Hospital patients' preferences in decision-making

A questionnaire survey of 1040 patients from a Swiss university hospital

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Summary

Objectives: Assessing patients' preferences for shared decision-making and receiving information.

Design: Cross-sectional cohort study.

Setting: University Hospital in Northwest Switzerland.

Participants: 1825 in-patients (mean age: 58 years, 48.7% female) were asked to participate, 1040 patients responded (59%).

Main outcome measures: Proportion of positive answers to two questions depicting typical elements of shared decision-making plus a question asking for patients' information needs. These questions were embedded in a questionnaire sent to patients two weeks after discharge from the hospital, asking for perceived deficits during their hospital stay and socio-demographic characteristics.

Results: 779/947 (79.1%) agreed to the statement: "One should stick to the physician's advice even if one is not fully convinced of his ideas". 620/945 (65.6%) agreed to the statement: "It should completely be left to physicians to decide on a patient's treatment." 914/952 (96%) agreed to the statement: "Even when the news is bad the patient must be informed." Older patients and less educated patients are more likely to agree with the first two statements, patients with a non-Swiss cultural background favour the information needs statement slightly less than other patients (92.4 vs 96.7% agreement). The severity of illness had no influence on agreeing or not. However, patients who disagreed on any statement were more likely to report a lack of information from the hospital.

Conclusions: A substantial number of patients in this study wanted the physician to take medical decisions. Yet, almost all patients wanted honest information about their health status. Health professionals have to find out to what extent an individual patient wants to be involved in decision-making.

Key words: shared decision-making; information needs; in-hospital patients

Introduction

Within the context of patient-centred communication shared decision-making has become one of the shibboleth's in modern medicine [1–3]. This development is based upon ethical considerations respecting the patient as "unique human being" [4], or upon ethical arguments asking for a more balanced power distribution between patient and physician [5]. Stewart, Mead and Bower [1, 6] listed several components of patient-centred physician behaviour including an egalitarian attitude towards the patient, and the willingness to take into account biological, psychological, and social aspects of suffering – the biopsychosocial model [7].

Whether patient-centred communication yields positive results is a matter of debate [6, 8, 9]: Neither for the patient's satisfaction, enablement, nor medical outcome, the published evidence was clear. The most frequently quoted paper in favour of a patient-centred approach [10] investigated an intervention on the patients' side: if patients were taught to express themselves more clearly their health outcome improved. This paper rather supports the idea of teaching patients to communicate in a doctor-centred way than the reverse. The study by Kinmonth et al. [11] described that physicians could be taught successfully to follow a patient-centred consultation style, however, on most medical outcome data these patients fared worse than patients who were treated by doctors who be-

haved in a traditional way. The question whether patients wish to be involved in decision-making has yielded conflicting results. Based upon a patient questionnaire Little [12] stated that patients wanted their ideal doctor to: talk about their illness experience, be able to communicate, be interested in which treatment they wanted. On the other hand, McKinstry's [13] showed that in three out of five problems presented in video vignettes patients preferred doctors who made decisions!

Given this insecurity we investigated how in-hospital patients responded to two questions that depict typical elements of shared decision-making [14], namely the wish to be involved in medical decisions. Furthermore, we investigated whether information needs could be differentiated from the wish to participate in decision-making and to what extent these responses could be predicted by socio-demographic characteristics and patients' subjective health.

Methods

Patients and Instruments

Within a three months period all patients of the University Hospital of Basel received a letter two weeks after their discharge from the hospital asking them to fill in an enclosed questionnaire. Patients who did not respond to the first attempt were sent a second letter. 1825 patients were asked, 1040 patients responded (59% response rate). The following socio-demographic characteristics were assessed: age, education, living alone, gender, type of health insurance, (Swiss) German as mother tongue, cultural background, perceived success of treatment at the end of the hospital stay (5 point Likert scale from "much better than expected" to "much worse than expected"), and self rated health (4 point scale: very good, good, fair, bad).

We used a questionnaire that is based upon the German version of an instrument first published by Delbanco and Cleary [15–18]. The questions were grouped according to the different phases of hospitalisation. They centred on admission, in-hospital phase, and discharge; the total number of questions was 56 including socio-demographic items.

In the in-hospital part the questionnaire included three questions on patients' involvement in decision-making and on patients' information needs, which could be answered on a 4 point Likert scale: fully agree, slightly agree, slightly disagree, fully disagree. The questions were:

How much do you agree with the following statement:

A) "One should stick to the physician's advice even if one is not fully convinced of his ideas" (Follow physician's advice)

B) "It should completely be left to physicians to decide on a patient's treatment" (Physician should decide)

We also included a question targeting patients' information needs:

C) "Even when the news is bad the patient must be informed" (Information)

Furthermore, we asked patients to what extent they needed help with daily activities (sum score of 1 = yes/ 0 = no concerning: getting dressed, eating, to get from the bed to a chair, to get to the toilet, to take a bath or a shower, walking within the room, take a walk outside, using public transport).

Data analysis

The two positive and the two negative responses to each of the three questions were converted into a dichotomous variable (agree or disagree) for further analysis.

The inter-correlation of the three questions showed that information needs were not highly correlated with the two other items (Pearson's correlation coefficient r <.10), while these were moderately correlated which each other (r = .51).

In a two-step explorative approach all three questions were analysed separately on a bivariate level (ANOVA or correlation analysis) with the eleven socio-demographic parameters to establish predictor candidates for the multivariate analyses. In a second step multivariate estimation models for the prediction of patient preferences and on patients' information needs were built in a stepwise process using the predictor candidates established (multivariate logistic regression, forward stepwise procedure, PIN <0.05, POUT >0.10 in the likelihood ratio [LR] test). All statistical analyses were run on SPSS10. Logistic regression modelling followed the suggestions of Hosmer & Lemeshow [19]. Furthermore, sociodemographic data were compared to the total sample of patients being treated in 2001 at our institution (N = 24.264) to analyse whether there was a significant sampling bias.

Results

Data were gathered in the Department of Surgery (n = 514), in the Department of Gynaecology and Obstetrics (n = 77), in the Department of Internal Medicine (n = 330), in the Neurology and in the Dermatology Department (n = 106). For 13 patients allocation was missing. Assignments to clinics had no effect on the relationships reported in this paper. Socio-demographic characteristics of included patients are listed in table 1.

Mean age in the total sample of patients sub-mitted to the University Hospital in 2001 is 57.0 years (SD = 19.9, Median = 59, Range = 14–104, IQR = 33) and thus, lower than in the survey sample. Females are slightly underrepresented in the study cohort: 49% as compared to 52.7% in the total sample.

As table 1a shows especially young females are underrepresented in the study cohort (27.9% vs 35.9% in total) due to a lower recruitment rate in the gynaecology clinic (7.5% of the patients in the

study sample compared to 13.2% in the group of all patients).

The distribution of patients' responses to the three specific questions is listed in table 2.

Of the socio-demographic variables described in table 1 the following three contributed significantly (LR-test at least p <0.05) to the responses concerning Follow your physician's advice in the multivariate model: age (persons with higher age were more likely to agree to the statement), edu-

cation (persons with shorter education were more likely to agree), and perceived success of treatment (the higher the success the more likely an agreement). Percentages of agreement to question A according to age, education and perceived success of treatment are shown in figures 1 to 3 respectively. Coefficients and overall model parameters of the multivariate regression model are given in table 3.

Of the socio-demographic variables described in table 1 the following five variables contributed

Table 1

Sociodemographic characteristics.

Parameter	Type of measurement	Descriptives
Age	Continuous (years)	Mean = 58.0, SD = 18.3; Range = 14–98, Median = 61, IQR = 28
Education	Ordinal: 3 categories	<10 years: 24.5%, 10–15 years: 51.1%, >15 years: 24.3%
Living alone	Dichotomous: yes / no	Alone: 27.2%
Gender	Dichotomous: male / female	Female: 48.7%
type of health insurance	Dichotomous: private / not private	Private Ins.: 17.4%
(Swiss) German as mother tongue	Dichotomous: yes / no	Swiss German: 71.2%
from another cultural background	Dichotomous: yes / no	Other culture: 15.3%
perceived success of treatment	Ordinal: 5-point Likert (1 = much better – 5 much worse than expected)	Mean = 2.32, SD = 1.01
self rated health	Ordinal: 4-point Likert (1 = very good – 4 = bad)	Mean = 2.23, SD = 0.80
help needed at admission	Sumscore 0–8 out of 8 dichotomous items	no help needed: 71%, Mean = 0.90, SD = 1.83; if help needed: Median = 2
help needed at discharge	Sumscore 0-8 out of 8 dichotomous items	No help needed: 80%, Mean = 0.54, SD = 1.39 if help needed: Median = 2

Table 1a

Patient distribution by age and gender in survey sample and for all patients submitted to the hospital in 2001.

Age / gender	Male		females		total	
	survey	total	survey	total	survey	total
Up to 44 years	23.4%	23.2%	27.9%	35.9%	25.6%	29.9%
45–60 years	23.8%	27.6%	23.5%	18.4%	23.7%	22.7%
61–72 years	28.6%	25.7%	23.1%	16.8%	25.9%	21.0%
73 and more years	24.2%	24.2%	25.6%	28.9%	24.9%	26.4%
total	100%	100%	100%	100%	100%	100%

Table 2

Patients' responses to shared-decision making preferences and information needs.

Question	Fully agree	Slightly agree	Slightly disagree	Fully disagree	Valid N
A) One should stick to the physician's advice even if one is not fully convinced of his ideas	441 (43.4%)	338 (35.7%)	115 (12.1%)	83 (8.8%)	947 (100%)
B) It should completely be left to physicians to decide on a patient's treatment	321 (34.0%)	299 (31.6%)	173 (18.3%)	152 (16.1%)	945 (100%)
C) Even when the news is bad the patient must be informed	830 (87.2%)	84 (8.8%)	25 (2.6%)	13 (1.4%)	952 (100%)

Table 3

Multivariate estimation model for question A) Follow physician's advice. Only significant predictors included.

Predictor variable (in order of inclusion)	b	SE (b)	Sig (LR)	OR	95% CI
Level of education (in years, 3 levels)	–0.605	0.134	<0.001	0.546	0.419–0.711
Age (in years)	0.023	0.005	<0.001	1.024	1.014–1.034
Perceived success of treatment (5 levels)	–0.253	0.085	<0.01	0.777	0.657–0.918

Numerical coding:
Level of education: three levels, <10 years (coded as 1), 10–15 years (2) 15+ years (3)
Age: measured in years of age (range = 14–98), coefficients given are for 10 years
Perceived success of treatment: five levels, from much better than expected (1) to much worse than expected (5)
Legend: b = Regression coefficient; SE(b) = Standard error (b); Sig (LR) = significance of Likehood-ratio test for variable;
OR = Odds ratio; 95% CI = 95% Confidence interval (lower and upper limit) for OR.
Overall model parameters: (N[valid] = 806, G[model] = 61.1, df = 3, p <0.001; Hosmer-Lemeshow's C = 4.8, df = 8, p >0.70;
Nagelkerkes R^2 = 0.11).

Table 4

Multivariate estimation model for question B) Physician should decide. Only significant predictors included.

Predictor variable (in order of inclusion)	b	SE (b)	Sig (LR)	OR	95% CI
Age (in years)	0.030	0.005	<0.001	1.031	1.022–1.040
Level of education (in years, 3 levels)	–0.631	0.123	<0.001	0.532	0.418–0.677
Mother Tongue Swiss German (dich.)	0.772	0.190	<0.001	2.163	1.492–3.137
Perceived success of treatment (5 levels)	–0.277	0.077	<0.001	0.785	0.652–0.881
Gender (dich.)	–0.502	0.166	<0.01	0.605	0.437–0.838

Numerical coding:
Age: measured in years of age (range = 14–98), coefficients given are for 10 years
Level of education: three levels, <10 years (coded as 1), 10–15 years (2) 15+ years (3)
Mother Tongue Swiss German: yes (1), no (2)
Perceived success of treatment: five levels, from much better than expected (1) to much worse than expected (5)
Gender: male (1), female (2)
Legend: b = Regression coefficient; SE(b) = Standard error (b); Sig (LR) = significance of Likelhood-ratio test for variable;
OR = Odds ratio; 95% CI = 95% Confidence interval (lower and upper limit) for OR.
Overall model parameters: (N[valid] = 789, G[model] = 119.6, df = 5, p <0.001; Hosmer-Lemeshow's C = 14.5, df = 8, p = 0.05;
Nagelkerkes R^2 = 0.19). Deletion of parameter "gender" (last to get into model) would improve Hosmer-Lemeshow's C to: 7.4
(df = 4, p >0.45).

Table 5

Multivariate estimation model for question C) Information (even if bad news). Only significant predictors included.

Predictor variable (in order of inclusion)	b	SE (b)	Sig (LR)	OR	95% CI
Other cultural background (dich.)	0.874	0.387	< 0.05	2.397	1.123–5.114

Numerical coding:
Other cultural background: yes (1), no (2)
Legend: b = Regression coefficient; SE(b) = Standard error (b); Sig (LR) = significance of Likelihood-ratio test for variable;
OR = Odds ratio; 95% CI = 95% Confidence interval (lower and upper limit) for OR.
Model parameters: (N[valid] = 888, G[model] = 4.5, df = 1, p <0.05; Hosmer-Lemeshow's C = not available; Nagelkerkes R^2 = 0.02).

significantly (LR-test at least p <0.05) to the responses concerning The physician should decide on my treatment: age (persons with higher age were more likely to agree to the statement), education (persons with shorter education were more likely to agree), perceived success of treatment (the higher the success the more likely an agreement), Swiss German as mother tongue (persons having a foreign language were more likely to agree) and gender (men were more likely to agree). Model parameters: (N[valid] = 789, G[model] = 119.6, df = 5, p <0.001; Hosmer-Lemeshow's C = 14.3, df = 8, p >0.05; Nagelkerkes R^2 = 0.19). Coefficients for the model are given in table 4.

Only one socio-demographic variable described in table 1 contributed significantly to the responses to the question concerning information needs. In the bivariate as well as in the multivariate analysis a slightly more pronounced agreement was found in persons with a different cultural background. However, due to the strong ceiling effect

explanation of variance was limited. Model parameters: (N (valid) = 888, G (model) = 5.5, df = 1, p <0.05; Hosmer-Lemeshow's C = not available; Nagelkerkes R^2 = 0.02). Model parameters are given in table 5.

Figure 1 illustrates the percentage of agreement to the three questions A, B and C by age groups (quartiles circa). 95% confidence intervals for the values measured are given too.

Figure 2 shows the percentages of agreement to the three questions by years of education, while figure 3 shows the relationship between the percentages of agreement and the parameter perceived success of treatment.

An important negative finding related to the relationship between help needed at admission or at discharge: even though the responses to these items varied substantially they had no influence upon patients' preferences for shared decision-making or information needs.

As age and gender have an influence on the

Figure 1

Patients' preferences for: A) Follow physician's advice, B) Physician should decide, and C) Information (even if bad news) by age groups.
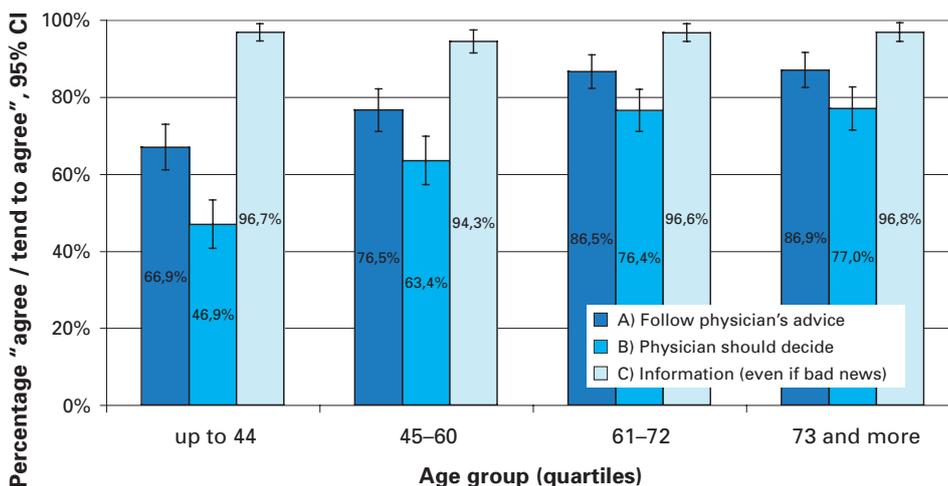
percentage of affirmative responses we calculated adjusted rates taking into account the difference between the study sample and the whole patient sample in 2001. For statement A) the age-adjusted rate would be 78.5% instead of 78.1%; for statement B the age and gender-adjusted rate would be 64.8% instead of 65.5%.

Discussion

Taken together the data indicate that a substantial proportion of patients did not favour shared decision-making. However, as younger age and higher education increase patients' wish to be involved, this picture might change in the future. Yet, another point emerges quite clearly: all patients unanimously wanted information!

Basically, our data corroborate the findings of McKinstry [13], indicating that in more acute or more severe clinical problems patients are inclined to hand over responsibility to their physician. Along this line patients who are so ill that they need hospitalisation favour a physician who takes over responsibility for medical decisions – which is the main result of our investigation. However, this does not seem to be a simple linear relation: if we assume that the amount of help needed at admission and at discharge is a good indicator of the

severity of a clinical condition, this does not influence patients' preferences. Thus, if a relationship exists between the severity of a disorder and the tendency to hand over responsibility, as suggested by some authors (eg [14]), this is not obviously so within a cohort of clinic patients. On the other hand patients do not provide their physicians with a free ticket for taking over responsibility: if they view their status of health as worse than anticipated, they are more prone to make decisions autonomously.

A major critique of the findings could be a too limited approach of the patients' preferences. However, neither the theoretical construct of shared decision-making nor the methodology of its assessment is well defined; no golden standard exists [14]. Social desirability might have biased the responses [20]. We tried to reduce this type of bias
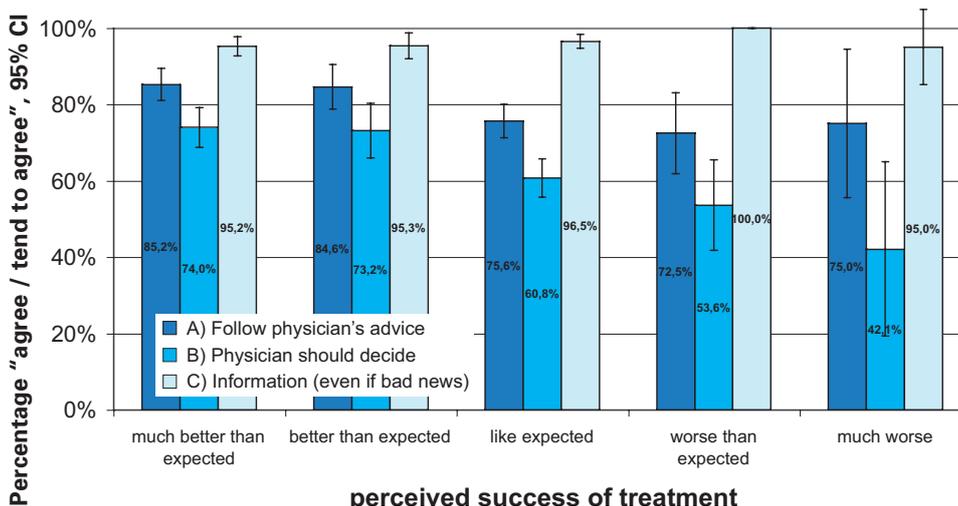
Figure 2

Patients' preferences for: A) Follow physician's advice, B) Physician should decide, and C) Information (even if bad news) by years of education (grouped).
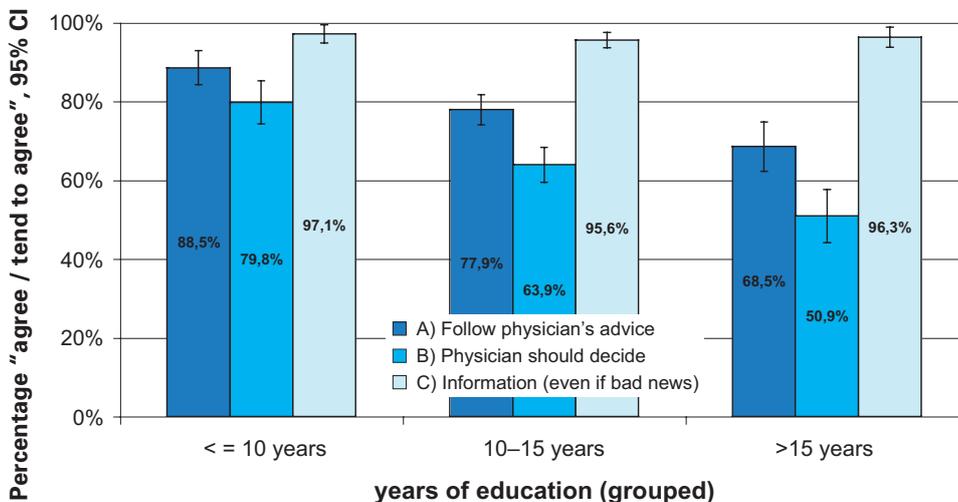
Figure 3

Patients' preferences for: A) Follow physician's advice, B) Physician should decide, and C) Information (even if bad news) by perceived success of treatment.

by postponing sending the questionnaire by two weeks after discharge from the hospital and by avoiding any personal contact between a member of the research team and patients. Based on the lack of an association between patients' desire and preference for shared decision-making, we think that social desirability did not induce a substantial bias in our patient sample. Another problem with the current data is the lack of information on non-responders. We do not know in which regard patients who did not respond differ from those who sent in the questionnaires. In research on patient satisfaction non-responders pose a major problem because it is assumed that patients who are the least satisfied do not bother to fill out a questionnaire. However, we have no good reason to assume that a similar sampling bias significantly distorts the responses to the three questions under study in this paper [19]. The practical implications of our results are the following: it is impossible to predict patients' preferences for shared decision-making. A majority of hospital patients wants their physicians to take over responsibility. An open exchange of options and defining personal preferences will help to identify those patients. This leads to what we call the communication paradox: without a patient-centred approach the health care professional will never find out whether an individual patient wants a paternalistic physician or nurse for the remainder of the interaction. This conclusion does not weaken the basic right of every patient to receive high quality, individualised and accessible information.

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