
DISCLOSURE: ETHICAL AND POLICY CONSIDERATIONS

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ON HORMONE RECEPTOR TESTING**



Key points

- Traditional medical ethos:
 - deception for the 'good of the patient'
 - Evolving standard for past 50 years:
 - openness with patients
 - Intimate link between trust and truthfulness
 - Adverse incidents challenge ethos of openness in healthcare
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Traditional medical ethos

‘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)

19th century Medicine

- “Truth is only safe when diluted.”
 - “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.”
 - Oliver Wendell Holmes (1871)
 - *Trustworthiness required deception*
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Why was deception advised?

Attitudes towards and beliefs about patients:

- Medical professionals:
 - Possess superior knowledge and skills which patients lack
 - Understand better than their patients
 - what information they need to know
 - what information they are capable of handling
 - Know what is best for their patients
 - Patients like gullible children
 - Adopt protective attitudes
 - Overly optimistic prognoses, avoiding discussion of death, emphasize the positive
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Better for patients not to know what we know...

Oken: 1961 survey of 219 physicians in US

- 90% would **not** disclose diagnosis of cancer to a patient
 - Feelings of pessimism over disclosure
 - Worries about impact on patients
 - Would deprive patients of hope
 - *...the truth is unbearable...*
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The courts sometimes accepted this...

- A patient not told a large needle left in her perineum
 - Her physician did not want to cause her ‘excessive worry’
 - “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)
 - But...was this deception done for the patient or to protect the practitioner?
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If you cannot help...

- ‘Do no harm’: the core principle of traditional medicine
 - Disclosure causes undue / unnecessary worry
 - Well-being prioritized over information providing (*“What good will it do?”*)
 - Tactfulness? Caring? Deception?
 - Influenced by the meagre impact of therapy upon disease
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New professional ethos

A sea-change beginning in late 1960's,
influenced by:

- Improvements in care
 - Effective treatments provide choice
 - True choice requires information
 - Societal trends
 - Greater emphasis upon autonomous choice, less upon 'therapeutic good'
 - A need to know
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Patient attitudes

- Samp and Curreri (1957):
 - 87% of cancer patients and their families felt a patient should be told the truth about diagnosis of cancer
 - President's Commission on Ethical Problems in Medicine (1982):
 - 94 % of patients wanted 'to know everything' about their condition, 96% wanted to know a diagnosis of cancer
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New ethos of truthfulness

- A sea-change, not a tsunami
 - Some fields of medicine have adapted more easily than others
 - Resistance:
 - Where effective treatment lacking
 - Where options seem limited
 - Where less direct patient contact (eg. Pathology, Radiology)
 - A revolution in attitude that is still spreading
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New attitude: truthfulness

Novack's 1979 survey of American physicians:

- 97% would disclose a diagnosis of cancer
 - An almost complete reversal in practice of telling patients the truth (at least as far as the diagnosis of cancer goes)
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What do patients want?

- To be kept informed
 - Not necessarily to make decisions
 - To feel supported
 - “Whom can I rely upon?”
 - “Whom can I trust?”
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What does trust in medicine require?

- That uncomfortable truths be kept hidden?
- That patients be protected from negative emotions?
- Or, that professionals should strive to create a 'true impression' in the patient's mind?

(Cabot, 1903)

Modern professionalism

- British Medical Association (2004):
 - the “relationship of trust depends upon ‘reciprocal honesty’ between patient and doctor”
 - Canadian Medical Association (2005) - doctors must:
 - provide patients with information that might, from the patient’s perspective, have a bearing on medical decision making and
 - communicate that information in a comprehensible way
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Trust in truth

- Trust necessary for the therapeutic relationship

(Goold, 2002)

- Trustworthiness and truthfulness inseparable
 - *Truth-telling*: not necessarily telling 'everything' but: *intending not to mislead or deceive*
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Patient-centred care

- The primary ethical principle: ‘respect due persons’
 - Treat patients as adults, not children to be looked after
 - Rather than ‘How can the patient stand being told?’, ‘How can the patient stand *not* being told?’
 - Disclosure = the ‘default’ position
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The role of truth-telling: Principles

- Enables patients: (Autonomy)
 - To live their lives as they see fit
 - To make informed choices about medical and non-medical decisions
 - Fosters good outcomes: (Beneficence)
 - Improves clinical interventions
 - Encourages doctor-patient concordance
 - “Do I have to explain why? *Just so that I know.*” (Justice, Autonomy)
 - Their right to know
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Information sharing

- Causing psychological harm to patients by disclosing the truth has not been borne out by research
 - Most people want to know
 - But 10-20% don't:
 - A problem for disclosure to 'populations at risk'
 - Can minimize this risk by careful individualized information sharing
 - Tell truth carefully, explain consequences, acknowledge uncertainties, provide supports
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Institutional trust

- *Trust must be gained and maintained, not only by individual providers, but also by their institutions* (Scott, 1995)
 - Betrayal of trust if providers and/or institutions act in self-protective and deceptive ways
 - Faced with hazardous situations, what are the responsibilities of institutional officials?
 - Consider this case....
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Trust betrayed: the negligent ship owner

[W. Clifford. The ethics of belief. 1877]

A shipowner was about to send to sea an emigrant-ship. He knew that she was old, and not overwell built at the first; that she had seen many seas and climes, and often had needed repairs. Doubts had been suggested to him that possibly she was not seaworthy. These doubts preyed upon his mind, and made him unhappy; he thought that perhaps he ought to have her thoroughly overhauled and refitted, even though this should put him at great expense. Before the ship sailed, however, he succeeded in overcoming these melancholy reflections. He said to himself that she had gone safely through so many voyages and weathered so many storms that it was idle to suppose she would not come safely home from this trip also. He would put his trust in Providence, which could hardly fail to protect all these unhappy families that were leaving their fatherland to seek for better times elsewhere. He would dismiss from his mind all ungenerous suspicions about the honesty of builders and contractors. In such ways he acquired a sincere and comfortable conviction that his vessel was thoroughly safe and seaworthy; he watched her departure with a light heart, and benevolent wishes for the success of the exiles in their strange new home that was to be; and he got his insurance-money when she went down in mid-ocean and told no tales.

Duty of trustees / stewards

- To believe carefully in the light of reason
 - “The sincerity of [the ship owner’s] conviction [that his ship was seaworthy] can in no wise help him; because *he had no right to believe on such evidence as before him.*”
 - To exercise appropriate supervision
 - To act reasonably to prevent harm
 - *When doubts arise, ignore them at your & your patient’s peril*
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Adverse events and disclosure

- Error / adverse incidents in medicine
 - Harms caused by healthcare
 - Potential for harm from hazardous situations
 - Not the errors themselves that threaten confidence in healthcare, but the *attitude* towards them
 - Failure to take them seriously
 - Public dismayed by lack of accountability
 - Secretiveness especially corrosive to trust
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Incidents as emergencies

- Critical incidents not just harmful to patients
 - Undermine patient / family confidence
 - Without forthright transparency, worries only increase
 - Call for prompt professional 'resuscitative' efforts by those involved
 - They are true 'systems failures'
 - Imperil the public trust in healthcare
 - Require systematic response at all levels of healthcare system
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Timely truthtelling: Policy rationale

- *The more serious the incident – i.e., the greater the harm or the risk thereof -- the faster the response should be*
 - Policy objectives:
 - To ensure a timely response
 - To assure the public that events are taken seriously
 - To give patients / families a ‘true impression’
 - To prevent harms to future patients
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Information sharing: Policy

- Individuals and institutions responsible for the incidents must notify affected / at-risk patients
 - Notification: as soon as possible after event has been identified, when the patient is capable
 - Best done in person, with adequate time, in a comfortable, private setting: allows empathy, encourages trust
 - Communication by phone, fax, or registered mail -- acceptable but only in cases of great geographic distance or where timely direct communication not feasible.
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Information sharing: Process

- ‘Cold calls’ to affected individuals or their families by persons unknown to the patients to be avoided
 - Media notification of affected individuals only when all other means of contact have been exhausted
 - Disclosure a process; should not await definitive answers about what went wrong
 - Where death or serious injury occurs, those involved should disclose incident to families within hours
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“Honesty is the best policy.’ OK! Now, what is the second best policy?”



Don't settle for 2nd best!

Conclusions: Professional responsibility

- Patient safety the responsibility of all health care professionals, whether directly involved in patient care or not
 - Professionals & their institutions must have a system in place by which hazardous findings / incidents can be communicated to the patient and/or treating team
 - Public's trust in healthcare requires transparency and truthfulness
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THANK YOU!

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