Should the state fund assisted reproductive technologies for HIV-discordant couples in South Africa who want to have children?

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Assisted reproductive techniques (ARTs) can provide a way for HIV-serodiscordant couples to safely fall pregnant. However, their high cost raises concerns about distributive justice, especially now as we are laying the foundation for a national health insurance. Considering that the right to access reproductive healthcare services is specifically mentioned in the South African Constitution, a discussion surrounding ARTs and their funding is warranted. This article argues that the state does not have a moral duty to provide ARTs for serodiscordant couples in the current socioeconomic environment that SA finds itself.

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HIV-positive patients on antiretroviral (ARV) therapy have managed to reclaim much of their lives from the grip of the disease. However, HIV is largely a sexually transmitted infection, and interventions such as condom usage, which protect the uninfected from the infection, also preclude procreation via conventional means. Assisted reproduction techniques (ARTs) that were pioneered to assist couples with fertility issues now find another valuable use in serodiscordant couples (in which one partner is HIV-positive and the other HIV-negative) who desire to have children. In the situation where the male partner is HIV-positive, techniques such as sperm washing and intrauterine insemination may be used to protect the female partner from HIV infection. In the situation where the female partner is HIV-positive, the concern of vertical transmission to the infant needs to be considered. Some authorities suggest that the female partner needs to be virally suppressed for 6 months prior to conception to keep the risks of vertical transmission low.[1] In this case, *in vitro* fertilisation and intracytoplasmic sperm injection may be used to protect the uninfected male partner. Despite being revolutionary, and offering the possibility of what was once considered impossible, the cost of ARTs runs into tens of thousands of rands per cycle, meaning that for the majority of people it remains out of reach.[2]

In considering the use of ARTs in people affected by HIV, several ethical concerns have been raised. Some have questioned the risk of HIV transmission to the infant, and suggest that subjecting a child to that risk may be considered unethical.[3] Others have raised the issue of the potentially harmful side-effects that ARV therapy may have on the unborn child.

Further to these concerns, some have raised the issue of the expected lifespan of people infected with HIV, suggesting that a parent's potentially limited life expectancy could affect child rearing.[3]

This article, however, will not address these concerns, but solely examine the question of ART funding.

The health of a nation: Why South Africans are dying

South Africa (SA) has the world's largest population affected by HIV/AIDS.[4] Hundreds of thousands of people continue to die each year from a lack of access to ARVs, which can change an HIV/AIDS diagnosis from a fatal condition to a manageable disease. Less than half of those who are infected are on ARV therapy. According to the World Health Organization (WHO), HIV/AIDS is the leading cause of death in SA.[5] However, since HIV is treatable, the real leading cause of death of South Africans is a lack of treatment (which not only depends on ARVs, but also on doctors, nurses, pharmacists, clinics and hospitals). Poverty, then, is truly the leading cause of death in this country.

In the late 1990s, medical science made a leap forward in the treatment of HIV. An ARV combination was formulated that produced dramatic results in those dying of AIDS. These ARVs were heralded as 'life-saving'. However, their cost was far beyond the reach of most patients in Africa, a continent that shouldered the overwhelming burden of the disease. And despite the victory by campaigners in eventually obtaining generic ARVs at a reduced cost (it now costs USD125 per patient per year), the sheer number of patients affected in SA still multiplies that cost into billions of rands each year.[6]

One of the particularly tragic effects of HIV infection is the fact that it affects the young, previously healthy and vital members of the population. Untreated, it leaves large segments of the working population incapacitated – striking a country where it should be strongest, hitting hard at the most productive group of its population, leaving in its wake innumerable orphans, a crippled workforce and a skyrocketing fiscal deficit.

Over 20% of children under 5 years old are stunted by malnutrition, and up to a third of SA children have not received basic vaccinations.[5] More than two-thirds of children from impoverished households live below the 'dollar a day' mark, indicating extreme poverty.

Maternal mortality in SA is still much higher than the targets set by the Millennium Development Goals.[7] SA's maternal mortality rates are still more than twice that of Brazil, a country with a similar economic profile.[8]

It is against this background that pertinent questions around resource allocation beg to be asked – the rands and sense of ARTs in SA.

ARTs range from intrauterine insemination (IUI), which is the most basic technique, to *in vitro* fertilisation (IVF), intracytoplasmic sperm injections (ICSI) and semen decontamination in male patients who are HIV-positive. Huyser *et al*.[2] estimated that for a single treatment involving IUI, which is the least expensive of the treatments mentioned, the cost would amount to more than ZAR9 000. This treatment has a success rate of only 15% per month. Patients often require 2 - 3 cycles, translating to ZAR27 000 in the best-case scenario, to result in a single pregnancy. This amount is enough to provide ARVs to 16 patients for an entire year (based on a rate of USD1:ZAR 13.3). *In vitro* fertilisation has a higher success rate, but comes at a higher cost. A single cycle costs more than ZAR50 000.

Countries in the developed world provide no cover or only partial coverage of treatment by the state. In the USA, which has the world's largest economy, the state does not pay for ARTs.[9] Australia provides only a partial subsidy to its citizens for ARTs.[10] If these first-world countries cannot afford to pay for these therapies, how is it possible to expect SA to do so?

ARTs for couples who are HIV-negative

If ARTs can be used to help subfertile couples just as they can help HIV-serodiscordant couples, why then should HIV-negative couples be excluded from the consideration for state funding? This only adds to the unfeasibility of state funding of ARTs, since in order to be ethically correct, the state would have to consider funding the treatment of the entire collective of people who could potentially benefit from ARTs, and at these numbers it makes it even more of an economic impossibility.

An argument from justice

The state functions within economic constraints and struggles with resource limitations. If it were to fund expensive ARTs for a large section of the population, it would mean that a significant chunk of resources would have to be sacrificed from other healthcare initiatives. SA's healthcare system is struggling to keep up with rising healthcare costs. It is fair to say then that funding ARTs means diverting resources from somewhere else – be it childhood immunisation, ARVs or safe obstetric care. This bears examining from the perspective of the notion of distributive justice, which is defined as 'fair, equitable and appropriate distribution determined by justified norms that structure the terms of social co-operation'.[11]

The fundamental idea behind utilitarianism is the promotion of utility (good) for the greatest number of people. In providing a means for a serodiscordant couple to have a child, it can be argued that the good or happiness brought about is limited to the couple. Providing ARVs, on the other hand, saves the *life* of someone. It allows them to be productive members of society. It enables them to work and earn a living, raise a family, pay taxes and contribute to society. Recall that strikingly, the cost of the cheapest form of ART could treat 16 HIV-positive people for a year. It becomes clear that no utilitarian argument could favour state-funded ARTs on the balance of the number of people whose lives would be saved by funding ARVs instead. The amount of utility produced by ARV therapy far outweighs the utility brought about by a single pregnancy with ARTs.

Egalitarianism suggests that resources be equally distributed to all people. SA's limited budget suggests that if healthcare rands were distributed equally among all citizens, it would be a very thin spread indeed. The state would have to now fund the more than 8 million people who do not utilise public healthcare, in addition to the 42 million who do.[12] This would set the threshold for each person at a substantially low level. No-one would be able to afford ARTs, and certainly those with HIV would not be able to afford both ARVs as well as ARTs. An egalitarian approach therefore means that state-funded ARTs are impossible in our country.

Communitarianism suggests that communities decide how resources would be distributed. A key feature of communitarianism is the idea that the welfare of the community is prioritised over the welfare of the individual. This theory of distributive justice bears a striking resemblance to the African notion of *ubuntu* (the SA concept of ubuntu is shared with many other sub-Saharan cultures, although referred to by other names, e. g. *umundu* in Kenya and *vumuntu* in Mozambique,) which recognises that we do not exist in isolation and that by ensuring the welfare of the collective, we ensure our own welfare as well.[13] How would state-funded ARTs fare when viewed through the framework of communitarianism and *ubuntu*? At first glance it may appear that, if limited resources can be used to bring safe drinking water, sanitation and basic essential drugs to community, the utilisation of a large portion of that resource for a single couple would not be in the best interests of the community and would not be sanctioned by *ubuntu*. However, it must be appreciated that procreation and child-bearing are highly valued in African culture.[14] The inability to bear children may have significant negative psychological and social effects on African women. These may include loss of social status, social isolation and marital instability.[14] Women bear a disproportionate procreative responsibility in African society, and are often held solely responsible if a marriage does not produce children.[15] As such, the concept of fertility in African culture (particularly from the point of view of women) is highly complex. While *ubuntu* as a cultural entity may be understood in its wider context, there is still much work that needs to be done before it can be accepted as a fully fledged moral theory.

Taking this into consideration, it may be difficult to determine how *ubuntu* might prioritise ARTs, particularly in the situation where a choice exists between life-saving ARVs for many and ARTs for the few.

This particular constellation of factors (the complexity of fertility from an African cultural viewpoint, the incompleteness of *ubuntu* as an accepted moral theory and the economic realities of healthcare funding and prioritisation) is sufficiently complicated that a separate detailed philosophical examination of them is warranted.

Virtue ethics suggests that justice is a virtue that society should possess. However, the application of virtue ethics to individual situations often does not provide us with an answer as to what to do. This is not surprising, since the focus of virtue ethics is on *who to be* rather than on what to do. In choosing between ARVs or ARTs, a virtue ethics argument may be used on both sides to justify either choice.

Priority-setting and a Rawlsian approach

Countries across the globe, whether developing or industrialised, all face the problem of funding healthcare within a limited budget. All countries have to grapple with the problem of determining which healthcare services the state can afford to fund, i.e. which they have to set as priorities.[16]

Some countries, such as Norway, have set out to formulate a set of principles to guide the setting of priorities – e.g., does the treatment prevent catastrophic consequences? Other places, such as New Zealand, and Oregon in the USA, list specific services in order of importance. Despite the differences in the way in which countries prioritise services, one thing seems to be almost universally accepted: preventative care (which includes basic immunisations and screening for diseases) and primary healthcare (e.g. diarrhoeal diseases in children, and family planning) should always form the core of a decent minimum level of care.

Rawls described a hypothetical situation where decision-makers stand at what he called the original position behind the veil of ignorance, i.e. having no knowledge of the place that they would eventually take up in society, only knowing that they have the capacity to determine beforehand the distribution of society's goods and services. What this amounts to is a situation where decision-makers ensure that the least well off in society have at least their basic needs taken care of, since any one of those decision-makers could end up taking the position of the least well off.

Taking Rawls' theory of justice into consideration, the suggestion can be made that the fairest way to distribute services would be to decide on a minimum level of state-funded healthcare that would be available to all. Would we then be comfortable to play the lottery of life and be born into a society that funds ARTs, but not maternal care or lifesaving ARVs? Or would one roll the dice more easily knowing that basic healthcare, preventative medicines and lifesaving drugs are provided by the state even if sophisticated medical services are not?

SA has not even secured the position of having met its decent minimum healthcare requirements for all its citizens; therefore, a Rawlsian approach would not favour state-funded ARTs, since the funds allocated to ARTs may be used more effectively to provide basic care for a greater number of patients.

'Ought implies can' – the Kantian perspective on state duty

Kant considered the idea that what we 'ought' to do (in order to be morally and ethically right) should fall within the reach of our capabilities – i.e. 'ought implies can.'

Current conditions in SA limit the degree to which the state can fund healthcare. Basic healthcare needs are not being universally met owing to, among other things, economic limitations. It would be unwise to take resources aimed at addressing this problem and redirect them to sophisticated ARTs that do not address the needs of the majority, are not life-saving and are prohibitively expensive. Therefore funding of ARTs by the state falls outside of its current capabilities, and from a Kantian perspective there is no moral duty on the part of the state to fund them.

Wants v. needs

Wiggins[17] suggests three conditions for considering something a 'need'. Firstly, not having the item of need would harm one's functioning as a human being; secondly, there are no available alternatives; and finally, the item of need is integral to the person's life having at least minimal value.[17]

Safe drinking water, food and ARV drugs can clearly be considered 'needs'. For those with HIV, a lack of ARVs may very well be equated to a lack of food or water. Ultimately, without ARVs, these patients will die.

In examining the desire to have one's own biologically related child, we see that it falls short of Wiggins' criteria for deeming it a 'need'. People can live and be productive members of society without having children; indeed, many do so intentionally. But it is Wiggins' second criterion, that of there being no alternative, that is particularly relevant to SA.

There are more than three-and-a-half million orphans in SA.[18] More than half of this number have been orphaned as a result of losing their parents to AIDS. With this number of children desperately in need of a home, some difficult questions need to be asked in regard to adoption being an alternative to ARTs. Would the state be acting responsibly and ethically in funding ARTs for HIV serodiscordant couples when there are so many children already in need of a home?

Loewy, in an online comment quoted on http://bioethicsdiscussion.blogspot.com, makes a convincing argument in terms of distinguishing exactly what our 'wants' and 'needs' actually are. He suggests that 'having your own child may be a want, but it surely is not a need.'[19] He makes the case that medical care (first-tiered, essential services) is not a want but a need, and a decent society should provide that. Loewy admonishes that:

> 'Being unable to have my own child is no more a "need" than is my having perfect pitch is. It seems perverse to me that a society and world which already have more than it can take care of … goes out and with great effort and the use of many resources tries to make more of what we already have but neglect severely. [sic]'[19]

In Maslow's hierarchy of needs, the need for family and friends (or love and belonging) occupies the third level of needs. What this suggests is that the need to have a child (or what essentially amounts to the *desire* to have a child) cannot be viewed as having equal importance to satisfying our physiological needs (which are addressed by basic medical care).

The inability to have children may affect people's lives in deep and significant ways. Their unfulfilled desire to have children may lead them to feel that their lives are incomplete and of a lower quality than they would experience if they were to have children. But does having a child necessarily improve the quality of life of infertile couples or couples who may need ARTs for medical reasons (such as HIV)? A few studies provide some surprising answers. In a study undertaken in the USA, Abbey *et al*.[20] found that infertile women who later became parents experienced greater global wellbeing, but decreased marital wellbeing. Infertile men experienced fewer of the positive improvements than their wives after having a child, and still experienced diminished marital wellbeing. Another study using data from Germany[21] found that after 2 years of having had a child, a previously childless couple's level of happiness reverted back to their pre-childbirth levels, suggesting that having a child may not be an enduring solution to the dissatisfaction felt from being childless. Studies investigating the effects of adoption on marriage have produced conflicting results; however, in her review

of the topic from a Canadian point of view, Ward[22] suggests that biological parenthood and parenthood via adoption share many similar challenges and effects on the marriage.

Is it then appropriate for those couples affected by HIV (but benefitting from ARVs) to now ask the state to fund even more interventions that are not life-saving, at the expense of ARVs that could save others? It is unreasonable to expect the state to meet *all* our needs and desires.

A response to the rights-based argument for government funding

The Bill of Rights[23] guarantees all citizens certain rights and freedoms, including the right to have access to 'healthcare services including reproductive healthcare'.

Some would argue that these are sufficient grounds to expect the state to fund ARTs. However, this is only a *prima facie* obligation.

The International Covenant on Economic, Social and Cultural Rights (ICESCR) has taken cognisance of the fact that not all socioeconomic rights can be realised immediately.[24] It echoes the understanding of 'progressive realisation' of rights that is found in the SA Bill of Rights.

The Bill of Rights makes clear which rights are non-derogable. These include the rights to life, dignity, equality, freedom and security, freedom from slavery and rights pertaining to the protection of children. All of these rights are negative rights, i.e. they do not place the burden on the state for the provision of something; rather, they require that something *not* be done. Access to healthcare services, however, requires the provision of something material or of some service. It is therefore a positive right. Additionally, it is derogable, implying that there may be circumstances under which that right may be limited. Indeed, section 36 deals entirely with the limitations of rights.

One can appreciate that not all rights exist on the same level. Some rights are clearly more fundamental, more basic and less negotiable than others.

According to Vasak,[25] the right to healthcare is a second-generation human right, while the right to life is a first-generation right. From this viewpoint, second-generation rights (largely social and economic rights) may be limited by the availability of resources.

The ruling of the Constitutional Court in the 1997 case of *Subramoney v Minister of Health*[26] made clear that it is the duty of the state to 'take reasonable legislative and other measures, within its available resources, to achieve the progressive realisation of each of these rights'.

Therefore it is clear that healthcare (including reproductive healthcare and advanced reproductive techniques), and the degree to which it can be provided by the state, is limited by the economic realities of our time. As such, a rights-based argument for state funding of expensive ARTs would fail to be convincing.

Conclusion

The landscape of SA today is one of a healthcare system in crisis, while its population is dealing with the world's largest share of HIV infection. While there is no denying the negative effects of childlessness on certain couples, those effects can hardly be compared with the life-threatening effects of HIV without ARVs, or with suffering through childhood malnutrition, or any of the other severe diseases that can be treated by basic medical care but still require funding. Providing ARTs at the expense of the state cannot be a part of the national strategy to improve the health of our nation. None of the many theories of distributive justice could realistically envision this as a viable solution in our country, when even wealthy nations cannot justify the expense of ARTs from government funds. Even a rights-based argument could not demand that the state fund ARTs, since the Constitution acknowledges the limitations of our resources. SA currently has several pressing health concerns and priorities, and all the information at hand suggests that ARTs are not one of them.

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