Expert patients and AIDS care

A literature review on expert patient programmes in high-income countries, and an exploration of their relevance for HIV/AIDS care in low-income countries with severe human resource shortages

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Abbreviations and acronyms

AIDS	Acquired immuno-deficiency syndrome
ART	Antiretroviral treatment
ARVs	Antiretrovirals
CBO	Community based organisation
CCM	Chronic Care Model
CDC	Centers for Disease Control and Prevention
CDSMP	Chronic Disease Self-Management Programme
GIPA	Greater Involvement of People Living with HIV/AIDS
GNP+	Global Network of People Living with HIV/AIDS
HBC	Home based care
HIV	Human immuno-deficiency virus
HRH	Human Resources for Health
ICCC	Innovative Care for Chronic Conditions Framework
IMAI	Integrated Management of Adolescent and Adult Illness
LMCA	Long-term Medical Conditions Alliance
MAP	Multi-country AIDS Programme for Africa
MoH	Ministry of Health
MSF	Médecins Sans Frontières
NGO	Non-governmental organisation
NHS	National Health Service
OI	Opportunistic infection
PLHA	People living with HIV/AIDS
SHCI	The Sharing Health Care Initiative
TAP	Treatment Acceleration Programme
TNP+	Thai Network of People Living with HIV/AIDS
VCT	Voluntary counselling and testing
WHO	World Health Organisation

Summary

Antiretroviral treatment in low-income countries with severe HRH constraints.
Since antiretroviral drugs (ARVs) became available and antiretroviral treatment (ART) was proven feasible also in low-income countries, massive efforts have been undertaken to scale-up ART for the millions of people in need in sub-Saharan Africa, the region with the highest HIV-prevalence worldwide. Yet, in most countries of the region this scale-up has to occur on the basis of very weak national health systems, and one of the biggest bottlenecks it is facing is the severe lack of human resources for health (HRH), particularly in Southern Africa. ART poses a fundamentally new challenge for these health systems as it is transforming HIV/AIDS from a deadly disease into a chronic condition for which millions of people will need lifelong care. Yet, in many areas the shortages especially of medical doctors, but also of nurses mean that the health systems are currently not even able to deliver basic health services to the population.

Present ART delivery models are very intensive in their use of skilled medical and paramedical staff and projections suggest that they can only be scaled up in countries where the HRH situation is less severe, such as South Africa. In other sub-Saharan countries, such as Tanzania, Zambia and Mozambique, scaling up ART to all the clinically eligible people within the next ten years according to the presently most widely used delivery models, would exceed their total current stock of medical doctors. A number of ART projects are trying to tackle the HRH problematic by delegating certain tasks from medical doctors to other cadres. While this task-shifting is certainly an important step, we contend that it will not be enough for scaling up ART in the high HIV-prevalence countries with the most severe HRH shortages. In the present report we argue that an altogether different approach to HIV/AIDS care and treatment might be required for overcoming the HRH bottleneck. Our review of the experiences with chronic disease management in the high-income countries in the North shows the potential relevance of the expert patient concept for HIV/AIDS care in low-income countries with severe HRH constraints.

Self-management for chronic diseases in the North. In the second half of the 20th century it was realised that the shift from acute to chronic disease as the main cause of illness in the industrialised countries required new and different care models. One particular aspect of most chronic care models was a change in the traditional patient-doctor relationship which was found to work less well for the management of chronic than for acute illnesses. Patient self-management came to play an important role for the management of diseases such as asthma, chronic heart conditions and diabetes. The most important aspect of self-management is the realisation that people with a chronic condition are those that have the most comprehensive expertise in dealing with that condition. This expertise is the result not only of their knowledge about its medical aspects but, crucially, also about all aspects of day-to-day living with it. Courses in chronic disease self-management build on this insight by using lay people who are themselves living with a chronic illness as tutors for other patients. Evaluations of self-management programmes have shown that not only the health outcomes often improved but also that patients in many cases reduced their use of the health services.

In 2001, after evaluating many small-scale self-management programmes, mainly organised by voluntary organisations, the National Health Service (NHS) in the UK started with the implementation of a nation-wide self-management programme under the name of 'Expert Patients Programme'. Early evaluations show good results and indicate that the expert patient programme has significantly reduced the use of health services, such as general practitioners' consultations, outpatient visits, accident and emergency attendances and physiotherapy use.

Roles of PLHA in ART programmes in the South. It is this aspect of the expert patient programme in particular that makes it interesting for HIV/AIDS care in countries with severe HRH constraints. Currently, people living with HIV/AIDS (PLHA) assume a number of different roles in the care and treatment of this disease. All programmes and projects we know of use PLHA for certain tasks, mainly in the areas of health promotion and prevention, home based care, adherence support and treatment literacy activities. In some places, PLHA associations have organised such activities themselves, in other places, HIV/AIDS projects have recruited PLHA volunteers to take over a number of circumscribed tasks. According to our knowledge there is no example of direct PLHA involvement in the delivery of ART.

PLHA as expert patients: an untapped resource? We argue that the huge pool of PLHA in high HIV-prevalence countries is an important, and yet untapped resource for scaling up ART in settings with severe HRH constraints. Many of them have lived for many years with the disease and have been involved in various aspects of care and support for other sufferers from HIV/AIDS. Yet, their role in the fight against AIDS has never been conceptualised as that of professional expert patients. For making the ART scale-up possible in countries with severe HRH constraints, it might be a promising option to explore the potential capacities of PLHA associations in order to identify selected individuals and provide them with the specific medical and psychosocial training necessary for fulfilling the role of expert patient tutors. With the aim of making ART delivery less medical doctor intensive one would have to investigate in how far PLHA expert patients could assume responsibility for medical tasks such as CD4 counts and follow-up of uncomplicated patients on ART. In certain contexts it might even be considered to go beyond this and involve expert patients in the initiation of ART.

Certainly, the development of national expert patient programmes would pose its own challenges for health systems, for example in terms of training and of coordination with the established infrastructure of the traditional medical and paramedical interest groups. Still, we argue that the traditional medical model for ART delivery is incompatible with the severe HRH shortages in many African countries with high HIV prevalence, and that tapping the pool of experienced PLHA and conceptualising and organising their work in expert patient programmes has the potential of making the scale-up of ART a reality in these countries.

Introduction

Antiretroviral treatment in low-income countries

After pilot projects had shown the feasibility of ART (antiretroviral treatment) in the poorest regions of the world, and the prices of ARVs had steeply decreased, several major global health initiatives have started to make HIV/AIDS a priority and have considerably increased funding for the fight against AIDS. [i] Large-scale efforts are now underway to scale up ART, and last but not least the G8 has declared their support for achieving the goal of universal access to ART by 2010.[1] However, despite ambitious plans, new momentum and increased funding, access to HIV treatment in low-income countries continues to fall short of the growing need. The latest WHO '3 by 5' progress report from June 2005 reported 1 million people on ART in low- and middle- income countries.[2] Even though this was a considerable increase from around 400,000 people on ART in December 2003, it fell still short of the milestone of 1.6 million set in the '3 by 5' strategy for June 2005. Data and trends at that time indicated that reaching the goal of providing 3 million people with ART by the end of 2005 would be unlikely.[2] The gap between the need for ART and the numbers currently receiving it is especially huge in most of sub-Saharan Africa where the ART coverage lay at 11% in June 2005.[2] In Tanzania, Malawi, Mozambique and Zambia only about 3%, 10%, 4% and 12%, respectively, of people in need of ART were receiving it by June 2005. According to the WHO, the countries with the highest coverage in sub-Saharan Africa were Botswana and Uganda, each with 56%.[3]

Human resources for health and scaling up ART in low-income countries

Scaling up ART to the millions of people in need remains an enormous challenge, particularly in the low-income countries with high HIV prevalence because many of their health systems are at present lacking the capacity to provide even basic health care to the population, let alone deal with the additional burden of scaling-up ART. One of the main constraints for delivering health care in many low-income countries is the serious shortage of human resources for health (HRH), especially medical doctors. This shortage is particularly severe in sub-Saharan Africa where thirty-one countries do not meet WHO's "Health for All" standard of one doctor per 5 000 population and at least twenty have no more than one doctor per 20 000 population. The Joint Learning Initiative estimates that sub-Saharan Africa would have to triple its current workforce in order to come close to reaching the Health Millennium Development Goals.[4]

Even though the lack of qualified health professionals is not a new phenomenon in sub-Saharan Africa, it is only in the last couple of years that the 'chronic HRH shortage' in has developed into a 'HRH crisis' of serious proportions. Many health systems in the region are currently experiencing two separate, but mutually reinforcing, developments culminating in this HRH crisis. On the one hand, their supply of available health workers is diminishing at an unprecedented scale and on the other hand, the need and demand for health care is greatly increasing. The former is mainly the result of increased out-migration of doctors and nurses ('brain drain') and increasing attrition rates due to HIV/AIDS, the latter is mainly due to HIV/AIDS.

AIDS poses a challenge for health systems that is fundamentally different from all other health problems ever faced. Transforming a deadly disease into a manageable chronic

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[i] The most important are e.g. the global health initiatives of 'new players', such as The Global Fund, PEPFAR and the Clinton Foundation, and the initiatives of 'old players', such as '3 by 5' of the WHO, the MAP and TAP of the World Bank.

one turns millions of people into chronic patients, in need of life-long regular follow-up.[i] Yet, while it is increasingly being recognised that the lack of HRH is a major bottleneck for scaling up ART, particularly in Southern Africa, there are still only a handful of studies of the HRH requirements for this. Indeed, up to now the main focus has been on showing that ART is possible in a given context, and that early results are usually good, or even excellent. However, the staff needs for putting and keeping people on ART have rarely been documented in a rigorous way. Nonetheless, there is enough information available from different sources to show that current ART projects are so intensive in their use of medical doctor time that a massive ART scale-up according to their delivery models looks unrealistic against this background of severe HRH constraints.[6] Smith, for example, has projected that if Zambia and Mozambique were to scale-up ART with their current ART delivery models for all the clinically eligible people within the next 10 years, they would require only for this activity, two and four times as many doctors, respectively, as their total current stock of doctors.[7] Kurowski and Wyss have studied the HRH requirements for scaling-up MDG related priority health interventions in Tanzania and Chad. Their study shows that the doctor and nurse requirements for these selected interventions, including ART scale-up, would exceed their availability by a factor of three.[8]

The following table illustrates the magnitude of the HRH shortages in relation to the potential workload of HIV/AIDS in selected countries.

	Medical doctors per 100,000 population	Nurses per 100,000 population	PLWHAs (in thousands)	Total population (in thousands)	PLWHAs per 100,000 population	**PLWHAs per medical doctor**	**PLWHAs per nurse**
Malawi	1	26	900	12,105	7,435	**7,435**	**286**
Mozambique	2	21	1,300	18,863	6,892	**3,446**	**328**
Zimbabwe	6	54	1,800	12,835	14,024	**2,337**	**260**
Tanzania	2	37	1,600	36,977	4,327	**2,164**	**117**
Rwanda	2	21	250	8,387	2,981	**1,490**	**142**
Zambia	7	113	920	10,812	8,509	**1,216**	**75**
Swaziland	18	320	220	1,077	20,427	**1,135**	**64**
Botswana	29	241	350	1,785	19,608	**676**	**81**
Uganda	5	54	530	26,699	1,985	**397**	**37**
South Africa	69	388	5,300	45,026	11,771	**171**	**30**
Cambodia	16	61	170	14,144	1,202	**75**	**20**
Thailand	30	162	570	62,833	907	**30**	**6**
Brazil	206	52	660	178,470	370	**2**	**7**

Table 1: Doctors and nurses available and PLHA in selected countries[9]

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[i] A simple calculation exercise with rough numbers can illustrate the challenge ahead. WHO's aim is to have 3 million people on ART by 2005 out of the 6 million in need of treatment in low- and middle- income countries. With 700 000 people on ART in December 2004, 2.3 million additional people would need to get access to ART during 2005. Let us assume that from 2006 on, an additional 3 million people will be in need of ART annually, and ART services world-wide will continue to expand by putting 2 million on treatment every year, and that the annual mortality rate of people on treatment will be 10%. Then, the health systems of low- and middle- income countries would have to deal with around 10 million patients on ART by 2010, 14 million by 2015 and in 2025 this would level off at around 18 million. In a country with 30% sero-prevalence, unchanged HIV incidence and an effective ART programme which is putting two-thirds of those in need on ART, almost 10% of the adult population could be on ART by 2010, a figure that may even increase to 18% by 2025. Consequently, adult sero-prevalence would increase to close to 40% in 2010 and even to 48% in 2025.[5]

Faced with the severe HRH shortages, a number of projects have started to design less doctor-intensive ART delivery models, in which certain tasks are delegated from health workers with higher to those with lower qualifications.[10-12] WHO's *Integrated Management of Adolescent and Adult Illness* (IMAI) model is designed to make ART delivery feasible in the context of HRH shortages by task-shifting. The simplified ART protocols delegate a number of tasks from medical doctors to nurses and from nurses to community health workers.[13] Such task shifting to make ART delivery less HRH intensive is an important and promising development which is very much needed. Yet, we argue that for the countries hardest hit by HIV/AIDS and with the weakest HRH base, a more radical rethink of ART delivery may be needed if the aim remains to scale up ART and to maintain millions of people on ART. We think it might be useful to look at recent developments in chronic illness care in high-income countries, and in particular explore whether the concept of the 'expert patient' as a different approach to ART delivery does not hold promise too.

Learning from chronic disease care in the North?

HIV/AIDS, as a long-term chronic illness (especially when ART is available), is ravaging many societies in the high HIV/AIDS burden countries with severe HRH constraints. The health systems in these low-income countries have neither the required number of HRH for scaling-up ART nor do they have experience with care models for chronic conditions.

In high-income countries, on the other hand, the predominant disease pattern has become one of chronic illness rather than acute disease in the second half of the 20th century. Thus, the past couple of years have seen numerous efforts to transform parts of the health care systems in these countries into systems better prepared to provide care for patients with chronic conditions. A central component of all models for chronic disease care is the altered relationship between patients and health service providers. For the effective management of a chronic disease it is deemed essential that the patient assumes an active role in its management, which is a departure from the traditional 'medical paradigm' where the patient is seen as a passive recipient of care and treatment from the medical doctor.[i]

We are of the opinion that the millions of people on ART in need of life-long care in many low-income countries pose a fundamental challenge for today's ART models, with their heavy reliance on the medical and paramedical professions. The escalating demands for long-term care risk to become unbearable for the health systems in many low-income countries, and we need to question the appropriateness of a 'medical paradigm' for ART in high-burden HIV/AIDS countries.[15] There is a need for innovative, 'de-medicalised' delivery models, based primarily on the communities and on the capacity and resourcefulness of the people living with HIV/AIDS (PLHA) themselves, with professional back-up when required. For this purpose, we think it might be useful to explore the role of the patient in the concepts of chronic disease care, as they function in several high-income countries.

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[i] This drawback of the traditional medical style has been nicely described by Glin Bennet as follows: "Powerful rituals such as examining and prescribing are more charismatic in the absence of adequate explanation. The problem with this contrived exercise of medical authority is that overwhelming evidence suggests that it is not very effective. The often quoted reason for this style of communication is that it will make patients do what is good for them. The sad fact seems to be that more often they do not."[14]

A.   Self-management for chronic diseases in the North

Health care and the challenge of chronic illness: The beginnings of self-management

It was at the end of the 1970s that scholars, especially in the US, began to argue that our health care models were ill-prepared for dealing with chronic diseases which had become the main cause of morbidity and mortality in western societies. The 'medical model', in which the health care professional diagnoses and prescribes and the patient complies was said to work well for acute conditions but to be less effective for chronic conditions. The 'public health model' was deemed equally ineffective, as its role was to prevent disease or to assist with early diagnosis. It was argued that it had not been effective in stopping the increase of chronic conditions largely related to the aging of our populations.[16]

The need for a new means of delivering care to people with chronic conditions prompted these scholars to pioneer new avenues in the management of chronic disease. They took up the idea of patient self-management, which was first used in relation to asthma in children,[17] identified it as a necessary part of treatment and elaborated it further into a chronic disease management programme in its own right. The concept of "self-management" refers to a patient's ability to understand their condition, to make decisions, take appropriate actions and manage and organise their access to key elements of their care. In order to improve the outcomes of chronic care, it was argued, patients would have to be taught the skills of self-management. A key indicator of a patient's ability to self-manage their disease is the degree to which they have a feeling of self-efficacy. 'Perceived self-efficacy' is a term borrowed from behavioural theory where it is defined as "people's beliefs about their capabilities to produce designated levels of performance that exercise influence over events that affect their lives".[18]

Chronic disease self-management programmes

The realisation that people with chronic diseases do not only deal with disease-specific but also with many common issues such as pain management, depression, lifestyle changes and the need to develop coping skills, has led to the development of generic self-management programmes. The most widely known and used as a model for the development of individual programmes worldwide is the Chronic Disease Self-Management Programme (CDSMP) developed at Stanford University.[19]

The Stanford course is extremely standardised and the university insists that the programme is only used under licence and that no unauthorised alterations to the manual are made. The course lasts six weeks with weekly meetings of circa two hours and is characterised by three features:

1. "It has been developed using the experiences of people living with long-term illness as the start point
2. It is run in community settings with a heterogeneous group of people
3. It is lay led, which means it is delivered by lay tutors all of whom are living with a long-term illness."[19]

Number three, i.e. the use of trained lay people with chronic illness as tutors for other patients is often described as a key feature of the CDSMP.

The main differences between this self-management model and the traditional medical models of care lie in the roles of both the health care professional and the patient. The latter has to become able to self-manage the disease on a day-to-day basis; the former has to learn to "act as a partner in care"[16]. This means, the health professional will take on the role of a consultant, a resource person who offers treatment suggestions.

According to the CDSMP the three tasks of self-management are (1) medical management of the condition, (2) changing and creating new life roles[i], and (3) dealing with the emotional consequences of having a chronic disease.[16] While most 'traditional' patient education programmes are aimed at disease-specific knowledge and encouraging compliance with medical regimes (and most patient support groups focus only on the emotional tasks), self-management programmes crucially include all three tasks and teach them in a problem-based way. In order to successfully deal with these three tasks, patients have to acquire the following five skills: (1) problem solving (2) decision making (3) resource utilisation (4) forming a good patient – health care provider relationship and (5) taking action.[16]

The problems as perceived by the patients are always at the centre of a self-management course, a pedagogical choice that is often justified with examples from 'traditional patient education' and its effect on the management of chronic diseases. Bodenheimer for example, argues that diabetes care is not only about knowledge. "If it were, it would be hard to explain why 74 percent of persons with diabetes have uncontrolled blood pressure [and] 71 percent have elevated lipid levels".[20] According to the author, an important reason for this poor management of diabetes is that patient education is not based on the patients' perceived problems and physicians do not know how (or lack the time) to help patients change their behaviour.

Self-management as part of chronic care models

Today, self-management is not normally a stand-alone programme but an integral part of chronic care models wherever they are being implemented. The most widely acknowledged chronic care model (CCM) has been developed by Wagner from the MacColl Institute for Health Care Innovation in Seattle.[21] They reviewed more than 70 different chronic disease management activities and on the basis of their observations developed a chronic care model, as a structure for organising health care for chronic conditions. The four components of this model are (1) self-management support (2) delivery system design (3) decision support and (4) clinical information systems. Particularly in the USA, the CCM has been used extensively to improve chronic disease management.

In response to the growing prevalence of chronic diseases world-wide, the WHO formed an 'Observatory On Health Care for Chronic Conditions' which reviewed the CCM and its relevance and acceptability for low-income countries. The CCM was revised and enlarged into the 'Innovative Care for Chronic Conditions Framework' (ICCC).[22] In this framework, too, self-management plays an important role, is enlarged to include the patients' family and is found in the component of "prepared, informed, and motivated patients and families". According to the ICCC patients and families should be informed about their condition, including expected course, complications, strategies to prevent complications and how to manage symptoms. They should be motivated to change to healthy behaviours, adhere to therapy and self-manage their condition. They should lastly be prepared to manage their condition at home, which includes "having the necessary medications and medical equipment, self-monitoring tools and self-management skills".[23]

Self-management programmes: Examples

Especially in the Anglo-Saxon world, there is an abundance of disease-specific self-management programmes, managed either by a disease-specific self-help charity or by

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[i] To explain the meaning of this term, Lorig gives as an example a person with back pain who needs to change the way he or she gardens or participates in favourite sports.[16] Another example would be the housewife with diabetes needs to discover new food items and learn new ways of preparing the meals.

individual health care organisations (in the US). Yet, as far as we are informed, there are only two examples where national health policies are aiming at integrating self-management programmes in the public health systems and implementing them nationwide. The more important for our purpose of lesson-learning is the *Expert Patients Programme* in the UK. The second is the *Sharing Health Care Initiative* in Australia.

United Kingdom: The Expert Patients Programme

The term 'expert patients' has become widely known due to the thus labelled policy initiative of the UK's Department of Health, described in its publication in 2001 "*The Expert Patient*: A New Approach to Chronic Disease Management for the 21st Century".[24] It is not a new development in itself but the UK became the first country to undertake and fund a national initiative to establish self-management as one pillar of the national health system. Expert patients have been defined 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."[25]

The notion of patients as experts is based on the observation that many patients with a chronic condition seem to know more about it than the health professionals who are treating them. These patients have an insider's knowledge about their illness and, based on this, make day-to-day decisions about it.[26] However, not every chronic patient becomes an expert in their disease, not everyone is managing their disease in a way that enhances well-being. Due to the predominant pattern of doctor-patient relationships in the western societies, in which the patient is a passive recipient of expert advice and treatment from his/her doctors, many chronic patients do not develop the skills to optimally self-manage their disease as

> "the success of medical science has engendered a passivity in the minds of the lay public which has flattered the doctor's sense of power and self-esteem. It has also caused people to assume less and less responsibility for what happens to their bodies and their minds."[14]

In the UK, where according to the Department of Health 17.5 million adults live with a chronic condition,[24] the way to a nationwide expert patient programme was paved by health related charities, which started to include the Stanford chronic disease self-management course in their range of activities in the mid nineties. The first to develop its own self-management programme based on the Stanford model in 1994 was the charity 'Arthritis Care'. Since then, a number of other charities, such as the 'Manic Depression Fellowship', the 'Multiple Sclerosis Society', the 'British Liver Trust' and 'Diabetes UK' to name but a few, have accumulated several years of experience in training people with chronic conditions in self-management using the CDSMP manual.[27]

In 1998, the British Department of Health started to support financially an action research organised by the Long-term Medical Conditions Alliance (LMCA), whose remit it was to develop knowledge about self-management and increase the number of self-management programmes in the UK. In its 1999 White Paper "*Saving Lives: Our Healthier Nation*", the Department of Health announced for the first time its plan of an Expert Patients programme "which will help more people with chronic illness to take control over the management of their condition"[28].

The introduction of self-management programmes into the NHS began in 2001 with a pilot phase of three years which saw the start and evaluation of local self-management programmes. Today, self-management is being mainstreamed within all NHS areas, an activity that is foreseen to last until 2007.[24] This development has followed a pattern typical for the UK where the voluntary sector has the unique function of pioneering and

experimenting with new ideas, with the underlying assumption that the state will step in and mainstream the service once this has been shown to work.[29]

In each of the country's 28 strategic health authorities[i] the Expert Patients Programme of the NHS employs a certain number of lay people with chronic illnesses to train others in self-management skills. 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.[30]

While the initial set-up of a national team of self-management trainers and tutors did not intend to establish a new professional group, it has given rise to questions about new health workforce configurations within the NHS. Currently the programme is still very young and the relationship between trainers and tutors and the different stakeholders within the NHS does not yet seem to be clearly delineated. Yet, according to some observers, the group of expert patient trainers is showing signs of establishing a new 'professional project.'[ii] Trainers have, for example, attempted to set up conditions for referral to their courses which do not involve other professional groups. According to Kennedy this might be seen as a first step towards gaining a monopoly over the right to work in a specialised way with a particular group of clients.[32] Still, how the self-management trainers and tutors will develop as professional groups within the NHS is still uncertain and will depend not only on policy decisions within the Department of Health but also, crucially, on the degree of collision with the interests of other professional groups, such as specialist chronic care nurses.[32]

Currently the *National Primary Care Research and Development Centre* is carrying out research projects to evaluate process issues, clinical outcomes and personal experiences related to the introduction of the Expert Patients Programme in the NHS.[iii]

Australia: The Sharing Health Care Initiative (SHCI)

In 1999 the Australian Department of Health and Ageing initiated a new primary care package for older citizens and those with chronic conditions. Part of this package was the SHCI. The objective of the SHCI is to test a range of self-management models by supporting twelve demonstration projects throughout the country in order to identify models that could be suitable for the Australian health care system.[33]

From internet research it seems as if the Australian initiative is putting less emphasis on the role of patients with chronic disease as tutors for other patients and more on the shared responsibility for disease management between patient and physician. The Flinders Self-Management Model, which has been proposed for introduction in the health system, emphasises very much the enhancement of the individual patient's self-management skills but does not mention anything on the active role chronic patients can assume with regard to teaching and training of other people.[34]

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[i] Strategic Health Authorities are decentralised levels of the NHS.

[ii] Larson described a professional project as "the efforts of members of an occupation to work collectively to increase their status and economic prospects".[31]

[iii] The National Primary Care Research and Development Centre was established by the Department of Health in 1995 to undertake a programme of policy related research in primary care. For their research on the expert patients programme see their website: http://www.npcrdc.man.ac.uk/ResearchDetail.cfm?ID=117#Top

Self–management programmes: Evaluations and opinions

Evaluations

Both described national programmes are still in the process of being evaluated, and until now we only have the results of an internal evaluation of the pilot phase of the Expert Patients Programme in the UK. This evaluation shows that the Programme provides "significant numbers of people with long term conditions with the confidence and skills to better manage their condition on a daily basis" and "significant reductions in service usage", i.e. in General Practitioners' consultations, outpatients visits, Accident & Emergencies attendances and physiotherapy use.[35] For the mainstreaming phase of the programme only preliminary process evaluation results of the Expert Patients Programme have already been published. The recommendations for implementing the Expert Patients Programme into the NHS emphasise the importance of giving it a higher profile with several stakeholders, such as the decentralised health authorities and physicians.[36]

There is, however, already a substantial body of research on various aspects of other self-management programmes. Most literature on self-management focuses on disease-specific programmes, less on more broadly-based programmes integrating self-management into health care systems.

Most evaluations of self-management programmes focus on improvements in the core self-management elements from the patient's perspective, such as for example increased knowledge, skills and sense of self-efficacy. Self-efficacy is regarded as a cognitive predictor of health behaviour and has been proven to be related to improved health behaviour, motivation and well-being. [37-39]

Outcome measurement of self-management programmes has focussed on health status and health service utilisation. This has most extensively been researched in disease-specific programmes, such as diabetes[40-43], asthma[22] and arthritis[44]. Fewer evaluations have focussed on generic self-management programmes for various chronic conditions.[45-47] Overall, experts agree that there is a sufficient body of evidence for positive outcomes of self-management programmes with regard to enhanced self-efficacy and healthy behaviour as well as health status and health service utilisation.[24;27] These outcomes are often contrasted with the results of traditional patient education. Bodenheimer, for example, presents a CDC review of the effects of patient education on the clinical outcomes of diabetes care, which indicates that patient education by itself (without a component of self-management) is not sufficient to improve clinical outcomes and that greater patient knowledge does not correlate with improved glycemic control. [22] A Cochrane review of patient education in asthma of adults has shown similar results, i.e. no improvement in health outcomes through patient education alone.[22] In contrast, Lorig et al. report a statistically significant improvement in health behaviours in a cohort study of a generic chronic disease self-management programme.[47] Tang found significant improvements in body mass index, total cholesterol and high- and low-density lipoprotein among the participants in a diabetes self-management programme.[43]

What is interesting for our purpose is that many studies report reduced health service utilisation, a fact that is making self-management attractive for many health policy makers.[11] Lorig for example have assessed the effect of a self-management programme on four types of health care utilisation, i.e. visits to physicians, visits to hospital emergency departments, number of hospitalisations, and number of nights spent in a hospital. They noted a reduction in the number of visits to emergency departments and trends towards fewer visits to physicians and fewer days in hospital.[47] Other studies have confirmed these effects of self-management programmes. Kemper presents studies showing that already in the 1980s the effects of various interventions to encourage, what Kemper calls self-care include a reduction in health care utilisation for various

conditions.[48] Fewer emergencies and hospital admissions by people who attend self-management courses have also reduced health care cost in some cases.[46]

One limitation of the research literature that could be assessed for this report is that it is only looking at the impacts of once-off self-management interventions. Thus, effects of self-management courses are observed only for a limited time after the intervention. The selection of study participants should also be taken into account. In all the studies we know of, participants were aware of being in a study context and had formally agreed to partake in the study-related activities for the entire duration of the study. Therefore we do not yet know much about the effectiveness of 'real-life', long-term self-management programmes such as is being introduced in the NHS.

Another limitation is that the vast majority of self-management studies have been conducted in high income countries with well-functioning health care infrastructures. This bias is certainly explained by the fact that self-management programmes, in the full sense of the Stanford model, have only been introduced in these countries and not yet in low-income countries.

We know of one study that evaluates a chronic disease self-management programme in Shanghai, China. This study found that the CDSMP was "acceptable culturally to Chinese patients (…) improved participants' health behaviour, self-efficacy, and health status and reduced the number of hospitalizations (…)".[45]

Judging from the number of publications, self-management programmes also seem to focus mainly on the 'classic' chronic diseases, such as diabetes, coronary heart disease and asthma. Thus we only found one article on HIV/AIDS and self-management. This article presents the results of a randomised controlled trial to evaluate the acceptability, practicality and short-term efficacy of a self-management programme.[49] The study results confirm that self-management is acceptable, practical and efficacious in the short-term for a wide range of chronic diseases, including HIV/AIDS.

Opinions

According to our knowledge no research has been conducted on why patients choose or choose not to participate in a self-management programme. Therefore we cannot say anything about the likelihood of a majority of people with a chronic condition wanting to be involved in self-management initiatives. It is very much possible that a substantial number of people prefer to remain within the traditional patient-doctor relationship. Yet, the success of self-management programmes in the eyes of patients who have joined them is unquestionable. Many interviews have been conducted with patients who are active in this kind of programmes, be it as expert patient trainers, tutors or course participants. All of them report finding the self-management support very useful, and for many the activity as expert patients and the participation in self-management groups has meant a significant improvement in well-being.[32;50-53;53]

Health policy makers in the UK and Australia have expressed their support for self-management programmes, partly on the basis of the body of evidence for improved health outcomes in chronic conditions, partly because they promise cost-saving opportunities for their national health systems.[24;54]

The most critical attitude regarding self-management and the expert patients programme seems to prevail among medical doctors, even though no research of an individual self-management programme has looked at the aspect of physician perspectives. A few articles and preliminary evaluation results concerning the expert patients programme indicate that many physicians are critical with regard to the introduction of the programme in the NHS. Thus, Jardine quotes a survey showing that 50% of general practitioners in the UK feared the expert patients programme would mean more work for themselves. Another fear is that patients will "become troublemakers", questioning the doctor's advice and suggesting alternative treatment options etc.[51] The preliminary

results of the national evaluation of the Expert Patients Programme mention the "lack of engagement by local health professionals" as one factor contributing to difficulties in recruiting chronic patients to the courses. Interviews showed that physicians were often critical towards the merit of lay-led disease management programmes and feared their competition with professional approaches to chronic condition management.[36]

In the UK, the Royal Pharmaceutical Society regards the Expert Patients Initiative as a very promising development which will offer "a huge opportunity for pharmacists to provide high quality information and help patients to become experts".[52] The society's vision reaches from the community pharmacy becoming a more important point of contact with the primary health system for the expert patient to the active participation of pharmacists as resource persons in Expert Patients Groups.[52]

In conclusion we can say that the expert patients programme as a nation-wide extension of the concept of self-management holds the promise of increasing the well-being of people living with many diverse chronic conditions while at the same time reducing the burden of chronic care on the 'traditional medical infrastructure'. It looks very well possible that new professional cadres, who are living with a chronic illness themselves, will take charge of many aspects of chronic care. However, early evaluations have shown that the integration of this new programme into the NHS will require careful negotiation with the 'traditional stakeholders' such as physicians and specialised nurses.

B.   Roles of People Living with HIV/AIDS in ART programmes in the South

We have taken a closer look at the expert patient concept for chronic diseases because we think it might hold some promise regarding HIV/AIDS care and treatment in developing countries with severe HRH constraints. In these settings, it is of paramount importance to find ways of reducing the burden of HIV/AIDS related work on the scarce stock of medical doctors and qualified nurses. We think it worth exploring the possibility and potential of recruiting expert patients from the big pool of PLHA in order to supply ART programmes with the much needed HRH. For this purpose we want to examine the different current roles of PLHA in ART programmes in low-income countries and then examine if and in how far the concept of expert patients could help increase and improve their involvement.

Origin of PLHA self-empowerment

Our literature research has shown that in many countries PLHA are involved in all areas of a comprehensive response to HIV/AIDS, i.e. in health promotion, prevention, care and treatment and impact mitigation, and additionally in programme management and policy-making. This present state is the consequence of a self-empowerment process that began with the establishment of the first association of PLHA, the so-called *People With AIDS(PLA) self-empowerment movement*, in the United States in 1983. Globally, an international network of people living with HIV was initially formed in 1986, and later became the *Global Network of People Living with HIV/AIDS* (GNP+). On the African continent the first PLHA association, *The AIDS Support Organisation* (TASO) was established in Uganda in 1987.

Today most countries have at least one PLHA association, and the majority of HIV/AIDS programmes in low-income countries are run with some kind of involvement of PLHA.

The concept that PLHA ought to participate in the decisions that directly affect their lives dates back to 1983. At the second national AIDS Forum in the US, the *PLA self-empowerment movement* demanded that PLHA "be involved at every level of decision-making and serve on the boards of directors of provider organizations [and] be included in all AIDS forums with equal credibility as other participants, to share their own experiences and knowledge".[55]

The principle of the 'Greater Involvement of People Living with HIV/AIDS' (GIPA) was formally recognized at the 1994 Paris AIDS Summit, and in 2001, the United Nations Declaration of Commitment on HIV/AIDS endorsed the GIPA principle.[56] The WHO, in the guiding principles of their '3 by 5' initiative, postulates the "Centrality of People Living With HIV/AIDS. The Initiative clearly places the needs and involvement of people living with HIV/AIDS at the centre of all of its programming".[57]

Activities of PLHA in the fight against HIV/AIDS

Looking at the roles of PLHA in the fight against HIV/AIDS we can distinguish between the 'use' that is being made of them by individual projects and programmes and the activities undertaken by separate PLHA groups or associations. The majority of the latter seem to have been initiated as mutual support groups of people affected by HIV/AIDS who have subsequently increased their range of activities.

Our internet and literature research of national and other HIV/AIDS programmes as well as PLHA associations in low-income countries aimed at identifying all areas in the fight against HIV/AIDS in which PLHA are currently involved. From this research it seems that the main fields of PLHA involvement are health promotion and prevention.

The *Centre for AIDS Development Research & Evaluation* (CADRE) has come up with similar findings in their study of AIDS-related activities of 88 community organisations, many of them PLHA associations, involved with HIV/AIDS in South Africa. Almost 90% of these organisations were involved in prevention activities, 70% provided care and support services, more than 60% provided training and less than 28% were involved in treatment (for tuberculosis, sexually transmitted infections , opportunistic infections or ARVs), mainly focussing on treatment literacy.[58]

Health promotion and prevention. Many individual HIV/AIDS programmes involve PLHA associations or smaller PLHA volunteer groups in population-based education and awareness campaigns. This is done in settings as diverse as for example the urban *Médecins Sans Frontières* (MSF) project in Khayelitsha, South Africa, which is collaborating with the *Treatment Action Campaign* (TAC) in education and community awareness campaigns[59] and the rural MSF project in Thyolo, Malawi, which is involving hundreds of community volunteers, many of whom are HIV positive, in prevention activities.[i] A hospital-based ART project in Kenya has hired some of their HIV-infected patients for various tasks, among them community education.[60] TASO involves PLHA in their projects throughout Uganda for the same task of awareness building.[61] Moreover, dozens of PLHA associations in various countries are involved in a range of promotion and prevention activities that are not necessarily linked to a more comprehensive medical programme.[ii] Health promotion activities run by PLHA aim at the community at large as well as at HIV positive people in particular. For example, with community awareness campaigns, adolescent sexual health education and condom promotion PLHA associations directly target healthy behaviours and fight stigma related to HIV/AIDS. The prevention and health promotion activities aimed at HIV positive people include for example information about nutrition, common opportunistic infections and the nearest health services providing ART etc.

Care and Treatment. The majority of programmes providing care and treatment of HIV/AIDS, including ARVs, involve PLHA in some way or another. It seems that usually these PLHA are directly linked to the treatment site, which means they belong to its HIV-positive patient pool and have volunteered to become actively involved in the continuum of HIV care which is often referred to as 'peer support'. The most common tasks of PLHA have to do with **treatment adherence support**. The MSF project in Khayelitsha, for example, has several peer support groups differentiated according to the duration of treatment of its members.[59] TAC is also very active in the promotion of treatment literacy.[63] In Chiradzulu, Malawi, where MSF has another ART project, several PLHA have formed their own support group for adherence, which is assisted by professional counsellors.[64] In Zambia, the HRH crisis has prompted the national HIV/AIDS programme to train PLHA and other community members to address issues such as adherence and supportive counseling. The MoH has started to contract PLHA groups and community -based organisations to support treatment literacy.[65;66] In the ART projects of MSF in Cambodia, PLHA volunteers are used to track down patients on ART who have not shown up for their appointments.[iii]

Several HIV/AIDS projects involve PLHA in their **counselling** activities. Some employ individual HIV positive people as counsellors for their VCT programme others for adherence counselling. In Thyolo, it is the home based care (HBC) volunteers, many of whom are HIV positive, who have been trained in early HIV case detection and who

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[i] Personal communication with MSF project staff in Thyolo, Malawi

[ii] A global directory of PLHA association, published by USAID, lists PLHA associations for most African and Asian countries, the majority of which are involved in prevention, promotion and advocacy activities.[62]

[iii] Personal communication with MSF project staff in Siem Reap, Cambodia

routinely refer patients to the project's VCT and ART services. More than two thirds of the project's VCT clients have come after encouragement from a HBC volunteer.[67] According to personal information, it seems that TASO, the biggest PLHA association in Uganda, is not only organising VCT but planning to extend their VCT centres to include the offer of CD4 testing.

Other tasks of PLHA in this category of the continuum of care for HIV/AIDS include **home based care** (HBC) for AIDS patients. The PLHA volunteers usually receive some training from the formal health facilities or specialised NGOs in HIV related symptoms and opportunistic infections (OIs) and are equipped with some basic drugs and materials for treatment. The most extensive collaboration we know of is the one we observed in Thyolo, Malawi. Here, MSF has built on existing community support groups, provided them with training in some medical aspects of HBC and is now collaborating with the HBC teams for early case detection. The HBC network has broad community coverage and serves as a supplier of clients for VCT and patients for initiation of ART.[67] There are other examples such as the national Red Cross Societies in Uganda, Botswana, Mozambique and South Africa, who employ PLHA as volunteers for HBC, prevention and awareness building activities.[68] Malawi's Global Fund Project "The national response to HIV/AIDS" plans to develop a national HBC infrastructure, by empowering and investing in existing community-based PLHA groups and encouraging the creation of new ones.[69] As the majority of PLHA associations were founded with the aim of providing mutual support, HBC remains one of their core activities. We have found PLHA groups involved in HBC in most African countries affected by HIV.

While it has become relatively commonplace for HIV/AIDS projects to involve PLHA in some way in the administration of treatment for chronic HIV problems and OIs, we have not come across any examples of direct PLHA involvement in the **provision of ART**. Their involvement in treatment activities was restricted to treatment literacy and adherence monitoring and support. An interesting study by Sidaction describes this situation for CBOs and PLHA groups in Kenya where many community-based structures are filling gaps in the public health system by providing support and care for the population in remote rural areas.[70] Even though PLHA groups are extensively involved in HBC, most of them do not include access to ART. The authors write that there would be a real possibility of HBC volunteers assuming different roles and becoming agents for treatment access if they are provided with the necessary allowance and training. Yet, "PLHA have generally been called upon to offer services on a volunteer basis, leading to a high turnover of experienced and qualified staff", a potential that could be tapped for ART provision if properly supported.[70]

The advocacy work of PLHA associations can also be grouped under treatment as it is in most cases related to access to ART. The most known and vocal groups are the Treatment Action Campaign (TAC) in South Africa and the Thai Network of People Living with HIV/AIDS (TNP+), who have both been campaigning for increased access to treatment for many years.[71;72]

A recent survey of community-based organisations facilitating access to ART in Africa shows that 70% of organisations are involved in ART access issues, around 60% in psychosocial follow-up of ART patients and in training on ARTs. 50% were involved in the medical follow-up of ART patients and 26% were providing ART prescriptions.[73] A closer look at the organisations providing ART revealed that they all employed professional medical staff for the prescription of ARVs. We did not find any involvement of PLHA in the prescription process.[i]

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[i] Still, as most organisations do not have their own website we had to rely on the summaries of activities by Sidaction. These might not do justice to the entire range and arrangements of each

Impact mitigation. Many PLHA, be it as individuals or be it as groups, are engaged in impact mitigation activities such as care of and support for orphans and 'Other Vulnerable Children'. Nutrition support and household assistance are also part of many PLHA associations' catalogue of activities. Several PLHA have a broad offer of services, ranging from positive living seminars for HIV positive people to seminars in income generating activities.[62]

Other areas of PLHA involvement. In many countries PLHA have a voice in HIV/AIDS related **policy making**. The importance of their involvement on this level has been frequently emphasised by influential organisations such as UNAIDS and WHO. An important step forward was the requirement by the Global Fund to Fight AIDS, TB and malaria, to include representatives of civil society in general and of people affected by HIV/AIDS in particular in the country coordinating mechanisms (CCMs), which play a crucial role in the development of project proposals for funding by the Global Fund. Particularly in South Africa, several PLHA associations offer **legal support** to HIV positive people in cases of workplace discrimination or insurance and pension issues.

A. versus B. PLHA as expert patients: An untapped resource?

Relevance of self-management for comprehensive HIV/AIDS care

In the first part of our review we could present examples of how self-management as a component of chronic care in high income countries can have a positive influence on healthy behaviour and well-being of people with a chronic illness as well as improve health outcomes and service utilisation. In the second part we showed the various areas of health promotion and prevention, care, treatment and impact mitigation where PLHA in low income countries with high HIV/AIDS burden are currently involved.

In this third part we want to argue that conceptualising the involvement of PLHA as 'expert patient work' could potentially improve outcomes for the HIV positive individuals in all the listed areas, while crucially reducing the workload of HIV/AIDS for medical personnel. While the objective of expert patient programmes for chronic diseases in high-income countries is not in the first place a reduction in health service utilisation, there is sufficient evidence that expert patient programmes do reduce health service utilisation while improving health outcomes. We argue that this aspect of expert patient programmes holds interesting potential for the context of ART in settings of severe HRH shortages and that it would be worth exploring further existing PLHA initiatives that could possibly progress towards an expert patients programme.

Since it is the aspect of care and treatment for PLHA that is most intensive in its use of medical doctor time, we want to look at the potential role of PLHA as expert patients in reducing health service utilisation for ART in developing countries. In order to reduce measurably medical doctor contacts, an expert patient programme for ART in HRH - constrained settings would have to focus more than its predecessors for other chronic conditions in high HRH density countries on medical treatment as part of self-management.

organisation's activities. It might be interesting to do more in-depth research of the ART delivery models used by the community organisations that claim to provide ARV prescriptions.

Aspects of current PLHA involvement in ART delivery related to self-management

Some features of ART programmes have to do with patient empowerment and could be building blocks for an expert patients programme. First, there are the **peer support groups** of PLHA, which have been initiated in all the ART delivery projects we know of. The formation of patient groups for mutual support is the basis of any expert patient programme. However, the peer support groups linked to ART projects are, as far as we know, not receiving the professionalized, structured support of expert patient groups but rather function as traditional self-help groups. While it is common for health personnel to organise information sessions with the PLHA support groups, we have not come across a systematic training approach for PLHA group members. Second, the emphasis of ART projects on intensive VCT and ART **counselling** can have aspects of individual self-management training, in that it can be problem-based and encouraging for the patient. However, from several talks with counsellors we have got the impression that in many cases the focus of counselling is mainly on traditional patient education rather than self-management skills. Third, **HBC** delivered by PLHA can be seen as another building block for an expert patients programme. Normally, HIV positive HBC volunteers receive training from the health service they are related to. Their first-hand knowledge as people directly affected by the disease is thus enhanced by physiological and medical background knowledge. These people are therefore able to understand the people under their care not only to a certain extent medically but also emotionally and socially as they themselves are sharing similar experiences as PLHA.[i] However, the HBC programmes we have come across are only comparable with expert patient initiatives to the extent that PLHA are trained to become experts in certain fields of HIV-related problems. Apart from this aspect, HBC programmes rather follow the traditional pattern of health service provision, in which some individuals are trained to treat others. In contrast, in expert patient programmes the tutor, who has a chronic disease himself, is not only trained in disease-specific medical knowledge but also in teaching self-management skills to others with a chronic disease.

Conclusion: Possible ways of tapping the pool of PLHA expert patients?

In order to make the delivery of ART less medical doctor intensive, it might be worth developing the potential of PLHA beyond their use in support functions as described above. What is currently lacking is a conceptualisation of their possible professional involvement as expert patients.

As the previous chapters have shown, hundreds of PLHA support groups exist in most of the countries with high HIV/AIDS burden. Many of these groups are the outcomes of community-based initiatives and have accumulated many years of experience dealing with all aspects of HIV/AIDS. The capacities of these groups could be systematically explored in order to identify their potential as expert patient resources. In this way it might be possible to identify selected individuals and provide them with the specific medical and psychosocial training necessary for fulfilling the role of expert patient tutors.

Any expert patient programme would have to be context-specific and require the careful identification of possible professional tasks to be fulfilled by the PLHA. In a

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[i] The importance of personal experience has also been recognised for other areas. An example where it plays a crucial role is the Belgian initiative to fight poverty, in which the active participation of the poor in poverty reduction strategies is seen as a necessary condition for their success. The initiative has established a new professional cadre, the "Experience Experts in Poverty and Social Exclusion". These are empowered poor people who have been trained to bridge the gaps between the traditional poverty-reduction structures and their target group, the poor themselves.[74]

participatory process, PLHA groups and the medical- and paramedical staff could together examine the whole range of activities related to HIV/AIDS care, treatment and support with the aim of identifying each partner's role in this continuum of care.

In order to make ART delivery less doctor intensive, it would be important not to look only into non-medical HIV/AIDS related tasks but also to explore the possibilities of PLHA expert patients assuming responsibility for medical tasks such as CD4 counts and follow-up of uncomplicated patients on ART. In certain contexts it might even be considered to go beyond this and involve expert patients in the initiation of ART.

Extending the expert patient idea could mean creating national PLHA expert patient networks. Such networks could be more than an offspring of individual ART delivery projects but be entirely run by PLHA. Its institutions may then become the first and most frequent points of professional care for PLHA.

Certainly, the development of such expert patient networks would require good communication and collaboration with the traditional health service infrastructure for which it would pose a number of new challenges. Traditional paramedical training institutions, for example, would have to expand their course offers and prepare special tutors for the running of training courses for expert patient tutors. Also, as we have described in relation to the expert patient programme in the UK, apprehension from the established medical (and paramedical) interest groups may pose a serious barrier for the development of a PLHA expert patient programme. [36;51;75] Therefore, the development of such a programme would need to be context-specific and from the start to be developed with the participation of all stakeholders.

We argue that the traditional medical model of ART delivery is incompatible with the severe HRH shortages in many African countries with high HIV prevalence, and that especially the potential reduction in the use of health care makes the expert patient approach an interesting option for HIV/AIDS care.

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