

**A descriptive study of the attitudes of  
doctors, working at clinics and day hospitals  
in the Cape Metropole to patients with HIV/AIDS.**

*by*

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## LIST OF ABBREVIATIONS

<b>AIDS</b>	Acquired Immune Deficiency Syndrome
<b>ATICC</b>	AIDS Training Information and Counselling Centre
<b>AZT</b>	Zidovudine
<b>CDC</b>	Centres for Disease Control
<b>HCWs</b>	Health Care Workers
<b>HIV</b>	Human Immunodeficiency Virus
<b>MASA</b>	Medical Association of South Africa
<b>PCP</b>	<i>Pneumocystis carinii</i> pneumonia
<b>PCR</b>	Polymerase Chain Reaction
<b>PWAs</b>	Person with HIV/AIDS
<b>SAMDC</b>	South African Medical and Dental Council
<b>TB</b>	Tuberculosis

## **ABSTRACT**

HIV/AIDS is a fairly new condition. Despite a large amount of published literature regarding its clinical aspects, there is a paucity of South African research and information relating to the attitudes and feelings of the physicians who diagnose, care for and make decisions with regard to these patients, especially children. Several studies suggest that health care workers who provide clinical care for Persons with HIV/AIDS (PWA's) may have an intolerant attitude towards them.

As the number of children with HIV/AIDS increases, the burden of care will shift to health care workers at primary level care. It was therefore decided to assess the attitudes of doctors at primary level care facilities in Cape Town, towards paediatric patients with HIV/AIDS. The results of this study are crucial given the increasing exposure of doctors at this level to HIV/AIDS patients and understanding their response to its management.

The objectives of the study were to: assess whether doctors' knowledge of the patient's HIV positive status affects their attitudes and management of the patient; assess doctors' perceived competency with regard to the management of paediatric AIDS; determine doctors' opinions with regard to HIV testing, the utilisation of diagnostic investigations and treatment; determine doctors' main concerns with regard to the management of paediatric patients with HIV/AIDS.

A descriptive, cross-sectional survey was conducted amongst all doctors working at the clinics and day hospitals in Cape Town during the period February to April 1997.

Seventy-eight doctors (51% response rate) working in the clinics and day-hospitals in Cape Town each completed an anonymous self-administered questionnaire.

Doctors in this survey generally displayed a positive, humanistic attitude towards children with HIV/AIDS. In the majority of cases the knowledge of the child's HIV positive status did not impact negatively on their management of the child. Interestingly, 86% of respondents felt that they would always/mostly take extra care in applying universal precautions when they know that the child is HIV positive.

There is a lack of confidence in their counselling and clinical competency in the management of children with HIV/AIDS. The main source of information with regard to paediatric HIV/AIDS is journals (69%), followed by in-service training (53%) and colleagues (49%). In contrast, the preferred sources of information were in-service training (68%) and organised discussion groups/workshops (65%).

Most were in favour of routine HIV testing of pregnant women and informed consent for HIV testing. However, not everyone agreed that pre-HIV test counselling was necessary in the case of children. Confidentiality of positive

test results was not favoured in the majority of cases (65%) and disclosure even without the consent of the patient/carer was supported.

Priority concerns relating to the management of paediatric HIV/AIDS, were lack of support in the community for parents and children, lack of policy and management guidelines and the lack of resources in the health services to cope with the burden of care.

This study identifies the need for specific training in HIV/AIDS for medical doctors at primary level care facilities. The foundation of this training must begin with medical students during their clinical years but training and support should continue through in-service training. Training strategies, which address the clinical and psychological challenges presented by this disease, should be employed.

In addition, clinical guidelines, which are relevant to South Africa and evidence-based, should be adopted nationally. Resources should be available to support these guidelines.

It is further recommended that policies be underpinned by appropriate legislation which protects the rights of patients and health care workers in order to minimise the effects of individual attitudes and biases with regard to the treatment of PWAs.

# CHAPTER 1

## INTRODUCTION

### 1.1 Background and Aims

HIV/AIDS is a fairly new condition. Despite a large amount of published literature regarding its clinical aspects, there is a paucity of South African research and information relating to the attitudes and feelings of the physicians who diagnose, care for and make decisions with regard to these patients, especially children.

In the Cape Town metropole, secondary and tertiary hospitals currently manage and monitor patients with HIV/AIDS at dedicated outpatient clinics. Although these facilities have a role in the management of patients with HIV/AIDS, most of the clinical management could take place at the primary level of care (in the context of the re-organisation of health services in South Africa). However, there is a perception among hospital-based doctors at secondary and tertiary level that primary level care is inadequate and uncoordinated and that health care workers (HCWs) lack the competence to manage children with HIV/AIDS.<sup>1</sup>

In addition, several studies<sup>2-9</sup> suggest that health care workers who provide clinical care for Persons with HIV/AIDS (PWAs) may have an intolerant

attitude towards them. These attitudes are manifested in issues such as reluctance to treat, or do procedures which are perceived as putting the health care worker at risk of infection, and even in the expressed opinion of the right to refuse care.

Moreover, the unique nature of this condition raises many clinical and ethical issues and dilemmas. Yet, unlike most developed countries (for example, the United States of America, Canada, Australia and Britain) there are no set protocols issued by the Department of Health in South Africa for the management of children with HIV/AIDS. This places the onus of decision-making with regard to the management of these children squarely on medical practitioners at all levels of care and individual health authorities, who may or may not provide the appropriate interventions. Knowledge and understanding of doctors' attitudes will aid in the design of training programmes and the development of appropriate management protocols. Furthermore, as the number of children with HIV/AIDS increases, the burden of care will shift to HCWs at primary level care.

It was therefore decided to assess the attitudes of doctors at primary level care facilities in Cape Town, towards paediatric patients with HIV/AIDS. The results of this study are crucial given the increasing exposure of doctors at this level to HIV/AIDS patients and understanding their response to its management.

Although the role of nurses in the care of these patients is indispensable, the focus of this study is limited to doctors for two reasons. First, the health

services at the day hospitals in the Western Cape are primarily 'doctor driven'. Second, doctors determine the type of clinical management patients receive.

## **1.2 Research Question**

The study sought to address the following question: "What are the prevailing attitudes of doctors working at clinics and day hospitals in Cape Town to the management of paediatric patients with HIV/AIDS?"

## **1.3 Objectives of the study**

The study aimed to:

1. **Assess whether doctors' knowledge of patient's HIV positive status affects their attitudes and management of the patient.**
2. **Assess doctors' perceived competency with regard to the management of paediatric AIDS.**
3. **Determine doctors' opinions with regard to HIV testing, the utilisation of diagnostic investigations and treatment.**
4. **Determine doctors' main concerns with regard to the management of paediatric patients with HIV/AIDS.**

## **1.4 Definitions**

### **Attitude**

According to Fishbein and Ajzen's theory of Reasoned Action, the major determinant of behaviour is the intention to perform that behaviour. Intentions, in turn, are directly influenced by attitudes and the subjective norms.<sup>10</sup> It is also commonly held that one's own beliefs, perceptions and knowledge, help to formulate attitudes which are then manifested in behaviour.

For the purposes of the present research, feelings, perceptions and opinions of doctors regarding selected issues in HIV/AIDS management, are used as proxy indicators of their attitudes. A more precise definition of attitudes is beyond the scope of this study. Several validated instruments, developed to identify attitudes to HIV/AIDS support this approach.<sup>11,12</sup>

### **HIV/AIDS patients**

Patients referred to in this study are those, under 13 years of age, who are confirmed positive for HIV on a combination of ELISA and PCR tests and/or satisfy the CDC criteria for AIDS.

### **Cape Metropole**

This refers to the area which falls within the boundaries of the Cape Metropolitan area which was under the jurisdiction of the Cape Town City Council and the Cape Metropolitan Council during the period when the survey was undertaken. The Cape Metropole has now been divided between the

following local government structures: City of Cape Town, City of Tygerberg, South Peninsula Municipality, Oostenberg Municipality, Blaauwberg Municipality, Helderberg Municipality (see map: Appendix 1).

### **Carer/s**

This refers to the person/s other than biological parents taking care of the child.

### **Clinic**

Refers to a health facility where traditionally preventative and promotive health services were provided. These facilities provided tuberculosis treatment, "well baby clinics" which included growth monitoring and immunisation, as well as the treatment of sexually transmitted diseases (pre-HIV era). Since commencement of the process of restructuring of the health services in South Africa, clinics are expected to integrate curative care into their routine services. These facilities are managed by local authorities.

### **Day Hospitals**

These facilities historically provided ambulatory care and curative services. A maternity obstetric unit may be attached to this service but functions independently under the auspices of the tertiary maternity hospitals. Under the new health plan, these facilities are expected to provide comprehensive primary health care, and like the clinics, form part of the district health system. These have been re-named "Community Health Centres". For the purposes of clarity, the term "day hospitals" will however be used in this paper since the

term is still widely used in reference to these facilities. These facilities are managed by the Provincial Health Department.

### **Management of patients**

This refers to the clinical and psychosocial management of the patient.

## CHAPTER 2

### LITERATURE REVIEW

#### 2.1 Incidence and prevalence of HIV/AIDS

It is estimated that by December 1997, 30.6 million adults and children worldwide were living with HIV/AIDS of whom approximately 20 million are in sub-Saharan Africa and in Southeast Asia. It is further estimated that 2.3 million people died of AIDS related diseases during 1997. Furthermore, 5.8 million people acquired the infection during 1997, 590 000 of them children. This is equivalent to approximately 16 000 new infections every day of the year, including those in children infected at birth or through breast feeding. Sub-Saharan Africa is considered to have the fastest growing HIV epidemic in the world. Southern Africa continues to be the part of the continent worst affected. In 1997, 43% of pregnant women tested in a major urban centre in Botswana were HIV positive while in some areas in Zimbabwe, up to 59% of pregnant women are infected.<sup>13</sup>

South Africa estimates that approximately 50 000 people are infected every month.<sup>14</sup> The antenatal survey provides the only reliable data on the extent of the HIV/AIDS epidemic in South Africa and is limited to the fertile female population (15-49 year olds). Based on the eighth national antenatal survey, conducted by the Department of Health in 1997 amongst pregnant women

attending antenatal clinics of the public health services, the national HIV prevalence rate is estimated at 16.01%. The prevalence for the Western Cape Province is estimated at 6.29%. However, some areas in the Cape Metropole have a higher prevalence than the figure estimated for the province (Khayelitsha (10.35%) and Guguletu (12.15%). Although the Western Cape figures are still the lowest in the country, the levels of infection have doubled since 1996 (1.6% to 2.4%).

These data suggest that health workers at the primary level of care will increasingly be faced with the management of children with HIV/AIDS as the incidence of HIV escalates in the female population.

Some suggested, albeit controversial, methods to control and monitor the spread of HIV/AIDS include mandatory HIV testing, anonymous screening and notification.

## **2.2 Health care workers' attitudes re: HIV/AIDS**

At present in the Western Cape, the specialist services offered to patients with HIV/AIDS are at the main teaching hospitals in Cape Town. These services emerged out of the interest and concern of doctors who of their own accord improved their knowledge about HIV/AIDS. The services were offered because of doctors with a special dedication and interest in working with these patients. The Red Cross Children's Hospital sees approximately 80% of children diagnosed with HIV in the Western Cape Province. An outpatient

clinic at the hospital is operational on a weekly basis for children with HIV/AIDS.<sup>15</sup>

Significantly, patients have indicated that they preferred using these facilities to the primary level health facilities which were often closer to their homes. This is confirmed by anecdotal reports from other academic hospitals.<sup>16</sup>

Similarly, a qualitative study<sup>17</sup> conducted at an inner-London teaching hospital, indicated that parents attending this facility expressed a high level of satisfaction with the specialist paediatric care at the teaching hospital but had little confidence in the expertise of other hospitals, general practitioners and health visitors. The study concluded that, given the increasing number of HIV-infected mothers and children, in future the caseload and expertise of the secondary and tertiary centres would need to be shared with the primary health care team.

Insufficient knowledge about HIV/AIDS and its related issues, negative attitudes and the resultant practice could jeopardise the doctor-patient relationship and quality of care provided to patients with HIV/AIDS.<sup>5, 9</sup> For example, a survey in Nigeria indicated that a quarter of the doctors surveyed would hesitate to treat a person with AIDS, while 1 in 3 would refuse to carry out surgery despite adequate precautions.<sup>18</sup> A study in Oxford in which nurses and doctors were surveyed, indicated that accurate knowledge about HIV infection and positive attitudes to the care of HIV patients were highly correlated. However, anxiety about HIV infection, which could interfere with the optimum care of patients, affected one quarter of the staff surveyed.<sup>19</sup>

An assessment of the attitudes and knowledge of medical students at London and Cambridge found that one third of students believed that many health care workers were at high risk of acquiring HIV at work and one fifth thought doctors had the right to refuse to treat people with HIV.<sup>20</sup> If similar attitudes pervade our health care system, they may adversely influence the care received by patients with HIV infection.

### **2.3 Health Care Workers' Attitudes regarding Ethical and Legal obligations in the management of HIV/AIDS**

It is important to locate HCWs' attitudes regarding their ethical and legal obligations when managing PWAs, in the prevailing legal context in South Africa. HIV infection falls within the legal definition of a "communicable disease" in the Health Act.<sup>21</sup> Although many of the regulations governed by this Act have never been applied to people living with AIDS, it is inappropriate to HIV infection and AIDS since these include measures of infection control such as quarantine, isolation and detention which would create a climate of fear and denial which in turn would encourage the spread of the epidemic rather than curb it. Because of the limited way in which HIV is transmitted, casual contact between infected and healthy persons does not present a similar threat to public health as most other communicable diseases.

In the absence of specific legislation governing HIV/AIDS, ethical guidelines and recommendations for HIV/AIDS management have been devised by

several professional bodies such as the SAMDC, MASA, The College of Medicine of South Africa and the AIDS Advisory Group of the Department of Health.<sup>22</sup> It is therefore not surprising that the recommendations from these various bodies are not uniform and at times controversial. Notwithstanding, the legal parameters have been tested with regard to issues such as informed consent for HIV testing, as in the case of *C v Minister of Correctional Services* (1996)<sup>23</sup> where the legal position is set out as follows:

“It is axiomatic that there can only be consent if the person appreciates and understands what the object and purpose of the test is, what an HIV positive result entails and what the probability of AIDS occurring thereafter is. Evidence was led in this case on the need for informed consent before the HIV test is performed .... Because of the devastation which a positive result entails, the norm so developed contains as a requirement counselling both pre- and post-testing, the latter in the event of a positive result.”

and

confidentiality, as upheld in the case *Jansen van Vuuren v Kruger* (1993),<sup>24</sup>

“...HIV-related information was personal and private and could not, in the absence of an overriding legal duty, be disclosed without the express consent of the individual.”

Health care professionals face many ethical issues in the care of persons with HIV/AIDS. These include, amongst others, the allocation of scarce resources, informed consent for HIV testing and disclosure of positive status

(i.e. confidentiality). Possibly the most daunting ethical decisions arise in the treatment of persons with HIV/AIDS. These are not necessarily “new”. They occur whenever doctors face patients with an incurable, contagious and life threatening disease which may result in conflict between the rights of the individual and public health protection. However, in the case of HIV/AIDS, prejudice and ignorance compound these ethical dilemmas.

Paediatric HIV/AIDS is unique as it deals with the disease in children who are often the first members in the family to be diagnosed with HIV infection. In addition, infants who test positive at birth are a unique patient population. A positive HIV antibody test result does not necessarily mean the infant is HIV infected. There are no adult patients who test HIV positive yet are merely at risk for being infected.<sup>25</sup> The ethical dilemmas facing the clinician are therefore more pronounced.

Despite the legal requirements in South Africa for informed consent for HIV testing, data suggest much dissent among practitioners in this regard. Studies in Soweto<sup>26</sup> and Cape Town<sup>27</sup>, found that most doctors thought that pre-test consent was never necessary when screening hospital admissions and performing diagnostic tests among children. This is in conflict with statutory requirements and the view of the SA Medical and Dental Council (SAMDC) which states that pre-test informed consent is mandatory.<sup>28</sup> A study which investigated doctors’ attitudes to HIV antibody testing of surgical patients found that 48% of the sample felt testing without consent was acceptable, while 84% believed presurgery testing would protect them (i.e. ensure their safety from infection during surgery).<sup>29</sup> According to the

SAMDC no HIV test may be done without the informed consent of the patient. McLean and Jenkins (1994) support this guideline, contending that "in each case there is no good reason for the requirement of informed consent to be significantly waived" (p669).<sup>7</sup> However, in the Soweto study most doctors felt that consent is generally not necessary and thus an HIV test was commonly perceived as similar to other tests for which consent is not specifically obtained.<sup>26</sup> Similarly, the Cape Town study<sup>27</sup> found that 50% of doctors dealing with children do not obtain informed consent for an HIV antibody test. Some have argued that "unless doctors, as has always been customary, are free to request medical investigations as they see fit, the epidemic will never be quantified and controlled."<sup>30</sup>

International ethical codes and human rights laws appear to accept informed consent as a universal expression of respect for persons. It has been suggested that it is respect for human dignity that compels health care professionals to obtain the consent of patients in ways that are comprehensible and consistent with the person's language, custom and culture.<sup>31</sup> Interestingly, some researchers found that only 25% of doctors perceived language as an obstacle to obtaining consent.<sup>27</sup> Still others acknowledge that while little research has been done on the ideal circumstances and process for pre-HIV test counselling, they point out that increased testing and knowledge about HIV in the patient community should result in HIV-testing becoming just another one of the tests and procedures that doctors, in their daily practice, discuss with their patients.<sup>32</sup> Although they argue that pre-HIV test discussion should form part of this consultation and the differential diagnosis process and not be divorced from routine

medical care, they go on to point out that specialist counsellors must be made available to help with HIV positive patients.

Several studies<sup>26,27,30,32</sup> have suggested that there are problems with the practical implementation of informed consent not least of which is the view that the “doctor knows best”. A study in Australia<sup>31</sup> highlights the inordinate faith, which some patients have in the medical system to protect them and do things in their best interest, a belief, which is probably pervasive in South Africa. Some parents felt that the “laborious” procedure of explaining all the pros and cons of enrolling their children in a clinical trial was unnecessary since they would do what the doctors say anyway. Similarly, a common reason cited by doctors for not obtaining informed consent, was their belief that patients and parents (in the case of minors), expect doctors to know what is medically best for them.<sup>27</sup>

An important implied feature of consent is the assurance of the confidentiality of the HIV test result. In a case which came before the South African courts, *Jansen van Vuuren v Kruger*<sup>24</sup>, the Appellate Division held that HIV-related information was personal and private and could not, in the absence of an overriding legal duty, be disclosed without the express consent of the individual. The SAMDC has stated that doctors should ensure that sexual partners are informed.<sup>24</sup> This should preferably be done with the patient’s consent; but, where consent is not forthcoming, the doctor is urged to inform the partner. These guidelines imply that the doctor has an overriding legal obligation to inform a third party (namely, the sexual partner) of the HIV positive status of the patient. However, the context in which the issue of

confidentiality is commonly raised relates to referral of a patient to another health care worker and the principle of consent for disclosure applies in these instances.

The fact that some health care workers feel that they have a right to refuse to treat a patient with HIV/AIDS<sup>3, 8-9,18-19, 33-34</sup>, raises further ethical and legal dilemmas. A study conducted in South Africa<sup>8</sup> found that 71% of respondents had witnessed discrimination towards patients with HIV/AIDS. Examples of discrimination included patients being refused treatment, so-called “suboptimal” treatment and discriminatory remarks towards patients.

The above-mentioned studies have shown that fear of contagion and prejudice are some of the factors contributing to health care workers’ reluctance to treat patients with HIV/AIDS. Despite reassurances such as those expressed by the Interim SAMDC that adherence to universal precautions is the most effective action that will significantly protect health care workers against infection by HIV and other blood-borne pathogens, it remains a major concern.<sup>24</sup>

Furthermore, despite evidence that paediatric HIV infection is no longer the rapidly fatal disease it once was believed to be, but rather a chronic disease of unknown incubation and life expectancy, many infants labelled HIV positive face discrimination in terms of treatment and resources being withheld from them.<sup>35, 36, 37</sup>

Two fundamental ethical principles emerge in the studies cited above, namely beneficence and distributive justice. In other words, decisions regarding management of patients with HIV/AIDS should be based on, the best interests of the patient, applied in such a manner, that scarce resources are not consumed excessively by some, at the risk of causing deprivation in others.<sup>25</sup> Notwithstanding, the choices presented to the clinician may not be obvious since what may be considered to be in the patient's best interest is subjective and may be clouded by the clinician's prejudice rather than reality. On the other hand there are very real tensions in setting health care priorities for South African children.<sup>37</sup> The ethical, moral, political and economic considerations influencing the distribution of health care resources in a country with a legacy of inequity and disparity is a daunting task which has to be done on a macro level and filter down to a local level with input from a local level upwards.

Hence, the ethical and legal challenges presented to doctors in their endeavour to manage PWAs should be viewed in its wider social context rather than from a narrow bio-medical viewpoint. The trend towards making conceptual changes to the education and training in medicine in recent years supports this view. It is argued that "... a solid core of scientific knowledge and professional skills, increasingly influenced by the primary care approach, must be combined with a humanistic approach to individuals and an informed understanding of the social underpinnings of health and disease in individuals and populations..." (p 1664).<sup>38</sup>

## **2.4 Implications for training**

AIDS raises issues for which conventional medical training does not adequately prepare doctors. A pilot survey at Somerset Hospital indicated that 78,6% of the doctors did not feel confident about their medical expertise in relation to the treatment of paediatric AIDS patients and none felt absolutely confident about having the counselling skills necessary to relay a positive diagnosis to the family.<sup>2</sup> This finding illustrates that health care professionals are seriously challenged to meet the psychosocial needs of HIV infected patients and their networks of partners, families and friends.

A survey done amongst medical students at the Cae Hill Campus of the University of the West Indies concluded that "it has become evident that emphasis should be placed on ethical and attitudinal training within the faculty of Medical Sciences. Our future doctors have to be trained to effectively manage the many psychosocial, ethical and legal problems that will be generated by the AIDS epidemic" (p815).<sup>33</sup>

It has been found that in-service educational programs on AIDS are successful in allaying the irrational fears of staff and enhancing compassionate care to AIDS patients.<sup>39</sup> However, health care professionals require specific educational programs with regard to HIV/AIDS so that they will safely provide high quality care to people affected by HIV/AIDS.<sup>40</sup> Researchers have found that factual information alone does not suffice to

dispel excessive concern about HIV/AIDS. The training and education of medical personnel, should include cognitive and emotional components.<sup>41</sup>

This training should include medical ethics and legal issues, which would stimulate thinking about issues with which doctors will be confronted with in daily practice. It has been suggested that “the central problem in the ethics of medical practice is not so much poor thinking about an ethical problem but lack of awareness of ethical issues raised in everyday medical practice”(p231).<sup>42</sup>

## **2.5 Implications for policy**

The development of policy guidelines should extend beyond the views and attitudes of those who develop them.<sup>43</sup> The attitudes, perceptions and feelings of those who bear the burden of decision-making with regard to the management of paediatric patients with HIV/AIDS need to be considered. There is no clear policy on diagnostic protocol for AIDS patients in South Africa. The result is that doctors treat patients intuitively, based on their experience of the disease. This influences the kind of care patients receive.

Studies<sup>8-10, 6, 27,</sup> have shown that the statutory requirements and doctors' practices with regard to informed consent for HIV testing are at variance. This has implications for the implementation of the present policy guidelines on informed consent.

Policy guidelines for ensuring confidentiality are necessary to protect the rights of patients without jeopardising the therapeutic relationship between the health service providers and the patients. It is therefore important to determine how HCWs perceive confidentiality and the reasons for disclosure.

The need for screening for HIV should be determined in the context of its prevalence and the resources available to manage the resultant issues (such as obtaining informed consent, post-test counselling and provision of prophylactic treatment regimens). There is currently no national policy on testing for HIV though the South African Law Commission has put forward recommendations for legislation to the Minister of Health.<sup>24</sup>

This study was therefore an attempt to determine the views and attitudes of doctors directly involved in the daily management of paediatric HIV/AIDS patients at a primary level of care. It will hopefully inform the process of development of guidelines for the management of paediatric HIV/AIDS. It is envisaged that the results of this study will be utilised to devise management protocols that address the particular needs of patients, while taking into account the challenges facing doctors responsible for this care.

## **CHAPTER 3**

### **METHODOLOGY**

#### **3.1 Study Design**

This was a descriptive, cross-sectional survey of all doctors working at the clinics and day hospitals in the Cape Metropole.

#### **3.2 Study Sample**

In addition to services at secondary and tertiary hospitals, there are approximately 100 clinics and 40 day hospitals (now referred to as community health centres) offering primary level health services in the Cape Metropole. The study sample included all doctors employed at the City Council clinics (16 filled posts),<sup>44</sup> Cape Metropolitan Council clinics (18 filled posts)<sup>45</sup> and Day Hospitals (120 filled posts at 41 day hospitals)<sup>46</sup>. The sample comprised full-time, half-day and sessional staff employed during the period February - April 1997.

### **3.3 Techniques of data collection**

Data were collected by means of an anonymous, self-administered questionnaire. The questionnaire used in this study was adapted from previous surveys undertaken at the three teaching hospitals attached to the University of Cape Town Medical School.<sup>47</sup> The questionnaire was piloted among a convenience sample of doctors [N=6] working at clinics and day hospitals. Further adaptations such as improvements in clarity, relevance to primary level health care services and language, were made before the final questionnaires were administered to participating doctors.

Structured questionnaires, comprising mainly closed questions (see Appendix 2), were handed to clinic doctors at meetings and workshops (N=34) and hand delivered at various day hospitals (N=120). These were returned by hand or post in a sealed self-addressed envelope.

Content validity of the questionnaire was tested amongst experts in the field of HIV and AIDS management. The validity of the questionnaire in relation to actual practice may be challenged since responses and practice were not correlated to determine congruency. The reliability of the questionnaire was not tested and it is possible that respondents may have responded differently to re-questioning. Since the majority of the respondents indicated that they had never or seldom managed a child with HIV/AIDS, their responses may reflect anticipated rather than actual practice. In addition, despite anonymity, responses may have been subject to a social desirability bias if participants had responded in a socially acceptable rather than "truthful" manner.

### **3.4 Data Analysis**

The questionnaires were analysed by the researcher using EPI INFO 6. Chi-square tests were used to examine differences in doctors' responses according to facilities, frequency of involvement with patients with HIV/AIDS and length of experience. Percentages were rounded off to the nearest number.

Qualitative data was examined using content analysis.

### **3.5 Ethical considerations**

The questionnaire was anonymous and confidential. The results obtained will only be used to achieve the aim of the study, i.e. assessing the current views and attitudes of paediatric doctors to their HIV/AIDS patients in order to inform the process of continuing medical education and protocol development. No names of patients or doctors will be divulged. The Research Ethics Committee of the University of Cape Town approved the study.

## **CHAPTER 4**

### **RESULTS**

Results presented are for all respondents irrespective of health facility. Results were stratified by facility but only significant (i.e.  $p$  value =  $\leq 0.05$ ) differences in responses between variables are reported (see Appendix 7 for detailed results stratified by facility).

#### **4.1 Response Rate**

A 78/154 (51%) overall response rate was obtained with a higher response rate from doctors working at clinics 29 (85%) than doctors at day hospitals 49 (41%). This difference in response rate between facilities was significant ( $p = 0.01$ ).

#### **4.2 Demographic Details of Respondents**

The profile of respondents is outlined in Table 4.1.

Sixty two percent of respondents were female. However, the differences between variables, based on gender, were not statistically significant. Approximately half of the respondents had less than five years experience of working at primary level care facilities.

**TABLE 4.1: Social demographic characteristics of respondents**

	<b>N</b>	<b>(%)</b>
<b>Gender :</b>		
Male	30	38%
Female	48	62%
<b>No. of years since qualification (MBChB):</b>		
<5 years	14	18%
6-10 years	12	15%
>10 years	52	67%
<b>Facility</b>		
Clinics	29	37%
Day Hospitals	49	63%
<b>Employment status:</b>		
Full-time	53	68%
Half-day	5	6%
Sessional	20	26%
<b>Length of employment experience at Primary level facility:</b>		
<6 months	11	14%
7-12 months	1	1%
13-23 months	10	13%
2-5 years	18	23%
6-10 years	18	23%
>10 years	20	26%

### **4.3 Frequency of involvement with children with HIV/AIDS**

Twenty (27%) of the respondents reported that they had **never** been involved in the management of children with HIV/AIDS, 39 (53%) said they had **seldom** and 14 (19%) said they had **often**.

### **4.4 Policy Issues**

Respondents were asked to what extent they would agree or disagree with possible clinical and ethical policy options regarding HIV/AIDS. Their responses are summarised in Table 4.2.

Whereas (67%) were in favour of HIV testing for all pregnant women, only 12% favoured routine testing for all children at curative services. A similarly low percentage (15%) would favour discrimination against HIV positive children in an emergency. Whereas 65% of respondents agreed that informed consent must be obtained for HIV testing in children, in contrast 65% believed that HIV status of a patient should be disclosed to a third party even without consent from a patient/carer. More doctors at clinics (76%) than doctors at day hospitals (59%) favoured informed consent for HIV testing in children while more doctors at day hospitals (43%) than doctors at clinics (21%) felt that disclosure even without consent of the patient/carer, was acceptable.

Approximately two thirds of respondents believed HIV positive children should be given prophylactic regimens for conditions such as tuberculosis and PCP.

Respondents were asked to choose a reason (from three given options) for stating the patient's HIV positive status on a referral letter when referring a patient to another HCW. The majority of respondents (54%) felt that the primary reason for stating the HIV positive status of a child on a referral letter is to facilitate optimal care. While 15% felt that it should be written for the protection of the health care worker, 28% felt that it should be to both protect the health care worker and facilitate optimal care of the patient.

Doctors' frequency of involvement with children with HIV/AIDS was significantly associated with reasons for disclosure. More doctors who reported being involved in the management of children felt that the reason for disclosure of the patient's HIV status on a referral letter was for optimal care (60% vs. 35%;  $p$  value = 0.03; Chi-square = 6,88).

**Table 4.2: Advice to Policymakers**

<b>Statement</b>	<b>Total</b>	<b>Agree*</b>	<b>Disagree*</b>
	<b>N</b>	<b>N %</b>	<b>N %</b>
All pregnant women should be tested for HIV.	78	52 (67%)	26 (33%)
All children presenting for curative services should be routinely tested for HIV.	77	9 (12%)	68 (88%)
Informed consent must be obtained for HIV testing in children.	78	51 (65%)	27 (35%)
Children who are HIV positive should be given prophylactic treatment regimens e.g. PCP, TB prophylaxis.	74	50 (68%)	24 (32%)
The HIV positive status of the patient should not be disclosed to a third party (even another health care worker) without the consent of the patient/carer.	78	27 (35%)	51 (65%)
In an emergency situation HIV positive children should receive the same priority as those with unknown status.	76	65 (86%)	11 (14%)

\* Response categories were collapsed as follows: agree (strongly agree and agree) and disagree (strongly disagree and disagree). (Refer to Appendix 3 for table of complete response categories).

## **4.5 Influence of knowledge of HIV positive status on Management**

Respondents were asked whether knowledge of a child's HIV status would affect clinical management (see Table 4.3). Response rates from the categories always and mostly were combined.

Knowledge of a patient's HIV/AIDS status would strongly influence most doctors to take extra care in applying universal precautions and to spend more time with a patient's mother (86% and 85% respectively). Knowledge of HIV/AIDS status was less likely to have a strong influence on the time doctors spent with patients and whether they would refer to a tertiary centre (43% and 35% respectively). Knowledge of HIV/AIDS status would 'never' affect the decisions of most doctors (63%) to use invasive procedures or to avoid diagnostic investigations for symptoms such as fever and diarrhoea (47%). One third of respondents would generally refer an HIV positive patient to a tertiary hospital for treatment they routinely offer in other conditions such as TB.

**Table 4.3: Impact of knowledge of HIV status on management**

	Total	Always/ Mostly		Sometimes		Never	
	<i>N</i>	<i>N</i>	%	<i>N</i>	%	<i>N</i>	%
You will avoid invasive procedures (such as taking blood, suturing).	76	7	10	21	28	48	63
You will take extra care in applying universal precautions e.g. gloves.	78	67	86	8	10	3	4
You will avoid diagnostic investigations for symptoms such as fever and diarrhoea.	78	9	12	32	41	37	47
You will spend more time examining an HIV positive child than an HIV negative child.	77	33	43	32	42	12	16
You will spend more time in discussion with the mother e.g. evaluating mother's understanding of implications of HIV infection.	78	66	85	11	14	1	1
You will refer a symptomatic HIV positive child to a tertiary hospital for treatment of conditions which you would routinely treat in an HIV negative child e.g. TB, skin conditions.	78	26	33	40	51	12	15

## 4.6 HIV/AIDS Training and Perception of HIV/AIDS Management Skills

Doctors were asked to identify their main sources as well as their preferred sources of information regarding paediatric HIV/AIDS (Table 4.4).

**Table 4.4: Current vs preferred sources of HIV/AIDS Information**

Source	Main Source*	Preferred Source*	P-value
Journals	54 (69%)	34 (43%)	<0.01
In-service training	41 (53%)	53(68%)	0.08
Organised discussion groups/workshops	29 (37%)	51(65%)	<0.01
colleagues	38 (49%)	18(23%)	<0.01
other (specify)	1(1%)	1(1%)	N/A

\*More than one response per respondent was possible therefore totals exceed 100%.

### Current Sources of HIV/AIDS Information

For both clinic (72%) and day hospital (67%) staff, journals were the main source of information with regard to paediatric HIV/AIDS, while in-service training (48% and 55% respectively) was the second major source of information. Doctors at both facilities also ranked colleagues as an important source of information.

## Preferred Methods of Continuing Education

Doctors at both facilities ranked in-service training and organised workshops/discussion groups as the most preferable methods for continuing education. One respondent specified the method of in-service training as rotation through the specialist clinic at Red Cross Children's Hospital. Colleagues did not rank highly as a preferred source of information even though 49% of respondents reported colleagues as a main source of information (see Table 4.4).

Respondents were asked to indicate whether they had attended the ATICC HIV/AIDS training course held for doctors. Their responses are illustrated below (see Table 4.5). The Western Cape AIDS Training and Information Centre conducts courses in HIV/AIDS for doctors working at primary level care facilities. These courses are conducted once a week, after hours, over a period of 4 weeks. The course content includes counselling and clinical management.

**Table 4.5: ATICC Course attendance**

Facility	YES		NO		(N)
	N	%	N	%	
Clinic	16	55	13	45	29
Day Hospital	21	43	28	57	49
<b>Total</b>	<b>37</b>	<b>47</b>	<b>41</b>	<b>53</b>	<b>78</b>

Slightly more than half the respondents had not attended an ATICC course. However, when one examined attendance according to facility, more doctors (55%) at the clinics have attended than those at the day hospitals (43%).

Respondents were asked who they thought should be responsible for conducting the pre-and post-HIV test counselling. The responses are listed below (see Table 4.6).

**Table 4.6: Responsibility for Pre-and Post-test Counselling\***

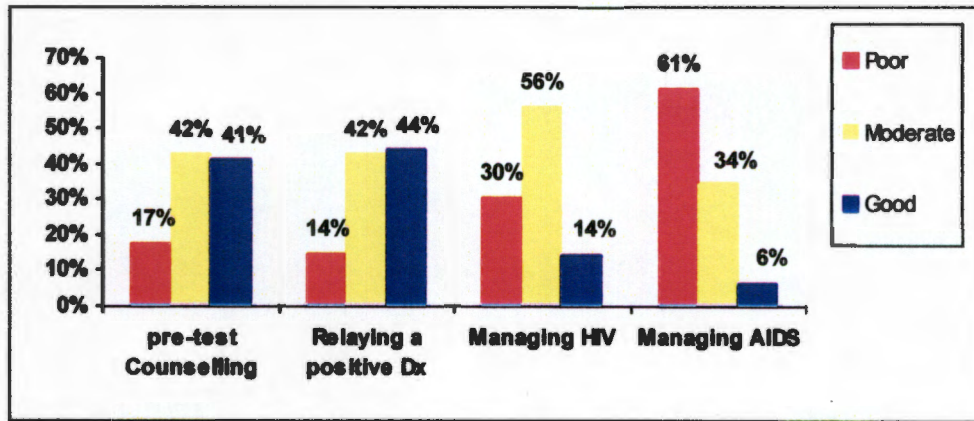
<b>Options</b>	<b>Pre-test N=77</b>	<b>Post-test N=75</b>
The doctor requesting the test	45 (58%)	49 (65%)
Another HCW	24(31%)	23 (31%)
Either of the above	35 (46%)	28 (37%)
Other (specify)	5 (6%)	10 (13%)
It is not necessary	2 (3%)	0

\*More than one response was possible therefore totals exceed 100%.

Whereas most respondents felt that the doctor requesting the HIV test should be responsible for both the pre- and post- test counselling (58% and 65% respectively), a significant number felt that it could be done by either the doctor or another HCW (46% and 37%). In contrast, 3% of respondents felt that pre-test counselling was not necessary but none felt this way about post-test counselling.

Respondents were asked to rate their perceived ability to manage children with HIV/AIDS. The responses are summarised in Fig. 1.

**Fig.1: Perceived competency of HIV/AIDS management skills\***



Response categories were combined as follows: unable/poor; moderate and good/excellent.

The full spectrum of responses with regard to the perceived competency of the doctors is illustrated in Table 4.7 below.

**Table: 4.7: Perceived ability to manage HIV/AIDS**

Skill	(N)	Unable	Poor	Moderate	Good	Excellent
Ability to do pre-test counselling	78	0	13 (17%)	33 (42%)	30 (38%)	2 (3%)
Ability to relay a positive diagnosis	77	0	11 (14%)	32 (42%)	33 (43%)	1 (1%)
Ability to manage symptomatic HIV infection	77	1(1%)	22 (29%)	43 (56%)	10 (13%)	1 (1%)
Ability to manage full-blown AIDS	77	11 (14%)	36 (47%)	26 (34%)	3 (4%)	2 (3%)

Almost twice as many respondents felt unable or poorly equipped to manage a child with AIDS compared to symptomatic HIV infection (61% versus 30% respectively). This difference was statistically significant (p value = 0.0006; Chi square = 14.67). In contrast, a fair proportion of respondents rated their ability to relay a positive diagnosis and to undertake pre-test counselling as good or excellent (44% and 41% respectively).

## 4.7 Concerns with Regard to Care of Children with HIV/AIDS

Respondents were asked to rate five major issues surrounding the management of children with HIV/AIDS in order of priority (Table 4.8). Each item was prioritised on a rating scale of 1-5. The number 5 was given to the highest priority while 1 was given to the lowest priority. It was possible to assign the same rating more than once to different variables. The respondents' ratings were combined and ranked in order of frequency.

**Table 4.8: Major concerns listed in order of priority\***

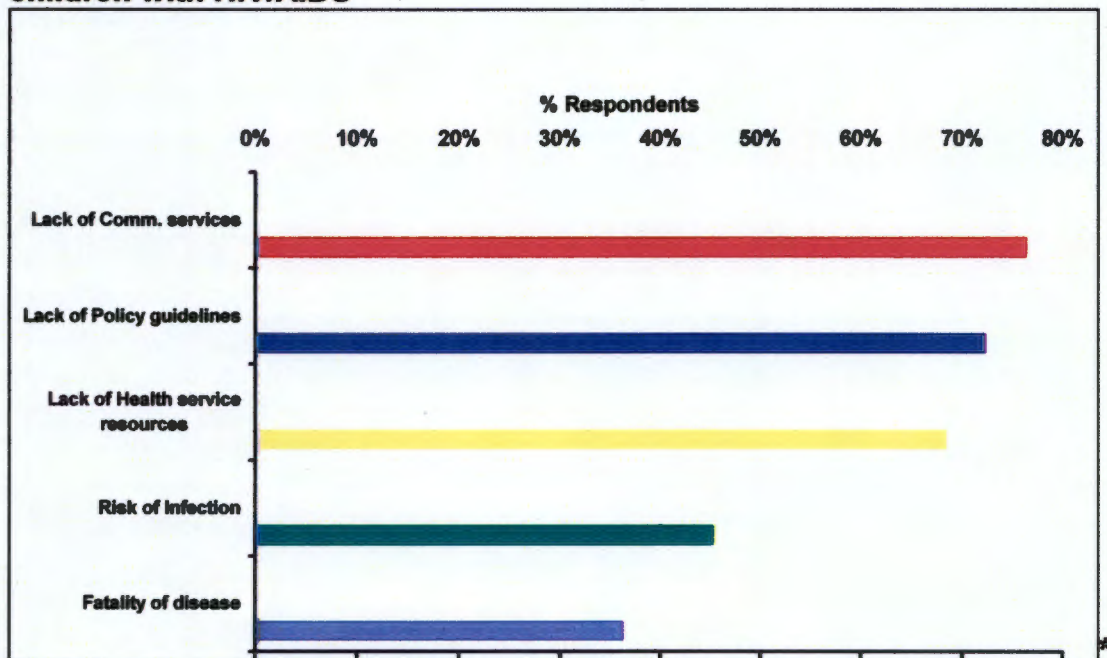
RANKING (1-5)	N	No. of responses per rating*				
		1	2	3	4	5
The lack of resources in the community to support parents.	78	4 5%	5 6%	10 13%	21 27%	38 49%
The lack of policy guidelines from health authorities re: the management of children HIV infection.	77	3 4%	5 6%	13 17%	21 27%	35 45%
The lack of resources at your health facility (including drugs, personnel for counselling, room for privacy).	78	3 4%	8 10%	14 18%	22 28%	31 40%
The risk of infection from the patient through needlestick/sharps injury.	77	14 18%	11 14%	17 22%	11 14%	24 31%
The fatality of the disease.	76	16 21%	8 11%	25 33%	12 16%	15 20%

\*5 = highest priority; 1 = lowest priority.

**Note:** Individual respondents could assign a particular rating (e.g. 5) to more than one variable. Thus percentages may exceed 100%.

The cumulative responses indicating the order of priority from highest to lowest, are illustrated in Fig. 2 below.

**FIG. 2: Prioritisation of concerns with regard to the management of children with HIV/AIDS**



Categories 4 and 5 (highest priorities only) are collapsed.

#### 4.8 Responses to open-ended Questions

Respondents were given the opportunity to list any other concerns with regard to the management of children with HIV/AIDS in general (Appendix 5) and more specifically in their health care setting (Appendix 6).

Minimal differences exist between the major concerns indicated by the researcher and the themes, which emerged from individual responses to the open-ended questions. Respondents provided a range of comments. These included their concern for the lack of resources within health care services, the community and the wider economic resource burden caused by managing HIV/AIDS and the need for training of doctors in the management of children

with HIV/AIDS. Other issues raised were their lack of involvement with children with HIV/AIDS, prevention and ethical and moral concerns.

Concerns regarding lack of resources at health facilities were stated by some respondents as follows:

“We have major concerns regarding management of all children that are ill with very poor resources.”

and

“ [There is an] inadequacy of human resources both medical and nursing.”

and

“... maintaining their nutritional status is very important [however] we are unable to include them on the PEM scheme before they become underweight for age.”

and

“[There is] a lack of space and staff. There is no time to counsel adequately.”

and

“[lack of] access to treatment.”

The problem with regard to the fragmentation of services for adults and children emerged:

“Children and mothers should be managed together and not seen individually at separate institutions.”

and

“The setup for mothers is not good and they often have no follow-up. I dislike the secrecy involved with this disease, it is not a crime to be a child with HIV.”

and

“Often the treatment of mothers and children are (sic) fragmented even at

primary care level between “paeds” doctor and “adult” doctor.”

Concerns about the lack of resources in the community to care for patients with HIV/AIDS were expressed by some as follows:

“Who will care for the child if the mother and possibly the father also have HIV/AIDS and die from this?”

and

“The closure of [ a community based paediatric AIDS project] will leave a big void in the day to day management of these children.”

Clinical management concerns were expressed in terms of lack of opportunity for diagnosis of HIV infection in children at the primary level, as well as lack of competency in making a diagnosis. Respondents wrote:

“Children always come to us with a diagnosis already. Often they are being followed up somewhere else. We usually continue whatever treatment was started.”

and

“Due to the lack of follow-up of patients and the poor [ability] to [diagnose on the basis of a physical] examination for AIDS (feeling for spleen or liver is a luxury), it is very seldom that a diagnosis is made a PHC centres. There should be clinical guidelines.”

One respondent indicated perhaps that the lack of opportunity for diagnosis at a primary level could be overcome through earlier identification: The method of identification was not specified.

“[We need] better identification, timeously.”

The need for training in clinical management of children with HIV/AIDS was expressed in various ways, some are:

"I'm happy to get involved and meet the challenge but definitely need more information, guidelines/protocols and protocols on appropriate referrals."

and

"I feel that there should be a workshop outlining all the aspects that we should and could know about such a child regarding diagnosis, ethics and management."

The acknowledgement of the support and guidance of experienced colleagues was expressed in several comments, some of these are:

"I was lucky in the way that I had people with more experience than myself to help me."

and

"We are fortunate in having people who are excellent in managing HIV/AIDS in children."

Yet another, while acknowledging the need for training, points out the constraints upon a doctor in service to avail her/himself of training opportunities:

"I need training but as a sessional worker this means loss of income."

Some other contentious and ethical issues were raised in relation to HIV/AIDS in children, some comments in this regard are:

“[I am concerned about] the referral of patients [from secondary and tertiary level] who are too sick for ambulatory care - when, how, to any point? Terminal patients [are] competing for resources at secondary and tertiary institutions, should we not just palliate. This is a major ethical-moral dilemma.”

and

“What about sterilisation of parents [who are HIV positive].”

and

“[What about] testing of siblings and parents [of a child who is HIV positive].”

Finally, one respondent shared some optimism based on his/her experience of treating adults with HIV/AIDS:

“I don't see children but encourage adult sufferers to keep [their] spirits up, [I] treat infections if CD4[cell counts] or Viral load is high. [I] try to get them on trials [to access treatments] and keep them hopeful for full life and even cure.”

#### **4.9 Feelings expressed with regard to management of children with HIV/AIDS**

Many respondents said they felt depressed (41%), challenged (34%), frustrated (36%) and incompetent (24%) when managing a child with HIV/AIDS.

The full range of feelings expressed by the respondents is listed in Table 4.9.

**Table 4.9: Feelings evoked re: treatment of children with HIV/AIDS**

	Total N=76	
	N	%
Depressed	31	41%
Frustrated	27	36%
Challenged	26	34%
Incompetent	18	24%
Anxious	14	18%
Useful	12	16%
Positive	10	13%
Other *	8	11%
Optimistic	3	4%
Afraid	2	3%
Waste of time	1	1%

# More than one response was possible, thus percentages exceed 100%.

- \* sad
- \* haven't seen enough cases to have an opinion
- \* lacking in knowledge
- \* protective
- \* frustrated by lack of essential medications
- \* inadequate
- \* frustrated by secrecy
- \* only contact I've had was in a tertiary setting

## CHAPTER 5

### Discussion of Results

Despite intense personal effort on the researcher's part, the overall response rate was only 51 percent, with day hospitals in particular reflecting an even lower rate. There are several possible explanations. Low response rates for self-completed questionnaires are well described in the literature.<sup>48</sup> In addition to methodological problems inherent in survey research, the researcher encountered several practical problems. The doctors at the day hospitals were not easily accessible due to their patient load and the fact that they did not have regular meetings, which all doctors attended. Despite support from the authorities for the study, the response from individual doctors was unsatisfactory. A total of 49 out of the possible 120 doctors from day hospitals responded.

Since the postal system to some of the health facilities is unreliable, the researcher had to rely on hand deliveries. The fact that the questionnaires were returned in self-addressed envelopes and anonymously, meant that delivery could not be verified nor was it possible to send a second set of questionnaires. This was particularly problematic for Day Hospitals.

In contrast, the response at the clinics was very good. This could be due to the fact that there were fewer doctors employed at the time and the fact that they meet regularly and were therefore easily accessible. Permission was given to the researcher to address the doctors at a meeting about the survey

and to personally distribute the questionnaires. Most questionnaires were returned the same day.

Despite the relatively low response rate, missing data on returned questionnaires were minimal.

The fact that 62% of respondents were female may have influenced the outcome of this survey. It may be that those who responded were concerned about or interested in the subject,<sup>49</sup> thus accounting for the overall positive attitude displayed toward children with HIV/AIDS in this survey. However, in practice, the female respondents constituted 65% of sessional staff, which implies that they are not easily accessible to those in need of care and it may be more problematic for them to be available for training opportunities with regard to HIV/AIDS.

Most respondents reported that they had seldom or never been involved in the management of children with HIV/AIDS. Most doctors based at the clinics held this perception (81%). Surprisingly, except for attitudes towards reasons for disclosure on referral letters, frequency of involvement with the management of children with HIV/AIDS was not significantly associated with opinions or attitudes. But, this may be due to low numbers (those who responded "always" N=14). The fact that disclosure of the patient's HIV positive status on a referral form evokes a significant difference in opinion between the groups may be directly attributable to practical experience. This experience may have taught the importance of eliminating the need for unnecessary diagnostic tests and re-testing for HIV at the next level of referral

and thereby save time and money. The issue of confidentiality should not be taken to the extreme within the health care setting. Disclosure of the patient's HIV positive status between the health care team is essential for the optimal care of the patient if the notion of a continuum of care is subscribed to. Thus, policies in relation to confidentiality should adopt this principal of the continuum of care. Health care workers should act ethically by maintaining confidentiality within the health team. The health team in this context is defined as " all HCWs responsible for the care and treatment of the patient." This implies that the maintenance of confidentiality is not institution based. However, caution must be exercised when referrals between the formal health sector and the NGO or CBO sectors occur. It must be ensured that the patient's permission is obtained when making a referral beyond the formal health sector.

The relationship between attitudes (including willingness to care for) and experience in the care of patients with HIV/AIDS is inconclusive despite several studies on attitudes towards people with HIV/AIDS. It has been found that greater prior experience with HIV-infected patients was associated with less resistance to providing care. A survey amongst HCWs found that physicians and nurses in areas of lowest HIV incidence were more averse to caring for HIV-infected patients.<sup>49</sup> Yet another, found that negative or restrictive attitudes towards PWAs were associated both with less knowledge regarding HIV transmission and fewer contacts with them.<sup>50</sup> However, other studies which showed that health care workers employed at high HIV incidence hospitals tended to be more experienced in caring for this patient population but less inclined to perform certain tasks in relation to them.<sup>51</sup> Still

other researchers have found no significant relationship between the level of experience caring for HIV-infected patients and attitudes concerning providing care.<sup>4,5</sup>

In general, the majority of respondents displayed a tolerant attitude towards children with HIV/AIDS. This is demonstrated by their opinions with regard to equal access to emergency treatment for HIV positive children, access to prophylactic treatment regimens, willingness to perform invasive procedures on these children, willingness to spend more time examining the child and counselling the mother. In other studies of attitudes towards people with HIV, the responses may have been clouded by the participant's bias towards groups of individuals within the HIV patient population such as homosexuals, IV drug users and prostitutes. Children with HIV infection, in contrast, are generally viewed as the 'innocent victims' of the disease since vertical transmission is the major mode of transmission. It may therefore be hypothesised that generally a more positive attitude would be displayed towards them.

Generally responses indicate that the knowledge of the child's HIV positive status would not always negatively influence their attitude towards, and management of, the child. However, there is a bias towards treating them differently to those whom doctors do not know to be infected, or, those found to be negative for HIV infection.

The majority of respondents (67%) support the routine testing of pregnant women but not children. The breakthrough in the reduction of perinatal

transmission with the use of Zidovudine (AZT) has stimulated research, debate and in some cases action around identifying HIV positive pregnant women in time to apply the intervention.<sup>52</sup> This practice presupposes that all the necessary support and treatments are available to cope with the resultant positive results. HIV testing as a component of a patient's diagnosis and treatment is relatively non-controversial and may be carried out in a manner, which offers containment for the patient. However, the psychological effects of being informed about one's HIV status in a society which still discriminates and offers very little, if any support and treatment, can be devastating. Policy makers in developed countries have not embraced routine screening for HIV.<sup>53, 54</sup> Without the necessary legal and ethical guidelines and resources, South Africa should approach adoption of this strategy with caution. Routine antenatal HIV testing programmes are expensive but may be justified in areas of high prevalence and access to interventions for reducing vertical transmission.<sup>55</sup> Access to voluntary HIV testing for pregnant women may be more feasible within the constraints of resources in the health care setting.

The adoption of universal precautions which views every patient as potentially HIV positive, weakens the force of arguments in favour of routine testing for the protection of health care workers and others.

In this study, the high proportion of respondents who would practise universal precautions should be viewed as a positive finding. In similar view, 63% of respondents indicated that knowledge of HIV status would NOT cause them to avoid invasive procedures.

In contrast, this study shows that knowledge of the child's HIV positive status will at times impact negatively on critical areas of care. These include, the performance of invasive procedures and diagnostic investigations for common symptoms such as fever and diarrhoea. Knowledge of the child's HIV positive status would impact on the decisions of 38% and 33% of respondents respectively. This may be linked directly to fear of contagion through occupational exposure. This is borne out by the result that 73% of respondents reported that they would *always* take extra care in applying universal precautions when treating a *known* HIV positive child. A similar study showed that when treating patients with actual or possible HIV infection, many doctors and nurses often take too many precautions because of these fears, even during non-invasive procedures.<sup>49</sup> While universal precautions are an essential aspect of clinical practice, this concern about contagion by patients can have a negative influence on staff attitudes towards patients with HIV/AIDS. It may make the difference between a child receiving the appropriate intervention which will impact on his/her survival and quality of life, or receiving inappropriate, sub-optimal care thereby reinforcing the notion of the futility of providing care for these children. Some researchers found that nurses who reported higher risk of occupational exposure to HIV infection were significantly more likely to feel fear and to feel care for HIV-infected children was futile and were less willing to provide care.<sup>51</sup> However, they concluded that the risk of acquiring infection was not sufficient to dissuade caregivers from either their positive attitudes toward patients or willingness to care for them. On the other hand, the reluctance of the majority of doctors to do diagnostic tests for common symptoms in HIV/AIDS such as diarrhoea and

fever, may be related to the lack of resources at the health facilities rather than reluctance to provide optimal care.

The fact that more than half the respondents admitted that they would sometimes refer a symptomatic HIV positive child to a tertiary hospital for treatment of conditions which they would routinely treat in an HIV negative child, could be an indicator of several factors. The reasons for the responses were not determined in this study.

However, the following assumptions are postulated based on the findings and general comments of respondents in this study. Inappropriate referral may be due to a lack of confidence in dealing with the treatment of these children. Many respondents did not feel confident about their clinical management skills in regard to children with HIV/AIDS. One of the respondents said “.... We rely on that clinic [Red Cross Hospital Outpatient Infectious Diseases Clinic] for instructions and tend to refer all queries back to them...”, Only 14% and 7% of respondents perceived their competency to deal with a child with HIV and AIDS respectively, as ‘good’ or ‘excellent’. The fact that few of the respondents had experienced regular involvement with these children, may be another reason for this response. Lack of resources, such as drugs, at the facilities may be another likely reason. This is borne out by the following comment from one of the respondents, “Treatment for them is obviously expensive especially because of investigations needed. We are also reluctant to look after them in the community health centres where one doctor sees an average of 60 patients a day”. The perception that the tertiary levels have specialist expertise may be another reason why these children are often

inappropriately referred. A comment by a respondent illustrates this point, "This [AIDS] has become a specialist discipline, specialists should be responsible for the care of HIV positive children and adults."

The fact that more than half the respondents (53%) said they would always spend more time with the known HIV positive patient has implications. Once the number of HIV positive patients attending primary level care facilities increases, this aspiration will be thwarted and the resultant levels of frustration, already experienced by doctors, may increase. This response seems idealistic when one considers that doctors see up to 60 patients per day (as reported by one of the respondents). On the other hand, there is a need for counselling and support for these patients but this function does not have to be performed by the doctor. These structures need to be developed within the health care system, which provide these services as part of the continuum of care for HIV positive patients and their families.

The results indicate the desire by doctors for more structured training with regard to the management of HIV/AIDS. While most of the respondents (69%) obtained their information from journals, the majority preferred in-service training (68%) and organised discussion (65%) as methods of acquiring knowledge about HIV/AIDS management. The current opportunities afforded doctors in this regard are limited. Doctors working at the clinics are more likely than those working at day hospitals to be able to receive this input since they meet on a regular basis. However, in this study those who are employed in sessional posts (at clinics) lament the fact that attending workshops would affect their earning potential since they are only

paid for hours worked. The ATICC course, which is conducted after hours, affords doctors a further opportunity to increase their knowledge of the management of HIV/AIDS. The study revealed that more doctors at the clinics than those at day hospitals have utilised this opportunity. It appears that doctors, in service, are difficult to reach for training and the most appropriate time for influencing doctors with regard to the management of HIV/AIDS is during their clinical medical training, though this is unlikely to be enough.<sup>43</sup>

The respondents' lack of confidence about their counselling and clinical skills for managing children with HIV and AIDS should serve as a warning to health authorities responsible for primary level care. This perception however, is not limited to doctors at primary level but also exists amongst doctors working at secondary and tertiary levels in Cape Town.<sup>26, 43, 47</sup> As the numbers of patients with HIV/AIDS increase, the burden for health care will rest increasingly on the primary level care services.

In order to address the complex issues surrounding HIV/AIDS the approach to training must be changed from one, which is focussed on the biology and epidemiology of HIV, to one which includes experiential learning. This approach will address the fears, discomfort and attitudes to the various ethical and legal issues inherent in the management of patients with HIV/AIDS. This view is supported by various studies.<sup>33, 50, 56</sup> which conclude that while knowledge about HIV/AIDS is crucial, there is a need for attitudinal transformation. There is sufficient evidence that experiential learning scenarios are more effective in changing prejudicial attitudes and allaying

unwarranted fears about HIV/AIDS, than programmes, which address knowledge alone.<sup>40-41, 58-60</sup>

In addition, current constraints on the health services in South Africa and the Western Cape, in particular, will force HCWs to make ethical decisions with regard to diagnostic interventions, treatment and care for patients with HIV/AIDS. Training in medical ethics is perceived to be of substantial benefit to doctors in confronting the actual ethical issues encountered in daily practice.<sup>39</sup> It has been suggested that the most effective teaching in ethics is concentrated on specific cases and is taught in the clinical years by teachers who are role models.<sup>61</sup> The role of the consultants and professors as role models was also highlighted in the studies by Friedland<sup>26</sup> and Cox<sup>39</sup> respectively. For students to understand HIV/AIDS and their role in providing care, which exemplifies a humanistic approach and is grounded in a scientific understanding of the disease, the learning experience must be carried through from the lecture theatre to the ward, where the reaction and attitude of the professor and consultant towards the patient with HIV/AIDS, is observed.

Negative emotions were reported in 68% of the responses with regard to the question 'how does management of a child who is HIV positive make you feel?' The majority of respondents said they felt depressed (41%), challenged (34%), frustrated (36%) and incompetent (24%). Negative feelings about providing care for these patients in this study are high. It should be borne in mind that these are probably anticipated feelings in most cases since the frequency of involvement by the respondents is not high.

However, in their study amongst nurses, Berkowitz and Nuttall (1996) found that in a small percentage of cases, increased contact did not lead to less distress in caring for patients with HIV/AIDS. Also, older nurses experienced more distress in caring for these patients. Feelings of distress in caring for patients with HIV/AIDS may impact on health care workers' willingness to care. These feelings may result from lack of knowledge about HIV/AIDS or the management of patients with HIV/AIDS or "burnout" <sup>5,9,16,26-27,29, 60</sup>.

It is interesting to note that the priority concern of these doctors at primary level care facilities, is the lack of support in the community for families infected and affected by HIV. This concern, raised as a top priority, is not surprising when one considers the fact that the secondary and tertiary institutions refer these patients to the primary level for follow-up and maintenance treatment, but, there are few, if any, referral agencies for further support and management at the disposal of the primary level facilities.

The lack of management guidelines emerged as the second most important concern and the need for training in the management of children with HIV/AIDS was one of the recurring themes running through the general comments and unprompted concerns raised by the respondents. There is a need for clear guidelines and resources to support the clinician in providing care for patients with HIV/AIDS without having to resort to discriminatory practices based on the individual clinician's experience (or lack thereof). This may yet be one of the greatest challenges facing our health services as budget cuts, hospital closures, staff retrenchments and the resultant malaise amongst remaining HCWs pervade the system. The respondents' concern

about the lack of resources in the health services illustrates the fact that an appropriate response from the authorities to these challenges is urgently required. It may also account for some of the negative feelings, such as 'depression' and 'frustration' identified by respondents, which exist about the treatment of children with HIV/AIDS. Other issues raised by respondents such as the concern about the fragmentation of services for HIV infected families further highlight the flaws within the health services. The mother (who is often the person who brings the child to the health facility) and child are often seen at different facilities on different days. Other siblings, husbands or partners are not routinely included in the care management.

The findings in this study relating to the major concerns of doctors, are in contrast with that of surveys done amongst doctors working at hospitals, which report the risk of HIV infection from patients as the major concern.<sup>4, 19, 43, 47</sup> The fear amongst junior doctors in hospitals, with regard to needlestick injuries is linked to their inexperience with regard to certain invasive treatments and diagnostic procedures.<sup>26, 43</sup> The need for these procedures may be less common at primary level care centres and/or doctors may be more experienced.

Policies in respect of the controversial aspects such as HIV testing, confidentiality and informed consent should be supported by legislation in order to ensure the protection of the rights of the patient as well as those of the HCW. These issues are often controversial because they relate to the often competing rights of patients and doctors, as well as power relations either in the health care setting or work place. In the state of Florida, USA, for

example, the legislature has addressed the subject of immunity from civil or criminal suits for the disclosure or nondisclosure of information about HIV infection by HCWs under certain conditions.<sup>54</sup> There have also been attempts at revising legislation in respect of HIV/AIDS in South Africa. The South African Law Commission has been investigating aspects of law reform relating to HIV/AIDS since 1993. In 1996 the Minister of Health appointed a new law commission and tasked them with the development of recommendations in this regard. However, at the time of writing, draft legislation had not been promulgated.

## **5.1 Limitations of Study**

The low response rate, particularly from day hospitals, compromises the generalisability of the results. It may be that those who took the time to complete the questionnaire already have a more positive disposition towards patients with HIV/AIDS than those who did not.

The fact that the survey only tested the feelings and perceptions of doctors in order to gauge their attitudes, may be a limitation since their practice was not verified in order to determine whether congruency prevailed.

A further shortcoming is the limited experience of the respondents with regard to the treatment of children with HIV/AIDS. Therefore their responses were hypothetical, rather than based on experience and practice. This, in turn, may be responsible for doctors' positive attitudes and even in some cases, their idealistic approach towards the management of children

with HIV/AIDS (such as extra time spent examining the patient, talking with the mother and providing equal access to emergency care). Alternatively, doctors' positive responses may reflect a tendency to give socially acceptable responses to sensitive issues, suggesting a social desirability bias.<sup>48</sup> Still, attitudinal consistency across responses seems to confirm genuine concern and optimism regarding children with HIV/AIDS.

## **CHAPTER 6**

### **Conclusions and Recommendations**

#### **6.1 Conclusions**

The majority of doctors at primary level care facilities reported infrequent involvement in the management of children with HIV/AIDS. Despite this, most displayed positive attitudes towards these children.

Most felt that they lacked the necessary clinical and counselling skills to manage children with HIV/AIDS. For example, twice as many doctors felt unable or poorly equipped to manage children with AIDS as opposed to those with HIV. The results of this study indicate that the Continuing Medical Education programmes related to HIV/AIDS were inadequate. There was a discrepancy between the manner in which doctors in practice obtain their knowledge of HIV/AIDS management, and the manner in which they would prefer to receive it.

The majority was not in favour of routine testing of children, but supported such testing among pregnant women. Whereas most agreed that informed consent was necessary for HIV testing in children, a third of the respondents did not share this opinion.

Those doctors with experience in managing children with HIV/AIDS, felt that disclosure of the patient's HIV status on the referral form was important. The reason given by this group was "to facilitate optimal care" as opposed to the response of the less experienced doctors who indicated that the reason for disclosure should be for the protection of the health care worker.

Caring for children with HIV/AIDS had a negative psychological impact on the carers. Despite the fact that only a small percentage of the respondents reported regular contact with children with HIV/AIDS, negative emotions (such as feeling depressed, frustrated, hopeless) were reported in a large proportion of the respondents.

The major concerns raised by doctors at the primary level of care were the lack of resources in the community for families living with HIV/AIDS, the lack of policy guidelines for the management of children with HIV/AIDS and the lack of resources at the health facility.

## **6.2 Recommendations**

- The HIV/AIDS related **training** needs of medical students and doctors, in service, should be addressed urgently. Strategies that address both the clinical and psychological challenges presented by this disease should be employed. Experiential methods of training which allow participants to explore and confront their fears, anxieties and feelings about HIV/AIDS will provide the basis for a humanistic, positive approach to dealing with

patients with HIV/AIDS. This method was successfully employed at the medical school of the University of Cape Town during an elective on human rights and ethics.<sup>60</sup>

- Innovative strategies of reaching working doctors for training (especially those in sessional posts) should be developed.
  
- **Clinical guidelines**, which are specifically developed to address the clinical features of HIV/AIDS in the South African context, must be developed. The content should be evidence based and updated on a regular basis. There is sufficient evidence that HIV infection can be managed in such a way that infected persons can continue to live productive and good quality lives for a number of years. Early intervention for HIV infected children prevents some of the life threatening and costly diseases resulting from a compromised immune system. These guidelines should include the range of treatment options universally available as well as options available within the financial constraints of the public health sector. The need for feasible and appropriate guidelines has become increasingly urgent as the epidemic spreads throughout the country. Several groups of professionals in the different provinces (Kwa Zulu Natal,<sup>61</sup> Gauteng,<sup>62</sup> Western Cape<sup>63</sup>) have compiled various guidelines which address these issues. However, as with the earlier documents, developed on an ad hoc basis, there is no uniformity or mandatory compliance. National guidelines for the management of HIV/AIDS in children should be co-ordinated by a body such as the SA Paediatric

Association, with input from its constituency. The National Department of Health should endorse these guidelines.

- **Policy guidelines** should take into account HIV/AIDS issues as they relate to children. These include HIV testing in children and informed consent, confidentiality and disclosure of the HIV positive status of a child to a third party, as well as treatment protocols which address the ethical issue of withholding or withdrawal of treatment in children with AIDS. In developing these guidelines, cognisance should be taken of the practical constraints of daily management such as rotating staff and inaccessible or absent parents / guardians which impact on this requirement for obtaining consent for HIV testing (as with other procedures). Often the reality is that once the child has been admitted into the care of the hospital, the parents cannot afford to travel back and forth while 'neglecting' other siblings at home. Studies have shown that policy and practice do not necessarily correlate, particularly with regard to informed consent.
  
- Resources should support clinical and policy guidelines with regard to HIV/AIDS. For example, there is a need for ensuring access to the following (especially at the primary level of care): protective equipment for the application of universal precautions and counsellors in the health care setting, both for health care workers (in relation to needlestick injuries) and patients (for pre- and post-test counselling). Access to HIV tests and prophylactic treatments are essential at the primary level of care.

➤ Finally, while this study focussed on the attitudes of doctors towards the management of children with HIV/AIDS, the responsibility for their management is not the sole responsibility of the clinician. HIV/AIDS is a disease, which affects more than one member of a family simultaneously and has multifaceted implications, which extend beyond the scope of medical practice. Thus, ideally, a multi-disciplinary team should manage patients with HIV/AIDS, in a co-ordinated manner. The continuum of care should extend from the primary level of care (including community based care) through to the tertiary level of care and back. Success in follow-up and patient care has been linked to care co-ordination from a point of service. This point of service may evolve from the point of diagnosis of the patient. It should be noted that the point of entry on this continuum may be, and often is, at the tertiary level.<sup>64-67</sup>

### **6.3 Recommendations for future research**

- ❖ Pilot training courses that offer the medical student and the practising physician the range of information and experience in HIV/AIDS management should be implemented and evaluated with a view to informing the current process of the transformation of the medical curriculum.
- ❖ There is a need to determine parents' preferences and perceptions with regard to the methods used in obtaining informed consent for HIV testing in children. The debate regarding the "need" to obtain consent for screening tests has been ongoing within the domain of the health care sector. Perhaps the influence of the opinions of the parents will lead to consensus on the issue.

- ❖ The same study should be repeated to determine whether there is any difference in opinion as a result of more exposure to HIV-infected children.
  
- ❖ A specific study of doctors working at day hospitals should be undertaken, once an effective means of increasing the response rate amongst this target population has been developed.

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# Appendix 1

## Western Cape Province : Cape Metropole Region, Distribution of Named HSRC Clinics



## Appendix 2: Survey on paediatric HIV/AIDS

### INSTRUCTIONS FOR COMPLETING THE QUESTIONNAIRE

Where a question is followed by a series of options, please CIRCLE or Tick(✓) the appropriate response. A space for general comments appears at the end of the questionnaire, but please feel free to expand on your answers at any point.

**PLEASE ANSWER ALL THE QUESTIONS**

1. How many times have you been involved in the management and /or diagnosis of children with HIV/AIDS? Never / seldom / often

2. If you should advise policy makers, to what extent would you AGREE or DISAGREE with the following statements? (Please rate your answers )

**1 = Strongly Agree**

**3= Disagree**

**2 = Agree**

**4 = Strongly**

**Disagree**

All pregnant women should be tested for HIV. 1 2 3 4

All children presenting for curative services should be routinely tested for HIV. 1 2 3 4

Informed consent must be obtained for HIV testing in children. 1 2 3 4

Children who are HIV positive should be given prophylactic treatment regimens eg. PCP, TB prophylaxis. 1 2 3 4

The HIV positive status of the patient should not be disclosed to a third party (even another health care worker) without the consent of the patient/ carer. 1 2 3 4

In an *emergency* situation HIV positive children should receive the same priority as those with unknown status. 1 2 3 4

3. The HIV positive status of the patient being referred to another health worker should be noted on the referral letter for the following reasons:  
**(choose the options which best reflect your opinion)**

For the protection of the health worker.

To facilitate optimal care of the child

Should never be disclosed

**Please Turn Over**

4. Would the knowledge of the child's HIV positive status impact on your management in the following ways? (Please rate your answer )

1 = Always  
2 = Mostly

3 = Sometimes  
4 = Never

You will avoid invasive procedures (such as taking blood, suturing). 1 2 3 4

You will take extra care in applying universal precautions e.g. gloves 1 2 3 4

You will avoid diagnostic investigations for symptoms such as fever and diarrhoea. 1 2 3 4

You will spend more time examining an HIV positive child than an HIV negative child. 1 2 3 4

You will spend more time in discussion with the mother e.g. evaluating mother's understanding of implications of HIV infection. 1 2 3 4

You will refer a symptomatic HIV positive child to a tertiary hospital for treatment of conditions which you would routinely treat in an HIV negative child e.g. TB, skin conditions. 1 2 3 4

5. What are your main sources of information with regard to paediatric HIV/AIDS? (Tick (√) all that apply)

- journals
- in-service training
- organized discussion groups/workshops
- colleagues
- other (specify) .....

6. What are your preferred methods of continuing medical education with regard to paediatric HIV/AIDS? (Tick (√) all that apply)

- journals
- in-service training
- organized discussion groups/workshops
- colleagues
- other (specify) .....

7. Have you attended the ATICC\* course for doctors? Yes  No   
(\* AIDS Training Information and Counselling Centre)

8. Pre HIV test counselling should be done by: (tick (√) the block which best reflects your opinion):

- The doctor requesting the test
- Another health care worker
- Either
- Other (specify).....
- It is not necessary

9. **Post HIV test counselling should be done by:**  
**(tick (√) the block which best reflects your opinion):**
- The doctor requesting the test
  - Another health care worker
  - Either
  - Other (specify).....
  - It is not necessary

**How do you perceive your ability to manage children with HIV/AIDS?  
Please rate (circle) below .**

10. How would you describe your ability to do pre test counselling ?      **Unable    Poor    Moderate    Good**  
**Excellent**

11. How would you describe your ability to relay a positive diagnosis to the parents?      **Unable    Poor    Moderate    Good**  
**Excellent**

12. How would you describe your clinical ability to manage a child with symptomatic HIV infection?      **Unable    Poor    Moderate    Good**  
**Excellent**

13. How would you describe your clinical ability to manage a child with full blown AIDS.      **Unable    Poor    Moderate    Good**  
**Excellent**

14. Listed below are 5 major issues surrounding the management of children with HIV/AIDS. How would YOU rank (5,4,3,2,1) all these concerns?  
**(5 = Highest priority , 1 = lowest priority)**

The risk of infection from the patient through needlestick/sharps injury.      **1    2    3    4    5**

The lack of resources at your health facility (including drugs, personnel for counselling, room for privacy)      **1    2    3    4    5**

The fatality of the disease (hopelessness of treatment)      **1    2    3    4    5**

The lack of resources in the community to support parents.      **1    2    3    4    5**

The lack of policy guidelines from health authorities re: the management of children with HIV infection      **1    2    3    4    5**

15. Do you have any other concerns with regard to the management of children with HIV/AIDS? (specify)

.....  
.....

16. How does managing a child with HIV/AIDS make you feel? Tick  $\checkmark$  whichever are true for you. Tick at least one which is closest to the way you feel!

Waste of time  challenged

Afraid  positive

Frustrated  useful

Incompetent  optimistic

Anxious  depressed

Other.....

.....

17. Any other comments with regard to the management in your setting of children with HIV/AIDS - not covered in this survey?

.....  
.....

18. Kindly  $\checkmark$  tick in the appropriate box:

i. When did you obtain your MBCHB?  
< 5 yrs ago  6 - 10yrs ago  > 10 yrs ago

ii. Type of health facility in which you are working:  
clinic  day hospital

iii. On which basis are you employed?:  
Full-time post  5/8post (1/2 day)  Sessional post

iv. How much experience do you have working at clinics/day hospitals? (not hospitals)  
0- 6mths  7-12mths  13 - 23mth  2yrs-5yrs  6yrs - 10yrs   
>10yrs

v. Gender: Male  Female

**THANK YOU SO MUCH FOR YOUR CO-OPERATION!!**

**Please Turn Over**

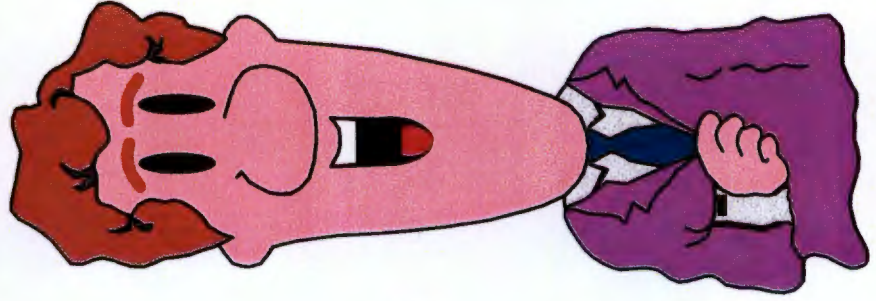
## Appendix 3

### Advice to Policymakers

Statement	Strongly agree		Agree		Disagree		Strongly disagree	
	Clinic	D/Hos	Clinic	D/Hos	Clinic	D/Hos	Clinic	D/Hos
All pregnant women should be tested for HIV N=78	10/29 34.5%	27/49 55% 47.4%	7/29 24%	8/49 16.3% 19.2%	10/29 34.5%	11/49 22.4% 26.9%	2/29 7%	3/49 6.1% 6.4%
All children presenting for curative services should be routinely tested for HIV. N=77	1/29 3.45%	2/48 4.2% 3.89%	1/29 3.45%	5/48 10.4% 7.8%	11/29 37.9%	23/48 47.9% 44.1%	16/29 55.2%	18/48 37.5% 44.1%
Informed consent must be obtained for HIV testing in children. N=78	7/29 24%	13/49 26.5% 25.6%	15/29 51.7%	16/49 32.6% 39.7%	4/29 13.8%	15/49 30.6% 24.3%	3/29 10.3%	5/49 10.2% 10.25%
Children who are HIV positive should be given prophylactic treatment regimens eg. PCP, TB prophylaxis. N=74	5/28 17.8%	11/46 23.9% 21.6%	10/28 35.7%	24/46 52.1% 45.9%	9/28 32.1%	10/46 21.7% 25.6%	4/28 14.3%	1/46 2.1% 6.7%
The HIV positive status of the patient should not be disclosed to a third party (even another health care worker) without the consent of the patient/carer. N=78	3/29 10.3%	10/49 20.4% 16.7%	3/29 10.3%	11/49 22.4% 17.9%	17/29 58.6%	22/49 44.9% 50%	6/29 20.7%	6/49 12.2% 15.3%
In an emergency situation HIV positive children should receive the same priority as those with unknown status. N=76	13/27 48.1%	22/49 44.9% 46%	8/27 29.6%	22/49 44.8% 39.4%	4/27 14.8%	5/49 10.2% 11.8%	2/27 7.4%	0/49 0% 2.6%

# General Comments

- “The TB clinical care system is inadequate to handle HIV/AIDS cases”
- “Parents / guardians are reluctant to accept the fact that the disease is incurable or present...”
- “The setup for mothers is not good and they often have no follow-up.”
- “I dislike the secrecy involved with this disease - it is not a crime to be a child with this disease.”
- “HIV/AIDS places a financial burden on the state and a manpower burden on the public health sector.”
- “It is cruelty (sic) to bring babies into the world who will soon be orphaned. We must all help.”

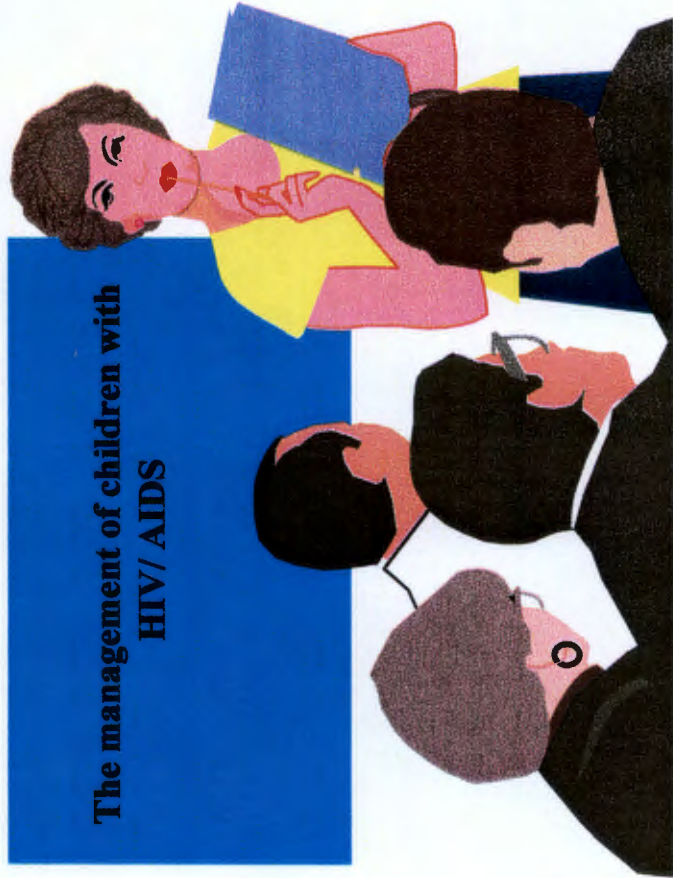


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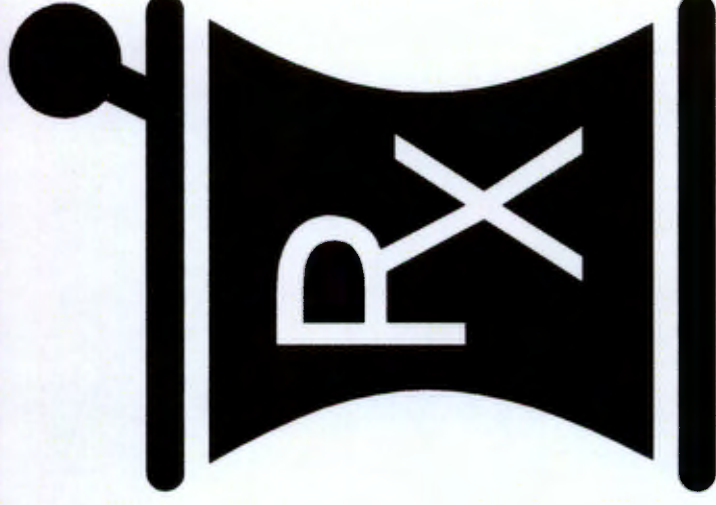
# Concerns: Training



- We need workshops re: children with HIV/AIDS (diagnosis, ethics and management)
- “In-service training and workshops should be organized for the training of all medical officers and other medical personnel in the management of HIV/AIDS in children since the primary care facilities are the first line of contact in the health delivery system.” (sic)
- “I need training but as a sessional worker this means loss of earnings.”(sic)

# Concerns : Treatment

- Lack of access to treatment
- Treatment is expensive because of investigations needed.
- Treatment for mothers and children are fragmented even at primary care level between paediatric doctors and 'adult' doctors.
- We often don't get the opportunity to diagnose but continue prescribed treatment.
- We need better identification of cases, timeously.



## APPENDIX 7

### RESULTS STRATIFIED BY FACILITY

A 50.6% overall response rate was obtained comprising of 85.29% and 40.83% from the clinics and day hospital doctors respectively. The difference in response rate between the facilities was statistically significant ( $p = 0.01$ ).

**Response rate:**

Facility	No. Respondents	Possible No. Resp.	rate (%)
Clinics	29	34	85.29%
Day Hospitals	49	120	40.83%
<b>Total</b>	<b>78</b>	<b>154</b>	<b>50.6%</b>

**P value = 0.01 →**

**Question 1**

How many times have you been involved in the management and / or diagnosis of children with HIV/AIDS?

The majority reported that they were seldom involved in the management of children with HIV/AIDS with more doctors at the clinics than day hospitals having this perception. There was a significant difference in experience between the two facilities ( $p= 0.004$ ).

Facility	Never	Seldom	Often	Total
Clinic	2 (7%)	21(75%)	5 (17.8%)	28
Day Hospital	18 (40%)	18 (40%)	9 (20%)	45
<b>Total</b>	<b>20 (27.3%)</b>	<b>39 (53.4%)</b>	<b>14 (19%)</b>	<b>73</b>

**P value = 0.004 →**

## **Question 2**

If you should advise policy makers, to what extent would you agree or disagree with the following statements?

There was no significant difference in responses to any of the questions between doctors at the two facilities.

### **Testing of pregnant women**

The majority of respondents were in favour of HIV testing for pregnant women with 55% of day hospital doctors strongly in favour of this practice.

### **Testing of all children at curative services**

The majority of respondents (44.1%) strongly disagreed with testing of all children presenting for curative services.

### **Mandatory informed consent**

The majority of respondents (65.3%) agreed that informed consent must be obtained for HIV testing in children.

### **Access to prophylaxis for HIV positive children**

The majority of respondents (67.5%) agreed that HIV positive children should be given prophylactic treatment regimens for conditions such as tuberculosis and *Pneumocystis carinii pneumonia* etc.

### **Disclosure to third party**

The majority of respondents (65.3%) felt that the HIV positive status of a patient should be disclosed to a third party even without consent of the patient/carer.

### **Equity re: access to care in emergency**

The majority of respondents (85.4%) felt that HIV positive children should receive the same priority as those with unknown status - with 46% of respondents feeling strongly about it.

Statement	Strongly agree		Agree		Disagree		Strongly disagree	
	<i>Clinic</i>	<i>D/Hos</i>	<i>Clinic</i>	<i>D/Hos</i>	<i>Clinic</i>	<i>D/Hos</i>	<i>Clinic</i>	<i>D/Hos</i>
All pregnant women should be tested for HIV  (Total No. of responses: 78) <i>p value = 0.36</i>	10/29 34.5%	27/49 55%	7/29 24%	8/49 16.3%	10/29 34.5%	11/49 22.4%	2/29 7%	3/49 6.1%
		<b>47.4%</b>		<b>19.2%</b>		<b>26.9%</b>		<b>6.4%</b>
All children presenting for curative services should be routinely tested for HIV.  (Total No. of responses: 77) <i>p value = 0.41</i>	1/29 3.45%	2/48 4.2%	1/29 3.45%	5/48 10.4%	11/29 37.9%	23/48 47.9%	16/29 55.2%	18/48 37.5%
		<b>3.89%</b>		<b>7.8%</b>		<b>44.1%</b>		<b>44.1%</b>
Informed consent must be obtained for HIV testing in children.  (Total No. of responses: 78) <i>p value = 0.28</i>	7/29 24%	13/49 26.5%	15/29 51.7%	16/49 32.6%	4/29 13.8%	15/49 30.6%	3/29 10.3%	5/49 10.2%
		<b>25.6%</b>		<b>39.7%</b>		<b>24.3%</b>		<b>10.25%</b>
Children who are HIV positive should be given prophylactic treatment regimens e.g. PCP, TB prophylaxis.  (Total No. of responses: 74) <i>p value = 0.11</i>	5/28 17.8%	11/46 23.9%	10/28 35.7%	24/46 52.1%	9/28 32.1%	10/46 21.7%	4/28 14.3%	1/46 2.1%
		<b>21.6%</b>		<b>45.9%</b>		<b>25.6%</b>		<b>6.7%</b>
The HIV positive status of the patient should not be disclosed to a third party (even another health care worker) without the consent of the patient / carer.  (Total No. of responses: 78) <i>p value = 0.24</i>	3/29 10.3%	10/49 20.4%	3/29 10.3%	11/49 22.4%	17/29 58.6%	22/49 44.9%	6/29 20.7%	6/49 12.2%
		<b>16.7%</b>		<b>17.9%</b>		<b>50%</b>		<b>15.3%</b>
In an emergency situation HIV positive children should receive the same priority as those with unknown status.  (Total No. of responses: 76) <i>p value = 0.17</i>	13/27 48.1%	22/49 44.9%	8/27 29.6%	22/49 44.8%	4/27 14.8%	5/49 10.2%	2/27 7.4%	0/49 0%
		<b>46%</b>		<b>39.4%</b>		<b>11.8%</b>		<b>2.6%</b>

### Question 3

The HIV positive status of the patient being referred to another health worker should be noted on the referral letter for the following reasons: (Choose the options that best reflect your opinion)

The majority of respondents (53.8%) felt that the primary reason for stating the HIV positive status of a child on a referral letter is to facilitate optimal care. While 15.3% felt that it should be written for the protection of the health care worker, 28.2% felt that it should be to both protect the health care worker and facilitate optimal care of the patient.

Facility	Health worker protection(1)	Optimal Care (2)	Both 1&2	Should never be disclosed	Total no. respondents
Clinic	5 (17.2%)	19 (65.5%)	5 (17.2%)	0 (0%)	29
Day Hospital	7 (14.2%)	23 (46.9%)	17 (34.7%)	2 (4%)	49
<b>Total</b>	<b>12 (15.3%)</b>	<b>42 (53.8%)</b>	<b>22 (28.2%)</b>	<b>2 (2.5%)</b>	<b>78</b>

P value = 0.21

### Question 4

Would the knowledge of the child's HIV positive status impact on your management in the following ways?

#### Avoiding invasive procedures

The majority of respondents (63.1%) felt that they would never avoid invasive procedures on a child because of his/her HIV positive status. No doctors at day hospitals but 6.9% of doctors at clinics said that they would always avoid invasive procedures on an HIV positive child.

#### Extra care in applying universal precautions

The majority (73%) felt that they would always take extra care in applying universal precautions given the knowledge of the child's HIV positive status. On the other hand 3.8% felt that they would not take extra care (more day hospital doctors than clinic doctors would).

### **Avoid diagnostic investigations**

Almost half the respondents (47.4%) felt that they would never avoid diagnostic investigations for symptoms such as fever and diarrhoea in HIV positive children and none felt that they would always.

### **Spending more examination time**

The majority (41.5%) responded that they would sometimes spend more time examining a child who is HIV positive, while 11.7% said they would always spend more time. 15% of respondents felt that they would never spend more time.

### **More counselling time**

Approximately half (52.6%) the respondents felt that they would always spend more time in discussion with the mother for example, in evaluating the mother's understanding of the implications of HIV infection while 14% said they would sometimes.

### **Inappropriate referral**

More than half the respondents (51.2%) admitted that they would sometimes refer a symptomatic HIV positive child to a tertiary hospital for treatment of conditions which you would routinely treat in an HIV negative child, for example, TB and skin conditions, while 21.8% said they would mostly.

	Always		Mostly		Sometimes		Never	
	<i>Clinic</i>	<i>D/hos</i>	<i>Clinic</i>	<i>D/Hos</i>	<i>Clinic</i>	<i>D/Hos</i>	<i>Clinic</i>	<i>D/Hos</i>
You will avoid invasive procedures (such as taking blood, suturing). <b>Total No. respondents: 76</b> <b>p value = 0.32</b>	2/29 6.9%	0/47 0%	2/29 6.9%	3/47 6.3%	7/29 24.1%	14/47 29.8%	18/29 62%	30/47 63.8%
		<b>2.6%</b>		<b>6.6%</b>		<b>27.6%</b>		<b>63.1%</b>
You will take extra care in applying universal precautions e.g. gloves <b>Total No. respondents: 78</b> <b>p value = 0.12</b>	17/29 58.6%	40/49 81.6%	6/29 20.7%	4/49 8.16%	5/29 17.2%	3/49 6.1%	1/29 3.4%	2/49 4%
		<b>73%</b>		<b>12.8%</b>		<b>10.2%</b>		<b>3.8%</b>
You will avoid diagnostic investigations for symptoms such as fever and diarrhoea. <b>Total No. respondents: 78</b> <b>p value = 0.47</b>	0 0%	0 0%	5/29 17.2%	4/49 8.2%	11/29 37.9%	21/49 42.8%	13/29 44.8%	24/49 48.9%
		<b>0</b>		<b>11.5%</b>		<b>41%</b>		<b>47.4%</b>
You will spend more time examining an HIV positive child than an HIV negative child. <b>Total No. respondents: 77</b> <b>p value =0.70</b>	3/29 10.3%	6/48 12.5%	7/29 24.1%	17/48 35.4%	14/29 48.2%	18/48 37.5%	5/29 17.2%	7/48 14.6%
		<b>11.7%</b>		<b>31.2%</b>		<b>41.5%</b>		<b>15.6%</b>
You will spend more time in discussion with the mother e.g. evaluating mother's understanding of implications of HIV infection. <b>Total No. respondents: 78</b> <b>p value = 0.51</b>	15/29 51.7%	26/49 53%	8/29 27.6%	17/49 34.7%	6/29 20.7%	5/49 10.2%	0/29 0%	1/49 2%
		<b>52.6%</b>		<b>32%</b>		<b>14%</b>		<b>1.2%</b>
You will refer a symptomatic HIV positive child to a tertiary hospital for treatment of conditions which you would routinely treat in an HIV negative child e.g. TB, skin conditions. <b>Total No. respondents: 78</b> <b>p value = 0.26</b>	4/29 13.8%	5/49 10.2%	4/29 13.8%	13/49 26.5%	14/29 48.2%	26/49 53%	7/29 24%	5/49 10.2%
		<b>11.5%</b>		<b>21.8%</b>		<b>51.2%</b>		<b>15.3%</b>

### Question 5

For both clinic (72.4%) and day hospital (67.3%) staff, journals were the main source of information with regard to paediatric HIV/AIDS, while in-service training (48.2% and 55.1% respectively) was the second major source of information. Doctors at both facilities also ranked colleagues as a major source of information.

What are your main sources of information with regard to paediatric HIV/AIDS? (Tick all that apply)

Source	Clinic N=29	Day Hospital N=49
Journals	21 (72.4%)	33 (67.3%)
In-service training	14 (48.2%)	27 (55.1%)
organized discussion groups/workshops	16 (55.1%)	13 (26.5%)
colleagues	15 (51.7%)	23 (46.9%)
other (specify)	1(lay publications)	0

**p value = 0.34**

### Question 6

What are your preferred methods of continuing medical education with regard to paediatric HIV/AIDS? (Tick all that apply)

Doctors at both facilities ranked in-service training and organized workshops/discussion groups as the most preferable methods for continuing education. One respondent specified the method of in-service training as rotation through the specialist clinic at Red Cross Children's Hospital.

Source	Clinic N=29	Day Hospital N=49	Total N=78
Journals	13 (44.8%)	21 (42.8%)	34 (43.6%)
In-service training	21 (72.4%)	32 (65.3%)	53 (67.9%)
organized discussion groups/workshops	16 (55.1%)	35 (71.4%)	51 (65.3%)
colleagues	9 (31%)	9 (18.4%)	18 (23%)
other (specify)	1* (3.4%)	0	1 (1.2%)

\*Rotate through Infectious diseases clinic at Red Cross Hospital

**p value = 0.54**

### Question 7

Have you attended the ATICC\* course for doctors?

\* AIDS Training Information and Counselling Centre

More than half the doctors (55%) at the clinics have attended an AIDS training course for doctors at the ATICC. Less than half (42.8%) the respondents at the day hospital had attended a course.

Facility	Attended course	Did not attend course	Total
Clinic	16 (55%)	13 (44.8%)	29
Day Hospital	21 (42.8%)	28 (57.1%)	49
<b>Total</b>	<b>37 (47.4%)</b>	<b>41 (52.5%)</b>	<b>78</b>

**p value = 0.41**

### Question 8

Pre HIV test counselling should be done by:

Few respondents (3.4% and 2% at clinics and day hospitals respectively) felt that pre HIV test counseling was not necessary. Significantly, more doctors at the day hospital felt that the doctor requesting the test should do the pre-test counselling ( $p = 0.05$ ). Most respondents (58.4%) felt that the doctor requesting the test should conduct the pre-test counseling. Most doctors at the clinics (55.1%) felt that either the doctor or another health care worker could do it. Some (6.4%) felt that a trained counselor, social worker or lay counselor should do it.

Options	Clinic N=29	Day Hospital N=48	Total N=77
The doctor requesting the test	7 (24%)	38 (79.1%)	45 (58.4%)
Another health care worker	8 (27.6%)	16 (33.3%)	24 (31.1%)
Either	16 (55.1%)	19 (39.6%)	35 (45.5%)
Other (specify)	2* (6.9%)	3# (6.2%)	5 (6.4%)
It is not necessary	1 (3.4%)	1 (2%)	2 (2.5%)

\* Social worker; Trained counsellor

# Lay counsellor who speaks the same language as patient; Social worker; Trained counsellor

**p value = 0.05 →**

### Question 9

Post HIV test counselling should be done by:

The majority of respondents (65.3%) felt that the doctor who requested the test should provide the post test counselling with 80% of doctors at the day hospitals expressing this opinion. No respondents felt that post test counselling was unnecessary.

Options	Clinic N=29	Day Hospital N=46	Total N=75
The doctor requesting the test	12 (41.4%)	37 (80.4%)	49 (65.3%)
Another health care worker	10 (34.5%)	13 (28.2%)	23 (30.6%)
Either	11 (37.9%)	17 (36.9%)	28 (37.3%)
Other (specify)	4 (13.8%)	6 (13%)	10 (13.3%)
It is not necessary	0	0	0

**P value = 0.33**

### How do you perceive your ability to manage children with HIV/AIDS?

#### Question 10

How would you describe your ability to do pre-test counselling?

42% of respondents rated their ability to do pre-test counselling as 'moderate', while 2.5% rated it as excellent. None reported that they were unable to do it while 16.6% rated their ability as 'poor'.

Facility	Unable	Poor	Moderate	Good	Excellent	Total
Clinic	0	3 (10.3%)	10 (34.5%)	15 (51.7%)	1 (3.4%)	29
Day Hospital	0	10(20.4%)	23 (46.9%)	15(30.6%)	1 (2%)	49
<b>Total</b>	<b>0</b>	<b>13(16.6%)</b>	<b>33 (42.3%)</b>	<b>30(38.4%)</b>	<b>2(2.5%)</b>	<b>78</b>

**p value = 0.25**

### Question 11

How would you describe your ability to relay a positive diagnosis to the parents?

51.7% vs. 37.5% of doctors at clinics and day hospitals respectively rated their ability to relay a positive diagnosis to the parents as 'good'. No one felt unable to do so while 14.2% rated his or her ability as 'poor'.

Facility	Unable	Poor	Moderate	Good	Excellent	Total
Clinic	0	4 (13.8%)	10(34.4%)	15(51.7%)	0(0%)	29
Day Hospital	0	7 (14.6%)	22(45.8%)	18(37.5%)	1(2%)	48
<b>Total</b>	<b>0</b>	<b>11(14.2%)</b>	<b>32(41.5%)</b>	<b>33(42.8%)</b>	<b>1(1.2%)</b>	<b>77</b>

**P value = 0.56**

### Question 12

How would you describe your clinical ability to manage a child with symptomatic HIV infection?

The majority of respondents (55.8%) rated their clinical ability with regard to the management of symptomatic HIV infection in children as 'moderate'. One doctor at the day hospital rated his/her ability, as 'excellent' while one doctor at the clinic felt 'unable'.

Facility	Unable	Poor	Moderate	Good	Excellent	Total
Clinic	1(3.4%)	8(27.5%)	14(48.2%)	6(20.6%)	0	29
Day Hospital	0	14(29.1%)	29(61%)	4 (8.3%)	1(2%)	48
<b>Total</b>	<b>1</b>	<b>22(28.6%)</b>	<b>43(55.8%)</b>	<b>10(13%)</b>	<b>1(1.2%)</b>	<b>77</b>

**P value = 0.30**

### Question 13

How would you describe your clinical ability to manage a child with full-blown AIDS?

The majority of respondents felt less confident to manage a child with full blown AIDS and rated their ability as poor (46.7%) while 14.2% felt that they were unable to do so. 33.7% respondents rated their ability as 'moderate'. Only 6.4% felt confident about their ability in this regard.

Facility	Unable	Poor	Moderate	Good	Excellent	Total
Clinic	4(13.8%)	12(41.3%)	10(34.4%)	3(10.3%)	1(3.4%)	29
Day Hospital	7(14.5%)	24(50%)	16(33.3%)	0	1(2%)	48
<b>Total</b>	<b>11(14.2%)</b>	<b>36(46.7%)</b>	<b>26(33.7%)</b>	<b>3(3.8%)</b>	<b>2(2.6%)</b>	<b>77</b>

P value = 0.25

### Question 14

Listed below are 5 major issues surrounding the management of children with HIV/AIDS. How would YOU rank all these concerns? ( 5 = Highest priority; 1 = Lowest priority)

#### **Risk of infection from patient**

More doctors at the day hospital (33.3%) than those at clinics (27.5%) ranked risk of infection from the patient through needlestick and sharps injuries as a major concern. This was given the highest ranking. More doctors at clinics (27.5%) than doctors at the day hospitals (12.5%) ranked it as the lowest priority concern.

#### **Lack of resources at health facility**

More day hospital doctors (45%) than clinic doctors (31%) ranked their concern for the lack of resources at their health facility as a high priority. Only 2% and 6.9% of doctors at the day hospitals and clinics respectively ranked this as a 'lowest priority' concern.

**Fatality of the disease**

Approximately one third of respondents felt that the fatality of the disease was of 'moderate' concern to them. More doctors at clinics (24%) than day hospital doctors (17%) ranked this concern as a high priority for them.

**Lack of resources in the community**

More than half the respondents expressed the lack of resources in the community to support parents of children who were HIV positive, as a high priority concern.

**Lack of policy guidelines**

The lack of policy guidelines was expressed as a high priority concern by almost half the respondents (44% and 48.2% of doctors at day hospitals and clinics respectively.)

**Summary of major concerns**

In order of priority respondents therefore felt that lack of resources in the community for parents, lack of policy guidelines for the management of children with HIV/AIDS, lack of resources at the health facility, the risk of infection from patients and the fatality of the disease were major concerns.

Listed below are 5 major issues surrounding the management of children with HIV/AIDS. How would YOU rank all these concerns? (5 = Highest priority; 1 = Lowest priority)

RANKING (1-5)	Clinic					Day Hospital				
	No. of responses per rating					No. of responses per rating				
	1	2	3	4	5	1	2	3	4	5
The risk of infection from the patient through needlestick/sharps injury <b>Total no. of respondents: C=29, D=48, Total=77</b> <b>p value = 0.55</b>	8 27.5 %	4 13.7 %	6 20.6 %	3 10.3 %	8 27.5 %	6 12.5 %	7 14.5 %	11 22.9 %	8 16.6 %	16 33.3 %
The lack of resources at your health facility (including drugs, personnel for counseling, room for privacy) <b>Total no. of respondents: C=29, D=49, Total=78</b> <b>p value = 0.59</b>	2 6.9 %	4 13.8 %	6 20.7 %	8 27.5 %	9 31 %	1 2 %	4 8.1 %	8 16.3 %	14 28.5 %	22 45 %
The fatality of the disease <b>C=29, D=47, Total=76</b> <b>p value = 0.54</b>	5 17.2 %	4 14 %	7 24 %	6 21 %	7 24 %	11 23 %	4 8.5 %	18 38.2 %	6 13 %	8 17 %
The lack of resources in the community to support parents. <b>Total no. of respondents: C=29, D=49, Total=78</b> <b>p value = 0.14</b>	3 10.3 %	0	5 17.2 %	6 21 %	15 52 %	1 2 %	5 10.2 %	5 10.2 %	15 30.6 %	23 47 %
The lack of policy guidelines from health authorities re: the management of children HIV infection <b>Total no. of respondents: C=29, D=48, Total=77</b> <b>p value = 0.41</b>	0	2 7 %	3 10.3 %	10 34.4 %	14 48.2 %	3 6.2 %	3 6.2 %	10 20.8 %	11 23 %	21 44 %

Question 15

Do you have any other concerns with regard to the management of children with HIV/AIDS? Other concerns/opinions expressed by the respondents are listed in the table below.

Clinics	Day Hospitals
<ul style="list-style-type: none"> <li>This [AIDS] has become a specialist discipline; specialists should be responsible for the care of HIV positive children and adults.</li> </ul>	<ul style="list-style-type: none"> <li>I feel that there should be a workshop outlining all the aspects that we should and could know about such a child regarding diagnosis, ethics &amp; management.</li> </ul>
<ul style="list-style-type: none"> <li>I make no difference in handling them [HIV positive children] than 'regular' children.</li> </ul>	<ul style="list-style-type: none"> <li>Inadequacy of human resources - medical and nursing.</li> </ul>
<ul style="list-style-type: none"> <li>Yes, maintaining their nutritional status is very important- we are unable to include them on the PEM scheme before they become underweight for age.</li> </ul>	<ul style="list-style-type: none"> <li>Access to treatment</li> </ul>
<ul style="list-style-type: none"> <li>The referrals of patients who are too sick for ambulatory care - when, how, to any point? Terminal patients competing for resources at secondary and tertiary institutions - should we not just palliate? This is a major ethical-moral dilemma.</li> </ul>	<ul style="list-style-type: none"> <li>Treatment for them is obviously expensive especially because of investigations needed. We are also reluctant to look after them in the community health centres where one doctor sees an average of 60 patients a day.</li> </ul>
<ul style="list-style-type: none"> <li>I have not been kept up to date sufficiently. Need basic workshops. Because RXH is 'elitist children's hospital' - we in services outside are not kept sufficiently on track.</li> </ul>	<ul style="list-style-type: none"> <li>In-service training and workshops should be organized for the training of all medical officers and other medical personnel in the management of HIV/AIDS in children. Since the primary health care facilities are now the first contact in the health care delivery system.</li> </ul>
<ul style="list-style-type: none"> <li>Who will care for the child if the mother and possibly the father also have HIV/AIDS and die from this?</li> </ul>	<ul style="list-style-type: none"> <li>Often the treatment of mothers and children are fragmented even at primary care level between 'paeds' doctor and 'adult' doctor.</li> </ul>
<ul style="list-style-type: none"> <li>I'm happy to get involved and meet the challenge but definitely need more information, guidelines/protocols and protocols on appropriate referrals.</li> </ul>	<ul style="list-style-type: none"> <li>We have major concerns regarding management of all children that are ill with very poor resources.</li> </ul>

<ul style="list-style-type: none"> <li>• Children always come to us with a diagnosis already. Often they are being followed up somewhere else. We usually continue whatever treatment was started.</li> </ul>	<ul style="list-style-type: none"> <li>• The closure of Thuthuzela Abantwana* will leave a big void in the day to day management of these children.</li> </ul>
	<ul style="list-style-type: none"> <li>• It is cruelty to children to bring into the world babies who will be orphaned soon. We should all help.</li> </ul>
	<ul style="list-style-type: none"> <li>• Financial burden on state and the manpower burden on public health sector.</li> </ul>
	<ul style="list-style-type: none"> <li>• Children and mothers should be managed together and not seen individually at separate institutions.</li> </ul>
	<ul style="list-style-type: none"> <li>• Better identification, timeously.</li> </ul>

\*Thuthuzela Abantwana was a community-based home care programme for the support of children and their families with HIV/AIDS. This was a two-year demonstration project initiated by the Child Health Unit, UCT. This project was handed over to an NGO in 1997 and has continued its functions under another name.

## Question 16

How does managing a child with HIV/AIDS make you feel?

Many respondents said they felt depressed (40.7%), challenged (34.2%), frustrated (35.5%) and incompetent (24%) when managing a child with HIV/AIDS.

The full range of feelings expressed by the respondents is listed in the table below.

	Clinic (No. of responses) N= 29	Day Hospital (No. of responses) N= 47	Total N=76
waste of time	1 (3.4%)	0	1 (1.3%)
afraid	1 (3.4%)	1 (2.1%)	2 (2.6%)
frustrated	8 (27.6%)	19 (40.4%)	27 (35.5%)
incompetent	4 (13.8%)	14 (30%)	18 (24%)
anxious	4 (13.8%)	10 (21.2%)	14 (18.4%)
challenged	12 (41.3%)	14 (30%)	26 (34.2%)
positive	3 (10.3%)	7 (15%)	10 (13.1%)
useful	4 (13.8%)	8 (17%)	12 (16%)
optimistic	1 (3.4%)	2 (4.2%)	3 (3.9%)
depressed	13 (44.8%)	18 (38.2%)	31 (40.7%)
other*	4 (13.8%)	4 (8.5%)	8 (10.5%)

**p value = 0.63**

- \*
  - sad
  - haven't seen enough cases to have an opinion
  - lacking in knowledge
  - protective
  - frustrated by lack of essential medications
  - inadequate
  - frustrated by secrecy
  - only contact I've had was in a tertiary setting

## Question 17

Any other comments with regard to the management in your setting of children with HIV/AIDS - not covered in this survey?

The need for training and policy guidelines emerged strongly in the general comments expressed by the respondents. The need for the management of 'families' with HIV/AIDS at the same health facility was expressed by more than one respondent.

Clinics	Day Hospital
<ul style="list-style-type: none"> <li>• seldom see HIV positive children</li> </ul>	<ul style="list-style-type: none"> <li>• Continuing education at schools and in the community re: safer sex options.</li> </ul>
<ul style="list-style-type: none"> <li>• TB clinical system inadequate to handle HIV/AIDS cases.</li> </ul>	<ul style="list-style-type: none"> <li>• In-service training for doctors and nurses.</li> </ul>
<ul style="list-style-type: none"> <li>• I need training [in HIV/AIDS management] but as a sessional worker this means loss of income.</li> </ul>	<ul style="list-style-type: none"> <li>• We have not seen children with HIV yet (probably doctors in the 'under 5 clinic' see them.</li> </ul>
<ul style="list-style-type: none"> <li>• I was lucky in the way that I had people with more experience than myself to help me.</li> </ul>	<ul style="list-style-type: none"> <li>• Testing of other siblings and parents</li> </ul>
<ul style="list-style-type: none"> <li>• Due to the lack of follow-up and the poor examination of AIDS (feeling for spleen or liver is a luxury), it is very seldom that a diagnosis is made at PHC centres. There should be clinical guidelines.</li> </ul>	<ul style="list-style-type: none"> <li>• Need to manage 'families' or 'mothers and children' together.</li> </ul>
<ul style="list-style-type: none"> <li>• Management of children with HIV/AIDS still done predominantly at RXH - we rely on that clinic [ID outpatient clinic] for instructions and tend to refer all queries back to them. There is a need for this care to be decentralised.</li> </ul>	<ul style="list-style-type: none"> <li>• We are fortunate in having people who are excellent in managing HIV/AIDS in children.</li> </ul>
	<ul style="list-style-type: none"> <li>• What about sterilisation of parents?</li> </ul>
	<ul style="list-style-type: none"> <li>• The set-up for the mothers is not good and they often have no follow-up. I dislike the secrecy involved with this disease - it is not a crime to be a child with HIV.</li> </ul>
	<ul style="list-style-type: none"> <li>• I don't see children but encourage adult sufferers to keep spirits up, treat infections if CD4 or viral load is high. Try to get them on trials etc. (Keep them hopeful for full life and even cure).</li> </ul>
	<ul style="list-style-type: none"> <li>• The reluctance of parents/guardians to accept the fact that the disease is incurable or present and complications resulting from HIV.</li> </ul>
	<ul style="list-style-type: none"> <li>• The lack of training for health care workers with regard to management of HIV+ children.</li> </ul>
	<ul style="list-style-type: none"> <li>• Lack of space and staff. No time to counsel adequately.</li> </ul>

### Question 18

Length of experience working at clinic/day hospital in relation to number of years qualified (When did you obtain your MBCHB?)

#### 0-6mths experience

	MBCHB			
	<5yrs	6-10yrs	>10yrs	Total
Clinics	1 (3.4%)	0	0	1 (3.4%)
Day Hospitals	8 (16.3%)	1 (2%)	1 (2%)	10 (20.4%)
<b>Total</b>	<b>9 (11.5%)</b>	<b>1 (1.3%)</b>	<b>1(1.3%)</b>	<b>11 (14.1%)</b>

#### 7-12mths experience

	MBCHB			
	<5yrs	6-10yrs	>10yrs	Total
Clinics	0	0	0	0
Day Hospitals	1(2%)	0	0	1(2%)
<b>Total</b>	<b>1 (1.2%)</b>	<b>0</b>	<b>0</b>	<b>1 (1.2%)</b>

#### 13-23mths experience

	MBCHB			
	<5yrs	6-10yrs	>10yrs	Total
Clinics	0	2 (6.9%)	1 (3.4%)	3 (10.3%)
Day Hospitals	1(2%)	1(2%)	5 (10.2%)	7 (14.2%)
<b>Total</b>	<b>1(1.2%)</b>	<b>3 (3.8%)</b>	<b>6 (7.7%)</b>	<b>10 (12.8%)</b>

#### 2-5yrs experience

	MBCHB			
	<5yrs	6-10yrs	>10yrs	Total
Clinics	0	1 (3.4%)	6 (20.7%)	7 (24.1%)
Day Hospitals	3 (6.1%)	3 (6.1%)	5 (10.2%)	11 (22.4%)
<b>Total</b>	<b>3 (3.8%)</b>	<b>4 (5.1%)</b>	<b>11 (14.1%)</b>	<b>18 (23%)</b>

**P value = 0.33**

#### 6-10yrs experience

	MBCHB			
	<5yrs	6-10yrs	>10yrs	Total
Clinics	0	2 (6.9%)	9 (31%)	11 (37.9%)
Day Hospitals	0	2 (4%)	5 (10.2%)	7 (14.2%)
<b>Total</b>	<b>0</b>	<b>4 (5.1%)</b>	<b>14 (17.9%)</b>	<b>18 (23%)</b>

**P value = 0.87**

**>10yrs experience**

	MBCHB			
	<5yrs	6-10yrs	>10yrs	Total
Clinics	0*	0*	7 (24.1%)	7 (24.1%)
Day Hospitals	0*	0*	13 (26.5%)	13 (26.5%)
<b>Total</b>	<b>0</b>	<b>0</b>	<b>20 (25.6%)</b>	<b>20 (25.6%)</b>

\*unable to calculate p value

**Experience of respondents stratified by facility and gender**

**Females**

Facility	0-6mths	7-12mths	13-23mth	2-5yrs	6-10yrs	>10yrs	Total
Clinic	1 (3.4%)	0	3 (10.3%)	4 (13.8%)	8 (27.6%)	5 (17.2%)	21 72.4%
Day Hosp	9 (18.3%)	1 (2%)	1 (2%)	7 (14.2%)	3 (6.1%)	6 (12.2%)	27 55.1%
<b>Total</b>	<b>10 (12.8%)</b>	<b>1 (1.3%)</b>	<b>4 (5.1%)</b>	<b>11 (14.1%)</b>	<b>11 (14.1%)</b>	<b>11 14.1%</b>	<b>48 61.5%</b>

p value = 0.05 →

**Males**

Facility	0-6mths	7-12mths	13-23mth	2-5yrs	6-10yrs	>10yrs	Total
Clinic	0*	0*	0*	3 (10.3%)	3 (10.3%)	2 (6.9%)	8 27.6%
Day Hosp	1 (2%)	0*	6 (12.2%)	4 (8.1%)	4 (8.1%)	7 (14.2%)	22 45%
<b>Total</b>	<b>1 (1.2%)</b>	<b>0</b>	<b>6 (7.7%)</b>	<b>7 (9%)</b>	<b>7 (9%)</b>	<b>9 (11.5%)</b>	<b>30 38.4%</b>

\*p value cannot be calculated.

**Type of post held stratified by facility**

Facility	Type of Post			Total
	Full-time	Half-day	Sessional	
Clinic	16 (55.1%)	1(3.4%)	12 (41.3%)	29
Day Hospital	37 (75.5%)	4 (8.1%)	8 (16.3%)	49
<b>Total</b>	<b>53 (67.9%)</b>	<b>5 (6.4%)</b>	<b>20 (25.6%)</b>	<b>78</b>

p value = 0.04

The majority of respondents (67.9%) are employed on a full-time basis. More sessional staff (25.6%) than those who have half day posts responded. Most sessional staff who responded were based at clinics (41.3%). Most of the respondents in half day posts, were at the day hospitals (8.1%). The posts occupied by the respondents differed significantly according to the health facility (p= 0.04).