

## CLINICAL ETHICS

## Physicians' evaluations of patients' decisions to refuse oncological treatment

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**Objective:** To gain insight into the standards of rationality that physicians use when evaluating patients' treatment refusals.

**Design of the study:** Qualitative design with indepth interviews.

**Participants:** The study sample included 30 patients with cancer and 16 physicians (oncologists and general practitioners). All patients had refused a recommended oncological treatment.

**Results:** Patients base their treatment refusals mainly on personal values and/or experience. Physicians mainly emphasise the medical perspective when evaluating patients' treatment refusals. From a medical perspective, a patient's treatment refusal based on personal values and experience is generally evaluated as irrational and difficult to accept, especially when it concerns a curative treatment. Physicians have a different attitude towards non-curative treatments and have less difficulty accepting a patient's refusal of these treatments. Thus, an important factor in the physician's evaluation of a treatment refusal is whether the treatment refused is curative or non-curative.

**Conclusion:** Physicians mainly use goal oriented and patients mainly value oriented rationality, but in the case of non-curative treatment refusal, physicians give more emphasis to value oriented rationality. A consensus between the value oriented approaches of patient and physician may then emerge, leading to the patient's decision being understood and accepted by the physician. The physician's acceptance is crucial to his or her attitude towards the patient. It contributes to the patient's feeling free to decide, and being understood and respected, and thus to a better physician–patient relationship.

When a patient decides to refuse a recommended oncological treatment, the physician is faced with questions about the background of this decision, the patient's arguments, the acceptability of the decision, and the patient's role in the decision making process. The physician has to evaluate the patient's decision: Is it sensible, responsible, and judicious? Often the evaluation is then directed to the question: Is the patient's decision rational or not?<sup>1, 2</sup> The actual standards of rationality in these cases, however, are not clear. The question therefore arises: On what basis do physicians distinguish between their patients' rational and irrational arguments?

In medical ethical literature, rationality is described in various ways. Rational choice has—for example, been described as the choice that maximises expected utility or that satisfies the patient's aims and values most.<sup>1</sup> In other cases, having "good reasons" is at the centre of the evaluation of rationality.<sup>2–4</sup> Savulescu and Momeyer state that "It is rational for a person to perform some act if there would be a good reason to perform that act if the facts were as he/she believes them to be."<sup>2</sup> A pilot study revealed that a physician's evaluation of the rationality of the patient's decision is crucial to their attitude towards the patient: if a physician thinks the patient's refusal is not based on good reasons, he or she is often inclined to consider the decision as irrational and will keep trying to convince the patient to accept the treatment.<sup>4</sup> The evaluation of "good reasons", however, raises another question: What makes a reason a good reason—"good" in a medical context, "good" in a patient context, or "good" in both?

The purpose of this article is to gain insight into the standards of rationality used by physicians. We focus on two aspects of this issue. Firstly, we describe what is meant in daily medical practice by rational decision making and discuss what physicians understand by "good reasons" to

refuse recommended oncological treatment. Secondly, we discuss what motivates a patient to refuse a treatment and how this is communicated to their physician.

## METHODS

The present study is based on indepth interviews with patients and physicians. All patients had refused a recommended oncological treatment. In this study refusal meant the patient did not start treatment at all; or stopped during treatment; or refused a part of a recommended treatment but accepted another (for example, accepted surgery but refused chemotherapy). A qualitative research method was adopted to explore patients' deliberations that led to refusal of a recommended oncological treatment and to determine physicians' evaluations of the treatment refusals. The study was approved by the medical ethics committees at the study sites. All patients gave written informed consent.

## Participants

Patients who have refused an oncological treatment are difficult to enrol for a research sample.<sup>4</sup> One reason may be that after their refusal, they have withdrawn from the medical circuit and are therefore not easy to approach. Another reason may be that after their withdrawal, patients no longer want to be involved in medical research, either because they do not want to be confronted by hospitals or doctors again or because they are too ill to be interviewed. The patients included in this study form a rather unique sample and deserve our gratitude.

A total of 30 patients (mean age 58 years, range 23–91) were interviewed. The inclusion criteria were: (a) age more than 18 years; (b) able to speak and understand Dutch; (c) having cancer; (d) life expectancy of more than three months; and (e) having refused a recommended oncological treatment. The patients were asked to participate by general

practitioners (n = 5) and by specialists in a university hospital (n = 6) or in general hospitals (n = 2) in the Netherlands. Dutch associations for patients with cancer were willing to spread information about the study. Patient members of these associations (n = 17) responded themselves to the call to participate. All patients recruited by the physicians or those who responded themselves between January 2001 and April 2002 were included in the study if they met the inclusion criteria. We included both patients who had refused a recommended treatment with higher potential benefit (curative treatment, n = 10) and patients who had refused a recommended treatment with lower potential benefit (non-curative treatment, n = 20). Demographic and clinical characteristics of the patients are given in table 1.

A total of 16 physicians were interviewed from among the physicians who recruited the patients. Eight general practitioners (50%) and eight (general) oncologists (50%) were selected, including younger and older (mean age 49 years, range 29–60), male (n = 11, 69%) and female (n = 5, 31%) physicians with few to many years of working experience (mean 18 years, range 2–29), and from different settings (general practice, university hospital, and general hospital). The interviews were carried out between May and October 2002.

### Interview procedure

Each patient interview was carried out at the patient's home and lasted between 60 and 120 minutes. We used indepth interview techniques—that is, the interviews contained some general topics and no close ended questions.<sup>5</sup> The interview topics covered demographic and clinical characteristics of the patient; the course of the disease; communication with physicians about the recommended treatment; the patient's attitude to the recommended treatment; and the patient's perspectives of the future. The interview topics were formulated after examining the relevant literature and undertaking preliminary observational studies. In these studies, 72 patients were observed during their visits to five different oncologists at an oncological outpatient clinic in the Netherlands. From the transcripts, various aspects of the discussions between physicians and patients about recommendations for treatment were noted and converted into interview topics.

Each physician was interviewed at their office. The interview lasted between 30 and 60 minutes. The indepth interview topics covered the characteristics of the physician;

working experience; curative versus non-curative treatment and palliative care in oncology; the physician–patient relationship, especially concerning treatment decisions; patient autonomy; physician's beneficence; and treatment refusals and their rationality. At the end of the interview, the medical history of one patient who participated in the study was presented as a case (see box 1), and the physicians were asked to give their opinion about the rationality of the patient's decision.

### Analysis

All the patient and physician interviews were audiotaped and transcribed. A descriptive qualitative approach was used to analyse the interviews.<sup>6</sup> During the analysis, we used computer software (Kwalitan 5.0; VAM Peters, Radboud University, Nijmegen) for multiple text management, including coding, locating, and retrieving key materials, phrases, and words. Each interview was divided into several segments. The segments were coded and the codes were organised into categories and put into a tree structure. A second independent researcher supervised the process of data management.

## RESULTS

### The medical perspective

Mrs S's case (see box 1) was presented to all the physicians in the study. They were asked whether they would judge her decision as rational or as irrational.

*Physician 1:* If it is related to previous communication breakdown combined with an enormous amount of fear thus preventing the patient from forming a good idea of what that cancer can do if it is not treated, and no good decisions are made, then I find it irrational. Or at least something I would try to change.

### Box 1: The case of Mrs S

Mrs S is 54 years old. After a period of fever and pneumonia, she was diagnosed as having bronchial carcinoma (non-small cell lung cancer in the upper right pulmonary lobe). The attending physician recommended surgery in which part of the lung would be removed (lobectomy). Mrs S decided to refuse the recommended surgery.

*Mrs S:* "I was afraid, and this fear was based on the mediastinoscopy [a diagnostic procedure carried out behind the sternum in the upper part of the chest cavity, which she recently had undergone; TvK]. I awoke when I was still in the operating room. I think something was not timed very well. A tube was still in my throat. I don't know if the tube was in my trachea or in my throat. I don't know, but I heard someone say that the surgery had been successful. And I was choking, I pulled out the tube and immediately afterwards I was transferred to the recovery room and there, for one and a half hours, I had terrible shortness of breath. I really thought I would suffocate."

"At that moment I thought: What if I had to undergo such a lobectomy? Then I would be in intensive care for three or four days. What if I keep getting that suffocating feeling. I know that they may make it technically possible for me not to really suffocate, but the feeling is terrible. I took three days to reflect on that, and then I decided for myself, no surgery. I am afraid. It is fear, fear of the surgery, and what may come afterwards."

**Table 1** Demographic and clinical characteristics of the patients included in the present study (n = 30). Values are n (%)

|   |         |
|---|---------|
| Sex   |         |
| Men   | 12 (40) |
| Women                                       | 18 (60) |
| Marital status                              |         |
| Single/divorced, widowed                    | 13 (43) |
| Married/registered partnership              | 17 (57) |
| Education                                   |         |
| Primary school/lower level secondary school | 9 (30)  |
| Middle level secondary school               | 6 (20)  |
| Advanced professional/university            | 15 (50) |
| Cancer diagnosis                            |         |
| Breast                                      | 11 (37) |
| Gastroenterological                         | 8 (27)  |
| Urological                                  | 3 (10)  |
| Gynaecological                              | 2 (7)   |
| Pulmonary                                   | 2 (7)   |
| Haematological                              | 2 (7)   |
| Other                                       | 2 (7)   |

*Physician 2:* Well, those experiences, if they are based somehow on facts that I can verify, I could find that rational. But when I have the feeling that it is not based on facts, I find it very irrational.

The physician interviews revealed that physicians mainly emphasise the medical perspective when evaluating what are good reasons, and thus, what is rational. This perspective consists of a system of terminologies, deliberations, and expressions that are common in medical practice. The physicians indicated that if a patient's refusal was based on reasons related to the kind of tumour, the prognosis, and/or the side effects of the treatment, they were rather inclined to evaluate these reasons as good reasons and to accept the refusal. Moreover, the physicians felt that rational arguments are related to those reasons that are scientifically proved, such as the chance of the treatment being effective or gaining medical benefit. If a patient refuses oncological treatment because he or she does not want to experience the side effects, a physician judges this decision to be rational if side effects are indeed expected to occur.

*Physician 3:* If the chance of effectiveness is small and the price one has to pay is high with regard to side effects, I can imagine someone saying: "It is not worth all the trouble and at this moment I have few complaints, thus why should I?". I find that a rational argument.

A significant factor in the physician's evaluation of a patient's decision is the phase of the patient's disease; the distinction between the curative and palliative phases of the disease and treatment processes plays an important role in a physician's evaluation and acceptance of a patient's refusal for treatment.

*Physician 4:* Well, if patients could just really realise what they may be missing, with the treatment they could get if they continue, if they at least know that. Then I could accept it [treatment refusal]. And I'm talking particularly about palliative treatment. As for a cure, I would always be willing to go a bit further and possibly involve some colleagues.

### Curative treatment

The interviews revealed that when a physician thinks there is a reasonable chance of cure, a patient's treatment refusal is often judged as irrational and is difficult to accept for the physician. Physicians evaluate the decision to accept or to refuse a recommended oncological treatment as a decision about life or death: when the patient refuses treatment, he or she chooses for disease progression, with a greater chance of dying from the disease. They consider the decision to refuse curative oncological treatment out of proportion. From a physician's point of view, the consequences of the decision are enormous and cannot be compared with the possible side effects of the treatment. In other words, according to the physician, the benefits of being treated are much greater than the price the patient has to pay.

*Physician 4:* Those tubes [of Mrs S], I do not find that rational. It is not such a big problem compared to the fact that she can remain alive. The patient does not see the right relation between the proportions [sic]. It's like when you say that your cat will be alone for one day—that has no relation to what you can gain from it [treatment]."

Age also seems to play a role in the physician's evaluation of a patient's refusal of curative treatment. Physicians find it easier to accept a treatment refusal by an older than a younger patient.

*Physician 5:* Concerning chemotherapy, which can also cure the elderly, I can imagine some people would not want that. I would agree to not giving chemotherapy with a curative intention. Concerning young people, I find it hard not to offer curative treatment, because that is simply choosing death. In such cases I am the attending physician who will try to win someone over.

### Non-curative treatment

When a physician is of the opinion that cure is no longer an option, the decision of a patient to refuse oncological treatment seems easier to accept compared with the situation in which there is a reasonable chance of cure. The appropriateness of the decision about non-curative oncological treatment directed at palliation, which includes choices about prolonging life as well as quality of life, is perceived differently from the decision about curative oncological treatment. The consequence of refusing non-curative oncological treatment may be that the patient will die a few months earlier, but it is not a matter of life or death. Physicians are of the opinion that in the palliative phase the most important thing is accurate interpretation of the patient's wishes, and in these circumstances it is the patient who decides what a "good" palliative phase actually means. The interviews revealed that physicians find the degree of rationality of patients' arguments less important from a medical perspective when it comes to decisions about non-curative treatment compared with decisions about curative treatment: in the palliative phase, the best option for the patient is at the forefront, and this option does not have to be in agreement with the best medical option.

*Physician 4:* And when that patient just says, "Well, for me it is not a matter of a long life, I just want a good quality of life and I just want to do some nice things", yeah, I find that a very good reason.

Life expectancy seems to play an important role in the physician's evaluation and acceptance of a patient's refusal of non-curative treatment. For example, patients with breast cancer can receive non-curative treatment for a very long time. A patient with a prognosis of a five year palliative phase, could, by her decision to refuse treatment, shorten her life by several years. That decision is much more difficult for a physician to accept compared with a decision about a palliative phase lasting only a few months. In the latter case, refusing oncological treatment could mean that instead of, for instance, six months, the patient's prognosis would be three months.

*Physician 6:* For some treatments, like for metastasised stomach carcinoma, you wonder whether or not you should carry it [treatment] out. And if patients say, "I don't want it", I will not say they have to. Regarding breast cancer, I am more inclined to convince patients of the usefulness of the treatment, because there are some very valuable palliative treatments. ... The tumours respond very well and very good palliative effect can be attained. As such, the patient's complaints disappear and they will benefit from the treatment for a long time. ... Concerning

breast cancer you will try to convince patients, whereas in stomach cancer you will try but to a lesser degree.

As with refusal of curative treatment, age also seems to play a role in the physician's evaluation of a patient's decision to refuse non-curative treatment, mostly in combination with life expectancy. When it is expected that a recommended treatment will prolong a patient's life by several years, the decision of a younger patient to refuse treatment is more difficult to accept than when an older patient makes the same decision. If the aim of the recommended non-curative oncological treatment is to prolong life by several months, the age of the patient—that is, whether the decision to refuse is made by a younger or an older patient—usually does not make a difference to the physician's acceptance of the decision.

To illustrate this point, Mrs S's case can be used again as an example. As revealed by our empirical study, if Mrs S's decision concerned curative treatment, physicians would find it very hard to accept it: the decision is irrational from a medical point of view since it is very unlikely that she would have the same experience again. If the decision concerned non-curative treatment, physicians would find it easier to accept it, even though Mrs S's life expectancy can be prolonged by the treatment. In the latter case, the physician is inclined to place more emphasis on the patient's considerations about fear, experiences, and personal wishes and desires than on whether their arguments are rational or irrational from a medical perspective.

*Physician 1:* It is irrational, but for her [Mrs S] it is reality.

*Physician 7:* Why she [Mrs S] does it is irrational, but the decision is easy to sympathise with, that's the problem.

From the last quote, it appears that a physician may sometimes experience problems when evaluating the patient's decision. The physician may judge the patient's treatment refusal as irrational since the decision, from a medical point of view, is not based on good reasons. The decision is based on emotions and on arguments that result from a false impression of things—that is, from earlier experiences of the patient that are not likely to occur a second time. At the same time, however, the same physician may— from a patients' perspective—sympathise with the decision.

### The patient's perspective

The reasons why patients refuse oncological treatment are diverse (table 2).

Both medical and personal considerations seem to play a role in the patient's decision to refuse treatment, but personal values and experiences predominate. For example, patients may find it important to occupy themselves—painting, playing tennis, or walking in the mountains. If the side effects of chemotherapy would prevent them from carrying out these activities, the patients in the present study indicated that the meaning of their life would be gone and quality of life decreased. Our empirical study revealed that patients find quality of life to be very important. It was clear that many patients believed that quality of life was incompatible with receiving oncological treatment. More than half chose not to be treated because they believed that treatment would not result in a better quality of life and would only cause side effects and/or increase or induce symptoms. Some patients indicated they would rather live for a little lesser time than prolong their lives with all kinds of troubles due to treatment.

**Table 2** Reasons why patients refuse a recommended oncological treatment

|   |
|---|
| Believe in the body's own curative possibilities                                |
| Do not want a stoma   |
| Do not want to be ill due to the treatment                                      |
| Do not want to be used as a guinea pig  |
| Do not want to enter into menopause, still wanting a child                      |
| Do not want to fight anymore  |
| Do not want to lose a breast  |
| Do not want to lose hair  |
| Do not want to reach old age with dementia, incontinence, and dependency        |
| Do not want to spend valuable time in hospital                                  |
| Have accepted death   |
| Have a lot to cope with, want to take time to do that                           |
| Have already reached old age  |
| Have fear of treatment  |
| Have no trust in treatment/medical establishment                                |
| Resist chemotherapy; consider it poison   |
| Treatment decreases quality of life   |
| Treatment will not result in cure, is only life prolonging                      |
| Want to continue playing tennis, making paintings, or walking in the mountains  |
| Want to stay in control   |
| Want to take responsibility for themselves                                      |
| Want to work on the initial cause of the cancer, not just removing the symptoms |

*Patient 1:* my quality of life will diminish when you remove a large part of the small intestine.

*Patient 2:* nevertheless have a fine life, higher quality of life, without chemotherapy.

*Patient 3:* that I risked suffering side effects from the "pleasant" radiotherapy that actually would diminish my quality of life scared me stiff.

*Patient 4:* we can postpone death with chemotherapy. But then, in this period of postponement, how will I live? What will my quality of my life be like? Thus, I have to give up quality.

For some patients with breast cancer, losing a breast plays an important role in their decision to refuse surgery. Such a decision is based on important considerations of the patient's life: keeping her breast may reflect personal values such as identity, dignity, and/or integrity. The importance the patient attaches to her personal values underlies her refusal for treatment, and, apparently, her personal values are so important that she uses them as an argument for a decision that may have far-reaching consequences.

As also revealed in the case of Mrs S, patients' personal considerations that underlie a treatment refusal are often based on earlier experiences or on stories and experiences of others. The interviews revealed that most patients referred to their own experience or that of others as a source of knowledge as to what they can expect from being treated or not. These experiences seem to highly inspire patients' decision making.

*Patient 5:* Besides, two days before I went to my GP, I had buried my friend who had been ill for six years. She had undergone all the standard things and suffered horribly. She was groaning with pain when I visited her at the hospital and I found it just terrible. ... Afterwards I buried another friend who was also ill for six years. ... I saw these friends of mine. I saw them suffering. ... And since I have

witnessed and seen all of that, I think well then perhaps just let me go, but don't torture me.

Much of the criticism by patients who refused treatment is related to the fact that treatment is often offered as the "standard treatment", based on statistics. Our patients indicated that they did not recognise themselves in these statistics. Moreover, they found it important to be approached as individuals.

*Patient 6:* I think, you can say whatever you like, but of course for them I am only a case. And they apply a lot of statistics to it. "If we do that, this will happen and so many will survive. If we don't do that, so many will die." I think, that's not how it works. I am an individual, I have my history, I have all different kinds of perspective.

When offered treatment as the "standard treatment", some patients feel they are not being given sufficient room to reflect on the recommended treatment. Personal considerations, based on norms and values to which they attach great importance, are not allowed to play a role.

*Patient 7:* You have to get the chance, I think, as a human being, to be allowed to reflect on it [treatment], to consider what are the consequences and then only decide whether or not you can or want to do it. At that time, that was absolutely not the case. That was it, that was standard. ... But a patient with cancer is his own "hands-on" expert and physicians have to pay much more attention to what the patient himself experiences. They can learn a lot from their patients, like trying not to say, "This is the European standard, these things make up the treatment and that's what you have to do".

## DISCUSSION AND CONCLUSION

Our study revealed that when patients decide to refuse a recommended oncological treatment, the physician's perspective may not concur with the patient's perspective. Only few studies have investigated the reasons why patients opt for or against treatment. According to Fried *et al*, the burden of treatment, the outcome, and the likelihood of the outcome all influence patients' treatment preferences.<sup>7</sup> Slevin *et al* described how patients make a cost-benefit assessment of chemotherapy before opting for or against radical treatment. Chance of a cure, prolonging life, and relief of symptoms were weighed.<sup>8</sup> Siminoff and Fetting investigated factors affecting treatment decisions in the case of breast cancer. They found that patients who did not accept their physician's treatment recommendation weighed the benefits of treatment against the probability and severity of side effects.<sup>9</sup> Studies examining the types of trade-off patients with early breast cancer make between benefits and side effects reveal that women with milder side effects (less toxicity) judged smaller benefits worthwhile and that small improvements in survival were sufficient to make adjuvant chemotherapy worthwhile.<sup>10 11</sup> In addition to weighing improvements in survival and side effects, women with dependants and social support judged smaller benefits worthwhile.<sup>10</sup> Our results show that a patient's decision to refuse a recommended oncological treatment is not particularly based on weighing the pros and cons of treatment from a medical perspective. The decision relies, in particular, on personal values and/or experiences, which seem not to be based on a general moral point of view but seem to have a circumstantial basis—that

is, the patient takes his or her own circumstances, at this very moment, as a starting point.

From both the medical and the patient's perspective, good reasons can be given for refusing oncological treatment. The two perspectives may overlap to some extent, but large parts may not concur. Patients' treatment decisions, which are based on personal values or experiences, most of the time fall outside a medical perspective and are judged by physicians as irrational. The meaning and use of the term "rationality" from a medical perspective and from a patient's perspective can in our view be described by using the terms "goal oriented rationality" (*zweckrationalität*) and "value oriented rationality" (*wertrationalität*) as distinguished and defined by Max Weber.<sup>12</sup> Goal oriented rationality is directed at effects considering a certain goal. It is part of instrumental rationality; the effectiveness of the relation between means and ends is most important. Value oriented rationality is not directed at effects, but at a system of values. In our view, the distinction between a medical perspective and a patient's perspective is based on physicians mainly using goal oriented rationality. Physicians have means (medical treatment) to reach a goal (cure the patient, prolong survival, or improve the quality of life). They weigh the costs and benefits of medical treatments, they opt for the best treatment, and they want to use this treatment to help the patient. However, physicians also seem to use value oriented rationality—for example, a patient who refuses a medically advisable treatment runs against the physician's feeling of doing well. Similarly, patients also seem to use goal oriented rationality but to a lesser degree. They do consider advantages and side effects of treatment, but concerning treatment refusal, they mainly use a system of values—that is, they use value oriented rationality. Thus, both seem to use value oriented as well as goal oriented rationality but physicians put more emphasis on the latter and patients on the former. Moreover, physicians' value oriented rationality is based on a general moral point of view (for example, doing well), and patients' value oriented rationality has a circumstantial basis.

Nowadays, it is clearly established in medicine, ethics, and law that a competent patient has the right to refuse medical treatment. There is no difficulty if a patient's refusal concurs with the clinical evaluation, but the issue becomes problematic when a patient's refusal conflicts with medical opinion.<sup>13</sup> Physicians interpret decisions conflicting with medical opinion mostly as irrational, and irrational decisions are difficult to accept. When the patient expresses a non-rational preference, physicians face a dilemma between their duty to care for a patient and respect for patient autonomy—that is, the personal choice of the patient. A physician may try to convince their patient to agree with the doctor's viewpoint by discussing medical facts to ensure that the patient understands his or her situation. Coercive methods to force patients to agree, however, easily lead to miscommunication and abandonment of the patient.

We argue that the issue is less problematic if physicians interpret "good reasons" to refuse a recommended oncological treatment from both the medical and the patient's perspective based on specific values. This already occurs in the case of non-curative treatment. Physicians find it less difficult to accept a patient's refusal of a non-curative treatment even if the refusal is, from a medical perspective, based on irrational grounds. Then the physician seems to place more emphasis on the patient's value system. When a physician attempts to see the patient's perspective, this may be enhanced by discussing the physician's and patient's value-oriented rationalities in such a way that the circumstantial basis of the patient's rationality is understood. Respecting the patient's perspective in the acceptance of treatment refusal is important for the physician-patient

relationship. The physician's acceptance is crucial to his or her attitude towards the patient: if a physician does not accept the treatment refusal, he or she is often inclined to persist in convincing the patient to accept the treatment.<sup>4</sup> This results in patients experiencing that they are not really free to make their decisions, leading to frustration and miscommunication.<sup>14</sup> If a physician does accept a patient's treatment refusal, this will contribute to the patient's feelings of being free to decide, to be understood and respected in his or her decision, and thus contribute to a better physician-patient relationship.

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