CLINICAL ETHICS

Finnish doctors and the realisation of patient autonomy in the context of end of life decision making

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Patient autonomy is a fundamental principle in end of life decision making. However, its realisation may take a variety of forms. Discourse analysis was conducted in a qualitative interview study of 19 physicians. The physicians made use of three different discourses, each of which contained a specific understanding of patient autonomy and a physician's proper activities in the context of end of life decision making.

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End of life decision making confronts physicians with difficult issues, and the role of interaction is emphasised. A widely accepted ethical principle in the western world in this context is the promotion of patient autonomy.[1 2] It is also included in the Finnish Law on the Patient's Status and Rights (1993), which states that competent patients should be treated by consensus and that they have the right to refuse any present or future treatment, including life sustaining treatment. The constitutive principle of patient autonomy conveys the idea of clarifying and respecting patients' wishes. Patients' informed consent is required for decision making. However, patients do not generally have the right to demand treatment that is not considered to be biomedically effective. In our previous studies, a great majority of Finnish physicians and nurses reported that they considered patients' views as decisive in end of life decision making.[3 4]

The realisation of patient autonomy can be interpreted in different ways at the level of the doctor–patient relationship. The published literature presents several theoretical approaches. First, physicians can simply inform patients and then respect their choice.[1 5 6] Alternatively, they can assist patients in evaluating their values and preferences, and present them with the most suitable treatment alternative.[1 5–8] Physicians can also attempt to influence a particular patient's choice through negotiation, if they believe that the person is not making the best possible choice from his or her or society's point of view.[1 6] Furthermore, at an extreme level the promotion of patient autonomy takes the form of a consumerist doctor–patient relationship, in which sceptical patients choose from all the available treatment alternatives.[1 5 7] These different approaches convey various views of patients. They are supposed to be knowledgeable and rational decision makers in the informative and consumerist approaches. Others may give physicians a more active role and delineate the dependency of patients. Farber *et al* interviewed physicians regarding their activities in end of life decision making and found activities similar to the first two approaches. In their study, some physicians simply informed patients and allowed them to make their own decision, whereas others elucidated patients' views and assisted them in the decision making. The third group of physicians offered patients solutions that were based on both medical knowledge and the patients' views.[9] The study of Farber *et al*, however, reports only on physician activities. Studies focusing on physicians' understanding of patient autonomy and the way in which they ground their activities in end of life decision making are lacking.

In addition to the role of patients in the decision making, the role of surrogate decision makers is also of importance. Many patients are unconscious by the time end of life decisions are made,[10] and, in such cases, relatives need to represent them. The position of relatives is an area of confusion, and opinions vary about the extent to which relatives' views should influence treatment decisions.[1 11] In this respect, the law in Finland is also in the process of change. Currently, relatives need to be consulted about treatment decisions made on behalf of incapacitated patients, but an amendment to the law is planned that would require the consent of patients' representatives for all significant treatment decisions. We have not identified studies that have focused on physicians' understanding of relatives' role in end of life decision making.

A specific feature of end of life decisions is that they are often considered to take place in a clinical group in which relatives and nurses are also involved. Nurses' participation in the decision making process is increasingly encouraged, based on their possibility of mediating information and acting as advocates for patients.[12] The relationship between physicians and nurses in this context has, however, been studied to only a limited extent.

In conclusion, end of life decisions take place in a controversial milieu in which the realisation of patient autonomy is especially challenging and can be interpreted in different ways. Our study aimed to reveal issues that have not been investigated previously: how physicians understand the realisation of patient autonomy, how they establish their activities, and how they view the position of relatives and nurses in the context of end of life decision making. After carrying out a large quantitative study on Finnish physicians' attitudes,[3] we conducted an interview study among them. Using discourse analysis as a qualitative approach, we investigated the various meanings that these doctors assigned to both their social environment and their actions.

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METHODS

The data were gathered by qualitative theme interviews, which we then analysed by discourse analysis, a qualitative method widely used in the social sciences. People's talk about their attitudes and activities often has goals other than those of pure description, and treating their talk as directly reflecting some inner or outer reality may be misleading.[13] [14] In this case, an approach such as discourse analysis, which considers talk as being constructed, offers a better tool.

In discourse analysis, the constructed nature of talk means that people are constantly applying cultural meaning systems to present their attitudes and activities as meaningful. This does not mean that they purposefully and consciously attempt to portray themselves in a certain way in social situations, but that thinking as such involves constructing issues as meaningful. In essence, as issues always have the potential for a multitude of viewpoints, people grasp reality only through selecting certain meanings. Cultural meaning systems offer a wide variety of meanings that appear in the form of cultural discourse. Individuals can choose from among many discourses and make them suit their own purposes. Discourse also often frames certain speaker positions for individuals. As such, these positions connote descriptions of the person or of others, and can be distinguished as identities.[14] [15]

Discourse analysis has been applied in health research to show how medical reality is socially constructed. For example, Apker and Eggly used it to show how physicians use biomedical discourse to construct their doctor identity as scientific, objective, and non-emotional, in order to resist requirements for a holistic approach that would decrease physicians' authority.[16] Mishler described how physicians and patients make use of contrasting "voices" (or discourses) such as the voice of medicine and the voice of the life-world.[17] Atkinson, on the other hand, revealed how different physicians apply competing voices (discourses), such as the voice of science and the voice of experience, that serve to legitimate their opinions about a disease and its treatment.[18]

We held qualitative theme interviews with 19 Finnish physicians, of whom 11 were women. All the participants had many years' work experience in making end of life decisions themselves, and most were specialists. They represented the following specialties: internal medicine (4), anaesthesiology and intensive care medicine (4), oncology (3), geriatrics (2), neurology (2), primary health care (1), and surgery (1); two other interviewees worked in terminal care.

We asked physician acquaintances to participate, and then used the snowball effect to recruit more. The interviews took place in the participants' work places, and generally lasted slightly over an hour. Each question was semi-open and proceeded from the general to the personal. If new repetitive themes emerged, new questions were targeted towards them. The physicians were asked about decisions to forgo life sustaining treatment for patients with a serious illness. The themes concerned the fluency and systematic nature of end of life decisions, about learning to make such decisions, problems related to these decisions, the elements of a successful decision, positive and anxiety provoking experiences of physicians, the roles of the patients, relatives, nurses, and physicians in the decision making, and health care professionals' activities in cases of conflict. In the analysis, the answers are understood as textual wholes, not as reflecting some outer reality. This means that one cannot interpret the physicians' talk as directly reflecting their actual activities; it can be interpreted as reflecting the way they understand their social environment and their activities.

The analysis was carried out by coding the themes that emerged in the interviews. We then looked for similarities and differences between the physicians' talk. Such similarities and differences were evident in their characterisation of the parties involved as emotional and "subjective" versus rational and "objective", in their descriptions of patients' and their relatives' needs in the decision making, and in their views of a physician's proper actions in responding to these needs. The descriptions brought about discourses concerning the physician–patient (or relative) relationship in the context of end of life decision making.

RESULTS

In their talk, the doctors established three different discourses about end of life decision making, termed "the informer discourse", "the supporter discourse", and "the analyst discourse". The women doctors applied the supporter and analyst discourses more often than the men. The physicians often oscillated between the supporter discourse and the other two discourses, whereas the informer and analyst discourses did not usually appear together in the talk of a particular physician.

The informer discourse

The informer discourse centred on the view that end of life decisions have to be consistent with patients' expressed wishes. This reflects the recent guidelines on end of life decision making. The physicians who mainly applied this discourse, the "informers", did not mention difficulties concerning the process of obtaining patients' opinion, but considered patients as rational and objective decision makers. According to them, autonomy is realised if the ethical rule of asking patients their views is kept. The informers therefore described their role as simply presenting medical facts to patients and respecting their choices. Consequently, the decision making appeared primarily biomedical (scientific) in their talk. The informers said that they discussed with relatives to inform them and to gain knowledge of patients. The problem with relatives was that "they were not the patient"—that is, the rules that were applied to patients could not be applied to the relatives, who also lacked the medical knowledge essential for effective decision making. If the relatives opposed physicians' decisions, they had no other option but to exclude them from the decision making, or to comply with their request if it concerned a restricted issue. In the first extract below, a patient's objectivity when he or she is sufficiently informed is obvious, and this physician describes how he informs the patient and respects his or her choice as such.

> *Physician (respondent)*: We try to respect the fact that the patient might want to refuse treatment. We explain the medical facts and if, even after this, they want to refuse treatment, we will respect that.

> *H-MH (interviewer)*: How does one conciliate [if the relatives disagree with the treatment of the patient]?
> *Physician:* Those are usually the people who are more difficult, those who cannot change their opinion, even if others disagree. We won't start fighting, so we just won't write those three letters [DNR] and just keep on treating that patient longer and see what comes of it.

In the latter extract, the physician describes relatives as difficult and demanding, but does not give any explanation for this. The relatives seem to be difficult because of a failure to understand "others", which refers primarily to medical professionals; in other words, they are difficult because they lack medical knowledge. There is nothing the physician can do.

The informers considered nurses' role in end of life decision making as comprising information delivery regarding patients' physical condition. They portrayed nurses as medical professionals having slightly limited knowledge, and described their relationship with them as somewhat hierarchical. The informers also described their own professionalism in terms of good medical skills and experience.

> *H-MH*: How much do nurses affect these decisions?
> *Physician*: They don't really affect them, but you can sense the so-called dual messages, if the nurse's opinion is to stop treatment … The basic principle is that … we make sure it is clear what we are trying to do … so that the patient's own nurse would see why we continue the treatments, and that there would be no frustration caused from burdensome treatments without any effect.

> *H-MH*: How do you think one learns to make these decisions?
> *Physician*: You don't just learn it [to make treatment decisions on end of life care], you have to work for years and see those patients and become familiar with that disease and the prognosis and progression of it, and it [this knowledge] slowly comes to you. And you notice here as well that the younger doctors can't do it and that the senior doctors have to get involved.

The supporter discourse

The supporter discourse viewed patients and relatives as vulnerable in end of life decision making, and potentially being unable to understand the consequences of an end of life decision. The physicians applying this discourse, the ''supporters'', emphasised that patients or relatives could misunderstand how the decision would affect patients' quality of life or different aspects of their life, and would therefore err in their decision making; or they could become so anxious that they would fail to make a decision. The supporter discourse incorporated an understanding of patient autonomy as potentially restricted. These physicians therefore concluded that patients and relatives needed a physician's assistance in end of life decision making.

In order to guarantee patients' and relatives' understanding of the situation, the physicians' activities were directed towards clarifying patients' and relatives' views and, in case of misunderstanding, towards explaining and negotiating. Physician characteristics such as patient centredness and empathy were stressed. In the next extract, a physician describes how she attempts to portray the consequences of treatments in a way that patients can understand best.

> *Physician*: We'll try to show what it means in real life that if, by some miracle, you survive you will be permanently immobilised and dependent on other people's help and you cannot communicate, then most people understand.

To minimise patients' and relatives' anxiety, the physicians said that the issue of treatment withdrawal should be broached with caution and without forcing discussion. A physician has to proceed by sounding out the parties concerned and personally clarifying to what extent they wish to participate, then advance the negotiations as far as each person wishes. These physicians also offer recommendations on care. They described building a sort of ''safety net'' for the patient and relatives in case they do not wish to participate, or if they wish to proceed in the direction of the physician's decision. It was also important to give time for the negotiations, listen to the other parties' opinions, give

pertinent information, describe the matter clearly and in different words, and offer empathy. The following extract gives a picture of an empathetic and patient centred physician who tailors her words both to serve individual patients' needs and to avoid causing anxiety.

> *Physician*: I often approach this issue [of withdrawing active treatments] by asking what they know and want to know, and I want those things to come from the patient and the relatives as questions, rather than just me alone taking the info to them. This is how I make sure that the info will have a soft landing and that they will understand. Because if I just pour that info on them, they won't be able to deal with it all.

The supporters discussed how nurses also participate in the activities of supporting patients and relatives in decision making. They concluded that nurses were able to provide information on both patients' physical state and on the patient's and relatives' views. These physicians described a less hierarchical relationship with nurses than the informers. They stressed cooperation and the importance of open discussion with nurses.

> *H-MH*: How do you see the nurses' role in these decisions?
> *Physician*: Well I think it is, like, very important, because the nurse is the one the patient makes conversation with and the nurse might know the patient so well that even if the patient says that yeah, it's okay, the nurse can see from the sweating and the deciding that the answer is not the one the patient would have really wanted to give, you know, when four doctors keep on shoving him to say yes.

Physicians' professionalism was associated with the establishment of an emotional connection between physicians and patients and their relatives, successful psychological support, and a decrease in patients' or relatives' anxiety. These physicians described themselves as being emotionally close to patients and relatives.

> *H-MH*: What positive experiences do you attach to these end of life treatment decisions?
> *Physician*: They definitely are moments of deep and delicate meetings with the relatives and the patients, and they do mostly involve experiences of unity and good care in, like, the entire medical and nursing community.

The analyst discourse

The analyst discourse constitutes a view according to which patients and relatives are often emotional in the face of life and death decision making, and according to which objective autonomy is difficult to achieve. Patients could be moved by ''subjective'' influences such as depression, the wish to please the physician, denial of death, feelings of guilt, changing wishes, and relatives' promotion of their own rather than patients' wishes. The analyst discourse also comprised doubtful and critical voices of autonomy. The physicians mainly applying this discourse, the ''analysts'', concluded that they needed to evaluate both patients' and relatives' competence for decision making and to support them in accepting the medical facts. In their talk, these physicians thereby took a slightly less patient centred and a more leading position than the supporters. In the next extract, the physician voices suspicion of patients' treatment wishes, gives psychological explanation for these wishes, and describes her attempt to support patients' acceptance of the medical facts.

Physician: The patients have an unbelievable number of unrealistic expectations, even after we have told them that the path of healing treatments has reached its end. That they hold on to that spark of hope, and even getting to go home, often has such a psychologically encouraging and strengthening effect on the patient that the patient feels healthier and better and thinks that this will induce some kind of a new healing process. That's when you often have to gently tell them ''let's take it one day at a time'' and see what kind of treatment options might be wise and sensible.

Similar to the supporters, the analysts also said that they included nurses in the activities of supporting patients and relatives in the decision making process, and considered them as working partners rather than subordinates. However, they evaluated nurses according to the same psychological frame of reference with which they described patients and relatives; they considered that health care professionals could also allow subjective influences to affect their manner of interaction with patients and relatives. Furthermore, the same psychological analysis was extended both to themselves and to other physicians. They emphasised that their professionalism included, in addition to good interaction capabilities, competence in dealing with death and with their own anxieties. In the following extract, the physician offers self-analysis and attempts to improve his own performance by a better understanding of his own psychological defences.

H-MH: Do you think that the reasons for withdrawing treatment are usually good, or are there questionable reasons?
Physician: It is still an issue in hospitals and I can see it in myself as well, that it is, you know, difficult to face something and think about it, in a way that things just keep rolling ahead in a certain way. And then you find yourself in a situation and it is distressing, especially to the nurses, that there is nobody there to take responsibility for taking care of it.

DISCUSSION

In this study, the participant physicians displayed three different discourses in their talk about end of life decision making, namely, the informer, the supporter, and the analyst discourses. These represent various ways of understanding the reality of end of life decision making. They also convey different views about patient autonomy. The benefit of this method was that we were able to elucidate the way in which the physicians seem to analyse and understand the process of end of life decision making and establish their clinical activities.

The position of physicians appeared differently in the three discourses. In the informer discourse, the physician was a medical professional and a leader of a hierarchical medical team, who interpreted the ethical guidelines in a direct manner. The informers viewed patients as objective and rational decision makers who merely needed information from their physician. In the supporter discourse, patients were regarded as potentially unaware of the consequences of their choices on their quality of life and different aspects of their life, and were regarded as potentially hindered by anxiety that could disturb their decision making. These patients therefore needed assistance from the physician, who appeared as their supporter and protector. The physician was essentially patient centred in his or her activities. In yet another configuration, the analyst discourse viewed patients as fallible in the decision making process, mainly because of subjective influences. These physicians needed to evaluate and support their objectivity. This position is less patient centred and more physician leading than the supporter discourse. The supporter and analyst discourses also described decision making as teamwork with nurses.

The position of relatives in the decision making process also varied somewhat in the different discourses. The informers considered relatives to provide them with the information they needed, and, in return, it was their responsibility to inform the relatives of the medical decisions. They thought that the problem with relatives was principally that the relatives' ethical guidelines differed insofar as they did not have the medical competence needed for such decision making. If the relatives disagreed with the treatment, the informers decided either to exclude them from the decision making process or to comply with their request if it concerned a restricted issue. Finnish law regarding the position of relatives on decisions concerning incapacitated patients is changing at the moment; in future it may influence the views presented by the informers. The supporters represented the decision making process as an intersubjective matter and described relatives' role in relation to their social importance to patients. The analysts, on the other hand, evaluated the relatives in the same manner as they evaluated patients.

According to the literature, autonomy as a concept has two different meanings. It can mean either someone's right for something or someone's capacity for doing something.[19] The former interpretation can be placed in the informer discourse and the latter in the supporter and analyst discourses. The supporter and analyst discourses were not, however, used to dismiss patients' (or relatives') right to make decisions; they assigned to the physician the duty to support their capability in this regard. The informer discourse is the leading discourse in ethical debate and in jurisprudence because it takes the form of a clear rule and is therefore most easily regulated. The dominance of this discourse is occasionally problematic because the other discourses clearly have their place in praxis, based on the extent to which the participant physicians applied them. The informer discourse may dismiss patients' difficulties in making end of life decisions. The other discourses take these difficulties better into account. The trouble with the supporter discourse is that some patients may consider it as being overly protective, whereas the analyst discourse carries the risk that the doctor's viewpoint predominates.

In discourse analysis, people are not considered to ''invent'' discourses but to acquire them from cultural meaning systems and to refine them to suit their own purposes.[14] Western medical schools and clinical culture exhibit a diversity of perspectives and discourses[20]; the discourses of this study can be traced back to these. First, the informer discourse constructed physicians as medical experts and leaders of a hierarchical medical team. These are features that are linked to the traditional view of doctors.[16] Interpreting the realisation of patient autonomy as a direct guideline is as follows. This realisation serves the maintenance of the traditional identity of a purely medical professional, because it then forms an additional task whereby doctors can preserve their identity as solely a *medical* professional. The supporter discourse, on the other hand, emphasised physician characteristics such as caring, emotional support, and protection. This resembles discussion about values in—for example, holistic medicine.[7] Lastly, the analyst discourse described physicians as analysts and therapists of patients, a view typical of psychotherapy. Both the supporter and analyst discourses resemble—for example, the discourse by Balint of the therapeutic physician–patient relationship, in which physicians orientate towards revealing the hidden psychosocial needs of patients, and respond to these as well as to biomedical needs.[21]

In conclusion, these physicians offered different interpretations of patient autonomy. End of life decision making is a highly negotiable issue. The physicians were attempting to make sense of the guidelines and clinical problems by applying various discourses in their talk about end of life decision making. The study shows that the doctors' talk reflected different ways of understanding patient autonomy. The benefit of a qualitative method such as discourse analysis is that it can show minute details and nuances in the ways in which different doctors talk about this controversial topic, which is indeed beyond the scope of quantitative research.

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Competing interests: none declared

The ethics committee of the Hospital District of Helsinki and Uusimaa approved the study protocol.

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