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Conflict of Interest
The authors declare no conflicts of interest.

Abstract

Informed consent is a mandatory ethical and legal requirement in clinical practice. The doctrine of informed consent, itself is taught in every medical curriculum, with the patient's autonomy held at the highest regard. Yet, this practice rests on a deceptively tidy premise wherein a competent patient receives information about the nature and consequences of the procedure or examination that they will undergo, understand it, and voluntarily accept or decline such an intervention. This paper argues that consent is often reduced in practice to a signed form in low-literacy, multilingual, family centered settings like Nepal, falling short of what the ethical framework requires and that the framework gives little practical guidance when patients wish to decide with or through their family. It raises the question of how informed the informed consent truly is. The proposed solution for this gap is to adopt relational autonomy into practice where the patient can decide who they want to bring into the decision-making process while extending rather than replacing the individualist model of western framework.

Introduction

A 64-year-old Tamang woman, who has never gone to school, in a district hospital places her thumb print on a surgical consent form, which has been read aloud to her in Nepali by a ward attendant. Her family is in attendance and have accepted the procedure hours earlier before she was even asked and the woman agrees because disagreement is an alternative she has never imagined for herself. Every legal formality entailing a signature, a witness, a named procedure has been satisfied. But has she actually consented to anything? It's hard to say she has in any meaningful sense.

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The 2021 census records that Nepal is home to over 124 languages across different provinces[1]. A patient who has been admitted from a remote village in hills may speak a dialect the attending physician has never heard. The patient may have never held a pen in their life other than to write their name, and may have never been asked to give their personal opinion on something that has already been decided by the literate members of their family. In our experience on the wards, consent forms are often written in written in formal Nepali or English, dense with clinical terminologies, asking for a signature, which more or less serves as a means of legal protection for the physicians rather than a genuine transaction of understanding.

The Western Model's Assumptions and where it breaks down in Nepal

The dominant model from Beauchamp and Childress's principalism, treats valid consent as a process that comprises of four components: disclosure, comprehension, voluntariness, and competence[2]. Informed consent is about whether a patient understands the information and makes a voluntary decision themselves and does not require patients to necessarily be literate, speak English or sign a document. Beauchamp and Childress, and earlier Faden and Beauchamp have also distinguished between informed consent as an autonomous authorization from a formal institutional or legal requirement and they recognize that competent patients may waive their right to information.[2,3] But the limitation of this framework is that it provides limited guidance on how meaningful understanding and voluntary decision-making should be achieved in practice in settings like Nepal. It does not fully address practical barriers such as language differences, low literacy, unequal power relationships between patients and health care providers, and limited opportunities to ask questions. In Nepal, where written consent is required for services like surgery, anesthesia, and obstetric care, this results in consent forms being signed without patients necessarily understanding the information. Hence, the limitation lies in the gap between ethical principles of the framework and their practical application in resource-constrained and socially unequal healthcare settings.

Nepali is the mother tongue of 44.9% of the population and a second language for a further 46.2%, so many patients speak another mother tongue[1]. While the language barrier may not be universal, it is concentrated among those without formal education. Clinical textbook words do not have easily usable equivalents in most local languages and, in our experience, translation occurs with the help of an untrained ward attendant or the relative who themselves may not have understood the procedure. Not only does this breach the confidentiality of the patient but also distort understanding through unrefined translation[4]. Language isn't the only problem; understanding also is. Someone who may have low health literacy doesn't mean they have low intelligence. They can understand disease through an entirely different lens and draw conclusions from planetary influence, diet, balance between energies or karma rather than the biomedical model. A Nepalese study of 350 surgical patients found that 95.4% reported the consented form was understandable and 77% had read it in full yet most of them could not say who would perform the operation, what were the alternatives and what

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were the consequences of no treatment, and only 16.28% were satisfied with the procedure[5]. The actual comprehension diverged almost completely from the stated comprehension of the consent form and if this is the reality of consent in an urban hospital, it leaves you much to imagine what's the painful extent in remote village hospitals. In a government teaching hospital in Kathmandu, where 73.9% of patients were illiterate, consent was mostly obtained from caregivers, yet 86.4% reported satisfaction, which the authors read as cultural acceptance of caregiver-led consent.[6]

The next problem is that in many Nepali households, important decisions related to health aren't made by the patient alone but they are made by the head of the household, who is mostly the husband or the eldest son, especially when the patient is a woman. This happens routinely for procedures like caesarean section, sterilization, even though legally the decision is solely of the patient. In the same above-mentioned study, caregivers giving consent were more often the male family members (63.1%) which the study attributed to traditional gender roles and the limited involvement of women in decision-making.[6] There's also a social pressure not to question or refuse the doctor especially if they perceive doctors to be 'busy' or 'short-tempered' which means that free choice has been compromised before the process even starts.[7]

Studies have made arguments that the whole idea of individual informed consent reflects a western, individualistic way of thinking, and doesn't fit societies that make decisions collectively. Examples include interviews with 12 researchers at one South African university, concerned with research consent[8]

But respecting culture can also become an excuse for ignoring what a patient actually wants. An example being a husband continuing to make decisions on behalf of his wife's body in the name of respecting culture. Informed consent has existed with one of the main purpose to treat women and poor as people who can actually decide for themselves and not just remain as a backdrop where decisions are made for them and not by them. Letting a family member make decision cannot always mean its respect for culture but it can mean taking away someone's authority over their own body and calling it a tradition.

A version of consent that might actually work here

The answer isn't to throw out individual consent and at the same time, it isn't to force a western framework of individual decision onto every patient either. What might work is relational autonomy, in which autonomy is exercised through relationships as well as apart from them, where people can make their own decisions and have a say in who gets to be involved in said decision.[9] Based on this concept, we propose 4 values to guide this practice of consent: 1) The patient has the decision making authority; 2)the patient decides how the decision will be made including who is involved and whether any part of it is delegated; 3) the clinician focuses on whether the patient understands the information and is making a voluntary choice without undue influences, without judging their preferences or imposing the clinician's own values; and 4) the clinician

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provides the conditions that make the choice possible through language, privacy, and information.

In the existing model, the involvement of family is optional and the patient is assumed to be able to speak freely, understand, and make a choice independently. Under relational autonomy, since family involvement is expected in settings like Nepal, the clinician, through a trained interpreter where needed, should first start with asking every patient how they wish their decisions to be made (alone, together with family, or a trusted person). The clinician should examine whether that decision is freely formed and record it. This strengthens the voluntariness and disclosure component which fails most often in traditional settings.

A patient can freely decide to bring their family into the decision and if that choice is genuinely theirs, it's still the patient exercising control over their own care. Then, the second step would be disclosure about the procedure to the patient and to anyone the patient has chosen, followed by teach-back method; and the third step should constitute documentation of the patient's decision. Documentation should record who was present, the interpreter used, the patient's stated preference on how the decision is to be made, and the patient's own words on how they understand and why they choose a certain procedure, not only a signature.

Most of these steps overlap with existing practice and we do not claim them to be new[2]; voluntariness is already a core element and waiver is permitted in the standard account, shared decision-making places the patient's preferences and their involvement itself at the center, and teach-back is an established check of understanding. We suggest that the relational approach make it a default for the decision about information disclosure, reach the people the patient has chosen rather than patient alone or family alone; for this approach to treat relationships as resources as well as possible threats to decision-making so that the question becomes whether that patient endorses the particular arrangement while knowing that alternatives exist rather than only whether they are free of coercion; and for clinicians to attend to the conditions under which a choice is made, primarily being privacy, language, and opportunity to consider alternatives.

Distinguishing delegation from coercion is a skill that must be taught to every medical student and clinician. Practically speaking, delegation is a choice that the patient makes voluntarily when asked in private, and knows they may withdraw at any time. Coercion is suggested when the decision is made before the patient is even asked, when the patient cannot be interviewed without a relative present, when the patient defers reflexively without giving any reason or they have a fear of the consequences of disagreeing. We suggest that medical schools teach this through structured open-ended questions (for example, "what would happen if your decision were different from your family's?" "would you feel comfortable telling your family you want something different?". The students should rehearse these conversations with simulated patient encounters. They should be observed and given proper feedback while doing so and students should also know whom to approach, such as senior clinician or senior health worker when they suspect coercion. Clinicians should routinely speak to patients

privately, and ask understand how decisions are usually made in the family, whom they want involved and whether they know they can refuse the procedure or withdraw their delegation without facing any consequences. The patients should be encouraged to explain their decisions and reasons behind it in their own words. Their account should also be consistent when speaking privately and in the presence of family. Inability to speak privately, or privately expressed disagreement, fear of losing family support or facing violence, and signs of intimate partner violence should raise concern for coercion. However, deference to family members alone should not be regarded as an evidence of coercion and the voluntary choice should be respected. If coercion is suspected, clinicians should allow more time for discussion, repeat the private conversation, and remind the patient of their right to decline. A senior clinician should be involved, and hospital social services or a One-stop crisis management center (OCMC)[12] if there are any signs of pressure or violence. While these questions aren't validated tests for coercion, they can guide conversations. These are proposals, and their effectiveness in Nepal is yet to be evaluated. Hence, relational autonomy needs to be brought into medical training.

Additionally, interpreters and translated forms support disclosure, teach back and visual aids support comprehension, and the private first conversation supports the voluntariness component of the existing model. Using trained interpreters instead of relying on relatives can help to bridge this gap. But trained interpreters can be difficult to find, so one can consider taking the help from community health workers once they are trained in confidentiality and neutral interpretation, who can help facilitate between the doctor and the patient. Especially in Nepal, such community health workers can be a great help to relational autonomy, since Nepal already has around 50,000 female community health volunteers (FCHVs) who are involved in bridging local households to health posts and hospitals.[10] With them being volunteers, it might raise confidentiality concerns and their use as interpreters is yet to be evaluated, so this would need proper piloting. The patient should be asked to teach back in their own words rather than just asking "do you understand?". While it costs time which is a scarce resource in underfunded public wards, it costs far less than the harm of a procedure that the patient has never understood.

Using pictures and visual consent aids with patients with limited literacy can work well in multilingual settings as seen in Africa. A diagram of caesarean section or chemotherapy will communicate across a gap that dense paragraphs can alone not bridge[11]. Translating consent forms into major regional languages and checking the authenticity of translation should be done beforehand so that decisions can be made swiftly without any delay.[6]

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Conclusion

What troubles me the most as a student on wards is how quickly consent form becomes a compliance tool for protecting the hospital medicolegally while doing little to protect the patient's actual understanding. We are instilling a potentially dangerous practice into generations of new students while sitting behind the mask of an informed consent that isn't really informed. Informed consent should mean what its name promises; the patient who is being treated should actually understand what is happening to them, in a language that makes sense for them, and explained with compassion rather than hurriedly. The western model should be extended instead of discarding it so that it begins by asking who a patient wants involved in their decisions and checks that the answer is the patient's own. It will take time but we can get to a point where consent is treated not just as a paperwork but a clinical work in its own right.

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