

End-of-life decision-making: a descriptive study on the decisional attitudes of Italian physicians

*Claudio Lucchiari,¹ Marianna Masiero,² Gabriella Pravettoni,³
Gianluca Vago⁴ & Robert L. Wears⁵*

Abstract

The research on medical decision-making is growing in three main directions: emergency treatment, treatment of chronic disorders, palliative care. The increasing occurrence of chronic diseases, in particular, cancer, has generated a new interest in decision-making procedures in this medical domain. Furthermore, the role of physicians working in different and complex settings and the role of patients and informal caregivers, who are supposed to play an active part in the treatment flow, are now important subjects of research in all parts of the world.

In this framework, we conducted a survey on Italian physicians concerned with end of life care. The aim of this study was to describe which factors might influence the decision-making style in this context.

Our data clearly showed that the medical decision-making process in incurable illnesses represents a complex and delicate context. Several modulating factors are present in order: medical, ethical, social, and cultural. Physicians, in formulating their own therapeutic decisions, seem to be influenced by three key elements: the patients' need for information and treatment involvement; the interaction between survival time and quality

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¹Department of Social and Political Studies, University of Milan, Via Conservatorio 7, 20122 Milano. E-mail: claudio.lucchiari@unimi.it

²Department of Social and Political Studies, University of Milan. E-mail: marianna.masiero@unimi.it

³Department of Social and Political Studies, University of Milan. E-mail: gabriella.pravettoni@unimi.it

⁴Department of Social and Political Studies, University of Milan. E-mail: gianluca.vago@unimi.it

⁵Emergency Medicine Department, University of Florida. E-mail: wears@ufl.edu

of life, and the role of the informal caregiver (the family). Future research will be required to better understand both patients' and physicians' needs in this critical domain.

Keywords: Decision-making, Patient, Role of caregiver, End of life decision

1. Introduction

Shared medical decision-making is generally defined as an ideal way of handling decision-making in medical settings (Charles, Gafni, & Whelan, 1997). Though the generalities of this method are largely accepted, the basic shared decision making principles are not really always applied. There are many different reasons for this dichotomy between the practical, conceptual and also moral origins, especially in the case of terminally ill people. The present descriptive study is going to examine some of these reasons pointing out a physician's behavior when facing clinical choices concerned with one's end of life. This examination was performed in order to better realize the way a medical decision is made from the point of view of a general medical decision-making study, which involves an increasingly growing number of specialists in different fields (physicians, psychologists, sociologists and others). The decision-making studies are nowadays applied in various clinical fields like emergency medicine, treatment of chronic diseases and palliative care. This last element is strictly correlated with the particularly delicate subject of the end of life, where medical decisions of a technical character deal with its emotional, ethical and legal aspects. Consequently, the study of critical aspects which physicians take into consideration when they have to make their decisions is of a particular importance.

Commonly, the interest towards this field of research is growing due to the factors like the patients' need for information, involvement in treatment, consumer' interests and the general evolution in the nature of medical activities. This evolution in the relation between physicians and patients has been caused by a constantly growing illness duration as well as by its frequent acutization. The constant increase in chronic disorders and, in particular, of cancer, has generated a notable request of studies on this issue, and, since the physicians have to operate constantly in very complex and structured settings, the medical decision-making processes should be analyzed as well. On the other hand, the necessity to analyze through specific empirical studies the part which a patient plays is of increasing importance when, being an active part of the treatment flow, they have to choose between different therapeutic options which can cause positive or possibly negative effects on their life, as well as on the part of informal caregivers in assistance of terminally ill patients (Kaplan & Frosch, 2005).

The shared medical decision-making model is just one of the existing models and it can be found between paternalistic and informed models in related literature. In the shared decision-making model the power of control over the decision-making process is entirely entrusted to a patient. The interaction between patients, physicians and others (family members, for instance) is the starting point in the deliberation for the final decision-making (Gaston & Mitchell, 2005). So, a patient has to be well-informed on aetiology, symptoms, diagnostic methods, prognoses, advantages and eventual

risks of different treatments in order to evaluate together with a physician the possible alternatives of treatment in a conscientious and critical way. Thus, information is a crucial “power” for a patient (Shannon-Dorcy & Wolfe, 2003), i.e. it is an essential condition for so-called empowerment of a patient.

There’s an interesting branch of research considered to be a part of shared medical decision-making connected with an actual problem of end of life care, which is focused on study of medical decision-making processes in case of terminal illnesses, with particular attention to cancer disease care. The first observational study on end-of-life care medical decisions was performed in Italy in 2001-2003 by the *European End of Life Decisions (EURELD)* and involved general population level of research without being restricted to a particular field of medical care (intensive therapies, newborn cares or others). In this research there were involved the following European states: Italy, Switzerland, Belgium, Holland, Denmark and Sweden (Miccinesi, Fisher, Paci, Philipsen, Cartwright, van der Heide, *et al.*, 2005; Bilsen, Norup, Deliens, Miccinesi, van der Wal, Lofmark, *et al.*, 2006).

The obtained results show that in the European countries half of those persons who don’t die suddenly are assisted at their final phases of life with the intention of providing them with a tolerable quality of life rather than just simply prolonging their lives (Miccinesi, 2005). It has been observed, however, that there’s a big difference between Italy and the rest of the European countries examined. It means that the decisions taken by the Italian physicians are different by type and frequency of decisions from those made by their European colleagues. First of all, the medical decisions on end of life care in Italy are connected with minimization of suffering by intensification of therapy and, moreover, the decisions of non-treatment are taken about five times less in comparison with those taken in Holland, Switzerland, Belgium, Denmark and Sweden.

As for the Italian physicians, the focal point of the *Eureld’s* ethical discussion is the decision of non-treatment. On the other hand, 75% of the European physicians believe that the refusal of treatment from the side of a patient must be respected. In conclusion, only one half of the Italian participants in the research compared to at least 2/3rds of the other countries’ physicians do follow the above binding directives of non-treatment or vital therapy suspension. In order to understand the way of decision-making formulation by physicians, it is necessary to take into consideration how the part ascribed to a patient and relation between a physician and a patient may govern the decision-making in addition to the individual physician’s emotional state, their experience and professionalism. The vision of a patient considered to be competent is widely spread in the North America and at the North Europe, where a patient’s family assumes crucial position for decision-making process as well (Gaston & Mitchell, 2005). Nevertheless, the results emerged from a different studies show that there’s necessi-

ty of direct information in communication between a physician and a patient not only in Anglo-Saxon context (where the patients are usually informed on all important details), but also in South European context, where such a straightforwardness is generally considered to be more problematic (Varetto, 2004, Lucchiari, Pravettoni, Vago, & Boiardi, 2006; Lucchiari, Pravettoni, & Vago, 2008; Hubbard, Kidd, & Donaghy, 2008). Consequently, the medical system should be able to be attentive to patient's requirements and to satisfy their needs (Kaplan & Frosch, 2005). It means that medical practitioners have to be able not only to provide patients with professionalism, respect to beliefs and convictions, but also have to meet their needs into being involved into the treatment details and therapeutic choices.

A terminally ill person needs to be particularly involved with the medical staff and even receive a sense of empathy from them. In this context there may be an open, frank relationship obtained between physician and patient, thus any therapies or special treatments may assume their important significance even if these are just mere palliative responses. In this framework we conducted a survey on physicians' habitual kinds of approaches to decision-making in cases of care for terminally ill people, considering various parameters which, as mentioned before, can influence the relation between a physician and a patient and, consequently, the corresponding decision-making processes. The aim of this study was to describe medical decision-making processes on end of life cares of cancer diseases and analyze the possible factors which, as various sources report, might influence the decision-making style of medical staff in this context. Thus, we have tried to identify some theoretical parameters on physicians' approach to the shared decision-making model by means of a questionnaire prepared ad hoc for this study.

2. Materials and methods

The main tool used for this examination is presented by a questionnaire prepared ad hoc for this study and composed of twenty two items in a form of a multiple-choice test. The preparation of this test was based on information present in the Italian and the international contemporary literature on end of life care medical decision-making. The validity of its layout and contents had been prior analyzed by means of discussion with a panel of experts before its definite version was obtained. The questionnaire is divided into four areas of survey.

First area: patient's part in the medical decision-making. This area is supposed to find out the main characteristics and peculiarities in the relation between physicians and patients with special attention to patient's role in the treatment itinerary. The items have been organized in a way to learn the

physicians' attitude in evaluation of patients' decisional ability as well as the shared decision-making model advantages and disadvantages.

Second area: clinical decision variables. Here, the clinical and objective parameters used by physicians for therapeutic decision-making are examined using the items of this area.

Third area: subjective decisional variables. In this area, on the contrary, the non-clinical parameters which may influence more or less on a physicians' actions are analyzed. Are there any patient's features, apart from symptoms of a disease, which can influence the decision-making process?

Forth area: in this section, the influence by a family member (informal caregiver) on the therapy selection by a specialist is examined.

The set of options in the present test is represented by the four-level Likert scale (disagree, quite agree, agree, strongly agree). This questionnaire was distributed by email in the period between July and October 2008. The target of this study were the physicians dealing with terminally ill people with the medium range between six months and one year of foreseen survival from the date of final diagnoses. This target was selected from the staff of hospitals, research institutes, centers for palliative diseases, hospice all over Italy, as well from the specialists of different medical areas, like: oncology, pediatric oncology, surgical oncology, hematology, therapists of palliative diseases. As a summary, 650 e-mails were distributed and 102 valid replies were received thereafter. Respondents characteristics may be found in table 1.

Table 1 - *Respondents characteristics*

		mean	sd
age		44.32	6.3
gender	men	n 60	% 59
	women	42	41
medical specialty	Oncology	77	75
	Pediatric Oncology	17	16
	Neurology/Neurosurgery	8	9

A descriptive analysis were conducted, considering level three and four of the Likert scale as complete positive response (agree) to an item. When particularly interesting trends were found, non parametric tests (χ^2 and Mann-Whitney test) where used to validate specific hypothesis.

3. Results

As a result of descriptive analysis performed with the use of questionnaires, the information emerged is useful to understand the decisional behavior of the physicians participated in this survey. Hereafter, its most significant items are divided by their areas of pertinence and then commented upon.

First area: patient's part in the medical decision-making

So, 68% of the physicians participated in this analysis consider that it is not correct to assume detached behavior towards the patient at the moment of diagnosis communication (item 4). Anyway, only a very small percentage of the physicians (11.5 %) declared themselves to be absolutely in agreement with this strategy. Though, 61.2% of the specialists do agree with an affirmation from the item 21 which asserts that sometimes a physician's emotional involvement in relation to a patient may be in ethical contrast to his scientific position. Thus, feedback to the above two statements seem to prove that even if there's an awareness about the importance of emphatic relations with a patient, at the same time there's some caution about consequences which such an emotive relationship can produce. It is clear that these considerations are not so easily manageable since the context of "end of life" implies anxiety, fear and anguish among patients, relatives and physicians.

Item 5 clearly shows that the majority (65%) do agree that a patient should be informed on their real conditions. A patient has a right to know the diagnosis and a physician has to communicate this fact. But, considering the possibilities of an ill person to stand and gain certain information, it is necessary, however, that the news about their real conditions be communicated gradually and with a certain sensibility. Until the Sixties it was commonly accepted that the fatal diagnosis should never be communicated to a patient. Nowadays the situation has changed as was confirmed by the results of our survey as well. Nevertheless, 78.2 % of the participants in this study do agree that there are some communicational problems between a physician and their patients (item 20). This fact was already mentioned in different sources of related literature. Our statistics just highlight the difficulties which physicians face in communication with their patients (and corresponding parents). So the physician, in order to establish a therapeutically valid relationship with a patient, has to try to formulate his messages in a clear and unequivocal form to avoid patient and relatives' anxiety. However, communication between a physician and a patient is complicated and implies facing significant obstacles (like the use of particular difficult to understand terminology; difficulties in the relationship established between a physician and patient; difficulties connected with the reality of the disease).

Item 14 examines the physicians' approach to a patient's request on interruption of therapeutic treatment. The participants in the survey were divided almost equally between the four options of answers present in the test. In Italy the delicate discussion on artificial life sustenance of terminally ill people in the final stage of their illness is still open, so the results obtained are more than realistic. Besides this, 69% of the specialists declare in favor of sustaining an attempt at survival prolongation by therapeutic means even if a patient requests anticipating the "natural" end of life (item 17). It is worth saying that 40% of the physicians declared to "quite agree" on this, since there's some ambiguity related to legal, clinical and moral aspects of the relation between a physician and patient, and the way the patient is considered. This was confirmed also by statistics on opiate substance use for pain control of cancer diseases at an advanced stage. So, 75% of the specialists declared to agree completely with the necessity of discussing with a patient the use of such substances or their upgrade, showing in this way their will to share the decision-making process with a patient in an active manner.

Second area: clinical decision variables

Item 1 is supposed to highlight the double nature of cancer disease in advanced stage ill person treatment. A physician treating terminally ill person knows very well about the impossibility to save their life, so his efforts should get them to improve the quality of the rest of patient's life. Only 14.3% of the practitioners declared to disagree with this statement.

Items 9 and 10 analyze physicians' opinion on the value of terminally ill people life quality. According to our studies, the life quality of a patient is considered to be an important point (82%) for a therapeutic decision-making process involving searching for a best solution, as well as life duration and age of a patient.

Third area: subjective decisional variables

Forty-one point four percent of participants agree to modify their decision from patient to patient taking into consideration, thus, not only their pathological characteristics but also the psychological (item 13). Items 7 and 8 try to examine physicians perception of patient's attitude during the curative relations. Ninetysix point six percent of specialists consider that patients try to assume an active position in the therapeutic process as soon as they come to know their diagnosis. Besides that, the specialists reveal that they find more active and involved patients under 40 as they try to participate in the therapeutic decision-making process.

In conclusion, the answers to item 12 show that 65% of physicians do agree on different approaches to younger patients (under 40), as they try to provide these patients with longer period of survival even if this may imply more aggressive and sophisticated therapies. As our survey shows, there's no any difference between women and men's reactions to their illness. The

survey participants do consider that there's almost no gender difference in therapeutic itinerary for patients.

Forth area: informal caregiver's part

Item 15 analyzes the physicians' approach to the terminally ill patients' family members. Forty-two point nine percent of specialists quite agree with the statement that terminally ill person's family members may decide on the treatment options instead of the patient itself (in case the conditions of an ill person make this necessary). At the same time, 25% of the specialists do disagree with the above statement, meanwhile, only 31.2% of the participants, contrarily, would give the whole responsibility of choice to family members. Thus, this item brings into discussion the informal caregivers' role in the treatment of patients terminally ill with cancer. Generally, in most of the cases, an informal caregiver corresponds to one of the close relatives (husband or wife, parents, children). In fact, the major part of support and assistance received by an ill person is provided by their family members. It is clear that, in such a context, the spirit of collaboration and trust should be established between medical staff and patient's family members. Our survey, however, confirms that very often this relationship is complicated and of a conflicting nature. This relation is complicated, in fact, because it is influenced by factors of a moral, clinical and legal nature which are not always easily analyzed.

This situation is highlighted by answers to items 18 and 19. Even if 90% of the specialists do agree completely with the statement that the family members (or, persons close to a patient) have to be involved in the decision-making process; item 19, however, shows a very different picture of reality. In fact, about 51% of physicians declare themselves not to be influenced on their decisions by patients' family members, while about 47% affirm an opposite position (only 2% of the specialists agree and others didn't answer on this item). It is clear that we are witnessing the representation of two different realities. So, we can suppose that this variable, in the context of our analysis, serves us to distinguish two different approaches, which we will define as sharing and non-sharing.

Hence, considering item 19 to be two-level fixed factor (agree/disagree) and analyzing the answers available by means of non-parametric significance tests for 2 independent samples (Mann-Whitney U), it became possible to identify the significant differences between these two approaches. In details, the specialists from "sharing" approach group declare to agree with the item 1 (palliative cares attitude; $U = 414.50, p = .02$), with the item 3 (consideration of patients' needs; $U = 448.00, p = .05$), with the item 13 (evaluation of patient's reaction; $U = 402.00, p = .01$), with the item 18 (family members' involvement; $U = 404.50, p = .01$), with the item 20 (communicational problems perception; $U = 436.25, p = .05$) and with the item 21 (physician's emotive involvement; $U = 398.50, p = .01$).

Effectively, the two approaches differ neatly one from the another in correspondence with role of physician, patient and patient's family members. The specialists from the "non-sharing" group declare themselves to be emotively detached and have some kind of "paternalistic" decision-making style, where the participation of patients and their family members, being important in any case, is considered useful for comparison and not as a point for orientation. Besides this, the physicians from this group seem to pay less attention to the problem of communication between a physician and a patient, so they report it with less conflict, more easily manageable. It is curious to point out that the "sharing" group is composed mainly of female physicians, who show particularly high scores (i.e., they do *absolutely agree*) for the items 1, 3 and 21 (table 2).

Table 2 - Gender difference between "sharing" and "non-sharing" group ($\chi^2 = 7.19, p < .05$)

		Gender		
		Males	Females	Total
Group	Non-sharing	39	16	55
	Sharing	21	26	47
Total		60	42	102

As the results of our survey show, female physicians are generally more attentive to the patients' needs (item 1), besides that, the results confirm that they seem to be more aware of interdependence between emotional involvement and decision-making styles (item 21). Never the less, the male specialists declare to be more attentive to the patient's will in their decision-making process (item 3). But this doesn't mean major human sensibility towards the patients, but merely that the male doctors seem to be more open to accept a patient's point of view and competences as an active participant in therapeutic decision-making itinerary.

4. Discussion

The present survey clearly shows, that the medical decision-making process on terminally ill people care represents a very complex reality and

is subject to the influence of a medical, ethical, social and cultural character, which may result in even very different approaches to these problems from physician to physician. Nowadays, due to technology improvement in research and approaches to varying treatments of diseases, a physician becomes the recipient and “carrier” of very complex scientific knowledge much more than in the past. This progress implies a huge responsibility in medical decisions, and these responsibilities require a constantly present, particular attention in terms of management and research in order to provide patients with therapy which meets their needs and supports a physician in the execution of his difficult job.

The present study on medical decision-making processes on end of life care has brought to light some interesting points. First of all, the importance of the relation between a physician and a patient has emerged. This relation consists of the following set of elements: the patient playing a double role of a personality on one side and of the ill person on the other who needs an assistance the physician with his professionalism and personal characteristics, and the context where their relation takes place. In this relation between physician and terminally ill patient, the patient is subject to the physician’s actions. This emotive and affective interdependence should be considered in the medical practice analysis. The relation between a patient and a physician is influenced by different elements from the sides of both parties. At this point, it is very difficult to identify the way these personal elements influence the treatment process. There were two research projects conducted in Italy on this issue, first one first performed by Marasso *et al.* on 1988 (Marasso, Cianfruglia, Crotti, De Falco, & Tamburini, 1988) and the other one by Tamburini and colleagues on 1988 (Tamburini, Gamba, & Marasso, 1988), and it was revealed that the physicians’ behavior and relation to a patient differs from one medical category to another.

In the second place, there’s an importance of communication in terms of therapy (i.e., that a patient has a right to know the diagnosis and a physician has to communicate it to him). This information should be communicated according to the ability of a patient to understand and work out the information received. Every ill person has their unique features and character, so it is not absolutely possible to apply the same “ready-made” relational method to all patients or their families. The form, quantity and sort of information to be communicated to a patient should be defined by a physician each time according to the patient and his characteristics. With the help of a personalized approach, it is possible to let a patient decide on the quality and quantity of information he needs for better understanding the therapeutic situation. This method assures better sharing of difficult therapeutic decisions to be taken between a physician and patient. Taking into consideration the subjective parameters allows a physician to center his attention first of all on a fundamental parameter of life quality along with its duration and, more generally, to control the symptoms (the objectivity). Our

survey has examined the subject of communication as well. The communication between a physician and a patient may lead to development of a therapeutic relationship based on trust and sharing of specific therapeutic targets. Our data shows that the specialists participated in the survey are aware of this fact and there's also a significant difference between their targets in this communication. Besides this, many of them affirm facing problems in such a difficult communication with patients and their family members. Thus, it is very important to support a physician on this issue. During the last ten years Italian physicians have become always more disposed to inform their patients on the malignant character of their disease (Costantini, 2001). Considering results of some surveys conducted on Eighties, like one of Costantini and his colleagues (Costantini, De Marinis, & Nosedà, 1992), which clearly showed that from 80 families of people with lung cancer on advanced stage, 82% of patients was not informed on their diagnosis (Costantini *et al.*, 1992), we can affirm that the improvement in the last years on this issue is of great importance. One of the following surveys performed by Ruggeri showed that only one half of 2088 examined patients with advanced stage of cancer disease had even a remote feeling about their real diagnosis (Ruggeri & Cortesi, 1999). Consequently, it is a big importance to provide the medical staff with training on communicational skills. For example, Kaplan (Kaplan, 1996) proved with the help of his survey on more than 7.000 patients and 300 physicians, that the medical staff with communicational studies background involves more frequently their patients into the decision-making process, and, consequently, there's the highest level of satisfaction among these physicians and their patients. But, in oncology the problem of communication is more sophisticated due to the emotional factor that affects patients, their family members and physicians. Surely, the taboos associated with the cancer and, especially, with death make it difficult to talk about. Very often communication in oncology is characterized by silence and divergence between medical staff and patients' family members (Tomamichel, 1999), as the results of our survey seem to prove it as well. In fact, the specialists participated in the survey seem to understand the difficulties of relations between physician and patient with consequent problems of treatment quality from one side and professional satisfaction of the practitioner from another. Nevertheless, it seems like there's the necessity, at least for one group of the examined specialists, to simplify the above situation with the help of decisional styles, which can avoid the patients' subjective parameters in order to reduce the ambiguity and uncertainty related with legal and moral aspects that may turn to be difficult to solve.

The third important point emerged from this survey is the perception of life quality value. The major part of the questioned specialists agree on the high importance of their patients' life quality. Making therapeutic decisions based on life quality means to intensify the symptoms' control, which, in

some cases, may be a request to anticipate life's final termination, or, at least, it means not to consider the patients' survival to be an irrevocable target. This may lead to alteration of clinic decision-making models in case of terminal cancer diseases. This fact was proved by different national and international studies on this issue (Danti, Sirigatti, Gabbrielli, & Cavallini, 2006). In details, it becomes very complicated to manage the relation between quality of life and its duration considering personal features of different patients. It means, as statistics show, that there's a different approach to survival duration in case of younger patients. Probably, because they show themselves to be more active, to be more culturally enriched, and are more prepared to ask questions regarding the therapeutic choices and attempts to evaluate their treatment options, while elderly people or people with a less-strong cultural background trust the physicians more and let them make the therapeutic choices.

The fourth and the last significant point examines caregivers' importance in assistance of terminally ill people. Patients' family members greatly influence the physician's decision-making process. This may be explained by the fact that an ill person receives major support and assistance from their family members. Usually, as the survey conducted by Palliative Care Italian Observatory showed, a caregiver is identified with a woman (patient's family member) who takes care of all needs and requirements of a patient (Corli, Pizzuto, Natri, & Marini, 2005). Physicians agree on the informal caregivers' importance, but still, as the results of our survey show, they are not considered so much either for the establishment of relations with a patient nor for important medical decision-making. In addition, a not always positive and easy relationship can be established between medical staff and patients' family members. Consequently, it appears that the improvement of relations between medical staff and patients' family members is required not only to provide a patient with better support but also to guarantee an optimal treatment quality from the side of the medical staff.

In conclusion, we would like to point out that from our survey there emerged some important issues related to the palliative care context. Nowadays, this context is subject to a very dynamic evolution determined by medical progress and conditions of a cultural and social nature like the evolution of relations between physician and patient (patient's emancipation) as well as the evolution of social representation, always less idealized and more problematic, of physicians. Besides this, there's a moral question within the domain of palliative care, which is strictly related with the biological testament issue, which can't be solved with or without the help of an operational unit organization and turns-out to be very critical for the experience and decision-making process of a physician.

The specialists participating in the survey have highlighted the physicians' role in the context of decision-making at the end of life situations as very problematic and complex. Still, the approach to the sharing deci-

sion-making among the specialists doesn't prove to be that homogeneous. As mentioned before, this model is considered to be an ideal, to which an application in real situations doesn't always correspond. There are, actually, a lot of problems related to this argument, and, sometimes, it turns-out to be much easier to apply a more directive decisional style, which may be considered to be the best one. In conclusion, the data related to the gender differences of the shared decision-making approach was very interesting, i.e., the male specialists are more overt than female specialists, who declare themselves to be more attentive to a patient's needs but less interested in getting involved in the decision-making process.

The results of our survey, though partial and limited due to exiguity of participants, suggest that there's the necessity to discuss the matter of medical shared decision-making more thoroughly in order to involve patients with relative family members into the treatment decision-making process, and provide physicians with support in the management of problematic areas like communication and control of emotions.

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