Special Section: Bioethics Beyond Borders

Patient Engagement at the Household Level

A Feasible Way to Improve the Chinese Healthcare Delivery System Toward People-Centred Integrated Care

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Abstract: Influenced by the people-centered integrated care (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, community), patients are more likely to be empowered and activated through an individualistic approach. Thus, engaging patients at the household level appear to have been overlooked so far. Supported by ethical values and practical evidence, this article attempts to address the importance of engaging patients at the household level in shaping the Chinese healthcare system with the PCIC model orientation, and thus recommends four strategies for empowering and activating patients at the household level in the Chinese context.

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

Introduction

Healthy China 2030 was drafted recently to deal with the emerging challenges of China's rapidly aging population and its increasing burden of noncommunicable 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-centered integrated care (PCIC) model. Using this model, the Chinese healthcare delivery system should be reorganized 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.[1] Accordingly, how to improve patient engagement is the top concern of Healthy China 2030.

Patient engagement has been recognized 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 conceptualization 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 decisionmaking, and creating a supportive environment).[2] Likewise, the measures proposed de facto implicate the core action areas of empowering and engaging patients that are recommended by Healthy China 2030.[3] Although there are three levels of engagement (i.e., individual, household, and community),[4] patients are more likely to be empowered through an individualistic approach, because contemporary bioethics has a remarkable ability to address patient autonomy.[5] Considerable research concentrates on how to protect and promote patient autonomy from different perspectives, including discussion of the protection of

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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.[6] 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 decisionmaking, and creating a supportive environment.[7] 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."[8] 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, therefore, the key element that should not be missing when discussing how to construct an effective Chinese healthcare delivery system oriented toward the PCIC model targets.

Accordingly, this article 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. I 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, I 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 Chinese healthcare. To certify the feasibility of engaging patients at the household level from a practical perspective, I explore four dimensions of the Chinese context (i.e., Confucian tradition, the household registration system, health insurance schemes, and correlative legislations). Based on the analysis previously mentioned, I 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 so as to develop proper strategies for engaging patients at the household level in China. Specifically, I 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 decisionmaking process, and (4) using the development of healthy families as a parallel pathway for creating a supportive environment for patient engagement.

Engaging Patients at the Household Level: Personal Responsibility plus Family Support

As has already been summarized, 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, from a philosophical perspective, of engaging patients at the household level.

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 decisionmaking.[9] Emphasizing 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,[10] 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.[11] In concrete terms, if two people are equally well off at the very beginning, and one of them opts to reduce his or her wealth in some way voluntarily, then the eventual inequality between their wealth statuses is justified.[12] This basic standpoint can be traced back to a special distinction between "brute luck" and "option luck" from Ronald Dworkin.[13] Accordingly, a just society should be responsive to people's voluntary choices ("option luck") while remaining insensitive to their "brute luck" in distributing resources.[14] 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 behavior. Because of this viewpoint, luck egalitarianism has long been criticized for abandoning negligent victims.[15] To defend luck egalitarianism, ideas for meaningful countermeasures have been raised from different perspectives, such as Ronald Dworkin's mandatory health insurance scheme, Shlomi Segall's adoption of the principle of solidarity, and Nicholas Berry's strategy of multiple principles.[16]

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 prioritizing 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 behavior within the Chinese families, because family relationships (e.g., birth, marriage, or adoption), as a solid source of family support, bind family members together.[17] The way we propose adopting the principle of solidarity therefore differs slightly from that of Shlomi Segall. Alongside personal and social responsibility, I assert that a position should also be accorded to family support and care in light of the Chinese values and traditions. In other words, family members should take the obligation to support each other when "the abandonment of negligent victims"[18] occurs. To offer a simple example: luck egalitarianism holds that a just healthcare

system should not compensate individuals when they choose reckless behavior 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 therefore makes sense, in terms of defending the implementation of luck egalitarianism in shaping the Chinese healthcare delivery system toward balancing people-centered care and sustainability.

The preliminary idea behind engaging patients at the household level is to emphasize patients' 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 among family members implies that the feasibility of engaging patients at the household level is highly contextual and culture based. I 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 legislations), in order to find more practical evidence for justifying the feasibility of engaging patients at the household level in China.

Practical Evidence for the Feasibility of Engaging Patients at the Household Level in China

Confucian Society and Chinese Bioethics

Confucian ethical tradition attaches great importance to the virtue of *ren* (benevolence) and *xiao* (filial piety).[19] From a Confucian viewpoint, the individual human being is incomplete without belonging to a family.[20] 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.[21] To a large extent, this viewpoint decides the family-based character of the healthcare system in these societies, such as emphasizing the role of the family in healthcare decisionmaking.

As a Confucian society, China preserves the tradition that family plays a crucial role in healthcare decisionmaking.[22] As Ruiping Fan 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."[23]

In most cases, physicians would comply with the opinions of family members even when the patient is competent.[24] This indicates that Chinese bioethics assigns the family a privileged position in the essential dimensions of healthcare (e.g., informed consent and decisionmaking), thus differing from Western bioethics, which prioritizes 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, make the most appropriate healthcare decisions in the best interests of the patient.[25] Furthermore, with family support, patients are believed to be better prepared both psychologically and physically.[26]

Contrary to the traditional relationship between one physician and one patient, Chinese 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.[27] Involving family members in healthcare is, therefore, a way of preventing such self-sacrificing behavior. Family support is also of great importance for patients who need long-term care (e.g., the elderly with disabilities) or who have 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.[28]

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.

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 among family members.

The household registration system exerts a significant influence on access to social benefits, such as education and healthcare.[29] 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 that it is this categorization that has generated the inequality in the social benefits in China so fundamentally, in particular the access to healthcare.[30] 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.[31] Following the Guiding Opinion, the reform focused on the innovation of population management by abolishing 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.

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 participate in the Urban Employees' Basic Medical Insurance (UEBMI), and people born in urban China but without employment participate in the Urban Residents' Basic Medical Insurance (URBMI).

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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,[32] 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 him- or herself has been insured by the URBMI, but his or her 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. However, it was seen as dishonest behavior in the past and, therefore, prohibited at that time. Nowadays, because of 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.[33] Furthermore, scholars even advocate integrating all three health insurance schemes into one household-based rural-urban basic health insurance scheme.[34]

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.

Legislation in Relation to Family and Healthcare

Although China, like many other countries, does not have a unified health law, China's legislation relating to family and healthcare comprises plenty of regulations, such as Article 15 of the Law on Protection of the Rights and Interests of the Elderly (2015 Amendment), which 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; and four regulations (i.e., Article 20, Article 21, Article 26, and Article 27) of the Marriage Law relating to reciprocal responsibility among family members. Article 26 of the Law on Practising Doctors (2009 Amendment) stipulates the involvement of family in the informed consent.[35]

Regarding eldercare and filial responsibility, 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, 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."[36]

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.[37]

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 in which 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 conditions truthfully. However, care shall be taken to avoid any adverse impact on the patients. Doctors shall get approval from the hospital and the consent of the patient or family members before conducting clinical treatment on an experimental basis."[38]

This Article carries two layers of meaning: physicians must tell the patient's condition to the family members truthfully and without delay, but physicians 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 his or her health condition. It also indicates that, with such a provision, patients cannot exercise any self-sacrificing behavior for the sake of their family, and physicians are able to comply with their truth-telling obligation.

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

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.[39] 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.

Building Health Literacy: Health Literacy as a Family Asset

As Healthy China 2030 summarized, health literacy is the ability to read and understand health-related information so that people are able to take care of their health.[40] As Don Nutbaum summarized, 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, whereas 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.[41] 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 is a family issue. According to Healthy China 2030, accessible and understandable health information

is fundamental to patient engagement; however, health information is merely one prerequisite in assisting patient engagement. Patients with a low level of health literacy are still likely to make more mistakes in understanding and adhering to a physician's prescribed treatments.[42] Therefore, involving a patient's family members in assisting that patient to read, understand, and adhere to a physician's diagnosis and treatment is beneficial 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. Therefore, 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 is 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.[43] 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, considering health literacy as a family asset lays more emphasis on the responsibility of the older generation in terms of cultivating a healthy lifestyle.

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.[44] These dimensions indicate that the individual patient may face a situation in which he or she is forced to perform certain duties (e.g. recording blood sugar, taking prescribed medication, and performing a rehabilitation practice at home) or to give up addictions (e.g., to drink, cigarettes, or even drugs). But as none of the foregoing are easy to achieve, extra assistance is required, such as support from peers, family, and friends.[45] Here, Healthy China 2030 suggests that patients should participate in self-help groups in order to acquire peer support.[46] Nevertheless, studies show the effectiveness of peer support to have mixed results (positive effects for certain illnesses, but no obvious influence for some others).[47] 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 with peer support, family support seems to be more emotionally effective and more functional in helping patients handle 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 example, patients may feel self-blaming or even take self-sacrificing actions for the sake of their families.[48] However, these negative outcomes can be prevented by involving family members at the earliest stage of diagnosis and treatment, such as emphasizing the involvement of the family in the shared decisionmaking healthcare process.

Shared Decisionmaking: Family-Based Informed Consent

Being respectful and responsive to a patient's expectations and preferences in healthcare stimulates the adoption of a shared decisionmaking process.[49] The shared decisionmaking process, as the essential element of the PCIC delivery model, is believed to be beneficial to a physician's diagnosis and treatment, not only in terms of improving the improvement 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 the term "shared." In many Western countries, "shared" means that patients and their physicians are working together to discuss treatment plans and to set treatment goals. In this sense of "shared," respecting and protecting patient autonomy is the "golden rule" guiding the healthcare decisionmaking process. For example, patients in the Netherlands are entitled to a "right not to know."[50] In effect, this leaves it up to the patient rather than the family to decide whether he or she will be told certain healthcare information. Even in the most extreme cases, in which telling the truth may impose a heavy psychological burden on the patient, physicians still need to inform the patient rather than the family when the patient's health condition allows.[51]

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 physicians, but also by patients' family members. There are several evidence-based studies demonstrating that treatment plans are usually finalized on the basis of the opinions of patients' family members in China.[52] Therefore, in addition to professional knowledge and patient preferences, physicians 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 decisionmaking process has already been put into practice by some local governments in China. For example, Shanghai has implemented a family doctor system that encourages patients and families to exercise joint efforts in setting treatment plans and goals.[53]

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"[54] to complement regulations. To date, 10 cities have joined the healthy cities movement as pilot cities in China.[55] 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 would. 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.[56] 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 practices medicine in the neighborhood. 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 a patient's family members. Although this statement appears to conflict with Western bioethics, which prioritizes respect for, and the protection of, patient autonomy, it is not prohibited by Chinese bioethics.

Concluding Remarks

Overall, engaging patients at the household level is believed to be more feasible in shaping the Chinese healthcare system toward 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 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 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 emphasizing family support in promoting a patient's self-management skills, to involving families in shared decisionmaking, and to developing healthy families as a parallel pathway for creating a supportive environment for patient engagement.

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

Notes

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