

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*

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## 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.

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**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.<sup>1</sup> The burden of managing NCDs in low income settings is even higher.<sup>2</sup> According to a WHO report, about 80% of NCDs occur

\* Corresponding author. Tel.: +86 01082036625.

E-mail address: [moonxy@126.com](mailto:moonxy@126.com).

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

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.<sup>6</sup> 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.<sup>5,7</sup>

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.<sup>5</sup> 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.<sup>8</sup> In Canada, a trial introducing

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

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.<sup>8</sup> 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.<sup>6</sup> 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.<sup>10</sup>

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.<sup>6</sup> 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).<sup>6</sup> 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.<sup>11</sup>

Information availability in the Western world has transformed patients into informed consumers of health care.<sup>11</sup> 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.<sup>12</sup> 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.<sup>6</sup>

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.<sup>13</sup> 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

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