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Original Paper

Treatment Decisions in Palliative Cancer Care: Patients' Preferences for Involvement and Doctors' Knowledge About It

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The aim of this study was to evaluate the extent to which hospitalised patients with advanced cancer and a palliative treatment goal wanted to be involved in the process of making treatment decisions and how well their physicians actually knew their preferences for participation. 59 hospitalised patients with non-curable cancer, 86 hospitalised patients with chronic non-neoplastic disease, and 115 non-hospitalised persons were surveyed with a standardised questionnaire. In addition, the physicians of the hospitalised patients were asked to complete a similar questionnaire. The majority of patients with advanced cancer wanted to decide either by themselves/mainly by themselves (9%) or to collaborate and decide together with their physician (73%), compared with 17% and 49%, respectively, of patients with chronic non-neoplastic disease, and 40% and 56%, respectively, of the non-hospitalised persons (difference between groups: $P = 0.001$). Younger age, higher education, employment and higher Karnofsky index were significantly associated with active involvement. The agreement of patients' preference with their physicians' assessment did not exceed chance. In conclusion, most patients wanted to participate in a decision regarding their treatment, although physicians were unaware of their patients' preferences. © 1997 Published by Elsevier Science Ltd.

Key words: decision making, patient preference, cancer care

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INTRODUCTION

THERE IS an ongoing debate about how much patients should participate in the process of making treatment decisions [1]. Some argue that patients, when they can, should always be offered choice, especially when the available therapies differ in risk and outcome [2]. Others feel that the physicians, because of their daily experience with similar situations and their medical knowledge, might be in a better position to judge and decide on the optimal treatment.

For a practising physician, it is a difficult task to estimate what risks are worth taking for an individual patient. Moreover, offering choice to patients may result in more satisfaction with care and in a better acceptance of treatment [3]. Other patients may be overwhelmed by the complex information required to make a valid choice. Some may try to avoid responsibility and possibly self-blame for an unsuccessful outcome, and prefer that the physician decides on their treatment.

Demographic factors as well as disease-related factors affect patient preference for participation in treatment decisions [4, 5]. Sutherland and associates [6] asked 52 radiotherapy patients with cancer about their preferred role in decision making and 63.5% preferred a passive role. In another study from Canada [7], 59% of newly diagnosed cancer patients wanted physicians to make treatment decisions on their behalf. However, patients in this study were often in a situation where cure was achievable. Particularly in palliative care situations, little is known about patients' preferences and nothing is known about the doctors' knowledge about it. The latter, however, determines whether the patients are able to play the role they wish.

Therefore, we examined to what extent hospitalised patients with advanced cancer and a palliative treatment goal wanted to be involved in treatment decisions, and we evaluated the knowledge of the treating physicians about their patients' preferences. In addition, the personal socio-

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demographic and disease-related factors associated with the different preference for participation in decision making were described.

PATIENTS AND METHODS

Study populations

Patients with advanced cancer and a defined palliative treatment goal, who had been admitted to the Department of Haematology and Oncology, and partly, to the Department of Gastroenterology at the University of Ulm, Germany, between February and June 1995, were included in this study. Hospitalised patients were screened for eligibility by interviewing the treating senior house officers. Accepted palliative goals were either the alleviation of existing symptoms or the prevention of impending problems [8]. Patients had to be coherent and be physically able to fill out the questionnaire by themselves. Additional information regarding diagnosis, stage of disease and goal of treatment were collected from patient charts.

To assess the effect of illness and, respectively, the life-threatening aspect of a illness, two comparison groups were formed. Firstly, patients with a chronic disease but without neoplasia were recruited from the same wards. In order to be eligible for this study, they had to suffer from a chronic disease that required continuous medication or medical surveillance and their life expectancy had to be estimated by the caring physician to be more than 3 years on the basis of their underlying disease. Secondly a control group outside the hospital was recruited to investigate the effect of illness in general on preference choices. These were participants of a senior college at the local university ($n = 43$) and voluntary blood donors of a nearby community ($n = 72$). The first were participants of one particular university course and the latter were randomly selected in order of appearance.

Preference assessment

A research assistant asked each eligible patient for participation and handed out the questionnaire together with written information about the study objectives. It comprised questions regarding education, living conditions, occupational status and a question regarding the extent of the patient's participation. A self-administered questionnaire regarding the extent of a patient's preference for participation was translated into German following the questionnaires of Sutherland and associates [6] and Degner and Sloan [7] (see Appendix A). Simultaneously, the treating physicians were asked to complete a similar questionnaire during the same visit and before they could communicate with the patients. In it they were asked how much they thought the patients wanted to be involved in treatment decisions (Appendix B).

Statistical analysis

To assess the association of the various groups and the preference for participation in decision making, the Pearson chi-squared statistic was calculated. The association between other personal, sociodemographic and disease-related factors and preference for participation was characterised in the same way. For this purpose, persons preferring an active role (answers A and B of the patient questionnaire, see Appendix A) were compared to persons preferring a collaborative role (answer C) and to persons preferring a passive role (answers D and E). In the group of in-patients, the agreement among patients as stated by the patients themselves and as rated by the caring physician was evaluated. Therefore, the weighted kappa-coefficient and the 95% confidence limits were calculated to show whether there was any significant agreement exceeding chance [9].

Table 1. *Personal and sociodemographic characteristics of the* 260 *study subjects*

	Patients with advanced cancer	Patients with chronic non-neoplastic disease	Non-hospitalised persons
Number [*n*]	59	86	115
Mean age ± SD (years)	58.6 ± 12.2	58.2 ± 17.8	47.9 ± 16.7
range	21–83	18–89	19–85
Female (%)	49	51	60
Status on Karnofsky performance scale mean (%) ± SD	75.0 ± 19.6	78.2 ± 19.6	n.a.
Education (%)			
none,	2	6	1
≤9 years	58	70	44
10–12 years	29	23	45
>12 years	12	1	10
Occupation (%)			
in training	2	2	4
employed	32	27	54
unemployed	2	4	3
retired	48	49	27
housekeeping	15	19	11
Marital status (%)			
single	12	12	27
married	64	65	57
separated/divorced	7	8	4
widowed	17	15	11

n.a., not available.

Table 2. Distribution of patients' preferences for participation in decisions regarding their treatment according to group and other characteristics

		Preference			
Characteristics	*n*	Active	Collaborative (%)	Passive	*P*-value (chi^2-test)
Group					
Patients with cancer	59	9	73	18	
Other patients	86	17	49	34	
Non-hospitalised	115	40	56	4	0.001*
Age					
<60 years	153	33	55	12	
≥60 years	107	15	62	23	0.002
Sex					
female	142	27	60	13	
male	117	24	55	21	0.3
Education					
≤9 years	152	20	55	25	
>9 years	108	32	62	6	0.001
Occupation					
employed	104	34	58	8	
others	156	20	57	23	0.001
Marital status					
married	159	24	61	15	
others	101	28	52	20	0.4
Comorbidity†					
yes	69	10	64	26	
no	76	17	54	29	0.4
Karnofsky performance scale†					
≤70%	51	14	41	45	
>70%	85	12	69	19	0.002

*After stratification for age. For one person of the non-hospitalised subjects sex was not recorded; †assessment for in-patient sample only. Karnofsky index was not available for 1 patient with cancer and 8 patients with chronic non-neoplastic disease.

RESULTS

A total of 260 subjects were included in the study. The response rate was 83% among the patients and over 89% among the non-hospitalised participants. Table 1 shows the baseline characteristics of the three groups. The mean age for the patients with cancer was 58.6 years and for the patients without cancer 58.2 years. The subjects currently not in a hospital were younger with a mean age of 47.9 years.

Sex distribution was balanced in the hospitalised group, whereas there were more women among the control group from outside the hospital. Of the patients with cancer, 32% were currently employed, compared with 27% of the non-cancer patients and 54% of the non-hospitalised subjects. In all three groups, most of the persons were married or lived in a marriage-like relationship.

The majority, namely 64% of the patients with cancer, had neoplastic disease of the lymphatic or haematopoietic tissue and 36% had solid cancers. Of the patients with cancer, 31% had an additional diagnosis recorded in the charts. The majority of the patients without cancer suffered from cardiovascular diseases (48%, ICD-9, position 390–459), followed by digestive disorders (23%, ICD-9, position 520–579) and metabolic and nutritional disorders (14%, ICD-9, position 240–279). Of the non-hospitalised subjects, 79% considered themselves free of any disease.

When asked which role subjects wanted to play in a decision process regarding their treatment, the following distributions were observed (Table 2): 9% of the patients with cancer preferred to make decisions mainly on their own, 73% preferred a collaborative role together with the doctor and 18% preferred the doctor to make a decision on their behalf. In comparison, 17% of the patients with non-neoplastic disease wanted sole control over the decision, 49% preferred a collaborative role and 34% wanted the doctor to make the decision on their behalf. Of the persons representing the general population (non-hospitalised persons), 40% preferred to make the decision themselves, 56% a collaborative role and only 4% wanted to leave the decision to the doctor. The difference among all three groups was statistically significant (after stratification for age, *P*-value = 0.001). Younger age was independently associated with preferring a more active role (see Table 2). In general, subjects of or under the age of 60 years more often wanted to play an active part than patients above the age of 60 years.

Gender was not associated with any given preference. However, educational and occupational status were associated, in that patients with more than extended education tended to want more control in the decision making process as did employed persons. Marital status was not statistically associated with preference, and neither was comorbidity of the in-patients. Status on the Karnofsky performance scale (less than or equal to 70% compared to patients with an index over 70%) showed a significant association with patients with a status less than or equal to 70% who tended to give away control.

All involved physicians responded to the questionnaire. Table 3 describes the physician–patient relationship and the clinical experience of the physicians. Although 17% of

Table 3. Physician–patient relationship and clinical experience of physicians who proxy-rated in-patients about their wish to be involved in treatment decisions

		Patients with advanced cancer (%)	Patients with chronic non-neoplastic disease (%)
Physician had known patient for ($n = 18$)	<1 week	17	17
	1 week– < 1 month	39	64
	1 month– < 6 months	24	14
	>6 months	15	1
Physician's clinical experience ($n = 18$)	<1 year	41	45
	1– < 3 years	34	35
	3–5 years	9	6
	>5 years	17	14

patients were known by the physician for less than 1 week, 39% of the cancer patients and 64% of the patients with non-malignant disease were known for between 1 week and 1 month and 24% and 14% between 1 month and 6 months, respectively. Furthermore, 41% of the patients were rated by physicians with less than 1 year's clinical experience. However, a considerable number of the physicians had 1–3 years or even more than 5 years of clinical experience.

Table 4 shows the agreement of the patients' preferences as stated by the patients themselves and their physicians' assessment of the degree to which they thought the patients wanted to participate in a decision regarding their treatment. The correspondence of patient preference with their physician' assessment was compared using the kappa-coefficient to correct for chance agreement. The coefficient was not statistically different between both patient groups and therefore both groups were analysed together. Complete agreement was achieved in 36% ($n = 52$). Physicians underestimated patients' preferences for involvement in 36% ($n = 52$) because they rated patients as passive when indeed they preferred an active ($n = 5$) or collaborative role ($n = 39$) or patients were rated as collaborative when indeed they preferred an active role ($n = 8$). Physicians overestimated patients' preferences in 28% ($n = 41$) because they rated patients as active when indeed patients preferred a collaborative ($n = 23$) or passive role ($n = 8$) or rated them as collaborative when the patients preferred a passive role ($n = 10$). The weighted kappa-coefficient was 0.1 (95% CI – 0.02–0.21), therefore indicating only chance agreement. There was no association between duration of physician–patient relationship or clinical experience of physician with degree of agreement (data not shown).

DISCUSSION

The present study examines and compares the interest of participation in the process of making treatment decisions in hospitalised patients with advanced cancer and a palliative treatment goal, in hospitalised patients with chronic non-neoplastic disease and in a group representing the general population. Overall, the vast majority of the patients with advanced cancer preferred a collaborative role and wanted to decide together with their physician. Some even preferred to decide actively by themselves on the choice of treatment, and less than 20% wanted to leave the decision mainly to their treating physician.

Table 4. Agreement between patient preference as stated by patients themselves and as rated by their physicians

	Proxy rating by physicians (n(%))		
	Active	Collaborative	Passive
Patient preference ($n = 145$)			
Active	7 (5)	8 (6)	5 (4)
Collaborative	23 (16)	23 (16)	39 (27)
Passive	8 (6)	10 (7)	22 (15)

Weighted kappa-coefficient = 0.1 (95% CI – 0.02–0.21).

Analysis of physicians' knowledge about their patients' preference revealed that physicians did not know their patients' preferences for involvement in the decision process. This is in analogy with the observation that the physicians' assessment of their patients' quality of life did not correlate with the patients' self-rating [10].

The observation that only a small minority of patients prefer an active role is consistent with the studies by Degner and Sloan [7], and by Sutherland and associates [6]. In contrast, in a study by Blanchard and associates [11], 69% of patients with cancer stated that they would prefer to participate actively in decisions regarding their health. This may be explained, at least in part, by a different wording of their questions, i.e. by the lack of distinction between an 'active' or 'collaborative' way of participation.

The majority of patients with cancer preferred a collaborative role in the decision-making process, which demonstrates the patients' desire for communication with the doctor in such a difficult situation. In contrast, in other studies most of the patients wanted the physicians to decide on their behalf [6, 7]. This may be due in part to differences in the social and cultural background. Furthermore, in contrast to the other two studies, patients with cancer in our study consisted of a population with non-curable disease and palliative therapeutic options only. They were all informed about their situation. A reasonable explanation would be that patients with a likelihood of cure rely more on their physicians' expertise to choose the appropriate treatment and therefore prefer a more passive role in the decision making process. In addition, patients with advanced disease may have had longer time to have a critical look at their disease and the care givers. As we know, patients' preferences change towards a more active role with time [12].

Demographic factors are known to influence the patients' preferences for information and for participation in disease management. In general, younger patients seek a more active role than older patients [13], and education is also a predictor for patients' preferences for participation [7] which was overall confirmed by our study.

When looking at these results, the following limitations have to be considered: the patients with cancer were a highly selected patient group at a university clinic and well informed about the non-curable nature of their disease. All were in a sensitive situation with pending treatment decisions. In comparison, neither the patients without cancer nor the non-hospitalised persons were in acute life-threatening conditions. This completely different emotional situation may explain at least some of the differences observed.

One of the major implications of the presented data is that most of patients with cancer in a palliative treatment situation prefer to develop treatment decisions in a collaborative way together with the physician, and some even want to steer the decision making process actively. It is well known that patients with cancer wish to be well informed about their diagnosis, outlook, therapeutic options and side-effects of the treatment [11, 14]. There is evidence that active (i.e. well informed) patients feel more satisfied [15], but a long interaction time seems necessary to fulfil patients' desire for information and participation in medical decisions [16]. Therefore, the communication process has to be organised in a way that ensures that patients receive the adequate amount of comprehensible information that makes participation possible.

Giving patients too little information is a serious problem, and the patients' preferences for long-term versus short-term benefits are influenced by the amount of verbal explanation provided to them [17]. Moreover, patients with cancer are much more likely to accept radical treatment when compared with people who do not have cancer, including doctors and nurses [18]. This should be taken into account when discussing treatment options with cancer patients.

Furthermore, physicians did not know their patients' preference for participation. Most important, the patients' desire for participation was underestimated in 36%, but it seems important to recognise their wish to participate.

In a similar study in the U.S., the SUPPORT investigators also documented shortcomings in communication between physicians and patients with a life-threatening diagnosis [19]. This investigation regarded patients' preferences for cardiopulmonary resuscitation (CPR). Only 47% of physicians knew their patients' preference of avoiding CPR. In this study, however, additional resources to enhance the physician–patient interaction in the form of a skilled nurse who communicated with patients and physicians and documented patients' preferences failed to improve the patient–physician communication and the physicians' knowledge of their patients' preference for CPR.

In our study, we conclude that a more formal and feasible approach should be established for physicians to evaluate the patients' willingness to participate in treatment decisions. Making patient preferences a topic for physicians when they inform the patient about the risks and benefit of possible treatment strategies would be desirable and might improve patient satisfaction, as well as quality of life and treatment outcome.

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APPENDIX A

Wording of the patient questionnaire

How would you like a decision to be made regarding your treatment today, assuming you have a serious disease?

Consider a situation with various treatment possibilities that may involve different health outcomes and associated risks (e.g. surgery or only medicinal treatment).

A. I prefer to make the decision on my own.

B. I prefer to make the decision mainly on my own, after considering the arguments of my doctor for or against each treatment.

C. I prefer to make the decision together with my doctor.

D. I prefer that my doctor makes the decision about which treatment I will receive, after he has heard my opinion.

E. I prefer to leave the decision regarding my treatment totally to my doctor.

Answers A and B were considered as an active role, C as collaborative and answers D and E as passive roles.

APPENDIX B

Wording of the doctor questionnaire

How do you think the patient would like to decide about treatment preferences today assuming that she/he has a serious disease?

Consider a situation with various treatment possibilities that may involve different health outcomes and associated risks (e.g. surgery or only medicinal treatment).

A. I think the patient prefers to make the decision on his own.

B. I think the patient prefers to make the decision mainly on his own after considering the arguments of the doctor for or against each treatment.

C. I think the patient prefers to make the decision together with the doctor.

D. I think the patient prefers that the doctor makes the decision about which treatment he will receive, after hearing the patient's opinion.

E. I think the patient prefers to leave the decision regarding treatment totally to the doctor.

Answers A and B were considered as an active role, C as collaborative and answers D and E as passive roles.