Acts of loving kindness

Michael J. Goldberg

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An inflection point is a turn or bend from a direct course. Medical care, as we have known it, is at an inflection point; and I am concerned with its trajectory.

We have developed a remarkable array of therapies that can both prolong life and improve its quality. We have developed cardiac and orthopedic techniques that permit the elderly to seek more active lives in spite of having indulged themselves in an epidemic of obesity, heart disease, and diabetes. We have developed new antibiotics that are keeping us one step ahead of the ever-increasing number of resistant bacteria. We have developed potent chemotherapy, bone marrow and stem cell transplants that cure cancer, and powerful drugs to reduce the adverse side effects of those treatments. We have developed the skills to make spines straight, legs perfectly aligned, and limbs longer. We save people from motor vehicle accidents that previously were fatal. We have deciphered some fundamental flaws in DNA; flaws that produce variations in humankind and horrific diseases.

These accomplishments have come with some unintended consequences.

A generation of professionals, whether they are in business, law, sports or medicine, has all but abandoned the idea of duties and responsibilities and has substituted in their place, rights and privileges [1]. It is an age of entitlement. Rights and privileges have become the fabric of American society. They have become the expected norm, the basis for negotiations; and in the case of medicine, they have jeopardized our social contract with the patient. They

have placed physicians, patients, payers, and policymakers at odds; and while many physicians and hospitals have reaped substantial financial benefit, the disparities in the access to healthcare have deepened.

Financial conflicts of interest are rampant. While patients are accustomed to seeing trinkets bearing drug company names and logos in their doctor's offices, few are aware that the relations between many doctors and industry run far deeper [2]. The pharmaceutical and equipment manufacturing industry capture the loyalty of physicians with gifts and lavish meals; pay them as consultants even though they may do little or no consulting; funds their research often with the caveat that the manufacturer owns the raw data, and offers memberships on drug company advisory boards, positions that command tens of thousands of dollars annually. Young physicians, now heavily in debt at the beginning of their careers from educational loans, are particularly vulnerable to industry's financial rewards, especially when they see their senior role models availing themselves freely of such largess.

Patients have an unquenchable thirst for data. The Internet is filled with health Web sites, chat rooms, non-peer-reviewed publications, and advertisements disguised as scientific reports. Report cards are issued by self-serving and self-appointed accrediting agencies. Because the ability to separate fact from fiction is challenging, patients look to us to be their guide through this information maze. Patients have wanted to become part of their own health decision-making, and with the current popularity of patient-centered care, patients are being offered various options and then being asked to decide for themselves what to do. The fundamental difference between data and information is often obscured. In this age of high-tech manuals and self-help books, patients have been made to feel that on their own, they just don't know how to do it. I

M. J. Goldberg (✉)
Department of Orthopedics, Children's Hospital and Regional
Medical Center, University of Washington, 4800 Sand Point
Way NE, Seattle, WA 98105, USA
e-mail: michael.goldberg@seattlechildrens.org

often see new mothers with stacks of books and manuals and, all the while not realizing that they know far more about child rearing and nurturing than they think they do.

The public is calling for accountability. From teachers to students, from government leaders to bureaucrats; from titans of industry to labor union leaders, everyone is being asked to be accountable. But calls for accountability for physicians resonate particularly well with the public. Physicians and surgeons are easy targets for both regulators and the popular press demanding physician accountability. This is a reaction to our resistance to being transparent. There is a reluctance of physicians to share data; an unwillingness to incorporate patient-based information into the fabric of the office visit; and an inability to see how data collection will benefit the participating doctor. It is clear that registries and performance measures would benefit patients and even benefit the regulators and the payers, but it is not clear how performance measurement would benefit the doctor. Many observers have concluded that physicians will not participate in such reporting unless it is linked to getting paid or becoming certified.

A fundamental tenant of healing is trust. When it comes to how we deliver care today, that trust has been damaged. Some would argue that it was the result of managed care schemes that created the perception that care was being limited; or that trust was damaged because of public disclosure of complex financial relations between industry and doctors; or that trust was violated when the safety of research subjects was knowingly put at risk. Because we feel so vulnerable when we are ill, a loss of trust in those who care for us is devastating. It is equivalent to betrayal by a friend or a spouse. Indeed, it has been said that trust itself is healing. Trust enhances ones responsiveness to treatments, to medicine and to surgery.

While researchers, scientists, physicians, and surgeons have made great strides in curing disease, those who practice in our medical community have fallen behind in healing and comforting our patients. Doctors are simply better at curing disease than they are at healing the person who is afflicted. Every malady comes with a human attached. For those whose health is failing, who disease is incurable, I hear doctors talk of new research; of new drug trials; of cutting edge technology; of soon to be innovative measures. I do not hear the simple words: "There is nothing more I can do for your disease; what can I do for you."

The press loves last-ditch heroic medical interventions: Doing something in the face of a seemingly hopeless situation, such as implantation of mechanical hearts into the chest, or insertion of embryonic stem cells into the brain. Heroic measures seem to be needed by both patients and their doctors. Must desperate times call only for desperate measures? I think not. I might suggest that these dramas

would play out quite differently if the measure of success were something different than the number of days survived in the intensive care unit.

A goal of all physicians and surgeons is to sustain hope. All too often rigorously controlled evidence-based clinical trials point out the lack of therapeutic effectiveness of many of our interventions. When the treating physician tells patients or parents that nothing more can be done, or that there is little evidence that a treatment works, the family is left with a sense of hopelessness. That void is often filled by alternative or complementary practitioners. Although what is promised may well be overstated, or over interpreted, the complementary and alternative treatments are performed in a caring environment; where there is physical contact; where adequate time is spent with the patient; and where hope is sustained.

So what is the point of all this? It is, and I am saddened to say it, but today, those who currently practice medicine will not fill the ever-increasing need that our patients have to be comforted and healed. Both clinicians and researchers are on a path devoted to preventing disease, (with new vaccines for example), or to curing disease (with new minimally and maximally invasive procedures). Having that focus creates a gigantic void. The day will come; in fact it may already be here, when our traditional healers are too busy, too disinterested, or too focused elsewhere. They will no longer heal. Who will take their place?

In the days before antibiotics and before chemotherapy, and before complicated surgery, the day to day care of the sick fell to family and friends. While we busily go about our business of cutting and curing, why not turn over the responsibility for caring and comforting to the lay public? Should we, as physicians, encourage it, support it, and as pediatric orthopedists, be leaders in this transfer of care?

I am not talking about families rallying when all else has failed. That seems to be a time when many step forward, which is all well and good, but it is not enough. I am not talking of only death and dying. I am arguing that parents, family and friends be in charge of comforting the living; comforting and caring for those with non-fatal conditions. They will learn and be responsible for comforting and healing those with total hip replacements and broken bones; those with flu and diabetes; those with aches and pains and arthritis and gallbladder surgery and toeing in.

Initiatives to train young doctors to be more sensitive; initiatives to improve communication with patients; initiatives to make care more patient centered is not the solution in either the short or long term. When all is said and done, comforting and caring will come from the public, from patients and parents, from families and friends; or it won't come at all. It will be parents healing their sick children; children healing their parents; and friends responsible for the comfort of friends.

Can we embrace such an idea? Can we transfer the responsibility? Can we make the time and be willing to instruct and inform so that there is some basic understanding of the disease process. Are we willing to share the limited health care dollars with families to ease their financial burden as they perform this care?

I note with some futility, that in every city, in every community there are a number of walks and marches to “find a cure.” A walk to find the cure for diabetes. A walk to find the cure for breast cancer. A walk to find the cure for AIDS. The monies raised go to research, which will find the cause of the disease; and then once the cause is found can the cure not follow shortly behind?

For the elderly, and for most of my pediatric patients with birth defects and chronic neuromuscular conditions, the cause of their diseases is not known. And when the cause is found, it will be of only modest interest to them. For most of my patients, there is little hope for cure. In our healthcare system, life for them is a search for comfort and caring. It is a search for healing and for sustaining hope. It is an arena where I have worked for 30 years and have loved every minute.

Will you be there for me when I need that healing and comforting? In an age of quick fixes, fast-food, instant messaging, and immediate gratification, the need to care and comfort, the need to reduce suffering and to sustain hope, is becoming increasingly difficult to fulfill. Must we do it? Must we, as pediatric orthopedists, perform acts of loving kindness? Can't we focus only on the technical aspects of the surgery; the pedicle screw and the Ilizarov? I would like you to believe that performing acts of loving kindness is our duty and responsibility. That it is our social contract with humanity. That it is the covenant we made with medicine and with each other [3].

References

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