



Lost in ‘Culturation’: medical informed consent in China (from a Western perspective)

Vera Lúcia Raposo¹

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Abstract

Although Chinese law imposes informed consent for medical treatments, the Chinese understanding of this requirement is very different from the European one, mostly due to the influence of Confucianism. Chinese doctors and relatives are primarily interested in protecting the patient, even from the truth; thus, patients are commonly uninformed of their medical conditions, often at the family’s request. The family plays an important role in health care decisions, even substituting their decisions for the patient’s. Accordingly, instead of personal informed consent, what actually exists is ‘family informed consent’. From a Western perspective, these features of Chinese law and Chinese culture might seem strange, contradicting our understanding of doctor-patient relationship and even the very essence of self-determination and fundamental rights. However, we cannot forget the huge influence of cultural factors in these domains, and that ‘Western’ informed consent is grounded on the individualistic nature of Western culture. This article will underline the differences between the Western and the Chinese perspectives, clarifying how each of them must be understood in its own cultural environment. But, while still respecting Chinese particularities, this paper advocates that China adopt patient individual informed consent because this is the only solution compatible with human dignity and human rights.

Keywords China · Confucianism · Health care delivery · Familism · Informed consent

Introduction: a brief overview of patient’s informed consent in China

All around Asia patient’s informed consent assumes specific notes, primarily described by the role of family in receiving information about the patient’s health condition and ultimately the legitimacy of relatives to decide about medical treatments. This study will focus in the Chinese case, trying to describe its main features in this regard and analyse them from a western perspective.

Chinese law imposes informed consent for medical treatments, but the Chinese understanding of this requirement is very different from the European one, mostly due to the influence of Confucianism. Although the existing model for patient’s informed consent is grounded in a long lasting and highly respected philosophical tradition, it raises complex issues regarding its compatibility with human rights doctrine

and with current predominant trends in health law and doctor-patient relationship.

For instance, a sad episode that occurred in Beijing in 2007 has been reported in the legal and ethical literature involving a pregnant woman in prolonged labour whose delivery was delayed at the family’s (husband/boyfriend and mother in law) request so that the baby could be born on a lucky day. This delay was against the doctor’s opinion, who advised that a caesarean birth should be immediately performed due to the huge risk of intrauterine asphyxia. Due to the lack of proper medical care, some hours later both mother and child were dead.¹ More than one reason explains this episode, including a general mistrust against health care professionals (Nie et al. 2018c).² Li and Wen argued that the tragic outcome of this case was not due to Confucianism nor even to the Chinese law inspired by it given that both the doctrine and the law allowed the doctor to intervene to save the patient’s life in an emergency even

✉ Vera Lúcia Raposo
vraposo@umac.mo; vera@fd.uc.pt

¹ Faculty of Law, University of Macau, Room 2043, E32, Avenida da Universidade, Taipa, Macau, China

¹ <http://articles.latimes.com/2007/dec/25/world/fg-birth25>.

² Also about the lack of trust between patients and their families and doctors, see Chan (2018); Nie et al. (2018a, b); Yan (2018); Zou et al. (2018).

without the family's consent (Li and Wen 2010). However, as Cheng, Ming and Lai pointed out, Chinese scholars have found it difficult to escape from 'the ghost of patriarchal authoritarianism from familism' (Cheng et al. 2012, p. 437). In other words, even when the law has excluded strict familism, respect for the decisions of the family have continued to haunt health care practitioners. Therefore, it is not difficult to understand that sometimes they have preferred to look to the family for support instead of simply complying with the law.

One of the most dramatic cases related with informed consent happened just recently in Shaanxi Province, leading to the suicide of a young woman. The woman was admitted in the hospital when she was 41 weeks pregnant, and immediately the doctors concluded that the foetus had a large head circumference, meaning that a vaginal delivery could be risky for the woman. Despite the medical recommendation of a caesarean, the family (her husband and the husband's family) refused this procedure and insisted on a vaginal delivery (the reasons are unknown). In her suffering, the patient tried several times to persuade the family to agree to the caesarean, but without success. Thus, lacking the family's consent, the medical team did not perform the intervention. In despair, the expectant mother jumped from a fifth-floor window, killing herself and the foetus.³

This paper will start by describing the existing legal framework in China in this regard, clarifying how the existing norms are usually interpreted by courts and applied in day to day medical practice. Subsequently it will refer the main feature of Confucianism, the philosophical base for this particular understanding of patient's informed consent, especially having in consideration the so-called "familism", as the attribution of the power to be informed and to decide to the family. Based on this description, the paper will confront the basic premises of familism with human rights doctrine, namely the right to patient's self-determination. It will then analyse if one single model of medical informed consent can be imposed in all cultures and jurisdictions, in light of the ideas of cultural relativism. Finally it will present a conclusion regarding the legitimacy of Chinese familism and its prospective evolution in the future.

³ <http://www.bestchinanews.com/Health/13405.html>, <http://www.scmp.com/news/china/society/article/2109804/pregnant-chinese-woman-commits-suicide-after-family-refuse-allow>, <http://says.com/my/news/pregnant-china-woman-jumps-to-her-death-after-family-refuse-to-give-consent-over-c-section> and <http://shanghaiist.com/2017/09/05/pregnant-woman-jumps-to-death.php>.

The existing legal norms pertaining to informed consent

Norms within the domain of health care delivery

In the People's Republic of China ('China'), consent for medical acts is mandated by various legislative norms (Du and Rachul 2013), including Article 40 of the 1982 Regulations on Medical Work (医院工作制度);⁴ Article 33 of the Regulations on the Administration of Medical Institutions (醫療機構管理條例), enacted in 1994;⁵ Article 62 of the Detailed Rules on the Implementation of Regulations on the Administration of Medical Institutions (醫療機構管理條例實施細則), also enacted in 1994;⁶ Article 11 of the Regulation on Handling of Medical Accidents (醫療事故處理條例), enacted in 2002;⁷ and Article 10 of The Basic Norms of the Documentation of the Medical Record (病历书写基本规范), enacted in 2010.⁸

⁴ Regulations on Medical Work of the People's Republic of China, April 7 1982, at http://0-www.pkulaw.cn.umaclib3.umac.mo/fulltext_ext_form.aspx?Db=chl&Gid=1254&keyword=%E5%8C%BB%E9%99%A2%E5%B7%A5%E4%BD%9C%E5%88%B6%E5%BA%A6&EncodingName=&Search_Mode=accurate&Search_IsTitle=0. Article 40(6): 'The patient's relative or company should sign the consent form before the operation...'

⁵ Regulation on the Administration of Medical Institutions, 26 February 1994, at <http://en.pkulaw.cn/display.aspx?cgid=267142&lib=law>. Article 33: 'When offering surgery, special examination or special treatment, a medical institution shall obtain the consent of a patient, and obtain the consent and signature of his or her family or related; when the consent of a patient is unavailable, the medical institution shall obtain the consent and signature of his or her family or related; and where the opinions of a patient are unavailable and there is no family or related on the scene, or other special circumstances are present, the managing physician shall offer a medical treatment plan and implement the plan after obtaining the approval of the principal person in charge of the medical institution or the authorised responsible person'.

⁶ Detailed Rules on the Implementation of Regulations on the Administration of Medical Institutions, 29 August 1994, at <http://www.chinacourt.org/law/detail/1994/08/id/20577.shtml> (Chinese version). Article 62: 'A medical institution shall respect patients' right to know about their condition, diagnosis and treatment. To offer surgery, special checks and special treatments, necessary explanations shall be given to patients. Where the situation is inappropriate to be explained to patients for the implementation of protective medical measures, patients' families shall be informed of the relevant situation'.

⁷ Regulations on Handling Medical Accidents, 4 April 2002, at http://www.npc.gov.cn/englishnpc/Law/2007-12/14/content_1384186.htm. Article 11: 'Medical institutions and their medical workers shall, in their medical activities, truthfully inform patients of the situations of their illness, curative measures, medical risks and other related matters, and timely answer patients' inquiries; however, they shall avoid the occurrence of any adverse effects to patients'.

⁸ The Basic Norms of the Documentation of the Medical Record, 22 January 2010, at http://0-www.pkulaw.cn.umaclib3.umac.mo/fulltext_ext_form.aspx?Db=chl&Gid=126863&keyword=%E7%97%85%E5%8E%86%E4%B9%A6%E5%86%99%E5%9F%BA%E6%9C%AC%E8%A7%84%E8%8C%83&EncodingName=&Search_Mode=accurate&Search_IsTitle=0 (Chinese version). Article 10: 'For the medi-

The Law on Practicing Doctors of the People's Republic of China (執業醫師), enacted in 1998, deserves special attention. In Article 26 it stipulates: 'Doctors shall truthfully tell the patients or their family members about the patients' condition. However, care shall be taken to avoid adverse impact on the patient. Doctors shall obtain approval from the hospital and the consent of the patient or family members before conducting clinical treatments on an experimental basis'. According to this law, the patient is in the exact same position as his or her relatives in terms of obtaining information and providing consent. One can even argue that family members are placed in a dominant position because it can be understood—and within Chinese culture this might be a frequent scenario—that information about a patient's health condition will distress him/her, leading to recurrent information being provided to the relatives instead of the patient.

Another tricky regulation can be found in Article 24 of this law: 'For emergencies and critical cases, doctors shall adopt emergency treatment measures and shall not refuse to provide emergency treatments'. The lack of reference to informed consent suggests that in those situations informed consent is not required. Of course, emergency situations demand a specific solution, and waiting (perhaps indefinitely) for the patient's consent could postpone the medical intervention, eventually leading to serious injury or even death. In these situations, Western legal orders tend to operate on the basis of presumed consent, and some institutions even demand that doctors conduct subjective evaluations, that is, make decisions based on the patient's values and beliefs.⁹ Because this possibility is not mentioned in the law, we conclude that the doctor must always provide medical care in emergency situations, even disregarding the patient's desires.

In sum, there are several legislated norms that require the patient's informed consent. However, some of these (for instance, the Regulations on the Administration of Medical Institutions) give both the patients and their relatives the same right to be informed and make decisions, in practical

terms, leaving the entire decision to the latter. In this study we intend to demonstrate that such a practice is against human rights and fundamental rights recognised to patients and is currently being rejected by several Chinese scholars.

Other norms

The core concept underpinning patient's informed consent is also grounded in other norms outside of the health care delivery system. This is the case with the General Principles of the Civil Law of the People's Republic of China (中华人民共和国民法通则),¹⁰ enacted in 1986 and considered to be one of the most important pieces of legislation existing within the Chinese legal system. Article 4 of the law requires that '[i]n civil activities, the principles of voluntariness, fairness, making compensation for equal value, honesty and credibility shall be observed'. It may be a long shot; however, some scholars have pointed out that the voluntariness principle can provide a legal basis for informed consent (Cui and Yang 2008).

The Tort Law of the People's Republic of China (中华人民共和国侵权责任, henceforth Tort Liability Law),¹¹ Chapter 7, also addresses informed consent, stating that it is the duty of the health care staff to inform the patient; otherwise, the medical institution can be held liable. This is one of the most relevant regulations on this subject.

First of all because of its mandatory nature. In light of the previous existing norms there was not tort liability for the violation of informed consent nor, therefore, any compensation. The obligation to provide informed consent has, in actual practice, been more of a recommendation than a mandate, with little impact on the doctor/patient relationship. However, Articles 57 and 58 of the Tort Liability Law impose the duty as a legal obligation, and those who disregard it can subject the medical institution that employs them to liability.¹²

Footnote 8 (continued)

cal activities in which the written consent of the patient should be obtained, the informed consent should be signed by the patient himself. When the patient does not have the complete civil capacity, it should be signed by a legal representative; when the patient cannot sign because of illness, it should be signed by the person authorised by the patient; in order to save the patient, if the legal representative or the authorised person cannot sign timely, it may be signed by the person in charge of the medical institution or the authorised person in charge.'

⁹ This is the case of Article 156 of the Portuguese Criminal Code and Article 150 of the Macanese Criminal Code. With regard to presumed consent for medical treatments, especially as stated in these norms, Andrade (2012); Raposo (2012); Raposo (2013).

¹⁰ General Principles of the Civil Law of the People's Republic of China, 4 December 1986, at <http://www.lawinfochina.com/display.aspx?id=18525&lib=law&SearchKeyword=&SearchCKeyword=%c3%fl%b7%a8%cd%a8%d4%f2>.

¹¹ Tort Law of the People's Republic of China, 26 December 2009, at <http://www.wipo.int/edocs/lexdocs/laws/en/cn/cn136en.pdf>.

¹² Analysing Chinese caselaw we can find some judicial decisions making health care providers accountable, based on Tort Liability Law. For instance, the case judged on 17 June 2007 by the Intermediate People's Court of Shaoyang, City of Hunan (湖南省邵陽市中級人民法院) (at <http://ccl.cn/14021.html>). In this case, the medical personnel did not inform the patient about the alternative treatments available (namely, that there was an alternative to surgery) and carried out the surgery directly. Another example is the case judged on 1 January 2008 by the Intermediate People's Court of Wenzhou City of Zhejiang (浙江省溫州市中級人民法院) (at <http://ccl.cn/6911.html>).

Secondly, due to the level of detail. Some provisions of the Tort Liability Law contain comprehensive descriptions of informed consent, clarifying the requisites that have been obscured in disparate norms (Zhu 2014). For example, Article 55 states that ‘[d]uring diagnosis and treatment, the medical staff shall explain the illness, condition and relevant medical measures to their patients. If any operation, special examination or special treatment is needed, the medical staff shall explain the medical risks, alternate medical treatment plans and other information to the patient in a timely manner, and obtain the written consent of the patient; or when it is not proper to explain the information to the patient, explain the information to a close relative of the patient and obtain the written consent of the close relative. Where any medical staff member fails to fulfil the duties [set forth] in the preceding paragraph, and causes any harm to a patient, the medical institution shall assume the compensatory liability’.

Despite its merits, this particular legal solution, established under the Tort Liability Law, has been criticised by Chinese scholars (Zhu 2014). As seen above, it distinguishes between the general duty to inform and a special duty to inform (Chen 2014; Wu 2013), depending on the specific medical act in question: diagnosis or treatment for the former and ‘surgery, special examination or special treatment’ for the latter (Chen 2014). However, the words ‘special examination’ and ‘special treatment’ raise some issues because the Tort Liability Law does not define them. However, we may refer to the definition provided in Article 88 of the Detailed Rules on the Implementation of Regulations on the Administration of Medical Institutions, in which ‘special examination’ and ‘special treatment’ refer to the activities of diagnosis or examination that: (i) involve the risk of adverse effects; (ii) are performed on patients with special body conditions or critical clinical situations; (iii) are performed within clinical trials; or (iv) involve economic costs susceptible of causing a heavy financial burden to the patient.

Another issue raised by Article 55 is related to the definition of ‘close relatives’, which has not been clarified under the standard (Li and Rachul 2013, pp. 26–32). According to a note delivered by the Supreme People’s Court on Issuing the Opinions on Several Issues Concerning the Implementation of the General Principles of the Civil Law of the People’s Republic of China¹³ (最高人民法院印发《关于贯彻

Footnote 12 (continued)

In this case, the medical personnel did not inform the patient about the high risk of complications after surgery. See also the case judged on 1 January of 2011 by the People’s Court of Ning’an City of Heilongjiang (黑龍江省寧安市人民法院) (at <http://ccl.cn/18550.html>). In this case, medical personnel did not inform the patient about the risk of surgery and the post-surgery risks.

¹³ Notice of the Supreme People’s Court on Issuing the Opinions on Several Issues concerning the Implementation of the General Principles of the Civil Law of the People’s Republic of China, 4 February 1988, at <http://en.pkulaw.cn/display.aspx?cgid=3689&lib=law>.

执行<中华人民共和国民法通则>若干问题的意见) this term includes spouses, parents, children, brothers and sisters, paternal and maternal grandparents and grandchildren. Further, although Article 55 is very detailed in the way information is to be provided, it is not detailed enough. There are no instructions on how information is to be transmitted or what information is to be imparted.¹⁴

Likewise, the circumstances under which the medical staff can disregard the patient’s rights and ask for consent from (close) relatives are unclear. The dubious statement—‘when it is not proper to explain the information to the patient’—is open to interpretation. Not only has there been no clarification of the specific scenarios the norm refers to (e.g., when the patient might become upset with that information; when he/she might become severely stressed; when the information is so damaging that disclosing it might involve serious risks for the patient’s health condition; when the patient is too young to understand or too old to cope with the information), there has been no indication of who is entitled to make the assessment (a court, the hospital’s ethics commission, the doctor, the patient’s relatives or someone else).

Many have pointed out the empty space left by Article 55 and have demanded more intervention from lawmakers (Li and Rachul 2013; Zhu 2014). However, to be fair, most Western legislations do not include further specifications of what constitutes informed consent, except perhaps in cases concerning such things as reproductive techniques, abortions and especially risky treatments. Most aspects of informed consent have actually been shaped by legal scholars and subsequently reviewed by the courts through their decisions. However, although these decisions are considered to be precedent, they may still be open to interpretation.

Medical informed consent in Chinese legal system

Forms of expressing consent

In China (and generally in Western legal systems) consent can be oral (Chen 2014; Wu 2013), except when it relates to ‘surgery’, ‘special examinations’ or ‘special treatments’, for which written consent is required under Article 55 of the Tort Liability Law; routine treatments do not require written

¹⁴ But see Article 11 of the 2002 Regulations on Handling Medical Accidents do further specification. Cf. 2002 Regulations on Handling Medical Accidents, 20 February 2002, at http://english1.english.gov.cn/laws/2005-07/25/content_16885.htm. Article 11: ‘Medical institutions and their medical workers shall, in their medical activities, truthfully inform patients of the situations of their illness, curative measures, medical risks and other related matters, and timely answer patients’ inquiries; however, they shall avoid the occurrence of any adverse effects to patients.’

consent, however, information must still be provided and consent obtained (Wu 2013). The problem is, as Chinese scholars have expressly pointed out (Chen 2015), that when consent is verbal, it is very difficult to prove in court that it has been given unless the patient has acknowledged it.

If medical personnel fulfil their duty to inform and the patient does not express clear disagreement with his or her treatment, either orally or in writing, it is presumed that consent has been given (Wu 2013). In such cases the Chinese legal system does not require patients to expressly articulate their consent to medical treatment, but only to refrain from disagreeing.

Content of the information provided

The content of the information disclosed has been the subject of several legislated norms (Chen 2015; Hu 2015).

Article 11 of the 2002 Regulations on Handling Medical Accidents establishes the duty of medical staff to inform patients of their diagnosis, proposed treatments measures and medical risks, and to answer any questions they may ask.

Article 55 of the Tort Liability Law mandates that patients be informed of their medical condition and the medical acts to be performed during diagnosis and treatment. However, if an operation, special examination or special treatment is recommended the information must also contain broader content that includes 'medical risks, alternate medical treatment plans and other information [related] to the patient'. That said, the law fails to clarify what kind of medical risks should be disclosed (e.g., the most frequent ones, the most severe ones or both) and what other information is considered to be equally relevant (Li and Rachul 2013). In the West, these risks have also rarely been specified, and it has been left to scholars and to courts to clarify them. Therefore, Western standards appear to be no more detailed than the Chinese ones.

In all cases, the information provided should be truthful. Nevertheless, in clinical practice, that does not always happen. Chinese hospitals often face financial constraints. Thus, there may be a tendency to overreact a patient's medical condition and mislead him or her into providing informed consent for expensive but useless medical treatments (Li and Rachul 2013).

Analysing Chinese case-law we have found several decisions in which the hospital has been held liable for failing to provide all of the information necessary for informed consent. For instance, there have been decisions in which the hospital did not inform the patient or his/her family about a sudden change of surgeon during a surgery,¹⁵ a change in the

treatment plan during surgery¹⁶ or the cost of treatment.¹⁷ In the latter case, it is hypothetically possible that the hospital would be held liable for damages the patient has suffered if there has been a large divergence between the cost that was communicated to the patient and the actual cost following medical treatment.

The right to be informed and to consent

Article 55 of the 2009 Tort Law imposes a duty to inform on 'medical staff', that is, doctors. This directive is exactly the same under the law in the West, and it is actually difficult to find any alternative to it. However, with regard to the people entitled to receive information and provide consent, Chinese law strongly differs from Western law.

Until the 2002 Regulations on Handling Medical Accidents were enacted, the rule was that both the patient and his or her relatives (or even what was called 'other relevant persons') were involved in the informed consent process. This was the solution provided under Article 33 of the 1994 Managerial Regulations of Medical Institutions (医疗机构管理条例)¹⁸, the 1998 Law on Medical Practitioners (中华人民共和国执业医师法)¹⁹ and the 2000 Technical Specifications of Clinical Blood Transfusions (临床输血技术规范).²⁰ In sum, medical institutions were not permitted to

¹⁶ See the case judged on 19 July 2010 by the Intermediate People's Court of Urumqi (乌鲁木齐市中级人民法院), at <http://www.ccl.cn/16334.html>.

¹⁷ See the case judged on 1 January 2004 by the Intermediate People's Court of Guangzhou City of Guangdong (广东省广州市中级人民法院), at <http://ccl.cn/11785.html>.

¹⁸ Regulation on the Administration of Medical Institutions, 26 February 1994, at <http://en.pkulaw.cn/display.aspx?cgid=267142&lib=law>. Article 33: 'When offering surgery, special examinations or special treatments, a medical institution shall obtain the consent of a patient, and obtain the consent and signature of his or her family or related; when the consent of a patient is unavailable, the medical institution shall obtain the consent and signature of his or her family or related; and where the opinions of a patient are unavailable and there is no family or related on the scene, or other special circumstances are present, the managing physician shall offer a medical treatment plan and implement the plan after obtaining the approval of the principal person in charge of the medical institution or the authorised responsible person.'

¹⁹ Law on Practising Doctors of the People's Republic of China, 26 June 1998. At <http://www.asianlii.org/cn/legis/cen/laws/lotprocomp511/>. Article 26: 'Doctors should truthfully explain the patient's condition to the patient and his family members provided that attention is paid to avoid an adverse effect on the patient. Doctors should obtain the approval of the hospital and the consent of the patients themselves or their family members for experimental clinic treatments.'

²⁰ Technical Specifications of Clinical Blood Transfusion, June 2000, at http://0-www.pkulaw.cn.umac.mo/fulltext_form.aspx?Db=chl&Gid=31216&keyword=%E4%B8%B4%E5%BA%8A%E8%BE%93%E8%A1%80%E6%8A%80%E6%9C%AF%E8%A7%84%E8%8C%83&EncodingName=&Search_Mode=accurate&Search_IsTitle=0. Article 6: 'Before the decision of blood transfusion, the

¹⁵ See the case judged on 8 December 2011 by the People's Court of Tianshan District of Urumqi (乌鲁木齐市天山区人民法院), at <http://www.ccl.cn/61151.html>.

perform any surgical interventions, special examinations or treatments unless two conditions were met: the patient consents and the patient's relatives or other relevant persons also consent.

In contrast, the 2002 Regulations on Handling Medical Accidents directed that information must be provided to the patient unless it is inappropriate or impossible to do so, and only then can the family intervene. This solution was closely followed by Article 55 of the 2009 Tort Liability Law and by the Basic Norms of the Documentation of the Medical Record from 2010. Thus, the patient is now the only one that must provide informed consent, unless this is impossible, in which case the patient's consent will be substituted for the family's (Zhu 2014).

Nonetheless, in day-to-day practice, the relatives continue to be called on in the first instance (Li and Rachul 2013), and usually the informed consent form is signed only by one family member representing the entire family. In a study from 2015, Bian (2015) estimates that most physicians continued to request that family members sign the consent form and only 17% of the interviewed physicians said they asked the patient to sign. Thus, although the most recent norms require information and consent to be provided by the patient (Bian 2015), the actual practice still follows the traditional family consent procedure.

Exemption of duty to inform

In some situations, Chinese law allows a doctor to intervene without the patient's informed consent (Li and Rachul 2013). The first of these is the emergency situation, for example, when a patient requires medical care but is unable to provide consent at that moment (Article 56, Tort Liability Law; Article 33, Managerial Regulation of the Medical Institutions). Western law also tends to allow this, but only when it can be presumed that the patient would not oppose the treatment under the given circumstances (referred to as presumed consent). Intervention without consent has also been permitted to protect public health when there are exigent circumstances such as health epidemics, as it was seen at the time of the SARS pandemic.

The most problematic exception to informed consent from the Western perspective is when action is taken after

Footnote 20 (continued)

attending physician should explain to the patient or his family the adverse reactions from the transfusion of blood coming from the same type and from a different body, as well as the possibility of the spread of disease through the blood, obtain the consent of the patient or his family and obtain the signature on the 'Blood transfusion treatment consent form.' For the urgent blood transfusions to non-self-conscious patients without the signature of their family, it is necessary to report to the medical function department or to leadership who consents, puts on file and registers it in the medical records.'

a determination has been made that it is inappropriate to disclose information to a patient. Under Western law, this is referred to as the therapeutic exception, because it includes cases in which the information would distress the patient in such a way that it could jeopardise his or her recovery (Cave 2017). The Chinese exception is much wider, and can basically operate in any situation in which the family argues (even without solid grounds) that the information would upset the patient. This understanding comes from the broad range of the expression used: 'when it is not proper to explain the information to the patient' (Article 55, Tort Liability Law), which leaves space for a long list of exceptions.

Confucian familism and the patient's informed consent

The confucian perspective of the person

Confucianism is the predominant cultural and philosophical doctrine in East Asia and some of the most defining features of Chinese society are influenced by it (Li and Moreira 2009). For example, the Confucian notion of the person (Tsai 2001) theorises that each individual is constituted by a vertical dimension (one of autonomy and self-determination) and a horizontal dimension (one of relationships and altruism). The individual is inserted into a community in which the most important element is not him or her, but the family (familism). For the family to operate successfully, decisions cannot be taken by each family member independently, but must be made by all of them together (Li and Wen 2010).

When China was predominantly an agrarian society, Confucianism united family members for their common economic gain. Today this concept still survives in areas such as business, marriage and health care (Li and Wen 2010; Chen and Fan 2010). Because the individual is not as important as the family he or she belongs to, individual self-determination and personal consent are subjugated to the collective well-being (Chen and Fan 2010).

The relevance of confucian familism to medical informed consent

Confucian familism influences the way medical informed consent is provided in China. Information is disclosed to the family, and often only to it, and not to the patient. Usually the patient is only informed if the family agrees, so the family filters which information the patient may receive (Li et al. 2007).²¹ Furthermore, family members are the ones

²¹ What these authors perceive as an advantage I perceive as a violation of privacy rights, especially when involving extremely sensitive data, as it is the case of HIV, referred in the study of Li et al.

who ordinarily decide whether a medical act will be performed, and they sign the informed consent form even if it pertains to a competent adult patient (Cheng et al. 2012).

'Family consent' is not solely the involvement of family in the process of proving consent (something also happening in the West and not necessarily detrimental), but rather the attribution of the power to decide on health care matters to the family and not to the patient. The family is the one that receives health information, decides if the patient shall be informed or not and, in the end, takes the medical decision.

'Familism' is a broader concept, connected with Confucian doctrine, according to which the family, not the individual, is the most important element. Familism, as a specific ramification of Confucianism, is what justifies family consent.

Family consent is not only due to Confucian familism and to its emphasis on family values, but also to other more pragmatic reasons. On the one hand, financial motifs, since state-funded welfare is almost non-existent in China, so the kind of health care provided to the patient will affect the remaining family members financially (Tsai 2008; Hui 2008). On the other hand, for reasons related with the particular challenges faced by Chinese health care providers, that are frequently assaulted and even killed for angry patients and relatives; so, to look for the family's support is a wise way for physicians and nurses to physically protect themselves. But in the theoretical level Confucianism remains as the philosophical corner stone of family consent.

The participation of the family in medical health care is not unusual in Western societies. Traditionally, in Western cultures, the power to make medical treatment decisions on the patient's behalf did not rest with him or her. However, the decision was not up to the family as much as it was to the doctor, turning this model into a form of medical paternalism (Buchanan 1978; Bassford 1982). Until the middle of the last century, the family made these decisions in conjunction with the doctor (Macklin 1999). The Western understanding of a patient's autonomy has only become dominant in recent times. Nonetheless, over time, the core concept of the patient's self-determination has become firmly established within the European culture (first in the Nordic countries and only later in the South, predominantly Catholic). Today, the role of the family as the decision maker has largely been eliminated. In some cases, especially in specific communities, the family keeps its role as the main adviser and it is not excluded that sometimes family is the real decision-maker; but according with the law in place in western jurisdictions the only one allowed to consent is the patient, assuming he/she is a competent adult.²²

²² A legal representative, usually a family member, is assigned to children or incompetent patients.

Chinese scholars appear to be divided over the role of familism in health care delivery. Mainstream scholars have defended it, mostly based on the role it has played in the family, the core cell of Chinese society, underlying its virtues for protecting the patient's best interests (Chan 2004a; Chen and Fan 2010; Cong 2004; Fan 1997; Fan and Li 2004; Fan and Tao 2004). However, some have objected to familism, arguing that it is unfounded in modern China (Zhang 2012; Li and Wen 2010; Zhu 2014; Dai 2003; Ding 2010). In between these two polarised positions, other scholars have attempted to reconcile Chinese familism with the modern concept of patient autonomy, a kind of moderate familism (Cheng et al. 2012; Bian 2015). However, as discussed below, moderate familism is at risk for becoming a moderate failure.

Familism and the patient's best interests

Those in favour of medical familism have argued that it is the best way to protect the patient's interests. This conclusion can only be understood in the context of how a patient's autonomy is specifically interpreted in the Chinese culture.

In Western cultures the patient is considered to be in the best position to assess his or her best interests. The patient's decision is accepted even when it is objectively harmful to him or her as a reasonable person would see it (Glover 1977; Beauchamp and Childress 2001; Harris 2003). Consequently, in the West, the patient (assuming he or she is a competent adult) can refuse any medical treatment, even a lifesaving treatment, and neither the family nor the doctor can impose it on him/her (LaVigne 2013). A forced intervention on a patient would most likely be considered a crime, either against his or her physical integrity or against his/her self-determination (Andrade 2004, 2012; Raposo 2013).

Conversely, in Chinese culture, the perception is that the patient's illness renders him or her incapable of making such an assessment. This conclusion is particularly true in the case of older patients. Decisions are usually taken by their adult children, even when they are still competent to decide for themselves. Based on the concept of 'xiao' (孝), that is, the duty to provide good care to parents (Chun-yan and Tao 2004), children make health care decisions to protect their parents from unfortunate news (Chun-yan and Tao 2004).

Because medical decisions in China rest mainly with the family, it turns the binomial doctor-patient relationship into a triangular doctor-patient-family relationship (Cong 2004), based on the idea that the family knows better than the patient how to protect his or her best interests.

Patient autonomy and family autonomy

Whereas in the West the idea of autonomy is purely individualistic, recognising the dignity of the person, in China, autonomy is only meaningful in the context of the community,

either the family or the larger community. Fan called this concept ‘family autonomy’ (Fan 1997, p. 315). Instead of a patient’s self-determination, the main value is the family’s self-determination, and instead of the individual being at the centre of decision-making, the family occupies that position (Ho 1995). In sum, ‘family autonomy’ is a concept used to describe the protection given to family-decision making, making a parallel with the notion of ‘patient’s autonomy’ used in the west.

Therefore, whenever a doctor consults with a patient, he is actually creating a relationship with the entire family (Tsai 2008), based on the idea that health matters are not to be decided by the patient, but by the family (Fan and Li 2004). In other words, the patient decides but in harmony with the family (Fan 1997), whose role is to protect the patient.

The concept of ‘family autonomy’ (Fan 1997, p. 315) is interesting, but it fails to recognise that the family unit is not a legal entity entitled to autonomy. ‘Family autonomy’ does not really exist, in the same way that there is no ‘family dignity’, or human rights belonging to the family. Only an individual person is entitled to rights and dignity, including the right to self-determination. The family, of course, has legal and ethical value; however, its primary function is to provide an environment in which the individual can fulfil his or her objectives.

Modern (and moderate) familism

In recent times, traditional familism has incorporated a new (and more moderate) understanding, conforming to the Western concepts of individual human rights, autonomy and a patient’s self-determination, that have become increasingly entrenched in Chinese legal culture.

One of the main advocates of this moderate thesis has been Chan (2004b), who suggested that ‘individuals are embedded in a network of relations and are identified in terms of their connections with others’ (Chan 2004b, p. 99) and that ‘individuals are bound together by ties of concern and caring, empathy and reciprocity’ (Chan 2004b, p. 95). Although this approach is appealing in theoretical terms, from a practical perspective it is difficult to conceive of how all these ideas are interrelated. A patient can aspire to reach a harmonious consensus with his or her family, however, that rarely happens, and Chan does not clarify who has the last word in a medical decision in that case. Put more precisely, even though the objective is to reach a medical decision that is agreed to by the patient, the relatives and the doctor (and actually this mutual agreement is also the main objective in the Western law),²³ chances are that a common decision will not be reached.

²³ Indeed, even though relatives are not called upon to decide in Western law, they are consulted. The main aim is to avoid objections from the relatives that may jeopardise the patient’s recovery and disturb the doctor-patient relationship.

Some Chinese scholars who are experts in Confucianism have acknowledged that the Confucian model does not give all of the decision-making power to the family, but rather looks for a harmonious balance between the doctor, the family and the patient. Ideally, they should all reach a harmonious decision instead of one person being vested with the power to decide. This is the case of Li and Wen (2010) and Fan and Tao (2004). These latter authors argued that moderate familism is an attempt to articulate a vision of the patient that will uphold his or her autonomy and at the same time support a vision of family integrity. Nie also states that the basis of the Chinese culture—Confucianism—does not contradict the idea of patient informed consent (Nie 2001).

The idea of harmony is an essential value to Confucian philosophy, as the basis of prosperity both for the family and the Nation, as stated in an old Chinese proverb: ‘A family in harmony will prosper in everything’. The problem is that this portrayal of harmony is more utopic than real and in day-to-day medical practice conflicts between the patient and the family are frequent. Thus, it has been necessary to establish who has the final decision and that power was assigned to the family.

A more practical and effective solution to moderate familism in clinical practice was adopted by some Chinese hospitals that have implemented a model that appears to be more efficient and pragmatic than the one proposed by scholars: during the admission process, patients sign a form indicating which family member is entitled to provide consent on his or her behalf, a solution that obtained the approval of some scholars (Zhu 2014). It is not clear if this “appointment” is supposed to be valid only inasmuch the patient becomes unable to provide consent (because he/she is in a comatose state or under anaesthesia, for instance) or in any situation, as a kind of transference of decision-making power, but the second hypothesis seems more likely. Both solutions represent interesting ways of involving family members (at least, one family member) in the decision process without abandoning the core idea of patient’s individual consent. The first hypothesis is actually very similar to the one adopted by many western laws in what regards the nomination of a health care proxy, in which the patient appoints a trusted person to take decisions as his/her representative in health matters in case the patient becomes unable to consent.

Other reasons behind chinese familism

In addition to Confucian familism there are other motifs, and even more pressing reasons that have led Chinese doctors to continue ignoring patient informed consent. These have not been ethical or moral reasons, but very pragmatic reasons, connected to the difficult economic, legal and social characteristics of health care provisions in China.

The traditional model that provided free medical services to the population, or at least state-subsidised services, has given way to another model in which a large part of health care costs are borne by the patient. However, most Chinese patients lack the money to pay for increasingly expensive treatments and they also lack a medical insurance scheme that help them cover such expenses. Therefore, in fear of not being paid, health care providers turn to the family, looking for its support, and hopefully its money (Ding 2010).

Second, medical conflicts in China can have drastic consequences. There are several reasons for such conflicts, related to accusations over poor health care, defensive medicine and expensive but unsuccessful and useless treatments (Liebman 2013; Kearney 2012; Wang 2009). In fact, the drastic reduction in public subsidies has forced hospitals to find other ways to maximise their resources and obtain new sources of funding, using methods that have elicited criticism from both the patients and the public authorities. The risk of litigation has been so high that doctors have tried to involve families in the decisions to be made (Ding 2010).

Third, this scenario has created great discontent amongst Chinese patients and their relatives. Suing doctors is not enough anymore, and violence seems to be the next step. Thus, in China, is not uncommon to hear about doctors being beaten or even killed (Zhang and Sleeboom-Faulkner 2011; Xu 2014; Zhao et al. 2014; Yueju 2014). Fearing these consequences (litigation and above all violence), doctors tend to comply with all decisions taken by the family, hoping that if a patient dies, the family will not pursue them.

Cultural relativism and the transposition of patient's informed consent to China

An analysis of the philosophical roots of patient informed consent (Neves 2004) demonstrates that this is predominantly a Western idea, based on values like individualism and autonomy that characterise the Western world.²⁴ In contrast, Chinese culture is oriented towards the family and the

community in general, placing the individual in a minor role (Nie 2000).

From a Western perspective, a patient's autonomy plays the leading role, without which the core idea of patient's dignity is undermined (Engelhardt 1986). Modern medical ethics have been tremendously influenced, both in theory and in practice, by the four principles approach to bioethics, which was generally developed for the 1978 Belmont Report through the work of Thomas Beauchamp and James Childress (Beauchamp 2011). According to this model, a physician's moral obligation to his/her patients is defined by four ethical principles: respect for autonomy, no maleficence, beneficence and justice (Faden and Beauchamp 1986). Self-determination has priority over traditional medical principles (Engelhardt 1986), such as beneficence or lack of maleficence. In the past, it was believed that the doctor (more so than the family) knew better (Buchanan 1978; McClanahan 2013); however, now, if a doctor acts without a patient's informed consent, he or she is at risk for a civil lawsuit and the payment of compensatory damages, or even criminal prosecution (Monteiro and Veloso 2001; Raposo 2013). The patient's wishes and preferences define what treatment should be used in any particular case (Tsai 2008).

Certainly, the reforms claimed nowadays in China in this matter are not the sole product of western ideas. Chinese legal and ethical development has a 'mind of its own' and there is an increasing production of Chinese studies on human right and on patient's informed consent. But the fact is that the core idea that informed consent must be provided by the patient was born as a western idea, that is, a product of philosophical developments that originally took place in the western world, and actually it is frequently accused of being a purely western product, not suited for other cultures and jurisdictions.

Even in the West, the individual nature of consent has been contested in favour of a more family-oriented form of informed consent (Kuczewski 1996), and also in Western countries there are those who have advocated for the involvement of family members, especially within certain cultural communities (Kuczewski and McCruden 2001). However, having the family involved is not the same as having the family deciding. The family should, of course, have a say in health matters, as it has in all important issues in our lives, and should support the patient in the decision making process. Nonetheless, the final decision must be made by the patient.

In contrast, in a paternalistic approach to medicine and bioethics, beneficence rules over self-determination and any therapeutic decision is referred to the doctor, even overriding a person's autonomous decision, because the patient is not deemed to have enough knowledge or ability to decide, even if he or she is a competent adult. That is exactly the reason why lawmakers and ethicists have created the concept of

²⁴ When referring to the western world this paper is referring to Europe and the US (although the same reasoning could be applicable to other parts of the world, such as Australia and New Zealand). In these jurisdictions the existing laws and the predominant values are based on the idea that consent for medical acts rests purely with the individual patient (apart from minors and mentally ill patients). Certainly, there are western jurisdictions in which this basic rule suffers some exceptions in particular situations, but from a general perspective it is accurate to describe western medical informed consent as an individual patient's informed consent. However, we do recognize that the dichotomy western bioethics/Asian bioethics is inevitably artificial (Nie and Fitzgerald 2016; Sleeboom-Faulkner 2016) and simply intends to describe the general features in place in different parts of the world, without the pretense of accurately describing their particularities.

informed consent, as a mechanism to provide information to patients so they can decide based on having proper knowledge (Webb 2013).

The seminal aspect of Confucianism is that the power to decide is not so much conferred on the doctor, but the family, and it is the family that interacts with the doctor. The physician's role is basically to maintain harmony between the family members and to override eventual conflict (Tsai 1999).

Due to these cultural differences and the 'Asian values discourse' (Seeberg et al. 2004, p. 88), one can argue whether Western informed consent can (or even should) be applied in China. It has been stated that 'typical Western ideas should not be directly applied to Chinese practice without reinterpretation or modification' (Li and Wen 2010, p. 593).

This argument is seductive at first blush because it appears to respect cultural diversity and the so-called 'Asian values'. In a world in which multiculturalism has become the centre piece, this seems to be the only possible approach.

However, other arguments should also be taken into consideration (Cheng et al. 2012). First, we may discuss whether in today's world there is such a thing as 'Asian values'. Second, even if they exist, wouldn't the holders of those values be ready and eager to embrace patient informed consent?

The existence of specific Asian values (and specific Western values) has been criticised by Nie (2001), arguing that it is too simplistic to assume that all Western cultures are individual-oriented whereas Chinese culture is exclusively collective, forgetting the pluralism of both cultures. According to this author, the entire argument regarding 'cultural differences' is based on dichotomies: 'individualism vs. collectivism; individual autonomy vs. family decisions; individual liberty vs. social/common good, the individual vs. the collective/community; individual rights vs. personal virtues, individual development and perfection vs. family and filial piety; contract vs. trust; self-determination vs. self-examination; freedom vs. duty and obligation; heterogeneous vs. homogenous; evolutionary vs. static' (Nie 2001, pp. 67–68) that do not correspond to the actual reality (Jacobsen and Bruun 2000).

In the Western world we can still find collectively oriented communities in which medical decisions continue to be referred to the doctor and/or relatives (Nie and Fitzgerald 2016), even if it violates the law. Concealment is still used in some situations in doctor-patient relationship (mostly by the doctor and not so much by relatives), so, it is not fair to say that all western informed consent can be characterized by complete disclosure. Nonetheless, disclosure and personal patient decision are the main rule in the western world, both in the law and in actual medical practice.

Analogously, as Nie (2001) pointed out, in China, some communities are more individualistic. After all, China is a vast country. Instead of referring to a single 'Chinese

culture', we should talk about several 'Chinese cultures' to respect China's cultural diversity. However, by pointing out features of Chinese informed consent we are not ignoring the plurality or diversity of Chinese culture, nor basing our reasoning in stereotypes (Nie 2011), but simply describing existing norms of Chinese law and their current use in day to day medical practice all around mainland China (and even in Greater China).

Even if there are specific Asian values that are incompatible with patient informed consent, it can still be argued that Chinese culture is changing and that younger generations tend to have an approach that is similar to the West. China is not universally collective, and it is becoming even less so.

Secondly, it should be underlined that informed consent is a question of human rights and human dignity and there is a hard core of these values that cultural specificities cannot undermine.

We can accept that cultural relativism admits some differences in the way human rights and human dignity are understood in different cultures. In fact, the ideas of cultural relativism/cultural diversity (Chattopadhyay and Vries 2013) and specific Asian values were well recognised in the Bangkok Declaration on Human Rights (Final Declaration of the Regional Meeting for Asia of the World Conference on Human Rights), in which several Asian countries committed themselves to the human rights discourse, but at the same time recognised 'that while human rights are universal in nature, they must be considered in the context of a dynamic and evolving process of international norm-setting, bearing in mind the significance of national and regional particularities and various historical, cultural and religious backgrounds' (paragraph 8). Still, the cultural relativity argument is not unimpeachable. The 'cultural excuse' cannot override core values at this stage of the development of mankind and there are indeed core basic values that should be universally respected (Have and Gordijn 2011).

That is not to say that culture is irrelevant to the law. Laws should respect the particular cultural framework in which they are applied. Otherwise, they risk being misunderstood and therefore useless. This is the reason why legal transplants that disregard cultural specificities are usually doomed to fail. Each law should be adapted to the particular community in which it will be applied and have in consideration the specific values in place. Even though many refer nowadays the 'globalisation of ethics' (Harris 2000, pp. 298–299), the fact is that basic notions such as 'personal autonomy' and 'patient's rights' still vary widely across cultures (Akabayashi and Slingsby 2006; Gostin 1995; Ho 2006), leading to the edification of the concept of 'cultural sensitivity', proposed by Gostin (Gostin 1995).

Informed consent, as many other matters in health care delivery (rituals to deal with birth and death, conceptions about nudity and sex, confidence in science or in tradition),

is profoundly shaped by the cultural environment. Concepts such as the notions of individuality and autonomy praised by John Stuart Mill (Hammami et al. 2014), Kantian autonomy (Hammami et al. 2014; Varelius 2006), and the ideas of thinkers such as Hugo Grotius and Thomas Hobbes were also decisive for western individual consent.²⁵ So, there is undeniably a specific cultural ground for western informed consent. The Chinese case is also an example of a cultural product (even though nowadays is mainly sustained by other reasons, not related with culture). Cultural influences are not necessarily negative and, more than that, they are unavoidable. In a sense informed consent cannot be totally 'rescued' from culturation (i.e., culture, values, religion), neither in the West nor in China.

But culture and tradition cannot justify disrespect for human rights. There are some limits to the extent that culture can shape informed consent and those are limits imposed by human rights, which operate as the last frontier of what can be legally (and ethically) acceptable. There is no such a thing as a 'common morality' (Nie and Fitzgerald 2016, p. 224), but there are basic principles of human rights that must be respected in every single situation. Surely we should promote 'cross-cultural understanding and dialogue' (Nie and Fitzgerald 2016, p. 227), but bioethical proximity should not be mistaken with a complete ethical relativism (Macklin 1998), in which everything becomes acceptable, under the cover of respect for multiculturalism.

Let's take a well-known example: female excision. It can be argued that this practice is grounded in cultural traditions and in religious convictions and consequently deserves respect. But because there is an evident and gross violation of women's rights we simply do not allow it in the West, we put pressure on the jurisdictions that still allow this practice and many of those countries are actually changing their policies in this regard.

Coming back to the particular case of informed consent, there is no human right belonging to the family (as a distinct entity from his various members) to take this kind of decision (actually, the family is not an entity able to hold rights, only the family members are). There is no human right from any family member to take these decisions. But there is certainly a human right, belonging to the person himself/herself (i.e., the patient) to take decisions involving his/her life, health and body, grounded in several other rights: right to bodily integrity, right to health, right to self-determination. Family consent violates all these rights and for this reason cannot be admitted, not even if grounded in historical motifs and physiological reasons.

²⁵ Even though western authors do not fully agree on the influence of each of these trends and about the exact notion of autonomy underneath patient's informed consent.

It is totally in opposition with the most basic understanding of human rights to force a patient to be submitted to a medical act that he/she does strongly reject or to deny a patient the medical care she/she prefers (assuming his/her preference is in accordance with medical *leges artis* and is suitable to his/her medical condition) and sometimes absolutely need in order to stop pain and even to preserve life. In China, cases of forced medical acts or medical care denied to patients in need by relatives are common. There is no way to use culture to justify these gross violations of human rights.

This is not an argument that 'my informed consent is better than yours', but rather one that suggests when gross violations of patient's rights—the only ones that matter in this discussion—take place it cannot be in any other way. There is only one informed consent, the one that respects a patient's rights. This should be the only model in place, except when the patient expressly and freely defers the decision to his or her relatives.

Neither am I defending that the current model of informed consent, in which the decision rests solely in the patient, should be transposed to China, without any adaptation to the surrounding cultural, ethical and philosophical environment. Legal transplants blind to the involving reality are deemed to fail. In China family needs to have a relevant word to say in health care delivery, at least until Confucianism persist as the many philosophical background of Chinese culture. Probably the role of family in China cannot be the same as in the West and will always hold a stronger power to influence the patient than in the West, since those are matters the law cannot totally prevent and the role of family is deeply grounded in Chinese culture. But family cannot be the decision holder in health care issues; that title belongs to the patient and solely to the patient.

Final remarks

As with many other matters, in medical ethics, one size does not fit all, and the Western way of thinking is not necessarily the best. Having said that, there are still questions for which there is only one answer and only one model. Patient's informed consent is one of them.

The only kind of medical consent compatible with human rights and human dignity is the one based on the patient's individual choice (without rejecting the influence of family advice and recommendations on that choice). Of course the respect for patient's individual rights must also have in consideration the cultural environment and this delicate equilibrium between human rights and cultural sensitivity may lead to slightly different models of informed consent in China and in the West. But the core basis of the model cannot be other than patient's individual decision.

Probably most Chinese scholars would conclude that Confucian tradition can and should be maintained. Not being Chinese or an expert in Confucianism, my conclusion is different. Mine is the perspective of a Western person, patient and legal scholar living in China. From this very personal perspective I believe family informed consent represents a violation of basic human rights of patients, namely self-determination over body and health and respect by individual decisions.

I also believe that as time goes by, familism will tend to weaken and patient's autonomy will take the lead. An increasingly educated population; the continued opening of China to the rest of the world, allowing many foreigners to reside here; the movement of Chinese doctors and Chinese legal scholars to others parts of the world and their return home with new ideas; the demand by international organisations that patient informed consent be required for hospital accreditation²⁶; and the disclosure of serious incidents involving patients who have been deprived of the power to decide will impose a new model.

China is a surprising country that constantly moves in new directions whilst managing to maintain Chinese traditions and values. One can expect that in this manner China will continue to be grounded in Confucianism, but will fully respect a patient's individual rights, including the right to informed consent.

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References

- Akabayashi, A., and B. T. Slingsby. 2006. Informed consent revisited: Japan and the U.S. *The American Journal of Bioethics* 6(1): 9–14.
- Andrade, Manuel da Costa. 2004. Consentimento em direito penal médico: O consentimento presumido. *Revista Portuguesa de Ciência Criminal* 14(1/2): 117–148.
- Andrade, Manuel da Costa. 2012. Art. 156. In *Comentário Conimbricense do Código Penal, Parte Especial, Tomo I*, 2nd ed., 595–631. Coimbra: Coimbra Editora.
- Bassford, H. A. 1982. The justification of medical paternalism. *Social Science and Medicine* 16(6): 731–739.
- Beauchamp, T. L. 2011. Informed consent: Its history, meaning, and present challenges. *Cambridge Quarterly of Healthcare Ethics* 20: 515–523.
- Beauchamp, T. L., and J. F. Childress. 2001. *Principles of biomedical ethics*. 5th ed., New York: Oxford University Press.
- Bian, Lin. 2015. Medical individualism or medical familism? A critical analysis of china's new guidelines for informed consent: The basic norms of the documentation of the medical record. *Journal of Medicine and Philosophy* 40(4): 371–386.
- Buchanan, Allen. 1978. Medical paternalism. *Philosophy and Public Affairs* 7(4): 370–390.
- Cave, Emma. 2017. The ill-informed: Consent to medical treatment and the therapeutic exception. *Common Law World Review* 46(2): 140–168.
- Chan, H. 2004a. Informed consent Hong Kong style: An instance of moderate familism. *Journal of Medical Philosophy* 29: 195–206.
- Chan, H. M. 2004b. Sharing death and dying: Advance directives. Autonomy and the family. *Bioethics* 18: 87–103.
- Chan, C.S.-C. 2018. Mistrust of physicians in China: Society, institution, and interaction as root causes. *Developing World Bioeth* 18: 16–25.
- Chattopadhyay, Subrata, and Raymond De Vries. 2013. Respect for cultural diversity in bioethics is an ethical imperative. *Medicine, Health Care and Philosophy* 16(4): 639–645.
- Chen, Fei (陳飛). 2014. An interpretation and examples of the latest civil liability law of the People's Republic of China (最新中華人民共和國侵權責任法配套解讀與實例). Beijing: Law Press China.
- Chen, Yunfang (陳雲方). 2015. Guidelines on litigation and mediation of disputes between doctors and patients (醫患糾紛訴訟與調解指南). Beijing: Law Press China.
- Chen, Xiaoyang, and Ruiping Fan. 2010. The family and harmonious medical decision making: Cherishing an appropriate Confucian moral balance. *Journal of Medicine and Philosophy* 35(5): 573–586.
- Cheng, Kam-Yuen, Thomas Ming, and Aaron Lai. 2012. Can familism be justified? *Bioethics* 26(8): 431–439.
- Chun-yan, Tse, and Julia Tao. 2004. Strategic ambiguities in the process of consent: Role of the family in decisions to forgo life-sustaining treatment for incompetent elderly patients. *Journal of Medicine and Philosophy* 29(2): 207–223.
- Cong, Yali. 2004. Doctor-family-patient relationship: The Chinese paradigm of informed consent. *Journal of Medicine and Philosophy* 29: 149–178.
- Cui, Rongchang (崔榮昌), and Ping Yang (楊平). 2008. Communication between doctors and patients under the legal perspective (法律視角下的醫患溝通). *Chinese Journal of Current Hospital Administration* 6(5): 80–81.
- Dai, Qingkang. 2003. Informed consent in China: Status quo and its future. *Medical Law International* 6(1): 53–71. <https://doi.org/10.1177/096853320300600104>
- Ding, Chunyan. 2010. Family members' informed consent to medical treatment for competent patients in China. *China: An International Journal* 8(1): 139–150.
- Du, Li, and Christen Rachul. 2013. A brief review on informed consent laws in China. *Health Law Review* 21(2): 26–32.
- Engelhardt, Tristram. 1986. *The foundation of bioethics*. 2nd ed. New York, NY: Oxford University Press.
- Faden, Ruth, and Tom Beauchamp. 1986. *A history and theory of informed consent*. New York: Oxford University Press.
- Fan, Ruiping. 1997. Self-determination vs. family-determination: Two incommensurable principles of autonomy. *Bioethics* 11: 309–322.
- Fan, Ruiping, and Benfu Li. 2004. Truth telling in medicine: The Confucian view. *Journal of Medical Philosophy* 29: 179–193.
- Fan, Ruiping, and Julia Tao. 2004. Consent to medical treatment: The complex interplay of patients, families, and physicians. *Journal of Medicine and Philosophy* 29(2): 139–148.
- Final Declaration of the Regional Meeting for Asia of the World Conference on Human Rights (the Bangkok Declaration, 1993). <https://monash.rl.talis.com/items/E5644ACF-5B94-3131-468B-65D0C276BD5B.html>. Accessed July 10, 2017.
- Glover, J. 1977. *Causing death and saving lives*. Harmondsworth: Penguin Books.
- Gostin, L. O. 1995. Informed consent, cultural sensitivity, and respect for persons. *JAMA* 274(10): 844–845.
- Hammami, M. M., Al-Gaai, E. A., Al-Jawarneh, Y., Amer, H., Hammami, M. B., Eissa, A., and Qadire, M. A. 2014. Patients'

²⁶ See, for instance, the requirements of the Joint Commission in this regard (Joint Commission 2016).

- perceived purpose of clinical informed consent: Mill's individual autonomy model is preferred. *BMC Medical Ethics*. <https://doi.org/10.1186/1472-6939-15-2>.
- Harris, John. 2000. Research on human subjects, exploitation, and global principles of ethics. *Interdisciplinary Science Reviews* 25(4): 298–306.
- Harris, John. 2003. Consent and end of life decisions. *Journal of Medical Ethics* 29(1): 10–15.
- Have, H. Ten, and B. Gordijn. 2011. Travelling bioethics. *Medicine, Health Care and Philosophy* 14(1): 1–3.
- Ho, D. Y. F. 1995. Selfhood and identity in Confucianism, Taoism, Buddhism, and Hinduism: Contrasts with the West. *Journal for the Theory of Social Behaviour* 25(2): 115–138.
- Ho, A. 2006. Family and informed consent in multicultural setting. *The American Journal of Bioethics* 6(1): 26–28.
- Hu, Fengbin (胡鳳濱). 2015. *Judgment rules and applicable standards to the dispute of medical damage compensation (醫療損害賠償糾紛裁判規則與適用標準)*. Beijing: Law Press China.
- Hui, Edwin. 2008. Parental refusal of life-saving treatments for adolescents: chinese familism in medical decision-making re-visited. *Bioethics* 22(5): 286–295.
- Jacobsen, Michael, and Ole Bruun, eds. 2000. *Human rights and Asian values: contesting national identities and cultural representations in Asia*. London: Routledge Curzon.
- Joint Commission. 2016. Informed consent: More than getting a signature. Quick Safety 21. https://www.jointcommission.org/asset/s/1/23/Quick_Safety_Issue_Twenty-One_February_2016.pdf. Accessed July 11, 2017.
- Kearney, L. 2012. Why China's 2010 medical malpractice reform fails to reform medical malpractice. *Emory International Law Review* 26(2): 1039–1078.
- Kuczewski, M. G. 1996. Reconceiving the family: The process of consent in medical decisionmaking. *Hastings Center Report* 26(2): 30–37.
- Kuczewski, Mark, and Patrick J. McCruden. 2001. Informed consent: Does it take a village? The problem of culture and truth telling. *Cambridge Quarterly of Healthcare Ethics* 10: 34–46.
- LaVigne, Andrew Joseph. 2013. The right to refuse life sustaining treatment and competency: potential solutions to protect and promote patient autonomy. Law School Student Scholarship. Paper 259. http://scholarship.shu.edu/student_scholarship/259. Accessed September 15, 2017.
- Li, Tianbo, and Gillian Owen Moreira. 2009. The influence of Confucianism and Buddhism on Chinese business: The case of Aveiro. *Journal of Intercultural Communication*. <https://www.immi.se/intercultural/nr19/tianbo.htm>. Accessed June 5, 2017.
- Li, En-Chang, and Chun-Feng Wen. 2010. Should the confucian family-determination model be rejected? A case study. *Journal of Medicine and Philosophy* 35: 587–599.
- Li, Li, Stephanie Sun, Sheng Wu, Chunqing Lin, and Zunyou Wu, and Zhihua Yan. 2007. Disclosure of HIV status is a family matter: Field notes from China. *Journal of Family Psychology* 21(2): 307–314.
- Liebman, B. L. 2013. Essay: Malpractice mobs: Medical dispute resolution in China. *Columbia Law Journal* 113: 181–264.
- Macklin, Ruth. 1998. A defense of fundamental principles and human rights: A reply to Robert Baker. *Kennedy Institute of Ethics Journal* 8(4): 403–422.
- Macklin, Ruth. 1999. *Against Relativism: Cultural diversity and the search for ethical universals in medicine*. New York: Oxford University Press.
- McClanahan, Carolyn. 2013. Dinosaur doctors and the death of paternalistic medicine. *Forbes*, Feb 19, 2013. <https://www.forbes.com/sites/carolynmcclanahan/2013/02/19/dinosaur-doctors-and-the-death-of-paternalistic-medicine/#14cae6a06af3>. Accessed September 22, 2017.
- Monteiro, Jorge Sinde, and Maria Manuel Veloso. 2001. *Portugal. In cases on medical malpractice in a comparative perspective*, eds. Michael Faure, Helmut Koziol, 172–187. Wien: Springer.
- Neves, M. Patrão. 2004. Cultural context and consent: An anthropological view. *Medicine, Health Care and Philosophy* 7: 93–98.
- Nie, Jing-Bao. 2000. The plurality of Chinese and American medical moralities: toward an interpretive cross-cultural bioethics. *Kennedy Institute of Ethics Journal* 10(3): 239–260.
- Nie, Jing-Bao. 2001. Is informed consent not applicable in China? Intellectual flaws of the “cultural difference argument”. *Taiwan Yi Xue Ren Wen Xue Kan* 2(1–2): 67–74.
- Nie, Jing-Bao. 2011. *Medical Ethics in China: A Transcultural Interpretation*. London: Routledge.
- Nie, Jing-Bao, and Ruth P. Fitzgerald. 2016. Connecting the East and the West, the Local and the Universal: The methodological elements of a transcultural approach to bioethics. *Kennedy Institute of Ethics* 26(3): 219–247.
- Nie, Jing-Bao, J. D. Tucker, W. Zhu, Y. Cheng, B. Wong, and A. Kleinman. 2018a. Rebuilding patient–physician trust in China, developing a trust-oriented bioethics. *Developing World Bioeth* 18: 4–6.
- Nie, Jing-Bao, L. Li, G. Gillett, J. D. Tucker, and A. Kleinman. 2018b. Toward a trust-oriented bioethics: lessons and inspirations from China. *Developing World Bioeth* 18: 56–64.
- Nie, Jing-Bao, Y. Cheng, and X. Zou, et al. 2018c. The vicious circle of patient–physician mistrust in China: Health professionals' perspectives, institutional conflict of interest, and building trust through medical professionalism. *Developing World Bioeth* 18: 26–36.
- Raposo, Vera Lúcia. 2012. To act or not to act, that is the question: Informed consent in a criminal perspective. *European Journal of Health Law* 19: 379–390.
- Raposo, Vera Lúcia. 2013. *Do ato médico ao problema jurídico: Breves notas sobre o acolhimento da responsabilidade médica civil e profissional na jurisprudência nacional*. Coimbra: Almedina.
- Seeberg, Jens, Kusum Verma, Manju Mehta, Renuka Dutta, and Renu Addlakha. 2004. Family autonomy and patient rights to healthcare in an ‘Asian values’ context. *Folk* 45: 87–104.
- Sleeboom-Faulkner, Margaret. 2016. “(East) Asia” as a platform for debate: grouping and bioethics. *Kennedy Institute of Ethics Journal* 26(3): 277–301.
- Tsai, D. F. 1999. Ancient Chinese medical ethics and the four principles of biomedical ethics. *Journal of Medical Ethics* 25(4): 315–321.
- Tsai, D. F. 2001. How should doctors approach patients? A confucian reflection on personhood. *Journal of Medical Ethics* 27(1): 44–50.
- Tsai, Daniel Fu-Chang. 2008. Personhood and autonomy in multicultural health care settings. *American Medical Association Journal of Ethics* 10(3): 171–176.
- Varelius, Jukka. 2006. The value of autonomy in medical ethics. *Medicine, Health Care, and Philosophy* 9(3): 377–388.
- Wang, H. 2009. A dilemma of Chinese healthcare reform: how to re-define government roles? *China Economic Review* 20(4): 587–806.
- Webb, Hannah. 2013. Cultural conflict in medicine: A moral debate between paternalism and patient autonomy. Honors theses. Paper 2380.
- Wu, Zuxiang (吳祖祥). 2013. *Medical damage liability (醫療損害責任)*, 中國政法大學出版社. Beijing: China University of Political Science and Law Press.
- Xu, W. 2014. Violence against doctors in China. *Lancet* 384(9945): 745.
- Yan, Y. 2018. The ethics and politics of patient-physician mistrust in contemporary China. *Developing World Bioethics* 18: 7–15.
- Yueju, L. 2014. Violence against doctors in China. *Lancet* 384(9945): 745.

- Zhang, Xinqing. 2012. Reflection on family consent: Based on a pregnant death in a Beijing hospital. *Developing World Bioethics* 12(3): 164–168.
- Zhang, X., and M. Sleeboom-Faulkner. 2011. Tensions between medical professionals and patients in mainland China. *Cambridge Quarterly of Healthcare Ethics* 20: 458–465.
- Zhao, L., X. Y. Zhang, G. Y. Bai, and Y. G. Wang. 2014. Violence against doctors in China. *Lancet* 384(9945): 744.
- Zhu, Wei. 2014. The Tort Law of P.R. China and the implementation of informed consent. *Asian Bioethics Review* 6(2): 125–142.
- Zou, X., Y. Cheng, and J.-B. Nie. 2018. The social practice of medical guanxi (personal connections) and patient–physician trust in China: an anthropological and ethical study. *Developing World Bioethics* 18: 45–55.