

USING INFORMATION THERAPY



TO PUT PATIENTS FIRST

DR ANIRUDDHA MALPANI, MD

EDITED BY ROHAN PASRICHA

Using Information Therapy

To put Patients First

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Using Information Therapy to put Patients First

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Printed in India

This book is dedicated to all patients in India
with the hope that Information Therapy
will allow all of us to become e-patients –
engaged, empowered and enlightened !

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Promoting Information Therapy in India

Information Therapy is an idea that seems so simple and obvious that you might wonder – why do we need a book on this? Doesn't every doctor educate and inform his patients? Do we really need a new buzzword for something that is so basic? The tragedy is that Information Therapy, despite being an unbelievably simple concept, is not implemented routinely today – hence the need for this book.

It is commonly argued that the primary problem concerning the Indian healthcare system is the shortage of doctors, and the need to invest more money in training new ones. While opening medical colleges is rather profitable for politicians, this does not address the underlying issue. More doctors create more demand for medical services, and much of this medical care is unproven, unnecessary, and expensive. Too many doctors can lead to overtesting and overtreatment – and not always to better medical care!

Our initiative, Health Education Library for People (HELP), has adopted an innovative approach. Conceived over ten years ago, it is India's first patient education library. Our website, www.healthlibrary.com, focuses on empowering patients with information. As time has progressed, we have realised that the entire ecosystem needs an overhaul to fix the underlying issues that plague healthcare in India. We have adopted the following holistic approach to tackle this complex challenge.

If doctors themselves do not have access to reliable information, then how much good can educating patients do? In India, the tragedy is that doctors rarely bother to be abreast of the latest advancements in healthcare. A majority are content with depending on their friendly medical representative and attending conferences sporadically. With the phenomenally rapid advances that occur in medicine on a regular basis, their knowledge base is shockingly confined to outdated medical textbooks. Few invest in buying new editions of these textbooks or subscribing to medical journals. This is why our next step, in partnership with Elsevier, the world's largest medical publisher, was to provide the

MDCConsult database - the world's largest online medical library, with over 100 full-text medical books and journals, to Indian doctors, at half the price that US doctors pay.

We also realised that while many Indian patients spend hours online sorting through masses of information, much of the content provided by Indian hospitals is devoid of any real value to the patient. An example of this is evident in the sharp contrast between the Apollo Hospital and Mayo Clinic websites! Our next initiative has been to collaborate with Healthwise, USA (www.informationtherapy.in), the market leader in providing online patient educational content, so that Indian hospitals now have access to affordable and reliable content for their websites.

We have also realised that there is a major shortage of graphic content designed for Indian patients. This is why we have invested in PEAS (www.peasonline.com), the frontrunners in developing patient-friendly content for patients in India. We feel this market is now set to boom, as more and more patients demand reliable, easy-to-understand educational materials from their doctors and hospitals.

While there are millions of Indian patients online, where are all the doctors? To address this, we have invested in Plus91 (www.plus91.in) to help encourage doctors to publish their own websites. We have made this process easy and inexpensive, so that every Indian doctor can establish his or her own digital clinic. We hope that this will help set up a positive cycle.

The road ahead is still a long one, but one that's filled with promise. And our ultimate goal, a patient-friendly, high- quality Indian healthcare system makes the journey all the more worthwhile. This book is one step in that direction. These are exciting times, and we are happy to be playing such an active role in this transformation !

What is Information Therapy?

Information Therapy is the prescription of the right information, to the right person, at the right time to help make a better health decision. This information cannot be just generic information, so much of which is easily available online. In fact, easy access to so much information at the click of a button has made both doctors and patients highly sceptical about the usefulness of this information in real life. Excessive information has resulted in information smog, causing greater confusion and uncertainty, since a lot of it is unreliable and misleading.

Information Therapy refers to prescription-strength information, tailored to the patient's needs. Such information cannot just be of theoretic value – it must result in a tangible good. It should help the patient make better decisions. So what do we mean by the 'right' information? Who decides what is right and what is wrong?

The right information needs to be evidence-based; approved by experts; up-to-date; easy to read and understand; available in different formats (local languages and audiovisual formats); and referenced. Producing such high-quality information is not a walk in the park. We underestimate the cost and complexity involved in doing so. This is one of the reasons why there is such little quality information available in Indian regional languages – no one has invested the time and the trouble to create this as yet, since they still do not see the value in doing so. The right person means that this information needs to be delivered to the patient (and his caregivers), who will make (or help in making) the decision (or behaviour change). The right time means it should be provided when the patient needs it – just in time to help make a better medical decision (or to improve a health behaviour).

There are many ways of delivering this powerful tool. Information Therapy can be clinician-prescribed, system-prescribed, or consumer-prescribed. At present, most patients get information through their own research. However, they are often not knowledgeable enough to conduct searches that provide valuable results. Ideally, the information should be prescribed by doctors – but this is likely to happen regularly only when they get paid for this! The good news is that hospitals and health insurance companies that systematically

implement Information Therapy applications will be in a better position to gain market share, profitability, and prestige over those that do not. They will hopefully start doing so routinely because it makes business sense for them.

Healthcare is changing and we now have to deal with a rapidly evolving ecosystem. It may take us some time to get there, but we can learn a lot from what is happening in the US today. The healthcare system there is under a lot of stress, since they have empowered consumers (who demand time, information, control, and service) and embattled doctors (who are burnt out and resentful because they are starved of time and poorly compensated). There is a new focus on quality that promotes safer medical care and a move towards pay for performance; a new way of validating what works and what does not in medicine (the science of evidence-based medicine); and technology to reach out to consumers – thanks to the Internet, which connects anyone, anywhere to top-quality information 24x7. These drivers create a compelling case for Information Therapy – a new approach to healthcare that revolves around an expanded patient role.

The future of healthcare will emerge in the following ways:

- Every clinic visit will be preceded or followed by Information Therapy prescriptions.
- Every medical test and surgery will be preceded and followed by Information Therapy prescriptions.
- Every hospitalization will engage patient and family support through Information Therapy prescriptions.
- Information prescriptions sent between in-person visits will extend the continuity of care.

Information Therapy is a very cost-effective solution that allows the healthcare industry to adopt the long-promised shift to patient-centered care. As Kahlil Gibran said, 'Progress lies not in enhancing what is, but in advancing toward what will be.' Information Therapy is the future – and in India, using our medical and IT expertise, we can outdo the rest of the world and become leaders in this space. This book explores how Information Therapy impacts all players in the healthcare ecosystem – patients, doctors, hospitals, health insurance companies, pharmaceutical companies and the government – and how it can help all of us.



1

Lost in the Information Maze?

Mrs Chopra, 45, was recently diagnosed with diabetes. Her doctor followed the standard protocol, prescribing her medicines, and advising her on diet and exercise. She was not content with the advice though. This was something that was affecting HER body, and she wanted to dig deeper for answers. She wanted to know how she could better take care of herself, and while she respected her doctor's advice, she wanted more information that would set her confused mind to rest. She did what most patients in India and around the world would do – log on to the World Wide Web. A casual search for 'Diabetes' returned 268,000,000 results, with the first as always being Wikipedia, a helpful

but often inaccurate portal. Mrs Chopra did not receive accurate, definitive information on her ailment, with different websites suggesting different measures to control diabetes. Frustrated, she simply stuck to her doctor's advice. Whether she could have done more for herself, she would never know.

Fifty years ago, the major problem was that patients had insufficient information. All the knowledge was locked up in medical books and journals, and this information asymmetry forced patients to put their doctors on a pedestal. Patients felt helpless, and they were unable to question their doctors due to their limited knowledge on medical matters. Today, there has been a sea change, but ironically, patients are still helpless! This is because they have access to too much information, a major chunk of which is wrong, inaccurate or outdated. Thanks to Google, patients can effortlessly unearth thousands of pages of information on any topic, but this information is poorly organised and is not put in context, which means that patients often find themselves at sea while surfing the web to find specific answers to their queries.

Why is too much information as dangerous as too little? This is because there is a marked difference between data, information, knowledge and wisdom! Moreover, there is no effective quality control when it comes to the internet, which further aggravates the problem. It is common to find two different websites suggesting diametrically opposite things. This frustrates and confuses patients, and they wonder who to trust and why.

How can patients judge whether the information is reliable or not? There have been numerous initiatives to assist them in evaluating the quality of information but, unfortunately, most patients are not equipped with sufficient knowledge to be able to differentiate between 'good' information and 'bad' information. The sad truth is that many commercial websites can be well-designed and attractive, but under that garb, the information they provide is completely false. Their primary agenda is to sell you something, and not to educate you, which means it is easy to be misled.

This is where Information Therapy comes in! Information Therapy is the prescription of the right information, to the right person, at the right time to help make a better

health decision. Information Therapy will both revolutionize the role of information in healthcare and enable patient-centered care.

Who better to provide Information Therapy than the government? After all, a major role of the government is to look after the health of its citizens! While the UK and USA governments appear to be on track, the Indian government lags behind in providing this key service to its citizens. The NHS in the UK (www.nhs.uk) provides a comprehensive database for patients, assisting them in helping themselves. There are also links that inform you of the nearest hospitals, pharmacies, GPs, rehabilitation centres, and the like. In the USA too, the FDA website (www.fda.gov) does a splendid job of informing and educating patients about recent developments in healthcare. Moreover, patients in these countries are well aware of their rights, enabling them to make informed choices and adopt a no-nonsense approach to healthcare. In India, such an approach is seriously lacking, and patients are generally left to fend for themselves, relying on information on the web that could take them down the wrong path.

Patients need reliable information – a trusted guide who takes them through the healthcare information maze. Ideally, one's personal doctor should assume this role, but sadly, most doctors cannot afford to spend so much time. So who can patients turn to for help? Librarians are information specialists, and can help in separating the wheat from the chaff. After all, they have no commercial interest in selling patients anything. The Medical Library Association of USA (www.mlanet.org) has taken phenomenal strides in this direction. It comprises 1,100 institutions and 3,600 individual members in the field of health sciences, all working to ensure that the best healthcare information is available to all.

There are also initiatives that provide quality seals to ensure that the information being provided to patients is reliable and of top-notch quality. An example of this is the Health on the Net Foundation (www.hon.ch). Health insurance companies in the USA such as United Healthcare (http://www.uhc.com/health_and_wellness.htm) and Aetna (<http://www.besmartaboutyourhealth.com>) have invested a lot of time and energy in educating their patients, and it makes business sense for them to produce high-quality information for their clients, since prevention is far better than cure. However, Indian companies are still

lagging behind and have a long way to go before they can catch up!

To fill this gap in India, HELP, a non-profit organization which runs the world's largest free patient education resource centre has partnered with Healthwise to use the latest technology to empower patients. The sole mission of the Healthwise Knowledgebase is to empower patients with Information Therapy! Healthwise helps patients make better healthcare decisions by:

1. Promoting self care and helping them to do as much for themselves as possible.
2. Providing them with evidence-based guidelines, so that they can ask for the right medical treatment that they need – no more and no less.
3. Equipping them with veto power, so they can say 'No' to medical care when they don't need it, thus preventing overtesting and unnecessary surgery.

The Healthwise Knowledgebase (www.informationtherapy.in) is a free database that acts as a virtual guide, enlightening patients on their ailments, so they can take the right path to healthcare. Patients can also log on to the Health Education Library for People website (www.healthlibrary.com), where they can ask any question about a particular ailment.

What of the future? With advances in telemedicine and internet penetration and speed, it is possible that the web will allow patients to access an online virtual doctor with impeccable bedside manners, who can guide and reassure patients, enabling them to make informed choices about their health!



2

Bridging the doctor-patient communication gap

When Mrs Bhatia had swollen, painful knees, her physician made the right diagnosis of osteoarthritis. While prescribing the standard course of anti-inflammatory medicines for her, he did not provide her with a list of the possible side effects. Mrs Bhatia, on the other hand, also did not tell him that she had a peptic ulcer. The medicines caused her ulcer to start bleeding, leading to an emergency gastroscopy to control this. Frustrated with her doctor for not warning her, Mrs Bhatia complained to her friends and neighbours about her doctor's incompetence. This greatly unsettled her doctor, a caring physician, who felt betrayed that his reputation was being tarnished for no fault of his.

Every doctor wishes to see his patients get better. The strong urge to help and heal others is the primary driving force for choosing medicine as a profession. It is the ultimate service profession, and since it entails a one-on-one relationship, good doctors devote a lot of their time and energy in keeping their patients happy. Apart from making doctors feel good about themselves, patient satisfaction also makes immense business sense. Contented patients are the best source of new patients. Word-of-mouth marketing goes a long way in expanding a doctor's practice. This is why happy patients make for happy doctors!

Unfortunately, not all patients respond well to treatment. Medicines do not always work, and the human body is unpredictable. Most patients understand that the outcome of medical treatment is uncertain and that just because a problem occurs, this does not mean that the doctor was incompetent or negligent. Sadly, not all patients adopt such a mature approach. They are angry and need to vent their frustrations, and a doctor is an easy target! Some get abusive (both in real life and online), and others may even get violent. Rather than sit dispassionately with their doctors, they often end up bad-mouthing them and damaging their hard-earned reputations.

What's worse, this sets up a negative vicious cycle. Doctors who have been abused by angry patients often start becoming resentful. They start practising defensive medicine and distancing themselves from patients to protect themselves. Also, doctors talk amongst one another, gathering from other doctors' experiences that patients can be vengeful (for no fault of the doctor's), and that doctors need to protect themselves from their patients! It is tragic that affairs have come to such a sorry state. A lot has been written about how the doctor-patient relationship has deteriorated in recent times. While many people are happy to blame doctors for this, unfortunately, no one has highlighted the role that patients play in damaging this relationship. Any relationship is a two-way street, and a doctor who has been sued or abused is no longer going to be the same person he was before the ugly episode.

It is a vicious cycle – unhappy patients create unhappy doctors, which in turn again create unhappy patients, since such doctors do not take good care of their patients and often end up disrespecting them and providing poor quality care. The doctor-patient relationship

starts deteriorating and becoming adversarial!

Many studies have shown that patients do not sue a doctor simply because of an undesirable outcome. Most patients do understand that doctors are not Gods, and that medicine is not an exact science. However, if the doctor does not bother to communicate effectively with the patient after such an outcome, this is the equivalent of adding insult to injury. As George Bernard Shaw said, “The single biggest problem in communication is the illusion that it has taken place.” Patients then get upset and find outlets to express their anger. The best way to prevent this problem is to ensure that patients have realistic expectations. However, doctors are often too busy to be able to sit down and talk patients through all possible outcomes, and most doctors do not want to scare off their patients by talking about risks and complications!

This is why providing Information Therapy through websites and videos is such a great way of obtaining informed consent. It allows patients to understand what the likely outcomes are, at their own pace, in an unhurried, relaxed manner, so they have the time to think it through and make decisions accordingly. It saves the doctor time too, since he does not have to repeat the entire process himself for each patient. It ensures that all possible outcomes have been properly discussed; after all, sometimes doctors may forget some points too, when they are pressed for time. Finally, from a risk management perspective, clever websites that take informed consent online allow documentation of the fact that all risks and complications were properly explained to the patient, thus protecting the doctor in case of a lawsuit. Effective communication helps build relationships, and goes a long way in building a healthy doctor-patient bond that is mutually beneficial.



3

Synergising alternative medicine with conventional therapy

Mrs Sharma's house help, Anita, was afflicted with eczema and needed money for treatment. Her employer willingly gave her the money, thinking Anita would opt for conventional treatment. However, she instead went to a 'famous doctor' in her locality. This 'doctor' did not have training in medicine, but he did have a clinic. The only information below his name was 'Ayurvedic doctor'. Unfortunately for Anita, he was a quack, with no real training in Ayurveda. His spurious drugs exacerbated the eczema condition,

making it worse than before. After learning about Anita's bitter experience, Mrs Sharma, also a believer in alternative medicine, took her to a dermatologist while also consulting a trained, qualified naturopath.

Modern medicine often evokes awe. Massive gleaming hospitals, expensive computerized equipment, and sophisticated scanning machines appear very impressive and reassuring when you are afflicted with a disease. However, paradoxically, even though the effectiveness of medical technology has improved considerably, more patients than ever before are dissatisfied with their medical care today. This situation has resulted in a move towards 'alternative' medicine, which has become increasingly popular all over the world. Even in the United States of America (the bastion of high-tech scientific medicine), more than 50 percent of the patients have consulted an alternative medicine practitioner, mainly because they were unhappy with modern medical care.

There are many reasons for this growing unhappiness with modern medicine. Patients increasingly feel that medicine has become excessively commercial. They are unhappy with the impersonal nature of modern medicine, especially when the doctor spends more time looking at their reports rather than with them. While it is true that patients need technology, they also need tender, loving care; after all, doctors need to look after not only their medical problems, but also their emotional needs! Moreover, while modern medicine excels in certain areas (such as complex surgery for the repair of birth defects and the use of antibiotics for serious infections), it has failed miserably in the areas of disease prevention and the management of the myriad chronic illnesses (such as diabetes, hypertension and heart disease) to which modern human beings are prone to, owing to their lifestyle.

Alternative medicine, on the other hand, offers a markedly different perspective. Rather than focussing on a person's medical problems in isolation, alternative medicine treats the patient as a whole; hence the popular term, holistic medicine. Doctors practicing alternative medicine sit down and talk to the patient; they add the element of personal touch, and ask many questions. Such attention feels good, and is in refreshing contrast to the modern doctor who rarely has even 15 minutes to spend with the patient. Often, tender

loving care and personal attention are all that alternative medicine practitioners have to offer, but they offer it very well indeed! There is no doubt of the efficacy of the placebo effect, and many ailments will get better when the patient has someone he can talk to. Moreover, the simple act of a comforting touch can have a therapeutic effect. Alternative medicine doctors are very good at reassuring patients, which is in sharp contrast to the cold scientific approach of western medicine.

Unfortunately, the practice of alternative medicine in India today leaves a lot to be desired. For one, such medicine does not have a universally accepted scientific basis; hence, it is difficult to rigorously analyze its claims. Since there is no need for formal publication or peer review in alternative systems of medicine, there is little scientific documentation available about their efficacy or side-effects, making it difficult to confirm or dispute claims. Consequently, one has to blindly trust the doctor. Authoritative journals or texts are difficult to find. Most publications use little scientific rigour and are based mostly on anecdotal case reports, with little documentation or proof. Since there is no official monitoring of alternative medicine practitioners, anyone can make tall claims and get away with them. Also, there are few formal training requirements, and anyone can practice alternative medicine, with minimal skills or qualifications. This had led to the mushrooming of unscrupulous practitioners or 'quacks', who are out to make a quick buck.

Alternative medicine practitioners need to be made accountable for their actions to ensure that they are up-to-date with their education. Also, some type of peer review mechanism needs to be put in place to ensure the safety of the public. Otherwise, there is a grave danger that medicine can become a 'bastardised' system (for example, there are homeopathic practitioners in India who prescribe allopathic antibiotics for coughs and colds). This can have a considerably detrimental effect on patients. Even worse, it actually amounts to cheating patients both financially and emotionally, since they decided to shun allopathy for a more 'natural' approach!

Alternative medicine has its place in society, but the above issues must be addressed. One of the reasons for this sorry state of affairs is that alternative medical systems receive little official support and minimal funding. The situation often deteriorates into a conventional

versus alternative medicine confrontation, with each system belittling the other, and this is a real tragedy. By ignoring alternative systems, doctors may be depriving patients of better medical treatment options.

There is one common underlying principle of medicine that doctors should always keep in mind – patient health is top priority. Essentially, all doctors are on the same side. We all want our patients to get better, no matter what system of medicine we practice! Then why discredit each other?

The combined knowledge of both old and new healing modalities is ultimately superior than a single-model approach to health and well-being. After all, no system of medicine can claim to have a monopoly on knowledge! What is needed today is a clinically responsible balance between the science of modern medicine and the comfort of alternative medicine. We need to combine the best of both worlds, much like fusion music does, and physicians from both ends of the spectrum can learn from each other. Indian doctors must be willing to blend an open, receptive mind with the scientific discipline needed for rigorous research. If they adopt such an approach, they can become world leaders in providing the best medical care to their patients, given our immense patient population and rich traditional medical knowledge base.

This is where Information Therapy can play a key role and help to bridge the gap. There is still immense confusion about alternative medicine systems with regard to what works and what does not. For one, many of these systems do not have a sound scientific basis, which is why modern doctors are so sceptical about their claims. After all, if you progressively dilute something, common sense will tell you it will become less effective. How can homeopathy make the astounding claim that a higher dilution increases potency? Isn't this counterintuitive and illogical? However, just because we cannot understand the scientific rationale behind alternative medicine doesn't mean that it does not work. There are lots of drugs in western medicine for which we do not understand the precise mechanism of action, but we still use them all the time.

Sadly, a lot of alternative medicine practitioners are quacks. They take advantage of the fact that many of these systems do not require formal training or licensing. They pick up a ND or MD degree from some online university, label themselves as ‘doctors’, and start practicing. To make matters worse, they take great pride in making tall, ridiculous claims. Thus, they promise to cure everything and anything – something which no self-respecting doctor (or patient) can possibly accept. They end up losing all credibility and a result of which the entire system of alternative medicine gets a bad reputation. There must be stricter laws in place that prevent such quacks from flourishing. Public awareness is of paramount importance.

Alternative medicine, when practiced with integrity and sufficient medical knowledge, can be helpful. There is lots of empirical evidence that alternative medicines do work well for some conditions – but no system is a panacea for all ills. Sadly, rather than working out a common solution, there are mainstream versus alternative medicine battles. These are primarily being waged for financial reasons, since systems that acquire legitimacy can earn their practitioners lots of money!

Why does western ‘modern’ medicine pejoratively label other systems as being complementary or alternative? This smacks of cultural arrogance – after all, Ayurvedic medicine and Chinese medicine boast of a far longer track record than western medicine! And western medicine does not have a monopoly on knowledge. Patients simply want to get better. Most do not really care how. Then why have this silly demarcation and unnecessary mud slinging? Instead, we can use all this energy to learn from each other!

Personally, I hold the opinion that there are only two types of medicine – effective and ineffective. The dirty little secret is that lots of accepted ‘treatments’ in western/ mainstream/ scientific medicine are ineffective and have never been proven to cure. These include billion dollar interventions, such as cholesterol reducing drugs, disc surgery for back pain, and bypass surgery. So conventional medicine, just like its alternative counterpart, can also be misleading. It is important for practitioners of both systems to see the larger picture.

How do we separate the good from the bad and the ugly? Information Therapy can come to the rescue! The goal of effective Information Therapy is not to label treatments, disparage them or make prejudiced judgments. It has an uncomplicated mission – provide authentic, reliable information, and allow patients to make well-informed decisions. Then whether they head to an MBBS-qualified physician or one with a degree in alternative medicine or consult both is entirely up to them. A healthy dose of Information Therapy will ensure that they make decisions based on knowledge and facts, and not whim or fancy!



4

How can we get doctors to prescribe Information Therapy?

Mr Rathod had been experiencing pain in his abdomen, so he went to his GP for a check-up. After examining the test reports, his doctor told him that he had 'Cholelithiasis'. Mr Rathod was taken aback, thinking it was a serious disease, only to breathe a sigh of relief when he was informed that the simpler definition for his ailment was 'gallstones in the gallbladder', a fairly common condition that is easily treatable. When it comes to interacting with patients, using simple, jargon-free language is of the essence. Imagine

if a doctor told you that you had ‘Xerostomia’? You would think ‘oh, woe is me.’ Well, all it means is that you have a dry mouth! So how do doctors communicate in an unambiguous manner to their medically uninformed patients? Information Therapy to the rescue, again!

The word doctor is derived from the Latin word, docere, which means ‘to teach’, and teaching patients is something all doctors think they are good at! Most feel their bedside manners and communication skills are impeccable, because illusory superiority is a cognitive bias which afflicts doctors as well, since they are not immune to the Lake Wobegon effect (named after Garrison Keillor’s fictional town where ‘all the children are above average’). Communication, however, is a two-way street, and sadly, most patients do not think that doctors are good teachers. All patients want detailed information regarding their ailments and many feel that their doctors do not bother devoting enough time explaining their problems to them. Additionally, many patients observe that when doctors do explain, they use complicated medical jargon that is beyond their understanding. Patients also feel that sometimes their doctors seem too busy and unapproachable, so they hesitate in asking too many questions.

If doctors are indeed smart and know that patients want more information about their illnesses, then why don’t doctors routinely prescribe Information Therapy? There is no conspiracy of silence here! The sad truth is that most doctors simply do not understand the importance of Information Therapy. It is not that doctors enjoy keeping their patients in the dark, so they can extract money from them. Most doctors are happy to share information with their patients, and educating them will not turn them into medical professionals. Patients will still need to come to their doctor to get the treatment they need. The core problem is that educating patients is still not a top priority for doctors. They have a completely different worldview. Since they are doctors and know a lot about medicine, they sometimes assume that their patients are equally well-informed, which of course is not the case. Many will use jargon without even realizing that it is going above the patient’s head. ‘Medicalese’ has become their primary language!

Doctors suffer from the ‘curse of knowledge’, just like all of us. We know what we know,

and we know it so well that we assume that everyone else knows it just as well as we do. This is why doctors sometimes overestimate the ability of their patients to understand what they are talking about – they naively believe that if they know all these medical terms, their patients will too. Moreover, the primary focus for most doctors is providing quality clinical care. Sometimes, they are so busy doing this that they just don't have time to educate their patients. There is no question that doctors are busy people, and they will always remain busy. However, if doctors can use tools that make it easy for them to prescribe Information Therapy without disrupting their workflow, they will be happy to do so.

The trick is to make the patient do the work, using the self- service model supermarkets do, versus the old fashioned kirana shop! In the kirana store, all products are fetched by an assistant from shelves while customers wait in front of the counter and indicate the items they want. This is a very labour- intensive and therefore also quite expensive. The shopping process is slow, since the number of customers who can be attended to at one time is limited by the number of staff employed in the store. Supermarkets, on the other hand, make customers select their own goods and cart them to the front of the store to pay for them, so that they can service a much larger number of customers by making them do most of the work! Similarly, Information Therapy tools allow patients to serve themselves, so their doctor's precious time can be used for more productive and empathetic patient interaction.

What can we do to persuade doctors to prescribe Information Therapy routinely?

1. Some will start doing so when they realize the value that Information Therapy adds to their practice – and to their patients. These are the 'early adopters' – who pick up on new trends, and use them cleverly. They take pride in delighting their patients; and will use new technology and tools to do so.
2. Many will prescribe Information Therapy when they see leading doctors doing so regularly. We are all social animals, and the herd mentality is strong amongst doctors as well!

3. Some will start when they are pushed into doing so by their patients. Patients do have clout, even though they often do not realize it! Doctors cannot survive without patients, and if enough patients start clamouring for information, doctors will toe the line and start offering it.
4. Let us not forget that doctors are rational human beings, and will respond appropriately to the right financial incentives. Once they get paid for providing Information Therapy (either by the government or by health insurance companies), many will start routinely providing this to their patients.

Doctors must be provided with access to a wide variety of inexpensive, easy-to-use tools, so that they can easily prescribe Information Therapy. Different doctors have different working styles and their patients have different learning needs. It is possible to use technology cleverly and efficiently, so that we can cater to these diverse requirements by using a combination of text, audio and video, which can be tailored to the individual patient's and doctor's needs. Sadly, many doctors are still unaware of the wide variety of tools that are already available for educating patients; this is why they still don't make effective use of them. Perhaps, some technology therapy needs to be prescribed to doctors first so that they are well- equipped to dispense Information Therapy to their patients!



5

How I prescribe Information Therapy

My patients, Mr and Mrs Gupta, are sitting in the waiting lounge of my clinic, awaiting their turn. The usual gamut of magazines is in front of them. But do these serve any purpose? Instead, my receptionist gives them a comic book about IVF, so they can learn more about their treatment options. This puts them in a better frame of mind, and many of their doubts get resolved even before they come in. The beauty of Information Therapy is that it can be used in many innovative ways!

I am an IVF doctor, and I put my heart and soul into treating my patients. IVF is often the last resort for infertile couples, and, understandably, these couples will have countless questions about IVF. This is an expensive treatment, and they are investing immense time, hope, and energy in building their family. Since the outcome of IVF is always uncertain, they have a lot of doubts and misgivings. There are still many myths and misconceptions surrounding IVF, and many women are worried that IVF babies are 'weak'; or that all IVF pregnancies are multiples; or that the hormonal injections taken for IVF will make them fat or cause them to develop ovarian cancer in the future. Moreover, infertility often impacts the entire family (and not just the couple), and decisions about medical treatment are made in consultation with many family members.

I proactively use Information Therapy to clear doubts and answer questions. This helps ensure that everyone is on the same page. Since I provide this information, patients are reassured that I am open and transparent. They know they are in safe hands, since they can see that I am well informed and knowledgeable. The fact that I am an expert in my field makes them put their faith in me.

Information Therapy needs to be embedded in clinical workflow, and we start providing Information Therapy well before the patients come to us for a consultation. We do this online, using many channels, including our website (www.drimalpani.com); videos on YouTube (<http://www.youtube.com/user/aniruddhamalpani>); and social media, including Twitter (<http://twitter.com/drimalpani>) and Facebook (www.facebook.com/Dr.Malpani).

Web-based information prescriptions have major advantages:

1. I can update the information quickly and easily.
2. The information is accessible to all my patients around the world. Using Google translate, patients can read it many different languages!
3. The information can be presented in an interactive and engaging manner through the use of animation and videos (www.ivfindia.com).

4. Delivering the information does not cost me anything.
5. Patients can absorb and review the information at their own pace – and for free!

Isn't all this expensive? Who has the time to do all this? Yes, it is expensive and time-consuming, but the beauty is that once you have done it, you can use it many times, for many patients, and over many years! 'Create once, use multiple times' is a very cost-effective proposition. Updating and maintaining content is much easier once you are familiar with the process.

Even better, you can get your patients to contribute to your online resources. For example, we have a section called Success Stories (<http://www.drimalpani.com/ivfsuccessstories.htm>). We request our patients to write about their infertility story and their experiences at Malpani Infertility Clinic and then upload this to our website. This first person account helps other infertile couples when they are making decisions regarding their treatment, as they are getting information from someone who has been there, done that! We also encourage our patients to act as email buddies, to help other infertile couples in distress. I always remind my patients that helping others is a great way of helping yourself.

The internet has become an important source of health and medical information. However, a significant amount of health-related information on the Web is inaccurate, unreliable, or untrustworthy. By creating our own content, we can direct patients to information that is of high quality, appropriate to their condition, and consistent with our approach to treatment. This helps them to save time and stops them from getting confused or misled. Patients still depend on doctors to provide the most credible answers to their health questions.

In addition to providing Information Therapy online, we also provide it in the real world. When patients come to the clinic for a consultation, we give them with an IVF comic book while they are waiting for an appointment. Thanks to such Information Therapy, my consultations have become much easier. I do not have to waste time going over the basics and can focus quickly on the patient's key concerns. The fact that I am an author reinforces

their confidence in my professional competence and helps to reassure them that they are in safe hands. Doctor shopping is a fact of life in today's world, and since we provide this information proactively, our patients prefer coming to us, because they can see that we are open and transparent.

All our educational materials help to ensure that patients have realistic expectations of their treatment. While it is true that our success rates are excellent, it is also a fact that the outcome of any IVF cycle is always uncertain, and patients need to be prepared for failure. Reading about this in black and white helps them to understand the limitations of our technology.

Patients often forget a great deal of what is told to them. This is why we give them a DVD to take home, which they can review at leisure – often with other family members. This helps to reinforce my message, and it also ensures that we stand out amongst the other IVF doctors that they have visited. During and after the IVF treatment, we encourage patients to remain in touch by email. I find this a very efficient way of answering questions. This way we don't have to play telephone tag – and since everything is in writing, patients don't get confused or forget things. We also have a FAQs page on our website, which helps us to proactively reassure patients and put their doubts to rest.

We know that different patients have different learning styles, which is why we use diverse tools to deliver Information Therapy. On our site at www.ivfindia.com, we have developed a wide variety of educational tools, including e-learning courses, animated cartoon films, games, and YouTube movies. Providing this kind of Information Therapy has helped me to become a better doctor. It ensures that I look at the world through my patient's eyes, so it is easier for me to be empathetic. Also, since we help patients to have realistic expectations, they don't get emotionally shattered if the cycle fails, and they are able to cope better with the emotional roller coaster ride that often accompanies IVF treatment!



6

Doctors need Information Therapy too!

You're a doctor from one of the best medical schools in the country. You aced your class, and know medical terms like the back of your hand. One day, a patient comes in with an ailment, and while you think you know everything about the problem, his detailed, extraordinary questions stump you! He is not the regular, accept-whatever-the-doctor-says sort of patient. He's well-informed and has done extensive research on his illness. You could refer him to a specialist, but how will that enhance your own medical knowledge?

Doctors need Information Therapy too! A doctor's major asset is his professional

knowledgebase. As medical science progresses, doctors need to keep up with current trends. Medical textbooks get outdated quickly – and new editions and medical journals can be very expensive. Unfortunately, most doctors today are dependent on their ‘friendly’ medical representatives for information on all the latest advances in therapeutics, and these reps are not always the most reliable source of information. This is why the Medical Council of India (MCI) has made Continuing Medical Education (CME) compulsory for doctors. The motive behind this move is to enable doctors to invest in educating themselves, so that they remain abreast with the latest medical advances. When equipped with this knowledge, doctors will be in a better position to provide state-of-the-art medical care to their patients.

The only form of CME credits that the MCI recognizes is attendance at a medical conference. This medical conference has to be approved by the council (presumably based on the quality of the content provided); and doctors who attend approved conferences get a certain number of credits for their attendance. Doctors need to prove that they have accumulated the required number of credits every year if they want to renew their registrations. The biggest problem is that in real life, medical conferences are terrible tools for teaching doctors! Lectures are the most inefficient form of transferring information.

Have you ever attended a medical conference? If you ever do, you are likely to find half the audience outside in the hallway – chatting, collecting freebies at the stall, and eating. Most are fast asleep once the lights are dimmed, while other doctors go out shopping or sightseeing once lunch is over. Few speakers have the eloquence and presentation skills to grip their audience since most are selected based on a quid pro quo basis – ‘If you invite me as a speaker for your conference, I’ll invite you for mine.’ This is why most conferences have the same speakers talking on the same topics. Most presentations are boring and poorly prepared. They often contain outdated information, prepared at the last minute by a junior resident doctor, who has lifted information straight from the internet. The speaker then reads out the text on the slides, and tries to show off his erudition. The only reason doctors can get away with this is because few doctors in the audience are listening, and most doctors know even less than what the speaker does! This is why the ‘learning’ that doctors derive from conferences evaporates so quickly!

The reality is that these conferences are an utter waste of time and money. Can we really afford to waste the doctor's precious time on such insipid conferences that offer no real value or enhance the doctor's knowledge? We need better tools to ensure that doctors remain up-to-date. If a doctor's knowledge becomes outdated, he or she ends up losing patients to well- equipped specialists in corporate hospitals. Being poorly informed can also be embarrassing for doctors, when their patients with internet printouts know more about their disease than they do! The biggest problem arising from such ignorance is lawsuits for medical negligence – a doctor's worst nightmare. This is why when doctors are stumped by difficult patients, they refer them to a specialist or expert, who then helps them to learn more about the management of that particular problem. However, this kind of learning is very episodic and opportunistic, and not all consultants are good at educating family physicians!

Doctors do not choose to remain wilfully ignorant about medical advances. The reality is that, in a busy practice, when doctors spend all their time taking care of their patients, it is very hard to keep up. The trick is to deliver Information Therapy to the doctor 'just in time' – exactly at the time he needs it. This means the best way of providing it is when he is actually seeing a patient with a perplexing clinic problem. Today, the vast majority of doctors have easy access to the internet – either through a PC, laptop, or their smartphone. This is why many will turn to the internet to keep themselves updated. While there are many online free resources, such as Medscape (www.medscape.com), and WebMD (www.webmd.com), the sad truth is there is very little high-quality, free medical information available on the net. Much of it is patchy and unreliable.

It must be emphasized that Information Therapy for doctors does not just comprise learning from medical books and journals. The scope of Information Therapy goes much beyond that. It is equally important for physicians to learn to see things from a patient's perspective. Doctors sometimes take patients for granted, not realizing that conversing with a patient can open new doors of knowledge, and lead to more effective diagnosis.



7

How patients can contribute to Information Therapy

Doctor Sourav Bose was finding it difficult to manage Mr. Aditya Rao's diabetes. Though he had changed the dose of the insulin thrice, his blood sugar levels remained high. He was at his wit's end and did not know what to do. He put it down to 'non-compliance' and wrote Aditya off as a 'difficult patient'. He failed to recognize that by spending more time with his patient, delving into his lifestyle, and asking him why he was having a hard time with following the treatment plan, he could have come up with an effective solution. Aditya was

as much to blame! He should have discussed the practical difficulties he was facing with taking the insulin injections in his office, as advised by the doctor, instead of meekly accepting his doctor's advise – and then failing to follow it!

Information Therapy traditionally means the prescription of the right information to the right person at the right time to help make a better health decision. However, if we accept the fact that patients are at the centre of the medical universe and that it is patients who are the true experts on their illness, then an equally important part of Information Therapy should be the provision of information from the patient to the doctor! The patient's personal perspective is as important as the medical perspective through which the doctor views the world.

Why has this been neglected so far? Why don't more patients provide Information Therapy to their doctors? This kind of patient education has a long and respected history. While writers have written on what it is like to be a patient since time immemorial, one of the most important books that taught doctors to re-look at things from the patient's perspective was Norman Cousins's classic, *Anatomy of an Illness*. In fact, there is now an entire genre of books that does this very well. This is called pathography – a narrative that gives a voice and face to the illness experience, by bringing the person behind the disease to the forefront!

Pathography is a very useful teaching tool. It helps doctors to learn empathy, so they can learn to see things from the patient's perspective. For example, though I am an IVF specialist, I am not infertile myself. By reading first person accounts of the trials and tribulations faced by infertile couples, I learn a lot about the problems that my patients face – problems that they may not be willing to talk about when they meet me for the first time. All doctors learn medicine from their patients. As Sir William Osler said, 'He who studies medicine without books sails an uncharted sea, but he who studies medicine without patients does not go to sea at all.' Unsurprisingly, his best-known saying was 'Listen to your patient, he is telling you the diagnosis', which aptly emphasizes how much a good doctor can learn from a patient!

Doctors usually remember their most challenging patients or their most complex and difficult cases all their life – these often form the defining moments in their professional careers. It is true that these exceptional patients teach us a lot and good doctors treasure them, since they learn the most from them. These are a doctor's 'memorable' patients – many of whom teach us what not to do! Intelligent doctors learn from their patients all the time, but this can only happen if patients are willing to teach them. These are the 'expert patients' - those who are articulate and treat their doctors as partners in their medical care.

Doctors can learn from every patient, but only if patients learn to speak up, and doctors learn to listen. It is not that doctors are going to learn medical facts from each patient – but each patient is unique and has valuable insights to offer. Patient feedback helps doctors to improve their services, and even complaints are gifts, when taken in the right spirit! Unfortunately, there are still many barriers to getting feedback from patients. Most patients are inhibited and do not have the courage to displease their doctor by telling him the unpleasant truth. If patients want their doctors to do a better job, they need to learn to speak up. Most dissatisfied patients today just walk out of the doctor's clinic and never return. They find a better doctor – but by failing to give the doctor honest feedback, they lose the opportunity to help him improve and do a better job with his next patient. Similarly, most doctors are too busy to ask for feedback, and most continue deluding themselves that they do a perfect job with every patient.

Hopefully, the internet will allow patients to offer critiques and criticism more easily. There are now many doctor-rating websites, where patients are encouraged to provide their opinions about their doctors. This kind of patient-generated content will help doctors to get their act together, if they are willing to keep an open mind and try to resolve problems. Thanks to the Web, smart patients have adopted a number of clever initiatives towards improving medical care. These e-patients, of whom the most prominent is Dave (www.patientdave.com), are speaking up and claiming their rightful place in the healthcare ecosystem, so that patients now have a voice which is heard, and more importantly, respected.

Online patient support groups have a lot of clout – and crowdsourcing the collective experiences of hundreds of patients can actually help advance medical research, as proven by innovative sites such as PatientsLikeMe (www.patientslikeme.com). Patients are also collaborating to fund clinical studies, so that doctors can research on topics that are of interest to patients, and not just on areas that pharmaceutical companies find remunerative. Patients have also taken a lead role in simplifying medical research so that it becomes understandable to other patients. Cochrane Collaboration (www.cochrane.org) is a fine example of how it is important for researchers, providers, practitioners, and patients to collaborate. 28,000 people from over 100 countries work together to help healthcare providers, policy makers, and patients make informed decisions about healthcare. Such collaboration is imperative in today's times. When individual knowledge turns into collective knowledge, medical care is substantially enhanced.



8

Please ask for Information Therapy

Vandana Gupta

Vandana Gupta was diagnosed with Hodgkin's lymphoma, but her doctor's busy schedule and lack of communication skills resulted in her knowing practically nothing about her ailment, apart from its name. However, she wasn't going to be one of those patients who took things lying down. Insufficient information about her illness led Vandana to start a patient-support group

for patients with cancer called V Care, which prescribes patient-friendly Information Therapy. She recounts her experiences.

‘You have Hodgkin’s Lymphoma, but we will treat you.’

A chilling silence engulfed the room, as the doctor delivered those words. All I could comprehend was that I was afflicted with a serious ailment. That was all I knew, and the doctor did not have the time for further explanations, so my husband and I were left with no choice but to scan through information in a medical encyclopedia (Google did not exist 18 years ago!). Reading about Hodgkin’s provided us with greater insight, and we were shocked to realize that it was a type of cancer. The next day, we met the doctor in a crowded room at a leading hospital in Mumbai. In barely five minutes, I was shooed out of the room with a prescription in my hand and instructions to go to the day care center to start chemotherapy.

In one day, I had to learn so many new words – Hodgkin’s lymphoma, day care, and chemotherapy – without understanding the meaning of these terms. My husband made the ‘mistake’ of asking the doctor for some information. We were promptly handed a medical journal article which was published to teach doctors how to handle the side-effects and complications of the medicines used for treating Hodgkin’s disease. This was the worst possible thing that could have happened. The doctor was trying to be helpful, but after reading the article (laden with statistics and complex technical terms), both of us started wondering why treatment was being prescribed at all, and whether it was even beneficial taking the treatment, since the chemotherapy would cause all the organs to fail anyway!

I sincerely wished that the professional, the doctor whom I trusted, had prescribed some information along with the diagnosis and medicines. I would have been empowered and the starting point of this empowerment would have come from my doctor who was going to help me fight this life- threatening disease for the next six months. However, despite my bitter experience, I have forgiven the doctor. I guess he was complying with our request and trying to ‘arm’ us with information, but he forgot that the information must to be

tailored to the patient's needs. Otherwise, the information can actually be detrimental. Sadly, the doctor did not have access to patient educational materials – and may not even have known that they existed!

Two days later, in the dead of the night, I got a phone call from my uncle (he lives in Leeds, hence the midnight call) congratulating me. Puzzled, I asked him the reason, and he said 'If you had to have cancer, you have the best one.' Of course, this was hardly a consolation for me. All I could think was that I had cancer and it was a serious issue. I simply could not fathom anything 'good' about my illness. The one good thing however that emerged as a result of this lack of information was the birth of the V Care foundation. I started this after completing my treatment, and my goal was simple – to provide information to patients in terms they could understand. Having suffered the results of an information famine during my treatment, I wanted to do my best to make sure that other cancer patients did not go through the same experience purely because of the absence of doctor-prescribed Information Therapy!

Doctors and patients seem to come from completely different worlds, especially in India. Doctors usually are highly privileged, affluent, upper-class professionals, who think, read, and write in English. Patients, on the other hand, come from all strata of society. Many are illiterate; they can only understand their regional language; they are poor; and have limited ability to read, write, and understand. Given these constraints, it is not sensible for us to blindly adopt the U.S. model for providing Information Therapy – this would never work in India. This is both a challenge and an opportunity. Indian doctors and patients are smart and by working together, they can devise clever inexpensive solutions that are tailored for India. The Information Therapy movement must ensure that information is universally available and tested on real patients, so we know that it does effectively serve their needs. Different patients have different learning styles – some people process written material easily, while others need visual information or interactive communication. Multiple approaches will help in ensuring that Information Therapy reaches out to everyone.

The diagnosis of cancer – a life threatening disease – sends patients (and their family members) into a state of shock. Such patients must be made familiar with hospital

procedures – for example, the implications of being registered in a particular type of category (free, general, private, etc). The patient should be informed of the various tests that would be required, and a general time frame in which they need to be done. Every centre should have patient-support groups, and information about these groups should be routinely shared with patients. Medical treatment can be very expensive, and ideas about the cost (and sources of financial assistance), blood requirements, long stay facilities, available treatment options such as chemotherapy, radiation, and surgery, and the role they play in treatment, must be provided in a non-threatening environment. It may not be the doctor's job to do all this – and in fact, it is not sensible use of the doctor's time to even ask him to do so. But it is the doctor's job to ensure that the patient has easy access to all this key information. With this kind of guidance, the patient and his caregivers are prepared for what to expect, and their involvement with the treatment starts from the first day. It also builds a good reputation for the hospital, since it shows that the hospital really cares about its patients. Even today, there are patients who come from villages, expecting to return home in a few days, not being aware that treatment for cancer could go on for a couple of months or more.

Patients equipped with information are in a more confident frame of mind to meet their doctors. Doctors too are happier interacting with knowledgeable patients – it makes their life much easier if they do not have to spend precious time explaining the basics to each patient. Once the diagnosis is known, then the patient would like more information before the treatment commences. The biology of the patient's cancer can be explained, along with the available treatment options. Patients must be told what to expect, possible side- effects, success rate of every treatment, survival statistics and prognosis, and the future course of action if things do not go as planned. The practice of providing information proactively to patients will help them to contribute to their personal healing.

Engaging the patient is powerful medicine! Doctors sometimes forget that a consultation is very stressful for a patient, and fifty to eighty percent of everything that a patient hears in a doctor's clinic is forgotten (or distorted) by the time he or she gets home. This is why ongoing Information Therapy sessions will help patients immensely. It is not necessary for doctors to do this personally. They can train volunteers and clinical assistants to provide

this information. This reassures patients because they now know that they are in the hands of a genuine, caring person. Well-off patients have easy access to the internet, but often they complain that the information they receive from their doctor is markedly different from the information on the net, and they do not know whom to trust or how to make sense of this conflicting information.

The end of the treatment often marks the end of the frequent doctor-patient meetings, and while doctors get busy taking care of new patients, their former ones are often left high and dry! The treatment is now over, but what next? Can they celebrate? Is this really the light at the end of the tunnel they were looking forward to, or is it the start of another uncertain journey? More sessions of Information Therapy at this time would be of great benefit to patients. How they can take care of themselves at home, and what follow up is required must be explained to patients to avoid making them feel neglected and uncared for. They must be assured that their doctors are just a phone call away, should there be any doubts or concerns. Such queries are common among cancer survivors, especially in the first year. Is that fever just a viral infection? Or is it a more ominous sign? A patient's mind plays lots of games, and Information Therapy can help to settle problems which may be minor to a doctor, but are a source of major stress to the patient!

There is a huge gap in what a doctor knows and what the patient understands. The ideal situation would be to actively engage patients so that they are completely aware of all the intricacies of treatment. Information Therapy is a great tool which enables the doctor to achieve greater patient participation. This is true, even for illiterate patients, provided the tools are designed thoughtfully. As a patient advocate, I would like every patient to be provided a recording of the conversation and an after-visit summary routinely. For patients, visiting a doctor or hospital is not just a clinical encounter – it is a visit to a trustworthy and knowledgeable professional who has the power to find the right treatment and assist them on the road to recovery.

Doctors, apart from being entrusted with the obvious responsibility of ensuring that their patients get better, also need to be able to comfort their patients and put their doubts to rest. All patients are deserving of respect – and the best way to empower patients is with

Information Therapy. Who is better positioned to provide this to them than their team of health professionals, in whose hands they place their lives?



9

Minimizing risk, Maximizing safety

Dr Rajan Madhok
Dr Nikhil Datar

Ramesh Sawant was in a deluxe suite in a corporate private hospital, recuperating from the multiple injuries he had sustained in a car crash. Just when he seemed to be getting better, he acquired an HCAI (healthcare-associated infection). Who was responsible for this? The doctors, the hospital

staff, or his relatives? Can Information Therapy prevent such incidents from occurring?

What is patient safety?

Hippocrates, the father of medicine, exhorted doctors to ensure that their patients did not suffer unnecessarily and his dictum, 'First, Do No Harm' (Primum non nocere), has been the guiding principle for doctors worldwide. Medicine in those days was empiric and literally a 'hit and trial' affair, which is why such a caution was needed. With the recent dramatic advances in science and technology, most people naively assume that although modern medicine cannot cure everything, it must be much safer. Whilst they would be largely right, it is wrong to assume that modern medicine is completely safe. 21st century medical care is much more complex, so organising and delivering it safely is a major challenge. Medical knowledge is evolving rapidly, making it difficult for doctors to keep up with newer trends. Since there are so many different players involved now (primary care physicians; organ specialists; nurses; physician assistants; hospitalists; technicians; medical informatics specialists; and administrators), there is limited understanding of how healthcare systems can be made to function smoothly. Compared to other safety critical industries (especially aviation), medicine has not yet fully adopted the principles and practices necessary to ensure that complex healthcare can be delivered safely. The Institute of Medicine's report 'To err is human' assessed that modern healthcare was the sixth leading cause of death; and that more deaths were caused by iatrogenic errors, as compared to breast cancer or road traffic accidents in the USA (<http://iom.edu/Reports/1999/To-Err-is-Human-Building-A-Safer-Health-System.aspx>). It has been estimated that almost one in ten patients suffers an adverse event in the hospital; and there is a one in 300 chance of dying in a hospital due to a medical error. Modern medicine is clearly a two-edged sword: on the one hand it can alleviate suffering and on the other hand it can cause harm. Patient safety therefore has become an important public health issue.

How can Information Therapy help to ensure safer care?

Let us take one example to see how this may work. Healthcare-associated infections

(HCAI), acquired in a hospital or clinic, are the most frequent adverse events in healthcare delivery worldwide. Millions of patients are affected by HCAI worldwide each year, leading to significant mortality and financial losses for health systems. Of every 100 hospitalized patients at any given time, 7 in developed and 10 in developing countries will acquire at least one kind of HCAI. The burden of HCAI is also significantly higher in low-income countries than high-income ones, especially in intensive care units and in neonates. For example, newborns are at higher risk of acquiring HCAI in developing countries, with infection rates three to 20 times higher than in high-income countries (http://www.who.int/gpsc/country_work/gpsc_ccisc_fact_sheet_en.pdf).

Practicing good hand hygiene is a simple measure that can drastically reduce the chances of getting an HCAI. This led the World Health Organisation (WHO) to launch a global campaign to improve hand hygiene among healthcare workers: 'SAVE LIVES: Clean Your Hands' is a major component of 'Clean Care is Safer Care' and can help reduce the spread of potentially life-threatening infections in healthcare facilities.

This is not a new revelation, and the benefits of hand hygiene have been well documented in the past. Semmelweis in 1847 demonstrated that obstetricians could considerably reduce the number of women dying after labour by simply washing their hands between deliveries. However, he had great difficulty convincing his colleagues to do so and was hounded out of his hospital attachments for daring to speak out against doctors. Sadly, getting healthcare professionals to change their existing practices has not become any easier since then!

This means we now have a choice. We can continue relying on healthcare professionals to follow good practice to protect patients from HCAI (even though we know that they will often not do so in real life); or we can explore whether patients can do something about it.

This is where Information Therapy can play an active role. It can be used for the following:

- Advising all patients of the importance of HCAI since not many patients are aware of the magnitude of the problem;

- Educating patients and their relatives about the importance of hand hygiene and getting them to use disinfectant hand sanitizers while in hospitals. This is especially important in India, where relatives play such an important role in providing nursing care to patients;
- Making hospitals publish their statistics of hospital- acquired infections. Ideally there should be open reporting of data, showing trends and improvements over time; and Getting patients to request the healthcare professional ‘touching’ them to wash their hands before doing so.

So, here is a sample Information Therapy prescription for a patient going into a hospital:

- Please be aware that hospitals are dangerous places and that your hospitalisation can cause you to acquire an infection.
- You can reduce your chances of getting an infection by limiting the number of your visitors; and by asking them to wash their hands and using disinfectant.
- Do request your doctors and nurses to wash their hands before touching you or doing a procedure.

This kind of openness and transparency can empower patients; and reinforce the fact that the hospital is doing all it can to ensure that patients are safe and that the risk of errors is being actively minimised.

The Planetree model (www.planetree.org) is an excellent example of how hospitals can significantly improve patient outcomes and reduce patient errors by actively involving patients (and their family members) in medical care. It is the patient who has the most at stake; and by ensuring that patients are well informed, hospitals can help to reduce complications and errors considerably. This will improve patient satisfaction scores and increase patient loyalty, which in turn will result in better hospital occupancy and boost their bottom line. It will also help to reduce the risk of lawsuits because of medical errors.

This prescription can be in the form of written notes, or in an audiovisual form since the use of multimedia can improve patients' understanding and retention by over a third. In summary, Information Therapy increases the patient's 'ownership' and helps the patient to explore alternatives by empowering them to choose appropriate care and set realistic goals. The doctor-patient relationship becomes more open, being partnership-based rather than paternalistic; and shared decision-making can be achieved.

Information Therapy is equally useful in the doctor's clinic as well. We all know that often a patient will need to visit different specialists. Unfortunately, as a result of this, care gets fragmented, and problems such as drug interactions are very common. By ensuring that the patient knows exactly what medications he is taking and why, these preventable problems can be avoided with the help of Information Therapy. Information Therapy acts like an immunisation against ignorance. It helps to make sure that things don't fall through 'in between the cracks' and puts the patient back in charge!

Challenges and opportunities for Information Therapy

To make Information Therapy work, we have to address some challenges. First, most people are still unaware of the problem of unsafe care: they believe that modern medicine is a force for good and that doctors and nurses are highly professional people and that they are in 'safe hands'. So we do need to acknowledge that there is a problem and that it is imperative to promote safer care. Second, we still do not know enough about the extent of the problem. How many incidents are occurring? Where? When? What kind? We need to ensure that appropriate data is collected. This will help us to understand the underlying causes of these errors and enable us to design solutions. Finally, do patients or their carers/relatives feel empowered enough to question, and indeed challenge, their doctors? Even doctors often shy away from questioning their own personal doctors when they are ill!

Information Therapy can be a major force in improving patient safety, and we need to create an ecosystem where patients can safely demand that they be given Information Therapy; and doctors can feel comfortable doing this routinely and proactively. Today, there are a number of organisations and initiatives to promote the involvement of patients

in improving healthcare safety.

WHO Patients for Patient Safety: Patients for Patient Safety (PFPS) emphasises the central role of patients and consumers in improving the quality and safety of healthcare around the world. (http://www.who.int/patientsafety/patients_for_patient/en/).

Action against Medical Accidents: Action against Medical Accidents (AvMA) is an independent non-profit organisation that promotes better patient safety and justice for people affected by a medical accident. A 'medical accident' is where avoidable harm has been caused as a result of treatment or failure to treat appropriately. (<http://www.avma.org.uk/>).

Technology can help as well. We are learning how to design and deliver better healthcare, by looking at system designs, and hence are able to identify and eliminate steps where mistakes could occur. Information Technology has a very important role – by having a unique identifier for every patient, and a single electronic health record, we can provide timely and accurate information to both patients and their doctors.

The delivery of the right information, at the right time, to the right patient, by the right doctors and nurses should no longer be left to chance; every patient should get this routinely as part of their care in the 21st century. Sir Muir Gray, the Chief Knowledge Officer of the NHS in England, talks of high-quality information provided directly to the patients being the way forward for the transformation of healthcare. In the recent reforms being proposed by the Government in the NHS in England, the Minister has made it clear that he wants a health service where patients are in the driving seat, not as passive recipients of care but as equal partners with healthcare professionals – 'No decision about me, without me' – and this cannot happen without huge doses of Information Therapy. Let us use the opportunities available to us to overcome the challenges and get the care that we all want and deserve for ourselves and for our dear ones.



10

Medicines –

The good, the bad, and the ugly

Mrs Kapoor visited her GP for a 'nagging pain' in the stomach. Her GP prescribed her a course of antacids. While Mrs Kapoor did get some temporary relief with the medicines, she decided to visit a specialist. The specialist gave her stronger tablets and she took them, while also continuing her GP's medication. This interaction of drugs exacerbated her problem, and she found herself back to square one. As an educated patient, Mrs Kapoor should have informed the specialist of the medicines that she had been taking.

It might have resulted in a different prescription and a better outcome.

The right drug for the right patient in the right dose by the right route at the right time: this golden rule sums up the ideal prescription – and it seems like such a basic and simple rule. What's disturbing is how often this rule is broken today in daily medical practice. However, the good news is that Information Therapy prescriptions can ensure that we follow this simple rule. Medicines are powerful – and every drug can have beneficial effects and undesirable effects. Information Therapy ensures that the following questions have been clearly answered before taking any medicines.

What should you do if you are taking other prescribed or over-the-counter medicines? What are the short- and long- term risks associated with the medicine? Are there less risky alternatives? What should you do if you inadvertently miss a dose? The list is not exhaustive. As a patient, it is your right to ask as many questions as you wish to clear any doubts.

Your first step should be to read what your doctor has written (no matter how illegible the writing may be), and to clearly understand what the 'hieroglyphics' mean. Don't leave with questions unanswered: ask your doctor or chemist for an explanation of any confusing terms on your prescription. A very useful reference book you should consider purchasing is the Indian Drug Review. This book is easily available at any medical bookshop and is an excellent compilation of details on all the prescription drugs available in India: for instance, their cost; dosage; therapeutic action; drug interactions; and side-effects. Though this book has been written for doctors, it is easy enough for any layperson to use. Not only will this book help in understanding the medicines you are taking, but it may also help you to save money, since you can select a less expensive brand of medicine, after discussing the matter with your doctor.

Your doctor can also help you save money by prescribing generic drugs. 'Generic' means that the drug is not protected by trademark registration; and the generic name of a drug is usually a shortened form of its chemical name, so that any manufacturer can use it when marketing a drug. Usually, a manufacturer uses a trade name (or brand name) as well as a

generic name for a drug, and you should be able to identify the generic name and the trade name of every drug you are taking. Generic drugs are generally priced lower than their trademarked equivalents, largely because the former are not as widely advertised as the latter. Also, do keep in mind that for certain drugs, it is not advisable to ‘shop around’ for an alternative since differences can exist between the brands of certain drugs.

The amount of medicine you buy at a particular time depends on several factors, the most obvious one being how much money you have, or how much the insurance company will pay for each purchase. Medicines to treat heart disease, high blood pressure, and diabetes may be purchased in bulk because you will need to take such medicines for prolonged periods. The chances are that you will pay less per tablet or capsule by purchasing large quantities of drugs, and save quite a bit of money. Do ask the chemist for a bulk discount!

While medicines are useful in the treatment of certain illnesses, the overuse of drugs has taken its toll, not only in the form of unnecessary expenses but also in the form of sickness, and even death, as a result of an adverse reaction to the medicine. Patients still believe that there is a pill for every ill – and this desire for instant relief translates into billions of rupees for millions of pills, potions, ointments, and powders. The pharmaceutical industry is the second-most profitable in the world – right after illegal drug trafficking! Most people take one medicine at least weekly, and more than 25 percent of the world’s population consumes drugs on a daily basis. Most patients are not happy unless doctors prescribe medicines – whether or not they really need them. Often, doctors too will contribute to this ‘overmedication syndrome’, and the huge advertising budgets as well as the largesse of pharmaceutical companies lure them to continue doing so on a regular basis.

You must, however, understand that no drug is without its side-effects – after all, anything that has the potential to benefit your body also has the potential to do harm. A ‘therapeutic effect’ is a desired effect, and a ‘side-effect’ is an undesired effect – but both are simply effects of the same drug on the body, and go hand in hand. Remember that 80 percent of all ailments are self-limiting and require no treatment. Therefore, think carefully about the costs and risks as well as the benefits before taking any medicine.

You should be especially wary when your doctor prescribes the ‘latest’ and newest drug. For one, such a drug is likely to be much more expensive than its ‘older’ counterparts. Drug companies nowadays spend large amounts of money in order to induce doctors to prescribe their newest products because they are much more profitable for them. Also, remember that newer does not always mean better – in fact, new drugs may be more dangerous. Since they have not been used for long enough, some of their harmful effects may not become apparent until many patients consume them over a long period of time. Older medicines, which have been tried and tested over many years, are a safer bet, since doctors have considerable experience with them and are aware of their risks and benefits. For example, Duract, a new non-steroidal anti-inflammatory drug (painkiller), was withdrawn from the market just a year after being approved for use in the USA (after having undergone rigorous testing), since it was linked with a dozen cases of liver failure, four of them fatal!

Surprisingly, no one knows how many deaths, injuries, and side-effects prescription drugs cause each year – there is no agency which monitors these effects. Who’s responsible for this modern epidemic of drug-induced disease? All of us! Pharmaceutical companies, for a less-than-rigorous study of their approved drugs; physicians, who incorrectly prescribe drugs, or over prescribe the ‘latest’ drug; patients who don’t follow instructions or don’t tell their physicians about the other drugs they are taking; and even government agencies for not monitoring drug safety more effectively. As a patient, you can help to protect yourself from a therapeutic misadventure by not opting for a newly-approved drug unless there aren’t any other, well-established alternatives.

Older people are especially prone to the problem of unnecessary drugging. Often, once a doctor starts a patient on a medicine, the latter continues taking it, whether or not he needs it anymore. And each specialist adds to the drug overload, without having a clue about what else the patient is taking. Not uncommonly, it turns out that only one or two of the assortment of drugs is really needed and, once the unnecessary medicines are eliminated, the patient starts feeling much better. In contrast to today’s enthusiasm for drugs, it is wiser for you to be a ‘therapeutic nihilist’, in order to let the body heal itself whenever possible.

What can you do to help prevent medication errors? The answer is simple. Learn to ask questions. Just because you haven't been trained as a doctor doesn't minimize the important role you play in preventing errors with regard to your medicines, or those for your family. By the very process of asking questions about your medicines, you understand why you are taking them, how to take them, and what to expect so that you can detect potential errors. The most common causes of medication errors are similar drug names, similar packaging and labelling, and illegible prescriptions.

The following factors should always be borne in mind:

- Avoid medicines to the extent possible. Pregnant women, for example, generally get along fine without drugs (or with very few drugs).
- Periodically, bring all your medicines, including over-the-counter drugs, to your doctor for review. Ask your doctor for an information prescription, so you can check for drug side-effects and interactions. Be sceptical of patently extravagant claims made by pharmaceutical advertisers.
- Remember that 'big guns' are not needed to treat self-limiting or non-dangerous diseases, and that side-effects of medicines may well create more problems than the original illness.
- Take oral medicines as far as possible. Such medicines are usually equivalent to injections and are both cheaper and safer. Many patients still naively believe that injections are more 'powerful', but this is purely a myth!
- Beware of physicians who prescribe new medicines at each visit without modifying or discontinuing previously prescribed drugs. Many patients are not happy unless the doctor gives them a medicine for their problem, even if this is not required – and most doctors are happy to pander to their patient's fancy. In fact, many patients still judge the calibre of doctors by the length of their prescriptions and by the cost of the medicines they prescribe!

- Taking two or more drugs at a time can complicate matters considerably, since they can interact with each other, resulting in either adverse effects, or a reduction in their efficacy. The best way of minimizing this problem is to limit the number of drugs you consume, taking only what is strictly necessary.

OTC DRUGS

Drugs that can be purchased without a prescription are referred to as over-the-counter (OTC) drugs, and these have become a worldwide phenomenon in the present era of globalization. Common OTC medicines include pain relievers, laxatives, cold-relieving preparations, and antacids. They are consumed rather indiscriminately by millions of people, but think carefully before purchasing an OTC drug. Do you really need a medicine in the first place? For example, rather than popping a sleeping pill into your mouth every night, a glass of warm milk may provide a better solution for your insomnia. Similarly, simple measures such as steam inhalation and salt- water gargling can provide as effective relief from a sore throat as can medicines. Unfortunately, most people would rather take a pill for every ill. More than 100 OTC drugs are available for treating the common cold – none of which have been shown to be effective.

Just because a medicine is available over the counter does not mean it is completely safe, and you should always check with your doctor before taking it. Sometimes, OTC drugs can actually be harmful. For example, taking painkillers over many years can cause kidney failure and swallowing tablets to self-treat a fever may mask certain illnesses such as tuberculosis or malaria. Don't just depend on a friend's advice or on your chemist's suggestions: always discuss OTC drugs with your doctor.

You should also discuss your medication with your chemist. Unfortunately, chemists still represent an underutilized resource in India. Every chemist's shop must have a duly qualified and trained pharmacist. Pharmacists are professionals who have done a four-year course in a pharmacy college and are knowledgeable about medicines and their effects. If you have any doubts, seek out the pharmacist in the chemist's shop; the clerk or the shopkeeper may not know anything about medicines.

You should be able to identify your medicines properly. Many errors are made at home by taking a wrong tablet or capsule that appears similar to another family member's medication. The ability to recognize your medicines can help in preventing you from consuming the wrong drug. If you believe an error has occurred, contact your doctor, pharmacist, or nurse as soon as possible. Do not take the medication until all your doubts have been dispelled.

As far as possible, patronize the same chemist for prescriptions drugs as well as over-the-counter drugs. A complete record of your medication history can be kept at the chemist's shop, and some modern chemists have now installed computers that allow them to store the details of the medicines you are taking. This precaution is especially important if more than one physician has been prescribing medicines. A competent pharmacist can also spot hazardous combinations of medicines, and help you avoid possible dangerous drug interactions. Always keep medicines in their original containers. Many drugs look alike and this can cause an 'identification crisis'. Never use another person's medication; and never experiment with medicines just because a friend recommends them. Similarly don't 'play doctor' by lending your medicines to your friend or relatives. Discard all medicines once they have reached their expiry date.

Always remember that you are the one taking your medicines. Therefore, ensure that you are well informed about them, so that you can take them safely. Every time a medicine is prescribed, please make sure that Information Therapy is prescribed with it as well. In most instances, it is as important as the medicine itself!



11

Listening to the patient

Leslie Kelly Hall

Don Kemper

Mr Jones runs a thriving cardiology practice. Apart from being a very competent doctor and an expert in his field, there's an all-important ingredient in his formula for success – Patient Response. Dr Jones' team uses Electronic Medical Records (EMRs) which are accessible to the patient through a patient portal; and ensures that appropriate feedback is obtained after every consultation. Patients are proactively asked if they have any concerns about

their treatment plan; and regular emails are sent to ensure that patients are coping well. This active involvement of patients in their treatment is what truly sets him apart from many other well-meaning but less proactive doctors.

The greatest untapped resource in healthcare is the patient. More often than not, an engaged and activated patient can make the difference between healthcare success and failure.

Through EMR systems, we have begun to tap that resource by prescribing information to the patient just in time to help him or her make a better health decision or to support a higher quality of self-care. Still, there is something important to consumer empowerment that is missing. Consider this:

- It's true that people can 'pull' a full array of medical information and decision-support tools from the Web.
- And, increasingly, doctors can 'push' the most relevant information and tools for each individual patient through their electronic medical record systems.

But today, there is no good way to get the patient's voice captured within the medical record. Until we can 'pay' better attention to the patient's perspective, much of the patient's potential will continue to go untapped. Pull, push, and pay strategies are all needed to maximize engagement.

Patient response is a new way to ensure that the patient's voice is well heard in creating care plans, in deciding among treatment options, and in advancing the doctor-patient partnership. With patient response, patient-centered care becomes possible. Only by paying attention to the values and preferences of our patients can we achieve sufficient patient engagement to put the patient at the centre of care.

Patient response defined:

- Short definition: ‘Patient response’ is the documentation of the patient’s preferences and responses to physician’s requests within the clinical record.
- Full definition: ‘Patient response’ is the documented record of a patient’s treatment, care plan, self-management, and health education preferences and responses to clinical and administrative questions, presented in the clinical record using HL7 standards, to help the clinicians support shared decision making and patient activation. Such a patient response is usually, but not always, in direct reply to a clinician’s information prescription or query to the patient.

Patients who are actively involved through information prescriptions and patient response will make better care plan management actions at home. Physicians who ask their patients to do more self-management and shared decision making can achieve better clinical outcomes, raise patient satisfaction, and reduce the cost of care. When patients are involved and informed, they can ask for the care they need, say ‘no’ to care they do not need, and do as much for themselves as possible. There is no better way to engage patients than to assure them that their voice will be heard in treatment and care plan decisions.

The stage is set for patient response

Stage I of the ‘meaningful use’ rules is helping to define new ways in which electronic health records (EHRs) and related health information technologies (HIT) can more actively engage patients in their care. Meaningful use rules require that clinicians prescribe ‘patient-specific educational resources’ through their EHR systems. They also require hospitals to send discharge summaries and preventive services reminders to patients. These rules will help more patients to receive the information and tools that they need to play a more effective role in their own care. This information prescription phase is a necessary step toward full patient engagement.

One-way information is not enough

While informing patients is a key step in unlocking the patient's potential, one-way information, by itself, is not enough. Until the physician can see, in the clinical record, the patient's response to a query or decision aid, there is little chance that the patient's voice will be heard. Patient-centered care will never be attained until the patient's voice is in the clinical record and the doctor pays attention to it.

A patient response is much like a medical test result

You can think of a patient response as being much like a medical test report that comes back into the record for the clinician to use in making a better diagnosis or treatment plan.

- Just as the test is done at the clinician's request, so, too, is the patient response done in reply to a physician's request, query, or information prescription.
- Just as the test results come back to a predictable place in the patient's record and in an expected format that is easy for the clinician to quickly scan within a time-limited workflow, so, too, is the patient response presented in a predictable place and expected format.
- And just as an automated analysis of a medical test highlights test results that are out of normal range, so, too, does an automated analysis of the patient response flag any aspects that are important to the care plan development.

Physicians are often unaware of what their patients are thinking. Did I answer all her questions? Is he planning to change his diet to prevent diabetes? Does she agree with the care plan? Did she have important symptoms that I didn't ask about? Is she also using complementary medicines to manage her complaints? Too often there is just no time in a clinic visit to probe for the answers.

Patient response can improve the doctor-patient relationship and care outcomes by promoting empathy. With patient response, the doctor gets to learn the patient's perspective

in a short time, and the patient gets the satisfaction of knowing that his voice was heard. Both enjoy the rewards of improved medical outcomes.

Here are five examples of patient response with benefits for both doctors and patients:

1. **Pre-visit summaries** : Pre-visit summaries are patient responses to a set of questions sent to a patient in advance visit and interactively probe the patient's symptoms, concerns, level of knowledge, and expectations for the visit. By starting with a succinct summary of the patient's responses, the doctor can get to the point of the visit faster and serve the needs of the patient with more time available for education, motivation, and joint care planning. Pre-admission summaries can do much the same for improving the quality and efficiency of hospital admissions, so patients don't have to waste time filling multiple forms. A patient response to acknowledge patient readiness, including receiving necessary forms and consents, increases patient involvement and improves the hospital's efficiency
2. **Patient-specific education materials and self-management learning programs** : When a clinician sends the patient an information prescription or self-management program, it is important to know if the information or program is making a difference. If requested, patient response provides information back to the record regarding:
 - Whether the material was read;
 - Whether the program was completed; and
 - What self-care actions were started or planned.

Patient response allows the physician to appreciate successes, empathize with struggles, and provide motivation for additional efforts.

3. **Patient decision aids** : Shared decision making has been shown to improve patient outcomes and satisfaction while lowering costs. However, the value of a patient's use of a decision aid is diminished if patient insights gained from the decision aid never get back to the physician. With patient response, physicians can quickly assess if the

patient is ready to make the treatment decision and what patient preferences and concerns should be considered in the decision process.

- 4. Medication and preventive services adherence :** Patient response helps the physician know if and why a patient has either not filled or not taken a prescription medication. It also allows for fast, structured reporting of symptoms related to drug interactions or reactions. Without learning why a patient is not taking a prescribed drug, a clinician has little chance of achieving adherence. Patient response to preventive service reminders can also alert clinicians about why they are declined and whether additional information is needed.
- 5. Advance care planning :** Advance directives are another form of a patient response. By implementing advance directives using patient-response standards, this documentation becomes more accessible to the patient, more available to the clinician, and more easily transferred to those who have a need to know them.

Patient response implemented across a spectrum of uses such as those described above will enhance the doctor-patient partnership while encouraging patient inputs to a shared care plan. And with a bit of creative thinking, we can motivate higher degrees of patient accountability by tracking patient responses.

Patient response and quality

Patient response supports quality initiatives in many areas of policy, reform, and health improvement. Consistent with the government's Partnership for Care initiative to provide better care at lower costs, patient response provides a concrete way to bring together patients and their caregivers. Patient response can validate that the patients and their families understand how to be safe from hospital-acquired diseases; that the care plans are understood; and that instructions given to patients are acted upon as they transition between care settings and home.

When patients are allowed to report on their care experiences, quality-reporting initiatives

are supported and customer service improvement opportunities are created. Patient response allows for patient participation in research and surveys in a meaningful way, integrated within existing workflows.

Standardizing patient response

Observations and results provided to clinician orders are a fundamental feature in all EHRs. Thousands of these transactions move within any one hospital, hundreds of thousands between providers and labs, and millions across large integrated delivery systems, on a daily basis.

To maximize mainstream adoption, the existing HL7 technology standards and interoperability framework must be enhanced to integrate patient response into the clinician's current workflow. The case for building on existing standards is a strong one:

- **Ease of integration** : Contextually aware, patient-specific data is already available and easily transitioned to incorporate patient response.
- **Existing practice** : Orders, observations, and results are already widely adopted and familiar. They are easily enhanced to incorporate patient response.
- **Mapped to episodes of care** : Just as medical test results are matched to a specific episode of care, the information prescription and corresponding patient response can be matched as well.
- **Automated analysis and flagging** : Automated analysis and flagging will make patient response an added blessing to the workflow of a clinician. A quick glance at the flagged responses will tell much of the patient's story that is now available only through extended conversation well beyond today's workflow limits.

At last, a reason for the public to embrace EMRs

Until now, the public's response to their \$30 billion investment in EMRs has been less than enthusiastic. Their biggest concern is that someone will steal their data and they don't yet

see a compelling benefit to justify the risk. The combination of information prescriptions and patient response will dramatically change public opinion about the value of EMRs. People have concerns about electronic banking as well, but their fears are overpowered by the convenience that electronic banking gives them. In the same way, when people experience how being an informed, engaged, and respected member of the healthcare team helps them to get better care, their fears of the harms from medical data theft will be greatly moderated.

Conclusion

At this point, patient response is just a gleam in the eyes of a handful of healthcare innovators. However, the path from idea to reality can be travelled quickly. It took less than 10 years from the publication of Information Therapy to the publishing of the meaningful use rules that took information prescriptions mainstream. And now that Information Therapy has paved the way for patient response, its road can be travelled far more quickly.

To make this happen, work is needed in three areas:

1. **Standards enhancement** : People who have HL7 standards experience can join in an effort to modify existing standards to allow for the new functionality of patient response.
2. **Policy development** : People who have the ear of the government can promote the value of patient response as being essential to real meaningful use; patient-centered care; and the triple aim of better care, better health, and lower cost.
3. **Application development** : People who have an interest in each of the cases described above can develop and test applications that can be integrated into EMR systems to achieve breakthroughs in the evolution of accountable care.

If we want patients to behave as empowered partners in their own healthcare, we need to respect them. Patient response is a great tool that allows patients to speak up — and doctors to listen!



12

How Hospitals can earn Patient Loyalty

Mr Puri is standing outside the ICU ward with his brother-in-law and in-laws. It has been three hours since his wife's surgery, and he is worried sick. 'How is she coping?', 'Does she need anything?', 'Has she eaten something?' are some of the questions in his mind. He attempts to ask the hospital staff for answers, but they refuse to placate his fears, giving him the standard answer: 'Wait till the doctor arrives.' Frustrated, he is left with no choice but to sit in the waiting lounge outside with his family members, a 'lounge' that lacks even basic facilities like tea and coffee.

Customer Relationship Management (CRM) is a tool which all service industries employ to keep their customers happy. Since hospitals are in the business of serving patients, one would expect hospitals to use CRM routinely, but most hospitals in India still do not bother utilizing this valuable tool. Given the chronic shortage of beds, most hospitals continue to take the approach that patients do not have a choice as to where they can go for treatment, which is why most hospital staff adopt a high-handed attitude towards patients. Stories of hospital staff rudeness and arrogance are innumerable, and this is reflected in the increasing number of incidents of violence against doctors and hospitals.

On the bright side, new progressive corporate hospitals are willing to learn from the hospitality industry, and are willing to implement CRM to provide their patients with a better experience when they come to the hospital. However, another tool that needs urgent implementation is PRM. No, it is not Patient Relationship Management that is being discussed here (though a lot of hospitals do not do a good job of that either!), but Patient Relatives Management. The need for this is much more acute in Indian hospitals! When most patients come to a hospital in India, they are accompanied by a bevy of friends, neighbours, and relatives. Sadly, these people are often ignored and neglected by the hospital staff and management. Most hospital staff members consider them to be a nuisance and tolerate relatives as a necessary evil. There are very few amenities available for family members, even for those who are on a 24-hour vigil outside the ICUs. Relatives are understandably concerned and worried about their loved one's health. They are key decision makers, and need to be educated and informed about what to expect. They need to be addressed politely and kept updated about the clinical status of the patient. Unfortunately, this is rarely done. Doctors (and sometimes, the more senior they are, the worse their habits!) seem to take a perverse pride in making relatives wait endlessly and often for completely flimsy reasons. They are not willing to share information about what goes on behind the intimidating doors of the operation theatre and ICU. This is why family members often get angry with doctors, and when the patient dies, they vent their frustration by burning down the hospital or beating up the doctors.

Doctors are very busy, and many may not have enough time to talk to even their patients, let alone their relatives! This lack of communication can cause frustration, and

after bottling it up, relatives will often vent their resentment when a mishap occurs, even if the doctor was not to blame. This is a systemic problem, which can be addressed proactively by the hospital management. In order to protect doctors, who are now feeling very vulnerable, the government is passing laws

and hospitals are beefing up their security. However, this is a very short-sighted fix. It is far more important that hospitals start investing time, money and energy in educating patient's relatives, so they have realistic expectations of the outcome of the medical treatment. Dissatisfaction arises when there is a mismatch between expectations and reality, and helping relatives to have realistic expectations will help in reducing dissatisfaction with doctors and hospitals!

The most effective way of doing so is by setting up Patient Education Resource Centers (PERC) in the hospital. The PERC can be run by nurses and librarians and will help to educate patients and their relatives, so they know what to expect during their hospital stay. As Indian hospitals strive to attract medical tourists and match global standards (for example, by getting JCAHO accreditation), documenting that patient education has been provided is going to be an integral and indispensable part of patient care. The PERC will become an important department of the hospital. In the Mayo Clinic, the Dept of Patient Education occupies an entire building!

Not only are PERCs important for risk management, they are also very cost effective. All these relatives are prospective future customers for the hospital (after all, everyone falls ill at some point of their lives!). If they are treated with respect, they are likely to return to the same hospital for their own medical care when they need it.

We all know that the best kind of marketing is word-of-mouth marketing. Instead of wasting money on advertising in the press, it makes much more sense for hospitals to invest it in PRM. Relatives (and the patient's visitors) are potential customers. Why not educate them about health and illness? In a hospital, everyone has a much more heightened sense of their own mortality. When people visit a friend who is sick, they are much more acutely aware of their own frailty, and are more health conscious! Questions like 'What can I do

to ensure that my husband does not get a heart attack like his elder brother did?' race through their mind. Reaching out to these relatives through a Patient Education Resource Center to help them learn more about their health can reap big dividends for the hospital because they are much more likely to seek medical assistance in a hospital which has taken the time and trouble to educate them.

PERCs can also be very useful for educating and training paramedical staff. The hospital support staff (such as ward boys and the janitorial staff) plays a very important role in serving the patient's daily needs. However, they are often not very well informed about hospital procedures. The PERC can be used to educate and train them, so they are more responsive to the patient's special needs, thus improving the relationship between patients and hospitals, and reducing untoward incidents.

PERCs can be strategically located in the hospital lobby, and they offer an inexpensive way for hospitals to provide a value-added service that differentiates them from the competition. They cost very little to set up, and need minimum space and staff. Indeed, they are a very cost-effective investment in Information Therapy!



13

Promoting Information Therapy is good for pharmaceutical companies

Mrs Sethi's persistent dry and itchy skin condition was recently diagnosed by her dermatologist as 'Eczema', a fairly common condition in the medical world. However, Mrs Sethi was not too familiar with it. She went to the chemist to buy the ointment that her doctor had prescribed. She read the leaflet accompanying the tube, and instead of reassuring her, it accentuated her fears. The side-effects section made her feel that the medicine would worsen her condition, not realizing that such undesirable effects were only

reported in large doses and in extreme cases. If the pharma company had provided more understandable and patient-friendly information along with the standard leaflet, it would greatly help assuage Mrs Sethi's fears.

In the past, pharmaceutical companies were held in high regard because the drugs they helped to discover saved lives and helped fight diseases. Today, on the other hand, they get lots of bad press. They are seen to be greedy because they overcharge for their drugs; they waste a lot of money on advertising; they develop drugs which 'treat' unimportant lifestyle issues; and are thought to be unethical because they indulge in underhand practices to encourage doctors to prescribe their medications.

The good news is that Information Therapy provides a great opportunity for pharmaceutical companies to restore their tarnished reputations – and companies which adopt this will become market leaders. Pharma companies have to reach out to two distinct segments – doctors and patients. Let's look at both of these individually, and see how Information Therapy can help pharma companies to do a better job. Traditionally, drugs were prescribed by doctors, and pharma companies spent a lot of money convincing doctors to prescribe their brands. This has become increasingly harder, as the market has become very crowded, and there are lots of 'me-too' brands.

The traditional way companies influenced doctors to dispense their brands was by using medical representatives (reps or MRs). Their role was to establish a personal relationship with the doctor and then to leverage this relationship to cajole the doctor into prescribing their brands. However, this became increasingly difficult, and many companies started resorting to underhand practices (such as bribing doctors or sponsoring them for overseas medical trips) in order to favour their brands. It is also a fact that MRs are no longer very effective. Doctors have wised up to their tricks, and since they are so busy, many will no longer even agree to see reps anymore! MRs are an expensive resource, and many companies find that they no longer provide value for money. Since they cannot give the doctor expensive gifts (providing costly freebies to doctors is now illegal under the new Medical Council of India rules), they no longer enjoy as much clout with doctors as they once did.

Pharma companies who want to continue influencing doctors will have to adopt new techniques and many have learnt that providing Information Therapy is a much more cost-effective and ethical solution. Companies have always provided educational materials about their drugs, but a lot of this used to be biased and incomplete. Instead of this, if they now invest in providing doctors with Information Therapy tools – both for continuing medical education for the doctor and for his patients, this is likely to be far more useful to the doctor. A doctor's professional knowledgebase is his most powerful asset and doctors need to be well-informed and up-to-date. Merck has taken a leadership role in ensuring doctors in the U.S. are updated, by providing them with free access to many medical textbooks and journals through their portal, www.merckmedicus.com. Indian companies are starting to follow in their footsteps by gifting medical books and medical journal subscriptions to doctors. Many have started offering doctors free subscriptions to online medical libraries, thus creating a win-win situation.

Most Indian doctors now have an internet connection, but many still do not use this for their professional activities. This is a great opportunity for a forward-thinking pharma company. By providing online subscriptions to medical journals, the company is encouraging doctors to go online daily to keep abreast of all the latest information. They can then use these online channels to market their products to doctors, without having to spend on MRs! E-detailing is soon going to become the most prevalent method of reaching out to doctors, since it is inexpensive and can be tracked very efficiently. It can be delivered to the doctor's desktop, and it is much easier to reach many more doctors through this route. As a new generation of computer-savvy doctors in India becomes the leaders in their field, this will become an increasingly popular option. It has been predicted that in 2020, the pharmaceutical industry will spend 90% of its marketing communications budget on digital channels and 10% on face-to-face channels. Medical education will be delivered in a multi-media format and will most often be consumed in doctor's offices. It will be the norm for the pharmaceutical industry to deliver 'whole products' and not just medicines. These will include services and information to add value and deliver better patient outcomes. International medical conferences will still happen, but more than 90% of the content consumption from these meetings will happen remotely and digitally.

While the traditional customer for the pharma company was originally the doctor, marketing to the end-user (the patient or the consumer) has become increasingly important. Doctors write the prescriptions, but it is the patients who actually take the medicines! Since pharma companies want to reach out to consumers directly, they now spend a lot of money on DTC – direct to consumer marketing. This is still in its nascent stages in India, but given the huge impact it has had in the USA on increasing drug sales, it is simply a matter of time until Indian companies start using DTC in a big way. However, DTC has backfired since pharmaceutical companies in the U.S. have suffered an image problem by releasing dishonest DTC campaigns, which have been heavily criticized. Indian companies need to be smart and learn from these mistakes. Rather than spend on DTC, which is seen to be advertising, they need to invest in creating disease specific websites that focus on providing Information Therapy to the patient. Disease management is ‘trust marketing’ – patients log on to websites because they want to learn how to manage their illnesses – and a pharmaceutical company which provides them with reliable information will be seen as trustworthy.

Any time a patient takes a drug, he has lots of questions about it. What are the side-effects? Risks? Complications? A study showing that patient compliance with treatment for high blood pressure was less than 50% revealed the following interesting facts. Many patients are afraid of medications, their side-effects, and the lacklustre attitude of their doctors. If we need to improve patient compliance, we need to analyse the patient’s perspective – and we can do this by putting patients in charge of their game plan, so they can become active partners in their healthcare. A patient who understands why he needs to take medications for high blood pressure all his life does not need cajoling or bullying!

Patients need answers to their questions about their medicines, but doctors and pharmacists are often too busy to answer ‘routine’ questions. This is why pharma companies are required to provide patient information leaflets with their drugs – but sadly, these leave a lot to be desired. They are hard to read – and even harder to understand! Clever companies can use the patient information leaflet as a valuable tool to establish a direct digital relationship with the patient. The leaflet could provide the website address where the company provides more information about that drug and the disease it helps to

treat. Since the information is online, it can be very detailed and extensive, and this can inspire confidence in the patient. Patients could register on the site and get their questions answered by medical experts, thus getting their doubts resolved. They could sign up for an ezine which would allow the company to provide them with more information about their ailments and available treatments. This kind of permission marketing can help companies to build a database which is worth its weight in gold! The site could act as a nucleus for the formation of online patient-support groups, and expert patients could provide valuable feedback to the company about their wants and needs. This is a major opportunity and will allow clever companies to build a direct relationship with patients – something which is especially important for patients with chronic illnesses. The lifetime value of these patients can be enormous, but sadly, no Indian company has yet taken the initiative in reaching out to these patients, who are now spending a lot of their time online.

Information Therapy gives pharma companies an opportunity to reach these influential patients, because it allows them to create a partnership with the patient. Patient education programs can increase patient adherence and retention and provide an excellent return on investment. For example, patient counselling tools for physicians can increase calls from physicians requesting MRs to come back to the clinics and replenish these tools. Digital, customized patient progress self-monitoring tools can motivate patients to stay in therapy, helping both doctors and patients.

Patient education by pharma companies is not new and Eli Lilly and Co. began its Diabetes Interactive Network in the USA in the mid-1990s. However, Indian companies have failed to use the internet to bond with their patients. They can learn a lot from pharma companies abroad, which invest extensively in Information Therapy to improve patient compliance. For example, in Australia, Mirixa uses a web-based clinical system to enable pharma companies to use community pharmacists to deliver personalised medication-related patient care. This increases customer loyalty and improves their market share. Pharma companies that offer their patients online value added services to help them manage their disease have already seen how helpful this is. An excellent example is www.avonex.com by Biogen which sells Interferon for the management of multiple sclerosis. Why aren't other companies using similar tools? One possibility is that they are worried about whether

these sites are compliant with Indian regulations. It is true that they need to be careful since the information which they provide is in the public domain. This means that it cannot be about marketing their product – it has to be about helping the patient manage his disease. This is why Information Therapy can be so helpful – it helps the pharma company focus on the patient's need, and not on their product!

Progressive pharma companies all over the world are using facebook and other forms of social media to reach out to their patients. The affluent Indian is already online, but Indian pharma companies are still lagging behind. If they use Information Therapy to empower patients, they will be able to reach out to many more Indians – and the general public will once again see the pharmaceutical industry in a positive light and as being an important player in improving human health.



14

Why Information Therapy makes business sense for health insurance companies

Ketan Shah, a sales representative for a major health insurance company, has his work well cut out. The senior management has asked him to maximize sales of insurance policies to keep the company ahead of its rivals. Yet, this is a very short-sighted approach. Instead, if the company looked beyond the obvious profit motive and directed its efforts towards ensuring the health and well-being of its clients, this would not just attract more customers and increase revenue, but also build lasting relationships. Providing Information

Therapy to their customers makes tremendous business sense!

No one wants to fall ill, but when you do, the last thing you want to worry about is the doctor's bills. This is why purchasing a health insurance policy to protect yourself against the financial losses caused by a medical problem has become so important. Medical care has become increasingly expensive and unaffordable and a health insurance policy can provide financial protection, ensuring that you can afford the best medical care.

The traditional form of health insurance is called indemnity insurance (also known as fee-for-service), in which the insurer pays for the cost of covered healthcare services after they have been provided. In most indemnity insurance plans, patients are free to choose their own doctors or hospitals. In the past, the health insurance business in India was a monopoly, so the only medical insurance policy available for most of us was Mediclaim, through the subsidiaries of the General Insurance Corporation (GIC). Today, with increasing liberalization, the insurance business in India has been opened to the private sector, and there are now many more options to choose from. While this extra choice is great, because companies are competing with one another to offer customers the best deal, having so many options can be confusing!

Given the huge Indian middle class; the fact that medical care costs are escalating every year; and that the government infrastructure is not able to provide basic healthcare, experts believe that the health insurance market is going to boom over the next few years. However, for historical reasons, most health insurance companies in India are still losing money and scrabbling for market share. This is actually a great opportunity for a health insurance company, which is willing to think out of the box, to stand out from the crowd.

What do customers want from a health insurance policy? Their basic needs are protection from financial loss because of hospital bills; free access to doctors and hospitals they want to go to; no fine print for exclusions; reasonable costs; convenience at the time of hospitalization so they don't have to pay first and then claim the money from the company (what is called a cashless' transaction); prompt payment of medical claims; quick processing

of claims; minimal paperwork; and friendly customer service.

Today, since there are so many companies competing for business, they all have great marketing campaigns and are happy to sign up customers left, right, and centre because they want to increase their market share and they know that once signed up, most customers usually stay for life. However, most Indian health insurance companies are still stuck in the past when their only role was limited to paying the hospital bills. All they seem to do is collect the premium every year and pay the medical bills (claims) when customers fall sick and need hospitalization. What's worse is that while they are very efficient at collecting the premium, when it's time to pay out the claims and settle the hospital bill, they create a lot of unnecessary hurdles in order to delay making the payment, causing a lot of grief and anguish to the customer. This is why health insurance companies have received so much bad press recently.

This is short-sighted. Remember that a health insurance policy should not just provide illness care, but should also help us to remain well. In the USA, which has the most evolved health insurance market, things are very different. Insurance companies have realized that spending on medical care after a person falls ill is expensive for them. It is much more cost-effective to invest money in educating, counselling and motivating people to remain well, so that they do not fall ill in the first place – after all, prevention is better than cure. In fact, in ancient India, this was a well-accepted principle and the doctor (whose job was to keep the family in good health) was paid only as long as everyone was healthy. If anyone fell ill, the payments stopped until they recovered. Innovative health insurance companies in India need to come up with a modern version of this model – and providing Information Therapy is a great way of doing this.

Now, there are many options available to insurance companies which they can use to help their customers remain healthy. These include tools for counselling, lifestyle improvement, weight loss, and smoking-cessation programs. Many of these can be provided online, which makes them inexpensive to deliver. Just look at the wellness tools which the United Healthcare website at http://www.uhc.com/health_and_wellness.htm offers to its U.S. customers, or the Aetna website at <http://www.besmartaboutyourhealth.com>. And

compare this with any Indian health insurance company website. The difference is clear.

Indian health insurance companies need to leapfrog and use the Web to deliver Information Therapy to their customers.

Most affluent Indians are now online and because it's so inexpensive to develop web services and applications in India, it's very cost-effective for insurance companies to deploy these. Once they have the email addresses of their customers, they can encourage them to submit their claims and pay their premiums online – again saving both the insurance company and the customer time and money. They can also offer discounted memberships to gyms, spas, yoga classes, meditation retreats and counselling sessions, to help their customers adopt a proactive approach in managing stress and fighting off disease.

Similar tools can be used to help patients with chronic illnesses manage their disease better so they don't need hospitalization. Hospital care has become very expensive and teaching patients to take care of themselves is a powerful therapeutic intervention. This is called 'disease management' and is an integral part of providing Information Therapy. It has been applied abroad for a wide range of diseases, ranging from asthma to hypertension to diabetes.

These programs are cost-effective for the insurance company to offer – and they don't need to spend too much on them either. An excellent example is the recent study from Partners Health Initiative (PHI) in Anderson, South Carolina which showed that they saved an estimated \$34.5 million in 30 months – thanks to simply gifting a copy of the world's largest selling patient education book, the Healthwise Handbook, to all their customers!

The lesson is clear – not only is there a business case for health insurance companies to be investing in Information Therapy, but it's also a great way of helping them win more customers and keeping their customers happy. Knowledgeable customers should demand that health insurance companies provide them with Information Therapy tools to promote their health.



15

Healthcare entrepreneurs, disruptive innovation, and Information Therapy

Mr Ashok Jain

Mr Kumar has been running a successful medical practice since the last sixteen years. However, he hasn't evolved with the changing times. He still doles out his regular prescriptions, and rarely ever engages his patients in their treatment. This is making him lose out on new patients, and many of his existing ones are deserting him to go to doctors who practise in well-equipped

corporate hospitals. Interestingly, he is facing competition not just from more well- informed doctors but also from non-medical entrepreneurs!

Simply talking to patients and dispensing health information is not the same as providing Information Therapy. Patients are anxious and worried because medical procedures are complex and expensive; and doctors often use jargon to make even simple matters more complicated! Information Therapy is required by patients to reduce their anxiety, increase their compliance, and get better results. Doctors also need it so they can get better treatment outcomes, more loyal patients, and less medicolegal complications. In a sense, Information Therapy is akin to the other IT (Information Technology) – they both improve decision-making and overall quality of life. In fact, a controlled clinical trial (which doctors love to do!) would show that Information Therapy is much more potent than a Placebo (the standard by which all medicines are measured).

It is a huge business opportunity. We need to remember that healthcare spending in India today accounts for less than 4.2% of the GDP, whereas in most developed countries, it is 6-9% and in the USA, it is as much as 16%. This means that there is immense growth potential. All doctors are not just medical professionals. Since they run a practice, they are also entrepreneurs (even though they sometimes do not recognize this). One would expect doctors, who are educated and intelligent, to be able to clearly see this opportunity and work on developing tools to improve the system. However, this is easier said than done. Did Nokia see the iPhone usurping the market? Barnes and Noble never understood the potential of Amazon, Microsoft did not understand search engines, and Google did not foresee the power of social networking. Marketing Myopia turns the mighty into mere mortals! The healthcare industry has become sick, and disruptive innovations are needed to heal it.

Since doctors deal with patients daily, clearly they can see these opportunities as well. So why don't they capitalize on them? I feel that there are many reasons for this. For one, doctors are part of the problem themselves. They are so used to making patients wait that they don't even realize that this unnecessary waiting creates a lot of patient dissatisfaction. All doctors think they have great bedside manners and excellent communication skills, so

they feel they personally don't need to improve. After all, if they weren't good, would they be so busy and have so many patients waiting to see them? Why fix something that isn't broken?

Also, most doctors are quite conservative. They are taught to accept the status quo – and many believe that what was fine for my medical professors is fine for me. Medical training does not teach doctors to think out of the box or encourage risk-taking, which is why very few of them have the courage to strike out on their own. Some also feel that they lack the managerial skills required to run a business. Moreover, there are very few role models for them to emulate, so these business opportunities are often well-disguised.

The trouble is that doctors cannot see the forest because they are too close to the trees – they are so focused on taking care of each individual patient that they lose the ability to think in terms of the big picture. The tragedy is that even though they are often in the best position to craft effective solutions, since they are smart and understand the pain points of both doctors and patients, they have failed to do so, and this gap has been filled by others like me who can see the opportunity!

Medical entrepreneurs need to grab new opportunities and think beyond their clinical duties and responsibilities. They need to understand their patients' requirements, and realize that prescriptions are not enough. They need to understand the power of Information Therapy. Doctors, with all their skills and medical knowledge, are in the best position to harness the power of Information Therapy. If they do not, non-medical entrepreneurs like me will grab this opportunity.

Since the last decade, Oxygen has been taking advantage of the Oxygen TV brand. We have 2,500 TVs installed in doctor's clinics in 12 cities all across India which help to engage patients and educate them, before their consultations with the doctor. This way, patients do not get upset with their doctors if they are late, since they can utilise this time to learn more about how to improve their health. We have been able to successfully monetize this, because companies which sell consumer health products are very happy to pay for the service of displaying their ads to patients who are waiting in their doctor's clinics. They

are a captive audience – and because they are very aware of their health problems at this time, they are much more receptive to learning more about their health. We expect to grow three times in size in the next five years!

Since doctors deal with patients daily, why don't more of them take advantage of these business opportunities to improve their net worth? Where are all the medical entrepreneurs in India? I am hopeful that with the constant advances in an ever-changing healthcare world, a new shift in the healthcare domain will take place, in the form of medical and non-medical entrepreneur partnerships and doctors will be willing to put down their stethoscopes and start thinking big. This, like all healthy partnerships, will create a win-win situation for both parties, and go a long way in extending the scope of Information Therapy.



16

IT for IT

Nrip Nihalani
Aditya Patkar

Our society still hasn't yet evolved enough to give HIV patients the dignity they deserve. So when Mr Aggarwal was diagnosed with this disease, he felt lonely, depressed, and shunned by society. His doctor suggested that he join an online community where other HIV patients were sailing in the same boat. Days after 'going online', Mr Aggarwal is a changed man, thanks to all the healthy group discussions and success stories of treatment. He has come to terms with his illness,

feels positive about treatment, and most importantly, knows that he is not alone.

Information about the patient is the lifeblood of medicine. Modern technology has enabled new ways in which we store and share this information for many to use, reuse, improve and share some more.

In this day and age of the internet, mobile phones and social media, patients are empowered with the possibility of real- time communication, 24/7 access to information, and live community feedback. Today's patients have been exposed to numerous avenues besides the ones which our forefathers were aware of. Such exposure has empowered this generation of patients to ask for better care, better facilities, cheaper alternatives, and more useful ways of using technology to provide healthcare as well as healthcare information. However, in spite of large amounts of information being available today, a big problem that exists is that the information is not necessarily usable when and where it is most needed.

To effectively facilitate Information Therapy, Information Technology (IT) must bring about a marriage of ideas with utility; IT has to ensure that all the players of this ecosystem come together to improve information management for the benefit of the patient, healthcare professionals, and decision- makers throughout the healthcare sector. Only then can Information Therapy be provided to various participants of the healthcare ecosystem through the following stages of an illness:

- Diagnosis and information gathering;
- Finding a provider;
- Soliciting a second opinion;
- Accepting a diagnosis;
- Participation in research; and
- Being a patient advocate.

For technology to be truly successful, there should be sustained focus on the different avenues of Information Therapy. We explore 5 avenues with roadmaps below:

Avenue 1: Medical information sources

IT vendors must work at creating patient-friendly reliable trustworthy healthcare and medical information databases. These can be about medicines, diagnostics, decision trees, side-effects, precautions, etc. A great example of this is the Healthwise Knowledgebase at <http://healthlibrary.com/healthwise>.

Technology should evolve to allow for more effective ways for updating information in such knowledge bases and wikis are a good model. These could be based on curation, criticism, and collaboration to ensure that it is self-adjusting, effective and patient-centred. Advances in social technology will provide new ways for spreading this information, and innovation in delivery mechanisms will facilitate easier ways for people to consume this information.

This will help in:

- Creating informed patients;
- Creating valued sources; and
- Ensuring poor sources are filtered and discarded.

Avenue 2: Digital Identities for healthcare providers and provider information sources

The logical first step in creating rich databanks of provider information is to create identities for providers in the electronic world. The simplest way to do this is to create websites for doctors, clinics, and hospitals. This may not necessarily be individual websites for those who don't want to invest in one, but simpler, informative, single web pages that fulfil the purpose of creating an identity for them.

Such websites can be optimized to convey services, location and contact information, medical notes, special cases treated, and the like. Such optimization will help in disseminating useful

provider information to people looking for the same. This isn't advertising, it's a service. People today face many choices and are hampered by lack of information. Improving their ability to find information quickly is beneficial to them.

Technology vendors must provide easier ways for provider information to be located and searched, and this should be available through different types of media. They must:

- Create searchable directories of doctors and hospitals and other healthcare providers; and
- The directories should allow users to grade and provide feedback about the healthcare providers they have interacted with, in a controlled environment.

Avenue 3: Patient-doctor communication

True engagement comes about through two-way, mutually- beneficial conversations. Technology must create multiple ways to facilitate both formal and informal patient-provider communication. The telephone made a huge impact on the way we communicate, and so did email. Newer technologies must be used to offer ease of use, larger acceptance, and lower costs. Many providers today communicate with their patients using Skype, Google chat, and even Facebook. Technology must build on such success stories while also allowing patients to protect their privacy and confidentiality.

Avenue 4: Health Information Exchanges

Technology vendors must work together to create Health Information Exchanges (HIEs) based on interlinking of electronic medical records, electronic health records, laboratory data and patient health records across providers and patients. This helps in:

- Providing patients with the option to switch doctors easily;
- Allowing doctors to easily refer patients to other doctors for a second opinion; and
- Enabling direct access to laboratory data for physicians.

The creation of a huge databank of medical data including symptoms, diagnostics and prescriptions (in which the data is ‘anonymised’ to protect patient privacy) can help to improve the cost-effective delivery of effective medical care and promote evidence-based medicine. HIEs must be designed to allow innovators to be able to create novel ways of using and sharing the vast volume of data within HIEs as long as patient and provider confidentiality is not compromised.

A major roadblock in health exchanges is that data is stored by various knowledge bases, EMR and EHR vendors, and portals in their own formats. Devices also use divergent technology to record and store information. But as with Imaging and the DICOM compatibility norms, new standards such as HL7 and CCR are breaking down barriers for the exchange of data in healthcare information, to allow data to flow smoothly.

Avenue 5: Online health communities

For years, patients have liked to work in groups, to support each other, to help themselves cope with illnesses which their near and dear ones don’t understand, and to seek advice from others who have similar ailments. Bringing people together in collaborative dialogue to explore social conditions that are the major influences of health and illness generates deeper collective awareness and community-driven action. Since individuals don’t see their lives partitioned into online and offline worlds, online communities should be given as much value as offline ones. A variety of online communities must come up for connecting patients quickly and privately with others who share similar health experiences.

Technology for creating online communities allows just about anyone to set up an online community, replete with video and audio chats, whiteboarding, discussion forums, and bulletin boards. This enables the creation of an integrated digital ecosystem which simultaneously addresses both individual and social dimensions of health. It also allows patients to engage with each other and involves providers too.

Case studies showcasing IT providing effective Information Therapy using the avenues discussed above:

- A hospital website provides emergency response numbers which earlier would only be found in a phone book. This improves the delivery of emergency medicine by providing real-time information through e-health channels.
- A gynaecologist's website allows a patient to calculate her schedule for check-ups and ultrasound visits and set reminders for the same. Earlier, she would have to get it written down by the doctor; now all she needs to do is log on to her trusted doctor's website and check the dates herself. E-Health helps people plan their long-term healthcare through tools that promote and help them to understand what they need to do.
- Cancer patients after chemotherapy sessions feel low and unhappy, and are tired of the emotional stress involved. They never talk to anyone and shy away from contact. When they are online, they have a new lease of life, being able to interact and get support from other patients. Moreover, they can do this anonymously! Learning simple remedies and tried and tested tricks from expert patients who know and feel what they are going through because they have 'been there, done that'. The power of e-health through online patient forums and support groups allows information to flow freely – and since this is digital, it's much more easily available and accessible.
- A patient in a remote village in South India suffering from acute pain in the abdomen has to make do with the local village doctor's prescription. A year later, a telemedicine pilot allows this same patient to get a second opinion using a remote video link. He is able to identify what's happening to him via the printouts he gets from the telemedicine centre; and realizes that he must work at improving his diet if he wants to prevent his acid reflux.

Both the ITs – Information Therapy and Information Technology – must work synergistically to create a wonderful future for healthcare – one that is modern and simplifies the life of patients and doctors.



17

Doctor.com

As an IVF specialist, I am often inundated with questions. While I would gladly answer all of them, this is sometimes not practical, owing to my busy schedule. This is where my website comes into play. One can find comprehensive information on IVF treatment, success stories of other patients, FAQs, details of my clinic timings, and many more resources. Most of my patients' doubts are put to rest, even before they come to me for an appointment. A doctor's website can be a very cost-effective tool in delivering Information Therapy.

Not too long ago, most doctors in India were unaware of the concept of an email address! This might be hard to believe, but it's true! However, times have changed dramatically, and today most doctors use email regularly. But even that is not enough. If you are a doctor, you need to have a personal website. This rapid pace of change is symbolic of how quickly things are changing in today's world. In fact, it is my contention that doctors in private practice in India can no longer afford to not have their own website. Just like how you need a telephone line to practice medicine, a website has become an integral part of modern medical practice – and doctors who are not proactive are likely to get left behind!

The key to your success is your ability to keep your patients happy and to provide them with excellent medical care, and your website lets you provide many value-added services for your patients. It can provide basic details such as:

- The timings of your clinic;
- Directions as to how to get to your clinic;
- Information on the specialized services you offer;
- Why you are better than other doctors;
- Answers to patients' commonly asked questions (FAQs); and
- Post-procedure instructions.

This means you can use your website to serve your patients round the clock without requiring them to call or visit, making your website a valuable support centre. Your website allows you to answer your patient's queries by email. Patients will always be curious about their ailments, and many will use the internet to find information. Please do not underestimate your patient's intelligence. Many will spend hours hunting for information, in order to help themselves get better. If they do not have a computer, they can go to the cybercafé. Even illiterate patients do have relatives who can conduct internet searches for them! However, most patients would much rather get information from their own doctor, and if you provide this information on your website, your patients know they can trust it.

Most doctors have now started seeing patients coming with internet printouts of pages and pages of unreliable and irrelevant information. If you put up your own website, you can guide your patients towards reliable sources of information, thus saving your patients the frustration of wading through endless pages of garbage and misinformation! Remember that Indian patients want information about diseases common in India – so they want information on malaria rather than cystic fibrosis. By providing this information, you establish yourself as a credible expert. You can refer patients to your website at the end of the consultation, so they can educate themselves. Patients appreciate this – and word of mouth will help you get more patients.

This is actually a huge opportunity for forward-thinking Indian doctors. There is very little content about health and medicine in Indian regional languages today. Any doctor who is willing to take the time and trouble to set up a website and provide this content in his local language is likely to become a star in a short period of time. This will take some work initially, but this is an investment from which you can reap enormous returns in a short time. Internet penetration in India is increasing by leaps and bounds, and Indians have easier access to a mobile phone today than they have to a toilet!

The good news is that it has become very easy to publish in Indian local languages, and because you can use Indian companies to do so, the cost of publishing a website is a fraction of what it would be in the USA. Play to your strengths and make the most of these great opportunities to achieve instant global presence! Your website can help you to attract new patients. Indian medical care is very cost-effective, and a website is valuable for informing NRIs of your medical expertise. Soon, it will become a routine for patients in India to research about their doctors, as it is in the USA, and your website can help patients to find you. At our website, <http://www.DrMalpani.com>, we answer over 20 queries a day, as a result of which we get direct patient referrals from all over the world. Remember that internet-savvy patients may be slightly different from your average patient. They are well-informed, used to getting second opinions, and can be quite demanding. Most are affluent and know exactly what they want, so they will keep you on your toes!

It is very hard for patients to trust someone they have never seen or met, and this is why it is so important that your website should be information-rich and full of content which is of value to patients. If patients understand that you are interested in empowering them with information, they are much more likely to trust you. The more you give away, by being generous with your knowledge and sharing it, the more you will get in return.

Even though many doctors today understand the importance of having their own website, they often fall victim to procrastination, and do nothing concrete about this. Others are worried that setting up a website is expensive, while some do not know who to contact since many web designers do not have the technical expertise to publish medical websites. In order to address this problem, Plus91 (www.plus91.in), in which I am an angel investor, offers customised websites for doctors, tailored to individual preferences, for as little as Rs. 10,000 per year – and they can publish your website too, so it is live within just 2 days. You can see what your website will look like at www.websitefordoctors.in.

Ideally, all doctors and clinics should have their own websites, where their patients can find reliable, updated information on their health problems. Your website will showcase your talent and help you grow your practice ethically, so you do not have to worry about giving cuts and kickbacks. This will help your patients as well, who will become aware of the latest medical facilities you offer. The transparency that the web imposes will help to improve your relationship with your patients, by allowing much more open communication between them and you. While it may seem that email is impersonal, the truth is that patients can be far more communicative by email than they are face to face because they do not have to worry about how many other patients are waiting, and can pour out their hearts to you! Interacting with your patients online will help you to become more patient-centric and empathetic, because you will get a much better idea of what your patients are thinking about and what they want. It will save you time as well, since once you upload answers to common queries as FAQs, your patients will not feel the need to ask you the same questions repeatedly.

Once you have your own website, you can also start exploring social media (Web 2.0) to reach out proactively to your patients. Tools such as Facebook and Twitter are very

useful in projecting yourself as an authority – make the most of them!

You need to have realistic expectations of what your website can do for you. In India, the number of internet users is not yet as high as in the USA, so don't expect patients to start pouring in the day your website goes live! Just having a website is not enough – remember that there are over a million websites out there. You need to promote your website actively. Print your website address (URL) on your business card and your stationery, and display it in your waiting room. Encourage patients to visit your website – most will be happy to follow their doctor's orders! And if your website has content which is useful to them, and which is updated on a regular basis, many will happily visit it regularly and even refer many of their friends to your site as well.

You can also design a monthly ezine, to keep patients coming back to your site. Your staff should constantly be on the lookout for interesting pieces for the next month's issue. This creates a direct link to your website, but does require commitment to keep the content fresh. You can employ a webmaster to do this for you, to ensure you do a good job. Your website is an image of your clinic so make sure you do a professional job. Also, ensure that you reply promptly to queries and emails. It's a good idea to check out competing websites, so you can see what they are doing, but don't blindly copy their content. Your website can help to keep you on your toes both professionally, since you need to update your medical knowledge to provide fresh content for your website and to answer queries received by email from patients in all parts of the world, which means this is a great method of Continuing Medical Education (CME); and technologically, since you will need to keep abreast of computer and internet technology. A website is valuable even for doctors in rural areas, who are often cut off from the rest of the world. This is a useful way of keeping in touch and contributing to the medical knowledgebase.

Some doctors are worried that having their own website may be misconstrued as a form of advertising. However, the internet is a very valuable means of educating patients, and doctors need to be at the forefront of providing reliable information to their patients. After all, if we do not take the responsibility for educating patients, then who will? The future of medical care is e-healthcare, with the promise of online medical records, online pharmacies,

telemedicine, patient education, and an ever-expanding list of exciting opportunities. The opportunity to help our patients navigate the wealth of information on the World Wide Web and better educate themselves is now in our hands. We owe it to ourselves and to our patients. As a doctor, if you do not rise to this challenge, your friendly competitor down the road will do so and take away all your patients!



18

Switched on - Using mobile phones to deliver Information Therapy

Dr Ankit Khambhati

Dev, a business consultant, uses his smart phone to send his blood glucose readings and insulin dosage titration schedule to prevent hypoglycemia, with the help of a mobile application provided by a disease management web portal he subscribes to. Far away in Santa Rosa USA, Michelle, a 35- year-old homemaker with polycystic ovaries, uses her mobile chat to communicate

with her personal health manager seated in a hi-tech call centre in Mumbai, who tracks her lifestyle and motivates her to comply with her medications and diet regime. In Udaipur, parents of children going to a public school receive SMSes on health check-up reminders, wellness tips, and recipes for healthy options for their children's tiffin boxes.

Information Therapy or evidence-based health information has been proven to motivate patients and trigger behavioural changes, which is important in preventing and managing non-communicable diseases like cancer, diabetes, obesity, and heart disease. Globally, mobile health solutions are offered in a variety of formats:

- Health awareness and prevention e.g. text messaging;
- Healthcare management e.g. disease monitoring; and
- Healthy lifestyle e.g. promotion of fitness and wellness.

The power of mobile phone services must not be underestimated. For example, studies have shown that a mobile phone counselling service could help people with HIV to stop smoking (in the short term). Patients who availed of this service were four times more likely to quit cigarettes for seven days as compared to patients who did not. Interestingly, such counselling also substantially increased the chances of patients quitting smoking completely. It is clear that mobile phones are an effective medium and can be used to reach out to patients with different ailments.

India has over 700 million mobile phone subscribers, and with mobiles becoming cheaper, the number of subscribers is growing rapidly. Worldwide, the number is 4 billion. Today, every mobile handset is capable of at least sending and receiving SMSes in different languages. With emerging 3G and 4G spectrums offering uninterrupted data services and seamless video chats on mobile phones, visiting clinics for common ailments and check-ups will soon become old-fashioned. While data security concerns with m-health applications loom large, the success of m-commerce in the retail sector is quite encouraging.

It is not only the patient who is going to benefit from smart phones! Information Therapy works only if the healthcare provider is well informed. For the doctor, the Tablet can be the new clinic, with tools like online CME, online video consultation, electronic health records, and medical device integration. Similarly, social media, viral videos, and application downloads can be the new mantra for pharmaceutical and medical device manufacturers, both for creating patient awareness and for marketing to doctors. Mobile applications for e-opinion, e-investigation, anthropometry, and disease monitoring could be used by the healthcare insurance industry for better risk underwriting. With the evolution of e-commerce, clinics, hospitals, diagnostic centres, and Third Party Administrators (TPAs) can collect payments through the phone, making it easier for patients to pay for healthcare services at the point-of-care, thus improving efficiency.

Communication is evolving rapidly. Mobile phones no longer simply serve the standard purpose of answering and receiving calls. In the healthcare world, mobile phones can be effectively used to facilitate better communication between healthcare professionals and their colleagues and patients. Information Therapy and m-health are all set to revolutionize healthcare delivery in India and globally. Yes, there are many challenges, but the clever use of technology can help to overcome these hurdles.



19

Medical librarians – An underrated resource!

Vasumathi Sriganesh

When Mr and Mrs Shukla's child was diagnosed with 'Down's syndrome', they wanted all possible information on the illness. Endless hours of searching on Google provided little useful information, driving them to frustration. On a friend's advice, they visited a consumer health library. There, a helpful and informed librarian scanned through the catalogue and

gave them a list of popular books on the subject, many of which were written by the parents of children with Down's syndrome. In today's high-tech age, visiting a library was the Shuklas' last resort. However, it clearly ended up being the best one.

'Information Therapy is the prescription of the right information, to the right person, at the right time to help make a better health decision.' This simple definition of Information Therapy raises many questions. How can information have therapeutic effects? What do we mean by 'the right information'? Isn't every person who needs health information a 'right person'? And is there a 'right time' to provide health information? Isn't now as good as any time? This chapter will explain how a medical (or health sciences) librarian can help in the provision of the right information to the right person at the right time.

The problem with information and information delivery

Health-related information is useful if it is available to us in the right doses at the right time, but only if it is authentic and beneficial. The problem is that very often – and alarmingly so – the information that we get is inaccurate. In such cases, the information can be actually harmful, rather than being helpful. It may be the result of wrong research. It may be outdated. It may be too complicated for us to understand. It may not be available unless we are ready to pay a substantial fee. And sometimes, we simply do not get information because our healthcare providers forget to tell us some facts or instructions. This could happen due to human factors like their overly busy schedule, or they may assume that we already know these facts.

A simple example illustrates this:

A lady went for a blood sugar test. A lab technician drew her blood when she was on an empty stomach. She was then told to eat and come after two hours. She went home, ate after an hour, and came back within two hours of her first visit to the lab. A clearer instruction would have been, 'Come back to give a sample two hours after you have eaten.' For the technician, this was routine knowledge. Without realizing this, he had assumed that

anyone who came for this test would know these facts. A simple handout for such patients would have made a big difference. In this case, luckily, the patient herself had a doubt and gave the second blood sample after another hour.

Information Therapy and the role of a medical librarian

Medical librarians can add major value in providing Information Therapy. They will usually have a Master's degree in 'Library and Information Sciences'. During their training, librarians learn a lot about the various types of information resources; the way information is structured and organized; and how to search correctly, using structured techniques to get the right information quickly. Librarians are information specialists – they know how to classify and retrieve information. During their training, they also learn how to evaluate the quality of the resource: Is it comprehensive? Is it biased? Is it suitable for the reader? They are trained to pick out the best resources, based on the user's query and needs. Since a librarian works with information resources daily, she specialises in ensuring that they are utilized optimally.

It is important to note that a medical librarian will not make a diagnosis or provide advice about a treatment – that's the doctor's job! Librarians will collaborate with doctors to ensure that patients get the information that they need. Patients should treat the librarian as a researcher on their medical team – and discuss the information they unearth with their doctors.

Librarians classify Information resources in several ways, and it is a good idea to understand this.

By its contents:

- Basic resources – textbooks, dictionaries, telephone directories;
- Research resources – journals – where research is published on an ongoing basis; and

- Analytical resources – where experts study all available research, analyze it (through a systematic process), and then synthesize it, presenting unbiased facts, evidence, and guidelines to help others to provide the right healthcare.

By the format in which the information is published:

- Primary resources – journal articles, original research papers;
- Secondary resources – lists (or databases) that lead to primary resources; and
- Tertiary resources – lists (or databases) that lead to all available secondary resources.

By target audience:

- Based on its utility to doctors, nurses, dieticians, consumers and patients.

By medium of publication:

- Print, offline electronic resources like CDs, and the internet.

Medical librarians ensure that the information that a patient or consumer seeks will be sourced from authentic and reliable resources. They will search every available resource as required and will contact other information professionals for additional help if required.

Examples of Information Therapy and some specific experiences:

As a former librarian at HELP, I can share some examples of how we used Information Therapy to help patients.

- A young mother of an autistic child came to the library to know more about the condition. Our team of librarians was able to provide her with books, pamphlets, and magazine articles in the library collection, since we had catalogued them in detail,

through our library software. The mother was very grateful because the library had such an extensive collection and that we were able to get out everything in minutes for her. She mentioned that she got a lot of ‘day-to-day’ and ‘common-sense’ information that would hold her in good stead when helping her child to cope with autism.

- A lady brought her daughter-in-law who was pregnant. In Indian culture, it was uncommon for girls to proactively learn a lot about pregnancy and labour – especially about 15 years ago. The two sat in the private area reserved for viewing videos and watched one on pregnancy and labour. They were happy to have watched it and to us librarians, it appeared that their bond strengthened through this.
- A doctor called us, and told us that his wife had recently delivered a baby who had a rather rare condition, where a part of the brain was absent. In medical terms, this was known as ‘Agenesis of the corpus callosum’. This happened when internet access was in its early days in India. The doctor did not require medical information on the condition, but he was keen on finding out how he could get in touch with other parents who had babies with a similar condition. We did a search and presented him with websites and also gave him the address of a support group that offered more information and help to parents like him. He called us again in a few days and said that the support group had asked him if he would be a local resource in India and that he had happily agreed.

In each of these cases, the librarians helped patients with information that they would not have easily got from their doctors for several reasons. Providing this kind of information creates a positive virtuous cycle – and the doctor whom we helped has been able to help many more parents as well.

Specialized information provision

Librarians sometimes have to provide information on very specific queries that a patient may have. Examples are:

- Does the long-term use of a particular drug cause cancer?

- A relatively new drug has caused adverse effects – is it really safe?
- Is it important to rest in bed or to continue to be active if you have back pain?

There are evidence-based sources of information that answer these queries. These sources are updated on a regular basis and are created by experts who continually research every available publication on the topic and publish the 'evidence'. There was a time when librarians answered such questions only if a doctor prescribed Information Therapy. Today, the trend has changed as there is now an increasing awareness of the 'right to health information'. Librarians possess certain strong personal traits like maturity, empathy and a love of interacting with people. The skill to use these and at the same time providing the necessary privacy and confidentiality while delivering their services is something that every librarian must cultivate!

Why are librarians considered as ideal providers of Information Therapy?

- Librarians are helpful professionals and patients find it easier to ask them questions that they may forget to (or be reluctant to) ask their doctor, given the stress of the consultation and the paucity of time.
- They are trained to interview patrons for their information needs, so they can help them formulate their requirements correctly.
- They are objective and neutral because they do not have any vested interest in influencing the patient's medical decisions.

The role of librarians is not restricted to helping only patients. Medical librarians are trained and experienced in conducting medical literature searches. They are often asked to locate a specific medical journal article by a doctor when he encounters a patient with a rare problem. Their expertise in drilling down and finding the most relevant references or information can often make a significant difference in the quality of medical care which a patient with a complex or rare problem will receive.

For instance, abstracts from most medical journals are published free online in PubMed – (www.pubmed.gov). Doctors and patients can search the medical literature themselves, using this excellent resource. However, they often get lost and may not be able to find critically important information because they have not searched using the right keywords (MeSH terms – which are very special in PubMed). PubMed is a complex database, and the experience and expertise that a medical librarian brings makes all the difference between a useful search and an exercise in futility.

With Google at our disposal, one might wonder whether we still need librarians and libraries. Contrary to popular belief, Google does not cover all the resources on the internet. And not all information is available online – free or for a fee because a lot of high-quality information is locked up in books! Google searches the entire internet, and since it's not intelligent enough to distinguish between relevant and irrelevant information, its search results are often unreliable and outdated, which can harm rather than help. Of course, a librarian can help you use Google itself to get better answers. If patients need in-depth answers and have got upset, frustrated and lost on the internet (which is often the case), they are far more likely to appreciate the immense value which a librarian can add in holding their hand and helping them to find prescription-quality information.

Sadly, medical librarians are an unappreciated and underutilised lot in India today, and we have failed to take advantage of their unique skill sets. In fact, in countries like the U.S., medical librarians accompany doctors on their rounds, so that the medical staff can make optimal use of medical journals and databases. Ideally, every hospital should have a consumer health library (which could be a part of the medical library) so that just as doctors send their patients to chemists, they can also refer them (or their relatives) to the library for Information Therapy.

Information Therapy is an integral part of the healthcare process. Doctors may not be able to explain every single detail to their patients. Instead of wasting time wading through information on the Internet (where a lot of it may be misleading), using a library's resources (print and electronic access) and a librarian's help can make a world of a difference to patients.



20

Healthier reporting using Information Therapy

Prateik Roy, a reporter for a tabloid, reads a recent study on the internet that suggests a possible cure for cancer that is currently in the testing phase. However, he misinterprets the entire meaning of the study and writes an article titled ‘CURE FOR CANCER FOUND’. How often have you picked up a tabloid, flipped to the medical section, and seen such a headline, only to be disappointed when you read the rest of the article? We live in the ‘Breaking News’ era where everything is sensationalized by the media. How do we

ensure that health reporters benefit from Information Therapy too?

We all rely on the media for our daily fix of the latest news. While making sense of the share prices in the financial section of a newspaper is fairly straightforward, how does one interpret or understand medical stories? We are now awash in a flood of health information, and barely a day goes by without a report of a spectacular new cure for a formerly incurable illness. However, many people find themselves increasingly frustrated in the face of the barrage of confusing and contradictory health advice. Unfortunately, the media is often guilty of oversimplifying or exaggerating results. Moreover, headline writers may focus on an angle that gives a distorted impression, which often means that facts are sacrificed for greater circulation figures.

Many reasons can be attributed to the somewhat shoddy standard of reporting in the mainstream press with respect to medical matters. Editors crave for stuff which is 'new', and doctors and hospitals are only too happy to boast about their latest gadgets and gizmos. Reporters are often not specialized enough to understand the technicalities of medicine. They do not do their homework properly, and this leads to misreporting, a common occurrence in India. It is a sad fact that although most newspapers and magazines have a battery of expert financial reporters, few have full-time, knowledgeable health medical reporters.

Information Therapy for reporters can help to ensure accurate news reporting. Reporters need access to reliable updated information, so that they can make sense of the stories that doctors and hospitals present to them. This will allow them to separate the wheat from the chaff, and interpret the story for their readers, so they can give them a fair and balanced perspective.

A very interesting study (www.plosmedicine.org/article/info:doi/10.1371/journal.pmed.1000323) showed that it does matter who writes the news stories that cover the benefits and harms of healthcare interventions. Stories written by specialist health journalists working for a single media outlet were superior to those written by other groups. Traditional broadsheet newspapers scored highest and commercial human interest

programs consistently returned the poorest scores. It is presumed that these differences reflect not only the professional skills of journalists, but also editorial policies that dictate the target audience, the writing style (favouring human interest over evidence), the length of the article, and the extent to which it serves particular sectoral interests (e.g., a patient support group or identifiable victims of a disease). These findings are not surprising, but some of the differences were large and likely to translate into flawed information for consumers, with an adverse effect on health literacy.

In recent years, sites that monitor the completeness and accuracy of medical news reporting have been established in Australia (www.mediadoctor.org.au), Canada (www.mediadoctor.ca), Hong Kong (www.mediadoctor.hk), and the U.S. (www.healthnewsreview.org). These sites use the following criteria to judge the quality of the reporting:

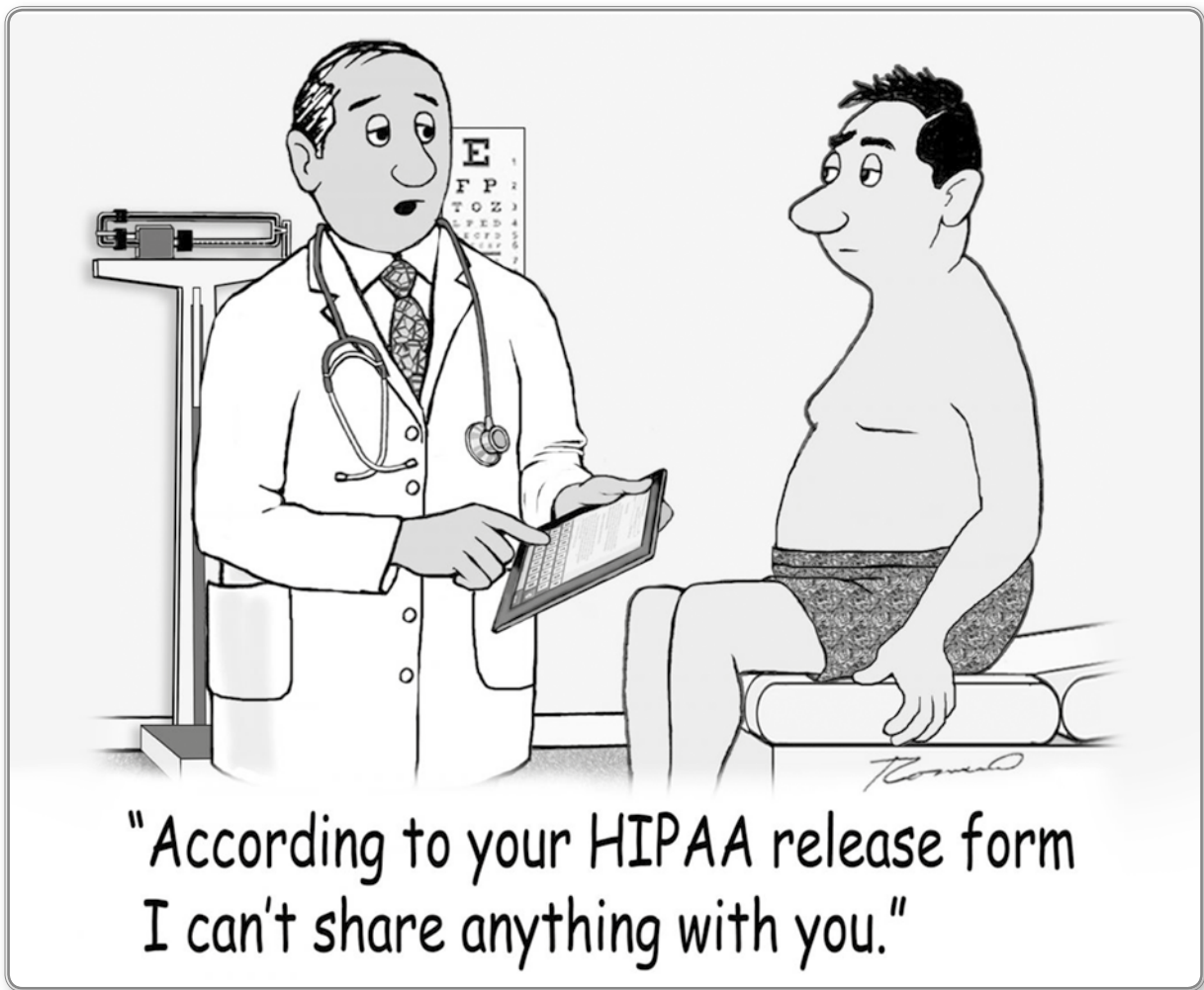
- Reported on the novelty and availability of the intervention;
- Described any treatment or diagnostic options available;
- Avoided elements of disease mongering;
- Reported on evidence supporting the intervention;
- Quantified the benefits, harms, and costs of the intervention;
- Consulted with independent expert sources; and
- Did not rely heavily on a media release.

A good journalist will ensure that all important information associated with new treatments are reported, including benefits, harms, costs, adverse effects, and availability. This is not an easy task for many reasons. There are constraints of space, which is always at a premium in a newspaper. It can be very hard to provide sufficient context about medical minutiae in 600 words! Also, doctors are often not very articulate; and because they love using medical jargon, it can be hard for the reporter to translate this into terms which a layperson can understand. Deadline pressures make a bad situation worse as it can be hard to find knowledgeable doctors who are willing to provide background information and context. Finally, competitive pressures amongst journalists means that they try to ‘outscoop’ each other – and this is something which PR agencies sometimes take undue advantage of, so as to get their stories into the media, whether or not they actually deserve to be printed. Promoters of new therapies employ professional public relations companies to prepare

press releases that over-emphasise the benefits and underplay the potential harms of new products. Lazy reporters compound the problem and some simply hand in the press release as a story, so they don't have to do any fact finding or research at all. Finally, editors sometimes prefer doctor-bashing stories that portray doctors in a bad light, and this is a line reporters are often forced to toe.

It is possible to improve standards of health reporting. One of the best ways of doing this is to ensure that health reporting is given the importance it deserves. Health stories should only be done by full-time health reporters who must have easy access to Information Therapy. Newspapers should ensure that their reporters can easily access the full text of medical books and journals, so they can refer to primary, reliable sources of medical knowledge. Even if health reporters are not doctors, they need to acquire the skills to understand and critically assess the medical literature. Armed with this background information, they can write more accurate and meaningful stories, and not get intimidated by medical experts who use incomprehensible medical terms. It would also be useful to ensure that every health story has a link to an online version. This way, even if the print space is limited, interested readers can go online, where the reporter can add more depth and background to his piece, to ensure that it does not get misinterpreted.

The truth is that the lay press plays a crucial role in communicating health messages and notifying the public about research findings and new treatments. Members of the public often base their opinions on what they have read or heard in the press, and subsequently, press cuttings are presented to doctors and become the basis of discussions about treatment decisions. Often, doctors themselves may first hear about developments through the media, and it is the media's responsibility that the reporting is balanced and backed with credible research. Sensationalizing of insignificant stories simply to generate better circulation figures or higher TRP ratings should be avoided. Since health stories can have such a major impact on readers, reporters must stick to serious reporting, if they want to be taken seriously! Information Therapy helps them to do just that.



21

Do patients have a Right to Information?

Being afflicted with a serious disease is a difficult time for a patient. So when Mrs Shah was diagnosed with cancer, she wanted to know everything from her doctor. 'Why do I need radiation?', 'Is there any alternative?', 'What are the possible side effects of such a treatment?', 'What stage of cancer is this, and will I be completely cured?', 'What is the success rate of radiation treatment?' were some of her queries. Years ago, such questions would not even occur in a patient's mind, and he or she would trust her doctor blindly. Even worse, many doctors would not even bother to explain the treatment options to

patients. However, today, just like the RTI Act has made government officials accountable and thus enhanced the relationship between the government and the public, Information Therapy helps to build a more transparent doctor-patient relationship.

The Right to Information (RTI) act has come as major breakthrough in good governance. It encourages transparency, reduces corruption, and inspires citizens to be more assertive about their rights, because bureaucrats are now more accountable to the public. Earlier, some government officials abused their power with impunity. They could easily manipulate the 'rule book' to suit themselves, as a result of which ordinary citizens (who were usually in the dark about their rights) were rendered helpless. However, with the advent of the RTI Act, citizens are now in a position to ask questions – and demand written answers! The official concerned has no choice but to respond with the needed documentation. This has resulted in a healthy respect for the average citizen among officials and bureaucrats, who now think twice about hiding information from citizens.

If Information Therapy was similarly made compulsory, this would help to improve the doctor-patient relationship as well – after all, good doctors have always been happy to share information with their patients!

Unfortunately, some doctors still do not believe in levelling with their patients. This is why patients feel that they are at their doctor's mercy, and every word from their doctor's mouth is treated as the gospel truth. When doctors had the upper hand and were used to making all the decisions, this resulted in a paternalistic style of practice. While this might have been advantageous in certain situations, it does not fit in with today's times. Patients today want to play a more active role in making decisions that impact their lives. They do not like feeling handicapped as a result of incomplete and insufficient information.

Good doctors understand the importance of having a well- informed patient and will do all they can in their capacity to provide Information Therapy. Some doctors may not be so proactive, and will require patients to ask for information before they dispense any. In

the U.S., progressive health insurance companies are making it mandatory for doctors to keep patients in the loop about any risks or complications arising from their treatment, however small or insignificant. Even better, they are actually reimbursing doctors for dispensing Information Therapy, and this incentive is helping to create a win-win situation for everyone!

There is a great opportunity in India today for the IRDA (Insurance Regulatory and Development Authority) to make the documentation of Information Therapy compulsory every time a patient submits a claim for medical treatment expenses against his or her health insurance policy. This will ensure that patients are kept fully informed, and will also help the insurance company to reduce their expenses, as unnecessary surgery and overtreatment will be nipped in the bud.

Patients have the right to be thoroughly informed about their illnesses. Doctors who invest that extra effort in providing their patients with substantial doses of Information Therapy initiate a positive cycle, where there is transparency in the relationship. This helps foster confidence among patients, who feel that their doctors are interested in helping them get better, and that the relationship between them is not just a monetary one. Doctors also benefit from intelligent patients who ask questions. Healthy discussions might reveal some issues that a doctor might have overlooked, which could have resulted in a poor outcome.

Information Therapy need not be restricted to just providing medical facts about an illness. By providing information about local and regional medical facilities; the names of specialists; their addresses; and the services they provide and their costs, it can actually also help to clean-up the medical system.

It's a sad fact of life that medical practice has become corrupt today, because consultants, hospitals, diagnostic labs, and imaging centres give cuts and kickbacks to doctors to induce them to refer patients to them. Information Therapy can help to eliminate cuts and provide a lot of transparency by informing patients about the costs of procedures, where these are available, and the names of specialists in that field – both in real life and online. Armed with this information, patients need not feel powerless, and can easily get second opinions and shop around for more cost-effective treatment options.

By cutting out the middleman, they can get better quality services at a lower cost.

Empowering citizens with the RTI Act has helped to encourage them to take a proactive role in governance, thus helping to create a more vibrant democracy. Similarly, embedding Information Therapy within every medical encounter can also help patients to assume a more active and involved role in their healthcare – and this can make for happier patients – and happier doctors!



22

FutureGov – Transforming healthcare by prescribing information

Rajendra P Gupta

Mr Sharma, an NRI living in the UK, required an operation for a deviated septum. His GP referred him to an ENT specialist at the local NHS hospital, where he could get this done free of cost. The NHS website (www.nhs.uk) provided him with comprehensive information on his condition.

If Mr Sharma had done the same surgery in India at a government hospital, it would have been free here as well, but the quality of care delivered and patient satisfaction levels would have been very different. And Information Therapy would be out of the question! How can the Indian government learn from the governments of developed countries and provide effective, quality-focused Information Therapy?

When it comes to healthcare, the government's role is threefold: financier, provider, and regulator. However, the Indian government's efforts in these directions are far from satisfactory. Citizens spend for over 78% of total healthcare expenditure from their own pockets, and often get a bad deal in return. It is clear that the government is unable to finance the entire healthcare of the nation. Also, it cannot provide healthcare at all levels (primary, secondary, and tertiary care). Even as a regulator, the Indian government has not progressed beyond basic accreditation of facilities to ensure quality healthcare.

With a massive population of 1.2 billion, prevention appears to be the only cure. We cannot afford to build hospitals across India, and even if we did, it would be financially unviable to run and sustain them. So what can be done? If effective prevention has to be implemented, adequate, relevant, and comprehensible information must be provided to citizens.

Starting point of healthcare: Healthcare begins with awareness. In the absence of awareness, the healthcare system tends to be abused by providers and overused by patients! It is imperative that the government creates empowered patients, and the best way to do that is by providing information to citizens about their health and healthcare. The government must act as a catalyst and promote information dissemination about health and illness in simple, local language. Thanks to technological advances, there are now many ways through which the government can reach out to the common man. These are not only cost-effective, but also act as a visible indicator of the government's interest in the health of its citizens. The funding for such activities can come through private-public partnerships.

Toll-free health help lines: The government should set up toll-free help lines to answer citizen's medical queries. These could be partly automated, using IVR, and run by call centres staffed with pharmacists, nurses, and doctors. India has approximately 800 million mobile phones, and it is believed that 70 percent Indians have access to mobile phones – directly or indirectly. Callers could be mapped from the location of the call, and guided to the nearest available facility should more tests or treatment be required. The option to remain anonymous must be available, should the caller so desire.

The government could mandate healthcare as a VAS (Value Added Service) for all cellular service providers. It is high time that the Ministry of Health develops information that is specific to diseases like obesity, diabetes, hypertension, and the like, and make it available for free download on all cell phones for its citizens. Another option is setting up a web-based SMS alerts service, to which people are able to subscribe free of cost.

Pharmacies

Over 700,000 (seven hundred thousand) pharmacies exist across the country. Pharmacies are used as the first point of contact for a majority of healthcare problems by most Indians. Apart from being easily accessible, pharmacists are happy to provide solutions to common ailments, and visiting a pharmacy for minor health issues is also cheaper than going to a doctor. This national network of pharmacies could be effectively used to provide Information Therapy to every Indian! Pharmaceutical companies can also be encouraged to install 'point of care' healthcare information kiosks at pharmacies. The pharmaceutical company can use this to advertise their products, and patients would benefit as they would have easy access to reliable information. Hopefully, these kiosks will become as popular as ATMs!

Incorporating health in the school curriculum: It is time to separately attend to both the urgent health challenges (to manage chronic diseases) and the important challenges (to address child health). By teaching children about their health, we can ensure that they are knowledgeable about basic issues related to good health and symptoms of sickness.

Online health Library: The government must buy copyrights of a few leading healthcare books and articles and make them available for free download at the Online National Health Library. We need to learn from the initiatives which the UK (<http://www.nhs.uk>) and the U.S. governments (www.medlineplus.gov) have taken!

UID Smartcards for Healthcare: The UID smartcard initiative by the Indian government also represents a huge opportunity. It is possible to store basic demographic data on these smart cards, and link it to EHRs (electronic health records), thus allowing us to deliver customized Information Therapy in regional languages.

In this digital age, where Information Technology drives down cost and increases speed and reach, the government must set the right priorities for encouraging awareness and education for healthcare. Information Therapy is a logical step in this direction. It is high time that every Indian receives quality healthcare, and the government must ensure that no stone is left unturned to achieve this ambitious, but not impossible, goal. Better governance in terms of providing quality public healthcare will result in healthy citizens who are more productive, and a prosperous, happier country.



23

Creating content in India on a shoestring budget

Mr Parag Vora

Ram Khare, a security guard in a Mumbai suburban society, visits a doctor for his chronic cough, which is diagnosed as 'bronchitis'. His doctor gives him medicines along with printed material on how bronchitis can be managed effectively. This handout is in three languages – English, Hindi, and Marathi. However, that doesn't solve the issue. Ram Khare can't read or

write. How does Information Therapy come to the rescue here?

‘Effective patient education ensures that patients have sufficient information and understanding to make informed decisions regarding their care.’

American Academy of Family Physicians’ Guidelines for Patient Education

In order for Information Therapy to be effective, the patient education materials used must be both accessible and understandable. Whenever I pose a simple question to doctors about their approach towards patient education and what tools they use for this purpose, their knee-jerk response is – ‘We use print material.’ Printed material indeed is one of the most commonly used forms of patient education worldwide.

They are either in the form of typical handouts given to patients by healthcare professionals or can be accessed via various health websites. These materials are and always will continue to be one of the most cost-effective methods of patient education for the masses. I am not contesting the efficacy of printed material, but I am sure that this is not always the best solution in poor countries where health illiteracy is so widespread, and where many health education materials are difficult to understand. This is especially true in India which is many countries within a country! As a result, we miss out on harnessing the power of patient education. Hence it is important to apply a patient-centered approach to developing patient educational material.

As a company involved in developing effective patient education material, we have come across various challenges and situations which have helped us create some simple yet effective ways of delivering patient education material using various media. High-quality patient education material respects the principles of adult learning and should be able to:

- Adapt teaching to the patient’s level of readiness, past experience, cultural beliefs and understanding;
- Create an environment conducive to learning with trust, respect and acceptance;

- Involve patients throughout the learning process by encouraging them to establish their own goals and evaluate their own progress;
- Provide motivation by presenting material relevant to the patient's needs; and
- Provide opportunities for patients to demonstrate their understanding of information and to practice skills.

Barriers in creating patient education material

To overcome the communication barriers created by poor health literacy, it is important to put the patient first when developing educational materials. In India, patient education is still a comparatively new field. While designing engaging patient education material, we come across various issues, practical problems and challenges. The most important of these problems are:

- Financial considerations;
- Misconceptions about disease and treatment;
- Low literacy and comprehension skills;
- Fear of doctors;
- Language barriers;
- Negative past experiences with doctors; and
- Denial of personal responsibility and a sense of fatalism.

Over time, we have been able to build a team of doctors, artists, and digital graphic specialists. We can tap into our experience and expertise in this niche area to produce a

wide variety of materials which are adapted to Indian conditions. We have made a conscious decision to use the animated format. This is universally understood, so we do not have to reinvent the wheel every time we create new content.

We now have a library for over 150 hours of unique content; and given the fact that skilled computer professionals charge much lesser for their time in India, we can produce high-quality graphic digital patient educational materials for Information Therapy at a fraction of what it would cost in western countries. Since we are addressing a neglected market, but are using high-tech tools to do so inexpensively, we feel the future is very bright.

Elements of successful patient education:

Interactivity

- Educational materials should be engaging and leave an impact on the patient's mind, thus increasing patient confidence and fostering fast recovery.
- Ease of access and navigation also forms a key feature of patient education programs, thus facilitating easy understanding of the healthcare plan.
- It should help the patient to develop a positive approach towards his/her health-related problems and not scare him.
- It should help to dispel common myth and misconceptions.

Language

Verbal communication between patients and doctors should ideally be in the same language. But in a country like India, it is impossible for a doctor to know all the regional languages and dialects. A knowledge-rich patient education material dubbed in multiple regional languages can solve this problem for doctors.

Cultural beliefs

Culture affects how people communicate, understand, and respond to health information. To produce positive health outcomes, it is important for health organizations and doctors to recognize the local cultural beliefs, values, attitudes, traditions, language preferences, and health practices. This means that it's often necessary to customise patient education materials for local needs. The use of modern digital media allows us to do this easily.

Infrastructure requirement

Multimedia patient education materials can be used with a wide variety of devices. The good news is that many doctors own smartphones which can be easily used to facilitate one-on-one dialogue with the patient. Print materials should be placed where they can be accessed easily and the visuals are not distorted.

Types and tools to deliver patient education material:

Oral communication

Communicating one-to-one with the patient is and always will be the cornerstone of effective patient education. In today's scenario, it is very important the doctor spends enough time answering all of the patient's queries. Quality is more important than quantity.

Print

As I mentioned earlier, print material is the most economical and effective way of teaching patients. It is always good to give patients written explanations of their conditions and treatments. One should always look out for materials containing trusted content but at the same time make sure that the materials are suitable for everyone. When choosing printed materials, one should remember that the layout and graphics play an important role. We have used a wide variety of printed materials, including:

- Handouts;
- Leaflets;
- Posters;
- Flashcards;
- Pop-up books;
- Comic books; and
- Illustrated books.

Multimedia material

Video and other multimedia presentations are more effective than traditional, printed patient education methods in increasing short-term retention of information. However, they should be used as a supplemental part of the patient education process. Even the most well-produced multimedia patient education material will not be effective if there is no window to discuss the content with the doctor.

- Since multimedia uses visuals and graphics, it helps overcome language barriers. The new clever touch screens are very user friendly, and allow even illiterate patients to assimilate information efficiently!
- A doctor may sometimes forget to provide some information about a condition / procedure during a consultation, but multimedia content is always consistent.
- Multimedia material is a better choice than print when patients have low literacy levels.
- One major advantage of video is that it's possible for the doctor to document that

the patient was adequately educated and the consent which the patient gave for the treatment was truly informed consent. This can help in risk management!

A major advantage of modern audiovisual media is that it is all produced in a digital format. This means that it can be delivered through a wide variety of channels and platforms, to a large number of devices, including TVs, PCs, and smartphones. This means that it's possible to deliver the content inexpensively, no matter where the patient is – whether he is in a hospital bed or in a small village.



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Learning from the USA

Don Kemper

Mrs Patel had retired and was spending time with her son in the **USA**. Since her right knee was causing her much discomfort, she visited a doctor who told her that she would require knee-replacement surgery. She had already had her left knee successfully replaced in India. Since there was considerable time before she returned to India, she thought it was best to have the surgery performed in the **U.S.** itself. Mrs Patel was thoroughly impressed with the

manner in which the whole process was done, right from pre-operative visits and counselling to post-operative care and information prescriptions. She felt that such an active involvement of patients was seriously lacking when she was operated in India. How can we emulate the Information Therapy model of the United States? We have all the resources – we just need the intention.

Information Therapy is on the cusp of becoming a mainstream part of American medicine. Since the publication of Information Therapy in 2002, the prescription of patient self-management and decision support tools is becoming embedded within medical practice in America. Healthwise has played a catalytic role in making that happen. As the infrastructure to allow Information Therapy matured, the regulations to require it were written and business plans to support it were developed.

Healthwise (www.healthwise.org) is a not-for-profit organization, founded in 1975 with a mission ‘to help people make better health decisions’. Through policy advocacy, program development, and delivery services, Healthwise has been able to advance the basic Information Therapy concept — prescribing the right information to the right person at the right time — as an integral part of the process of care.

The origins of Information Therapy

In the early days, Healthwise used books and workshops to promote its mission. The Healthwise Handbook is a basic self-care guide for families. It covers most common health problems with clear guidance on what can be done at home and when to call for professional help. Healthwise has distributed over 35 million self-care handbooks, primarily in the U.S. and Canada. Since 2009, the Healthwise Handbook has been distributed in India through the Health Education Library for the People (HELP). Healthwise also taught hundreds of nurses and health educators to present workshops in self-care to tens of thousands of people across the United States.

In the early 1990s, Healthwise began development of the Healthwise Knowledgebase with its goal of covering all of medicine, organized around treatment decisions and presented

in terms that the general public can easily understand. At first, the information was used by nurses in call centres who gave guidance to patients on when to seek care and how best to prepare for it. Then, with the popularization of the internet in the mid-1990s, the Healthwise Knowledgebase was made available directly to the public. In the years since, the Healthwise Knowledgebase has been licensed to hundreds of hospitals, health insurers, health maintenance organizations, disease management organizations, government agencies, and health portals for distribution on each organization's websites for use by their patients, members, or users.

It seemed at first that reliable, trustworthy information, available freely on health websites, would be enough to inform and engage patients in their care plans and health decisions. Not so. It is true that millions began searching for information on the internet, but when they tried to bring that information into conversations with their doctors, it just didn't work. The physicians could not trust the information without reading it first nor did they have time to read it. Even when consumers found high-quality information, the impact it had on their treatment decisions was quite limited. Information Therapy was born out of the idea that if physicians prescribed information to their patients, they would be more likely to trust it and more likely to listen to their patient's better informed perspectives. Simply stated, Information Therapy is the prescription of the right information to the right person at the right time in order to make a better health decision or to change a health behaviour. Advances in electronic medical records, government incentive programs, and the increase of patient activation in healthcare have all combined to make information prescriptions an increasingly important aspect of healthcare in America.

Information Therapy in the U.S. today

The growth of Information Therapy is directly linked to the expanded use of electronic health records (EHRs). Prior to 2009, the expansion of EHR use in America was quite slow with less than 20% of doctors using EHRs. In 2009, the Health Information Technology for Economic and Clinical Health Act, or HiTECH Act, was passed by the U.S. Congress. HiTECH promised that the government would reimburse doctors and hospitals for much of the cost of their adoption of EHRs. However, to qualify for reimbursement, professionals

and hospitals must demonstrate something that the government calls ‘meaningful use’.

These include a number of Information Therapy–related capabilities, such as:

- Patient-specific educational resources (health information specific to the patient’s individual needs) need to be available in the EHR.
- The EHR should be able to automatically send patient reminders for preventive services.
- The EHR should provide discharge summaries for hospital patients.

The HiTECH Act boosted Information Therapy adoption in two dramatic ways. First, as a result of the reimbursement incentives, most hospitals and clinics are now planning to adopt EHR systems. The American Medical Association has reported that 51% of U.S. physicians are now using EHR systems due in significant part to reimbursement incentives. Some estimates now project that 80% of the nation’s hospitals will qualify for the stage I meaningful use reimbursements.

Second, along with the growth of EHR is coming a greatly increased use of Information Therapy — and the good news is that it’s not only for the forms of Information Therapy mandated by the reimbursement requirements. Since the vendors supplying EHR systems must now provide for the capability to prescribe information to patients, the systems can now easily expand to provide other important information- based services for the patient and the doctor.

The Infobutton standard

The Health Level 7 International Context-Aware Knowledge Retrieval standard has been widely adopted since 2007. Nicknamed the ‘HL7 Infobutton standard’, it facilitates the delivery of a set of standardized information about the patient, the provider, and the activity of a specific care encounter or moment in care. An Infobutton manager (or

equivalent) accessed by an EHR application can then pull the relevant information needed for improving care at that point. In most cases, the Infobutton has been used to bring up decision support information for the clinician.

This same HL7 standard can also be used to trigger relevant, education orders or ‘information prescriptions’ for the patient. While the knowledge request can be triggered by the click of a button, the button click is not always necessary. The information prescriptions can be automatically generated by the system as well, based on the context of the patient’s particular moment in care, for presentation in a handout or a secure message, or on the personal health record (PHR).

The adoption of the Infobutton standard has made it easier for many diverse EHR systems to deliver patient-specific information and tools from many different health education and Information Therapy providers. Such increasingly wide adoption is speeding the movement of Information Therapy into the mainstream.

Information Therapy by health plans and health insurers

Health Information Technology (HIT) has also advanced the mainstreaming of Information Therapy within health insurance companies and health plans. While health insurers have long had the economic incentives to help their subscribers make smart health decisions, two things have blocked their progress: timely information and the trust of their members. Progress is being made in both areas.

Improving timeliness: U.S. health plans now get almost continuous data streams about patient medications from the pharmacy-management companies. A new medication prescription can be enough to trigger an information prescription that guides the patient toward improved self- management for a newly diagnosed chronic condition or an indication of a change in patient status. Similarly, the absence of a predicted medication prescription refill can provide a trigger for information to help the patient learn about the importance of medication compliance (for example, when a hypertensive patient does not refill his prescription for antihypertensives within a defined time period).

Hospitals and doctors are also providing patient billing information much more quickly, although most data is still far from current. The data is coming in with more information and in a higher quality than ever before. All this is allowing health plans to use predictive modelling and analytics to identify patient needs earlier and with more accuracy than they could in the past. The better they know the patient's needs, the more effectively they can deliver information prescriptions.

Overcoming mistrust: Health insurers have never been considered to be a trustworthy source of information, because patients suspect that their information is biased in favour of reducing costs. While that perception is not likely to change soon, health plans are drawing patients into their websites and self-management programs through the use of incentives and value-based benefits.

'Value-based insurance design' describes an approach for adjusting insurance benefits to remove barriers to essential, high-value health services for a particular individual. Value-based insurance design lowers the cost to the patient for services likely to reduce long-term costs and discourages unproven or cost-ineffective services through less favourable pricing policies. The same technology platforms are also being used to adjust individual benefits based on the patient's commitment to completing prescribed learning programs that promote self-management of the patient's condition. These incentives are often effective in getting patients to engage in more education and to accept more accountability for personal health management.

Crossing the payment chasm

In 2001, the (U.S.) Institute of Medicine's report on 'Crossing the Quality Chasm' created an urgent call for fundamental change to close the quality gaps in American healthcare. Ten years later, many (though not all) of the quality gaps have been narrowed. Today, there is the realization that the high cost of care, even more than the quality gap, is threatening the sustainability of our healthcare system.

In response, the Accountable Care Act passed in 2010 laid out a myriad of payment

reform experiments to test how best to bend downward the healthcare cost curve. The experiments include:

- Pay-for-performance incentives;
- Accountable care organizations;
- Patient-centered medical homes; and
- Bundled payments.

In each case, the objective is to moderate fee-for-service economics by other forms of payments that more readily support prevention, self-management, and value-based purchasing. It's worth pointing out that in all these cases, a shift in payment structure would encourage an increased use of Information Therapy.

However, today in America, the physician that does the very best job of encouraging prevention and health promotion gets paid the same (or often less) than the physician who does very little, if any at all. Today, hospitals are driven by competition to add more technology, more modern facilities, and more aggressive marketing with little regard for the value-based impact on health. As these new payment reforms change incentives for doctors and hospitals, the use of Information Therapy to engage, inform, and motivate patients will become essential.

Opportunities for an Information Therapy explosion in India

The concept of Information Therapy has evolved over the past decade in the United States. It is only now entering the mainstream of American medicine. The basic idea of prescribing the right information to the right person at the right time is a universal one that can improve healthcare and health in every nation of the world. However, each nation will have to develop the idea within its culture and infrastructure and with the resources available. For India, the opportunity for an Information Therapy explosion is enormous.

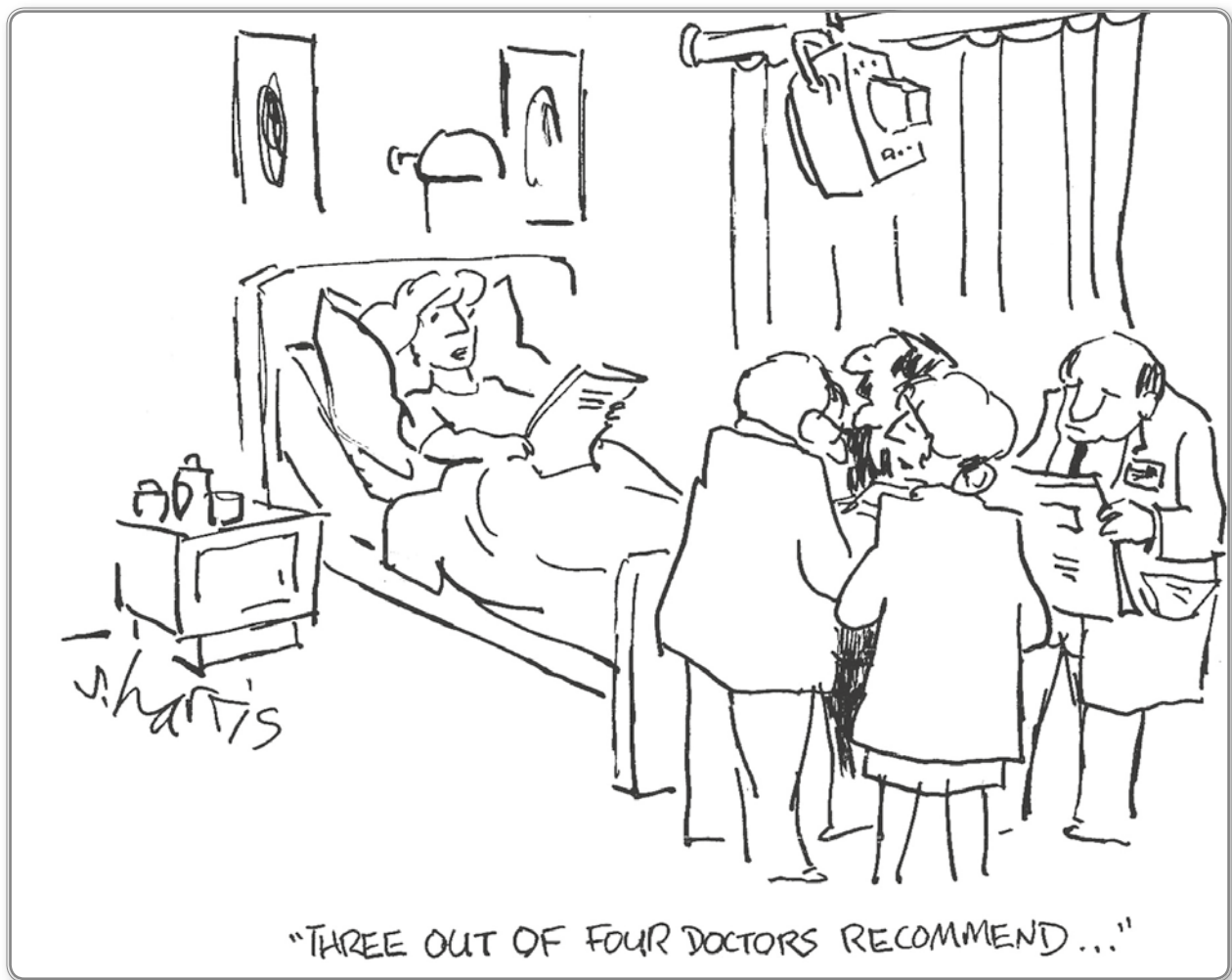
To thrive, Information Therapy requires three things:

- An infrastructure of information technology that can deliver patient-specific information prescriptions in real-time response to patient needs;
- A source of trusted consumer health information to support shared medical decision making and guided self-management for long-term conditions; and
- A medical culture that respects the role of the patient.

India is known, worldwide, as an IT powerhouse. Indian software engineers are among the best in the world. Internet access to the population is expanding quickly and at low cost - particularly through the nearly ubiquitous presence of mobile phones. The infrastructure is in place to leapfrog Information Therapy development in much of the developed world.

India also has substantial resources for educating its people to better manage their own health problems. Organizations like Health Education Library of the People (HELP), which have provided health education resources to the people of Mumbai for over a decade, are now serving the nation's population through their websites and outreach programs.

Is the Indian medical culture ready to embrace an informed and activated patient? The answer will depend entirely on the Indian champions of Information Therapy — their creativity, sensitivity to culture, and openness to ideas. With the right leadership, India could quickly become a world leader in Information Therapy. The time is ripe.



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E-patients – Engaged, Empowered, and Enabled experts

It's only fitting that in a book which talks about how we can use Information Therapy to put patients first, the last word goes to the most important person in the healthcare space – the patient! Jay's blog, **Stork Stalking**, can be accessed at <http://aboutplanb.blogspot.com/>. She is my role model of an e-patient – the expert patient who is active and articulate and is changing the face of medical care. There is great power in Participatory Medicine – and when used along with Information Therapy, Health 2.0 can transform healthcare.

To explain how Information Therapy has helped me, I need to provide some background. I am, by profession, a scientist, whose extensive training has included an education in all the life science disciplines (which include immunology, cell biology, genetics, biochemistry, neurobiology, and developmental biology). This training has given me an advantage that few patients outside the medical field possess. My condition is an infertility of sorts. I am a single woman, who is trying to conceive using donor sperm. At first, it seemed like everything was right with me. All my tests looked absolutely perfect on paper. I conceived on my first attempt. Everything went smoothly until the end of the first trimester, where I discovered that my baby had died, around 7 weeks. Most people, at this point, would have just had a D&C, but would not test the products of conception for an abnormality because their doctors would never order this test voluntarily at that point. It was my training as a scientist (which instills a need to have answers for everything) that primarily compelled me to ask the doctor to run the karyotyping test for my baby. Many women who have suffered multiple miscarriages start having this test done only after the third loss – as a result, they are left with no idea of what went wrong the first few times and hence do not have the information to know which treatment option would be best suited.

As a patient, you have to be your own advocate. No doctor is going to go that extra mile for you, unless the doctor taking care of you is a physician you personally know. Without this, the factors that dictate the medical care you receive are statistics and economics – many tests are not run and only a standard protocol is followed. It is very easy to be aggressive and go the extra mile when you have been trained like me. But what do you do if you have not had that training? Google everything – try every single permutation and combination of query phrases. While writing this article, I googled ‘tests to run after a miscarriage’, just as a training exercise. I did not need to do this after my own loss, but had I done so, the first page that pops up tells you to do a karyotyping.

So Google – Then, spend a few hours reading the results and then use Wikipedia to try and make sense of it. I also read the original scientific studies, either using the Google Scholar or the ‘Pubmed’ databases. It is very easy for me to say, ‘Go through this massive amount of information and make sense of it.’ But what if you are somebody who hated biology in school and are struggling with an incredibly vast information overload? Even

the most uneducated, biology-hating patient can become an expert, if the determination is there. You don't need to become a doctor, but you can easily become an expert patient. There are lots of patients online, who will be happy to hold your hand and help you, even if your doctor is not willing to do so! Far worse than having to deal with an information overload in a subject you detest is the sense of not understanding what you are up against. If you are lucky and have a good physician, that can go a long way, but not all of us are guaranteed to have good physicians. There is nothing as painful as the combination of a bad doctor and an ignorant patient.

Sometimes, you can find the answer to your own problem. Continuing my story, we found that my baby was a boy, with a normal XY karyotype. Most pregnancy losses exhibit abnormal genetics. My doctor at that time looked at this result, and flatly turned down my request to run more tests. I saw another doctor, who did order some tests and discovered a mild thyroid autoimmunity that I was subsequently treated for. I went on to try to conceive again, and succeeded immediately. Unfortunately, that story had the same ending, another pregnancy loss at a similar time point. Shortly after my second loss, I met Dr Malpani, who ordered a test for a hormone called AMH. While giving blood, as a stroke of blind luck and happenstance, I decided to get my Vitamin D3 levels tested. I wish I could claim that this all-important test had been ordered by me as a result of extensive and logical internet searching, but no, it was about as fortuitous and accidental as the discovery of penicillin. When my AMH results came back, they were low. It was a grim, scary result that did not make sense. The only other abnormal finding in my blood work panel was that I was also Vitamin D3 deficient. This is the point where the internet was of profound use to me – I googled 'AMH and vitamin D3 deficiency' and found a study which showed that Vitamin D3 can bind to the AMH gene and 'switch' it on. It is then a logical argument that if you are Vitamin D3 deficient, you might have issues with AMH synthesis. I decided to increase my Vitamin D3 levels and retest my AMH, and like magic, it went up, and stayed up. If I had not found all this by myself, it probably would never have come to light. It was a combination of incredible serendipity and using the internet well. This has been my one giant payoff from my incessant googling, but there have been many, many small ones as well. Being well informed can save you many missteps.

When you are lost and looking for answers, message boards are also good places to log on to. And then there are blogs. Blogs, in my experience, are not that good for gaining information, but they can be very useful from an emotional standpoint. Be it cancer or infertility, both are horribly isolating. If you suffer from any disease or condition, you are probably one person surrounded by about 50 other healthy people who will never have such an issue. Moreover, while they are genuinely sympathetic, they are uncomfortable when you talk about this problem and have short attention spans when you are going on and on about it. Basically, it is not their problem. Blogging gives you a way to connect to people who WANT to listen to you, who can provide the kindness that can only be generated by empathy, since they too have had the same experience as you. Plus, the act of writing down what you feel can be incredibly cathartic. Being in ill health, for any reason, is incredibly stressful. Blogging helps take away some of that stress. If you can start a blog, then do. It has helped me tremendously in my darkest days.

In summation, yes, the internet is an incredibly valuable resource. Not using it, and continuing to allow a doctor to make all these tremendously important decisions for you, while not having a clue about what is happening, is not prudent and can be potentially dangerous. What's the point of being literate if you refuse to read? Is there a downside to having access to tons of information available? Yes. You need to look at the 1000 little details, and then step away, and get a true sense of the big picture. This is not at all easy, and many people can look at one tiny study and panic, many times, unnecessarily. You can get hopelessly confused by all the contradictory information out there; and trying to decide on which path to follow can be very challenging. This often leads to paralysis by analysis! How do you deal with this? As an example, I've seen many, many studies that show that if you test positive for anti-thyroid antibodies, you might be at a higher risk for miscarriage. Then there are the studies that show it has no effect. There are doctors in both camps and honestly, nobody has a real clue. That is most often the crux of the issue – nobody knows the right answer. What do you do? You look at the suggested fix to the problem – is it safe, inexpensive and easy? If it is, go for it, whether you believe it to be a problem or not. If it is not an easy fix, then that is where the real issues lie. Sometimes, we have to put our faith in something expensive, difficult, or even potentially dangerous while not knowing whether it will work.

When nobody knows what is the right call to make, and everybody is straddling the fence, if you know enough and have the strength to do so, then you should be the one that makes the decision as to which path to take. Sometimes, this is the best that we can hope to do. I have learned that you rarely regret the things you do – you usually regret the ones you don't. When you are at a crossroads, please remember the Serenity Prayer –

*God grant me the serenity to accept the things I cannot change;
the courage to change the things I can; and
the wisdom to know the difference.*

At the end of the day, you should have the peace of mind that you did your best, and Information Therapy can help you achieve this goal.

All of us will be patients some day. What can we do to ensure that we get the best medical care when we fall ill?

Information Therapy - the right information at the right time for the right person - can be a powerful medicine! Ideally, with every prescription, your doctor should prescribe information; and in a perfect world, every clinic, hospital, pharmacy and diagnostic centre would have a patient education resource centre, where people can find information on their health problems.

This book explores how Information Therapy impacts all players in the healthcare ecosystem - patients, doctors, hospitals, health insurance companies, pharmaceutical companies, and the government - and how it can help all of us.

Information Therapy can help to heal a sick healthcare system - and everyone has an active role to play in making this a reality!



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Dr Aniruddha Malpani is an IVF specialist who runs the world's largest free patient education library, HELP, at www.healthlibrary.com.

He has authored many books, all of which are available online free at www.thebestmedicalcare.com. These include: How to Get the Best Medical Care; Successful Medical Practise; Patient Advocacy - Giving Voice to Patients; and Decoding Medical Gobbledygook.

His passion is patient empowerment; and he believes that patients are the largest untapped healthcare resource; and that we need to use patient power to heal our sick healthcare system (www.patientpower.in)



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