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# Norwegian Healthcare Professionals' Perceptions of Patient Knowledge and Involvement as Basis for Decision Making in Hematology

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**P**atients differ in their knowledge of illnesses and their desire to be involved in the treatment process. Some patients may be informed and make active decisions about treatment procedures (Henwood, Wyatt, Hart, & Smith, 2003), but others tend to avoid involvement (Lupton, 1997). Some research indicated that patients who involve themselves in treatment enhance the potential for building partnerships with healthcare professionals (Fox, Ward, & O'Rourke, 2005; Koelen & Lindstrom, 2000; Willems, De Maesschalck, Deveugele, Derese, & De Maeseneer, 2005). However, other studies suggested that informed patients make healthcare professionals cling to power by controlling information and dismissing patients' efforts to theorize or explain their condition (Henwood et al.). Healthcare professionals' perceptions of patient knowledge and involvement influence the decision-making process, but little research has studied the dynamics between those aspects of treatment.

## Background

Nurses affect the quality of care of patients with cancer (Ferrell, Virani, Smith, & Juarez, 2003). Quality of care is dependent, in part, on how patients are allowed to approach their illness. Patient involvement is based on patients' knowledge of their illness and treatment opportunities (Donaldson, 2003). Most patients with cancer in palliative care prefer a collaborative role and want to share decision making with their physicians, but some prefer to make decisions alone. However, fewer than 20% want to leave decision making to physicians (Rothenbacher, Lutz, & Porzolt, 1997). Other studies suggested that patients with life-threatening disease prefer a passive role in decision making (Stiggelbout & Kiebert, 1997); about half of

**Purpose/Objectives:** To investigate how healthcare professionals relate to patients with different levels of knowledge and involvement in their disease and treatment.

**Design:** Qualitative, exploratory approach based on semi-structured interviews.

**Setting:** A hematologic outpatient clinic in Norway.

**Sample:** 5 nurses and 5 doctors.

**Methods:** Semistructured interviews were conducted, recorded on audiotape, transcribed, and analyzed with qualitative techniques.

**Main Research Variables:** Patient knowledge, patient involvement, and decision making.

**Findings:** Study participants perceived that they had stable, basic relationships with patients and were flexible toward patients with different levels of knowledge and involvement. Healthcare professionals grouped patients into four behavior types: passive, withdrawn, uncooperative, and expert. The perceived behaviors formed the basis for relationships involving shared or nonshared decision making.

**Conclusions:** Patients' perceived propensity in mastering medical knowledge affects how healthcare professionals involve them in decision making. Healthcare professionals' tendency to see relationships with patients as asymmetric and stable may inhibit patients' ability to involve themselves in their healthcare decisions.

**Implications for Nursing:** This study's findings can be used to raise awareness of how nurses' biases about patients influence shared decision making. Nurses should be aware of a tendency to exclude patients from decision making if they perceive that patients are incapable of involving themselves.

patients with cancer aged 73 years or older favor a passive role in treatment decision making (Elkin, Kim, Casper, Kissane, & Schrag, 2007). However, whether patients are capable of informed decision making is unclear (Ferrell et al.). In addition, Gattellari, Buttow, & Tattersall (2001) suggested that few patients were

explicitly offered choices in their treatment or given time to clarify their understanding.

The exclusion of patients from decision making may be explained by healthcare professionals' perceptions of patient involvement. Elkin et al. (2007) found that oncologists' perceptions of patient involvement and preferences for prognostic information generally were inconsistent with patients' stated preferences. Other studies (Bruera, Sweeney, Calder, Palmer, & Benisch-Tolley, 2001; Bruera, Willey, Palmer, & Rosales, 2002; Rothenbacher et al., 1997) also suggested that healthcare professionals' perceptions of patient preferences for decision making are not concordant with patients' own perceptions. Degner et al. (1997) found that only 42% of women with breast cancer (N = 1,012) believed they had achieved their preferred level of control in decision making. As a result, this article will investigate how healthcare professionals perceive patients' knowledge and involvement and discuss implications for decision making.

## Methods

The present study focused on healthcare professionals' perceptions of themselves and how they perceived and interacted with patients to gain an in-depth understanding of respondents' experiences. The study did not investigate what the professionals actually did; therefore, the study was based on interpretative traditions in qualitative research with semistructured interviews. The study was approved by the Regional Committee for Medical Research Ethics in central Norway.

## Setting

In Norway, hematology is a specialist branch of education in internal medicine. Accreditation involves 2.5 years of service in departments of internal medicine or hematology and at least six months of service in departments of oncology that treat lymphoma. No standardized hematology education exists for nurses, but the hematology unit in the present study developed its own module-based nursing education on the subject. Nursing programs in Norway include three years of theoretical and practical education at the university level. In Norway, about 250 patients are diagnosed with myeloma and 130 are diagnosed with acute leukemia annually (Health Library, 2008).

## Participants and Recruitment

The participants were staff members of a hematologic outpatient clinic. Five physicians (all men with doctorates in medicine or philosophy) and five nurses (all women) were interviewed. All participants had worked at the clinic for several years. The unit treats about 700 patients annually; most present with myeloma or leukemia. Patients' frequency of doctor visits varied from daily to yearly.

## Interviews

Fifteen interviews (2 introductory, 10 in-depth, and 3 follow-up) were conducted. The two introductory interviews were held with the chief medical officer and a nurse as a pilot study that formed the basis for the in-depth interviews. The in-depth interviews lasted from 1–1.5 hours. All staff members were interviewed once, and three (the chief medical officer and two nurses) participated in follow-up interviews to clarify unusual findings. In addition, a group interview was conducted to obtain a response on the preliminary analyses.

The interview guide focused on how the healthcare professionals related to patients with different levels of knowledge about their disease and involvement in their treatment. Participants were asked to elaborate on how they perceived different types of patients and how they behaved toward them. The questions were followed up with queries about themes suggested to be important to the roles of healthcare professionals (e.g., power, authority, knowledge, status) (Timmermans & Berg, 2003). The interviews followed a theory that aims to obtain a phenomenologic understanding of interviewees' beliefs on a topic (Kvale, 1996); therefore, the subjective experiences of the respondents were explored.

## Analysis

Ten in-depth interviews were audiotaped and transcribed; preliminary and follow-up interviews were transcribed directly. All interviews were conducted in Norwegian. Transcripts initially were grouped into themes and clusters in a tree structure with computer-based software. The themes formed the basis for discussion between the authors, who read the transcripts of all three interview categories. The discussions became the foundation for final analysis. Excerpts from the transcripts were presented at a research meeting that used the present study's data to develop an independent analysis. In addition, the findings were discussed with the participants during a one-hour focus group interview to clarify and shape the results. The quotes were edited for readability and translated into English.

## Results

The healthcare professionals in the present study described a fundamentally stable and basic relationship with all patients. The descriptions of how professionals perceived patients depending on their level of knowledge and involvement were categorized into four groups: passive, uncooperative, withdrawn, and expert (see Table 1). The authors developed the labels for each category based on how the healthcare professionals described patients' behavior; therefore,

**Table 1. Healthcare Professionals' Perceptions of Patients Based on Patient Knowledge and Involvement**

Perceived Behavior	Level of Knowledge	Level of Involvement
Passive	Low	Low
Uncooperative	Low	High
Withdrawn	High	Low
Expert	High	High

the labels are not descriptions of specific patients but concepts used to characterize how healthcare professionals in the study perceived patients.

### Fundamental Relationship

Healthcare professionals described a fundamental relationship with all patients. Nurses as well as specialists emphasized that all patients need comfort and care, regardless of behavior. Healthcare professionals described themselves as the point of connection between patients' sickness and wellness. Professionals added that the connection was inherent in the patient-provider relationship and could not be challenged. Doctors and nurses expressed that every patient needs a firm, strong, and comforting healthcare professional whether the patient is independent or not. Some described the relationship as a feeling of untouchable power; others felt duty-bound to provide a helping hand.

**Doctor:** It is in the geometry of the situation that the specialist always will be in power, even if we allow for more negotiation now. . . . There will always be use for doctors, priests, and shamans [laughs]. . . . You can't rationalize yourself out of a situation where you need comfort and help.

**Nurse:** The fact that he [a difficult patient] shows up is a sign of trust and compliance.

### Passive Patients

Healthcare professionals described the largest group of patients as being very passive with neither the desire nor the capability to seek additional knowledge or involvement in the treatment process. Some patients explicitly expressed that they did not want to be involved or receive information; clearly, those patients sought to avoid the responsibility associated with involvement and knowledge. Other patients were perceived as capable and strong enough to take some responsibility in decision making but completely succumbed to healthcare professionals' advice; the professionals perceived that the behavior was reasonable, particularly in the

beginning of the disease trajectory. Professionals believed that being diagnosed with a terminal condition was so shocking that patients often were incapacitated throughout the treatment process.

**Nurse:** Many [patients] do live in this old [mind set] that the things we say are the only right things. [They] completely accept what we do and tell them and follow the advice we give them. [They] want to know nothing more than that. . . . Some choose consciously to not [seek knowledge]. . . . It is frightening, you know, if you are entering a condition of illness because there is so much information. It is terrifying what it tells you about how the disease is, how the treatment is, what may happen. . . . They don't manage to relate to it or deal with it, become more scared than informed, saying, "I don't want to know anything more, I completely succumb to you, you are the ones who know this. I relate to that." Most are like that, [including] the young ones.

Passivity was viewed as normal patient behavior. Healthcare professionals expressed a need to adopt a firm and authoritarian role toward passive patients to show the correct course of action. Professionals did not consider their behavior to be patronizing; professionals believed that they were responding to patients' wishes to know and involve themselves as little as possible. As a result, professionals maintained their omnipotent and omniscient roles by giving patients what they wanted rather than imposing on the relationship.

### Uncooperative Patients

Healthcare professionals described uncooperative patients who wanted to be involved in the treatment process without having much knowledge. Professionals said that the information obtained by uncooperative patients often was not applicable or relevant to their treatment. For example, some patients brought Internet printouts or referred to magazine articles without understanding or being able to relate the information to their own treatment or illness. Uncooperative patients were perceived by the healthcare professionals as involving themselves simply because they wanted to be in control. Healthcare professionals said they perceived uncooperative behavior either as a reflection of personality type or as a result of reluctance toward treatment.

**Doctor:** You have some quarrellers who are very obstinate and demand this and that. They don't need to be expert patients; they are more the quarrelsome and difficult personality type. . . . This group is much harder to relate to. Picking quarrels, being critical. Then [the patient-provider relationship] can be very difficult.



**Doctor:** I have a patient who refuses to take gastroscopy. He simply will not take it. He knows that his diagnosis will not be altered by this test, and I have to say that I agree. However, being medically trained, I would like to also do this last test, to sort out every eventuality. I will try to discuss this further with him, and then we will see how it ends.

Healthcare professionals said that uncooperative patients often suggested treatment steps that the doctors and nurses did not perceive as beneficial. In those situations, professionals focused on talking and discussing options with patients. Professionals tried to make patients understand that they needed cooperation and offered the best treatment available, then explained why the other option was not necessarily better.

**Nurse:** They have knowledge of this and that treatment, have read of the chances for a cure, and so on . . . and demand for this treatment . . . and they have read of a 100% possibility of cure. Well, we just have to tell them that even if you think so, it is not the case. It's up to us and the doctors to explain that there is never a guarantee to get well.

## Withdrawn Patients

Withdrawn patients were perceived to be informed but had no wish to take part in treatment decisions. Healthcare professionals described them as a small group of knowledgeable patients who did not want to involve themselves, such as patients with medical degrees. Some withdrawn patients informed healthcare professionals that they had information about other treatment methods but did not try to influence decision making. Withdrawn patients were passive but could let healthcare professionals know that they had other opinions.

**Nurse:** No, he [a withdrawn patient] does not necessarily do [as I say]. Some might, but others may also stick to what they have read some place, stick to their belief in that. Despite their acceptance of the treatment they receive, it is as if they would have preferred another.

Professionals wanted to show firmness in their interactions with withdrawn patients. Instead of explaining and giving information to withdrawn patients, professionals focused on the instrumental parts of treatment. Professionals emphasized the need to remain confident in their interactions with withdrawn patients.

**Doctor:** In the cases [of treating doctors], I find it important that one does not try to do something special, something extra with those patients, try to invent something that is even better. . . . It is important in these cases that one does what is normal.

## Expert Patients

The smallest group of patients were described as being well informed and actively involved in treatment. Those expert patients were perceived as team players. Healthcare professionals said that expert patients were able to reference and discuss medical information. Expert patients only discussed biomedical information, not issues such as complementary and alternative medicine or subjective illness experiences. Healthcare professionals described the biomedical information as accurate, relevant, up to date, and scientifically reliable. Expert patients used the Internet as a resource or had obtained information from healthcare professionals outside of the unit. The patients also were described as active and demanded to be involved in treatment decisions. Healthcare professionals perceived expert patients' high level of involvement as a contribution rather than interference.

**Nurse:** They know a lot, and you get the feeling once you enter the room and start talking to them that [an expert patient] knows a lot about his disease. It is a nurse's job to understand and characterize the patient, what he knows and doesn't know, if he has insight. So when you first meet a patient, he starts to tell, and you know if he understands or not, and you do some characterizing. An expert patient is very active from the first moment, you might say.

Expert patients were unique and motivated healthcare professionals to adopt a special role. Instead of explaining, telling, or acting instrumental, healthcare professionals worked with those patients as team players striving for a common goal.

**Doctor:** If you're going to relate to an expert patient, you'll need to adopt him in your team. . . . You discuss until you know what to do. He is much more of a team player than an ordinary patient would be. You cannot impose something on the expert patient; you need to play on a team together.

## Discussion

### Uninformed Patients

In the present study, patients who were perceived as uninformed were categorized as either passive or uncooperative. Passive and uncooperative patients differed in their levels of involvement. Passive patients apparently did not want to be involved, whereas uncooperative patients wanted to be involved but healthcare professionals did not allow them. Uncooperative patients were active but were not allowed to make decisions based on their own knowledge. Healthcare professionals' negotiations with uncooperative patients focused on stressing collaboration and explaining why their solutions were

appropriate rather than incorporating the patients' knowledge into treatment. Healthcare professionals may have disregarded the patients' information because those patients were perceived as uninformed or the knowledge did not benefit the treatment. Even if some of the patients' information was not relevant to treatment, the healthcare professionals' behavior suggests a disregard for patients' perspectives in general. If the healthcare professionals could not make sense of patients' knowledge, they may have dismissed efforts to theorize or explain the information (Henwood et al., 2003). Professionals also would disregard uncooperative patients' subjective knowledge of their illness, which is important for patient involvement (Donaldson, 2003).

Healthcare professionals' approach toward passive patients was based on the belief that those patients did not want to be involved in treatment and, therefore, that the patients were uninformed. However, the perception that the patients were uninformed may have reinforced the healthcare professionals' beliefs that passive patients were incapable of involving themselves. As a result, the professionals maintained a domineering position that inhibited passive patients from taking active roles. Healthcare professionals' perceptions of patient involvement often are inconsistent with patients' perceptions (Elkin et al., 2007); the lack of negotiation and discussion may have supported healthcare professionals' impression that patients were uninformed and uninvolved. Although healthcare professionals may have perceived correctly that passive patients did not want to involve themselves, that perception also may have restricted those patients from developing a desire for involvement.

The present study's results suggest that when healthcare professionals perceive that patients are uninformed, those patients are dismissed from additional involvement in decision making. Perceptions of patients as passive (not wanting information) or uncooperative (having the wrong information) may further hinder patients from partaking in decision making.

### Informed Patients

The two groups of patients perceived by healthcare professionals as informed also differed in their levels of involvement. Expert patients were allowed to involve themselves in decision making, whereas withdrawn patients were excluded. Healthcare professionals perceived withdrawn patients almost in the same manner as uninformed patients. However, unlike uninformed patients who lacked pertinent information, withdrawn patients may have had knowledge that could benefit treatment but did not want to collaborate or make treatment decisions alone (Rothenbacher et al., 1997). Expert patients had excessive biomedical knowledge and the ability to develop social relationships with healthcare personnel, resulting in a high level of shared decision

making. Professionals' perceptions of expert patients as "team players" suggested that they collaborated on an equal level with those patients. Professionals clearly emphasized relevant objective information as important to their perceptions of productive patient involvement. Professionals may have related to patients with relevant information more easily. In addition, healthcare professionals could attribute additional meaning to interactions with patients perceived to have relevant knowledge; such meaning is important for a sustainable relationship and may have formed the basis for expert patients' involvement in decision making (Weick & Roberts, 1993). The integrated relationship probably helped providers to view expert patients' knowledge as a benefit rather than a challenge to their role.

The present study's results suggest that patients who are able to translate their illness experiences into objective medical information build partnerships with healthcare professionals more easily. The results disagree with Donaldson's (2003) suggestion that patients' subjective knowledge is important for a viable collaboration. Healthcare professionals may communicate more easily with patients who use their medical vocabulary and, therefore, are more likely to allow those patients to partake in decision making.

### Strength and Limitations

The authors believe that the present study is the first to explore and present a model for how healthcare professionals perceive patients with different levels of knowledge and involvement. A limitation is that the data are from interviews with healthcare professionals only; consultations and interviews with patients likely would provide different results. Additional research is needed to clarify how healthcare professionals' accounts correspond with their daily patient-interaction patterns. Another limitation is the small sample of 10 informants. In accordance with Kvale (1996), participants were recruited until saturation was reached. The final interviews did not offer new findings, so 10 participants were deemed sufficient. Data saturation was confirmed in three follow-up interviews.

### Nursing Implications

Nurses and physicians categorize patients according to perceived medical knowledge, forming the basis for patient-provider relationships that may be difficult for patients to influence. The basic asymmetric relationship found in the present study supports Foucault's (1980) notion of biomedical power. Biomedical power combined with low perceptions of patients' ability and interest to involve themselves may result in interaction patterns that limit patients' ability to participate in decision making. Nurses should be aware of the tendency to construct

asymmetric relationships based on their own perceptions of patient knowledge.

The present study also identifies areas of research that need additional development. The actual behavior of nurses who interact with patients with different levels of knowledge and involvement should be studied to reveal whether nurses' perceptions correspond with actual behavior; the present study's findings can help design such a study. In addition, patients' perspectives should be studied to determine how patients see their own level of knowledge and involvement versus how nurses perceive and include them in the decision-making process.

## Conclusion

Healthcare professionals' perceptions of patient knowledge influence how patients are involved in decision

making. Patients who can communicate biomedical knowledge involve themselves in ways that are perceived as beneficial, but patients who lack that ability may be active and engaged but are excluded from decision making. Those perceptions are stabilized by an asymmetric view of the patient-provider relationship that further limits patient involvement. By being aware of that bias, healthcare professionals may be able to increase shared decision making with patients.

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Digital Object Identifier: 10.1188/09.ONF.E93-E98

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