Preface

UTILIZING MULTIPLE INTELLIGENCES FROM THE “USER DRIVEN HEALTH CARE LEARNING NETWORK” TO ANSWER INDIVIDUAL HEALTH INFORMATION NEEDS

“If what you are trying to communicate is not entertaining all you can do is write it in a journal” – Woody Allen (2012).

The reader is invited to join a rapidly evolving network of people who are driven by one single passion, “learning.” We welcome you to review with us a “learning” journey that all of us began perhaps even before we were born.

“Ontogeny repeats phylogeny” is a hypothesis that may conjure a vision of the single cell gradually dividing to produce multiple cells specializing into cellular networks performing different functions of one large multi-cellular animal. This picture is superimposed on a hazy background picture of the forces of evolution driving the first cell in its primeval sea until it specializes over the ages into a multi-cellular being that can even walk on land.

Most humans may not like to learn much about how these cellular networks function in our bodies and yet there are times when we fall ill and curiosity may lead us to wonder why and where in our body the origin of the problem is.

One of the most important elements that binds together our cellular networks is “communication,” be it through the exchange of molecules or any other postulated mechanism. Human networks closely mimic collaborative cellular organization in the sense that they are bound together by communication, which allows them to organize into teams and colonies performing different functions. For the majority of human evolution, this communication has been face-to-face and synchronous between different individuals, until the birth of the cave men, who began recording their exploits in “cave-paintings,” and the first alphabet was born.

The alphabet has, over a few thousand years, transformed the human race into asynchronous communicators beginning in letters and stories that could be savored at an individual pace and privacy until this neo-communication phenomenon progressed to create a breed of humans, men and women of letters, quintessential asynchronous communicators who became labeled as “academics.” Information technology and, consequently, computer mediated communication has created an explosion in “asynchronous communication” like never before, and this may appear to resemble a room full of people with just the sound of their pecking at computer keys, their conversational responses varying in time from immediate to days later, with a silent emoticon-driven emotional banter to match. Some of us may like to label this a postmodern world.
The above-mentioned “academic” scenario is as useful as it appears scary. We are posed to create a world where most people are likely to “read up” before responding to each and every natural language communication such that many responses could lead to decisions or actions that are “evidence”-based and drawn from a “consensus” of “generalized” human opinion, which is more likely to be politically correct. In health care this “correctness” can be life saving (and even apolitical). Ever since the internet was born, individual patients and their relatives have tried to (primarily asynchronously) look for better evidence-based information reflecting a generalized consensus to answer many of the queries generated while dealing with their illnesses. This is all the more true of chronic illness, where faith in a single health professional’s ability is tested on the altar of time and patients quickly realize the importance of learning from “multiple intelligences” of different health professionals, more so as the patient’s problems may involve multiple systems and multiple dimensions ranging from the physical to the psychological that may be difficult for a single health professional to tackle with modern health professional training, where most health professionals learn to specialize in narrow disciplines and hone their skills in those areas. In such a situation, a patient would need to be shunted across multiple health professionals involving multiple waiting times, multiple interviews, and telling the same story over and over again. A natural solution to this conundrum in this age of ICT would be that instead of the patient, his/her data/information may travel through a network of connected health professionals that can offer the “multiple intelligences” desired and appropriate to the case at hand.

The objective of a journal platform developed by our network has been to document this “individual patient” effort toward contextual learning about their disease, along with efforts of other stakeholders in the health care ecosystem to provide their patients with information. Optimal information flow increasingly appears essential to achieve optimal health outcomes. What if we had a system where instead of one health professional, a patient could have a network of “health professionals” and “similar patients” supplying them with all the information they would need toward effective healing? Would it resemble a kind of input-process-output system where a patient’s informational input may be processed by a “network” of health professionals and similar patients to produce an optimal solution output?

Our “User Driven Health Care Network” was created to support this dream of global optimal information flow to generate an ideal health care ecosystem. We have, in the past few years, begun communicating with a few rural remote patients (none of them had ever used a computer), as we wanted to help them understand their illnesses better, and they responded to it in their own manner by sending their handwritten letters after scanning them from an Internet cafe (doubling up as a tele-health center). We were aware of HIPAA guidelines, and the solution we adopted was to make the Internet cafe owner remove all patient identifiers as per HIPAA guidelines, along with getting an informed consent signed by the patient in their own language.

We use a list of botanical names (plants common to our area) as patient user names and encourage patients to plant the same as well as look after their health (and record) as they would nurture the plant. This apparently quirky idea has not gathered full steam yet.

We have involved online medical students to learn from our asynchronous emailed communications with the patients—in some ways similar to how they learn synchronously in the hospital, and in many ways different, as they can contextually engage with the clinical problems in the patients in a more detailed and informed manner. They, however, do not directly communicate with the patients. Subsequently, our network expanded in a big way after a few dedicated rural physicians from central India started sharing their patient data with our learning network on a regular basis, and many more health professionals across the globe started responding to them.
The time remit of our “user driven health care” network is that we prefer communicating asynchronously (at our own time) through Web space. Many of the individuals in our network have never spoken to each other synchronously, and yet we remain bound by an asynchronous bond of positive information flow that may influence positive health outcomes for our largely asynchronously communicating patients.

Currently, our “user driven health care network” continues to expand and processes patient information input (after removal of identifiers) to generate “conversational learning threads” with solutions that need to be shared online for further processed learning inputs.

Individuals in our network are trying to develop a “one click” registration of any online user’s “health record/diary,” where an automated botanical user name would be allocated to the person on clicking “register.” An image of the same plant is pulled automatically from Google Images, and the person registered receives a simple message along with the plant image asking him/her to equally take care of the plant as well as his/her health.

The aim of our “User Driven Health Care” (UDHC) learning network is to help people make sense of their disease and also use these as case studies for shared learning and further processing among other “Internet user” stakeholders (be it medical students, other health professionals, or even similar patients and their concerned relatives or other professionals who are just interested in helping people manage their health...for example they could help to rearrange the largely unstructured narrative data based on a structured format, etc).

Other than the above Web-based model, we have attempted to utilize a journal platform to create a global forum for researchers and practitioners to advance the knowledge and practice of user-driven learning in healthcare and connected disciplines. The emphasis here is on learning through clinical problem solving that may help to answer some of the above questions. The current compilation emanates from the first year of this very journal. We began the first issue by asking the question (Biswas, 2011), “Can we use an online journal platform to propagate a learning environment where interested and articulate candidates with basic computer literacy with or without degrees in any discipline such as BA Humanities, Social Sciences, B Tech, B Sc Math, Physics, and Chemistry, etc., join and foster a multidisciplinary approach to healthcare?”

Can this interested group of human online users be expected to develop and propagate heightened health awareness and education among healthcare users (patients and their relatives) in the community? Does improved health system awareness in terms of safety and quality of care augment healthcare outcomes in the community?”

While the last two questions still remain unanswered, the overwhelming responses of certain patients from all walks of life has largely answered our first query in the affirmative and provided ample encouragement to our team on the feasibility of this approach.

Greenop and Thomas begin with a patient narrative that discloses the complex manner in which information from multiple health professionals and patient relatives may shape a patient outcome. The narrative takes us back to a pre-user-driven health care era when most such health care conversations and negotiations were synchronous and face-to-face. The patient narrative summarizes the essence of why “user-driven health care,” with its emphasis on transparent dialogue, is here to stay with these words, “Too many people have tried to cure me; too many people have tried to control me; but too few people have tried to talk to me…. Patients, whatever their condition, do not live in laboratories so compromises must inevitably be made. It is therefore imperative that care is negotiated within the realms of reality rather than being prescribed for ideal patients living in ideal worlds. To achieve this, responsibility not only to self but also others must be openly acknowledged and even encouraged so that dialogue and not monologue is the way forward” (Greenop & Thomas, 2011).
Siju Oommen George in his patient narrative exemplifies how health care conversations and negotiations currently help patients worldwide to sort out their own health problems, sometimes with the support of their health professionals but more often with support of other non-health professionals with similar illnesses.

David Elpern shares “a joint patient and health professional narrative which emphasizes possible utilities of a persistent clinical encounter between patients and health professionals toward improving health outcomes. It illustrates one of the important objectives of ‘User Driven Healthcare’ that notes an increasing influence of asynchronous email as well as electronic social networking between patients and health professionals as transformative toward the future of healthcare” (Elpern, 2011).

Joan Young shares how in 1997 “she used her technical background to construct a website where in addition to her story she incorporated as much information as she could about her disease and also added a discussion group. By the immediate and overwhelming global response she received, it was obvious there was a large, unmet demand for health information and sharing. She made sure her website provided an open exchange of information. The website went on to become the largest organization in the world supplying information and support for people diagnosed with her illness. It also attracted the attention and funding from pharmaceutical companies and some of the very specialists who had once glossed over her story. The companies and doctors welcomed the exposure to the thousands of potential patients and customers” (Young, 2011).

Rupert Whitaker points out one of the lurking dangers of misusing “User Driven Health Care” (UDHC) wherein “these pro-market services look for short-term products/solutions on which to build long-term profit; patients, as consumers, demand the more expensive blue pill (because that’s what the pharmaceutical company told them they need, through direct advertising) rather than, say, the more health-effective but effortful challenge of non-pharmaceutical treatment. This is the conundrum of pro-market solutions to medicine: they are inherently counter-productive to society’s medical needs” (Whitaker, 2011). However, the very nature of online transparency and dialogue between “multiple stakeholder intelligences” that forms the cornerstone of UDHC may ensure that it is not counter-productive.

In the same issue of the journal, two authors present their attempts at developing “user driven health care” solutions to the above patient-related problems related to sparseness of “dialogue and transparency” in health care.

Oikonomou et al. illustrate the developmental framework of a user-centred solution that requires observation in the context of people’s work, and helps the design team to build a rich picture of the situation at hand, created from the multiple perspectives of stakeholders. These multiple perspectives contribute “multiple intelligences” to the health care information ecosystem they are trying to create, and similarly Waidyanatha et al. share the concept of utilizing “collective intelligence” to affect a “multi-partner initiative by disseminating information and tapping into the intelligence of dispersed yet connected individuals and groups that hold the ability to push health best practices to the next level” (Abbott, 2010).

While the above are examples of multi-partner publicly funded large scale “User Driven Health Care” UDHC initiatives, Elpern and Foong in the third issue of the journal illustrate a Web-based UDHC conversational learning system termed, ‘Virtual Grand Rounds in Dermatology’ (VGRD) that has been developed on a smaller individual scale by two Dermatologists from US and Malaysia over the last decade that eventually became large because of regular online inputs from health professionals and patients across the world.

This issue was particularly focused on “Lupus Erythematosus,” and Tayabali et al. begin a series of “Lupus patient” accounts that are further discussed by a journal audience all through our UDHC network,
which also forms part of this journal’s editorial board. A final year medical student feedback on the same “patient narrative” reads, “as a final year medical student, when I read this passionate narrative, I could almost visualize the life of an SLE patient unfold before my eyes; and this quoted line from Tayabali et al., ‘It is an almost humiliating experience to have to describe pain on a numbered level of 0-10’ effectively highlights the lacunae we tend to overlook while evaluating and assessing a patient. In our efforts to quantify and objectively measure symptoms as relative and subjective as pain, we apparently remain ignorant of the ‘complex trajectories’ that most of the chronic disease processes seem to take.”

Another “patient narrative” that illustrates a self directed “user-driven health care learning” model only too well is that by Kirkpatrick et al., where the author describes how in her quest to find the answers to her addiction problem, she transformed herself from a struggling “computer user,” who could barely type, to someone who managed to finish a Diploma in Computing, and in 2006 an Open University B.A. in mixed subjects, before moving on to begin an honors degree in Psychology in the hope that this would help her to find the missing answers. By the time she graduated in 2009, she learned how to confidently access the information that she needed online.

Three articles reflect the UDHC network’s association with other Web-based sharing and publishing platforms such as BMJ, Cochrane students journal club, and social networking in medical education groups like “tabula rasa” that illustrate an exploratory approach in creating stimulating medical education resources in the form of interactive conversational learning. Biswas et al. demonstrate how “through ‘patient-centered case-based conversations’ between medical students and facilitators, students discover the subject and learn actively along with the facilitator who gradually guides them through the case-based problem in a nearly asynchronous manner on a Web-based forum.” Dayan et al. describe “interactive conversational learning between health professionals who present topics related to their practice either in the form of a case-based uncertainty or a general uncertainty around treatment decisions. Through these conversations, health professionals discover newer insights into the topic being discussed and learn actively along with an online group of health professionals who guide each other contextually through the discussion.” Chandra et al. describe their Web-based learning platform, “The Cochrane Students’ Journal Club” (CSJC), which is an online resource put together by a diverse team consisting of medical students, health professionals, educationists, and health policy makers. Ranging from diagnostic tests to treatment interventions and alternate therapies, the journal club focuses on scenarios commonly encountered by medical students during clinical rotations and initiates a discussion centered on them. CSJC aims to incorporate the best of evidence-based healthcare and contemporary clinical medicine and present it to students at the grass root level to promote the skills of scientific appraisal and writing.

UDHC is primarily a “health-education” movement that attempts to bridge the gap between health professional education and practice by asynchronously putting the patient at the center of all health professional learning. Health professionals all over the world are adapting to the new wave of “patient-centered health care” that is not only empowering but also an avenue for generating fresh insights on how to better our lives through “contextual learning” in health care.

Association of American Medical Colleges–Howard Hughes Medical Institute (AAMC–HHMI) in 2009 created multiple levels for developing medical school competencies for health professional education, and at each level it advocates a consideration of the patient’s macro-world in terms of prevention, diagnosis, and management, even as health professionals learn more and more about underlying cellular and molecular micro-world interactions that create our human body, particularly the pathology in those interactions (AAMC, 2009).
While this is a definite positive step, for most health profession education students it can get difficult to negotiate these hierarchical levels while engaging with real patients at point of care. The question is are they currently encouraged and supported well enough to “learn” while engaging with real patients at the point of care and are their learning outcomes easily co-relatable with patient health outcomes?

While the current emphasis of most medical school systems is on factual content memorization toward clearing structured summative assessments does help to some extent in dealing with patient problems, a climate of Big-Pharma market-driven Continuing Medical Education (CME) lectures and rote memorizing “factual” MCQs toward getting into gate-locked residency programs poses a bigger threat, threatening to completely do away with real-practice-based curricula that can enable health professionals to ideally manage “clinical complexity.” Medical educators across the world have begun to create headway out of this impasse by making case-based MCQs popular so that the next step toward getting students more easily interested in “real clinical data” becomes less difficult for the UDHC learning network.

More and more academics have started realizing that learning requires “open access.” Our quest to foster a multidisciplinary approach to healthcare through a journal platform is considerably driven backward if we operate on a closed-access platform. This is the reason that this editorial shall remain in the closed pages of a journal (as Woody Allen recommends), meant just for the confines of a library.

A Web-based transparent “user-driven health care” system currently under construction can consider-ably help to address this issue, if used as an open and contextual health care information delivery system for “users,” such as patients, their relatives, and diverse health professional stakeholders, to draw on the data generated by these very “users” to collate, analyze, and share the results through our academic journal platform. This may bring us closer to Allen’s greater goal of engaging and entertaining a wider audience in the true spirit of celebrating human life.

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REFERENCES


