

PATIENT'S RIGHTS AND THE PRACTICE OF OBTAINING INFORMED CONSENT: THE NEED FOR SOME CORRECTIVE MEASURES

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The current issue of the journal contains an extremely useful study by Farhan Amin and colleagues entitled "An audit of information provided during pre-operative informed consent" which highlights the practice of obtaining informed consent in our public healthcare facilities. The authors have concluded that the practice is below international standard and ethical acceptability. The quality of informed consent can be improved by increasing awareness regarding ethical issues and educating the healthcare professionals regarding patient's rights.

Patients have a right to fully participate in the decision regarding their treatment but what goes on in most of our hospitals is just a formality wherein the patients or their relatives are asked to put in their thumb impression or signature. They are seldom provided the detailed information simply because the treating physicians are too busy and have no time. Not only that it is usually the technicians, nursing staff or paramedics who carry these papers to the patients for thumb impression/signature. In few cases it could be the resident medical staff but seldom the attending physician.

In one such case, a patient admitted in a surgical ward for excision of recurrent hemangiopericytoma was found in a state of shock and depressed. Enquiries revealed that

patient was depressed on seeing a very big resected area without any skin covering on his back. It was a mistake on the part of the surgical team that while taking informed consent, the patient was not fully informed about the expected size of resection. After counseling and reassurance with the facts about skin grafting, the patient started taking interest in his treatment.¹

Bhutta has alluded to the difficulties faced while obtaining informed consent from patients in developing countries particularly for clinical research. Even procedures recommended in different guidelines are difficult to follow for various reasons. He has emphasized the importance of "understood consent" rather than going for informed consent.²

The Consent Form which the patient or his/her relatives must have signed is not a proof that the patient was fully informed regarding material risks inherent in treatment, invasive, surgical procedures and whether the patient did understand the information fully. It is also important that the patient is competent to give informed consent.

The information provided to the patients must include the nature of patient's condition, the need for suggested mode of treatment or invasive, surgical procedure, what it entails, the anticipated prognosis, duration of treatment, procedure, risks involved and the expected benefits, alternate treatment options available, cost, whether the procedure is irreversible, time required for the procedure, recovery period, need for monitoring and long term follow up if needed and the consequences if treatment is not provided at all. If the

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patient is educated, it is always helpful to provide him/her some written information about the treatment modality, procedure before any discussion takes place between the treating physician and the patient. This discussion should be continued on each visit and the informed consent should be taken when it is decided to initiate treatment.¹⁻³ However, what happens in our healthcare facilities is that the healthcare professionals do not give due importance to patient's rights and informed consent. Moreover, since the treating physicians are too busy, signature or thumb impression on Consent Form is obtained at night before the procedure or a day earlier which is not correct. It is also important that salient points of the discussion which takes place and particularly if the patient asks some questions to have more information should be documented. The documentation should include procedure specific information and name of the physician taking informed consent. If the patient is uneducated, it is still no excuse to bypass the process of the consent. It is just that it is harder for the person who is taking consent to come down to the level of communication that such a person can understand.

Who should take informed consent: Ideally it is the senior member of the treating team since he or she has the overall responsibility. The physician involved in discussions with the patient should be fully competent having sufficient knowledge so that he or she can communicate the risk, benefits or alternate treatment options. The professional specialty organization can play a vital role in developing procedure specific scientific information outlining material risks. The patient can also be suggested to have second opinion before signing the Consent Form. This will minimize the chances of any litigations in case of any serious side effect.

In case of medical emergency when the patient is unconscious, hence not able to give consent, the patient is considered to have given consent to treatment. However it is essential that the circumstances of emergency and the patient's incompetence to give consent, should

be properly documented. For example in the aftermath of the recent earthquake in Azad Kashmir, Northern Areas and some parts of NWFP in Pakistan,, many emergency surgeries were performed; some of which even involved amputations. The patients can challenge the decision to opt for amputation in the absence of their informed consent. While taking patients informed consent, patient's competency, comprehension, needs and desire for details must be considered.

Patient's relatives or members of the healthcare teams cannot give consent on behalf of patients who are incompetent or unconscious. In all such cases it is desirable that the healthcare teams should involve those who are close to the patients to find out patient's values and preferences before their loss of capacity to give informed consent, unless there are previous instructions by the patient not to involve some particular individuals.⁴

As regards informed consent by paediatric patients, it must be understood that a child achieves his capacity to give consent on his behalf not when he reaches a particular age but "when the child achieves sufficient understanding and intelligence to enable him to understand fully what is proposed." And in case of conflict between the parents as to which parent might provide consent, or between parents and child whether the child is competent to give consent on his/her behalf, some countries have relevant laws making it necessary to refer the matter to courts to give a decision.³ However, the person who is asked to consent on behalf of an incompetent person should receive the same detailed information regarding risks, as the person who would be treated, if that person was competent to give consent.

The Federal Health Ministry, Government of Pakistan has now constituted a National Bioethics Committee. Pakistan Medical Research Council (PMRC) in collaboration with WHO EMRO recently organized a training workshop. One of its recommendations is that Institutional Ethics Review Committees (IERCs) will be constituted in all the healthcare facilities/medical institutions to ensure ethical clearance of all

scientific research studies in which informed consent is an important component.⁵ These committees can also ensure improvement in the practice of taking informed consent from patients being treated in these hospitals. At present different medical institutions, healthcare facilities have different set of Forms for obtaining informed consent. In some cases while consent is taken for any invasive, surgical procedure, the patient is seldom asked to give consent for anesthesia nor are they informed about any of their adverse effects. A vast majority of the patients in developing and Third World countries including Pakistan which have low literacy rate, are either not aware of their rights or cannot appreciate the importance of informed consent. Apart from educating the public, the healthcare professionals also need to be educated about the importance of patient's rights and the value of their informed consent so that the patients can fully participate in their disease management. It will

be ideal if we can develop a comprehensive Informed Consent Form which can then be translated into Urdu and different regional languages so that the purpose of obtaining informed consent is fully met and the patients get full information about their disease management which they also understand. Hopefully in the days to come sufficient progress will be made to improve the practice of obtaining informed consent which is ethically and internationally acceptable.

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