CANCER PATIENTS’ VIEWS AND EXPERIENCES OF PARTICIPATION IN CARE AND DECISION MAKING

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Key words: cancer patients; decision making; informed consent; participation

The purpose of this study was to explore the views and experiences of adult cancer patients about patient participation in care and decision making and the preconditions for this participation. The data were collected by means of focused interviews; in addition the patients completed depression and problem-solving instruments. The sample comprised 34 cancer patients from the haematological and oncological wards of one university hospital in Finland. The results revealed considerable variation in the patients’ views on their participation in care and decision making. Some of the patients understood participation either in terms of contributing to the decision making or in terms of expressing their views on treatment options. Some considered that their participation in care was impossible.

Patient participation in care and decision making was promoted by good health, access to information, assertiveness, good interactive relationships with nurses and physicians, and encouragement by nurses and physicians to participate. Factors restricting such patient participation were poor health, ignorance, anxiety, age, time pressures of staff, lack of time, high staff turnover and poor interactive relationships.

With regard to participation in medical decision making, the patients were divided into three groups: (1) active participants (n = 7), (2) patients giving active consent (n = 9), and (3) patients giving passive consent to medical decisions (n = 18).

Introduction

The status of patients has changed quite dramatically during the past few decades. The paternalistic approach that looks upon them as passive objects has given way to a concept that stresses their active participation in decision making about their own care. Medicine and nursing science use different concepts to refer to active patient participation, such as partnership,1,2 shared decision making,3–5 and patient participation6 and involvement7,8 in care. Patients’ right to take part in care is safeguarded by guidelines on professional ethics and, in some countries (including Finland), by means of legislation.9

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Dating from 1993, the Finnish Act on the Status and Rights of Patients requires that patients are given information about their state of health, the significance of the treatment, various alternative forms of therapy and their effects, and other significant factors associated with the treatment. This information must be given in such a way that the patients can understand it. Furthermore, care must be planned in mutual understanding with the patients. If patients refuse certain treatments or procedures, they must be cared for in other medically acceptable ways.

The purpose of this study was to examine the views and experiences of cancer patients about their participation in their own care and decision making, and the preconditions for this participation.

Review of the literature

Patient participation is an extremely complex concept. It may be defined in terms of active patient involvement, but very often it is understood in terms of participation in decision making. Decision making is often associated with medical decisions only, but patients also take part in decision making that has to do with nursing care. Participation in decision making varies on a continuum that ranges from total passivity to extreme activity. In the former case patients may want the physician to make all decisions on their behalf. This may be owing to a conscious decision on the part of the patient to remain in a passive role, or it may be due to other factors such as inadequate information. An active patient, on the other hand, wants to take part in the decision making. He or she may even call into question a physician’s decision and may wish to make the decision independently. The patient may take part in shared decision making, which means that he or she and the physician reach a decision jointly, with mutual approval. Sutherland et al. state that informed consent can be considered to represent a minimum degree of shared decision making in the form of patient consent to treatment prior to any intervention.

One of the most important preconditions for participation in decision making is information; the patient must have access to adequate and accurate information because valid decisions must be based on a that person’s perception of the diagnosis, prognosis and realistic options. Ubels and Lowenstein stress that the provision of information has to be grounded in the patient’s values. This is crucial in enabling the patient to choose the medical option that is most consistent with his or her values. However, the available research evidence suggests that there are still problems with respect to the provision of information. For instance, the study by Coulter et al. showed that some patients were aware of no more than one single treatment option. According to Ubels and Lowenstein, it is very hard to assess what is a suitable amount of information, what kind of information patients wish to receive and how they want to receive that information. Amir found, in a study on the information provided by physicians to cancer patients, that the most realistic information was given to enquiring patients who, in the physician’s view, were relatively intelligent.

However, the provision of information does not in itself suffice as a foundation for patient decision making; patients also have to understand what they are told. Mackillop et al. found major shortcomings in this respect. About one-third of a
group of patients with metastases were unaware of their presence and some patients who were receiving palliative care believed they were still having curative care. In the early stages of treatment, when it is still quite common that patients have not yet accepted the situation, excessive information may make it difficult for them to absorb everything. In this case, patients show a tendency towards the selective reception of information. An increased volume of information therefore does not necessarily lead to more conscious decision making or to greater patient satisfaction.

Patient competence is one precondition for decision making. This includes the patient’s capability to understand that there is a choice and that choices have consequences. A competent person has the competence to comprehend relevant information, the ability to weigh the benefits and the risks of proposed procedures, and the capacity to reach a reasonable decision. In addition, patients must understand their own situation and pursue their own goals before they can reach an informed decision. Patients’ decision-making competence may be adversely affected by difficulties in understanding the information provided and by fears and anxiety. Neither illness nor age can be considered automatically to reduce competence.

It is essential that participation in decision making is voluntary. The research evidence on patient willingness to take part in decision making is somewhat contradictory, possibly because of differences in the way that participation is defined and understood. Willingness is also a dynamic quality that may vary over time or in different situations. For instance, Biley observed that a patient’s current health status is associated with his or her willingness to take part in decision making. That willingness may be affected by confirmation of the diagnosis, which usually gives rise to a personal crisis but at the same time requires prompt action to be taken to commence treatment. Degner and Sloan found in their study that 59% (n = 436) of cancer patients wanted the physician to take the decision on their behalf, while 64% (n = 482) of healthy people believed that they would want to make their own decisions on cancer care. Buchanan et al. observed inconsistencies in cancer patients’ attitudes towards their participation in decision making. Some of the respondents wanted to make the final decision themselves, although they also accepted the physician’s veto in taking decisions on alternative treatments.

In shared decision making the professional who proposes a certain course of action needs to respect the person in question by regarding him or her as a competent, autonomous individual. There also needs to be a sense of trust between the patient and the proposer so that the patient can be assured that the information given is credible and in their best interests. There exist no uniform criteria on the kind of relationship that promotes decision making between patients and physicians or nurses, but in each case the qualities and preferences of both parties have to be taken into account. For instance, encouragement of the patient to take part in decision making and the provision of information by nurses and physicians both have a positive impact on patient participation in the process. In particular, nurses and physicians must be willing and prepared to involve the patient in the decision-making process, otherwise shared decision making will not be possible. Problems with staff communication, such as their
failure to provide all the information the patient needs, or the assumption that the patient is unable to understand medical information, will obviously deter patient participation,\textsuperscript{47} as does a lack of time on the part of nurses and physicians. According to a study by Luker \textit{et al.},\textsuperscript{48} breast cancer patients did not regard nurses as significant sources of information because they were under constant time pressure.

Every patient has the right to take part in his or her care and the related decision making,\textsuperscript{10} but to what extent is the realization of this right meaningful to patients? The available evidence suggests that participation means different things to different people. An intervention study among breast cancer patients carried out by Lauri and Sainio\textsuperscript{44} showed that all patients ($n = 92$) felt it was important that they should receive information about their own care; 89\% wanted their opinion to be sought. They also considered it to be important that they should have the opportunity to express their own views on the care and treatment they were receiving. About half of the patients thought they had received sufficient information; less than half said they had received more or less adequate information, while 4\% indicated that they had received no information at all. About one-fifth of the respondents indicated that their views had not been requested prior to the decision making and that they had not had the opportunity to express them. It was concluded that access to information and the encouragement of patients to take a more active part in decision making helped to relieve their stress and anxiety. Similar results have also been reported in earlier studies.\textsuperscript{39,45,49,50}

\textbf{Purpose of the study and research questions}

This study was concerned with the views and experiences of adult cancer patients concerning patient participation in care and decision making. The following research questions were addressed:

1) How do patients perceive and understand patient participation in care and the preconditions for that participation?
2) What kind of experiences do patients have about their participation in decision making and its preconditions?
3) How do patients perceive the meaning and relevance of their participation in decision making?

\textbf{Methods}

\textbf{Sample}

The study population comprised 34 (18 men and 16 women) voluntary cancer patients from the haematological and oncological wards of one university hospital in Finland. Patient recruitment was based on the following criteria: age 18–55 years; at least two months since the cancer diagnosis; sufficiently good physical and mental health to answer the questions presented; and the giving of informed consent. The mean age of the respondents was 44 years (range 24–54). Over half of the respondents were married or lived with a partner; the rest were
unmarried. Twelve of the patients were from the haematology wards, 22 from the oncology wards.

Data collection and analysis

Permission to conduct the study was obtained from the senior physicians, nurse managers and the hospital’s ethics committee. The patients were recruited by nurses on the basis of the criteria mentioned and were asked to give their informed consent. This was requested in writing, using a form that provided all the relevant details of the study. It also stressed that participation was entirely voluntary and that the information provided by the patients would be treated in the strictest confidence. The interviewer, who was one of the researchers, repeated all these points prior to the interviews. Fourteen patients refused to take part; the reasons for the nonresponse were not requested.

The data were collected in focused interviews as well as by using tested instruments designed for the measurement of patient depression and general problem-solving skills. Prior to the interview, the patients completed a depression scale developed by Salokangas et al.,\textsuperscript{51} which is based on a 20-item screening scale by Barret et al.\textsuperscript{52} The scores ranged from 0 to 30; patients scoring more than 9 points were classified as depressed. Problem-solving skills were measured with the personal Problem-Solving Inventory (PSI) developed by Heppner and Petersen.\textsuperscript{53} This is a Likert-type instrument consisting of 32 items, with a possible range of scores from 0 to 160. The instrument is divided into three areas: (1) problem-solving confidence: items that assess confidence in problem-solving activities; (2) approach–avoidance style: measures whether an individual approaches or avoids different problem-solving activities; and (3) personal control: involves elements of self-control. A successful problem solver has a low score in all three areas. The patients completed the instrument either immediately after the interview or returned it later in a sealed envelope. All interviewees completed the depression scale instrument, but one did not complete the PSI.

The interview material was collected in September and November 1999. The first step involved four pilot interviews, on the basis of which minor adjustments were made to the interview scheme. The themes covered concerned patients’ views and experiences on their participation in their care and decision making, and factors related to participation, as well as the meaning of participation. Where necessary follow-up questions were asked concerning how the decision on care had been reached, whether any alternatives had been offered, whether the patient had expressed any views or opinions, how the patient had received the information, and what were the factors seen to restrict or promote their participation in care and decision making. The interviews were carried out either in the patient’s room or in some other room where the patient and the interviewer could be alone. The duration of the interviews ranged from 20 minutes to 1.5 hours and the general atmosphere was very positive. All interviews were carried out by the same researcher (CS). They were tape-recorded with the patient’s consent and transcribed to make sure that the patient’s account was recorded as accurately as possible.

The first step in the data analysis involved reading through the interviews several times in order to form an overall picture of the material. Next, the same
A researcher who had conducted the interviews carried out a more detailed analysis, but the other researchers involved also took part in the classification and interpretation of the material. The analysis was based on qualitative content analysis, using the data analysis programme, ATLAS, developed in Germany. Analysis of the interview transcripts was based on the method of reduction, classification, comparison, interpretation and deduction. The unit of analysis was an expression or a sentence that conveyed a clear meaning that was relevant to a research question. In the first stage the interviews were classified according to the main themes of the interview: views on participation in care and decision making and its preconditions; personal experiences of participation in medical and nursing decisions; which factors promoted and restricted participation in decision making; and the significance of participation to the individual patient. The main categories were then divided into subclasses describing the phenomenon in question. At the next stage the researchers assessed the classification by re-reading all the interviews and comparing the overall impression formed of the patients’ views and experiences. The main categories included in the final classification concerned participation in medical treatment and divided the respondents into three groups: those actively involved in their care; those who gave their consent actively; and those who gave their consent passively. The results were examined according to these three classes. The results for the depression and problem-solving instruments were analysed quantitatively by counting the scores for each patient, as set out in the instructions for the respective indices, as well as the mean scores for each of the three classes.

Results

Views on participation in care, and in decision making and its preconditions

The patients’ views on participation varied considerably. Some of the patients understood participation in terms of being involved in decision making or in terms of expressing their views on different treatments. Others were of the opinion that it was impossible for patients to take part in care and the related decision making. The majority defined participation in terms of asking questions and/or obtaining information. It was also defined in terms of communicating feelings and symptoms to nurses and physicians, and in terms of compliance with nurses’ and physicians’ orders.

The preconditions for patient participation in care and decision making were analysed through factors promoting and restricting participation, which are presented in Table 1. Promoting factors included, for example, good health, obtaining information, and patients’ desire to participate and be active in the process. Patient access to adequate and comprehensible information was considered to be an important precondition for participation. Most of the patients thought that taking an active role was basically a matter of personality. One said that no one can be transformed into an assertive person in hospital; one has to be already active. On the other hand, another patient said he thought he was more involved in cancer care than he was otherwise in life because this was a matter of life and death.
Patient-related factors restricting participation in care and decision making included poor health, ignorance, fear and age. The most significant factor was poor physical and mental health, giving rise to fatigue and problems with receiving information. Another important restrictive factor was ignorance. The respondents felt that they did not have enough information to allow them to take part in decision making. Fear may also act as a deterrent against participation; patients may be afraid of confronting reality and the future as well as people seen to have authority, such as physicians. Some patients said that older people find it hard to hold their own and they are less interested in their own life and in getting better than are younger people. A lack of faith in their own influence also restricts their participation.

Table 2 describes factors related to interactions between nurses, physicians and patients that either promote or restrict patient participation. A good relationship is important in promoting patient participation. When nurses and physicians are known to the patient and are friendly, positive, and show that they genuinely care, it is easier for patients to take part in their own care. Many respondents stressed the importance of personal chemistry and personal relationships. Nurses and physicians were expected to encourage patients to take part and to provide the information required by the patients. Patients wanted nurses to serve as intermediaries and pass on information to physicians.

Factors restricting participation in care and decision making included poor interactions between the different parties, a lack of time on the part of nurses and physicians, a lack of staff resources and high staff turnover. As far as interaction was concerned, patients mentioned incompatible personalities, arrogance on the part of nurses and physicians, quick-temperedness and an objectifying approach.
to patients. It was widely considered to be problematic that nurses and physicians do not have enough time to talk to patients. When patients realized that the staff were working under time pressure, they were inclined not to bother them with their questions. Patient participation in care and in decision making is also restricted by the fact that physicians cannot spend enough consultation time with their patients, and that high staff changeover rates adversely affect continuity.

**Experiences of participation in decision making**

*Patients actively involved in decision making about medical treatment*

The seven patients in this category (five men, two women) took an active part in making decisions concerning their medical treatment. Three of them had an academic education, two a college education, one was self-employed and did not indicate the level of education, and one was a student. Each of them had a different disease: myelofibrosis, chronic lymphatic leukaemia, acute myeloid leukaemia, sarcoma, and cancer of the bladder, rectum and lymph nodes. The youngest patient was aged 24 years, the oldest was 52.

With just one exception these patients had been diagnosed with cancer more than one year previously; the longest time since diagnosis was nine years. The patient who had been diagnosed within the past year had fallen ill 10 months previously. None of these patients was depressed; the depression scores ranged from 1 to 7, with a mean of 4 points. The scores in the problem-solving test ranged from 62 to 79 (mean 70). The scores for all three different areas were low, particularly so for the approach–avoidance styles, meaning that the patients in this group had good and diverse problem-solving strategies.

One patient had been allowed independently to decide on her treatment.
Chemotherapy had proved ineffective, so the patient and her next of kin were allowed to decide whether or not they wanted to continue with the treatment. The other patients in this group had exerted pressure, demanded, manipulated or expressed their views when treatment options had been considered, for example:

I was having radiotherapy and they were thinking should they continue or not and there were a couple of experts there and they were giving a lot of thought to it and I said what I thought and in a sense I was involved there and yes in general we have talked about it.

All interviewees except one were satisfied with the decision and with how that decision had been reached. However, the patient who had had to manipulate physicians felt that patients had to be extremely assertive if they were to have any say at all in their care. The patients had also been able to influence their care in other ways. For instance, one had been able to make regular appointments with a psychiatrist. Another had been able to choose on which day of the week he came in for chemotherapy, to fit it in with his job. One patient had managed to speed up the tests that were carried out: ‘I think the pressure helped to bring forward my tests by about two weeks. The physicians tend to get annoyed if you keep pressurizing them and trying to speed things up.’

These patients had taken part not only in decision making concerning their medical treatment but also in nursing care. They had taken part in deciding on what meals they would have and on aspects of personal hygiene, holiday arrangements, the choice of needed medication, and the use of intravenous drips.

Participation in decision making and obtaining information was important to the patients because they felt it concerned their own life and what should be their own decisions. The information they received also helped them to plan their life ahead. The respondents considered that there had been some problems with regard to receiving information. They had not received enough written information, particularly during the early stages of their illness. One said that he had received conflicting information because of ignorance on the part of junior physicians and a high staff turnover: ‘So then I saw this junior physician and he knew absolutely nothing and it’s almost impossible to have any conversation there because there’s this pile of papers and he knows nothing more about it than I do.’

Half the patients in this group had obtained information about their illness and its treatment from the Internet, cancer associations and the literature. However, the primary sources were nurses and physicians. Some respondents thought the best way to obtain information was to ask questions, because they found it difficult to pick out what was relevant from the superficial information they received from other sources. One said he had occasionally read his own medical records to learn more about his condition.

In this group the most typical respondent who had taken an active part in medical decision making was a man aged about 40 years who had been diagnosed with cancer about four years previously. He was not depressed and his problem-solving skills were better than other patients in this group. He was content with the way in which the decisions regarding his treatment had been made, and rather satisfied with the information made available to him. He had sought for infor-
information from the Internet and books, but primarily from the physician in charge. This patient had taken an active part in both medical and nursing decisions.

Patients actively consenting to medical treatment

There were nine patients who actively consented to medical treatment, six women and three men. Five had a college education, one an academic degree, and two vocational schooling; one was a student. The youngest patient was aged 31 years, the oldest was 53.

Two of the patients suffered from acute leukaemia, one chronic leukaemia, two breast cancer, two sarcoma and two thyroid cancer. Over half of these patients had been diagnosed less than one year previously. The shortest duration since diagnosis was 10 weeks, the longest seven years. Depression scores varied from 0 to 16, with the mean being 7 points. Two of the patients scored over 9 points and were classified as depressed. The problem-solving scores ranged from 54 to 96 (mean 78). In the areas of problem-solving confidence and personal control, the scores for decision making were not quite so good as in the group of participants who were actively involved in decision making, but it was clearly worse in the area of approach–avoidance styles.

The patients in this group were involved in deciding on alternatives to medical care in the sense that they had been specifically asked to consent to the treatment they had been offered or asked whether or not they were willing to take part in the care offered. However, no alternatives had actually been given to these patients: ‘In practice it was the only option, but whether I agreed or not that was a decision I made myself.’ One patient said, ‘The first question they asked was whether I’d accept the treatment or not. That’s a pretty tough question if you consider that you can be in just about any mood that day.’

In general the respondents were satisfied with the way the decision on treatment had been made. However, there were some exceptions. Some were critical about the lack of information, and about the absence of alternatives and justifications before they were asked to give their consent. Some respondents considered that they had not been involved in nursing decisions, although some had taken decisions regarding meals, the need for medication and personal hygiene.

Access to information was considered by the patients to mean quality care. It affected their mood, relieved their anxieties and helped them to adapt. Over half of the patients in this group indicated they were not satisfied with the information they received, complaining that they had not received sufficient information. One of the respondents had a highly traumatic experience resulting from unclear information, when a physician had spoken to her about something she had not understood, causing her considerable stress and anxiety. These patients had talked to both nurses and physicians to obtain the information they needed. It was widely felt that the only way to get the required information was to be independent and assertive: ‘You have to be extremely active because otherwise you’ll be pretty much in the dark as far as the disease is concerned if you didn’t ask. You have to ask these things yourself.’

One respondent was curious about why nurses were not allowed to answer many of the patients’ questions. She considered that contact with the physician was so little that it would be easier for patients to obtain the information they needed directly from the nurses. Another respondent complained that physicians
frequently said they did not know the answer to questions asked by the patients: were they really so inexperienced; did they really not know; or were they perhaps reluctant to say what they did know? Over half of the respondents had actively sought information from sources other than nurses and physicians. Some had learned what they knew from books and cancer journals; one had obtained information from the Internet and from friends who had cancer.

The average patient who had actively consented to medical treatment was a woman aged 45 with a college education and with a cancer diagnosis made less than one year ago. She was in rather low spirits but by no means depressed. Her problem-solving skills were somewhat weaker than those of the patients who had taken an active part in decision making. She was not fully satisfied with the way in which the decisions had been reached or with her access to information. She required more information from both nurses and physicians. This average patient would have actively sought information from books and cancer journals, but not taken an active part in nursing decisions.

Patients passively consenting to medical treatment
This group comprised 18 patients (10 men and eight women) who had not actively taken part in any decision making on medical treatments. Eight had completed vocational and school degrees, five had a college education, three had academic qualifications, and two were students. The youngest patient was aged 24 years, the oldest 54 (mean 44). Four of the respondents had acute leukaemia, three lymphoma and three stomach cancer; the remainder suffered from cancers of the lung, brain, rectum, breast, tongue and adrenal gland. Two of the patients had not yet been given a definite diagnosis. The longest time since diagnosis was 12 years, the shortest two months. The majority (12) of the patients had been diagnosed more than six months ago. On the basis of the depression scale, two patients suffered from depression, with the scores ranging from 1 to 18 (mean 5). The mean score for the problem-solving inventory was 81 points (range 55–107). The scores for all three domains were higher than in the other groups, but they showed only a marginal difference compared with those indicating active consent.

These patients had not taken part in decision making on their medical treatment. They had not been asked to give their consent, but they had given their passive consent by not refusing to accept the treatment provided. They had been informed of the decision made either by one physician or a team of physicians: ‘It’s this collective of physicians that draws up the plan and they like presented it to me and of course I had nothing to say about it because I don’t understand anything.’

Most of the respondents were satisfied with the way in which the decisions on medical treatment had been made. They considered that the physicians were the experts in cancer care while they themselves ‘knew nothing’. In the view of one patient who was still in the early stages of treatment, it was impossible at this point to become involved in making decisions but, if the treatments were to prove ineffective, then the patient could decide whether or not to continue. Only one patient indicated she was dissatisfied, complaining that she had not been involved in making decisions on her care. However, this patient had been involved in the care other than by making decisions on medical treatment. A few patients had managed to postpone the start of their treatment by one week. They had been
involved in nursing decisions concerning, for example, their meals, the medication they needed and intravenous drips. To some extent the patients had also been involved in making decisions together with nurses on times for leaving for home and for holidays.

Access to information was important first and foremost because it helped to alleviate patient anxieties. It removed uncertainty and patients were better able to monitor themselves and detect alarming symptoms. For some, information motivated them to persist with the treatment. The patients regarded access to information as a precondition for good treatment. A very small minority of patients believed that information was of no major significance to them, but that all that mattered was the efficacy of the medical treatment. Some said that they did not want to know everything, such as about their prognosis or about the mechanisms involved in chemotherapy. In order to learn about things that were unclear to them, the patients asked both nurses and physicians. Almost half of them had had experiences of inadequate access to information. At least one admitted that he knew very little about his illness and treatment:

You really learn far too little about this illness and its treatment unless you work really hard to find out. You really have to grab hold of the physician and ask what does this mean and what is happening now.

The respondents did not always understand all the information they received; some complained that they sometimes did not always understand the medical terms that the physicians used. One suggested that nurses should do their own rounds, after the physicians, which would give patients the opportunity to ask them to clarify what the physicians had said:

It’s such a hectic situation that there are several physicians there all together and they’re talking more with one another and in between they’ll tell you something and there are so many things there that you can be completely blocked. But the nurse will talk you through these things at the same level as you are.

Some of the patients actively sought information. Most typically, they resorted to various cancer booklets and other patients. If something was not clear to them, they turned first to other patients in the same room. However, one respondent pointed out that to some extent false information tends to circulate among patients. Four patients had used the Internet to search for information; a few had read some of the literature. Information was also requested from friends and relatives who had a health care training.

Patients who gave passive consent to medical treatment were typically either male or female, aged 44, who had been diagnosed less than six months ago. They had vocational or school-level qualifications. They were not depressed and had somewhat poorer problem-solving skills than the patients in the other two groups. These patients were satisfied with the way in which decisions had been made concerning medical treatment, but they had received inadequate information and did not always understand the information they had received. They had actively sought information from various booklets on cancer and from other patients, and had been fairly actively involved in nursing decisions.
Discussion

There is a lack of consensus about how the reliability of qualitative research should be measured.\textsuperscript{56,57} Sandelowski\textsuperscript{56} prefers to speak not about internal validity but about credibility. A qualitative study is deemed credible if it reveals accurate descriptions that the people having that experience would immediately recognize from the description as their own. In interviews the researcher obtains first-hand experience, and the focused interview in particular allows participants to raise issues and topics that the researcher might not have considered.\textsuperscript{58}

Data reliability depends ultimately on the researcher’s competence and interviewing skills.\textsuperscript{58} In qualitative research the aim is to understand meanings rather than the truth, as in positivistic philosophy, where there is only one reality.\textsuperscript{57,59,60} The interviews were conducted by one researcher (CS) who has prior experience of practical nursing and research with cancer patients. This in itself contributed to reliability because the interview situations and the interviewer’s interpretations of those situations were the same for all patients. At different stages the interviewer also consulted the other researchers, who on some occasions conducted their own parallel analyses. The different stages of the analysis have been easily traceable on computer, and all the researchers involved have been able independently to assess the progress of the analysis, which has also been the subject of several joint discussions. Every possible effort was made to make the analysis as transparent as possible. Reliability was also enhanced by the use of computer software that allowed for a comprehensive coding system, which reduced the risk of having classifications based on single, isolated phenomena.

There are fewer threats to external validity in qualitative research because the study of the phenomena is in the natural setting and with few controlling conditions.\textsuperscript{56} In this study, all the participants were interviewed in the same situation (i.e. while receiving treatment in hospital). The interviews were carried out in peaceful surroundings. There were no interruptions except in one interview (caused by the setting up of an intravenous drip). All patients took part in the study voluntarily. Fourteen patients refused to take part in the interviews. It is quite common for people to refuse to take part in this type of study because of physical and mental fatigue due to the illness or the desire to maintain one’s privacy. The researchers were prepared for a fairly high number of refusals, but no decision was taken in advance on the final size of the research material. It was agreed with staff on the wards concerned that all patients who met the research criteria should be asked if they would agree to take part and that data collection should be continued as long as necessary (i.e. until saturation point had been reached and the arrival of new participants no longer produced new information relevant to the research problem).

The results of our study indicate that the concept of participation remains fairly unclear to patients, as was also underlined by Cahill.\textsuperscript{41} If patients, nurses and physicians do not have a consistent understanding of the concept, it may be difficult in practical situations to have real patient participation. For many patients, participation is not part of decision making, even though in some studies\textsuperscript{13,14} it is defined and understood precisely in terms of participation in decision making. In the care of cancer patients it should be made clear exactly what nurses and physicians mean by participation in care and how the patients themselves...
understand the concept. It is important to find out in what way patients want to take part in their own care and decision making, because an important precondition for decision making is that participation is voluntary. In this study, there were some patients who were not willing to take part in decision making. Similar results have also been reported in other studies concerned with cancer patients.

Over half the patients in this study had not taken part in decision making in any way, even though the current Act on the status and rights of patients provides clear instructions on how patient participation in care should be promoted. Even those who had actively consented to treatment had not been given any alternatives, nor had they received sufficient information, so not all the conditions for shared decision making were present. In the future, at least one basic challenge for the care of cancer patients is to reach a situation of shared decision making. Patients must be given a clear opportunity to take part in decision making by involving them in discussions and providing adequate and readily comprehensible information about different treatment options and a sound basis for choosing the recommended option. Research evidence indicates that many patients do not necessarily want to take responsibility for decision making but simply require to have access to adequate and relevant information.

The patients considered that participation in their own care and decision making required considerable courage and reasonably good health; they thought they should also be active and not too old. In this way patients are capable of acquiring information, confronting different situations without fear, being willing to participate and have a support person. In addition, there should be good relationships between patients, nurses and physicians. Patients expect nurses and physicians to be active, to encourage them, to provide information and to have enough time to talk to them. These are quite considerable demands, but they clearly reflect the reality in hospitals today.

Education, access to information, problem-solving skills and a sufficient length of time since diagnosis all promoted patient participation in decision making on medical treatment. Patients with a higher level of education took a more active part in this decision making, as has been shown in earlier studies. These people had searched for additional information on the Internet, but primarily they had asked questions of their physician. Physicians provide specific information, which, according to Siminoff and Fetting is what cancer patients need in order to make informed decisions on the basis of their own preferences. A study by Hack et al. showed that breast cancer patients who wanted to take an active role in their treatment decision making required detailed information. Patients who took an active part in decision making had fallen ill much earlier than those who gave their passive consent, so they had possibly learned to live with their cancer diagnosis and were no longer in a state of shock. Degner and Sloan also arrived at the same conclusion. Those who took an active part in decision making had better problem-solving skills than other patients and were involved more often in problem-solving activities. Indeed, Deber stresses that decision making usually requires prior problem solving. In the current study the majority of active patients were men, as was also the case in the report by Llewellyn-Thomas et al., although many studies have reported that men are more passive than women.
Patients who actively and passively consented to treatment did not differ significantly from one another in relation to the factors just mentioned. Passive patients had a lower level of education and they had fallen ill more recently. Both groups said they had not received enough information. However, they had obtained additional information from other sources. Those who had consented passively to treatment had obtained information from other patients or information booklets. Some made it clear that they did not want to know everything, as has been noted in another report. It is noteworthy that active participation in nursing decisions was not directly associated with decision making on medical treatment. Patients who took a passive part in medical decision making were actively involved in nursing decisions. Decisions concerning nursing care are associated with patients’ everyday life and their physical and mental well-being, so it is easier for them to understand their meaning and to participate in appropriate decision making.

The results of our study offer new insights into the development of nursing practice. It is important for nursing staff to recognize how patients want to take part in decision making concerning their treatment and to understand what this means to patients. In the early stages of care patients need access to definite and readily understandable information on what participation in decision making really means. Our results lend support to the earlier evidence that cancer patients want to know about their illness and its treatment. Nurses need more time to concentrate on giving information, but the main problem in practice is how to enable this. Patients require time and encouragement so that they can take an active part. They expect their nurses to act as advocates for them vis-à-vis the physician, who for some patients is a more remote and busier person than the nurses. According to some studies, patients who take an active part in treatment have shown better treatment results and increased satisfaction with care. In this study, the highest level of satisfaction with care and treatment, with the influence they had and with their access to information, was shown by patients who took an active part in their own care. However, these patients had had to fight for their right to take part in decision making through their own efforts and their own skills. The impact of participation in decision making on patient recovery and well-being is an interesting question that certainly deserves closer attention in future research.

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References


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