



Commission of Inquiry on Hormone Receptor Testing

DISCLOSURE: ETHICAL AND POLICY CONSIDERATIONS

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Abstract

Failing to tell the truth to patients and the public was common practice in medicine in times past. However, over the past 50 years, in North America at least, the standard has turned squarely in the direction of openness with patients. I will examine ethical considerations for and against truth-telling in medicine, reflect on how these apply to the disclosure of adverse events in healthcare and, finally, discuss the core aspects of policies regarding disclosing adverse events.

MEDICINE'S PAST

Historically, medicine has been known for its rather stingy approach to truth-telling. Consider the origin of the phrase 'doctoring the truth' : "to treat so as to alter the appearance, flavour, or character of, to disguise, falsify, tamper with, adulterate, sophisticate, cook" (Oxford English Dictionary, 2002). Hippocrates advised against disclosure to patients, encouraging physicians to hide their methods from the ill. Oliver Wendell Holmes (C, 1982), writing in 1871, captured this Hippocratic attitude: "Your patient has no more right to all the truth than he has to all the medicine in your saddle-bags, if you carry that kind of cartridge-box for the ammunition that slays disease. He should get only just so much as is good for him" (p.528).

Medical Paternalism

This was the prevailing attitude until 40 or 50 years ago, even in Western democratic societies with some sort of commitment to 'informed consent'. Who else, other than a patient's doctor, would know the ideal amount of information to share with that patient? This is the attitude of medical 'paternalism' which is based on the premise that medical professionals, possessing superior knowledge and skills, should know what is best for their patients. This includes understanding better than their patients themselves what information they need to know and are capable of handling. Of course, this 'benevolent dictatorship' by higher powers was not unique to medicine but was common in all areas of social life.

What was perhaps unique to medicine was that non-disclosure was advocated because of concern for the 'patient's welfare' alone. Doctors were 'to do no harm' first and foremost. If words could wound, then these were to be avoided. If no medical good could come from disclosure of bad news, there was no point in revealing to patients certain facts or truths about their condition. Indeed, just because the truth could cause patients harm –worry, anger, depression – it was felt to be in their 'best interests' to remain 'uninformed'. A happy life over a knowledgeable life. Patients, like children, were to be 'looked after' by kind and wise physicians. Paternalism was not unique to physicians; all of the healthcare professions – nursing, psychology, physical therapy -- drew their ethos from the same inspirational well.

For the Good of Patients

For the longest time, society and the courts went along with this attitude. At a time when effective treatments were lacking for many serious illnesses, there was concern that disclosing such diagnoses might cause a patient to lose the will to live, despair, falter and decline. A thin theory of human psychology – that humans were fragile and easily suggestible – loomed behind the profession's reluctance to take patients into its confidence.

This was a forgiving time. For example, in a 1953 case concerning a gynecologist who accidentally left a large needle in a patient's perineum following an episiotomy but did not inform her because it might cause her "excessive worry", the judge opined that this failure to disclose was acceptable as it was done for her own good.

"I cannot admit any abstract duty to tell patients what is the matter with them...it all depends on circumstances...the patient's character, health, social position..." (*Daniels v. Heskin*, 1954)

Medical Attitudes

Failing to be truthful with patients was common in times past. Oken's well-known 1961 survey of 219 physicians in the United States found that 90% would not disclose a diagnosis of cancer to a patient. Many expressed pessimism and

futility about cancer treatment and so saw no point to disclosing. Others feared their patients would become depressed or commit suicide if the truth were told.

Professional attitudes changed in the subsequent two decades – no doubt in part because some cancers became amenable to treatment. A survey of 264 American physicians in 1979 showed that 97% would now disclose a diagnosis of cancer (Novack, Plumer, Smith, Ochitill, Morrow, and Bennett, 1979), an almost complete reversal in the practice of telling patients the truth, at least as far as the diagnosis of cancer goes. More recent studies of professionalism in medicine illustrate the profession's allegiance to honesty and veracity with patients (Campbell, Regan, Gruen, Ferris, Rao, Cleary, et al, 2007).

Nonetheless, old attitudes die hard in areas of medicine where diseases have little effective treatment. For example, suspected diagnoses of dementia and multiple sclerosis were commonly not revealed to patients in the recent past. A court in Ontario in the 1990's failed to find fault with a neurologist and a family physician who, *for more than 7 years*, did not tell a patient that she likely had multiple sclerosis. In fact, the patient discovered her diagnosis only when she attended a different neurologist. The court nevertheless assessed no liability, viewing the diagnosis as "speculative", and concluded that at the time in question (the early 1980's) most physicians would have acted as the first neurologist then did (*Symaniw v. Zajac and Birnbaum*, 1996). Dementia and multiple sclerosis are now more commonly disclosed, in North America at least, in part on account of useful treatments now being available.

Patient Views

The development of effective treatments was not the primary reason for the medical profession's change in view around truthful disclosure, however. A 'therapeutic' rationale was not needed by most patients – they wanted to know the truth long before clinicians were convinced this was a good idea. Studies as far back as 1950 revealed that the overwhelming majority of patients wanted to be told if the examination revealed a diagnosis of cancer. Typical was one conducted by Samp and Curreri (1957) in which 87% of a group of 560 cancer patients and their families felt a patient should be told the truth about this diagnosis. An American survey in the early 1980's by the President's Commission on Ethical Problems in Medicine (1982) revealed that 94 % of patients wanted 'to know everything' about their condition, 96% wanted to know a diagnosis of cancer, and 85% wanted to know a realistic estimate of their time to live, even if this was less than one year. More recent reports have indicated that over 90% of respondents would want to be told a diagnosis of Alzheimer's disease (Erde, Nadal, and Scholl, 1988) and over 80% of patients with amyotrophic lateral sclerosis want as much information as possible (Silverstein, Stocking, Antel, Beckwith, Roos, and Siegler, 1991). Studies of older patients, sometimes thought to be less interested in the truth, have shown that almost 90% want to be told the diagnosis of cancer (Ajaj, Singh, and Abdulla, 2001).

The Rise of Self-Determination

The increasing recognition that patients are persons with the right of self-determination, rather than passive individuals to be taken care of by benevolent healthcare providers, lies at the root of modern medicine's attitude shift towards more truthful disclosure. Not divulging accurate information prevents patients from autonomously making informed decisions about whether to have or forego medical treatment. On a larger level, failure to provide information that may be of central importance to patients' futures means depriving them of one means by which they can live as they see fit. As Elian and Dean wrote in their 1985 article, rather than asking, "Can the patient stand being told?" one should ask: "Can the patient stand *not* being told?" (p. 28). Imparting accurate information about an illness that will affect how they will lead their lives in the future allows patients to plan for that future.

Respect Due Persons

Thus, patients may have an interest in information that concerns who they are as people – this may be above and beyond what is needed to be known for informed consent to medical treatment (an aspect of disclosure that is of most import to clinicians.) Whether patients *do* anything with medical or 'personal health information', as it is now called, is a separate issue from that of treatment choice. For example, a patient's desire to take an active role in making decisions

about treatment “may be less strong than [simply] the need for clear and accurate information”(Fallowfield, Hall, Maguire, Baum, and A’Hern, 1994, p. 448). It is the patient-centred modern emphasis upon autonomy which is not found in the Hippocratic canon.

In this modern view, patients should be told the truth because of the respect due to them as persons. This is the ‘democratic’ as opposed to therapeutic rationale for truth-telling. *We, as healthcare providers, share information with patients not to get them to accept our treatment recommendations, not to placate their emotions, but in order that they can live their lives the way they see fit.* the truth can empower them and encourage authenticity and autonomy. Empowering patients has been recognized as one of the central goals of modern medicine, as important as the amelioration of suffering and the prevention of premature death.

Interviews with patients generally support this perspective. For example, in a study done before any treatment for MS existed (Elian and Dean, 1985), patients with the disease felt they had a right to know what was wrong with them. Some were angry about being asked why they wished to know. One said: “Do I have to explain why? Just so that I know.” (p.27)

TRUTH OR CONSEQUENCES?

Utilitarian vs Deontological Approaches to Disclosure

There is a theme evident in the medical profession’s traditional approach to disclosure and truth-telling. Medicine has a largely ‘utilitarian’ approach to

providing information to patients. *Utilitarianism* judges the merits of an option by its *consequences*: the Truth is to be dispensed according to its benefits and not offered if harmful. In other words, the ends may sometimes justify the means. But according to whose standards of utility are we to judge the harms and benefits of disclosure? The patient's? The doctor's? The patient's family's? Society's?

The contrasting ethical theory of *deontology* judges an action's moral acceptability depending on its adherence to a rule which should always be followed irrespective of the consequences. In other words, there are intrinsically moral rules which persons are duty-bound to follow. But according to whose sense of duty? And what if duties collide?

Duty or consequences? Which theory gives the best account of morality? Neither does – for professional purposes we ought to combine both approaches. We try to maximize good outcomes *and* also adopt rules such as the obligation to respect privacy.

Truthtelling in Modern Medicine Defined

Truthtelling is the modern attitude and practice of being open and forthright with patients. It encompasses disclosure. Information necessary for patients to 'make sense' of their condition or situation is conveyed. It is not necessarily about telling the 'whole truth and nothing but the truth', usually an impossible task. *Truthtelling is about intending not to mislead or deceive.* There are so many ways to mislead patients, it takes clinicians some work and thought to decide

how best to present patients with information in comprehensible and unbiased ways (Bowling and Ebrahim, 2001). Cabot wrote in 1903 that the physician's duty is to strive to create a "true impression" in the mind of the patient about his or her condition and thereby foster the covenant of trust between physician and patient.

The Covenant of Trust

Trust is at the heart of the doctor-patient relationship. Trust in the healthcare professional enables patients, among other things, to reveal private information, to expose their vulnerabilities, and to accept the professional's recommendations for treatment in the face of uncertainties. Trust enhances the efficacy of any offered treatment and is a necessary component of a satisfactory clinician-patient relationship (Goold, 2002). *Trust must be gained and maintained, not only by individual providers but also by their institutions* (Scott, Aitken, and Mechanic, 1995). Patients can experience a betrayal of this trust when their providers and/or their institutions act in self-protective and deceptive ways.

Not to tell patients the truth about events pertinent to their condition requires deception and sometimes collusion by others to cover up the troubling events. One deception often involves a network of lies and cover-up. Bok (1979) notes "*it is easy to tell one lie but hard to tell only one*" (p. 26). Such deceit undermines the bond of trust between the healthcare provider and patient and produces "corrosive worry" (p. 247) in patients who are deceived.

Proper disclosure to patients saves providers from entering this labyrinth of lying. It maintains the trust that patients have in their particular healthcare providers and, more importantly, in the medical system in general.

Modern Professional Codes of Ethics

Truthful disclosure is now an accepted tenet in modern medical professionalism. The British Medical Association (2004) in this regard notes that the “relationship of trust depends upon ‘reciprocal honesty’ between patient and doctor” (p. 41) and also encourages the sensitive delivery of bad news. The Canadian Medical Association’s (2005) Code of Ethics recommends that physicians provide patients with whatever information that might, from the patient’s perspective, have a bearing on medical decision making and communicate that information in a comprehensible way.

ARGUMENTS OVER TRUTHTELLING

Truth-telling increases patient compliance with prescribed medications (Greenhalgh, 2005), reduces morbidity such as pain (Egbert, Battit, Welch, and Bartlett, 1964), and anxiety (Luck, Pearson, Madden, and Hewett, 1999) associated with medical interventions, and improves patient comprehension of medical decision-making (Woloshin, Schwartz, and Welch, 2007). Nonetheless, there is still reluctance to tell the truth to patients for a variety of reasons.

Harm to Patients

It has been argued that disclosure does not always lead to good outcomes: it can result in labeling patients and result in loss of insurability, shunning, discrimination, and exile. (Think of how patients diagnosed with leprosy, AIDS, or schizophrenia were and are treated.) Sometimes, however, it is not the diagnosis but the path to the diagnosis that causes the greatest concern. What can be very difficult for patients is being told of the uncertainty as to when and how badly a condition will affect them. These uncertainties are magnified by the inevitable waiting for testing to be done and the results to be made available. If there are suspicions that all is not right with the accuracy of the testing process – suspicions that are not addressed in an urgent way – this, too, will make the ‘bad outcomes’ of disclosure even harder to bear.

The traditional concern about causing psychological harm to patients by telling them the truth has not been borne out by research. For example, giving patients very detailed information about the risks of hernia surgery did not increase their anxiety (Kerrigan, Thevasagayam, Woods, McWelch, Thomas, Shorthouse, et al, 1993). Warning patients about the potential side-effects of certain prescribed drugs (anti-hypertensives, antibiotics, and anti-inflammatory pills) did not make it more likely they would experience such side-effects (Lamb, Green, and Heron, 1994). Greater information disclosure to advanced cancer patients did not increase poor patient outcomes and only increased their anxiety levels, in this

study, if accompanied by encouraged participation in their own care (Gattellari, Voigt, Butow, and Tattersall, 2002).

Destroying Hope

It used to be (and still is in some places) thought that healthcare professionals would destroy a patient's hope by disclosure. In one US study, physicians, who reported that they commonly tell cancer patients the truth, said they did so in a way intended to preserve 'hope' and 'the will to live', both valued notions in US society (Good, Good, Schaffer, and Lind, 1990). For similar reasons, compared to their North American counterparts, gastroenterologists from southern and eastern Europe are less likely to be candid with patients about serious disease (Thomsen, Wulff, Martin, and Singer, 1993).

But hope can be maintained in many ways. Hope does not require dishonesty (Groopman, 2005). Doctors who withhold critical information about a diagnosis and its prognosis from patients are denying them the opportunity to live and die as they see fit – this practice denies patients an opportunity to cope and hope on their own terms. Very ill patients may want someone to look after and guide them, but this does not necessarily mean a preference for ignorance or deception. Allowing others to make decisions for oneself, to be 'taken care of' in the full sense of this phrase, can be consistent with wishing to remain informed about one's condition (Ingelfinger, 1980). This healing milieu relies upon an atmosphere of trust between patients and providers. Threats to the network of trust should be taken as threats to the enterprise of healthcare generally.

The 'Right' Not to Know

Studies suggest that 10-20% of all patients do not want to know the details of their condition. This waiver may be a legitimate preference on the part of patients and is, in general, their 'right not to know'. No one should have the truth forced on them. However, this ought to be an 'informed refusal': persons declining information need to know, in choosing not to know, that they may be denying themselves potentially life-prolonging diagnostic testing and treatment.

Cultural Influences

Not surprisingly, there may be cultural influences upon truthtelling preferences. For example, one study found a greater percentage of Korean-born patients preferred to be given less information than did US-born patients (Blackhall, Murphy, Frank, Michel, and Azen, 1995). In Italy, lack of candour about the diagnosis of Alzheimer's disease is common (Pucci, Belardinelli, Borsetti, and Giuliani, 2003). In our multicultural society, it is important to take such cultural attitudes into account when making decisions around medical disclosure.

Nevertheless, while certain cultural traditions seem to militate against truthfulness, there are several caveats:

- cultural attitudes are not fixed,
- recent trends suggest a global interest in obtaining information and a decline in 'professional discretion' to withhold it,

- all members do not necessarily share their culture's totems and taboos. Each person is unique and should be 'offered the opportunity to know the truth' (Freedman, 1993).

Information sharing

Nondisclosure and deceit can harm patients in many ways. For example, if not informed about their medical condition, they may fail to obtain medical attention when they should or accept unnecessary aggressive treatments. They also may make life decisions they may later regret if not fully informed. Most importantly, nondisclosure and deceit in medicine undermines the covenant of trust between patient and healthcare provider.

*Unless patients have indicated a preference not to be informed, the assumption should be that they **would** want to be informed* – especially if there are significant results pertinent to their wellbeing. Uncertainty is not always problematic (Logan and Scott, 1996). Informing patients about the uncertainties and the range of available treatment options allows them to appreciate the complexities of medicine, to ask questions, to make informed and realistic decisions, to assume responsibility for those decisions, and to be better prepared for untoward outcomes of care.

Studies show that the way in which the information is given may be just as important as the information itself (Brown, Boles, Mullooly, and Levinson, 1999). Poor disclosure practices, even if the information conveyed is accurate, can have

devastating consequences for patients (Shattner, 2002). Such disclosure is typically done too hurriedly, in the wrong setting, without appreciation of the patient's circumstances, and without addressing the patient's real needs and fears.

Care must be taken that information is given at the right time and in the right place, "a compassionate milieu" (Mann, 1981). Even if telling the truth does have some negative consequences, this does not in itself warrant nondisclosure. It is important to break bad news carefully and considerately: in person, sitting down, in a comfortable setting, with a trusted professional, prepared for emotion, ready to answer questions, having all the time needed, and being knowledgeable about the next steps. The news may be brutal for a patient, the telling of it need not be (Jonsen, Siegler, and Winslade, 1992, p. 63).

ADVERSE MEDICAL INCIDENTS

Deception – or the failure to be fully truthful -- about untoward incidents in healthcare is increasingly an area of particular concern for the medical professions and their institutions. When mishaps occur, the healthcare professional's reaction can be one of shame, guilt and embarrassment. "Shame is so devastating because it goes right to the core of a person's identity, making them feel exposed, inferior, degraded; it leads to avoidance, silence." (Davidoff, 2002, p. 623). Nonetheless, this cannot override the damage done to patients and their trust in the healthcare system if they are not told about such adverse events. The ethical underpinnings of truth-telling in medicine are particularly

applicable to the disclosure of adverse medical incidents. Patients must be told of adverse events because that information may be crucial to decisions they must subsequently make about their medical health, just because they are due the respect of being told the truth, and so they can maintain their trust in the medical system.

The cases of medical harm that prompt patient and public concern are those seriously adverse events where:

- there is a perception of a 'cover-up' by those involved, and/or,
- no one has taken responsibility/been held accountable, and/or,
- many patients have been harmed (due to a correctible hazard in the medical environment, such as an impaired colleague or defective device), and/or,
- patients and families must pursue legal action to obtain answers, and/or,
- those implicated in the mishap have not taken corrective action.

Honest Communication about Adverse Events

When things don't go well, truthfulness and forthrightness are important protective factors against legal actions initiated by patients (Davies and Bacon, 1990). Justice Krever, in a judgment regarding medical negligence, wrote that the court action might have been avoided had the physician taken the patient 'into his confidence' (*Stamos v. Davies*, 1985). The doctor didn't do so and the

patient felt he had no choice but to sue in order to obtain a better explanation for his injury.

One study revealed that over 90% of patients want to be informed about even minor errors in healthcare (Witman, Park, and Hardin, 1996). Promptly informing patients and families in a straightforward way what is known about harmful incidents fosters a healthier and more realistic understanding of medical care and may prevent mistrust.

While error disclosure may be no guarantee against suits and complaints, such honesty can reduce the punitive 'sting' that sometimes accompanies judgments against clinicians and their institutions. Surveyed individuals were more likely to seek legal action if they discovered that mishaps affecting them were not openly disclosed to them (Mazor, Reed, Yood, Fischer, Baril, and Gurwitz, 2006).

DISCLOSURE POLICIES

Healthcare institutions have been encouraged to adopt robust policies and procedures that address the disclosure of error and adverse incidents. At the core of disclosure policies must be an affirmation of truth-telling. The objective of the institutional and professional response is to give patients/families a 'true impression' of a critical incident or adverse event as thoroughly as possible. The policy must affirm the need and capacity for an urgent, patient-centred response to adverse events. To maintain the public's trust and the confidence of every patient, professionals must see to it that they and their institutions are ready to

respond to healthcare safety meltdowns. *Critical incidents are a form of medical emergency imperiling trust that requires prompt professional 'resuscitative' efforts by those involved. Critical incidents that involve more than one patient require swift attention from the highest levels of the healthcare institution.*

There are now recognized to be three essential elements to be addressed in all adverse event policies (Canadian Patient Safety Institute, 2008).

When to Disclose

When adverse events transpire,

- the default assumption should be that patients/families want to be informed about harmful events that may affect/have affected their welfare,
- the decision about notifying patients rests with the individuals and institutions responsible for the incidents,
- 'timely' disclosure is key. *The more serious the incident – that is, the greater the harm or the risk thereof -- the shorter the delay in notification should be,*
- disclosure should take place as soon as possible after it has been identified, where possible, when the patient is stable and able to understand and appreciate the information,
- where death or serious injury occurs, those involved should disclose the incident to families within hours,

- initial disclosure should not await definitive answers about what went wrong.

How Should Error be Disclosed?

When an adverse event has been discovered,

- the most responsible clinician ought to lead the discussion of the incident,
- this individual should be a trusted clinician known to the patient/family,
- disclosure would be best done in person, with adequate time, in a comfortable, private setting,
- less direct means of notification – phone call, fax, or registered mail -- are acceptable but should only take place in cases of great geographic distance or where timely direct communication is not feasible,
- ‘cold calls’ to affected individuals or their families by persons unknown to the patients are a recipe for disaster and disappointment,
- media notification of affected individuals should only ever happen when all other means of contact have been exhausted.

What Should be Told?

During the discussion of the event with the patient/family, one would expect,

- an admission of regret and apology for the incident. Such admissions need not (and indeed should not) await definitive investigation of an adverse event. They are not admissions of liability but empathic expressions acknowledging outcomes that no one wanted (to even

hesitate for a moment to offer an apology to a patient harmed by medical care is akin to considering whether one ought or not to help save a drowning child. It is to have, as the philosopher Bernard Williams (1981) wrote, “one thought too many,” p. 18),

- a disclosure of the sequence of events leading to the incident as far as known,
- a disclosure of the incident’s likely consequences, and any corrective treatment,
- a disclosure of the steps taken to prevent the incident’s recurrence,
- answers to any questions the patient/family may have,
- an offer to meet again as needed to promote understanding.

Who is Responsible for Telling?

The problem today is what Balint (1988) called the ‘collusion of anonymity’ when different healthcare professionals are involved in the care of a patient, it is all too easy for the patient’s care to fall between the cracks and for no one person to be responsible. In modern healthcare, where multiple specialties and professions are almost always involved in the care of a patient, this failure to provide coordinated and comprehensive leadership can have serious repercussions for the patient. The responsibility for patient welfare and communication with the patient does not end if one claims to be only indirectly involved in the care of a patient.

To meet these expectations, the following recommendation for radiologists (Berlin, 2005) could apply to any healthcare professional – *whether or not they provide direct patient care*. He or she:

- must coordinate his or her efforts with those of other healthcare professionals involved in the care of the patient,
- must have a system in place whereby unusual, hazardous findings can be communicated to the patient and/or the treating team, and
- may have a duty to communicate directly with the patient if he or she is unable to contact the most responsible clinician in a timely way.

What About the Public Interest?

Critical events have a way of becoming public knowledge very quickly these days – lapses in confidentiality, digital recorders, cell phones and cameras – all make it hard to hide from public scrutiny critical incidents, especially those involving more than one patient. The institutions involved are also responsible for informing the public when significant adverse events occur in order to help maintain public trust in the healthcare system. Public notification, done carefully to protect personal health information, should be undertaken after every effort has been made to inform directly affected patients or families. This is important in order to prevent public doubts and worry about the commitment of public officials to the safety and reliability of the healthcare system. Lacking the public's confidence and trust in the healthcare system, the whole enterprise may be

grievously wounded and the legitimacy of medicine called into question. Such trust, once lost, is hard to regain.

BOTTOM-LINE REGARDING TRUTHTELLING

There are no statute 'laws' requiring healthcare professionals and administrators to be honest with patients or the public. There are, however, patient and public expectations, moral obligations, and professional duties that require a commitment to truth-telling and transparency on the part of healthcare providers and those responsible for the management of the healthcare system. This openness is especially important for the best management of adverse incidents – events which not only harm patients but also call into question the trustworthiness of healthcare professionals and their institutions. Disclosure policies for adverse medical events are critical to buttressing the truth-telling practices and attitudes of healthcare professionals. Properly applied, they can help regain some of the trust in the healthcare system that adverse events can undermine.

JUDGMENTS

Daniels v. Heskin [1954] IR 73 at 86-87 (SC)

Stamos v. Davies [1985] 52 O.R. (2d) 10 (H.C.): 25-26

Symaniw v. Zajac and Birnbaum (Ontario Court, General Division), 1996. Court File no. 93-cu-67230 cm)

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