

Awareness, knowledge and attitude towards informed consent among doctors in two different cultures in Asia: a cross-sectional comparative study in Malaysia and Kashmir, India

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ABSTRACT

Introduction: Informed consent is now accepted as the cornerstone of medical practice, with reasonable patient standards typically considered to be appropriate in the developed countries; however it is still challenged in many developing countries. The objective of this descriptive study was to evaluate the perceptions and practices among attending medical professionals in matters relating to informed consent in selected hospitals.

Methods: A questionnaire-based cross sectional survey among doctors in the two tertiary care hospitals, one in Malaysia and the other in Kashmir, was performed.

Results: Awareness on informed consent was universal with “reasonable physician standard” as the most popular choice. As compared to doctors in Malaysia, doctors from Kashmir showed a tendency to reservedly disclose medical information (p-value equals 0.051) and withhold it, if it was deemed potentially harmful (p-value is less than 0.001) or requested so by relatives (p-value is less than 0.023). They also withheld some information from female patients (p-value is less than 0.001). When consent was refused despite needing life-saving intervention, the majority of both respondents (73 percent versus 80 percent) considered intervention without consent to be justified. Respondents from Malaysia felt that parents could refuse treatment on their children’s behalf on the basis of their beliefs (p-value is less than 0.001).

Conclusion: Despite a very high awareness

of informed consent, the model chosen reflected age-old medical paternalism. Doctors’ opinions are accorded a larger role in clinical decision-making in Kashmir. The results emphasise the need for doctors to change their attitude and acknowledge the patient’s autonomy, which is the basis of modern medical ethics, and yet still be aware of the cultural and religious views of the local population.

Keywords: clinical decision-making, informed consent, medical ethics, patient autonomy

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INTRODUCTION

Medicine is essentially a moral practice constituted by intrinsic moral convictions.⁽¹⁾ Trust is an indispensable factor in this relationship. Good bedside manner, technical competency and communication skills are the physician’s behaviours most strongly associated with patient trust.⁽²⁾ The changing medical practice of the 20th century has given place to patient’s autonomy and informed consent (IC). The age-old “paternalistic approach” has been replaced by the patient’s right to self-determination, which is recognised and protected by law.⁽³⁾ IC is the autonomous authorisation of a medical intervention/treatment with knowledge of the possible consequences.⁽⁴⁾ In this context, consent is seen as a new code of practice for the medical profession motivated by societal changes. In the common law, the standard of medical care to disclose risks has been laid down by the Bolam test in 1957 by the famous English case of *Bolam vs Frien Hospital Management Committee*.⁽⁵⁾ The patient must be told the nature and purpose of the procedure/treatment, its benefits and potential risks/side effects. Failure to communicate and disclose potential risks is considered medical negligence. Consent forms facilitate and document this authorisation.

Based on a review of literature available on the

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practice of IC, three standard models of IC are evident:

1. Reasonable physician standard. This standard allows the physician to determine what information is appropriate to disclose and states that the physician's role is one of a guardian. Most research in this area shows that the typical physician tells very little to the patient and his values and preferences for treatment are not explored. This standard is also generally considered inconsistent with the goals of IC.
2. Reasonable patient standard. This standard focuses on considering what a typical patient would need to know in order to be an informed participant in the decision. The physician is merely a basis of information and the patient makes all the decisions.
3. Subjective standard. What would this patient need to know and understand in order to make an informed decision? This standard is the most challenging to incorporate into practice, since it requires tailoring information to each patient.

Some aspects of medicine are fundamental and timeless. Clinicians must be prepared to deal with changes and reaffirm what is fundamental. A doctor cannot merely offer medical information, statistics, research results, and ask the patient to decide. Hence, a certain amount of paternalism will prevail by recommending a specific action to a particular patient. But assumptions that the doctor knows best and the patient is a layman, who lacks medical knowledge and experience, has no place in modern healthcare. Patients today are health consumers and should actively participate in medical decision-making, as it has considerable beneficial effects in overall outcome and satisfaction.⁽⁶⁾ Several authors have suggested shared decision-making as an ideal model of IC in which both the patient and clinician share information with each other, take steps to participate in the decision-making process, and agree on a course of action.^(7,8)

Many studies strongly support a patient-centred approach in clinical practice,^(9,10) however, some cultures may not consider it ideal. Respect for autonomy may mean allowing a person to delegate certain decisions, if that is his or her wish. Disclosing the diagnosis or prognosis to patients, especially when it relates to potentially fatal illnesses like cancer, is not the norm in many parts of the world. In Italy, France, Eastern Europe, much of Asia, Central and South America, and the Middle East, physicians and patients often feel that withholding medical information is more humane and ethical.⁽¹¹⁾ According to Navajo patients' and families' beliefs, direct information about risks from a procedure or a diagnosis is harmful and that talking about death can actually hasten its arrival.⁽¹²⁾

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% conducted a discussion about treatment alternatives, risks and uncertainties.⁽⁸⁾ A recent survey of medical professionals in Singapore 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, 16.1% did not explain the benefits of the proposed treatment, while 17% did not discuss the alternatives available, and 29.8% fared poorly in assuring confidentiality of medical records.⁽¹³⁾

The doctors are obliged to ensure that the patient or the surrogate is adequately informed about the nature of the patient's medical condition, the objective of the proposed treatment, possible alternatives, and possible outcomes. It is good practice for the healthcare team to involve those close to the patient in order to find out about the patient's values and preferences before a loss of capacity ensues. When a patient lacks the decision-making capacity, an appropriate surrogate should make the decisions on his behalf, ideally one who knows the patient's preferences and acts in his best interest. But in extreme emergency situations where a patient is unable to consent, e.g. due to unconsciousness, a doctor may perform emergency treatment based on the doctrine of necessity to save lives. Privacy and confidentiality are other important patient rights as well as fundamental tenets of medical care.⁽¹⁴⁾ However, doctors should be aware of the risks of invasion of privacy in the present era of computerised record keeping and sharing of patient care among numerous medical professionals.

With the revolution in information technology, the patients and their family members are much better informed about medical matters and want to actively participate in decision-making, and these realities must be considered in clinical practice. Medical doctors, out of respect for themselves and their patients, must obtain IC. In Malaysia, studies on this issue are very few and to the best of our knowledge, none has been done in Kashmir, India. We therefore aim to investigate the perceptions and practices among attending medical professionals in matters relating to IC in selected hospitals in Malaysia and Kashmir.

METHODS

This study was conducted in two hospitals, the Hospital Tengku Ampuan Afzan (HTAA), Kuantan, Malaysia and Sri Maharaja Hari Singh Hospital (SMHS), Srinagar, Kashmir, India. HTAA is an 800-bed tertiary care state level hospital in the state of Pahang, the biggest state in Peninsular Malaysia with a population of about 1.6 million. It is also the teaching hospital for the medical faculty of the International Islamic University Malaysia. Malaysia is a multi-racial, multi-faith developing country, where a western-oriented information delivery policy has

been adopted in the medical curriculum. SMHS is a 650-bed tertiary state level hospital in Srinagar, which has a population of about 1.2 million. The hospital also caters to patients from the peripheries of the Kashmir Valley. It is also the teaching hospital for the Government Medical College Srinagar, previously ranked among the top ten institutions of India. Many doctors from HTAA were trained abroad and nearly all doctors from SMHS were trained locally, as revealed by the questionnaire.

This was a hospital-based cross-sectional survey using a questionnaire. The questions were framed around issues of medical paternalism, IC, medical ethics and patient autonomy. Doctors were also asked how they make ethical judgments in the face of dilemmas. The questionnaire had a cover page explaining the importance of IC because of modern ethical issues and medicolegal consequences. The three standard models of IC were also described. It also touched on confidentiality issues. The 35-item questionnaires were randomly given to the doctors selected from the medical registries of both hospitals, excluding the junior house officers and interns. They were approached individually and requested to complete the forms at their leisure, if they agreed to participate. The forms were collected again after contacting the respondents.

This study was approved by the pertinent ethical committees of the respective faculties and hospitals. Unlike Malaysia, India has a predominant paternalistic culture. It motivated us to do the present survey, as it was a valuable opportunity to compare medical decision-making in the two states. This is the first study of its kind to present comparisons between groups of doctors in these two cultures. Statistical analysis was done using the Statistical Package for Social Sciences version 10. (SPSS Inc, Chicago, IL, USA). χ^2 test was used to compare the proportions among different groups and a p-value of less than 0.05 was taken as statistically significant.

RESULTS

50 questionnaires (62.5%) from HTAA and 48 (60%) from SMHS were completed and returned from a total of 80 distributed to each hospital. Doctors who failed to return the questionnaire despite three reminders were classified as non-responders. The grades and gender of all respondents are summarised in Table I. Almost all doctors from both HTAA (100%) and SMHS (98%) regarded IC as important with reasonable physician standard model as the predominant choice (Table II). However, only 85% respondents from SMHS regularly obtained consent in practice. Age, literacy and mental status were considered important indicators for the ability to consent, and the legal consent age of 18 years was universally accepted in both hospitals. Most doctors from HTAA (98%) would give the same information to their patients regardless of

Table I. Gender and grades of all respondents.

	HTAA n = 50 (%)	SMHS n = 48 (%)
Gender		
Male	38 (76)	42 (88)
Female	12 (24)	6 (12)
Grade		
Consultants/Professor	4 (8)	6 (12)
Specialists/Registrar	28 (56)	24 (50)
Senior medical officers	18 (36)	18 (38)

gender, in contrast to doctors from SMHS (69%) who preferentially withheld some information from female patients ($p < 0.001$). Respondents from HTAA were satisfied with the existing hospital consent form, compared to only 33% from SMHS ($p < 0.001$). The HTAA ethics committee was known to most of the respondents (72%), while only (23%) respondents from SMHS were aware of the existence of an ethics committee ($p < 0.001$). Privacy and confidentiality were more appreciated in HTAA than in SMHS ($p < 0.003$).

All respondents accepted that disclosing diagnosis was in the patient's best interest (Table III) but respondents from SMHS regarded patients as generally less willing to be told the whole truth ($p < 0.006$). Respondents from SMHS showed tendency to reservedly disclose medical information, and would withhold it, if it was deemed potentially harmful ($p < 0.001$) or requested so by relatives ($p < 0.023$). Withholding information was also considered justified from both sets of respondents, significantly more so from HTAA, especially when risk of suicide is involved (66% versus 50% [$p < 0.038$]). The responses on a patient's inability to give consent are summarised in Table IV. Less than half of the respondents regarded IC as valid (46% HTAA versus 40% SMHS), despite varying the patient's decision-making capacity on a daily basis. When IC was not given despite needing life-saving intervention, the majority of the respondents considered intervention without IC to be justified. Parents (73% HTAA versus 83% SMHS) were considered the most legitimate surrogate for IC. Respondents from HTAA felt that parents could refuse treatment, on their children's behalf on the basis of their beliefs ($p < 0.001$) and that they could assign some role to the court to obtain IC ($p < 0.005$). Both sets of respondents felt that the hospital director may also play some role in IC determination.

DISCUSSION

It is encouraging to note that despite the present state of political turmoil in the Kashmir valley, general awareness on IC was universal with "reasonable physician standard" as the most popular choice. This standard is generally

Table II. Awareness of informed consent and specific issues.

	HTAA n = 50 (%)	SMHS n = 48 (%)	p-value
Aware of IC	50 (100)	47 (98)	0.9
The best model for informed consent*			0.06
Physician's standard	21 (42)	31 (65)	
Patient's standard	16 (32)	7 (14)	
Subjective standard	13 (26)	10 (21)	
I regularly obtain informed consent	50 (100)	41 (85)	0.005
The best person to obtain consent			0.2
Nurses	0 (0)	4 (8)	
Consultants	21 (42)	13 (27)	
Medical officers	28 (56)	30 (63)	
House officers	1 (2)	1 (2)	
Competence to give consent			0.9
Age	6 (12)	1 (2)	
Literacy	3 (6)	1 (2)	
Mental status	13 (26)	15 (31)	
All of them	28 (56)	31 (65)	
Same information given to male or female patients	49 (98)	33 (69)	< 0.001
Seek consent because of legal requirement	24 (48)	22 (46)	0.9
Satisfaction with existing consent form	40 (80)	16 (33)	< 0.001
Presence of hospital ethics committee	36 (72)	11 (23)	< 0.001
Privacy and confidentiality	44 (88)	34 (71)	0.003

*refer to text for explanation of model types.

considered to be inconsistent with the goals of IC. It is worth noting that medical paternalism occurs to some extent in most societies and probably cannot be eliminated.⁽¹⁵⁾ Medical practice is a moral practice and it requires doctors to make judgment on what is best for their patients. The responses on the other two models were quite similar and these were somewhat unexpected, considering the predominant paternalistic culture in SMHS as opposed to HTAA, as the figures seemed to be disputing this assumption. The limitations of this study include the potential for information bias. The respondent may be providing an anticipated response that is acceptable to the researcher, instead of reflecting the actual response in a real-life situation. Other possible reasons include a small sample size or an invalid assumption. Unlike in Malaysia, doctors in Kashmir have an authoritative position in decision-making and are held in high esteem by society. Their authority is hardly ever challenged, and their advice, seldom questioned. They are supposed to reassure and comfort the patients, not to frighten them. Malpractice suits against physicians and hospitals hardly ever occur.

As there are limited hospitals in Srinagar, the work load on these hospitals is very heavy and the doctors are taxed beyond their capabilities.⁽¹⁶⁾ The doctors have to

work very hard and therefore spend less time with details. IC requires time and patience, both of which are deficient in such busy clinics and these are reflected in the results. A lack of education among patients is another hindrance in achieving this goal. There is a general lack of awareness of individual rights in Kashmir.⁽¹⁷⁾ Health expenditure is borne mostly by the family, due to limited resources, giving the family a central role in decision-making. There are no third party payers, and a health insurance system is nonexistent. The family is the fundamental unit of society, and people generally live in extended families with collective earnings, with interdependent members taking an interest in all matters pertaining to life and death. Most patients avoid the responsibility of decision-making and defer this role to the family or the doctor. Women, in particular, do not give consent unless they get approval from their husband or the head of the family. In some societies, women cannot make medical decisions for themselves; instead, that right is accorded to their husbands.⁽¹⁸⁾ It is, therefore, surprising to note that 31% of doctors from SMHS would disregard gender difference, perhaps reflecting their more educated status, by eliminating gender bias. There is also no concept of nursing homes for the aged or for the terminally ill and debilitated patients, in the Kashmir Valley. They are cared

Table III. Doctors' perception on informing patients of their diagnosis.

	HTAA n = 50 (%)	SMHS n = 48 (%)	p-value
IC is in patients' best interests	43 (86)	40 (83)	0.7
Patients want the whole truth	44 (88)	31 (65)	0.006
How much information to give a patient if the diagnosis is unfavourable, e.g. cancer			0.015
Brutally frank	12 (24)	3 (6)	
Truthfully reserved	38 (76)	45 (94)	
If truth is deemed harmful, I will still break the news			< 0.001
Yes	22 (44)	20 (42)	
No	16 (32)	27 (56)	
Others	12 (24)	1 (2)	
I will ignore the family's request to withhold information			0.023
Yes	32 (64)	17 (35)	
No	18 (36)	31 (65)	
When is it justified to withhold truth?			0.038
Suicidal intent	33 (66)	24 (50)	
Refusing treatment	5 (10)	7 (15)	
Depression	4 (8)	14 (29)	
Others	8 (16)	3 (6)	

for in their homes, usually by the female members of the extended family.

When patients choose to refuse consent/treatment, many doctors would involve family members in making a consensual decision. Less than half of the respondents regarded IC as valid, despite varying the patient's decision-making capacity on a daily basis. IC requires that patients fully understand the information given, but if the patient is incapacitated due to a serious illness/mental condition, an appropriate surrogate should make the decisions, ideally one who knows the patient's preferences and can therefore act in his best interest. The patient must be told what has been done and why, as soon as he has sufficiently recovered his mental faculties. When IC was not given despite needing life-saving intervention, the majority of respondents considered intervention without IC to be justified. In an extreme emergency situation, where a patient is unable to give consent due to unconsciousness, a doctor may perform emergency treatment based on the doctrine of necessity or implied consent to save lives.

Regarding questions on ethics committees and satisfaction with existing consent forms, it is not unexpected to see that doctors from SMHS were neither aware of the existence of such a committee nor satisfied with the existing consent form. This is in contrast to the results from HTAA. Regarding privacy and confidentiality, respondents from SMHS could not entertain privacy concerns due to the lack of infrastructure, as well as time, to discuss matters in private.

All respondents believed that disclosing diagnosis

results was in the patient's best interests, but respondents from SMHS believed that patients do not want the whole truth. This is, again, a reflection of prevailing paternalism. There was no difference in the extent of information disclosure but we believe that a bigger sample size from SMHS may show the tendency to withhold information. There is also a lack of willingness in telling patients the whole truth. When the truth was deemed harmful, respondents from SMHS would not break the news to the patient and would also withhold information upon the family's request. Respondents from both hospitals would withhold truth if patients expressed suicidal intent or suffered from depression. In life-threatening diseases like cancer, unlike at HTAA, the norm in SMHS would be to conceal information from the patient and instead, reveal it to a dominant family member. As disclosure of bad news is fraught with intense emotions from both the patients and the family, the doctors often use alternative terms such as "growth", "mass", and "tumour". This is done to protect patients from emotional and physical repercussions upon hearing the actual diagnosis. In addition, telling the direct truth is perceived as cruel and uncaring, and may even result in the removal of the patient from medical care.

The practice of partial disclosure, however, persists in many countries and is even endorsed by professional bodies, in order to protect patients or to sustain the doctor-patient relationship.⁽¹⁹⁾ Even in the United States, Koreans and Mexican Americans, among others, feel that the family, and not the patient, should be informed of the terminal diagnosis and that the family should be

Table IV. Issues regarding patients' inability to give consent.

	HTAA n = 50 (%)	SMHS n = 48 (%)	p-value
IC is valid despite patients' varying decision-making capacity	20 (40)	17 (36)	0.6
In life-saving situations, I will proceed regardless of IC	38 (76)	33 (83)	0.42
If IC is refused despite life-saving situations, I will			0.01
Seek surrogate consent	37 (74)	37 (77)	
Seek implied consent	1 (2)	8 (17)	
Withhold procedure	12 (24)	3 (6)	
Ideal surrogate decision-maker			0.2
Parents	36 (72)	40 (83)	
Spouse	9 (18)	8 (17)	
Children	4 (8)	0 (0)	
Close relatives	1 (2)	0 (0)	
Agree that parents can refuse treatment on behalf of their children	38 (76)	15 (31)	< 0.001
Court can be asked for consent	48 (96)	35 (73)	0.005
Hospital director can be asked for consent	33 (66)	40 (83)	0.05

the primary decision-maker.⁽²⁰⁾ For example, the word "cancer" connotes death, and it is presumed that patients would be so paralysed by the news that they cannot make autonomous decisions. Therefore, they should be protected from this despair.^(18,21) Telling the truth is an ethical obligation, but attitudes about truth-telling also vary across cultures.⁽¹⁸⁾ Doctors should use their best judgment when disclosing the diagnosis, particularly if the information is unfavourable. The extent, depth, timing, and technique of truth disclosure must then be tailored to the individual patient's wishes. Cultural issues and family requests must also be considered as they may have an important influence in the clinical outcome and satisfaction of the patients and their families.⁽²²⁾ In certain parts of the world, preserving community norms and family relationships are more important than individual autonomy.

Even within the same culture or society, patients' preferences differ in information disclosure; not all patients want to know everything all the time. Older/illiterate, socially conservative patients and those with serious illnesses prefer less information and avoid decision-making as they think it is the doctor's job to advise them. In contrast, younger and more educated patients show greater interest to know the details and want active participation in decisions regarding their care. Depending on the nature of the patient, doctors must exercise discretion on what information and decision-making role the patient desires. Doctors may feel more comfortable in discussing a serious diagnosis like cancer if the patient has a stable personality, strong family support, and religious beliefs. They feel reluctant if the patient is female, elderly, less educated, or unemployed.⁽²³⁾ Similarly, if a patient is depressed, irrational and suicidal,

then caution is advised lest full disclosure contribute to greater harm. Ordinarily, both family and patient can be kept informed, but judgment is required on what level of information the patient can handle and when the family should be involved.

In recent years, there has been a sharp decline in the ethical conduct of the medical practitioners all over the world. Ethical issues attract widespread public attention, and debates about them are covered regularly in the press. Medicine is being looked upon as a business, with the patient being regarded as a consumer. Cases of negligence and malpractice are being brought to courts. The situation is reflected in the judgment of the Indian Supreme court:

"Such organisations, who in the garb of doing service to humanity, have continued commercial activities and have been mercilessly extracting money from helpless patients and their families and yet do not provide the necessary services."⁽⁵⁾

In this case, a child with typhoid fever was admitted to the hospital, and upon receiving a wrong injection by a nurse, collapsed and suffered irreparable brain damage. The court found the mistake unpardonable.

Malaysia follows the common law principles of negligence and it is the duty of the doctor to disclose the material risk to the patient (1996 5 MLJ193). The Malaysian high court case of *Inderjeet Singh all Piara Singh v Mazlan bin Tasman + ors* (1995 2 MLJ 646) furnishes a glaring example of medical negligence. In this case, the plaintiff fractured his pelvis in a road accident. Doctors repeatedly catheterised him, in spite of suspecting urethral injury. As a result, the patient's bladder was detached from the urethra. The court found the doctors guilty of neglecting to carry out either an urethrogram

or cystoscopy, to ascertain the exact condition of the patient's urethra. In the recent case of *Dr Soo Fook Mun V Foo Fio Na & Anor*,⁽⁵⁾ the Malaysian court of appeals held that the standard proof of negligence still applied for the reason that Bolam test rightly places a fair threshold for the plaintiff to cross in an action of medical negligence.

In response to this, doctors have resorted to defensive medicine, asking their patients to undergo a battery of tests, which are not only expensive, but often result in false-positive results,⁽²⁴⁾ consultations from doctors of other subspecialties, medical insurance coverage and avoidance of risky procedures. This results in the exponential rise of healthcare costs, thus creating a heavy burden on patients and generating many unwelcome effects. There is some evidence that trust in physicians has decreased over the past quarter century, a period characterised also by increased attention to patient autonomy.⁽²⁵⁾ In an era of rapid globalisation where the boundaries and borders have begun to blur, we must keep abreast of different standards of reasoning and acknowledge the autonomy of patients. The traditional paternalistic approach, family requests to withhold information and reluctance to question or discuss must be reconsidered. In addition, further broad-based research is needed for a better understanding of various cultures. Keeping their socioeconomic and religious beliefs in consideration, re-examining the ethical tenets of the medical practice, and their application in changing healthcare settings, is a necessary exercise.

In conclusion, little is known about the extent to which medical professionals involve their patients in decision-making. The current study has highlighted some issues with regard to the practice of obtaining IC in two cultures. Despite possessing a very high IC awareness, it is not reflected in the numbers that doctors regularly obtain and practise IC. The prevailing model in SMHS reflected age-old medical paternalism. The doctor's opinions are accorded a substantial role in clinical decision-making in Kashmir. Our results are consistent with the view that cultural context and family variables have important influences in this process. The results emphasise the need for doctors to change their attitudes, and acknowledge the patient's autonomy in a rapidly-changing world, by educating their patients regarding their rights and responsibilities as consumers of healthcare. Only then will shared decision-making be feasible.

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