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The harm principle and the ethics of routine antenatal HIV testing in South Africa

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Under South Africa's 'opt-in' policy of HIV testing, only about half of the 80% of pregnant women having access to prevention of mother-to-child transmission (PMTCT) of HIV programmes accept HIV testing – a test that is necessary for entry into the PMTCT programme.¹

To alleviate the general problem of low uptake of HIV testing, some parties (including Justice Edwin Cameron of the Supreme Court of Appeal of South Africa) have advocated a policy of routine 'opt-out' HIV testing which, in an antenatal care setting, would mean that pregnant women are tested unless they indicate otherwise.² Such an opt-out policy would, however, be unacceptable in South Africa (SA) as it is deemed not to satisfy the counselling and informed consent requirements stipulated by law. The Health Professions Council of South Africa and the South African Medical Association hold similar sentiments.³

Insofar as the opt-out approach is not deemed sufficiently voluntary, it can be regarded as coercive or limiting of liberty. Questions may then be raised about individual liberty (or right to autonomy) and when it may be justified to restrict this. In the case under discussion, it specifically raises the issue of whether the putative tension between the pregnant woman's autonomy and the widely presumed parental responsibility of acting for the child's benefit should ultimately lean in favour of the unborn child or the mother. Posed differently: under what circumstances is it justified for a woman to choose to opt out of a programme which could reduce the chances of passing HIV to her child from about 35% to about 2%?⁴

In attempting to answer this question, one may refer to the so-called liberty-limiting principles whose utility is in defining conditions in which coercive measures may be justifiably imposed in a free society. In this paper, I use the harm principle (perhaps the best known of the liberty-limiting principles) to argue for routine antenatal HIV testing in SA. I argue that, in a context where there is access to HIV treatment and for the woman who has decided to take the pregnancy to term and is under no genuine fear of partner violence related to HIV testing, the coercive policy of routine testing is justifiable as it promises to prevent severe and wrongful harm to the unborn baby. This will build on McQuoid-Mason's recent work in which he used the four principles approach to argue for routine testing.³ I commence with a brief exploration of the concept of harm itself, followed by observations of what such concepts mean for the case in point.

The harm principle

The harm principle states that '[t]he only purpose for which power can be rightfully exercised over any member of a civilized community, against his will, is to prevent harm to others'.⁵ Despite its apparent simplicity, the harm principle is 'a mere convenient abbreviation for a complicated statement that includes, among other things, moral judgements and value weightings of a variety of kinds'.⁶ Two issues concerning the principle also need noting:

- The harm principle may be applied *ex ante* or *ex post*; the *ex post* version holds that a coercive measure can only be justified if it in fact prevents or reduces *certain harm*, while the *ex ante* allows the coercive measure if it prevents or reduces *risk* of harm.⁷ Our present discussion will concern itself with the *ex ante* in which actions are not certain to cause harm but have such a significant probability of producing consequences so bad that any chance of their occurrence may be deemed unacceptable.
- The proposed coercive measure does not only need to be necessary, but also should be superior to any other non-coercive alternatives of trying to achieve the same ends.⁷

Feinberg's concept of harm

At the heart of the harm principle seems to be the question of exactly what constitutes harm. One prominent interpretation by Feinberg conceives harm as 'the thwarting, setting back, or defeating of an interest'⁶ (an interest meaning: having a stake in something). Interests so defined can be of the ulterior or of the welfare type.

Ulterior interests consist of an individual's ultimate goals and aspirations (e.g. academic aspirations), which define what an individual's idea of a good life is but are not necessarily things that one *absolutely* needs for survival. Welfare interests, in contrast, are the minimal basic goods that are common to all people regardless of their conception of the good life, and include such interests as being alive, free, healthy, in supportive relationships, etc. Because they are so basic, they can be seen as the basis for moral rights that one can reasonably claim against others. In Feinberg's words, welfare interests 'cry out for protection'⁶ because their violation constitutes serious harm to an individual.

In what sense, then, is harm referred to in the harm principle? According to Feinberg, 'only setbacks of interests that are wrongs, and wrongs that are setbacks to interest ...'⁶ are to count as harms in the harm principle; wrongful harms are defined as any indefensible or inexcusable setting back of another's interests.

One may ask how great such an indefensible harm should be for the harm principle to warrant coercion to prevent it. Here, Feinberg suggests that the legal maxim *De minimis non curat lex* (The law does not concern itself with trifles) should apply. This maxim excludes trivial harms from legal protection, as legal interference with trivia may result in more harm than it prevents, not only to the person who has been harmed, but even to his/her victim as well. For my purposes here, it is perhaps enough to simply observe that, whatever the definition of a trivial harm may be, it cannot produce an outcome where frustrations of *welfare* interests become trivial harms.

The harm principle and the ethics of routine antenatal HIV testing

In the following, I defend the thesis that, according to the harm principle, and except where there is a genuine fear of partner vio-

lence, the coercive policy of routine testing is justifiable because it may prevent severe and wrongful harm to the unborn baby.

1. Declining the HIV test (and therefore PMTCT) exposes the baby to unacceptably high risk. Both the probability of infection and the magnitude of the consequences of infection, according to the *ex ante* view, would warrant the use of the harm principle. Regarding PMTCT, the choice as mentioned is roughly between a 35% chance of infection (without PMTCT interventions) and a 2% chance with PMTCT. I find no reason to believe that anyone, having accepted these figures, can dispute the notion that a 35% chance of becoming HIV-infected is unacceptably high. The magnitude of the infection, if it occurs, is similarly indisputable. About 20% of those children infected through MTCT proceed to AIDS or die in their first year of life, while more than half would die by age 2.⁸ Compared with their uninfected counterparts, their overall mortality rates are ninefold and greater.⁸ Without antiretroviral drugs (ARVs), most HIV-infected children, with ever-weakening immune systems, will die before their fifth birthday from opportunistic infections.

Some may dismiss this picture of paediatric HIV as overly pessimistic, given the era of ARVs which have so transformed the lives of HIV-infected persons. While I accept that these drugs have indeed greatly improved the quality and prolonged the lives of those afflicted, I do not believe that this in any way alters the morality of the issues at hand. For example, the presence of a surgeon on stand-by should not justify or lessen the injuries inflicted on one person by another, even with the prospect of the surgeon promptly attending to the injuries.

2. The resulting HIV infection sets back the child's welfare interests, which constitutes serious harm to him/her. To some, the harms alleged here are in fact implausible as the subject in question is a prenatal being who possesses no actual interests of his/her own. This stance is, however, mistaken in view of the expectation that, all things being equal, the child will be born and that this consideration in itself makes it reasonable to ascribe to the child certain future interests which would then have the potential to be set back, even before that potential person becomes an actual person.⁶ Feinberg, in arguing for this point, tells the anecdote of a motorist who, in running over a pregnant woman, causes damage to the fetus, which is later born deformed and chronically ill. Here it could be said that the child's future interest of normal mobility was set back during his/her prenatal life.

With HIV infection, the child's basic welfare interest in being healthy and long-lived is frustrated as he/she faces a shortened life with limited prospects for achieving any ulterior interests that she/he may grow to develop; it is noteworthy that the fact that it may be just one of the welfare interests affected does not make the harm any less serious or acceptable. As Rescher observed, 'welfare interests, taken together, make a chain that is no stronger than its weakest link' as deficiencies in one area cannot be compensated for by superiority in another.⁶

3. The mother's action is the only one that can reduce the risk. Actions of third parties cannot reduce the risk of this serious harm to the child's welfare interests. One may argue that the woman's decision to opt out should be viewed as an omission which merely allows harm to occur and is not a harmful act *per se*. If indeed the act-omission distinction matters, the question then would be whether omissions count as do acts, in relation to the harm principle. I maintain, as does Feinberg, that the acts-omission distinction should not matter in the harm principle. If one perceives the harm principle as a harm prevention tool, then the difference between acts and omissions is irrelevant, as each of

these 'acts' can equally result in harm.⁶ The ultimate end of forbidding people from actively causing harm is harm prevention, and it would be misguided to think that it could be achieved if others were still allowed not to prevent harm even when they could reasonably be expected to.

4. Abstention from PMTCT is unjustifiable (and therefore wrongful) as it could typically be done without an unreasonably high risk to the mother. By unreasonable risk here, I mean (to use Peter Singer's words) 'without thereby sacrificing anything of comparable moral importance'.⁹ The sacrifices in question, in this case, equate to what are commonly cited as 'barriers' to HIV testing in PMTCT programmes. Studies have identified the following barriers, among others: (i) fear of knowing one's status, (ii) fear of stigma, (iii) negative attitudes of health workers, (iv) perceived lack of support from male partners.^{10,11} One can make the following general comments regarding these barriers:

4.1 From a programmatic point of view, there is no reason why these should stop the establishing of a routine testing programme as they merely suggest that such a programme would need mechanisms to address all these concerns.

4.2 It is unclear how the decision to decline an HIV test really escapes these perceived barriers when one considers that, for an infected mother and child, these would be inescapable realities when the disease ultimately presents.

4.3 Even if these were not inescapable, it would be a dubious choice for a mother to make 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 these challenges.

On balance, it would appear that the risks implicated here are less than the risk of premature death and poor health that babies face if they become HIV-infected. As such, a decision not to face the inconveniences to prevent serious harm to the child is unjust and constitutes wrongful harm. An important exception here, related to HIV testing, could be that of fear of violence from a partner. It is an exception because partner violence can result in unacceptably high risks to the mother, even including death. With such risk levels, potential harm to the child should not be seen as wrongful or unjust as it occurs in a context of excusable reasons. However, reports tend to show that such partner violence is usually not unpredictable; therefore, there would plausibly be cases where the possibility of fear of partner violence may not in itself be a factor in opting out of PMTCT programmes. One study, for example, showed that behaviour such as alcohol abuse, verbal abuse, having more than one current partner, and a previous history of violence by the male partner are predictive of partner violence;¹² therefore the converse should apply where such behaviour is absent.

5. Routine testing, as a coercive measure, represents a mechanism for safeguarding the baby's moral rights from this unfair harm. By continuing with the policy of voluntary testing, with its low uptake rates, South Africa continues to compromise the welfare rights of vulnerable children – rights which cry out for that society's protection.

These conclusions should not, in my view, have much bearing on the closely related subject of abortion, in which the main issue seems to be whether the fetus's moral status outweighs the woman's right to control of her body. The fact that the pregnant woman in consideration here voluntarily decides to take the pregnancy to term, when the option of abortion exists, I believe marks an important difference between the present subject and that of

abortion and its related issues of moral status in prenatal life. The decision to take the pregnancy to term shifts matters from 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 whom she intends to give birth to.

5.1 Routine testing could result in more harm than good. In the context of the harm principle, this is a serious concern because, if it is correct, it could invalidate the use of the harm principle to justify routine testing. As already mentioned, the coercive action taken must be superior to other alternatives if it is to be justified by the harm principle. More harm, it may be argued, could result in the following:

Fear and distrust of health facilities. Routine testing policy could result in women not seeking antenatal care and health care in general for fear of HIV testing. Furthermore, routine testing may in fact not even achieve the goal of reducing mother-to-child HIV transmission, as there is no causal link between testing and effective uptake of preventive interventions by pregnant women. While these are credible concerns, lessons from Botswana's opt-out system, which evoked the same concerns upon its inception in 2004, should not be ignored. A recent paper 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 uptake now of any PMTCT programme in Africa.¹³

Gender bias and its possible consequences. Another concern could be that routine testing in PMTCT will result in more women being tested for HIV than men, meaning that any disadvantages associated with HIV testing (like stigma) will disproportionately affect women. This extra liberty-limiting layer would be an unwelcome outcome when one considers the already compromised status of women's rights. The harm, then, that routine testing could do in this setting would discourage and further alienate women from their attempt to exercise their moral agency in their communities.¹⁴

Several replies can be made here. The issue that would in fact have been problematic is if women were 'singled out' *arbitrarily*. There is, however, a clear rationale as to why any PMTCT policy aiming to prevent harm to children would have to target pregnant women. As already mentioned, it is the mother's decision of enrolling in a PMTCT programme that can reduce the risk of HIV transmission *in pregnancy* to the baby. Needless to say, PMTCT is not the only plausible HIV prevention programme. Making a case for routine testing of women, in response to a specific issue of PMTCT, does not suggest that no such case could be made for other target groups in the community, if the merits for such a case existed.

As per the issue of stigma, the following also can be noted: (i) as already said, not testing voluntarily for HIV does not make one escape the inevitable eventuality of an AIDS diagnosis; (ii) it would be morally questionable if one should shift the burden of HIV-related stigma to unborn children who, if infected, are likely to face that stigma at a very young age, when they lack the psychological coping mechanisms which adults (supposedly) possess. Indeed, also from a utilitarian perspective, it is unclear how a strategy of dealing with HIV-related stigma should result in more people being born HIV-infected, and more people not testing and being treated for HIV infection; and (iii) where stigma to the HIV-infected exists, the solution is not to stop prevention strategies – as the World

Health Organization and others have rightly suggested, any prevention strategy needs to be accompanied by stigma-reduction mechanisms and policies.

Regarding the longstanding general issue of women's vulnerability and socially sanctioned power imbalances, it is important to acknowledge and highlight it as a legitimate and serious matter deserving due consideration. Addressing it, however, should not stop PMTCT. It would be unfortunate to suggest that this complex, enduring societal phenomenon must be solved first, before children's welfare interests can be taken seriously.

Conclusion

I have argued that, although an opt-in system for HIV testing in PMTCT is ideal from a civil liberties standpoint, it has proved incompetent in securing the welfare rights of South Africa's children. Routine testing, advocated in the paper, has been offered as an alternative which seems to take seriously the prevention of wrongful harm to the welfare rights of our coming generation.

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