

Caring for VIPs in the Hospital: the Ethical Thicket

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Key words: VIPs, privacy, media, quality of care, fairness and justice in the allocation of scarce resources, private death

IMAJ 2006;8:746–750

Caring for VIPs – Very Important Persons – is disorienting for a healthcare system. VIPs challenge standard routines of care as the system struggles to engage the most prominent and most honored physicians in emerging medical decisions about the patient's care. But, as all in medicine know, and most will acknowledge, the most eminent may not, at that point in their careers, be the most medically sophisticated or technically skilled. The outside world, which usually knows little about the acute care of specific patients, clamors to be taken inside the private and confidential zone of medicine where uncertainty is often the paramount characteristic of care, to be informed minute by minute about the most intimate medical decisions concerning this precious, public person. The family, generally protected in its grief, must weep publicly as no space is protected for the excesses of anguish. Note however, that not all VIPs are created equal; media visibility – an essential index of celebrity – may not correspond to more calculating social evaluations that determine some actual measure of value to society. Rock stars, sports figures and critical national leaders should not, in times of real medical scarcity, exert equal moral claims on medical resources.

This article will argue that according VIP status and instituting VIP practices raises three weighty ethical problems: quality, privacy, and an amalgam issue created from the interaction of notions of fairness, equity and justice. Finally, it will argue that VIP treatment may deprive the patient and family of one precious gift of medical care – the right to a private, timely and unimpeded death.

Quality

Certain types of patients challenge established paradigms. The “hateful” patient attacks the healthcare team and has dependency needs that smother crisp plans of care [1]. Other sorts of “difficult” patients, and family members, demand more than their share of attention and garner more than their fair share of the physical and staff resources of the institution [2]. But, perhaps, equally dire possible effects can be connected to medical visits of the VIP – the medical colleague, celebrity actor, well-connected businessperson, sports figure, politician, or foreign ruler. What all of these special patients have in common is that they challenge, and often disrupt, established paths of care whose very familiarity provides safety

In the last years, as evidence-based medicine established its clear hegemony [3] over individual physician experience as the basis for care, variability in medical practice and the frequency

of medical error have emerged as critical targets for making medicine safer. It has been gradually acknowledged that medicine as an art and even as a science must be subordinated by medicine as an industry in pursuit of patient safety. The thinking that led to this re-conceptualization emerged from an analysis of aerospace disasters (the space shuttle *Challenger*) and other industrial mishaps. The conclusions of industry, first adopted in medicine in the subspecialty of anesthesiology [4], focused on human error as the “latent” event that was permitted to escape by the inadequacy of systems. The human factor underlying error, it was agreed, existed as a subset of a faulty system. Errors can cause harm and the ethical commitment to “do no harm” is violated if the systems do not operate to actively prevent individual mistakes.

Quality improvement is thus an ethical concept as well as a healthcare delivery system obligation [5]. If patients are to permit themselves to trust, a condition that all commentators on the doctor-patient relationship acknowledge to be a precondition for effective care, their trust must encompass not only the physician to whom they relate, but also the system in which she is embedded. Trust is central to an instrumental analysis of the doctor-patient relationship. Trust fosters communication, which then provides the platform for the partnered formation of specific medical plans reflecting the wisdom and experience of the physician and the values and desires of the patient. As theories of fault have evolved from the bad actor to the deficient system, the ethical obligation of physicians has changed from an exclusively personal commitment to a shared personal/institutional one. The physician must be able to offer, “Trust me and trust the system in which I work.” VIP care that bypasses the quality-tested systems of medical delivery risks violating this individual and institutional commitment.

Doctors practice in systems and these structures either enhance or diminish the possibility of providing excellent care. The doctor and the patient live under the direction of institutional protocols, which either permit and foster, or preclude and foil, mistakes. Unfortunately, it is precisely these carefully crafted protective systems that are most likely to be varied by the arrival of a VIP. The ethical challenge to medicine is to provide ethically and medically sound and excellent care even if the patient's eminence and prominence appear to warrant special treatment. It is precisely those established patterns of practice that might be jettisoned by the arrival of a VIP; ones that provide protection for the patient and, not sufficiently emphasized, for the provider.

The report by the Institute of Medicine of the National Academy of Sciences report on quality, *Crossing the Quality Chasm* [6], is directly relevant to this discussion. In this report the Institute of Medicine [7]:

...calls for improvements in six dimensions of health care performance: safety, effectiveness, patient-centeredness, timeliness, efficiency, and equity; and it asserts that those improvements cannot be achieved within the constraints of the existing system of care. It provides a rationale and a framework for the redesign of the U.S. health care system at four levels: patients' experiences; the "microsystems" that actually give care; the organizations that house and support microsystems; and the environment of laws, rules, payment, accreditation, and professional training that shape organizational action.

This expanded agenda for quality is clearly precluded by the "special" care that bypasses established systems. Thus, as quality and patient safety achieve increasing prominence in the public discussion of medicine, and become central to the ethical commitment of physicians, processes that sidestep established systems developed to ensure quality are recognized as flawed and may not meet the current community standards for care. Structures that have been subjected to the measures of quality improvement – design, pilot, evaluate, implement – should be trustworthy for providers and patients. They exist because they have identified possible errors and acted to minimize their potential for harming patients. They are protective for patients and shield physicians from the horrible personal and professional consequences of harming a patient. If key components of quality systems are bypassed to meet the supposed needs of the VIP, there is a greater risk that a protective element will be eliminated, resulting in the escalating possibility of medical error and patient harm.

Consider the following case as an example of VIP care:

Mr. M was brought to a State university hospital following a fall at home. Mr. M was a national politician who lived in the community and was a strong supporter of the state medical center and medical school in his town. After falling at home, he complained of severe back pain. Mr. M's physician was out of the country. The patient called a senior local physician who he had never seen before on the recommendation of the chairman of the Board of Trustees at the medical center. That physician rarely made house calls, but in acknowledgement of the celebrity of the patient and the source of the referral visited this patient at home. The patient indeed had severe back pain that the doctor felt was accounted for by muscle contusion due to the fall. His back exam revealed muscle spasm; the neurologic exam was normal. The physician provided medication for muscle spasm in addition to writing a prescription for an anti-inflammatory medication. He advised the patient to visit his regular physician if the back pain persisted.

Within 48 hours, Mr. M. came to the Emergency Department with severe bilateral leg pain. An MRI showed spinal cord injury associated with recent vertebral fracture. Mr. M was then seen by the chairmen of Medicine, Orthopedics, Neurology, and Neurosurgery – who all made entries in the chart. His radiographs were read by the chief of Neuron-radiology. Of note, none of these chairmen was regularly involved in patient care at the time of Mr. M's admission, but felt obligated to participate because of Mr. M's celebrity status. Mr. M had emergent decompression of his spinal cord performed by the chairman of Neurosurgery. In addition, the senior administrators of the hospital and several members of the Board of Trustees visited Mr. M just before surgery.

Postoperatively, staff on the medical unit complained to their supervisors that they found it difficult to deliver routine care to the patient, because of the large number of prominent visitors requesting information and special treatment for Mr. M. Mrs. M complained to the nursing supervisor that her husband's pain was not consistently relieved and that it was impossible for him to rest. Incoming phone calls were stopped at her request.

Despite the timely surgery, the patient quickly developed a dense paraplegia. He had a prolonged hospital course further complicated by nosocomial infections with sepsis, congestive heart failure and pressure ulcers.

The family sought outside consultation and several national experts were granted temporary privileges by the hospital to examine and help with treatment. In one instance, an internationally known urologist from another institution in discussion with Mr. M mentioned the possibility of an occult malignancy as the cause of his urinary symptoms. This led to overwhelming anxiety for Mr. M, who developed respiratory distress and required intubation and mechanical ventilation within four hours of the urologist's consult. Malignancy had been considered by the hospital's consulting urologist, but was thought to be a remote possibility that did not require further investigation or discussion, particularly because of Mr. M's severe anxiety.

The narration above describes a stormy course of care that can be characterized as: disordered, unorthodox, fragmented and disorganized. It is, unfortunately, a generic description of VIP care. It bypasses systems and relies on academic eminence as the grounding for clinical expertise. Query whether this eminent treatment staff served this patient well? We can never know. However, we would argue that, in all likelihood, a staff more accustomed to addressing these complex medical problems, led by a single skilled physician who was able to coordinate care and communicate with the patient and the family, would have delivered a higher quality of care, avoiding the under-treatment and over-treatment that characterized Mr. M's care.

Privacy

The second ethical issue in the care of a VIP is that of privacy. Privacy and confidentiality are both endangered species in medicine. They were first imperiled by the process of payment and supervision that accompanied the attempt of payers to bring some coherence and rational reimbursement methodology to

medicine. Even in countries with single payer systems, the ethical requirements for evidence-based medicine and quality review have required a level of outside scrutiny that threaten the heretofore protected doctor-patient relationship that was the bedrock of the promise of confidentiality. These are the necessary casualties of improved practice and enhanced quality. We no longer permit a physician to erect a small tent of control over the patient and exclude others from involvement in and scrutiny of what care is provided. The practice of medicine no longer offers keys to a fiefdom; that fact has implications, as previously discussed, for quality but also for privacy.

Medical care in a hospital, especially an academic medical center that trains new physicians, has not evolved to be a private affair. Especially in teaching hospitals, shifts of staff care for the patient in eight-hour segments. In these systems, the basis of quality care is the sharing, not the protection of information. For patients, and even more for family members, this multiplicity of players presents challenges to clear and consistent communication. But, by and large, this sharing of information stops at the walls of the hospital. Outside of this sphere of sharing, it is up to the patient or family to reveal information to more disassociated and distant others. This is not the case for VIPs.

Consider one of the more high profile medical care cases in recent United States medicine that engendered scholarly discussion [8] and tremendous media publicity. What follows are some detailed descriptions in the *New York Times* following the transplantation of a liver into the baseball player and U.S. icon, Mickey Mantle:

The rejection, which doctors called "light," was expected and was being treated with high doses of steroids, said Dr. Goran Klintmalm, medical director of the Baylor Institute for Transplant Sciences. Doctors performed a biopsy of the former baseball star's new liver Wednesday morning after blood tests showed signs of diminished function, Klintmalm said. Mickey Mantle began a new round today in his fight for life with a transplanted liver – a battle within his body, which is trying to reject the vital organ implanted two weeks ago. (*BASEBALL*; New Liver Woes for Mantle, June 23, 1995)...MICKEY MANTLE rode his exercise bicycle for about 10 minutes yesterday and has been walking around the transplant floor at Baylor University Medical Center in Dallas. (*SPORTS PEOPLE: BASEBALL*; Recovering Mantle Rides Exercise Bicycle, June 17, 1995)...Dr. GORAN KLINTMALM, the medical director of the Baylor Institute for Transplant Sciences in Dallas, said yesterday that MICKEY MANTLE has begun digesting solid foods and that a biopsy drawn by a needle inserted into his new liver showed it is functioning properly without signs of rejection. (*SPORTS PEOPLE: BASEBALL*; Mantle's Recovery Is Proceeding Well, June 15, 1995).

Why should we, the public, and the readers of the *New York Times*, know these intimate details about the life of this patient? Mickey Mantle was a person whom the public adored. He was among the greats of baseball history and had captured the heart of the public, as the media attention reflected. But the intimate details of his alimentary system are not matters for public consumption, or, for that matter, digestion. Why should this have been made public? Because people want to know and medical institutions have capitulated to the insatiable need of the media/entertainment complex to fill that need and to, by the way, enhance the reputation and status of the medical institution providing the care. In 1981 when Ronald Reagan was shot, the coverage of the president's trauma and recovery was covered in detail but not in as much detail as was the care of Mickey Mantle. Conventions of press coverage change. Just compare the present with the discrete coverage of Presidents Roosevelt and Kennedy whose medical conditions and personal life were shielded from public scrutiny. Now the public wants all information all of the time; ethically, fulfilling these desires violates the rights of the patient. The rights of patients to have their medical privacy protected should apply equally to the care of a VIP. It is a standard of care which must be met.

To puncture the balloon of privacy prevents family members, and it is usually they and not the actual patient who need protection, from dealing with the complicated, usually unresolved business of serious illness or the death of a loved one. It is no secret in a post-Freudian era that family feelings are conflicted as a patient dies; love, anger, rage about the patient's prospective abandonment, fear, loss – all of these emotions and more spill out as the patient is dying. Most families have the privilege of being overwhelmed, irrational, raging and devastated, in private. VIP family members need to ferret, carve or scratch out such a hidden space to permit themselves this conflicting range of emotions and to play out the interfamily conflicts that often surround the illness and death of a family member. Family members of VIPs thus receive less, not more, of the goods that medicine can provide.

Allocation of scarce resources

There is a third, and most important ethical issue involved in treating VIPs, and that is the reality of fairness and justice in the allocation of scarce resources. To return to the issue of Mickey Mantle's liver:

Ethicists and transplant surgeons said they were not questioning whether it was appropriate for Mr. Mantle to have gotten a new liver so quickly – he was the sickest person in his geographic area with blood type O and so was first in line when a liver from a donor with his blood type became available. But, they said, the real trick is to get on the transplant list in the first place.

These experts said that whether a patient gets on a list for an organ depends very much on the person's social circumstances and psychological

profile, how rich he or she is and how well he or she is able to manipulate the organ transplant system. (Getting on the Transplant List is the First of Many Hurdles, Gina Kolata, *New York Times*, June 10, 1995)

Medicine, as other public and quasi-public structures, has become increasingly transparent. This is especially the case in the allocation of scarce resources. Solid organs for transplantation are the present exemplars of this category. In contrast to merely *expensive* elements in medicine, intensive care unit beds, for example, which are costly and, by virtue of institutional budgeting, become limited and scarce, solid organs are genuinely scarce. A donor liver, usually procured under difficult circumstances, once transplanted into a recipient deemed most acutely in need of the organ, helps only that single recipient. It is not renewable or reusable. These organs are allocated in the United States under the aegis of UNOS (United Network for Organ Sharing) according to relative medical needs of the patient. But factors extrinsic to medical need can effect the recipient equation:

If the patient's doctor decides to refer the patient to a transplant center, the next hurdle is demonstrating an ability to pay. "You have to pass the critical wallet biopsy," Dr. Caplan said. "Let's say I find out I need a liver transplant. I go to the medical center and before I get any tests done, the business office talks to me. These transplants are very expensive. It costs \$10,000 to \$20,000 for them even to evaluate you, and you may have to travel to get to one of these places." (Getting on the Transplant List is the First of Many Hurdles, Gina Kolata, *New York Times*, June 10, 1995)

In the case of Mickey Mantle, celebrity was likely a factor in his listing and access to an organ despite his history of alcoholism. There is a standard for access to a liver transplant and experts disagreed about whether he met that standard. Thus, a seemingly transparent and just system can be corrupted by prominence and money. Not surprising but discouraging. It has been suggested that Mickey Mantle's questionable access to a liver, despite the argument of some transplant surgeons that it was an ethically acceptable allocation, discouraged organ donation in the aftermath of this well-publicized case. Sometimes perceptions of fairness are as important as the fact of fairness itself.

However, recent discussions of the potential pandemic spread of H5N1 avian influenza virus, bird flu, compel the consideration of the fair allocation of scarce resources in the setting of a global medical emergency, including a recalibration of notions of equity, fairness and justice. In this discussion the potential for VIPs to benefit from enhanced access to vaccine, antiviral medication and ventilators, has been part of the international discussion agenda and will, we predict, forever change how VIP access to care is analyzed.

The notion of who is a VIP requires a new definition in a

pandemic. One of the most comprehensive discussions of allocation of scarce resources in an epidemic was held by the Toronto Pandemic Influenza working group [9], an alliance of all the relevant health, public health and social welfare organizations in Toronto, Canada, under the leadership of the public health authorities. Toronto is particularly sensitive to these issues, having experienced the SARS epidemic. Canada is also a nation with universal access to care and, consequently, a strong public health component of its healthcare planning and delivery system. In the Toronto plan there is a particularly interesting chart that describes the plan for prophylaxis in the event of an approaching pandemic. There are six categories/groups of persons who will receive priority for prophylaxis. They include: Front-line Health Care Providers; Key Health Care Decision Makers; Essential Health Care providers; Public Health Responders, Essential Health Support Services; Pandemic Societal Responders, and Key Societal Decision Makers.

This plan – arrived at publicly, supported widely and publicized broadly – has no place in it for the notion of the random VIP as wealthy or well-connected persons. That does not mean that these individuals will not attempt to bypass this societal queue and gain unjustified access to the system. Persons of privilege, those accustomed to using their wealth and position to access the most desirable places in society will, we can assume, continue to act as they have in the past. The question will be whether ideas of fairness will displace practices of privilege. Toronto seems committed to notions of justice, fairness and the needs of society as the guiding principles for future distribution of scarce resources.

Israel has particular experience with designing mass casualty plans for its citizens [10]. Despite its clear egalitarian and utilitarian notions of care... "the goal of treatment in a MCS [mass casualty situation] is to deliver an acceptable quality of care while preserving as many lives as is possible," there is a reference to the need to appoint a special officer to deal with VIPs and the media and to minimize the disturbances that these persons create. The content of the category of VIP is left undefined.

The SARS epidemic, the prospect of an influenza pandemic, and the ever-present threat of bioterrorism have created the need for careful thought about the allocation of scarce resources in these sorts of situations. The consensus is clear, as reflected in an article discussing the allocation of ventilators in a pandemic: namely, development of triage criteria must reflect basic medical ethics principles. However, in a resource-poor environment, the traditional bioethical focus on patient autonomy (which assumes respect for the individual's freedom to make decisions) shifts to a utilitarian or "distributive justice" model that attempts to do the "greatest good for the greatest number" with the resources available [11]. This article goes on to argue that, citing the Society of Critical Care Medicine Ethics Committee, "triage policies should be disclosed in advance to the general public and, when feasible, to patients and surrogates on admission." The clear purpose of this process, as described in the article, is to attempt to enlist family members in the process by which their loved ones will be deprived of care in the hope that the idea of "fair process

effect” will blunt their criticism and enlist them in the generalized utilitarian notions that are offered as the greatest protection for all.

What the Toronto plan makes clear, and the critical care article underscores, is that mass casualty plans do not leave room for the manipulation of the randomly powerful but do protect the key societal decision-makers, those whose position in and importance to society requires their support in order to guide society through its crises. This is a small fraction of the usual VIP contingent.

A good death

Finally, is the matter of a good death. There is no question after the Schiavo case – where family members, the courts, the United States Congress and the President of the United States all debated the care of a woman in a permanent vegetative state – that permitting death in the U.S. is a contested matter. This is the norm in many first-world countries where prolonging the dying process is a possibility. Two year olds who die of fully preventable malaria in sub-Saharan Africa are not proffered the opportunity to avoid, let alone contest, death. But in resource-rich countries, what counts as a medically and ethically acceptable care plan that might permit death is often an explosive discussion.

Religious belief is clearly part of the equation of permissibility, but so too is publicity. Once descriptions have been publicized in the media it is far harder to withhold aggressive interventions that so often precede death. It is now clear from the medical literature that most of the deaths in the hospital are to some degree negotiated [12,13]. Intensive care units can sustain organ function even after the official diagnosis of brain death. Whether medicine sustains life, for how long and under what conditions, are all matters for discussion, negotiation and decision. This negotiation should be guided by the personal values and religious commitments of the patient, now reflected by the family. These negotiations, often facilitated by mediation [14], constitute a delicate process, most often affecting those who cannot ever recover to a prior level of health. These decisions, although ethically appropriate, tend to wilt under the lights of publicity that often accompany the care of the VIP. Given deeply held and shared patient and family values, this is a shame for

the patient, condemned to languish in an existential limbo, and for the family prevented from grieving.

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