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Parental consent or refusal to consent to HIV testing in children

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PARENTAL CONSENT OR REFUSAL TO CONSENT TO HIV TESTING IN CHILDREN

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A research report submitted to the Faculty of Health Sciences, University of the Witwatersrand, Johannesburg in partial fulfilment of the requirements for the degree of Master of Science in Medicine in the field of Bioethics and Health Law

Johannesburg, 2009

DECLARATION

I, Keith Duncan Bolton declare that this research report is my own, unaided work.It is being submitted for the degree of Master of Science in Medicine in the field of Bioethics and Health Law of the University of The Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at this or any other University.

Signed: .....

This ..... day of .....….. 2009

Dedicated to all those thousands of children who have suffered and died from this diabolical disease.

ABSTRACT

Parental Consent or Refusal to Consent to HIV Testing in Children

The acquired immune deficiency syndrome (AIDS) continues to represent the greatest infectious threat to humans of all time. It is estimated that some 33 million people are currently infected with the causative organism, the human immunodeficiency virus (HIV). More than 2 million of these are children. The AIDS epidemic now has its epicenter in sub-Saharan Africa where 75% of deaths occur. The treatment of AIDS with antiretroviral drugs (ARVs) has changed the outcome from inevitably fatal over months to years, to a chronic but manageable condition. Adherence to treatment is essential for maintaining good health and avoiding the development of resistance.

Young children with HIV infection usually obtain the virus from their infected mother at, or about the time of birth or via breast milk. Prevention of mother to child infection (PMTCT) is possible through the use of ARVs and this has resulted in a dramatic decrease in infected children in the developed world. Poor provision and uptake of PMTCT in the developing world means that many children are still being infected. In these environments, over 60% of the children who die are infected. Treating these children with ARVs will usually prevent death and return the child to a good quality of life in the family. It is necessary to test the child for infection before embarking on life-long complex treatment and this is done by testing blood or saliva for the virus or antibodies to the virus. A positive test in the child is usually a proxy for a positive test in the mother and this obviously has profound implications for her life. In all infants suspected of infection, a test is advised. In the Rahima Moosa Mother & Child Hospital about 10-15% of mothers refuse testing for their infants. These children are therefore denied the opportunity for life-saving treatment.

This essay discusses the reasons why mothers may refuse HIV testing for their infants and explores the possible ethical choices and responses of healthcare workers to this refusal.

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Introduction:

The AIDS epidemic has cut a swath of destruction through South Africa leaving death, disease and untold misery in its path. The timing of the epidemic could not have been worse for our emerging democracy. The brunt of the medical effect is felt by the most productive sector in the society, young adults, and arguably, the most vulnerable members of our society, children. The epidemic has drastically changed the nature of medical practice for all our healthcare professionals but in no sectors is this truer than the disciplines of internal medicine and paediatrics.

The Human Immunodeficiency Virus (HIV), causative organism for the disease, has been studied more extensively than any other pathogenic organism, yet cure from AIDS remains but an aspiration, its treatment complex, and prevention whilst identifiable, is difficult. The disease thrives best in those members of the community who are poor and already vulnerable. The relationship between poverty and HIV infection is by no means simple, and is denied by some. This has been explored by Nattras (2009) who concludes that there is no definite evidence of a direct link between poverty & HIV. However, he concedes that malnutrition and economic vulnerability may well increase the risk of HIV infection as they link to an environment where risks and risk-taking behaviour may be linked to economics. In our clinical experience, many of the infected patients using our services live in informal urban settlements where violence, woman & child abuse

and food insecurity are commonplace. Public service health facilities are therefore at the centre of the provision of care.

My personal observations after more than 40 years of association with the State health facilities leads me to believe that these services are chronically underfunded, ill equipped, and lack professional and support staff, equipment and other services . The sexual transmission of AIDS and the early association of the disease with the gay population resulted in massive stigmatization of those infected and affected. National denialism by the highest governmental officials and the Department of Health seriously inhibited a prioritization and national response to the infection (Thom & Cullinan 2009).

The scale of the infection is unprecedented with about 25% of pregnant women testing positive. The medical effects of the disease fill textbooks and scores of new medical journals are published in the field. There are also widespread deleterious effects in education, the economy, and almost all sectors of our human endeavour.

The effects on health-care workers cannot be over-emphasized. As stated by Richter *et al.* (2009:200) “providing care for HIV-positive hospitalized children is extremely stressful for both health care professionals and caregivers. It may provoke feelings of helplessness and lead to emotional withdrawal as a

mechanism for blunting the tension of caring for ill and dying children. While this helps staff and caregivers to cope with feelings of distress, it may compromise the child's care."

Children, who become infected, are usually infected from their mothers, mostly around the time of birth or from ingestion of infected breast milk. Moral and ethical dilemmas abound. In this essay, I have attempted to address only one major area, of many, that affect the paediatrician caring for children with AIDS. In South Africa, some paediatric clinics have as many as 60% of their children testing HIV positive (Personal communication, Ashraf Coovadia, 2009). Testing children for HIV is essential for confirming the diagnosis and planning treatment. Treatment with Anti-Retroviral drugs (ARVs) is essential for their long-term survival.

Many mothers refuse consent to test either themselves or their infants and in doing so deny themselves and their offspring the possibility of treatment. In our hospital (Rahima Moosa Mother & Child Hospital), approximately 10-15% of mothers counselled refuse consent to testing their children (unpublished and anecdotal data). This is despite a motivated team of healthcare workers dedicated to providing comprehensive care to HIV positive children and their families.

While the informed competent adult has the legal and moral autonomy to choose whether to accept or reject medical intervention, the under-age child relies on the surrogate responsibility of the caregiver for their well-being. The healthcare worker may appeal to the State to act against the wishes of the surrogate (usually the parent) where he or she feels that this is in the child's best interests.

This paper was planned to have an empirical arm aimed at an attempt to discern reasons (from a questionnaire given to mothers or caregivers attending a paediatric outpatient department) they would consent or not to either be tested, or have their ill child tested for HIV. Due to an unforeseeable staff problem, it was impossible to carry out that type of research at the time. Thus, this work is presented as a preliminary report that intends to highlight some of the ethical problems faced by paediatricians and staff as they work and care for probable HIV/ AIDS suffering children.

It will explore some of the options and ramifications arising from these situations and try to plot an ethical or moral set of choices that are available to the paediatrician. I will set out the background information from a medical and clinical ethical point of view before using a clinical scenario as a framework to discuss some suggested options and possible solutions.

Chapter 1: An Overview of HIV

It is almost impossible to remain completely up to date regarding the statistics pertaining to the spread of HIV and the AIDS epidemic locally and around the globe. The UNAIDS/WHO update for 2008 estimated that about 33 million people were living with HIV and of these, approximately 2 million were children under the age of 15 years. Sixty seven percent of persons living with AIDS were living in sub-Saharan Africa and this region was the site of 75% of AIDS deaths in 2007 (UNAIDS 2008:32).

Regarding South Africa, the first child that I was aware of who had died from the HIV/AIDS occurred more than 20 years ago. The child was apparently infected through surrogate breast-feeding and rapidly succumbed to the disease in the second year of life. Shortly after this, in the mid 1980's, a prevalence study in the antenatal clinic at the then-Baragwanath Hospital[1] showed that 0,3% of mothers tested for HIV were positive (unpublished data). The latest published National Annual Antenatal Prevalence data from the South African Department of Health (2007; Avert 2009) reports a prevalence of 28%.

From this report we note that there are marked prevalence differences between the provinces from the lowest (Western Cape) of 12.6% to the highest (KwaZulu-

[1] Now the Chris Hani-Baragwanath Hospital

Natal) of 37.4%. Gauteng has a prevalence of 30.3%. The disease has the highest prevalence in the sexually active age groups with the greatest prevalence in those aged 25-29 years. Females in this age group are infected in a ratio of 2-3: 1 when compared to males. [2] These, of course, are the "mothers" of the patients presenting to paediatricians.

The overall prevalence in young children in South Africa is about 5% (Personal communication, Ashraf Coovadia, 2009), most of whom contract the disease through mother-to-child transmission at or about the time of birth or through infected breast milk. In late adolescence, the prevalence increases to about 9% because of sexual activity commencing. For the purposes of viewing the holistic picture of the negative effects of HIV/AIDS on children, I have largely relied heavily on the WHO review entitled *The role of the health sector in strengthening systems to support children's healthy development in communities affected by HIV/AIDS* (Richter L. 2006).

This extensive report was published in 2006 and the main author is Prof. Linda Richter, a renowned South African academic psychologist. Children are adversely affected by AIDS in many ways. The most obvious group is those infected by the

[2] There are biological explanations why heterosexual women are at greater risk than heterosexual men for acquiring HIV infection when exposed. This relates, in part to the number of receptors available to the virus in the vagina. This is a similar explanation to increased risk in the uncircumcised versus the circumcised male.

virus. Other groups include those children living with chronically infected parents, AIDS orphans, and those older children, prematurely given the responsibility of heading-up families. In the global context and especially in the epicentre of the epidemic in sub-Saharan Africa, most children with infection die prematurely.

The human immunodeficiency virus is transmitted from mother to child by three major routes;

a) In-utero - In pregnancy across the placental barrier before the onset of labour. This route is relatively uncommon.
b) Peri-partum – At or around the time of labour and delivery
c) Post- partum – mostly through mothers breast milk

1.1 Prevention of mother to child transmission (PMTCT)

PMTCT is feasible and practical by the combination of all or some of the following interventions (Zeichner & Read 2006: 107-109):

i) Prevention of trans-placental viral transmission. This is done by lowering the viral load in the pregnant mother-to-be. Transmission across the placenta is not completely predictable but depends largely on the viral load in the mother. High viral loads occur in two major clinical situations. The first is very early after

primary HIV infection in the mother during the sero-conversion period. The mother may have flu'-like symptoms or be asymptomatic. She may test negative for HIV at this time. The second situation with high maternal viral loads is late in the course of the maternal infection when the mother's immunity has fallen to critical levels and she is exhibiting frank AIDS.[3] The lowering of viral load depends on the administration of ARVs. This is usually done per protocol depending on maternal indications but forms an important method of PMTCT in the private sector and in developed countries. These interventions are not currently part of the South African Government's PMTCT protocol but this is changing.

ii) Administration of ARVs before the birth to the mother and after birth to the baby. There are various protocols for this; the simplest (and cheapest) is to administer a single dose of Neviripine orally to the mother during labour and the baby shortly after birth. This reduces the mother-to-child transmission from about 30% to about 10%. More complex and prolonged ARV regimes substantially decrease transmission even further. The South African National Department of Health has adopted a multidrug protocol and this is the mainstay of PMTCT.

[3] The common co-existence of HIV infection and pregnancy is obviously to be expected – both conditions being sexually transmitted. Pregnancy is a condition of decreased immunity and the progression of HIV infection is enhanced in pregnancy. The majority of woman infected with HIV are, as to be expected, clinical well but there are women in all stages of the disease.

iii) Caesarean delivery. Elective Caesarean delivery further lowers transmission rate from mother to child. This practice is followed in some countries and by some obstetricians in the private sector but is not currently feasible in the public sector in South Africa.

iv) Safer Infant Feeding Practices. The live virus is secreted in mother's milk. The infant is at risk for acquiring HIV infection from this route. Breast feeding increases mother-to-child transmission by about 15%. Factors which increase this risk of transmission are not all known but include the viral load in the mother and contamination of the milk with maternal blood (through cracks & abrasions). The oral route is not an "efficient" way for the infant to acquire infection and thus, infected milk does not inevitably result in infection.

Factors which increase infection in the baby include prolonged breast feeding, sores and infections in the infant's mouth (such as "thrush") and "mixed" feeding where anything other than breast milk is given to the child. Contaminated water and food seems an important determinant of the increased risk of mixed feeding. As an option to avoid post-natal mother-to-child transmission via breast-feeding, the State has included free formula milk for mothers who choose not to breast feed.

The major problem with this option is that failure to breast feed has other major disadvantages for child survival and long-term well-being. The paediatrician or

healthcare practitioner is advised to give education and non-directive counselling to mothers in this regard but the "correct" choice (breast or bottle?) in HIV infected mothers remains an area of hot debate among specialists in the field. The complexities in these choices is well covered by Buskens and others. (Buskens *et al.* 2007:1101-9).

The World Health Organization (WHO 2001) and the South African Department of Health (National Department of Health 2008) recommends the following:

> "When replacement feeding is *acceptable, feasible, affordable, sustainable and safe*, it is recommended that HIV infected mothers avoid all breastfeeding; if the available replacement feeding does not meet all of these criteria, exclusive breastfeeding is recommended during the first months of life."

The South African Health Department is reviewing the provision of free infant formula.[4]

[4] While the provision of formula will avoid HIV transmission in breast milk, free access for the first six months of life is expensive and the mother may not be able to sustain this expense beyond this period. The milk provided on contract is also easily identified from the container and may stigmatize the mother.

The successful implementation of PMTCT in the USA has virtually seen a halt to new AIDS cases in young children there (Zeichner & Read 2006: 84, 126). Thus, wherever successfully introduced, PMTCT is highly effective in reducing paediatric HIV infection. A substantial decrease in infant deaths in the Witbank area of Mpumalanga can be attributed directly to better application of PMTCT (van Rensburg 2005:51-53). However, there have been major obstacles to the provision of PMTCT in South Africa. The programme has been applied in a patchy fashion although more than 90% of health facilities that offer maternity services are now covered. One of the stumbling blocks is the poor uptake of testing by women. Universal testing of all women during pregnancy would have a profound effect on identifying HIV infected mothers and improve opportunities for preventing mother-to-child transmission.

A precedent exists as universal serological testing for syphilis (WR Test) in pregnancy has been the practice for decades. WR Positive women are treated with penicillin. If a mother escapes testing, there are many institutions that will then, routinely administer penicillin to the untested newborn infant. No process for special consent for these practices exists.

HIV infection in South Africa (and elsewhere) has been given "special" legal and social status and to some extent, this impairs management of patients'.[5] Armstrong recently reviewed the suggestion of mandatory testing for HIV in pregnancy in a high prevalence region. He discussed the ethical arguments for and against this recommendation and came to the following conclusion;

"While mandatory testing is ethically plausible, particularly when coupled with guaranteed access to treatment and care, the discussion argues that the moment to employ this strategy has not yet come. Many barriers remain for pregnant women in terms of access to testing, treatment and care, most acutely in the southern African setting, despite the presence of national and international human rights instruments aimed at empowering women and removing such barriers. While this situation persists, mandatory HIV testing during pregnancy cannot be justified" (Armstrong 2008:1).

While one may recognise the problems Armstrong raises, a missing element remains. This is the fact of a pregnancy and the fate of the fetus. In an ethical

[5] The emergence of HIV as an epidemic coincided to some extent with the emergence of the development of "Era of Human Rights". The nature of AIDS is such that it is highly stigmatized because of the sexual transmission of the disease, the initial recognition in the gay community and the risks associated with multiple partners. These and other factors led to the disease being distinguished from others in the way it is dealt with; examples include consent to testing is complex and requires extensive counselling and the fact that specific rights have been developed to protect the HIV positive person in the community. These factors often inhibit the ease of diagnosis and treatment.

dilemma, greater weight should always be given to an “innocent”- in this case, a fetus or child. Another question that may be raised is who decides when, if ever, the ‘situation’ will ever be optimum for mandatory testing.

Testing for HIV in South Africa is performed in an “opt-in” fashion. This means that the patient should voluntarily request testing. Regulations require that prior to testing, the patient should be fully counselled (pre-test counselling) and when the results are communicated, further counselling is required (post-test counselling). Written informed consent is obligatory. Parental or other surrogate consent is required before testing minor children. This whole process is referred to as Voluntary Testing & Counselling or VCT. VCT is widely offered at health facilities in South Africa.

One of the success stories for improving the uptake of testing and consequent in PMTCT interventions has been demonstrated by neighbouring Botswana (Creek *et al.* 2007:106). Botswana had an even higher national HIV prevalence rate South Africa (37.4% in 2003). They previously followed an opt-in testing policy and had low uptake. In 2004, the then President, Festus Mogae, declared that HIV testing should be “routine but not compulsory”. The country switched to an opt-out policy. This involved group counselling in antenatal clinics and, for those who did not object, routine testing. The percentage of women who knew their status at

the time of delivery rose from 47% to 78% and PMTCT interventions rose from 29% to 56%.

This change in policy resulted in thousands of children being born HIV-free. There were no measurable adverse effects. Many clients interviewed were relieved by the new policy saying “they never wanted HIV to be treated differently in the first place and that health workers were the source of HIV stigma”.

1.2 The child with HIV infection

When a child is born to a mother infected with HIV, the overall transmission to the newborn is of the order of 35%. This will occur if no attempt is made to prevent mother to child transmission. Even where adequate PMTCT is provided, there are some cases where the transmission cannot be successfully blocked. (Caldwell & Rogers 1991: 3)

Failure of successful PMTCT has resulted in millions of children being infected world-wide but especially in sub-Saharan Africa. Most of these infants and children suffer from a progressive, chronic, wasting disease relieved only by their death.

The progression from asymptomatic HIV infection to full-blown AIDS and death is much more rapid in children than in adults (Zeichner & Read 2006: 51). Adults may expect a latent period of 5-7 years or longer before their immune system is compromised and they begin to suffer from opportunist infections. Regarding children, there are two recognizable peaks in the rate of progression to full-blown AIDS. In about 1/3 of children infected with HIV, the clinical progression to symptoms, AIDS and death may be considered as rapid.

The underlying reasons for rapid progression are not fully understood but include timing of infection (*in-utero* vs. peri-partum), the initial viral load, and some inherent individual characteristics of the immune system. Whatever the cause, an infant with rapidly progressive HIV becomes symptomatic in the early months of life and if left untreated progresses soon to AIDS and is dead before the second birthday (Ibid, 51).

It has recently been recognized that their there is a very early peak in excess mortality in South African infants occurring at 2-3 months of age which can be ascribed to HIV infection (Bourne *et al.* 2009: 102). The child often dies from the first or second infection and these infections may be "classical" rather than "opportunist". Treatment of these children with ARVs is feasible and the recent CHER study (Violari *et al.* 2008: 2238) has shown that these children benefit from very early drug treatment (in the first few months of life) and before symptoms

are prominent. For this protocol to be of benefit, it is important that the diagnosis of infection is confirmed early. These authors note that a good PMTCT program is fundamental, including early diagnosis in the baby (at 6 weeks of age).

The less-rapid progressors behave more like adults with AIDS. They make up about 2/3 of children with vertically acquired HIV infection. They may be well for a number of years and then tend to present with opportunist infections. When they are left untreated, they too follow a down-hill course with death most often occurring in the “middle” childhood years (6-12 years). These older children are very amenable to ARVs and make up the bulk of children in our ARV program. In our institution, during 2007, there were a total of 151 child deaths of which 60% occurred during the first year of life and 60% were related to HIV infection.

Our hospital has a very active PMTCT program in place but the high mortality persists. About 10-15% of mothers in our institution refuse HIV testing for themselves and their child. What is of concern here is a mother who, recognising that her child is ill brings him to hospital (thus demonstrating love or concern), yet she refuses to rule out the possibility of HIV infection via self or child testing. Moreover, this refusal takes place within the context of home-language counselling in which the benefits to the child of the medical teams’ knowledge of his or her HIV status is sensitively explained.

What responses might we imagine, what societal influences or fears could be pictured which would stand as barriers to a mother (or caregiver) being unable or unwilling to have their ill child tested for HIV? I suggest that there are two major societal factors that play a role in failure to test. The first is the role of the Traditional Healers and HIV/AIDS and the second is Information & Disinformation by the South African Government regarding HIV infection and AIDS.

Chapter 2: Societal factor

2.1 The Role of Traditional Healers

In sub-Saharan Africa, the ratio of medical doctors to the population is 1: 40,000 while the ratio for traditional healers to the population is 1: 500 (Cook 2009:261). The utilization of traditional healers by the indigenous African population is ubiquitous. Seventy percent of patients consult a traditional healer as their first choice (Puckree *et al.* 2002: 248).

According to Cook (2009), in South Africa there are five basic categories of traditional healer: the Inyanga – an herbalist, the Sangoma – a diviner, the Prophet or Faith Healer – a person who integrates Christian rituals and traditional practices, the traditional birth attendant and the traditional surgeon. The latter two are not usually involved with children with HIV/AIDS. A further source of

traditional healing (while not always strictly of African origin) may be obtained from over-the-counter medications especially "Dutch" medicines. A report by Friend-du Preez *et al.* (2009:344) discusses the use of traditional health care by children under six as reported by the mothers. Respondents were recruited from the Birth to Twenty cohort study[6] and health facilities in greater Johannesburg/Soweto. About three quarters of mothers in the study had or would utilize traditional healers for their children. The types of traditional interventions used on the children and the prevalence of usage include *imbizo* (oral mixtures) [49.5%], *spuit* (enemas)[24.3%], *umgcabo* (scarifications)[29.1%], topical medicines [15.5%], *ukushunqisa* (incense/inhalations)[20.4%], church treatment (prayers & holy water)[12.6%], *isiphandla* (amulets)[8.3%], and *stuips* (Dutch medicine) [77.7%]. Ninety percent of mothers claimed to be Christian. Perceptions that traditional healers are successful in their treatment are high. In the study by Puckree *et al.* (2002:250), 89% of participants felt healed after consulting a traditional healer.

[6] The Birth to Twenty Study is a South African longitudinal cohort study. For seven weeks between March and June, in 1990, 3273 children were born in the metropolitan area of Johannesburg-Soweto and enrolled into a long-term birth cohort study that will follow them and their families for the next 20 years.

Hassim et al (2007) reflect on the South African Traditional Health Practitioners Act 35 of 2004, which prohibits traditional healers from diagnosing or treating patients with HIV/AIDS, cancer, or other terminal illness. This Act was only signed into law in 2008. Considering HIV/ AIDS in children, the symptoms are protean and usually the underlying immune deficiency is concealed behind a common childhood symptom such as rash, diarrhoea, wasting etc. Even paediatricians trained in the recognition of HIV infection are not capable of making an accurate clinical diagnosis of AIDS in their patients. There are many false-positives and false-negatives. Thus, legislation notwithstanding, it is ridiculous to believe that traditional healers - as currently practicing - could be expected to accurately diagnose HIV infection in children.

Researchers Peltzer, Mngqundaniso & Petros (2006:689) have shown that traditional healers can be trained to improve and retain their knowledge of HIV/AIDS, at least regarding adult patients. And this may be true, however as van Bogaert noted, an estimated 80% of those practicing traditional medicine in South Africa are charlatans; those who are simply defrauding the public need to be identified (and penalized). Those who are actually traditional healers need to undergo rigorous and continuing education concerning not only HIV transmission but also how to identify HIV/AIDS symptoms. Of course, it is not that simple.

Although there are different types of traditional healers, their approaches to illness all focus on holism. Consultation and treatment includes the patient (or a representative), his or her living and deceased family, friends, and enemies. It is commonly claimed that the cause of many illnesses or disorders is the result of displeased ancestors, or witchcraft. It is possible to consider that in HIV/AIDS cases, particularly as paediatric diagnoses is complex, that ancestors or others take the blame while the child continues to suffer.

Demonstrations by traditional healers at the International AIDS Society Conference (Durban 2000) and at the offices of the Treatment Action Campaign (TAC) (Muizenberg 2004) indicate that they believe they should be recognized for their role in *treating* HIV infection. This contravenes the Traditional Healers' Act, yet as traditional healers dominates and still are the first point of healthcare contact, it will take both a great amount of time, political will, and education to alleviate this situation.

2.2 Information & Disinformation by the South African Government regarding HIV infection and AIDS

A recently published book by Thom & Cullinan, Virus*, Vitamins & Vegetables* (2009), documents in detail the denialism, obfuscation, and obstruction to the

development of a rational approach by the South African Government to the HIV epidemic over the past 15 years.

President Mbeki was outspoken in his doubt that the human immunodeficiency virus was the cause for AIDS. He surrounded himself with local & international dissidents and was supported at every turn by the then Minister of Health, Dr Tshabala-Msimang. Between the two of them they not only cast doubt on the existence of AIDS as an infection but they questioned the validity of serological tests (especially those performed in South Africa); and perhaps the biggest harm they incurred was the labelling of antiretroviral drugs as too toxic to dispense.

It required legal action by professionals, NGOs and society at large, to force the State to provide prevention and treatment. The Minister was a huge supporter of alternative treatment and in this she attracted the support of the traditional healers. Regarding the use of traditional medications (in this case *ubhejane)* for treating AIDS, she was quoted as saying,

Apart from its medicinal values, African traditional medicine also defines us as a people. It is this heritage amongst others that we are not simply going to give away purely because of the humiliation we get subjected to for the things we believe in (ibid: 145).

The ultimate result of this painful period in our medical history is to leave the indigenous African population-, especially the poorest and most vulnerable - fearful and confused regarding the way to address the possibility of HIV infection in themselves and their children.

One may understand the position of those who ushered in the first democratic elections being hesitant to address the results of the antenatal clinics' anonymous HIV testing (recorded from the late 1980's). Namely that in the excitement and joy of being free, and having rights, it would have been lamentable to inform the public that a deadly sexually transmitted disease was present. Also in the early years of the epidemic, HIV was considered a "gay" disease and black Africans tend to deny homosexuality's existence. However, by the mid 1990's heterosexual and MTC transmission had been clearly identified.

While one may understand why denialism took different forms, it still does not answer the question, was it ethical; who was harmed, who was helped?

Chapter 3: Case Study

3.1 Siphiso's Story – (A theoretical construct)

Siphiso Vilakazi is a six-month old baby boy who is admitted to a local Johannesburg hospital. His mother, Abigail, has noted that he has had recurrent episodes of diarrhoea and coughing and is losing weight. She says his weight loss has occurred over a period of about two months. Siphiso is her first child, born by normal vaginal delivery in a rural clinic in northern KwaZulu following an uneventful pregnancy. Siphiso's father, Raymond, is a student and plays a generally supportive role but is unable to offer financial assistance. The couple does not live together; Raymond stays with his parents in the township, while Abigail lives in informal housing with her older sister. Abigail works as a domestic and pays a "granny" to care for the baby while she is at work. Abigail breast-feeds the baby at night and this is supplemented by formula feeds and soft porridge.

Examination of the baby reveals him as thin and undernourished; well below the lower level of normal for age. The clinic "road-to-health" card[7] shows that the

[7] The Road-to-Health card system is a WHO-instituted record system that allows the mother of an infant the opportunity to have a current and standardised record of her child's growth, development, vaccine records and general well-being. It is completed by healthcare workers and hand-held by the mother or guardian.

fall-off in growth has occurred over the past three months. Siphiso is slightly dehydrated and lethargic. He has evidence of a recent visit to a traditional healer with *muthi* smeared over the fontanelle and a circle of fresh scarification marks around the umbilicus. He displays severe oral and peri-anal thrush (Candida infection) and generalized enlarged lymph glands. He is breathing faster than normal. On auscultation, Siphiso shows features of bronchopneumonia. An X-ray of the chest is suggestive of pulmonary tuberculosis.

Siphiso's overall condition leads his healthcare givers to suspect strongly that he has underlying AIDS with opportunist infections. He is investigated and treated for tuberculosis, gastro-enteritis, and candidiasis. He responds to treatment to some degree but does not gain weight. Despite counselling, Abigail refuses HIV testing for both Siphiso and herself.

After a few days in the ward and after the enteritis has settled, Abigail requests that Siphiso be discharged. She says that she intends to take Siphiso to her maternal grandmother in rural KwaZulu for further care. In stating this, the hospital caregivers realise Abigail wishes to consult with her wider family, the village elders and the traditional healer regarding further management. She is referred to the hospital social worker for further counselling. Abigail however remains resolute and requests to sign a form refusing further hospital treatment. The doctors who are caring for Siphiso are in a quandary.

They believe that Siphiso's best interests [8]would be served by confirming the HIV infection and in due course, commencing anti-retrovirals. They also realize that for successful treatment of AIDS, long-term adherence to treatment with ARVs requires buy-in from Abigail. An alternative would be to apply to the courts for legal guardianship of the child; removing him from his mothers care either for the short- or long-term. What course should the health care personnel follow?

This sort of scenario confronts paediatricians, doctors, and nurses throughout South Africa, on a daily basis.

Chapter 4: Ethical and moral issues

4.1 The responsibility of the paediatrician

The healthcare of children is as old as our species. In antiquity, childrearing was predominately under the purview of women although fathers often played more than a minor role in the child's education and care. In addition, various other adults took part in a child's life e.g. "midwives (who also served as the baby's paediatrician) and nurses (both wet and dry)" (French 1995:16).

[8] When the state intervenes in family matters, it does so in the name of the "best interests of the child". Exactly what this term means is subject to various interpretations by e.g. social service personnel, scholars, medical professionals, and the law. Thus, the term may be viewed as vague and value laden but at a minimum the outcome should be the provision of the least detrimental alternative possible for the child (Goldstein, *et al.* 1997).

The specialty of Paediatrics is a 'modern' and relatively new development. A German physician, Abraham Jacobi (1830-1919) is generally considered to have founded the specialty and when he immigrated to the USA in 1848, he fought tirelessly on behalf of children's health (Burke 1998:309-11). By 1860, a number of children's hospitals had sprung up in United States cities mainly because general hospitals refused to admit sick children. In 1888, the American Pediatric Society was founded with Jacobi as its first President.

In South Africa, the discipline of paediatrics was usually considered as a branch of Internal Medicine. The first full-time professor of paediatrics at the University of the Witwatersrand (Prof. H de V Heese) was "only" appointed some 40 years ago. Not surprisingly therefore, the roles and responsibilities of doctors caring for children towards their wards have only been recently refined. These roles and responsibilities do not differ substantially from those that apply to adult patients except in the fact that they recognize the particular vulnerabilities of children as patients.

In October 2007, the General Medical Council of the United Kingdom (GMC.UK.) published their first guidelines on the roles and responsibilities of doctors who care for children (GMC 2008). These guidelines include sections on communication, decision-making, consent & the capacity thereto, treatment

refusals, confidentiality and many other issues related to paediatrics. The guidelines have a strong legal bias with many references to peculiarities in Commonwealth law. However, the principles expounded in this report are not unique and they echo the position of all doctors currently practicing Western medicine and caring for children. Many of these principles expressed in the GMC.UK (2008: 3-8) document apply to the decisions and dilemmas created in the Sipho's story as follows:

a) ... doctors must safeguard and protect health and well-being of children and young people. Well-being includes treating children and young people as individuals and respecting their views, as well as considering their physical and emotional welfare;

b) When treating children and young people, doctors must also consider parents and others close to them; but their patient must be the doctor's first concern.

c) Children and young people may be particularly vulnerable and need to be protected from harm; they can often find it difficult accessing services or defending their rights; and they often rely on others for their well-being. They may have particular communication needs and (they) may need help to make decisions.

d) Children and young people are individuals with rights that should be respected.

e) Doctors should always act in the best interests of children and young people. This should be the guiding principle in all decisions which may affect them. But identifying their best interests is not always easy. This is particularly the case in

relation to treatment that does not have proven health benefits or when competent young people refuse treatment that is clearly in their medical interests. There can be a conflict between child protection and confidentiality, both of which are vitally important to the welfare of children and young people.

Generally, a paediatrician is skilled at providing appropriately specific medical care for children from the time of their birth until and including puberty. In South Africa, there are no specific medical recommendations as to the age at which paediatricians should relinquish care and this varies from practice to practice. The majority of patients using the services of specialist paediatricians are under the age of two years. The norm is that paediatrician's work harmoniously with the child's parents as in most cases all the role-players have the child's well-being at heart.

In cases when the child is able to comprehend the nature of the treatment and the expected outcomes, then it is recommended that the child-patient is included in the discussions and allowed to contribute to decision-making. The child may be expected to *assent or dissent* to his or her investigation and treatment. The age at which assent is sought is generally from about the age of seven years but this depends on the emotional and intellectual development of the specific child (Bartholome 1995:315). Assent by children is useful and desirable in that it obliges the doctor to consider the child-patient as central to decisions. However,

in practice this has little real impact as it is usually overridden by surrogate consent when this is deemed in the child's best interests. In cases of an older child with AIDS, assent should be sought but this is often not the case. In the case of a young child (such as Siphiso in our case) assent does not apply.

4.2 Consent for Treatment in Children

For a doctor to embark on a course of investigation or treatment of a patient without consent is ethically wrong and would legally constitute assault (or "battery" in the USA). Patients are often in a vulnerable position and must be assisted to realize their right to direct what happens to their bodies, a basic tenet of autonomy.

Children are generally not considered capable of giving or refusing medical consent in healthcare until the age of about 16 years but this age varies from country-to-country and situation-to-situation (See later the discussion on the "Special Case" of HIV). In general, based on recognising a child's developmental needs, the State purports to seek the assurance that all children have a secure membership in a family with at least one adult that is legally designated to act as a 'parent'. Children below the age of medical consent rely therefore on a surrogate or proxy consent for their protection. This is usually through the parent

or legal guardian but in exceptional circumstances the State may use the doctrine of *parens patriae* to act as surrogate in *loco parentis.*

Consent is invalid unless it is shown to be "informed". For consent to be considered valid, the patient or surrogate must be told the nature of the investigation or decision or treatment or procedure. They must understand what reasonable alternatives are available to the proposed intervention. Moreover, they must understand the relevant risk, benefits, and uncertainties attached to each alternative. In addition, a healthcare professional must be assured of the patient's *understanding.*

Consent should be voluntary and must be freely given. There should be no coercion, manipulation, or undue persuasion. There should be no improper social or economic rewards. The patient or surrogate should be free from pain or undue emotional distress when consent is obtained.

Finally, the patient or surrogate must give authorization for the intervention. Generally, this authorization of consent is *tacit* or *understood*. For instance, when a paediatrician performs a clinical examination on a child, he asks the mother to undress or expose the child and explains that he wishes to, say, listen to the heart or palpate the abdomen. The very presence of the child in the facility and assistance in the examination by the mother constitutes tacit consent.

When the consequences of an intervention may be profound or the risk to life or limb substantial, then it is prudent for the doctor to obtain *specific* consent. In these circumstances, it is advisable to obtain *written* consent. There is usually no legal requirement for written consent but written consent avoids later factual disputes. Consent is always between the patient (or their surrogate) and the individual doctor. Consent is invalid when it is not individualized and/or structured to encompass unique personal beliefs, values, and goals and therefore "blanket" consent is always unacceptable.

Modern Western medical practice is strongly founded on the ethical (and legal) tenet of individual autonomy. This is a relatively new development in the practice of medicine. Medical practitioners would, in the past, usually assume the responsibility for their patient's well-being and without much discussion decide on a course of management. In these situations, a patient would blindly trust the "wise physician" and follow their advice. This paternalism (or the less sexist term; parentalism) survived for centuries as central to the doctor-patient relationship. It still pertains in many situations. The idea of paternalism is grounded in the trust that patient's give to their physicians; to always act in a way that would promote their well-being. Nowadays, the idea of 'strong-paternalism' is considered ethically unacceptable because no room was given for the patient to express his

or her views. 'Weak paternalism', on the other hand, does allow for patient involvement yet the final decision is generally delegated to the physician.

The role of the medical practitioner has changed radically in the past century in the developed world. There have been many co-existing reasons for the changes. Doctors have been shown to have betrayed the trust of their patients. The "honourable and noble" position of doctors has been eroded by many things e.g. the horrors of the complicity of physicians in Nazi Germany and elsewhere, the pursuit by physicians of excessive individual wealth and status, health insurance and third party intermediaries and many other factors. The mystery and wisdom of "knowledge" in matters of health was previously held and closely guarded by physicians. These days' subjects such as anatomy, physiology, and health are taught at primary schools, albeit not in the same depth as in medical training. The Internet is widely, instantly accessed by many patients and this has made the practice of medicine readily available with all of the pros and cons involved.

In our context, there may be major differences in the relationship between "western" doctors and their African patients when compared to the western doctor-patient model. Most African patients coming to State-funded, public health facilities in South Africa have first visited a traditional healer (Cook 2009:264) or have accessed traditional medicines prior to utilizing the State health facilities (Friend-du Preez *et al.* 2009:344). Traditional healers though, for

the main, do not come under the scrutiny of ethics yet they are strongly paternalistic in their practices.

African patients often appear to be confused or even disappointed by the need for the western doctor to take a detailed history and perform a clinical examination before coming to a diagnosis. This may occur as many traditional healers have utilized divination to achieve the same goal at much a faster pace.

Group autonomy (as opposed to individual autonomy) is another dimension that needs to be considered in this African scenario. The current western model of (individual) autonomy recognizes that "individuals enjoy a privileged position of moral dominion over their self-regarding affairs." (Wellman 2003:265). This leads to the position that we should be allowed freely to choose a course for ourselves where this choice is not harmful to others. This autonomous choice is independent of whether or not the outcome is "favourable" to the individual who chooses. One may try to persuade the individual of the folly of their choice but one may not forcibly intervene.

In the context of Siphiso's story, Abigail wishes to consult with the elders and traditional healer regarding his further treatment. It is usual in all families and societies that advice from family and friends is often sought and occasionally taken. In the context of African traditional life, this may be carried further to a

situation where decisions may be made in a collective manner for, by the group, and after consultations with ancestors. This African form of collectivism is not strictly comparable to the more well known European or Eastern systems. The idea that black South Africans are all collectivist is of course simplistic and there are marked changes in our social structure that have occurred since democratization. This has been studied by Vogt (2007) and she observes that;

... culture is a dynamic construct open to change in response to changes in the environment such as shifts in the socio-historical and socio-political context. Therefore, outdated, stereotypical categorizations of ethnic groups in South Africa as strictly Collectivist or Individualist that possibly applied during the Apartheid era, may no longer be relevant. In particular, the abolition of racial segregation has brought individuals from different cultural and ethnic backgrounds into closer contact with one another (ibid: 36).

Notwithstanding these changes, Abigail, in our construct, may be expressing a return to typical collectivist or communalistic characteristics, which because she knows well, trusts more. Often in Africa, this is referred to as *Ubuntu.*

Ubuntu is a "humanist philosophy focusing on peoples' allegiances and relations with each other" (Forster 2006:287). There is a Zulu maxim *umuntu ngumuntu ngabantu* which may be loosely translated as "a person is only a person through

others" and this forms the pillar of Ubuntu. Many argue that It should not be seen as an oppressive type of communalism which then destroys individual identity but rather a positive supportive interdependence. Archbishop Desmond Tutu (2008) explains Ubuntu as follows:

One of the sayings in our country is Ubuntu – the essence of being human. Ubuntu speaks particularly about the fact that you can't exist as a human being in isolation. It speaks about our interconnectedness. You can't be human all by yourself … We think of ourselves far too frequently as individuals, separated from one another, whereas you are connected and what you do affects the whole world.

In the spirit of Ubuntu there would be for instance, no orphans since the roles of mother and father are not vested in a single individual with respect to a single child. This is commonly evident in urban African culture today where the term ''brother'' and ''sister'' apply to not only siblings but also cousins and relatives that are even more distant. Decisions taken by leaders on behalf of individuals may be expected to have wide-reaching effects on the group as a whole. Traditional justice dispensed under conditions of Ubuntu attempts to correct against damage to the wider community. In such a system, the idea of individual rights is not considered as an overarching norm; the survival and well-being of the group is primary.

On the other hand, some make the claim that with the advent of HIV, the idea of Ubuntu has become perverted. Teenagers make the claim that they will not use HIV prevention measures because our ubuntu culture allows us 'to die together'. Others say that Ubuntu is simply a concept referring to an early and natural stage in the development of a social system designed to ensure community survival. It has also been mentioned that Ubuntu is merely an invention to ensure male-domination (class discussion 2008).

Thus far, we know that Siphiso most likely has HIV/AIDS and that his mother has refused both testing and medical treatment. We have identified that the medical specialty of paediatrics is a modern development aimed at the provision of medical treatment and care for children. Siphiso, an infant, relies on the decision of his parent to make decisions concerning his healthcare (alternately, the law is a possible way of appeal). The treatment, its benefits, burdens or alternatives, fall under the umbrella of the Informed Consent process that obliges all healthcare professionals to respect the autonomy of adult competent individuals to make their own choices (or the choices concerning their children) based on full disclosure. We do not know exactly why Abigail chose to refuse medical treatment and travel to her community in Kwa-Zulu Natal. Perhaps she wants her child treated in 'the old ways', perhaps she does not understand the benefits of early treatment, or perhaps she does not want to be associated with a 'sick' child and any resultant social consequences. Yet, the fact remains that Abigail has the

right to choose for what she considers to be an action which is in Siphiso's "best interests", a term which we will explore more now in depth.

4.3 In the Child's Best Interest

Good mothers, we are told, will do all that is possible to protect their child; in common speak, they put their children above themselves. Can we categorise our case mother as "bad" because she refuses consent to test her child because of her perceived (or real) consequences of a positive test on her own life, rather than placing the best interests of her child first? There is no doubt that many factors feed into such a mother's decision. Much of the discussion around the refusal by parents to consent to medical treatment for a minor child hinges on an assessment of the child's best interests. The right to refuse or grant informed consent does not disappear for incompetent persons such as infants- rather it is a right that must be exercised on their behalf. It is of course usually difficult to precisely define the child's best interests and a great deal of controversy will often surround that determination. Generally, the parents of a child best understand the unique needs of their child and are motivated by love and concern to make decisions that are beneficial for the child. The interests of other family members may conflict and may be harmed by a simplistic and narrow

decision in favour of a single member. Parents are best positioned to weigh up the competing interests of individuals in the family.

There must however be a limit to the respect owed to parental decisions regarding their children. We should not allow consideration of culture, religion or family insecurity to seriously compromise the health or survival of the child. When the paediatrician stands at the bedside of his young patient, ready to apply the "best interest standard", he uses a combination of objective and subjective criteria to rank potential benefits and hazards. Kopelman (2007:377) has suggested three "necessary and jointly sufficient features" to be applied when evaluating the validity of the best interest standards. These are:

First, the decision makers should use the best available information to assess the incompetent person's immediate and long-term interests and set as their *prima facie* duty that option that maximizes the person's overall or long term benefits and minimizes burdens.

Second, decision-makers should make choices for the incompetent person that at least meet a minimal threshold of acceptable care; what is at least good enough is usually judged in relation to what is reasonable and informed persons of good will would regard to be acceptable were they in the person's circumstances.

Third, decision makers should make choices compatible with moral and legal duties to incompetent individuals who are unable to make decisions for themselves.

Parents must be given authority to decide what is best for their child and they should not lose this authority if they provide care that is minimally acceptable. Obviously, there may be debate as to what is acceptable. When applying the Standard in practice it does not require the decision must strive for what is ideal but rather what is reasonable. For instance, there seems to me to be no ethical justification to consider that it is in the child's best interests to remove a poor but thriving African child from his family, home and culture only to be transplanted into the care of an unstable Hollywood couple with all the money in the world!

The South African Bill of Rights (South African Government Information 1996) requires that the following rights of the child are to be secured:

"Every child has the right to a name and a nationality from birth, to family care or parental care or alternate care, to basic nutrition, shelter, health care and social services. They also have the right to be protected against maltreatment, neglect, abuse or degradation….They are entitled to insist that their best interests are of paramount importance in every matter."

One of the most difficult areas to contend with when applying the best interests standard, is deciding on the threshold for intervention.

Where the intervention is acute, life saving and "once-off", then the decision is relatively easy. An example that comes to mind would be performing an exchange transfusion for severe jaundice on the newborn child of a Jehovah's Witness couple. As concluded by an American judge, Justice Rutledge (U.S. Supreme Court 1944); "Parents may be free to become martyrs themselves. But it does not follow that they are free, in identical circumstances, to make martyrs of their children."

McQuoid-Mason (2005:30) recently reviewed the legal position for this situation in South Africa[9]. He concludes, "Although parents have the right to dignity, privacy, and freedom of conscience and religion, the High Court has held that such rights are superseded by a child's right to life in cases where the child's life is at risk". Now that this has been tested in the highest Courts, it is no longer necessary in these circumstances for the paediatrician to apply to the courts for permission to proceed. The parent's refusal is judged unlawful and the doctors will be acting lawfully if they proceed with a blood transfusion. The best interest of the child in this case is seen largely in the context of the life-threatening medical risk to the child. Little consideration is given to the profound religious consequences to the family and perhaps the child. Loss of salvation is not a trivial consequence. In my own experience, children from Jehovah's Witness families

[9] Although this article refers specifically to refusal by a Jehovah's Witness mother for blood transfusion in a newborn, the precedent will surely hold for other similar instances where the minor child is at risk for life or limb.

who have received blood are taken back into the fold and given love and care but this may not always be the case. It must be remembered that the legal right granted to the doctor to proceed without further ado is only true in the case of medical emergencies. I presume that in cases where there is sufficient time, the parents should be allowed an opportunity to be heard.

Intervening on behalf of the child in the case of a grossly negligent and uncaring parent is another relatively easy decision for a paediatrician. As an example, let us take the case of the child from a dysfunctional home with an alcoholic mother and abusive father. The child presents with severe malnutrition, is dirty and unkempt, shows signs of physical abuse and is unvaccinated. Acting in the child's best interests, most healthcare workers would immediately remove the child to a place of safety, even against the wishes of the parents. After investigation and confirmation of the circumstances by social services there may be attempts to rehabilitate the family or the child may be permanently removed from the home and fostered elsewhere.

In all cases, there must a weighing up of the pros and cons before the awesome decision is taken to oppose parental wishes. In many cases, the doctor must decide whether to oppose the wishes of a well-meaning but "misguided" parent. Here things are much more difficult. The parent may be influenced by a myriad of complex issues. They may be in the grip of fear or depression or overwhelmed by pain, drugs, or their own poor physical state. In such circumstances, their

decisional capacity may be warped or biased. I believe that the AIDS epidemic in sub-Saharan Africa creates a milieu where all these factors may be prevalent. We must also consider the background climate of misinformation and disinformation that was disseminated by the State and Health Department with regard to HIV. Added to this is the attempt to integrate alternate health practitioners, in the form of traditional healers, into the health team.

Rhodes & Holzman (2004:372-4) have attempted to give guidance when trying to weigh-up the reasons given by a surrogate for refusal of treatment. They have adapted Scanlon's "three concentric domains" analogy. In this, the "central core" reflects the kinds of principles that people everywhere could reasonably reject. Judgments in the second domain reflect particular core reasons that reasonable people could prioritize differently. The third domain, or outer circle, reflects reasons that other reasonable people could refuse. This third domain is the difficult area for the healthcare worker. Reasons from this domain may be idiosyncratic or shared only by some particular social or cultural group. Let us consider, for clarification, a paediatric example constructed from each domain.

Central core: A surrogate refuses neurosurgery for a newborn with a massive cerebral haemorrhage and a futile prognosis. (Most reasonable people would refuse this)

Second Domain: A surrogate refuses further treatment for a two-year old with myeloblastic leukaemia in relapse. The chances of cure are 5% and the treatment

particularly noxious and prolonged. (Many reasonable people could justifiably debate the intervention or prioritize differently)

Third (Outer) Domain: A surrogate refuses appendisectomy for an infant with acute appendicitis. The mother prefers to follow her faith and to pray for favourable ancestor intervention.

It may not always be easy or straightforward to place the situation clearly into one or other domain. Linked to the above we must consider the obvious; the likely outcome if the doctor embarks on treatment. Is there likely to be a) a poor outcome, b) an uncertain outcome or c) a good outcome?

Douglas Diekema (2004: 243-64) argues that the Best Interest Standard is not practical as a tool for intervention by the State against surrogate parental wishes for their child. He advocates the use of the "harm principle" in these cases. He quotes JS Mill in this regard who argued, "The only purpose for which power can rightfully be exercised over any member of a civilized community, against his will, is to prevent harm to others. His own good, either physical or moral, is not a sufficient warrant."(Mill 1993). Diekema states that the "characteristic of parental decision-making that justifies interference is not that it is contrary to the child's best interest, but rather that the decision poses some harm to the child." The introduction of this standard, if replacing the best interest standard is perhaps a bit simpler to apply but has many similarities. A "harm threshold" needs to be defined before intervention is to be contemplated. To some extent, it

lowers the ideal of “best” interests to “basic” interests. This implies that State intervention should never be trivialized but only initiated where there is likelihood of significant harm. Diekema further proposes eight conditions that must be met before medical treatment is considered against parental objections:

1. By refusing to consent, are the parents placing their child at significant risk of serious harm?

2. Is the harm imminent, requiring immediate action to prevent it?

3. Is the intervention that has been refused necessary to prevent serious harm?

4. Is the intervention that has been refused of proven efficacy and therefore likely to prevent the harm?

5. Does the intervention that has been refused not also place the child at significant risk of serious harm and do its projected benefits outweigh its projected burdens significantly more favourably than the option chosen by the parents?

6. Would any other option prevent serious harm to the child in a way that is less intrusive to parental autonomy and more acceptable to the parents?

7. Can the state intervention be generalized to all other similar situations?

8. Would most parents agree that the state intervention was reasonable?

I would add another condition that would pertain to the case in point[10]:

9. Does the State have the financial capability, the human and other resources and the political will to follow the intervention to its logical conclusion?

4.4 The accuracy of Surrogate Decision Makers

There is no good objective experimental way of accurately measuring whether a parent has acted in their child's best interests. Hindsight is always perfect vision but there are often too many subjective variables to consider what might have been the case if another course had been followed. It is estimated that in a 20 year period from 1975-1995 some 172 children died in the USA after their parents rejected medical care on religious grounds (Hughes 2005:247). Of these children, 140 suffered conditions for which survival rates exceeded 90% if there had been timely intervention and 18 more could have survived at a rate exceeding 50%. These cases have resulted in the removal of religious exemption clauses from the statutes of most States in the US. In these "gross" examples it is quite clear that the parents had not acted in their child's best interests.

The accuracy of surrogates to take well-meaning decisions in the dependant's best interests is difficult to study. Although not absolutely analogous to parent-

[10] The provision of comprehensive antiretroviral therapy requires sustained and on-going access to extensive infrastructure including drugs, laboratory services, healthcare personnel etc. To date, this has not been universally available throughout the country.

child surrogacy, there have been studies constructed to test the accuracy of surrogate decisions between close family members. Shalowitz et al. conducted a systematic review of this subject (2006: 493-7). They concluded that patient designated and next-of-kin surrogates fail to predict patients' end-of-life treatment preferences accurately in at least one third of cases. Although these constructs use "substituted judgment standards" rather than "best Interest standards" they do serve to show that your nearest and dearest often don't know, or choose not to follow, your life-and-death preferences.

Discussions

I have created a common scenario that challenges many paediatricians serving South African children. The crux of the dilemma facing this doctor is as follows:

i) Siphiso is a six-month old boy with stigmata highly suggestive of HIV infection and AIDS.

ii) His mother, Abigail refuses permission to test Siphiso for HIV.

iii) Abigail wishes rather to obtain treatment for Siphiso from a traditional healer.

iv) Could ARVs be given to Siphiso without confirming HIV infection?

v) Should the doctor approach the courts for permission to test Siphiso for HIV?

vi) Should Siphiso, if positive, be treated for AIDS against his mother's wishes in his "best interests" even if this requires his removal from his mother's care?

The diagnosis

The combination of clinical features found in Siphiso is highly suggestive but not diagnostic of AIDS. Failure to thrive, poor weight gain and malnutrition, in the face of adequate feeding suggests an underlying infection such as AIDS or tuberculosis and the combination of the two is particularly common. Prominent lymph gland enlargement is suggestive of HIV but not specific. Candida is a hallmark of HIV but common in infants, even those with normal immunity. The prudent doctor should test for HIV. It is not feasible to commence HIV treatment with ARVs without confirming the diagnosis. Treatment is complex and at present, must be continued, life-long.

The Test

The test required to confirm the diagnosis in a six-month old baby is the HIV Polymerase Chain Reaction test for viral DNA (HIV-PCR). This test is highly specific and sensitive. It is much more expensive than the serological HIV ELISA test. The ELISA test detects host antibodies to HIV and a positive test in an infant in the first 18 months of life *may* reflect prenatal, passively acquired maternal

antibodies and therefore may reflect maternal infection in an uninfected baby. If the HIV-PCR is positive on the child, it would by inference, strongly predict that the mother would herself be positive. This would have been adequately explained to the mother in the pre-test counselling – a positive test in her baby is a proxy for a positive test in herself. Abigail is currently physically well and it is easy for her to convince herself that she is not infected with the virus. If Abigail becomes aware of her status, even inadvertently, it gives her the opportunity, if HIV positive, to modify her sexual behaviour to protect others but also to avail herself of monitoring and early treatment. Attempts by the counsellor and medical and nursing staff would often heighten the fear and anxiety in the mother and may produce an increased resolve to avoid testing. The mother has little support. She is unmarried; the child's father is an unemployed student. Her only support locally is her sister who is desperately poor and the two live in a squatter camp. It is not surprising that Abigail wishes to return to her family in rural KwaZulu where she has some social support structures. If, as is likely, Siphiso and his mother are both infected with HIV and are allowed to leave the hospital it is highly unlikely that they will obtain the necessary medical investigation and treatment to prevent their progression. It is likely that Siphiso will die within a few months.

Acting in Siphiso's Best Interests and Avoiding Harm

It is assumed that Abigail believes that she is acting in Siphiso's and her own long-term best interests by refusing HIV testing. Her decision is taken under unfavourable circumstances. She is probably scared and confused and outside of reasonable support from family and friends. Her own good health may lead her to deny the likelihood that she could be the source of his ill health. This may be compounded by the "official" denialism which previously pervaded Government thinking. There may be added smouldering racial tensions; where HIV may sometimes been perceived as representing Western criticism of the African way of life. The doctors in the hospital will likely be predominantly white or "coloured" and may accentuate perceptions of racial discrimination. In all of this however, Abigail cannot be considered to represent an idiosyncratic or peculiar social group as the majority of mothers from similar circumstances (85-90%) will consent to testing. Let us then apply Diekema's eight criteria to ascertain whether intervention against the mother's wishes should or could be considered.

i) By refusing consent to test Siphiso for HIV, is Abigail putting him at significant risk of serious harm? The answer to this must be YES as without a diagnosis of HIV infection he will be denied appropriate treatment and will die. There is no empiric evidence that any dietary or traditional herbal medications have any success in controlling the progression of HIV to AIDS and AIDS to death.

ii) Is the harm imminent and is immediate action required? “Imminent” and “Immediate” are relative terms with no absolute definition. What is true is that Siphiso’s condition is grave and needs urgent treatment (within weeks).

iii) Is the treatment that has been refused necessary to prevent harm? Abigail has refused testing of Siphiso for HIV. Without a positive test, ARVs cannot commence. If he is positive then ARVs are essential for survival.

iv) Is the treatment efficacious? At present ARVs are the only intervention that has been shown to improve the outcome from AIDS; converting a debilitating and lethal illness to one with an expected significant prolongation of a good quality of life.

v) Does the proposed intervention also bring significant risks and do the benefits outweigh the risks? There is no doubt that ARVs are drugs with toxic potential and that treatment is not always successful. However, in our institution more than 1000 children are now on chronic treatment of AIDS with ARVs with follow-up of up to 5 years. In the vast majority of cases, side effects have been uncommon and manageable.

Younger children with rapid progression of AIDS have a worse prognosis than average but should survive with ARV treatment in most cases. At present, treatment is life-long and the full implications of this for a six-month old cannot be predicted (or trivialized). On the other hand, it is possible that a cure will be

forthcoming in the near or distant future. The patients must be alive to avail themselves of this.

vi) Is there any other less intrusive and more acceptable effective option? No.

vii) Can the State intervention be generalized to all other similar situations? I think that the same arguments would usually hold true for similar situations. Examples would include the diagnosis and treatment of other chronic infections such as tuberculosis, although in the case of TB ultimately a full cure can usually be predicted. A diagnosis of tuberculosis in the child may carry the implication of other infected family members and, like HIV, is stigmatized in the community. Juvenile diabetes mellitus requires lifesaving diagnosis and lifelong chronic intervention and, in the USA, has usually resulted in intervention by the State when parental refusal has been challenged. In the case of childhood malignancies, the decision for the State to intervene against parental wishes will be much more complex. This will depend on the prediction of ultimate cure. If, (as in a recent USA case (AP 2009) involving a 13 year-old boy with Hodgkin's lymphoma) the predicted cure rate is 90% with treatment, versus 5% without, then State intervention is warranted. If the figures were reversed then respect of the mother's autonomy would be proper.

viii) Would most parents agree that State intervention is reasonable? This is not easy to answer but we do know that 85% of parents in similar circumstances

to those confronting Abigail, consent to HIV testing is usual (unpublished anecdotal data from Rahima Moosa Mother & Child Hospital).

ix) Diekema did not suggest this question but I think it is an important addition i.e. Does the State have the capacity and will to follow-through on all the implications of the intervention? This appears to me to be the most difficult aspect with which to contend. In my experience, quite a few mothers have consented to HIV testing on their babies, on the condition that the mother is not informed of the results of the test. This has occurred when the request has been made in the situation of a newborn child who, if positive, "requires" a once-off dose of Nevirapine for PMTCT. This implies that in these cases, at least, the mother is refusing consent to test her child because of the consequences of a positive test on her own life, rather than that of her child. In the current scenario, is it likely that Abigail would refuse to care for Siphiso if his test were positive?

The care of an HIV positive child requires painstaking attention to the protocol. Half-hearted or slap-dash treatment is likely to result in poor disease control, a high incidence of drug side-effects and the development of resistant HIV strains which may have deleterious effects on the child and even the wider community. If Siphiso is tested and then treated with ARVs against his mother's wishes, then the State must consider the possibility of permanently removing him from her care and providing a reasonable alternative. Despite the huge problem of HIV-

related orphans in South Africa, it has not yet proven necessary to invest massively in institutional care for these children. This is directly related to the strong extended family traditions among Africans and the culture of ubuntu. The State has supported the system with the provision of extensive expansion of the social grant system. This capacity is not unlimited and is difficult to administer. The increasing number of child-headed households suggests that there is little spare capacity remaining.

The practical and psychosocial consequence of committing large numbers of children with AIDS to institutional care is a solution that may not be in the best interests of the child, the community or the State.

Family-centered care.

It seems, from considering the all the variables in the scenario, that the paediatrician is faced with two choices, both with very unsatisfactory outcomes. If the decision is made to allow Abigail her own autonomy and her role of providing surrogate autonomy for Siphiso, then the paediatrician relinquishes his/her own medical ethical duty to act in the child's best interests.

From my observations, this is the usual state of affairs currently applying in the health services in South Africa. If, on the other hand, the paediatrician decides to

act in what he perceives to be the child's best interests, then he/she will apply that the courts act *in loco parentis* and allow the testing (and subsequent treatment) of Siphiso. This may well entail removing Siphiso from the care of his mother and placing him in a foster home or institutionalizing him for the provision of his basic and medical care.

This would likely have profoundly negative effects on Siphiso. More than this, this situation is common in South Africa and there would be massive social and economic problems if this course were to be widely followed.

Is there a third choice? Over the past decade or more, there has been recognition that especially the hospital-based paediatrician is limited in the ability to provide optimal care to children in the existing paradigm. This has resulted in the concept of the development of family-centered care in paediatrics. In 2003 the American Academy of Pediatrics published a Policy Statement on Family-Centered Care and the Pediatrician's Role (Eichner & Johnson 2003:692). The core principles of this care include;

i) Respecting each child and his or her family

ii) Honoring racial, ethnic, cultural, and socio-economic diversity and its effect on the family's experience and perception of care

iii) Recognizing and building on the strengths of each child and family, even in difficult and challenging situations

iv) Supporting and facilitating choice for the child and family about approaches to care and support

v) Ensuring flexibility in organizational policies, procedures, and provider practices so services can be tailored to the needs, beliefs, and cultural values of each child and family

vi) Sharing honest and unbiased information with families on an ongoing basis and in ways they find useful and affirming.

These are lofty ideals and the concept has only been partly successfully followed in highly developed countries with adequate medical and social infrastructure and staffing. Pettoello-Mantovani and colleagues (2009:1-3) have recently commented on the importance of cultural diversity and cultural competence for family centred care. Cultural competence is defined as a set of values, behaviours, attitudes and practices within a system, organization, and programme or among individuals, which enables them to work effectively cross culturally. Further, it refers to the capability to respect the beliefs, language, inter-personal styles and behaviours of individuals and families receiving services, as well as staff who are providing such services. There is often a chasm between the western-trained doctor and the traditional culture of his/her African patient. For the effective institution of modern medical care, we need to somehow

narrow that gap. The current teaching of clinical medical ethics seems to imply that ethical models are applied in conditions of stability, order and uniformity. This is unfortunately, currently, rarely the case where more often there are multiethnic and multi-faith situations with differences concerning issues around sexual relations, kinship patterns, perceptions of modes of healing, dietary preferences and moral norms (Turner 2001:593). She further goes on to say that, "we must not fall into the trap of fostering 'frozen' accounts of discrete, highly bounded moral traditions". We need to think out of the "ethical box".

We need to explore the possible actions that will result in an increase in the number of mothers who will consent to testing their babies (and themselves) for HIV and how to strengthen the chances of adherence to the strenuous treatment regime for prolonged ART. In the first instance, we need to institute empirical research to clarify the reasons why some mothers (up to 15%, currently) refuse to test. How do these mothers differ from a control group who agree to the test? It would then be imperative to address their presumed fears, ignorance and rationalizations.

Secondly, it seems to make sense to improve the support from the wider family and community with regard, not only, to HIV testing but also to initiation and adherence to treatment. Many, if not most, Africans have a somewhat ambiguous approach to Western medicine. They prefer to integrate this system into the more pervasive traditional concepts of disease and healing. Doctors

trained in the Western system are naturally loath to work in partnership (or even in peaceful parallel) with practitioners who diagnose by divination, who believe that disease is a consequence of ancestor displeasure and who treat with spells, incisions and often, noxious herbs. Yet, if we are to encourage our patient's in their autonomy, ultimately do most good and improve distributive justice then we may have to try to limit the potential harm in the equation.

As mentioned earlier, the most widely used traditional healing in South Africa involves one or more of the following routes; the *inyangas,* the *sangomas*, the *prophets* and *traditional Dutch medicines*. It is my opinion that the first two options and the last are least compatible with "peaceful co-existence" with Western medicine with regard to the diagnosis and treatment of HIV/AIDS..

Conclusions

The paediatricians providing care to African children infected and affected by HIV/AIDS face many complex ethical problems. Dealing with these issues in an equitable manner requires not only careful consideration of the currently applied Western medical ethical principles but also requires a deep understanding of the cultural norms of the patients. The major ethical issue dealt with in this paper is the dilemma of the paediatrician (or other healthcare worker) who faces refusal

of consent to HIV testing and/or treatment by a parent or caregiver for their minor child. There are two obvious diverse and mutually exclusive solutions to this problem. The first is to allow the parent her/his autonomy to decide not to treat this child. In my experience, this is the common path followed; allowing thousands of children to disappear "off the radar" and often to be lost to follow-up by the health services and to die of AIDS undiagnosed and untreated. The alternate decision would be to use the available legal framework to force the parent to allow diagnosis and treatment. This would create huge individual tensions within the family and often a breakdown of the functional doctor-patient relationship. Moreover, on a large scale, this course of action would result in thousands of children being removed from parental care for the necessary sustained treatment. This would paralyze an already overburdened health and social service system.

Using a utilitarian approach; when faced with two "evils"; choose the lesser of the two. If this is the case, then I suggest that one should therefore "err on the side of life" and act in the child's best interests by removing the child from the parents and allowing the State to act *in loco parentis.* This option is, however, shortsighted and not practical on a large scale. I have therefore argued that we need to consider new alliances within traditional African society to make our "Western" medical system more acceptable. The traditional African churches seem to offer a viable and acceptable route to explore in this regard.

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Appendix Research Ethics Committee