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# **Informed Consent for Voluntary Counselling and Testing for HIV infection in South African Mothers and Children**

An assessment of burdens and consequences and an argument  
for a modification in the process of informed consent

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Submitted in partial fulfilment of requirements  
for the degree of Master in Philosophy (Bioethics)

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## **Abstract**

The HIV/AIDS epidemic is devastating Africa. The continent lacks the material resources to treat infected persons or to support those affected by the epidemic. One great resource in Africa is the cohesive strength of families. Because of a fear of stigma, HIV infected persons tend not to disclose their diagnosis to their families. This non-disclosure perpetuates stigma, because ordinary people do not discover that their own family may be affected by the epidemic. Non-disclosure also results in the loss of specific family support to infected individuals and the loss of general family support as a national resource. The standard method of taking informed consent prior to HIV testing of pregnant mothers has the effect of enhancing non-disclosure, because of its inherent focus on the patient as an isolated, autonomous decision maker. This dissertation advances the thesis that an alteration in the process of informed consent, to involve the family in deliberation prior to consent, will facilitate disclosure of an HIV-positive diagnosis to the family. Disclosure will have the positive effects firstly of giving the mother access to the emotional support of her family and secondly of serving to educate the family, and through the family society as a whole, that ordinary, virtuous women can be infected with HIV.

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## **I. INTRODUCTION**

The Acquired Immunodeficiency Syndrome (AIDS) epidemic due to the spread of human immunodeficiency virus (HIV) infection in Sub-Saharan Africa is an unprecedented health emergency that demands more from health care workers than any previous epidemic. The dimensions of this threat are such that every man, woman and child in this region will in some manner be affected by HIV/AIDS.<sup>1</sup>

As with any epidemic of contagious disease, it is of vital importance that the exact dimensions of the threat are known. Knowledge of HIV status is restricted in Africa because of a lack of access to voluntary counselling and testing (VCT) and poor uptake of VCT. Knowledge of the HIV status is also restricted by the fear of stigma and a tendency among those infected not to disclose their HIV status.

Epidemics of contagious disease tend to submerge human rights. The HIV epidemic raises the fundamental dilemma of how to resolve the tension between privacy rights of the individual and the duty of government and health service to prevent the spread of HIV infection. The challenges to health care workers are to control any departure from the principle of respect for basic human rights and to impose the least intrusive and most thoughtful and humane measures to achieve justifiable epidemiological objectives.

Fundamental human rights exist because of the humanity of each person, not only because they are written down in law and constitutions. Safeguarding the rights of people with HIV/AIDS is essential on ethical and moral grounds. Promoting the rights of everyone – without exception – is the most powerful way of promoting the rights of the individual person

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<sup>1</sup> World Bank, *“Intensifying action against HIV/AIDS in Africa: Responding to a developmental crisis”* Washington DC: World Bank, Africa Region, 1999

### ***The tension between disclosure and confidentiality***

The practice of protecting confidentiality, which is part of the process of informed consent, has the potential to limit the spread of knowledge regarding the epidemic and may act to isolate the affected mother and child from support. In developing countries, with their manifest lack of counsellors and lack of a public service-based support system, the process of confidential informed consent could leave the affected person without any emotional support; and the community without a source of information about the epidemic.

Spread of the epidemic can only be controlled by the avoidance of high-risk sexual behaviour. For people to restrict themselves to safe behaviour, they have to understand that infection with HIV is a real and present danger. While general education should have some effect, knowledge of the positive HIV status of friends and family members is essential to help people understand the actuality of risk. Therefore, disclosure of status by HIV positive individuals to their families is a critical issue in the control of the HIV epidemic.

Clearly, disclosure exposes the HIV positive individual to the risks of stigmatisation and ostracism from the family. Intuitively, it would seem that expecting an HIV positive person to disclose her<sup>2</sup> diagnosis puts her at risk of these harms and infringes upon her rights for the exclusive benefit of society.

In this dissertation, I argue that at least in the case of the African woman, our intuitions regarding privacy and disclosure are wrong.

#### ***An outline of argument:***

- While it is true that for the present, the majority of women do not disclose their HIV diagnosis to their families, there is limited empirical evidence to show, in the case of African women living in Cape Town, that

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<sup>2</sup> Since this dissertation deals mainly with the plight of the HIV positive woman and her children, personal pronouns when applied in general, will be in the feminine gender.

disclosure of diagnosis to partners and to family does not, in the great majority of cases, lead to rejection or ostracism.

- While non-disclosure may protect the woman from the stigmatisation associated with HIV/AIDS, her decision not to disclose imposes upon her all the 'work' of self-stigmatisation. She has to interact with her family, and often with authority figures that support her, as though she (and her child) do not have HIV/AIDS. Her decision not to disclose may also impinge on the acts and functions of those health care workers who share her knowledge and are pledged to respect her individual privacy and protect her confidentiality.

- The woman who chooses not to disclose her HIV diagnosis to her family, and particularly to those from whom she would traditionally derive the closest emotional support, suffers the loss of such support. This is perhaps most pertinent for the unmarried African woman, who would look to her mother and to an extended family for support with an ill child. She suffers more than she would from the disease alone, because she loses access to an emotional resource that has the potential of enabling her to realise the best care for herself and her sick child.

- The woman who chooses not to disclose deprives her family network of the opportunity to plan for her eventual sickness and death or to make provision for the care of orphans.

- The woman who determines not to disclose, chooses the very action that is most likely to perpetuate the stigmatisation she most fears. Until disclosure by virtuous women demonstrates to ordinary people that HIV infection can happen to anyone, the popular conception that HIV/AIDS is the consequence of promiscuity will not be dispelled. While it is true that in this sense a woman's disclosure risks personal stigma for the sake of a societal good, the woman herself is also a potential beneficiary, since she is a member of the stigmatised group. Within the family her well-established virtue may outweigh the risk of stigma.

While the process of informed consent for HIV testing is appropriate in Africa in terms of respect for individuals as moral persons, this dissertation argues that the

‘standard’ consent process is flawed because it fails to account for the African role of family and authority figures in decision making:

- The process of pre-test counselling is flawed, because the woman is not warned of the emotional and material consequences of knowing her positive HIV status when her family and its authority figures do not know.
- The process of pre-test counselling is flawed because the mother is not invited to involve her family in a deliberation over the decision to be tested (or for her child to be tested) and hence the mother is led to an act in conflict with her family tradition. This has the potential consequence of isolating her within her family.
- If the traditional decision makers in the family are exposed to the possibility of a positive HIV test in the course of pre-test counselling, the HIV positive woman is saved from the very difficult task of breaking the bad news of her diagnosis (and sometimes the diagnosis of her child). She is also protected from the alternative, should she choose not to disclose, of emotional isolation.
- For the family, hearing of a potential problem before it has been confirmed by a test result has the effect of cushioning the shock of subsequent bad news and may lessen the chance of their adverse response to the woman.
- It is postulated that exposing decision makers in the family to the possibility of a positive result prior to the test, given the solidarity and extensiveness of the African family, means that it is ‘the family’ that is counselled and tested, rather than an individual family member. Disclosure within the family becomes a given and disclosure beyond the family becomes a family question.
- If the ‘standard’ process of informed consent for HIV testing has the default result of enhancing the probability of non-disclosure, then it has deleterious effects for the woman, for her child, for the family, her health care workers, sex partners and for society at large

This dissertation therefore argues that the ‘standard’ process of informed consent should be strengthened for use in Africa (and possibly in other societies where family

structures are extensive and function around authority figures) by a standard invitation and encouragement of the mother to request family involvement at the point of pre-test counselling:

- The woman will be informed of the potential advantages of consulting with her family before agreeing to an HIV test and offered assistance in explaining its possible outcomes to family members. She will be told that even if her family disagrees with her being tested, she will be entitled to return and have the test done if that is her choice.
- The woman will be informed of the potential emotional and social consequences of a positive test and the possible outcome and consequences of non-disclosure to others, including her family. She will therefore, as an autonomous person, be able to weigh up the harms and benefits of consulting her family. Should she decide that involving her family would cause more harm, than benefit, she could make the autonomous decision to decline the option to deliberate with her family.
- Should the family decide after deliberation that the woman (or child) should not be tested, and this familial decision is accepted by the woman, this might appear to be a limitation of her autonomy, but it would also be a practical illustration of the crucial nature of her interrelationship with her family.
- Should the family decide against the test, the woman would be free to return for a test should she so wish, without choosing to deliberate further with her family. Were she to do so, she would be exercising an autonomous choice, presumably with the knowledge that in her particular case, the harm of family involvement would outweigh any benefit.
- Were the woman to agree to deliberate with her family but not return for testing, it might be that she has made an autonomous determination not to be tested. This would be in keeping with the principles underlying informed consent.
- This modification of the standard process of informed consent would require offering family pre-test counselling to family members as well as the mother. This would be appropriate in view of the effect of HIV/AIDS on

African families and because of a general need for education and de-stigmatisation. The cost and labour of such counselling would be recouped from access to family support as a resource, the beneficial consequences of disclosure and the increase in societal knowledge and understanding of HIV/AIDS.

- These modifications to the standard process of informed consent might be criticised by Western practitioners, since it has the potential to infringe on privacy and clearly threatens the concept of individual autonomy over the decision to be tested. It may however be that the value of family deliberation would be recognised in parts of Western society and in other societies where extended families with authority figures are the norm.

### ***A statement of the thesis of this dissertation***

The thesis of this dissertation is:

***‘That the process of informed consent, although appropriate in Africa as an exercise in the recognition of autonomy, when applied in the case of African women may have the unexpected and deleterious effect of isolating her from a traditional support base and enhance the likelihood of non-disclosure of HIV status, and should therefore be adapted to meet the needs of this special situation’***

### ***An outline of this dissertation***

I first present (in Chapter II) the theoretical background for a debate around my proposal for a modification of the consent process for HIV testing in Africa. A very brief analysis is presented of the philosophical and moral base for the practice of what I will refer to as ‘standard’ informed consent.

Chapter III reviews the arguments for and against the applicability of the process of ‘standard’ informed consent in Africa, with particular emphasis on the ‘cultural relativist’ argument against the practice of informed consent and the African philosopher Godfrey Tangwa’s presentation of African ethical and moral thought.

Chapter IV describes an empirical study of the patterns of disclosure of the diagnosis of HIV infection amongst a group of women attending an HIV/AIDS follow-up clinic for children in Cape Town. The social and material support systems of these women are also described. 'Paradoxical relationships' where women enjoy material support from persons to whom the diagnosis has not been disclosed are highlighted. Rates of disclosure to family and traditional sources of support are presented as evidence for a general trend to non-disclosure.

These findings are extended in Chapter V with reference to the literature dealing with the uptake of voluntary testing and counselling (VCT) in Africa. I show how poor access to health care affects the uptake of VCT, that non-disclosure is prevalent and present *prima facie* evidence of failure in the 'standard' consent process and a block in flow of information to the society at risk.

In Chapter VI, I review the benefits and burdens of HIV testing *as they might be experienced by an African woman*, in an attempt to explain the poor uptake of VCT in many parts of Africa, and why women tend not to disclose their positive HIV status. I discuss stigmatisation as a cause of non-disclosure (and *vice versa*). I show how, although the practice of informed consent is appropriate in Africa in respect of its recognition of individual autonomy, if exercised in a culturally insensitive manner, it may lead to the consequences of social isolation and loss of traditional support for HIV-infected mothers and children.

In chapter VII the subject of pre-and post-test counselling is discussed. The provision and nature of counselling in the West is compared with what is available in Africa. Because material constraints will impair the provision of state-funded long-term support and counselling, it is argued that the strength of the African family should be exploited to supplement the shortfall. I present a proposal for a modification in the consent process and discuss details of its implementation and a possible range of consequences.

In conclusion, in Chapter VIII, I draw together the observations and arguments made in the prior sections. I summarise the observations and arguments that favour my thesis, explore their deficiencies and also summarise possible objections to my thesis. I conclude with recommendations regarding future research.

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## **II. INFORMED CONSENT: ORIGIN, PURPOSE AND SOME CONSEQUENCES**

This chapter presents some basic background facts about informed consent. Respect for privacy is discussed as an aspect of informed consent and in relation to the thesis of this dissertation; it is pointed out how an excessive focus on recognising the patient's right to privacy might adversely affect the outcome of the process of informed consent in Africa.

### ***Introduction***

The power to make medical decisions was at one time the domain of physicians. The Hippocratic Oath makes no mention of patient's rights and in fact requires her to be shielded from the facts. Complex social changes in the West have resulted in general acceptance of the idea that patients have a right to know about their health, to be informed about diagnostic and treatment options open to them, and to choose among alternatives<sup>3</sup>. Most would now regard traditional practice based on the physician's beneficence to be unacceptably paternalistic and authoritarian<sup>4</sup>. Personal values affect health care decisions and physicians have a duty to respect the autonomy, rights and preferences of patients and their surrogates.<sup>5</sup>

### ***Informed consent and respect for autonomy***

Respect for individual autonomy (self-rule) is a generally accepted moral principle in Western culture. Informed consent in medical practice is seen as a cultural institution in service of this principle. More specifically, to respect an autonomous agent is to respect that person's capacity to make choices and take action which accords with his or her personal beliefs and values. This respect for autonomy is based on the assumption that persons (usually) want to make autonomous decisions for themselves.

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<sup>3</sup> Faden R, Beauchamp TL, King NM. *A History and Theory of Informed Consent*. Oxford University Press, New York, 1986.

<sup>4</sup> Childress JF. *Who Should Decide? Paternalism in Health Care* Oxford University Press, New York 1982.

<sup>5</sup> Beauchamp TL and Childress JF. *Principles of Biomedical Ethics*. 4<sup>th</sup> Edition. New York, 1992.

There are however, communities where communal decisions and hierarchical patterns of decision-making take precedence over personal choice, and it is possible that autonomous choice, exercised in such a community in the course of 'informed consent', in a manner contrary to the 'shared morality' in that community, may be less than an unproblematic, obvious good<sup>6</sup>.

### ***The practical application of informed consent.***

Three elemental conditions are posited for autonomous action:<sup>7</sup> These are intentionality, understanding and an absence of controlling influences. The act of consent is only *informed* consent by a person if she: receives a thorough disclosure regarding the choice she is making; comprehends the disclosure; acts voluntarily in consenting, is competent to perform the action of consenting and then performs the act of consenting.

In the full sense, a 'gold standard' informed consent is 'an autonomous action by a person that authorises a professional health care worker to initiate a medical plan.'<sup>8</sup> The severe constraints on gaining fully informed, voluntary consent, particularly in the context of the African epidemic of HIV/AIDS, will be discussed and developed in the following chapter.

Based on the Western version of the 'gold standard' for consent, the following elements should be included in eliciting a woman's consent for an HIV test on herself or her surrogate consent for an HIV test on her child:

1. **Information:** The mother should have an explanation in understandable language of the nature of the presumed illness; the nature of the diagnostic procedure; the availability of treatment or the lack of it and any probability of success with treatment; the meaning - to the mother - of a positive test; the

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<sup>6</sup> Turner L. An anthropological exploration of contemporary bioethics: the varieties of common sense. *J Med Ethics* 1998;**24**:127-133

<sup>7</sup> Faden RL, Beauchamp TL, King NMP. *A History and Theory of Informed Consent*. New York Oxford University Press. 1986

<sup>8</sup> Faden RL, Beauchamp TL, King NMP. *A History and Theory of Informed Consent*. New York Oxford University Press. 1986

non-existence and unproven nature of 'alternative' treatment; the advisability, advantages and disadvantages of disclosure of the diagnosis to the child's father (and the mother's current sexual partner if this is a different person) and to the mother's family; the nature of HIV-related stigma; and any other information specific to the local situation, the mother's economic status and relevant cultural usage

2. Assessment of the mother or child's **understanding** of the above information.
3. Assessment (if only tacit) of the mental capacity ('**competence**') of mother and /or child to make the decision to be tested.
4. Assurance that the mother has the right to refuse the test. (This is the condition of that consent should be **voluntary**, that the mother has 'the right not to know')

There is an important distinction to be drawn between the autonomy of the person and the capacity of a person for autonomous action in a given situation.

### ***Failure of consent***

Consent may fail as a process if the person deciding on consent makes a non-autonomous choice as a consequence of ignorance, coercion or non-disclosure of pertinent information.

Consent may fail as a process if the person (in the case of this thesis, an African mother) is not recognised as an autonomous agent with due appreciation of her capacities and perspectives, the right to hold certain views and to act on personal beliefs and views. This sort of respect for autonomy is connected with the deontological idea that human beings are intrinsically valuable as human beings and that they should be treated as ends in themselves.<sup>9</sup> Consent may fail because a mother is presented with the option of an HIV test, without understanding that she has the right to refuse. She may so misunderstand because of the imbalance of power she perceives between herself and the health care worker and agree because she wishes to please.

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<sup>9</sup> Faden RL, Beauchamp TL, King NMP. *A History and Theory of Informed Consent*. New York Oxford University Press. 1986.

Consent may fail as a process (or at least fall far short of the ‘gold standard’) when a new and unfamiliar set of circumstances, threats, and facts create surroundings and choices unprecedented in a person’s experience. In such a novel situation the mother exercising choice may have so little experiential basis for reflection that her action (making a decision or choice) becomes non-autonomous. In such a state she is entirely open to coercion and suggestion and does not have the capacity to render an authentically autonomous choice.<sup>10 11</sup> These remarks address what others have called the condition of authenticity, which requires that actions faithfully reflect values, attitudes, motivations and life plans that the person reflects on when considering a choice of action. Some authorities do not consider authenticity a necessary condition for autonomous action.<sup>12</sup> Nevertheless, the surroundings and facts facing an African mother who is confronted with the possible diagnosis of HIV/AIDS might well be such that she is unable to consider consent for an HIV test in an authentic way.

### ***Informed consent as a process***

Informed consent should be a process. The pre-test HIV counselling session is an introduction to the topic and the start of a conversation or dialogue. The goal of the process is to develop the mother’s comprehensive understanding of the clinical situation so that she understands the complex consequences of a positive diagnosis. Unfortunately, the setting in which health care is delivered in Africa will rarely promote dialogue. Pressure of work will rarely provide time and the scarcity of the health care resource and distances to travel make it unlikely that the process of consent will extend over time. These problems are discussed in more detail in the section describing the uptake of voluntary testing and counselling for HIV in Africa.

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<sup>10</sup> Frankfurt H. Freedom of the will and the concept of a person. In Watson G (Ed) *Free Will*. Oxford. Oxford University Press 1982.

<sup>11</sup> Dworkin G Autonomy and behaviour control. *Hastings Center Report* 1976;23-28.

<sup>12</sup> Faden RL Beauchamp TL King. *A History and Theory of Informed Consent*. New York. Oxford University Press. 1986.

### *Informed consent and privacy*

The link between respect for autonomy and a respect of privacy is through the idea that all persons have equal intrinsic value. This idea underpins both the right to privacy and the rights to autonomy and freedom of choice. Neither the right to privacy nor the right to freedom of choice are absolute, since clearly the interests of two or more persons may overlap and clash and the interests of individuals may clash with the interests of society. Hence the state may override a patient's medical decisions, even within the zone of privacy. In the case of HIV/AIDS, whether in Africa or the West, one must assume that the patient's rights to privacy are invariably under threat in the course of health care delivery. The less formal and the more community based and less 'professional' health care delivery becomes, the more likely privacy is likely to be breached.

The conflict between individual privacy and the public 'need to know' is presented as a central issue in the HIV/AIDS epidemic, but this is misleading, since it is not the identification of HIV positive individuals, but the avoidance of 'high-risk' behaviour by uninfected persons that will limit the epidemic. The public need to know has more to do with the creation of a public understanding of the immediacy of the infectious threat.

According to the 'standard' process of informed consent, the woman's (or mother's) privacy rights would be respected, regardless of the tension between these rights and the need of the public or her immediate family to know. According to the thesis of this dissertation, and as will be discussed in other chapters, as important as a woman's privacy right is, exclusive focus on this dimension of the informed consent process may be potentially harmful, not only to the interests of society, but to the HIV-positive woman's interests as well.

### III. INFORMED CONSENT FOR HIV TESTING IN AFRICA

This chapter presents further background against which to debate the suggested modification to the 'standard' process of informed consent. It reviews a discussion, conducted largely in the medical literature, on whether informed consent is appropriate for application in Africa.

#### *Moral relativism and informed consent in Africa*

Within a culture we view our morality as an implicit agreement about what 'ought' to be done.<sup>13</sup> According to the idea of moral relativism, the imposition of a moral view upon people or communities with alternative views and values constitutes cultural imperialism.

In the case of informed consent, the conviction that patients want to make informed choices about the medical care they receive is based on the (Western) assumption that people generally want to make autonomous decisions for themselves. Yet in a community where hierarchical patterns of decision-making take precedence over personal choice there may be little room for the notion that people ought to provide autonomous consent to treatment. On this view<sup>14</sup> it is argued that the notion of 'informed consent' can only have meaning within a community sharing Western values and moral views on autonomous decision making. While physicians doubtless share a widely held core of medical morality,<sup>15</sup> the argument goes, there should at least be some healthy scepticism regarding the validity of applying a complex Western moral construct such as informed consent across cultural boundaries.

According to some<sup>16,17</sup> the African person is said to perceive herself as an extension of his kindred and an intermediary between ancestors and future generations. Since

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<sup>13</sup> Harman G. In Krautz M and Meiland JW (Eds). *Relativism cognitive and moral*. London. University of Notre Dame Press. 1982.

<sup>14</sup> Veatch RM. Abandoning informed consent. *Hastings Center Report* 1995;25:5-12.

<sup>15</sup> Brody H and Miller FG. The internal morality of medicine: Explication and application to managed care. *J Medicine and Philosophy* 1998;23:384-410.

<sup>16</sup> Christakis NA Fox RC. Informed consent in Africa. *N Engl J Med* 1992;327:1101-1102

<sup>17</sup> Campbell ID Rader AD. Community-informed consent for HIV testing and a continuum of confidentiality. *Tropical Doctor*.1999;29:194-195

the African does not consider herself to be an independent person in her own right, authority for consent is located in the family, or in the head of the village, tribe or kindred. It is therefore argued that an insistence on first person consent is a form of medical-ethical imperialism.

In my own view, it is doubtful whether Western and African cultures are so much in parallel that (in the sense used by Thomas Kuhn) they represent independent and incommensurable paradigms: There are after all some moral values that hold for all human beings. The principle of equality (and hence respect for autonomy) would appear to be one of these universal values. Writing from his perspective as a member of the Nso' tribe in Senegal, Godfrey Tangwa<sup>18</sup> throws light on the African perception of personhood. In the Nso' conception, only (and all) human beings are deemed to be moral agents, with moral obligations and responsibilities. Human beings are moral agents because they are human; and are due moral consideration and desert purely because they are human. In this sense then, and in accordance with the universally accepted value of equality, individual humans are moral 'persons' in every way.

The fact that people living in a particular culture might attend and defer to the views of family and community leaders does not necessarily negate their right to first person ('one-on-one') informed consent, or make them less informed participants in the process.<sup>19,20</sup>

While there is an intercultural distinction between collectivist and individualistic notions of personhood, it is probable that persons from any culture will balance self-interest with other interests, so that collectivist values do not necessarily trump those of individuality. Within any collectivist culture, there will be persons who define themselves in an eclectic fashion and there may be times and situations in which they will choose to place their personal individualistic interests first. It would therefore be

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<sup>18</sup> Tangwa G. The traditional African perception of a person: Some implications for bioethics. *Hastings Center Report* 2000;**30**:39-44)

<sup>19</sup> Gostin L. Ethical principles for the conduct of human subject research: population-based research and ethics. *Law Med Care* 1991;**19**:191-201.

<sup>20</sup> (Isselmuiden CB and Faden R M. Research and informed consent in Southern Africa. *N Engl J Med* 1992;**326**:730.

wrong to assume that persons from collective societies lack a sense of autonomy and should therefore somehow not 'qualify' for first person consent.<sup>21</sup>

It is possible that the African idea of personhood is changing<sup>22</sup> in the light of increasing urbanisation of a previously rural population. It is also probable, given that the continent does not have a single homogeneous culture that ideas about individual identity may differ in different parts of Africa. In any case, were one to seek community consent, or consent from some community leader rather than from the person herself, there is a practical problem of identifying leaders of households, clans and villages; and no guarantee that the best interest of individuals or the community will be served by such leadership consent. Because this sort of consent is not between the two parties directly involved, it is open to manipulation by researchers, village leaders, heads of households and government officials.

On the other hand, while the African concept of universal human moral agency seems to indicate that individuals may be approached as autonomous persons, there are pertinent differences in world-view between Africans and Westerners. Tangwa<sup>23</sup> sees the many different African cultures to be very similar to one-another in their metaphysics, attitudes and customs. While both Western and African concepts of the person understand her to be a fully self-conscious, free, rational and self-determining being, the African concept differs from that of the West, in that it does not divide humanity into moral categories. Nor does it rigidly distinguish between persons, superhuman spirits, non-human animals, plants, inanimate objects and forces. Within this world-view, transmigration, reincarnation and transformation within and across species are believed to be possible. African philosophy is manifest in African peoples who, as a group, share elements of a common culture, world-view, certain ideas, convictions, attitudes and practices. While all of these can be attributed to the group, this does not imply that there may not be exceptions at the individual level: In other

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<sup>21</sup> Lindegger G, Slack C Vardas E. HIV vaccine trials in South Africa – some ethical considerations. *S Afr Med J* 2000;**90**:769-771.

<sup>22</sup> Isselmuiden CB and Faden RR *ibid*.

<sup>23</sup> Tangwa G. The traditional African perception of a person: Some implications for bioethics. *Hastings Center Report* 2000;**30**:39-44.

words, it is possible for the individual to share the group view but to reserve eclecticism and autonomy in certain respects.

It is therefore possible to think of multiform cultures sharing in certain values and beliefs, but also possible that an urbanised African might choose to live by adopted value systems. There is a paucity of social and cultural analysis to illuminate this issue. The questions it prompts in respect of informed consent require further research.

A view congruent with the thesis of this dissertation is that it is appropriate to implement informed consent as a process in Africa, because in the sense that each person is a moral agent, she should be respected as an individual. But inasmuch as (and if) she thinks of herself and her family or clan as a collective unity, each person should also be treated as though she were a part of that unit. Hence, as I will elaborate in a following chapter, when consent is sought for performing an HIV test, the woman should be offered an opportunity and encouraged to deliberate the decision to be counselled and tested with her family - rather than to consent in isolation.

### ***Alternatives to first person consent in Africa***

#### *Community consent*

A form of inferred community consent has been utilised by expatriate European health care workers living and working in African communities.<sup>24</sup> These workers operate on the assumption of 'extended confidentiality' within communities. Confidentiality is assumed to extend beyond the doctor-patient relationship to include the patient's family and his community. Community informed consent recognises the integrity of the group and its power to protect against hardship. Children growing up within the community develop an internally derived group identity. Within the group it is assumed that there is a mutual and reciprocal desire to care and be cared for.

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<sup>24</sup> Campbell ID and Raider AD. Community informed consent for HIV-testing and a continuum of confidentiality. *Tropical Doctor* 1999;29:194-195.

Such a group, these workers believe, may through tradition and usage establish a trusting relationship with a hospital, based on mutual respect. Within such a relationship, it is contended, testing for HIV may be accepted as a part of life and rigid pre-counselling may be less necessary than in the West.

The term community delineates a wide variety of human associations. Campbell and Rader presumably use the term to describe a geographic collection of aboriginal persons, in a village or settlement, who share common culture (particularly relating to health) traditions, economic resources and canon of knowledge.<sup>25</sup>

This approach has a strong element of paternalism and is based on assumptions made by the health care workers who are necessarily outsiders to the community they serve. Their basic assumptions about individual attitudes to confidentiality may be unwarranted and would have to be investigated from a socio-anthropological point of view. The idea that a relationship of trust might obviate the need for pre-test counselling – the essential element of which is information and education to enhance self-help – would appear to be counter-productive in the long run.

A family might equally be considered to be a community of people. Under certain circumstances and in certain cultures, as for example in China, where there is an emphasis on harmony, responsibility and respect for parents and ancestors rather than a focus on rights and autonomy, medical decision-making and consent would primarily involve deliberation with the family - and not with the patient in isolation.

### *Tacit consent*

In the United Kingdom in 1987, the British Medical Association passed a motion stating that HIV testing 'should be at the discretion of the doctor and should not necessarily require the consent of the patient' on the assumption that the patient's consent could be presumed. Legal counsel advised that non-consensual testing could expose doctors to liability for assault or negligence. The motion was withdrawn.<sup>26</sup>

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<sup>25</sup> Weijer C Emanuel EJ. Protecting communities in biomedical research. *Science* 2000;

<sup>26</sup> Anonymous. Human immunodeficiency virus (HIV) testing. *BMJ* 1987;295:911

A physician cannot rely on a patient's 'tacit' consent. Informed consent for HIV testing should be implied, presumed or assumed. All the elements of voluntary informed consent as presented in Chapter II should be contained in the process.

### *Mandatory testing*

Universal mandatory testing in Africa would be unethical because of a lack of reasonable benefit to the individual. Mandatory testing of African groups at high risk is rejected for the same reason and because it is not group membership, but group behaviour that constitutes risk of infection.

Because there is no curative treatment for HIV/AIDS and because there would be little use for the results obtained, mandatory screening campaigns have been labelled 'ineffective, unnecessary, intrusive, discriminatory and counterproductive.'<sup>27</sup> This statement was made before the widespread introduction of anti-retroviral agents for prophylaxis against vertical mother to child transmission (MTCT), but would hold true for parts of Africa and South Africa where MTCT prophylaxis is still not accessible.

In South Africa, HIV testing is only carried out with informed consent. HIV infection is included among prohibited grounds for discrimination in the Employment Equity Act and hence pre-employment screening is prohibited.<sup>28</sup>

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<sup>27</sup> Office of the United Nations High Commissioner for Human Rights and the Joint United Nations Programme on AIDS. *HIV/AIDS and Human Rights. International Guidelines*. United Nations, New York and Geneva. 1998

<sup>28</sup> South African Law Commission. Discussion Paper 68, Project 85. *Aspects of the law relating to AIDS*. Pretoria. The Commission.1996.

### *Mandatory HIV screening of pregnant women*

About one third of infants born to HIV-positive women will be infected with the HIV. Two thirds of the infected infants will have acquired their infection via the placenta or in the course of delivery. Ingestion of maternal breast milk will infect the other third.

In 1994 the US Paediatric AIDS Clinical Trial Group protocol 076 (ACTG 076)<sup>29</sup> demonstrated that the perinatal administration of Zidovudine (AZT) to mother and child could reduce the rate of vertically transmitted HIV/AIDS by about two thirds. This success has stimulated debate about how best to offer HIV testing to pregnant women and prophylaxis for mother to child transmission (MTCT) to those found to be infected. HIV testing recommendations in the USA and the United Kingdom have been altered from targeting at-risk groups to universal coverage and voluntary counselling and testing of all pregnant women.<sup>30</sup>

In South Africa, universal access to anti-retroviral therapy to prevent MTCT is an urgent health care priority. This treatment is currently available at some hospitals and clinics in the Western Cape Province, in isolated hospitals in Gauteng and at other hospitals as part of clinical trials. At these centres, HIV testing is conducted with voluntary informed consent. Since MTCT prophylaxis is not currently universally available, in South Africa or the Southern African region, mandatory testing of pregnant women in the sub-continent would serve no useful purpose.

In the last week of January 2001, it was announced that the South African Government intended to offer universal prophylaxis to HIV positive mothers. Infants born to HIV positive mothers will receive a post-natal course of antiretroviral therapy and a supply of infant formula (to prevent HIV transmission via breast milk). This service would alter uptake of voluntary counselling and testing in South Africa and might cause some to call for mandatory testing of all pregnant women in this country. For the reasons elaborated above, a universal programme offering voluntary

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<sup>29</sup> Conner EM Mofenson LM Zidovudine for the reduction of prenatal human immunodeficiency virus transmission; pediatric AIDS Clinical Trials Group Protocol 076 – results and treatment recommendations. *Pediatr Inf Dis J.* 1995;**14**:536-541.

<sup>30</sup> De Cock KM Johnson AM. From exceptionalism to normalisation; a reappraisal of attitudes and practice around HIV testing. *BMJ* 1988;**316**:290-293

counselling and testing for pregnant women remains a more practical and ethical option than mandatory screening.

#### *Routine and compulsory testing of newborns*

It has become possible to test children for HIV at an early age by means of polymerase chain reaction (PCR) based techniques. Early identification of infected infants entails benefits in terms of optimal management. For the reasons elaborated above, newborns should only be tested after informed consent has been obtained from the mother. In the case of African newborns, the process of informed consent should permit the mother an opportunity of deliberating on her decision with her family.

#### **Summary**

Informed consent, with its respect for autonomous choice, is consistent with the African idea of personhood, despite the individual's powerful ties to family and community. As will be shown, it is possible to retain the central autonomy of informed consent in Africa, while enhancing the process in order to ensure an outcome that is ultimately in the best interests of the mother and consistent with her traditional way of making decisions

#### **IV. DISCLOSURE AND NON-DISCLOSURE OF HIV STATUS: EXPERIENCE IN A PAEDIATRIC HIV CLINIC POPULATION IN CAPE TOWN**

This chapter describes how mothers attending an HIV out-patient facility for HIV-infected children in Cape Town had handled the knowledge of their HIV status, following 'standard' practice first person informed consent, without family consultation or deliberation regarding the decision to consent to HIV testing. It sets out in detail the findings of an investigation into their pattern of disclosure. Assuming that there can be no specific emotional support without disclosure it also presents the strengths and weaknesses of their current support networks.

##### ***Background***

The paediatric service at Groote Schuur Hospital in Cape Town offers a dedicated 'walk-in' HIV out patient follow-up service for children diagnosed with HIV/AIDS. Mothers attend the clinic once a month. Each child receives a physical examination, including an anthropometrical assessment, treatment for intercurrent infection, and nutritional supplies from a protein energy malnutrition (PEM) feeding scheme. The mother's health is monitored, and mother and child see a dietitian and an occupational therapist at every visit and a social worker as needed. Two Xhosa-speaking home-based care workers from the Red Cross Society of South Africa and a Tswana-speaking registered paediatric nurse conduct group discussions in the course of the clinic. Many of the approximately 150 mothers currently attending have struck up friendships and alliances and have been observed to support one another when their children fall ill and at times of bereavement. Other than PCP prophylaxis, no specific therapy is available and none of the children receive anti-retroviral therapy (ART).

This clinic operates in a climate of 'positive denial'. Success in the form of a child's weight gain is applauded. Parties celebrate Christmas and Easter. Each clinic morning becomes a support group meeting for the mothers and a play-group for the children.

A questionnaire-based interview was conducted with each mother to assess the patterns of disclosure of HIV status and family support structures. This questionnaire

was part of patient care in the clinic and the signed consent of each mother was recorded prior to each interview.

### ***Objective***

The objective of the study was to evaluate the extent of disclosure and sources of family support available to mothers and their children with HIV/AIDS

### ***Subjects and Methods***

Xhosa-speaking health care workers conducted questionnaire-based interviews with 90 mothers attending a hospital-based paediatric HIV-follow-up clinic. Each mother was questioned in private, in a semi-formal, conversational manner, in extension of the normal counselling carried out in the clinic.

### ***Outcome measures***

The study was designed to identify, locate (by geography and family association) and enumerate the persons informed of the diagnosis by the mother. The sources of the mother's material and emotional support were identified in the same way. The mother reported both beneficial and adverse consequences of disclosure up to the time of study.

### ***Statistical analysis***

Statistical analysis was performed by calculation of odds ratios (OR) using the Epi Info 'Statcalc' statistical package.

### ***Results***

#### **Maternal data**

Mothers ranged in age from 17 to 41 years with a mean of 24 years. Forty-seven mothers had one child, 24 had 2 children, 6 had 3 children, 8 had 4 children and one mother had 5 children. Few fathers attend the clinic and fathers were not interviewed.

Three grandmothers, whose daughters have died and who attend the clinic with their grandchildren were also interviewed, but their data is not included in the analysis.

### **Persons informed (See Table 1)**

Mothers informed the father of the child of the diagnosis more often than they informed any other person. In each case this disclosure was the first time she had revealed the newly acquired knowledge of her positive HIV status to anyone. This disclosure occurred in 55 of 88 cases where the father was alive – or 62.5% of the total. Of the fathers informed of the diagnosis, 34 were living in a stable relationship with the mother and 21 were not cohabiting with the mother. Nineteen mothers were married to the father of the child. Of the uninformed fathers, 10 were living in the Eastern Cape, 19 were living in Cape Town, but not cohabiting with the mother and 4 were living with the mother. The father was more likely to have been informed if cohabiting with the mother (OR = 12.78 [2.89<OR<143.31]) and if the mother was more than 24 years old (OR=12.83[2.45<OR<76.99]). Disclosure of the diagnosis to the father was unrelated to the time elapsed since diagnosis.

Twenty-two women had informed their own mothers – maternal grandmothers to the child. Seventy-two grandmothers were still alive, so that only 30.3% of women who had the opportunity to inform their mothers had done so. Rate of disclosure to the maternal grandmother was not influenced by maternal age (over or under 24 years). The maternal grandmother was less likely to have been informed of the diagnosis by mothers living with the fathers of their children (OR=3.55[1.09<OR<11.91]) but disclosure to the father was neither more or less likely to be associated with disclosure to the maternal grandmother.

The maternal grandmother was significantly more often informed of the diagnosis if she lived in Cape Town than if she lived elsewhere (generally in the Eastern Cape). Of the 22 maternal grandmothers informed of the diagnosis, 4 lived in the Eastern Cape and 18 lived in Cape Town. Of the 50 grandmothers not informed, 30 lived in the Eastern Cape and 20 lived in Cape Town. The mother was therefore significantly more likely to have disclosed the diagnosis to a grandmother living in Cape Town than in the Eastern Cape ( $\text{Chi}^2 = 9.11$ , [Yates correction]  $p < 0.003$ ). Grandmothers

were no more likely to be informed by mothers in a stable relationship (living together) with the father of the child than when that was not the case.

Only twelve mothers (13.3%) had disclosed the diagnosis to the whole family. Twenty-five mothers (27.7%) had informed no one of the diagnosis and were therefore isolated in their knowledge of the diagnosis, apart from the staff and other mothers at the clinic.

**Table1: A breakdown of the pattern of disclosure among 90 mothers.**

<b>Person(s) informed</b>	<b>Number</b>	<b>Per cent of total</b>
<b>Father of child (n=88)</b>	<b>55</b>	<b>62.5</b>
<b>Maternal grandmother (n=72)</b>	<b>22</b>	<b>30.3</b>
<b>Whole family</b>	<b>12</b>	<b>13.3</b>
<b>Grandmother, not family</b>	<b>10</b>	<b>11.1</b>
<b>Family not grandmother</b>	<b>4</b>	<b>4.4</b>
<b>Sister alone</b>	<b>2</b>	<b>2.2</b>
<b>Aunt alone</b>	<b>2</b>	<b>2.2</b>
<b>Uncle</b>	<b>1</b>	<b>1.1</b>
<b>Sister-in-law</b>	<b>1</b>	<b>1.1</b>
<b>Nobody informed</b>	<b>25</b>	<b>27</b>

Thirteen (18%) of 69 mothers with family in Cape Town had disclosed the diagnosis to them. Six mothers had told some family members of the diagnosis, but 51 mothers with local family had not disclosed to any family member.

### **Consequences of disclosure**

In no case had disclosure resulted in rejection of the mother by her family. In cases where the mother had informed her own mother, the news was generally received

in sadness and with support. The father was sometimes reported as being angry ('he didn't talk to me for a week') but was generally accepting and supportive. The mothers were not asked whether the father had subsequently had himself tested. In two cases the father absconded following and presumably as a result of disclosure. In one case the father had assaulted a mother violently some months after disclosure. In no other case had disclosure resulted in immediate or subsequent violence.

In every case where the maternal grandmother had been informed of the diagnosis of HIV infection, the news was greeted with sadness and acceptance. There was no case in which disclosure led to rejection or ostracism. This was true for all other episodes of disclosure to family and friends.

### **Persons supporting the mother (Table2)**

Mothers most commonly reported the father of the child as their primary source of emotional and material support. This was the case for 29 mothers- 32% of the total. Nineteen mothers reported the maternal grandmother as their primary support. Of these, fourteen had informed their mothers of the diagnosis. A summary of sources of support is recorded in Table 2.

Fifty-five fathers provided material support for their children, including 14 who did not cohabit with the mother and 6 who did, but had not been informed of the diagnosis. Thirty fathers did not provide support, of whom 10 lived in the Eastern Cape and 20 lived in Cape Town and its environs.

In all, ten mothers were living with or received support from persons to whom they had not revealed the diagnosis.

**Table 2: Sources of support to mothers of HIV positive children:**

<b>Primary support</b>	<b>Number</b>	<b>Per cent of total</b>
<b>Father of the child</b>	<b>29</b>	<b>32.2</b>
<b>Maternal grandmother</b>	<b>21</b>	<b>23.3</b>
<b>Sister</b>	<b>12</b>	<b>13.3</b>
<b>Brother</b>	<b>6</b>	<b>6.6</b>
<b>Aunt</b>	<b>4</b>	<b>4.4</b>
<b>Mother-in-law</b>	<b>2</b>	<b>2.2</b>
<b>Uncle</b>	<b>2</b>	<b>2.2</b>
<b>Friend</b>	<b>2</b>	<b>2.2</b>
<b>No support at all</b>	<b>12</b>	<b>13.3</b>

Of the non-supporting fathers, 14 had been informed of the diagnosis of HIV and 20 had not. Of 10 non-supporting fathers living in the Eastern Cape, 4 had been informed of the diagnosis and six had not. Of the local non-supporting fathers, none of the 10 who had not been informed of the diagnosis had ever been in a stable relationship with the mother. Four fathers were reported to have abandoned the mother on account of the pregnancy.

A wide range of extended family was reported to be alternative sources of primary support.

### ***Discussion***

The overwhelming majority of mothers in stable relationships had disclosed their diagnosis to the father. The minority of mothers were married, but marital status did not correlate with disclosure to the father. Younger women, women not living with the fathers of their children and women who had children by men now living in the Eastern Cape, were less likely to have informed the fathers of their diagnosis. From the fragmentary data offered by this study it appears that fathers who had not been informed of the diagnosis seemed more likely to have been involved in brief physical encounters with the mother, or to have absconded because of the disclosure of

*pregnancy, rather than because of disclosure of the HIV diagnosis. This finding would have to be corroborated by in depth interviews and patient narratives.*

Relatively few mothers had told the maternal grandmother of their diagnosis. Disclosure was unrelated to the grandmother's domicile or to whether or not the mother was in a stable relationship with the father of her child. The reason for non-disclosure to the mother was not sought in the questionnaire. Some mothers volunteered that they had not told their own mothers because the latter were ill or 'too old'. Other mothers indicated that they were 'not yet ready' to inform their own mothers.

Where the diagnosis was disclosed to the family, the mothers uniformly reported that the news was accepted with sadness, but that they had been pledged full support.

In the tradition of Xhosa-speaking people, the maternal grandmother has responsibility for the emotional and material support of the sick children of an unmarried daughter. Given the empirical evidence presented here and elsewhere in this dissertation, many mothers keep the information that they have tested HIV positive to themselves. They choose not to disclose their diagnosis, but to accept the burden of the loss of close emotional support, which they could traditionally expect to enjoy in the case of any other serious illness.

The great majority of mothers had restricted information regarding their infection to the father of the child or had not told anyone. A total of 80 of the 90 mothers (89.5%) had handled information in this way. Only 10 had told family members without having informed the father.

The rate of disclosure to partners (married or living together) observed in this study is significantly higher than that noted in a study conducted on a similar population in Cape Town two years earlier.<sup>31</sup> The increasing rate of disclosure to partners may be an indication of an understanding of just how pervasive the HIV epidemic has become, how innocently the HIV infection may be contracted and therefore an

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<sup>31</sup> Fransman D McCulloch M Lavies D Hussey G. Doctors' attitudes to the care of children with HIV in South Africa. *AIDS CARE*. 2000;12:89-96

indication also of a lessening of stigma. If this is the case, it may be expected that an increase in the rate of disclosure in general will result in a decrease in the ambient level of stigma. The challenge is to implement public health strategies that will enhance this progress. It is the thesis of this dissertation that a modification of the consent process designed to include the family is one such strategy that deserves consideration.

***An intercultural vignette:***

The following vignette, from the same HIV clinic, shows how the 'standard' process of taking informed consent, despite respect for autonomy and privacy of the mother may result in an adverse outcome and how an authoritative family member of a different culture may view the process.

A maternal great aunt arrived at the clinic unannounced, with her niece (an unmarried mother) and the niece's healthy 6 month-old child in tow. The niece had been seen and counselled at birth after having been diagnosed as HIV positive during pregnancy. She was not living with the father of her child, but she had informed him of the diagnosis. He was not supporting the child because he was unemployed. The child was seen at birth and had an HIV PCR (polymerase chain reaction) test performed at 6 weeks, which had proved negative. At that time the doctor had given no thought to any other family member besides the mother and her child. The mother had left the clinic with congratulations but without a follow-up appointment.

At the time of the aunt's unannounced visit to our clinic, the child was thriving, but the mother had just revealed her own diagnosis to the family. The great aunt, who was a community nurse, knew of the possibility of vertical transmission of the infection and had not believed the mother's assurance that the child had had a negative PCR test. When questioned, the great-aunt confirmed that her niece had informed her of her own diagnosis and of the infant's test result. With the niece's consent, the doctor confirmed both the niece's HIV status and the negative PCR result of the baby to the great-aunt. The great-aunt was very angry that the clinic had not informed her of her niece's diagnosis at the time of the birth, since she considered herself to be the sole support of both her niece and her great-nephew. She considered that she had the right

to have been informed from the outset, because should anything happen to the mother she would be left to look after the baby. No argument could satisfy her insistence that she was the head of the family and that consequently her niece had no right to privacy, and the doctor no duty to respect her confidentiality. On the contrary, she informed the doctor that she would be reporting him for not having performing his duty as she saw it.

This 'inter-cultural vignette' indicates how individuals living according to traditional African values might be angered by attitudes and performance of non-African (and African) doctors who adhere to other values and principles. The great-aunt saw herself, and was apparently generally accepted, as the authority figure in the family and in her home. In her view, her niece was not empowered to make autonomous decisions and had no right to privacy in respect of the diagnosis of her HIV infection. Because the doctor had not discussed the diagnosis with the great-aunt, she considered him to be in dereliction of his duty to herself as head of the family to the family and to her niece (by not having treated the latter in accordance with the family's world-view). Her anger was apparently due to her perception that the doctor, through his actions had frustrated her role as head of the family.<sup>32</sup> This case is a clear example of how informed consent to HIV testing, with subsequent respect for patient confidentiality, might create dislocation within the family.

It would be congruent with the thesis of this dissertation that consultation with the family prior to the initial HIV test (that was in fact done on the mother while she was still pregnant) would have resulted in the aunt having had a better understanding of the facts around vertical transmission of HIV from mother to child. The aunt (one hopes) would have been more supportive of her niece's predicament and more appropriately happy that her great-nephew had escaped a fatal infection. Though it is less important, the aunt is also clearly less likely to have found herself in conflict with the health care workers attending to the child later on.

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<sup>32</sup> Preston-Whyte E. Women who are not married: fertility, 'illegitimacy', and the nature of households and domestic groups among single African women in Durban. *S. Afr. J. Sociol.* 1993;24:63-71.

### *A second intercultural vignette*

A desperately ill, nine month old HIV positive child was admitted to the paediatric ward for what after four weeks was to be his terminal illness. He was first seen with his unmarried Xhosa-speaking mother, who was a personable and apparently healthy woman of twenty-three, working long hours as a waitress. She informed the ward staff that although she was not herself able to spend much time with the child, her mother (the child's maternal grandmother) would be in the ward the next day.

The grandmother duly arrived and it soon became clear that she was not aware of the child's underlying diagnosis. As the child's condition did not improve despite everything the doctors were doing, she grew more and more upset and angry and started indicating that she wished to remove the child. She wanted it seen by someone in her husband's family who had healed the mother when she was sick with 'the same illness' at the same age. The doctors could not inform the grandmother that the child had HIV/AIDS because they felt they had to respect the mother's privacy and her decision not to disclose the child's HIV status. They nevertheless felt that the grandmother might privately have suspected this diagnosis. The mother insisted that she did not want the grandmother to know the of the child's HIV infection.

One evening the grandmother threatened to remove the child, who was oxygen-dependent and receiving intravenous antibiotics, from the ward by force. The doctors on call contacted the mother at work and she insisted that the child should on no account be removed from hospital. The grandmother had to be restrained and the police were called. The grandmother eventually went home.

She returned some days later and for the next week or more sat at the child's bedside night and day and generally refused to communicate with the doctors. Each procedure (taking blood, replacing an intravenous line) caused her great anger and upset. Eventually, when the child was *in extremis* and the care team had to discuss a decision not to resuscitate the boy, the mother relented and gave permission for the grandmother to be informed of his HIV infection. The mother remained in the ward while the consultant informed the grandmother. The grandmother received the information tearfully, repeating over and over again that her daughter was a virtuous

woman who had known only one man and that she could therefore not understand that her daughter could have the HIV infection. She eventually accepted the information as the truth. The grandmother and her daughter were at the boy's bedside when he died a day later.

This vignette is presented to illustrate the suffering that may be caused because of non-disclosure of the diagnosis of HIV infection. The child suffered because of the unhappiness of the grandmother and because she and the doctors were in disharmony. The grandmother suffered because she was in the dark and could not understand why the child was not responding to treatment. She remained uninformed although she was the intimate and faithful caregiver of her unmarried daughter's child, according to Xhosa tradition. The doctors suffered because they had information that could help the grandmother (whose position and actions they respected, despite her anger) but could not, faithful to their Western ethical tradition and respect for the mother's privacy, disclose the child's underlying diagnosis. The mother suffered through the paradox of being able to accept the grandmother's material care of her child, but unable to enjoy her emotional support.

This second vignette is also an illustration of a clash of traditions. It is congruent with the thesis of this dissertation that such clashes should prompt the reassessment of basic assumptions and traditional ways of taking informed consent. The standard form of first person informed consent, with its concomitant respect for individual autonomy, could be adapted to meet the needs of another culture - in which responsibility for the care of the unmarried mother's child falls squarely upon the grandmother - if at pre-test counselling, the mother is advised to inform her own mother of her need for an HIV test and to deliberate with her over the decision to permit the test before consenting. The counsellor could offer pre-test counselling to the grandmother, should she wish to be included.

This vignette also illustrates the nature of HIV stigmatisation and a logical way to counter it. Had the grandmother known from the start that her daughter was HIV positive; she would have understood that 'virtuous' women could contract HIV infection. Her altered perception might have been conveyed to family members and many other people, without necessarily having revealed her daughter's HIV status.

These two vignettes represent personal observations made in the course of the implementation of a service designed to deliver comprehensive care to mothers and children suffering from the infection and consequences of HIV/AIDS. They are but two stories of many that could be collected in the course of the in-depth anthropological research that is necessary to discover how HIV/AIDS affects persons in Africa. The findings they describe are congruent with the thesis of this dissertation, which is that 'standard' informed consent with its emphasis on the respect for privacy of the individual may not be in the best interest of the African woman, or consistent with her traditional method of decision making and should be adapted to meet the special requirements of the traditions that surround her.

University of Cape Town

## **V. UPTAKE OF VOLUNTARY COUNSELLING AND TESTING FOR HIV IN AFRICA**

It is critical to the successful management of the HIV/AIDS epidemic in Africa that people should be persuaded to be tested for HIV infection. When people present themselves for testing, the systems in place should deliver the following outcomes:

- People who know their HIV status
- People who understand the disease, its methods of transmission and ways to protect themselves
- People who know what care they and their children need; and where to find it
- People who are willing to share the knowledge of their diagnosis with those family members who would ordinarily provide them with emotional and material support in time of sickness

This chapter introduces evidence from the medical literature to show that health delivery systems in Africa cannot at present be depended upon to deliver the necessary services or outcomes upon which success against the HIV epidemic depends. These data are presented to argue that the systems currently in place are wasteful of the sparse services that are available.

It is suggested that in order to be successful against the HIV epidemic, two major elements of a health care system should be in place:

1. People should be motivated to undergo testing by an appropriate health care package for HIV positive persons. This should include at least access to prophylaxis against *Pneumocystis pneumoniae* pneumonia (PCP prophylaxis) and prophylaxis against vertical transmission for pregnant women.
2. In order for those services that are available to be used most efficiently, voluntary testing and counselling should be offered in a manner that

takes account of local culture and tradition. This, according to the thesis of this dissertation means that the process of informed consent should be adapted, so as not to isolate women from their families or to isolate families from information regarding actual cases of HIV infection.

### ***Introduction***

In the developing world, access to testing is limited because of limited access to health care. Where health budgets are constrained, a lack of testing, or testing without specific informed consent is a likely default option. A shortage of counsellors is likely, and counselling is unlikely to be adequate.

Relative to the population at risk, few people in Africa currently have access to voluntary counselling and testing for HIV. Yet even with the limited service available, an analysis of studies that report the uptake and efficiency of voluntary HIV counselling and testing Africa indicates empirical evidence of a breakdown in its implementation. This failure of voluntary counselling and testing has serious implications for any effort to restrict the HIV/AIDS epidemic. It is also argued that the inefficiency of the current system may be accounted for by the implementation of culturally inappropriate methods of obtaining informed consent for HIV testing.

### ***Data from the literature***

In a prevalence study conducted in rural Zambia, more than 93 per cent of a randomly collected sample of subjects gave voluntary consent for an anonymous salivary HIV test. In a separate study, 37% of the original sample declared themselves 'initially willing' to undergo voluntary counselling and testing. Less than 10 per cent of these subjects actually reported for voluntary counselling and testing and less than half of this remaining group returned for their test result and post-test counselling.<sup>33</sup> It is significant that this study was performed where there were no particular structures in

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<sup>33</sup> Fylkesnes K Haworth A Rosenvard C and Kwana PM. HIV counselling and testing: overemphasizing high acceptance rates a threat to confidentiality and the right not to know. *AIDS* 1999;13:2469 – 2474.

place for the follow-up of HIV-infected persons. The poor uptake of voluntary counselling and testing may have been a pragmatic response to the lack of incentive to know the diagnosis. It could also be evidence that some Africans do not share the assumption that knowledge of one's HIV status in itself necessarily a good<sup>34</sup> since for some people the benefits of voluntary counselling and testing and knowledge of their diagnosis are limited by the availability of appropriate medical care.

In a study conducted in Kigali, Rwanda, less than two-thirds of a group of women who had tested positive in a voluntary counselling and programme returned to hear their test results. A positive HIV test result was an independent predictor of failure to return for a result. Of the women who did return, more than 80 per cent had informed their partners of the test. Yet only 10 per cent of partners so informed presented themselves for voluntary counselling and testing.<sup>35</sup> This finding suggests a good understanding of risk of HIV infection – perhaps as a consequence of education in the course of counselling – but also suggests a fear of the loss of privacy, with implications for the subjects' perceptions regarding the confidentiality of the process of consent.

Less than 5 per cent of an urban population in Nairobi, Kenya declined participation in a voluntary counselling and testing programme for HIV.<sup>36</sup> Despite the excellent uptake of voluntary counselling and testing and an intensive education campaign, only 4 per cent of women requested their test results spontaneously. This experience eventually led the investigators to inform only those who asked for their test results. It was assumed that the knowledge was unwanted by the remainder because they were in stable relationships and did not want the burden of knowledge or to disclose their HIV status to a partner. It was also assumed that HIV positive women in stable relationships posed a low threat for spread of the infection. These women had complied with a request to consent for testing, but their failure to request results suggests that they did not regard their consent as an autonomous act, or that they

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<sup>34</sup> Sweat M Gregorich S Sangewa G et al. Cost effectiveness of voluntary HIV-1 counselling and testing in Kenya and Tanzania. *Lancet* 2000;**356**:113-121.

<sup>35</sup> Ladner J, Leroy V, Msellati P et al. A cohort study of factors associated with failure to return for HIV post-test counselling in pregnant women: Kigali, Rwanda 1991-1992. *AIDS* 1996;**10**:69-75

<sup>36</sup> Temmerman M N. Letter. *N Engl J Med* 1992;**327**:1102.

chose not to know their test results through autonomous choice or that they had consented merely to please the health care worker who had offered them the test.<sup>12</sup> Ultimately, it is likely that these women were fearful of the truth (on account of the nature of the disease and the stigmatisation of HIV positive persons) and that their decision not to discover the test result was an autonomous choice.

At an antenatal clinic in Nairobi, Kenya, only 51 per cent of a relatively well-educated sample of attendants agreed to have their blood tested for HIV. These women had a reasonable expectation of fair access to health care, with access to PCP prophylaxis, but not to ART or to ART prophylaxis against mother to child transmission (MTCT). Of those who agreed to a test, 34 per cent thought they should be asked for consent prior to testing and 62 per cent thought an HIV test should be mandatory. Ninety-five per cent wished to be notified of their results and 92 per cent indicated that they would themselves notify others of the result of their test. Fourteen of 17 women who had previously tested positive had informed their partners.<sup>37</sup> All the respondents stated that they would not want to fall pregnant if they tested positive. This study<sup>38</sup> and others<sup>39</sup> have reported that an assurance of confidentiality improves the uptake of voluntary counselling and testing. The refusal of a large number of these women to be tested indicates rational autonomous choice, given the limited benefit of knowing their HIV status in their particular situation.

An international study of the acceptability of voluntary HIV testing among women at antenatal clinics found an overall acceptance rate of 69% in 13 settings. This study included sites in Burkina Faso, Cote d'Ivoire, Thailand, Zimbabwe and Zambia and also a site in Soweto, South Africa. The acceptance rate was mainly affected by a low rate of return for test results, because acceptance of the test itself was high.<sup>40</sup>

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<sup>37</sup> Marjan RSR and Ruminjo JK. Attitudes to prenatal testing and notification for HIV infection in Nairobi, Kenya *East Afr Med J*. 1996;**73**:665-669

<sup>38</sup> Kim YM Marangwanda C and Kels A. Quality of counselling of young clients in Zimbabwe. *East Afr Med J* 1997;**74**:514-518)

<sup>39</sup> Irwin KC, Valdiserri RO and Holmberg SD. The acceptability of voluntary HIV-antibody testing in the United States: A decade of lessons learnt. *AIDS* 1996;**10**:1707-1717)

<sup>40</sup> Cartoux M Meda N Van de Perre *et al*. Acceptability of voluntary HIV testing in pregnant women in developing countries: An international survey. Ghent international working group on mother-to-child transmission of HIV. *AIDS* 1998;**12**:2489-2497

### ***Pregnancy in Africa: Autonomy and choice***

Other experience in Africa indicates that knowledge of HIV status does not affected women's reproductive behaviour.<sup>41 42</sup> This does not necessarily suggest that women are unable to make rational choices regarding the prevention of vertical transmission of HIV, but rather that their personal autonomy of choice with regard to pregnancy is less powerful than the strong pressure on African women to bear children.

### ***Interpretation of these data in terms of the thesis of this dissertation***

This review indicates that African women can act upon the offer of VCT in an autonomous manner, in that at least sometimes they elect to avoid information that to them would be burdensome and without benefit. These data indicate that in the populations under study HIV testing along 'standard' lines did not often achieve any of the goals set out at the start of the chapter. Clearly a lack of incentive in terms of appropriate health care and fear of stigma could have dissuaded many women from finding out their status. Access to health care is vital and little can be done to increase levels of knowledge of HIV status without it. But as I will argue, the efficiency of uptake of what HIV testing there is can be improved if culturally sensitive methods of counselling and informed decision-making processes are implemented.

This review also suggests the possibility of a more general flaw in the consent process, since the behaviour of mothers subsequent to their granting of consent (though rational, evidently autonomous and understandable) is not concordant with their apparent consent to testing. It seems probable that some (and in some cases the majority) of these mothers consented to testing because it was apparently the health care worker's idea of 'the right thing to do' and that they were passively coerced, either by some perceived disparity of power, or by their own willingness to please.

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<sup>41</sup> Heyward WL, Batter VL, Malulu et al. Impact of HIV counselling and testing among child-bearing women in Kinshasha, Zaire. *AIDS* 1993;7:1633-1637)

<sup>42</sup> Allen S, Serufilira A, Gruber V et al. Pregnancy and contraception use among Rwandan women after HIV testing and counselling. *Am J Public Health* 1993;83:705-710.

Another explanation for the failure to return for test results is that where access to health care is difficult (because of the cost of transport or the distance to the testing clinic), a second visit to hear the result imposes an insurmountable material burden upon the mother. This may well be true in many literally cashless parts of the African community. The solution to this material problem would be on site same-day counselling and testing. But if the thesis of this dissertation is correct and if properly informed consent in Africa should permit time for consideration of the implication of a positive test result, and even deliberation within the family if it is desired, then on site testing with a test result reported on the same day is likely to have the harmful consequence of isolating the mother in her knowledge of the diagnosis.

The subjects' failure to return for the results of a test to which they had consented could also be regarded as renegeing on a contract. This interpretation carries the implication of a lesser degree of self-regard, and hence perhaps a lack of a sense of personal autonomy. However, such an interpretation would seem to carry some cultural bias and seems less likely an explanation than that these women, in avoiding knowledge of their diagnosis, simply knew what was good for them.

Much of the information presented above suggests that lack of access to those health care facilities that would make HIV testing a rational choice is the limiting factor in the uptake of voluntary testing and counselling in Africa. Given that these facilities may never exist, it is all the more important that what is available is used most efficiently. It is congruent with the thesis of this dissertation that the emotional and material support of the extended African family is a vital and available resource in the fight against HIV/AIDS. Counselling and testing should therefore be conducted in a manner most likely to exploit that resource.

## **VI. THE BENEFITS AND BURDEN OF HIV TESTING**

It is sometimes assumed that it is necessarily a benefit to know one's HIV status. This chapter examines this assumption and shows the reasons why it has not always been true in the West and is not true in many parts of Africa. It is shown how the mother's decision to consent to HIV testing may harm her. Particular attention is given to the potential harm of stigmatisation, and violence following disclosure.

The chapter concludes by examining the tension between the woman's desire to protect herself against stigmatisation and her need for emotional support that can be provided by her family and suggests how, by a modification in the 'standard' process of taking consent for an HIV test, this tension may be resolved.

### ***Introduction***

It is often argued that knowledge is a good. In the case of the knowledge of one's own HIV status, such knowledge has been said to:<sup>43</sup>

1. Enable one to plan better for the future. (Based on the assumption that one is materially able to plan.)
2. Assuage one's concern over the exact cause of one's ill health (an assumption is made that the mother can accept the fact that she and her child have an incurable disease and no access to treatment).
3. Enable one to open discussion with sexual partners over potential risk behaviour.

Programmes offering voluntary counselling and testing are established in the belief that infected persons have a right to know their diagnosis and on the assumption that most infected people would wish to know their diagnosis. From the public health point of view, voluntary counselling and testing for HIV are the portal to health care, treatment and support.

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<sup>43</sup> Sweat M Gregorich S Sangewa G et al. Cost effectiveness of voluntary HIV-1 counselling and testing in Kenya and Tanzania. *Lancet* 2000;**356**:113-121.

The provision of sufficient and adequate voluntary counselling<sup>44</sup> and testing would seem to be a necessary condition for ethical management of the HIV/AIDS epidemic just as the provision of sufficient and adequate health care facilities are a necessary and valid condition for the uptake of voluntary counselling and testing by the general population. Knowledge is not a good when there is no power to act upon it.

### *The history of HIV testing policy in the West*

Tracing the history of the public reaction to the introduction of HIV testing in the United States of America shows how a well-organised and vocal group of persons reacted to a perceived invasion of those rights. This exercise throws light on how rational and autonomous African women might consider and decide upon uptake of voluntary testing and counselling for HIV.

In the 1980's, initial responses to the HIV epidemic in the USA followed traditional responses to previous outbreaks of other highly contagious infectious disease. There were calls for mandatory testing, nominal reporting of cases to a central registry, contact tracing and attempts at isolation. With the outbreak of the HIV epidemic public health traditionalists pressed for HIV infection to be managed under the broad statute established to control sexually transmitted disease (STD) and other communicable disease. Typically this minority identified with conservative political movements. Liberals and the democratic left opposed such efforts and an alliance of gay leaders, civil libertarians, physicians and public health officials developed a policy that made an exception of AIDS amongst other infectious diseases.

The introduction of the HIV-antibody test in 1985 was met with controversy, since the then at risk group of asymptomatic carriers (homosexual men) saw little benefit to knowing their sero-status. The switch to voluntary testing with informed consent and anonymous testing, also known as "AIDS exceptionalism" was a response to evidence

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<sup>44</sup> (Abdool Karim Q T Tarantola D As Sy E and Moodie R. Government responses to HIV/AIDS IN Africa: what have we learnt. *AIDS* 1997;11 (Suppl B): S143- S149.

of stigmatisation of and discrimination against the homosexual men amongst whom the Western epidemic first broke out.<sup>45</sup>

Attitudes to testing changed around 1989, when the first successful prophylactic treatment for opportunistic infection (prophylaxis against *pneumocystis carinii* pneumonia – PCP) became available. Gay men’s organisations urged members to establish their serological HIV status. With the emergence of new (protease inhibiting) anti-retroviral drugs in 1996 there was an unequivocal demand for diagnosis and active management.

Now that anti-retroviral therapy (ART) is available in Western countries, and the efficacy of ART in the prevention of mother to child transmission (MTCT) has been proven, proponents of coercive measures support mandatory testing of pregnant mothers, notification and other measures of disease control that were effective in curtailing tuberculosis and syphilis.

The argument against proactive coercive testing for HIV infection is that it will focus upon marginalized minority populations, that still lack adequate access to ART and the sort of health care facilities needed to support it. Coercive public health strategies will simply drive marginalized communities underground and beyond access to HIV/AIDS and health care education. The cost of coercive measures will draw off resources currently used for HIV education and attempts to modify risk behaviour and the combination of these effects will, once again, be most severely felt amongst the poor and the marginalized.

Arguments against mandatory HIV testing are equally valid in Africa and the response to HIV testing among the powerful and influential gay activists in the USA sets a useful standard against which to measure African responses to voluntary counselling and testing.

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<sup>45</sup> Bayer R Public health policy and the AIDS epidemic. An end to AIDS exceptionalism? *N Engl J Med* 1991;324:1500-1504.

## ***The harms of AIDS-related stigma in Africa and discrimination against HIV positive persons***

There is a perception held at high level in Africa that people with HIV infection are immoral and bad and the root cause of their own problem. Janet Museveni, First Lady of Uganda is an example of someone in an influential position who holds such a view<sup>46</sup>, as does one of the King of Swaziland's senior advisors, Tfohlongwane Dlamini<sup>47</sup> (Chair of Swaziland National Council Standing Committee, advisor to King Mswati III). These attitudes and views clearly threaten the dignity and well being of affected persons and of affected women and children in particular.

AIDS is still seen by some as retribution for sin. It is a popular conception that people who have contracted HIV/AIDS through sexual practices or drug use have got what they deserve. In the United States of America, attitudes of intolerance to homosexuals are part of a traditional and politically conservative perspective.<sup>48</sup>

The stigma associated with HIV/AIDS threatens the physical and psychological well being of people perceived to be infected with HIV. Stigma has also impaired society's ability to provide treatment for HIV/AIDS and to prevent further transmission of HIV.<sup>49,50</sup> Delay in seeking health care is closely related to attempts to avoid stigma<sup>51</sup> and stigma plays a major role in non-disclosure.

African women who accept MTCT prophylaxis and elect not to breast feed have the added burden of explaining their reason for bottle feeding to their partners (who might not be informed of the diagnosis of HIV infection) family and to the community in which breast feeding is the norm. Bottle-feeding of the infant carries a clear risk of

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<sup>46</sup> [http://www.forerunner.com/forerunner/X0852\\_Ugandas\\_First\\_Lady\\_o.html](http://www.forerunner.com/forerunner/X0852_Ugandas_First_Lady_o.html)

<sup>47</sup> Zuniga JM. *Report from the president*. IAPAC Monthly. October 2000. p 287

<sup>48</sup> Johnson SD. Model of factors related to discriminate against people with AIDS. *Psych Rep* 1995;**76**:563-572.

<sup>49</sup> Gerbert B Maguire BT Bleecker T *et al*. Primary care physicians and AIDS: attitudinal and structural barriers to care. *JAMA*;**266**:2837-2842.

<sup>50</sup> Herek GM Capitanio JP. Public reactions to AIDS in the United States: A second decade of stigma. *AmJ Public Health*. 1993;**83**:574-577.

<sup>51</sup> Johannson E, Lang NH, Divan VK *et al* . Gender and tuberculosis control: Perspectives on health-seeking behaviour)

stigma. The mother's mental and psychological effort to counter this stigma must count as a considerable burden and a sacrifice.

There is a pressure of conduct on persons marginalized by their HIV status, who are forced to limit the access of others to information about the stigma, or must assume the character of a discredited individual.<sup>52</sup> Other mothers practice what has been termed 'defensive mothering'<sup>53</sup> as a basic social posture. These women adopt protective strategies, preparing their children for orphanhood, preventing spread of infection and defending the equanimity of their daily lives by controlling their negative thoughts.

Stigmatisation of people with HIV/AIDS as a public health message by leaders of governments and by religious leaders is counter-productive and wrong, because the message implies that HIV cannot infect 'good' people.<sup>54</sup> The fact is, that at this time in the African epidemic, HIV is established in the general community and is spread by entirely 'normal' behaviour. Because it is firmly established in the public mind that bad people with promiscuous behaviour spread HIV, few accept that they have close friends and relatives dying of the disease. Those who are infected hide the information from their family and friends because they do not wish to acknowledge their infection and accept the persona of a bad, promiscuous person. Hence stigma blocks the transfer of knowledge regarding the realities of the epidemic and inhibits the public health response to the disease.

Africa is stigmatised as a part of the world most seriously affected by HIV/AIDS. Discussion of sexual behaviour in Africa continues to be surrounded by value-laden assumptions and to be charged with political implications. Public discourse about AIDS in general is clouded by persistent reference to racial stereotypes, moralistic reasoning and xenophobia. Africa is generally stigmatised as a 'basket case'. Blatant racism contributes to the notion that efforts to help Africa's people reduce their risks are futile. Anthropologists contribute to the 'hopelessness' of the African stereotype

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<sup>52</sup> Goffman, Erving. *Stigma*. Prentice-Hall: Englewood Cliffs, New Jersey, 1963.

<sup>53</sup> Ingram D Hutchinson SA. Defensive mothering in HIV-positive mothers. *Qual Health Res.* 1999;9:243-258

<sup>54</sup> Whitty JM. *Lancet* 1999;354:2147-2148

by perpetuating assumptions that Africans do not understand the germ theory of the spread of disease. (In fact, many people, not only in Africa, hold several concepts of disease causation, often in parallel).

Stigma becomes a barrier to the care of persons with HIV/AIDS by the extended family, since infected persons fear that to acknowledge infection means to be thrown out and shunned. There are data to suggest that, despite the fact that the socially sanctioned behaviour of male partners is the most likely cause of initial infection, in some African societies, women tend to be blamed for bringing HIV into a family.<sup>55</sup>

Misconception affects the way health care is delivered in Africa and is likely to manifest itself in ways that further aggravate stigma. In a study conducted amongst health care workers in Kampala, Uganda, investigators found that 35 per cent of doctors and nurses were afraid to care for AIDS patients because they feared contagion. There was a high rate of misconception around risks of infection. Staff thought one could contract HIV/AIDS by 'working with' patients (25 per cent), by sharing a glass (25 per cent), by being sneezed on (39 per cent) and by shaking hands (28 per cent).<sup>56</sup>

Attitudes of doctors looking after children in the Cape Town teaching hospital complex (Groote Schuur, Red Cross War Memorial Children's and Somerset Hospital) have been surveyed and reported. This study indicates that a significant proportion of doctors would treat HIV positive children differently from HIV negative children.<sup>57</sup> How much of this difference relates to stigmatisation and unfair discrimination, and how much is due to a practical assessment of the benefit of specific interventions could not be determined from this study. Nevertheless, the majority of doctors reported themselves fearful of needle stick injury and some 23 per cent of the sample indicated that they were 'less likely' to treat HIV positive children with intra-venous antibiotics, an observation which could suggest unfair

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<sup>55</sup> The National Strategic Framework for HIV/AIDS Activities in Uganda- 2000/1 to 2005/6.

<sup>56</sup> Mungherera, M van der Straten A Hall TH *et al.* HIV/AIDS- related attitudes and practices of hospital-based s in Kampala, Uganda. *AIDS* 1977;11(suppl):S79-S85.

<sup>57</sup> Fransman D, McCulloch M, Lavies D, Hussey G. Doctors' attitudes to the care of children with HIV in South Africa. *AIDS CARE*. 2000;12:89-96

discrimination or a failure to appreciate the natural history of HIV infection in children.

Aboriginal groups in Canada and Australia suffer from discrimination rooted in a view descended from colonialism: Things are the way the dominant group sees them.<sup>58</sup> In South Africa, despite a change to majority rule, and although white South Africans are no longer politically dominant, many white persons remain in influential positions and would hold the view that the HVI/AIDS epidemic among blacks is somehow morally the fault of the black people themselves.

### ***Harm through a paradoxical perpetuation of stigmatisation***

A sad paradox is that virtuous women perpetuate their own stigmatisation because they do not disclose their diagnosis. This is because every virtuous woman who chooses not to disclose her diagnosis withholds evidence that one need not be promiscuous to become infected with the HIV. In Africa, the rate of infection in the sexually active population is so high that promiscuity is not a necessary condition for infection. 'Virtuous' women are infected by men who give them no cause to presume any risk of infection or perceive any need for precaution against infection. Yet HIV positive women fear stigmatisation on the grounds that their infection proves promiscuity.

### ***Harm through violence against HIV positive women***

Media reports of individual cases of sometimes-fatal assault on women who have disclosed their HIV status have created the impression that it is always dangerous for a woman to reveal her diagnosis. AIDS activist organisations also emphasise this danger, possibly with the goal of publicising evidence of stigma.

Systematic study of HIV-related violence to women does not bear out the thesis that HIV status or disclosure of the diagnosis is strongly associated with physical abuse. In the USA, although men are more often victims of violent crime, women are 5 to 8

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<sup>58</sup> <http://www.aidslaw.ca>

times more likely to be victims of assault in intimate relationships. Factors contributing to a risk of assault in this situation are poverty, unemployment, drug dependency, a history of childhood sexual and physical abuse, age less than 30 years and homelessness.<sup>59</sup> Some research has suggested that disclosure of the diagnosis to partners may trigger violence,<sup>60 61</sup> but this observation has not always been reproducible.

In a U.S. probability sample of 2864 HIV-infected adults, 20.5 per cent of women reported physical harm since their HIV diagnosis. Nearly half of these women perceived their HIV diagnosis to be the trigger for violence. Factors predictive of HIV-related violence were similar to factors associated with violence for any reason. The act of disclosing the diagnosis was not itself associated with violent reactions and the findings of this study did not support the hypothesised increased risk of violence in the period immediately following disclosure. Drug dependency, homelessness and unemployment were the factors most strongly associated with violence within partnerships or relationships.

In a study of African-American women, it is reported that 97 per cent had disclosed their diagnosis and 64 per cent had done so to more than 5 people. Forty-four per cent reported negative consequences of disclosure, involving a loss of friends, verbal abuse, family rejection and physical abuse (in four per cent of cases).<sup>62</sup>

In studies conducted in Nairobi, Kenya, Temmerman<sup>63</sup> found evidence of violence in 6 per cent of 342 positive subjects. However, only 66 subjects had informed their partners of the diagnosis and 13 of these (nearly 20 per cent) became victims of

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<sup>59</sup> Zierler S, Cunningham WE, Andersen R et al. Violence victimisation after HIV infection in a US probability sample of adult patients in primary care. *Am J Public Health*. 2000;**90**:208-215)

<sup>60</sup> Rothenberg KH Paskey SJ. The risk of domestic violence and women with HIV infection: implications for partner notification, public policy and law. *Am J Public Health* 1995;**85**:1569-1576)

<sup>61</sup> North M, Rothenberg KH. Partner notification and the threat of domestic violence against women with HIV infection. *N Engl J Med* 1993;**329**:1194-1196

<sup>62</sup> Gielen AL Fogarty L O'Campo P et al. Women living with HIV: disclosure, violence and social support. *J Urban Health*. 2000;**77**:480-491`

<sup>63</sup> Temmerman M, Ndinya-Achola, Ambani J and Piot P. The right not to know HIV-test results. *Lancet* 1995;**345**:969-970.

violence or were rejected. While it would seem that, in this setting, women who share the diagnosis with a partner are at risk of grave consequences of disclosure, it is noteworthy that one study has reported a background rate of violence against pregnant women in Kenya to be as high as 43%,<sup>64</sup> which may indicate that a disclosure of positive HIV status is not of itself an immediate stimulus to violence. Uniformly low rates of violence reported following disclosure of the diagnosis to the woman's partner should encourage counsellors to support disclosure in all but relationships with a prior history of violence, drug abuse or homelessness.

### *Patterns of Disclosure*

It is believed that few people living with HIV in South Africa voluntarily disclose their sero-status. In a study conducted on mothers attending paediatric HIV outpatient clinics in Cape Town, it was found that only 51 per cent of the sample had told anyone of their diagnosis. Thirty-four per cent had told the father of their affected child, seventeen per cent had told their mothers and only five per cent had told their household of the diagnosis.<sup>65</sup> This finding may be compared with findings in the later study of disclosure and family support, which forms part of this dissertation, indicating that more than sixty per cent of mothers had disclosed to the father of the child and thirty per cent of mothers whose own mothers were still alive had told them of the diagnosis. These increases in disclosure hopefully reflect a change in levels of stigma.

The acceptance among partners of HIV positive status may be expected to change as the frequency of infection increases and the community becomes familiar with the natural history of infection. In Kigali, Rwanda a cohort of 47 women were interviewed in 1988 and again in 1991. They reported an increase in acceptance,

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<sup>64</sup> Raikes A. Pregnancy, birthing and family planning in Kenya: changing patterns of behaviour in: a health service in Kisii district. Centre for Development Research Copenhagen. Reported by Nahlen BL et al. *Lancet* 1995;**345**:1507-1508.

<sup>65</sup> Kuhn L, Mathews C Fransman D *et al.* Child feeding practices of HIV-positive mothers in Cape Town South Africa. *AIDS* 1999;**13**:144-145

understanding and support from their partners, but 21% had still not told their partner of the test result.<sup>66</sup>

***The tension between the need for privacy and the need for emotional support: the potential harm of non-disclosure***

Non-disclosure as a consequence of informed consent for HIV testing could be harmful to the mother's partner (unless he is HIV positive), to society and to the affected mother and child.

*Harm to the partner*

Clearly the information is immediately vital and non-disclosure immediately harmful if the HIV-positive woman is sexually active with an HIV-negative man.

*Harm to society*

If one considers society to be a living, complex interactive system, then it should be intuitively evident that the survival of the system and its ability to thrive must be dependent on its ability to register and adapt to signals indicating danger, as is the case for any sentient being. Non-disclosure of HIV status according to this model may be interpreted as a potentially harmful blockade of important protective signals. The consequence of non-disclosure is a long-term harm to the community and to society because of a cumulative effect of the non-delivery of vital signals. This model explains the current high rate of HIV infection in Southern Africa. People who were infected did not know it, because the infection left them well. There was no physical incentive to be tested for HIV and so the signal (a positive HIV test) was not generated. By the time people with HIV infection became ill, the damage of contagion had been done, and a great many asymptomatic people were passing the disease on.

Non-disclosure is both a physical and a psychological block to the protective signal. The psychological signal, congruent with the thesis of this dissertation, is the message

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<sup>66</sup> Keogh P Allen S Almedal C et al. The social impact of HIV infection on women in Kigali, Rwanda: a prospective study. *Soc Sci Med* 1994;**38**:1047-1053

that HIV/AIDS is really possible within a given family, kindred and community. The loss of signal results in a defective perception, within the family, kindred or community: Not only is HIV/AIDS seen as less of a real threat and therefore less to be feared and guarded against, but the family, kindred and community also lose the opportunity to observe the true natural history of an HIV infection in a member. They do not discover that ordinary, virtuous people (such as the mother usually is) can contract HIV infections and this defect in their experience helps to perpetuate the idea that only bad and promiscuous people are at risk of the disease. They also lose the opportunity of interacting with and caring for the affected person and perhaps of rehearsing roles they might later be called upon to repeat.

This pattern of non-disclosure has implications for the dissemination of information about HIV infection and for the enhancement of stigma. If the 'ordinary' people, who fall victim of the epidemic in the course of unexceptional behaviour (that would not be thought of as 'high-risk' or promiscuous by the women themselves, or by other members of their society) do not disclose their diagnosis to their intimate circle of family and friends, two vital messages will not be delivered:

1. Ordinary people living unexceptional lives can become infected in the face of a pervasive HIV epidemic.
2. Stigmatisation of all people with HIV infection as undesirably promiscuous is wrong, because in a pervasive epidemic promiscuity is not a necessary condition for becoming infected with HIV.

Because these messages are undelivered, stigma will not be removed from those diagnosed with HIV infection and future disclosure by other infected persons will remain constrained. Stigma imposes a constraint on disclosure and non-disclosure in turn constrains the removal of stigma. By not disclosing their HIV status to their families, women contribute to the perpetuation of what they fear. While it is true that in this respect a woman's disclosure sacrifices privacy and risks personal stigma for the sake of a societal good, the woman herself is also a potential and future beneficiary, since she is a member of the stigmatised group. Within the family there is also the possibility that the weight of evidence in favour of her well-established virtue may provide a counter-balance for the impulse to stigmatise her.

### *Harm to the woman's family*

It is congruent with the thesis of this dissertation, that it is the families and friends of infected persons who have a 'need to know' about particular infected persons, not to stigmatise and avoid them, but in order to understand the actual fact of the infection (and infectious risk) of ordinary people. In this case 'ordinary people' are defined as those who would not fit into a popular conception of a 'high risk' category. Families must be permitted to observe the 'normality' of people who become infected with HIV.

There is a tension therefore between the privacy rights of the infected woman and the needs of her immediate family. The ethical dilemma is that while the ordinary individual has the right of privacy, her privacy is preserved at the cost of the loss of the message that ordinary persons in Africa may become infected in the normal course of their lives and that therefore, everyone should act in a manner that protects against risk.

If it were made easier for all women to share their diagnosis with their families, stigmatisation would die a natural death in the face of a steady accrual of evidence that virtuous young women do contract the infection. The HIV infection would then be seen for what it often is in Africa: an unfortunate accident that happens to ordinary people. Should the tide of opinion move in this direction, it would speed up the rate of disclosure, which in turn will decrease the prevalence of stigmatisation.

### *Harm to the mother and her child*

In the case of an African mother consenting to an HIV test, confidentiality and respect for privacy confer the benefits of protection from stigmatisation and risk of violence upon disclosure. The potential harm of privacy to the mother seems to be the loss of access to traditional sources of social psychological and material support if her family do not come to know her diagnosis. This harm is amplified in those parts of Africa where health and counselling resources are sparsely distributed and where the mother's loss of psychological support from her family cannot be substituted by state-funded systems of health care delivery.

The consequence of non-disclosure for a mother is the loss of specific social support. Because her family members do not share in her knowledge, they cannot share in her grief and suffering, or know that they should provide her with emotional support. Interpersonal relationships within families provide social support and a sense of well being both by overall benefit of support and by a process that protects persons from the adverse effects of stressful events.<sup>67</sup> The quality and quantity of such support and protection depends critically on disclosure and the number and significance of the people who have been informed of the diagnosis.

The child suffers vicariously from the mother's lack of emotional support and specifically if the family, in the case of an uninfected child is not able to plan ahead to provide for the care of orphans.

### ***Non-disclosure and informed consent***

There is no empirical data available on the influence of informed consent on rates of family disclosure and very little information on the consequences of disclosure. The sample of mothers reported on in Chapter IV had given first person informed consent for HIV testing without family consultation. All mothers in this study cohort had pre-test counselling, but in no case had it been suggested to the mother that she might wish to consider deliberating the decision for her child to be tested with her family before going ahead. In no case had it been explained that the test might result in knowledge about herself and the baby that she might not feel able to share with her family, and that might as a result cause her a loss of customary and traditional support.

It is not possible to determine from the study reported in Chapter IV how the diagnosis of HIV infection had affected the way the mother saw herself as a member of her family, kinship or society, or whether the infection had changed her relationships with her family and kinship. This would be a subject for further research, as is suggested in the concluding chapter.

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<sup>67</sup> Cohen S Wills TA. Stress, social support and the buffering hypothesis. *Psychological Bulletin* 1985;98:310-357

The study found that in this population, disclosure to the father's child did not result in abandonment or physical harm and that disclosure to the family did not result in rejection. On the contrary, the news of the HIV infection was met with sadness but also with acceptance. From these findings it is possible to argue that the encouragement of disclosure through family consultation prior to a decision regarding consent would at least not lead to harm, but could greatly benefit the woman if the family response to disclosure were to match what was found in this survey.

It would require a comparative prospective study of similar cohorts of women to extend these findings and to establish whether a modification in the process of consent might result in a better outcome with respect to disclosure and family support.

Nevertheless, there seems to be an intuitive claim that a family's pre-knowledge of the risk of a diagnosis of HIV is likely to be more conducive to support (and easier for the mother to communicate) than a blunt disclosure of the diagnosis. Therefore it seems reasonable that a mother should be advised in the course of pre-test counselling, to go back to her family or to an authority figure in her family in order to consult on the desirability to agree to an HIV test.

The fear of stigmatisation is doubtless a very important part of what constrains women from disclosing their infection to their immediate family. An adaptation in the process of informed consent during the taking of consent itself, which would allow and encourage family deliberation over the decision to be tested, may increase the likelihood of disclosure of a positive diagnosis. Disclosure would be enhanced, because the woman would be discussing the need for a test and probability of her infection, rather than having to face the daunting task of revealing the cold fact of her status to the family after it becomes known to her. Her family would have some ownership of the decision to consent to testing and hence would also have natural access to the test result. In a sense, and particularly in Africa, given the close nature of the African family, it would be the family itself that would be undergoing the test.

## VII. COUNSELLING FOR HIV TESTING

In this chapter the 'standard' pre-test HIV counselling process is presented. A modification is then proposed, in line with the thesis of this dissertation, which it is argued will enhance the outcome of the process. The modification to 'standard' pre-test counselling is described in detail and possible consequences of this modification are discussed.

### ***Introduction***

There is universal recognition that voluntary HIV testing should be performed in a non-stigmatising environment with pre- and post-test counselling.<sup>68, 69, 70</sup>

Ideally, 'standard' counselling before the test should:

- Address the need for testing
- Describe the technical aspects of the test
- Provide accurate information about HIV
- Discuss past risk behaviour
- Explain future risk reduction strategies
- Explain the implications of a the test result, particularly if positive, to the mother and child
- Explain the right to refuse the test or to refuse knowledge of the test result
- Explain what appropriate health care and specific treatment is available

In the African context the following modification to pre-test counselling is proposed:

- Explore the likelihood and desirability of deliberating with the family and other members of the subject's support network on the decision to consent to testing

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<sup>68</sup> UNAIDS *Policy on HIV Testing and Counselling*. Geneva: UNAIDS August 1997.

<sup>69</sup> Office of the High Commissioner for Human Rights and the Joint United Nations *Programme on HIV/AIDS. HIV and Human Rights*. International Guidelines. New York and Geneva. 1998

<sup>70</sup> SA Law Commission. *Discussion Paper on Aspects of the Law Relating to AIDS*. Discussion

paper68. Project 85. Pretoria. The Commission. 1996

- Discuss the potential advantages of disclosure, such as access to emotional and material support from the family
- Discuss the merits and possible dangers of disclosure
- Discuss the nature and likelihood of stigmatisation
- Discuss how positive HIV status might be disclosed to sex partners and family

Post-test counselling should provide emotional support and help the patient to find the most appropriate medical and social support.

Someone sensitive to issues of sexual identity, culture and socio-economic living conditions should perform counselling. Language and approach should be appropriate to the client/patient. Counselling for HIV/AIDS should be a dialogue over time and the pre-test counselling session should mark the onset of a therapeutic relationship. While conventional counselling for sexually transmitted disease is didactic, HIV counselling should be supportive. Such counselling seeks to enhance self-determination, boost self-confidence and to improve quality of family and community relationships, and quality of life.<sup>71</sup>

In practice, people tested for HIV infection often receive little or no counselling. It is a labour intensive exercise. Where health resources are stretched, counselling is likely to be granted low priority. Doctors in particular do not have sufficient time, or are not compensated sufficiently well for the time it takes to counsel. Counsellors are invariably too few. Community health nurses often lack the skills or the personality required to be an effective counsellor.<sup>72</sup> Furthermore, there is a tacit and pervasive assumption amongst practitioners that pre-test counselling may discourage people from being tested, because it creates tension around the test and the decision on whether or not to have it done. This is an understandable but unfortunate and fallacious view.

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<sup>71</sup> Silverman D Perakyla A Bor R. Discussing safer sex in HIV counselling. Assessing the communication formats. *AIDS Care* 1992;4:69-82

<sup>72</sup> Grinstead OA van der Straten A. counsellors perspectives on the experience of providing HIV counselling in Uganda and Tanzania: the Voluntary HIV-1 Counselling and Testing Efficacy Study. *AIDS Care*. 2000;12:589-610

Clearly, counselling is the essential element of VCT most likely to alter behaviour and to introduce life-saving information into the (thus far uninfected) community. It is worrisome that the quality of counselling even in a well-funded society such as the USA is in question. In Africa, where broad access to anti-retroviral therapy is still years away, counselling appears to be the only effective module of HIV/AIDS management available. It is therefore vital to the public health effort to contain HIV infection, that adequate numbers of properly trained counsellors are mobilised and that the quality of their work is carefully monitored and controlled. The quality and training of counsellors represents an ethical issue, firstly because of their cost in the face of scarce health care resources (in developing countries) and secondly because if training is neglected, inadequate counselling represents an opportunity cost and undermines the overall HIV/AIDS management effort.<sup>73</sup>

Recent studies have raised concerns about the quality and efficacy of the counselling process.<sup>74</sup> Although these programmes are adequately funded in the USA, a quality assessment study has found that identification of positive patients takes precedence over counselling, that counselling is often perfunctory and/or inappropriate and that there is considerable variation in the content of counselling, the training of counsellors and the intensity of the session.<sup>75</sup> These disappointing findings are all the more so for countries in Africa, where sufficient numbers, let alone quality, of counsellors are a distant goal. Since these findings suggest that professional counselling may not provide the answer to the support of HIV positive persons, their further message for Africa is that alternative forms of patient support should be sought. It is congruent with the thesis of this dissertation that such support should be sought in the families of affected persons. The strength of intra-family bonds should be exploited and developed in this regard, but this resource will only be available if disclosure of HIV status within the family can be facilitated.

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<sup>73</sup> Abdool Karim Q, Tarantola D AS Sy E, Moodie R. Government responses to HIV/AIDS in Africa: what have we learnt? *AIDS* 1997;**11(Suppl B)**;S143-S149

<sup>74</sup> Selwyn P Carter R Schoenbaum E *et al.* Knowledge and antibody status and decisions to continue pregnancy among intravenous drug users. *JAMA* 1989;**261**:3567-3571

<sup>75</sup> Sikkema KJ and Bissett. Concepts, goals and techniques of counselling: review and implications for HIV counselling and testing. *AIDS education and prevention*. 1997;**9(Suppl B)**;14-26

Pre-test counselling (whether in the West or in Africa) should be more intensive than is currently the case. There is a dilemma as to who should deliver such intensive counselling. If an intensive long-term therapeutic relationship is the goal, then the doctor will have time constraints in delivering the appropriate service. On the other hand, referral for counselling has consequences for the doctor-patient relationship. The solution might lie in the development of integrated teams of health care workers to share the different aspects of care and counselling. Another solution, described below, is to utilise the unique strengths of the African family in counselling.

The African context differs from that of the West because of the heterosexual and unrestricted nature of the epidemic. Because of the high rate of infection, 'normal' sexual behaviour can readily result in infection. The emphasis in counselling of uninfected persons should be to raise consciousness about the stark reality of the HIV infection risk. Empirical evidence for the tendency not to disclose with current methods of counselling and informed consent has been presented in prior chapters.

#### *A modification to the process of informed consent*

In the African context and according to the thesis of this dissertation, a vital goal of counselling should be the notification of partners and family. Involving the family in pre-test counselling, by consent of the woman and hence by voluntary extension of individual patient autonomy, would best serve the goal of family disclosure. Instead of the 'standard' approach to informed consent, which emphasises the woman's autonomy and places a premium on respect for her autonomy, the thesis of this dissertation suggests the introduction of a modification to the consent process:

- The woman, or mother of the child for whom an HIV test is contemplated should specifically be requested to consult with her family or with an authority figure in her family prior to giving consent for the test.

- She should be informed that the reasons for a family consultation relate to disclosure of the diagnosis, to the consequences of non-disclosure, to the lack of public sector facilities for emotional support for HIV positive persons and to her access to the traditional strength and emotional support to be found in African families.

- She should be warned of the possibility of stigmatisation.

- She should be asked to consider how she thinks her family would receive the mention of an HIV test and to consider the loss of emotional support should she decide to carry the burden of knowledge of her HIV-positive status alone.

- She should be asked to decide on the basis of her knowledge of attitudes and opinions within her family, whether or not to consult with the family.

- She should not be asked to consider the good of society when making her decision.

There are several possible outcomes resulting from these proposed modifications to the consent process:

- The woman might indicate that she does not wish to consult with her family. The test should be performed with her autonomous informed consent, in the manner she requests.

- She could indicate the wish to consult, but not return for the test. This may mean that she has decided against the test, which is an appropriate and autonomous response to the consent process; or that she has consulted with the family or authority figure and a decision has been made against testing. In this event it is not clear whether the mother has lost her autonomy as a consequence of the modified consent process. She may agree with this decision, as being in both her best interests and that of the family. Alternatively, she may have been influenced by her family to act in a way that she believes is contrary to her interests – a decision she disagrees with, but feels unable to resist in the context of her familial

obligations. How African women understand their autonomy and how HIV/AIDS affects their view of themselves is clearly a subject that requires further anthropological research.

- The mother may return alone and indicate that her family have decided that she should have the test. The test may then be performed in recognition of this autonomous assertion, on the assumption that family have received sufficient information about HIV. The less certain assumption is made that, having broached the possibility of HIV infection to the family, the mother will find it easier to disclose her diagnosis, should she test positive.

- The mother may return with one or more members of her family, in which case facilities should be available for group counselling, and possibly for testing of additional members of the family.

- The mother may return and indicate that, although the family does not want her to agree to a test, she has nevertheless decided that she should be tested

Pro-active pre-test counselling to discuss a positive test result with the family as a possibility rather than an established fact seems intuitively preferable and more humane option, than expecting the infected person to announce the stark reality of a positive test result to her family on her own.

If there is a general understanding of how prevalent the infection is among 'good' and 'normal' people, and of how innocently it may be acquired, there should be a change in perception and a reduction in the level of stigmatisation of HIV positive persons. This is the sort of communal goal that has been set in Uganda with its HIV/AIDS 'openness' campaign.

Extended post-test counselling will be difficult to provide in Africa, because of material constraints. This is yet another reason why the family should be involved

in the process of diagnosis from the outset and why family resources should be exploited to provide the counselling and support that is a long-term need for the HIV infected mother and child.

Although the proposed modifications will carry costs, in that they will take more time, may delay testing and will sometimes result in rejection of testing, these will be recouped from access to the previously unexploited resource of family support. The goals of HIV testing will be met, in that more people will know about the disease and its prevalence and will understand its modes of transmission and how to protect themselves against it.

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## VIII. CONCLUSIONS AND RECOMMENDATIONS

### *A summary of this dissertation*

First person informed consent is appropriate according to the African view, described by Godfrey Tangwa, that all humans are moral agents. First person consent should be practised in Africa, but with sensitivity to the cultural differences between Africa and the West. Health care workers taking consent also have to be aware of the coercive effect of the great imbalance of power between the health care worker and the African subject and of the effect on a woman of unfamiliar circumstances and facts. Family deliberation because of the 'extensive' African view of personhood, would not violate rights of the individual.

A review of alternatives to first person informed consent and concludes that there is no alternative that does not violate human rights or pose the threat of marginalizing or driving infected persons underground. Mandatory testing is shown to be unacceptable in all but very circumscribed and special circumstances

Although there is convincing argument that first person informed consent is appropriate in Africa there is *prima facie* evidence to suggest that the 'standard' method used to obtain consent for performing an HIV test in Africa may fail, in the sense that mothers who have consented to testing do not return for test results and that dissemination of information regarding actual HIV infections is clearly impeded.

Evidence is presented in support of the contention that disclosure does not inevitably result in violence or family rejection and ostracism. Potential violence is not a sufficient argument against disclosure. Violence is predictable from a history of previous violence and other risk factors. The minority of women in Africa would be at risk of violence and they can receive appropriate counsel.

Non-disclosure of HIV status to family is prevalent among Xhosa speaking women living in Cape Town and is also frequent in the rest of Africa. These women have thus far been tested and counselled in the 'standard' way. Individual cases described in Chapter IV illustrate the ethical dilemmas created when the 'standard' process of

informed consent, with respect for patient confidentiality is followed by non-disclosure; and how the respect for the autonomy and privacy of an individual leads to confrontation and suffering. A change in the way consent is taken, so that women are offered the opportunity of involving the important people in their support systems in the decision, may offer a way of avoiding this suffering and these dilemmas.

Fear of stigmatisation appears to be the main motive for non-disclosure, but non-disclosure also perpetuates stigma, because the fact that most HIV infections in African women are contracted by ordinary women in stable relationships with one partner is obscured. For the sake of the delivery of apposite information to the community at risk (which is in the case of Africa is the whole community) it is important that a strategy be developed to break the cycle of stigma and non-disclosure. Modification of the consent process to involve the family in the course of pre-test counselling may be such a strategy. While the mother might risk stigmatisation, the risk of this is low, given the outcomes following disclosure as reported in Chapter IV. The woman who discloses also stands to gain great personal benefit from access to emotional support from her family.

In Africa, with its poorly developed health care system, access to adequate post-test counselling and support for the many people infected and affected by the HIV/AIDS epidemic is unlikely to be achieved through state-supported structures. The strength of the African family must be exploited to provide the sort of emotional support needed. Without disclosure, families will not be able to provide this support. Family deliberation at the stage of pre-test counselling, because it will serve to inform the people who need to know would appear to offer best opportunity of family support.

A model of African society is presented as a complex interactive system that for its survival is dependent on its ability to register and adapt to signals indicating danger, as is the case for any sentient being. Non-disclosure is seen as a serious obstruction to the flow of information regarding HIV and the risk of infection, with potentially lethal consequences to society.

A modification to the 'standard' process of informed consent is described in Chapter VII. This modification proposes that the African woman who is being counselled

prior to an HIV test on herself or her child should be invited and advised to deliberate with her family before deciding on consent. The reasons for the introduction of this modification are given in detail and it is explained how it would help to shield the woman from the unexpected and deleterious effects of the 'standard' process of informed consent.

### ***Possible objections to the thesis of this dissertation***

The thesis of this dissertation states that there is a problem with the application of informed consent for HIV testing in Africa that may be corrected by a modification of the consent process. This dissertation does not test this assertion by means of research but sets out to demonstrate the difficulties with informed consent by a study of patterns of disclosure and support and by adducing evidence from a review of the literature. The thesis is not proven by this dissertation, but it does indicate the nature and extent of some of the deleterious outcomes of informed consent. The suggested modification to the process of informed consent is presented in detail and its possible outcomes are discussed.

The evidence presented from various studies in Central and Southern Africa refutes the possible argument that the thesis of this dissertation is spurious, since it shows that that first person informed consent is universally applicable. Further evidence, indicating failures in the implementation of voluntary counselling and testing, counters the possible argument that African culture is so similar to Western culture that no modification of the consent process is necessary.

It may be argued that stigma and lack of access to medical treatment accounts for poor uptake of voluntary testing and counselling and the apparent failure of the 'standard' process of pre-test counselling and proposed imperfections in the consent process have nothing to do with it. This assertion is not proven either. Future research may be able to distinguish the effects of stigma from those of failure of the consent process.

It may be argued that the modification suggested to the consent process, namely that women be given the opportunity to consult with their families before consenting to a

test is too cumbersome, that it would require too many counsellors and may result in women not returning for the test. These objections could be met with the following arguments:

- Where there is no haste in performing an HIV test on an ill child or at an antenatal clinic, a delay in consent can be accommodated without harm.
- The benefit that accrues to society in terms of the spread of knowledge about HIV/AIDS and to the mother through access to family as a support resource outweighs the cost of counsellors and return visits.

It may be argued that since an opportunity for deliberation leaves the woman open to coercion by the family, any benefit derived from the proposed modification to the 'standard' informed consent process is outweighed by the woman's potential loss of autonomy. This may be so, and would be an undesirable consequence of the modification. The question of the African woman's sense and exercise of autonomy is difficult. It may be that she is so much a part of her family that their preference becomes her preference, but this is an assumption for which more anthropological data is required, particularly in the context of HIV/AIDS.

### ***Turning back the HIV/AIDS epidemic***

Plans to limit the spread of the heterosexual HIV/AIDS epidemic in South Africa have generally centred on education regarding safe sex and the supply of condoms. These plans have generally not addressed the needs of HIV positive persons and only recently has it been announced that the government intends to introduce prophylaxis for mother to child transmission.

It is doubtful whether the fragmentary approach followed thus far will have any real effect in controlling the spread of HIV/AIDS. What is needed is a comprehensive plan, managed and monitored in a seamless, integrated way. The elements of this plan should include education, access to voluntary counselling and testing and access to care for infected persons. The ideal is an educated population providing patient driven demand for counselling and testing in a stigma-free society:

- Every sexually active person must be educated about risk of infection, high-risk behaviour and signs and symptoms of the disease.
- There must be an accessible health care resource to provide testing and a health care benefit for those testing positive.
- Education and the *knowledge that a health benefit will accrue* must motivate persons at risk to seek counselling and testing.
- HIV counselling and testing must be available and performed with consent.

These elements have been in place in the United States of America and have resulted in the limitation of infection in at-risk populations (although for other reasons infection rates in the gay population may be on the increase again). In South Africa, there are particular deficiencies in a general access to health care – and hence to HIV testing facilities, a lack of benefits for persons who test positive and a shortage of counsellors.

Some of these deficiencies are being addressed. The recent announcement of plans to introduce universal prophylaxis against mother to child transmission will provide a great incentive for pregnant women to have themselves tested. Great deficiencies in general access to health care, access to testing and counselling remain, and will have to be addressed before the epidemic can be turned around.

Besides the implementation of plans and remedies elaborated elsewhere, the South African response to the epidemic must develop its own innovations to improve on what has gone before. One such innovation would be to harness the strength of the African family in the counselling and support of HIV positive persons. But this cannot happen if ambient stigma against HIV/AIDS means that families are not informed when individual members discover their infection.

Because health services in Africa cannot provide adequate support for HIV infected mothers and children, it is vital to their personal interests that they are not isolated from their families, and that they be permitted to tap into the great strength of the cohesive African family for their emotional support. The thesis of this dissertation

argues that 'standard' implementation of informed consent, through its emphasis on individual autonomy and respect for privacy has the unexpected and deleterious effect of increasing the chances that the mother will not disclose her diagnosis to her family. Non-disclosure leads to the loss of empathy and emotional support, with ill effects for the woman and her child. While it is possible (though not likely, given the limited evidence presented in this dissertation) that disclosure may lead to stigmatisation by the family, non-disclosure imposes a certain self-stigmatisation on the mother, in that she has to work to maintain a false image of herself within her family and produce spurious explanations of symptoms, illness and visits to hospital.

It is congruent with thesis of this dissertation furthermore, that disclosure to family is a vital link in population education, without which an accurate message regarding the risks of infection to ordinary people will not be delivered. The onward link from education to health care access, access to testing, testing to knowledge of HIV status, knowledge of HIV status to public awareness, particularly in Africa, is family disclosure. To this end, all relevant tasks carried out by health care workers should be re-examined to assess whether in their present form and method they best serve to facilitate voluntary disclosure of HIV status to partners and family.

This indicates an important direction for future research: Into the dilemmas surrounding the application of informed consent as a process in non-Western countries, where the tradition of individualism and personal autonomy is less obvious and strong. In Nguni speaking persons there is less separation between a persons and their family and persons are not distinct from their universe.<sup>76</sup> How the infected person and her experience of illness are woven into the fabric of an African family are future questions for anthropological research. The answers may help the health care worker operating in the Western paradigm, when obtaining first person informed consent from a pregnant woman for an HIV test or from a mother for an HIV test on her child, to understand what she is doing - and to whom.

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<sup>76</sup> Lauraine Vivian. An HIV positive baby. Abstract submitted to the conference. 'Children in their places' Brunel University London June 2001.