

The World to be Gained: The Future of the Doctor–Patient Encounter

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INTRODUCTION

The following is a real situation, altered slightly for publication:

Madeline Casey, a 60-year-old university philosophy professor, presents with an intensely itchy and uncomfortable generalized macular–papular rash of two months’ duration. Recently, she has also noticed small masses in her neck and groin. It takes one month before her primary care practitioner can see her. The masses are noted but receive no attention.

Prof. Casey is referred to a dermatologist to ‘rule out’ bedbugs.

A diagnosis of idiopathic dermatitis is made, and various cortisone creams are prescribed. She is followed for six months, during which time the rash gets worse, more painful, and excoriated.

Prof. Casey is referred to another dermatologist, but two months before seeing him, she has a painful occurrence of zoster. She has a strong sense that she is more ill than her doctors think. There is no change in the diagnosis of dermatitis.

The second dermatologist advises her to stop scratching herself and recommends meditation.

By sight, a third dermatologist diagnoses Prof. Casey’s rash as being dermatitis herpetiformis, a painful rash linked to gluten sensitivity. Dapsone and dietary advice resolve the primary rash. Unfortunately, Prof. Casey feels no better. She is losing weight, and the swellings have become more discrete masses in her neck, groin, and upper chest. She is told she must have had a ‘cold’.

Things are complicated now. She is very fatigued and considers long-term disability, but she is ineligible, as there is no ‘serious disorder.’

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Concerned about the results of some blood work that had been done, the third dermatologist refers Prof. Casey to a hematologist. His examination reveals that she has diffuse lymphadenopathy and an enlarged spleen.

Over the next few weeks, he assiduously orders tests, biopsies, and other specialist visits. These finally reveal the underlying cause of Prof. Casey’s recent maladies; she has an advanced form of non-Hodgkin’s follicular lymphoma (NHL).

Prof. Casey accepts the recommendations for chemotherapy, but in three months, her illness transforms into a more aggressive B-cell lymphoma. It has taken her two years to receive effective care.

Prof. Casey wonders if anything could have been done better and sooner. Were the lapses in her care due to miscommunication? Despite the limitations in the medicine of the present, Prof. Casey’s care would have no doubt been more expeditious had certain care providers listened to her more carefully. However, patients who present with common problems are treated symptomatically and expectantly. Common diagnoses are considered first, and other, more ominous conditions are reserved for the more recalcitrant cases. It’s often a hit-and-miss process, and in this case, the first physicians missed the mark because they did not consider the more ominous conditions that can lurk behind persistent, seemingly benign presentations. They failed to sufficiently take into consideration anomalous data, such as her swollen nodes and—perhaps most importantly—the patient’s intuition that this wasn’t a routine illness.

Each point in Prof. Casey’s story is noteworthy, as there is considerable latitude for the management of her condition by practitioners who see her. What could that original rash have

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been? What, if anything, did it have to do with the zoster? How urgently should she have been seen? Should her lymphadenopathy and lymphoma have been handled in a different way?

There is something chaotic and haphazard in medicine of the present. Healthcare practitioners rely heavily on their intuition. How far do you, as a practitioner, follow a patient's symptom or sign? Is it something routine or something potentially more ominous? How beneficial will a particular drug be for a patient? Answering these questions, in turn, depends on many factors: how well you know and listen to the patient, how closely you follow them, what your previous experiences with similar complaints and illnesses have been, how much time you have, and how easily you can consult with others. In addition, obviously, it depends on how much is known about the conditions the patient is experiencing. In Prof. Casey's story there seems to be a considerable gap in skills and clinical intuition between her physicians.

This so-called 'empirical' approach to medical care is changing.

CHANGING MEDICINE

Advances in the science of medicine have made choices and options available to patients and the public that were heretofore considered impossible, for example: hip replacement in a nonagenarian, HIV eradication in a baby, deep brain stimulation for movement disorders, thrombolytic therapy for acute cerebral and cardiac ischemic events, embryonic cultivation outside the womb, and intensive cardiovascular support for multiple organ failure. These advances offer the prospect of real choice to patients. They can choose from among the various ways of proceeding, including the option of doing nothing.

This changed medicine in the twentieth century in fundamental ways from that which had preceded it. What came before it was medical practice that was as secretive as it was ineffective. With medicine's scientific transformation came a gradual tectonic shift from physician-based medicine to patient-directed care. This shift has penetrated some disciplines more than others, some countries more than others, and some institutions more than others. It is a shift that medicine is still undergoing, and it will continue to dominate medical practice for the next century.

Pressures from the courts and from the public from the early twentieth century have resulted in medicine becoming more ethically sensitive as it has become more scientifically robust. Especially critical has been the elaboration of the rights of patients to be informed about and be empowered to participate in decisions about their care. The promise of future medicine is to continue that breach of the paternalism of traditional medical practice. That tradition included: (1) a hierarchical structure of healthcare, with the preferences of the patient at the bottom, (2) silence and secrecy regarding medical practice, (3) individual doctor-based decision-making, (4) idiosyncratic non-evidence based medical practice, (5) fragmented and heterogeneous healthcare, and (6) healthcare with little regard for the social determinates of well-being.

These characteristics do not exhaust pre-twentieth-century medicine, and they still persist in many areas of healthcare today. Let's just say that the tide has turned: away from hierarchy to

transparency and trust, away from silence to truth-telling and open communication, away from physician solo-flying to interdisciplinary care, away from intuitive care to the incorporation of best-evidence into decision-making, away from simply accepting the regional variation in medical practice and safety to a better understanding of appropriate care, and away from episodic healthcare interventions to practices that are community-based and prevention-oriented.

These changes will not happen all at once. They require a commitment to continuous quality improvement. However, they are already being incorporated into healthcare management, and they will become increasingly important as the century advances. As well, the new digital technologies and information exchange will make it possible to realize the prospect of truly individualized care: not only as to the incorporation of personalized genomic medicine, but also as to an improved capacity for incorporating patient preferences and values into the decision-making matrix.

It has been said that the future of medicine lies in conversation: the conversation between the healthcare provider (who may well not be a doctor but will be part of a team that will include a doctor) and the patient.¹ It may seem at first glance that computerization in medical care will depersonalize healthcare. It need not do so. The new technologies of information may improve the prospects of patient-based care in being able to better capture and retain these conversations and to make them available to others in the patient's circle of care. This, in turn, may help to ensure consistency in patient care and to reduce fragmentation.

THE PROMISE OF FUTURE MEDICINE

How might Prof. Casey fare under the improved care of the future?

First of all, she will not have to wait so long to see her healthcare provider. She will receive care in a multi-professional, community-based clinic that will accommodate requests for urgent assessment.

Second, from the get-go she will be knowledgeable about medical conditions by accessing information on the Internet, and she will be cautioned by her practitioner about serious conditions that she might have and about symptoms that might be concerning.

Third, all health professionals will have had training in the art and science of communicating with patients and other healthcare professionals.

Fourth, Prof. Casey will be more involved in the healthcare process. Rather than waiting several months to see what happens, she will be proactively encouraged to return to a multi-disciplinary clinic for an early re-assessment. Alternatively, this re-assessment will be done in her home via new modalities of information capture, such as the use of encrypted forms of e-mail and applications that are able to turn a digital phone into a hand-held medical monitoring device.² Professionals will be proficient in the use of such technology, for example, by encouraging patients and their families to submit pictures of rashes that could be shared with others to evaluate less common conditions.

Fifth, rather than relying on intuition as regards her diagnoses, the healthcare provider will have access to her genomic and exomic make up. So both she and Prof. Casey will know to which diseases she is susceptible and what serious problems might lurk

behind common or seemingly benign symptoms or signs. As well, diagnostic procedures currently too complex or expensive to use in primary care—such as PCR testing, genomic profiling, quick section tissue diagnostics—will be readily available, making rapid diagnosis possible and obviating the need for some specialty involvement. While not currently present in the clinic, these procedures soon will be.

Sixth, once a serious condition such as NHL is identified, her own genomics and the genomics of the malignancy may tell her practitioners what drug regimen may work better for her. This will also help take some of the guess—work out of therapeutics.

Seventh, as science advances (and it will do so, exponentially), we will better understand the molecular basis of disease and will have interventions, such as directed antibodies, clonal therapies, or immune-boosting vaccines that will selectively target malignant tissue.

Eighth, effective therapies will not just eradicate disease and prevent premature death, but they will also improve the patient’s quality of life. Appropriate medical decision-making will reflect patient values as to what is important and valuable to the patient. Better technology will not be better if not combined with assiduous attention to and communication with patients.

Prof. Casey’s story could be one of many situations that will characterize twenty-first century healthcare. Conversations between physicians and patients will continue over assistance in dying and end-of-life care. Controversy will continue over the nature of life at its beginning and its end. Negotiation and consensual decision-making will typify the healthcare of the future.³

CONCLUSION

In brief, the prospects for medicine are, in some ways, quite bright. Barring some worldwide conflict (unfortunately always possible), medicine can progress both morally and scientifically. However, it will not do so automatically. Situations of urgency and adversity in even the world’s most advanced countries may cause some practitioners to act in questionable ways.⁴ The continued progress in medical affairs will require a commitment to transparency and communication by ethically sensitive practitioners, and in this way, practitioners will show themselves worthy of the public’s trust.

There are many problems that medical practitioners on their own cannot fix such as the persisting inequality of the sexes, the ever-growing inequality between the rich and the poor, and the insufficient attention paid to the famines, wars, and pestilence affecting billions of people on the planet.⁵ These worldwide problems are where the real advances in healthcare must be made in the twenty-first century.⁶

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