

# Article

## **American Individualism v. Taiwanese Family Paternalism: Contemplating Taiwan’s Attempt to Americanize Legal Regulation of Health Information**

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## I. INTRODUCTION

Health information<sup>1</sup> is considered so highly sensitive that many countries have established or drafted specific legal regulations to protect it, such as the “Standards for Privacy of Individually Identifiable Health Information” (hereinafter *HIPAA Privacy Rule*) in the U.S.,<sup>2</sup> the “Health Information Privacy Code” in New Zealand,<sup>3</sup> and the “National Health Privacy Code” in Australia.<sup>4</sup> In Taiwan, the Department of Health (DOH) plans to propose a new law for protecting the privacy and security of patient health information. The Science and Technology Law Center of the Institute for Information Industry was sponsored by the DOH to proceed with relevant legal research; it has already prepared a report—The Analysis of the Initial Suggestions for Legal Regulation of Protecting Privacy and Security of Health Information in Our Country (hereinafter *Initial Suggestions for Legal Regulation*)—providing initial suggestions.<sup>5</sup>

As is the case in the drafting of many other statutes in Taiwan, Western (especially American) laws and legal assumptions have played a significant role when researchers have provided legislative suggestions regarding the project. For example, the *Initial Suggestions for Legal Regulation* often appeals to the provisions of the *HIPAA Privacy Rule*, because the *HIPAA Privacy Rule* is so detailed and comprehensive.<sup>6</sup> *Initial Suggestions for Legal Regulation* stresses patient autonomy regarding health information;<sup>7</sup> undoubtedly, this reflects an appreciation of the American assumptions of individualism and respect for autonomy, and the document is deeply influenced by it.

While I support the adoption of informed consent, which realizes autonomy, as an important step for our development of medical law,<sup>8</sup>

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1. Health information means any information related to the past, present, or future physical or mental health or condition of an individual. See 42 U.S.C. § 1320d(4) (1996).

2. 67 Fed. Reg. 53,182 (Aug. 14, 2002) (to be codified at 45 C.F.R. pt. 160, 164). This standard is an administrative regulation which the Secretary of Health and Human Services is authorized to make by the Health Insurance Portability and Accountability Act of 1996 (HIPAA), Pub. L. No. 104-191, 110 Stat. 1936. Thus, it is often called the HIPAA Privacy Rule or HIPAA Privacy Regulation.

3. Health Information Privacy Code, 1994 (N.Z.).

4. See Australian Government Department of Health and Ageing, The Proposed National Health Privacy Code (July 22, 2004), <http://www7.health.gov.au/pubs/nhpcode.htm>.

5. Zih Syun Gong Ye Ce Jin Huei Ke Ji Fa Lyu Jhong Sin [The Science and Technology Law Center of Institute for Information Industry], *Wo Guo Yi Liao Zih Syun An Cyuan Yu Yin Sih Bao Hu Fa Jih Guei Fan Fang Siang Chu Bu Jian Yi Fen Si* [The Analysis of the Initial Suggestions for Legal Regulation of Protecting Privacy and Security of Health Information in our Country] (on file with author).

6. See *id.* at 5-6, 8-9, 11-12.

7. *Id.* at 7-10.

8. For the justification of informed consent, see, e.g., 1 PRESIDENT'S COMMISSION FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE AND BIOMEDICAL AND BEHAVIORAL RESEARCH,

imitating Western/American law without reflecting comparatively upon the local culture is problematic. In the words of Frankenberg, “Comparative Law is somewhat like traveling.... As long as we understand foreign places as like or unlike home, we cannot begin to fully appreciate them, or ourselves,” but rather should pay “close attention to detail—variety and heterogeneity.”<sup>9</sup> Comparison is “a way of getting it straight—‘it’ being the ‘true’ story of similarities and dissimilarities between legal cultures, traditions, systems, families, origins, solutions and ideas.”<sup>10</sup> Unfortunately, many researchers and policymakers do not pay enough attention to “variety and heterogeneity” in different cultural contexts but often simply transfer foreign law outright. This approach may result in an unforeseeable disaster, of which Taiwan’s current attempt to incorporate U.S. legal regulation of health information could end up being an example.

The analysis in *Initial Suggestions for Legal Regulation* does not show an awareness that the importance of family values in Taiwanese medical culture has led to different practices in the flow of health information. Under the principle of respect for autonomy, health information should be given to competent patients but kept generally secret from others. However, current practice in Taiwan, as well as in many other East Asian countries, designates that when a patient is diagnosed with a fatal disease, physicians often inform family members but withhold the diagnosis from the competent patient. This practice contrasts practices grounded strongly in the value of American individualism. In other words, there is a conflict between an American regulatory assumption and a Taiwanese medical practice. This article attempts to analyze and respond to the problem of transplanting American law outright to Taiwan without contemplation of cultural divergence.

The claim of this article is that directly transferring American health information regulation to Taiwan will lead to problems due to the different medical cultures of the two countries, and that Taiwan’s new law should leave some room for its current medical practice, along with an awareness of various and changing cultural attitudes. I will lay this argument out in four parts. Part II illustrates autonomy as a central value in American bioethics and medical law, especially in the legal regulation of health information. Part III explores family paternalism as a social phenomenon in Taiwanese medical practice and analyzes the relationship between family paternalism and current law involving health information. Because

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MAKING HEALTH CARE DECISIONS 41-47 (1982). JESSICA W. BERG ET AL., INFORMED CONSENT 18-24 (2d ed. 2001).

9. Günter Frankenberg, *Critical Comparisons: Re-thinking Comparative Law*, 26 HARV. INT’L L.J. 411, 411-12 (1985).

10. *Id.* at 425-26.

of the differences between the U.S. and Taiwan, in Part IV, I present the predictable problems that will arise from the Taiwanese imitation of American health information law without careful consideration. Finally, Part V offers some suggestions for the new law.

Although the major goal of this article specifically aims at suggestions for Taiwan's proposed law regarding health information, its values go beyond that concern. Because many countries are melting pots composed of various ethnicities and cultures, the recognition of and suggestions concerning cultural awareness that this article lays out would enlighten not only Taiwanese but also other countries' medical laws and ethics. In addition, this article stands to make valuable theoretical contributions. It could shed light on the importance of understanding cultural practices through comparisons between family paternalism and individualism. It also, at the very least, vividly suggests that a desirable law should be bound and defined in terms of time and location, for "everything is deeply rooted in time and place, and in the richness of the social matrix."<sup>11</sup>

## II. AUTONOMY IN AMERICAN LEGAL REGULATION OF HEALTH INFORMATION

Autonomy plays a significant role in American legal regulation of health information. This is easy to grasp, since individualism has long been one of the U.S.'s central national values. More precisely, this section will take the *HIPAA Privacy Rule*, which is the major regulation concerning health information in the U.S. and a major influence on Taiwan's proposed law, as an example, to reveal that health information law has created rights and obligations in order to embody the idea of autonomy.

Respect for autonomy has been established as the central guiding principle in American contemporary bioethics and medical law. Throughout its unique history, American culture has emphasized individualism, regarding a person as a separate, independent, and self-reliant entity, not only in comparison with Asian countries but also in comparison with European society.<sup>12</sup> It is not surprising that autonomy becomes an assumption in various American fields, including both medicine and law. In particular, in the late 1960s and 1970s, the development of patient autonomy was involved in considerable changes in the larger social environment in the U.S.. The patient's rights advanced to

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11. Lawrence M. Friedman, *The Law and Society Movement*, 38 STAN. L. REV. 763, 769 (1986).

12. See, e.g., BERG ET AL., *supra* note 8, at 20-21; GEORGE J. ANNAS, SOME CHOICE 63-72 (1998); STEWART MACAULAY ET AL. EDS., LAW & SOCIETY 165 (1995).

give the individual more freedom from oppressive physicians.<sup>13</sup> Hence, contemporary bioethics and medical law, taking autonomy as a central value and widely adopting informed consent to embody the idea of autonomy, emerged.

As is the case with other medical laws, autonomy plays a critical part in health information privacy law. As Gostin and Hodge observe, “[p]olicymakers have responded to public concerns about privacy by enacting laws that tend to accentuate the value of autonomy. Individuals are often granted significant levels of control over how their health data are accessed, used, and disclosed.”<sup>14</sup> Because the *HIPAA Privacy Rule* is the major legal protection concerning health information privacy in the U.S., Gostin and Hodge use it as an example to reveal the basic “anti-disclosure rule,” which holds that without the individual’s informed consent, disclosure of identifiable health information is generally prohibited.<sup>15</sup>

Specifically speaking, we can find personal autonomy as to health information embodied in many specific provisions of the *HIPAA Privacy Rule*. At first, the *HIPAA Privacy Rule* mentions that a covered entity<sup>16</sup> can disclose protected health information to patients themselves.<sup>17</sup> More important, the Rule clearly expresses patients’ right of access to their health information. “[A]n individual has a right of access to inspect and obtain a copy of protected health information about the individual in a designated record set.”<sup>18</sup> In contrast, a covered entity cannot disclose protected health information to third parties without valid authorization, subject to some exceptions.<sup>19</sup> The term “authorization” indicates the personal right of the patient to control health information. The patient may authorize and direct the flow of health information and may also refuse to authorize and thereby block health information from any disclosure.

Although a number of exceptions exist, generally these exceptions are narrowly tailored to certain circumstances. For example, a covered entity may disclose certain information to a family member or other relative, if that information is “directly relevant to such person’s involvement with the [patient]’s care or payment related to the [patient]’s health care;” in this case, such person should be only the person who is involved with the

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13. BERG ET AL., *supra* note 8, at 21.

14. Lawrence O. Gostin & James G. Hodge, Jr., *Personal Privacy and Common Goods: A Framework for Balancing under the National Health Information Privacy Rule*, 86 MINN. L. REV. 1439, 1449 (2002).

15. *Id.*

16. Covered entities include health plans, health care clearinghouses, and certain health care providers. 45 C.F.R. § 160.103 (2002).

17. 45 C.F.R. § 164.502(a)(1)(i).

18. 45 C.F.R. § 164.524(a)(1).

19. 45 C.F.R. § 164.508(a)(1).

patient's care or payment in the first place.<sup>20</sup> In addition, a covered entity may disclose some information when notifying a family member, but what may be revealed is limited to the patient's "location, general condition, or death."<sup>21</sup> These exceptions are designed for special circumstances, such as giving necessary information for facilitating the patient's care or notifying someone that the patient is in the hospital. It is still very true that disclosure to a third party, including a family member, generally requires the patient's authorization.

The analysis above clearly shows the critical position of autonomy in the *HIPAA Privacy Rule*. Specifically, under the *HIPAA Privacy Rule*, patients have the right to access their own health information, while physicians have the obligation to keep the information confidential from third parties.

### III. FAMILY PATERNALISM IN TAIWANESE PRACTICES AND LAWS REGARDING HEALTH INFORMATION

In contrast to the U.S., medical practice and laws surrounding health information in Taiwan reveal somewhat different features. In particular, autonomy is tempered by family values. With respect to health information, I will explore special medical practices in Taiwan in Subsection A and illustrate Taiwanese statutes that concern health information in order to discuss the relationship between the law and that special medical practice in Subsection B.

#### A. *Family Paternalism in Taiwanese Medical Practices*

Although Western culture has deeply influenced modern Taiwanese society,<sup>22</sup> family values are still highly influential in Taiwan. This is particularly true in the medical field, where these values have led to different practices regarding the flow of health information. Some other East Asian countries place similar emphasis on family with respect to the flow of health information. This similarity among East Asian countries with a common cultural source reflects the fact that this medical practice is embedded in traditional culture.

One outgrowth of traditional culture in Taiwan is that family members

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20. 45 C.F.R. § 164.510(b)(1)(i).

21. 45 C.F.R. § 164.510(b)(1)(ii).

22. Considering the focus of this article, it is worth noting that personal privacy has drawn much attention in recent years in Taiwan. Privacy has become a hot issue as the focus of social events and legal discussions. Due to the influence of Western/American culture in recent decades, the Western conception of privacy has become established in Taiwanese legal and value systems. See e.g., Shin-Yi Peng, *Privacy and the Construction of Legal Meaning in Taiwan*, 37 INT'L LAW. 1037 (2003).

play a prominent part in a patient's health care. We find families take a vital position in at least the following respects:

[1] [F]amilies are the major bedside caretakers for patients including those who are hospitalized. All hospitals in Taiwan, for instance, provide free army beds for patient families to borrow so that they can stay overnight by the bedside caring the patients....

[2] More than 90% of surgical consent forms were signed by the families, regardless the patient is competent or not. The Department of Health in Taiwan then added a footnote in its second version of the 'Model Surgery Consent Form,' stating that families are qualified signers only when the patient is incompetent or unable to sign. It does not, however, change the practice....

[3] In the particular subject of life-or-death decisionmaking, patients are blocked out from the very first beginning. It is common that patient families ask or even beg physicians to withhold 'bad news,' mostly the diagnosis of cancer, from the patient. Believing that devastating news will defeat the patient's will to fight against the underlying disease, patient families usually screen medical information for the patient. If a patient does not even know what in fact he/she gets, physicians often ask, how can a valid informed consent be obtain?<sup>23</sup>

The observation above reflects the dominant position of families in Taiwanese medical circumstances. At least in the medical context, family functions in Taiwan are undoubtedly much more powerful than in the U.S. or other Western countries. The fact that scholars uses the term "family paternalism" to indicate the medical reality in Taiwan<sup>24</sup> makes a great annotation to the predominance of the role of families there.

For the purposes of this article, the third point mentioned in the quotation above deserves closer inspection. In the case of a fatal diagnosis, especially of cancer, Taiwanese physicians may withhold from patients their real condition, but disclose the information to their families upon the families' request.<sup>25</sup> In other words, health information that isn't

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23. Hsiu-I Yang, *Bad Living than Good Death? A Culture Analysis of Family Paternalism in Death and Dying in Taiwan* 5 (Dec. 12, 2002) (paper presented at IV Asian Bioethics Conference, Seoul, Korea, Nov. 22-26, 2002, on file with author).

24. *See id.*; Shuh-Jen Sheu et al., *Ethical Decision Making on Truth Telling in Terminal Cancer: Medical Students' Choices between Patient Autonomy and Family Paternalism*, 40 *MED. EDUC.* 590 (2006).

25. *See also id.* at 590-91; Michael Cheng-Tek Tai & Tsung-Po Tsai, *Who Makes the Decision? Patient's Autonomy vs. Paternalism in a Confucian Society*, 44 *PUB. HEALTH* 558, 560 (2003).



even known by the patients themselves is given to families without the patient's consent or even awareness. The rationale behind the practice is that many people think it is harmful to reveal to patients the truth about their terminal conditions, and the family as a desirable support group under Taiwanese culture shoulders the responsibility of taking care of and making decisions for the patient.

Similar phenomena also exist in other East Asian countries, such as Japan and Korea. For example, many commentators have described that Japanese physicians avoided revealing the diagnosis of cancer to the patient but instead talked about medical matters with family members.<sup>26</sup> Within Korean culture, a case arose involving a fifty-nine-year-old Korean woman who had immigrated to the U.S. ten years previously. Her family asked the surgeon not to tell her any "bad news" but to say instead that she would soon be leaving the hospital. They also questioned the surgeon about surgical procedures and risks, though the surgeon responded that he could not disclose this information without the patient's permission or presence.<sup>27</sup> A study conducted in Los Angeles County more comprehensively shows that only 35% of Korean Americans, much less than African Americans and European Americans, believe that a patient should be told a terminal prognosis.<sup>28</sup> Meanwhile, most Korean Americans (57%) believe that the family should make the decision about the use of life support and only 28% believe that the patient should make that decision.<sup>29</sup> Thus, we can recognize that the phenomenon that medical information practices may defer to the family also exists in Korean culture. Cultural preferences in Japan, Korea, and Taiwan, countries that share a common cultural source, mutually prove the nature of the cultural roots of this reality regarding the flow of health information.

Nevertheless, we should pay attention to current transitional trends.<sup>30</sup> Commentators have observed that the Japanese are gradually changing their attitudes. The number of people who want to be fully informed and

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26. Robert B. Leflar, *Informed Consent and Patients' Rights in Japan*, 33 HOUS. L. REV. 1, 20-21 (1996) [hereinafter Leflar, *Patients' Rights*]; Robert B. Leflar, *The Cautious Acceptance of Informed Consent in Japan*, 16 MED. & L. 705, 707 (1997); Agatha Lambris, *Informed Consent for All? Not Quite! A Comparison of Informed Consent in the United States and Japan*, 17 TEMP. INT'L & COMP. L.J. 237, 250-54 (2003); George J. Annas & Frances H. Miller, *The Empire of Death: How Culture and Economics Affect Informed Consent in the U.S., the U.K., and Japan*, 20 AM. J. L. AND MED. 357, 373-75 (1994); ANNAS, *supra* note 12, at 69-71; Fumikazu Takeda, *Informed Consent in Japan*, 37 INTERNAL MED. 1, 1 (1998).

27. Elysa Gordon, *Multiculturalism in Medical Decisionmaking: The Notion of Informed Waiver*, 23 FORDHAM URB. L.J. 1321, 1341 (1996).

28. Leslie J. Blackhall et al., *Ethnicity and Attitudes toward Patient Autonomy*, 274 JAMA 820, 821 (1995).

29. *Id.*

30. When considering the relationships between law and society, a very important point is that "culture is subject to change." See DAE-KYU YOON, *LAW AND POLITICAL AUTHORITY IN SOUTH KOREA* 32 (1990).

the rate of disclosure of cancer are both increasing rapidly.<sup>31</sup> Reflecting this change, the report issued in 1995 by the Commission for the Study of Informed Consent, on the issue of informing patients of a cancer diagnosis, stated: in keeping with the desire of an increasing proportion of Japanese to be informed, physicians should “pursue the possibility” of revealing the diagnosis while taking into consideration each individual patient’s wishes and condition.<sup>32</sup> Due to this development, as Leflar foresees, the day is coming when “the disguising of a cancer patient’s prognosis will subject a physician to professional obloquy and legal liability in Japan just as in the United States.”<sup>33</sup> This transitional trend has also surfaced in Taiwan. Under the influence of powerful Western/American cultures, new generations largely accept individualism and regard autonomy as natural. We lack the empirical research to show the changing curve precisely in Taiwan, but the Japanese situation offers a great exemplification of what is happening and will continue to happen under this inevitable trend.

In sum, the prominent position of families in medical affairs leads to special practices concerning the flow of health information. These practices are not fortuitous but rooted in Taiwanese cultural tradition, as they are culturally based in other East Asian countries. However, it is also notable that Western culture, especially American individualism, exercises a strong influence on Taiwan, resulting in the trend toward changing people’s values.

B. *Legal Regulation of Health Information in Taiwan: Is the Door Open for Family Paternalism?*

Does current Taiwanese law follow the same principles as American law, or does it have special, distinct roots in the medical practice mentioned above? The Medical Practice Act and Computer-Processed Personal Data Protection Act are current Taiwanese laws involving health information. The Medical Practice Act, which regulates health care institutions and medical practices, includes some provisions that create obligations regarding confidentiality and information. In addition to these medical provisions, the Computer-Processed Personal Data Protection Act, which broadly protects personal information, also applies to health

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31. Lambris, *supra* note 26, at 254-55; Takeda, *supra* note 26, at 1; Miho Sekimoto et al., *Patients’ Preferences for Involvement in Treatment Decision making in Japan*, 5 BMC FAM. PRAC. 1 (2004), <http://www.biomedcentral.com/1471-2296/5/1>.

32. *Infomudo Konsento no Arikata ni kan-suru Kentokai Hokokusho: Genki no Deru Infomudo Konsento o Mezashite* [Report of the Commission for the Study of Informed Consent: Toward an Invigorating Informed Consent] 4 (1995), cited in Leflar, *Patients’ Rights*, *supra* note 26, at 107.

33. Leflar, *Patients’ Rights*, *supra* note 26, at 108.

information, since health information falls within the scope of personal information.<sup>34</sup> Below, I will analyze these two acts to show that current Taiwanese law does not present the same picture as American law.

The Medical Practice Act doesn't allude explicitly to patients' autonomy in controlling their own health information, though it includes a provision protecting patients' privacy. Article 72 requires that "without justifiable reason, the health care institution and its personnel shall not disclose patients' condition or health information which they know or possess by their professional work." Therefore, basically, patients' health information should be kept private and secure from being accessed by others. However, Articles 63 and 81 create some exceptions. For example, pursuant to Article 81, while diagnosing and treating a person, the health care institution shall convey relevant information to "the patient or her/his legal representative, spouse, relative, *or* person with interest" (emphasis added).<sup>35</sup> Because all parties in the provision are simply connected by the conjunction "or" without further directions, it is hard to construe that physicians have a prior obligation to inform patients. This provision seems to purport that medical professionals have broad discretion in deciding whom to inform. It is undoubtedly true that when the patient is a minor, the health care institution should inform the patient's legal representative about the patient's condition. However, it is not clear when the health care institution should/could reveal information to a competent patient's spouse, relative, or person with interest.<sup>36</sup> As a result, this provision opens a door for physicians to legally inform certain people even without the patient's permission or awareness. Patients still seem not to be deemed masters of their own health information, because the plain meaning of the article does not place a basic obligation on physicians to inform patients, and it is left to the discretion of physicians to inform other relevant people without the patient's consent.

Regardless of why the legislature left this door open in Articles 63 and 81, undoubtedly these provisions could keep family paternalism alive.

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34. Article 3 of the Computer-Processed Personal Data Protection Act defines "personal data" as "a natural person's name, date of birth, identification number, physical features, finger print, marriage status, family, education, occupation, health condition, medical record, financial condition, social activities, and other data sufficient to identify said person." It is a reasonable interpretation that personal data includes health information, because "health condition" and "medical record" are enumerated in the definition.

35. Article 63 similarly states the obligation to inform "the patient or her/his legal representative, spouse, relative, or person with interest" in the context of *surgery*. In addition, Article 63 requires consent from the party above ("Before conducting surgery, the health care institution shall inform the reason, average, side effect, and risk of surgery to the patient or her/his legal representative, spouse, relative, or person with interest, and receive the consent form signed by the party above, except in an emergency.").

36. "Person of interest" is a legal term that appears quite often in various statutes. In some circumstances, we might be able to infer its specific content. However, in many circumstances, including here, it is extremely vague.

It is possible that the legislature intentionally allowed physicians to inform families instead of the patient, under the common social sense at the time the Act was passed.<sup>37</sup> Even if the provisions stem from other causes, such as medical paternalism or legislative laziness, in practice, physicians could lawfully exercise their discretion to inform any person falling within the group containing the patient, legal representative, spouse, relative, *or* person with interest. As a result, family paternalism, which is incompatible with American medical law, could survive the provisions of the Medical Practice Act in Taiwan.

The Computer-Processed Personal Data Protection Act, passed in 1995, is a fairly Westernized and detailed law. The government referred to many Western countries' legislations when this Act was drafted as a response to the crisis of personal privacy arising from our global information age. Naturally, individual autonomy in controlling personal information, regarded as an advanced conception, is an important assumption in this Act. "Written consent" is one of the justifications for gathering, processing, or using personal information, according to Articles 7, 8, 18, and 23 of the Act.<sup>38</sup> For instance, Article 18 sets forth that "a non-government organization should not collect or process by computer personal data unless for a specific purpose and satisfying any of the following requirements: (1) that the organization collects or processes by computer the personal data upon *written consent* from the party concerned; (2) that the organization has a contractual or quasi-contractual relationship with the party concerned and no potential harm to the party concerned would occur; (3) that such personal data is already in public domain and no harm to the major interest of the party concerned would occur; (4) that collecting or processing by computer the personal data is necessary for academic research and no harm to the major interest of the party concerned would occur; and (5) that the organization complies with the laws with respect to Article 3, Subparagraph 7, Item 2 of this Act and special regulation of other laws" (emphasis added). In addition, this Act grants a series of individual rights regarding personal data, including the rights to: (1) inquire and request to access; (2) request to acquire copies; (3) request to amend or correct; (4) request to cease processing and using;

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37. The Medical Practice Act was enacted in 1986. Current Articles 63 and 81 were revised and moved from Articles 46 and 58 in 2004. Despite revision in 2004, the change was not substantial. Article 46 of the old Medical Practice Act requires the health care institution to convey relevant information to and receive consent from "the patient or her/his spouse, relative, or person with interest" before conducting surgery. Article 58 of the old Medical Practice Act requires the health care institution to convey relevant information to "the patient or her/his families."

38. Article 7, 8, 18, and 23 provide regulation respectively on government organizations' collection and computer processing of personal data, government organizations' use of personal data, non-government organizations' collection and computer processing of personal data, and non-government organizations' use of personal data.

and (5) request to erase.<sup>39</sup> Accordingly, we can see that autonomy is an important basis of the Act, which does not consider the family factor.

However, we would be making a mistake if we believed that the Computer-Processed Personal Data Protection Act blocks medical family paternalism. First, because this Act does not focus on medical affairs, although granting individuals the right to request to access personal information, it does not lay an obligation on physicians to actively inform patients. Second, the individuals' control over the flow of their personal information is shaped by a number of broad and vague clauses providing exceptions to strict personal autonomy. For example, in Article 18, mentioned above, there are four clauses besides "written consent" that could justify the collection or processing of personal data. Among these clauses, at least clause (2) overbroadly extends the scope of the exemption, because contractual and quasi-contractual relationships exist almost everywhere, and the requirement that "no potential harm to the party concerned would occur" is too ambiguous to have a restrictive effect. Furthermore, the Act restricts the use of personal data simply by requiring the use to correspond with the purpose of collection.<sup>40</sup> As a result, by identifying communication with families as the action for medical purposes, which is the purpose of previous collection, physicians may easily escape from the constraint of the Act. Third, and more important, though it is possible to narrowly construe the provisions towards the principle of autonomy, in fact people have never used this Act to fight against physicians or health care institutions based on disclosures to families.<sup>41</sup> In other words, even though this Act contains the spirit of autonomy, and this spirit may arguably lead to an interpretation precluding family paternalism, Taiwan's "law in action" on health information has not yet truly followed this "law in books."<sup>42</sup> As a result, in reality, the Act has not thoroughly blocked the medical practice of family paternalism.

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39. Article 4 of the Computer-Processed Personal Data Protection Act.

40. The provision addressing the use of personal data in the setting of non-government organizations is Article 23, which mandates that the "use of personal data by a non-government organization shall be within the necessary scope of the specific purposes of collection." The same article further provides that the "use beyond the specific purpose may be made under any of the following circumstances: (1) that the use is to enhance public interests; (2) that the use is to avoid emergent danger to the life, body, freedom, or property of the concerned party; (3) that the use is necessary for preventing grave damages to rights and interests of others; and (4) that the use is with written consent of the concerned party."

41. Although incomplete, a search conducted by the author on April, 2007 through the Judicial Yuan Law and Regulations Retrieving System failed to find any related case.

42. One valuable insight of the law and society movement is its sense that not only the written law but also the legal system in practice deserves careful attention. See MACAULAY ET AL. EDS, *supra* note 12. The first reference observing the divergence between the law in the books and the law in action might be an article by Pound. Roscoe Pound, *Law in Books and Law in Action*, 44 AM. L. REV. 12 (1910).

The above analysis of current Taiwanese law reflects a transitional, but still divergent, legal pattern from American law. Family paternalism could survive current legal regulation. In terms of the Medical Practice Act, the provisions even contain an apparent open door for family paternalism. Although this current law is incoherent and insufficient in many aspects, the fact that the law does not completely block current practices regarding health information may itself echo social values, to some extent.

#### IV. PROBLEMS ARISING FROM TAIWANESE IMITATION OF AMERICAN LAW CONCERNING HEALTH INFORMATION WITHOUT AWARENESS OF THE DIFFERENCES BETWEEN THE TWO COUNTRIES

The information presented in Parts II and III illustrates some important differences—where the law and medicine are concerned, at least—between Taiwan and the U.S.. Due to these differences, rashly importing American autonomy-oriented regulations concerning health information to Taiwan may pose problems.

An outright transplantation of American law into Taiwan will create a gap between legal obligations and current medical practice. Specifically speaking, importing American medical law and health information privacy law will impose two obligations on physicians regarding health information. First, according to the rule of “informed” consent, physicians will have an obligation to give patients health information, such as their condition and proposed treatment. Second, physicians will have an obligation of confidentiality so as to prevent health information from being accessed by others. However, these obligations are not completely consistent with current medical practice in Taiwan. In the case of a fatal diagnosis, especially of cancer, requested physicians now may disclose the information to families, but withhold it from patients at the family’s request. As a result, physicians who follow traditional medical culture will breach the two obligations described above. In the meantime, families who request access to patients’ health information will also be deemed to be unlawfully attempting to intrude on patients’ health information privacy, though they may believe they are acting in a culturally, and perhaps even legally, correct manner.

This inconsistency between the proposed law and current medical practice might have considerable implications. At first, we may find setting an excessively high standard of autonomy to be unrealistic, for the more the law deviates from common practices, the more inefficient it will be. Passing a new law does not immediately change people’s minds. Although stressing personal autonomy in lawmaking is easy and costless, we have to be aware that enforcing a high standard of autonomy demands

a heavy price. More important, the fairness of enforcing a high standard of autonomy is questionable. Many family members who request information and many physicians who keep information from patients but disclose it to families do so, because they believe they are acting in patients' best interest. Most of them do not intentionally try to harm patients, but rather attempt to help them in the way they regard as right. A law with a high standard of autonomy will frustrate those people's goodwill by regarding it as illegal. Furthermore, the government might end up suddenly imposing a punishment on people who did not fully perceive the new regulations and understand why what they were doing was now wrong. A punishment of this kind would be cruel in the sense of not carefully taking into account that many people were facing legal changes that did not correspond with their values. In short, a high standard of autonomy might predictably impact existing Taiwanese medical reality, and we are not yet ready for this impact or even sufficiently aware of its approach.

The transitional trend makes the problem even more complicated. I mentioned in Part III Section A that new generations might tend to be more individualistic and autonomous. On the one hand, traditional attitudes and practices are still common and must be considered. On the other hand, because the culture is changing, traditional attitudes and practices alone no longer fully represent Taiwanese culture. For instance, the terminal patient may belong to the old generation, while the descendants of the patient may belong to the new generation and its different cultural attitudes. Precisely speaking, during this transitional era, people's attitudes may fall into any place on the spectrum between extreme family paternalism and extreme autonomy. Moreover, Taiwanese society consists of multiple ethnical groups, which may not present exactly the same cultural pattern. As a result, there is no clear rule to follow, because different people may have different cultural preferences. Families of the patient themselves may struggle personally over the difficult question "to tell or not to tell," if they know the patient's condition. Physicians face challenges of whether they should tell patients and/or the families, which brings into play not only their own ethical views, but also the divergent pressures from patient preferences and family desires. This complex phenomenon makes it invalid to arbitrarily conclude that autonomy totally conflicts with Taiwanese society and to rashly advocate establishing a rule based on family paternalism.

Merely imitating American law as an approach to creating new Taiwanese law appears easy, but is really quite problematic. Due to the inconsistencies between American law and Taiwanese medical practice in respect to health information, roughly importing American health information law to Taiwan may lead to considerable social impact. In addition to noting that Taiwanese medical culture does not completely

follow the principle of American autonomy, it is critical to pay attention to the cultural transitional trend in Taiwan, in which neither extreme autonomy nor extreme family paternalism really represents Taiwanese values. As a result, the proposed law demands more deliberate design.

#### V. SOME SUGGESTIONS FOR THE NEW LAW IN TAIWAN

Based on recognition of the problems arising from the inconsistency between American legal regulation and Taiwanese medical culture, I argue that while imitating American health information law, the forthcoming new law should leave a little room for current practice that results from the prominent role of the family. Unfortunately, due to the aforementioned transitional trend, the new law faces the more complicated challenge that a single, fixed standard of information cannot keep pace with people's various cultural attitudes. To respond to this tough situation, I suggest that the new law in Taiwan leave some discretion to physicians for considering cultural variation and that it require physicians to be aware and considerate of cultural variation. To be more specific, I lay out my suggestions in the following five points.

##### A. *Requiring physicians to be aware of patients' cultural preferences*

The new law should include language to guide physicians towards paying attention to patients' cultural preferences. The relationship between physicians and patients could be more than a matter of mechanical contact. Especially in the cases of cancer and other terminal illnesses, where the relationship is usually sustained for a period of time, it is possible for physicians to know their patients' needs better. In this transitional era, a patient's cultural preference should be one important factor for physicians to consider.<sup>43</sup> The dialogue between physicians and patients contains the roadmap of the patient's values. For example, before the results are told or an exploratory test is even taken, a physician may ask the patient, "Do you want to know your condition and proposed treatment?" Although many patients might desire to know, it is still possible the physician may receive an answer such as "I have no idea. Just talk to my son." This is the kind of answer that would reflect a specific cultural preference. Furthermore, to perceive patients' cultural preference, the "values statement" may be a useful practical tool, one that has been used in the U.S. to reveal in advance patients' feelings and beliefs about

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43. Even outside of the context of transition, Bert et al. have also suggested that patients may have different decisionmaking preferences, and physicians should get to know about them. BERG ET AL., *supra* note 8, at 29.



treatment when they cannot make their own decisions.<sup>44</sup> For the purposes proposed here, certain questions could be developed and added to the values statement, in order to reflect patients' preferences concerning the flow of health information. These just are a couple of possibilities for the clinical situation. The law, as a costly, inflexible, and forceful norm, is unsuitable for regulating something too specifically. But adding some language concerning cultural variety could play an effective part at least in reminding physicians to be aware of patients' cultural preferences.

B. *Giving room for consideration of withholding information from patients*

In terms of informing patients, the new law should leave physicians some discretion to consider the patient's personal conditions and decide not to tell. Strictly requiring physicians to inform patients is not necessarily better for patients in some circumstances. For example, some patients' own cultural preferences may tend toward indifference to their medical affairs and may tend toward allowing their families to deal with everything for them. As another example, the rationale behind shielding patients from the truth is that people believe the truth may lead patients to serious depression and/or losing the will to live; accordingly, a patient's personality and mental condition become considerable factors. Another consideration is the timing of the telling, because a patient's emotional and mental condition may change from time to time. If, after cautiously considering the patient's personality, mental condition, and family requests, the physician recognizes that telling the truth at this moment will seriously defeat the patient's will to live, and the physician decides to temporarily withhold information from the patient, this choice should not be illegal. Although it is improper for the law to set up too detailed of rules to direct physicians' consideration regarding patients' preference, emotional and mental condition, and so on, when the new law requires physicians to respect a patient's right to know, it should leave a little discretion to physicians to judge if withholding some information may more greatly benefit the patient in special circumstances.

C. *Giving room for consideration of disclosing information to families*

In terms of confidentiality, the new law should leave some discretion to physicians to disclose patient health information to families in some circumstances. In the case that certain patients' cultural preference is to

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44. For the values statement, see FAY A. ROZOVSKY, CONSENT TO TREATMENT 169 (2d ed. Supp. 1999).

allow their families to know and deal with medical affairs for them, it is reasonable to disclose information to families. Even in the case where the patient's cultural preference and personal will are not clear, disclosure to families is not necessarily wrong. As was mentioned in Part II Section B, in the U.S., the *HIPAA Privacy Rule* has set up some exemptions to keeping information confidential from families. In Taiwan, the scope of exemptions should be even broader. It is not easy to establish clear rules, but at least we can ask that some factors be taken into consideration, such as the relationship between the patient and the family. When a patient's children are present, they are more suitable candidates for release of information than, for example, the patient's nephew or more distant relatives. In addition, we may also take the family's attitude into account. Disclosing to families who actively request knowledge is easier to justify than doing so to more passive ones.

D. *Reexamining the law in light of cultural change*

The new law should require the legislature or administrative agency itself to periodically reexamine the provisions and to compare them to present patient expectations and medical practice, because as the transitional trend continues, an established standard may become outdated fairly quickly. In particular, as people's cultural attitudes tend toward becoming more individualistic and autonomous, one day Taiwan may be able to dispense with giving physicians relatively broad discretion. To dispel medical paternalism, which has been recognized as a weighty problem in the Taiwanese medical environment,<sup>45</sup> legislators should narrow physicians' discretion when suitable. To follow the changing reality and pursue a more tailored legal regulation, those responsible for constructing and monitoring new law must frequently investigate present patient expectations and medical practices. We presently lack survey data about medical reality, because most people do not pay attention to this issue, and nor do they endeavor to conduct empirical studies. It is therefore a good idea to incorporate into law the government's responsibility to constantly research and reexamine the law.

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45. See Hsiu-I Yang, *Shei Lai Tong Yi? Shei Zuo Jyue Ding?—Cong Gao Jih Hou Tong Yi Fa Ze Tan Bing Ren Zih Jhu Cyuan Jih Li Lun Yu Shih Ji: Mei Gao Jing Yan De Kao Cha* [Who Consents? Who decides?—On the Theory and Practice of Patients' Autonomy from the Law of Informed Consent: American Experience], 20 TAI WAN FA SYUE HUEI SYUE BAO [LAW FORUM] 367, 396 (1999).

E. *Improving medical professional ethics and education to prompt cultural awareness and helpful dialogue*

In pursuit of the goals of prompting cultural awareness and helpful dialogue with patients, the new law should establish mechanisms to create or assist in the creation of incentives to encourage vigorous development of medical professional ethics and education. As a softer, more flexible social norm made by medical professionals themselves, professional ethics could give more detailed direction that might be complied with more willingly. Hence, professional ethics could adequately fill the hole the law leaves where the law is unsuitable to regulate too specifically, and it could produce different regulative effects from the law. To enhance a medical environment with cultural awareness, medical professionals and academic groups should develop guidelines to direct physicians in approaching patients' cultural values and to help physicians deal with patient interactions,<sup>46</sup> and the law may require, prompt, or support the medical community to do so. Besides professional ethics, medical education must play a central role. Education is a powerful tool that profoundly alters reality. In order to pursue a medical environment with cultural awareness, medical education should incorporate more learning and training content about cultural awareness and communication skills,<sup>47</sup> and the law may require, prompt, or support medical education systems to do so. Because cultural variation is often neglected as an issue, it is necessary to remind the medical community to bear it in mind through the law.

The five suggestions above, a compromise between extreme individualism and family paternalism, may prevent severe social impacts when we endeavor to protect privacy, which is a significant individual right. They may also prove to be a better match with Taiwan's current cultural reality than purely Western or American laws and guidelines.

## VI. CONCLUSION

Exploring American autonomy and Taiwanese family paternalism in the medical context displays some inconsistency between American medical legal regulation and Taiwanese medical culture. Due to this

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46. Gordon, *supra* note 27, at 1355.

47. *Id.* In terms of communication skills, Takeda argues that lack of them is one of the main reasons why few cancer patients in Japan are told the truth. Takeda, *supra* note 26, at 1. As an example, Sheu et al. have suggested group discussion as a teaching method to enhance students' ethical consideration in the context of truth telling in terminal cancer cases. Sheu et al., *supra* note 24.

inconsistency, roughly importing American law concerning health information without further contemplation might lead to serious social consequences. Therefore, I suggest that while imitating the American law concerning health information, the forthcoming new law should reflect awareness of cultural difference and leave room for certain current practices. In addition, due to the cultural transitional trend, the new law faces a more complicated challenge, in that it should also make an effort to keep pace with various and changing cultural attitudes.

In Part V, I presented my suggestions in five concrete statements. Simply speaking, I think the new law should require physicians to be aware of patients' cultural preferences. In the meantime, the new law should also give physicians room to consider withholding information from patients and disclosing information to families in certain circumstances. In addition, the new law should require itself to be reexamined regularly to follow cultural changes, and should include provisions to require, prompt, or support vigorous development of medical ethics and education for the enhancement of cultural awareness and dialogue.

I see making a new law, including the introduction of informed consent, in order to protect the privacy and security of health information, is a necessary road to embark on, because current legal regulation in Taiwan is not adequate to face both traditional concerns and modern challenges. Through DOH's ongoing legal reform, strides can be made toward bettering the health information environment. On the other hand, legislators must consider that suddenly transferring American autonomy outright into Taiwan's new law without contemplating social variation is not an efficient approach. All concerned should pay close attention to the real world in which the law will apply. Only when cultural and social reality is well understood will a properly tailored law emerge.

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