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University of the Witwatersrand

PARENTS' PERCEPTIONS OF HIV COUNSELLING AND TESTING IN SCHOOLS: ETHICAL, LEGAL AND SOCIAL IMPLICATIONS

by

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In partial fulfilment of the degree of

MSc Med (Bioethics and Health Law)

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FACULTY OF HEALTH SCIENCES

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DECLARATION

I, Ruth Gwandure declare that this research report (Parents' perceptions of HIV counselling and testing in schools: Ethical, legal and social implications) is submitted for assessment for the MSc Med (Bioethics and Health Law) degree. It is my own unaided work except where I have explicitly indicated otherwise. I have followed the required conventions in referencing the thoughts and ideas of others. It is being submitted for the degree of MSc Med (Bioethics and Health Law) at the University of the Witwatersrand, Johannesburg. I confirm that the research report has not been submitted previously for any degree or examination in any other university.

Signature_____ Date_____

DEDICATION

To all my brothers and sister who lost their lives to HIV and AIDS.

To my mother for dedicating her life to caring for the orphaned and vulnerable children left behind as a result of HIV and AIDS

ABSTRACT

Given the high prevalence of HIV and AIDS in South Africa, particularly among the 12-25 year age group, the study set out to understand the perceptions of parents regarding the proposed school-based HIV Counselling and Testing (HCT) campaign planned by the Department of Health in collaboration with the Department of Education. This campaign is aimed at encouraging teenagers to get tested and to know their HIV status in the hope that such knowledge will reduce the number of new infections. The target market of the HCT campaign includes high schools because they have a significant number of adolescents and young adults who could benefit from HCT campaign (SANAC, 2010:11). The research looked at the ethical, legal and social implications of the HCT campaign in schools as perceived by parents. Semi-structured interviews were conducted with a sample of 20 households. Among the main findings was that parents were generally in favour of the HCT campaign but believed that participation in the programme should be voluntary. They anticipated that the HCT programme could potentially affect children's emotional well-being, particularly if ethico-legal issues of consent and confidentiality were violated and social issues of stigma and discrimination were not handled sensitively. They emphasised that the campaign needed to consider children's vulnerability and should seek to protect them in the process. Findings are discussed in terms of their implications for promoting bioethical principles in implementing the HCT campaign.

Keywords: HIV/AIDS; counselling and testing; parents; schools; teenagers; ethical principles

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CHAPTER ONE

INTRODUCTION TO THE STUDY

1.1 INTRODUCTION

According to Abdool Karim and Abdool Karim (2010:51), HIV/AIDS is arguably the worst infectious disease that has claimed human life around the world, the most adversely affected region being sub-Saharan Africa. These authors believe that there is no segment of society that can claim to have escaped the effects of HIV/AIDS in Africa. According to UNAIDS (2012:1), South Africa is experiencing challenges relating to the high HIV infection rate among the youth, with 5.6 million people estimated to be living with HIV and AIDS and a prevalence rate of 17.8%.

In this country poverty and violence exacerbate HIV and AIDS vulnerability in the general population. Migration from within and outside South Africa also contributes to the prevalence of HIV in the country (Abdool Karim and Abdool Karim (2010:50). Women and children are reported to be the main victims of violence and sexual assault (Shisana, Rehle, Simbayi, Zuma, Jooste et al., 2009:2). Some of the women have resorted to prostitution as a survival strategy and a means of acquiring an income, thereby exposing them to HIV infection.

Furthermore, women in South Africa have a high risk of dying of AIDS because statistics show that females in the 12-25 year age groups are the worst affected because they engage in unprotected sexual activities (Shisana, Rehle, Pillay-Van-Wyk, Hallett, Zuma, Carrara and Jooste, 2010:20). In support of this claim, Abdool Karim and Abdool Karim (2010:50) maintain that not only is there a higher prevalence of HIV and AIDS in women; there is also a higher prevalence of HIV in young girls. It is reported that most of the women living with HIV and AIDS acquired the virus in adolescence (SANAC, 2010:8). Early infection has been noted in both males and females from the age of 15 to 29 years even though in males HIV infection is reported to occur at a later age than girls (SANAC, 2010:6). Chapman, White, Pettifor, Migurungi, Ross, Pascoe, Cowan, Grosskurth, Buve, and Hayes (2010:556) purport that HIV prevalence is much higher in adolescents in the age range of 15 to 19 years. Although this reported variation in gender varies from place to place, nevertheless, in girls it is noted to occur earlier than in boys because they

are tested for HIV when they fall pregnant and in some cases perform abortions. The risk behaviours which expose them to HIV infection are evident in the high prevalence of unwanted pregnancies and abortions. However, the prevalence of HIV in boys could be underreported in that they do not fall pregnant nor perform abortions because of the nature of their sexuality. They are only captured in the surveillance system if they are infected by sexually transmitted diseases such as syphilis, gonorrhea and other infections. Nevertheless, researchers agree that sexual debuts are reported to occur before the age of 12 in both girls and boys (Shisana et al., 2008:64). This observation underlines the vulnerability of school children to HIV infection in South Africa.

1.2 Statement of the Problem

In a bid to alleviate HIV risks in schools, the South African Department of Health has embarked on a massive HIV Counselling and Testing (HCT) Campaign to test children for HIV as a way of increasing awareness and responsibility in relation to sexual activity. According to Govender (2012: 7), HCT forms part of the "basket of services" offered by the new Integrated School Health Programme (ISHP). It is envisaged that in addition to a range of other services, every learner will be offered the option of taking an HIV test so that they are aware of their HIV status for their own safety and for the safety of their sexual partners (SANAC, 2010:11). At the time of initiating the study, this campaign was about to be launched in high schools where the learners were expected to be 12 years and older in order to meet the legal requirement for consent to HCT according to the Children's Act No. 38 of 2005[1]. The targeting of high school learners in HCT was considered relevant as research indicates that many high school learners are sexually active (Shisana et al., 2010:31). In this regard the involvement of parents in HCT was considered of paramount importance in HIV prevention because they have ethical, legal and social obligations regarding the health of their children. Although parents are not directly involved in HCT, they are expected to offer emotional and psychosocial support to their children during and after the campaign.

[1] Children's Act No. 38 of 2005

The HCT is a massive campaign that has been adapted by the National Department of Health (NDoH) as an expansion of the current voluntary counselling and testing (VCT) programmes. HCT is a slight shift from VCT in that it is introduced by the healthcare provider on the occasion of any patient's visit to any health facility for any ailment. Despite the existence of health facilities, the HCT is being introduced in high schools in a bid to curb the disease among the youth. Though the HCT remains voluntary it has placed an obligation on the healthcare workers to explain to patients the need to know their status and the importance of doing so regularly as part of health seeking behaviour. The target market is anyone who is sexually active from 15 years and older. It is anticipated that secondary schools have a formidable number of young adults who could potentially benefit from this massive campaign (SANAC, 2010; NSP, 2007).

This intended launch of the HCT campaign was based upon the premise that there has been a rise in HIV infection in adolescents (UNAIDS, 2006; Chapman et al., 2010; Shisana et al., 2009). According to South African HIV and AIDS epidemiological statistics, the highest number of people living with HIV/AIDS falls within the range of 15 to 25 years of age. Introducing HCT in schools was felt to be justified in order to widen the range of support given to all South Africans living with HIV and AIDS as well as influencing behaviour change in learners in South African high schools who are mostly in the HIV risk category of 15 to 19 years of age (SANAC, 2010:6; NSP, 2007). It was posited that the earlier the learners know of their HIV status the better the chances for behaviour change to occur (NSP, 2007). The NDoH assumed that if the learners realised their status and received support as early as possible, the rate of new infections could decrease.

1.3 Rationale for the Study

Anecdotal evidence suggests that the rolling out of HCT in high schools could have ethical, legal and social implications. For example concerns have been raised that the HCT campaign could have negative effects on the children's well-being if it is not well planned and monitored. There was fear that the rolling out of the HCT might elicit stigma and discrimination in the school community as well as in the families of affected children. Children who may test positive for HIV could suffer social exclusion

from their peers and teachers. As a result they might not be allowed to participate in certain sporting activities. It was also anticipated that testing positive for HIV could result in grief reactions in the affected children as well as parents affected by the pandemic. Consequently, it was considered important to explore parents' perceptions in this regard.

Moreover, it was regarded as important to investigate the parents' understanding of their children's rights. The Children's Act stipulates that the legal age of HIV testing without parental consent is 12 years or under, as long as the child understands the risks and benefits of HIV testing[2]. It is the right of children in high school to participate in HIV testing without parental consent but the parents may not be aware of their children's rights and their reactions may increase children's vulnerability. Domestic violence could erupt as a result of children's participation in the HCT campaign. Ideally HCT practitioners are expected to act beneficently. In addition, the campaign could promote the best interests of children in that it affords them the opportunity to take the initiative towards becoming an AIDS free generation. However, by targeting the children without involving the parents it could potentially cause harm and become a cocktail for disaster in different ways. Parents are needed to give support to children during and after the HCT campaign in schools. Parents also need to be informed of their limits when it comes to children's health rights. It may be contrary to the values of the parents to allow a child take an HIV test, abort pregnancy[3] or acquire contraceptives without their consent despite the children's rights to do so without parental consent. Concerns have also been raised regarding distributive justice and the inappropriate distribution of scarce resources needed to implement the campaign.

Some people feel that decision-making should be left in the hands of children so that they are not put under undue pressure by their parents to test and disclose their results (Lines, 2011). The HCT Guidelines have not explained the approach that is going to be used to safeguard children from possible verbal and emotional abuse by parents and caregivers who may threaten them not to participate or alternatively coerce their children to participate in the HCT campaign. The HCT campaign in schools may increase the children's vulnerability where parents are not aware of the

[2] The Children's Act No. 38, 2005
[3] Choice on termination of Pregnancy Amendment Act 38, 2004

limitations of their roles in the campaign. It cannot be taken for granted that parents are aware of the law and the rights of their children without determining how much they know and what their reaction to the HCT campaign might be. It was therefore anticipated that the study would throw light on their concerns and would yield important recommendations for the implementation of the campaign in an ethical manner.

1.4 Purpose of the Study

The main aim of the study was to ascertain how a group of parents of children in high school perceive the roll out of the HIV counselling and testing (HCT) campaign in high schools in relation to ethical, legal and social issues.

1.5 Brief Overview of the Research Methodology

The research design was exploratory-descriptive in nature and was located within a qualitative paradigm. The research tool used was a semi-structured interview schedule and data was collected via individual interviews. Participants were parents of high school learners recruited using snowballing sampling. Data was analysed using thematic content analysis.

1.6 Definition of Key Constructs

HIV Counselling and Testing (HCT) is a provider initiated counselling and testing programme that promotes routine HIV counselling and testing by healthcare providers. It gives clients the ability to opt-out as and when they see fit (Makhunga-Ramfolo, Chidarikire, Farirai and Matji, 2011).

Human Immunodeficiency Virus (HIV) is the virus that causes Acquired Immune Deficiency Syndrome (AIDS) by replicating itself and destroying helper T-cells (UNAIDS 2006).

Non-maleficence means to do no harm or doing as little harm as possible (Dhai and McQuoid-Mason, 2011:14).

Beneficence implies doing good for others and promoting others' interests and wellbeing (Dhai and McQuoid-Mason, 2011:14)

Autonomy is defined as a norm of respecting decision-making capacities of those capable of self-determination (Beauchamp and Childress, 2001:12).

Justice means an ethical obligation to treat each person in accordance with what is right and proper (Dhai and McQuoid-Mason, 2011:175).

Distributive justice refers to fair, equitable, and appropriate distribution in society determined by justified norms that structure the terms of social cooperation (Beauchamp and Childress, 2001:327).

1.7 Limitations of the Study

- *Sampling strategy*: A small, non-probability snowball sample was used which precluded generalisation or transferability of the findings to the broader population of parents of adolescents.
- *Ethnic group*: Only one ethnic group was used that is, Black African persons which in turn limits generalisation or transferability of the results to other population groups in South Africa.
- *Geographical area*: For the purpose of convenience, research participants were recruited from one predominantly Black township in Gauteng which limited generalisation of the findings to other areas.
- *Social desirability bias*: It is possible that some parents may have furnished socially desirable responses to some of the questions. Grinnel and Unrau (2011:575) define social desirability or impression management as "a response in which research participants tend to answer questions in a way that they perceive as giving favourable impressions of themselves".
- *Response to a hypothetical situation*: Parents indicated how they would respond if their children were found to be HIV positive. However it is possible that they may react differently in the real life situation.
- *English as the medium for interviews*: Although all the parents could speak and understand English, the fact that English was not their home language constitutes a further limitation of the study.

1.8 Organisation of the Report

Chapter One provides an introduction to the research while Chapter Two describes the theoretical backdrop to the study. Chapter Three provides a detailed description of the research design and methodology. Chapter Four contains the presentation and discussion of the results that emerged from the study and Chapter Five encompasses the conclusions and recommendations that emanated from the research.

CHAPTER TWO

LITERATURE REVIEW

2.1 Introduction

HIV/AIDS is a debilitating illness that has claimed the lives of parents, siblings and children in most households in Sub-Saharan Africa (Fortson, 2011). In fact, Abdool Karim and Abdool Karim (2010:48) state that “AIDS is claiming more lives in Africa than the sum total of all wars, famines and floods to date, leaving many hundreds of thousands of orphaned children”. South Africa has had its own share of the deaths of parents and children as a result of HIV/AIDS. Hardest hit are poor African families that lack education, jobs and live below the poverty datum line. As a result of HIV/AIDS, many families are left headed by children, grannies or under care-givers, who could be relatives or well-wishers.

The NDoH has invested much research in HIV prevention among the youth in general but with limited success in preventing HIV infection (Abdool Karim and Abdool Karim, 2010:49). A great deal has been achieved with respect to the procurement of HIV treatment medicine and in promoting the health of people living with HIV and AIDS (PLWHA), although the incidence of HIV among the youth is still high. Unlike in early years, HIV is no longer considered a “death sentence” to people who contract it but rather as a chronic condition because it can now be treated through the use of antiretroviral (ARV) medicine. However, for the NDoH to be able to have full control of the disease people need to have the courage and initiative to get tested. Nevertheless, it remains a challenge among health educators in South Africa to encourage individuals and communities to take an HIV test because of the stigma attached to the disease (Chao, Gow, Ankitola and Pauly, 2010:563).

According to the Centers for Disease Control (2009:1), it was observed that, in the United States of America, HIV-infected persons who were not aware of their serostatus were more likely to infect others. Such individuals did not reduce their HIV risk behaviours. On the other hand, the Centers for Disease Control (2009:2) argues that many infected persons, once they get tested and know their HIV status, are more likely to engage less in HIV risk behaviours. They are also likely to seek to protect themselves from re-infection and they usually protect their partners by

insisting on safer sex. Consequently, by rolling out HIV Counselling and Testing (HCT) in South African high schools, it is argued that youth who know their HIV status, would be more inclined to seek early counselling and treatment in case of infection. For these reasons, the NDoH has taken upon itself the task of encouraging people to take HIV tests by introducing the HCT campaign throughout the country.

2.2 Bioethical issues inherent in the HCT campaign

The HCT campaign is expected to follow the bioethical principles of autonomy, beneficence, non-maleficence and justice so that it does not harm the children or infringe their rights. HIV testing is not mandatory but is a person's choice (UNAIDS, 2006). Hence there are concerns that since HIV counselling and testing is not mandatory the children who are going to participate in the HCT programme may be at risk of harm through being coerced or forced by their superiors to participate in the HCT campaign in schools (Yezingane Network,). However, abiding by the ethical principles would enable the children to enjoy their rights while they participate in the massive HCT campaign. Their participation would empower them with the knowledge about their HIV status and ways in which to protect themselves from being infected or infecting others (SANAC, 2010). Nevertheless, it should be noted that recommending the HCT does not ensure that individuals will agree to be tested (Mullins, Braverman, Dorn, Kollar and Kahn, 2012:173) which is why it is important to protect children from being coerced and forced to participate in HCT.

On the other hand, parental involvement in the awareness of the campaign may help children open up to their parents and convey their wish to participate in order to gain parental support during the process since children are not fully autonomous (Kling, 2001:218). It is also a concern that if parents are not made aware of children's rights and the importance of the campaign it will be difficult for them to accept the results that might emerge as a result of the HCT programme (Zhao, Li, Fang, Zhao, Hong, Lin and Stanton, 2011). Many parents are not aware of their limitations regarding children's sexual health rights. Some parents may not allow their children to take an HIV test without their consent. Some parents may even become violent towards their children because they want to be consulted by their children before they take part, whereas children have the right to do so without parental consent. However, it is

possible that instead of exercising their rights, children may choose to not participate in HCT because they may be afraid of their parents' reactions.

Parents not only need awareness in this campaign; they also need basic education on how to discuss sexuality and reproductive health rights with their children. Hence if parents are able to discuss these issues it may complement the life skills learnt at school (MacPhail, Pettifor, Coates and Rees, 2008:96). Furthermore, informed consent is likely to be infringed by teachers because of the role they play in loco parentis. Teachers spend most of their time with children at school but they may not be aware of children's right to consent to an HIV test without parental consent. Like parents, teachers need to be made aware of the Children's Act No. 38 of 2005 and that it is against the law to coerce or force children to participate in the HCT campaign. The ethical principles are found in the International Bill of Rights, the Convention on the Rights of Children, The African Charter, the South African Constitution, Act 108 of 1996[4], and the Children's Act No.38 of 2005. The principle of autonomy in HIV testing emphasises informed choice and the need to respect confidentiality in the process of the HCT campaign. The most salient ethical issues include informed consent, confidentiality, beneficence or the best interests of the child and non-maleficence and justice. Each of these principles is discussed separately as follows:

2.2.1 Informed consent

Respect for autonomy is protected in the Convention on the Rights of the Child[5] which recognises the right of children to express their views freely in all matters affecting them, the views of children being given due weight in accordance with the age and maturity of the child. Autonomy according Beauchamp and Childress (2001:12) is the norm of respecting decision-making capacities of those capable of self-determination. A person's constitutional right to bodily integrity and privacy is violated if his/her blood is tested without informed consent (McQuoid-Mason, 2009:26). Moreover, the Constitution of the Republic of South Africa[6] is in line with

[4] Constitution of the Republic of South Africa, Act 108 of 1996 (28)
[5] Convention on the Rights of the Child, 1990, article 12.1
[6] The constitution of the Republic of South Africa, Act 108 of 1996 op cit

the International Bill of Rights. The Children's Act No.38 of 2005[7] acknowledges that consent for an HIV-test on a child may be given by the child, if the child is 12 years of age or older; or under the age of 12 years and is of sufficient maturity to understand the benefits, risks and social implications of such a test. The parents may not be aware of this Act which means that they need to be made aware so that they do not insist on making all decisions. Children are a vulnerable group who need protection by the law so that they could become autonomous beings. As a result of the Nuremburg Trials, the Universal Declaration of Human Right and several other codes and guidelines emanating from World Medical Association, the value of autonomy and self-determination have been recognised (Dhai and McQuoid-Mason, 2011:69). Informed consent is the autonomous authorisation of a medical procedure or participation in research which is done voluntarily and with full understanding of the risks and benefits of the procedure (Beauchamp and Childress, 2001:78). In this case when children participate in the HCT campaign it should be their right to make informed decisions without influence but with understanding of their own choices. The paternalist behaviour of parents can only be altered if parents' awareness is improved. Parents' participation in the HCT should ideally assume mainly a supportive role. Compelling children to take an HIV test without their consent is in breach of a person's autonomy and is a violation of bodily integrity, dignity, and privacy. According to van Oosten (1996:167), the main purpose and duty to inform is to protect the patient's freedom of choice and right to self-determination placing the patient (as a lay-person) in a position to make a rational decision based on knowledge and appreciation of his or her medical situation. In the absence of such information, real consent is lacking asserts Van Oosten (1996:167).This scenario was seen as a breach of autonomy in the case of Castell v. De Greef, (1994,4)[8] where a procedure was performed on a patient who did not fully understand the risks of the procedure and assumed harm. Children as defined by the Constitution is anyone under the age of 18, but because of their diminished autonomy it has been realised that the children at the age of 12 years or sometimes below can make informed decisions in matters concerning their wellness as long as they are given sufficient information and are of sufficient maturity to make informed choices and this is in their best interests. This protection is because they have diminished autonomy.

[7] Children's Act No.38, 2005 s130 (2) (a)
[8] Castell v. De Greeff 1994 (4) SA 408 (c)

However, it is well recognised that as children develop, they also in parallel develop decision making capacities. Dhai and McQuoid-Mason (2011:70) state that imbalance of information increases patient vulnerability which implies that when giving information to children it should suit their level of understanding.

2.2.2 Confidentiality

The purpose of parental involvement in HCT is to protect children's constitutional right to bodily integrity and privacy[9]. In addition parental involvement in HCT is meant to give children support they need in case they are HIV positive. Parents and all the stakeholders involved in the HCT campaign are expected to understand the need for confidentiality. Confidentiality is an aspect of informational privacy which prevents redisclosure of information that was disclosed in a confidential relationship (Beauchamp and Childress, 2001:304). It is expected of the health practitioners to keep any patient information confidential because they have pledged to do so through the Oaths which they take on graduation. These impose such duties as protection of confidentiality (Mappes and Degrazia, 2001:68) even though in some cases they are found wanting. Healthcare practitioners can only share confidential information amongst each other if they are both involved in managing the patient on condition that this information has relevance to the case (Dhai and McQuoid-Mason, 2011:87). Parents should be made aware that they may only know the child's HIV status with the approval of the child. The child has a right to confidentiality which includes not sharing information with parents. Sometimes teachers, parents and relatives may be privy to a child's HIV status, they need to be made aware that they are bound by privacy laws and so, too may not (generally) divulge information of this nature.

Since HCT is going to be performed in schools, children need reassurance that their information is going to be kept confidential by the implementers of the campaign. It is important in that lack of trust by the children could result in low levels of participation. This could be because of loss of friends, emotional devastation and discrimination (Beauchamp and Childress, 2001:308). Participation in the HCT campaign could

[9] The Constitution of the Republic of South Africa Act 108 of 1996 s12, s14

increase children's vulnerability if adequate measures are not in place to protect their rights, including that of confidentiality. It is important for all stakeholders in this campaign to be aware of these issues.

Furthermore, parents might know that information about HIV testing should be kept private and confidential but they may not be aware of the effects of disclosing such information. Parents may assume that since they are the legal guardians of their children they have the right to disclose information on the children's health to anyone without the consent of their children. There was evidence that confidentiality had been breached even by a well-trained medical practitioner in the case of McGeary v. Kruger WLD[10], the plaintiff felt that he suffered an invasion of privacy and had been injured in his rights of personality and his right to privacy (Taitz, 1992:577). McGeary wanted to apply for a life insurance policy and went to his doctor for an HIV test and was found to be HIV positive. The doctor later breached confidentiality by disclosing McGeary's HIV status to his colleagues, and within days the message spread throughout the community. The courts ruled in favour of the plaintiff in this regard. In terms of the National Health Act[11] confidentiality can be breached in certain circumstances such as when required to do so by the law or if non-disclosure poses a threat to public.

Furthermore, the Children's Act[12] stipulates that all cases of child abuse must be reported. In the HCT campaign there would be circumstances where breach of confidentiality would be in the best interests of the child. The health practitioners involved in HCT are bound by law[13] to disclose the HIV status of their clients in accordance with the law. This disclosure is applicable when the client is under the age of 16 which puts them in the category of victims of abuse. Currently, it is an offence for people below the age of 16 years to engage in sexual activities with people of the same age, younger or older, even if the sexual acts were consensual. This means that if one or both of the persons engaged in consensual sex are below the age of 16, they are committing a criminal offence (Strode, Slack and Essack, 2010:247). The implication is that once the child discloses in the HCT campaign

[10] McGeary v. Kruger WLD (16 October 1991) Case no. 25317/90
[11] The National Health Act s14 (1) and (2)
[12] Children's Act s110
[13] The sexual offences act s54 (1)(a)

sessions that he or she had sex, the healthcare practitioner is bound by law to inform those persons responsible for child protection. If the sexual offender lives with the child or in the vicinity of the child, the child has to be removed from the locality and family and taken to a place of safety. Disclosure in these circumstances can lead to child being separated from the family. This is a potential harm of disclosure. This requirement in turn poses a dilemma that before consenting to taking an HIV test the healthcare professional is expected to inform the child that he/she is bound by law to breach confidentiality in order to protect the child from further harm if the child has a sexual partner. In addition, children must be informed that if they test positive their sexual partners may also need to be informed in order to prevent re-infection as well as gaining access to treatment if necessary[14].

2.2.3 Beneficence, Non-maleficence and the Best Interests of the child

The principle of beneficence refers to a moral obligation to act for the benefit of others by helping them further their important and legitimate interests (Beauchamp and Childress, 2001:166). It is important to note that the best interests of the child should be the central concern of the HCT campaign but at the same time it is important to minimise potential harms such as coercion, duress and confidentiality breaches. The healthcare professionals implementing the HCT campaign have the duty to do no harm to their patients (Beauchamp and Childress, 2001:120). Aspects of non-maleficence in the HCT campaign include not subjecting patients to cruel degrading treatment, coerced consent or unlawful interference with children's privacy. The Convention on the Rights of the Child,[15] and the African Charter on the Rights and Welfare of the Child[16] state that in all actions concerning the child whether undertaken in public or private, the best interests of the child shall be of primary consideration. This clause takes into account the need to protect the child from harm or abuse. It is the child who is given the opportunity to make decisions concerning his/her health but with the guidance of an adult. Beneficence is recognised in the provisions of the Constitution of South Africa[17] that state that everyone has right to access to healthcare, access to information and the right of

[14] The HPCSA Guidelines for Good practice s.9
[15] Convention on the Rights of the child, article 3(1) and article 12
[16] African Charter on the Rights and Welfare of the Child article 4(1)
[17] The Constitution of South Africa s27(1) and s28(1)

access to reproductive healthcare. Section 28 further asserts that a child's best interests are paramount in every matter concerning the child. The Children's Act No.38 of 2005[18] stipulates that every child that is of such an age, maturity and stage of development as to be able to participate in any matter concerning that child has the right to participate in an appropriate way and views expressed by the child must be given due consideration. This precept is portrayed in the case of McCall and Meyer v. Gerber[19] and Martens v. Martens[20] where the young children displayed maturity in their decisions regarding the parent with whom they wished to live. This case was about custody of children as a result of divorce and with the satisfaction of the court that the children had intellectual and emotional maturity to give their expression of preference. Children were allowed to choose the parent with whom they wanted to live. Hence, in South Africa the human rights and legal instruments are robust in fostering the best interests of the child.

2.2.4 Justice

Justice and equality

The HCT campaign will target all high schools in South Africa. The schools in this country differ in terms of resources and environment due to historical factors. It is with this understanding that the implementers have to treat all the children who are going to participate in the HCT campaign equally without discrimination. Beauchamp and Childress (2001) define justice as fair, equitable and appropriate treatment in the light of what is due or owed to persons. Justice and fairness are enshrined in the provisions of the Constitution[21] where it is stated that everyone should be treated equally with dignity and may not be unfairly discriminated against either directly or indirectly on one or more grounds, including race, gender, ethnicity and other factors. The Promotion of Equality and Prevention of Unfair Discrimination Act (PEPUDA) [22] is an anti-discrimination law and prohibits discrimination by government, private

[18] Children's Act no. 38 , 2005, 2(10)
[19] McCall and Meyer v. Gerber 1999(3) S A 650(0)
[20] Martens v. Martens 1991 SA 287 T
[21] The Constitution of the Republic of South Africa s9
[22] The Promotion of Equality and Prevention of Unfair Discrimination Act , 2000 (PEPUDA or the Equality Act, Act No. 4 of 2000)

institutions and individuals. In line with this Act, the National Policy on HIV and AIDS[23] stipulates that no learner or educator with HIV and AIDS should be discriminated against directly or indirectly and learners with HIV and AIDS should be treated in a just, humane and life affirming manner.

Distributive justice

In terms of justice, particularly distributive justice and allocation of scarce resources, the question arises whether there will be sufficient appropriately trained personnel to conduct pre and post-test counselling, and sufficient health care personnel to administer HIV tests as part of the HCT programme. Distributive justice is defined as a fair, equitable and appropriate distribution determined by justified norms that structure terms of social cooperation (Dhai and McQuoid-Mason, 2011:145). In this case problems with distributive justice arise when there is scarcity of qualified healthcare professionals. High school learners are a very vulnerable group, and lack of qualified personnel could result in doing more harm than good. The quality of health services provided during the HCT campaign depends largely on the knowledge, skills, motivation and deployment of the people responsible for the organization and delivery of health services (WHO, 2011). The HCT campaign intends to visit all high schools in South Africa giving every child the opportunity to participate in HIV testing. The NDoH is operating at a deficit of qualified health care professionals (HSRC, 2008:4) it is unlikely that the distribution of qualified healthcare professional will be able to meet the demand and supply in schools during the process. According to Beauchamp and Childress (2001:226) "problems with distributive justice arise under conditions of scarcity, and competition to obtain goods or to avoid burdens." In the HCT campaign, scarcity of qualified personnel is a cause for concern in that it could possibly lead to malpractice on the part of healthcare professionals and burden avoidance by Government which could result in causing harm to learners. The problem could lead to breach of confidentiality because people who are supposed to work as support staff might end up doing the work of the

[23] National Policy on HIV and AIDS for Learners and Educators in Public Schools and Students and Educators in Further Education and Training Institutions 1999 s3

professional healthcare personnel, especially in resource poor communities in order to meet the demand created by rolling out of the HCT campaign.

2.3 Social Issues

The diagnosis of HIV in a child is likely to cause pain in parents. It is anticipated that the HCT programme in high schools could potentially have negative consequences for the child and the parent. For example, a diagnosis of HIV in a high school child could result in collateral damage to the family and immediate community, if they are stigmatised by association with HIV and AIDS. Although the aim of HCT is noble, there could be unintended consequences for the social fabric of society. In addition, there could be psychosocial problems associated with an HIV diagnosis such as teenage suicide, depression, homelessness, and substance abuse. Girls could be forced to marry people who are infected with HIV if parents reject them. In the case of boys, they could become aggressive and violent towards their parents, women and teachers due to low self-esteem or as compensatory behaviour (Petersen, Bhana, Myeza, Alicea, John, Holst, McKay and Mellins, 2010:971). Children diagnosed with HIV could leave school and seek employment because they have feelings of being rejected by the family, peers, and the school system.

These potential problems could arise if the HCT programme is handled in a haphazard and hurried manner without proper planning and consultation. If the HCT campaign is implemented by people without proper training and qualifications in managing the emotional well-being of adolescents, the programme could have a damaging and lasting effect on parents' and children's psychosocial well-being (Peltzer, Tabane, Matseke and Simbayi, 2010:381). While some schools might abide by the ethical principles of carrying out HIV testing among school children, other schools might coerce or manipulate children into acquiescing to an HIV test against their volition, conscience, or readiness to take the test. Some parents might force their children to take the test as required by the school principal. Refusal to take the test in the presence of teachers and peers could be an uneasy decision for the child; as extreme courage will be required for the child to challenge peer and institutional influence (Shisana et al., 2010:64).

2.3.1 Stigma and “othering”

Stigma is a word that was created by the Greeks to refer to bodily signs designed to expose something unusual and negative about the moral status of the signifier (Goffman, 1963:11). Green (2009:14) defines stigma as a distinguishing mark of social disgrace, while Goffman (1963:13) sees stigma as a profoundly discreditable attribute that could lead a person to be deemed almost inhuman. Young, Hlavka, Modiba, Gray, Van Rooyen, Richter, Szekeres, and Coates (2010:621) noted in their research that HIV related stigma is highly prevalent in Africa, particularly in South Africa. In many developing countries persons living with HIV and AIDS experience high levels of stigma and discrimination, and AIDS-related stigma has an enormous negative impact on their social relationships, access to resources, and psychological well-being (Bos, Schaalma and Pryor, 2008).

Stigmatization has always been there as a social construct that drew a line between different social classes and races (Green 2009:56). In the past, many people with disabilities and any sign of deformities lived with stigma in that they were perceived as different from other members of the society (Goffman, 1963). Similarly, many black people were perceived as backward, illiterate and as having conservative family values (Young et at., 2010:622) Today stigma has become more associated with HIV (Herek, Capitanio and Widaman, 2003). Stigma attached to being HIV positive has been extremely negative in that having HIV and AIDS is associated with immorality, carelessness, promiscuity, intravenous drug use and homosexuality. Society generally regards people living with HIV and AIDS as having done that to themselves and as a result they deserve to suffer (Bos, Schaalma and Pryor, 2008). Society has also excluded people with HIV out of fear that they would spread the disease. According to Green (2009:56), previous studies have shown that there is an increase in stigma especially when the disease is contagious. Even though the ways in which HIV is transmitted are well known and understood, society tends to exaggerate the risk of contagion thereby giving rise to stigma (Green (2009). HIV related stigma has resulted in discrimination, social exclusion, abandonment,

rejection and abuse of PLWHA. This impact has brought about feelings of shame, guilt and self-blame to HIV victims.

A key dynamic underpinning stigma, is the notion of distancing or “othering” which describes the process whereby people who are different to us are perceived as outsiders and less than “insiders”. There is a dividing wall of hostility between the insider and the outsider and persons living with HIV and AIDS are often perceived as “the other” and branded as undesirable (Deacon, Prosalendis and Stepheny, 2005).

In South Africa statistics have shown that many adolescents have their sexual debut mostly from the age of 12 years (Shisana et al., 2008:64). This sexual activity exposes them to sexually transmitted diseases, teenage pregnancy and HIV. These factors would appear to justify the need for learners to participate in HCT. However, stigma is one of the psychosocial problems that might deter the success of the HCT in schools.

2.3.2 Discrimination

When stigma is enacted, the result is discrimination (UNAIDS, 2005:9). Social discrimination results when people label a person living with HIV and AIDS as an out group. Allport (1954:51) defines social discrimination as denying to individuals or groups of people the equal treatment they deserve. Mummendey and Wenzel (1999:159) further define social discrimination as “an in-group’s subjectively justified unequally disadvantageous, evaluation or treatment of an out-group”. Discrimination, as defined by UNAIDS (2000*)* in the *Protocol for Identification of Discrimination Against People Living with HIV,* refers to any form of arbitrary distinction, exclusion, or restriction affecting a person and in the case of HIV a person’s confirmed or suspected HIV status. Stigma can lead to discrimination and other violations of human rights which affect the well-being of people living with HIV in fundamental ways (UNAIDS, 2005:6). In some countries people who are HIV positive are restricted from receiving visas and life insurance among others (Green, 2009:57). In the early days of the epidemic some people lost their jobs because they disclosed their HIV status to their employers, although it is currently against the law to discriminate against anyone because of their HIV status, as it is a violation of human

rights (UNAIDS, 2005). The Employment Equity Act[24] stipulates that "no person shall be discriminated against in any employment policy or practice on one or more grounds including HIV status among others and medical testing of an employee is prohibited unless legislation permits or it is justifiable."

With the rollout of HCT there is a possibility of learners in schools being discriminated against by the school as well as their peers. Discrimination could occur in different forms such as refusal to share a desk with the learner or even refusal to be in the same class with the affected child and over exaggeration of danger by teachers and peers if and when the learner is sick. Learners could also be excluded from participating in sport. The reason for discrimination would be based on the fear of contagion and contamination as spelt out by Green (2009:57). Potential discrimination could impact on school attendance in that learners may shy away from coming to school because of feelings of rejection, guilt and shame. Some learners may even prefer to leave school because their coming to school would be a constant reminder of their HIV status (Zhao, Li, Fang, Zhao, Lin, and Stanton, 2011).

With regard to HIV counselling and testing in schools, social discrimination may be experienced by learners who would have tested positive for HIV. The in-group, their school community could discriminate against them by preventing equal exploitation of school resources such as sharing bathrooms. Some bathrooms might be allocated to the in-group and the out-group would then not be allowed to enjoy such facilities. The same could happen in the sporting activities where learners who test positive to HIV may not be allowed to participate in many of these because of fear of contamination during injury (van Vollenhoven, 2003). While the laws may not allow such discrimination, the practice on the ground could well be different. The learners who test positive to HIV could end up being an identifiable cohort which is easily discriminated against. The social discrimination could also lead to bullying. Before HCT is rolled out these factors need to be addressed so that discrimination is not legitimized.

[24] The Employment Equity Act no. 55 of 1998 chapter 2 s6(1) and s7(2)

2.3.4 Disclosure

Disclosure of HIV status often brings about conflict in many African families (Brown and Lourie, 2000:86). This conflict usually occurs in the way people perceive persons living with HIV. The stigma attached to the disease tends to make people avoid disclosing their HIV status because it results in them being judged, prejudiced, isolated and discriminated against. According to Green (2009:67), "there is clear association between stigma and disclosure about being HIV positive whereby fear of negative reactions from others acts as a deterrent to disclosure". Disclosure is a way of communicating one's status to a member of the family, sexual partner or to a friend. This process is meant to give the person moral and emotional support. Green (2009:67) reiterates that non-disclosure can lead to social isolation and less social support being forthcoming. According to the WHO guidelines, disclosure should not be mandatory; it is a person's choice to disclose their HIV status and to whomever they may wish to disclose. Health practitioners emphasise the importance of disclosure to their patients without force or coercion, but they are expected to respect their patients' autonomy by maintaining confidentiality. It has been found that even though patients are encouraged to disclose their HIV status, the only people to whom they usually feel free to disclose their HIV status, are mostly health practitioners (Green, 2009:67).

HIV Counselling and Testing in Schools also emphasises the respect for patients' autonomy by respecting their decisions whether to disclose their HIV status or keep it confidential. However, clinicians are required by law to report sexual abuse that may have been inflicted on to minors[25]. The age of high school learners in South Africa usually ranges from 12 years to 19 years. Since 12 year olds can consent to HIV counselling and testing without consulting their parents, if any 12-16 year old tests positive and admits to any sexual contact, the concept of confidentiality is overridden by the best interest principle. The best interest principle seeks to protect the well-being of the child involved by protecting him/her from further harm. This principle could then allow disclosure of the child's HIV status to the family, which could be mother, father, grandparents and caregivers. Bonuck (1993, in Ross and Deverell, 2010) maintains that the psychosocial impact of HIV and AIDS on families

[25] Sexual Offences Act No. 32 of 2007 s54(1)

usually begins with disclosure of HIV infection. The family learns about their child's HIV status through disclosure and the reaction of the family may be either supportive or may create an atmosphere of rejection and shame. In some cases the disclosure may result in violence against the child instead of protecting him/her. The family may feel that their social status has been affected. Some children may be abandoned by their families because of the fears that the disease could be communicated to them. Family feuds may also arise as a result of HIV disclosure. The child may be discriminated against by his/her own family, for example, be restricted from sharing utensils, crockery and bathrooms (MacPhail, Pettifor and Coates, 2008).

2.4 Conclusion

In conclusion, the rollout of HCT would appear to be necessary in curbing the HIV prevalence and incidence and would fulfil the National Strategic Plan (NSP) that up to 70% of sexually active groups in South Africa should have been tested for HIV by 2011 and provided with treatment and support (NSP, 2007:64). The main concern is that the process should not be implemented without proper planning as it may create more harm than good. Moreover, ethical principles need to be adhered to in the implementation programme and social issues also taken into consideration.

CHAPTER THREE

METHODOLOGY

3.1 Introduction

This chapter provides a detailed explication of the study by describing the aims and objectives, research design, research question, study population and sampling, research instruments, research procedure, pre-testing of the research tool, method of data collection, setting for the study, data analysis and ethical considerations.

3.2 Research Questions

What do parents know about the HCT campaign and what are their views in this regard?

3.3 Aims and Objectives

Primary Aim

To ascertain how parents of children in high school perceive the roll out of the HIV Counselling and Testing campaign (HCT) in schools in relation to ethical, legal and social issues.

Specific objectives

i. To explore parents' views about the HCT campaign to be conducted in high schools.

ii. To determine whether parents would be in a position to engage with their children on the HCT campaign.

iii. To elicit information on parents' awareness of the Children's Act no. 38 of 2005 with regard to HIV testing.

iv. To ascertain parents' views about knowing their children's HIV test results and their perceived reactions to such results.

3.4 Research Strategy

The study adopted an exploratory-descriptive research strategy located within an interpretive qualitative paradigm and based on data derived from semi-structured interviews. The interpretive qualitative perspective states that “reality is defined by the research participants’ interpretations of their own realities” (Williams, Unrau, Grinnel and Epstein, 2011:53). Qualitative research seeks out the ‘why’, not the ‘how’ of its topic through the analysis of unstructured information like interview transcripts, open ended survey responses, and videos. According to Strauss and Corbin (1998:12), qualitative research can refer to persons’ lives, lived experiences, behaviour, emotions, and feelings as well as about organisational functioning, social movements, cultural phenomena, and interactions between nations.

3.5 Study Population and Sampling

The study population comprised parents with children attending high schools. The sample was purposively selected. According to Terre Blanche, Durrheim and Painter (2004:139), purposive sampling implies that “sampling depends not only on availability and willingness to participate, but that cases that are typical of the population are selected”. In terms of selection criteria, only parents with children in high school were recruited to participate in this research. Katlehong was chosen as the research site because the population located in this area closely represents the majority of the South African population and not because it is an area where HIV is prevalent. Snowballing sampling was used until data saturation was reached. Snowball sampling occurs when the participants help recruit future participants by making chain-referrals resulting in the group growing like a rolling snowball (Terre Blanche, Durrheim and Painter, 2004:139). In this research project snowballing was most effective in that it would have been difficult to find parents with children in high school without waiting for them in schools. Snowball sampling has advantages and limitations. The advantage is that the researcher is able to reach populations that are difficult to sample when using other sampling methods. The process is simple, cheap, and cost-effective and needs fewer workforces (Patrick, Pruchno and Rose, 1998:299) though it may take more working hours.

The limitation of the snowball sampling method is that the researcher has little control over the sampling, as the participants the researcher obtains depend mainly on the previous participants that were interviewed. Another concern is that the researcher usually has no idea of the true distribution of the population and of the sample (Penrod, Preston, Cain and Starks, 2003:102). Data saturation occurs when the researcher is no longer able to elicit any new information (Terre Blanche, Durrheim and Painter, 2004:372). Data saturation was reached after interviews with 20 parents. The interviews were conducted in 20 households. The participants referred the researcher to other parents in the area after first obtaining permission to disclose their contact details to the researcher.

3.6 The Research Tool

The interview schedule comprised eight open-ended questions that were prepared ahead of time and are set out in Appendix A. However, additional questions emerged during the interview, thereby allowing both the interviewer the flexibility to probe for details and the person being interviewed the opportunity to discuss issues and ask questions. Semi-structured interviewing is guided only in the sense that some form of interview guide, provides a framework for the interview (Opie, 2009:118). The researcher used this approach because it allows for two-way communication and gives room for probing and gaining of a range of insights on specific issues.

Table 3.1 Rationale for inclusion of items in the interview schedule

Item/question	Rationale for inclusion
1. Demographic data	- *Gender of parent:* Inclusion of the item on gender was designed to determine whether parents who participated were male or female and whether their gender influenced the way they felt about the HCT campaign. - *Age*: The inclusion of this item was

	meant to determine whether the age of parent influenced the way they felt about their children's participation in the HCT campaign. - *Gender and number of children:* The gender of the children was designed to ascertain whether the concerns of parents were influenced by the gender of their children. It was also included to determine whether the number of children in school would influence the way parents felt about the entire process. Devlin (2006) emphasizes that demographic data provide further insight into research findings.
2. What do you think about the government's intention to counsel and test all children for HIV who are willing to participate in South African high schools?	- The rationale for including this question was to gain insight into the knowledge and awareness of parents in relation to the HIV counselling and testing campaign and how they felt about it.
3. What do you think about letting your child take an HIV test in school without your approval? Would you let him/her?	- This question was asked in order to understand parental involvement in their children's participation.
4. Would you be interested in knowing your child's HIV test results? How would you react if your child tested positive for HIV?	- This question was posed in order to find out if parents were interested in knowing their children's HIV status and what their reactions might be.
5. What do you think about discussing HIV positive results with your child?	- The purpose of this question was to ascertain whether parents were willing to communicate with their children about matters of children's sexual health in relation to HIV.

6. Would you be able to keep the HIV results of your child to yourself or would you need to tell someone else?	✚ This question was designed to assess whether parents understood the concept of confidentiality.
7. The law allows children at the age of 12 years or under to take an HIV test without the consent of their parents if they are of sufficient maturity to understand its risks and benefits. What are your views about this law? Do you believe it will work considering the resources in this country?	✚ Parents were asked this question to find out how they felt about the Children's Act. Parents were required to give their views on whether they felt that the law was applicable and feasible to apply in South Africa.
8. Do you think there are challenges that are likely to arise as a result of the HIV counselling and testing campaign in schools? What are the challenges? How do you think these challenges would affect you as a parent?	✚ These questions were designed to elicit information on the fears and concerns the parents might have had about the HCT campaign.
9. Do you think testing children for HIV in school would benefit them? In what way would it benefit or disadvantage them?	✚ Parents were asked these questions in order to understand their attitudes towards HIV testing and to discover if they were able to perceive any benefits deriving from the campaign.
10. Do you have anything else to say about the campaign?	✚ The question was meant to enhance understanding of any views parents might have had about the HCT campaign that were not included in the earlier questions.

3.7 Research Procedure

Permission to carry out this research was sought from the Human Research Ethics Committee (Medical) (HREC). After being granted permission the researcher travelled to the Katlehong area to invite parents with children in high school to participate in the study. The first two parents helped in creating the snowballing effect by contacting other parents and referring the researcher to those colleagues who were interested in participating. Permission was first obtained from the persons concerned before their contact details were given to the researcher. The researcher then arranged with the participants regarding the time and place to meet them for the interviews. All parents preferred to have the interviews conducted in the comfort of their homes.

3.8 Pre-testing the Research Tool

A small pre-test using five parents was conducted to assess suitability and duration of the interview. According to Collins (2003:230), pre-testing is the final stage in the making of the research tool. During the pre-test the duration of the interview was found to be between 30 to 45 minutes depending on how much information the participant furnished. It was deemed important to use a pre-test in this research because it is a good planning strategy that helped clear the way for the researcher and enhanced validity and reliability of the research tool (Collins, 2003:231). The five participants who were included in the pre-test did not form part of the main sample of this research. They were not included in the main sample of the research even though they came from the relevant population of parents, because the main purpose was to test the feasibility of the interview schedule. The pre-test was carried out in order to reveal unanticipated problems with either question wording or instructions to skip some questions. It also helped in seeing whether the interviewees understood the questions and could give useful answers. In this study the pre-test did not lead to any changes in the interview schedule.

3.9 Method of Data Collection

The researcher used semi-structured interviews. According to Opie (2009:118) a semi-structured interview “allows for deviation from a pre-arranged text and to

change the wording of questions or order in which they are asked". Opie (2009:118) also maintains that semi-structured interviews impose shape on the interview to avoid aimless discussions.

The interviews were conducted privately in the participants' homes. The latter were interviewed individually at times when they were available. They were allowed to ask questions before filling in their consent forms.

The researcher interviewed the participants in English. Although all participants could speak and understand English, the fact that English was not their home language constituted a limitation of the study. Audio-taping of the interviews was optional and was conducted with participants who gave consent to audio-taping. It was considered important for the researcher to audio-tape the interviews in order to allow for direct quotations during data analysis, which enhances trustworthiness.

3.10 Setting for the Study

According to Clacherty and Budlender, (2003:21) Katlehong is located 35 kilometres east of Johannesburg in Gauteng province. It is a high-density suburb with six informal settlements in the southern part of Katlehong. There is serious overcrowding in this area, for example, in a tiny yard, shacks are constructed for rent and a single toilet usually serves from five to six families or more. Katlehong is surrounded by industries but the level of unemployment is still very high. It is the second largest black community after Soweto. Clacherty and Budlender (2003:21) described Katlehong as a large sprawling shack area characterised by extreme poverty and high levels of crime and violence. For this reason the police kindly offered to accompany the researcher in and out of the area when the interviews were conducted at night.

3.11 Data Analysis

After gathering data, all the responses given by the participants who granted permission for tape-recording during interviews were transcribed and written down in relation to each question. The responses were categorized into themes for the

purpose of thematic content analysis. Grinnel and Unrau (2011:561), define content analysis as “a data collection method in which communications are analysed in a systematic, objective, and quantitative manner to produce new data”. In undertaking the thematic content analysis five steps that are recommended by Terrre Blanche, Durrheim and Kelly (2006) were followed as they are aligned with interpretive data analysis. These steps include (1) *familiarisation and immersion*, which involved listening to the tapes and reading through the transcripts and notes several times; (2) *Inducing themes*, whereby recurring themes or categories were noted; (3) *Coding* which entailed marking different sections of the data as being examples of particular themes; (4) *Elaboration*, which involved revising the themes by combining similar themes into single themes; and (5) *Interpretation and checking*, which encompassed writing up the analysis using thematic categories as sub-headings, interpreting the analysis and checking the categorisation of themes with the researcher’s supervisor.

In order to enhance trustworthiness in qualitative research, data needs to be credible, transferable, dependable and confirmable*,* otherwise it loses its strength through threats to external validity (McMillan and Schumacher, 1993).

Credibility according to Lincoln and Guba (1985:296) is an evaluation of whether or not the research findings represent a credible and believable conceptual interpretation of the data drawn from the participants’ original data. In this research credibility was enhanced by the thick detailed description of the setting and the provision of sufficient contextual information about the fieldwork site. *Transferability* is the degree to which the findings of this inquiry can apply or be transferred beyond the bounds of the project thereby allowing readers to be able to apply it in their own situations (Krefting, 1991:219). Although some of the findings may be applicable to other groups and settings, the use of a small non-probability sample precluded transferability of the results to a broader population of South African parents.

Dependability is an assessment of the quality of the integrated processes of data collection, data analysis, and theory generation. *Dependability* was enhanced by providing a detailed description of data collection and analysis in order for future researchers to be able to repeat the same work and may be gain the same result. Dependability was also enhanced through using the same researcher to conduct all these interviews. *Confirmability* is a measure of how well the inquiry’s findings are

supported by the data collected (Lincoln & Guba, 1985). The researcher made use of correspondence checking to enhance *confirmability* whereby theme categorisation was verified by the supervisor.

3.12 Ethical Considerations

Voluntary participation

Participation in this research project was voluntary. Participants were free to withdraw from the study if they wished to do so. Participants were told that there was no penalty for withdrawing from the study or for refusal to participate.

Informed consent

Participants were required to complete informed consent forms as a precondition for participating in the study. The researcher explained the purpose of this research to the participants. An information sheet explaining what the study entailed was given to participants. If participants were illiterate, the researcher explained to them in the simplest way for them to understand and to decide whether they wanted to participate or not.

Informed consent is intended to protect individuals against unwanted procedures and to acknowledge the individual's capability to decide for him or herself whether or not to participate in any research. According to Bunnik, Schermer and Janssens (2011:6), informed consent "allows individuals to exercise their fundamental right to decide". This principle was ensured by "providing participants with clear, detailed factual information about the study, its methods, risks and benefits and the freedom to refuse or withdraw without penalties" (Terre Blanche, Durrheim and Painter, 2006:72).

Confidentiality

All information was kept confidential. Participants were assured that their names would not be used in the research in order to safeguard their right to privacy. With the permission of the participants, the researcher invited a third party to help her make notes of the conversation while interacting with the participants. The third

person was needed because most of the parents were not comfortable with tape recording. Only five parents consented to tape recording.

Ethical clearance

The researcher obtained approval from the Human Research Ethics Committee (Medical) of the University of the Witwatersrand before the study commenced. It is a requirement in research that involves humans to seek ethics clearance in order to protect participants from harm. It is stipulated in the Health Act No. 61 of 2003[26] that an independent accredited research ethics committee must approve all research with human participants.

Avoidance of deception

In this research deception was not used because all participants received information about the study. All procedures were explained to them and there was no misleading information. In accordance with the principle of non-maleficence, deception was avoided as it is fundamentally wrong (Wassenaar, 2006).

3.13 Summary of the Chapter

This chapter provided a detailed description of the research design and methodology used in the study.

[26] Health Act, 61 of 2003, 9(71)

CHAPTER FOUR

RESULTS AND DISCUSSION

4.1 Introduction

In this chapter, findings are presented and discussed in accordance with the objectives of the study. Closed-ended quantitative items are analysed using descriptive statistics, while qualitative responses are analysed in terms of themes articulated by participants. Themes are presented in relation to the frequency with which they were expressed. Grinnel and Unrau (2011:461) maintain that "although numbers are typically associated with quantitative studies, it is acceptable to use numbers in qualitative ones to document how many participants expressed a particular theme". Each theme is illustrated with verbatim responses, which allow the voices of participants to be heard.

4.2 Profile of participants

Table 4.1 Profile of participants (N=20)

CATEGORY	No	RANGE	AVERAGE
Parental status			
Father	7		
Mother	12		
Caregiver	1		
Parental age		28-53 years	40 years
Father		40-53 years	45 years
Mother		28-47 years	37 years
Children's age		12-18 years	14 years
Children's gender			
Male	14	13-18 years	14 years
Female	15	12-17 years	13 years
Ethnic group	Black		

The total number of participants in this research was 20. Table 4.1; 13 were mothers and seven were fathers. The age range of all parents was 28 to 53 years, while the average age for all participants was 40 years. The ages of participants' children ranged from 12 to 18 years which placed them in the adolescent stage of the life cycle. However the analysis of responses revealed no substantial differences between mothers and fathers and between those with one child versus those with more than one child, regarding their views on the proposed HCT campaign. The participants all came from one ethnic group i.e. Black Africans, as they were all recruited from a township in Johannesburg within Gauteng province. That no other South African population groups were represented constitutes a limitation of the study.

4.3 Results in respect of OBJECTIVE 1: Parental views about HCT to be conducted in schools

Figure 4.1 depicts the themes that emerged in relation to parental views about the proposed HCT programme to be conducted in schools.

In favour of HCT because it can enable children to know their status and act responsibly

Figure 4.1 shows that this theme was articulated most frequently by participants. Eleven parents supported the HCT campaign in that the children would be able to know their HIV status and would be able to act responsibly. For example, they noted that it was *"…important that they know their status", "…must know their status…"* This theme is reflected in the statement by SANAC (2010) that one objective of the HCT campaign is to mobilise people to know their status which is expected to contribute to positive behaviour change. One parent said: *"…something can be done before…",* while another commented, *"…they can live careful and risk free life."* Some parents were in favour of the campaign because they perceived that it gave their children the power to act responsibly. Further examples which encapsulated this theme included: *"…in order to know how to behave", "…for her own benefit", "…children are safer than before…I know my child is safe…"* This view is supported by the Centers for Disease Control (2009:2) which maintains that many infected

persons, once they get tested and know their HIV status, are likely to engage less in HIV risk behaviours. The Human Science Research Council (HSRC) (2008:3) reiterates the notion that people who are aware of their HIV status are less likely to engage in behaviours that would spread the disease than those who have not been tested.

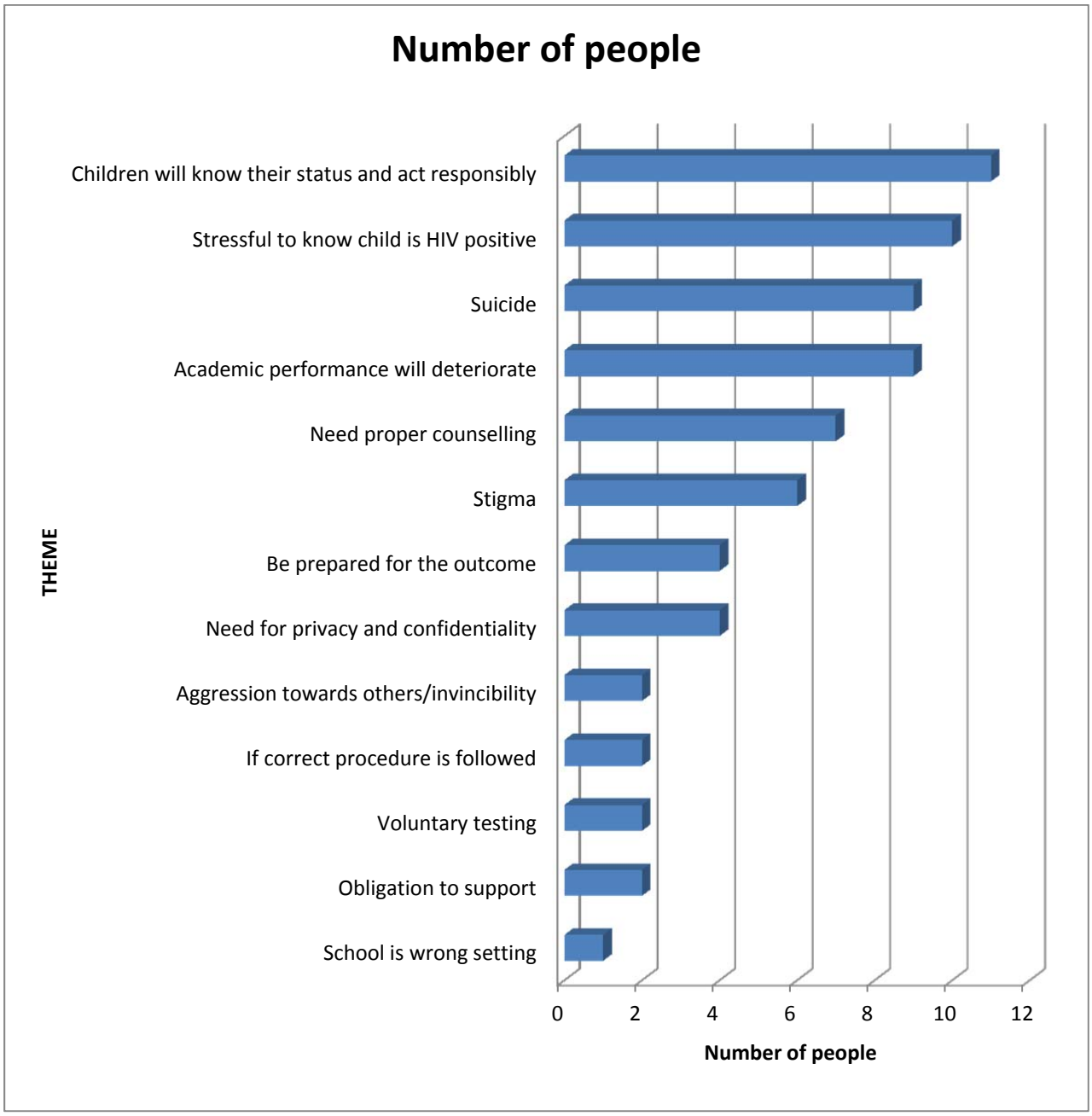


Figure 4.1 Parental views about HCT to be conducted in schools (N=20)

Stressful to know that child is HIV positive

Six parents expressed their fears that knowing their children's HIV status would cause stress and emotional instability at home and at work. For example, one parent said, *"It depresses me as a parent to know that my son is HIV positive",* while another stated: *"I will not be able to go to work or do anything…will affect me at work…".* In support of this viewpoint, Antle, Wells, Goldie, DeMatteo and King (2001) report that stress symptoms were highest among primary caregivers of HIV positive children.

Five parents were of the opinion that the HCT campaign would jeopardize their relationships with their children. They felt that knowing that a child was HIV positive would make them angry and likely to insist that their children identify their sexual partners as well as force them to terminate their relationship with the person concerned. For example, *"…would strain relations with my son…affect relations with parents…can disturb my relations with my children…"* They were afraid of the tensions that might occur as a result of their children participating in HCT and knowing that they were HIV positive the parents might end up meddling in children's affairs wanting to know their sexual partners or how their children became HIV positive. One parent reflected that she did not expect her child to be participating in any sexual activities because the child was too young to do that, so taking an HIV test would be proof that the child was engaged in adult activities.

Academic performance will deteriorate

Five participants were of the view that their children's performance at school would deteriorate after their participation in HCT because those who received positive results would experience severe stress. As a result of HCT they anticipated that children would not want to go to school and their performance would deteriorate, while other children would end up missing school or dropping out of school completely. For example, one parent said, "*education is going down".* Other parents echoed this same sentiment when they commented, *"…why our children fail because", "…children are going to fail badly…"* These responses reflected the parents' concerns about the potential effect of the HCT on their children's school performance.

Four parents anticipated that their children would refuse to go to school if they tested positive for HIV. For example, one parent commented, *"…will never go school…will stop going to school and doing school work… will refuse to go to school."* Another parent believed that even when forced by parents to go to school, *"…children will bunk school…children go on the street…"* They were of the opinion that the entire HCT process, though beneficial, would yield negative results by contributing to the number of children on the streets. In line with parental concerns, Zhao, Li, Fang et al. (2011) state that knowing one is HIV positive may affect the child emotionally and socially which would in turn result in the child wanting to leave school as well as negatively affecting his/her academic performance.

Disagree with HCT because it will cause suicide

Nine parents articulated the view that telling children that they were HIV positive would cause them to commit suicide because it would be difficult for them to cope with news of that nature. The following responses reflected this theme: *"…children are gonna commit suicide…killing themselves…going to die in numbers…can see lots of suicides…foresee many suicides…may kill themselves".* One parent expressed the notion that if children cannot bear the prospect of failing matric, it will be even more difficult for them to accept their HIV status. One parent mentioned that girls kill themselves in the Eastern Cape using tank pills when they fall pregnant. "Tank pill" is the local name for aluminium phosphate, a pesticide used to preserve grain in the Eastern Cape province (Meel, 2011:116). The parents believed that it would be far worse when those same children discovered their HIV status, especially the ones that turned out to be HIV positive. In support of this concern, Rawoot (2011:22) reports that "according to the Eastern Cape department of education's learner mortality report, 106 children committed suicide last year followed by 96 deaths between January and June this year." Consistent with this viewpoint, MacPhail, Pettifor, Coates and Rees (2008:92) highlight the fact that among the youth who participated in their research half of them expressed fear of an HIV diagnosis and mentioned that they might contemplate suicide.

In favour of HCT but proper counselling of children needed to prevent suicide

Seven parents articulated this theme, saying that there was a need for proper counselling in order to prevent suicide. For example, one participant commented, "…

they need to give them proper counselling before they do that …otherwise many children are going to kill themselves…provide proper counselling…" Njeru, Blystad, Shao, Nyamongo and Fylkesnes (2011:5) support the idea of appropriate counselling by explaining that counselling is an essential and acknowledged HIV testing regime. This finding suggests the need for proper counselling of the children in order to prevent them from committing suicide. In this way, one can fulfil the ethical duties of beneficence and non-maleficence.

Stigma associated with HIV

Six parents were of the view that their children would be stigmatised at school because of the nature of the disease which was associated with promiscuity and careless behaviour. Wagner (2011:85) echoes parental concerns saying stigma is still present partially due to cognitive associations with immoral behaviour like unfaithfulness, promiscuity, and prostitution, out of which accusations and blame towards people infected with the virus originate. For example, one parent noted, *"…because of its history…it means you are promiscuous".* The parents were particularly concerned about the labels their children would receive from their peers and teachers. For example, one parent commented, *"…with all those labels, our children are going to be teased and laughed at…"* Knowing one's HIV status was viewed in a way that brings shame and humiliation to both the parent and the child as reflected in the response: *"…someone is ashamed…being HIV positive is humiliating."* These responses encapsulated the fear of both stigma and 'othering" as described by Deacon et al. (2005). Four parents believed that children diagnosed with HIV would not want to associate with others because they would feel that they would be ridiculed. For example, *"…they start to laugh at me…would not want to mix…"* In support of the parents' views Chao, Gow, Akintola and Pauly (2010:568) maintain that "stigma remains a major impediment to improving the situation that HIV positive teachers and students find themselves in South African schools" which has led to the refusal of many HIV positive persons to identify themselves voluntarily. People who are HIV positive are often afraid to come into the open because they fear discrimination. In the school situation learners who are HIV positive are likely to be discriminated against by both teachers and their peers when they get sick or when they want to take part in sports. The fear of contagion may exacerbate discrimination. For this reason, the HCT implementers should educate people before

engaging in their campaign in order to prevent harm and uphold the principle of non-maleficence.

In favour of HCT but parents must be informed and well prepared for the outcome

Four parents stated that they needed to be prepared and consulted by their children before the latter could be allowed to participate in HCT. They emphasised that their children were their responsibility and as such they needed to give consent for their children to participate in the campaign. They felt that the campaign organisers had the responsibility to counsel and prepare parents for the outcome of the HCT. For example, some comments included: *"…must prepare us", "...consult parents before…my child is my responsibility…"* Consistent with this finding, MacPhail, Pettifor, Coates and Rees (2008:96) noted from their research that parents needed counselling in order to help them cope and accept the outcome of their children's HIV results. The responses from parents again underscored the need for future counselling of parents regarding the campaign, so that they might be adequately prepared and able to make informed decisions regarding their children's participation.

In favour of HCT but the process must be private and confidential

Four parents indicated their concern for confidentiality and privacy of the HCT programme. For example, *"…information must be kept private and confidential", "…depends on how confidential is the process."* One parent raised this question regarding the issue, *"Are they going to do it privately?"* In this respect Heunis, Wouters, Norton, Engelbrecht, Kigozi, Sharma and Ragin (2011:5) support parents' concerns regarding confidentiality by emphasizing that many patients fear participating in HCT because they are afraid that their results will not be kept private and confidential. In their research Heunis et al. (2011:5) noted that patients were under the impression that the nursing staff and lay counsellors gossiped a great deal which hindered confidentiality. The implication is that parents need reassurance that their children's right to privacy is respected by the counsellors during the HCT process. Hoffman (2011) asserts that schools may pose serious ethical challenges to privacy, confidentiality and voluntary participation. In a school setting learners' reactions are likely to be watched by their peers and educators.

In favour of HCT if correct procedure is followed

Only two parents were of the opinion that if the correct procedure was followed there was nothing wrong with having HCT in schools. Examples encapsulating this theme included: "*…as long as the correct procedure is followed…"* and "*…think deeply and plan before trying to implement..."* In line with this finding, Gersovitz (2011:5) purports that HIV counselling and testing has to be done effectively following a set procedure. This finding indicated a need for thorough planning before implementing the HCT campaign. Set procedures should be followed correctly so as to protect children from harm, and meet the ethical requirement of non-maleficence.

In favour of HCT if child chooses voluntarily without being unduly influenced or coerced

Two parents emphasized that they would support their children's participation in HCT if they were able to make their own choices without being unduly influenced or coerced by anyone. For example, one parent said, *"…it should be her choice, not forced or influenced by friends"* while the other parent commented, *"…up to him if that's what he wants…"* According to the HCT Policy (2010), taking an HIV test during the HCT campaign should be voluntary and not mandatory as such children who are going to participate have to be given the choice to opt-in or opt-out. The learners as well as teachers need to be educated that taking an HIV test is a person's choice so that they do not coerce or compel learners to participate in the HCT campaign.

Aggression towards others and feelings of invincibility

One parent was concerned about the outcome of the HCT, namely, that if the child was found to be positive it might make him/her display aggressive behaviour towards other people. The parent concerned felt that this outcome might trigger *"…aggression towards parents and even teachers…"* In the parent's view, HCT was not going to bring about positive change for families and communities. Peltzer (2010:1246) concurs with this parental concern saying that adolescents who are associated with early sexual debuts are known to exhibit problem sexual behaviour including aggression.

Furthermore, one parent was worried that if sexually active children participated in HCT and were found to be HIV negative they might feel invincible and would not change their sexual behaviour but instead continue to endanger themselves and others around them. The parent explained: *"Others who have already been engaging in sex, if found negative would think that they cannot be affected by the disease".* Plattner (2010:59) elaborates on this view by saying, "The experience of an HIV test could result in people developing false beliefs about their HIV vulnerability, particularly when their test result is negative and those receiving a negative test result, might not just feel relieved but also start believing that they are safe and capable of preventing HIV infection". People who tested HIV negative once, particularly during the window period, might feel comfortable with their HIV negative status. Hence they might not perceive a need to test again at some later stage, and they might also not see a need for precautions to prevent HIV infection in future.

In a similar vein, Wickman, Anderson and Greenberg (2008:461) assert that "AIDS and HIV infection risk in this age-group result from the teen belief that their invincibility will protect them from infection while still continuing to practice unsafe sexual activity." For this reason children should be made aware that being HIV negative does not mean that they are invincible but that they are expected to practice safe sex or abstain from sexual activities.

Obligation to support

Two parents emphasised that supporting their children if they were found to be HIV positive was an obligation and not a choice. For example, one mother said, *"I am the only person who can give support",* while another repeated the same view saying, *"…needs parental support…"* In line with this view, Uphold, Shehan, Bender and Bender (2011:1) state that parental support provides children infected and affected with HIV with emotional and psychosocial stability.

In favour of HCT but school is the wrong setting

One parent argued that school is a place for learning and not the right place for HIV counselling and testing. She agreed that HCT was a good idea but that school was the wrong setting. For example she stated: *"I don't think it's a proper place to do that..."* This viewpoint is supported by Naughton, Hughes, Wilkinson and Boyles

(2011:528) and Yezingane Network (2011) when they raise concerns about generalized implementation of HCT in schools. According to these sources, the school is an environment for learning, and bringing HCT into a place of learning would bring about negative attitudes towards school.

4.4 Results in respect of OBJECTIVE 2: Whether parents would be in a position to engage with children on the HCT campaign

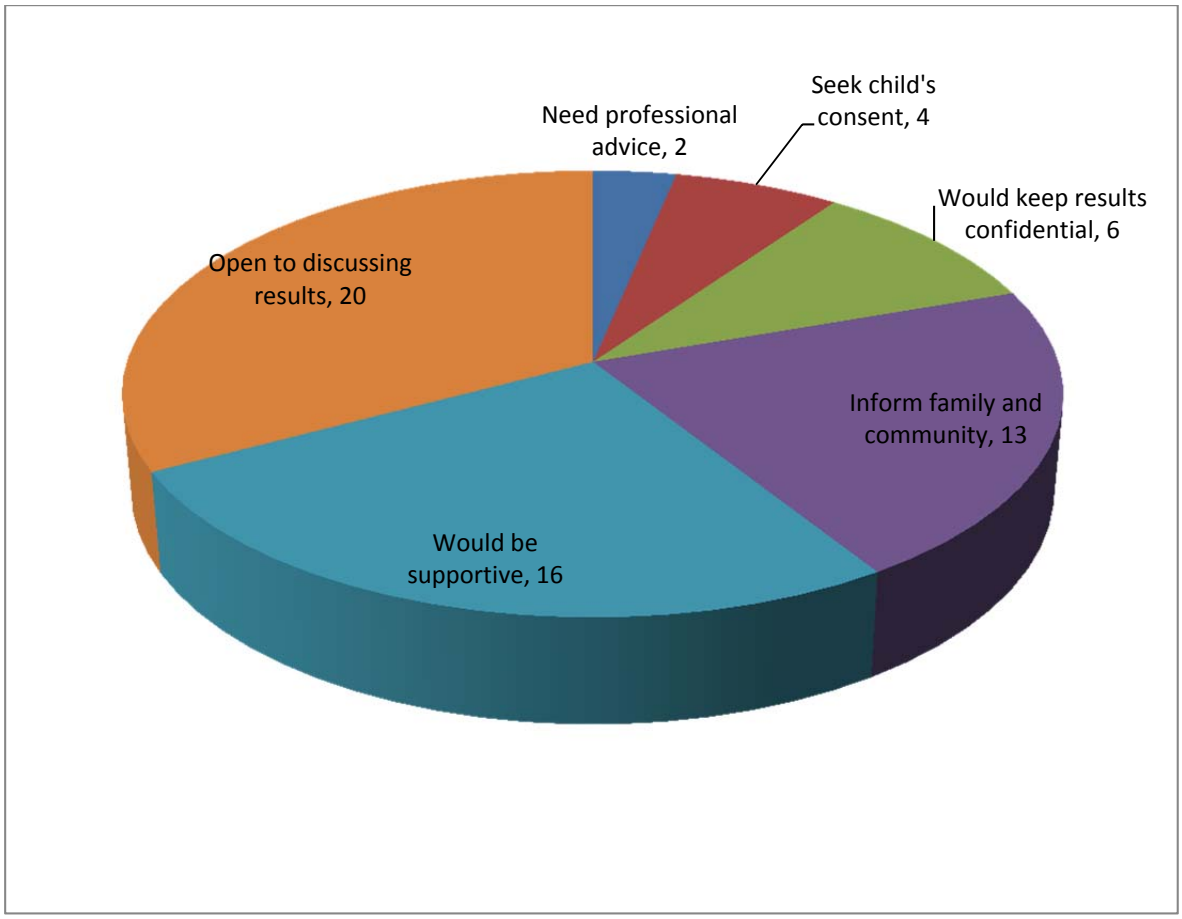


Fig. 4.2 Parents' views on engaging with children on HCT (N=20)

Open to discussing the results

Figure 4.2 indicates that all 20 parents confirmed that they would like to discuss the results with their children no matter the outcome of the tests. For example, "*…I will sit and discuss…I think I have to…yes will sit and talk…I have no option…I would do it to relieve him from pressure…".* Parents were of the view that sitting down and

talking to their children was very important whether the results of their HIV tests were positive or negative. Highlighting the importance of communicating with children about HIV, Poulsen, Miller, Lin, Fasula et al. (2010:1083) maintain that enhancing communication between parents and children, especially about HIV/AIDS may be an important strategy to prevent adolescent HIV risk behaviours. Poulsen et al. (2010:1084) further report that adolescents who talked with their parents about sexual issues, including HIV-specific discussions, were more likely to use condoms or have fewer sex partners compared to those who had not had such discussions. The extent to which HIV is talked about openly between parents and children may go some way in creating an environment conducive to reducing stigma (St George's Paediatric Team, 2003).

Supportive parent relations/ Obligation to support

Sixteen parents indicated that they would maintain supportive parent-child relations even if five of them perceived it as an obligation in that they had no choice but to be supportive for the sake of the child. "*…I will be with him in everything…I will support my child…to relieve him from pressure…it is not the end of the world…will try to find a solution together…do my role as a parent…"* According to MacPhail et al. (2008:97), most adolescents feel more comfortable disclosing to parents and family in order to derive support and ameliorate the effects of stress. MacPhail et al. (2008:96) also reported that parents spelt out that they would need to be a resource for their HIV-positive children. The opinions of parents in the current study suggested that they took their supportive role seriously. They also showed an understanding of the vulnerability of their children once they are diagnosed with HIV.

Would inform family, friends or community of the results in order to obtain support

Thirteen parents anticipated that they would not keep the results to themselves but would tell a friend, family member, church and support groups in their community, as reflected in the following responses: "*…will speak to a friend and my husband…would talk to somebody who is reliable…sometimes you need to tell because if you hide the child will suffer because no one will know his problem…talk to people around you…will talk to my mother…I cannot keep it to myself…two brains are better than one…"* These responses indicate that people affected and infected by

HIV need support from family and friends so that they are able to manage the emotional impact of the epidemic. The parents believed that without disclosing their children's HIV status to friends and family they would not be able to receive the support they needed. Consistent with parents' views, Singh, Chaudior, Escobar and Kalichman (2011:840) highlight the fact that family, neighbours, volunteer workers, and faith-based organizations have been identified as important sources of support.

Would keep results confidential

Six parents emphasized that they would keep the results confidential. Responses that encapsulated this theme included: *"…a secret that is not supposed to be told or heard…I will keep it between me and him…would rather keep it to myself. It is personal and confidential…will not tell…I will keep it to myself because people will judge me…"* In support of these parental concerns, MacPhail et al. (2008:98) assert that the fear of stigma is likely to prevent youth from testing for HIV and thereby retain support within the family. The responses from the parents showed that they respected the need for confidentiality but on the other hand demonstrated their fear of stigmatization.

Would seek consent from child for disclosure

Four parents believed that it was the child's choice whether or not to disclose his/her HIV status. They would seek consent from their children on whether to tell or not. "*…if he has to tell someone it has to be him not me…it depends on my child if he doesn't want me to tell somebody…it will be up to him if he wants to tell…she can tell someone if she wants to…"* The parents' opinions reflected in this theme displayed their respect for the ethical principle of autonomy. They maintained that they would give their children the right to decide whether to disclose their HIV status unlike other parents who assumed that it was their responsibility to disclose the HIV status of their children to family and friends which is sometimes against ethical requirements of confidentiality. Dhai and McQuoid-Mason (2011:89) reiterate that children have a right to privacy, and information about children who are old enough to consent to an HIV test may not be communicated to third parties including their parents and guardians without their consent.

Would need professional advice on how to cope

Two parents felt that it was better to seek professional advice than to tell anyone. *"…I would prefer to tell someone professional…we get counselling…"* According to the HCT policy Guidelines (2010:25), counselling should always precede and follow testing. Even if parents are not included in the HCT programme, it is vital that they receive professional counselling before their children take an HIV test and before being given their children's results so that they will be able to give support to their children.

4.5 Results in respect of OBJECTIVE 3: Parents' awareness of the Children's Act no. 38 of 2005 as amended in 2007 with regard to the age for HIV testing and the appropriateness thereof

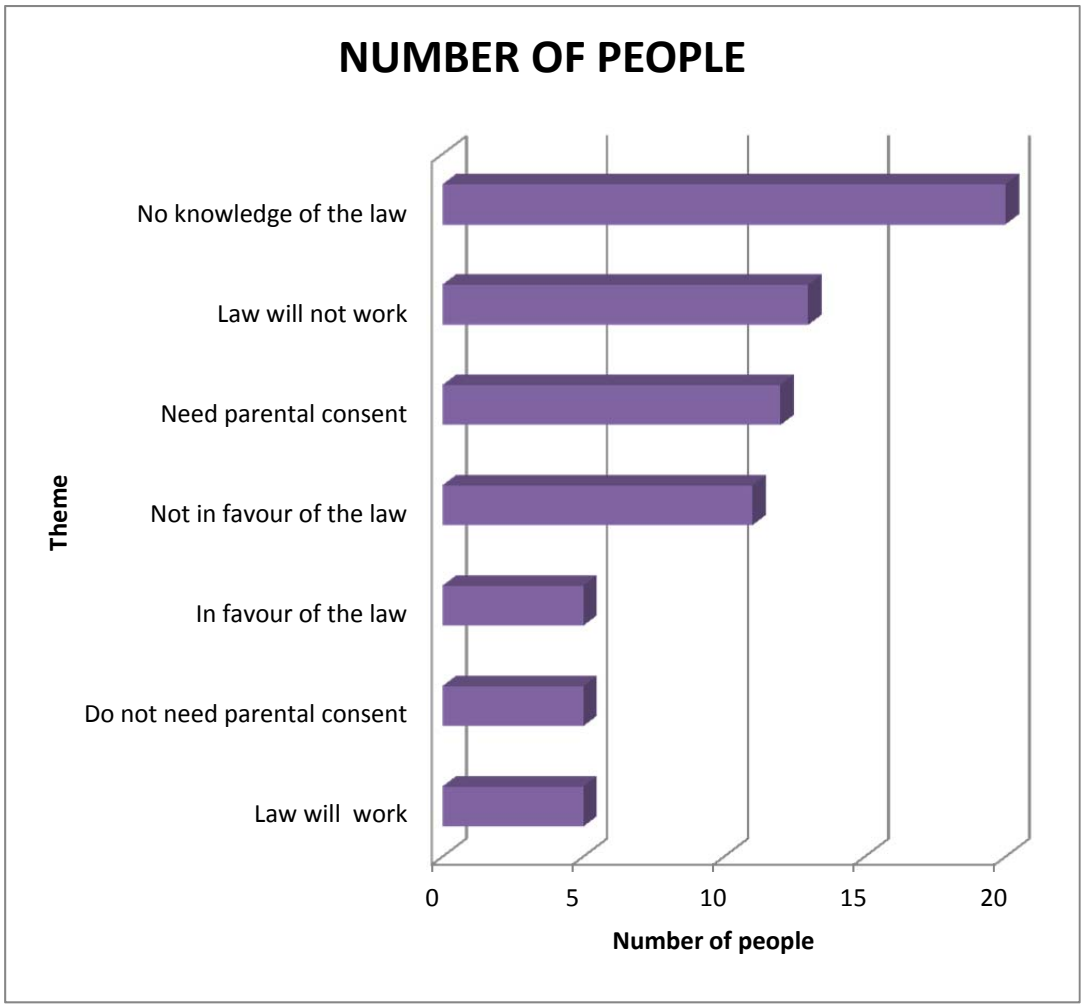


Fig 4.3 Parents' awareness of Children's Act re age for HIV testing and appropriateness thereof (N=20)

No knowledge of the law

None of the parents indicated awareness of the Children's Act No.38 of 2005 as amended in 2007. Eleven participants stated that they were not aware of this law and when told about some of the clauses were not happy about it. For example, *"…I did not know the law…it's not right a 12 year old is a minor…I had no idea…"* Two participants were teachers and they indicated that they had no knowledge of the Children's Act. Consistent with this finding, Ncube and Ross (2010:71) found that several parents in their study had no knowledge of the Children's Act and those who claimed to have the knowledge revealed very limited knowledge. These findings suggest that there was inadequate consultation with parents prior to the implementation of the Act. Hence there would seem to be a need for the government to create forums to engage with the parents before passing new legislation so that they are aware of laws that affect them and their children.

The Children's Act will not work

Thirteen parents articulated the view that the law would not work. For example, *"…I don't think it's gonna work…children are too young to be exposed to such laws…it will bring more confusion to the child…"* The parents' concerns were mainly related to the fact that the law gave too much freedom for the children who were still too young to exercise such rights. According to Ncube and Ross (2010:74), parents in their study felt disempowered while more power was given to children. While parents argue that children are too young, literature suggests otherwise (Kling, 2011:218). Consequently, the reality of the day was not the reality of the parents.

Need parental consent for HIV testing

Twelve parents were of the opinion that children needed parental consent to take an HIV test. Their concern was that the children were too young to handle news concerning HIV because it could be traumatising at their age considering the stigma associated with the virus. Their other concern was that taking an HIV test without parental consent or support might cause children to lose their lives through suicide. For example, *"…it is not right children cannot cope on their own, they need accompaniment of an adult…parents make the final decision in their children's welfare…for someone that age to be tested without parental consent or adult*

accompaniment sounds scary…children will be traumatised and commit suicide…they always need adult accompaniment…" Similarly, MacPhail et al. (2008:99) found that all parents in their research also raised concerns about testing without parental consent. These responses highlighted the ethical and legal issue of parental consent in the case of minor children because of concerns regarding vulnerability of children. Participants felt that children could be harmed in the process, which raises the ethical issue of non-maleficence.

Not in favour of the Children's Act

Eleven parents were not in favour of the law because they thought that 12 year olds were too young to be given such freedom and to engage in any sexual activities. For example, they said: *"...the age is not proper…but I am against it…the child is underage he is going there by himself and when he hears the results he is gonna be shocked…that is why our children doesn't respect us…these children are minors they cannot handle their status."* Ncube and Ross (2010:67) also noted that parents did not agree with certain clauses of the Children's Act and that their rights as parents were perceived to be violated as a result of this law. The parents were concerned about the age for testing because in their view children at the age of 12 years were not expected to be participating in sexual acts. Yet the research on the age of sexual debut suggests otherwise (Simbayi et al., 2010).

In favour of the Children's Act regarding age of testing

Five parents were of the view that the law was suitable for children aged 12 years and they supported it by saying, *"…that law I don't have a problem with it…it is a good law because now even children in primary school get a baby…I support the law. It is totally acceptable it is for the children's own benefit…"* Simbayi et al. (2010) concur with the parents' views by pointing out that the children's sexual debuts have fallen below the age of 15 years.

Do not need parental consent

Five parents believed that it was beneficial for children to take an HIV test without parental consent because it was for their own good and not for the benefit of their parents. For example, *"…because they do get involved sexually anyway…they must go test even in primary…boys and girls are doing this adult stuff and if they are free*

to get tested it means they will try to check themselves…sometimes children can be raped by people in their homes…" Related to the parents' views regarding abuse within the home, Stoltenborgh, Ijzendoorn, Euser and Bakermans-Kraneburg (2011:79) point out that in collectivist groups the needs of a group tend to be considered somewhat more important than those of an individual, resulting in ignoring sexual abuse of a child in order to protect the family from shame. Parents demonstrated awareness of child abuse leading to HIV and child abuse occurring within the home. Therefore, in some instances there might be a dilemma as to whether it is in the best interests of children to disclose to parents and caregivers.

The Children's Act will work

Only five parents anticipated that the law was going to work when they commented: *"…yes it will work but parents should not be excluded from the law…it is going to work…if everyone looks at it in a positive way it will work…it can work. It can assist in conscientising these kids…"* In line with these findings, Ncube and Ross (2010:74) maintain that the Children's Act No. 38 0f 2005 was adopted to empower children and emancipate them from exploitation which is in keeping with the Constitution of the country and the United Nations' Convention on the Rights of the Child. The Children's Act was perceived to be in the best interests of the child.

4.6 Results in respect of OBJECTIVE 4: Parents' views about knowing their children's HIV results and what their reactions would be

Parental desire to know their children's HIV status

Figure 4.4 indicates that this theme was the one most frequently expressed by participants. Nineteen parents articulated the wish to know their children's HIV results. Responses that reflected this theme included: *"…I would definitely want to know…what the aim if I am not going to know…how am I supposed to give support…"* These findings were consistent with those documented by MacPhail et al. (2008:99) who found that parents were interested in knowing their children's HIV status.

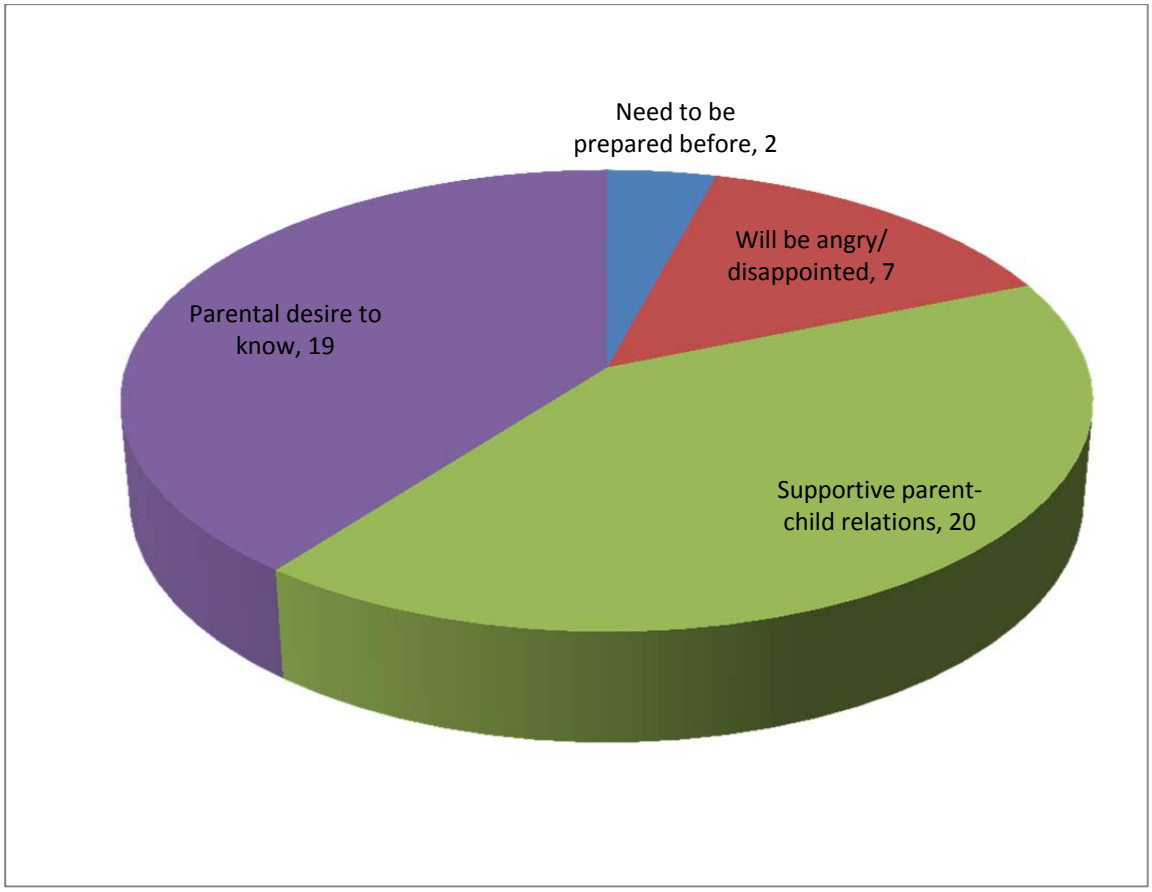


Fig 4.4 Parents' views re knowing children's HIV status and their reactions (N=20)

Parental desire to maintain supportive parent-child relations

Seventeen parents expressed the wish to retain supportive parent relations with their children saying, *"…I can't change anything I will have to give support…my role is to keep my child on his two feet…I will start embracing him and reassuring him that it's not the end of life…"* Parents were mainly concerned about how they would make their children feel good about themselves and embrace the disease without fear and guilt. In support of parents' concerns Denison, McCauley, Dunnett-Dagg, Lungu and Sweat (2008:101) maintain that factors such as family communication, positive parent-child relationships, and parental monitoring are also related to risk and protective behaviours of adolescents.

Parents indicated that they felt obliged to support their children since they were their parents. For example, *"…he is still my child he needs me….it is my duty as a parent*

to give support…I have to be positive so I can give support…" MacPhail et al. (2008:99) echo these views saying that parents generally tend to be supportive of children who disclose their HIV status.

Will be angry/ disappointed

Seven parents anticipated that they would be very disappointed and angry if their children tested HIV positive. They acknowledged that they would be angry but that their anger would not change anything. In the end they would still have to find a way to connect with their children and give them moral support. Examples of direct quotes illustrating this theme included: *"…as a parent I would be disappointed…you know shout and angry I would do that…I will be very angry I will not lie to you. She knows me when I am angry…I will be angry I will be very cross…"* In line with these findings, Antle et al. (2001:166) maintain that parents with children who are HIV positive experience chronic sorrow for their infected children.

Need to be prepared before given the results

Two parents were of the view that they needed to be prepared before they were made aware of the results. For example, *"…if I have been warned before…I need to be counselled before…"* Parents were more worried about their children's status and how they would be able to cope as caregivers. They perceived the need for counselling prior to being told about the results because of the fear of their own emotional reactions as noted by Antle, Wells, Goldie and DeMatteo (2001:166). Counselling is considered a prerequisite for the proper handling of testing and for ensuring effective HIV preventive efforts (Njeru, Blystad, Shayo, Nyamongo and Fylkesnes 2011:1).

However, a limitation of the findings in respect of Objective 4 is that they were based on a hypothetical situation. It is possible that some participants might have furnished socially desirable responses while others might react differently when confronted with the real life situation of their children being diagnosed as HIV positive.

4.7 Summary of the Chapter

This chapter presented the results of the study in relation to the four research objectives. Findings were discussed in relation to the literature and efforts were made to link findings to the relevant ethical, legal and social issues.

CHAPTER FIVE

SUMMARY OF FINDINGS, CONCLUSIONS AND RECOMMENDATIONS

5.1 Summary of the findings

In this research there were four objectives which led to the following findings:

Parents' views about HCT in schools

The first objective was to determine parents' views about the proposed HCT programme to be conducted in schools, and under this objective thirteen themes emerged. Some parents were in favour of the HCT because it would help children know their status and enable them to act responsibly. Other parents reported that they were afraid to know their children's HIV status as they anticipated that it would be stressful for them and would strain their relationships with their children. Parents expressed concern that as a result of HCT children's performance at school would be negatively affected and that some children might refuse to return to school. The issue of suicide was also raised in that some children might find this option to be their only way to deal with their HIV status. Parents suggested that proper counselling should be given during the process to prevent potential suicidal behaviour in children. Parents raised the issue of stigma stating that children might experience stigma as a result of HCT. They also emphasised that they needed to be prepared before the process was put in place. They noted the need for privacy and respect for confidentiality during the process and stressed the need to follow correct procedures. Parents felt that it was important to ensure that the process was performed voluntarily without coercion or undue pressure. Parents feared that HCT might provoke aggression towards others by those who tested positive, and that it might elicit feeling of invincibility in those who tested negative for HIV. Parents felt that giving support to their children during HCT was an obligation because their children needed their support. Lastly, one parent argued that a school is a wrong setting for HCT because it is a place of learning and not a healthcare centre.

Engaging with the children regarding the HCT campaign

The second objective was to determine whether parents would be able to engage with their children on the HCT campaign. In terms of this objective six themes emerged. All parents confirmed that they were interested in discussing the children's results and would maintain supportive parent-child relations irrespective of the outcome. Most parents reported that they would not keep the results to themselves. They would inform relatives, friends, church and community members as they needed their support. However, some parents reported that they would treat the results as a secret not to be divulged to anyone, and would keep the results confidential for fear of being judged. Some parents reported that they would seek consent from their children to disclose the results; otherwise they would keep the results confidential, while a few parents felt that they would seek professional advice on how to cope with the results.

Awareness of the Children's Act

The third objective was to ascertain parents' awareness of the Children's Act 38 of 2005 with regard to HIV testing and its appropriateness. Seven themes emerged from this objective. All the parents indicated that they had no knowledge of this law. The parents expressed the view that this particular law would not work because it afforded too much freedom to young children. Parents felt that children needed parental consent to take an HIV test because the results were potentially traumatising for their age. Most parents were not in favour of the Children's Act in that they felt that it gave 12 year olds the right to engage in sexual acts. However, some parents were in favour of the Children's Act saying that even 12 year olds were now sexually active and therefore needed to be protected. Some parents were of the opinion that the children did not need parental consent because it was for their own good. Some parents also felt that the law would work but only if parents were part of it.

Views about knowing their children's results

The fourth and last objective was to ascertain parents' views about knowing their children's HIV results and what their reactions would be. Five themes emerged from this objective. Almost all parents expressed the desire to know their children's HIV

status so that they would be able to support them. The parents expressed the need to retain their supportive parent relations with their children so that the latter could feel good about themselves after the campaign. The parents felt obliged to support their children since it was their duty as parents. Parents admitted that they would express their anger because they did not expect their children to be engaging in sexual activities but they understood that their anger would not change anything. They emphasised that they would expect the HCT campaign to prepare them for whatever outcome through counselling prior to the results being disclosed.

5.2 Conclusions

Parents' views on the proposed HCT campaign have shown that it could potentially be a very successful campaign with positive effects in the fight against HIV and AIDS in South Africa. But parents have also shown that HIV testing in high schools may have repercussions if the HCT programme is not well planned and if parents do not play an integral role in the programme. The success of the HCT campaign is based on the potential support it derives from parents; as such there is need to create awareness of the programme and highlight children's sexual rights to parents and teachers.

Parents' responses suggest that targeting the high school learners for HIV testing is likely to reduce the incidence of HIV thus helping to create an HIV free generation. The introduction of HCT in schools may encourage children of all ages who are sexually active to be tested for HIV at an early stage thereby reducing the prevalence of the disease. If the HCT campaign is implemented successfully the stigma attached to HIV is likely to be reduced.

Parents also reported that they had received little or no information concerning the HCT campaign and that they felt side-lined by the planners and implementers of the HCT campaign. Nevertheless, they felt that they had a greater role to play during and after the campaign. They felt that their role as parents in terms of supporting their children and taking care of them after they tested positive for HIV was not considered or respected. These findings suggested that the parents were not against the campaign but they needed awareness on how to deal with children infected and

affected after the campaign. The parents' call for appropriate counselling appeared to stem from a desire to protect children from committing suicide as well as to overcome the stigma associated with HIV.

5.3 Recommendations

Recommendations for pre-test counselling

The Department of Health should ensure that it is in a position to offer pre-test counselling over a period of time and not in a single session. This extended counselling could provide the learners with the opportunity to ask questions and give them time to make informed decisions. Many people do not have enough information on the importance of HIV counselling and testing. They are exposed to myths and stereotypes that are created every day in their communities by family and friends. Consequently, these myths need to be demystified before implementing the HCT campaign.

Recommendations for enhancing awareness

Awareness should be raised in children before the implementation of the HCT on why it is important for them to make their own free choice on whether to get tested or not. They are expected to understand the risks and benefits of taking an HIV test. However, it may be difficult for them to make such decisions when they receive pre-test counselling from lay counsellors who use language which is not easily understood, to encourage children to take HIV tests. Hence there is a need for qualified healthcare professionals to provide adequate counselling for the learners in more than one session.

Following the interviews it was noted that parents were not aware of the Children's Act No. 38 of 2005 as amended in 2007. As a result the implementers of the HCT programme should be in a position to create awareness of this Act among parents and teachers at large. Implementing the HCT without this awareness may result in children's rights being violated by their parents, caregivers, or teachers. Parents need to be given information on children's sexual rights, especially where the children have to make decisions concerning their sexuality. The schools also have a

responsibility in loco parentis which in turn gives them authority over children. It is feared that if the Department of Education in collaboration with the Department of Health does not educate the teachers about the ethical principles of confidentiality, informed consent, and children's sexual health rights, learners may be made to participate without their choice. However, if sufficient awareness is created, they will enable to allow learners to make their own choices without coercion or undue pressure.

Recommendations for involvement of parents and other stakeholders

Instead of creating conflict within families and increasing vulnerability in children, the HCT needs to involve all stakeholders who deal with children such as parents, educators and healthcare workers prior to the start of the campaign. It is the duty of health care professionals to safeguard the principles of beneficence and nonmaleficence during this crucial process.

Recommendations for promoting Bioethical principles in implementing the HCT campaign

The HCT Policy Guidelines may have stipulated that the implementation process will promote all bioethical principles, but monitoring the process is also important in that the implementers are not the planners or policy makers. There is therefore a need for qualified professionals to be on the ground to monitor the implementation of the HCT in order to protect children from harm.

It should be noted that the school system in South Africa could potentially be a risk area for the development of undesirable attitudes and behaviours towards HIV and AIDS programmes as the HCT campaign could contribute towards stigmatisation, discrimination, and isolation of children living with HIV and AIDS. If a sibling is being discriminated against, other siblings, young and old are likely to be negatively affected. If they are in the same school they may also face similar discrimination and social exclusion by others as their affected brother or sister. This discrimination in turn may sometimes lead to violence in a way to protect themselves as well as their vulnerable siblings. In some cases the family as a whole is likely to experience discrimination in the surrounding communities. Consequently, the implementers of the HCT need to prepare parents and learners on how to handle discrimination in the

event that their child or his/her sibling tests positive for HIV. Parents and siblings need to be prepared on how to behave when such situations arise.

If insufficient groundwork is done before its roll-out, the children are likely to experience stigmatization within the school community, by either teachers or their peers, leading to social isolation. The learners could also lose their friends upon disclosure of their HIV status. Hence parents need to be involved when setting the ground rules because parents are also affected by stigma as it does not only affect the child but also those closely associated with him/her. Programmes that target children should be able to include parents for them to be successful; otherwise they are likely to be met with strong resistance from parents. Parents have the capacity to bar their children from participating even though children may have a right to take an HIV test without parental consent, as they have diminished autonomy. Furthermore children need parental support during and after the campaign. Creating animosity between children and parents could negatively impact on the HCT campaign itself.

Moreover, in terms of distributive justice, there would appear to be a need to train sufficient personnel and equip them with the knowledge and skills needed to implement the HCT programme in a competent and ethical manner. The implementers should be able to respect children's rights by treating them fairly and equally during the campaign. They should be able to inform children before they take the HIV test that the healthcare practitioner is bound by law to disclose their status because of their age so that when they consent to testing they will be aware of the risks associated with HIV testing. Free and informed participation or refusal by children to be tested must be respected by the implementers of the HCT campaign and the schools. They should also take into account that there is need for adequate referral centres to help victims of abuse. There must also be treatment and appropriate support services for children. When reporting they should take into account where the child would be placed when removed from his or her home. The department of health as well as the Department of Education should put measures in place to ensure children are not discriminated against on the basis of their HIV status during and after the HCT campaign.

Recommendations for future research

There is a need for future research to replicate this research because it was conducted on a non-probability sample which precluded generalisation of the findings to the broader population of South African parents.

This research was conducted in Katlehong with one ethnic group. Consequently, it is proposed that the same study be carried out with other ethnic groups in different parts of the country to compare findings.

A further fruitful area of research might be to compare the attitudes of parents towards HCT programme before and after its implementation.

5.4 Concluding comment

HIV and AIDS have resulted in the loss of many lives in Sub Saharan Africa and finding a way that would reduce HIV incidence in adolescents would be welcomed. However, imposing ideas on communities can be met with strong resistance and lead to failure of a potentially good programme. Consequently, the HCT campaign should be planned with parents in mind, taking into consideration how they feel and their expectations of the programme. In this research, while parents welcomed the campaign, they demonstrated a lack of information on the campaign and the Children's Act which is pivotal to this activity from the legal perspective. Hence, implementation of the HCT campaign in schools should include preparing parents for what to expect through engaging with them as equal partners in the process.

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APPENDICES

APPENDIX 1

INFORMATION DOCUMENT

Parents' perceptions of HIV Counselling and Testing in schools: Ethical, legal and social implications.

Good day. My name is Ruth Gwandure and I am a student at Wits University doing an MSc Med degree in Bioethics and Health Law. As a requirement of the course I am doing a research study titled "Parents' perceptions of HIV counselling and testing in schools: Ethical, legal and social implications". The HIV Counselling and Testing campaign is going to be implemented by the Department of Health in collaboration with the Department of Education in the near future. This campaign is targeting high school learners as they are part of the group that have a risk of contracting HIV.

I am inviting you as parents to participate in the research study. I am inviting parents with children that are in high school to tell me what they think about the involvement of high school learners in the HCT campaign. You are under no obligation to participate.

The study entails an interview where you are required to answer questions that I have prepared for you. I will also ask open ended questions where you can explain as much as you can. You can refuse to answer any question if you feel uncomfortable with the way it is asked or with the demands of the question.

With your permission the interview will be tape-recorded. The purpose of tape-recording is to help me to remember what you have said and use these anonymous quotes in my study. No one other than my supervisor will have access to the tapes. You are under no obligation to consent to tape-recording. You may choose to participate without tape recording. The tapes recorded during the interview will be destroyed two years after the completion of this research, if there are any publications or six years if there are no publications.

There are no risks involved in this research whatsoever. Participation is going to be voluntary. There is no penalty for refusal to participate and anyone is free to discontinue participation at any time. There is no payment for participating in this research.

Your contribution may benefit all the parents with children in high school as well as children in high school in that it may influence the way the HCT campaign will be conducted.

Please feel free to ask me any questions you want before you decide to take part in this research. I shall answer all your questions to the best of my ability. If you have any queries please do not hesitate to contact my supervisor Prof. Dhai at (011 717 2718) Steve Biko Centre for Bioethics.

Thank you for sharing your time and views with me; your contribution is greatly appreciated.

This study has been reviewed and approved by the University of the Witwatersrand Human Research Ethics Committee. Should you have any queries about the ethics of the study please conduct Prof. Cleaton-Jones the HREC chairman at 011 717 1234.

Mrs Ruth Gwandure

APPENDIX 2

PARTICIPANT INFORMED CONSENT FORM 2

"Parents' perceptions of HIV counselling and testing in schools:

Ethical, legal and social implications"

I have been invited to participate in the research about parents' perceptions of HIV counselling and testing in schools. I have read the foregoing information/it has been read to me. I have had the opportunity to ask questions about it and the questions I have asked have been answered to my satisfaction. I consent voluntarily to participate in this study.

Signature of Participant: _____

Date: _____

Day/month/year

OR

I have witnessed the accurate reading of the consent form to the potential participant, and the individual has had the opportunity to ask questions. I confirm that the individual has given consent freely.

Print name of witness: _____

Signature of witness: _____

Date: _____ **signature of participant/** ☐

Day/month/year

Statement by the researcher

I have accurately read the information sheet to the potential participant and to the best of my ability made sure that the participant understands that the following will be done.

- Sign the consent form
- Engage in an interview with me
- Refuse to answer questions that make him/her uneasy
- Opt out at any time during the interview without penalty

I confirm that the participant was given an opportunity to ask questions about the study and all questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and consent has been given freely and voluntarily.

A copy of this form has been given to the participant.

Print name of researcher: _____

Signature: _____

Date: _____

Day/month/year

APPENDIX 3

PARTICIPANT TAPE-RECORDING CONSENT FORM

In addition to agreeing to participate in this study I voluntarily consent to having the interview tape-recorded. I understand that the tapes will not be seen or heard by any other person except the researcher and her supervisor. I also understand that no identifying information will be used in the transcripts or research report.

Signature of Participant _____

Date _____

Day/month/year

APPENDIX 4

SEMI-STRUCTURED INTERVIEW SCHEDULE REGARDING PARENTS' PERCEPTIONS OF THE HCT PROGRAMME

PARENT: MOTHER_____FATHER_____ AGE: _____

NO. OF CHILDREN IN HIGH SCHOOL: _____

GENDER: BOYS_____GIRLS_____

AGES OF CHILDREN_____

1. What do you think about the government's intention to counsel and test all children for HIV who are willing to participate in South African high schools?

   (a) How does it make you feel? (if participant is aware of the programme)
   (b) Where participant is not aware, explain and start again.

2. What do you think about letting your child take an HIV test in school without your approval?

Prompts if necessary:

   (a) Would you let him/her?
   (b) Why?
   (c) Why not?

3. Would you be interested in knowing your child's HIV test results?

Prompts:

   (a) How would you react if your child tests positive for HIV?
   (b) Why?

4. What do you think about discussing HIV positive results with your child?

5. Would you be able to keep the HIV results of your child to yourself or will you need to tell someone else?

Prompts:

   (a) Why?

(b) Why not?

6. The law allows children at the age of 12 years or under to take an HIV test without the consent of their parents if they are of sufficient maturity to understand its risks and benefits.

Prompts:

(a) Did you know this?

(b) What are your views about this law?

(c) Do you believe it will work considering the resources in this country? Please explain.

7. Do you think there are any challenges that are likely to arise as a result of the HIV Counselling and testing Campaign in schools?

Prompts:

(a) What are the challenges?

(b) How do you think these challenges would affect you as a parent?

8. Do you think testing children for HIV at school would benefit them?

Prompts:

(a) In what way would it benefit/ disadvantage them?

9. Do you have anything else to say about the campaign?