

**‘EXPERT PATIENT APPROACH’ TO THE MANAGEMENT OF CHRONIC ILLNESS:
APPLICABILITY OF THIS APPROACH IN LOW-INCOME SETTINGS**

By:

Eva Annan
Gender Mainstreaming Directorate
University of Education, Winneba
Winneba, Ghana
evaannan@gmail.com

Abstract

The paper assesses the applicability of expert patient approach to the management of chronic illness in low income settings. It draws on available literature on the subject matter to discuss and digest the topic. Various relevant aspects of the topic are discussed. Among the main headings discussed on the applicability of the approach in low income setting are national health system and funding, use of peer educators as tutors, trainers, social support groups, the use of information and communication technology as well as the mass media. Country-specific illustrations were brought to light to support the issues raised. The paper further noted among other factors that issues such as high illiteracy rates among the populace, poverty, national financial constraint, poverty, poor infrastructure, technological backwardness may always present themselves as challenges to the implementation of such an approach in low income settings. The paper therefore recommends that sufficient resources should be set aside by governments for its successful implementation and there should also be improvement in the infrastructural system in general in such low income economies to facilitate the process of implementation of the expert patient approach.

Keywords: expert patient, healthcare system, low income countries, infrastructure, poverty

Introduction

In the second half of the twentieth century, there was a shift in the disease pattern from acute to chronic illness in high income countries. This resulted in changes in the traditional medical infrastructure as a way of having to deal with this illness. One such strategy adopted for the management of this chronic illness was the introduction of expert patient approach in the United Kingdom and sharing health care initiative in Australia. Chronic disease management is now seen as one of the critical health strategies globally (Horton, 2007:1881). In low income countries the patterns of diseases is now gradually shifting from acute to chronic disease partly due to changing lifestyles of people. Currently, India, China, DR Congo, Ethiopia and Nigeria are among the 23 countries that account for a higher burden of chronic illness in developing worlds (Horton, 2007).

Jones (2003:11) defines expert patients as people who “understand that the quality of their lives is primarily up to them; believe they can exert significant control over their own lives; are determined to live a healthy life despite their chronic condition; are realistic about the impact of their disease; and have worked out what services exist and how they can be accessed.” Considerable research has

proven that this approach has had an impact on reducing the number of patients' visits to hospitals to see practitioners. Hence, this has reduced the pressure being put on existing health care facilities especially in the time of human resource for health shortage. As echoed by Van Damme (2008), expert patient approach has been a viable alternative to managing the treatment of HIV/AIDS in the context of Anti-Retroviral Drug (ART) rollout in countries faced with severe human resource constraints. However, other studies have also shown that such an approach as this expert patient is workable in areas where health care systems are functioning properly and medical infrastructures are well developed (Kober and Van Damme 2006; de-Graft Aikins et al, 2010). Others have also criticised this approach to be only effective to the management of 'classic' chronic diseases like diabetes, asthma, and coronary disease as was the case in China but not the management of HIV/AIDS treatment and care.

A number of different criteria exist for defining whether a country is considered a developing country or not. The definitions usually have to do with the country's right to receive development aid under the rules of a multilateral or bilateral agency. A few countries have been classified by one agency as developing and by another agency as developed. And countries have been known to differ in both directions with the status accorded them by development agencies (Sadowsky, 1996). In view of this, low income setting could mean a low income area or section within a developed country or low income area or section within a developing country or less developed country. For the purpose of this analytical paper, low income settings would be used to refer to low income countries where generally they have low levels of education for the majority of the population or that part of the population suffers from poor health, poor health systems, high infant mortality, poor housing and infrastructure, low GDP/GNP (Gross Domestic Product/ Gross National Product), technological backwardness and greater reliance on agricultural produce, high and rising levels of unemployment (Kintu 2008).

The aim of this paper is to demonstrate the extent to which 'expert patient' approach to the management of chronic illness could be applied in low income settings. It seeks to accomplish this by doing a critical evaluation of the structural incentives and structural constraints which could favour or impede the implementation of such an approach in low income settings. This paper is structured into two sections. The first section explicitly expatiates on the concept of 'expert patient' approach by tracing its origin and importance as well as how the concept has been applied in high income countries. The paper then proceeds to elucidate on the applicability of the 'expert patient' approach in low income settings. By doing a thorough analysis to reveal the challenges and practicalities involved in the implementation of such an approach to low income settings. The paper attempts a two way examination of how it is currently done in some low income countries and also an exploratory of how it could be done.

The Expert Patient Approach

This approach has its origin in the United Kingdom and other developed countries where in the 20th century the incidence of chronic illness was on the ascendancy. The underpinning rationale for the emergence of such concept lies in the fact that people living with non-communicable disease such as diabetes, asthma, stroke, cancer, arthritis, mellitus, mental illness and many other conditions often have considerable knowledge and capacity to manage their own condition and support others in doing so (Standing and Chowdhury, 2008; Kober and Van Damme 2006; Department of Health,

2001). The document produced by the United Kingdom's (UK) Department of Health clearly spells out the vision of expert patient to suggest a violent swing from 'the bad old days' when patients were passive consumers to a new Utopia in which empowered patients are better able to apply their skills and insight to manage their own illness (Tattersall, 2002). Expert patient approach therefore empowers patients to play central role in the management of their chronic illness (Department of Health, 2001).

In the UK, expert patient approach was applied through the emergence of programmes such as the expert patient programme. UK became the first country to undertake and fund a national initiative to establish self-management as one pillar of the national health system (Kober and Van Damme, 2006). The way to UK's expert patient programme began with health related charities which included the Stanford chronic disease self management course in their range of activities in the mid nineties. Some examples of the charities which developed their own self management course were Arthritis Care, Manic Depression Fellowship, the Multiple Sclerosis Society, the British Liver Trust and Diabetes UK among others (Department of Health, 2005). In 2001, the National Health Service (NHS) introduced self management programmes. It started with a pilot phase of three years which saw the start and evaluation of local self-management programmes and then later included the programme into all aspects of the NHS. In each of the country's 28 strategic health authorities the Expert Patients Programme of the NHS employs a certain number of lay people with chronic illnesses to train others in self-management skills (Kober and Van Damme, 2006:12). All of these trainers are managed at national level by two principal trainers who are answerable to the Department of Health. Additional volunteer tutors are recruited through their participation in self-management courses. A system of quality assurance ensures that the courses are run in a standardised way (National Health Service, 2006).

In the case of Australia, the Department of Health and Ageing initiated primary health care for older and people living with chronic illness lays less emphasis on the role of patient as tutors for other patients and more on the shared responsibility for disease management between physicians and patients (Kober and Van Damme, 2006).

How Expert Patient Approach Could Be Applied in Low Income Settings

The succeeding paragraphs present an analysis on how 'expert patient' approach could be applied in low income settings. It touches on issues of national government programmes such as health policy and funding, use of peer educators as tutors, trainers, social support groups, the use of information and communication technology as well as the mass media.

National Health System

Firstly, expert patient approach could be applied in low income settings when it is incorporated into the National Health System (NHS). This is how the original approach was done in high income countries such as the UK. This would make the empowerment of patients a health policy priority (Hamer, 2003). It could ensure that training courses/sessions would be carried out at regular intervals by hospitals and other accredited NHIS/NHS health centres in low income settings. These training sessions could be a period where health expert/health professionals would inform patients

about how to deal with the particular chronic illness. Nurses could then facilitate individual reflection, clarification and interpretation of knowledge, attitudes and beliefs in relation to their pathology and how to manage it (Hamer, 2003). In order to make such expert patients programmes affordable and sustainable especially in low income settings, state funds should therefore be strategically allocated for such programmes. This could serve as a way of securing the maximum participation of patients with chronic illness by way of providing subsidize and low cost expenses for such training courses. This could ensure that participant therefore either attends the training sessions free or pay at a cheaper rate. Also, health assistance could be recruited in carrying out such responsibilities of educating and counselling patients. For instance in Malawi, where the number of people living with HIV/AIDS are huge and the health professionals are often overburdened, health assistance (lower cadres of health workers) are employed to assist in carrying out education and treatment programmes for patients regarding anti retroviral drug use and treatment (Palmer, 2004:7; WHO, 2007).

On the other hand, as expert patient programmes become an integral part of national health systems in low income settings, resources must be purposefully allocated for its sustainability (Tattersall, 2002). In low income settings where funding for programmes is a big issue, it will become difficult to ensure the sustenance of such programmes in terms of paying for health assistance and also monitoring the standard of training courses. This is because people with chronic diseases may be among the minority groups of the population and as such there may be other pressing needs to be met. For instance, in Ghana, the first three diseases listed on the top ten chart's causes of morbidity and mortality does not include any long term illness. They are malaria, upper respiratory tract infection and diarrhoea (Ghana, MoH 2007). Incorporating 'expert patient' programmes into national health system would mean, it would have to compete with the country's prioritized concerns or issues on the national agenda for health. It may therefore not be seen as a good case for them to apportion huge financial resources from national coffers in support of such programmes when there are other competing demands to be met. This therefore presents a major challenge to the applicability of such programmes in some low income settings such as Ghana. Also, in Cameroon, studies have shown that as a result of financial constraint, health care workers are not well trained to provide health education on risk factors and also to provide effective treatment (de-Graft Aikins et al, 2010).

Additionally, in low income countries where majority of the population are plagued with financial constraints and poverty is highly not uncommon, it could be very difficult for them to afford the right kinds of meals or possibly change their diet to suit the information acquired through the expert patient programme or user-led management mechanism. As estimated by WHO (2005) 24 per cent of all death in Nigeria may be caused by chronic illness. In view of this, it is said that healthy diet, regular physical exercise and avoidance of harmful habits such as tobacco should help reduce the rates of death (WHO, 2005). Considerable evidence has shown that, in Nigeria about 80 per cent of the population live below the poverty line. The country's poor women and men depend primarily on agriculture for food and income and most of these farmers are small scale producers (IFAD, 2010). A subsistence farmer in the rural area suffering from diabetes may not be in the position to buy other foods other than the one he grows himself. With the increasing rate of chronic illness in this region, it becomes a challenge to make an 'expert patient' programme work effectively when majority of the population cannot afford to sustain the behavioural lifestyle strategy taught through

training courses by health professionals and other social support group. In furtherance of this argument, food security is again a major issue for many inhabitants of rural Malawi. Most rural dwellers in Malawi find it difficult to meet their food needs (Morris, 2006). In view of this, it becomes a challenge when patients with chronic illness are encouraged to change their eating habits to suit their health status.

Peer Educators

Secondly, peer educators could serve a major role in the management of chronic illness in low income settings. That is to say that people living with a particular chronic illness could also serve as educators or tutors and support group to new members of the illness. According to Mitchell-Funnell (2009), educational programmes for people with chronic disease such as diabetes may not be enough without an ongoing support from peer educators. Illustrating this further is the case of Malawi, the government has recommended as part of its strategy in dealing with human resource for health shortage, the use of peer educators in management of chronic illness such as HIV/AIDS (Palmer, 2004). Such peer educators provide essential information concerning the disease and how to better cope with the situation as well as help new members sustain changes made during the training courses/sessions. This approach has better enhanced new patients understanding on how to deal with their own illness.

However, cultural norms and values may be a major obstacle to the use of peer educators in low income settings. Two major forms of issues may come up. First is the issue of beliefs of patients and second is a 'threat' to the status of health professionals in terms of losing hold of some power. First and foremost, not all patients living with chronic illness would want to be empowered (Hamer, 2003: 167). Especially in an environment that most patients feel they are being properly treated only when they constantly visit the physician or other health professionals. They may not really value the role of peer educators as knowledgeable enough to render assistance to the management of their disease. The second touches on power dynamics in the health sector. As echoed by Tattersall (2002) and Hamer (2003), a much bigger stumbling block is that many doctors and other healthcare professionals feel uncomfortable with the idea of empowering their patients for self care. This is because some patients may challenge health practitioners on the kinds of medications to be given (Kober and Van Damme, 2006).

Moreover, voluntary organizations could also offer support to patients living with chronic illness. For instance in Ghana: Basic Needs, an international mental health NGO provides education, psychosocial support and opportunities for enhancing livelihoods for people living with epilepsy. The Ghana Diabetes Association provides information and education on diabetes especially through World Diabetes Day events. Increasing evidence has shown that advocacy groups help members to cope better with their conditions (de-Graft Aikins 2005; Atobrah 2010). Again, in Cameroon, there are a number of advocacy organizations for cancer. The Cameroon National Fight against Cancer organises screenings of prostate and cervical cancers twice every year. The Cameroon Baptist Church Programme also launched a mobile cervical cancer screening clinic using a US-donated military ambulance.

However, majority of these advocacy services may be located in the urban centres. As this has been the case in Ghana and Cameroon, most of these advocacy centres are found in the urban south and

chiefly the capital Accra in Ghana and Yaoundé in Cameroon (de-Graft Aikins et al, 2010). This therefore excludes a growing number of individuals living with chronic diseases in other parts of the country from accessing psychosocial support and advocacy services.

Information and Communication Technology

Thirdly, another factor which cannot be left out in the introduction of the 'expert patient' approach in low income settings is communication and electronic technology. In recent times, there has been a rapid increase in the use of internet as an information delivery mechanism. The accelerated transition of information to electronic media is making information resources of the world available to an increasingly global audience (Sadowsky, 1996). Information on how to management specific chronic illness can be easily accessed on the internet. There are a wide range of authority websites which provides information on health care and health management. In view of this, health professionals could encourage patients living with chronic illness to make use of online information so as to be better informed about up-to-date issues related to the management of chronic disease. During educational programmes organized by health specialists and professionals, basic health management information on specific and trusted websites could be introduced to patients. Governments could therefore play an active role in securing the rights equipment for accessing internet at faster and affordable rates to all citizens in such low income economies.

Conversely, internet accessibility may also cause a challenge to the implementation of 'expert patient' approach. The situation in low income settings is such that transport and communication infrastructure for the delivery of physical goods and information services are not well established (Sadowsky 1996; de-Graft Aikins et al, 2010). In view of this, only fewer households may have internet connections in their homes due to the expensive nature of such services. It may therefore become an issue when information on health has to be read online. Moreover, in some organizations internet accessibility is meant for only organizational requirements and responsibilities. Some offices do not even have internet access due largely to the cost involved in the supply, maintenance and repair of such services and computer facilities. In view of this, the individual may not have his/her own flexible moment to access health information on the internet. Hence, this will reinforce their lack of knowledge on the management of their own disease which leads to further deterioration of their condition. Also, accessing the internet from a cyber cafe may be slow in general and expensive for ordinary people in the community. Only the privileged few who can afford such services may benefit from the knowledge services they provide. Again, the use of the internet for accessing information may not go well with majority of the population who may be illiterate either in the reading of their own language or the particular language in which the information is being given (for instance English). This therefore presents a challenge to expert patient approach in low income settings as well. Hence, the states of physical communication structure and information delivery systems in low income settings are very important and should be taking into consideration in the course of introducing the 'expert patient' approach.

Mass Media

Also, the mass media could be a key site for disseminating information on chronic disease management. Mass media groups such as the radio, Television, newspapers and others could be encouraged to educate the population on how to manage chronic diseases. This may be done through the running of educational programmes frequently and most especially in local dialects by

health experts/ professionals. Appropriate times may therefore be set aside for the carrying out of such programmes on the radio so as to meet the specific needs of the targeted population. Again, special columns could be apportioned in newspapers to provide expertise information on the management of chronic disease in an 'easy to read' language. In this way the media plays the direct role of disseminating relevant information to chronic illness patient. In Ghana for instance, newspaper articles on cancer, sickle-cell disease, leukaemia, diabetes, hypertension and stroke appear in national publications such as the Daily Graphic and the Mirror, as well as their online versions (de-Graft Aikins et al, 2010). The local radio stations also tackle chronic diseases on their health programmes and present selected information on their websites.

However, national newspaper coverage is generally low and few people could read in low income settings (de-Graft Aikins et al., 2010). As it is often documented that literacy rate in high income settings is higher than in low income settings (UNDP, 2009; WHO, 2005). As identified in the study of Palmer in Malawi, one major obstacle to the 'expert patient' approach was illiteracy rate among the poor. With regards to this crucial issue of illiteracy there is the tendency for information given to be misinterpreted or misunderstood because of the medium of instruction. While radio has wider coverage, not all people can access particular radio programmes at their various places of habitation. In view of this, this medium may be very favourable to urban dwellers to the neglect of their rural counterparts. This could therefore be a major obstacle to educating the public on the management of chronic illness through this medium.

Conclusion

In conclusion, it is worth emphasizing that the 'expert patient' approach could undoubtedly be a good strategy for the management of chronic illness in low income settings. This is especially the case in an era where rights-based approaches are predominantly becoming effective measures in sustaining development programmes and also human resource for health care is increasingly becoming a major issue of concern in most low income settings. Empowering patients therefore to bear responsibility for their health would release the burden on the healthcare systems.

This approach could be applied by incorporating it into the national health system for low income settings. This has often been the case in high income settings such as the United Kingdom. In this light, funds would be purposefully set aside for organizing training programmes on expert patient to enlighten patients understanding of their own unique illness, peer educators or tutors could also be encouraged to play an active role through the formation of social support networks to provide emotional assistance and advise to new members living with chronic illness similar to their own, advocacy organizations could also provide psychosocial support to chronic disease patients as well as the use of internet and other electronic information could be accessed by patients on managing their illness.

However, it will certainly not work well in low income settings when applied prescriptively as done in other developed nations or high income settings. This is because of structural and institutional variations that exist between high and low income settings. In low income settings there are certain structural constraints which could make it difficult for this kind of approach to work efficiently and

effectively. Issues like high illiteracy rates among the populace, poverty, national financial constraint, technological backwardness among others may always present themselves as challenges to such an approach in low income settings.

In order for 'expert patient' approach to be applied to the management of chronic illness in low income settings, a holistic view must be taken of the structural systems in the economy and a pragmatic solution could be adopted in dealing with such structural issues such as poverty, illiteracy, technological backwardness among others. One way of going about this is for the government of such low income economies to play an active and a leading role in funding 'expert patient' approach with international financial assistance. Attempts must also be made to raise the living standards of the population so as to make it affordable for them to adopt a healthy behavioural lifestyle in support of the educational programmes. Education must also be placed as a top priority in the national agenda, so that literacy level could rise in order to ensure that basic health information can be readily assimilated and applied by patients. Again, in order to deal with issues of beliefs of the patient, it could be dealt with in terms of making the patient aware of her/ his rights and role in accessing effective health care. In the case of medical practitioners and other health professionals, patients' role should be incorporated into health ethical issues to ensure adequate level of empowerment for patients in chronic disease management.

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