Hospitals need to customise care according to patients' differing information-seeking behaviour

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ABSTRACT

INTRODUCTION: The aim of the study was to describe how often patients seek information about their disease in connection with contact to a hospital and to elucidate how information-seeking behaviour is related to the patients' perception of this contact.

MATERIAL AND METHODS: The study was based on patient surveys from the Danish county of Aarhus from 1999 to 2006 including eight public hospitals. The patients' information-seeking behaviour was related to patient characteristics, organisational context and patient perceptions.

RESULTS: Among the 75,769 patients who responded, 33.4% had actively sought information. The frequency of patients seeking information increased from 24.4% in 1999 to 38.3% in 2006 with a variation between organisational units ranging from 7.7% to 81.8%. The share of critical patients among those who actively sought information was 23.7% in 1999 and 18.1% in 2006 compared with 12.9% and 11.3% critical patients, respectively, among those who did not.

CONCLUSION: Having sought information correlated with negative patient perceptions. Despite convergence, differences between the perceptions of active and passive information seekers still remain. The health-care system should be prepared to serve patients who have different levels of knowledge.

PRACTICE IMPLICATIONS: The health-care system should continuously improve the service provided to patients with different levels of knowledge and different attitudes towards involvement. It is recommended to routinely ask patients about their information seeking and to include questions about patients' information seeking behaviour in patient satisfaction surveys.

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Patients are increasingly interested in taking responsibility when consulting health-care professionals [1] and technological developments have allowed many patients easy access to a large amount of diverse health information. Therefore, we have to realise that patients now and in the future will have different attitudes and qualifications for participating in decisions about their treatment [2]. Recommendations encouraging greater patient involvement must be viewed from within the context of the individual patient's wishes and situation [3]. The question of whether the health professionals have succeeded in meeting the needs of the individual patients should also address how patients with differing information seeking behaviour perceive their contact with the professionals [4, 5].

Until now, research has mainly focused on which factors encourage patients' information-seeking behaviour or how they search for health information. Empirical studies of the effect on outcome measures of different patient information seeking behaviours have therefore been recommended [6, 7].

To our knowledge, no study has been published on patient information-seeking behaviour and patient perception. It might be expected that increased information-seeking would improve patients' perception of their treatment based on the experiences of involvement and empowerment projects [8]. Conversely, it may be argued that active information-seeking, including internet searching, could result in a more critical attitude among patients, thereby causing defensive reactions from professionals [9]. Finally, the most critical patients might also be the ones most inclined to seek information in order to check the professionals.

The present study aims to investigate how often patients seek information about their disease in connection with contact to a hospital and how information-seeking behaviour is related to their perception of this contact.

MATERIAL AND METHODS

The article is based on data collected in Aarhus County from 1999 to 2006 as a part of patient satisfaction surveys. Both doctors and nurses were represented in a steering committee that determined the principles of the survey system, and the work was carried out by internal consultants employed by the county. The surveys were conducted in four rounds: 1999, 2001, 2003 and 2005. In 1999, the County had eight hospitals with 2,200

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TABLE 1

Percentage proportions of patients who actively sought information about their disease, 1999-2006 (N = 75,769).

	Inpatients (n = 30,857)	Outpatients (n = 33,378)	Surgical day patients (n = 3,675)	Medical day patients (n = 4,298)	Total (n = 72,208)
Round[a]					
1999-2000	25.9	30.6	17.7	37.6	28.4
2001-2002	29.0	36.0	24.0	40.4	32.7
2003-2004	30.4	37.9	30.6	43.3	34.6
2005-2006	33.6	42.2	34.6	46.1	38.3
Gender[a]					
Male	27.6	33.1	23.3	38.0	30.5
Female	31.4	39.6	30.3	44.8	36.0
Age group[a]					
0-18 yrs	35.5	44.3	18.5	45.2	39.1
19-39 yrs	39.7	46.8	31.1	63.7	43.6
40-59 yrs	39.2	43.7	30.5	51.2	41.6
60-69 yrs	25.4	29.4	18.8	33.8	27.6
70-79 yrs	16.3	18.2	10.8	20.8	17.4
≥ 80 yrs	8.5	12.8	8.8	11.7	10.2
Native language[a]					
Danish	29.8	36.9	27.6	41.5	33.6
Non-Danish	24.2	29.0	24.7	35.9	27.2
Education[a]					
No advanced education	22.1	27.0	18.2	31.9	24.8
Advanced education	44.3	49.6	36.9	60.6	47.6
Total	29.6	36.6	27.5	41.5	33.4

a) Statistically significant differences for all four groups of patients: $p < 0.001$, χ^2-test.

beds (132,000 discharges and 568,000 ambulatory visits).

The study included questionnaires for inpatients, outpatients and medical and surgical day patients in 49 departments. The four questionnaires were validated through cognitive interviews with 66 patients. The development of the surveys has been described in detail in a previous article [10].

The main purpose of the survey was to secure feedback from the patients to local departments. For most departments, all patients in the inclusion period were selected for the relevant subgroups. Departments with more than 400 patients in a subgroup, typically departments with internal medicine patients, participated with a sample of 400 patients selected at random from the patient registration system using the Danish 10-digit person identification number. All selected patients were mailed a questionnaire by the departments they had attended during the previous three months.

Some patients seek health information – others do not. Does this make a difference?

A department could use more than one type of questionnaire; typically, one was used for inpatients and another for ambulatory patients. The surveys were anonymous and no reminders were sent.

In all four questionnaires, one question assessed the patient's active information-seeking behaviour: "Have you personally sought information about your disease via patient associations, libraries or the Internet? (i.e. places other than the hospital or your own personal physician/specialist)". The response options were: "Have sought information" and "Have not sought information". Information-seeking behaviour encompasses an active choice by the patient to seek information and not just a general inclination to receive more information.

In addition, the questionnaires included a question concerning the patient's overall perception of the contact: "What is your overall impression of unit NN?", and 9-15 specific questions with an option to comment.

Analysis

The answers to the overall question were dichotomised, and patient scores of "Exceptional" and "Good" were coded as "Patients with no critical perceptions", where-

as patients answering "Good and bad", "Bad" or "Unacceptable" were coded as "Patients with critical perceptions".

Differences in active information-seeking behaviour were analysed for partial correlations with background variables using a $\chi 2$-test for trend. Correlations were also tested in a logistic regression model for inpatients and outpatients.

The patient's inclination to seek information was seen as a dichotomous dependent variable, and background variables expected to predict an inclination to seek information were seen as category covariates. For each patient category, we calculated an unadjusted odds ratio (OR) and an OR adjusted for background variables. For the ORs, the 95% confidence intervals (CI) and the p-values ($\chi 2$) are given.

The adjusted correlation coefficient for the estimated model is expressed with the correlation coefficient (Nagelkerke) as the ability of the estimated model to predict a patient's inclination to seek information. The model was estimated in SPSS version 17.00 using binary logistics.

Furthermore, a logistic regression analysis was conducted across the four questionnaires for each survey round in which overall perception was explained by the patient's information-seeking behaviour, age, gender, education, native language and patient type.

Trial registration: not relevant.

RESULTS

The response rates across the four rounds were 53.5% for inpatients, 57.9% for outpatients, 57.8% for medical day patients and 59.9% for surgical day patients. A total of 75,769 responses were received.

Patient information-seeking behaviour

The percentage of all patients actively seeking information in connection with their disease was 33.4 with an increasing trend from 1999 to 2006 for all four patient types ($p < 0.001$) (**Table 1**).

In all four patient groups, women sought information more often than men ($p < 0.001$). Both further (advanced) education and a younger age were associated with higher frequencies of information-seeking ($p < 0.001$ for both), with almost no information-seeking behaviour occurring in the oldest patients. Native Danish-speaking patients were slightly more active information-seekers than patients whose native language was not Danish (33.6% versus 27.2%).

Information-seeking behaviour was positively associated with several factors, i.e. being an in-patient and a female, having further (advanced) education, being a

TABLE 2

Active information-seeking behaviour among inpatients, 1999-2006. Logistic regression.

	n	Patients who actively searched information, %	Odds ratio unadjusted	adjusted[a]
Round				
1 (ref.)	8,053	25.9	1	1
2	8,129	29.0	1.17 (1.09-1.25)***	1.15 (1.06-1.25)**
3	7,247	30.4	1.25 (1.17-1.34)***	1.19 (1.09-1.29)***
4	7,428	33.6	1.45 (1.35-1.56)***	–
Gender				
Male (ref.)	14,531	27.6	1	1
Female	16,196	31.4	1.20 (1.15-1.26)***	1.16 (1.08-1.25)***
Age group				
0-19 yrs	3,200	35.5	5.90 (5.09-6.85)***	5.77 (4.44-7.49)***
20-39 yrs	5,292	39.7	7,08 (6.15-8.15)***	6.30 (5.12-7.77)***
40-59 yrs	8,433	39.2	6.93 (6.04-7.94)***	5.89 (4.81-7.21)***
60-69 yrs	5,683	25.4	3.67 (3.18-4.23)***	3.38 (2.74-4.16)***
70-79 yrs	5,077	16.3	2.09 (1.80-2.43)***	2.07 (1.67-2.57)***
≥ 80 yrs (ref.)	2,935	8.5	1	1
Education				
Advanced education	5,795	44.3	2.80 (2.62-2.98)***	2.29 (2.12-2.46)***
No advanced education (ref.)	15,217	22.1	1	1
Native language				
Danish (ref.)	29,203	29.8	1	1
Non-Danish	1,009	24.2	0.75 (0.65-0.87)***	0.68 (0.55-0.84)***
Type of admission				
Emergency	15,784	26.2	0.68 (0.64-0.71)***	0.59 (0.55-0.64)***
Scheduled (ref.)	13,962	34.4	1	1
Experience from before				
1 time (ref.)	18,259	28.3	1	1
2 times	5,499	28.4	1.01 (0.94-1.08)[b]	1.31 (1.15-1.50)***
3 times	2,222	32.8	1.24 (1.13-1.26)***	1.08 (0.98-1.19)[b]
> 3 times	3,523	39.5	1.66 (1.54-1.79)***	1.71 (1.54-1.91)***
Filled out by				
Patient (ref.)	25,869	30.1	1	1
Relative	4,730	27.0	0.86 (0.80-0.92)***	0.88 (0.76-1.02)[b]
Specialty				
Orthopaedic surgery (ref.)	3,767	21.8	1	1
Medicine	5,638	26.4	1.29 (1.17-1.42)***	2.16 (1.88-2.48)***
Gynaecology	2,704	34.7	1.91 (1.71-2.13)***	1.42 (1.22-1.66)***
Parenchymal surgery	3,818	28.1	1.41 (1.27-1.56)***	1.44 (1.25-1.67)***
Paediatrics	2,038	38.7	2.27 (2.01-2.55)***	2.81 (1.88-4.20)***
Medical specialty	6,968	35.0	1.93 (1.76-2.12)***	2.47 (2.17-2.81)***
Surgical specialty	4,909	28.1	1.41 (1.27-1.55)***	1.43 (1.25-1.64)***
Other	820	17.1	0.74 (0.61-0.90)**	0.99 (0.78-1.26)[b]
Overall assessment				
5 stars	8,629	24.9	0.1 (0.77-0.86)***	0.80 (0.74-0.87)***
4 stars (ref.)	16,543	28.9	1	1
3 stars	4,145	39.2	158 (1.47-1.70)***	1.37 (1.24-1.51)***
2 stars	514	46.7	2.15 (1.81-2.57)***	1.81 (1.41-2.33)***
1 star	408	54.2	2.91 (2.38-3.54)***	2.48 (1.87-3.29)***
Added comment				
Yes	10,328	32.5	1.60 (1.52-1.70)***	1.27 (1.17-1.38)***
No (ref.)	22,481	23.1	1	1
Total	30,857	29.6	–	–

) $p < 0.01$; *) $p < 0.001$. 18.4% of the searches are explained (Nagelkerke).
a) Adjusted for round, gender, age, education, native language, type of admission, experience, filled out by, specialisation, overall assessment and comment added. b) Statistically non-significant.

TABLE 3

Active information-seeking behaviour among outpatients 1999-2006. Logistic regression.

	n	Patients who use the internet, %	Odds ratio unadjusted	adjusted[a]
Round				
1 (ref.)	8,447	30.6	1	1
2	8,560	36.0	1.28 (1.20-1.36)***	1.26 (1.17-1.36)***
3	8,001	37.9	1.39 (1.30-1.48)***	1.42 (1.31-1.54)***
4	8,370	42.2	1.66 (1.55-1.76)***	–
Gender				
Male (ref.)	14,943	33.1	1	1
Female	18,288	39.6	1.32 (1.26-1.38)***	1.21 (1.13-1.29)***
Age group				
0-19 yrs	3,070	44.3	5.44 (4.67-6.35)***	3.65 (2.81-4.75)***
20-39 yrs	7,150	46.8	6.01 (5.21-6.95)***	4.30 (3.48-5.31)***
40-59 yrs	10,546	43.7	5.32 (4.61-6.13)***	4.76 (3.88-5.84)***
60-69 yrs	5,895	29.4	2.84 (2.45-3.30)***	2.58 (2.09-3.20)***
70-79 yrs	4,584	18.2	1.52 (1.30-1.78)***	1.51 (1.21-1.88)***
≥ 80 yrs (ref.)	1,851	12.8	1	1
Education				
Advanced education	7,553	49.6	2.70 (2.55-2.86)***	2.38 (2.23-2.55)***
No advanced education (ref.)	14,233	26.7	1	1
Native language				
Danish (ref.)	31,373	36.9	1	1
Non-Danish	1,241	29.0	0.70 (0.62-0.79)***	0.65 (0.54-0.78)***
Experience				
1 time (ref.)	7,309	29.5	1	1
2-3 times	10,061	34.2	1.24 (1.16-1.33)***	1.25 (1.14-1.37)***
4-9 times	9,984	41.7	1.71 (1.61-1.82)***	1.69 (1.54-1.86)***
> 9 times	4,680	45.7	2.01 (1.86-2.17)***	1.98 (1.77-2.21)***
Filled out by				
Patient (ref.)	29,415	36.4	1	
Relative	3,628	37.3	1.04 (0.97-1.11)[b]	Insignificant in the model
Specialty				
Orthopaedic surgery (ref.)	4,036	26.0	1	1
Medicine	5,908	43.9	2.22 (2.04-2.43)***	2.57 (2.27-2.91)***
Gynaecology	2,618	42.9	2.14 (1.93-2.38)***	1.65 (1.42-1.91)***
Parenchymal surgery	3,304	29.2	1.17 (1.06-1.30)**	1.39 (1.20-1.60)***
Paediatrics	1,318	60.3	4.32 (3.79-4.93)***	6.04 (4.41-8.27)***
Medical specialty	8,425	41.5	2.02 (1.86-2.19)***	2.20 (1.95-2.47)***
Surgical specialty	6,667	28.6	1.14 (1.04-1.24)**	1.36 (1.20-1.54)***
Other	671	20.0	0.71 (0.58-0.87)***	1.13 (0.87-1.46)[b]
Overall assessment				
5 stars	7,917	31.2	0.81 (0.76-0.85)***	0.81 (0.75-0.88)***
4 stars (ref.)	20,112	36.0	1	1
3 stars	4,012	48.0	1.64 (1.53-1.76)***	1.48 (1.34-1.62)***
2 stars	424	61.3	2.82 (2.32-3.44)***	2.40 (1.83-3.16)***
1 star	243	56.8	2.34 (1.81-3.02)***	2.46 (1.75-3.48)***
Added comment				
Yes	22,659	40.0	1.60 (1.52-1.68)***	1.24 (1.15-1.33)***
No (ref.)	10,718	29.5	1	1
Total	33,378	36.6	–	–

) p < 0.01; *) p < 0.001. 19.6% of the searches are explained (Nagelkerke).
a) Adjusted for round, gender, age, education, native language, experience, filled out by, specialty, overall assessment and added comment. b) Statistically non-significant.

Danish native speaker and having an inclination to comment (**Table 2** and **Table 3**).

In 2006, the frequency of patients seeking information ranged from 12.1% to 55.6% in the different inpatient departments (n = 39) and from 7.7% to 81.8% in the outpatient clinics (n = 77). Overall, active information-seeking was highest for both paediatric inpatients and outpatients, followed by medical and gynaecological patients, with the least information-seeking behaviour occurring among orthopaedic patients.

Active information-seeking and patient perceptions

Table 4 presents an analysis of active information-seeking correlated with overall patient perception in the four survey rounds after controlling for age, gender, education, native language, and patient type. The correlation between actively having sought information and assessing the unit negatively decreased significantly during the four rounds. For patients who actively sought information, the proportion of critical patients was 23.7% in 1999 and 18.1% in 2006; and for those not actively seeking information, the proportion was 12.9% and 11.3%, respectively.

In all four survey rounds, a significant difference was observed in the overall patient perceptions of seekers and non-seekers, respectively. This difference diminished over time, both for un-adjusted and adjusted ORs. A significant correlation between the proportion of critical patients and active information-seekers at ward level was found only in the first round ($r = 0.28$; $p = 0.01$), but not in the three subsequent rounds ($r = 0.10$; $p = 0.32$), ($r = 0.13$; $p = 0.20$) and ($r = 0.13$; $p = 0.21$).

DISCUSSION

The study showed that more than one-third of the hospitals' patients had actively sought health information from sources other than their physician or their hospital, and that active information-seeking increased over time. Outpatients and medical day patients were the most active information seekers, partly because their contacts are scheduled which allows them to seek information both before and after the consultation.

The proportion of patients with critical perceptions was higher among active than less active patients. However, there appeared to be a trend towards convergence in the sense that the proportions of critical perceptions of active and passive patients levelled out over time. The results indicate that the professionals seemed to be mastering a type of patient-centred communication sensitive to the different patient needs [3].

Different specialties seem to stimulate patients to seek information differently. Orthopaedic patients seek relatively little information, while paediatric patients

seek information more often. Thus, professionals with different specialisations may experience different organisational conditions that favour the use of different forms of consultation practices.

The timely association between information-seeking activity and patient perception has three potential explanations: 1) health-care professionals may have improved their communication with the active patient who has independently sought out health information; 2) active patients may have undergone a change from autonomous information-seekers to patients seeking information also on the professional's initiative [11]; and 3) The internet is changing constantly; it is not written in stone, but, rather, in line with the entire health-care field, it is constantly subject to competing logics [12]. If web sites increasingly contain professional knowledge and commercial information, they may have lost some of their potential for creating conflicts. Based on the available data, it is not possible to determine which, if not all, of the three mentioned explanations are relevant.

Though patients' information seeking is theoretically important, it is a phenomenon that is often not visible in the clinic. There are reports of patients who refrain from disclosing knowledge gained from the Internet [13, 14], which indicates that the purpose could be to obtain tacit control of the professionals [14, 15] or that they consider it controversial to put forward such knowledge [16, 17]. Thus patients may still behave as passive patients even though they have knowledge that would allow them to participate in an interactive consultation with the health professional [18].

The differences in perception expressed by active and passive patients in patient satisfaction surveys may provide important information for all health-care organisations. Huge differences in patient perception between active and passive patients may indicate a need for fundamental changes in how the two groups of patients are handled. Conversely, if there is only a minor difference, this may indicate that the organisation is able to deliver customised services that reflect the different needs of the two groups.

However, patients' activity levels are rarely assessed in patient surveys.

Our analysis of response rates among different groups of patients showed marginally higher rates among females and younger patients. This may indicate that patients' information-seeking behaviour is marginally overestimated in the present study. On the contrary, there are no signs of bias on overall patient perceptions. A recent study of selection bias in a Danish patient study showed no signs of severe selection bias among responders and non-responders according to perception [19].

TABLE 4

Correlation between active information-seeking behaviour and patients with critical perceptions, 1999-2006. Inpatients, outpatients, surgical day patients and medical day patients. Logistic regression.

All patient groups	n (N = 70,799)	Proportion of dissatisfied patients, %	Odds ratio unadjusted	adjusted[a]
Round 1 (1999/2000)				
Sought information	5,153	23.7	2.09 (1.93-2.27)***	1.81 (1.65-1.99)***
Did not seek (ref.)	12,918	12.9	1	1
Round 2 (2001/2002)				
Sought information	5,991	20.6	1.92 (1.77-2.09)***	1.68 (1.52-1.85)***
Did not seek (ref.)	12,249	11.9	1	1
Round 3 (2003/2004)				
Sought information	5,983	19.2	1.66 (1.52-1.81)***	1.55 (1.40-1.71)***
Did not seek (ref.)	11,184	12.5	1	1
Round 4 (2005/2006)				
Sought information	6,681	18.1	1.74 (1.59-1.90)***	1.61 (1.47-1.76)***,[b]
Did not seek (ref.)	10,640	11.3	1	1

***) $p < 0.001$.
a) Adjusted for gender, age, education, patient type and native language.
b) Not adjusted for education due to insufficient data.

Another potential methodological reservation is that the study is based solely on an analysis of a single question that distinguishes active patients from passive patients based on their information-seeking behaviour. We do not know if the information seeking stems from the internet or from other sources. The question, then, only offers a rough measurement because no consideration was given as to the issues of when, where, how, or to the quantity of information being sought. But we find it important that the level of information-seeking behaviour is consistent with other studies into citizens seeking health information online [7, 20].

Given the methodological reservations, the results indicate that it is possible for medical professionals to meet the various needs of the individual patients to some degree [5]. This positive result of the analysis cannot be generalised because it may depend on the specific context, including the governance systems used at the national or county level.

CONCLUSION

The study indicates that, over time, a large health-care system can respond in such a way that the number of negative patient perceptions among information-seeking patients can be reduced, while at the same time the perceptions of the non-information-seeking patients remain unchanged.

The health-care system needs to continuously improve its capacity to serve patients with differing levels of knowledge and different attitudes towards involvement because these patients create a need to customise

consultations and place demands on the health-care professionals' communication skills. The present study indicates that it is, indeed, possible to suit the preferences of different patients. It is recommended to routinely ask patients about their information seeking and to include questions about the patients' information seeking behaviour in future patient satisfaction surveys.

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