

Perspective

The “expert patient” approach for non-communicable disease management in low and middle income settings: When the reality confronts the rhetoric

Yue Xiao*

The Center for Health Policy Evaluation and Technology Assessment, The China National Health Development Research Center, Beijing 100910, China

Received 13 July 2015

Available online 4 September 2015

Abstract

This paper seeks to explore the relevance between the Western “expert patient” rhetoric and the reality of non-communicable diseases (NCDs) control and management in low and middle income settings from the health sociological perspective. It firstly sets up a conceptual framework of the “expert patient” or the patient self-management approach, showing the rhetoric of the initiative in the developed countries. Then by examining the situation of NCDs control and management in low income settings, the paper tries to evaluate the possibilities of implementing the “expert patient” approach in these countries. Kober and Van Damme's study on the relevance of the “expert patient” for an HIV/AIDS program in low income settings is critically studied to show the relevance of the developed countries' rhetoric of the “expert patient” approach for the reality of developing countries. In addition, the MoPoTsyo diabetes peer educator program is analyzed to show the challenges faced by the low income countries in implementing patient self-management programs. Finally, applications of the expert patient approach in China are discussed as well, to remind us of the possible difficulties in introducing it into rural settings.

© 2015 Chinese Medical Association. Production and hosting by Elsevier B.V. on behalf of KeAi Communications Co., Ltd. This is an open access article under the CC BY-NC-ND license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>).

Keywords: Non-communicable disease; Expert patient; Control; Management

Introduction

In most industrialized countries and many developing countries, non-communicable diseases (NCDs) have become the leading causes of death. Around 38 million people died from NCDs in 2012, of which 42% were “premature” deaths; their age at death was less than 70 years old.¹ The burden of managing NCDs in low income settings is even higher.² According to a WHO report, about 80% of NCDs occur

* Corresponding author. Tel.: +86 01082036625.

E-mail address: moonxy@126.com.

Peer review under responsibility of Chinese Medical Association.



in low and middle income countries, and the impact of NCDs is steadily growing.³ Meanwhile, HIV/AIDS has increasingly become a chronic disorder and needs long-term management.^{4,5}

In order to address the increasing burden of NCDs, some Western countries have explored patient self-management programs, or the so-called “expert patient” approach, in NCDs management. After decades of implementation, the “expert patient” approach has been proven to be a cost-effective strategy to reduce the severity of symptoms, decrease pain, improve life control and activities, and enhance the satisfaction of the patients in the UK.⁶ Meanwhile, in developing countries like China, researchers have begun to take an interest in introducing the “expert patient” approach in managing NCDs, such as HIV/AIDS, to address the shortage of health resource faced by these countries.^{5,7}

This paper seeks to explore the relevance between the Western “expert patient” rhetoric and the reality of NCDs control and management in low and middle income settings from the health sociological perspective. It firstly sets up a conceptual framework of the “expert patient” or the patient self-management approach, showing the rhetoric of the initiative in developed countries. Then by examining the current situations of NCDs control and management in low income settings, the paper tries to evaluate the possibilities of implementing the “expert patient” approach in these countries. Kober and Van Damme's study on the relevance of the “expert patient” for an HIV/AIDS program in a low income settings is critically studied to show the relevance of the Northern rhetoric of the “expert patient” approach for the developing countries' reality.⁵ In addition, the MoPoTsyo diabetes peer educator program is analyzed to show challenges faced by the low income countries in implementing the patient self-management programs. Applications of expert patient approach in China are discussed as well, to remind us of the possible difficulties in introducing it into rural settings.

Rhetoric of the “expert patient” approach in the developed countries

The recent past two decades have witnessed a noticeable shift in the paradigm of NCDs control and prevention in the Western health systems. In some innovative programs in the UK and the US, patients have been put into a center for NCDs management, and the patients' knowledge and experience are regarded as valuable resources to benefit both the quality of care and the patients' life.⁸ In Canada, a trial introducing

expert patients with NCDs as mentors for inter-professional training has proven to be effective.⁹

The origin of the idea of the “expert patient” can be traced back to the 1980s. Since then the Stanford Chronic Disease Self-Management Program (CDSMP) has been launched to provide support for patients with NCDs through organizing short participatory patient workshops. The 6-week long workshop is convened by two non-health professionals with certain kinds of NCDs, and aims to help patients to develop the skills needed for day-to-day management of treatment.⁸ In 2001, the UK has started an “expert patient” program (EPP), a lay-led training program, to promote the patients' active role in NCDs management.⁶ The development of the internal health market in the UK and the neo-liberal view of patients as consumers all contributed to the increased role of patients in healthcare and in the formation of the “expert patient” concept.¹⁰

The main thinking behind the UK “expert patient” approach is that the patients with chronic conditions need not to be mere healthcare recipients, but to take greater responsibilities and work with health providers managing their conditions.⁶ The UK government also regards the idea of the “expert patient” as an important policy to modernize health care and links it with patient empowerment, better quality of care and life, and the use-led National Health Service (NHS).⁶ It has been assumed that, with support from patient groups and information support from NHS, patients can develop a partner-like relationship with doctors and become key decision-makers of service provision.¹¹

Information availability in the Western world has transformed patients into informed consumers of health care.¹¹ In the UK's EPP program, the expertise of patients is regarded as the core component of health delivery, and can be promoted and enhanced through access to knowledge and skills.¹² In this sense, information is the key to empower the patient. The NHS has adopted a series of measures to make information available to patients; to name a few, the NHS Direct Online, the NHS Home Care Guide, and the National Electronic Library for Health.⁶

The new NCDs management paradigm emphasizes the patient-professional partnership, involving collaborative care and self-management education. Self-management education complements traditional patient education in supporting patients to build their confidence and self-esteem, and identify and solve problems with the support of professionals.¹³ Collaborative care requires some fundamental changes in the culture and structure of the service delivery system. The EPP in the UK recommends NHS to mainstream

the user-led self-management practice, and help health professionals to appreciate its value.⁶ An evaluation of an online expert patient program done by Kate Lorig and her colleagues show that peer-led training programs seem to reduce symptoms, improve health behavior, self-efficacy, and patient satisfaction with the healthcare system and it reduced service utilization in one year.¹⁴

However, the new type of patient–doctor relationship advocated by the EPP approach has been problematized by some authors. For one thing, some review studies show that the entrenched power of medical professionals has made it difficult to change a professionals' behavior.¹² What's more, patient expertise both assumes compliance to professional requirements and self-control over disease management, which may be self-contradictory in a sense. Some argue that professionals should recognize the relationship between their power and knowledge when sharing their expertise with patients. And some others warn that not all patients want to take up responsibility for their health and some may not have the competence to manage their illness.¹¹

Recently, Anne Rogers and her colleagues reviewed EPP policy development in the UK and found that health policy makers in the UK have supported EPP, disregarding the fact that many reviews have shown “weak or sparse” evidence for the long-term positive effects of patient self-management programs.¹⁵ They suggest that the promotion of EPP policy in the UK is actually related to resolving the aging population problem and the increasing demands for healthcare services, which is quite different from the official discourse of “putting patients at the center of NCD management”. In this sense, the rise of EPP can be regarded both as “renegotiation of the contract between the state and citizens in the area of NCD management” and as “care transition”, building up a “something for something” welfare-responsibilities for the rights to healthcare.¹⁵

NCDs control and management in low- and middle-income settings

NCDs claimed an estimated 35 million lives globally in 2005 (over 60% of all deaths worldwide), with 80% in the low- and middle-income countries.¹⁶ By 2030, 8/10 leading causes of death in the world will be chronic illnesses.¹⁰ The challenge faced by low- and middle-income countries in dealing with NCDs is huge, with 246 million people with diabetes and around 1 billion with hypertension.⁴ Meanwhile, HIV/

AIDS is increasingly becoming a chronic disorder needing long-term care. There are about 33 million people with HIV/AIDS living in developing countries.⁴ In low-income countries, 43% of deaths are projected to be caused by NCDs, and it is estimated between 2005 and 2015 about 137 million people in these countries will die from NCDs.¹⁷ In China, deaths related to NCDs account for 85% of mortality.

If unaddressed, NCDs will have huge social and economic implications on low- and middle-income countries.¹⁸ For instance, diabetes-related costs account for about 2–4% of GDP in most low- and middle-income countries.¹⁸ Cumulative economic losses to low- and middle-income countries from the top four NCDs are estimated to be over 7 trillion USD over the period 2011–2025.¹⁹ As estimated by the WHO, China's NCD costs claim 80% of national health spending, which is equal to 500 billion USD in 2015. The economic impact of NCDs goes beyond the costs of healthcare services: “Indirect costs, such as lost productivity, can match or exceed the direct costs”.⁹ In addition, a significant proportion of the total cost of care falls on patients and their families, which may threaten the livelihood of poor households in low-income settings.

Most of the low- and middle-income countries are facing a heavy disease burden from communicable diseases at the same time, and the double disease burden seriously constrains these countries' social and economic development. However, in low income countries, such as those in Africa, NCDs have not been given due attention in public health policies and their economic impact is underestimated.²⁰

A major impediment to effective control, prevention and management of NCDs in low and middle income settings is the incapable and poorly resourced primary healthcare system.²¹ Orientation to acute care also compromises these countries' chronic health service delivery.⁴ Moreover, in most low-income settings, private and informal sectors are providing most of the chronic healthcare. The service delivery is fragmented and quality of care is uneven.⁴

NCDs expert patient programs in low and middle income settings

Recent years have seen increased interests in the “expert patient” approach and some serious attempts to introducing it to NCD management in the developing countries. The Western “expert patient” approach, however, has been developed in a particular social and historical context. Nayar and her colleagues argue that

the implementation of patient self-help programs requires high-tech medicine and well-educated patient groups who no longer wanted to trust the experts alone. “Not all low- and middle-income countries possess these attributes”.²² Therefore, the implementation of patient self-management programs in low- and middle-income countries may be challenging. This section contains 3 case studies. It firstly analyzes a relevance study on introducing an “expert patient” program for HIV/AIDS care done by two Belgium researchers. And then, it takes a diabetes peer education program in Cambodia as an example to examine the relevance of the “expert patient” approach in the low income settings. With more stress on primary healthcare in recent healthcare system reform, many cities in China have initiated NCDs patient self-management programs and this has yielded lots of models and approaches. The final part of this section discusses different programs and summarizes the main models in China.

Expert patient and HIV/AIDS care in low income settings

In 2006, Katharina Kober and Wim Van Damme, two researchers from the Institute of Tropical Medicine, Antwerp, conducted a study on the relevance of the “expert patient” programs for HIV/AIDS care in low-income settings. They argued that in low-income settings, implementing expert patient programs might be a possible way to relieve the severe shortage of health resources faced by the delivery of antiretroviral treatment (ART). The authors regarded patient living with HIV/AIDS (PLHA) as potential expert patients and suggested that PLHA should be organized into national expert patient networks to deliver ARV care directly. The PLHA could even take the initiative in running the ART programs.⁵

Meanwhile, Kober and Van Damme expressed their concerns over coordination and communications with health service infrastructure in the low-income settings and barriers caused by medical (paramedical) interest groups' misinterpretation of patient self-management programs. They emphasized that the implementation of expert patient programs should be context-specific.⁵

In this study, Kober and Van Damme seemed to focus on the PLHA's potential role as substitutes for health professionals in low-income settings. This is divergent from the “expert patient” approach adopted in the developed countries, where expert patients are expected to work with health professionals in partnership and take up more responsibilities over the daily management of their conditions. In addition, even

though PLHA has already been widely involved in health promotion and prevention, peer education and home-based care programs in low-income settings, as argued by Kober and Van Damme, they may not have the proper knowledge of ART service delivery and can hardly ensure the service quality. Moreover, the authors did not make it explicit as to what are the challenges for achieving “good collaboration and communication” with “traditional health service infrastructure” in low income settings.⁵ How the weak health systems in low-income settings can accommodate the PLHA initiated ART programs might be another key challenge the authors would want to make clear. Again, they did not explain how to make medical or paramedical interest groups appreciate and understand the value of the expert patient approach.

MoPoTsyo diabetes peer education in Cambodia

Cambodia is among the poorest countries in the world, but with an astonishingly high prevalence of diabetes. As estimated by the Lancet in 2005, 255 000 of a population of 12 million are living with diabetes in the country.²³ The MopoTsyo Patient Information Center, an NGO set up by five Cambodians and a Dutch, has been working on peer education programs for diabetes patients in Cambodia ever since 2004, aiming to provide greater access to quality information about diabetes, high blood pressure, and NCDs.⁷

MoPoTsyo has created an Operational District (OD) educator network in urban slums and rural areas, with 18 peer educators and 800 patients. The general model is to identify a patient who has one of the conditions covered by the project and could write and has certain credibility in the community. The patient then establishes an education program on active urine glucose screening by teaching the other patients in his/her own community or village. He or she also counsels the other patients on lifestyle changes, asks them to record glucose strip testing, conducts follow-up, and reports back to the center on a regular basis. Most peer educators are retired, part-time farmers or running their own businesses. They work for MoPoTsyo as part-timers, paid in accordance with the quota of patients in their programs. There is non-material payment for the educators as well. They can win respect of their community. While on the supply side, MoPoTsyo contracts with specialized diabetes doctors and drug companies, to negotiate costs of treatments and drugs. However, differences in doctors' advice have been observed.¹⁹ Because MoPoTsyo has not gained financial support from the government; financial

sustainability has become a problem for the peer education program. Now it is working to approach the government to get funding support. Those peer educators from slum areas are invited to large promotional events by drug companies. Although drug companies showed interest in supporting the peer education programs, MoPoTsyo finds itself in a dilemma between bringing them on board as partners and being hijacked by their profit incentive. Meanwhile, it also is concerned with scaling up.¹⁹ From the above situations, one can see that the MoPoTsyo is a bottom-up initiative to experiment with the self-management model in a low-income setting like Cambodia, differing from the state-led EPP in the UK. It has worked out an innovative patient self-management model. By employing local patients with good credibility as peer educators, MoPoTsyo has tried to nurture self-care and changes in life styles at the community level. However, without policy and financial support from the Cambodian government or the formal health sector, it might be difficult for it to move forward in terms of sustainability and scaling up. The MoPoTsyo's peer educator is a far cry from the "expert patient" defined in the NHS strategy report; however, he or she is working practically on coaching self-care among ignorant patients in a setting with no or limited access to care. In this sense, the MoPoTsyo peer educators are "knowledge agents" in the pluralistic health system.²⁴ In a weak health system, how to work with the private sector is also a hard question for MoPoTsyo. With their vested interests, drug companies cannot be objective partners. What's more, the quality of care delivered by various health providers needs to be regulated, and MoPoTsyo, as a grassroots NGO, may have limited power over the quality assurance.

Matching the rhetoric with reality

In the face of increasing NCDs burden, both developed and developing countries need to explore new cost-effective approaches to address the control and management of NCDs. The low- and middle-income countries are facing many other challenges, ranging from fragmented service delivery and uneven service quality, to low efficiency and poor health outcomes. Therefore, the implementation of patient self-management programs in these countries may not be the same as in the developed countries.

Kober and Van Damme's study tried to use the "expert patient" approach in HIV/AIDS management in low-income settings, while MoPoTsyo Patient Information Center has innovatively created a diabetes

self-management model in Cambodia. The two examples illustrate two kinds of approaches to this new paradigm in NCDs management originated in developed countries. As discussed in the previous section, the "expert patient" approach has been conceptualized in the Western context and has its own challenges and concerns. Like the other development ideas generated in the developed countries, when applied in developing countries the "expert patient" approach needs to be adapted, as suggested by Kober and Van Damme, or to be explored in a wholly new way, as done by MoPoTsyo.

Nevertheless, both approaches recognized the complexity and context-specific feature of the "expert patient" concept. Kober and Van Damme suggested maintaining communication and coordination with the traditional health service system, which has been demonstrated in MoPoTsyo case as the key challenge of its self-management model. The MoPoTsyo case further explained Kober and Van Damme's concern over the medical interest groups' misinterpretation of the patient self-management program—the drug companies may have a different agenda when coming to the support of the program. Although differing from the Western "expert patient" model, the MoPoTsyo model may be more pragmatic in a rapid changing context like Cambodia. But without sector-wide support, how far it can go in terms of sustainability and duplicity is still a big question.

Both cases focused on peer education and acknowledged the importance of skills and knowledge required by NCDs management. Therefore, how a poor population can gain access to trusted and quality information in "unregulated" markets in low-income settings also needs to be addressed with seriousness.²⁴ In increasingly pluralistic health markets in low-income countries, the private or informal health sector must be allied in setting up self-management programs, but the formal health sector should play a key role in regulating the cooperation to avoid the impact of vested interests.

However, neither case extensively addresses the doctor–patient relationship; a factor which has been widely debated among authors in the developed countries. Patients in low-income countries, empowered by self-management programs like MoPoTsyo, will certainly see a change in their relationship with doctors. Will it be regarded as a challenge or welcome signal by health professionals in the low-income settings? Some authors have already cautioned that patient empowerment may mean a challenge to dominant notions in traditional bio-medicine.²²

Implications for China

China is a developing country with much diversified socio-economic situations in the Eastern, Middle, and Western regions. One can find Eastern cities with living standards equal to that of developed countries and remote and poor rural areas in the Western and Middle provinces similar to low-income countries in the world. Therefore, China is facing a fairly complex situation in introducing the “expert patient” concept to the country.

Self-management of patients with chronic conditions was firstly launched and studied in big cities in China around the mid 1990s, beginning with patients on dialysis and patients with heart and vascular diseases. The Shanghai Municipality launched the first Chronic Disease Self-Management Program (CDSMP) at that time, which started with a model combining professional lectures, chronic disease management skill training, and exchange and peer education among patients. In the early 2000s, diabetic and hypertensive patient self-management programs were launched in some big cities, such as Shanghai, Beijing, and Tianjin. Since 1998, Fudan University and some community service centers in Shanghai launched the “Community Hypertensive Patient Self-Management Program”, which proved to be effective.²⁵ Studies of various kinds emerged in the 2000s, with some focusing on peer education programs, while most of the others focused on feasible models and their effectiveness and impact.

Self-management education programs were proven to be more effective for the Chinese patients with hypertension, diabetes, and asthma in terms of boosting confidence, increasing knowledge and skills, and improving the quality of life. Most studies were conducted among relatively well-educated city residents, so further research is needed for rural residents.²⁶

With the rise of chronic illnesses in recent decades, China has developed strategic approach to major NCDs such as hypertension, diabetes and severe mental illness. Since 2009, community-based management for major NCDs has been included in national public health programs. With a severe shortage of general practitioners, we will see growing interest in activating patients' involvement in NCDs care delivery.

More recently, integrated NCDs care delivery has been piloted by some Eastern cities, such as Xiamen in Fujian Province and Hangzhou in Zhejiang Province, as a cut-in point for exploring integrated healthcare delivery proposed by the central government. Patient involvement and education has also been emphasized

in these local pilot programs. For instance, in Xiamen two community health centers have set up diabetic patient groups, and a mentoring program has been established to retain these patients. However, “expert patients” have not been fully experimented with and most education and coaching have been provided by nurses and health managers.

As a new paradigm for managing NCDs in the developed countries, the “expert patient” programs have been enthusiastically taken up and proved to have some benefits. From the above brief history of “expert patient” programs in China, we know that China has experimented with the “expert patient” approach in some urban areas and it was proven to have certain benefits for NCDs management by some Chinese studies. When promoting community-based NCDs programs under the new round of health reform, it is necessary for the Chinese health authorities to consider this cost-effective approach to NCDs prevention and control.

However, the approach may not be easily applied in developing countries, in similar settings as in rural areas in China, or low income countries. With their weak health systems and less-educated patients, in such settings it may be difficult to take up and scale up such programs; as was demonstrated by the HIV/AIDS peer education program and MoPoTsyo diabetic patient management program.

When introducing the “expert patient” concept in China, researchers and practitioners may have to adapt it or develop a context-specific approach, to reflect more Chinese realities. And more studies have to be conducted before introducing it into rural areas in the country.

References

1. WHO. *Global Status Report on Non-communicable Diseases*; 2014. <http://www.who.int/nmh/publications/ncd-status-report-2014/en/>.
2. WHO. *From Burden to “Best Buys”: Reducing the Economic Impact of Non-communicable Diseases in Low- and Middle-income Countries*; 2011. http://www.who.int/nmh/publications/best_buys_summary.pdf?ua=1.
3. WHO. *Preventing Chronic Disease: A Vital Investment*; 2010. 2005.
4. Beaglehole R, Epping-Jordan J, Patel V, et al. Improving the prevention and management of chronic disease in low-income and middle-income countries: a priority for primary health care. *Lancet*. 2008;9642:940–949.
5. Kober K, Van Damme W. *Expert Patients and AIDS Care: A Literature Review of Expert Patients Programmes in High-income Countries, and an Exploration of Their Relevance for HIV/AIDS Care in Low-income Countries with Severe Human Resource Shortages*. Institute of Tropical Medicine; 2006.

6. British Department of Health. *The Expert Patient: A New Approach to Chronic Disease Management for the 21st Century*. Crown Copyright. 2001.
7. MoPoTsyo. *Peer Education*; 2010. <http://www.mopotsyo.org/peereducation.html>.
8. *The Stanford Chronic Disease Self-Management Program*; 2010. <http://patienteducation.stanford.edu/programs/cdsmp.html>.
9. Towle A, Brown H, Hofley C, Kerston RP, Lyons H, Walsh C. The expert patient as teacher: an interprofessional Health Mentors programme. *Clin Teach*. 2014;11:301–306.
10. Abegunde DO, Mathers CD, Adam T, Ortegón M, Strong K. The burden and costs of chronic diseases in low-income and middle-income countries. *Lancet*. 2007;370:1929–1938.
11. Fox NJ, Ward KJ, O'Rourke AJ. The 'expert patient': empowerment or medical dominance? The case of weight loss, pharmaceutical drugs and the Internet. *Soc Sci Med*. 2005;60:1299–1309.
12. Taylor D, Bury M. Chronic illness, expert patients, and care transition. *Sociol Health Illn*. 2007;29(1):27–45.
13. Bodenheimer T, Lorig K, Holman H, Grumbach K. Patient self-management of chronic disease in primary care. *JAMA*. 2002;288:2469–2475.
14. Lorig KR, Ritter PL, Dost A, Plant K, Laurent DD, McNeil I. The expert patients programme online, a 1-year study of an Internet-based self-management programme for people with long-term conditions. *Chronic Illn*. 2008;4:247–256.
15. Rogers A, Bury M, Kennedy A. Rationality, rhetoric, and religiosity in health care: the case of England's expert patients programme. *Int J Health Serv*. 2009;39:725–747.
16. Bischoff A, Ekoe T, Perone N, Slama S, Loutan L. Chronic disease management in Sub-Saharan Africa: whose business is it? *Int J Environ Res Public Health*. 2009;6:2258–2270.
17. WHO. *The impact of chronic disease in low income countries*; 2005. http://www.who.int/chp/chronic_disease_report/media/low_income.pdf.
18. Alwan A, MacLean DR. A review of non-communicable disease in low- and middle- income countries. *Int Health*. 2009;1:3–9.
19. Van Pelt M. (2008). MoPoTsyo Information Center and diabetes peer education. A presentation on “Health and Social Protection Meeting”, sponsored by “Protecting the rural poor against the economic consequences of major illness: a challenge for Asian transitional economies (POVILL)” (POVILL is a European Commission supported project);2008.
20. WHO Regional Office for Africa. *Noncommunicable Disease Prevention and Control: Overview*. 2010.
21. Mohan S, Campbell N, Chocklingam A. Management of hypertension in low and middle income countries: challenges and opportunities. *Prev Control*. 2005;1:275–284.
22. Nayar KR, Kyobutungi C, Razum O. Self-help: what future role in health care for low and middle-income countries? *Int J Equity Health*. 2004;3:1. <http://www.equityhealthj.com/content/3/1/1>.
23. World Diabetes Foundation. *Cambodia in Dire Need of Diabetes Care*; 2007. World Diabetes Foundation website <http://www.worlddiabetesfoundation.org/composite-1183.htm>.
24. Standing H, Chowdhury AM. Producing effective knowledge agents in a pluralistic environment: what future for community health workers? *Soc Sci Med*. 2008;66:2096–2107.
25. Fu D, Fu H, Gu X, et al. Self-management of patients with chronic illnesses. *Chin J Prev Contr Chron Dis*. 2001;13:485–486.
26. Zhang L, Dong J. Progress of NCDs patient self-management. *Chin J Prev Contr Chron Dis*. 2010;18:207–211.

Edited by Yang Pan