Afterword

User-Driven Health Care: A Means to Achieve True Health Systems Reform?

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ABSTRACT

Health, illness and dis-ease are points on the experiential scale of well-being and occur in the presence as well as in the absence of identifiable pathologies. Health, illness and dis-ease in addition are influenced by many contextual factors of a person’s life. As such it is not surprising that people require many different inputs into their health care, many of which are non-medical in nature. As yet though, these issues have at best been insufficiently taken into account in the overall planning and provision of care and of health service structures. This chapter will take a conceptual rather than a technical or social perspective towards exploring user-driven health care. It views user-driven health care as an emergent phenomenon in the context of a rapidly evolving web-based communication infrastructure. It highlights that knowledge has many dimensions each of which contributes unique insights to the understanding of health as a personal adaptive experiential state that needs to be distinguished from the health professionals preoccupation with pathologies. Information technologies increase connectivity between people and the sharing of knowledge and experiences narrows the ‘gap between the expert in the pathology and the expert in the dis-ease’ which finally may give people the power to shift the attractor of the health care system to the health needs of the people, resulting in truly people-centred health care reform.

INTRODUCTION

User-driven healthcare may be defined as ‘Improved health care achieved with concerted collaborative learning between multiple users and stakeholders, primarily patients, health professionals and other actors in the care giving collaborative network across a web interface’. (Biswas, et al. 2008) In short user-driven health care promotes the concept of enabling patients and health professionals to meet their individual as well as joint needs – educational as well as
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emotional and social – whenever they arise. This has become possible by the rapidly developing and expanding IM/IT techniques like mobile phones, internet infrastructure and the Web 2.0 platform (Figure 1) (Biswas, et al. 2009). The increasing awareness, especially of patients, regarding the possibilities and limitations of 'current health care approaches' may enable the user-driven health care movement to become the tipping point to achieve true health care reform, reform that places the person and her health experience at the centre of the health care system.

This chapter will explore the notion of user-driven health care from a conceptual rather than a technical or social perspective. It views user-driven health care as an emergent phenomenon of the rapidly evolving web-based communication infrastructure that allows rapid exchange of information and perspectives between diverse sources with variable degrees of knowledge and/or authority. To fully appreciate user-driven health care potentials as well as limitations it will explore the notions of knowledge in relation to medicine, and the notion of health, illness and dis-ease in contrast to pathologies. These two concepts are fundamental to understanding the structure and function of health systems, and together they underpin the proposition of 'patient-centred' health system reform that would result in a truly person-centred health system.

KNOWLEDGE

There have been many philosophical discourses about the nature of knowledge and the following explorations are pragmatic in nature. Knowledge is as much about knowing what – naming facts and relationships – as it is about knowing how – explaining relationships and processes. More importantly though is the fact that knowledge has explicit, i.e. codified and easily communicable, and tacit, i.e. non-codified and therefore difficult to pass on, components. Michael Polanyi (1891–1976) explored the domain of tacit knowledge describing it as the domain of personal knowing. (Polanyi 1958) He contends that tacit knowledge largely shapes the way we perceive the world around us. In relation to medical sciences he stated that:

... personal knowledge in science is not made but discovered, and as such it claims to establish

Figure 1. A framework of user-driven health care (AMIN - xxxx; PHR - Patient Health Record; PSTN - Public Switched Telephone Network ; WAP - Wireless Application Protocol. with permission from Biswas (Biswas, et al. 2009))
contact with reality beyond the clues on which it relies. It commits us passionately and far beyond our comprehension, to a vision of reality. Of this responsibility we cannot divest ourselves by setting up objective criteria of verifiability – or falsifiability, or testability, or what you will. For we live in it as in the garment of our own skin.

For Polanyi, tacit and explicit are different but inseparable aspects of knowledge. Both can be learnt though the learning modes will be different. Tacit knowledge is largely transferred in an experiential way, it is unfolding as it happens – we see what we know, and we see what we need to know; it identifies our needs in the here and now.

Kurtz and Snowden, through the Cynefin (pronounced kun-ev’in) framework, have taken this further describing knowledge generation and management as both – the state as well as the process – of sense making (Kurtz and Snowden 2003). The Cynefin framework consists of different knowledge domains – the known, the knowable, the complex or emerging, and the chaotic or random – in relation to human thinking and organisational management. Figure 2 translates ‘the business of medicine’ into this framework.

Looking at the framework makes evident that we always operate in all domains some of the time, or move to and from one domain to another depending on our context or changing circumstances (Sturmberg 2009; Sturmberg and Martin 2008; Sturmberg with a contribution by Martin 2007).

Expanding the static picture into its dynamic underpinnings shows that new knowledge is generated as a continuous flow between the chaotic state of puzzlement to the complex state of relative uncertainty to the state of the known typically associated with expert knowledge. Only occasionally though will some new knowledge become unshakable.

Understanding knowledge as a dynamic phenomenon, and knowledge generation as an iterative process, has important implications for the delivery of health services on the individual level and the way we approach health care reform. At the health care delivery level the lenses of

Figure 2. The Cynefin framework of knowledge and knowledge generation in medicine (with permission Sturmberg with a contribution by Martin 2007)
knowledge as a fact and knowledge as a personal event overlap. Sharing the different perspectives allow patient and health care provider to learn, or more precisely, gain new knowledge about each other in the context of the patient's concern. Or put differently new meaning can emerge from the expert knowledge of the health care provider and the lifeworld\textsuperscript{ii} knowledge of the patient. (note: the health care provider can be substituted for by any person engaging with a patient, and the sharing itself can be by direct or indirect means).

The dynamic model of knowing is even more important when engaging with the health system and health system reform. No individual will have all the knowledge required to see and understand the interconnections within a huge and diverse health care sector. This is especially true as one also has to take into account the "non-medical" domains impacting on health, such as education, housing, work and working conditions, social and environmental infrastructure and so forth. It should be clear that the prevailing linear hierarchical structures of knowing are incongruent with the dynamic “needs” of knowledge and knowledge generation for a complex adaptive health system.

THE SEMANTICS OF HEALTH, ILLNESS AND DIS-EASE (THE SUBJECTIVE) VERSUS PATHOLOGY (THE OBJECTIVE)

Lakoff alluded to the notion that the way we talk (in metaphors) about things matters as the way we talk reveals how we perceive, how we think, and how we act (Lakoff and Johnsen 2003). Hence the terms health, illness and disease require some a-priori exploration as they are often used interchangeably and have no a-priori relation to the biologically based notion of pathologies. We usually clearly distinguished these from sickness, the social role ascribed to someone who is "not well",

People usually sought and continue to seek medical care when feeling ill or in dis-ease (the literal meaning of the otherwise ambiguous term disease) (Remen 2001). Lewis has argued that health, illness and dis-ease are points on the same subjective scale, and have to be distinguished from the biological changes of pathology (Lewis 2003). On this basis it is no longer tenable to accept equating disease with pathology (Fig 3). It is emphasised here that health, illness and disease can be experienced equally in the presence

Figure 3. The subjective verses the objective nature in health care. The health professional is the translator between the subjective and objective behind the person’s experiences about themselves.
as in the absence of identifiable pathologies, and that the subjective and objective – though often understood as mutually exclusive dualisms – are coexisting experiential realities.iii

The notion of pathology, i.e. the biological changes in body structures, as a result of noxious agents is a rather new one. In fact our understanding of most pathologies occurred only since the middle of the 19th century when the newly developing technologies like the microscope allowed us for the first time to see some of the biological changes associated with the phenotypical appearance of some dis-eases. However, as Kerr White and colleagues have shown in a seminal epidemiological study only about 1% of all illness/dis-ease experience has an identifiable underlying pathology (White, et al. 1961).

The most important task of the doctor has been that of the translator between the subjective and objective behind the person’s experiences about themselves (Egnew 2005), a point that has been largely lost, but never has it been as important as over the past 150 years, a time in medicine dominated by ever increasing scientific and technological approaches. However the limitations of the scientific and technological approach as the only means to cure humankind are becoming rapidly evident – for example, the latest belief that the human genome project will be able to clarify once and for all the ‘cause’ of any health problem is rapidly becoming a myth. The link between the genotypical and phenotypical picture of most pathologies is complex. Latest research has shown that one phenotypical pathology can be ‘caused’ by a wide variety of genotypes (Beckmann, et al. 2007; Lesnick, et al. 2007; Loscalzo, et al. 2007).

There is an urgent need to refocus on the sense-making work that underpins the healing professions (Egnew 2005; Remen 2001; Sturmberg with a contribution by Martin 2007). Making sense of or coming to terms with one’s ailment is essential to achieve health, especially if cure is not possible. Achieving health then becomes a continuous transformative process of adaptation, incorporating the subjective experiences described in the terms health, illness and dis-ease with the objective changes described by pathologies. If health, illness and dis-ease can be experienced as much in the presence as the absence of identifiable pathologies, how can this experience be conceptualised as a coherent whole?

Complex adaptive systems theory offers a framework through which to understand health as a personal experiential construct – health is

Figure 4. The complex adaptive model of health (with permission Sturmberg with a contribution by Martin 2007)
a balanced state between the physical, social, emotional and sense-making dimensions of one's being (Fig 4) (Sturmberg, et al. 2010; Sturmberg with a contribution by Martin 2007). Significant deviation from the balanced state in whatever direction is associated with the experience of illness and dis-ease. These figures present a particular state of health at a particular time in a particular patient. Reaching a particular point within the 'balance plane' is the result of ongoing dynamic movements within and across all its domains.

HEALTH: A DYNAMICALLY CHANGING STATE

The apparent paradox of health and dis-ease is exemplified in the following two figures. Both patients had a myocardial infarction of varying severity. The first experiences health in the presence of quite severe pathology – ischaemic post-MI cardiomyopathy. Here the patient has done the necessary adaptive work – on his own or through the facilitation of his health care providers – he found new meaning in his altered biological state (Figure 5).

In contrast the other experiences dis-ease in the absence of significant pathology – he sustained a non-transmural myocardial infarction without damage to his heart muscle and its pump function. Here the patient and/or his health care providers failed to do/facilitate the necessary adaptive work to achieve meaning from the experience of a threat to his self (Figure 6).

As these examples illustrate health (and for that matter illness and dis-ease) is a dynamic state. Health is constantly re-interpreted and re-constructed in the context of the myriad of ever changing influences in a person’s life. Each new state in the personal health experience generates particular challenges and needs, some of which require simple information, whereas others demand a deep search for knowledge and/or wise counsel.

THE USER-DRIVEN APPROACH REGARDING INFORMATION, KNOWLEDGE AND WISDOM

Getting the right information is only the start towards user-driven health care. E-technologies provide ready access to – often unreliable – in-

Figure 5. Experience of health in the presence of significant pathology (with permission Sturmberg with a contribution by Martin 2007)
formation, however information alone? does not
equate to knowledge. It requires considerable
skills to vet the content of websites, and it takes
further skill to use reliable information to generate
new knowledge.

Blogs and discussion fora allow the sharing of
information and experiences between people. This
is particularly helpful to people affected by “the
same” condition, and much of this sharing enhan-
ces their ability to make sense of their symptoms
and their illness, both of which strengthen their
psycho-immune responses that in turn enhances
their self-healing capabilities and enhances their
health experience (Kiecolt-Glaser, et al. 2002).

It is the enabling of the person to become an
active participant in the consultation – face-to-face
or virtual – that contributes to the achievement
of good patient care. Good patient care requires
an ongoing provider-patient relationship and
practical wisdom, also known as phronesis, of the
practitioner in helping her patient to adapt to her
changing health needs (Egnew 2005; Fugelli 1998).

These are the tenets of this book, and many
of the chapters give a deep insight into the wise
interactions resulting from a user-driven health
care approach, a couple which are highlighted here.

The importance of understanding the patients'
context on the structure and function of care de-

delivery is highlighted by Fitzpatrick. Effective and

efficient medical care systems must understand the
context they operate in and be cognisant about the
perceptions, social roles and expectations of the
people they cared for (Fitzpatrick - insert refer-
ence in relation to book chapter). No two health
systems can be structured to operate in the same
way, however, health system planner's can aspire
health services and their staff to deliver care that
meets the needs of their patients.

How important it is to understand context
and how easy it is to construe the 'reality' of the
people's and community's 'true' context is pain-
fully illustrated by Megan in the context of AIDS
in sub-Saharan Africa. A 'single paper' based on
speculation has demonised female sex workers as
the cause of the AIDS epidemic in sub-Saharan
Africa. However poverty is a major factor for
women to engage in sex work with its high risk
of contracting AIDS, though most see only a
small number of clients per week. Their poor
health is further compounded by societal stigma,
social isolation, and a disinterest of the police
and the health care sector for their well-being.

Figure 6. Experience of dis-ease in the absence of significant (with permission Sturmberg with a con-
tribution by Martin 2007)
The misunderstanding of these interconnected factors perpetuates the poor health of sex workers as it does the spread of AIDS. Interventions that overcome poverty have been shown to get these women away from sex work - a classical example of a small intervention resulting in a major change in a complex adaptive system (Megan - insert reference in relation to book chapter).

Young's personal story illuminates the limitations of the instrumental approach, arising from the belief of certainty inherent in the medical sciences, to health care. Young alludes to the power differential between health professionals and patients, and the perceived inability by many patients to say no to 'well-meaning' treatment suggestions that are incongruent with the patient's beliefs and aspirations. It also highlights an inability of many health professionals to view 'a problem' through the 'patient's lens'. Young's initiative to provide a forum for people affected by her dis-ease provides a new voice as much as it harnesses the 'wisdom of the crowd' to influence clinical decision making and fostering research agendas (Young - insert reference in relation to book chapter).

Sliedrecht and Kotzé's work emphasise the importance for health professionals to 'pro-actively' elicit patient expectations about their care in the context of spinal cord injuries. They also highlight the importance of the 'sense-making' work, as hard as it may be at times, required from patients and their carers to achieve 'healing'. Patient-centred care is clearly more than instrumental care, patient-centred care that aims to heal requires 'to be there in the moment' with the patient, to 'just be human' when it matters most (Sliderich and Kotzé - insert reference in relation to book chapter), a most important skill to be cultivated in all health care providers (Shankar - insert reference in relation to book chapter).

**CAN USER-DRIVEN HEALTH CARE BE THE CATALYST FOR TRUE HEALTH SYSTEMS REFORM?**

So far the central argument in this chapter has been that knowledge has many dimensions each of which contributes unique insights to the understanding of health as a personal adaptive experiential state. Achieving a good health experience requires the engagement of the person, and the notion of user-driven health care reflects the people's capacity and desire to be an active participant in the healing process.

It naturally follows that health should be the central concern of the health care system. System, or more precisely complex adaptive system, is the imperative term. Complex adaptive systems are characterised by self-organisation, requiring a system to be open and far from equilibrium, with ill-defined boundaries and a large number of non-linear interactions involving short-loop feedback. Most importantly all interactions within the system are focused around its attractor, or core driver.

Capra illustrated the characteristics and functions of complex adaptive systems through the bathtub vortex metaphor (Capra 1996). For the bathtub the attractor is the plug hole – pulling the plug leads to the water forming a vortex, and, as we all recall from our childhood experiences, any disturbance of the vortex in whatever way will always restore the vortex very closely to what it had been before the disturbance, demonstrating the self-organising function around its attractor – the plug hole.

Currently the core drivers of most health systems is either/or or a combination of financial constraint/financial gain and top-down 'pathology' management. In an ideal health care system the core driver would be the patient's health experience. In operational terms this translates to the needs of the patient being the organising force.
determining the inter-relationships between all the agents at and between all the levels within the health care vortex.

Figure 7 shows the health care vortex as a representation of the ideal health system driven by patient need. At each level the agents constantly re-organise their relationships and interactions according to this patient’s need (Sturmberg, et al. 2009).

A truly responsive health care system would seamlessly integrate the multiple needs of each patient. In such a seamlessly integrated health care system, the medical delivery component is only one part (or sub-system) of the overall system. The medical service delivery sub-system would interact with social, educational, work, transport, housing, environment, and infrastructure and so forth sub-systems, fully cognisant of the role of the interconnected emotional, social and environmental determinants/constraints on the health of this patient. The latter point alludes to the notions of determinants of health at the population level. The terms ‘determinants’ and ‘constraints’ in the context of complex adaptive systems arises from the interconnected nature of ALL agents and their interactions on the health experience of the patient.

The concept of user-driven health care emerged in the context of improved information technology. Information technologies increase connectivity between people and the sharing of knowledge and experiences narrows the ‘gap between the expert in the pathology and the expert in the disease’ which finally may give people the power to shift the attractor of the health care system from the top-down, fragmented by specific pathology interests and preoccupied by financial profits, to the health needs of the people. Incidentally this is

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**Figure 7. The 'Health Care Vortex' as a metaphorical representation of the health care system**
the philosophical and time-proven basis of medical care since time in memoriam across all cultures.

SUMMARY

User-driven health care is more than providing people with access to information through improving technologies. User-driven health care is the expression of people's deep-seated need to be an active participant in the therapeutic relationship with their healer. The user-driven health care technology gives people a voice or the means (or in system terms provides the little nudge or perturbation) that ultimately will shift the system's attractor so that the system will rearrange its structure and interactions to meet their health needs.

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REFERENCES


ENDNOTES

i From a medical philosophy point of view I prefer the term 'patient' (meaning the vulnerable) to the term 'user' which has a strong 'instrumental notion' to it, and reflects the sociologicallens of 'the medical encounter'. Pellegrino, ED, and DC Thomasma. 1981. A Philosophical Basis of Medical Practice. Towards a Philosophy and Ethic of the Healing Professions. New York Oxford: Oxford University Press.

ii Referring to Husserl’s notion of phenomenology

iii Lewis refers to Canguilhem as follows: In 1943, the medically trained French philosopher Georges Canguilhem posed an important problem that continues to be relevant to this day. Take a man, he suggested, who complains of no ailments and whose life is suddenly cut short by his being murdered or his dying in a car crash. For various French legal reasons, an autopsy is performed and the dead man is found to have a serious cancerous tumour – in Canguilhem's example, of the kidney. What then do we make of the man – did he have a disease or didn't he? Canguilhem, G. (1989). The Normal and the Pathological. New York: Zone Books. (p92)

iv A detailed discussion of these concepts can be found in The Foundations of Primary Care and Health at the Centre of Health Systems Reform – How Philosophy can Inform Policy The tenet here is that the system is only changing if there is a reason to do so. Enabled patients "demanding" a different approach to their care will "force" doctors and other health care providers to adopt a "different approach" - centred on the patient or people. In this sense the "demand for change" becomes "enabling" for all involved.

v Disease management focuses on the management of patients with discrete pathologies. Disease management programmes place a heavy emphasis on 'correct instrumental management' according to 'best practice guidelines' and vary greatly in terms of addressing patients' needs holistically.

vi Traditionally determinism refers to the causality of an unbroken chain of prior occurrences on the event of interest.