

Evaluating the right to autonomy argument in the debate on coercive antenatal HIV testing in South Africa

Mpho Selemogo, BMedSci, MB BS, MA

Chairperson, Nyangabgwe Referral Hospital Research and Ethics Committee, Botswana

Several authors have recently argued for coercive HIV testing policies of pregnant women in areas of high HIV prevalence such as South Africa which also have poor uptake in their prevention of mother-to-child transmission (PMTCT) programmes. The autonomy argument, which holds that it is within women's right to exercise their autonomy in opting out of such programmes, is the most cited argument for rejecting such proposals. This paper examines the autonomy argument and arrives at the conclusion that it is problematic, particularly in the context of a public health intervention, in view of the demands of other competing moral interests, and because it is silent on the ethics of the actual implications of the autonomous decision to opt out of HIV testing.

About a third of pregnant women in South Africa (SA) are thought to be HIV infected, and HIV/AIDS is said to be the leading contributor to under-5 mortality (57%).¹ The country has approximately 280 000 children (ages 0 - 14) living with HIV,² and the vertical HIV transmission rate is thought to be about 25%.³ SA's prevention of mother-to-child transmission (PMTCT) of HIV programme has been described as key to the survival of the country's women and children, as it is thought that up-scaling PMTCT services (along with improved infant feeding) could save about 37 200 children annually.⁴ One challenge for the PMTCT programme, however, is the unsatisfactory uptake of HIV testing by pregnant women. Under SA's voluntary HIV testing policy, only about half of the 80% of pregnant women who have access to the PMTCT programme accept HIV testing, meaning that only about a third of HIV-infected women receive appropriate prophylactic antiretrovirals to prevent vertical transmission of HIV.⁵

To address the challenge of poor uptake, coercive HIV testing of pregnant women in areas of high HIV prevalence such as SA, with functioning PMTCT programmes, has been suggested.^{6,7} Some favour mandatory testing policies where HIV testing is *required* as part of routine antenatal care services, while others support a system of routine testing under which the woman automatically gets tested unless she opts out of the testing. These proposals are supported by some evidence suggesting that coercive testing, in particular routine HIV testing, can increase PMTCT uptake. A recent paper, for example, concludes that Botswana's 'shift to routine HIV testing resulted in a dramatic increase in testing and in PMTCT service delivery without measurable adverse effects', giving it the highest current uptake of any PMTCT programme in Africa.⁸ These approaches may, however, be regarded as coercive (or liberty limiting) as they both lack emphasis on extensive counselling and informed consent procedures before HIV testing. As such they are not deemed sufficiently voluntary by some, including the Health Professions Council of South Africa and the South African Medical Association.⁹

Both consequentialist and non-consequentialist arguments have been advanced in rejection of coercive HIV testing. Among the latter, the autonomy argument stating that it is within women's right to exercise their autonomy in not enrolling in such programmes is the most frequently cited.¹⁰ A version of the argument is as follows:¹¹

1. An HIV-positive mother has an independent personhood and identity as an individual.
2. This individuality is distinct from her status as a mother (or mother to be).
3. This individuality gives her the same rights to autonomous life choices as men have, including a fundamental right to make health care decisions without having to think of her child first.
4. Because of the above, policy makers should stop subsuming women under the identity of mother alone, but should disaggregate women's personhood from motherhood to enable women to be seen as individuals with their own individual interests and needs, not to be used as means to achieve children's ends.
5. Programmes that do not recognise this violate women's human rights.

In advancing the case in favour of routine HIV testing in SA, this paper examines this autonomy argument and concludes that it is problematic, particularly when seen against a background context of a public health intervention, the presence of other competing moral interests, and the context of a communitarian society. My analysis will focus on the following observations regarding this argument: (i) its inadequate attention to other moral considerations at play in the dilemma (which relates to its apparent conception of autonomy as supreme among other ethical principles); (ii) its emphasis on a more individualistic conception of the autonomous self; and (iii) its emphasis on the right to autonomy with little or no consideration on the content of the decision being made. Before deliberating on each of these, I begin with a short synopsis of autonomy as a principle. Discussing the principle to the level and depth it warrants is, however, beyond the scope of this paper.

The principle of autonomy

The principle of autonomy is among the four so-called mid-level bioethical principles as popularised by Beauchamp and Childress.¹² It has its underpinnings in the influential Kantian conception of human beings as rational beings with capacity to self-legislate, making them ends in themselves. In health care, this principle means that a mentally competent patient has a right to influence and partake in decisions concerning his/her treatment.

Seen this way, autonomy may be said to be procedural in that it represents a mechanism for ensuring the patient's participation in treatment decisions.

A notable historical aspect of the current dominant interpretation of patient autonomy, as presented by Beauchamp and Childress for example, is that it emerged from a specific cultural context of the USA, one that has been described as being liberal and individualistic.¹³ It is recognised that its interpretation as a concept may differ from one cultural context to the other and that transferring the American rendering of autonomy to other cultural contexts, unmodified, may be problematic.¹⁴

Also of note is that while autonomy as a principle is influenced by Kant, it differs significantly from autonomy as conceived within Kant's moral theory. For Kant, autonomy was supreme over all other principles. For principlism, however, autonomy is neither an absolute right nor a supreme principle that always takes priority over all other principles. Beauchamp and Childress themselves caution against and reject what they call a 'misguided criticism' of their account of the principle which holds that the right to autonomy overrides all other moral considerations.¹² It is the absence of these other considerations and how they interact with the pregnant woman's autonomy that begins my criticism of the autonomy argument. Its lack of an account of the weighing of the different moral interests involved, showing how autonomy ultimately triumphs against all the other interests, signals exactly the construction of autonomy cautioned against above.

The competing moral considerations

One of the impacts of technological developments in obstetric medicine is the transformation of the *clinical status* of the fetus.¹⁵ Technologies such as ultrasonography and fetal tissue sampling mean that the fetus, which was once approached inferentially, can now have its own diagnoses and doctors can now interact with it in clear distinction from its host. As Mattingly notes,¹⁵ these technologies have shifted emphasis 'from unity to duality', with most doctors arguably now regarding the fetus 'as a distinct patient in its own right'. Under the preceding one-patient obstetric model, in which the pregnant woman was considered *one* complex patient of which the fetus was an integral part, the ethics were relatively easy to handle. The new two-patient model has, however, presented questions about how the familiar principles of beneficence, non-maleficence and autonomy ought to operate in such a unique doctor-patient relationship.¹⁵ The obstetrician, as a professional and moral agent him/herself, has ethical obligations not only to the pregnant woman but to the fetus as well, and of course ethical dilemmas may arise when the interests of the woman conflict with those that may be accorded to the fetus.

It is not my intention to go any further into the ethical complexities arising from such a conception of the obstetric patient. My purpose was simply to indicate that this is a complex area in which appealing to one principle only (i.e. autonomy) is bound to be unhelpful, especially when such a principle is not absolute. Considerations of justice for the unborn child, an interplay between the woman's interests and the 'interests' of the fetus, and the ethical obligations of the doctor to the two patients all seem to contribute significantly to the moral dilemma. I now turn to some of these different competing interests.

The interests of the fetus

The principle of beneficence places a moral obligation on the doctor to act for the benefit of both the mother and the fetus. Although the fetus itself may controversially be said to have no interests of its own, the interests and rights of the person it will become cannot lightly be dismissed, particularly when the woman wishes to take the pregnancy to term. The woman's decision to take the pregnancy to term is significant, as it shifts matters from issues of moral status of prenatal life and whether there is a moral obligation on the woman to carry the pregnancy to term (i.e. the abortion debate) to questions about the welfare of the baby she intends to give birth to. A duty not to cause harm needlessly could thus still be violated even though the harm in this case only expresses itself much later. In arguing for the plausibility of prenatal interests and harms, for example, Feinberg¹⁶ gives an anecdote of a motorist who in running over a pregnant woman causes damage to the fetus, which is later born deformed. Here it could be said that the child's future interest of self-locomotion has been affected during his/her prenatal life. For PMTCT it could be argued, as has been done in another paper,⁷ that according to the harm principle, and except where there is a genuine fear of partner violence, not enrolling in PMTCT may amount to wrongful harm to the unborn baby. Given that the right to autonomy may be rightly overruled if it results in harm to others, the recognition that harm to others may still be defined even where a fetus is involved should at least moderate strong claims to autonomy accorded to the mother.

The woman's interests

What may be regarded as the pregnant woman's interests, which when respected allow her not to enrol in PMTCT, may be taken to be what are usually cited as 'barriers' to participating in PMTCT programmes. These typically include factors such as fear of stigma, fear of knowing one's HIV status, not trusting health care workers, fear of breaches of confidentiality, and fear of lack of partner support.³ A general comment can be made that from a programmatic point of view there is no reason why these barriers in themselves should stop coercive HIV testing; they merely suggest that any coercive HIV testing programme needs to have specific in-built mechanisms to address each of these barriers.

At another level may also be the question whether any one of these barriers (or indeed any other reason that does not translate into a threat to the woman's life) should count as a valid consideration for not acting to benefit the unborn baby. Let us illustrate this with what is apparently the commonest barrier to testing: the fear of knowing one's HIV status. Is fear of sufficient weight to prevent measures that could potentially save the baby's life and prevent future suffering? As is the case with most fears its rationality is questionable in HIV testing, given that even if one does not test during pregnancy and the child is infected, the HIV test will be inescapable when the disease eventually expresses itself. Even if knowing one's status was escapable, it would be dubious for the woman to make a choice that puts her future child directly at risk of the things she herself fears. Arguably the mother, possessing better coping mechanisms as an adult, is the one in a better position to deal with the challenges of living with HIV. One could indeed also question whether such decisions influenced by fear should even be counted as autonomous, particularly in this case where the rejection of HIV testing actually undermines personal

autonomy in itself as it threatens the existence of the very agent that is exercising autonomy.

The public's interest

Public health practice has been construed as consisting of collective interventions that aim to promote and protect the health of the public.¹⁷ Public health therefore concerns itself with general societal well-being, rather than specific outcomes for any specific individual.¹⁷ While in clinical medicine an individual, in exercising informed consent, performs their own risk-benefit analysis to decide what to do, based on their own personal situations and beliefs, it is problematic in public health as the benefits (as well as the data on benefits) relate to the public, rather than to any individual *per se*. As a good from an individual's point of view may not necessarily be a good from a public health point of view, it may at times be counter-productive to give individuals, through elaborate informed consent procedures, opportunities to choose to abstain from programmes designed to safeguard the public interest.

Presumably for SA the rationale for the establishment of the country's PMTCT programme was the public health concern over premature deaths of children as a result of HIV. Once the programme was established in 2001 to reduce the nation's HIV-related mortality and morbidity in children, it was now the individual's imperative to contribute to its attainment. This public health dimension further compromises the autonomy argument. Public health interventions, as already suggested, are almost by definition incompatible with strong claims of personal autonomy. As Bayer and Fairchild¹⁸ have observed, population-based health measures require '... a willingness to recognize that the ethics of collective health may require far more extensive limitations ... on liberty ... than would be justified from the perspective of the autonomy-focused orientation of the dominant current in bioethics'. Of course there is no suggestion here that just because a case can be located within the public health context it should be insensitive to the protection of human rights, where that can be helped.

From such perspective, the autonomy argument appears to suffer a contextual problem; its advancement within a public health debate (where public goods precede individual claims) appears to be out of place. Moreover, individualistic approaches may be even more questionable when seen against the extraordinary ravages of HIV/AIDS in SA. As Clark has argued elsewhere using the concept of proportionate reason, the good that may result from collectivist and coercive approaches, namely the preservation of the lives of children and their mothers through preventing perinatal transmission of HIV and allowing infected mothers to get early treatment, may sufficiently compensate for the apparent evil of overriding personal autonomy rights.⁶

The individualistic autonomous self

The apparent tension between individual interest and public interest brings me to another issue presented by the autonomy argument: the individualistic *asocial* self. By asking us to separate motherhood and the individual, the autonomy argument appears to appeal to a rather de-socialised conception of the autonomous self; a self commonly labelled 'atomistic'. Tauber¹⁹ defines the atomistic self as one that 'maintains that underlying our social identities is a deeper inner sense of identity, one that is, in a sense, isolated and inviolate'.

Ironically, even the liberals who advocate for individual autonomy reject such a view of the autonomous individual. Beauchamp and Childress,¹² for example, note that the autonomy they defend '... is not excessively individualistic (neglecting the social nature of individuals and the impact of individual choices and actions on others) ...'. Feinberg²⁰ also observes that '[i]t is impossible to think of human beings except as part of ongoing communities, defined by reciprocal bonds of obligation, common traditions, and institutions'. Indeed it is unclear how we can ever realistically think of a pregnant woman as an un-pregnant individual, or not a mother-to-be. An autonomous agent, it seems, is neither excessively individualistic nor is it one of totalitarian socialism; it is, as Feinberg²⁰ suggests, one in which the individual's self determination 'is as complete as is consistent with the requirement that he is ... a member of a community'.

Against this background, the present case may be construed not wholly as a case of denial of autonomy but perhaps as an argument about the social conception of motherhood. Should the mother-child relationship be something that should be left up to individual assessment and choice, or is it something whose ends society should determine? A richer argument, it seems, is *not* one that tries to shed off the social ties or expectations but one that demonstrates how it has given such expectations due consideration.

Another issue is the deeper theoretical question regarding the form that personal autonomy should take in communal societies such as exist in SA. Should the local morality ultimately decide what is to be considered private (and therefore a protected sphere), or is the American individualistic interpretation of personal autonomy to be regarded as a global yardstick for how autonomy should be interpreted and defined? In the communitarian *ubuntu* societies of southern Africa it is perhaps even harder to see how claims of desocialised individualism can ever be tenable.

Concluding remarks

My overarching critique of the autonomy argument so far has largely not been on whether the woman has the right to autonomy or not; rather it is on whether the autonomous decision not to test is one that deserves to be respected. It is a critique of the contents of the decision: is the decision reasonable considering the unborn baby's interests, the public health interests, and the social expectations and responsibilities attached to expectant mothers? Such questions broadly challenge the notion of autonomy as a purely procedural and content-neutral exercise that focuses only on identifying those with the right to autonomy but neglects the actual contents of the autonomous choices made. Evidently a more productive development on the debate on autonomy rights and coercive HIV testing would be a shift of emphasis from the right to autonomy to the ethics of the actual autonomous decision of the pregnant mother to opt out of PMTCT.

We are led to the conclusion that if coercive HIV testing is morally unjustifiable, it is not on account of the fact that it undermines personal autonomy as presented. For the autonomy argument to have sufficient moral force, it has to enrich its conception of autonomy to one that best reflects the complexity of the competing moral values at hand. Such a rich concept of autonomy is one in which exercising autonomy is not merely procedural, but also one that considers the contents of the decisions being made, one not

excessively individualistic but one that recognises that individuals exist as social beings attached to social roles which embody within them certain expectations, and finally one that does not conceive of itself as inviolable or absolute.

I thank Dr M van den Hoven and Professor J J M van Delden, as well as two anonymous reviewers of this journal, for their input in the writing of this paper. The views and conclusions are the author's own and do not necessarily reflect the views of Botswana's Ministry of Health.

References

1. Coovadia AH, Goga AE, Schowalter L. Call to action: Prevention of mother-to-child transmission of HIV. *Southern African Journal of HIV Medicine* 2009;10(4, December):12-15.
2. UNAIDS. Country situation – South Africa. 2008. http://data.unaids.org/pub/FactSheet/2008/sa08_soa_en.pdf (accessed 1 April 2010).
3. Varga C, Brookes H. Factors influencing teen mothers' enrollment and participation in prevention of mother-to-child HIV transmission services in Limpopo Province, South Africa. *Qualitative Health Research* 2008;18:786-802.
4. Chopra M, Lawn JE. Saving South Africa's mothers, newborns and children – can the health system deliver? *South African Journal of Child Health* 2009;3:71-72.
5. McIntyre J. HIV in pregnancy – an obstetric blind spot. *South African Journal of Obstetrics and Gynaecology* 2006;12:118-120.
6. Clark PA. Mother-to-child transmission of HIV in Botswana: An ethical perspective on mandatory testing. *Developing World Bioeth* 2006;6:1-12.
7. Selemogo M. The harm principle and the ethics of routine antenatal HIV testing in South Africa. *South African Journal of Bioethics and Law* 2009;2:20-22.
8. Creek TL, Ntuny R, Seipone K, et al. Successful introduction of routine opt-out testing in antenatal care in Botswana. *J Acquir Immune Defic Syndr* 2007;45:102-107.
9. McQuoid-Mason D. Routine testing for HIV – ethical and legal implications. *S Afr Med* 2007;7:416-420.
10. Kenyon K. Routine HIV testing: A view from Botswana. *Health Hum Rights* 2005;8:21-23.
11. Zivi K. Contesting motherhood in the age of AIDS: maternal ideology in the debate over HIV testing. *Feminist Studies* 2005;31:347-374.
12. Beauchamp TL, Childress JF. *Principles of Biomedical Ethics*. 5th ed. New York: Oxford University Press, 2001.
13. Callahan D. Principlism and communitarianism. *J Med Ethics* 2003;29:287-291.
14. Hanssen I. From human ability to ethical principle: An intercultural perspective on autonomy. *Med Health Care Philos* 2004;7:269-279.
15. Mattingly SS. The maternal-fetal dyad: exploring the two-patient obstetric model. *Hastings Cent Rep* 1992;22:13-18.
16. Feinberg J. *Harm to Others*. New York: Oxford University Press, 1984: 96.
17. Verweij MF, Dawson AJ. The meaning of 'public' in 'public health'. In: Dawson AJ, Verweij MF, eds. *Ethics, Prevention & Public Health*. New York: Oxford University Press, 2007.
18. Bayer R, Fairchild AL. The genesis of public health ethics. *Bioethics* 2004;18:490.
19. Tauber AI. Sick autonomy. *Perspect Biol Med* 2003;46:489.
20. Feinberg J. *Harm to Self – the Moral Limits of the Criminal Law*. Vol. 3. New York: Oxford University Press, 1988: 47.