**Reading SAL: Communication, Truth, and Disclosure**

**Benjamin Freedman:** Offering Truth

Sometimes

(1) patients themselves don’t want to know—and they have the right to remain uninformed.

(2) families want the patient to remain uninformed—but the truth should still be offered to the patient—surrogates cannot remove from the physician his obligation to tell the truth.

--patients can defer information; but if they desire it, few families will resist.

Cultural or even individual differences may underlie different approaches to receiving truth about their own circumstances.

**Jay Katz:** Informed Consent. Must it Remain a Fairytale? (1990)

1. **Prehistory:** Some relevant court cases: *Salgo v. Leland Stanford University Board of Trustees* (Ca, 1957); *Nathan v. Kline* (Kansas, 1960)

   Case law decreed through these and some subsequent cases that physicians must share decision making authority with their patients—a radical change from the ancient tradition. (For instance, the 1847 AMA code is much closer to the Hippocratic approach.)

   The authority of the physician rested on (a) esoteric knowledge via education and experience (=knows more about illness and disease than the patient); (b) patients are ill, thus situationally and dispositionally non-autonomous; and (c) the assumption that professional ethics will prevent abuses, as well as encouraging beneficence. But those do not guarantee that the physician will have the same values (or priority among values) as the patient.

2. **Medical technology:** As medical technology improved and medical science advanced, more options became available. In the process the chart became an intermediary between the physician and the patient.

3. **Impact of law:** the court cases revealed the gap between old expectations and new reality. Some of the improvements in medicine exposed the patient to possible harms undreamed of by more primitive medical practice. So increased need to inform patients of possible harms and risks.

   (It is interesting that failure to warn about risks, malpractice, is considered negligence, but not battery—a different category of offence.)
"Arato v. Avedon" (Ca, 1992) made specific the need to disclose prognosis. Because it is a legal doctrine, the task of doing the work in a medical context remains to be done. The underlying concept is that physicians and patients must make decisions jointly—and for that to work, physicians must change their current disclosure practices. Only then will social policy be translated into medical policy.

4. But don’t kid yourself that there are no barriers to joint decision making:
   (a) medical uncertainty: In the light of what modern medicine still does NOT know, physicians must be willing to admit ignorance, acknowledge alternatives, and pay more attention to how to talk about these things.
   (b) patient incompetence: it’s not just condescension to acknowledge it; but we don’t know enough about it, and the situation is complicated by bad communication and variability in situation.
   (c) patient autonomy: the teachings on this subject are ambiguous, and it is balanced (as for instance by B&C) by beneficence and non-malevolence as competing principles in a confusing way.

5. The current state of physician/patient decision making: physicians themselves are ambivalent about their own priorities (which include prominently the quest for diagnosis and cure).

Katz’s summary: patients are adults, not children. It is not always the case that the best treatment is what is best. We need to acknowledge more openly the extent to which much remains uncertain. We need to recognize the possible merit in other views than our own. In short, trust your patients more.

Katz is a psychiatrist. Do you think that his professional specialty may affect his approach to this important ethical issue?

Francoise Baylis: Errors in medicine: Nurturing truthfulness

When errors lead to adverse [=bad] outcomes, physicians sometimes don’t reveal them.

Why not?
   1—causal chain may be uncertain; an adverse outcome is not necessarily due to an error, but may involve risk and chance as well.
   2—may be overdetermined or multi-factorial
   3—belief that disclosure does more harm than good
      --increased anxiety
      --loss of confidence in medicine or trust in physician
   4—self-interest or protection of colleagues
   5—fear of litigation

There is an institutionalization of denial, discounting causal role, and non-disclosure.

The professional acceptance of and encouraging of non-disclosure means that truth telling around
errors is shunned, and disclosure becomes supererogatory rather than a duty.

The solution is to change the attitudes surrounding error from blaming to improving the systems or skills that led to the problem.

We also need to correct a misapprehension about how truth is received: truth telling, even of unpleasant truths, enhances rather than eroding trust.

We need no-fault medical insurance and tort reform.

We need to institutionalize positive rewards for those who speak truth.

**Lainie Friedman Ross:** Disclosing misattributed paternity

When just mom comes to genetic counseling, she is the patient. But what are the obligations of genetic counselors for revealing misattributed paternity when it is the couple who are the patients?

96% believe confidentiality overrides disclosure: ‘genetic counseling should not be used in ways that disrupt families.’

LFR argues that NOT disclosing to the male wrongs him: it is deceptive and immoral.

Alternatives: not disclosing to either; disclosing to her, not him; saying “testing inconclusive.” She disagrees with all these options.

Objections to her position:

- potential threat to mother and child
- psychological risks to family
- failure to respect mother’s right to privacy

LFR argues that the obligation to disclose/ tell the truth overrides these concerns.

**Blackhall:** Bioethics in a Different Tongue

Context: end of life care and the ethnically homogeneous physician

Bioethics believes that the problem is too much futile care at the end of life, and the answer is advance directives. But inadequate care is as much (or more) of a problem; and not everyone wants to be involved in end of life decision making.

This paper is an empirical study of EOL attitudes and experiences of 4 ethnic groups on truth telling.
Methods: 200 elderly subjects from each of 4 groups [African Americans, European Americans, Korean Americans and Mexican Americans] were asked about truth-telling of diagnosis and [negative] prognosis.

Results: Preferences on being told varied across the different ethnic groups:

<table>
<thead>
<tr>
<th>Preferences</th>
<th>African-American</th>
<th>European-American</th>
<th>Korean-American</th>
<th>Mexican-American</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tell Diagnosis</td>
<td>87%</td>
<td>89%</td>
<td>47%</td>
<td>65%</td>
</tr>
<tr>
<td>Tell Prognosis</td>
<td>63%</td>
<td>69%</td>
<td>33%</td>
<td>48%</td>
</tr>
</tbody>
</table>

Themes:

- Because it’s me—my body!
- Ah—you know anyway—and ignorance is not bliss.
- Taking care of business (=control)
- Making peace (c God or man)
- It’s cruel to tell (> depression, loss of hope)
- If you know you die faster
- Some people can’t take it (usually said of others, not ones’ self…)

Some cultures are ‘high-context’; others are ‘low-context’; and truth telling varies between the two.

Conclusion: Truth-telling in EOL contexts can be a source of control—or can be cruelly disempowering. Which it is may depend upon the source of self-identity of the individuals involved: their individuality, or their relationships. And our place on that continuum may vary by cultural / ethnic background [or, feminists tell us, by gender, too].

We usually think of truth as a bivalent alternative: we either tell the truth, the whole truth or nothing but the truth, or withhold it. But that’s a crude oversimplification of the possibilities of human communication.

Recommendation: try to be sensitive to possible different cultural approaches to truth-telling —without, of course, falling into stereotyping.

How do these various appeals relate? Katz says doctors are to blame for not telling patients their diagnosis/prognosis; but clearly, not all patients want to hear it.

Should I assume, if my patient is Korean, that I should not offer a diagnosis of cancer, or a specific prognosis?
**T arasoff**

This is an important court case that mediates between the patient’s ‘right’ to confidentiality in the phn/pt relationship, and the duty to protect identifiable others.

Despite heated defense of the confidentiality obligation of physicians the defendants were sanctioned because of their failure to warn. The duty of confidentiality, in this case, was judged to be outweighed by the ‘public interest in safety from violent assault’, and “Tarasoff” laws were passed in many states making the exemption legal.