PATIENT EMPOWERMENT: CREATING EFFECTIVE PARTNERSHIPS BETWEEN THE PATIENT AND THE HEALTHCARE DELIVERY CHAIN

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SUMMARY

The delivery of healthcare has, over the past 2 500 years, been firmly entrenched in the domain of the physician. Since the 'Father of Medicine', Hippocrates (470 BC) created his vision for just, moral and ethical standards of administering and providing medical care for his patients, the information flow and decision-making responsibility has resided uniquely and solely in the formal and traditionally established physician-driven medical system. Patients were grateful, uninformed, unimpowered and entirely dependent on their physician's judgement, intent, knowledge and goodwill. In this role, the medical caregiver's image was akin to a god-like figure. Recently, however, during the explosion of the information and technology era, patients have been taking a more inclusive interest in their health and the various treatment options available to them. This article examines the benefits, risks, ethical dilemmas and emerging processes being offered to promote patient empowerment, and also proposes three different novel categories of empowerment programmes which could be to the benefit of all stakeholders in the healthcare delivery chain (HCDC).

INTRODUCTION

The medically trained physician has, for millenia, been the partisan purveyor and deliverer of healthcare, a situation described by some as '*le syndrome du bon Dieu'* (Jacque Kriel, personal communication) and often leading to a form of dysfunctional medical practice.[1,2] But, during the past 50 or so years, *parri-passu* with the emergence of today's technological age, the patient is becoming as well, if not better, informed about their various conditions. For example, self-help books were and are in every household's library (medical encyclopaedias, medical self-help books for families such as Dr Spock's childcare books). The advice of the local pharmacist (who now does screening cholesterol levels, random blood glucose tests, blood pressure measurements and even pregnancy and HIV screening) is freely asked for. In addition, the social power of a new generation of glossy magazines (brimming with healthcare advice and provocative advertising) and television medical 'chat' programmes (often poorly disguised marketing instruments sponsored by the manufacturers of commercially interested companies such as vitamin and mineral supplement alternatives) are extremely popular. People love the drama of health-related topics, especially if they can share in other people's misfortune. The power and reach of the new 'social media era' together with the explosion of the information technology boom through the powerhouse of the internet (with search engines such as Google) has changed the face of information access.

Digital technology can now even assist diabetic patients with 'step counting', using various personalised devices to ensure that they exercise enough every day.

Consequently, the ready and rapid access to information has altered the mindset of patients completely. From being sterile, inactive recipients of healthcare, patients are becoming proactive and informed enough to demand a 'partnership' culture with their healthcare providers. Patients now have the tools and information access to become rapidly empowered.

According to Wikipedia's definition of 'patient empowerment' as a concept, the recent outgrowth of the global health movement asserts that '… to be truly healthy, people must themselves bring about changes in their social situations and in the environment which influences their lives, not only in their personal behaviour'. These advocates list the following as key tenets of patient empowerment:

1. Patients cannot be forced to follow a lifestyle dictated by others.
2. Preventative and curative medicine requires patient empowerment for it to be effective.
3. Patients as consumers have the right to make their own choices, and the ability to act on them.

In order to identify the appropriate platforms, interventions and novel tools to create a patient empowerment culture,

I use the following definitions for an 'empowered patient':

Archetype 1: A patient who becomes well informed about their condition through various and diverse information channels, and who then works together subsequently in partnership with their physician to decide mutually on the most appropriate form of treatment, intervention and outcome options for the condition. The sanctity and authenticity of the patient's right to ultimately make their own choice for treatment is paramount and should be encouraged.

Archetype 2: A patient, who is connected to various self-help and common community networks, in order to share experiences, develop a sense of common purpose and to engender a sense of 'belonging' with similarly afflicted patients, whatever their condition may be. These networks can be created by digital technology platforms, or can be sponsored and formed by academic bodies, pharma companies and socially initiated groupings.

Archetype 3: A patient who becomes part of unique projects designed to give them back their self-esteem, the courage to bear their burden of disease with fortitude and to give them a sense of meaning and purpose in life, independently of the gravity or prognosis of their disease. Patients with diseases which hold a social stigma (such as HIV/AIDS, cancer, alcoholism, drug dependence and mental disease) are especially responsive to such interventions. Projects designed to give patients back their self-esteem and power often simultaneously create the conditions whereby they become powerful forces for change and renewal in their communities.

The paradigm shift in the HCDC is consequently now rapidly evolving. This evolution is creating both new problems, but then also many opportunities for those in the HCDC. New players such as healthcare funders, pharmaceutical companies, institutional and private hospital groups, 'over-the-counter' and alternative medicine manufacturers and traditional cultural healers have all become important stakeholders in what is today called the 'healthcare industry'. The value proposition and mandate of the historically dominant physician has consequently become co-owned by a plethora of new players, who are today an amalgam of providers of a wide range of services to the patient.

Regrettably, however, the patient is becoming increasingly confused by the explosion of facts and diverse proposed solutions, resulting in an even greater 'need-to-know' culture of information hunger.

Within this transformational turbulence, the value and cornerstone importance of both information and stakeholder connectivity remains central. One of the dilemmas is, of course, whether the required information availability is constantly and equally accessible everywhere (this connectivity differs between developed First World communities and emerging Third World communities) and whether it is validated and correctly interpreted by both patient and doctor in a balanced and scientifically relevant manner.

Nevertheless, the central premise is that the information and decision-making flow in terms of medical care today has reversed. It now runs in the opposite way, in that the patient is usually well (although not always wisely) informed of their condition and possible treatment options by the time they consult their doctor.

The question then begs as to whether the doctor today is redundant? An assessment of the average patient's opinion and faith in their information sources (other than that received through a medical consultation) has shown that patients put as much value on information and advice which they have obtained themselves, as they do by consulting their physician (personal communication, Hamelin). This is a growing reality. Medical information access channels available in the public domain are expanding exponentially, as both patients and healthcare providers are seeking new and reliable sources of information.

The explosion of health-related websites is a case in point. These sites vary in content and by sponsor. For example, the Governmental Agency for Healthcare Research and Quality of the US Department of Health and Human Services has created a website entitled www.ahrq.gov/questionsaretheanswer (accessed July 2012), where patients are instructed what to do before, during and after a consultation with their physician. They are encouraged to recognise that they cannot be forced to follow a lifestyle dictated to by others, and that they are entitled to make their own choices, together in an equal partnership with their physician, and act on them. Indeed, the concept of personal choice and co-responsibility in managing one's health is being incorporated into the discipline of Medical Ethics as a growing interest area in medicine. Even very young children now have well-defined choices in accepting or refusing treatment,[3] according to the Child Health Act of South Africa. The US website quoted above is aggressively advertised (*USA Today*, 23 November 2011) with full-page advertisements in globally circulated papers. Then there are therapeutically segmented sites, for instance, a website for patients with allergic disease, driven by the European Academy of Allergy and Clinical Immunology (www.infoallergy.com, accessed July 2012).

These are only two examples of governmental and organisational 'self-help' websites. There are thousands of other information channels. But regrettably, the quality of information and its relevance to any particular situation is, at best, fragmented and incomplete. Information on its own is worth very little.

Nevertheless, by the time a patient in a First World,

developed country sees their physician, they invariably know as much (if not more) about their condition than him or her. They are also eagerly prepared to litigate at any stage should there be any perceived or real act of omission or commission by the healthcare provider which leads to any adverse event or sequelae to treatment. Patient safety, with regard to the monitoring and tracking of side-effects and abnormal events after ingesting medication is therefore a growing concern, and physicians all now carry significant amounts of medical insurance cover (eg the Medical Protection Society, UK), far in excess of the situation years ago.

The question remains as to whether this empowerment, relating to the patient's own rights and choices, is balanced and augmented by the clear added-value benefits of their physician's judgement and an understanding of outcomes-based solutions which only a healthy and robust partnership with a physician will bring to any particular solution.

In addition, because of recently more stringent monitoring of organisational governance and ethical codes of behaviour between doctors, their patients and the global pharmaceutical industry, the terms of engagement and the unencumbered debate and discussion between these various stakeholders has become increasingly regulated.

It should be noted that patient empowerment and protection has also fallen under the spotlight in other areas. For example, the regulation of clinical development work with both new and established chemical entities has been tightened. The very fine ethical principles applicable to doing medical research on human subjects, as enshrined in the Declaration of Helsinki (World Medical Association General Assembly, Helsinki, 1964) has now gone through numerous additional iterations (the latest being in Seoul, Korea, in 2008). Some governments have been of the opinion that clinical trials have used patients as 'guinea pigs'[4] and new laws are constantly being promulgated to ensure the dignity, safety and empowerment of patients.

'What' then and, even more importantly, 'how' then, do the major stakeholders involved (see Figure 1) in the provision of optimal healthcare to patients develop and create an integrated, co-ordinated, relevant and structured partnership model which will increasingly empower patients within our regulated environment, while at the same time, ensure optimal healthcare and the elimination of risk?

EXISTING PLATFORMS AND INFORMATION SOURCES CURRENTLY AVAILABLE
These are broadly listed and discussed in the introductory comments of this article. These platforms are suitable for the Archetype 1 patient.

NEW EMPOWERMENT MODELS
There are three new categories of unique patient empowerment models which can be developed and integrated into a novel operating plan for both Archetype 2(a and b) and Archetype 3(c) patients.

a. Connectivity, networking and communication with common interest communities, using social networking media and telecommunications platforms. These novel and emerging adaptations of digital technology can be readily developed today, working closely with innovative and highly specialised digital agencies. The platforms, principles and marketing concepts used in creating common online communities are easily developed and are based on a software lifecycle methodology (SDLC) system.

b. Membership, participation and facilitation of therapeutic area interest groups, such as the disease-oriented patient empowerment (DOPE) programmes, encourage the patient to co-manage their disease in consultation with other similarly affected patient groups. This is a proposal and concept designed by Prof Robin Green, Professor and Head of Paediatric
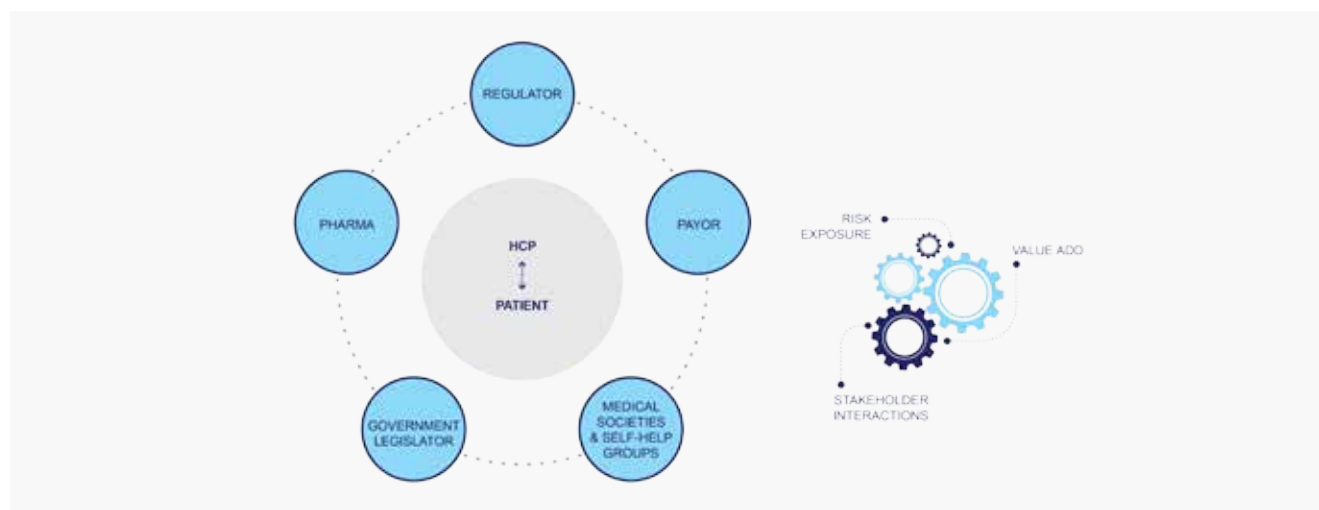

Figure 1: Stakeholder interactions

Pulmonology at the University of Pretoria, and past Chairman of the National Asthma Education Programme (NAEP) (Personal Communication).

c. Rolling out unique, therapeutically-based patient participation programmes, to elevate self-esteem and to create the optimum positive environment for mental and physical healing while the patients are dealing with their particular disease. The encouragement of patient advocacy and support is a cornerstone of this platform, such as the Moments in Time Project for example – a multidimensional project which connects oncologists, patients and our society at large. Apart from the passionate and artistically unique product deliverables, (visually appealing calendars, diaries and other products) the project has become extremely well branded, and has brought fundamental and meaningful support to hundreds of patients living with cancer. The project, which can be viewed on www.momentsintime. co.za (accessed March 2014), has influenced and changed the lives of thousands of patients living with cancer. The project can be presented as an example of patient empowerment and advocacy in the purist sense. One patient wrote:

'Thank you for this magical and life-affirming opportunity. You have given us dignity, self-respect, a purpose to fight the battle and a meaning for life. Moments in Time is not only about honouring patients, but more about honouring and encouraging those patients and loved one's who will gain strength from this project. You have my deepest respect and fond love …'

This concept can be expanded and tailored to any therapeutic area.

GAME-BREAKERS
There are numerous potential game-breakers which need consideration before a risk-free and workable implementation programme can be implemented. Both the advantages and the disadvantages for each stakeholder need to be appreciated, as well as the impact between stakeholders. For instance, failure to appreciate that the governmental and secular legal framework, the commercial imperatives, the healthcare providers' ethical considerations, the funders actuarial and social complexities, the regulator's safety and gatekeeping role and the pharmaceutical companies governance and conduct prerogatives will all need to work in harmony.

So, is the promotion of patient empowerment desirable or an unmitigated risk? Is it really an attractive option to encourage the patient to play a greater role in choices regarding their welfare? Are the downsides of any such initiative perhaps not ultimately to the patients' detriment? Because clearly passengers do not fly jet planes nor do airline captain's practise surgery! Is there more benefit

> **30% - 50 % non compliance in the USA**

> **Non-adherent vs. adherent risk for hospitalisation**
> ◊ **Diabetes (rises to 30% from 13%)**
> ◊ **Hypertension (rises to 28% from 19%)**
> ◊ **Other chronic illnesses (rises to 12% from 6%)**
>
> *Non-adherence cost in USA per annum - $290 billion*

Figure 2: Patient compliance as a surrogate marker for empowered patients

than risk in patients taking increasing responsibility for certain of their healthcare decisions?

Consequently, empowerment could be a negative development, although hardly avoidable in this era of modern information technology. 'Concern for impact' needs to be fully understood by all stakeholders. For instance, government agencies and licensing bodies for healthcare professionals (HCPs) could easily legislate against the use of electronic communication platforms between the HCPs and their patients. Equally, pharmaceutical companies would need to be aware of the risks when planning interventional strategies for their patients to avoid legal, regulatory and moral backlashes.

Questions should also be rightfully asked regarding the sources and validity of any information channels being accessed by the patient. Regulatory agencies may have legitimate safety and efficacy concerns regarding patient information leaflets for example, although websites and internet-based platforms are invariably not easily regulated.

Other than electronic and internet search engines, medical organisations and societies have begun to develop programmes which integrate educational advice into each patient contact. Some funders and medical aid organisations have begun to explore the facilitation of contact between HCPs and their own 'wellness programmes'. The largest medical aid in South Africa, Discovery Health, has offered financially incentivised 'reward' points to patients who join the National Asthma Education Programme (NAEP), who then receive dis-counts on a large number of health-related activities such as gym memberships, travel, etc. To date, this kind of access to medical information by bodies such as NAEP have been welcomed by the regulators, since the overall benefits to healthcare are obvious. While pharmaceutical companies cannot deal directly with patients, in this manner, they can directly influence this process by funding

Justice, integrity and morality will become the NEW order in our transitional world, in every aspect of human endeavour and striving.......

Figure 3: This is a process, not an event

NAEP and similar societies.

The downside of having patient information disseminated by the powerful press, television and the general print media is that these media often offer largely invalidated and unregulated sources of information.

PATIENT COMPLIANCE AS A SURROGATE MARKER FOR EMPOWERED PATIENTS

Data from the US healthcare system suggests that between 30–50% of patients do not take their prescribed medications. These non-compliant patients have significantly higher rates of hospitalisation and mortality compared to compliant patients. This is one positive reason for patient empowerment to be emphasised (Figure 2).

CONCLUSION

Using the principles, technologies and novel projects and platforms detailed above, in tandem with the existing information technology and internet-based search engines currently available, unique and mutually beneficial patient empowerment processes can be created and implemented by all the stakeholders concerned in the HCDC.

This momentum will become more relevant in the coming years, as the world moves into the new technology age (see Figure 3).

CONFLICT OF INTEREST AND FUNDING

This article has been peer reviewed.

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