Medical Expertise and Patient Involvement: A Multiperspective Qualitative Observation Study of the Patient's Role in Oncological Decision Making

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Key Words. Decision making • Patient participation • Qualitative research • Observation

ABSTRACT

Background. Decision making in oncology poses intricate ethical questions because treatment decisions should account not only for evidence-based standards but also for the patient's individual values and preferences. However, there is a scarcity of empirical knowledge about patient involvement in oncological decision making.

Methods. Direct, nonparticipant observation was used as a qualitative research method to gain an understanding of the interplay between medical expertise and patient participation in oncological decision making. Based on a multiperspective approach, observations were performed in three settings (tumor conference, ward round, and outpatient clinic) in the oncology department of a German university hospital. The observation transcripts were analyzed using central features of qualitative data analysis.

Results. Major differences were identified regarding the decision-making processes in the three settings related to

the patient's presence or absence. When the patient was absent, his or her wishes were cited only irregularly; however, patients actively advanced their wishes when present. Preselection of treatments by physicians was observed, narrowing the scope of options that were finally discussed with the patient. Dealing with decisions about risky treatments was especially regarded as part of the physician's professional expertise.

Conclusion. The study reveals aspects of decision making for cancer patients that have been underexposed in the empirical and theoretical literature so far. Among these are the relevance of structural aspects for the decisions made and the practice of preselection of treatment options. It should be further discussed how far medical expertise reaches and whether therapeutic decisions can be made without consulting the patient. *The Oncologist* 2014;19:654–660

Implications for Practice: This qualitative, observational study shows that the setting in which oncological decisions are made (tumor conference, ward round, or outpatient clinic) has significant influence on the decision-making process as well as on the outcomes. Furthermore, treatment preselection is observed, narrowing the scope of options that are finally discussed with the patient. Decision making in oncology should account not only for evidence-based standards but also for the patient's individual values and preferences; therefore, there is a need to further discuss how far the physician's expertise in oncology reaches and at what points the patient should be involved in decision making.

INTRODUCTION

Decision making in oncology poses intricate questions, not only because of the severity of the disease and its potentially fatal course but also because of the complexity of cancer treatments and the need for strong interdisciplinary cooperation [1, 2]. Because decisions made in cancer care should take into account the patient's personal situation and his or her preferences and values, the patient's role in decision making is relevant from both clinical and medical ethics perspectives [3]. Patients' preferences with regard to involvement in the decisions differ and are subject to variables such as

age, education, and sex [4]. Different models of patient participation in decision making have been put forward in the theoretical literature [5–7]. There seems to be consensus that, in general, patients should be informed about their diagnosis, treatment options, and prognosis and should be enabled to actively participate in treatment decisions. However, the interaction between the physician's professional expertise and the patient's perspective is not always clear.

The issue of patient participation in decision making in Germany has been intensively debated with respect to both

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legal requirements and clinical practice. Patients' rights were recently stressed by the enactment of a patients' rights act ("Patientenrechtegesetz") in 2013. Training programs on shared decision making have been initiated, and the German government endorses the issue of patient participation by funding research programs in this subject area [8].

There is, in general, a scarcity of empirical data on actual decision-making practice in oncological care. Most of the facts known so far are results from quantitative survey research indicating, for example, factors that predict the treatment a cancer patient receives [9–12]. However, surveys do not usually elucidate the reasons behind these correlations and the circumstances under which decisions in oncology are made. Qualitative research, in contrast, can help one to better understand the social practice and to identify relevant aspects. The most common type of qualitative research design used to explore decision making for cancer patients are qualitative interview studies examining, for example, patients' preferences, doctors' routines, or nurses' perceptions [1, 13, 14]. Qualitative interviews are restricted to the interviewee's perspective, whereas observation studies provide the researcher with the opportunity to become a direct witness of social practice [15]. Only a few observation studies have been directed toward decision making for cancer patients so far [2, 16–18]. Most of these studies have a specific focus, for example, on the patients' spiritual needs [17] or the quality of palliative care in the different stages of terminal disease [16].

This article reports the results of a qualitative observation study that was conducted in three situational settings in a German oncology department. The study forms part of a bigger project, Empirical-Ethical Interventions in Oncology (ETHICO), which is directed at the context-related development and implementation of interventions supporting decision making for cancer patients.

METHODS

Nonparticipant Observation

Data were collected from nonparticipant direct observation in the oncology department of a German university hospital. The department in which the observations were made can be regarded as typical of oncologic care in Germany with respect to the broad spectrum of diseases as well as the use of standard and innovative treatments. In an orientation period, we approached the field by attending a number of different meetings and events within the clinical routine. Our aim was to identify relevant "places of decision making" within the department. Three observational settings were then selected for further research: the tumor conference (TC), the ward round (WR), and the oncological outpatient clinic (OC). Because our main interest was in observing the roles of physicians and patients in decision making, we excluded other settings such as consultations with caregivers or meetings of the nursing staff. Our selection includes one setting in which medico-technical conversation dominates (tumor conference), one setting in which medico-technical and patient-provider conversations can be observed (ward round), and one setting that is dominated by patient-provider conversation (outpatient clinic).

The observations were initially documented in handwritten field notes and, thereafter, immediately transferred into

a word-processing program. We used an observation protocol to structure our field notes very roughly. Each digital transcript based on this protocol contains general data about the situation observed (e.g., date, time, people present) and short notes about each case. We initially characterized the social practice observed as descriptively as possible. In a later section of the transcript, our initial interpretations and intuitions are noted in addition to the self-reflection of the researcher regarding his or her influence on the social practice observed and the potential subjective factors affecting individual understanding of the situation. Furthermore, each transcript contains extensive descriptions of the settings (e.g., the rooms, the positioning of the people, their bodily behavior, and the overall atmosphere).

The observations were performed by three researchers (S.S., S.W., and J.S.) who have different educational backgrounds (medicine, philosophy, and social science). The involvement of investigators with nonmedical backgrounds was important with regard to methodical biases such as over-identification. In contrast, the medical backgrounds of two of the researchers helped foster understanding of medical facts and physicians' professional jargon. Some of the events were observed by two researchers at the same time to increase the intersubjective comprehensibility of the results.

The study has a nonparticipant design; however, it is known that the researcher's presence in observational research has an influence on the social behavior observed [19, 20]. In the tumor conference, we estimate that our influence on the social practice was rather small, but at the ward rounds and in the outpatient clinic, interaction between researcher and study participants was sometimes unavoidable. We tried to limit the observer influence by acting with reserve and by asking the participants to continue following their daily routines. However, even the research participants' knowledge about the presence of researchers from the medical ethics field may have had an influence on behavior. We discussed this and other aspects of our own influence on the social behavior observed in regular team meetings and with external researchers. The study has been approved by the research ethics committee of the medical faculty of Ruhr University Bochum, Germany (Reg. No. 4521-12).

Data Analysis

The data analysis was performed using ATLAS.ti 6.1.12 (ATLAS.ti Scientific Software Development GmbH, Berlin, Germany, <http://www.atlasti.com>) as a program for qualitative data management. The observation transcripts were analyzed and coded by the first author and one additional author (S.W.) independently. These two researchers have different disciplinary backgrounds. The codes given in an initial open-coding process express the semantic content of the data as understood and conceptualized by the respective researcher. During open coding, research memos were made explaining the allotment of codes and containing initial ideas for further data analysis. In the next step, selected codes were arranged in networks and grouped around a central category. In the following stages of axial and selective coding, further relevant properties and dimensions of the categories were identified and elaborated in an iterative process of constant comparison of the transcripts. The results of both coders were discussed

between them and a third author (J.S.) until a shared understanding was reached. Each setting (tumor conference, ward round, and outpatient clinic) was initially treated separately in the analysis. After the development of the initial categories, the semantic interdependencies (the relationships in terms of content) between the three units analyzed were worked out to identify thematic trajectories connecting the different settings.

The analytical process described follows central principles from the Grounded Theory approach as formulated by Corbin and Strauss [21]. This methodological background also has an influence on the relationship between empirical data generation and theories that are relevant to the subject of our research, such as normative-ethical theories or concepts of shared decision making. According to Grounded Theory, we did not base our empirical research on a clearly set hypothesis but approached the field in a methodologically open way; however, we were not able to completely avoid theoretical preconceptions. Our medico-ethical interest, for example, is mirrored in the three central categories that will be displayed under the Results section. In general, we tried to follow a hypothesis-generating rationale rather than seeking coherence between our data and already existing theories of medical decision making.

The following measures were taken to enhance intersubjective reliability, that is, to guarantee that the results are not based exclusively on a single researcher's perception. First, the project's methodological background, the methodical approach chosen, and the initial results emerging from the observations were discussed with an external social scientist with experience in qualitative observational research. Second, the observation transcripts were coded independently by two authors, as described above. Third, preliminary analyses of data and respective parts of the transcripts were discussed in the empirical ethics seminars and in the research colloquium of the Institute for Medical Ethics and History of Medicine, Ruhr University Bochum. These interdisciplinary meetings are attended by researchers with expertise in medicine, medical ethics, the social sciences, and other fields. Feedback from the seminar participants was used for a further refinement of the data analysis. Fourth, a member check of a selection of the results was performed through a group discussion including representatives of the physicians, the nursing staff, patient representatives, and the hospital chaplain. Several of the ethical problems identified in our observation study were presented to the participants. The participants were encouraged to comment on the accurate description, the practical relevance, and the possible perspectives for dealing with these challenges.

RESULTS

Altogether, 38 occasions were observed and a total of 309 cases were documented. The distribution of cases is shown in Table 1.

The patients suffered from a wide variety of oncological diseases, including solid tumors as well as hematological malignancies. Gastric, colorectal, and pancreatic cancer formed the most frequent entities. The spectrum of the patients' stage of disease ranged from follow-up after curative treatment to palliative care. A majority of patients in the ward round had advanced disease.

Table 1. Number of cases observed

Setting	No. of observations	No. of cases documented
Tumor conference	14	136
Ward round	10	104
Outpatient clinic	14	69
Total	38	309

The researchers did not gather full demographic and medical data from the study participants because of the nonparticipating design of the study. Furthermore, discussions between the authors and the institutional review board led to the decision that anonymity should have priority throughout the observation study. Consequently, the researchers did not ask about or take notes on the personal data of the study participants but restricted themselves to the information they learned from the nonparticipant observations. There were comprehensive case presentations in the tumor conference, whereas information about patients' medical situations was more limited at the ward round and in the outpatient clinic. With regard to the medical providers, the researchers know about providers' disciplinary backgrounds but do not usually have further individual-related knowledge (e.g., about professional experience).

The main findings of our qualitative data analysis will now be briefly summarized, starting with a short characterization of the style of decision making in each setting. Subsequently, the three main categories resulting from the qualitative data analysis will be displayed. All quotations are extracts from the observation transcripts, which are numbered consecutively (e.g., "WR5 17" means case number 17 discussed at ward round observation number 5).

Characteristics of Decision Making in the Three Settings

Tumor Conference

Decision making in the tumor conference is, at first glance, distinguished by a formalized and medical-professional way of communicating. Although the suggestions of the respective specialist (e.g., oncologist, radiotherapist, surgeon) are usually followed, his or her expertise is also questioned on some occasions. The evidence basis for the suggestions of the different specialists is not always made explicit. Furthermore, professional hierarchies have a decisive impact on the outcome of the tumor conference discussions. Because the patient is not present at the tumor conference, the patient as a person is brought into the discussions only by the case presentations, which partly include information about the patient's wishes or his or her psychosocial situation.

Ward Round

The processes observed during the ward round differ very much from those in the tumor conference because of the presence of the patients (and sometimes their relatives). A main distinction becomes apparent between the doctors' communication in the corridor before entering the patient's room (and after leaving it) and the doctor-patient

communication within the room; however, phases of purely medico-technical conversation were also observed in the patient's presence. These are sometimes interrupted by the patient actively advancing his or her position.

Outpatient Clinic

In the outpatient clinic, the physician has no possibility of discussions with other professionals but is talking exclusively to the patient, his or her relatives, and to the observer. Consequently, the outpatient clinic can be seen as the observational setting that is most directed at communication with the patient.

In general, the decision making observed in the oncology department is shaped by tension between medical expertise and the patient's role in decision making. In all three settings, the relevant question is which decisions can be made without consulting the patient—that is, on a “purely” medical basis—and to what extent should the patient be involved. Our main results will now be displayed on the basis of the three central categories: “selection of information,” “patient's will,” and “leeway given to the patient.” The main dimensions of these three categories are presented in Table 2.

Selection of Information

Essential parts of the ward round and the outpatient clinic consultations are dedicated to the disclosure of medical information to the patient. The physicians mainly inform the patients about the results of examinations, explain which drugs are to be given and their effects and side effects, and illustrate how certain symptoms can be explained medically. The language used to transmit the information to the patient and the amount of information given are subject to several contextual factors.

In the ward round, physicians predominantly discuss medical issues very openly with the patient; however, we observed that certain topics (e.g., presence of a malignancy, psychiatric disease, issues concerning death and dying) are not addressed as directly. Instead, the physicians apply language strategies (e.g., medical jargon) that help them avoid using words such as “cancer” or “depression” explicitly:

Patient points toward his abdomen talking about pain.

Doctor X to Doctor Y: “Is there a reason for that?”

Doctor Y (reluctant): “Yes, . . . it's a ubiquitous disease.” (WR5 2)

Patient complains that he cannot eat. Doctor X explains that, following gastroscopy, there is no mechanical problem.

Doctor X: “It is the ‘other’ problem” [by which he means psychiatric disease].

Doctor Y: “Then just add a ‘basic therapy’” [by which he means an antidepressant]. (WR5 17)

In the outpatient clinic, we observed that the physician's proposals for the patient are usually clearly set and very concrete. The patient is then asked whether he or she consents to the procedure; however, the physician's choice of the appropriate course of chemotherapy and the dosage are not always as evident as they may seem to the patient. This fact was noticed as a result of the conversations between

Table 2. Main dimensions of the central categories and their prevalence in the settings observed

Central category	Main dimensions
Selection of information	Taboo (WR) Disclosure of information to the patient (WR, OC) Medical jargon (TC, WR, OC) Patient's need for information (WR) Physician making suggestions for therapy (WR, OC) Who decides? (TC, WR)
Patient's will	Patient is more competent than physician assumes (WR, OC) Patient rejects therapy (TC, WR, OC) Patient's preferences regarding therapy (TC, WR, OC) Patient's values (OC) Patient suggests a therapy (WR, OC) Patient takes the responsibility (WR)
Leeway given to the patient	Dealing with risks (TC, WR, OC) Patient guidance (TC) Patient intervening in the decision making (WR) Patient is allowed to decide (WR, OC) Physician making suggestions for therapy (WR, OC) Patient rejects therapy (TC, WR, OC)

Abbreviations: OC, outpatient clinic; TC, tumor conference; WR, ward round.

the observer and the physician when the patient was not in the room:

Before the consultation with the patient, the doctor seeks out a new chemotherapy protocol. (Half speaking to himself, half to me, he says: “What shall I do with this woman?”) . . . He seems to have a selection of different protocols available. He does not discuss them with the patient but suggests the one he has selected. (OC8 3)

The patient has not been informed clearly about the dosage (this often happens, doctor decides about dosage alone after the patient has left the room). In determining the dosage, he says to me, “I will give him the full dosage; I think he will make it.” (OC9 1)

Physicians influence patients' perceptions of their disease and patients' knowledge about treatment options by the language they use and by the amount of information they transmit to the patients. Our observations in the outpatient clinic show that essential aspects of treatment, such as alternative therapies or dosages, are not brought into the doctor-patient conversation but rather are seen as subjects of medical expertise.

Patient's Will

The patient's will plays a crucial role in all three settings; however, a comparison between the tumor conference and the ward round reveals big differences in the way in which patients' wishes are integrated. Because of the patient's

absence from the tumor conference, his or her wishes are introduced only irregularly by the junior physicians presenting the cases (and sometimes by other medical staff later during the discussions). The patient's wishes are most frequently cited when a patient refuses diagnostic or therapeutic measures:

Dermatologist [presenting the case]: "The patient has always rejected chemotherapy so far. The tumor at the shank is infected with Gram-negative germs. We scheduled a thigh amputation for Monday, but the patient refused. She was discharged today with nursing service. She didn't want hospice." (TC7 8)

On only a small number of occasions is the patient's especially strong desire for treatment cited. This fact is often introduced by the psycho-social staff.

Social Worker: "He has an extreme desire for treatment; he wants to be treated here." (TC9 14)

In a limited number of cases, the physicians explicitly see a need for further investigation into the patient's wishes or preferences. Although in most cases physicians start with the assumption that the patient will consent, especially in palliative situations, the physicians are hesitant to set an indication without taking the patient's preferences into account:

Male patient, metastasized malignant melanoma, presented by dermatology:

Surgeon: "Does he want to be operated on?" (TC6 16)

Female patient, pancreatic cancer, inoperable, presented by surgery:

Radiotherapist: "Where does she come from? What will she let us do on her? Can we treat her?" (TC8 6)

In contrast, during the ward rounds, patients have the opportunity to actively state their will. Situations are frequently observed in which the patient suggests a certain medical procedure, sometimes even interfering with the physicians' professional discussions and adopting their technical language:

Doctors discussing which diagnostics should be carried out for staging:

Patient (interrupting): "But I also want endosono!" (WR7 15)

Patients during the ward round are even advancing detailed preferences regarding their treatment:

Doctor X talking to patient about the planned discharge and that he will get cortisone:

Patient: "50 mg, 5 days?"

Physicians laugh, did not expect that patient is so well informed that he even knows the dosage. (WR7 2)

A comparison between the observations in the tumor conference and those in the ward round reveals that the setting in which the decisions are made has a great influence on how the patient's will is respected. Furthermore, because the patients have the opportunity to actively advance their preferences during the ward rounds, the borders between purely medico-technical decisions and those influenced by patients

are much more flexible than they appear in the tumor conference.

Leeway Given to the Patient

A third important topic, closely connected to the selection of information, is the question of how much leeway is assigned to the patient in decision making. Physicians in all three settings implicitly differentiate between aspects for which the patient is allowed to make decisions and the realm that physicians regard as their own field of professional competency. This pertains, for example, to the question of who makes decisions with regard to risk.

The question of whether to offer a risky treatment is frequently discussed in the tumor conference. The specialists often consider the risks of specific treatments as their personal risks in being a surgeon or an oncologist. Following this idea, the physician has to decide whether or not he or she is willing to take the risk of a treatment:

Oncologist: "If I'm allowed to say this, 91 years and chemotherapy I don't do. I don't do that."

Radiotherapist: "Local radiation I do. Pelvic radiation I don't do." (TC8 4)

The reluctance to offer a risky treatment to an elderly patient seems to be driven by the overall idea of professional responsibility and the fear of causing damage or the patient's premature death.

Physicians on the ward round also make decisions in advance about whether or not a certain course of action should be offered to the patient. In the following example, options for treatment are discussed in the corridor before entering the patient's room. Although one physician suggests asking the patient for his opinion, the second physician stresses the indication as a necessary prerequisite for offering a certain treatment to the patient:

Doctors discuss whether or not a laparotomy should be performed:

Doctor X: "We have to talk to the patient."

Doctor Y: "If we do not set the indication, we don't set it." (WR3 6)

Following our observations, the extent of the power that the patient finally receives in decision making is dependent on whether physicians regard a certain issue as part of their professional expertise.

DISCUSSION

Our findings can be interpreted against the background of other socio-empirical studies as well as from a medico-ethical perspective. Quantitative research has shown that the variation in treatment at the end of life cannot be fully explained by patients' treatment preferences [22, 23]. Based on our qualitative observation study, we can now contribute to an explanation of this finding by stating that there are some aspects of cancer treatment that physicians regard as part of their medical expertise. This holds true, for example, with respect to the question of how much risk is taken or which chemotherapy protocol is offered to a patient. Regarding these questions, the clinical judgment of the individual physician plays a crucial role, possibly along with

his or her personal values regarding, for example, the question of whether a risky treatment is appropriate in noncurative cancer.

Our results can also be related to other qualitative research on treatment decisions for cancer patients. Although it has been reported from interview studies that doctors indicate they inform their patients fully about treatment options [1], our direct observations reveal that physicians make decisions before encountering the patient. Because physicians may not always be aware of this preselection of therapies (and also tend to answer in a socially desirable way), observational studies are an important methodological supplement to qualitative interviewing.

Furthermore, the results of our observations shed light on the importance of the situational context in which oncological decisions are made. Previous studies focused on decision making in settings in which the patient is either present or is not [2, 18]. Our methodological approach allows for conclusions about the differences in decision making in situations in which patients are present versus when they are absent.

The selection of therapeutic options observed in our study should also be discussed from a medico-ethical perspective. In this regard, our study can be contrasted with conceptual approaches to decision making in the medical encounter. It could be asked, for example, how far our findings support or deviate from models of shared decision making [5, 7]. If shared decision making is conceptualized as a process that includes the exchange of both information and treatment preferences between physician and patient as well as an agreement by the two parties [5], this is not completely mirrored in our study. At the same time, our study's results support recent approaches to shared decision making stressing that, instead of starting from the assumption of equally shared decisions, the extent of a patient's participation should be seen as a continuum of "degrees of sharing" [24]. Furthermore, our observations can be linked to the findings of empirical studies showing that the patient's lack of knowledge and the power imbalance in the physician-patient relationship form the main barriers to shared decision making [25].

Beyond that, our study sheds a light on the distribution of competencies between patient and physician. In the conceptual literature, the physician is often seen as introducing the medico-scientific aspects into the conversation, whereas the patient's role is mainly to express his or her preferences and values [6]. However, the findings of our study suggest that the line that can be drawn between "objective" medical facts and the patient's subjective interest is not as clear. Important decisions (e.g., whether a risky treatment is offered to the patient) that are often regarded as part of the physician's professional expertise include important value judgments and therefore should be raised in the physician-patient encounter.

Our study is based on a limited quantity of observations. All of them took place in the same institution, considering a restricted number of participants. Consequently, the personalities of the physicians had a great influence on the decision-making processes observed. Quantification of the behaviors as well as a generalization of our results to other clinical settings

are not possible. Both would require further quantitative research on a larger scale.

We have only seen extracts from the medical histories of the individual patients in our observations. We often do not know what happened before and after the situation observed. Last, we had to focus on a limited number of aspects in our analysis and thus had to leave out other relevant fields, such as the role of the nursing staff or the relatives' part in decision making for patients with advanced cancer.

CONCLUSION

Our observational study reveals aspects of decision making for cancer patients that have been underexposed in the empirical and theoretical literature so far. First, the presence or absence of the patient has a relevant impact on how the decision is made. Second, structural aspects (e.g., the procedures in the tumor conference, the styles of communication during the ward round) have a decisive influence on decision making. Third, preselections are made with regard to the treatment options that are finally offered to the patient.

More research would be desirable to address these issues in further detail and to examine how far the results from this observational study are generalizable to other clinical contexts. Physicians should be aware of the organizational and communicative structures that may influence their decision making for individual patients. They should recognize the narrowing down of treatment options that are finally offered to the patient. Clinical decision aids are an important support in this context.

In general, more thorough reflection would be desirable about where the line between medical expertise and patient involvement can be drawn and how patients can be adequately involved in making decisions for or against a specific treatment.

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DISCLOSURES

The authors indicated no financial relationships.

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Jan Schildmann, Jacinta Tan, Sabine Salloch et al. "Well, I Think There Is Great Variation...": A Qualitative Study of Oncologists' Experiences and Views Regarding Medical Criteria and Other Factors Relevant to Treatment Decisions in Advanced Cancer. *The Oncologist* 2013;18:90–96.

Implications for Practice:

Survey research indicates that there is considerable variation concerning treatment at the end of life that cannot be explained by clinical features or patients' individual preferences. This qualitative study adds to existing literature by providing information about physicians' distinctions (i.e., "active treatment" versus "palliative care") and related clinical as well as ethical implications in the context of care for patients with advanced cancer. In addition, the interviewed oncologists report a number of value-laden non-medical factors that are viewed as influential for decisions about the provision or limitation of cancer treatment against the background of often scarce evidence. The findings of this study suggest that, in clinical practice, multi-professional team discussions on value aspects of decision making and a systematic gathering and analysis of clinical data that can be applied to end-of-life practice may contribute to an improved evidence- and ethics-based treatment decision making in advanced cancer.