



New technology and illness self-management: Potential relevance for resource-poor populations in Asia



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ABSTRACT

Advances in technology have made it possible for many standard diagnostic and health monitoring procedures, traditionally carried out by qualified personnel within medical facilities, to be reliably undertaken by patients or carers in their own homes with a minimum of basic training. There has also been a dramatic increase in the number and diversity of both sources of information on health issues and the possibilities for sharing information and experiences over ICT-based social networks. It has been suggested that these developments have the potential to 'empower' patients, reducing their dependence on providers and possibly improving their quality of care by increasing the volume and timeliness of diagnostic data and encouraging active self-management of their condition, for example through lifestyle changes. Perhaps more significantly, it is also seen by many economies with ageing populations as a way to contain high and ever rising healthcare costs.

It has also been suggested that a move to greater self-management supported by expert networks and smart phone technology could improve the treatment of many millions of patients with chronic diseases in low and middle income economies that are also confronting the potential cost implications of epidemiological and demographic transitions, combined with the higher expectations of a more educated and knowledgeable population. There is now limited evidence that some fairly basic e- and mHealth interventions, for example in the areas of MNCH, malaria and HIV/AIDS can have a positive impact, even in resource-poor contexts. The aim here is to explore the extent to which further investment in technology could play a role in the development of an effective and affordable health sector strategy for at least some developing economies. It is suggested that the effectiveness of the approach may be highly dependent on the specific health conditions addressed, the nature of existing health systems and the overall socio-economic and cultural context.

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1. Introduction

Medical advances are continually providing new possibilities for extending life, sometimes by curing but more often by managing serious illness. These advances are however typically associated with an ever increasing cost of care, and there is considerable concern, even in some of the richest economies, as to how these costs will be met. If technological developments are contributing to the problem of healthcare funding, it seems reasonable to ask if they can contribute to a solution. One superficially attractive proposition which has attracted increasing attention over recent years is that using advances in ICTs to provide patients with the knowledge and equipment required to play a greater role their own treatment could not only prove beneficial in health terms (McDermott and While, 2013; King et al., 2012) but also in terms of

reducing the cost of care by limiting their reliance on expensive professional providers (Lindberg et al., 2013).

This approach is often set in the broader context of patient *empowerment*, a term which from a health care perspective is typically used to indicate the extent to which patients play an active role in decision-making in relation to their treatment. A literature review by Holmström and Röing (2010) indicates the wide range of possible interpretations of this concept, which extend from a basic willingness of medical practitioners to provide information and engage patients in discussion of possible treatment options, sometimes with the very traditional aims of encouraging compliance and adherence (Bissell et al., 2004), to full 'self-management', in which patients take the lead and "the health professional will take on the role of a consultant, a resource person who offers treatment suggestions" (Kober and Van Damme, 2006:9). There is general agreement that empowerment should be seen as a process, with power being transferred to a greater or lesser extent from provider

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to patient. That process is often conceived as one initiated and managed by well-intentioned providers: “the impression gained is of a normative perspective driven by professionals” (Thompson, 2007). But there may also be situations, particularly where medical services are perceived to be failing patients, in which self-empowerment is seen as the most effective healthcare seeking strategy (Kober and Van Damme, 2006:16).

A number of authors have voiced concerns at the level of enthusiasm for patient empowerment among some advocates of radical health sector reforms. They suggest that it is by no means obvious that this process is always welcomed: “whilst many commentators ... may believe that increased consumer/patient responsibility for health is the way forward, some patients are clearly not yet convinced” (Henwood et al., 2003). To state the obvious, most patients would rather be cured than empowered. The responsibility of being involved in treatment decisions may be seen as just one more burden, especially for those with a serious illness: “Many patients in palliative cancer treatment have no desire to take part in decision making as their condition progressively worsens” (Holmström and Röing, 2010:171). In such cases, some have gone so far as to argue that empowerment may be “popular with staff because it removes a responsibility for their patients’ pain that is practically and emotionally burdensome” (Salmon and Hall, 2003:55).

There are also suggestions that some providers may use the language of empowerment simply as a means of persuading patients to comply with proposed treatments (Henwood et al., 2003:591). In practice the ‘choices’ that a patient can make may often be strictly limited by resource constraints, either their own or those imposed by third-party payers. Salmon and Hall (2003) argue that in addition many patients tend to impose their own limits on

the range of possible treatment options. For them, “treatment decision-making simply meant coming to terms with the disease and acquiescing to the recommendations of the doctor” (p53). Enthusiasm for patient empowerment among some policy-makers has also been linked to their promotion of a consumerist approach to healthcare (McDonald et al., 2007). A major concern here is that patients who have been persuaded that they are ‘rational decision-makers’, able to assess the potential benefits, costs and risks associated with a given course of treatment, may be readily deceived by the extravagant claims of private providers, pharmaceutical companies and quacks. Here again, such concerns may be most relevant in cases of serious illness, where patients are anxiously hoping for a ‘magic bullet’ cure. A recent article (Will and Weiner, 2015) argues that the behaviour of patients may vary substantially depending on the specific type of health concern and that “sociologists should be cautious about assuming there will be demand for new medicines ... even in burgeoning health markets” (p9).

Alternative interpretations of the implications of recent developments in ICT for patient empowerment are illustrated in Figs. 1 and 2. In Fig. 1 (Griffiths et al., 2012:p2237) the traditional patient–doctor relationship takes centre stage. Both parties bring to this relationship their own, possibly overlapping, networks. On the provider, ‘supply’, side will be a range of expert networks including other health providers, managers and administrators, public agencies and medical technology and pharmaceutical companies, with access to massive commercial and public sector databases containing patient records, practice guidelines, research publications, data on drug trials, etc. It can be argued that the essential nature of these networks has not changed radically over recent years, the main impact of ICT developments being to make personal communications and access to data faster and more

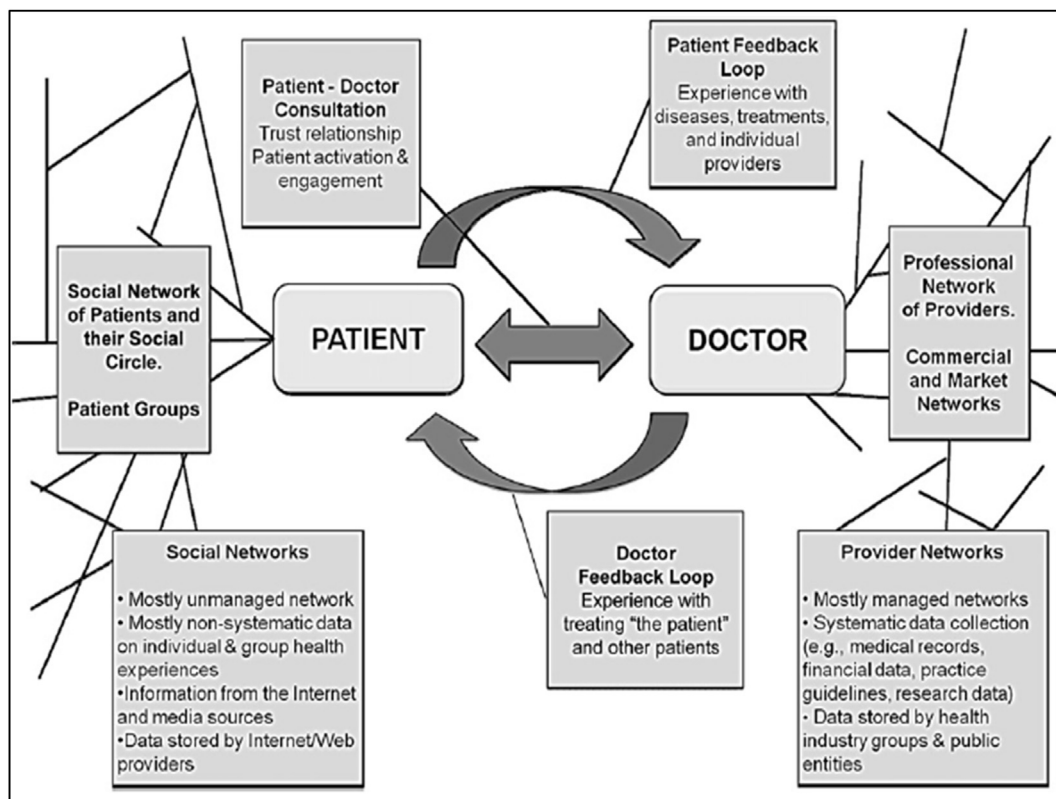


Fig. 1. Centrality of the patient–doctor relationship.
Source: Griffiths et al., 2012, p2237.

flexible – immediately, anywhere, anytime and on any device. On the ‘demand’ side, patients will generally have a network of relatives, friends and acquaintances, possibly including some with expert knowledge or relevant experience. In this case, as discussed further below, ICT developments have greatly expanded the potential size of this network by dramatically reducing the cost and effort barriers to verbal or written exchanges between its members. It has also provided, mainly via the internet, easy access to a vast array of largely unregulated sources of health information, though the ability of most to make effective use of this resource is at least debatable: “Left to their own devices, patients are likely to be guided by their desires and by commercial interests that bias the presentation of information” (Schulz and Nakamoto, 2013:p227). The implications for the patient–doctor relationship are not self-evident. Dedding et al. (2011) suggest that, depending on the context, “Internet health sites can: be or come to be a replacement for face-to-face consultations; supplement existing forms of care; create favourable circumstances for strengthening patient participation; disturb relations; and/or force or demand more intense patient participation” (p45).

An alternative model, designed with the needs of patients with chronic illness to the fore (van Olmen et al., 2011), is illustrated in Fig. 2. It can be seen as a response to the ‘paradigm shift’ advocated by Anderson and Funnell (2005) for the care of such patients. They argue that at present “health care professionals are socialized to a paradigm ... derived from the treatment of acute illnesses. In the acute-care system ... providers take responsibility for solving their patients’ problems”. Such an approach, they argue, is ill-suited to a time when healthcare is increasingly concerned with managing long-term serious illness, and leads to unsatisfactory outcomes for both patients and providers. In the proposed model an individual patient, supported by a peer group and possibly other ‘expert

patients’, commissions services from a range of providers. The patient uses ICT to gather information, which they may share with supporters and providers, and to monitor their own health status. Central to this proposal is the concept of ‘inverse information asymmetry’. The commonplace assumption is that patients are at a disadvantage in dealings with providers because their medical knowledge is limited. However, it seems plausible that those who live with an illness for many years could, with support, become more knowledgeable about their specific condition and its implications for themselves and their families, than a provider who may see them a few hours each year.

Of course there nothing new in the idea that people with chronic conditions can play a leading role in managing that condition. For example, the main UK diabetes charity (Diabetes UK, 2009) estimates that diabetics manage 95% of their healthcare, most only seeing providers “for a few hours per year”. Self-management includes not only diet and life-style changes but insulin injection and routine self-monitoring of blood glucose levels. The suggestion is that developments in ICT may make the self-management task easier or more effective and possibly provide patients with the knowledge required to obtain improved quality of care in negotiations with providers. This would involve easier access to medical knowledge in forms designed for the general population – ‘demystified’ health knowledge and reliable, user-friendly and relatively inexpensive medical equipment that can allow reliable self-assessment.

ICTs could also play a key role in terms of support networks. Where patients have easy access to the internet, there are a multitude of peer groups that will offer to assist them in managing their illness. These include an array of independent patient forums, either disease-specific (for example for AIDS (POZ) and various cancers (UKCLLforum, NET Patient Foundation)) or covering a range

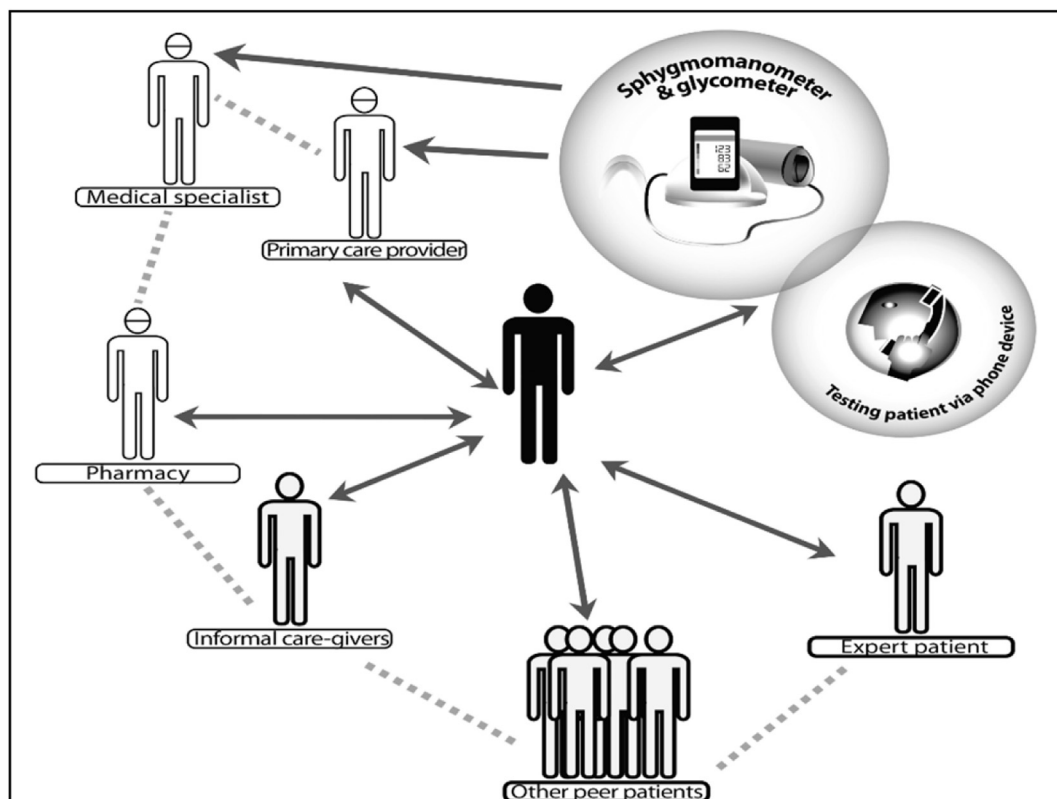


Fig. 2. The patient as the hub of disease management.
Source: van Olmen et al., 2011, p5.

of common conditions (e.g. [Healingwell](#)); sites managed by NGOs or advocacy groups (for example for diabetes ([Diabetes UK](#)) or mental illness ([Rethink](#))); an enormous number of health-related Facebook sites; and a wide range of forums hosted on sites managed by private companies (for example the Medhelp health forums ([Medhelp](#))).

The precise nature of the support offered to patients on such sites is often problematic. For example, Patientslikeme was set up when a relative of a member of a team of software engineers was diagnosed with a serious chronic illness. It would seem in many respects to merit its 'social enterprise' status ([Ellis et al., 2013](#)). However some of its funding strategies might cause concern: "We take the information patients like you share ... and sell it to our partners (i.e., companies that are developing or selling products to patients)" and "Every partnership we develop must bring us closer to aligning patient and industry interests" ([Patientslikeme](#), para 1). Alliances between patient groups and private companies appear to be widespread and are often opaque. In a recent study of 157 Italian patient and health consumer groups, 46 named at least one pharmaceutical company as providing funds. Only three of these reported the amount of funding ([Colombo et al., 2012](#)). The term 'astroturfing' has recently been coined to denote the mimicking of 'grass-roots' movements by commercial firms ([McCull, 2012](#)), a practice which is often impossible to detect over the internet. Companies obviously have a considerable advantage in terms of having the resources to develop very attractive, easy to access websites and to ensure that they figure prominently in the output of internet search engines.

To inform themselves as to whether or how to seek care, and to overcome information asymmetry in negotiation with providers, internet users can also access or download a wide range of digital medical encyclopaedias and disease-specific guides. Given the nature of the internet these may range from the official (e.g. [Healthfinder](#)) to the commercial (e.g. [Pfizer Life](#)), to the highly suspect (e.g. Dr Robot ([Genes, 2006](#))). ICTs can also facilitate and extend the links between patients and providers indicated in both [Figs. 1 and 2](#) above. The currently most popular mobile phone health 'app' in the US offers not only a symptom checker and medical dictionary but 24/7 access to qualified providers and prescription services for common drugs ([Greatcall](#)). A relatively recent development relates to 'electronic patient portals', using the internet to provide a registered patient with access to the medical data held on them by a provider ([Goldzweig et al., 2013](#)).

Patients can also be given or purchase a wide range of self-monitoring devices, generating data that can then be shared with providers. The Mobilicare chronic illness kit, developed in Brazil for home use, includes instruments to measure blood glucose, blood pressure, oxygen saturation, and lung function, a heart monitor, a pedometer, and a medical scale ([Roestler et al., 2013](#)). The Lifewatch V healthcare phone ([Lifewatch, 2012](#)) is a single instrument which, with suitable attachments, can undertake the same range of tests and also measure body fat, provide specific advice on diet and exercise and remind patients when to take medication. All of these functions and more are now also available on the most popular smartphones, as are a range of increasingly sophisticated attachments such as microscopes and stethoscopes. Those recently approved by the US FDA include an electrocardiograph, an ophthalmoscope, an otoscope and even an ultrasound scanner ([Kamerow, 2013](#)).

There has also been a torrent of 'Health-Related' apps for smartphones that claim to support individuals in maintaining or improving their health. It is generally assumed that more than 100,000 health related apps are now available on the two major software platforms, some produced by international bodies (e.g. [World Medical Association](#)), some by national agencies (e.g. [NHS Choices](#)), some by prestigious medical universities (e.g. [Johns Hopkins](#)) but most by commercial organisations (e.g. [WebMD](#)). [Fig. 3](#) provides a breakdown of 962 iPhone apps classified using the Health Education Curriculum Analysis Tool ([West et al., 2012](#)) as relating to personal health (as Apple retain control over iPhone apps it is possible to know how many there are and their intended use – Android apps can be written and circulated by anyone). Around 15% provide disease-specific information and a similar percentage recommend some form of treatment. These are probably of most relevance in terms of their potential value to those with a specific health problem – if the information they provide is reliable and determined primarily by medical as opposed to commercial or other considerations. It is obviously difficult for those without medical training to assess if any given app is likely to be helpful or at least benign. Many may assume that if an app is available from a reputable web-site that 'someone' must have approved the health-related information provided. However, in most cases this assumption will be incorrect.

For example, a recent article reports that the US Food and Drug Administration "has come under pressure to evaluate and bless all

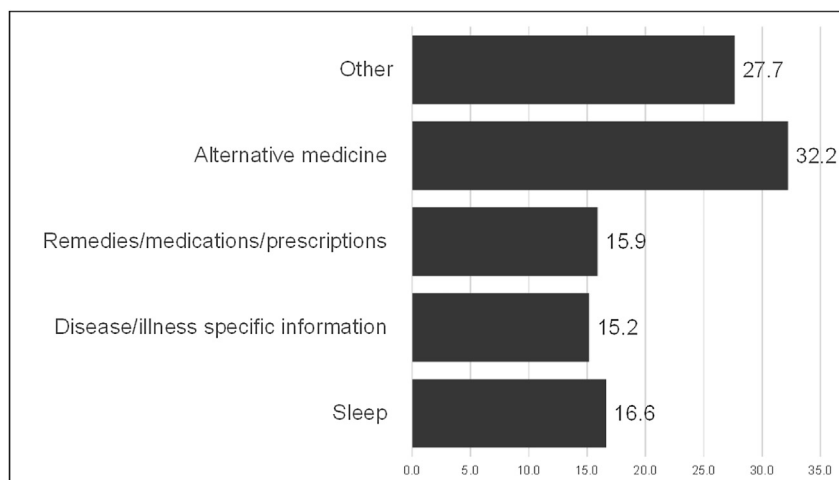


Fig. 3. Percentage distribution of 962 iPhone 'Personal Health' apps. Note: Individual apps may offer more than one of these options. Source: calculated from [West et al. \(2012\)](#), table 2.

these medical apps ... [but] Most ... will not be subject to regulation. ... we are still left with rafts of health related apps that give advice that is incomplete or plain wrong" (Kamerow, 2013). On the other hand there are those who fear that regulation could severely limit the potential benefits of these apps: "the mere mention of 'diabetes' would cause the app to be regulated by the FDA. Such regulation ... discourages the kind of education and motivational messages that our country needs to stem the tide of this disease" (Brooke and Thompson, 2013).

Support for the self-management of diabetes is one of the commonly cited applications of mobile phone apps in the health-care literature (Tran et al., 2012). They can address a wide range of activities including:

- Glucose tracking
- Medication alerts
- Insulin tracking
- Carbohydrate tracking
- Activity tracking
- Weight tracking
- Blood pressure tracking
- Checklists on diet and foodstuffs
- Time-series analysis of monitoring data, including trend charts

There is widespread concern in the areas of e- and mHealth at the lack of evidence to support claims of beneficial health outcomes (Tomlinson et al., 2013; Holtz and Lauckner, 2012). However, in a recent RCT, Kirwan et al. (2013) found that "the use of a diabetes-related smartphone application combined with weekly text-message support from a health care professional can significantly improve glycemic control in adults with type 1 diabetes". Similarly, one systematic review and meta-analysis identified 22 studies of the use of mobile phone apps for diabetes and concluded that there appear to be significant benefits in terms of glycaemic control (Liang et al., 2011).

2. Possible relevance in resource poor contexts

Are such innovations relevant for a low income household in the developing world, struggling to cope with serious long-term illness? Interestingly, Fig. 2 was taken from a paper (van Olmen et al., 2011) which proposes that they offer one of the few possible options in resource-poor environments, where there is no possibility of adequately funding a provider-based model of care given the demands of increasing numbers of patients with chronic disease. For example, it has recently been argued that in even in a country such as India, which has experienced rapid economic growth over recent years, it would be impossible "to simultaneously focus on NCDs and communicable diseases; ... such a utopian argument ignores the political and economic constraints that shape resource allocation" (Subramanian et al., 2013).

Given these resource limitations, Van Olmen et al. suggest "full self-management" as an alternative for low-income countries, facilitated by expert patient networks and smart phone technology". Patients, or more plausibly, groups of patients confronting similar issues, would use mobile technology to 'commission' care from a range of providers. This would involve activities ranging from the use of a personal mobile phone, now accessible even by many of the poorest households, to seek advice from relatives and friends, fellow sufferers, 'expert patients' or sympathetic qualified providers; to self-monitoring using probably collectively owned, smart phone-based medical equipment; to remote diagnosis and possibly prescription from a supportive public, not-for-profit or private facility.

Is this scenario realistic? The rise in mobile phone ownership even among relatively poor populations is now taken for granted.

For example, Bangladesh has a gross national income per capita of around US\$1,000, yet the 2011 DHS estimated that 89% of urban and 75% of rural households owned a mobile phone and a recent study suggests that over two thirds of the population had access to health tele-consultation services at the end of 2012 (Ahmed et al., 2014). Many of the medical apps described above are available free of charge or at low cost for those with suitable phones, and it can be reasonably assumed that the cost of such phones will continue to decline – the Indian manufacturer, Jivi, recently launched an Android smart phone costing just over US\$30 (Jivi). This will probably also be the case with simple medical attachments, for example those designed to measure blood pressure or blood glucose levels. A number of agencies are engaged in work to provide low-cost devices, including mobile phone based microscopes (Breslau et al., 2009), that are specifically designed for use in developing countries. More sophisticated devices will follow. For example an oximeter targeted at obstetric use in resource poor environments and expected to sell for less than US\$40 is currently under development (Kurzweil et al.).

There is certainly no shortage of attempts to bring the benefits of e- and mHealth to resource poor populations. The GSMA Mobiles for Development database of mHealth products and services in the developing world (GSMA) current details 680 interventions across Africa, Asia and Latin America. These interventions are diverse in nature but almost all are 'pilots' supported by international donors, NGOs, CBOs or commercial firms (typically healthcare and telecoms companies). Very few are self-financing. Though not often stated as a primary objective, it does seem plausible to see many as potentially relevant for illness self-management. Probably the largest group of such interventions are those using SMS text messaging to encourage population behaviours linked to improved health status or disease prevention, for example explaining the health risks associated with obesity, smoking or STIs (Buih et al., 2012; Déglise et al., 2012). Of greater interest in the present context, and with a somewhat stronger evidence base, is the use of targeted text messages sent, by providers or support agencies, to registered patients and providing advice relating for example to HIV/AIDS, pregnancy, weight loss or smoking cessation (Free et al., 2013; Gurman et al., 2012). In relation to the topic of this paper, a recent systematic review found "some, albeit very limited, indications that in certain cases mobile phone messaging interventions may provide benefit in supporting the self-management of long-term illnesses. However, the review also cautioned that "there are significant information gaps regarding the long-term effects, acceptability, costs, and risks of such interventions" (de Jongh et al., 2012).

There are also a range of different types of monitoring interventions. In terms of patient monitoring these have mainly involved the use of mobile phones by CHWs to report childhood illnesses, or to track the progress of women during pregnancy and in the period following a birth. Automated 'Alert Systems' are often used to trigger interventions based on these reports, which may involve a combination of voice and SMS (Ngabo et al., 2012). It seems plausible that similar procedures could be set up without the need for a CHW. A recent study on Malaria case detection and management in Bangladesh relied mainly on cases reported by household members using mobile phones (Prue et al., 2013). The recently established Human Resource Information System in Uganda (Uganda) might be seen as an interesting first step in provider monitoring. It allows open access to a database of information on registered and licensed healthcare providers, allowing members of the public to verify the qualifications claimed by those offering healthcare services. Effective and straightforward authentication of drugs, a long standing problem in many countries, may also now be possible for anyone with access to a mobile phone, with a number of companies offering a service that uses a

scratch-card technology similar to that used to purchase call time (Sproxil).

Many existing interventions could be seen as potentially contributing to a health information environment that is supportive of self-management. For example, much of the material and many of the mobile tools being developed for use by CHWs (Braun et al., 2013; Florez-Arango et al., 2011) could in many instances be used by patients or carers. A wide range of standard reference books are now available in digital format and many organisations are producing mobile phone-based reference materials for CHWs, currently mainly aimed at reproductive health and communicable diseases (OppiaMobile) but soon to include, for example, an e-book version of the general text 'Where there is no doctor' (Worldreader). There are also a variety of CHW 'job aids', materials intended for use in discussion with clients, such as cartoon drawings or videos that can be shown on mobile phones, that could clearly be adapted for use by patients, including those with limited literacy skills. One interesting model is that adopted by HealthPhone (Healthphone), a project undertaken by The Mother and Child Health and Education Trust, which aims to use a US\$3 memory card that can be inserted into a standard feature phone to provide a video reference library on health and nutrition for the general population. Similarly, an initiative such as Mobile Academy (Mobile Academy), which provides mobile phone-based online training courses for CHWs under the Ananya Programme funded by the Gates Foundation in Bihar, could provide a template for courses targeted at the general population, with modules covering a range of common acute and chronic diseases.

In many countries consultation with a qualified medical practitioner is often provided as a Value Added Service (VAS) by telecoms companies. For example Healthline (Grameenphone) (US\$0.06 per minute), is available to Grameenphone subscribers in Bangladesh and Mediphone (Mediphone) (US\$0.60 per consultation) to Airtel subscribers in India. Also in India, the Meradoctor (Meradoctor) company has adopted a different model, offering a subscription package (US\$50 per year) which includes telephone consultation for up to 6 people, prescriptions by SMS, and insurance for hospitalisation, disability and death. The issuing of prescriptions is an issue that is perhaps not sufficiently emphasised in discussion of such initiatives. In Bangladesh, for example, the law states that drugs can only be prescribed by licensed medical doctors to their registered patients, which would exclude the issuing of prescriptions over Healthline. This appears to be a major limitation as far as patients are concerned, especially those that customarily use unqualified providers who nonetheless provide a wide range of prescription drugs (Sudhinaraset et al., 2013). One of the main complaints raised in relation to a mobile phone service set up by the Bangladesh government was that callers with other than minor illnesses were typically advised to visit a hospital to obtain a prescription (Afroz, 2012, p51).

There are also a limited number of interesting initiatives which address the networking and support components of self-management. A number of HIV/AIDs programmes have pioneered the establishment of community and patient groups, primarily focusing on the promotion of lifestyle change and long-term adherence to treatment. However, in recent times there have been a number of apparently successful proof-of-concept exercises that have engaged communities and PLWHA (People Living With HIV and AIDS) in ART (Anti-Retroviral Treatment) provision (Rasschaert et al., 2014; Decroo et al., 2011; Selke et al., 2010).

With very limited resources, the International Centre for Diarrhoeal Disease Research, Bangladesh (ICDDR,B) has encouraged the formation of community based 'clubs' for those at risk of developing diabetes and/or hypertension in selected wards in Chakaria, one of the poorest sub-districts of Bangladesh (Moula et al., 2011).

At the end of 2009, some 3300 households were surveyed to identify those over 40 and offer them the opportunity to be screened for these two conditions. This was undertaken by community paramedics and midwives at local Village Health Posts which had been set up by the communities. Around half of those approached participated in the screening programme and went on to form 17 self-help clubs (10 for women and 7 for men). Most have remained active, with members taking exercise together, checking fasting blood glucose and blood pressure at regular meetings and consulting qualified physicians at ICDDR,B by mobile phone when needed.

The community based organisation MoPoTsyo in Cambodia (van Pelt et al., 2013), aims to create empowered patient networks, each consisting of 500 to 1000 registered members with diabetes, based on almost 140 'patient information centres'. These are run by 'peer educators', community members with diabetes who have received a basic training course, under the supervision of program managers who are also diabetic. Two studies in 2005 estimated that some 250,000 Cambodians were diabetic, with two thirds unaware of their condition (King et al., 2005). There is very limited support within the formal healthcare system. Individuals typically consult multiple public and private providers in a costly but often unsuccessful search for correct diagnosis and effective treatment (Men et al., 2012). The patient information centres identify new cases, provide targeted behaviour change information, monitor health status, and support access to qualified doctors and pharmacists when required. MoPoTsyo maintains a central computer database of patient records and the widespread availability of mobile phones facilitates the operation of the individual information centres and the overall network (see Fig. 4).

The Telemedicine Reference Centre Limited (TRCL), a private sector company focused on eHealth, has recently launched a chronic illness initiative in Bangladesh. It aims to offer a range of healthcare services for those with diabetes or hypertension on a subscription basis. As with the Indian example described above, a basic subscription (US\$10 per year) provides mobile phone access to qualified doctors. Patients will also receive relevant information and medical alerts via SMS texts and SMS prescriptions can be legally provided, because patients are formally registered with company doctors. The system is constructed around a 'Disease Management Portal' (Fig. 4). Registration involves the creation of a patient file which will hold all the medical records relating to interactions with the provider and which will be directly accessible to the patient. Patients will also be able to transfer data from home monitoring devices such as electronic glucometers and blood pressure monitors to this file. Home visits by qualified providers are also available (US\$10–20 per month) and the company has partnered with the Bangladesh Diabetes Association to provide in-patient facilities.

3. Discussion

As indicated above, though it is possible to argue for patient empowerment both in term of personal autonomy and on the basis that it will lead to improved health outcomes, for many policy makers it seems clear that the primary driver is the potential to control healthcare costs. Rising costs are a major concern in the highly industrialised countries and it seems evident that the position will be even worse in the developing economies, even those experiencing rapid growth. At the first European congress on patient empowerment in 2012, co-organiser Ilona Kickbusch argued that "In countries such as China and India, health systems will only be able to cope with the onslaught of chronic disease with patient empowerment" (The Lancet, 2012).

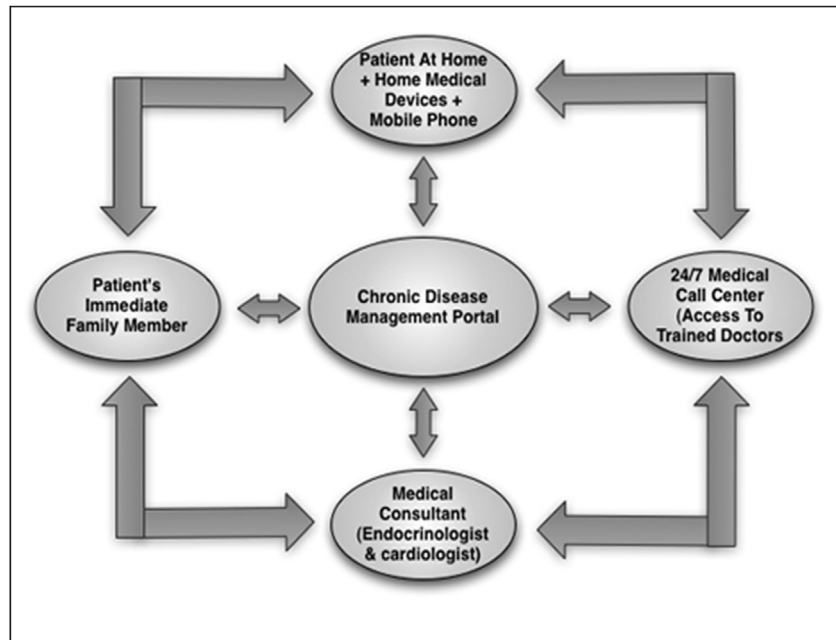


Fig. 4. TRCL/AMCARE model in Bangladesh.

However, empowerment in the context of a highly organised, highly regulated and well-resourced health system has very different implications for patients coping with complex, often marginally regulated health markets, routine cash-for-service payments even in the 'public sector' and an absence of qualified physicians and nurses in both public and private sectors, forcing reliance on a variety of community health workers, unaccredited providers, drug sellers and traditional healers (Ahmed et al., 2013). For poor individuals with a serious illness, and their families, there is a risk that empowerment may seem very much like abandonment. Schulz and Nakamoto (2013) argue against the tendency to assume that improved health literacy will necessarily lead to greater empowerment. As a general rule, 'knowledge is power' only for those who can use knowledge to improve their situation. In many of the health systems considered here, increased knowledge may imply simply an increased awareness that a patient has very few options, none of which are attractive.

Given the extent of existing resource constraints and the ever increasing demand for quality health services, even in poor rural areas, it is very tempting for some policy makers to promote the idea that support for self-management via eHealth initiatives might be able to deliver such services without the very substantial investment that would be required to train, equip and incentivise qualified providers to work in those areas. The title of a recent government initiative in Bangladesh, "Health Service through Mobile Phones" (Bangladesh, n.d.), perhaps illustrates the risk of excessive optimism as to the potential role of the technology. Any healthcare system should ensure access to basic diagnostic, treatment and referral services that are of reasonable quality and acceptable to the populations they are intended to serve. Advice from an on-call doctor with no prior knowledge of the patient or their circumstances, responding to a report of symptoms by an individual with little or no medical knowledge is not an adequate substitute. eHealth is often viewed through the lens of 'disruptive innovations' (Christensen et al., 2006), radical new approaches to service delivery that offer 'good enough' services at affordable cost, typically by limiting inputs by highly paid professionals to a minimum. There is a risk that some high profile eHealth projects that

claim the disruptive innovation status may be confusing 'good enough' with 'better than nothing'.

The three examples of self-management initiatives discussed above offer more grounds for optimism. They can be seen to some degree as being 'second best' options, in that those setting them up were driven by the failure of the existing health system to meet the needs of their members. However, they do illustrate the potential of diverse new approaches to disease management, even in very difficult circumstances. The survival of the Bangladesh clubs, given the limited support they have been provided, may seem surprising until one considers the impact of diabetes and/or hypertension on the lives and livelihoods of sufferers and their families in poor communities. The availability of an alternative to the costly, time consuming and typically unsuccessful search for reliable diagnosis and effective treatment they had experienced previously, would seem to have been a powerful incentive to persist, especially as that alternative was promoted by known, trusted doctors who remained in close contact by mobile phone.

The Cambodian initiative also started on a small scale, as a simple support network for diabetics in selected areas of Phnom Penh. It extended its activities to meet the expressed needs of its members, initially for consultation and prescriptions from supportive doctors, and then for a reliable and affordable supply of drugs from trusted pharmacists. In addition to the role of mobile phones in managing the network, the use of ICT in record keeping and patient monitoring appears to have been a key factor in advocating for additional support from funding agencies, which allowed the gradual expansion of the initiative and opened up the possibility of eventual adoption of the approach by the Cambodian government. The private sector initiative in Bangladesh is relative new and it will be interesting to see if this particular business model succeeds where previous efforts have failed. In many respects it closely resembles similar initiatives in the developed economies, relying heavily on ICTs to minimise costs and make its services affordable to a substantial proportion of the population, if not to the poorest.

A number of additional questions need to be considered in assessing the long term viability and value of such initiatives. First,

all three of the above were driven by a small number of key individuals, who invested enormous amounts of often unpaid time and in at least one case their own resources. What implications might this have for the possibilities of scaling up or translation of such models to other contexts? Second, effective gate-keeping functions are central to health systems in advanced market economies. In largely unregulated health markets these activities have to be undertaken either by patients themselves or by those individuals or agencies supporting them. It seems likely that this task will become increasingly difficult as an increasing number of commercial enterprises become aware of self-management groups as potential sources of income. Finally, it is clear that a very substantial part of the academic literature on self-management relates to a handful of chronic conditions: AIDS, diabetes, hypertension, etc. Does self-management imply abandoning the notion of an integrated healthcare system where resource allocation is at least partly linked to the overall burden of disease?

The key issue, as with many such innovations, would appear to be whether self-management groups are linked to intermediaries who are not just trusted but *trustworthy*, minded to work with 'the bottom billion' and not simply exploit them. It seems plausible that innovative technologies can further enhance the activities of established, successful patient groups and possibly allow the 'scaling-up' which has become the new holy grail of health interventions. They may even be able to enhance the regulatory environment within which self-management groups operate, for example by allowing effective and transparent tracking of health-care transactions, possibly drawing on lessons from the systems that allow clients to have faith in 'mobile money'. However, it is unrealistic to see technological advances as being the primary factor in determining whether such groups emerge and prosper.

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