

Special Section: Bioethics Beyond Borders

Macao Report

Informed Consent in a Multilingual and Multicultural Region, a Bioethical Challenge

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Abstract: Complying with the requirements of informed consent for medical procedures can sometimes be problematic, even when the hospitals are located in countries that are uniform in their language and cultural values. However, when hospitals are located in countries with diverse linguistic and ethnic communities, it becomes particularly challenging. This article examines how Macao, with four predominant languages—Mandarin, Portuguese, Cantonese and English—and two very strong cultures, Western and Chinese, strives to meet the challenges of informed consent. The situation is made even more complicated by a healthcare delivery in Macao that is mostly guided by Chinese ethical and cultural perspectives, whereas its law is inspired by the Western model.

Keywords: Macao; cultural diversity; language; doctor–patient relationship; informed consent

Macao as a Multilingual and Multicultural Region

The Special Administrative Region of Macao is part of the People's Republic of China, and is located on the southeast coast of the country. Nevertheless, under the principle "one country, two systems" Macao maintains its own legal system, public security force, currency, customs policy, and immigration policy.

Chinese (Chinese-Mandarin)² and Portuguese (although in a secondary position) are its official languages, but the majority of the population speaks Cantonese (a dialect of southern China) in day-to-day interactions, and many, particularly the oldest generation, speak only Cantonese. Both Mandarin and Cantonese share the same basic characters and are written basically in the same way; however, as spoken languages they are quite distinct, and not mutually understandable. The qualification of Portuguese as another official language is a legacy from the several centuries when Macao was under Portuguese administration,³ as established by Article 9 of the Basic Law of Macau.⁴

According to official data, more than 94 percent of Macao's population uses the Chinese language and only about 0.7 percent speaks Portuguese. However, some of the Chinese-speaking population born in Macao also speaks Portuguese, with some individuals being very fluent. Concurrently, some of the Portuguese-speaking population in Macau also speaks Cantonese.

Here is the strange paradox of Macao: its two official languages (Mandarin and Portuguese) are hardly ever spoken by the population. They have been replaced

This work was supported by the University of Macau, under Multi-Year Research Grant MYRG2015-00008-FLL "Medical liability, medical acts, and patient's safety. How can the legal and judicial experiences worldwide help to provide a legal framework for Macau and China?"

by two de facto languages: Cantonese and English. English is used as a kind of common language for communication.

In addition to the plurality of the languages spoken, there are cultural and worldview pluralities. Although Macao is a very small territory, it has a high population density, with people from multiple places of origin who are all very different in cultural and religious terms. According to the 2011 census data, among the 582,000 inhabitants at the time (Macao's estimated population is presently 642,900 inhabitants), 92.3 percent were of Chinese descent, 2.7 percent were of Filipino descent, and 0.9 percent were of Portuguese descent. In addition, Macao has communities comprising people from many other parts of the world, who have been attracted by the gambling industry.

Although there are no specific statistics regarding the composition of Macao's healthcare professionals, the percentages seem to be nearly the same: a large majority of Macanese of Chinese descent and people coming from mainland China, and a lower percentage of Portuguese and Filipinos.

Communication as the Basis of Informed Consent

Communicating all relevant medical information to patients so that they are able to make informed medical decisions is the cornerstone of modern medical law, and has led to its qualification as a separate *lege artis*, which, when violated, involves medical liability, even if the physician has not committed any technical error. As such, good communication is of paramount importance if the patient is to understand the information provided, ask questions, seek assistance, follow the therapeutic plan as advised by the medical team, and effectively maneuver through the operations of the healthcare system.

Informed consent becomes particularly complex when the physician and patient do not share the same language and/or values. Therefore, in healthcare situations in which linguistic and "cultural competence" are required,⁹ in order to promote successful interactions, the risk of vital information becoming lost in translation should not be underestimated.

A main challenge to effective communication is that informed consent is not limited to a "one time" interaction between the patient and a specific physician. Instead, informed consent is an ongoing activity involving various members of the healthcare team throughout the patient's continuum of care. This effort is necessary to promote patient satisfaction and safety. Indeed, if a patient speaks a different language or comes from a different cultural background, it can decrease the quality of healthcare services provided and result in litigation.

Particular Informed Consent Difficulties in Macao's Multilingual, Multicultural Population

The Language Issue

As a multilingual country, Macao faces several difficulties in obtaining a patient's informed consent, because often caregivers and patients do not share the same language. To examine these issues and their impact, this study describes the practice of informed consent in Macao's only public hospital, the Conde de S. Januário Hospital. Macao also has several health centers and private health

facilities, and it is reasonable to assume that informed consent practices do not vary substantially.

In envisioning adequate informed consent procedures, an obvious first step would be to identify the patient's primary language and record it in a way that informs all healthcare staff members of the preferred language of communication. In addition to recording language preference in the patient's medical chart, issuing language identification cards to patients would also be useful. ¹³ Unfortunately, in Macao none of these procedures is prescribed.

Preferably, all communication should take place in the patient's primary language. However, in cases in which this is impossible, another language in which the patient has proficiency should be used. In theory, resorting to another language should only be acceptable when the primary language is so rare as to make obtaining a fluent translator an unreasonable burden on the hospital. A major problem is that in Macanese healthcare services there are no translators; therefore, the use of a third language becomes a regular practice. Customarily, when patients and health professionals do not share a common official language, communication takes place in English. If that is impossible (because one or both parties are not comfortable speaking English), a team member, most often a nurse, translates one of the languages being used, even if that person has no proper training.

Another problem must be underscored: even when patient and physician are both Chinese nationals, there is no guarantee that they will understand each other, as there is a significant difference between spoken Mandarin and Cantonese. If one party only speaks Cantonese and the other only speaks Mandarin they will not be able to understand each other. Surprisingly, testimonies have shown that when this happens, the patients prefer Portuguese-speaking physicians and the use of a nurse as translator.

Several solutions can be considered to fill the communications gaps: (1) providing patients with audio records or written documentation in their primary language with relevant informed consent information; (2) training healthcare staff to operate as translators; and (3) retaining the services of a permanent interpreter for the hospital, calling in external translators whenever necessary, and using family members as translators.¹⁴ The strengths and weaknesses of these options are analyzed as follows.

Within the hospital environment, it is common to provide written forms of informed consent in a patient's language. In Conde de S. Januário Hospital, informed consent forms are written in the two official languages plus English, and must be completed in one of these three languages (presumably conforming to the language on the form). Curiously, the English version states that it is provided for reference only. Therefore, in cases of translation discrepancies, the Chinese or Portuguese forms prevail. In accordance with internal regulation, the signed consent form should be in a language in which the patient is proficient. For patients who are not fluent in any of the referred languages (Chinese, Portuguese, or English) there are no forms available.

The actual method of translation becomes crucial. Internal translations through computer programs should be avoided because of inadequate reliability. For example, sometimes Google Translator is used, which can lack accuracy¹⁵ and there is the risk of translations being too literal, or even bizarre. It is important to establish a mechanism to control translations, and at the same time verify that cultural specificities have been taken into consideration.¹⁶

Written documents or oral records of information, although useful, are not optimum because they are static statements, and studies have shown that patients prefer personal contact.¹⁷ If direct conversation with the physician is not viable because of language differences, the presence of someone to translate is indispensable, not only to provide patients with the required information, but also to help patients complete the hospital admissions form and understand the instructions for follow-up treatments, and even to ensure that the patient's identification is correct. Language differences can actually prove to be quite problematic, especially before a surgical intervention or other treatments that could have serious implications if identities are confused. 18 A case in point is Vo v. France, 19 in which the European Court of Human Rights was called on to decide the complaint of a woman who had entered a French hospital for a routine medical examination when she was pregnant. Because she was a foreigner and did not have an adequate command of the language, she was mistakenly given a procedure intended for another patient, with the resulting loss of her 20-weekold fetus.

Resorting to oral translations by healthcare professionals is not an efficient solution, because frequently the health staff lacks the necessary expertise in the language used by the patient and in which they are asked to communicate. At best, this arrangement only works with bilingual staff, but the fact is that most healthcare providers have only limited knowledge of a second language.

Alternatively, healthcare services could provide a permanent professional translator in loco. This could be a difficult plan to implement, especially in hospitals that receive patients from many different countries, because it would be impossible to predict which languages would be spoken and which translators would be required. In the case of Macao, probably professional translators for Cantonese, Mandarin, and English (eventually also Tagalog, because of the high number of Filipino migrants) would be sufficient, but even in this limited version the cost could be exorbitant.

Another (less expensive) option would be to have translators not permanently on site, but available to be called in on an as-needed basis. Nevertheless, this protocol has disadvantages. It can be time consuming, leaving patients and their families anxious, and it is not a practical solution for emergencies. In emergencies, a translation service over the phone may be used, although this solution has several limitations: the risk of misinterpretation is higher, it only works with small pieces of information, it can be unfeasible for patients with learning disabilities, and it can have dramatic consequences anytime it involves sensitive issues, such as when patients have to be informed that that they have a lifethreatening disease.²⁰

Precautions must be taken when using an interpreter efficiently, whether external or internal. For example, there is the duty of confidentiality. Because translators are not bound to medical secrecy as part of their professional duties, it is necessary to bind them contractually. This is crucial, because they deal with sensitive information, the disclosure of which could amount to a breach of privacy or, according to some laws, even a criminal offense. Translators should also be knowledgeable of the medical lexicon of the languages that they are being asked to translate.²¹ Some studies²² have shown that these requisites are not always fulfilled, and translators making serious mistakes in their translations are not uncommon.

Furthermore, translators should have abilities other than language proficiency. Because patients come from very different environments and backgrounds, translators must understand and be sensitive to the patient's culture, ²³ and the messages being conveyed.

In the absence of professional translators, Macanese healthcare services do resort to ad hoc translators; that is, those who use the same language as the patient and happen to be around. Usually, these are among the patient's relatives (or even close friends). Although some patients may initially feel more comfortable with their relatives and close friends, this solution presents many problems.²⁴

First, the information the patient receives may not be accurate, as the family member may not have the necessary language proficiency to understand the caregiver's explanation. Even if that person has mastery of the language being used, he or she probably does not have sufficient knowledge of medical issues to offer an accurate translation, making it difficult for patients to completely understand their situation.

Second, because translators may be very close to the patient, their objectivity may be compromised, and they may "color" the message communicated to the patient in an effort to protect that person from unhappy news. In addition, if the topic of conversation involves sensitive issues (e.g., sexually transmitted diseases, addiction, child abuse, or domestic violence), chances are that the family member will not pass on the information properly because he or she may be embarrassed. Children in particular should never be used as translators because they lack the mental and emotional capacity to understand the importance and sensitivity of the matters being discussed.

If the patient insists on using a family member, this decision should be respected and recorded in the patient's medical record. Some authors have argued that patients' decisions to use a translator of their own choosing (normally a relative) do not exclude the liability of the healthcare staff or hospital for the transmission of defective information.²⁵

From a theoretical perspective, there could be another option: to assign each patient a healthcare professional speaking the same primary language. To direct a patient to a particular physician because of their common language or culture is justified, as this is a reasonable and objective criterion by which to differentiate. The obstacle to this solution is not juridical or ethical, but practical. In effect, this possibility would only be viable in large hospitals, with enough physicians and nurses to allocate to patients using language as a criterion, and at the same time providing patients an adequate specialist to address their medical condition. In smaller hospitals—as is the case in Conde de S. Januário Hospital—it is most unlikely that there would be enough specialists with command of the languages in use. In following this criterion, patients would have to settle on physicians who speak the same language, but who lack expertise in a particular patient's health condition.

Proposals for the Multilingual Challenge of Macao

Macao still lacks an organized and uniform policy to deal with multiple languages. The procedure to be followed when a patient does not speak the language used in the hospital cannot be left to each physician, or even to each clinical director.

To the contrary, the hospital should create internal protocols so that all healthcare providers act uniformly. The protocol should clearly establish:

- 1) Where the patient's primary language is to be documented. Answer: The most reasonable option is in the patient's medical chart.
- 2) When the translator (preferentially a professional translator, if not a trained healthcare staff member) needs to be called. Answer: As soon as possible, once it is concluded that the patient does not have adequate proficiency in the physician's primary language or one in which he or she has proficiency.
- 3) Which procedures or tasks a translator should be used for. Answer: These basically include every act involving the patient, from admission to discharge.
- 4) When it is acceptable to use a family member as a translator. Answer: only if no other translator is available in time.
- 5) How to proceed when the patient refuses to use a translator. Answer: This refusal should be recorded in the patient's medical chart.
- 6) How to proceed with written forms of informed consent. Answer: The hospital must always have forms available in the most common languages used by its patients, although the hospital cannot cover every language. Therefore, when faced with an unusual language in which there is no written form of informed consent, the hospital must provide, whenever possible, an ad hoc translation of an existing form;
- 7) Which other documents should be translated. Answer: every document relevant to the patient must be presented to the patient in his or her primary language, including discharge instructions and the bill.

To summarize, communicating with patients in their native language is a mechanism not only for complying with informed consent, but also for promoting patient safety, respecting the patient's rights, and increasing the patient's satisfaction. For these reasons, hospital management should assume communication and translation as one of its key concerns.

The Multicultural Issue

Language differences are not the only obstacles that separate patients from physicians and impede communication. Each population has its own cultural values. For example, some patients may be uncomfortable being unclothed in front of the physician, others may only be willing to accept a physician of the same gender, and some may require specific end-of-life rituals or have particular ways of dealing with physical or emotional pain.

In the realm of informed consent, some cultures still maintain a tradition in which physicians are expected to make all medical decisions without even providing information to their patients. Another characteristic of some cultures is that consent for medical treatments may be given not by the patient, but by the patient's relatives;²⁶ for example, in the case of female patients in paternalistic societies.

Cultural differences have a decisive impact on the doctor–patient relationship and in Macao doctors and patients frequently face difficulties in this regard.²⁷ In the case of Macao, there are two very different cultures cohabitating the territory, and what qualifies as acceptable, or even desirable, to one may be repudiated by the other.

Nowadays, the Chinese culture is largely dominant, even in the practice of medicine. Most healthcare staff operating in the hospital have come from mainland China, and they are accustomed to following Chinese rules in terms of obtaining a patient's consent.

However, the Macanese legal order has basically been inherited from the Portuguese administration, and follows a Western legal order. Therefore, it is not unusual for conflicts to emerge between the way things are done in day-to-day practice and the way things should be done according to the law.

This difference is manifested in the division of decisionmaking between physician and patient, requiring a delicate balance between Chinese paternalism and Western autonomy. Both the Portuguese and Chinese cultures have historically been paternalistic regarding patients, but they are paternalistic in different ways. In the West, therapeutic decisions were usually up to physicians, whereas in China (and in Asia generally) the traditional perspective was to assign therapeutic decisions to the family. In both scenarios, decisions were made by persons other than the patient. Nowadays, however, the Portuguese legal order criminalizes medical interventions performed without the patient's consent (Article 156 of the Portuguese Criminal Code). This same standard is included in Article 150 of the Macanese Criminal Code, imposing a restriction on physicians any time a patient does not consent to a medical intervention.²⁸ The crime in question, entitled "arbitrary medical-chirurgical interventions," states the following: "The people mentioned in Article 144 [referring to healthcare professionals] that in view of the purposes referred to therein [therapeutic interventions in a broad sense], conduct effective intervention or treatment without the patient's consent shall be punished with imprisonment up to three years or a fine."

The law also clarifies, once again under the influence of the Portuguese legislation, that the patient must be fully informed of all relevant data before he or she can make the decision. Article 151 of the Criminal Code of Macao, entitled "duty of clarification," establishes the following:

For purposes of the preceding paragraph, the consent is effective only when the patient has been properly informed about the diagnosis and the nature, scope, magnitude and possible consequences of the intervention or treatment, unless it involves the communication of circumstances that, if known by the patient, would endanger his life or would be likely to cause serious harm to his health, physical or mental.

In contrast, patient information in Chinese culture is almost nonexistent in practical terms. Physicians frequently resort to omission and even deliberate obfuscation to protect the patient from the truth. It is the family members who end up deciding whether the patient is informed,²⁹ and family-oriented deception of competent patients is not unusual.³⁰

Another cultural particularity concerning informed consent relates to the person entitled to give consent. In Chinese communities, the most important decisions are made by the family (especially in the case of female patients or elderly patients). Therefore, the concept of personal consent for medical acts has been replaced by a kind of "family consent." In this sense, familism differentiates China from traditional Western paternalism. It is not the physician who decides what is the best for the patient, but rather the family, although the physician still plays an important role.³¹

Fan and Li refer to the familist feature of the medical act, as opposed to the individualist nature of the doctor–patient relationship in Western countries and in the Macanese law on informed consent. It is a legacy of Confucianism,³² the philosophical core of Chinese culture.

This practice is fully recognized under the law of mainland China, as stated, for example, in Article 55 of the 2009 Tort Law of the People's Republic of China (中华人民共和国侵权责任法):³³ "…obtain a written consent of the patient; or, when it is not proper to explain the information to the patient, explain the information to the close relative of the patient, and obtain a written consent of the close relative."

The same idea appears in Article 26 of the Law on Practicing Doctors of the People's Republic of China (中華人民共和國執業醫師法):³⁴ "Doctors shall tell the patients or their family members the patients' conditions truthfully. However, care shall be taken to avoid adverse impact on the patient. Doctors shall get the approval from the hospital and the consent of the patient or family members before conducting clinical treatment on an experimental basis."

Therefore, in Macao public hospital, healthcare providers (most of whom come from mainland China) systematically provide information to and request consent from the family, not the patient.

However, in Macau, the Criminal Code (the aforementioned Article 150 of the Criminal Code)³⁵ expressly imposes a requirement that the patient's consent be obtained. This is specified under the norms ruling the requisites to generally consent in harmful conduct by third parties (Articles 37, 38, and 150 of the Criminal Code). In the Macanese legal order, there is no special norm authorizing family members to consent to a medical act. Therefore, the general rule of personal consent applies, meaning that only minors and patients judicially declared incompetent could be legally represented by another in providing consent. In the Macanese legal order the relatives are not allowed to provide consent, even in cases of unconscious patients. In such situations, the physician is asked to presume the patient's consent, taking into consideration the specificities of the patient, such as his or her religion, profession, and values. The aforementioned Article 150 of the Macau Criminal Code states in Section 2 that a physician can intervene without the patient's consent whenever:

a) the consent can only be achieved with a postponement that will involve danger to life, or serious danger to body or health, or, b) the consent has been given to certain interventions or treatments, but a different one has been performed, because it was imposed by the state of the art and the experience of medicine as a mechanism to avoid danger to life, body or health, in any case as long as circumstances do not exist leading [one] to conclude with certainty that the consent would be refused.

Hence, according to this norm, the legal right to decide when patients are unable to decide for themselves does not fall to relatives; the decision is up to the physician, who must decide using substituted judgement as to how he or she believes the patient would have decided had the patient been in a condition to consent.

Curiously, all informed consent forms provided by the public hospital allow the signature of a family member, even for patients who are not minors or have reduced mental capacity, demonstrating that this is actually the hospital's common practice. Nevertheless, to ask for relatives' consent could expose the hospital to liability and litigation. In addition to violating the personal nature of informed consent under Macanese law (Articles 37, 38, and 150 of the Criminal Code), this practice infringes on the privacy law,³⁶ because by acting in this way, physicians are sharing very personal information about patients (health information) with other people, frequently without the patient's consent. The practice followed by the hospital is illegal, even criminal, in light of the applicable law in Macao.

Proposals for the Multicultural Challenge of Macao

Many refer nowadays to the "globalization of ethics." However, this is far from the real case in medical practices around the world. The notions of "personal autonomy" and "patient's rights" (or, generally, "human rights") vary widely across cultures. For these scenarios, Lawrence Gostin proposes the concept of "cultural sensitivity" as a way of respecting human dignity among different people. 40

Based on these ideas, it could be argued that the Western theory of informed consent is not always suited to other cultural backgrounds. The doctor–patient relationship and informed consent practices do not comprise a "one size fits all" model. However, the respect for cultural diversity cannot justify every instance, especially when human rights are at stake. As to what regards informed consent in Macao, some other argument should be considered.

Beginning with the legal argument, in Macao, and as long as the existing law continues in place, the current practice of asking consent from relatives and basically following the proceedings associated with informed consent in mainland China is illegal. Healthcare providers risk a civil lawsuit and even a criminal condemnation for not complying with the requisites enforced by law, namely by Article 150 of the Macanese Criminal Code.

A hypothetical proposal could be offered to change the existing law, in order to turn it toward a more "Chinese value-oriented" perspective, and bring it closer to the regulations of Mainland China. But here we face the human rights argument, based on the idea that there is a basic core of human rights that should be universally respected.

Attempts to enforce laws that disregard core values of the community are destined to fail, because each law has its own cultural environment and it should satisfy the needs of the particular population, which may be crucial to that group.

But "culturalism," or cultural relativism, cannot justify violations of human rights. Even in Mainland China, familism is not uniformly agreed upon among scholars. Although some of them sustain the maintenance of traditional familism in respect to cultural values, ⁴¹ others underline the contradiction between familism and existing human rights and patients' dignity. ⁴²

The position here is that, while still respecting the particularities of the large Chinese community living in Macao, the existing legal regime and its compliance, should be maintained. First, it should be recognized that Macao is a different China, not only because of the rule "one country, two systems," but foremost because its population is intrinsically pluralistic and heterogeneous. Second, the adoption of the individual informed consent model, based on the patient's self-determination, is being increasingly advocated in Mainland China, as the one that most effectively recognizes the rights of patients as autonomous persons. Someone else making

decisions in the patient's name is to turn the patient into an object of the decision rather than its maker, ultimately degrading his or her rights and dignity. Of course the patient can refer the decision to another person—such as the physician or a relative—but this has to be a result of the patient's autonomous decisionmaking. This is the model most suitable to Macau in that it best embraces individual sensibilities.

Conclusion

Macao faces a particularly challenging scenario with regard to issues of informed consent, given that it is a society profoundly divided between West and East, with a Portuguese-inspired legal order and a Chinese way of life. The practices that have been implemented in the Macanese public hospital are far from perfect and still require much improvement, especially because of their clear contradiction to the law in place.

Nevertheless, until now, healthcare authorities and the current mechanisms have managed to avoid serious patient injuries caused by lack of communication and have so far managed the difficulties that informed consent poses in such a pluralistic environment. They have done so not because of a planned strategy; but primarily because of the goodwill of the patients and physicians. The question is: how long can this "state of grace" be maintained?

Notes

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