

# Communal personhood and the principle of autonomy: the ethical challenges

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Mrs Zungu is 36 years old and a mother of 4 children. She has poorly controlled diabetes. She consults with Dr Brown, who tells her about the complications of poorly controlled diabetes. He also discovers that she is not using any form of contraception and discusses the option of a tubal ligation. Mrs Zungu agrees to discuss this with her husband. Dr Brown informs her that she does not need her husband's consent for a tubal ligation. Mrs Zungu insists that she must discuss this with her husband. Dr Brown reluctantly gives her a follow-up appointment for 1 week later. When she returns, Mrs Zungu informs Dr Brown that her husband has agreed that she should have a tubal ligation but he would like her to wait until his mother (who is the elder in their household) returns from the Eastern Cape. This is an issue that Mrs Zungu would like to discuss with her mother-in-law. Dr Brown has difficulty understanding this as he could never imagine his wife consulting with her mother-in-law before making important health-related (or any other) decisions. He becomes extremely anxious and irritable as Mrs Zungu may easily fall pregnant for a 5th time with serious consequences to her health and that of the baby while awaiting her mother-in-law's return. Mrs Zungu is not keen on using other forms of contraception.

Concepts of autonomy based in Western ethics may often compete with local ethical systems.<sup>1</sup> This conflict is illustrated in the case scenario above. The goal of bioethics education in the global context is to highlight the plurality of ethical worlds and to encourage a dialogue between these systems.<sup>2</sup> These are indeed lofty goals that are difficult to achieve within the scope of a paper of this length. Thus, discussion shall be limited to the principle of autonomy in relation to the communal nature of personhood. The points will be illustrated with reference to the principle of informed consent.

## THE BACKGROUND: THE PRINCIPLE OF AUTONOMY

Most ethics codes identify 3 basic ethical principles: respect for persons, beneficence and justice.<sup>3</sup> Beneficence requires us to secure the well-being of others by refraining from harming them. It also requires us to maximise possible benefits while minimising possible harms. Justice is concerned with the fair distribution of the burdens and benefits of research. Although the 3 principles are related, this paper focuses on respect for persons, which has the most direct bearing on the principle of autonomy.

Respect for persons requires that patients or research participants be treated as free and autonomous subjects.<sup>3</sup> It further requires that we should protect those whose autonomy is diminished, such as young children, the elderly, and the mentally disabled. An autonomous person is self-governing: he/she is guided by considerations, characteristics and desires that emanate from within the self, as opposed to being driven by externally imposed conditions and considerations. A person is autonomous to the extent that she/he is free from debilitating cognitive and other considerations that could possibly interfere with the capacity for rational thought.<sup>4</sup> The opposite of autonomy is paternalism, a process by which a clinician assumes decision-making responsibilities for another person against the latter's will, in order to safeguard the latter's good.

The principle of autonomy is based on the individualistic view of the person, which gained ascendancy in the Western world during the Enlightenment period. Traditional Western cultures regard the self as a bounded entity. In Western cultures, the person is defined with reference to internal psychological attributes, such as thoughts and

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emotions. The individual is thought to be in control of his or her own destiny and to exist independently of the social order (e.g. culture, gender, and history). Where relationships with others and the social order exist, these relationships are thought to be established through discretionary choice. People are socialised to be unique and to promote their own goals and interests. This view of personhood is known as an independent or the 'generalised' view of the self.<sup>5</sup>

### THE AUTONOMOUS SELF AND THE IDEA OF UNIVERSAL ETHICAL PRINCIPLES

The autonomous conception of the person leads to the idea that ethical principles are universal. Universalism is the view that the moral and ethical principles that inform our understanding of what is just and unjust, good and bad, transcend social and cultural contexts.<sup>1,2</sup> Hence, it does not matter where the person is located in context and time: he/she is subject to the same ethical principles. Ethical decision-making is a matter of individual legislation. It is guided by transhistorical principles which can be discovered independently by any rational moral agent.

#### Autonomy and informed consent

As mentioned previously, the principle of autonomy finds its most immediate application in the requirement of

informed consent. Respect for persons requires that patients or research participants should choose what shall or shall not happen to them and this involves them consenting voluntarily, in their individual capacity, to different investigations or forms of treatment or to participation in research studies.<sup>3</sup> Informed consent requires the full disclosure of information by the researcher/clinician, comprehension (understanding) and voluntariness (freedom from coercion and undue influence) on the part of the research participants/patients. In the individualistic conception of the self, informed consent is thought of in terms of civil rights.<sup>4</sup> The role of the physician or researcher is to supply the patient or research participant with information about diagnosis, prognosis, treatment options, risks and benefits and the like: it is left to the patient/research participant to exercise his or her judgement to determine the best course of action. The patient may engage with significant others in evaluating the information but in the final analysis, patient autonomy is the end goal.

The principle of first-person informed consent, it has been argued, should be adhered to universally,<sup>6,7</sup> failing which one runs the risk of violating the principle of respect for persons. In other words, whether the research project or clinical procedure is conducted in South Africa, Malawi, or the United States, informed consent should be obtained from the individual who is a participant in the research study or clinical procedure. This does not rule out approval by community members or relatives when requested.

#### First-person informed consent and communitarian societies

Attempts to implement first-person informed consent have met with problems in societies with a dominantly communitarian conception of the self.<sup>8</sup> It has been argued that in such societies, consent should be sought from family members or the community at large, rather than

the individual. The paradox is that within the Western ethical framework, bypassing the individual in favour of community or even family consent violates the principle of respect for persons. It could be argued, on the other hand, that the principle of respect should be extended to respecting the cultural traditions of the society in question. This view would lead to the endorsement of family or community consent where this is requested by members of the cultural community that is being researched. This would be consistent with some versions of relativism (the view that the principles defining what is just and unjust, good and bad, differ from one context to another).

The ethical quandary highlighted above exposes the problems of ethical universalism. Universal ethical principles are formulated at such a high level of generality (abstraction) that they fail to give guidance at the level of application.<sup>9</sup> Thus, a Western-trained clinician could argue that if the patient is given information about his or her illness, the principle of respect for persons has been fulfilled. A family member from a different culture, on the other hand, could argue that respect for persons is fulfilled by withholding potentially distressing diagnostic information from the patient. Ethical universals are higher-order (abstract) principles with varying local content.<sup>9</sup> As such, the same universal principle (e.g. respect) would be expressed differently depending on the social and cultural context. A mere knowledge of ethical principles is insufficient: one needs to be familiar with alternative ethical systems, especially the ethical systems of indigenous (Southern) societies. Given the centrality of the concept of the person to moral philosophy, studying alternative conceptions of the person is a good starting point. The following section briefly reviews the dominant view of the person in southern African societies and its implications for informed consent and ethical decision-making in general.

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### THE COMMUNAL VIEW OF THE SELF IN AFRICA

It is not my intention to espouse an essentialist African view of the self. Elsewhere I have written about the multiple and dialogic conception of the self in African thought and in general, but that is beyond the scope of this paper.<sup>10</sup> Thus, discussion shall be limited to the communal account of the self as it has been described in the general literature in order to contrast it with the Western individualistic conception of the self.

A number of authors have been of the opinion that, generally, the self in African societies (and indeed, other cultures as well) is relational.<sup>11-13</sup> The person is extended in space and time and is embedded in social and communal relationships. To be a human being does not require one to stand apart from others: selfhood requires an ongoing participation in a community of similarly constituted selves. Many African proverbs capture this view of the self, the best known being the maxim *umuntu ngumuntu ngabantu* (roughly, a human being becomes a human being through participation in a community of other human selves).

This (i.e. communal) conception of the self requires individuals to be fully aware of their responsibilities and obligations towards the family and the community in general. Ideally, the community nurtures individuals who in turn give back to it. It is for this

reason that the highest value is placed on positive human relationships. The equilibrium (well-being) of the community is preserved if individual members fulfil their respective obligations; failure to do so throws the entire community into a state of disequilibrium. In this scheme of things, the family is the most important aspect of one's social identity. Position and family hierarchy also matter: a deep respect for elders is cultivated and this gives them the socio-moral responsibility to promote the well-being of the family and the community at large. It should be noted that the status accorded to the elders must be earned. Further, elders do not dictate to the family or the community: instead, they bring their wisdom to bear when it comes to moral decision-making so as to safeguard the interests and well-being of the family or the community.

### The communal self and the emergent view of ethics

The view of ethics emerging from the communal approach to the self is not individualistic: it is based on communal decision-making and consensus. Consensus need not be substantive. The most important point is that a forum (*imbizo*) is created in which community members discuss the pros and cons of issues affecting them. The elders preside over the process, giving guidance where necessary. The elders summarise the discussion and give their judgement, which must reflect the views that were the most persuasive during the discussion, otherwise their views will be met with disapproval. Ideally, at no point do the elders dictate to the community.

This conception of decision-making and hence, ethics, is based on the following assumptions:

- Good knowledge is not imposed from above. Rather, it is constructed socially and communally through negotiation.
- Good knowledge maintains the social equilibrium (balance) of the social group as a whole.
- Attention should be paid not

to principles that have been abstracted from their context, but to the phenomenological and lived experiences of the people in question. Thus, good knowledge serves a practical purpose.

### INFORMED CONSENT AS SOCIAL NEGOTIATION

Having briefly considered the individualistic and communal approaches to the self, it is now appropriate to return to the question: what form should informed consent take in communal societies? It is unfortunate that this debate has been phrased dualistically, in terms of individual or 'community' consent. The debate has tended to reduce informed consent to putting pen to paper, which is consistent with the legalistic conception of consent.<sup>14</sup> In my opinion, informed consent is a semiotic (meaning-making) process by which various stakeholders negotiate the processes and procedures that should be followed in order to obtain informed consent in a particular cultural community.<sup>15</sup>

This applies to decision-making related to both clinical care and research. In a research study, this discussion should be started at the earliest possible stage and should involve local researchers and community representatives who are reasonably familiar with the community in question. The following are recommended:

- Researches should not conduct their work from a distance, using junior researchers or students to collect data. This communicates the idea that they do not care about the community except as the source of data for their experiments.
- Instead, researchers should engage relationally with the community in question. They should make a sincere attempt, over a period of time, to be familiar with the various forms of governance in the community to be studied, as well as the pros and cons of these forms of governance.
- Dominant models of decision-making

in the community in question should also be studied, including their pros and cons for potential participants.

This is obviously time-consuming but if the research has been formed as a *collaborative enterprise* with the community from the very beginning, it is not impossible to achieve. Informed consent should thus be conceptualised as an integral part of the research: it is not something one does at one point. It should involve a stepwise process of negotiating with all relevant stakeholders, including the actual research participants, who should eventually give their consent.

This conception of informed consent takes us away from the conception of ethics as the application of rules and principles according to a predetermined plan. It requires knowledge of a special kind – the knowledge to engage sensitively and relationally with the research participants and their respective communities. It also requires the researcher or clinician to reflect on an ongoing basis on how his/her own ethical systems influence the way he or she sees issues in relation to others' ethical systems. Unfortunately, instruction in competing ethical systems and personal reflection are not part of the mainstream medical education. This oversight needs to be rectified.

#### **The ethics of negotiation: an illustration**

The procedures used by Doumbo to obtain informed consent in Mali illustrate the negotiated view of informed consent espoused in this article.<sup>16</sup>

In a research project in Mali involving the study of 3 500 children exposed to malaria, permission to proceed was first sought from the village elders. Focus groups were then held with the heads of extended families, followed by discussions with the mothers whose children were likely to be part of the study. Finally, consent was obtained from the individual families whose children were part of the study. Doumbo argues that community representatives should be given an opportunity to visit the research centre in order to observe and ask questions about the experimental procedures, if necessary. Although lengthy, this process usually generates mutual understanding. Not only is its open-ended nature better suited to the needs of the local people; the process usually leads to the community gaining confidence in the research process.

#### **CONCLUSION**

Within the context of the doctor-patient relationship, as well as in the research setting, problems associated with individualistic and communal approaches to ethics are encountered. Where doctor and patient belong to different ethnic or cultural groups, there is a higher probability that views of personal autonomy may differ. This unavoidably has an impact on decision-making. It is important to be sensitive to these differences and to reach a mutually agreeable compromise. A semiotic approach to ethics, which involves ongoing negotiation and personal reflection, is recommended.

*References available on request.*

#### **IN A NUTSHELL**

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