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## TRUTH TELLING IN MEDICAL PRACTICE

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A standard principle of medical ethics asserts that a doctor shall deal honestly with patients. That requirement represents a shift in the doctor-patient relationship away from a more paternalistic model in which the doctor exercised considerable discretion in the amount of information divulged to a patient. A doctor is now required to tell the patient even unfavourable diagnoses and prognoses.

Much of the motivation for this shift is the doctrine of informed consent, the view that patients should have enough information about their condition, treatment options, and the risks and benefits to make reasonable treatment decisions. Informed consent is a result of a liberty right and is associated with the right to refuse or consent to treatment. Individuals are to be in control of their own destiny, choosing how their lives should unfold. Information is necessary for informed choices and the doctor is to assist the patient by providing such information.

Truth-telling has two wellentrenched philosophical bases. First, a Kantian focus on respect for persons and human dignity. On this view, morality is founded on treating others as we would like ourselves to be treated. Honesty and truthfulness embody the respect and dignity that we as persons would like to receive. Second, a utilitarian focus on maximising good consequences. On this view, morality attempts to produce the greatest happiness for the greatest number. Access to the truth is a vehicle for producing good consequences, since the truth enables us to maximise the good.

Too much emphasis on truth and honesty misrepresents many professional relationships, including those of doctors and their patients. Of course, doctors need to be altogether honest and forthright in their treatment of competent patients with strep throat or flu. In such cases, doctors are the professionals bringing knowledge to bear on a situation; the knowledge, if shared, would help in the healing and patients are entitled to have access to that knowledge, which they are paying for. Psychiatrists might need to be both less honest and less forthright with their distressed patients. A psychiatrist is in a therapeutic relationship in which the truth might interfere with the success of that relationship. In fact, it would be an astounding coincidence if divulging the truth always contributed to the health of a patient in therapy. On occasion, sharing the psychiatrist's knowledge might not contribute to a patient's health. Disclosing a diagnosis of severe depression with suicidal tendencies might interfere with the recovery of a competent but severely depressed patient. So too a doctor might not have to share the suspicion that a patient has cerebral palsy or lung cancer until that suspicion is confirmed. Honesty and truthfulness might require it, but humaneness might speak against it until there is further evidence.

The truth is one good among many, both in professional relationships and more generally. I am disinclined to tell my wife how she looks if she is having a bad day and is particularly vulnerable. That disinclination obtains even if she asks me directly how she looks, in which case I might be outrightly dishonest, not just misleading. I am similarly discreet in discussing with my students, papers that they worked hard on and are proud of. I might mislead them into believing that their efforts were not futile in producing a good result. I might not share with friends my views of their political or religious beliefs, even if they contain factual errors; even genuine friendships have their limits. Relationships and roles require more than truths. Students need encouragement, my friends' beliefs are not altogether my concern, and people need to think well of themselves.

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Moreover, there is an art to truthtelling, even when the truth needs to be told. The truth need not be told all at once; candour has its limits even when the aim is to inform. A doctor need not give the complete diagnosis and prognosis at the time of the first visit when the news is dire and unexpected.

There is another less philosophical side to the issue of truth and honesty that is important. The struc-

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ture of a doctor-patient relationship encourages a lack of total candour on the part of the doctor. In fact, it encourages doctors not to disclose much at all. The truth is often uncomfortable to share with patients very concerned about their health; it is often time-consuming to share information, and doctors have very little time — and sharing information is not as lucrative as other activities of doctors.

# Patients are entitled to informed consent and the right to refuse treatment.

Thus, the emphasis on honesty and truth-telling is important, especially as a corrective both to the old model of paternalism and to the self-interest of doctors. Patients are entitled to informed consent and the right to refuse treatment. But, the emphasis on honesty should not eliminate the important human skills of a doctor. Virtues like honesty and truthfulness are considerably more complicated than just a slogan.

#### JUDICIALLY SANC-TIONED SURGERY WITHOUT CONSENT OF THE PATIENT

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Is it legally permissible for a doctor to perform surgery on a patient who refuses to consent? This issue was raised dramatically in Cape Town recently when police requested that the High Court should order a suspect to submit to surgery in order to remove a bullet wanted for forensic investigation in a double murder case.

'...[A]ny bodily interference with or restraint of a man's person which is not justified in law, or excused in law, or consented to, is a wrong...'1 These words illustrate the common law manifestation of the principle of autonomy or right to self-determination, present also in the Constitution, which guarantees each person bodily and psychological integrity, including security in and control over his/her body.<sup>2,3</sup> In principle, South African law requires a justification for the performance of an otherwise unlawful act. Consent, as a form of justification, is a prerequisite to any kind of medical treatment or surgery. In the absence of consent, the surgeon may be liable for damages in a civil claim based on assault or open to prosecution in the criminal courts on a charge of assault (at common law) or of violating a particular statute (e.g. the Sterilisation Act No. 44 of 1998). A legally competent person may refuse to consent to treatment. No matter how unreasonable or bizarre such refusal may seem to anyone else, in general, the refusal must be respected.

Only in extraordinary circumstances can medical and surgical interventions occur without the consent of the patient or a surrogate. Such interventions would have to be justifiable or excusable in law. Possible extraordinary circumstances would include emergencies, where the best interests of the individual patient are at stake and the patient is unable to consent for reasons of unconsciousness or other incompetence. The extent of the intervention, however, would be limited to lifesaving or other immediate harm-preventing

actions. Therefore, cosmetic surgery would not be lawful without consent. Another example would be an emergency where the public health interest is at stake, such as when an inoculation campaign is required. This eventuality is generally foreseen and provided for by means of empowering legislation that requires the individual's right to refuse to be trumped by the public interest in particular circumstances e.g. the Health Act No. 63 of 1977 s. 33(1)(i) provides for compulsory vaccination in particular circumstances).

Where a court is called on to decide whether surgery should be performed on a person, it will be in circumstances in which the person is either incompetent and there is no proxy consent or the person is competent and has refused to consent to surgery. For the incompetent person, usually the court is called on to decide whether surgery is in the best interests of that person. Sometimes, even if proxy consent is available, the court is asked to decide the issue, such as where sterilisation of an incompetent person is being considered.4

The individual's right to refuse is balanced against the public interest in the effective administration of criminal justice.

In the case of the person who refuses to consent to surgery, an interested party asks the court to decide whether the individual's right to refuse should be overrid-

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den by other interests. A husband might ask the court, in the face of refusal by his pregnant wife, to order her to undergo a caesarean section to save the life of their unborn child. The State could ask the court to order a person suspected of involvement in a crime to undergo surgery so as to collect the evidence required for the investigation as per the search warrant. Here the balancing of the rights is different. The individual's right to refuse is balanced against the public interest in the effective administration of criminal justice. It is seen to be in the public interest for crimes, especially serious ones, to be investigated properly.

A right, such as that to refuse consent, can be limited only for sound reasons and according to proper procedures<sup>5,6</sup> and the limitation must be justifiable in a democracy based on dignity, equality and freedom.7 Where a serious crime, such as murder, has been committed and available evidence (of sufficient probative value) resides in the body of an individual, it is likely that, provided no serious threat of harm exists for him, he will be required to subject himself to surgery in the public interest. In 1985 a court in the USA8 found that to compel surgery would be an unreasonable search under the 4th Amendment of the Bill of Rights as the surgery required was risky and there was other evidence available. In Minister of Safety and Security v. Gaqa (2002)9 the bullet (the only material evidence available) could be removed without serious risk to the person and he was compelled to undergo surgery. In other words, the courts considered whether the threat of harm to the individual outweighed the public interest. Of course, in a situation like this, the right to bodily integrity is not the only right at stake. It can be argued that other

constitutional rights are also affected, like the right to remain silent and the right not to incriminate oneself. In each instance, however, the court has to consider all the affected interests and come to a conclusion on how to balance the rights. A further dilemma is whether the doctor must perform the surgery ordered by the court against the wishes of the patient. Can the doctor resort to a 'conscience clause'? The Choice of Termination of Pregnancy Act No. 92 of 1996 allows doctors to refuse to operate on the basis of conscientious objection. Refusal to carry out a court order, however, usually results in a charge of contempt of court and consequent punishment.

References available on request.

#### HIV/AIDS AND RESEARCHER-COMMUNITY COLLABORATION

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HIV/AIDS is devastating our most disadvantaged communities and populations.<sup>1,2</sup> Fairness demands that the wealthiest nations contribute significantly more resources to helping fight the epidemic, whether within or outside national borders.

However, resources cannot be employed effectively and efficiently without research about how to address HIV/AIDS in specific communities.

For example, the social factors that affect HIV/AIDS therapy and spread, how they affect it, and how best to deal with these factors, vary among communities.

Such research and subsequent implementation of anti-HIV/AIDS measures require extensive community-researcher collaboration. In these endeavours, principles of justice and respect for persons strongly support equal partnering between researchers and community, and community empowerment through capacity building. Here, important principles of justice and democracy are equal opportunity and equal basic liberties.3-5 Such principles for communityresearcher interaction underlie the approach called community-based participatory research.3-5 Capacity building means the development of skills, networks, databases, and other capabilities that enable communities to work more effectively to improve community health and well-being. Such empowerment also promotes the best use of resources by enhancing community ability to deal with future crises. Researcher-community collaboration further serves justice by working against exploitation - inhibiting use of a community for goals that do not serve that community's interest.

## Deliberation, difference, and equality

In determining and achieving researcher-community goals, 'deliberative democracy' approaches are promising. Such 'deliberation' occurs when all (or fairly chosen representatives of different groups) with a significant stake in an outcome gather to discuss and decide what goals to pursue and how to pursue them. Basic concepts of deliberative democracy include the following:

 Participants accept principles of equal opportunity, basic liberties, and respect for persons, and the goal of reaching mutually acceptable decisions.

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- Back-and-forth (dialogical) give and take promotes new solutions, empathic insight into others' views and experiences, and mutual respect. In this process, stories and narratives have great power to foster such insight and respect.
- Participants aim for positions based on reasons — statements or explanations of why a position should be adopted — that are acceptable to all in open discussion, even if they disagree about what relative importance to give those reasons, or how such reasons apply to the situation.
- Minority protections should be in place. Examples are requirements for accountability, publicity, and appeal mechanisms.

However, in the deliberative process many factors work against equal opportunity of community members to speak and be heard.

Rational or reasonable distrust by the disadvantaged that they will get a fair and respectful hearing may inhibit their openness to frank discussion.

First, rational or reasonable distrust by the disadvantaged that they will get a fair and respectful hearing may inhibit their openness to frank discussion.<sup>8</sup> For example, reviews show the rationality of persistent African American distrust

that the health care sector and health care research will treat them fairly.<sup>9</sup>

Second, majority norms or standards of discussion may effectively silence minority voices. For example, the USA dominant white group may favour 'rational' or 'reasonable' and 'cool' discussion. However, African Americans are more likely than whites to employ stories and emotional or expressive speech. Whites may disparage or look down upon these alternative styles and modes of expression, or may not really hear what African Americans say.

Thirdly, disadvantaged groups may put much greater stress on 'preliminaries', including greetings and civilities, than does the majority. Therefore proceeding to formal discussion promptly can create discomfort that further disempowers already disadvantaged community members.<sup>11</sup>

Fourthly, community participants' sense of inferior power because of less technical expertise can be silencing. 9,12

#### **Training implications**

In the light of the goals of deliberation and equal partnering, and ways that community participants can be silenced and disempowered during collective decision-making, researchers need training that:

- promotes understanding of collaboration principles and approaches
- explains community distrust and develops trust-building skills
- develops them into more sensitive, sincere, empathic respectful, and empowering listeners<sup>10</sup>

disposes them to discuss distrust and power differences openly with community participants in order to build trust and reduce power inequalities<sup>13</sup> (researchers should introduce power and distrust issues because they are the least vulnerable).

Accomplishing these ambitious training goals will often require major changes in educational programmes. Training goals for community members include the first goal mentioned above, and the understanding of research processes.

Given enough resources, equal and respectful researcher-community collaboration employing such a deliberative process has great power to combat and potentially to eliminate HIV/AIDS, and to empower communities to deal more effectively with later crises. Furthermore, such community capacity building essentially expands resources available to professionals and institutions that attempt to improve public health and health care services.

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References available on request.