But the story of leukemia—the story of cancer—isn't the story of doctors who struggle and survive, moving from institution to another. It is the story of patients who struggle and survive, moving from one embankment of illness to another. Resilience, inventiveness, and survivorship—qualities often ascribed to great physicians—are reflected qualities, emanating first from those who struggle with illness and only then mirrored by those who treat them.

Siddhartha Mukherjee, The Emperor of Maladies

One of the rites of initiation into the medical field is when a medical student performs his first blood draw. A rather simple procedure is looked upon with trepidation by the novice as one tries to find an appropriate vein and ignore the fact that the physician-healer at times, does have to morph into the role of a human mosquito. My first blood draw was preceded by some sage advice by the senior intern, and was apparently more psychological than methodical. “Just don’t look at the patient’s face else you might get nervous”. My patient, a forty year old mother-of-two on her second cycle of chemotherapy after a mastectomy for breast cancer, looked up and gave me a benign smile. She ignored the tremor in my hands and the apprehensive evasiveness in my eyes and gently urged me forward saying “My blood seems to have dried up in my veins, but you’ll still get it. Go on. Everyone has to start somewhere”. It took me three tries and as the murky red liquid filled the vacutainer, I finally let out a long breath. Since then, I’ve practiced and bettered the method of it all. But had it not been for an encouraging patient, my learning curve would have meandered towards the negative axes.

Healthcare currently faces multiple challenges and each challenge in turn presents with multiple dimensions extrapolated to its individual stakeholders. The reality which needs to be understood and acknowledged is that healthcare is not the purview of professionals and patients alone, but a constantly evolving
field which is shaped by the inputs and needs of multiple user groups. Though each group can be discerned by its characteristic traits and needs, the demarcation is but a nominal one. The user groups often interchange roles; patients transform to research advocates, healthcare professionals share their insights when they become the recipients rather than the deliverers of healthcare services, students evolve into teachers and mentors and so forth. Therefore in order to develop a self-sustaining model of care, one needs to incorporate three main fundamental aspects – collaboration, communication and compassion (Peabody, 1927).

The growing chasm between healthcare professionals and consumers is often attributed to communication barriers. Various stakeholders in the system, be it professionals or patients, students or policy makers, caregivers or caretakers, have to collaboratively innovate to identify the challenges, isolate the lacunae, innovate and plan effective solutions which can be implemented at the grass root levels. User-driven forums employ asynchronous medium of communications delivered by a web interface (such as social media networks, websites, email groups, online journal clubs) to provide a platform for various stakeholders to deliberate and channel the outputs of these discussions in a productive manner, namely the improvement of the delivery of healthcare (Biswas et al., 2008).

Health care professionals have to balance clinical dexterity with humanistic values and moral ideals (Bendapudi et al., 2006). Physicians such as Sir William Osler, whose teachings have influenced didactic paradigms of Medicine as a whole, often addressed the dilemma which plagues the profession at present – namely the transition of medicine from the bench to the bedside (Osler 1962). Patient narratives on user driven forums serve as a rich source of learning for students and young doctors by exposing them to the perspectives of the care-seekers. While web-based learning cannot, and should not, substitute hands-on clinical practice, it nonetheless serves as an important tertiary aide. The expertise and diagnostic inputs provided by senior practitioners convert narrative based learning to problem-based learning exercises, augment their clinical knowledge as well as subtly mould their bedside approach for similar encounters in the future.

Patient narratives are an oft ignored component of medical literature – original research articles and case reports often cater to the perspectives and paradigms of professionals rather than consumers. Patients play an integral part of user driven networks by providing the very foundation on which practice-oriented discussions can be built upon. Not only do patient narratives drive interactive learning, but the collaborative exchange of intellectual resources while processing a patient narrative helps physicians to form a cohesive peer support network, identify the concerns of their patients, provide a stimulus for evidence based learning, discussion and future research and also serve a reference resource for later use (Towle & Godolphin, 2013; Biswas, Maniam et al., 2008)).

Another benefit of user driven forums is their accessibility. The number of questions an informed patient has often extends beyond the duration of a clinical visit. In such cases, online resources such as user driven discussions aid patients to build upon their knowledge base and helps crowdsource unresolved issues towards a multidisciplinary team using technological resources. If implemented appropriately, these discussions could help reduce the evidence to practice gap that exists due to the disproportion between available information and physician time (Hesse, 2012). They can thereby serve as a vital link in the communication chain between the patient-caregiver dyad and healthcare professionals, forging an empathetic therapeutic alliance which is rewarding to all parties involved (Chu & Tseng, 2013; Salzburg Global Seminar, 2011).

The current issue of the International Journal of User Driven Healthcare focuses in particular on user narratives from patient survivors, physicians and researchers dealing with Cancer. Sourced from various user
driven forums, the compelling narratives and the discussions centered on them enable the reader to be a part of a user driven healthcare network, understand their role in it and experience first-hand the flow of the same.

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REFERENCES


