the agency for, the ability to act as an (authorized) agent for oneself, and thus to define one's wishes, values, and interests. However, whereas the notion of *agency over* provides us with limited analytical tools to discuss how interests are developed and maintained by different actors during an interaction, the very process of interest construction is central to discussions about how an actor may enact *agency for* different principals. Interest construction is one way to define a principal for oneself, and consequently, attempt to authorize oneself as an agent for that principal.

Meyer and Jepperson, however, focus on the cultural macro level, whereas we, in this paper, will target micro-level processes with the help of Goffmanian theorizing. When people face a new situation, Goffman (1986) explains, they routinely ask themselves: "What is going on here?" Through primary frameworks, individuals organize a social experience by extracting meaning from aspects of the scene that otherwise would be regarded as meaningless. Goffman then distinguishes two types of primary frames: natural frames and social frames. Natural frames concern "purely physical" acts (Goffman 1986:22) to which no intentionality is attributed, and no human actors steering them are presupposed. Social frames, on the other hand, presume the existence of an agent whose intentions, motives, and effort for control direct the event.

The use of frame analysis, however, is not an unproblematic one. According to Scheff (2005), it remains one of Goffman's most elusive concepts, often misunderstood, paraphrased without enough theoretical consideration, or harshly criticized. Among its criticisms, it has been suggested that frame analysis concerns a structural approach, and not an interactional one. Sharron (1981:505), for example, argues that

By proposing frame as "definable principles that govern events," he [Goffman] implies that the nature of interaction can be arbitrarily decided in advance. These frames do not slide into one another; they stand separate and unrelated. Furthermore, they can be classified, rather than constructed in an innovative and unique process of interaction.

Scheff (2005), nevertheless, refers to the notion of *keying* to highlight the interactional features of frame analysis. Important to the development of

Goffman's theory is the notion that the meaning of primary frameworks can be transformed. Through the process of keying, the original meaning of a framework can be changed, resulting in a different interpretation of what is going on. An insult, for example, may be keyed into a play by asserting that "I was only joking." Social reality is often constituted by mixed class events, perceived as primary frames and transformed events (i.e., games, rituals, practices, etc.). According to Scheff (2005:371), the notion of keying is "unavoidably social," it presupposes not only a common focus of attention, but also mutual awareness between the participants and their key signs, which are essential to understand the discourse.

An example of how framings associate with the two sides of agency, discussed earlier, is what Goffman calls "regrounding." This refers to activities performed outside their normal range of participation for motives different from those that govern ordinary actors (Goffman 1986). For instance, Goffman mentions the practice of shilling adopted in casinos, in which a gambler bets using the casino money. Instead of betting for personal gain (a motive governing the actions of ordinary gamblers), the shill is actually trying to engage other players, who otherwise would not want to play "head-on" against the dealer, to join the table. On the one hand, regrounding means to reframe an act in terms of "agency for." It changes the interpretation about whom the act is meant to serve. On the other hand, the ability to impose such a reframing attests to the enactment of "agency over"; agency over how other participants interpret and perceive the act.

Keying is reframing. An event once framed may be framed again in a different way (reframing); a given meaning of an act or event is constructed through

multiple layers of frames, each building upon previous ones (Goffman 1986). Given this complexity, different errors are likely to occur during the framing process. In a vague situation, individuals might find it difficult to distinguish which of two interpretations is the correct one; this is what Goffman (1986) calls *ambiguity*. Obviously, because framing errors are possible, individuals can disagree about what is going on in the situation, accounting for different versions of what is happening (*frame dispute*).

Our empirical setting consists of interviews in which physicians comment on an excerpt from the Act of the Status and Rights of Patients of 1992. This excerpt expresses and represents what we here approach as "the patient autonomy frame," used to interpret and make sense of events associated with end-of-life processes and treatments. Therefore, our immediate analytical target will be how the interviewed physicians respond to the patient autonomy frame in this kind of interview situation. On one level, we will focus on the interviewees' talk as argumentation and rhetoric in which they take a stance towards the patient autonomy frame and present justifications and accounts for their stances. On the other level, we analyze their argumentation as a framing activity in which they maintain or reframe patient autonomy.

Methodology and Methods

Analysis of Interview Talk as a Way to Study Frames and Framing Processes

Goffman himself analyzed framing as something that people do when they speak (Goffman 1981; 1986; Manning 1992), and this is commonplace in anthropological and socio-linguistic applications of frame analysis (Tannen 1993). These authors of-

ten focus the attention on how the participants in a conversation or interaction frame the ongoing activities when personally involved in them. Tannen and Wallat (1987), for example, analyze “medical examination” and “medical consulting” as interactive framings observable through video recordings of actual doctor-patient discourse. Similarly, an interview situation can be studied by analyzing how the participants frame the ongoing interaction between the interviewee and the interviewer (Ensink 2003).

Following Goffman (1986), however, we contend that events may also be framed by bystanders and other actors who are not directly involved in the events being framed. In our case, the interview as such was not a doctor-patient verbal interaction, but the interviewed physicians were talking about events occurring within such interaction. Despite sharing the research interview frame, however, they did not simply inform the interviewer about issues associated with patient autonomy, but actively engaged in framing and reframing these issues. What makes their action particularly interesting, of course, is that besides being occasional bystanders as in the interview situation, the interviewees are also regular and experienced participants in doctor-patient interactions through their profession.

Analyzing argumentation as framing combines ideas from rhetorical social psychology (Billig 1996) with frame analysis (Pesonen and Vesala 2007). As Goffman (1986) points out, framings can be contested and frames disputed, which implies that argumentation about frames is a relevant window for framings. Furthermore, one commonplace for supporting a critical stance towards a given framing is an alternative frame (Pesonen and Vesala 2007). According to Manning (1992), one of Goffman’s aims was to identify the lamination of frames, that is,

how meanings are often constructed through the superimposition of frames. Careful analysis of argumentation may help to uncover such laminations.

Interviewees, Interviews, and Context

Finland has an established tradition in accepting and promoting end-of-life care discussions. In 1971, it became the first country in the world to use a brain death diagnostic to determine the death of a person (Hildén et al. 2004). In 1992, the Act on the Status and Rights of Patients laid down patients’ constitutional rights, including the right to refuse treatment. “She/he may deny treatment or an operation even if it would be necessary to remove a danger to his/her health or life” (Ministry of Social Affairs and Health, Finland 1992).

The interviews were conducted in Finland with eight physicians from six specialization areas: anesthesiological pharmacology, nephrology, internal medicine, infectology, geriatrics, and pediatrics (Table 1).

Table 1. Characteristics of the participants (n=8)

Specialization	Position	Gender
Anesthesiological pharmacology	Medical director	M
Pediatrics	Pediatrician/Bioethics lecturer	M
Nephrology	Head of nephrology unit	M
Nephrology	Head of nephrology unit	M
Internal medicine	Chief physician	F
Internal medicine/ Geriatrics	Physician	M
Internal Medicine/ Infectology	Physician	M
Geriatrics	Physician	F

Source: Self-elaboration.

The main criterion to select the participants was that they had experience with the care of dying patients, having previously encountered advance directives on their daily practices. We identified potential interviewees through our academic network, and after first contacts, a snowball technique was used to recruit more participants. Before each interview, physicians received an informed consent document ensuring their identities would remain anonymous, and that the interviewer would safely store all the audio recordings. Also, at any time they could contact the researchers and decline their participation in the research; in that case, all stored material would be destroyed.

The interviews, conducted between October 2016 and January 2017, started with an initial query about the participants' professional and academic careers. A prompt (see: Pyysiäinen 2010), consisting of an excerpt from the Act of the Status and Rights of Patients, was used to invite the interviewees to comment on and discuss the patient's autonomy principle. The interviewer presented the text on a single sheet of paper. The interviewees were asked to read the text carefully and then were asked to comment on it freely. The interviewer played the role of active listener and made requests for more comments. The discussions over the prompts lasted between 40 and 60 minutes.¹

Following the Finnish Social Science Data Archive (2016) guidelines on data integrity, we used a verbatim mode to transcribe the material, including a word-to-word replication of the verbal

data, word accentuations, non-verbal expressions such as laughing, and lengthy pauses.^{2, 3}

The Nature of Analysis

The analysis started with a careful reading of transcripts. We then identified and organized all the evaluative stands the interviewees took towards the prompt, as well as the justifications and accounts that they presented to support these stances. After that, we interpreted all these comments in terms of Goffman's frame analytical concepts and organized them with regard to frames involved in the excerpt that the interviewees commented on. Finally, we scrutinized what kind of assumptions or versions of agency the interviewees used and constructed in their comments and framings.

The prompt that was presented to the interviewees consisted of two articles taken from the Act of the Status and Rights of Patients of 1992. The key point in the articles is the patient's right to refuse given treatments. In a more general view, the Act states the patient's right to self-determination and autonomy. Interpreted through frame-analytical lenses, the text is constituted by four layers of frames. First, at the "bottom" there is a "biological frame" in which disease and death are conceived as occurring without any intentional agent producing or steering them. The biological frame represents natural frames, a subcategory of primary frames. Second, on top of this, there is a "medical frame" that introduces the human agent, a professional who intervenes with the natural course of events,

² The first author conducted and transcribed semi-structured interviews. The analysis was done jointly by both authors.

³ In the excerpts presented in the analysis, "R" stands for the interviewer, while "I" stands for the interviewee (followed by a number to differentiate each one).

¹ Altogether three prompts were used, but in this article, we analyze only the discussions for the first one.

for example, through diagnostic and treatment skills. The inclusion of an intentional agent indicates that this frame represents the subcategory of social frames among primary frames. Thirdly, another social frame is involved: “the patient autonomy frame” suggests that the patient can interfere with the agency of a medical professional regarding the patient’s treatment. Finally, the Act itself designates a “legal frame” within which all the previous frames are nested. This is also a social frame as it implies an institutional collective social actor responsible for the Act. In the prompt, this frame creates a topmost level with a communicative function of legitimating and highlighting the patient autonomy frame.

In the following section, we display the analysis to show how our theoretical interpretations connect to the data.

Analysis: Reframing Patient Autonomy

In their immediate comments, all of the interviewees presented two-sided stands evaluating the Act and patient autonomy positively, but, in the same breath, making reservations regarding these. The interviewees said that the text is familiar to them, well prepared, and addresses important issues. Some said it corresponds well with everyday practices in the field. To these positive evaluations, however, the interviewees always attached “but” or “on the other hand.” Here is one example:

R: Ok, so what do you have to say about that?

I2: Well... (sigh), it’s, eh... It’s quite easy to agree with these texts, and I think, er, they have been very well prepared, so, hmm. Basically, if an adult, and a sane person, refuses any treatment, so we should obey or we should honor the will of the patient. But, of course,

life is not simple and, and there are, there are grey areas. For example, if a person... is diagnosed with a cancer of something, some other serious disease, he or she may be depressed in the beginning and express that he or she doesn’t want any care, any treatment, but when the time goes, a few days or a few weeks pass, so, it’s possible that the person changes his or her mind.

Most of the interviewees’ further comments focused on accounting for the reservations. There was variation and overlap between single interviewees. As a whole, however, several categories of arguments could be identified. In the following, we aim to show how these different arguments relate to framings involved in the prompt.

First, while expressing acceptance of patient autonomy promoted by the Act, the interviewees emphasized that the highest authority for physicians, however, is ethics:

I2: Law is the minimum, and ethics goes beyond that ... ((The Act)) is a good starting point, but... in real life, there are many shades of gray.

The interviewees referred to the Hippocratic Oath and stressed that the ethical imperative to safeguard a patient’s life overrules other values and interests. Thus, the ethical frame, not explicit in the prompt, was introduced. Although the legal frame was not questioned as such, it was placed within this ethical frame. The point was that the ethical, not the legal, frame actually legitimates medical actors. Interestingly, interviewees did not discuss patient autonomy as an ethical principle, although this would be quite an evident possibility in some other contexts. Furthermore, via the Hippocratic Oath, the ethical frame authorizes the medical expert as an agent to

serve the interests of the patient, and in a way defines these interests.

Second, regarding the patient autonomy frame, the interviewees brought out constraints and weaknesses in the patient's agency. One interviewee (I3) made a general claim that the growing emphasis on patient autonomy in recent decades has occasionally gone too far at the expense of other values. Otherwise, the comments focused on concerns that are more specific. It was argued that many patients do not want to engage in decisions over treatment:

I3: Of course, I have nothing against autonomy as such, but when I think of patients... the first question... the patients have, is not, "Can I make decisions about my life?" [**R:** Uhm]. The first question, probably, usually is, "Can you help me?" The more serious the condition is, the less I think the patient usually is interested in, whether he or she can make decisions about life.

Here, the interviewee leans on the biological frame to highlight the relevance of the medical frame, suggesting that the more serious the patients' condition is, the more prone they are to prefer physician's interference instead of insisting upon their autonomy. This is an example of a medical expert actually defining what the patient's interests are.

Further, the decision-making capacity was said to decrease in the course of progressing diseases for numerous reasons. Patients may not have enough or proper information about their condition and the available treatments. This may be caused by the patients' tendency to deny their situation or it may be because of the stressed patient's difficulty in focusing and making a mental note of what the physician is saying. There were also comments pointing out

that the patients may be severely depressed or in a psychotic state of mind so that they are not able to make choices about treatment.

In all, the comments that directly targeted the patient autonomy frame presented the patient's agency as constrained, vulnerable, unstable, and weak. In this way, the biological frame and the medical frame were brought to the fore, and the patient autonomy frame was pushed into the background. The comments downplaying the patient autonomy frame appear to challenge the patient's agency both in the sense of the ability to act as an agent making judgments over medical treatments and in the sense of patients acting as a principal defining their interests on which such judgments may be based. This line of reasoning suggests that physicians are more credible agents who can evaluate the patients' best interests, and act on their behalf.

Thirdly, and closely connected with comments highlighting limitations and weaknesses in the patient's agency, the interviewees also presented comments emphasizing that respecting a patient's self-determination does not exclude responsibilities and the physician's agency. Conforming to the ethical frame, mentioned earlier, these responsibilities include not abandoning the patient, or not causing harm:

I1: We want to respect the patients' right to self-determination. On other hand, the respectation of self-determination does not exclude the responsibility of the doctors, of the doctor when it comes to treatment, and the implication is that of the patients' or physician's [extreme] experience. Example, if the patient would like to have, hmm, a medicine which, which is known to be harmful to the patient, it is the doctor's responsibility not to deliver this medication to the patient,

no matter that would be according to the [patient's] self-determination.

The excerpt again demonstrates an overarching pattern in the data: patient autonomy is accepted, but the extent to which a patient may exercise this autonomy is seen as restricted by both biological factors and ethical imperatives. The interviewees also maintained that in the medical faculty, the physician is ultimately in command:

I1: It is yet imperative that it is the physician who decides. Hmm. Which treatment will be given in the, in the medical facility, and, hmm. Of cour... --- In that facility, the doctor is in charge. Suddenly, the individual patients are able to make, make their own choices, for example, alternative treatments—whatever we mean with alternative treatments. Also, in these, in these cases, we would like to have such an environment in communication that the patients could, and should tell about their own choices to the doctors, too.

Thus far, we have seen how the presented comments stress deficiencies in the patient's agency and the profound role of the medical actor's agency. We may interpret this as turning the mutual positions of the medical frame and the patient autonomy frame upside down compared to how these were originally present in the prompt, pushing the latter into the background and lifting the former to the front. However, it must be stated that, in their comments, the interviewees did not only evaluate these frames against each other. They also combined and reconciled the two frames so that instead of two separate frames a broader social frame appears, which focuses on the interaction and fit between the patient and the medical actor. Given the importance of interest construction, it becomes imperative that the actors

involved in the decision-making process come to an agreement on their roles in the agent-principal relationship. Next, we will explore this fourth subcategory of comments accounting for the reserved stands to the prompt.

The interviewees pointed out that physicians should provide patients with information and understanding regarding their condition and available treatments. This was said to be realized through conversation:

I1: The number one is always discuss, and discuss, and discuss. And provide, er, knowledge which is needed for the decision-making. If the doctor—if I know as a doctor, if there is a conflict in this issue, from my point of view, it is always very important to document that in the records, in the medical files of the patient, that there's a disagreement on a certain matter.

Most of the interviewees presented descriptions of discussions with patients to illustrate how treatment decisions are embedded in an ongoing interaction. In some cases, they highlighted how discussions enable physicians to enact their agency to steer the patient's decisions. In the course of the discussion, the patient may become convinced of viewpoints based on the physician's expertise, and get a feeling of being heard and receiving due attention, so that the situation will be favorable for the physician "to sell their ideas," as the phrasing in the next example shows:

I5: So you really let them tell their story, their views, their points, you make some questions, they have many questions about what has been done, or from the past year even. You might even have to start from twenty years ago, when someone died in the family

and it really was a bad experience, you have to hear that first. But, then, you understand what's the problem, what's the fear in the family; they are afraid of the same thing happening again, so you get the basics. Then, after that discussion, you get the idea of how the situation seems, how they feel. Then I always say examine your patients, so, listen to the heart, try to touch the patient, so you really concentrate. And then, after that, you can sit down and sell whatever ideas you have, because people they feel that they have been heard, they have been, er, really taken seriously, they have their time with the doctor, and then you, then you get this mutual understanding. Then the doctor originally tells what he or she thinks, it's good or it's bad. Usually people, they, listen.

Besides a way to influence the patient, the interviewees also depicted discussions as manifestations of collaboration in which the physician supports the patient's agency, and they produce the decisions jointly. The interviewees stressed that the choice of treatment is not always a simple issue. Concerning dialysis, for example, not all patients benefit from it, and it may even add to the patient's suffering. Thus, it is not only so that the physician would be trying to persuade the patient to accept the treatment. Rather, the physician may aim to shed light on the pros and cons of different alternatives and, in this way, assist the patient in making realistic and clinically informed judgments of treatments.

The social interaction frame was not evident in the prompt, although one sentence of the Act states that the patient has to be cared for "in mutual understanding with him/her [the patient]." Indeed, one of the interviewees did pay attention to this sentence in a way that illustrates our analytical conclusion about the social interaction frame emerging in the data:

I5: ((reading the prompt)) Ok, yeah. "Patient's right to self-termination," yes, I know this, yeah... It's very nice this mutual understanding, what it really means and how you'll get it. That's the key issue here. So that's the key of the communication, people have the right to refuse, but we have the responsibility to talk so that they understand what they are doing and what are the consequences, and things that happen. And sometimes it's not so easy. But, they can't demand treatment that the doctor thinks it's more harmful than good. That can be sometimes, that's more difficult with the relatives actually than with the patients themselves in palliative care But, it's the relatives who really... sometimes pushing, that something, this or that, should be done. Then it is a lot of talks and [reinsurance], why we can do that, or why it might be harmful, 'cause... their belief in medicine and their trust in medicine sometimes is... is amazing how people think that we must have something to do still in our back pocket, and, well, we haven't beaten death yet. That's difficult. But, it's, yeah, that's the key issue, mutual understating that's what we try to do.

The interviewees often stressed that there are gray areas and difficult issues involved in the notion of patient autonomy. Our interpretation is that these emphases capture well not only the notion of the deficiency of the patient's agency, but also the ambiguousness of the interaction between the physician and the patient. Within the frame of social interaction, the idea of patient autonomy appears somewhat blurred because the patient's agency is embedded in the interaction where the events are not necessarily attributable to any single actor alone. Hence, the interviewees' reserved stands are very understandable even though they evaluated patient autonomy positively as such. To this perhaps it should be added that the ambiguous nature of interaction may, at least in part, result from the fact that it is often

difficult to say when the negotiation concerns defining and deciding the proper medical treatments and when it concerns defining the patient's interests and therefore the nature of the patient as principal.

In addition to physician and patient, the social interaction frame may involve actors close to the patient, for example, family members, relatives, or friends ("loved ones"). Several of the interviewees mentioned these actors in passing; in particular in conjunction with the fourth category of comments mentioned previously. Patients' loved ones may present demands, questions, and criticism about treatments and medications. They can try to speak for the patient, and they have their worries over the well-being of the patient. Thus, the involvement of loved ones adds complexity to the social interaction frame. It means that additional agents, acting for the patient, appear on the stage trying to define the patient's interests.

Discussion

In this paper, we applied a relational view to agency and assumed agency to be something constructed and defined in relations and processes rather than a fixed disposition of separate actors (Emirbayer 1997). We analyzed physicians' talk as a process in which they construct versions of the patient's agency and the physician's agency through the active reframing of the notion of patient autonomy. The relational approach made it possible for us to show how physicians can maneuver a constellation of frames (Goffman 1986) and thereby define the patient's agency as weak and vulnerable in relation to the biological condition, and ethically legitimated agency of the medical expert, but as well concerning the ongoing interaction and negotiations between the patient and other actors. We further highlighted the

contextual embedding of agency construction by showing that physicians construct agency not only in terms of agency over something, but also agency for something or somebody (Meyer and Jepperson 2000; Niska 2015; Shapiro 2018).

Although the interviewed physicians considered the notion of patient autonomy a valuable guideline for end-of-life care discussions, they concentrated in presenting reservations and elaborating on these. In this regard, our results are in line with the previous literature about physicians' attitudes, which report critical remarks alongside a generally positive attitude (Hildén et al. 2004; Coleman 2013). Through analyzing qualitative interview data we showed how approving and reserved stands may coexist in a talk in such a way that the reserved arguments actually occupy the main role. Indeed, the variety of reserved arguments in our data seems to cover well the doubtful arguments towards advance directives, reviewed by Ditto and colleagues (2006). Likewise, they suggest certain levels of paternalism still permeate medical decision-making (Laine and Davidoff 1996; Kiesler and Auerbach 2006; Légaré et al. 2010; Pollard et al. 2014). We do not, however, claim statistical generalizability of a reserved tone in physicians' talk, but instead wish to draw attention to how this tone was constructed in the course of interviews with the physicians, and further, what assumptions about agency were involved in this process. The presented frame analysis was conducted to these ends.

Our analysis uncovered how the interviewees actively reframed the constellation of frames involved in the prompt presented to them. By nesting patient autonomy within biological and medical frames they, on the one hand, questioned the patient's agency, and, on the other, highlighted the superi-

ority of the physician's agency based on expertise. Thus, whereas the process of medicalization is often discussed at a macro cultural level, elaborating on the use of the biological and medical frame allowed us to grasp how medicalization operates at an interactional level—that is, it demonstrates that physicians rely on their professional knowledge to render aspects of patient's autonomy a medical issue (Conrad and Schneider 1980). It also exemplifies how tensions between competing cultural discourses (i.e., medicalization vs. bioethics) are elaborated at the grassroots level.

The use of autonomy as a tool to debate about social power positions is familiar in other contexts, as well (Stock and Forney 2014). In our data, we detected two constructions of patient autonomy. Both were present in the formulations of the reserved comments pinpointing deficiencies in the patient's agency. On the one hand, the comments contested the patient's agency over the treatments, namely, the patient's ability to understand, assess, and make decisions about medical options and issues. On the other hand, they questioned the patient's agency as an agent for oneself—one's ability to define one's interests.

The latter construction resonates, for example, with the idea that patient autonomy transcends its instrumental value so that individuals self-directing the outcomes of their lives is a value in itself, regardless of the outcomes (Lidz and Arnold 1993). Our interviewees, however, reframed patient autonomy by using an ethical frame suggesting that the physician is enacting agency for the abstract ideals of medicine as an institution (Hippocratic Oath). This further legitimates the physician's expertise and authorizes physicians to act as agents for patients. The agent position includes defining and interpreting

the patient's best interests, besides enacting professional proxy agency (Bandura 2006) on behalf of the patient. Interestingly, physicians are positioned as an agent for patients, but this agency is authorized by a principal higher than the patients themselves.

Our data attests agency of the interviewed physicians in the sense of an ability to use talk to reframe patient autonomy in delicate yet determined and credible ways so that the patient's autonomy is not negated or rejected, but is somehow constructed as vulnerable and deficient in comparison to that of the physician's agency. A further indication of the agentic use of framing in the interviews was the use of an interaction frame to reconcile the patient's autonomy and medical frame into a broader frame. In this broader frame, decisions evolve through interaction and negotiations between the patients, medical actors, and possibly also the patient's loved ones.

Our analysis applied the idea of elementary social frames as either built around single actors (individual or collective) making things happen or around the collection of actors in interaction, drawing directly from Goffman's (1986) frame analysis. The results of our frame analysis could be further reflected upon from the perspective of attribution research, where the tendency to make sense of events by attributing their causes to individual actors is a well-established conclusion regarding everyday thinking (Ross 1977). Attributing events to relations and interaction have gained much less attention, although studies are suggesting that people are quite capable of making relational attributions as well, at least if this is functional in their profession (Eberly et al. 2011; Vesala, Anderson, and Vesala 2017). In this light, the use of an interaction frame by our interviewees attests a degree of depth in their argumentation, although we did not elaborate on

different types of interaction frames (Tannen and Wallat 1987) in our data. Moreover, contrary to the argument that Goffmanian frame analysis constitutes a structural approach in which frames stand unrelated to each other (Sharron 1981), our analysis of interview talks demonstrates how physicians actively coordinate different, and often contradictory, frames while constructing the patient's agency.

Our interviewees used the interaction frame to tackle the ambiguous and open-ended nature of social encounters and negotiations between the patient and the medical actor. On the one hand, the interaction frame acknowledges patients as principals whose interests should be served and who should be heard as agents for themselves. On the other hand, when using the interaction frame, the interviewees depicted a process in which the interests and will of the patient are negotiated by participating social actors—actors who are potentially also serving other principals besides the patient. In such a framing, the patient's autonomy is constructed as the agency in the sense of participating in a negotiation or having a voice in a discussion. This deviates clearly, for example, from autonomy understood as the sovereign private ability to define one's interests. As pointed out by Frank and colleagues (1998), autonomy discourse does not account for all the variation in end-of-life care preferences; instead, it is necessary to supplement such discourses with relationship discourses.

By using the interaction frame the interviewees constructed the physician's agency as interpreting the patient's will and interests, and as managing the negotiations between themselves, the patient, and potentially the patient's loved ones. In some comments, the physician's ability to influence the patient through negotiation was stressed, while in

others, they could assist the patient. In both cases, the patient's autonomy was constructed as an agency deeply embedded in social processes, instead of a fixed mental capacity. Yet we should remember that our interviewees also presented general comments expressing approval of patient autonomy, pointing out that the patient's will and decisions should be respected and obeyed.

Conclusion

Previous studies (Ditto et al. 2006) found that patients have limited psychological resources to assess their situation and adequately choose between different end-of-life care treatments; such findings seem to challenge the central role that the notion of patient autonomy has in bioethics. Similarly, our analysis of physicians' talk showed that despite general approval of patient autonomy, they reframed this autonomy in ways that question patient's abilities to define their interests. However, departing from the notion that autonomy, or agency, concerns an inner property of patients, our findings have shown how physicians also reframe patient autonomy in terms of interaction in which patient agency appears as participation in negotiations during end-of-life care decision-making. As such, our findings have implications concerning the relationship between doctors, patients, and family members during end-of-life care decision-making. As far as the use of advance directives is concerned, such documents must function as discussion starters. We propose that these documents could be part of an ongoing dialogue between the many stakeholders invested in the process. Recognizing agency as a relational accomplishment may help conciliate the efforts of right-to-die movements in promoting the value of self-determination without circumscribing the role of physicians and family members.

References

- Andorno, Roberto, Nikola Biller-Andorno, and Susanne Brauer. 2009. "Advance Health Care Directives: Towards a Coordinated European Policy?" *European Journal of Health Law* 16(3):207-227.
- Andreasen, Paula et al. 2019. "Advance Directives in European Long-Term Care Facilities: A Cross-Sectional Survey." *BMJ Supportive & Palliative Care*. Retrieved February 17, 2021 (<https://spcare.bmj.com/content/early/2019/05/21/bmjspcare-2018-001743>).
- Auriemma, Catherine L. et al. 2014. "Stability of End-of-Life Preferences: A Systematic Review of the Evidence." *JAMA Internal Medicine* 174(7):1085-1092.
- Bandura, Albert. 2006. "Toward a Psychology of Human Agency." *Perspectives on Psychological Science* 1(2):164-180.
- Billig, Michael. 1996. *Arguing and Thinking: A Rhetorical Approach to Social Psychology*. Cambridge: Cambridge University Press.
- Clarke, Adele E. et al. 2003. "Biomedicalization: Technoscientific Transformations of Health, Illness, and U.S. Biomedicine." *American Sociological Review* 68(2):161-194.
- Coleman, Albert M. E. 2013. "Physician Attitudes toward Advanced Directives: A Literature Review of Variables Impacting on Physicians Attitude toward Advance Directives." *American Journal of Hospice & Palliative Medicine* 30(7):696-706.
- Conrad, Peter. 1979. "Types of Medical Social Control." *Sociology of Health & Illness* 1(1):1-11.
- Conrad, Peter. 1992. "Medicalization and Social Control." *Annual Review of Sociology* 18:209-232.
- Conrad, Peter and Joseph W. Schneider. 1980. "Looking at Level of Medicalization: A Comment on Strong's Critique of the Thesis of Medical Imperialism." *Social Science & Medicine. Part A: Medical Psychology & Medical Sociology* 14(1):75-79.
- Ditto, Peter. H., Nikki A. Hawkins, and David A. Pizarro. 2006. "Imagining the End of Life: On the Psychology of Advance Medical Decision Making." *Motivation and Emotion* 29(4):475-496.
- Dresser, Rebecca S. 2003. "Precommitment: A Misguided Strategy for Securing Death with Dignity." *Texas Law Review* 81(7):1823-1847.
- Eberly, Marion B. et al. 2011. "Beyond Internal and External: A Dyadic Theory of Relational Attributions." *Academy of Management Review* 36(4):731-753.
- Emirbayer, Mustafa. 1997. "Manifesto for a Relational Sociology." *American Journal of Sociology* 103(2):281-317.
- Emirbayer, Mustafa and Ann Mische. 1998. "What Is Agency?" *American Journal of Sociology* 103(4):962-1023.
- Ensink, Titus. 2003. "The Frame Analysis of Research Interviews: Social Categorization and Footing in Interview Discourse." Pp 156-177 in *Analyzing Race Talk: Multidisciplinary Perspectives on the Research Interview*, edited by H. van der Berg, M. Wetherell, and H. Houtkoop-Steensrta. Cambridge: Cambridge University Press.
- Fagerlin, Angela and Carl E. Schneider. 2004. "Enough. The Failure of the Living Will." *Hasting Center Report* 34(2):30-41.
- Finnish Social Science Data Archive. 2016. *Processing Qualitative Data Files*. Retrieved January 21, 2017 (<http://www.fsd.uta.fi/aineistonhallinta/en/processing-qualitative-data-files.html>).
- Frank, Gelya et al. 1998. "A Discourse on Relationships in Bioethics: Patient Autonomy and End-of-Life Decision Making Among Elderly Korean Americans." *Medical Anthropology Quarterly* 12(4):403-423.
- Freidson, Eliot L. 1970. *Profession of Medicine: A Study of the Sociology of Applied Knowledge*. New York: Dodd, Mead & Company.
- Goffman, Erving. 1981. *Forms of Talk*. Philadelphia, PA: University of Pennsylvania Press.
- Goffman, Erving. 1986. *Frame Analysis. An Essay on the Organization of Experience*. Boston, MA: Northeastern University Press.
- Hawkins, Nikki A. et al. 2005. "Micromanaging Death: Process, Preferences, Values, and Goals in End-of-Life Care Medical Decision Making." *The Gerontologist* 45(1):107-117.
- Hildén, Hanna-Mari, Pekka Louhiala, and Jorma Palo. 2004. "End of Life Decisions: Attitudes of Finnish Physicians." *Journal of Medical Ethics* 30(4):362-365.

- Kiesler, Donald J. and Stephen M. Auerbach. 2006. "Optimal Matches of Patient Preferences for Information, Decision-Making and Interpersonal Behavior: Evidence, Models and Interventions." *Patient Education and Counseling* 61(3):319-341.
- Kuczewski, Mark G. 1996. "Reconceiving the Family: The Process of Consent in Medical Decision-Making." *The Hasting Center Report* 26(2):30-37.
- Laine, Christine and Frank Davidoff. 1996. "Patient-Centered Medicine: A Professional Evolution." *JAMA* 275(2):152-156.
- Légaré, France et al. 2010. "Interventions for Improving the Adoption of Shared Decision Making by Healthcare Professionals." *Cochrane Systematic Review* 12(5):CD006732.
- Lidz, Charles W. and Robert M. Arnold. 1993. "Rethinking Autonomy in Long Term Care." *University of Miami Law Review* 47(3):603-623.
- Lopéz, José. 2004. "How Sociology Can Save Bioethics... Maybe." *Sociology of Health & Illness* 26(7):875-896.
- Manning, Philip. 1992. *Erving Goffman and Modern Sociology*. Cambridge: Polity Press.
- Meyer, John W. and Ronald L. Jepperson. 2000. "The 'Actors' of Modern Society: The Cultural Construction of Social Agency." *Sociological Theory* 18(1):100-120.
- Ministry of Social Affairs and Health, Finland. 1992. *The Act on the Status and Rights of Patients*. Retrieved August 24, 2019 (https://www.valvira.fi/web/en/healthcare/patient_rights).
- Niska, Miira. 2015. *Who Is Serving Whom? An Agency-for Perspective on Enterprise Promotion in Rural Finland*. Helsinki: University of Helsinki.
- Pesonen, Heikki and Kari M. Vesala. 2007. "Rural Development as a Frame Analytic Challenge for Religious Communities: The Case of Rural Parishes of the Evangelical Lutheran Church of Finland." *Social Compass* 54(2):281-293.
- Pollard, Lorraine et al. 2014. "The Impact of Patient Participation Direct Enhanced Service on Patient Reference Groups in Primary Care: A Qualitative Study." *Quality in Primary Care* 22(4):189-199.
- Pyysiäinen, Jarkko. 2010. "Co-Constructing a Virtuous In-group Attitude? Evaluation of New Business Activities in a Group Interview of Farmers." *Text & Talk. An Interdisciplinary Journal of Language, Discourse & Communication Studies* 30(6):701-721.
- Rose, Nikolas. 2013. "Personalized Medicine: Promises, Problems and Perils of a New Paradigm for Healthcare." *Procedia—Social and Behavioral Sciences* 77:341-352.
- Ross, Lee. 1977. "The Intuitive Psychologist and His Shortcomings: Distortions in the Attribution Process." *Advances in Experimental Social Psychology* 10(C):173-220.
- Scheff, Thomas. 2005. "Deciphering 'Frame Analysis.'" *Sociological Theory* 23(4):368-385.
- Shapiro, Susan P. 2015. "Do Advance Directives Direct?" *Journal of Health Politics, Policy and Law* 40(3):487-530.
- Shapiro, Susan P. 2018. "Standing in Another's Shoes: How Agents Make Life-and-Death Decisions for Their Principals." *Academy of Management Perspectives* 30(4):404-427.
- Sharman, Stefanie J. et al. 2008. "False Memories for End-of-Life Decisions." *Health Psychology: Official Journal of the Division of Health Psychology, American Psychological Association* 27(2):291-296.
- Sharron, Avery. 1981. "Frame Paralysis: When Time Stands Still." *Social Research* 48(3):500-520.
- Stock, Paul V. and Jérémie Forney. 2014. "Farmer Autonomy and the Farming Self." *Journal of Rural Studies* 36:160-171.
- Tannen, Deborah. 1993. *Framing in Discourse*. New York: Oxford University Press.
- Tannen, Deborah and Cynthia Wallat. 1987. "Interactive Frames and Knowledge Schemas in Interaction: Examples from a Medical Examination/Interview." *Social Psychology Quarterly* 50(2):205-216.
- Timmermans, Stefan. 2005. "Death Brokering: Constructing Culturally Appropriate Deaths." *Sociology of Health and Illness* 27(7):993-1013.
- Vesala, Kari M., Alistair R. Anderson, and Hannu T. Vesala. 2017. "Interactions and Entrepreneurial Agency. A Relational View of Entrepreneurs' Control Cognitions." *Archives of Psychology* 1(1). Retrieved March 27, 2019 (<https://archivesofpsychology.org/index.php/aop/article/view/11/28>).

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