

# Hospitalised patients' awareness of their rights: a cross-sectional survey from a tertiary care hospital on the east coast of Peninsular Malaysia

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## ABSTRACT

**Introduction:** Optimal patient care varies considerably from place to place and is influenced by scientific as well as social developments. The purpose of this study was to investigate awareness and pertinent issues regarding informed consent among hospitalised patients and to determine lapses, in order to improve the standard of care.

**Methods:** A questionnaire-based cross-sectional survey was conducted among inpatients at a tertiary care level hospital.

**Results:** 90 percent of patients were aware of their rights, and 85 percent had enough information regarding their illness and modality of treatment. However, treatment options were discussed with 45 percent of cases only, and 65 percent of patients were informed of their duration of treatment. Most of the patients from the surgical group, haemodialysis unit and those with minor ailments were very satisfied with the doctors (92 percent, 86 percent and 96 percent, respectively), as opposed to only 36 percent of cancer patients and 70 percent of acquired immunodeficiency syndrome (AIDS) patients (p-value is less than 0.0001). Almost all patients (99 percent) said that their religious beliefs were respected by the staff and they had no problems in accessing them in times of need. Informed consent was obtained by the doctor in 98 percent of cases and by the nurse in two percent. 98 percent of the patients mentioned that their treatments/examinations were conducted in an atmosphere of privacy and that their personal information was kept confidential by their doctors.

**Conclusion:** Patients were reasonably informed about their illness. Their privacy and religious beliefs were duly respected. Treatment options and the duration of treatment were not discussed

with all patients. Cancer and AIDS patients were less satisfied with the attending staff. The results suggest that there is a need for periodic surveys of patient satisfaction with the quality of care.

**Keywords:** informed consent, patient-centred care, patient confidentiality, patients' privacy, patients' rights

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## INTRODUCTION

The remarkable advances in medicine, nursing and scientific information during the last century have resulted in dramatic changes in the practice of medicine. With increasing sub-specialisation and high technology, doctors do take care of their patients but do not really "care" for them.<sup>(1)</sup> They rely more on sophisticated tests rather than on obtaining a high quality history and physical examination.<sup>(2,3)</sup> The medical history provides enough information to make an initial diagnosis in approximately 80% of cases and for that, one needs good communication in order to gain the patients' trust. Mutual trust is essential to the doctor-patient relationship, since patients who trust their doctors are more likely to be open with their doctors and derive the maximum therapeutic benefits. In the last decade, rapid changes in the healthcare delivery system and the social climate have resulted in considerable strain on this relationship. Studies have shown that communication skills, being caring, providing comfort and technical competence are the physician behaviours most strongly associated with patient trust.<sup>(4)</sup> "To cure sometimes, to relieve often, and to comfort always" is a French saying as apt today as it was five centuries ago, as is Francis Peabody's admonition, "the secret of the care of the patient is in caring for the patient."<sup>(5)</sup> Today, concerns about the patients' choice, respect for their values and preferences, and access to nursing care are becoming more complex. Patients' expectations are higher and they want the best. They want to actively participate in decision-making, proposed procedures or treatments and their various alternatives. General awareness of human

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**Table I. Demographic profiles and case selection of all the patients in the study.**

Characteristics	No. (%) of patients (n = 250)
Gender	
Male	147 (58.8)
Female	103 (41.2)
Ethnic group	
Malay	180 (72.0)
Chinese	44 (17.6)
Indian	16 (6.4)
Other	10 (4.0)
Religion	
Muslim	184 (73.6)
Christian	25 (10.0)
Buddhist	29 (11.6)
Hindu	8 (3.2)
Others	4 (1.6)
Education	
Primary	80 (32.0)
Secondary	119 (47.6)
Tertiary	16 (6.4)
Illiterate	35 (14.0)
Occupation	
Professional	20 (8.0)
Executive	11 (4.4)
Administrative	10 (4.0)
General worker	80 (32.0)
Unemployed	129 (51.6)
Diagnosis	
Advanced malignancy on palliative care	50 (20.0)
Chronic renal failure on haemodialysis	50 (20.0)
AIDS	50 (20.0)
Patients undergoing surgical procedures	50 (20.0)
Admissions for minor ailments	50 (20.0)

**Table II. Responses to issues related to informed consent, satisfaction and confidentiality.**

Responses to survey questions	No. (%) of patients (n = 250)
Diagnosis and modality of treatment explained	
Yes	213 (85.2)
No	37 (14.8)
Treatment options discussed	
Yes	113 (45.2)
No	137 (54.8)
Informed of duration of treatment	
Yes	163 (65.2)
No	87 (34.8)
Questions encouraged and clearly answered	
Yes	147 (58.8)
No	103 (41.2)
Access to nurse/doctor	
Yes	248 (99.2)
No	2 (0.8)
Awareness of rights	
Yes	227 (90.8)
No	23 (9.2)
Respect of beliefs	
Yes	248 (99.2)
No	2 (0.8)
Privacy	
Yes	246 (98.4)
No	4 (1.6)
Confidentiality of personal information	
Yes	244 (97.6)
No	6 (2.4)

rights has been on the rise. There has been much judicial activity on medical negligence for doctors on the standard of medical care in many countries like England, Australia, the USA, Singapore and Malaysia.<sup>(6)</sup> Due to the rising cost of healthcare, increased patient awareness and medicolegal issues, doctors are now more accountable to the public than ever before. Ethical issues attract widespread public attention, and debate about them is covered regularly in the press. The threat of medical litigation and the publicity that accompanies it will affect the way doctors approach their work. The Bolam test—a familiar concept to most doctors—is the measure of whether one has discharged his or her standard of care in the management of the patient. Judge McNair, in his judgment of the famous English case of *Bolam v Friern Hospital Management Committee (1957)*, stated: “a doctor is not guilty of negligence if he has acted in accordance with a practice accepted as proper by a responsible body of medical men skilled in that particular art...”<sup>(7)</sup>

The Bolam test, in substance, restrains the courts from scrutinising and evaluating the professional conduct of a doctor possessing a special skill and competence. However, it has been challenged in many jurisdictions such

as the USA, Canada, Australia, South Africa, Singapore and Malaysia. The recent Federal Court decision of *Foo Fio Na v Dr Soo Fook Mun and Assunta Hospital (2007) 1 MLJ 593* has brought the whole question of the Bolam test to a very critical position in Malaysia.<sup>(8)</sup> The then chief judge of Malaya, Tan Sri Siti Norma binti Yaakob, who wrote the judgment, said, “We are of the opinion that the Bolam test has no relevance to the duty and standard of care of a medical practitioner in providing advice to a patient on the inherent and material risks of the proposed treatment.” The Federal Court, in its conclusions, stated that “we are of the view that the *Rogers v Whitaker* test would be more appropriate and a viable test of this millennium than the Bolam test”. (In that case, Maree Whitaker became essentially blind after an unsuccessful operation on her right eye caused sympathetic ophthalmia in her left eye).

Doctors are understandably concerned with these recent developments. It can result in the practice of defensive medicine and potentially affect the quality of patient care. However, they should take comfort in the fact that they will be liable only if they fall below the standard of their peers. They must ensure there is informed

**Table III. Patients' satisfaction with doctors and nurses.**

Patient's condition	Satisfaction with doctors, no. (%)		Satisfaction with nurses, no. (%)	
	Very satisfied	Less satisfied	Very satisfied	Less satisfied
Advanced malignancy on palliative care	18 (36.0)	32 (64.0)	21 (42.0)	29 (58.0)
Chronic renal failure on haemodialysis	43 (86.0)	7 (14.0)	43 (86.0)	7 (14.0)
AIDS	34 (70.8)	14 (29.2)	37 (74.0)	13 (26.0)
Patients undergoing surgical procedures	46 (92.0)	4 (8.0)	42 (84.0)	8 (16.0)
Admissions for minor ailments	48 (96.0)	2 (4.0)	47 (94.0)	3 (6.0)
Total	189 (76.2)	59 (23.8)	190 (76.0)	60 (24.0)

consent (IC), which is recognised and protected by the law.<sup>(9)</sup> In order for ensure that IC is legally acceptable, it must meet the following criteria: (1) Consent must be informed to an adequate standard. (2) Patients must be competent to understand the relevant information and the decision at hand. (3) Patients must not be coerced into accepting treatment against their wishes.<sup>(10-12)</sup> Thus, IC is the autonomous authorisation of a medical intervention or treatment with knowledge of the possible consequences.<sup>(10)</sup>

Many of our patients have strong spiritual or religious beliefs that have a bearing on their perceptions of illness and their preferred modes of treatment. Respecting their beliefs and values and treating them with dignity are other important aspects of the doctor-patient relationship.<sup>(13,14)</sup> Privacy and confidentiality are other important patients' rights as well as fundamental tenets of medical care.<sup>(15)</sup> Any threat to them in the present era of computerised record-keeping and sharing of patient care among numerous medical professionals can undermine the therapeutic relationship and adversely affect patient care. Malaysia is a "multiracial", multi-faith and culturally-diverse nation with a population of over 26 million. It is a fast developing country where a "western-oriented" information delivery policy is adopted in the medical curriculum and the quality of healthcare services is emphasised with the elements of patient-centred care, client satisfaction and accountability. This study was performed in order to evaluate the perceptions and practices in matters relating to IC in the selected hospital, to obtain feedback from patients on the care that has been delivered and to identify important lapses in performance, which may help to improve patient safety.

## METHODS

This was a questionnaire-based cross-sectional survey investigating awareness and pertinent issues regarding IC among hospitalised patients. The study sample consisted of 250 hospitalised patients from Hospital Tengku Ampuan Afzan (HTAA). HTAA is a tertiary care 800-bed hospital in the state of Pahang – the biggest state

in Peninsular Malaysia with a population of about 1.6 million people. It is also the teaching hospital for the Medical Faculty of the International Islamic University Malaysia. The sample was selected purposively from different wards and disciplines, and all data was collected by a trained research nurse. Patients were approached in person and provided with a brief description and aim of the study. Their consent was obtained before they were asked to answer the questionnaire. Each question required a yes or no answer or multiple-choice answers. The questionnaire (in Bahasa Melayu) consisted of two parts: the first being information regarding the patients' demographic parameters, to look at the background of the study population; and the second part dwelled on information given to patients regarding diagnosis and procedures. They were also asked whether they were aware of their rights such as autonomy, privacy, confidentiality and access to the doctor/nurse in times of need. All patients recruited into the study were fully conscious and able to give consent. Unstable patients, paediatric patients and patients from the intensive care unit, coronary care unit and high dependency wards were excluded.

50 patients were selected from each unit. The patient categories included fully conscious advanced cancer patients on palliative care, patients with acquired immunodeficiency syndrome (AIDS), end-stage renal failure patients on chronic haemodialysis, patients undergoing surgical or gynaecological procedures, and a group of newly-admitted patients who had been hospitalised for less than 48 hours for a minor illness like viral fever, asthma, uncontrolled hypertension or newly-diagnosed diabetes mellitus without obvious medical complications. Statistical analysis was done using the Statistical Package for Social Sciences version 11 (SPSS Inc, Chicago, IL, USA). Chi-square ( $\chi^2$ ) test was used to compare the proportions among the various groups and a p-value of < 0.05 was taken to be statistically significant. This study was approved by the relevant ethical committees of the HTAA and International Islamic University Malaysia.

**Table IV. Informed consent for a diagnostic procedure.**

Aspects of patients' informed consent	No. (%) of patients (n = 195)
Staff who obtained the consent	
Doctor	192 (98)
Nurse	3 (2)
Informed of risk of procedure	
Yes	195 (100)
No	0 (0)
Informed of benefit of procedure	
Yes	183 (94)
No	12 (6)
Informed of right to accept/reject the procedure	
Yes	189 (97)
No	6 (3)

## RESULTS

A total of 250 patients were surveyed. Table I lists the demographical profile and diagnosis of the study population. The majority of the respondents were young; with a mean  $\pm$  standard deviation age of  $45 \pm 16$  years, and a range of 13–84 years. The literacy rate was 86% (primary through tertiary education). Table II summarises the responses to various issues related to IC, satisfaction and confidentiality. About 85% of patients felt that they were informed regarding their illness and modality of treatment; however, treatment options were discussed with only 45% of the cases and only 65% of patients were informed of the duration of their treatment. Privacy, confidentiality and respect of religious beliefs were appreciated by almost all patients. Although we had selected patients from five different groups, no statistically significant difference was noted in their overall responses, except in terms of their satisfaction with the doctors and nurses (Table III). Most patients from the surgical group, haemodialysis unit and those with minor ailments were very satisfied with the doctors (92%, 86% and 96%, respectively) compared with 36% of cancer patients and 70.8% of AIDS patients ( $p < 0.0001$ ). Almost similar findings were noted regarding satisfaction with the nurses.

Table IV summarises the responses to various diagnostic procedures. A total of 195 (78%) patients had undergone a diagnostic or surgical procedure, while others had only routine investigations in the ward. Except for four patients, consent was obtained by the doctor. Of the four patients, two had undergone gastroduodenoscopy and two had computed tomography of the thorax. Almost all (97%) stated that they were informed of the option of declining the procedure, while six (3%) patients recalled not being informed of that option.

## DISCUSSION

With the revolution in information technology and the

higher educational levels of the patient population, patients and their family members are now much better informed about medical matters, and they want the best. Another contributing factor is the rise in the standard of living, which has brought about a rise in consumer awareness and action, accompanied by expectations for higher standards of service. Healthcare has become more competitive due to the growth of private health services. Patient safety is the subject of much debate and concern. Therefore, it is vital that healthcare systems are designed to ensure patient safety and satisfaction. Patient satisfaction is one of the most important indicators of service excellence. Patients can certainly contribute by expressing their views on subjects such as information, communication, courtesy, privacy and the environment. They may complain about any lapses they notice in the quality of healthcare, even if it has not caused them any harm. Their experiences and evaluation of care can help to achieve positive change for patient safety.

Little is known about the extent to which medical professionals involve their patients in decision-making. Only a few studies have used direct observation of decision-making. Braddock et al evaluated audiotaped office visits of medical doctors and found that just 9% of decisions met their definitions of informed decision-making, while fewer than 10% had a discussion about treatment alternatives, risks and uncertainties.<sup>(12)</sup> In Singapore, a survey of medical professionals was carried out recently to investigate their perceptions and practices in matters related to IC. The results showed that 17.4% of those surveyed failed to ensure that patients and volunteers fully understood the methodology of the clinical trial, and 17.3% did not disclose the risks completely. In addition, 16.1% did not explain the benefits of the proposed treatment, 17% did not discuss the alternatives available and 29.8% fared poorly in ensuring the confidentiality of medical records. The survey found that most doctors comply with IC but with inadequate understanding.<sup>(6)</sup> Thus, in practice, doctors provide most patients with partial patient-centred care. Effort is required to ensure adequate IC, providing care that is respectful of and responsive to individual patient preferences, needs and values, and ensuring that patient values guide all clinical decisions. No amount of quality care will produce optimal results, unless patients are actively engaged in the management of chronic diseases like angina, asthma in adults, and diabetes mellitus in which most of the treatment plans must be carried out by the patients themselves.

It was encouraging to note that most patients in this study showed an awareness of their rights, and had enough information regarding their illness and modality of treatment. In general, they reported that physicians

did reply to most of their questions, with the exception of “treatment options” and to a certain extent, about the “duration of treatment”. This shows that, to a certain extent, our patients wanted to be involved in making decisions regarding their treatment. Cancer patients were less satisfied with the attending staff. This may be due to stress caused by the illness, uncertainty about their future and perhaps a loss of hope for a cure. Similarly, AIDS patients were less satisfied with the attending staff which may in part be due to their social isolation, unemployment or lost career opportunities. Their dissatisfaction may be compounded by actual variation in the care provided by the staff. Audits and surveys of medical practice continue to attest to the difficulty of ensuring optimal care among most patients, especially those with chronic illnesses.<sup>(16)</sup> Numerous studies have shown that the quality of healthcare varies in virtually all aspects of medicine and is often inadequate.<sup>(17-19)</sup> Socially-deprived areas experience a lower quality of primary care.<sup>(20)</sup> Moreover, quality does not seem to be consistent within hospitals for different medical conditions.<sup>(21)</sup> A recent study in Canada found that patients with diabetes mellitus, emphysema and severe mental disorders were less likely to receive appropriate oestrogen replacement therapy, lipid-lowering medications, or treatment for arthritis than patients without these conditions.<sup>(22)</sup>

There are some limitations to this study that need to be mentioned. Firstly, this study was conducted among inpatients from a single hospital; hence the results are not reflective of the prevalent clinical practice in Malaysia. Secondly, there is potential for information bias towards giving whatever the respondents thought would be an acceptable response to the researcher, rather than revealing the whole truth. Thirdly, the patients’ ratings of their attending medical professionals and staff may reflect their overall positive feelings toward them or submissive behaviour on their part; and finally, we could not be entirely certain that the selection process did not lead to some bias. However, a similar questionnaire-based cross-sectional survey conducted among doctors from the same hospital, showed consistency with the findings of this study.<sup>(23)</sup> That survey showed a very high awareness of IC among doctors in HTAA, but surprisingly veered towards the old model of paternalism in practice, where physicians determine what information is appropriate to disclose.

Surveys of patient satisfaction are an important tool by which healthcare systems can elicit their customers’ opinions on the quality of care. The majority of our study patients showed an awareness of their rights and had enough information regarding their illness and modality of treatment with the exception of “treatment options” and to a certain extent, about the “duration of treatment”.

Privacy, confidentiality and respect of religious beliefs were appreciated by almost all patients. Cancer and AIDS patients were less satisfied with the attending staff, which is relevant to the assessment of care they receive. More emphasis has to be placed on their care and any disparities or discrimination must be eliminated. Good teamwork will play a key role in its achievement. Our results suggest that there is a need for periodic surveys of patient satisfaction with quality of care.

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