Patient engagement at the household level: A feasible way to improve the Chinese healthcare delivery system towards people-centred* integrated care*

* This chapter is based on a published paper. Alternations have been made for the sake of integrality.

Liu, Z. (2018). Cambridge Quarterly of Healthcare Ethics. 27: 1–13.

ABSTRACT

Aim: The general aim of this chapter is to assess the recent reform proposal for China's healthcare system (i.e. Healthy China 2030) and to figure out the question: *How do we place patient personal responsibility fairly in healthcare in China to make the reform measures (i.e. measures derived from the people-centred integrated care (PCIC) model) more effective?*

Background: Influenced by the PCIC model, Healthy China 2030 was drafted recently with a special concern given to patient engagement. Although there are three levels of engagement (i.e. individual, household and community), engaging patients at the household level appears to have been overlooked so far.

Methods: This chapter performs a theoretical analysis on personal responsibility and luck egalitarianism. Furthermore, context-based study is also adopted.

Findings: Discussion in this chapter identifies an attribution of Chinese bioethics; that is, family-centred. Furthermore, it collects some practical evidence in supportive of addressing personal responsibility in health and healthcare. Supported by ethical values and practical evidence, it is safe to conclude that engaging patients at the household level is a feasible approach to shape the Chinese healthcare system with the PCIC model orientation. Accordingly, four strategies are recommended for empowering and activating patients at the household level in the Chinese context.

Keywords: patient engagement, personal responsibility, family, Chinese bioethics, China

3.1 INTRODUCTION

'Healthy China 2030' (WB et al., 2016, p. 52) was drafted recently to deal with the emerging challenges of China's rapidly ageing population and its increasing burden of non-communicable diseases. Supported by the World Health Organization (WHO), the World Bank Group (WB) and correlative governmental agencies, Healthy China 2030 aims to restructure the Chinese healthcare delivery system by using the people-centred integrated care (PCIC) model. Under this model, the Chinese healthcare delivery system should be re-organised around satisfying the healthcare needs of individual patients and families through the use of five strategies: (1) empowering and engaging people; (2) reorienting the model of care; (3) coordinating services within and across sectors; (4) strengthening governance and accountability; and (5) creating and enabling the environment.[47] Accordingly, how to improve patient engagement is the top concern of Healthy China 2030.

Patient engagement has been recognised widely as a fundamental component in constructing a high-quality and value-based healthcare delivery system. Questions on patient engagement have been discussed intensively in academia, addressing the conceptualisation of patient engagement, the importance of engaging patients and the feasible measures for improving the engagement of patients, e.g. cultivating health literacy, strengthening self-management skills, improving shared decision-making and creating a supportive environment. (See Barlow et al., 2002; Forbat et al., 2009; McCarley, 2009; Gruman et al., 2010; Barello et al., 2012; Ishikawa & Yano, 2011; Berkman et al., 2011; Carman et al., 2012; Hibbard & Greene, 2013; Castro et al., 2016). Likewise, the measures proposed above de facto implicate the core action areas of empowering and engaging patients that are recommended by Healthy China 2030. Although there are three levels of engagement (i.e. individual, household and community) (WB et al., 2016, p. 51), patients are more likely to be empowered through an individualistic approach, because contemporary bioethics has a remarkable ability to address patient autonomy (Wang, 2014). Considerable research concentrates on how to protect and promote patient autonomy from different perspectives, including discussion of the protection of patient rights, the liability of healthcare providers and the accountability of the state. There is also growing research advocating patients' personal responsibility associated with the increasing burden of lifestyle-related chronic diseases (Denier et al., 2013). As one crucial party in healthcare, the patient's family appears to have been overlooked thus far.

Engaging patients at the household level refers mainly to empowering and activating patients with the assistance of the family in building health literacy, strengthening self-management skills, improving shared decision-making and creating a supportive environment.

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[47] For a detailed introduction, please refer to http://www.who.int/servicedeliverysafety/areas/people-centred-care/strategies/en/ (last accessed 24 March 2019).

One matter needs to be clarified in terms of what we mean by 'family'. To avoid any ambiguity, family (or 'household') is conceptualised within a narrow scope, to include 'two or more individuals who are related by birth, by marriage or by adoption.'[48] In this context, family refers to the 'nuclear family' that merely includes mother, father and children. Therefore, it excludes all other kinships, such as grandparents and siblings. Admittedly, addressing the essential function of involving family in assisting patient engagement is highly contextual and culture-based. Chinese values and traditions show a high level of coherence in this respect. Engaging patients at the household level is thus the key element that should not be missing when discussing how to construct an effective Chinese healthcare delivery system oriented towards the PCIC model targets.

Accordingly, this chapter attempts to address the importance of engaging patients at the household level in shaping the Chinese healthcare system with a PCIC model orientation, and thus provides several recommendations on how to engage patients at the household level in the Chinese context. We begin with a philosophical reflection on defining what is meant by engaging patients at the household level. By invoking the notion of personal responsibility, and by briefly introducing luck egalitarianism, which is a responsibility-sensitive theoretical framework of healthcare justice, we believe that using personal responsibility as a distributive criterion, while adopting family support as a complementary consideration, should be plausible for achieving distributive justice in healthcare in China. To certify the feasibility of engaging patients at the household level from a practical perspective, we explore four dimensions of the Chinese context (i.e. Confucian tradition, the household registration system, health insurance schemes and correlative legislation). Based on the analysis above, we intend to approach the core action areas of patient engagement, as recommended by Healthy China 2030, by placing more emphasis on the role of the family to develop proper strategies for engaging patients at the household level in China. Specifically, we recommend the following four strategies: (1) cultivating health literacy as a family asset; (2) advocating family monitoring and family support to assist the improvement of patients' self-management skills; (3) adopting family-based informed consent in the shared decision-making process; and (4) using the development of healthy families as a parallel pathway for creating a supportive environment for patient engagement.

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[48] US Census Bureau, Census 2000 Profiles of General Demographic Characteristics; please refer to https://www.census.gov/prod/cen2000/doc/ProfilesTD.pdf (last accessed 24 March 2019)

3.2 ENGAGING PATIENTS AT THE HOUSEHOLD LEVEL: PERSONAL RESPONSIBILITY PLUS FAMILY SUPPORT

As already summarised, engaging patients at the household level refers mainly to empowering and activating patients with the assistance of the family. Compared with the individual and community levels, empowering and activating patients at the household level can easily be overlooked, especially when considering the individualistic feature of medical ethics. This subsection will therefore illustrate the importance of engaging patients at the household level from a philosophical perspective.

The underlying philosophical foundation for patient engagement is that people can take care of their own health if they are adequately empowered, which invokes the notion of personal responsibility. By and large, personal responsibility means holding individuals accountable for their own choices. This can be identified in a number of ways in healthcare, but in broad terms it means that people should manage their own health through building health literacy, improving self-management skills and being active in shared decision-making (Vincent, 2009). Emphasising personal responsibility in distributing healthcare resources is preferable, especially when there is a great need to secure the sustainability of a healthcare system.

Luck egalitarianism is a theoretical framework that assigns personal responsibility a central role to play in assuring the distributive justice of healthcare. Despite varied ideals,[49] luck egalitarians have reached an overlapping consensus on one basic claim: it is morally unacceptable that people suffer from inequalities in care caused by factors beyond their control (Segall, 2015). In concrete terms, if two people are equally well-off at the very beginning, and one of them opts to reduce their wealth in some way voluntarily, then the eventual inequality between their wealth statuses is justified (Huseby, 2016). This basic standpoint can be traced back to a special distinction between ‘brute luck’ and ‘option luck’ from Ronald Dworkin.[50] Accordingly, a just society should be sensitive to people’s voluntary choices (‘option luck’) while remaining insensitive to their ‘brute luck’ in distributing resources (Dworkin, 1981, p. 293; Dworkin, 2002, p. 287; Brown, 2005, p. 25). In order to distinguish ‘option luck’ from ‘brute luck’, luck egalitarianism adopts personal responsibility as its basic criterion. In health and healthcare, this means that individuals may get no reimbursement for their disadvantages if those disadvantages are the result of their own imprudent behaviour. Be-

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[49] There are diverse views of luck egalitarianism. They are different from one another primarily in the way of advocating equality. For instance, see Ronald Dworkin’s *equality of resources*; Richard Arneson’s *equality of welfare*; G. A. Cohen’s *equality of access to advantages*; Eric Rakowski’s *equality of fortune*; John Roemer’s *equality of opportunity*.

[50] According to Dworkin, ‘option luck is a matter of how deliberate and calculated gambles turn out … Brute luck is a matter of how risks turn out which are not in that sense deliberate gambles.’ Please refer to Dworkin, (1981), p. 293.

cause of this viewpoint, luck egalitarianism has long been criticised for abandoning negligent victims (Anderson, 1999). To defend luck egalitarianism, meaningful countermeasures have been raised from different perspectives, such as Ronald Dworkin's (2013, p. 299) mandatory health insurance scheme, Shlomi Segall's (2007) adoption of the principle of solidarity and Nicholas Berry's (2006) strategy of multiple principles.

Among these plausible proposals, adopting the principle of solidarity to complement luck egalitarianism is likely to be more feasible in the Chinese healthcare system, because China is a Confucian society prioritising the value of solidarity. In other words, the Chinese people attach great importance to the welfare of society above individual gains. But this is not to say that the Chinese people are absolutely willing to share their fate with strangers without calculating gains and losses. Yet sacrificing individual gains for family members is common behaviour within the Chinese families, because family relationships (e.g. through birth, marriage or adoption), as a solid source of family support, bind family members together.[51] The way we propose adopting the principle of solidarity thus differs slightly from that of Shlomi Segall. Alongside personal and social responsibility, we assert that a position should also be accorded to family support and care in light of Chinese values and traditions. In other words, family members should accept the obligation to support each other when 'the abandonment of negligent victims' (Anderson, 1999, p. 296) occurs. To offer a simple example: luck egalitarianism holds that a just healthcare system should not compensate individuals when they choose reckless behaviour voluntarily. In this case, individual patients are 'abandoned' by the healthcare system, but they could still ask for financial support from their family members in order to obtain healthcare, because their family members are obliged to offer support. Understanding the principle of solidarity by preserving a place for the family thus makes sense, in terms of defending the implementation of luck egalitarianism in shaping the Chinese healthcare delivery system towards balancing people-centred care and sustainability.

The preliminary idea behind engaging patients at the household level is to emphasise the patient's personal responsibility in managing their own health, while adopting family support as a supplementary consideration to prevent the individual patient from being abandoned by the healthcare system. Admittedly, laying stress on the mutual support and care between family members implies that the feasibility of engaging patients at the household level is

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[51] Marriage Law of the People's Republic of China (2001 Amendment): Article 21 (related by birth), Article 26 (related by adoption), and Article 20 and 27 (related by marriage). The English translation of these Articles is available online, please refer to http://en.pkulaw.cn/display.aspx?id=1793&lib=law&SearchKeyword=&SearchCKeyword=%bb%e9%d2%f6 (last accessed 24 March 2019). Law of the People's Republic of China on the Protection of the Rights and Interests of the Elderly (2015 Amendment): Article 15. The English translation of this Article is available online, please refer to http://en.pkulaw.cn/display.aspx?id=19790&lib=law&SearchKeyword=&SearchCKeyword=%c0%cf%c4%ea%c8%cb (last accessed 24 March 2019). Also, please refer to Moskowitz (2001). p. 711.

highly contextual and culture-based. We therefore provide a detailed explanation concerning four dimensions of the basic Chinese context (i.e. Confucian tradition and bioethics, the household registration system, health insurance schemes and correlative legislation), in order to find more practical evidence for justifying the feasibility of engaging patients at the household level in China.

3.3 PRACTICAL EVIDENCE FOR THE FEASIBILITY OF ENGAGING PATIENTS AT THE HOUSEHOLD LEVEL IN CHINA

3.3.1 Confucian society and Chinese bioethics

Confucian ethical tradition attaches great importance to the virtue of *ren* (benevolence) and *xiao* (filial piety).[52] From a Confucian viewpoint, the individual human being is incomplete without belonging to a family (Chen & Fan, 2010, p. 577). Confucian societies (e.g. Singapore and China) therefore value close family ties and attach great importance to the role of the family when drafting social policies (Wong et al., 2009, p. 53). To a large extent, this viewpoint decides the family-based character of the healthcare system in these societies, such as emphasising the role of the family in healthcare decision-making.

As a Confucian society, China preserves the tradition that family plays a crucial role in healthcare decision-making (Fan & Li, 2004; Chen & Fan, 2010, p. 579). As Ruiping Fan (2004, p. 179) states,

> ‘China medical ethics … remains committed to hiding the truth as well as to lying when necessary to achieve the family’s view of the best interests of patients.’

In most cases, physicians would comply with the opinions of family members even when the patient is competent (2002). This indicates that Chinese bioethics assigns the family a privileged position in the essential dimensions of healthcare (e.g. informed consent and decision-making), thus differing from Western bioethics which prioritises patient autonomy. But laying stress on the importance of family in healthcare does not equate to Chinese bioethics taking patient autonomy for granted. On the contrary, it attaches great importance to protecting patient autonomy, because family members are the people who are supposed to know the patient best, and who are able to provide the best interpretation of patient expectations and preferences, and who can therefore take the most appropriate healthcare decisions in the best interests of the patient (Lee, 2014). Furthermore, with family support, patients are believed to be better prepared in both psychological and physical aspects (Yung, 2014). Contrary to the traditional relationship between one doctor and one patient, Chinese

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[52] For the English translation of those basic virtues of Confucianism, please refer to Runes (1983), p. 338.

bioethics tends to cultivate the doctor-patient relationship with a strong involvement of family members. Studies show that in Confucian societies, patients, especially older ones, are likely to give up life-sustaining treatments for the sake of reducing the financial burden on their family members (Choi, 2004, p. 86). Involving family members in healthcare is therefore a way of preventing such self-sacrificing behaviour. Family support is also of great importance for patients who need long-term care (e.g. the elderly with disabilities) or suffering from life-threatening illnesses (e.g. a severe heart attack or cancer). Studies indicate that family support is a primary factor influencing the survival rate of such patients (Ell, 1996).

The Confucian ethical tradition thus underpins Chinese bioethics in terms of involving family in healthcare, thereby providing a cultural and ethical foundation for engaging patients at the household level in China.

3.3.2 Household registration system

The household registration system (*hukou*) has been in operation since 1949 for the administration of China's residents. People born legally in China acquire a personal registration card (*hukou* page) to be added to a household registration record (*hukou* booklet). The household registration record is issued per family; it thus certifies not only the legal residence of a citizen, but, more importantly, the relationships between family members.

The household registration system exerts a significant influence on access to social benefits, such as education and healthcare (Qiu, 2014, p. 113). At the very beginning, the household registration record was designed to identify an individual as a permanent resident of a specific place, either rural (agricultural household registration record) or urban (non-agricultural household registration record). Studies show it is this categorisation that has generated the inequality in social benefits in China so fundamentally, in particular the access to healthcare (Qiu, 2014, p. 113). This argument may be partially true, but the negative effects resulting from this classification should be eliminated with the implementation of the Guiding Opinion of the State Council on Deepening the Reform of the Household Registration System in 2014.[53] Following the Guiding Opinion, the reform focused on the innovation of population management by abolishing the classification of the agricultural and non-agricultural household registration records.

This ongoing household registration system reform is therefore believed to provide administrative support for corresponding policies regarding patients' household engagement, such as contracting each family as a unit with general practitioners (GPs), and creating a household-based medical file system.

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[53] State Council. (2014). Guiding Opinion of State Council on Deepening the Reform of the Household Registration System, para 9. Please refer to http://www.gov.cn/zhengce/content/2014-07/30/content_8944.htm (in Chinese, last accessed 24 March 2019).

3.3.3 Integrated health insurance

Influenced by the rural-urban household registration system, China's health insurance system also features a similar classification (with three basic types of health insurance schemes): people born in the rural areas participate in a health insurance scheme called the New Rural Cooperative Medical Scheme (NRCMS); people born and employed in urban China should participate in the Urban Employees' Basic Medical Insurance (UEBMI); and people born in urban China but without employment should participate in the Urban Residents' Basic Medical Insurance (URBMI). These three schemes differ slightly in terms of their reimbursement rates and benefit package. Some scholars argue that the different reimbursement rates may aggravate unequal accessibility to healthcare in China (Wang et al., 2012, p. 80). But de facto, the casual relation is very weak which can be demonstrated by the example of UEBMI and URBMI.

For quite a long time, sharing social medical insurance with family members has been customary among urban residents. In other words, if the patient has been insured by the URBMI, but their father is insured by the UEBMI and the reimbursement rate of the URBMI is slightly lower than that of the UEBMI, it would not be a surprise that the father is willing to use his health insurance to help the patient to get medication and treatment not included in the URBMI. Actually, it was seen as dishonest behaviour in the past and, therefore, prohibited at that time. Nowadays, due to the strong incentives of the mass population to share their social medical insurance, more and more local governments have selected pilot cities to implement a household-based 'sharing insurance' in the urban areas of China, which is de facto the integration of URBMI and UEBMI.[54] Furthermore, scholars advocate integrating the URBMI and the UEBMI, or even integrating all three health insurance schemes into one household-based rural-urban basic health insurance scheme (Zhou, 2010; Xia & Yin, 2010; Zheng, 2012; Yuan et al., 2015).

Although the integration of these health insurance schemes is still under discussion, the direction of these discussions has already indicated the potential feasibility of engaging patients at the household level in China. More importantly, it is believed that integrated health insurance schemes would contribute to the effectiveness of household-based engagement in terms of providing financial support.

3.3.4 Legislation in relation to family and healthcare

Although China, like many other countries, does not have a unified health law legislation relating to family and healthcare comprises many regulations. These include Article 15 of the Law on Protection of the Rights and Interests of the Elderly (2015 Amendment) which

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[54] In 2012, Guangzhou province initiated the experiment of family-based 'sharing insurance'. Thereafter, Chengdu and Shenzhen became the pilot areas of family-based sharing insurance in 2015. In 2017, the local government of Zhejiang province issued a series of supportive policies to encourage the development of family-based sharing insurance.

stipulates filial responsibility; Article 11 of the Law on the Protection of Minors (2012 Amendment) which regulates parental responsibility; Article 15 of the Law on Blood Donation; Article 21 of the Mental Health Law; four regulations (Article 20, Article 21, Article 26 and Article 27) of the Marriage Law relating to reciprocal responsibility between family members; and Article 26 of the Law on Practising Doctors (2009 Amendment), which stipulates the involvement of family in informed consent.[55]

Take elderly care and filial responsibility, for example. In the Confucian ethical tradition, the virtue of respecting and caring for older generations in a family is named *xiao* (filial piety). *Xiao* is not only a moral virtue that is valued and advocated by Chinese society, but it is also a mandatory responsibility affirmed by China's legislation, such as Article 15 of the Law on Protection of the Rights and Interests of the Elderly (2015 Amendment):

> 'The supporters shall ensure that the elderly suffering from illness receive timely treatment and care, and shall pay medical expenses for the elderly in financial hardship. For the elderly who cannot take care of themselves, their supporters shall bear the responsibility of taking care of them; and if they cannot take care of the elderly in person, they may, according to the will of the elderly, delegate the responsibility of caring to other individuals or institutions.'[56]

As stated in the second paragraph of Article 14 of the Law on Protection of the Rights and Interests of the Elderly, 'supporters' in this law refers mainly to the children of the elderly. Accordingly, it is stipulated in law that children owe their parents a duty of medical care. The value of family involvement is therefore clearly affirmed. Yet some scholars express their concern at the effectiveness of enforcing this Article, because parents may be reluctant to bring a lawsuit against their children (Moskowitz, 2001, p. 709; Edelstone, 2002; Ting & Woo, 2008).

Another typical example of family involvement relates to informed consent. In Western bioethics, informed consent should be given by the patient except in certain circumstances, such as emergency cases or situations where patients exercise their right not to know. However, Article 26 of the Law on Practising Doctors (2009 Amendment) affirms the involvement of the patient's family when informed consent is required:

> 'Doctors shall tell the patients or their family members the patient's condition truthfully. However, care shall be taken to avoid any adverse impact on the patients.

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[55] The English version of the legislation is available at the pkulaw database. Please refer to http://en.pkulaw.cn/ (last accessed 24 March 2019).

[56] The English translation of this Article is available online, please refer to http://en.pkulaw.cn/display.aspx?id=19790&lib=law&SearchKeyword=&SearchCKeyword=%c0%cf%c4%ea%c8%cb (last accessed 24 March 2019).

> Doctors shall get approval from the hospital and the consent of the patient or family members before conducting clinical treatment on an experimental basis.'[57]

This Article carries two layers of meaning: doctors must tell the patient's condition to the family members truthfully and without delay, but doctors must also take the patient's family's expectations and preferences into consideration, along with the patient's psychological condition, before letting the patient know their health condition. It also indicates that, with such a provision, patients cannot exercise any self-sacrificing behaviour for the sake of their family, and doctors are able to comply with their truth-telling obligation.

These regulations all legitimise the involvement of family in healthcare, and thus explain the legal reason why engaging patients at the household level is feasible in China.

3.4 RECOMMENDATIONS FOR ENGAGING PATIENTS AT THE HOUSEHOLD LEVEL

'Healthy China 2030 lists four core action areas of patient engagement, and correspondingly provides detailed guidance on how to approach these areas' (WB et al., 2016, pp. 52–64). Contrary to what is recommended in Healthy China 2030, we try to approach these areas by laying more emphasis on the role of the family in order to develop feasible strategies for engaging patients at the household level in China.

3.4.1 Building health literacy: health literacy as a family asset

As Healthy China 2030 summarised, health literacy is the ability to read and understand health-related information so that people are able to take care of their health (WB, 2016, p. 52). As Don Nutbaum (2008) summarised, health literacy can be interpreted from both negative and positive perspectives. The negative perspective interprets health literacy as a risk factor focusing on dealing with the impacts of low health literacy on health outcomes, while the positive perspective regards health literacy as an asset, which implies that a high level of knowledge and skills can be beneficial to personal health. Engaging patients at the household level mainly interprets health literacy from the positive perspective, meaning cultivating health literacy as a family asset.

Building health literacy is not merely an individual task, but a family issue. According to Healthy China 2030, accessible and understandable health information is fundamental to patient engagement. But health information is merely one prerequisite in assisting patient engagement. Patients with a low level of health literacy are still likely to experience more

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[57] The English translation of this Article is available online, please refer to http://en.pkulaw.cn/display.aspx?id=22771&lib=law&SearchKeyword=&SearchCKeyword=%D6%B4%D2%B5%D2%BD%CA%A6 (last accessed 24 March 2019).

mistakes in understanding and adhering to a doctor's prescribed treatments (Coulter & Ellins, 2007, p. 24). So involving a patient's family members in assisting patients to read, understand and adhere to a doctor's diagnosis and treatment is favourable and important, especially when considered alongside the evolving telecare services.

Younger generations of the family are generally considered to be more open to accepting and using new technologies such as e-health. So regarding health literacy as a family asset requires the provision of more opportunities to educate the younger generation in the use of e-health, expecting them to help the family's older generations. This is not, however, to say that the older generation can shirk their responsibilities in cultivating health literacy. As a family asset, the earlier high health literacy has been built, the more beneficial it will be for the family members, especially for the family's younger generations. Children under a certain age are highly influenced by their parents in terms of forming their eating style, undertaking physical activities and cultivating their personal characters (Trost et al., 2003). The level of the older generation's health literacy is a decisive factor in controlling the risks of certain illnesses, such as childhood obesity and autism. Here, taking health literacy as a family asset lays more emphasis on the responsibility of the older generation in terms of cultivating a healthy lifestyle.

3.4.2 Strengthening self-management skills: Family monitoring and family support

In accordance with Healthy China 2030, self-management education, self-monitoring, self-administered treatment and telecare are the essential dimensions of a patient's self-management skills (WB et al., 2016, p. 52). These dimensions indicate that the individual patient may face the situation where they are forced to perform certain duties (e.g. recording blood sugar, adhering to prescribed medication and performing the rehabilitation practice at home) or to give up bad habits (e.g. being addicted to drink, cigarettes or even drugs). But none of them are easy to achieve, so extra assistance is required such as support from peers, family and friends (Greca et al., 1995; Toljamo & Hentinen, 2001). Here, Healthy China 2030 suggests that patients should participate in self-help groups in order to acquire peer support (WB et al., 2016, p. 52). Nevertheless, studies show the effectiveness of peer support to have mixed results (positive effects for certain illnesses, but no obvious influence for some others) (Van Uden-Kraan et al., 2009; Van Uden-Kraan et al., 2011; McGowan ,2012; Chan et al., 2014; Markowitz, 2015; Zhong et al., 2015). Concerns are also raised in terms of a patient's willingness to seek peer support, and the potential negative influence arising from patients' experience-sharing.

Compared to peer support, family support seems to be more emotional and functional in helping patients overcome their illnesses. The relationships (e.g. birth, marriage or adoption) between family members are acknowledged as a solid source of family support, motivating family members to share their fate with one another voluntarily. But some studies observe that there is a link between family support and certain negative outcomes in healthcare. For instance, patients may feel self-blaming or even take self-sacrificing actions for the sake of their families (Carter-Edwards et al., 2004; Miller & Dimatteo, 2013; Choi, 2014, p. 86). Yet these negative outcomes could be prevented by involving family members at the earliest stage of diagnosis and treatment, such as emphasising the involvement of the family in the shared decision-making healthcare process.

3.4.3 Shared decision-making: Family-based informed consent

Being respectful and responsive to a patient's expectations and preferences in healthcare stimulates the adoption of a shared decision-making process (WB et al., 2016, p. 58). The shared decision-making process, as the essential element of the PCIC delivery model, is believed to be beneficial to a doctor's diagnosis and treatment, not only in terms of improving the correction and effectiveness of healthcare services, but also in restoring trust in the doctor-patient relationship.

It is noteworthy that a difference exists between Western and Chinese bioethics in how to interpret 'shared'. In many Western countries, 'shared' means that patients and their doctors are working together to discuss treatment plans and to set treatment goals. For this kind of 'shared', respecting and protecting patient autonomy is the 'golden rule' guiding the healthcare decision-making process. For example, patients in the Netherlands are entitled to a 'right not to know'[58]. In effect, this leaves it up to the patient rather than the family to decide whether they will be told certain healthcare information. Even in the most extreme case where telling the truth may impose a heavy psychological burden on the patient, doctors still need to inform the patient rather than the family when the patient's health condition allows.[59]

As already discussed, Chinese bioethics attaches great importance to the role of family in healthcare. Accordingly, 'shared' in the Chinese context should mean joint efforts not only by patients and their doctor, but also by patients' family members. There are several evidence-based studies demonstrating that treatment plans are usually finalised on the basis of the opinions of patient's family members in China (Li et al., 2016, p. 237). Therefore, besides professional knowledge and patient preferences, doctors should also take the expectations of the patient's family members into consideration, or even assign priority to the opinions of the patient's family members, when drawing up the treatment plan. Involving family in the shared decision-making process has already been put into practice by some local governments in China. For instance, Shanghai has implemented a family doctor system that encourages patients and families to exercise joint efforts in setting treatment plans and goals (WB et al., 2016, pp. 59–60).

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[58] Dutch Civil Code, Article 7, 449.

[59] Dutch Civil Code, Article 7, 448, para. 3.

3.4.4 Creating a supportive environment: healthy families as a parallel pathway

Healthy China 2030 concentrates on creating a supportive environment by developing healthy cities and using environmental 'nudges'[60] to complement regulations. To date, ten cities have joined the healthy cities movement as pilot cities in China (WB et al., 2016, p. 62). Although people's health is affected de facto by the interactions of environmental and social factors, developing healthy families is likely to bring benefits to the individual patient more directly than promoting healthy cities. But the intention is not to replace the healthy cities movement with healthy families; it is rather to adopt the promotion of healthy families as a parallel pathway for engaging the patient. Developing healthy families will also contribute to the development of healthy cities, because the family is always regarded as the basic societal unit.

Developing healthy families should be approached with corresponding institutional support. Here the Chinese government has responded actively. Taking the field of primary care as an example, the Chinese government has initiated nationwide implementation of GP services aimed at establishing and strengthening the primary care gatekeeping.[61] The system's design mandates that GP services are administered on the basis of Chinese households. In other words, it is each household, rather than the individual patient, which is encouraged to contract a GP who practises medicine in the neighbourhood. Meanwhile, the household registration system and the integrated reform of the health insurance schemes are paving the way for contracting GP services that are household based.

Another example of providing institutional support for healthy families is to create one united medical file for each household, along with the nationwide implementation of the GP services. The household-based medical file will be particularly helpful for detecting and diagnosing illnesses, especially hereditary diseases, at the earliest stage. As the responsible party, GPs are the most appropriate candidates to keep their clients' medical files confidential. They may only release an individual patient's health information if required by law or by a patient's family members. Although this statement appears to conflict with Western bioethics which prioritises respect for, and the protection of, patient autonomy, it is not prohibited by Chinese bioethics.

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[60] 'Nudges' is a new concept developed by Richard Thaler and Cass Sustein. It refers to an organised context ('choice architects') in which people are able to make better choices. A given example is that doctors have to provide alternative treatments for their patients. The activity of providing alternative treatments is exactly making a 'choice architect'. For detailed analysis, please refer to Thaler & Sustein, (2003, 2008); Sustein & Thaler, (2003).

[61] National Health and Family Planning Commission of the P. R. China 2016: Guiding opinions on advancing the contracts with general practitioners. Please refer to http://www.nhfpc.gov.cn/tigs/s3577/201606/e3e7d2670a8b4163b1fe8e409c7887af.shtml (last accessed 24 March 2019).

3.5 CONCLUDING REMARKS

Overall, engaging patients at the household level is believed to be more feasible in shaping the Chinese healthcare system towards the PCIC model.

The Confucian tradition and Chinese bioethics provide a solid cultural foundation for engaging patients at the household level. The household registration system and the integrating health insurance reform also provide the institutional basis for engaging patients at the household level. Family-related laws and regulations also explain the legal reasons why engaging patients at the household level is feasible in China. In light of the Chinese traditions and values, it is safe to conclude that involving the family should be beneficial in protecting patient rights. Future efforts need to be devoted, at least partially, to cultivating health literacy as a family asset, to emphasising family support in promoting a patient's self-management skills, to involving families in shared decision-making, and to developing healthy families as a parallel pathway for creating the supportive environment for patient engagement.

Although the feasibility of engaging patients at the household level is highly contextual and culture-based, emphasising the essential role of the family in healthcare is a valuable experience from Chinese bioethics that could also be beneficial for Western bioethics.

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