

## ARTICLE

# Person-centered healthcare in the information age: experiences from a user-driven healthcare network

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## Abstract

Person-centered healthcare is central to the practice of compassionate medicine. The practice of person-centered healthcare occurs when intuitive and organizational thinking is engaged harmoniously, rather than in competition. Present healthcare systems relegates core providers and patients to 10-minute appointments for the purpose of meeting budgetary or patient access targets. It is unrealistic to expect such a system to be sufficient to share values and expertise. Often, important questions are left to those without the experience or expertise to answer. Person-centered healthcare can empower people to escape from fragmented medical care and displaced knowledge. The roles of patient and doctor can better serve medicine by asking all to go beyond their assigned roles to communicate and form relationships. These working partnerships will respect individual and role-based values, strengths and weaknesses. Being a patient is a condition or state somewhere between death and life that it is common to all. The patient is not an entity, but a *person*. Providing medical care is a profession, it is what physicians do, not who they are. Without cooperation between doctor and patient, medical intervention loses power and effectiveness. The consultation may be temporarily seized by social force and dominance, but it is maintained by respect and relationship. Respect is earned and negotiated by listening, observing and then acting in the best interests of others. This requires sensitive negotiation and the desire to build the bridges in medicine between knowledge and need. Great negotiators make it their business to know the strengths, values, needs and limitations of others. Power is intrinsically bound to what we value. What we value is what we will invest in. Let us assess the conditions we have to work with, reason together and build respect, access and relationships in healthcare.

## Keywords

Evidence Based Health Care, online medicine, Open Data, patient compliance, Person Centered Health Care, physician values, shared decision-making, Tele-health, Tele-medicine, User Driven Health Care

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## Introduction

Shared decision-making is increasingly being recognized as an important tool in participatory medicine. It considers the available scientific evidence, as well as personal preferences and choices of the patient and the provider. This is highlighted in the Salzburg Statement on Shared Decision Making [1] which calls upon clinicians to “stimulate a two-way flow of information and encourage patients to ask questions, explain their circumstances and express their personal preferences” and to “tailor information to individual patient needs and allow them sufficient time to consider their options.” Perception and shared decision-making is complex [2]. The communication of personal values in medicine is found where uncertainty and humility are pre-conditions for unbiased evaluations [3]. User-driven healthcare

conceptualizes the creation of a ‘*healthcare blended-learning ecosystem*’ involving diverse stakeholders, ranging from medical practitioners and medical to patients and their relatives, communicating online, mainly asynchronously. The user-driven healthcare network is working to reduce roadblocks by exploring values and expertise as a community to ‘crowd-source’ solutions for optimal individual care.

Patient rights and empowerment movements have grown exponentially over the last decade. Shared data movements and clinical decision-making may employ slogans like ‘*having a voice; nothing about me, without me*’ and ‘*give me my damn data*’, all these expressions share the language of loss and blame. Vision and partnership are not built by crying for what we do not have, but instead by realistically assessing the situation as it is and working to build collectively what we have.

The challenge is to preserve individual values in the face of global technology. Present day experts dispense advice to a global consumer and use findings that may/may not be generalized to all humans (on the basis of quantitative research evidence - objective, absolute and rational). Individuals resist being measured in terms of impersonal data.

## The Open Cure

An understanding of 'open cure' is enabled by Salvatore Iaconesi, an Italian tactical media artist diagnosed with brain cancer in September 2012 [4]. After retrieving his digital records he found they were in a proprietary format that further isolated him from the potential to share his vision for an open cure. He hacked his digital imaging records and posted them with the reports online [5]. The following direct quote is from Iaconesi's interview with Patrick Lichty on Furtherfield.org:

"The first thing you notice at the hospital is that they are not really talking to you. Medical language is difficult and complex and they rarely take action to make things more understandable to you. This is really not "open", in any sense. And, in more than one-way, it is an explicit evidence of the approach which medicine has towards patients: they cease to be "humans" and become sets of parameters on a medical record subject to certain protocols and standards. When you are in the hospital, it's often as if you're not there. The only thing that matters is your data: blood pressure, heartbeat, magnetic resonance *etc.* Data formats may be, technically "open", meaning that they are described somewhere but they're really an explicit reflection that when you're sick you "step out of society". That data is usable and accessible only to "professionals" and to those people who have tools and skills to handle them" [5].

In the recent past, physical distances confined the practice of medicine to local healthcare experts who were armed with knowledge about their patients as individuals. In the absence of specialists, the wise and indispensable community doctor's knowledge was not confined to pills and potions, but extended to knowledge about their patient's way of life carved from the experience of relationship and observation. Biswas *et al.* note [6]:

"Unlike their predecessors, the present-day expert may not know all about their individual patients but only the fragments that they need to know that match their area of expertise. Also, the life of the present-day healthcare givers is often far removed from the lives of their patients unlike their know-all, do-all predecessors, who used to share the lives of their patients in more ways than one. The wise doctors' anecdotal wisdom and collective experience, although negligible in a global society, was of immense value in local communities where they were seeped in information about the details of their patient's lives that gave them a non-mathematical, but perhaps a grounded narrative and equally fair, impression of what suited their individual patient needs." [6]

The patients of this era frequently expressed satisfaction in terms of care and communication even though research points to education, global knowledge and technological advances as the drivers responsible for the extension of life and quality of care [7].

## User Driven Healthcare

As a group of concerned professionals we have engaged on how to effect change together. In 2008, we identified a person-centered 'user driven healthcare' (UDHC) model already active in web space that aimed at "*Improved healthcare 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*" [8].

UDHC has continued to develop this model using a person-centered online network that receives patient information from rural remote towns in India, primarily with the intent of offering therapy either in the form of information, peer support or advice on procedural interventions. Clinical inputs are received and transmitted by regional medical professionals in the form of scanned handwritten letters, faxes, personal communications and electronic formats. They are transmitted *via* email after removing patient identifiers to comply with international data protection standards. These are processed through our global network of online physicians who offer responses that will be conveyed by the moderator to the primary caregiver for the patient. In this climate, global expertise and physician/patient relationships are expanded in beneficial partnerships, increasing relationships and reducing information burnout.

Our goal is to share ways the person-centered model is currently active in web space, utilizing real world clinical vignettes from 'real person' patient inputs to our network either through email or as submissions to the *International Journal of User-Driven Healthcare*. We shall discuss them under 2 headings: (i) email patient stories and (ii) journal patient stories. The names of the healthcare providers/stakeholders have been removed from the emails and the emails have been edited to include only the relevant thematic content. Typographical errors/grammatical mistakes in the emails are corrected.

## Collaborative online intervention with email person and professional stories

### Person and Tele-Health One

From our tele-health pilot village, a patient contacted us through a handwritten letter. He reached us a week later from 1500 km away and because of our prior communication and collaborations we were prepared to offer effective and immediate intervention.

Figure 1 Patients hand written letter

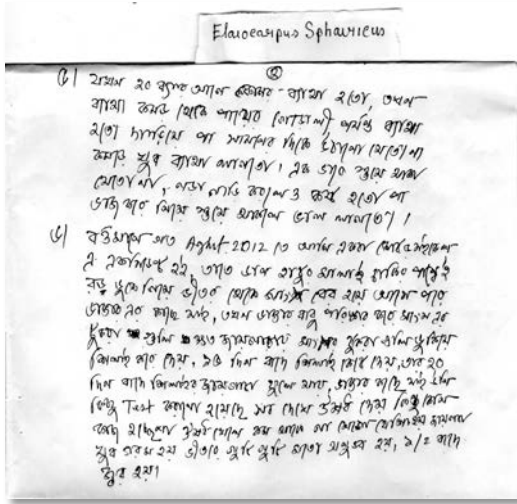


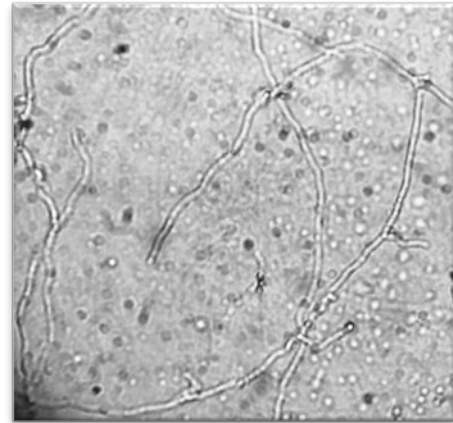
Figure 2 Clinical picture of swollen and inflamed skin



Figure 1 shows the patient’s handwritten letter which was scanned and emailed to us after substituting a botanical user name and Figure 2 shows the clinical picture of the swollen and inflamed skin around the right knee. Both were emailed to us in advance.

The patient suffered a motorcycle injury 2 months prior to contacting UDHC. The motorcycle handle penetrated his skin above the right knee. Initially, his local doctor sutured the area and gave antibiotics, but later the patient developed a high-grade intermittent fever with chills and a reddish patchy and nodular inflammatory lesion which he photographed and emailed to us. After his arrival he underwent the incision and drainage of an identified pus point. The pus culture was sterile for bacteria although it showed filamentous organisms on a wet mount (Figure 3).

Figure 3 Filamentous organisms on a wet mount



UDHC reviewed the literature to find fungal cellulitis (as evidence by the organisms seen on smear) reported after road traffic accidents [9]. While awaiting confirmation of the culture, the patient was given systemic therapy. These were some of the inputs from the microbiologists in our global UDHC email network:

SD, a molecular epidemiologist from Evanston, Illinois, USA, advised:

“Seems the correct history for a fungal infection. However most of the time the history is subtler and a history of injury is so distant or insignificant that it is ignored. It is difficult to ascertain the level of inflammation from the picture. Is it a wet mount? Were there many pus cells in the direct smear? A gram stain could help in such situations. Interestingly, many fungal species produce short distorted hyphae in the tissue. I couldn't quite figure out the septations and the width of the hyphae... if there are none and the hyphae are broad ribbon like, it is more likely to be the Rhizopus, Apophysomyces group. On the other hand if it is narrow and septate with acute angle branching, it is probably Aspergillus or similar. Remember you could see pigmentation in dematiaceous (black molds) fungi in a regular wet mount. Finally, though fungi are thought to be slow growing, they can sometimes grow in your regular blood agar media, especially the environmental fungi...no wonder they even grow on bread! So maybe you will get an answer before 6 weeks...You mentioned therapy...what did you put him on?”

RB, a professor of medicine from Bhopal, India and also one of the caregivers for this patient, replied:

“The patient has been put on oral Itraconazole 100mg twice a day for the next 6 weeks to begin with. Interesting that you mentioned Apophysomyces as this is the only case report we find when we key in 'fungal cellulitis and road accident.' This describes a fatal case related to Apophysomyces elegans [10]. Your comment about its growing well on blood agar is also positive for us as our microbiologists say that they had to actually aspirate the material from the blood agar bottle and transfer it to Sabourad's media (as there was no further pus from the patient available for a separate inoculation after our surgeons had drained it).”

The above discussion around the case reflects our online clinical problem-solving model. The person's personal concerns are reflected in his handwritten letter and were met through counseling and physiotherapy along with pharmacological interventions. The informational continuity will be maintained online by the village social worker that is also a collaborator in the network.

Other person-centered factors around this patient needed to be addressed. This man travelled 1500kms. He was torn between staying on to complete his treatment and going home to assist his son who was preparing for examinations. The patient and his wife were in an unfamiliar location, dealing with the uncertainty surrounding an uncommon diagnosis. His fever was still intermittent, signifying that his illness was unresolved. His physician favored switching to an intravenous regime. Arrangements for an even longer duration than the patient had initially planned for had to be accommodated.

Person and Tele-Health Two

Here, we present another patient, but his handwritten letter is in English. One major barrier to our collecting de-identified patient data and sharing them is the fact that most of the data have to be collected in the vernacular. Transcribing such data followed by translating it into English to offer it to a global network for receiving further clinical problem solving inputs is a tedious process that requires more manpower and we hope to improve our efficiency in this context as soon as possible.

Figure 4 and Figure 5. For explanation, see text

Figure 4

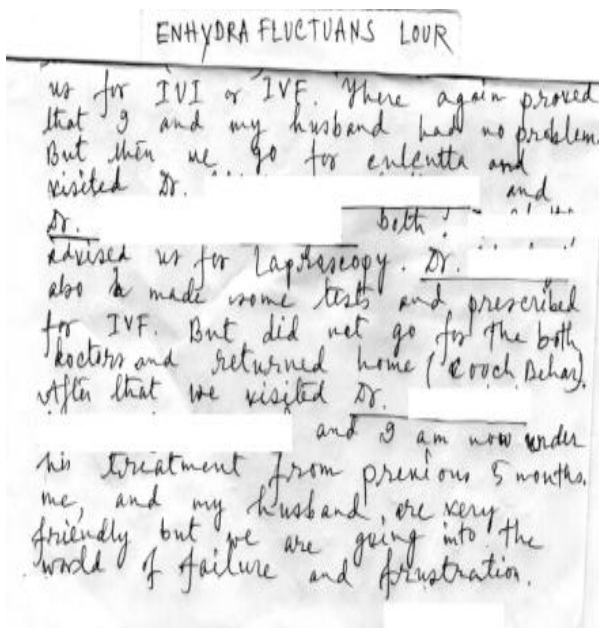
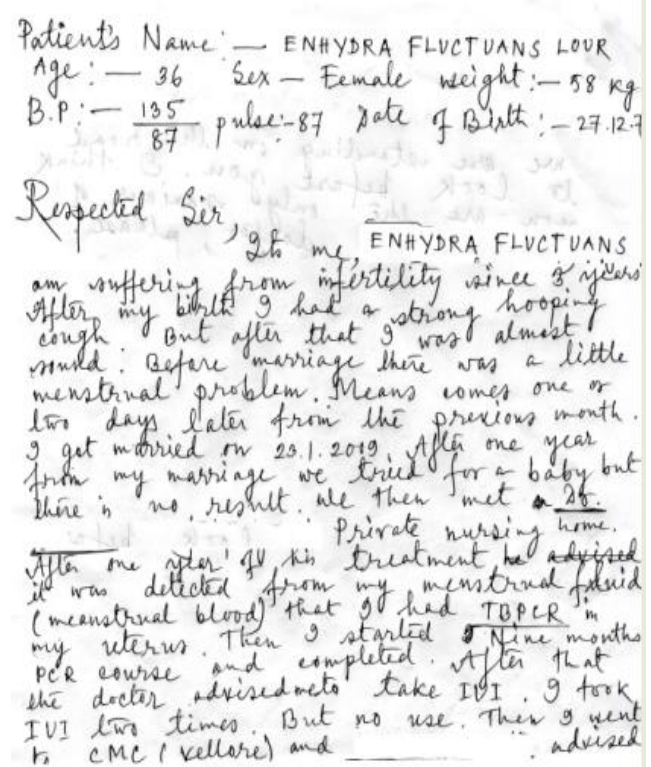


Figure 5



The above anonymized letters (Figures 4-5), as well as previous reports of investigations, were sent to our email-based network as attachments. In the introductory email, the network moderator RB asked:

“Can you help me by letting me know after going through the attachments if this case would fit into a diagnosis of unexplained infertility? What would be your approach and advice for this patient?”

The first response was from TR, an Obstetrician and Gynecologist in the network:

“From the reports she appears to be a case of unexplained infertility with glucose intolerance. However ovulation has not been documented assuming the proper workup has been done. Unnecessary investigations have been done. She was put on ATT on basis of PCR even though there is no indication the patient has active disease. However as it has been started, it may be completed. The plan of management followed in her case has been as per standard guidelines till date. She could undergo intrauterine insemination with controlled ovarian hyper-stimulation for 3 to 6 cycles or ideally because of her age (over 35) and two failed cycles she could go in for IVF directly. She needs counsel as IVF is no guarantee of success and it is difficult to undergo the therapy, hormones, injections, embryo transfer procedures and side effects such as body bloating. She needs to be mentally prepared for all of this.”

Our network reaches out to multiple health professionals from diverse backgrounds that share a lifelong interest in global health and the desire to help their fellow beings. The next response was from an internationally known pathologist, VK, from Chicago:

Table 1 For explanation and discussion, see text

<p><b>INPUT:</b></p> <p><b>History:</b></p> <p>26 y/o M, doctor currently on preparatory leave for postgraduate entrance examinations presents with moderate-severe back-pain.</p> <p><b>History of present illness:</b></p> <p>Pain started insidiously 10 previous and is localized to the lower cervical-upper dorsal paravertebral region on the right side. Spasmodic pain, with constant dull aching (rated by 4/10) exacerbating to spikes, (rated 7-8, 10) described as "severe" and restricting activity. Pt reports no loss in power or sensation in any dermatome and no restrictions in movement of the RUL.</p> <p>Patient notes his BP increases from a baseline of 140/100 to 190/100 accompanied by profuse sweating during severe pain. Pain is worse in morning or after lying down and in c/o soreness scapular region. Patient sees other identifiable triggers in terms of physical exertion or mental stress. Patient reports the problem has surfaced intermittently for 3 years. The first episode lasted 8-10 days and was similar in severity.</p> <p>Physical and mental stressors were present including a hectic posting in internship and accidental needle prick with subsequent Post Exposure Prophylactic regimen. Pain was similar with radiation and limited motion in his right arm.</p> <p>He presently notes bilateral difficulty in turning the head to either side or shifting positions while at rest. He was prescribed intramuscular Piroxecam and with temporary recovery after 10 days. Piroxecam did leave him with severe gastritis. Milder episodes resolved spontaneously in 2-3 days with only k 4-5g/day of Paracetamol. Frequency of such episodes was once in every 4-5 months.</p> <p><b>Current Medications for the pain:</b></p> <p>Paracetamol – 5g/day          Baclofen – 30mg/d          Alprazolam – 1mg/d          Myoril [thiocolcicoside] 3g/d</p> <p><b>Outcome</b></p> <p>Reports little-no pain relief on current medications, physiotherapy caused pain, it was discontinued after one session</p> <p><b>Co-morbid conditions:</b></p> <p>Hypothyroid with Thyroid Replacement Therapy (200µg).          Euthyroid as of 3 months ago          Borderline Hypertensive – baseline is 130/100</p> <p><b>Lifestyle factors:</b></p> <p>Sedentary, 14-15 hours/day deskwork          Sleeps 6 hours/d (spaced over 4-5 hours in the night and 1-2 hours in the afternoon). He reports no difficulty in falling asleep.          Normal appetite, no allergies mentioned          No h/s/o gastritis is present</p> <p><b>Additional investigations:</b></p> <p>MRI scheduled (today/tomorrow)</p>
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“Was AMH level done? Dr TR has put clearly. The anxiety of going through IVF is not to be underestimated. Adoption should be discussed as an option.”

VK questioned available resources and the expenses of IVF trials. RB in his reply stated:

“I have taken into account the low resource setting while exploring this decision. She has a chance till 40 to go for the ART option if she is prepared to realize the chance of success is not high”

### Person and Tele-Health Three

Finally, we come to a very urban and technological competent patient with a backache who had emailed a

meticulous history to our network through his friend (in order to protect his identity). Table 1 provides all relevant detail.

A first response from a similar patient and health professional advised the following:

“It is an interesting story and as often there may be obvious and obtruse causes.

The obvious causes could include poor workstation ergonomics and postural control - this would lead to an insidious, recurrent and persistent problem that will initially respond to NSAIDS. - whilst it sounds simplistic I am being serious - this is a very common cause of these sad stories and requires quite careful and expert physio/occupational therapy to retrain habits, with ergonomics training. Infection (TB) should have presented

itself more floridly by now - neoplasm would be low in the list - a scan would settle those issues.

Here's the obtruse cause - I do have a habit of getting them - so here goes:

The pain may well represent Levator Scapulae spasm and some pain in the Rhomboids and possibly retroscapular bursitis - these often happen together and would explain the dynamic component of the pain as well as its burning nature. It is very persistent and very troublesome.

Discuss this with the radiologist who might have some reading to do about views - special CT projection often helps.

P.S. Baclofen sometimes weakens muscles and perpetuates the problem - regular low dose Diazepam and topical NSAIDs may be better and safe enough - I found Diclofenac very helpful and I can use it for 2-3 weeks before my gastric mucosa tells me to stop for a while. Physiotherapy will help but it has to be a specialist in shoulder girdle issues."

AP, a clinical psychologist responded to this case as follows:

"Please add the qualifier I am not a medic:

What does the MRI look like? It likely shows a slight narrowing at c6-7 and L5-6 with some dehydration of disk height or/and bulges. Assuming no infection is present, it seems that he has a cervical facet injury and the ligaments in the cervical area are loose which triggers spasm, inflammation and nerve pain. I would try adding low dose gabapentin with the baclophen. If the Myoril is not working could it be dropped? His thyroid may need some more time to stabilize before his blood pressure comes down. He needs specialized instruction on mobilizing his facet joints, physical therapy to strengthen the stabilizing muscles in the cervical area. He may also benefit from doing nerve glides.

I advise he set his phone timer to go off every hour while studying and that he get up, change position, take a short walk as sitting is the most difficult posture with neck or back injury. I recommend ergonomically supportive sitting and sleeping conditions. If the neck is painful it can help to roll up a towel for underneath the neck for support. Alternating heat/ice can reduce inflammation and kick-start blood flow circulation."

(At this juncture we received a note from the patient: "The pain has been a little debilitating....I must say 75mg (or 112.5mg) of Tramadol helps with the pain temporarily. Thanks so much for forwarding this email to the UDHC network. I can see how this is therapeutic").

A response from DP, a consultant spinal surgeon in the UK, was as follows:

Difficulty in turning neck during acute exacerbation suggests paravertebral muscles spasm relieved by IM piroxicam

Pain worse on lying down - can mean several nonspecific things ranging from simple facet syndrome to lesions involving bone/pedicle of vertebral body.

BP rises and pt has profuse sweating. This could be a response to pain alone. Does he have a history of neuro-endocrine disorder?

Baclofen & alprazolam - completely inappropriate for neck/dorsal pain - should NEVER have been prescribed in a 26 yr old for such back-pain alone

Could not move his right arm during a previous episode. Was this simply related to generalized severe neck *pain* or an actual motor weakness? How long did this last for? If extended genuine arm problem - I would suspect pathology in the cervical spine and not lower down.

Suggest getting a plain X-ray of his neck and upper dorsal spine to assure alignment is satisfactory and pedicle and VB endplates are intact. Is his CRP, WCC, ESR and chest X-ray satisfactory?

An MRI of cervicothoracic spine should be performed to exclude degenerative causes as well as infective/benign oncological causes. You mention he is borderline hypertensive. Although very rare, I have had one young patient with metastatic pheochromocytoma to C-spine which we wrote up - so I would do the necessary tests to exclude this."

PJ, a hospitalist from Boston, Massachusetts advised:

"Sounds like wry neck to me. Sleep supine with thin pillow. Helps my episodes (doctor as patient). Would not have ordered MRI unless fever or motor/sensory abnormality. Agree with DP about medication choice (especially for a student preparing for exam!). Try hot pack and topical NSAIDs."

The next response received was from GJ, a Consultant Rehabilitation Specialist:

"The rule out is Pott's spine although non-progressive course for 3 years goes against. Elevated BP may be involvement of autonomic nervous system in cervicodorsal region and if so an opinion for stellate ganglion procedure may be obtained from pain clinic. Autonomic dysreflexia in spinal injuries have similar features. There is a chance of spinal SOL (prolapsed disc too). Look for neurocutaneous markers. Very rare may be tumors of the autonomic sensors. Anyway, MRI from a good center should help and should not be delayed. X-ray is also must before getting MRI."

MRI findings became available and suggested:

"Features of early degeneration with posterior bulge of c5-c6 and c6-c7 i.v.discs seen causing mild pressure on thecal sac and on exiting recess. Posterior bulge of c4-c5 i.v.disc is also seen. Mild left sided scoliotic tilt is noted. Dorsal spine, i.v.disc and dorsal cord do not show any significant abnormalities."

RR, a consultant radiologist opined that the report was normal for practical purposes. MM, a physician-scientist

from Vellore, India, suggested the study of 2 systematic reviews [11,12] to explore therapeutic options. RB replied:

“Summarizing for the benefit of our global audience, your first link which is a Cochrane review on vitamin D in adult chronic pain tells us that the evidence is not yet robust. The second Cochrane review also tells us that evidence for mobilization of chronic neck pains is even less robust. As is customary with many Cochrane reviews they end on the note that more research is needed. So on one hand in India we see this wave of Vitamin D intervention in chronic pain and yet the evidence is not robust.”

SB, a physician and managing director of a healthcare IT consultancy, shared a few anecdotes in his email:

“1. A doctor's Malady: We had a surgeon, who was a bit too knife-happy, operating 6 days a week from morning till late evening. Rarely used to do OPD (juniors did it; Post-op occasional. Most time spent in OT). Came with medium depression and backache of dorso-cervical area. After due deliberation and investigation, it was felt he rarely exposed himself to Sun. Prescription: Sunlight and injection of Vitamin D uneventful recovery occurred in 3 days.

2. I suffered from similar almost symptoms while preparing for PG exams. Severity became severe enough to need 10 days of bed-rest and injections of muscle relaxants and painkillers. I am just trying to underline the contribution of mental stress, which easily exacerbates or sometimes mimics physical aberration. Similar aberrations can be benign and asymptomatic in existing population but in presence of mental stress, become problematic...”

3. Over the years, many a physician has realized that it is not always the best practice to follow the best practice guidelines.”

AP, in her next email, added inputs based on personal experiences:

The methods of measuring pain are variable and subjective. So here is my subjective opinion to add to the mix. Vitamin D is cheap so why not? For me this works best when Vitamin C and K and calcium are added plus it is important to have magnesium and potassium in balance. As for diet, low glycemic higher protein makes a difference with good quality fruits and vegetables. I found electronic acupuncture (releases adenosine) to be helpful. Manual manipulation although not curative can be effective when combined with cervical exercise and nerve glides. Sacroiliac mobilization and strengthening/stretching exercises also help. LLLT cold laser is good for inflammation for some people but not for others, borrow one and try it rather than invest. I use a veterinarian model. Alternating hot and cold packs and using Epsom salts provide short-term relief. Massage and TENS provide short-term relief. Walking, swimming, biking and core exercises help if done on a regular basis.

Prolotherapy was effective for increasing mobility and reducing pain in the cervical and sacroiliac regions but was useless for low back/shoulder areas. I had minimally invasive back and neck surgery this helped a lot as it took pressure off the nerves, my only regret was I did not do it sooner. I agree with SB in that mental stress is a factor. For

this I do variable heart rate training, which calms my CNS and brings it back from fight/flight mode and then the muscles relax and I sleep better which allows my body to consolidate healing mechanisms. Posture training can make a difference as can good shoes and a memory foam mattress.

SB also added Jacobson's progressive relaxation technique in the list of beneficial exercises if the etiopathogenesis was stress related.

## Thematic summary of the UDHC approach

In all the 3 representative cases, presented above, the primary information (with identifiers removed as per international confidentiality norms) was received from the patients, either directly or through the moderator. Apart from the history and the investigation findings, the patients shared their narratives about the disease experience, which were then communicated with a global network of physicians/scientists/medical students/other stakeholders through a collaborative online interface. The UDHC web site <http://care.udhc.co.in/HOW/how.jsp> incorporates a hidden layer of patient input processing borrowed from ANN (artificial neural networks). The network collaborates actively to search the relevant evidence, which is then contextualized to the individual patient taking into account the myriads of extraneous factors that contribute to the 'clinical complexity', such as available resources, family support, employment pressures and the distance from the village to the hospital. This approach incorporates the individual experience-based expertise of the physicians, patient input and decision-sharing after consulting relevant evidence.

## Journal peer to peers and health professional collaboration narratives

The *International Journal of User-Driven Healthcare* was founded as a platform to disseminate the findings of the experiments with user-driven healthcare. While working as editor/guest editor of this periodical, RB and AP witnessed the collaborative networking of various stakeholders in an individual patient's health. Doctors and academics were impressed by the effort and transparency of the patient authors while the patients learned how difficult it was for their physicians to find ways to help them in emergent but uncertain fields of medicine [13]. Scientists were motivated to consider new ways of research that were patient and clinical provider inspired. As a result of the Traumatic Brain Injury issue, healthcare innovation spanned 4 continents, with authors receiving offers of assistance for projects, invitations to author textbooks, speaking engagements and funding of protocols. Collaborative multidisciplinary working groups were



formed to embark on substantial projects. Physicians and scientists shared their stories, sometimes with the co-authorship of their patients or family members [14]. We learned that a patient who is ill can lose all hope and identity, but can be healed by the sensitive practice of person-centered care [15].

## Relevance of person-centered user driven technology interaction

The current doctor-population ratio in India is approximately 1:2000 and the bulk of healthcare delivery systems focus mainly on the urban population, with the rural areas suffering from acute manpower and infrastructure shortage. Treatments in rural India provided without the advantage of telemedicine assistance and modern resources could be deemed palliative.

The present system signals the need for dynamic change. Djulbegovic *et al.* in 2011 analyzed data from 743 randomized clinical trials and found slightly more than half of new experimental interventions will prove to be marginally superior to existing treatments and very few will be substantially better [16]. Systematic reviews are a front line resource that will benefit from adaptation to match the current data flow. Mallett and Clarke reported in 2003, that the average Cochrane review in 2003 included 6 studies and 45,000 or 24,000 additional Cochrane reviews would be needed to cover the existing 300,000 references [17]. Carl Heneghan in 2012 used PubMed trends to demonstrate that the cumulative total of trials in PubMed for 2012 is 454,000: he estimates the number of reviews required to meet this increase in data is 75,700. By the year 2021, at least 50,000 trials per year will be added to PubMed. The volume of trials projected for publication in the next 10 years will exceed the numbers that have been published since the beginning of time [18]. Additionally, Shojania and colleagues found the average time from the publishing of a systematic review to the time of appearance of a signal for the need of updating was 5.5 years. It is needful to consider how these present methods must adapt to keep up and be fit for the purpose and challenges of future medicine [19].

The dynamic, progressive practice of medicine considers the foundational principles established by medical pioneers. While we may consider rural residents in low resource areas disadvantaged, there is still much to be learned from shared decision-making, transparency and partnership in care, just as we can respect and learn from the discipline and methods in practice today. Momentum increases globally for medicine practiced beyond the traditional boundaries of 2 standard deviations and population norms. Technology and multidisciplinary collaboration can make this possible; however, the 'data' will need to be expanded to represent patient experience and values.

In the Open Note study, patients were given access to their doctors' notes *via* a secure Internet portal. Beth Israel Deaconess Medical Center (BIDMC) in Boston, Geisinger Health System (GHS) in Pennsylvania and Harborview

Medical Center (HMC) in Seattle, participated. The total included 105 physicians and 13,564 patients. Patients were informed when the notes became available, but were not under any obligation to view them. The authors found 99% of patients in the research study wanted continued access to their visit notes following the research conclusion and no doctor opted to end this sharing of information. Patients cited improved understanding and increased quality of life due to the perception of more control over their care. Doctors reported that knowing patients had access to the notes changed the way they presented the content and helped them consider the care from their patient's perspective. Collaboration in care and respect was increased for both doctors and patients [20].

## Conclusion

Biswas *et al.*, in the *Journal of Evaluation in Clinical Practice* [6], noted:

"Today, we live on with the mixed approaches of controlled trial/systemic review-based medicine, generated by outcome-based clinical research and person-centered, narrative, process-based multidimensional medicine generated through interaction with individual patients. It is not beyond our capabilities to conceptually and pragmatically move beyond dichotomies and conflicts to improved consistency and coherence, beyond personal and group egos, in the higher aspirations for our patients' wellness and health."

Person-centered care has been hidden at the core of medical practice since time immemorial and current information technology (IT) has the potential to amplify it in a radical manner. IT can enable optimal person-centered care for patients and health professionals. We anticipate that collaborative and transparent learning, utilizing the enormous potential of health IT, can transform the modalities of healthcare delivery and can ensure and de-identified data will serve as a valuable learning resource to enable improved decision-making by utilizing meaning derived from multiple dimensions of the clinical encounter.

## Acknowledgements and Conflicts of Interest

RB is the Editor-in-Chief of *International Journal of User-Driven Healthcare* and Deputy Editor of *BMJ Case Reports*. AP has acted as a guest editor of one of the issues of *International Journal of User-Driven Healthcare*. TB has acted as a reviewer for the same journal in the past. All the authors have participated at some time in the learning network mentioned in this text. The authors declare no financial conflicts of interest and all the participants/stakeholders in this network participated on a voluntary basis and received no financial/other incentives for the same.



Some of the experiences shared in this article have on prior occasions been posted in some of the authors' personal blog posts and online tele-medicine forums such as <http://care.udhc.co.in/> and <http://www.ithinkwell.org/>. It is probable that some of the informational content here could match previous blog posts written by some of the authors or information posted on the tele-medicine website. In this article we have substantially expanded on our previous work and structured all that information in our service delivery platform with a context that offers more meaning. We believe that due to the increasingly asynchronous nature of real world communications in the coming future, this nature of restructuring will become more common.

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