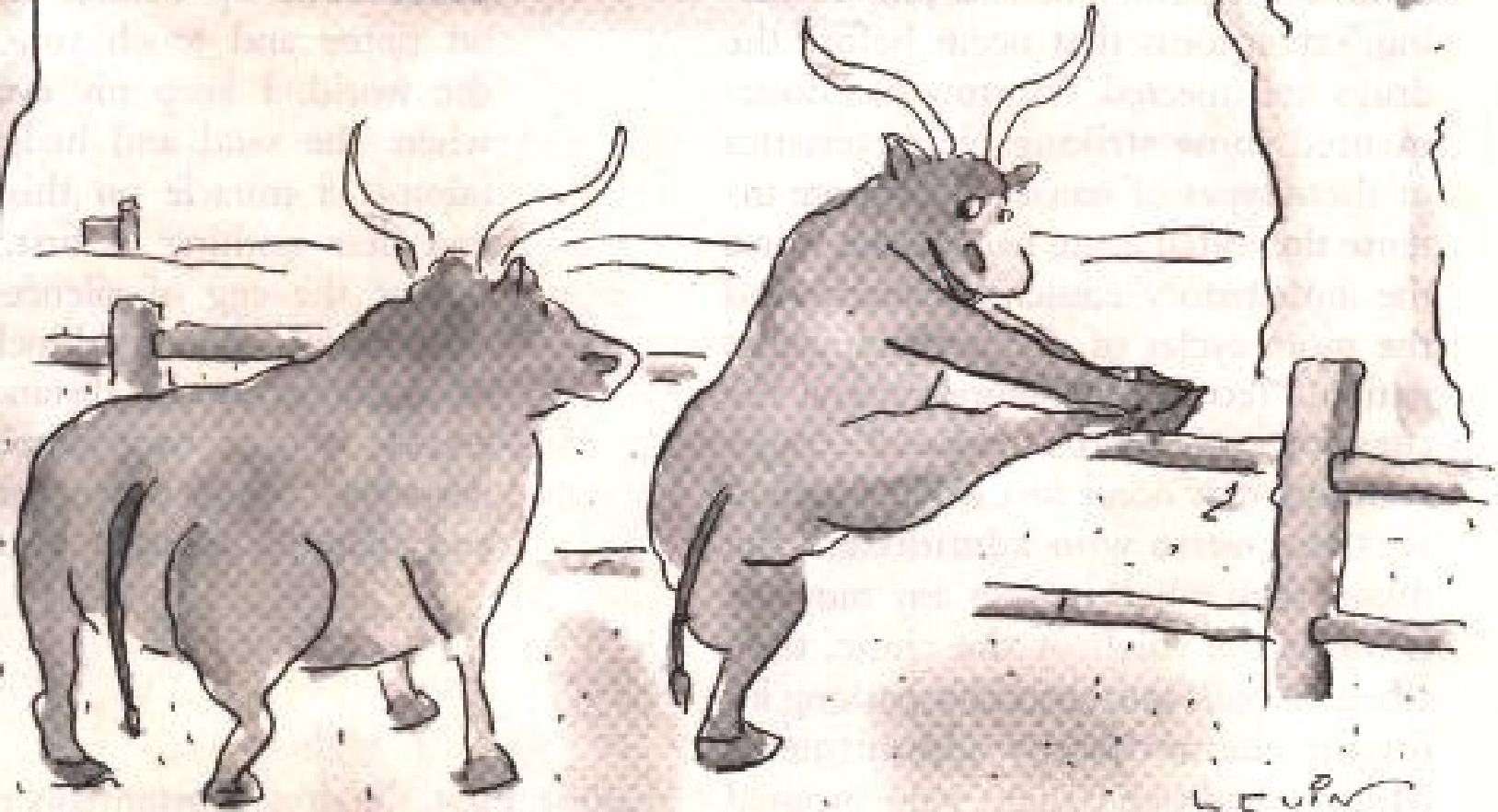


Children, Ethics and HIV/AIDS

**Respect, Benevolence and Justice
for Children with HIV and AIDS**

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"I'm thinking of doing Pamplona this year."

What has ethics got to do with it?

- Understand that we were all born equal...
- Do not use anyone as a means to your own ends (Emmanuel Kant)
- Seek the best possible outcome for the most (John Stuart Mill)

Mid-level principles of Bioethics

- Respect for Autonomy
- Beneficence
- Non-maleficence
- Justice

Autonomy issues

- Practical respect
- Privacy and confidentiality
- Adherence
- Consent
- Disclosure
- Autonomy and the youth

Practical Respect

- **Understanding ‘Equality’**
 - We were all born equal
 - ‘The golden rule’
 - There is no ‘Them’ and ‘Us’
 - We are all in this together
 - The principle that underlies teamwork
 - Getting things done to everyone’s satisfaction
- **Everyone deserves respect**

Autonomy - What is in it for the health care worker?

- **Shared responsibility**
- **Shared work**
- **An improved likelihood of long-term relationship and partnership**

Privacy

- A right held against society and the State
- As a synonym for *autonomy*
- A necessary personal zone
 - The right to have secrets
 - A space for intimacy
- A necessary sanctuary for family
- **Why disclosure is family business**

Supporting confidentiality:

- A pledge of silence from a professional carries added weight because of its value for persons and society

Sisela Bok Hastings Center Report 1983

Instrumental value of Confidentiality:

- **Patients can disclose**
 - **Into relationships of trust**
 - Family
 - Support systems
 - Health care workers
 - The clergy
 - **In order to benefit from psycho-social support**

Children and disclosure

- Family matters
- Age appropriate
- Progressive
- Safe
- Protected

MSF has developed tools

The burdens of disclosure:

- **Risk**
 - of stigmatisation
 - of physical abuse
 - of emotional abuse
 - of rejection
 - of ostracism

Burdens of non-disclosure:

- The ‘work’ of self-stigmatisation
- Loss of access to emotional support
- Deprives the family network of opportunity to plan
- Likely to perpetuate stigmatisation
- The idea that HIV/AIDS is due to promiscuity will not be removed.

Observing confidentiality:

- **Established rules in:**
 - Hippocratic oath
 - Declaration of Geneva
- **But remember...**
 - Information is more widely accessible than patients think
 - Electronic storage threatens confidentiality
 - Physicians may have dual loyalties
 - Records can be leaky

Pressure on confidentiality:

- Teams share
- Patients shop around
- Stored information

- Competing interests
 - **Employers**
 - **Schools**
 - **Law enforcement agencies**

Sisela Bok Hastings Center Report 1983

Infringements of confidentiality

- **Permissible v obligatory disclosure**
 - Weighed against the magnitude and risk of harm
- **Scope of obligation to protect third party:**
 - How far must one go?
 - What patient permission is required?
 - Should the patient be warned?
 - Is disclosure *permissible* or *obligatory*?

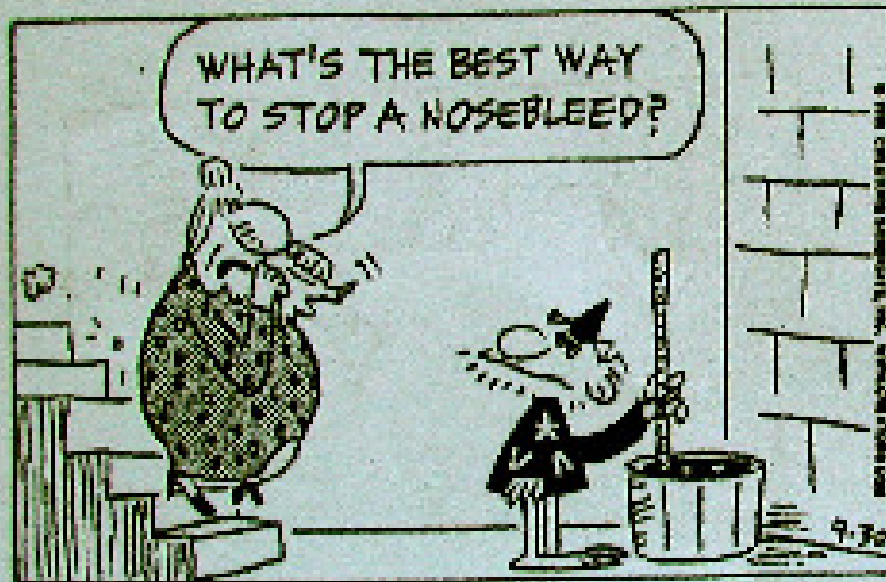
Confidentiality and the weak:

- Confidentiality of children, the aged and the poor is often breached

Another reason to respect privacy...

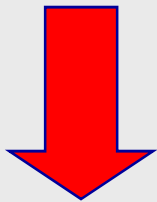
THE WIZARD OF ID

Brant Parker & Johnny Hart

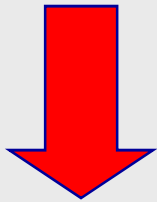


**Why you should worry
about the word
'adherence'**

Compliance



Adherence



Demand



Thinking about consent:

**A pregnant woman consents to
HIV testing**

Why is this woman consenting to the test?

- **This is an act of love and virtue:**
 - She understands the risks of vertical transmission
 - She seeks to protect her child as far as possible
 - She is willing to sacrifice her comfort for the sake of her child's safety
 - There is no necessary benefit to her

The burdens of consent:

- **The weight of decision**
- **The burden of isolation with bad news**
- **If she does not disclose:**
 - Loss of emotional support from the family
 - Loss of the flow of information to the family
 - With which to make decisions
 - With which to plan
 - With which to understand personal risk

Ticking Boxes for consent:

- Enhances the probability of non-disclosure
- Has the potential to ‘trap’ the mother with an impossible burden of knowledge
- Restricts the transmission of information to the family and to society

Relieving some of the burden of consent

- Provide an opportunity for deliberation
 - Share responsibility for a decision to test
 - Ease the burden of disclosure
 - Reduce the risk of isolation
 - Introduce the idea that HIV infection is possible in this family

VCT and disclosure:

- The standard method of taking informed consent prior to HIV testing has the effect of enhancing non-disclosure, paradoxically because of its respect for patient confidentiality.

Family deliberation prior to VCT:

- Disclosure will facilitate family support of individuals and the exploitation of the African family as a resource in the management of HIV/AIDS.

When should adolescents join the team?

- Have you ever watched eleven-year-olds play soccer?
- Have you ever watched fourteen-year-olds play soccer?

Practical beneficence

- **Doing your job well**
 - The need to be trained
 - The need to be professional
 - Networking
 - Finding new ways of doing things
- **Understanding suffering**
 - Poverty and its consequences
 - Social isolation and stigma
 - Illness and its symptoms

Practical non-maleficence

- Protect the vulnerable
 - Examine the impact and consequences of interventions
 - Do not do to others what you would not like done to yourself

Practical justice

- Managing scarce resources
- Gate-keeping
- Advocacy
- Increasing resources through our own efforts

An Ethical question:

Is what is what ought to be?

On being ‘stuck’ in a system:

‘The structure of the situation exerts a powerful influence on people’s actions and people’s actions help to keep those structures in place’

Michael Rowe *Hastings Centre Report* 2003;33:37-44

A statement of ethical intent:

- **What ought to be, can be....**

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**Thank you
for your
attention**

