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Nie, JB; Walker, ST; Qiao, S; Li, X; Tucker, JD (2015) Truth-telling to the patient, family, and the sexual partner: a rights approach to the role of healthcare providers in adult HIV disclosure in China. *AIDS care*, 27 Suppl 1. pp. 83-9. ISSN 0954-0121 DOI: <https://doi.org/10.1080/09540121.2015.1071772>

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DOI: [10.1080/09540121.2015.1071772](https://doi.org/10.1080/09540121.2015.1071772)

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## Truth-telling to the patient, family, and the sexual partner: a rights approach to the role of healthcare providers in adult HIV disclosure in China

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(Received 16 December 2014; accepted 8 July 2015)

Patients' rights are central in today's legislation and social policies related to health care, including HIV care, in not only Western countries but around the world. However, given obvious socio-cultural differences it is often asked how or to what extent patients' rights should be respected in non-Western societies such as China. In this paper, it is argued that the patients' rights framework is compatible with Chinese culture, and that from the perspective of contemporary patient rights healthcare providers have a duty to disclose truthfully the diagnosis and prognosis to their patients, that the Chinese cultural practice of involving families in care should – with consent from the patient – be promoted out of respect for patients' rights and well-being, and that healthcare providers should be prepared to address the issue of disclosing a patient's HIV status to sexual partner(s). Legally, the provider should be permitted to disclose without consent from the patient but not obliged to in all cases. The decision to do this should be taken with trained sensitivity to a range of ethically relevant considerations. Post-disclosure counseling or psychological support should be in place to address the concerns of potentially adverse consequences of provider-initiated disclosure and to maximize the psychosocial and medical benefits of the disclosure. There is an urgent need for healthcare providers to receive training in ethics and disclosure skills. This paper concludes also with some suggestions for improving the centerpiece Chinese legislation, State Council's "Regulations on AIDS Prevention and Control" (2006), to further safeguard the rights and well-being of HIV patients.

**Keywords:** HIV disclosure; patients' rights; privacy; cultural differences; family; China; partner notification

Patients' rights, including the right to truthful information, the right to informed consent and choice, the right to privacy, the right to freedom from discrimination, and the right to refuse even life-saving treatment, are now central in health law and policy around the world. The human rights approach has been promoted in such international documents as the UNESCO Universal Declaration on Bioethics and Human Rights (2005). HIV has presented a serious challenge to health and development since it was reported in 1980s. Because HIV transmissions may be associated with some behaviors viewed as morally wrong (e.g., drug use, commercial sex, etc.), HIV-related stigma and discrimination are persistent around the world. Thus, the disclosure of HIV seropositive status to a patient or related persons raises complex ethical issues in practice. In many situations, protecting patients' rights to privacy and freedom from discrimination may conflict with HIV secondary prevention purposes and others'

rights and interests (e.g., sexual partners of HIV patients). The subject of patients' rights and HIV disclosure has been widely discussed and debated globally. However, despite the increasing prominence of such rights, questions persist about whether these rights *should* be applicable and *how* they can be implemented in diverse socio-cultural settings, particularly in non-Western societies such as China.

In this paper, we focus upon three major practical issues facing healthcare providers: truth-telling to the patient, the role of family, and the duty to protect the sexual partner of the patient, and argue that the patient's rights framework can serve as a meaningful guide for Chinese healthcare providers in addressing HIV disclosure and reforming certain conventional but ethically problematic practices. Specific attention is given to the provider's duty to inform the patient and protect patient privacy, and on the practical skills, care and sensitivity required for HIV disclosure.

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### Current norms and practices: state regulation and a case

Like other parts of the world, contemporary China has been moving toward “an age of rights” (e.g., Xia, 2000), and the progress of this movement has been particularly rapid in the fields of healthcare and biomedical research including HIV disclosure and AIDS care. More and more patients and lay people in China are becoming conscious about and taking seriously their rights in health care, and increasing numbers of medical professionals are willing to respect their patients’ rights. This reflects a global shift in medical ethics over the last 50 years away from paternalistic models of care, grounded on a certain understanding of beneficence and non-maleficence, toward more patient-centered models grounded on autonomy and truthfulness.

On the national and social policy level, the patients’ rights approach has already started to be embraced, even in the official discourse. In relation to patients with HIV, it incorporates the patient’s right to truthful information, privacy, freedom from stigma or discrimination, and duty to prevent further infection. The State Council’s “Regulations on AIDS Prevention and Control” (2006) constitutes the centerpiece public policy document on the ethical, social, and medical issues related to HIV and AIDS. On the one hand, the legislation places a number of obligations on the patient, including a duty to provide truthful information to the medical professional and concerned public health authorities, and to inform sexual partner(s) of the diagnosis in an honest and timely manner (Article 38). It stipulates that the patient has a legal duty to take necessary measures to prevent the spread of the disease and not to spread the virus to others intentionally (Article 38), and that the patient has to bear civil and criminal liabilities if he or she intentionally spreads HIV to others (Article 62). At the same time, the legislation in general aims to protect the legitimate rights and interests of HIV or AIDS patients, including the right to be free from various kinds of discrimination and stigmatized treatment (Article 3). It legalizes the patient’s rights to truthful information and confidentiality. Article 42 stipulates that medical professionals have a duty to disclose the diagnosis of HIV to the patient himself or herself, or the guardian if the patient is incompetent or with diminished competence. Article 39 states: “Without the permission of the individual or the guardian, any institution or individual should not disclose the name, address, work unit, picture, medical history and other possible identifying information of the patient with HIV or AIDS.”

Meanwhile, HIV prevention and AIDS care in China have serious ethical and socio-cultural challenges as the following case demonstrates:

Mrs. Wang (not her real name), a woman in her sixties in northern inland China, was infected with HIV from her husband who was a paid blood donor in the 1990s. Her husband died from AIDS several years ago. Wang now lives with her daughter-in-law and a 5-year-old grandson in the village. Her son, Mr. Li went to work in Guangzhou, a developed coastal city in the south in order to increase the family income. Mrs. Wang decided not to take free HIV testing partly because of her fear of the HIV-related stigma and discrimination, including the possibility of being rejected by her son and his wife if she would be diagnosed as HIV-infected, and partly because she didn’t feel early diagnosis and treatment could benefit her. She remarked: “I have had a long life. I don’t care of its length at all”. However, her son Mr. Li was concerned about her HIV serostatus because Mrs Wang as a grandmother was taking care of Mr. Li’s son. He worried that his mother might transmit HIV to his son. At the request of her son, Mrs Wang was tested for HIV and the result was positive. Following the conventional Chinese practice, neither the medical professionals nor Mr. Li told Mrs. Wang about this diagnosis. Nevertheless, although being semiliterate, Mrs Wang was aware of the seriousness of her illness because she had similar symptoms to her husband and because her son prevented her from touching her grandson. Other people in the village were gossiping about the death of her husband and Mrs Wang’s illness. Mr. Li felt little compassion for his mother, partly because he believed that he had lost face in the village due to his parents. Meanwhile, Li was concerned about his own HIV status because he had unprotected sex with sex workers in Guangzhou. Li’s HIV test result turned out to be positive as well. His physician in Guangzhou urged him to tell his wife, but Mr Li indicated hesitation. The physician wondered whether, despite her duty to maintain patient confidentiality, she ought to inform her patient’s wife who lived far away from Guangzhou. She has no specific clinic guideline or regulations to suggest how she can deal with this situation, but relies on her past experiences and those of her colleagues. She had previously disclosed a patient’s HIV positive status to his wife for secondary prevention purpose. As a consequence the wife had divorced the patient and the angry patient had threatened to kill the physician.

The case raises many issues which include state and individual responsibility for HIV prevention and stigmatization related to HIV/AIDS. In the following, we focus upon the role of healthcare providers in HIV disclosure from a patients’ right approach.

### Human and patients’ rights as a Chinese value

Researchers on AIDS in China have observed that “*Under the influence of Western culture, service providers and decision makers in China have gradually began to recognize patients’ rights in decision making and the issue of confidentiality*” (Li, Lin, Wu, Lord, and Wu 2008, 8, pp. 240–241, italics

added). Western culture has had a positive and important role in advocating for changes in China through a number of channels. For instance, many programs and research projects relating to HIV in China are supported by Western institutions that emphasize the rights of HIV patients. However, it should be recognized that this emerging age of patients' rights in China is not solely due to such Western influences, but is rather a development motivated by Chinese patients, medical professionals, and lay people, and is endorsed by values inherent to Chinese cultural traditions. The idea that Chinese advances in human and patients' rights have been caused only by Western influence – a standpoint held by many Westerners and endorsed in the Chinese official discourse – has degraded the agency of Chinese people.

In both China and the West, Chinese cultural traditions have often been characterized as collectivistic or authoritarian in nature and as thus radically different to traditions of the West, and to such notions as human and patients' rights. For example, in their empirical studies on HIV disclosure in China, researchers have employed this Chinese-Western contrast to interpret their findings and to discuss the normative dimension on how HIV disclosure should be practiced in China (Chen et al., 2007; Li, Lin, Ji, Sun, & Rotheram-Borus, 2007, 2008). For them, the norm of patients' rights represents a Western value that is not culturally compatible with Chinese values and thus should not be ethically applicable in China.

It is not possible here to present an in-depth theoretical account of human and patients' rights in the Chinese milieu (e.g., Nie, 2005, 2011). Nevertheless, a few points should be made to briefly indicate the appropriate place of patients' rights within Chinese ethical traditions. The movement for human and patients' rights has been a truly global discourse, involving people from all continents and countries, including China (e.g., Lauren, 2003). Conceptions of human rights have been widely discussed, debated, and integrated into Chinese intellectual and political life since the late Qing dynasty (e.g., Fung, 2000; Svensson, 2002). They are articulated or at least implied in classical Chinese moral and political philosophy, most systematically in the work of Meng Zi (Mencius), a founder of Confucianism (see Roetz, 1993, 1999; Xia, 2002). Though privacy is currently less respected in China than in Western countries, pioneering studies demonstrate that classical texts from as early as the Warring States period (481–221 BCE) clearly expressed an acute awareness of and respect for privacy in healthcare practice. Similar examples may be found throughout Chinese history; for instance in the medical case histories of the Ming and Qing dynasties of late imperial China (McDougall & Hansson, 2002).

In other words, the thesis that a patients' rights approach is culturally incompatible to China has significantly oversimplified the great richness and future potential of indigenous Chinese cultural traditions (Nie, 2011). Admittedly, human and patients' rights are conceptually complicated and may have very different theoretical justifications and practical meanings in Chinese socio-cultural context. Our point here is that, rather than rejecting the value of patients' rights from the perceived but often stereotyped Chinese-Western cultural differences, the rights approach can be one of ethical aspiration to reform the certain conventional cultural practices and revive the vital but misrepresented traditional Chinese moral ideas and ideals.

For healthcare providers the serious ethical and practical challenge is thus not whether patients' rights matter in China, but *how* these rights should be respected and *what ought to be done* when these rights appear to be in conflict with other ethical concerns, such as the public good, the rights of others, and cultural practice.

### Truth-telling to patients

The cross-cultural differences and transcultural similarities of truth-telling on a global scale and in history are far more complicated than implied by the perceived dichotomy of disclosure in the West versus non-disclosure in non-Western societies such as China (Nie & Walker, 2015). Yet it is true that, as clearly shown in the case, in contrast to the practice of direct and truthful disclosure in most Western countries today, medical professionals in contemporary China often withhold information about terminal illnesses from patients, inform family members only, and sometimes even collude with relatives in lying to patients. Treating HIV as a kind of terminal illness like cancer, some physicians and family members still practice the so-called protective treatment, i.e., hiding the HIV diagnosis from patients because they presume that truth-telling would cause psychological harms and destroy hope (Qiao, Nie, Tucker, Rennie, & Li, 2015).

However, with the development of patients' rights in China, more Chinese healthcare providers are now truthfully informing patients of their condition. Numerous sociological surveys conducted throughout mainland China have shown that the great majority of Chinese patients want truthful information about their medical condition, even in terminal cases (for a review of the related literature, see Nie, 2011, pp. 120–123). Historically, while in the West truthful disclosure regarding a terminal illness did not become the ethical norm until the 1960s and 1970s (or even

later), many primary historical materials, including the biographies of hundreds of ancient medical sages and famous physicians in various dynasties, show that there was a long (if now forgotten) Chinese tradition of truth-telling, dating back at least 26 centuries. The Confucian moral outlook mandates truthfulness as a basic ethical principle and a cardinal social virtue which physicians ought to be guided by. So, the current shift away from the practice of avoiding truthful disclosure is not so much an imitation of Western (and thus foreign) ways, but rather a return to a long-neglected indigenous Chinese tradition (Nie, 2011, pp. 98–133, 2012).

For patients with HIV, the right to information and the right to make an informed choice in a context that is free from undue fear or pressure imply timely disclosure of diagnosis and treatment options, and that the diagnosis remains confidential to the patient–physician relationship. These rights fit squarely with the therapeutic goal of medicine, as prompt HIV disclosure to an HIV-infected individual has important implications for ensuring high-quality services throughout the continuum of HIV care. By contrast, HIV testing that is not tightly linked to prompt disclosure to the infected individual (and in turn their partners) can result in further HIV transmission, delays in initiating anti-retroviral therapy, and persistent high-risk behaviors. Thus, though disclosing information of a HIV diagnosis is likely to be difficult for the patient and perhaps harmful, hiding such information is likely to be more so (Nie & Walker, 2015).

The general harms of physicians not truthfully disclosing a terminal diagnosis are vividly portrayed in literary masterpieces such as Tolstoy's *The death of Ivan Ilyich* and carefully argued in contemporary bioethical classics (e.g., Katz, 2002). Lying about a terminal illness may leave the patient feeling isolated, uncertain, abandoned, and prevent him from participating in the decision-making of medical treatments. Such harms can also be identified in the case set out earlier by imagining the depths of fear, isolation, and rejection felt by Mrs Wang as she is left to guess the results of her test while observing the change in Mr Li's behavior toward her. Patient–physician trust is fundamental for effective health care, and truthfulness is the foundation of trust. Indeed, the practice of systematically withholding critical information from patients may be a contributing factor to the current crisis of patient–physician trust in China today.

### The role of family

The active role of the family in various social networks, including the patient–physician relationship, has been

widely discussed as among the most distinctive aspects of Chinese culture (e.g., Cong, 2004). This has implications for HIV disclosure and care provision (Chen et al., 2007; Li et al., 2008, 2009). HIV research in China has shown how kinship ties and family networks provide powerful support in a generally unsupportive local environment. Social network research from China has shown that HIV-infected individuals are more likely to disclose their HIV status to family members who provide social support (Zang, He, & Liu, 2014). Often, physicians first disclose the HIV diagnosis not to the patient but to a family head such as a parent or a spouse. They then assess the patient's condition and family situation to make a decision about how to inform him. In doing so, they assume that the patient's family should be involved in treatment as early as possible (Qiao et al., 2015).

This practice of informing family members before patients illustrates a potential tension between what has been called “Chinese familism” and patients' rights to information, privacy and independence; a tension which many physicians experience directly in their practice. However, this can be another “false dichotomy” (Nie, Smith, Cong, Hu, & Tucker, 2015), as the involvement of the family does not need to be in conflict with the patient's rights. As with health care generally, for HIV care to be fully effective it must engage with the patient's social and familial networks, and research has shown that openness about HIV and support in Chinese families positively impact on HIV patients (Li et al., 2009). This coheres with the right to support which is accorded to patients in most jurisdictions along with the other rights that have been discussed. Moreover, it does not negate the importance of those other rights, and when involving families in a patient's care the health-care provider should be alert to the possibility that the patient may need to keep some information private, or to maintain some degree of independence. While family involvement is often very beneficial to patients, it is not always so. This is shown in Mr Li's disregard for Mrs Wang, and the way family relationships can be broken down by a sense of social shame. The provider needs to be sensitive to such dynamics, and exercise careful judgment.

### Disclosure to the sexual partner

While few would now directly contest the importance of the rights to truthful disclosure, privacy, and confidentiality, it is also widely recognized that such rights should be moderated by the rights of others, and by the duties that a healthcare provider has to others in the community and to public health in general (e.g.,



Gillett & Walker, 2013). Perhaps the most prominent ethical question around HIV disclosure is whether health providers have a duty to disclose directly to the patient's family members, especially sexual partner(s). Like HIV care in general, this is a universal moral challenge for healthcare providers. Though an essential measure for disease control, a systematic literature review from China demonstrated that sexually transmitted infection (including HIV) partner notification has not been widely implemented, and that there is an urgent need in China for policies and guidelines regarding partner notification (Wang, Peng, Tucker, Chon, & Chen, 2012). While many Chinese medical professionals normally inform patients themselves first and then encourage them to tell their sexual partners for secondary prevention, it is common for healthcare providers to have difficulties persuading their patients to ensure their sexual partners undertake HIV testing. As a result, many health professional have to resolve the acute ethical conflict between protecting patients' confidentiality and preventing possible serious harms to another person (Qiao et al., 2015).

Ethically speaking, it is generally thought that people have a duty to inform others of serious risks and takes reasonable steps to prevent the perceived harm from occurring. However, the application of this basic rule is not always straightforward. In the context of health care, the healthcare provider must consider the impact of the information on the patient, including the effect this may have on ongoing care, the degree of benefit that an intervention could reasonably achieve, and other harms that may result as a consequence. These factors are especially salient in caring for patients with HIV, and make the ethical task of healthcare providers involved in such care particularly delicate. While it is clearly good if those at risk of infection are informed and assisted with preventive strategies, or treated if they are found to be infected, disclosure of a diagnosis of HIV without the consent of the patient may lead to other serious harms (for a summary of this debate see Beauchamp & Childress, 2009, pp. 307–309). There is, for instance, a concern that people will avoid being tested for fear of being denied privacy, and that consequently those who are infected or at risk remain outside medical help.

The healthcare professional should, whenever necessary, clearly inform patients that they (i.e., the patients) have a moral and legal duty to tell their sexual partner of their condition. If the patient refuses to do this, the healthcare professional in China (as elsewhere) should *be allowed* to breach confidentiality and take measures to see that those at risk are informed, so that they and others related to them can receive appropriate care. However, healthcare providers

should not be required to do this in all such circumstances. The laws surrounding these actions should give weight and scope to the judgments of the responsible practitioner, because the provider is best placed to determine whether there is a clear risk to others and a definite refusal on the part of the patient to inform them of this risk, and hence a need to refer the matter to a third party without authorization from the patient. In assessing whether or not it is necessary to do this, the healthcare provider must maintain a therapeutic commitment to the patient, be highly sensitive to the nuances of the situation, and exercise refined judgment. It is appropriate that this therapeutic commitment include a concern for those associated with the patient and at risk of infection, and that this concern include an expectation that the patient will inform them of this risk. Likewise, it is appropriate that the healthcare provider offers to support the patient in delivering this information, with an awareness of the importance of social and familial networks for the patient's well-being (Gillett, 2004, pp. 151–153). It is within the context of this kind of relationship that the provider is able to make the required judgment. The law, though essential in sustaining good healthcare practice, cannot take account of these relational factors, and thus could not ensure good management of such situations apart from such judgment. A law automatically forcing disclosure would introduce a coercive element into the patient–physician relationship, and may cause as much harm as it prevents.

### **Recommendations for policy and healthcare education**

Following the above discussion, some recommendations can be proposed to help improve policy guidelines. First, although the State Council's legislation acknowledges aims to protect rights of HIV or AIDS patient including the rights to truthful information and confidentiality and to be free from various kinds of discrimination, the general framework of patients' rights is lacking, or at best only implicit. We propose to add a statement in Article 3 that "the legislation safeguards the rights of HIV patients". Second, the cultural practice of the active role of family members in HIV disclosure for at least a significant portion of patients should be recognized. Wherever possible, healthcare professionals have a duty to facilitate the supportive role of the family and other social networks. Third, the legislation and policy guidelines should not avoid addressing the difficult issue of disclosing to the sexual partner. As we have argued above, healthcare professionals should *be allowed but not necessarily obliged* to disclose directly to the patient's sexual partner.

For healthcare providers to be adequately equipped to deal with the ethical challenges involved in HIV disclosure and HIV care in general, healthcare training and continuing education needs to incorporate the ethical, psychological, and social dimensions of health care. It is critical that healthcare providers are respectful of patients' rights and that they learn how to apply them in ethically complex situations. They must be taught the ethical basis of HIV disclosure policies, and how to communicate the diagnosis in a caring and supportive manner. This in turn requires appropriate training of disclosure skills for healthcare providers and post-disclosure counseling. Equally, healthcare providers need to understand the familial and social environment of an HIV-infected individual and take this into account when disclosing information. Psychological support should be in place to address the potentially adverse consequences of provider-initiated disclosure and to maximize the benefits of the disclosure. Thus, the ethical issues described are not isolated to some aspects of clinical practice and merely concerned with high-minded ideals or abstract principles. Rather, they have to be worked out in each particular context with sensitivity to the differences each case may present, and within a system integrating the biomedical, psychological, and social elements of care.

### Conclusions and limitations

This paper has discussed the importance of patients' rights in China and the practical implications for healthcare providers caring for those with HIV through focusing upon the need to disclose information directly to the patient, the issues of engaging families in care, and the ethical difficulties around informing sexual partners and others at risk. We have left out some important related issues. First, we have only touched on the duty of government in protecting the rights of HIV patients. The human and patients' rights movement has served as a powerful moral and political aspiration, partly because it limits the power of governments and of nation-states over communities and individuals, but also because it imposes duties upon governments and professionals to promote the well-being of individuals and patients. Related to this, there are potential legal barriers to implementing these approaches that should be considered in advocating for a more rights-based approach to HIV disclosure practices in China. China has historically had a weak rule of law and the current capacity of the legal system to enforce rights-based policies is relatively poor (Peerenboom, 2002). The gradual expansion of an independent legal system in China now underway

in China may facilitate the use of rights-based approaches. Second, we have not touched upon the issue of whether and how parental HIV information should be disclosed to children (Qiao et al., 2013a, 2013b). Furthermore, the role of gender in patients' rights to truthful information and decision-making needs to be considered. Feminism in general and a feminist human rights approach can offer insight into and practical proposals for eradicating persistent gender-related discrimination in China (e.g., Nie, 2004, 2010). Finally, as has been widely acknowledged social stigma associated with HIV has greatly hindered the care of HIV patients in China (e.g. Chen et al., 2011). A patients' rights approach can help to address this significant problem. All these dimensions certainly deserve separate studies.

To conclude, the ethical framework of patient's rights can serve as a meaningful guide for medical professionals in addressing the ethical challenges of HIV disclosure in the Chinese socio-cultural context. In adopting this approach, China will continue to contribute to the global struggle to ensure that HIV sufferers have not only adequate health care but the rights and dignity that neither disease nor socio-cultural environment should deprive.

### Acknowledgements

We are grateful to two anonymous reviewers for their constructive criticism which was very helpful in the rewriting of this paper.

### Disclosure statement

No potential conflict of interest was reported by the authors.

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