

## Saving the history of the defeated and the lost – ethical dilemmas in the midst of the AIDS epidemic.

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### Summary

"My life is broken!" These are the startling words of a young dying AIDS patient, one of many thousands dying daily in South Africa to-day. This essay tells the story of the encounter of one patient and one doctor. It tries to find answers to the dilemmas that face South African doctors by exploring the 4 ethical principles of beneficence, non-maleficence, autonomy and distributive justice. While these principles give certain guidelines in caring for patients, they create further dilemmas themselves. Are they really as neutral as they claim? Can they really help to protect the weak or are we left with a toothless tiger?

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### Introduction

"My life is broken." These words still ring in my ears. Time is rapidly running out for Maria M. At 26 years of age she faces an unnaturally early death. Unnatural, yet today an all too common, early death. As I stand next to her bedside in our local hospice I feel helpless. It is not the helplessness of medical ignorance, the uncertainty of diagnosis or treatment. It is not the helplessness of the young doctor trying to cope with his first dying patient. That sick feeling of professional helplessness when you realise that despite those 6 years of dedicated study, you are powerless to stop this person, who lies in the bed in front of you, from dying of some incurable illness. No, it is not that kind of helplessness. It is a helplessness that borders on hopelessness. The helplessness that wants to cry out, "IT'S NOT FAIR!" Maria is dying

of a preventable disease, Maria is dying of a treatable disease, Maria is dying because someone else has decided that the National Health Budget has other priorities. Like no other illness in my experience, AIDS faces me with more dilemmas, more torments of conscience, more fears and more frustrations.

And what about Maria? She too faces fears and frustrations. Does she know anything about the 4 principles of ethics? I doubt whether she has ever heard of beneficence, non-maleficence, autonomy and distributive justice. If she did, would it help her deal with her situation? Has knowing about them helped me, and what's perhaps more to the point, has it influenced the rich and the powerful to care for the poor and the weak? In this essay I will attempt to explore the relevance of these principles and the ethical dilemmas that arise in pro-

viding health care to HIV/AIDS patients in South Africa today, as we try to cope with the overwhelming reality of the AIDS epidemic.

### The Principles:

A principle implies a fundamental or general truth, a moral rule or a basic tenet. Gillon, based on the approaches of Beauchamp and Childress, and the rationalistic ethics of Immanuel Kant, has popularised the 4 so-called principles of beneficence (do good), non-maleficence (do not harm), personal autonomy (deliberate self rule) and distributive justice (fair adjudication between competing claims). In an increasingly secular, pluralistic society, the Western medical profession has been trying to find a common or universal moral language, a means of creating a common moral commitment and thus a means of resolving ethical conflicts.<sup>3</sup> Both Twycross and Latimer label these principles "cardi-

nal". This implies that they are fundamental and general, and thus applicable to all. Gillon, based on the work of W D Ross, describes them as "prima facie", meaning that they are binding unless one principle conflicts with another<sup>3</sup>. Each of the principles should be considered in relationship to the others. There should be not hierarchy of importance but an attempt should be made to reach an acceptable balance between them all. After discussing these principals in relation to the dilemmas facing us in caring for AIDS patients, I will examine the dilemmas that these principles themselves can cause.

### The Dilemmas:

A dilemma is a situation necessitating a choice between two equally undesirable alternatives or a problem that seems incapable of a solution<sup>4</sup>. Without a doubt, the AIDS epidemic presents numerous ethical dilemmas to everyone living in South Africa today, whether we are patients, doctors, politicians or ordinary citizens.

Rather than being general and vague I will concentrate on the dilemmas that confronted me with the care of my patient, Maria, as they are typical of the problems facing many doctors in South Africa today. I will not be able to address all the dilemmas but will cover sufficient to illustrate the application of the 4 principles.

### Distributive Justice:

Despite severe oral thrush, painful mouth ulcers and a troublesome cough, Maria smiled at me as I greeted her. Her large brown eyes shone out of deep sockets. She had done the usual round of doctors trying to find out why she was not getting better. Now she was too weak to work and her mouth too sore to eat. She was pale, feverish and her right lung was full of crepitations. The referring doctor reported that her chest X-ray was normal, however, I was worried about pneumonia or TB. The nystatin and co-trimoxazole she was taking, were not helping. Talking made her

cough more so I didn't ask too many questions. She was aware that she was HIV +. I explained that I would check her sputum for TB and in the mean time I would change her antibiotic and try to relieve her sore mouth and cough. I said nothing about her anaemia. I gently squeezed her forearm as I said goodbye. She smiled again.

Distributive justice is, I believe, one of the main dilemmas related to the care of AIDS patients. Very few ordinary South African can afford the cost of the anti-retroviral drugs at current prices. With 4,7 million South Africans infected with the virus and with an estimated 10 million dying in the next 10 years, the Government has been reluctant to make these drugs available to state patients. This is understandable, as the cost of these drugs alone would swallow the whole National Health budget. The question that could, however, be asked is whether the Health Budget is big enough? Why is so much being spent on defence for example? Is it justified at this time to spend R40 billion on armaments? Is the potential threat of war greater than the actual tragedy of the 250 000 AIDS sufferers who died last year?

The Government's battle with the international pharmaceutical companies is another interesting dilemma. Does the Government overrule the patent rights of these companies for such drugs as fluconazole and allow parallel importing of cheaper generic equivalents from the Far East? Is that stealing "intellectual" property or is it acting in the best interests of the majority of South Africa's citizens? Would that put us on a par with Mugabe and the redistribution of land? The fact that the USA has similar legislation and does not hesitate to overrule patent rights if this is deemed in the interest of US security, makes the protests of American companies sound a little hollow.

Let us return to Maria. She is

anaemic and may require a blood transfusion. In many state hospitals, especially those in rural areas, AIDS patients are not usually given blood, as supplies are extremely limited. The argument of futility is invoked. Is it justified to use a scarce resource for a patient who will die anyway when it may be needed to save the life of an HIV- patient? Admission to the ICU, use of a ventilator or transfer to a tertiary hospital is also governed by HIV status. As Maria is still not terminal I feel it would be justified to disregard this rule favouring a potential need in the light of a real one. The argument of futility is difficult to justify against the principle of beneficence. The doctor must be free to override it if it is in his patient's best interest. Actual need must outweigh potential need. If Maria had presented at the same time at a rural hospital as a shocked patient with a ruptured ectopic pregnancy, and if there was only 2 units of blood available, the choice would obviously favour the shocked patient. The doctor is, however, not obliged to give unnecessary or futile treatment just because the patient wants it.<sup>5</sup> Fortunately Maria's condition did necessitate a blood transfusion.

### Autonomy:

I scratched in the hospice's cupboard of "left over medicines" and found some flucanazole suspension and azithromycin tablets. I prescribed these together with 5 mgs of morphine sulphate solution 4 hourly. Should I have discussed these drugs in detail with Maria before prescribing them? Does personal autonomy not require that? In a sense that's true. What I did could be seen as paternalistic (I know what's best for you), however, paternalism is not the opposite of autonomy as Latimer claims<sup>5</sup>. One could certainly invoke the principle of beneficence (doing good) in the light of Maria's general weak condition and the fact that the unpleasant side effects such as nausea and constipation are not dangerous. To give her these drugs without a full expla-

nation was thus also not a violation of the principle of non-maleficence (do not harm). The benefit, treating the lung infection and relieving the pain, far outweighed the unpleasant side effects. In such situations, the welfare of the patient relies heavily on the integrity of the doctor and his strong sense of benevolence towards the patient. When the reason for the nausea was explained to Maria the next day, she was quite willing to continue with the medication. A patient more familiar with the various kinds of medication may have needed a different approach. A more detailed explanation may have been more appropriate prior to starting treatment. Sometimes there is the risk of the patient being unwilling, for apparently spurious reasons, to take the suggested medication. I have found it better to accept the patient's choice rather than to use coercion.

#### **Confidentiality:**

Had the referring doctor erred by indicating Maria's HIV status in his referral note without her consent? Are we entitled to that information if our lives are not at risk? (We should be taking universal precautions with everyone.) Is this a breach of confidentiality and autonomy? Some may agree, but I feel a strong case can also be made out for the fact that withholding such information may not be in the patient's best interest as it may cause delays in treatment or the unnecessary cost and delays of repeat testing. Does using a "secret" code on patient's notes ensure confidentiality? At our hospice we use the code T4. In my experience it does not ensure confidentiality as very soon the code becomes general knowledge and everyone at the hospice knows who has AIDS. Caring for an AIDS patient puts staff under stresses that they were initially not used to handling. Despite all my own medical knowledge, when I had to deal with my first AIDS patient in 1986, I could not stop myself imagining that the virus would get into me through the soles of my shoes! Needle stick injuries are not

uncommon and can cause sero-conversion. Post exposure prophylaxis is also not without risk. While knowing a patient's status does not ensure protection, it should modify treatment options. This was one of the reasons for choosing oral azithromycin over parental penicillin for the treatment of Maria's pneumonia. I thus feel all staff have a right to know the status of a patient. It would be unfair to confine this to the medical and nursing staff and to exclude the caregivers and even the cleaners. All staff should understand the need for confidentiality beyond the work environment.

Over the next few days, Maria's condition gradually improved, although she was very nauseous. By the end of the fourth day her mouth had healed, her cough had improved and her sputum tests were negative for TB.

I arrived to do a ward round during visiting time one evening. Maria's parents and another couple from their church were present in her room. Her father asked to speak to me, and so together with Maria's mother we went through to the lounge. Her parents wanted to know what was wrong with her. I asked them what they knew and they were rather vague. I indicated that I would first need to speak to Maria and get her permission to discuss the details. I then had to go back to the ward, ask the friends to leave and only then was I able to get Maria's consent. Her parents already knew the real diagnosis; they just wanted to make sure I concurred with the previous doctors. Maria did, however, not want anyone else to know not even her siblings. I had a fruitful discussion with her parents. In fact they had lost their eldest daughter in August last year also from AIDS. Maria's mother had as a result taken matters into her own hands and had already discussed the real diagnosis with her remaining children without Maria's permission. Was that a violation of confidentiality? Not according to her parents, as Maria

was female and unmarried, and therefore in the eyes of her parents and Zulu speaking people generally, still a minor. The parents viewed the safety of the remaining children as more important than the breach of confidentiality. Cultural differences need to be taken into account in such situations. Personal autonomy does not have the same meaning in more traditional cultures<sup>6,7</sup>. Decision making in such cultures is often corporate rather than individual. The emphasis Western society places on individual autonomy and freedom is viewed with great suspicion.

Maria's recovery meant we did not have to face the other common dilemma that confronts the doctor, namely the dilemma of what to write on the death certificate as the cause of death. Families often try to persuade the doctor to write some fictitious diagnosis in an effort to protect the deceased person's request for confidentiality. However, falsification of a death certificate is a serious offence carrying stiff penalties<sup>8</sup>. No other diagnosis creates such a dilemma. Although the stigma attached to the diagnosis makes the desire to keep it secret understandable, there is a negative aspect as well. Uganda has adopted a more open approach and disclosure is encouraged. This is one of the reasons why Uganda has been able to achieve behavioural changes and a remarkable reduction in its high national incidence while other African countries have not<sup>9</sup>.

#### **Beneficence:**

Once Maria was improving I tried to probe a little further regarding her personal circumstances. I knew her parents were caring and supportive. Both of them were employed in Pretoria. Maria has a 5-year-old child who is being cared for by his father's family. She and the father of her child were no longer on good terms. Maria felt that reconciliation with this man was not possible. She also informed me that she did not get AIDS from him. I felt uncomfortable about

enquiring more deeply into her personal affairs. It must have been hard for her to lie there in the hospice bed separated from her own child by distance and personal conflict. I understood now what she meant about her life being broken. Perhaps I should have persevered but as she did not ask for help in this matter, I changed the subject. I knew the family was very religious and so I asked how she felt about the future. Without hesitation she said she was not afraid of dying and that she was sure of going to heaven. We discussed this for a short while but again I did not pursue this matter much further. The next day she was so much better that I was able to discharge her. She almost danced out of the front door with the biggest smile I have seen in a long time. Beneficence must include more than medication and physical care but here great sensitivity is needed to ensure that no harm is done (non-maleficence) by forcing one's own solutions on a vulnerable patient. Perhaps I had given up too easily in my attempt to help Maria with her social and spiritual needs. (Perhaps I was really dealing with my own needs?) These issues create a dilemma for some doctors who may think social and spiritual issues are some-

one else's job. They need time, sensitivity and skills that many doctors feel they don't have. In reality leaving them for someone else usually means they are left unattended.

"My life is broken." We end where we began. For many, even for Maria herself, her life is broken. Like the branch of a tree, broken by a violent storm, it hangs limply, slowly dying. I have told her story because in the telling she lives on. It is as the philosopher, Paul Ricoeur says, necessary "to save the history of the defeated and the lost."<sup>10</sup>

#### Post script:

The four principles give certain guidelines in caring for patients, however, for some they create a number of dilemmas themselves. They have been developed in the context of a Western secular perspective. As has been pointed out they are not always appropriate in all cultural settings. Thus to imply that they are cardinal and binding is misleading. To our post-modern ears, Gillon's claim that these principles are morally neutral sounds a fine example of tolerance of the views of others. However, if all moral positions are neutral, can one really talk about ethics at all?<sup>11</sup> Is moral neu-

trality not an oxymoron? In addition, Gillon claims "that it is the process through which laws are enacted that confer moral legitimacy not the content of the laws." This claim is also open to serious question. It is a complete inversion of the tradition view that ethics should determine morality and that morality should determine the law. A law based ethic can very easily lead to the exploitation of the weak and the few. This weakness is widely recognised.<sup>12</sup> However, the solution of an international ethics committee as proposed by Singer and Benatar still leaves us with a toothless tiger. I feel that the call to a return to virtue has more merit than the relativism of the 4 principles.<sup>13</sup> The integrity of the doctor is a better safe guard especially when it is underpinned by an acceptance of the sanctity of human life and a morality determined by transcendent values. The 4 principles are based on a number of unstated presuppositions. Wilkinson questions these assumptions and asks if secularism is an adequate basis for medical ethics as it excludes a major part of reality from consideration.<sup>14</sup> While claiming neutrality, secularism unilaterally imposes its own point of view on all others.

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