

HEALTHCARE - PATIENT INTERFACE

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"The ignorant sailor and the learned physician will equally long, with the most craving anxiety, for green vegetables and the fresh fruits of the earth."

James Lind (1747)

"[This] is endemic to a system in which an expanding medical establishment, faced with a healthier population, is driven to medicalising normal events, converting risks into diseases and treating trivial complaints with fancy procedures . . . The law of diminishing returns necessarily applies."

Roy Porter (1998) **The Greatest Benefit to Mankind**

Abstract

Modern medicine has fixed its own birth date around the last years of the 18th century. The healthcare-patient interface must have gone through significant changes as caring for the sick emerged from being a noble mission, evolved into a consulting profession and advanced to its current standing as healthcare system. This commentary examines the reasons for the paradox of the growing discontent with modern medicine against the backdrop of one of the most impressive epochs of medical achievements in the past fifty years. While reliance on a decidedly technological base has been charged with weakening the humane face of today's biomedical science by some, the tangled interconnectedness that the health delivery system has introduced into its complex organizational structure is pointed out by others. The role and effectiveness of 'patient-centered care' as recommended by the Institute of Medicine and implemented by some hospitals and academic medical centers are reviewed. The question of the disturbing incidents of preventable medical errors recurring with alarming frequency and some of their remedial measures are examined with the observation that just as it is crucial to address technical and safety issues in the healthcare environment, it is equally important to pay attention to patient experience issues. Finally, the serious consequences of the 'healthcare vs medical care' schism pervading the minds of health policy makers in India are highlighted. The essay concludes with a brief look at the healthcare scenario of the future with specific reference to the interface and the emerging trends in health communication through social networking and transactional models in our rapidly emerging 'Connected Age.'

Key words: healthcare, medical care, interface, paradox, patient-centered medicine, system failure, communication, health financing, universal healthcare, social networking.

It is important to make clear the distinction between healthcare and medical care at the beginning of this commentary. Medical care implies diagnosing and treating illnesses where the beneficiary is the sick person, the patient. A strict definition of healthcare on the other hand should include, in addition to patient care, welfare measures like sanitation, nutrition and other schemes for health maintenance and promotion initiated and implemented by the state; and the beneficiary is the entire community. The two expressions however, have been used interchangeably in reports and articles on the subject. As the theme of the conference and the title of this presentation make pointed reference to the 'patient,' the comments in this paper will be centered on medical care.

Modern medicine has fixed its own date of birth as being in the last years of the 18th century.¹ Caring for the sick, however, had emerged as a righteous and noble mission from the most ancient times and in almost all ancient civilizations. The accounts and aphorisms of the earliest physicians like Hippocrates, Charaka and Susruta bear testimony not only to their skill and analytical logic in understanding and treating diseases but also to their abiding faith and dedication to the moral and ethical dimensions of their calling. Perusing their elaborate descriptions of illnesses and their remedies, one senses the refreshing setting of trust, awe and fortitude that must have pervaded the physician-patient interface of their times.

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The healthcare-patient interface has witnessed enormous changes ever since the care of the sick saw progressive evolution from being a healing art to a committed pursuit, a consulting profession and advanced into what is recognized as healthcare delivery system or healthcare 'industry' today. Some of the changes the care environment saw probably never left impressions big enough to be counted as historic and their effects were hardly felt by the public or the profession whereas others were momentous and transformative. The healthcare profession has seen more fluctuations of the latter category compared to other traditional professions like law because 'medicine alone has developed a systematic connection with science and technology.'² One is similarly inclined to agree with Michel Foucault's observation (on 'clinical gaze') that 'What has changed is the silent configuration in which language finds support: the relation of situation and attitude to what is speaking and what is spoken about.'¹ The stories and reports that keep coming in the media, consumer forums and professional literature provide examples of the extent to which the 'relation of situation and attitude' have not just changed, but changed radically in the past decades.

What has brought the growing discontent with modern medicine against the backdrop of one of the most impressive epochs of medical achievements in the past fifty years?

In his award-winning book *The Rise and Fall of Modern Medicine*, physician, journalist and author James Le Fanu comments specifically on this issue. 'Any account of modern medicine has to come to terms with a most perplexing four-layered paradox that at first sight seems quite incompatible with its prodigious and indubitable success.'³ In the 'four-layered paradox' that has undermined the healthcare-patient interface, Le Fanu mentions the following:

- Disillusioned Doctors - from 14% in 1966 to 58% in 1986 according to the London-based Policy Studies Institute.
- The Worried Well - a medically inspired obsession of people with trivial or non-existent threats to health.
- The Soaring Popularity of Alternative Medicine
- The Spiraling Costs of Health Care

Whereas the first three may be recognized as symptoms of the discontent, the fourth paradox is clearly important as its cause. The curious paradox of these paradoxes, Le Fanu feels, 'is precisely because medicine does work so well.'

To these may be added the overbearing influence of Health Insurance schemes and managed care practices especially prevalent in USA and the widespread impression among patients and their families about the failure of effective communication on the part of the care professionals.

Medical Educational Institutions and Academic Medical Centers will be expected to implement practice guidelines to overcome such paradoxes. Although the concepts of patient-centered care and communication skills have been included as part of the learning requirements in medical curricula, convincing and measurable outcomes of such steps are yet to come from primary and hospital-based patient care scenarios.

One of the reasons for the anomaly could be the transition of the clinician-patient interface from a warm and informal affair with its basis on empathy and understanding to a complex and rigidly orchestrated system engaging an assortment of experts, services and personnel. The nebulous interface over time morphed into what could only be described as a mighty fortress wherein physician income, prestige and power in an atmosphere of severe time-constraint defined the guiding principles of medical practice. It was perhaps not without reason that A. J. Cronin, who studied medicine at the University of Glasgow, chose to title his novel *The Citadel* seventy five years ago.⁴ Cronin's disparagement of the medical practice of his times portrayed in the novel is considered one of the important factors that helped to change the British Government's attitude towards medical practice, paving the way for the creation of the world's first National Health Service in 1948. (As a brief aside, it may be pointed out that the Indian connection with the story of *The Citadel* continued in the 1971 film *Tere Mere Sapne* - 'Your Dreams and Mine')

It would be instructive here to consider the distressing experience of a clinician on the treatment his wife received in a modern academic medical center (where he also worked as a clinical faculty) for a series of medical complications burgeoning off an allergic vasculitic neuropathy - thrombophlebitis, pulmonary embolism, myocardial infarction, ARDS and cardiac arrest.⁵ Dr. Southwick's report was published in the *Annals of Internal Medicine* almost twenty years ago. The story understandably remains an emotional one but could be justified, because, as the author says, 'Sometimes a

profound personal experience speaks louder than averages, standard deviation, or statistical significance.’ The list of disappointing experiences reported by the doctor includes:

- Seeming disregard by the Consultant Neurologist.
- The sense of being abandoned by his colleague clinician.
- Delegation of care by attending physician to senior resident and in some instances even to rotating interns / house staff.
- Preoccupation of senior clinicians with research work, professional conferences etc at the expense of time spent on patient care.
- The fragmented and at times impersonal care.
- Ambiguous assignments of responsibility for care.
- Inadequate transfer of information and authority.
- How academic physicians sometimes forget the sacred trust patients and families put on them.
- How the care remains fragmented among many specialists with little communication between them and little effort to integrate it.

In the midst of the mounting inventory of complaints, the author does not forget to mention and appreciate the astounding skill and ability of the acute-care, full-time academic physicians in reversing what could otherwise have ended as a fatal complication in his wife’s case.

Equally important, if not more, is the report of the revisit by the same doctor and his reanalysis of his wife’s case after a gap of 15 years.⁶ Unlike in the earlier report, the most important insight from reanalysis through the ‘lens of complex systems design’ stresses on the effects of the flawed and dysfunctional system in which the healthcare team operates rather than on fault-finding on any individual member of the team. ‘In a dysfunctional system, even the most conscientious physician may be viewed as uncaring’ feels the author. Findings from systems analysis of his wife’s case under six algorithmic stages convinced Southwick that consistent and acceptable delivery of healthcare can be guaranteed only by focusing on the systems of care delivery and working on quality improvement. After all, ‘patients and their families see the system and the physician as one.’

A dysfunctional and recalcitrant system brings to mind Cronin’s Citadel again.

The concept of ‘patient-centered’ medicine was introduced more than forty years ago by Enid Balint.⁷ In her reckoning, a ‘patient-centered’ as opposed to ‘illness-centered’ approach, should include, in addition to trying to discover a localizable illness or illnesses, everything the doctor knows or understands about his patient.

In a 5-day retreat in 1998 at Salzburg, Austria, the 64 participants from 29 countries created a mythical republic which they christened PeoplePower. For PeoplePower the participants developed a consciously utopian vision reflecting the hopes and aspirations of both providers and beneficiaries of a modern healthcare delivery system.⁸ An important feature of the system was the liberal use of computer-based guidance and communication systems to enhance the physician-patient relationship. The goal of the system, the authors say, “is a level of service that delights and surprises both the “caregiver” and the “caregetter” with unanticipated levels of excellence.” The operational dictum of PeoplePower was: nothing about me without me.

The ‘Patient-centered Medical Home’ proposed by the American Academy of Family Physicians may be a step in this direction.⁹ Another proposal, close to being ‘mythical’ again, is the scheme put forward by Dimitrios Sotiriou of Athens University for ‘Modern Asclepieions’ modeled after the famed healing centers of ancient Greece.¹⁰ A major goal of Modern Asclepieions is to make the concepts of inclusion, equity of access and citizen empowerment a reality by exploiting the potential of modern Telecommunications Technology. The World Summit on Information Society (WSIS) recently included the project ‘The Modern Asclepieion for Citizen Empowerment’ (MACE) as part of its stocktaking activity.¹¹ The theme was also presented at Med-e-tel 2005 Conference in Luxembourg.

The Institute of Medicine in the United States recognizes quality as a ‘system property’ and has included patient-centered care as one of its six quality aims based on its observation that a discrepancy exists between the kind of care that patients receive and the kind of care they should have.¹² The IOM defines patient-centered care as: Healthcare that establishes a partnership among practitioners, patients, and their families (when appropriate) to ensure that decisions respect patients’ wants, needs, and preferences and that patients have the education and support they need to make

decisions and participate in their own care. The IOM's six specific aims for improvement were built around the need for healthcare to be:

- Safe
- Effective
- Patient-centered
- Timely
- Efficient
- Equitable

Has proclaiming the ideal of patient-centered care and its induction into clinical practice and physician-training brought about measurable, or, more importantly, palpable outcomes? Or, as a recent commentary suggests, is it only a recent salvo, a rhetorical slogan? 'Patient-centered medicine,' the author of the NEJM article says, 'is above all, a metaphor. "Patient-centered" contrasts with "doctor-centered" and replaces a Ptolemaic universe revolving around the physician with a Copernican galaxy revolving around the patient.'¹³

Metaphor or not, it is agreed that the patient and physician today must coexist in a therapeutic, social, and economic relation in a complex system of shared and vastly interconnected prerogatives. This is the message one gets from Sanjaya Kumar's recent analysis of the gravity and overwhelming impact of preventable medical errors in the present "fractured" health system in USA.¹⁴ In a highly disquieting narrative, the author takes us through a step-by-step account of eleven instances of preventable adverse effects, six of which ended in death of the patient. Although the quality of in-hospital care and safety issues remain the predominant concerns in his book *Fatal Care*, one finds pointed recommendations for system correction at the end of each case. Proposals to 'Protect yourself in today's healthcare system' for example, appear consistently after the description of each story. 'Regardless of where the blame is placed,' Kumar tells us, 'the bottom line is that people and systems failed.' Reminding the readers that 'excellence does not mean infallibility,' he recommends that healthcare consumers must be the ones to drive future changes that will improve healthcare safety for all. One of the important features in this will be measures to foster effective communication among stakeholders.

'Why do these stories of bad patient experiences continue to appear from every health care system?' was the question raised more recently by the Toronto-based healthcare researchers Levinson and Shojania.¹⁵ Recounting two examples of bad patient experiences in hospitals - one in France and the other in the UK - Levinson and Shojania conclude that care often falls short of what patients want and expect. They feel that 'the overworked and stressed staff members are also unhappy with their inability to provide the kind of care they know is best for patients.' Frontline staff are often frustrated with infrastructure issues and problems with routine equipment such as beds, storage space, inpatient care areas, and procedures for repairing or replacing defective equipment. They feel these undermine their work and affect their morale. Just as technical and safety issues are addressed, it is equally important to pay attention to patient experience issues. Executive walk rounds in hospitals for example, can help to uncover frustrating infrastructure problems.

HEALTHCARE VS MEDICAL CARE SCHISM IN INDIA

The semantic distinction between healthcare and medical care mentioned at the beginning of this essay assumes greater relevance in the Indian context. Provision of acceptable standards of healthcare is the exclusive prerogative and responsibility of the nation state whereas establishing and running medical care and educational facilities can be shared with private parties and non-governmental organizations supported by a responsive civil society. A look at the scenario in post-independence India will show how the state has fallen severely short of achieving the former objective whereas the private enterprise in the country supported by a rapidly expanding middle class and an articulate civil society has been able to fulfill the requirements of the latter.

Several recent reports confirm India's appalling performance in many areas where the state's role is desperately needed - health, education, provision of safe drinking water, child immunization, clean environment and so on. In spite of its commendable record of economic growth, India has one of the worst records in human development - with rates of infant mortality, child malnutrition and figures for child immunization worse than those of countries like Bangladesh, Cambodia and Pakistan. The reason for the anomaly becomes apparent when one realizes that healthcare expenditure in India has remained pathetically low and continues to stay at or below 1.2% of the GDP which is less than that in many neighboring countries, not to mention industrialized nations.

The recommendations by the Public Health Foundation of India and the Lancet India Group towards achieving the ambitious goal of universal healthcare by 2020 are noteworthy.¹⁶ The proportion of out of pocket spending for health at around 75% in India remains the highest in the world. 'To sustain the positive economic trajectory that India has had during the past decade, and to honour the fundamental right of all citizens to adequate health care, the health of all Indian people has to be given the highest priority in public policy' says the report and adds that without mechanisms for health financing and universal health insurance schemes that would make health care universally accessible, even improvements in the quality of health services will not be provided to many people in the population. Many families are driven 'below the poverty line' after succumbing to unexpected healthcare expenses.

On the other hand, the significant achievements in medical care facilities the country has made - mostly under the private sector - in the last 25 or 30 years can be quoted as admirable examples of vision, dedicated pursuit of excellence and willingness to learn from and implement best practices followed in the finest centers in the world. It is not just that they have been able to bring the best that medical technology can offer - many privately run hospitals and academic medical centers have done precisely that - they have been able to establish high levels of patient care and safety standards and implement contemporary management practices in governing and running their institutions. Many examples of such institutions that have been recognized by national and global accrediting agencies like NABH, NABL, ISO, Joint Commission, American Association of Blood Banks etc., can be cited. They are able to attract patients from several countries for diagnosis and management of complex medical and surgical problems.

The startling discrepancy in the performance of healthcare as against medical care in India qualifies for the evocative phrase 'private success amid public failure' that Gurcharan Das employs in his penetrating study of the prevailing social-political-economic landscape in India.¹⁷ As in the case of its economy that has managed to flourish under a 'flailing state' or in spite of it, medical care too, in India, has been 'growing at night' - while the government sleeps! What we need to remind ourselves is that the expression - its seemingly veiled note of humor notwithstanding - needs to be taken seriously; especially when we consider the health of our nation, because, while lethargy is damaging, somnolence is deadly.

Coming back to the question of 'patient-centered' medicine as a fitting metaphor to initiate system-correction in the healthcare-patient interface, it would be prudent to remind ourselves that healthcare outcomes rely on an effective teamwork and communication between the patient and the doctor assisted by other professionals, all working in a collaborating system. As Charles Bardes (who was quoted earlier) says, 'A better metaphor might be a pair of binary stars orbiting a common center of gravity, or perhaps the double helix, whose two strands encircle each other, or - to return to medicine's roots - the caduceus, whose two serpents intertwine forever.'¹³ Or, will it be wiser to turn our gaze further back, and, as the tenacious Wagner in Goethe's Faust proffers, 'cast the mind into the spirit of the past and scan the former notions of the wise,'¹⁸ and consider establishing modern equivalents of Asclepieions, the venerable healing sanctuaries of the pre-Hippocratic era?

THE FUTURE

From the discussions so far, it is not certain if one is justified in entertaining guarded optimism on the healthcare profession's ability to learn from its perception of the human dimension in health and disease as much as it has learned from its experience in the practice of the science of medicine and shape a fitting social and economic organization for health delivery for the future. The striking paradox of public discontent against the background of the spectacular achievements of biomedical science mentioned earlier cannot be discounted; neither can the formidable complexities that the health system has introduced into its organizational settings be ignored. An inventory of likely stakeholders who will decide and guide the health system's objectives, policies and practices in future years will look even more challenging. The growing list of players and stakeholders will include:

- The patient, his/her family
- Doctors (Family Physician, Specialist, Consultant)
- Supporting healthcare workers (Nurse, Technician etc)
- Hospital administrators
- Government departments (Health, Finance, Social Welfare, Human Resources etc)
- Licensing & Accrediting authorities
- Pharmaceuticals/Medical equipment manufacturers

- Health insurance firms
- Information Technology/Robotics experts
- Other professional organizations (Architects, Education, Consumer Forum, Law)
- Social networking and transactional models in the rapidly emerging 'Connected Age.'¹⁹

Mutual consultations and consensus building across the divergent groups of stakeholders will assume greater importance in guiding healthcare planning and policies in future than the weight of authority of the medical profession with its jealously guarded autonomy as the sole and expert agent for such decisions. By the same token, in an era fogged up with such diverse factors as Acquired Immune Deficiency, antibiotic resistance, transplant surgery, joint replacement, assisted reproductive technology, regenerative medicine and robot-assisted procedures, the healthcare-patient interface is bound to experience novel tensions and turbulences hitherto unencountered. To this must be added the growing population of the 'worried sick,' who, burdened by medicalisation of normal events and fanned by lay publications and the media, demand redressal of non-existent or dubious pathologies in a setting of overstretched resources. Particularly nightmarish will be a scenario (though imaginary) where, as in Bertrand Russell's satirical story of robots that are 'indifferent to the joys of sense',²⁰ our health and well-being are overwhelmed and expropriated by an escalating population of androids – or worse still, by a band of robot-like professionals practicing the 'uncertain art' of medicine!

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