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HIV status disclosure to children by health care practitioners against parental consent in South Africa.

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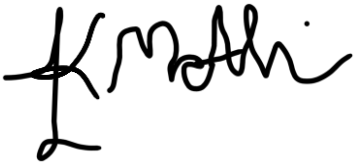
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ABSTRACT

Based on a report published by the UNAIDS, close to 2 million young people who have not reached age 14 are HIV positive (UNAIDS, 2015). With the development in antiretroviral therapy (ART), parents of these children and the professionals taking care of the children ought to grapple with the daunting burden of communicating their seropositive status to their children as they grow and become more curious. Revealing an HIV diagnosis requires talking to children and their parents about a potentially fatal, highly stigmatized, and highly contagious disease, and many parents and caregivers find this upsetting to their children. It has been found through research with young people who have gone through the disclosure process that they get to experience benefits which other children may not receive because of lack of knowledge (Gyamfi et al., 2015). Furthermore, some parents found it difficult to initiate disclosure because they felt that their children were not old enough to understand the information about health and illness (Gyamfi et al., 2017). I argue that disclosure to children between the ages of 6 and 8 is ethically justified if the child has matured enough and their best interests have been considered. I argue that rule utilitarianism is suitable for HIV partial disclosure because it requires that the rule of partial disclosure to children in the age group of 6 to 8 years to be followed when initiating disclosure, when they intend to maximize utility and benefit the child and as far as the child is of sufficient maturity. I further argue that even though the health care practitioner has dual loyalty to the child and their parent, the benefits of disclosure outweigh any harms that can happen because of disclosure. Finally, in my final chapter I argue for conditions under which it would be ethically justified to initiate disclosure with a child even against parental consent.

KEYWORDS: *disclosure, children, HIV, consent, age, maturity, capacity, well-being, dual-loyalty, competence, virtue, utility*.

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LIST OF ABBREVIATIONS

AAP	American Academy of Paediatrics
AIDS	Acquired immune deficiency syndrome
ART	Antiretroviral therapy
CRC	Convention on the Rights of the Child
FD	Full disclosure
HCP	Health care practitioner
HIV	Human Immunodeficiency Virus
HREC	Health Sciences Faculty Human Research and Ethics Committee
HSRC	Human Sciences Research Council
MTCT	Mother-to-child-transmission
NCCG	The South African National Contraception Clinical Guidelines
NCD	Non-communicable disease
NCPF	The South African National Child Participation Framework
NDoH	The South African National Department of Health
ND	Non-disclosure
NGO	Non-governmental organisation
PD	Partial disclosure
PMTCT	Prevention of mother-to-child transmission
SSI	Semi-structured interview
UNAIDS	The Joint United Nations Programme on HIV and AIDS
WHO	The World Health Organisation
WMA	The World Medical Association

Chapter1: Introduction and Background

1.1.1 HIV in children

Human Immunodeficiency Virus (HIV) is a viral infection which causes the white blood cells in the human body which fight infections to become weak and eventually die. Research states that the world has over 1.7 million children living with HIV below 14 years (UNAIDS, 2015). South African statistics found show that 230 000 children between the years of 0 to 14 years are living in our country (UNAIDS, 2015).

Most children living with HIV have acquired it from the mother during pregnancy, childbirth or breastfeeding. When the virus is left without medical treatment, HIV may advance into a more severe form known as AIDS- Acquired Immunodeficiency Syndrome, which is "a number of potentially life-threatening infections and illnesses that happen when your immune system has been severely damaged by the HIV virus" (NHS, 2024).

For a long time, children born with HIV would die from the illness due to lack of treatment. With the advancement of HIV counselling, testing, diagnosis and treatment through the initiation of antiretroviral treatment (ART), children who are born HIV positive are living well beyond the adolescent stage (Sabharwal, Mitchell & Fan 2018). Parents and health care practitioners (HCP) ought to disclose to the child their seropositive status when the child matures, and their curiosity develops. What the general public know about HIV is that it is an illness that can lead to death if it is not treated, it can be easily passed on from person to person and it comes with a stigma attached to it (Wiener et al., 2007). This means that communication with children regarding their HIV seropositive status makes the adults involved feel uneasy and some parents get worried that this kind of information may potentially cause stress for the child (Wiener et al., 2007).

The World Health Organization (WHO) as well as the American Academy of Paediatrics (AAP) encourages that between the health care practitioner and the parent, there should be a discussion and a plan for disclosure with the child (AAP, 1999; WHO, 2013). The health care practitioner may take the role of guiding and advising the parent in initiating partial disclosure with the child (AAP, 1999). Throughout my research, I will refer to parents, caregivers and guardians as parents. And where the term health care practitioner is mentioned, it refers to anyone who is offering healthcare diagnosis or treatment and counselling services to the child and their parent.

1.1.2 Disclosure

A practice in which a child is given appropriate information about their health and illness is known as Child disclosure. Child HIV disclosure is when it is brought to the child's attention that they are HIV positive by someone else like a parent or a health care practitioner. It may also entail making it known to the child the parents' positive HIV status or it may be the child revealing their own positive HIV status to people such as friends, family members or health care practitioners (De Baets et al., 2008; van Elsland et al., 2019; WHO, 2013). For this research, the child disclosure referred to, unless otherwise stated, is a child receiving knowledge about their positive HIV status from the parent, health care practitioner or both.

The AAP strongly emphasizes the importance of children living with HIV being informed of their diagnosis (AAP, 1999). Research from first world countries shows that the percentage of children who receive HIV disclosure ranges from 18 - 77%, the lower percentages being in the younger age group, and the higher percentage being the older children (Kallem et al., 2021). Similarly, research from the Global South which refers broadly to the regions of Latin America, Asia, Africa, and Oceania also reveals that the prevalence of disclosure in children and

adolescents is higher in the older children and lower in the younger children (Doat et al., 2019; Mahloko & Madiba, 2012).

Mahloko and Madiba (2012) found that 40% of children with HIV were who are on HIV treatment had received disclosure in South Africa (Mahloko & Madiba, 2012). This is slightly higher than the prevalence percentages found in countries such as Zambia which was found to be 37.8% (Menon et al., 2007). Disclosure rates are even lower in other African countries, for example researchers found disclosure to be 29% in Uganda and 21% in Ghana (Bikaako-Kajura et al. 2006; Kallem et al. 2011; Gyamfi et al. 2017). It is suggested that the low disclosure rates are due to health care practitioners not having set guidelines and protocols about when, how and who should initiate disclosure with the child (Kallem et al. 2011; Odiachi 2017; Gyamfi et al. 2017). In South Africa, according to The Children's Act 38 of 2005, a young person under 18 years is considered a minor, which means that the child cannot consent by themselves to disclosure (The Children's Act 38 of, 2005). Decisions about testing for HIV, initiating disclosure with the child and possibly starting the child on HIV treatment if they test HIV positive needs to be discussed with the parent and the parent needs to be the one giving consent for these interventions. A child has limited autonomy, and decisions about their treatment interventions need to be discussed with the parent, which means the parent makes the final decision for all interventions concerning the child.

A health care practitioner ought to be aware that when initiating the process of disclosure that they ought to get permission from the parent(s), and when a child is appropriately mature, the health care practitioner may seek assent - a process in which a child is informed of the proposed treatment or medical intervention prior to this being done, this includes participating in the process of disclosure (Cole & Kodish, 2013). Therefore, children are allowed to have autonomy in the form of participatory rights based on The Children's Act 38 of 2005 (Ganya et al., 2016;

The Children's Act 38 of, 2005). Section 129 emphasizes: "a child may consent to his or her own medical treatment provided that he or she is over the age of 12 years and is of sufficient maturity and decisional capacity to understand the various implications of the treatment including the risks and benefits thereof" (The Children's Act 38 of 2005).

Non-disclosure means that the child's diagnosis of their HIV status is kept a secret from them. This entails that even if the child has been taking medicine, they don't know what the reason for the treatment is. In other cases, non-disclosure means that when a child asks their parent(s) about their illness, no information is given to them, or other misleading information is given to them (Vreeman et al., 2013). This means that the child will be completely unaware of the illness and what it can do to their body.

Delayed disclosure is a form of non-disclosure whereby the child does not receive any information about their diagnosis until the parent feels that the child is old enough or mature enough to receive such information, usually when they are in their adolescence (Vreeman et al., 2013). Deception is when the child's or adolescent's condition is ascribed to a different illness, it is frequently coupled with non-disclosure (Vreeman et al., 2013).

Van Elsland et al. (2019) found that the disclosure comes in different forms and often one form of disclosure changes or progresses to a different form as a child grows and matures (Van Elsland et al., 2019). In my dissertation I discuss two different forms of disclosure: partial disclosure and full disclosure.

Partial disclosure is when a child is informed of his or her illness without calling the illness by its name. Full disclosure means that the child is provided with full information and has knowledge about the illness (van Elsland et al. 2019).

The WHO describes child disclosure as a series of progressive, on-going conversions involving the child regarding their medical condition as they grow up physically, emotionally, sexually and socially (WHO, 2013). This underscores that disclosure for children is a gradual process whereby a child is provided with information about their illness that is appropriate for their age, after which full disclosure can be initiated with a child once he or she has reached cognitive and emotional maturity to fully understand their disease. My stance is that disclosure should be initiated with the child as soon as possible, especially if they show signs of curiosity by asking questions about why they must take medication every day or why they must be taken to the clinic for regular check-ups. Partial disclosure to children at young ages is appropriate if the information that is being given to the child is in simple, understandable terms. When the child is of school-going age then more information about the illness may be introduced to the child (Liben et al., 2008). For a smooth and successful disclosure process, health care practitioners should build trust and relationships with children and their parents from the very beginning of the delivery of health services so as to make sure that they have rapport (Vreeman et al., 2013).

According to Van Elsland et al., (2019) making it known to the child that they have an illness called HIV has benefits on their health biologically, psychologically and socially. Some of the benefits mentioned are better adherence to treatment, reduced stress and anxiety, reduced morbidity and mortality, increased psychological functioning of the child and family, improved attitudes, self-confidence and quality of life, empowerment of the child with information and knowledge (van Elsland et al. 2019).

Furthermore, the other benefit of child disclosure is that there is less secrecy about HIV which could lead to reduced HIV stigma (Aderomilehin et al., 2016). With less stigma on HIV, there could be reduced victimisation of those living with HIV. As they mature into adolescence,

children develop a sense of individuality. Children who are living with HIV should start taking responsibility for their own treatment, sexuality and reproductive health (Mandalazi et al., 2014). Having said that, one of the benefits of disclosure is, as found by Gyamfi, et al. (2015), children who were aware of their status fared well in school and were more responsible when it came to adolescent sexual behaviour. Which means that there are possibilities of improving child health and welfare when disclosure to a child is initiated at an earlier age. Contrary to this, non-disclosure leads to non-compliance to treatment, and there are possibilities of treatment failure (Fetzer et al., 2011). Which means that the child's quality of life may be compromised if they are not complaint with treatment because the parent is worried the child will ask questions about why they need to take treatment. From a health perspective, quality of life entails the level of health or the lack of illness in a person's life, whether they are able to live in comfort, and whether the person is able to partake in and delight in life events.

In an ethics case studied by Cole and Kodish (2013), the parents request for their 9-year-old child to not receive any form of disclosure from the health care practitioners about her lymphocytic leukaemia diagnosis, the authors discuss a minors' right to know and therapeutic privilege (Cole & Kodish, 2013). They state that, it is important that while planning for disclosure, the parents and the health care practitioner must be on some form of agreement pertaining to the importance of disclosure. In situations whereby the parents request for the health care practitioner to not inform the child, the health care practitioner ought to balance the fact that the child has emerging or developing autonomy with the parent's decisional authority. Which means that as the child is growing up and becoming more independent, with this maturity they have the capacity to understand information about their health (Cole & Kodish, 2013). If the parents refuse for the disclosure process to be initiated with the child, then the health care practitioner must make the parents aware that they have the option to disclose to the child themselves, or they and the health care practitioner may disclose to the child together

or the health care practitioner may ultimately have to disclose to the child against parental consent (Cole & Kodish, 2013).

The health care practitioner may also emphasise to the parents that there is no option to lie to the child about the illness as this is a form of deception and may be ethically harmful to the child. If the health care practitioner is asked a direct question by the child about their illness, they ought to tell the child the truth. This would be the virtuous thing to do. The health care practitioner must be considerate of the child's developmental and cognitive capability to understand the specific details given to them about their illness (Cole & Kodish, 2013).

In cases where the health care practitioner is reported to the court or any regulatory authority by the parents for disclosing against their parental consent, the court will have to weigh both sides. The court would have to determine whether the health care practitioner's decision to disclose was in the best interest of the child or if the parent's decision for non-disclosure is in the child's best interest. For our country's context, The Children's Act 38 of 2005 stipulates: "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" (The Children's Act 38 of 2005). The court would also determine what are the possible harms or negative effects to the child posed by non-disclosure as per the parent's request (Auckland & Goold, 2019) and whether these are outweighed by the benefits of disclosure. In cases where the health care practitioner chooses to initiate the process of disclosure with the child against parental consent, they should inform their head of department so that the case can be reported to Department of Social Development provided they can prove that the non-disclosure is causing harm to the child.

When mentioning disclosure in my research, it means partial disclosure unless I specify the type of disclosure (National Department of Health, 2016).

1.1.3 Age and Disclosure

By South African law, the term 'child' is any person below the age of 18 years (The Children's Act 38 of 2005). A connection between disclosure and age has been found by researchers, children who are more mature (11 to 18 years) have a tendency to have information or ideas of their HIV status (Madiba & Mokgatle, 2017; Van Elsland et al., 2019a). "Research shows that most children living with HIV will only learn of their HIV positive status when they are in their adolescence"(Madiba & Mokgatle, 2017; Van Elsland et al., 2019).

The reasons why some parents may refuse to disclose to the child is because there is a chance that they would have to disclose their own status as well. They fear the emotional impact of disclosure (De Baets et al., 2008). They may be worried that the child will reveal their status to some members of the family and members of the public (De Baets et al. 2008). There are situations where the caregiver is not the biological parent; the caregiver may be worried about the child having some questions that the caregiver does not have answers to. There are also issues of guilt, blame and shame associated with disclosure and these result in delay of disclosure and sometimes delay in the child accessing treatment (Naidoo & McKerrow, 2015).

In an article published by Regina Bulali et al. (2018) a 6-year-old child may receive partial disclosure, and full disclosure should be completed by age 12 latest. The reason for initiating partial disclosure in this age group is because children can understand concrete ideas based on real events in the past and present and the child can link medicines to illness and health (Bulali, Kibusi, & Mpondo, 2018). Children in the school-going age-group possess the capability to grasp the nature and bad outcomes of illnesses, and how it feels to be sick (AAP, 1999). The main aim for partial disclosure is to make sure that the child has the understanding that

medicines support the body to keep well. The age range that will be the focus of my research is 6 to 8 years; forthwith a child refers to 6- to 8-year-old children. Along with age, the maturity of the child must be considered.

Disclosing a child's HIV status remains a contentious issue and the major determining factors in the literature are age and maturity, the steps to disclosure, the outcomes of HIV status disclosure and support post-disclosure. However, there is limited guidance on when health care practitioners in South Africa ought to inform or make it known to a child their HIV status, and how to navigate the next steps if the parent(s) of the child refuse to initiate or participate in the HIV status disclosure to their child.

1.2 Research Question

Is it ethically justified for a health care practitioner to initiate disclosure with a child living with HIV against parental consent?

1.3 Rationale for the study

There has been research done on disclosure of positive HIV status to adult patients and the positive effects it has on their medical, psychological and social health, however limited protocols on disclosing to children living with HIV makes it a health systems challenge (Gyamfi et al., 2015a).

A 2022 South African statistic published by the UNAIDS claimed that 230 000 young people aged from birth to 14 years are diagnosed HIV positive (UNAIDS, 2022). The UNAIDS published that 157 330 which only 47% of children who are diagnosed as HIV positive are receiving ART in South Africa (UNAIDS, 2015). Research on children living with HIV revealed that only a small proportion were aware of their HIV status (Doat et al., 2019b). Additionally, findings from another study focused on caregivers of HIV-positive children

indicated that most children typically learn about their status around the age of 10 (Doat et al., 2019b)

In my research I emphasize the importance of disclosing the positive HIV status to a child at an earlier age, specifically age 6 to 8 years. The WHO suggests that "disclosure should be initiated in children of 'school-going' age" (WHO, 2013). My research contributes to the current literature by arguing that it is reasonable and that there are benefits to partial disclosure in the above-mentioned age group. Using existing literature and arguments grounded on moral theories, I evaluate the initiation of partial disclosure for children between the ages 6 to 8 years. Given the benefits HIV disclosure to children, I argue that it is ethically justified for a health care practitioner to initiate HIV disclosure to children between 6 to 8 years against parental consent.

1.4 Thesis statement

I argue that it is ethically justified for a health care practitioner to initiate partial disclosure with children living with HIV between ages 6 – 8 years, even against parental consent, if it is in the best interest of the child and if the child has sufficient maturity.

1.5 Research Aim

To defend the thesis that it is ethically justified for a health care practitioner to initiate partial disclosure with children living with HIV between the ages of 6 – 8 years, even against parental consent, if it is in the best interest of the child and if the child has sufficient maturity.

1.6 Research Objectives

1. To compare the benefits and consequences of the status quo of non-disclosure and delayed disclosure with partial disclosure of a child's HIV status.

2. To analyse the dual loyalty dilemma the health care practitioner faces when the parent(s) refuses to initiate or participate in the HIV status disclosure of the child.
3. To argue for conditions under which it would be justified to initiate partial disclosure of a child's HIV status against parental consent.

1.7 Research Design

This dissertation is a purely normative research study, where I consider the relevant published literature and the major theoretical and normative framework. I apply these to my arguments to answer my research question "Is it ethically justified for a health care practitioner to initiate disclosure with a child living with HIV against parental consent?"

1.8 Research Methods

This research was based on desktop-and library-based research; no new data was collected or analysed, and the research did not involve human participants. I used internet search engines such as, Google to source articles from websites such as Bioethics, Developing World Bioethics, American Journal of Bioethics, South African Journal of Human Rights, Cambridge Quarterly Healthcare Ethics, etc. Some of the key words that were used to conduct the literature search included: disclosure, children, HIV, consent, age, maturity, capacity.

1.9 Argumentative outline

Premise 1: Early HIV disclosure to children is justified when it is age-appropriate, and it provides more benefit than harms for the child.

Early HIV disclosure to children is justifiable if there are clear and substantial benefits and limited and mitigatable risks (Gyamfi et al., 2015). "Utilitarianism is a moral theory that states that the morality of an action is determined solely by the value of its consequences" (Nathanson, 2024). Rule utilitarianism teaches us that acts are correct as long as they follow

set moral rules which produce a greater amount of goodness. Rule utilitarianism focuses on the good consequences that are brought on by a certain action being done to abide by a set rule. Rule utilitarianism is suitable for HIV partial disclosure because it requires that the rule of partial disclosure to children between the age of 6 to 8 years to be followed by health care practitioner, with the intention of maximizing utility and benefitting the child and provided that the child exhibits appropriate maturity.

Currently there is limited literature on HIV disclosure guidelines for children, therefore rule utilitarianism is better suited for my research because it focuses on the outcomes expected when following the rule to disclose to children from the ages of 6 to 8 years about their HIV status.

The major benefits of HIV disclosure with children that are identified based on research are 1) children can be initiated on ART at younger ages, 2) when children understand their condition, they are motivated to adhere to treatment 3) as children grow older, they can make responsible decisions pertaining to sexual behaviour (Gyamfi et al., 2015). Which means they are more likely to practise safe sex with their sexual partners (Van Elsland et al., 2019). Although underage sex is illegal in South Africa, there is clear evidence the sexual initiation is below the age of 16 years (Mchunu et al., 2012). HIV partial disclosure with children with regard to their seropositive status has been associated with less negative psychological and mental illness challenges such as depression and anxiety than children who in adolescence (Le Prevost et al., 2018).

It may be argued that there are risks involved in disclosing to a child. The child's status may be made known by the child to other persons who may not have good intentions for the child, this may lead to possible stigma and discrimination from family, friends or community members (Mahloko & Madiba, 2012). The child may blame the parent for transmitting HIV to them, this may cause mistrust between the patient and their parent. The child may internalize

the stigma and become demoralised to carry on taking medication (Nabukeera-Barungi et al., 2015). These negative outcomes after disclosure can be mitigated by early disclosure because the child grows up knowing that they have the disease. The child is then adherent to their medication so they do not experience the side effects of the medication which may happen if they default their treatment. This means the child is likely to have an optimistic outlook on their seropositive status. When a child is aware of their status, they generally fare well in school because their health does not cause them to miss school unnecessarily.

The disclosure process would be done in a stepwise manner in which the child receives pre-disclosure counselling. This ensures that the child is given information that is appropriate to their understanding and maturity. The process also ensures that the health care practitioner builds rapport with the child that they can have a safe environment to communicate their views, fears and concerns about illness before the term "HIV' is mentioned. This aids in guiding the health care practitioner about the information that the child may already have, and it gives the health care practitioner an opportunity to address any misconceptions and false information that cause stigmatization. The aim of disclosure is to make sure that the child understands on a personal level the importance of taking medical and having regular visits to the health care facility. It is thus imperative that the child knows that taking medication helps to keep them healthy. This means the child is likely to be more optimistic about their HIV positive status. The use of a multi-disciplinary team of social worker, counsellors, psychologist and behavioural therapist is essential in cases whereby there is accidental disclosure, mistrust or anger from the child towards their parent(s). And it is important that these services are utilised to make certain that the disclosure process is successful, and that the child can access these services in accordance with their rights based on the UNCRC: "The right to the highest attainable medical care and enjoy the best attainable state of physical, mental and spiritual health".

It may be argued that a parent is always acting in the child's best interest. Therefore, disclosure against parental consent is not justified because the parent is not posing any harm to the child by not disclosing to the child.

My stance is that there should be several attempts made by the health care practitioner to provide the parent with enough information about the benefits of disclosure, since it is assumed that the parent(s) would be acting for the child's best interest. There is also an option for a parent to go through counselling by themselves, group counselling with the family and for the parent and the child to go through counselling together so that the health care practitioner may be able to mediate and communicate the required guidance to both of them. However, if the parent still unreasonably refuses to disclose or participate in the disclosure to the child, when non-disclosure poses negative consequences to the child, the health care practitioner is justified in initiating partial disclosure with the child against parental consent.

Premise 2: A health care practitioner ought to show loyalty to the child by honouring the child's right to information about their own HIV status, even if disclosure is against parental consent.

Kyle Wilson defines dual loyalty as "conflicts that divide a health care practitioner's loyalty between two or more patients" (Wilson, 2009, p.5). The health care practitioner is faced with the dilemma of keeping the parent's HIV status confidential while having to reveal to the child his or her status. "Patient confidentiality is enshrined in law – National Health Act 61 of 2003 makes it an offence to disclose patients' information without their consent" (Medical Protection Society, 2012). Not only is there a legal obligation to keep a parent's HIV status confidential, but it is also ethical practice, and it is also found in the HPCSA guidelines on Confidentiality. However, by law a chapter on Health Care Information states that: "a child has a right to have

access to information regarding the causes and treatment of his or her health status" (Children's Act 38, 2005, Chapter 2, Section 13). Therefore, a health care practitioner's loyalty priority should be with the child because the child is their primary patient.

My stance is that the health care practitioner ought to try to where possible, ensure that they omit the serostatus of the parent(s) when initiating disclosure with the child. It is important that the parent's HIV status to the child is not revealed because it is the core aspect that holds the trust relationship that the parent and the health care practitioner may have. This can be done through partial disclosure; with partial disclosure the health care practitioner tells the child information that is appropriate for their maturity without mentioning the term HIV. Initially, during the disclosure process, the health care practitioner does not have to mention the modes of transmission and who the child may have gotten the HIV infection from until such a stage where extensive counselling has taken place, and the parent is ready to disclose that particular piece of information to the child. This is why preparation and counselling are important before, during and after the disclosure process.

According to the Declaration of Geneva, the health care practitioner ought to respect the parent's right to confidentiality. "All identifiable information about a patient's health status, medical condition, diagnosis, prognosis and treatment and all other information of a personal kind must be kept confidential, even after death" (WMA, 2022). Having said this, as the child matures, they may want to know more about their illness and how they got infected. The health care practitioner ought to educate and encourage the parent to tell the child how they contracted the HIV, or the health care practitioner ought to tell the child about the modes of transmission of HIV illness without stating that the child got infected from the parent. In this way the motivation behind the action of disclosure of the health care practitioner is justified because

the intention is to empower the child with knowledge. Furthermore, the health care practitioner honours the virtues of honesty and care.

Virtue ethics focuses on virtues, which are specific character traits that influence a person's actions (Hursthouse, 2013). Honesty, care, truth-telling, fairness and respectfulness are virtues that a health care practitioner ought to practice religiously to be considered a virtuous health care practitioner. Virtue ethics places less value on the consequence of an action and more value on the motivation behind pursuing certain actions. Disclosing the child's serostatus against the parent's approval for the sake of its benefits links more with virtues such as truth-telling, benevolence and fairness.

My argument is that a health care practitioner treating the child must prioritise the relationship they have with the child and must maintain the trust by disclosing to the child their HIV positive status even against parent consent. A counterargument is that a virtuous health care practitioner ought to value honesty and respectfulness, they should not disclose the status of the child because they ought to respect the parent's right to confidentiality.

My stance is that the level of trust that a health care practitioner and their patient have is important. The patient must always feel that their health care practitioner is doing what is best for them. The importance of disclosure must be emphasized to the parent(s) and they together with the health care practitioner must find ways to disclose to the child.

Furthermore, there is a possibility that the child will eventually find out how they contracted the HIV. It may be argued that there are psychosocial harms that the child will be affected by should the health care practitioner choose to initiate disclosure with the child against parental consent, such as anxiety and sadness. This may be because the trust relationship between the parent and the child may be negatively affected if the disclosure does not come from the parent. Furthermore, it would be most ideal if the child finds out from the parent than from external

sources such as relative or the health care practitioner. My response to this objection is that the health care practitioner should build a rapport with the child beforehand, thereby creating a better trust relationship so that by the time disclosure takes place, the child has no doubt that the health care practitioner has their best interest at heart.

Premise 3: There are conditions in which it is justifiable to disclose a child's HIV status against parental consent.

Firstly, it may be ethically justified for a child's serostatus to be made known to them when the child exhibits a specific level of maturity to understand the information being given to them. As stated in article 17 and section 13, chapter 13 (information on health care) children have a right to knowledge that is good for their health and well-being so that they can stay healthy (chapter 13, Children's Act, 2005; UNCRC). I argue that in circumstances where the child has demonstrated "sufficient maturity," whether it is through life experiences such children who have parents who suffer with chronic illness, or children who have experience with health care such as children who grow up with their own comorbidities such as asthma.

Children who have had previous hospital admission may demonstrate a different level of maturity as compared to their age mates, so they may receive disclosure against parental consent. Having said this, the health care practitioner should provide the child with counselling before and after the process as stipulated in the HIV guidelines (WHO, 2011). If the parent does not agree to disclose to the child or refuses for the health care practitioner to make the child aware of their seropositive status, then the health care practitioner may discuss the case with a social worker (Thomas, 2015). Involvement of a social worker may need them to involve the government social development office. The case may then be taken to the Children's court (Thomas, 2015).

I emphasise that disclosure is ethically justified when a child shows interest and curiosity about their HIV diagnosis. I make an attempt to explain curiosity as a virtue to living well. I explain the benefits of disclosure and how these can be sparked by the child's curiosity. I explain that it is the health care practitioner's onus to stimulate curiosity because the knowledge gained from initiating HIV disclosure discussions is beneficial for the child. I make provisions to say that the instances where curiosity may not be good, is if there is curiosity about their people's diagnosis or infringement of the parent's confidentiality. I argue that curiosity of the child is imperative for their well-being and cognitive development. I also reiterate the concept of capacity and maturity, and how these concepts should be assessed for the disclosure process to be successful and beneficial for the child. I argue that disclosure may be ethically justified in the process of preparing the child for decision making on HIV treatment and health. I make arguments to say that disclosure may be justified on the condition where the child is posing a risk to themself because of ignorance (e.g., defaulting). Furthermore, I argue that another condition where partial disclosure is justified is if the child is posing a risk to others because of ignorance (i.e., if they are sexually active or share needles). I make attempts to respond to any objections whereby disclosure may not be justifiable.

Having stated the above conditions in which a health care practitioner may disclose to the child their HIV status, my stance is that the current South African Law and guidelines allow for the health care practitioner to disclose to the child against parental consent within the appropriate context.

1.10 Research Outcomes

1) My dissertation will contribute towards the award of the Master of Science in Medicine degree.

2) To contribute to the existing knowledge about disclosure to children about HIV.

3) To contribute to the currently published literature that argues for it to be permissible for health care practitioners to disclose the HIV status of the child against parental consent.

4) To present my research at conferences and seminars.

1.11 Overview of Chapters

Chapter 1: Introduction and background.

The first chapter is the contents of the research proposal. It is comprised of the literature review covering the topics of disclosure, age, maturity, HIV, dual loyalty and the structure of the argumentative strategy.

Chapter 2: Age, disclosure and maturity: conceptual clarification

In the following chapter there is a focus on the concepts of maturity, disclosure and the chosen age group of 6 to 8 years. I discuss what it means to be a child according to the South African legislation. I discuss the rights of a child who is under the age of 18 years who is considered a minor by law. I discuss what it means for a child to participate in their own health care and the role of the parents in facilitating the development and maturity of a child so as to make them a competent participant in their own medical treatment. I delve deeper into the concept of partial disclosure and its relevance to children between the ages of 6 to 8 years. I explain how maturity is developed at different ages and through different life experiences that a child may face while growing up. I use the concept of maturity to support my argument.

Chapter 3: The benefits of partial disclosure in child HIV disclosure.

In the third chapter, I discuss the benefits of partial disclosure. I go into detail explaining how there are more benefits than harms when disclosure is initiated with the child. I

aim to argue that the benefits of disclosure outweigh the harms. I discuss the Principle of Utility and elaborate on how initiation of disclosure maximises the principle of utility, discussing both the potential benefits and the risks of initiating partial disclosure. I use rule utilitarianism to argue that if the rule of partial disclosure by a health care practitioner is ethically justified maximises well-being for the child.

Chapter 4: A health care practitioner's dual loyalty to the parent and to the child.

In the fourth chapter, I discuss the concept of dual loyalty. I develop my argument by explaining loyalty and applying it the disclosure process for a child. I go about explaining how the health care practitioner has a dual loyalty when he or she is treating a child because the child is still being taken care of by their parents. My stance in this chapter is that the health care practitioner ought to honour his or her loyalty to the child above and beyond any needs the parent may have. I argue that it is possible for the child to get disclosure of his or her HIV status without disclosing the parent's HIV status.

Chapter 5: Ethically justifiable conditions for child HIV disclosure against parental consent.

In the fifth chapter, I discuss conditions in which it would be ethically justified to initiate partial disclosure with a child against parental consent. This chapter is based on the concept of curiosity and how it can be used to encourage disclosure of the child's HIV status. I argue that a child between the ages of 6 to 8 years should have their HIV status initiated with them based on their capacity to understand the information given and based on how they demonstrate maturity. I argue that there are conditions in which a child may be posing a risk to themselves or to other people and this is a condition for disclosure to be initiated.

Chapter 6: Conclusion.

Finally, in the last chapter, I give a summary of the key concepts and principles used in my dissertation. I discuss the structured arguments that I used to argue that partial disclosure with a child who is in the age range of 6 to 8 years is ethically justified and follow up with the concluding remarks.

Chapter 2: Age, disclosure and maturity: conceptual clarification

2.1 Introduction.

This chapter clarifies key concepts which are essential to understanding the challenge of HIV disclosure to children. The aim of the chapter is to review the literature on the key concepts of disclosure, through classifying the different types of disclosure and make an appraisal of the most appropriate type of disclosure. Next, the appropriate age to initiate disclosure is explored, to inform the age group or range and type of disclosure that is appropriate to initiate. To further clarify and support the age range, this chapter describes maturity, and specifically considers maturity in the context of South African legislation use the developmental approach as explained in The South African Department of Health (NDoH) HIV disclosure guidelines to children and adolescents, I explain the concept of maturity and capacity, MacArthur's Competence Assessment tool and the four components of maturity which are often used in research participants to demonstrate that some 6 to 8 year old children have maturity and capacity to participate. I attempt to respond to some counterarguments about children's maturity and capacity to make decisions about receiving disclosure against parental consent. This chapter provides contextual and supportive information, to assist in defending the thesis.

2.2 Disclosure

Disclosure is described by the NDoH HIV disclosure guideline to children and adolescents as: "A process whereby a child gains knowledge of his/her HIV status" (NDoH, 2016). A step-by-step approach to providing children with information about their illness in a way that suits their age, ultimately leading to full disclosure when they have the emotional and cognitive capacity to understand it fully (NDoH, 2016).

2.3 Forms of Disclosure.

There is a common misconception that children living with HIV below age of 12 may not be mature enough to have disclosure about their HIV positive diagnosis (Madiba S., & Mahloko JM, 2012). A common thought that some parents of children living with HIV have been that these children may not have the capability to understand details about HIV, therefore these parents choose to not initiate disclosure with their HIV positive children (Madiba S., & Mahloko JM, 2012).

The process of disclosure is gradual, and can be categorised as non-disclosure, delayed, partial and full disclosure. Non-disclosure means that the parent or the health care practitioner choose to maintain complete secrecy about the diagnosis, and they do not provide the child with any information about the illness diagnosis (NDoH, 2016). This means that the child will be completely unaware of the illness and what it can do to their body (NDoH, 2016). Delayed disclosure is a form of non-disclosure in which a parent has the intention to disclose to the child, but they have not taken active steps to disclose to the child, in many cases parents have a specific older age in mind which they believe the child will be mature enough to receive disclosure (Van Elsland et al., 2018). Partial disclosure is when a child is informed of his or her illness without calling the illness by its name (Van Elsland et al., 2018). Full disclosure means that the child is provided with full information and has knowledge about the illness (Van Elsland et al., 2018).

Another kind of disclosure is accidental disclosure as described by the NDoH guideline is: The child becomes aware of their illness purely through an incident that is unpleasant and unplanned (NDoH, 2016).

Uncomplicated disclosure and Complex disclosure (table adapted from The NDoH HIV guidelines for children and adolescents)

Uncomplicated disclosure	Complex disclosure
Uncomplicated HIV disclosure to children involves sharing information about their HIV status in a straightforward and supportive way, without any additional stress, trauma, or confusion.	Complex disclosure occurs in situations of "atypical" transmission, such as through abuse or illegal activity, and is often linked to recent or ongoing trauma, a current crisis, or a non-supportive environment. It may also involve pathological bereavement, a child-headed household, caregiver vulnerability, or disability

Initiation of partial HIV disclosure in children involves gradually sharing limited, age-appropriate information about their HIV status, without revealing the full details of the illness right away. This process starts by introducing the child to basic concepts about health and their condition in a way they can understand, progressively leading to full disclosure as they mature emotionally and cognitively.

The main reasons why partial disclosure is the most appropriate form of disclosure for children in the age group 6- 8years is because it ensures emotional readiness for the child: It helps prepare the child emotionally, avoiding overwhelming them with too much information at once.

Partial disclosure builds trust: It fosters trust between the child and caregivers and the health care practitioner, making the eventual full disclosure less shocking and more supportive.

Partial disclosure promotes understanding: Partial disclosure helps children gradually grasp their health situation, allowing them to ask questions and adapt over time.

Partial disclosure prevents trauma: It reduces the risk of trauma or distress that could result from sudden, full disclosure when a child is not ready to process it.

Partial disclosure improves coping skills: Starting with partial disclosure helps children develop coping skills early on, which can be strengthened as they receive more information.

The next sections and chapters, where disclosure is mentioned, it refers to partial disclosure unless stated otherwise.

2.4 South African Analysis done on Child HIV disclosure

A South African analysis done on child disclosure assessed the different forms of disclosure in children aged 3 to 14 years and the different aspects related to disclosure in young people receiving Antiretroviral treatment (ART) (Van Elsland et al., 2018). Their study included 190 children, of whom 145 had not received any form of disclosure about their HIV status. Only 45 children in the study had received some form of disclosure. Partial disclosure had been initiated with only 28 children (14.7%). Seventeen children (8.9%) had received full disclosure. In the age group 3 to 5 years (49 children), none of them had received disclosure.

What researchers have found is that delayed disclosure may lead to accidental disclosure whereby the child finds out they are HIV positive without gaining this knowledge from their parent or from a health care practitioner (Van Elsland et al., 2018; Gyamfi et al., 2017). The problem is that often the child finds out their HIV status in a negative manner whereby there is stereotypes, bullying or stigma attached to the HIV (Van Elsland et al., 2018; Gyamfi et al., 2017). This may affect the child's attitude, behaviour or mental health (Van Elsland et al., 2018; Gyamfi et al., 2017).

In the same study, 11 of 89 children (12.8%) between the ages of 6 to 9 years and 34 of 52 (65%) adolescents (10 to 14 years) had received disclosure (Van Elsland et al., 2018). Based

on this study, there is clear evidence that a child's age is strongly associated with disclosure. With older children having received some form of disclosure as compared to the young children.

Gyamfi et al., (2017) studied the prevalence and barriers of HIV seropositive status disclosure to child they found that the age of the child was a quite common barrier to the disclosure process (Gyamfi et al., 2017). Most parents who participated in the study were under the impression that anyone under age 13 is not mature enough to grasp details about illness (Gyamfi et al., 2017). In this study, most parents knew the importance of disclosure, but they chose to delay communication with the child about their illness until the child was older to reveal their status. This means that the parents chose delayed disclosure.

According to the research, the ages at which parents wanted to initiate disclosure was between 6 to 19 years old (Gyamfi et al., 2017). It is clear from these studies that some parents may have refused for disclosure to be initiated with their child because they were under the idea that due to immaturity and lack of development children may not be able to grasp specific details about illness, therefore it makes disclosure futile (Gyamfi et al., 2017).

2.5 The Appropriate age for disclosure

The choice of the specific age range (i.e. 6 – 8 years) of the child. The NDoH HIV guidelines stipulates the following criteria for age-appropriate disclosure: Children above the age of 2 years should started being prepared for disclosure, the guidelines describe this stage as the toddler phase. During early childhood, the ages between 3 to 5 years, abstract ideas about health and illness can be brought up with the child. Gradual partial disclosure can be introduced during middle childhood, that is between the ages of 5 to 10 years. And finally, children between the ages of 10 years and above may receive full disclosure (NDoH, 2016). Understandably, the maturity of the child, the child's background, the child's current medical status (healthy,

growing well, lack of disability, etc.) family support, need to be taken into consideration when preparing for disclosure. Van Elsland et al., (2018) also highlight the importance of initiating partial disclosure with a child between these ages, they found in their study that the average age of a child who has received disclosure is 6.6 years old, which is the chosen age group for my dissertation.

The American Academy of Paediatrics (AAP) states that communication with children who have commenced school about their well-being and health is important (AAP, 1999). Similarly, the WHO also states that children who are in the school age should have their diagnosis discussed with them, the information ought to be appropriate for their age and development and the information ought to be given in thought-out steps so as to prepare for full disclosure at a late stage (WHO, 2013).

For the South African context, it is well-known that "a child of school going age is one between the age of 6 to 8 years" (Department of Basic Education, 2022). Based on Basic Education department's protocols, this is the recommended age for parents to enrol their children to start school. Anyone applying for grade one in the preceding year ought to be five years and then turning six years by the end of June the following year (Department of Basic Education, 2022). Most children in the "school-going" age group in South Africa are 5 years old, turning 6 years old while doing their first-grade year or the child starts school at 6 years old and then turns 7 years old while doing their first-grade year. It is important that a parent ensures that any child under their care attends school by age seven and that they are enrolled from the first school day of that year (South African Schools Act 84, 1996). The age group of children between the ages of 6 to 8 years is the chosen age for my dissertation.

2.6 Capacity and Maturity

The next two sections are about mental capacity and maturity. These two concepts have many similarities, because my research focus is about children, it is important to provide clarity on what makes these two concepts different. My aim in this section is to argue that maturity and capacity should not solely be linked to age, and that in some circumstances a child can have the conceptual capacity to understand information told to them.

The societal assumption is that all adults are mature, but not all adults will have the capacity to make appropriate decisions in every situation. It is clear that there are situations in which some people cannot make well-informed decisions, regardless of their age. People who have brief unconscious episodes, permanent loss of consciousness, or traumatic brain injury (injury to the brain which disrupts the functioning of the brain, this may lead to a person being unconscious for more than 6 hours or the person may have post-traumatic amnesia for more than 24 hours), infants and very small children, patients with advanced cognitive disability (these individuals may have difficulty remembering things, making decisions, concentrating or learning), and patients with progressive dementia whereby there is disruption in memory, attention, thinking ability, concentration and logical reasoning may not always have capacity to make appropriate decisions (Hawkins et al., 2020). In cases whereby an adult is unable to make decisions for themselves, a family member may be required to make certain medical treatment decisions on behalf of that person. There are instances whereby a health care practitioner makes the decision for a patient granted that it is for their patient's benefit. My stance is that age may not always entail that one has the maturity and capability to participate in some decisions or make decisions for themselves, it may in their best interest if their health care practitioner makes some decisions for them.

2.7 Mental capacity to participate and receive disclosure.

In this section, I briefly discuss the concept of mental capacity to deliver further clarity on what this idea means in terms of sufficient maturity in some children.

Capacity is a person's capability to grasp specific details proposed (the reasoning of the information or discussion, fathomable risks, and possible benefits), balanced with the ability to comprehend potential aftermaths of the choice they make after the details have been given to them (Hawkins et al., 2020). Derish and Vanden Heuvel (2000) emphasize that capacity means that a person is able to decide for themselves which decisions are good for them, and the health care practitioner can use tools to assess that ability. This includes the ability to participate, consent, assent to or decline medical treatment.

When we show respect for patient autonomy, it entails that as health care practitioners we know that patients have a right to choose what is best for themselves and that receiving or not receiving information about their health status forms part of this autonomy (Beauchamp & Childress, 2001). Though there may be differences based on different cases and scenarios, Hawkins et al. (2020) have stated these four elements (understanding, appreciation, reasoning and choice) to make up decisional capacity. My argument is that if a child can demonstrate these fundamental elements at any given age, then they have sufficient maturity to participate in HIV disclosure.

Firstly, the most foundational factor for mental capacity is understanding (Buchanan & Brock, 1989). For a child to be allowed to be in the disclosure process, a child must have some basic understanding of what is means to be healthy and what it means to be ill. Understanding can be considered as recognition of simple details and facts, and how these may be applied to daily life (Grisso & Appelbaum, 1998). Because partial disclosure involves the use of basic terms

and a breakdown of information, it is appropriate for children to grasp when disclosure is initiated.

Secondly, together with understanding, the child must demonstrate a level of appreciation of the information given, its significance and how it will affect them. Understanding the immediate aftermaths and the long-term aftermaths of any decisions made shows that the child grasps the information given (Hawkins et al., 2020). “The most minimal way of interpreting this requirement is to see it as requiring that the subject not only grasp the information but genuinely believe that it truly applies to him or her” (Hawkins et al., 2020). It may be argued that appreciation goes beyond just acceptance or belief of the facts given by the health care practitioner. The patient ought to see value in the information and facts given so that the information benefits the patient. The child may show appreciation of the information given through partial disclosure if they can see how it fits into their life on an everyday basis.

Thirdly, a person’s ability to reason is imperative. Reasoning means that the person has some mental aptitude to engage with the knowledge presented to them and is able to manipulate the information rationally. The inability to reason means that understanding and appreciation would not be possible. Some will even go as far as to say, to demonstrate the ability to reason, one ought to have the capability to weight the pros and cons and evaluate punitive consequences (Hawkins et al., 2020). Reasoning goes hand in hand with a child valuing the information being given to them, this means that the child shows that they know why it is important for them to be receiving this information. It may involve the child being given examples of how their daily life will be affected by the knowledge of the information given.

Lastly, the concept of choice entails that the child ought to have the capability to “state and communicate their choice” (Hawkins et al., 2020). As I have previous mentioned, the decision to initiate disclosure with the child is based on what their health care practitioner determines to

be the most beneficial for them, therefore the component of choice means that they do not take the final decision to receive disclosure as this decision is made by the health care practitioner and the parent. Capacity is important in determining choice and the child ought to have the chance to state their choice, whether it is verbal, in writing or gestures such as with sign language. Choice is particularly important for informed consent, and for assent in children under 18 years.

The MacArthur Competence Assessment Tool (MacCAT) is a semi-structured assessment tool which ought to be utilized to gauge a child's mental aptitude to make a choice. It gives some guidance which health care practitioners can use with regard to decision making capacity. Based on the MacCAT, when a child demonstrates mental capacity, the child should be capable to comprehend the information given to them about their HIV positive status, "the information given should include the anticipated steps of action, the expected beneficial outcomes, risks and possible consequences, and also the consequences of choosing not to follow the planned medical plan as advised by the health care practitioner" (Hawkins et al., 2020). The child is supposed to have the capability to grasp any information that is discussed with them long enough to make a decision. The child should be able to utilise or deliberate that knowledge during communication about disclosure. By communicating to the health care practitioner and their parent their opinions in different forms, including writing, drawing or sign language they are participating in disclosure.

2.8 Factors influencing maturity.

In this section, I briefly discuss maturity and the significant characteristics that influence the maturity of the child, my objective for this section is to explain what this idea entails.

Maturity is defined as "the proficiency of the individual to understand, assess and appreciate the repercussions of a given situation, and must therefore be considered when establishing the

individual capacity and maturity of a child" (United Nations General Assembly, 1989). It is this capacity that the health care practitioner must consider when he or she wants to initiate partial disclosure with the child.

Health care practitioners often assess maturity based on a development model. This is based on age-related developmental milestones. The developmental model asserts that a child is someone who is growing from stage to stage continuously with changes on the biological, psychological, and social aspects. Oftentimes, these growth stages, are related to the child's age but there are times when some children reach these stages outside of the expected pattern.

Growth and development do not happen at the same rate or stage for all children in the same age group, other children develop later. A range of factors have an impact on development such as gender, the environment and society. The general thinking about maturity in children throughout the world has now shifted away from age, towards approaches that consider the child's individual growth based on their environment, life experiences and their approach to daily life (Alderson, 2007). One child may be more mature than another based on their family life, upbringing, exposure to trauma, etc. (Havenga & Temane, 2015). Having mentioned this, it is important that disclosure be initiated with children between the ages of 6 to 8 years old.

During the disclosure process, the child's medical status and any previous incidents whereby the child may have been afforded an opportunity to partake in the decision-making should be considered (Pillay & Singh, 2017). Assessing developmentally appropriate understanding of information given by health care practitioners requires assessing maturity using methods that allow children to teach health care practitioners what they have learned (Pillay & Singh, 2017). If there are any questions about understanding the information, the health care practitioner may want to consult other professionals, such as social workers, psychologists, or child behaviour specialists.

Havenga and Temane (2015) believe that capability in the sense of maturity includes the physical, emotional and social development aspects as well. Alderson (2007) asserts that a child's personal experience with health care and being admitted into a hospital ward makes them more mature in this regard as compared to a child who has not been exposed to health care. Furthermore, this experience makes them have a better understanding when it comes to illness and health. Children who grow up with parents or family members suffering from chronic illnesses may exhibit more maturity with illness and the daily occurrences that come with having to take medication every day or having to have regular visits to the clinic. Therefore, my argument is that some children living with HIV are matured enough to receive disclosure against parental consent because of their experiences with health care and the chronicity of their illness.

In the United States there is a term that they use when a child below the age 16 demonstrates some level of maturity and is deemed capable to give legal agreement for his own treatment or has the capability to refuse treatment based on his ability to discern, understand and accept the aftermaths of the refusal (Cardwell v. Bechtol, 1987). They call them the "mature minor" (Cardwell v. Bechtol, 1987).

The requirement to be regarded as a mature minor, and for them to have the ability to consent against their parent's consent, there would have to be evidence which is clear and convincing, and the child would have to demonstrate proficiency to comprehend and value the information that is being given to them by their health care practitioner. The child would have to recognise how this knowledge impacts them. Once a child understands the importance of life-long treatment then they are more receptive to taking medication. Most children are happier when their lives closely resemble the lives of their peers, and once they have received disclosure and reassurance that the medication will make them healthier so that they can part take in the same

activities that their peers are also part-taking in, then they will be more complaint on medication.

If the health care practitioner chooses to initiate a medical intervention with a child who is considered a mature minor against parental consent and the parents take the matter to court, in the South African setting, it should have to be determined by the court that the child is mature based on his or her conduct and demeanour, age, experience, ability, degree of maturity and education and training. Furthermore, the American law has made it clear that the mature minor exception cannot be applied to all cases where health care practitioner is initiating disclosure with children or where they are responsible for treating the child (Cardwell v. Bechtol, 1987). This means that each case will need to be dealt with individually because each child's level of maturity and their circumstances will be different (Cardwell v. Bechtol, 1987). Additionally, it is the onus of the health care practitioner to use their own discretion when dealing with mature minors, but the court will have to weigh the benefits against the harms.

In the United Kingdom they use a similar concept called the Gillick competence. The Gillick competence assesses whether a child is of such maturity consent to some treatments and medical interventions without parental consent. If the matter is taken to court, the courts have to determine whether the child, who is younger than age 16, has adequate comprehension and aptitude to permit him or her to grasp and appreciate what a treatment plan entails and the capability to give agreement in writing or assent to that process or procedure (Department of Health, UK, 2009). For a majority of similar instances, the best interest standard is applicable.

It is also understood that Gillick's competence cannot be applied to each, and every medical intervention and that each child's case will be different from another. Furthermore, the Gillick competence is applied to "consent for treatment and not for refusal of treatment" (Department of Health, UK, 2009). This means that if a child is refusing treatment, then a parent or another

adult who has the responsibility to hold guardianship may overrule the child's ability to refuse treatment, or the court may overrule the child's decision.

Another concept within the realm of child autonomy and maturity is one of child emancipation. Child emancipation is a legal process whereby a magistrate can release a child from having to be cared for by their parent (Pillay & Singh, 2018). It is a legal process whereby various factors are taken into consideration (usually by a lawyer or magistrate) before the decision for a child to not be under their parent's control can take place. The reasons for emancipation may be coming from both the child and parent, or it may be a child by themselves deciding that they do not want to be under their parents' custody. There are circumstances where emancipation is temporary or permanent (Pillay & Singh, 2018). Emancipation is accepted by South African Law. Dickens Vs Daley (1956) is a case which was heard in the Natal Division of the Supreme court, even though this case is not a "medical" case, it is an example of tacit emancipation.

It can be argued that the emancipated child is a more mature decision maker than his or her agemates, either because they live independently from their parents' or families, or because they are married or because they have their own children. Furthermore, the assumption is that the child has adequate maturity to verify the information that is given to them about their health, they are able to apply the information, and they can decide for themselves what steps are required for them to take. They then can give informed consent to undergo a medical process, discussion or treatment (Marques-Lopez, 2006).

Currently, health care practitioners do not have set protocol for what determines maturity and often rely on their own clinical experience to make such decisions (Pillay & Singh, 2017). Because there are no set guidelines for disclosure in very young children, health care practitioners grappling with the disclosure against parent consent can use the developmental

approach, Gillick competence, mature minor, and child emancipation as a guide when dealing with young children (Pillay & Singh, 2017).

The parent ought to understand that child participation is also encouraged by international law. Furthermore, the parent ought to understand that health care practitioners are bound by law, and they should practice under this guidance. The United Nations states that "children shall be assured the right to express their views freely in all matters affecting them, their views being given due weight in accordance with the child's age, level of maturity, and what is in their best interest" (United Nations General Assembly, 1989). This means that within the confines of the law, disclosure with a child is ethically justifiable under international and local law.

In order for a health care practitioner to gauge a child's maturity, they need to be considerate of the following elements. Firstly, the child's cognitive functioning, this includes assessing the child's ability to remember details, the child's ability to concentrate, how they defend themselves when they are questioned, the amount of information they give in their statements and application of information given to practical tasks (Pillay & Singh, 2018).

Secondly, the health care practitioner needs to do an assessment of the child's abnormal behaviour or pathopsychology if there is any, to determine where any of the pathopsychology may disrupt their capability to comprehend and show appreciation for knowledge given (Pillay & Singh, 2018).

The third factor is the child's intellectual functioning, which needs to be assessed so that the health care practitioner should determine whether the child is intellectually capable to fully comprehend the magnitude of the decision to receive disclosure and to be able to respond appropriately to the information given by the health care practitioner (Pillay & Singh, 2018).

The fourth factor is social, moral, and emotional capability: this assesses whether a child can take active steps in a social setting and in social contexts to make decisions that are well thought-out (Pillay & Singh, 2018).

The fifth factor is personality development, here the health care practitioner ought to check the child's ability to control their impulses, the child's development of expressive behaviours, social skills, cognitive approaches, self-image, object representation, and regulatory processes (Pillay & Singh, 2018).

Factor six is physical incapacity and vulnerability, this means that the health care practitioner needs to ensure that if the child has any physical, mental or cognitive disorders, these are taken care of to ensure that the disclosure is appropriate for the child (Pillay & Singh, 2018).

Lastly, the cultural practices and concerns of the child regarding the evaluation process and its norms (Pillay & Singh, 2018).

The maturity of a child to receive partial disclosure against parental consent will be influenced by each child's experience with a medical condition, any history of previous hospital admissions, the child's relationship with the members of his or her family, the role they play in their social circles and the child's own development.

The counter argument is that given the shortage of resource and access to allied services in the South African public health sector this evaluation for maturity may be difficult because it may require a multi-disciplinary team.

My response is that the health care practitioner should not find it difficult to involve a multi-disciplinary team because disclosure is a process, bringing in allied experts including psychologists and social workers may prove to be the most ideal for the child because it will mean that the child is counselled, and other psycho-social issues are also dealt with while

evaluating the child's maturity for disclosure to be initiated. Furthermore, there are various guides such as the MacCAT, the Hopkin's Competency test and others competency and psychiatric questionnaires which have been thought to be useful in determining the maturity of children (Ganya et al., 2016). Admittedly, these guides may be used in determining whether a child is of sufficient maturity to consent to treatment, but the same tools may be useful in ascertaining whether a child has reached sufficient maturity to receive partial disclosure because they assess the child's overall maturity.

It is the responsibility of the health care practitioner to determine the child's level of maturity to receive disclosure and to also assess whether the disclosure is in the child's best interest. The best interest standard according to the CRC, states "that in all actions concerning children, whether undertaken by public or private social welfare institutions, court of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration"(MacPherson, 1989). Policies and procedures to address decision-making in all areas of health care must include the best interests' standards, especially when dealing with children. The best interest standard is often associated with consequentialism because of its tendency to lean towards calculating welfare, by balancing benefits and burdens, and aiming to maximise the good.

The child's best interests must be given top priority in all decisions, actions, behaviour, suggestions, services, and other measures, whether they are intended or not, that have anything to do with the child. When policies, regulations, and choices are made that have an impact on children directly or indirectly, the best interests of the child should be given the proper consideration and priority.

A critic may contend that the position health care practitioners can permissibly disclose seropositive status to children between 6 and 8 years is a categorical one that seems to be naïve

because it assumes that maturity and mental capacity are the same in all children in this age group.

I have stated in the previous paragraphs that there are instances in which children of the same age may have different levels of maturity. Furthermore, I have elaborated that some children of the same age may not have the same mental capacity to understand and appreciate information given about the disclosure of their seropositive HIV status.

I will reflect on some exceptions in which some children of the same age may not have the same level of maturity to receive disclosure. The NDoH HIV disclosure guidelines highlight instances whereby disclosure may become complex. It is in these instances whereby disclosure may not be appropriate or beneficial for some children who are between the ages of 6 to 8 years. Children who suffer with disabilities, children with vulnerable caregivers, child-headed households, children who are going through current crises, children who come from non-supportive environments, children who have recent trauma and children have gotten HIV through atypical transmissions (NDoH, 2016)

Firstly, children with developmental delays. With a frequency of 1–5%, global developmental delay and intellectual impairment are prevalent problems in all populations (Fieggen et al., 2019). In several afflicted individuals, the aetiology is either hereditary or the consequence of secondary damage to the developing brain, even if a precise cause is not often immediately apparent (Fieggen et al., 2019). Having said this, children with developmental delays ought not be disclosed to if the health care practitioner assess that the disclosure information may bring harm to the child or that the child will not be receptive to the information based on their cognitive disability or if it doesn't maximise the child's well-being. These are children who are assessed to have delayed milestones in their growth, which means they may not have the same level of maturity as their peers in the same age group.

The described benefits of partial HIV disclosure do not necessarily apply to all children between the ages of 6 and 8 in a uniform manner. Children's emotional, cognitive, and psychological development varies significantly, even within this age range. Therefore, making a categorical statement that healthcare professionals can permissibly disclose seropositive status to all children in this age group would not be universally appropriate.

Different children have developmental differences: Children develop at different rates, and some may not yet have the emotional or cognitive maturity to process partial HIV disclosure even within the 6-8 age range.

Secondly, not all children may be emotionally ready to handle the information, even in a partial form. Disclosure should be based on individual assessments of the child's psychological resilience and support system.

Family and environmental factors have a role to play. The child's family environment, support system, and any ongoing trauma or crisis must be considered. A stressful or non-supportive environment could make disclosure harmful rather than beneficial.

It is important to have an individualized approach. Health care practitioners should evaluate each child's situation individually, considering factors like their level of understanding, emotional state, and the presence of supportive caregivers before disclosing information.

In short, while partial disclosure can offer benefits, it must be tailored to the individual child's readiness and circumstances, rather than applied uniformly across all children in a given age group.

Another objection is that the global north and the global south do not share the same views, my stance is that some children from the global south may display adequate maturity to receive partial disclosure about their HIV status because they too like children in the global north are

sufficiently mature. In a South African study conducted by Simphiwe Madiba and Mathildah Mokgatle (2015), they studied the perspectives of health care practitioners in the disclosure process. A large number of the participants (89.3%) believed that there are benefits in disclosing the HIV status to a child and that children on ART should be informed of their HIV status (Madiba & Mokgatle, 2015). A similar study in Malawi assessed health care practitioners' perspective on disclosing to children between ages of 6 to 12 years their HIV status, and 98% of the health care practitioners indicated that it is important to disclose to children their positive HIV status. Health care practitioners and community members in rural Zimbabwe believe that some information about an African child's HIV status should be communicated to a child.

The effects of environmental factors on a child's cognitive development and maturity. There are various effects of the environment that influence the child's maturity. A young child's environment has a significant impact on their growth and development, regardless of the physical surrounds, mental and emotional health, or geographic location. A child's hobbies and activities might be greatly influenced by their physical environment, but their mental and emotional environments will shape how they surround themselves as adults.

Because of the environmental factors identified above, children who do not display the sufficient maturity necessary for disclosure due to these environmental factors may need to receive partial disclosure at a later stage in their life, possibly when interventions such as psychological therapy and involvement of a social worker has been incorporated in their treatment as this would not be in the child's best interest and furthermore the child's well-being would not be maximised.

2.9 A child between the ages of 6 to 8 years has a right to participate in matters that involve his or her own health.

The Children's Act 38 of 2005 presents a challenge for health care practitioners and parents at protecting and promoting the rights of children because the act recognises the child's ability to participate in matters that concern them. The act states 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" (The Children's Act 38 of 2005, chapter 2, section 2). To ensure that the child's right is upheld, this right has to be recognized and acknowledged by health care practitioners in the clinical setting and by parents in the broader societal environment.

My stance is that several provisions of The Children's Act 38 of 2005 are unclear when it comes to matters like children giving permission for treatment and the extent to which a child may participate in making decisions and participating their own health. The Children's Act 38 of 2005 uses excerpts such as sufficient maturity and mental capacity and the young person's capacity to understand and value the advantages, drawbacks, and other effects of therapy and surgery and HIV testing (The Children's Act 38 of 2005). But with regard to the practicality of these terms, there is a lot of room for different interpretations. There is a need for more policies and procedure guidelines when to comes to child HIV disclosure.

The South African National Child Participation Framework (NCPF) of 2018 is a document that guides all spheres of government, civil society, and different sectors to promote meaningful child participation in matters affecting their lives, ensuring their right to participate is fulfilled. The framework gives reference to child participation in the healthcare setting by stating that children should have a say in decisions regarding their healthcare, including the design and delivery of health services for them (NCPF, 2018). It is important that children, regardless of

age, are given information suited to their level of understanding so they can participate in decisions about their treatment or services, based on their age and maturity.

According to The Children's Act 38 of 2005 children of any age can seek sexual and reproductive health information and access condoms at clinics (The Children's Act 38 of 2005). This supports my argument that children have a right to participate in their own health care. Parents should not prohibit health care practitioners from initiating disclosure with children on the basis of age.

"Children need access to confidential medical counselling and advice where this is needed for the child's well-being or safety, and competent children should be able to consent to treatment in their own right" (NCPF, 2018. P.5). This affirms my viewpoint that any child who is able to develop opinions has the right to freely voice those opinions in decisions that have an impact on them and their health. In South Africa, The Children's Act 38 of 2005 emphasizes that "children over the age of 12 years can consent to their own medical treatment", and "a child under 12 can consent to disclosure if child is mature enough to understand the benefits, risks and social implications of such disclosure" (The Children's Act 38 of 2005). Consent allows children the chance to take part in their own health care, even when they are unable to give permission. They can say whether they agree or disagree with the suggested treatment or intervention. Although the child can only consent in this instance, it may be the first step toward allowing them to participate in their own medical care.

"The Best Interest of the Child is paramount in any participatory work with children to ensure that it is ethical, safe and meaningful" (NCPF, 2018, p.4). To help parents and health care practitioners respect the best interest's premise, the involvement processes must be transparent, amicable, relevant, and supported by child-friendly settings.

Child autonomy is a contentious issue. In my dissertation, I refer to autonomy in the sense that the child is recognised as a someone who has rights and is allowed the chance to express their views. My aim is not to say that the choice to receive (or not to receive) disclosure solely rests on the child, but the health care practitioner and the parent recognise that the child has a right to participate. Autonomy is an important part of learning for all children. A child with autonomy may take care of routine tasks on their own (within the appropriate age setting), become more responsible and independent, and eventually learn to make their own decisions. As a child matures, their autonomy enables them to become independent, and they learn to make choices based on their own interests, beliefs, and aspirations. “Autonomy is the ability of a person to act on their own free will” (Patel et al., 2022). “When a child has autonomy, even in limited ways, it helps build their confidence, self-esteem and independence” (Patel et al., 2022).

The Belmont Report states that “respect for persons incorporates at least two ethical convictions: first, that individuals should be treated as autonomous agents, and second, that persons with diminished autonomy are entitled to protection” (Belmont Report, 1979). Which entails that the health care practitioner ought to first ensure that they understand the following requirements: a child's autonomy, means that a child has a right to know their HIV status, a right to participate in discussions about their healthcare and treatment, and a right to ensure that any risks or harm to them are easily mitigated if they do occur.

According to The Children's Act 38 of 2005 and its amendment 41 of 2007, a health care practitioner must determine whether a child is sufficiently mature and whether they have the mental capacity to make decisions about their own healthcare, including decisions about treatment, surgery, HIV testing, and counselling. Of course, it is only important to give children the option to participate when it can be said that they are truly making their own judgments.

Therefore, it becomes necessary to define mental competence as soon as we try to specify the boundaries of this criterion.

A health care practitioner has the moral obligation to at all times respect their patient's autonomy, even in cases where the patient is a minor. Child participation in medical decisions is universally recognised and widely used, it forms part of respect for the child's autonomy even though such participation is not the same in all contexts (United Nations -UNCRC; African Children's Charter; Fokala & Rudman, 2020). This does not mean that the health care practitioner treats the child as a fully autonomous decision maker, but that there is recognition of the child's evolving maturity and mental capacity.

Children's right to partake in their own health treatment emphasizes the importance of the adults (health care practitioner and parent) encouraging this participation (Fokala & Rudman, 2020). For example, adults, particularly those who are legally obligated to care for children, have a responsibility to regularly assess a child's capability based on the age of the child, the child's maturity, and their capacity to make meaningful contributions to the decision-making process (Fokala & Rudman, 2020). The significance of this parental duty stems from the fact that, in contrast to other rights, the right to participation calls for a child to be actively involved in the process of making decisions about their health (Fokala & Rudman, 2020). The exercise or waiver of this right depends on the meaningful participation—or lack thereof—of the adults involved (Fokala & Rudman, 2020). Therefore, if the parent does not want to initiate disclosure with the child, then a health care practitioner may need to take a role in fostering the child's decisional making capacity by initially having simple conversations with the child about illness and health, which may then lead to partial disclosure.

The argument of young age and lack of maturity and the lack of a specified age for health care practitioners to work with has contributed to children being limited in their ability to part-take

in health treatment decision-making processes. In general, it makes sense that parents are concerned with not bombarding their children with information which may not benefit them, and that some children may not be matured enough to understand information discussed with them about their health, but my argument is that some child may have the maturity to understand at younger ages such as 6 to 8 years. Furthermore, it would be of disservice to a child for them to not have a chance to ask questions or partake in medical decision making when there is no specified age from guidelines such as The Children's Act 38 of 2005, which puts a limit on children's enjoyment of the right to participate.

2.10 Appropriate Age and Partial Disclosure

In this section I elaborate on the concept of partial disclosure and its appropriateness to some children between the ages of 6 to 8 years. I use a set of questions adapted from Funck-Brentano (1997) to show how a health care practitioner may initiate the disclosure process with some children between the ages of 6 to 8 years.

The Convention on the Rights of the Child, article 12 stipulates that "children shall be assured the right to express their views freely in all matters affecting them, their views being given due weight in accordance with the child's age, level of maturity, and what is in their best interest" (MacPherson, 1989) .

The AAP emphasizes that in most cases whereby children are sick, they usually receive simple explanations about their illness (colds & flu), what they should expect and their responsibilities when they are sick -fever would be demonstrated by a touch on the forehead; and when a child is sneezing they are told to cover their mouth and nose, they are kept away from other children so as to not spread their "germs" (AAP, 1999). Therefore, these simplified explanations and the actions associated with it are understood by the child. In the initial conversation with the child, the precise diagnosis name and prognosis of the illness are not as crucial. In accordance

with their level of maturity, children should be informed about the nature and effects of their condition as they become older, and they should be urged to take an active role in their own healthcare.

The AAP also emphasizes that the health care practitioner and the parent should adopt an individualised approach to disclosing the child's positive HIV status to the child. I argue that partial disclosure is the appropriate form of disclosure to initiate the disclosure process with children in the age group of 6 to 8 years, this goes in line with the recommendation that is made by the AAP which states that children in the early years do not need to know their diagnosis by name, but it is imperative that their medical condition is discussed with them in basic terms (AAP, 1999).

The aim of partial disclosure is to ensure that the child's right to participation is taken into consideration. According to international children's legislation such as The Convention on the Rights of the Child, children have the right to meaningful participation in all decisions that impact them as well as knowledge, respect, and engagement (MacPherson, 1989).

The process of disclosure includes a series of questions which the health care practitioner may ask the parent, this will help to identify whether a child has received any form of disclosure or not (Funck-Brentano et al., 1997). In this way, the health care practitioner can assess whether the child has not been disclosed to (non-disclosure), or whether the child has received partial or full disclosure (Funck-Brentano et al., 1997).

Furthermore, if the health care practitioner asks the parent whether the child has been informed of their HIV positive diagnosis and the parent responds with a "yes" then the child has received full disclosure (Funck-Brentano et al., 1997). If the parent answered "yes" or "no" to any of the following four questions below then the health care practitioner would be able to gauge whether the child has received partial disclosure or not (Funck-Brentano et al., 1997).

Firstly, the health care practitioner can start by asking the parent whether have had any conversation with the child about illness in general (without using the term HIV). Secondly, "what kind of conversation have you as the parent had with your child about HIV?" -it is important that the term HIV is used with this question because it differentiates the type of disclosure which has or has not occurred (Funck-Brentano et al., 1997). Another question that the health care practitioner may ask is whether there is any kind of ongoing conversation between the child and mother about the child's medical condition (Funck-Brentano et al., 1997). Fourth question would be whether the child has ever asked any questions about illness or HIV specifically. The health care practitioner needs to ask open-ended questions such as "Have you had any conversations with your child about why he or she has to take medication regularly or why they ought to have arranged check-ups at the doctor or at the healthcare facility"? (Funck-Brentano et al., 1997).

My stance is that once the health care practitioner has determined whether the chid has been disclosed to or not, or which form of disclosure the child has received, then they engage the child in appropriate discussions about their illness.

I contend that a child's age should not be the primary justification for withholding information about their own HIV status from them. In this section, I compare the age of consent used in the process of termination of pregnancy to the age used for HIV disclosure in children.

In South Africa, a female of any age can consent to a pregnancy termination without parental approval, I contend that a child between the ages of 6 and 8 has the maturity to receive partial disclosure without parental consent.

Section 129 of The Children's Act of 2005 highlights that "children over the age of 12 years can consent to their own medical treatment or that of their children, provided they are of sufficient maturity and have the mental capacity to understand the benefits, risks, social and

other implications of the treatment" (The Children's Act 38 of 2005). There are inconsistencies that exist in the South African legislation pertaining to the involvement or participation of children in their own healthcare. Strode et al. (2010) discuss how children below the age of 18 are considered "legal minors" and how they have limited capacity to act independently without their parents in decisions concerning their own healthcare (Strode et al., 2010).

However, the law does recognize the evolving autonomy of children and in some circumstances such as the termination of pregnancy, the legislation has made it such that children, including those under the age of 12, can act autonomously without their parents' permission. "Women of all ages have the right to terminate a pregnancy and should never be denied the service because of their age" (Choice on Termination of Pregnancy Act, 1996).

A medical abortion, formally known as termination of pregnancy, does not require a patient to have anaesthesia used or have any surgical procedures done as compared to a surgical abortion. The risks involved with this process include heavy and prolonged bleeding, fever and infection. Additionally, if there is retained products of conception, also known as an incomplete abortion, then a surgical abortion may need to be done. A surgical abortion has its own complications such as infection, uterine perforation, recurrent abdominal pains and discomfort, etc. (Singh & Maddow-Zimet, 2010). Furthermore, in addition to psychological harm like sadness, grief, and feelings of loss following a pregnancy termination procedure, some children who choose to terminate their pregnancies without parental consent may also experience clinically significant psychological illnesses like depression and anxiety (American Psychological Association, 2008).

The risks involved in the disclosure process is that the child may feel depressed or stressed after they have been fully disclosed to, which further supports my argument that partial disclosure is the appropriate form of disclosure because it allows the child to gain information

gradually, ensuring that when full disclosure takes place during the child's adolescent years the risk of the child feeling depressed or sad is alleviated. There have not been any similar risks or negative consequences associated with partial disclosure studied. Santamaria et al. (2010) found that children who had been told their HIV status were less anxious about their medical illness than youths who had not experienced any disclosure, furthermore there were no negative psychological effects associated with disclosure.

When you compare the risks involved in initiating disclosure with a child against the risks involved in the termination of pregnancy, termination of pregnancy is much more of a bigger decision, yet a female of any age may consent independently without a parent.

My stance is that termination of pregnancy has far greater risks than disclosing of HIV positive status to a child does. Furthermore, I argue that it is ethically justified to disclose to a child their HIV positive status against parental consent because the Choice on Termination of Pregnancy Act of 1996 permits a health care practitioner to assist a child of any age to terminate a pregnancy without parental consent even though the risks of a termination of pregnancy are greater than those of HIV status disclosure.

Finally, if a health care practitioner believes a child between the ages of 6 and 8 is old enough to grasp the facts, dangers associated, and advantages involved, they should be authorized to reveal their HIV status to the child without parental agreement.

Fokala and Rudman (2020) argue in their article that there should be a set age that is used as an indicator to say that when the child reaches that age they are mature enough to participate in medical decisions. They talk about a three-way partnership that should be established when there is medical decision-making between the child, the parent and the health care practitioner. They support my argument to say that a child may be competent to partake in medical decisions before age 12. And in cases whereby the child has been allowed to express their views, and it

is found by the parent and/or the health care practitioner that their view is not in their own best interest, then such a view or decision may be overridden by the parent and/or health care practitioner as long as it serves the interests of the child.

In the South African legislation, Children's Act "confers on children over the age of 12 years the right to participate in medical decision-making processes relating to the child" (Fokala & Rudman, 2020). "Therefore, section 129(2)(3) does not rule out a child under the age of 12 years as a competent participant" (Fokala & Rudman, 2020). "Rather, it confirms the participation of all children of a certain age in the three-way partnership" (Fokala & Rudman, 2020). The child's participatory role in the three-way partnership is dependent on how mature the child is, if the child fails to show an appropriate level of maturity then they will not receive disclosure until such a time that they show maturity (Fokala & Rudman, 2020). The Children's Act 38 of 2005 recognizes parents and health care practitioners as qualified to make pertinent choices based on the child's best interests in the event that the child is not old enough to justify a contribution (The Children's Act 38, 2005).

The child's right to participate in medical decisions does not limit a child between the ages of 6 to 8 years from participating as there is no specified age in The Children's Act 38 of 2005. "A child's right to participate does not identify a compulsory age limit that will mandate a child's involvement in a decision-making process" (Fokala & Rudman, 2020). I have argued that some children as young as 6 to 8 years should be involved in decisions concerning their health. Fokala and Rudman (2020) further explain that finding the developmental stage at which a young person obtains adequate competence to engage in a medical decision-making process while balancing the child's mental ability and right to be involved in the three-way collaboration is a challenging task (Fokala & Rudman, 2020). The case for using an age indicator to enable a child to take an active role in their own medical decision-making process

is argued below (Fokala & Rudman, 2020). A child's cognitive capacity to endure pressure often develops with age, therefore the validity of an age indicator is theoretically restricted in context (Fokala & Rudman, 2020).

My argument is that having a specified age, such as 6 to 8 years to initiate partial disclosure, provided that the child has sufficient maturity to participate by expressing their views, strengthens their right to participation by law. Having said that, I will reiterate that there may be children younger than my chosen age group who are sufficiently mature to receive partial disclosure.

Chapter 3: Theory of Utilitarianism, Principle of Utility and Rule Utilitarianism

3.1 Introduction.

In this section, I argue that the act of initiating partial disclosure with a child who is between the ages of 6 to 8 years provides more benefits than harms. I argue that partial disclosure is justifiable because utility is maximised. I also argue that partial disclosure is justifiable when the risks are mitigatable, and the harms are minimal. This chapter considers the benefits and risks of initiating partial disclosure for HIV positive children, through applying rule utilitarianism, to fulfil the first objective.

3.2 Theory definitions, descriptions and conceptual clarification

“Utilitarianism is a moral theory that states that the morality of an action is determined solely by the value of its consequences” (Nathanson, 2024). According to utilitarianism, the action that results in the greatest good is the one that is ethically correct. This broad assertion can be expressed in a variety of ways. It is important to recognize that the theory is a kind of consequentialism, wherein the right or good course of action is only determined by the outcomes that are generated. What sets utilitarianism apart from other moral theories is the extent of the pertinent consequences. According to the utilitarian perspective, one should prioritize the common good, which means taking into account both one's own and other people's well-being.

Jeremy Bentham (1748–1832) and John Stuart Mill (1806-1873), the Classical Utilitarian philosophers, connected pleasure with the good. Additionally, they maintained that we should strive to achieve "the greatest amount of good for the greatest number of people," or to maximize the good (Driver, 2022). According to Jeremy Bentham, deeds are morally wrong when they tend to bring about pain or misery and are morally right when they tend to bring

about happiness or pleasure (Driver, 2022). Combine this standard of morality with the belief that it is our duty to actively work toward promoting happiness for everybody (Driver, 2022)..

A further characteristic of utilitarianism is its neutrality and impartiality. Happiness ought to be the same for everyone. A utilitarian ought to have an unbiased approach in seeking to maximise benefit. And in many cases they ought to be impartial which means that upon considering which rule to follow or which action to take the happiness generated should not favour one party over another. This entails that when we are assessing the overall maximization of happiness, each person's happiness gets equal consideration (Rachels & Rachels 2019).

As Rachels and Rachels (2019) state: "equal amounts of happiness always count equally", everyone counts the same regardless of age, gender, ethnicity race social status etc (Rachels & Rachels, 2019). The concept of utility highlights "actions are to be judged by their usefulness in this sense: their tendency to produce benefit, advantage, pleasure, good, or happiness" (Waz, 2010). Furthermore, actions or behaviours are right as far as they promote happiness or pleasure, wrong as they tend to produce unhappiness or pain (Macloed, 2017). In sum, utilitarianism has three key elements of utilitarianism are:

1. Moral actions have instrumental, not intrinsic value
2. Moral actions must promote happiness and not unhappiness
3. Each person's happiness is equal.

The principle of utility is the extent to which benefit is promoted, and harm is avoided or reduced (Waz, 2010). An action is considered to be promoting utility or high utility, as viewed by Jeremy Bentham, if it frequently results in gains, advantages, joys, goodness, or happiness (Driver, 2022). The good that is maximized is the good that is objectively taken into account. This means that my good is not more important than anyone else's. Furthermore, everyone else is required to support the greater good for the same reasons that I am.

Because utilitarianism just has one evaluative principle do what creates the best consequences—it seems to be a straightforward philosophy. The theory is actually complicated because we need to know (at least) three things before we can comprehend that one simple principle: (a) what is good and bad; (b) whose good (i.e., which people or groups) we should strive to maximize; and (c) whether policies, actions, etc. are made right or wrong by their foreseeable consequences (i.e., the outcomes that we predict will occur based on the evidence that we have) (Nathanson, 2024).

"Act utilitarians focus on the effects of individual actions while rule utilitarians focus on the effects of types of actions (such as killing or stealing)" (Nathanson, 2024). Act utilitarians hold that we should always take the course of action that will result in the highest net utility when making decisions. They believe that the utility principle, which states that one should act in a way that maximizes overall results, should be applied case by case. The course of action that maximizes utility, or well-being, relative to alternative options is always the optimal one.

The overall utility of our actions will be less than the whole quantity of goodness that we might have created if we occasionally decide to do actions that result in less benefit than is feasible. Act utilitarians contend that this is why we should apply the utilitarian principle to specific acts rather than groups of related activities.

According to Rachels and Rachels (2019) there are arguments against act utilitarianism which has made modern philosophers stray away from it. Philosophers find that in some cases, there are consequences of act utilitarianism which cannot be morally justifiable even if it maximises happiness in a given setting. An example is peeping Tom is looking through their window at the neighbour who is undressing and takes pictures. The neighbour is unaware of this is not being harmed by this, yet Tom might experience happiness or pleasure from this. The neighbour, even if they may never know, has rights that Tom should respect, such as privacy

and dignity. Act utilitarianism can promote actions that are unjust. This is why we need (set of) rules that maximise utility and promote justice - this is what rule utilitarianism fulfils (Rachels & Rachels. 2019).

Rule utilitarianism teaches us that acts are correct as long as they follow set moral rules which produce a greater amount of goodness. A rule utilitarian holds that one must act in accordance with a rule that results in the most beneficial results for the largest number of people. By setting a rule to be applied in different circumstances, we ensure that the action carried out while following the rule will maximum utility regardless of the circumstance.

Rule Utilitarianism states that a person's action is morally justifiable if the action follows a justified moral rule that produces the best possible result in the particular situation. Rule utilitarianism then assesses whether an action is good or bad based on how much happiness, pleasure or well-being it creates for the affected person (Nathanson, 2024).

Nathanson (2024) goes on to explain that rule utilitarians have a "dual perspective" when it comes to moral rules. Firstly, there is a rule that is set with the expectation that the majority of the people will follow the rule. Secondly, the rule ought to produce the best outcomes for the greatest number of people affected by the rule. These two components work together. "According to rule utilitarians, a course of action is morally right if it complies with a morally right rule, and a moral rule is right if adopting it would enhance value in comparison to other hypothetical rules or the lack of any rules" (Macloed, 2016).

The main distinction between rule and act utilitarianism is that the former applies the utilitarian principle directly to the assessment of rules, while the latter apply the principle directly to the assessment of individual actions and then assess each action based on whether it complies with or violates the rules whose acceptance will result in the greatest utility (Nathanson, 2024). The principle of utility is a guide for choosing rules and not acts. Rachels and Rachels (2019) teach

us that we must first ask which set of rules should we first follow in order to maximize happiness. We then assess individual acts according to whether they abide by these rules (Rachels & Rachels, 2019). Furthermore, we adopt these rules with the idea that abiding by them, on a regular basis, may promote the overall well-being (Rachels & Rachels, 2019). Therefore, we no longer assess acts by the utility they generate but by how they conform to the rules that have been set.

Act utilitarians argue against rule-based moralities that assess a set or group of actions as right or wrong based on their expected outcomes. They argue that assessing a group of actions as right or wrong may not result in the same outcomes in different circumstances. Act utilitarians would rather focus on the likely effects of individual actions. Rule utilitarians argue that general rules or practices are more likely to have positive impacts in many situations than letting people behave in accordance with their own best judgment in each situation.

Rachels and Rachels (2019) state that "a serious problem with Rule Utilitarianism arises when we ask whether the ideal rules have exceptions. Must the rules be followed no matter what?." (Rachels & Rachels, 2019). In order to determine what benefit, we aim to maximise by following rule utilitarianism, we also need to consider the possible harms that may happen if the rule if followed or not followed.

Rule Utilitarianism is more applicable to initiation of partial disclosure with children of the appropriate age and maturity because this argument is positioned to all health care practitioners and not a case-by-case basis. This is because I will show that initiating partial disclosure maximises benefit and promotes the rights of the child. Furthermore, a rule utilitarian would recognise the benefit of involving the parent in the initiation process, thereby ensuring that the parent does not have to carry the burden; of disclosure alone, which increases happiness for the

parent, it improves the relationship between the parent and the child. This contributes to overall well-being for both the parent and the child.

3.3 Well-being, happiness and pleasure.

Well-being can be described as everything that is in itself good for someone. The famous Philosopher John Stuart Mill teaches that actions are right in proportion to the amount of happiness and pleasure they promote for the greatest number of beings, and wrong as they produce the reverse (Nathanson, 2024). This means that “an action or practice is right (when compared with any alternative action or practice) if it leads to the greatest possible balance of beneficial consequences (happiness for Mill) or to the least possible balance of bad consequences (unhappiness for Mill)” (Macleod, 2016).

According to classical utilitarians, the greatest amount of happiness and pleasure for the most people is the criterion for good or wrong, not only the agent's personal satisfaction. Therefore, the 'good' raises the proportion of group members who are content and pleased. The 'bad' causes more individuals to experience pain or lose enjoyment.

There are several uses for utilitarian reasoning. It may be used to any kind of logical decision-making as well as moral reasoning. It may be applied in a variety of situations and utilized while discussing the interests of various individuals and groups.

A person's level of well-being might be defined as how good their life is going for them. What is "good for" a person is what matters to them. Therefore, while it is reasonable to argue that health is a component of well-being, it is not the only factor that affects it.

The term "well-being" can occasionally be used interchangeably with other terms, such as "welfare," which refers to an individual's overall well-being, whether good or bad, or "happiness," which can be interpreted, as some utilitarians did start with Jeremy Bentham, as

the equilibrium between good and bad things in an individual's life (Nathanson, 2024). One may argue that happiness is inherently tied to well-being, or what is beneficial to me, and most people would agree that pleasure is beneficial.

Philosophers agree that circumstances and events that improve a person's well-being are ultimately advantageous to that individual (Nathanson, 2024). John Stuart Mill has been thought to be a qualitatively hedonistic rule utilitarian. A rule utilitarian holds that one must act in accordance with a rule that results in the most beneficial results for the largest number of people.

Jeremy Bentham's hedonism is the most basic type; it holds that a person's life will be better or worse depending on how much goodness or pleasure they can fit into it and how much harm they experience. How can the worth of the two experiences be determined? According to Bentham, the duration and intensity of the individual experiences are their two main characteristics (Crisp, 2021).

The child's well-being.

When deciding which course of action is best for a single person, utilitarian reasoning is utilized; it ignores the interests of other individuals and just considers how the many options would impact the interests of this one person. Therefore, it is applicable when we are considering the benefits the child will get from receiving disclosure and then weighing the benefits against the possible harms of disclosure.

Using Bentham's method of weighing out pleasure against pain, he talks about duration and intensity. This means that one can argue that the benefit of following a certain rule should last longer than the pain caused by the harm that is predicted.

The well-being of the child and the parent.

According to utilitarians, the greatest amount of happiness and pleasure for the most people is the criterion for good or wrong, not only the agent's personal satisfaction. Therefore, the 'good' raises the proportion of group members who are content and pleased. The 'bad' causes more individuals to experience pain or lose enjoyment.

Given their interest in political organizations and public policy, utilitarians like Bentham frequently concentrated on identifying the courses of action that would best serve the well-being of the relevant group. The well-being of the parent and the child is determined by the identifiable good outcomes of disclosure and any foreseeable harms that could individually affect the parent-child relationship. The utility principle is known as a concept of morality which encourages actions which bring about happiness and it opposes actions which bring about unhappiness. It is about actions that create “the greatest good for the greatest number” (Driver, 2024).

The well-being of everyone affected.

The well-known utilitarian principle, "every man to count for one, nobody for more than one," is sometimes attributed to Jeremy Bentham (Nathanson, 2024). For the rule to be morally permissible, it ought to be applicable universally so that it can allow us to calculate the utility of actions from an impartial perspective.

What are the actual consequences and possible harms.

This is about the outcomes of the rule being followed and the foreseeable harms and how one ought to mitigate them. To understand the actual vs. predicted outcome debate, one ought to consider contrasting two ideas. According to one (the actual consequence perspective), the optimum course of action is the one that yields the best results. According to the second point

of view, one acts morally when they take the course of action that maximizes their "expected utility." The positive (or negative) outcomes that one anticipates arising from a course of action and the likelihood that those effects will materialize are combined to form the anticipated utility.

The trust relationship

One of the main benefits of rule utilitarianism, according to its proponents, is the social influence of a morality based on rules (Nathanson, 2024). Our well-being greatly depends on our ability to trust others. Knowing what individuals will and won't do is a necessary component of trust. Adopting act utilitarians' perspective will greatly reduce the predictability of people's behaviour because they are dedicated to assessing each scenario based on a case-by-case method. This means that well-being will not be maximised if we cannot guarantee some level of trust for the majority of the time.

Therefore, by applying a rule utilitarian perspective, it can be argued that well-being through ensuring that there is trust will be generated a majority of the time if the rule which guides a specific action is followed a majority of the time. People would be less inclined to regard other individuals as dependable and trustworthy as a result. Because rule utilitarianism is devoted to rules and rules provide positive "expectation effects" that provide us with a foundation for understanding how other people are likely to act, it is not troubled by this issue.

Therefore, for a health care practitioner who is a rule utilitarian, trust is crucial because it underpins the stability and reliability of the moral rules that guide action. Rule utilitarianism emphasizes following general rules that, if widely adopted, would maximize overall happiness or well-being. Trust plays an essential role in ensuring these rules are effective and widely followed.

Consistency of rule following: Trust ensures that individuals believe others will follow the established moral rules, which encourages them to follow the rules as well. If people lack trust in others adhering to the rules, the overall system of rule-following could collapse, leading to less overall utility.

Trust promotes cooperation: Trust facilitates cooperation, which is necessary for many of the rules to generate the greatest happiness and well-being. Rules that promote cooperation—such as honesty, keeping promises, and fairness—depend on trust to function. When trust is present, people are more willing to engage in cooperative behaviour that benefits everyone.

A reduction in anxiety and conflict: Trust reduces uncertainty and anxiety about others' actions, leading to a more harmonious society. When individuals trust that others will act in accordance with beneficial rules, there is less conflict, fear, and suspicion, which in turn maximizes overall happiness and well-being.

Trust encourages moral integrity: Trust creates an environment in which individuals feel a sense of responsibility to uphold moral rules because they know others are depending on them to do so. This mutual responsibility reinforces the adherence to rules that maximize happiness.

Trust is important for long-term stability: Trust helps build long-term societal stability by reinforcing the idea that moral rules are not just temporary but are part of a lasting social contract. The presence of trust makes it easier to establish and maintain rules that contribute to long-term well-being.

Therefore, for a rule utilitarian, trust is a key component in ensuring that the moral rules designed to maximize happiness and well-being are consistently followed, promoting cooperation and reducing conflict. Without trust, the overall utility gained from rule-following would be greatly diminished.

Benefits

When a health care practitioner weighs the benefits versus the risk or harms of initiating disclosure with a child against parental consent, one may quantify the number of benefits of disclosure against the number harms of disclosure and may come to a conclusion that if there are more benefits versus harms, then disclosure against parental consent may be ethically justified.

1. In a study published by Vreeman et al. (2010) parents (caregivers and guardians), shared their opinions on sharing HIV status information with their seropositive children, they discussed the effects of this information sharing on the well-being, social relationships, and their children's improved adherence to ART. The parents emphasized that disclosure may lead to better adherence to ART, among other benefits (Vreeman et al., 2010). This reduces morbidity and mortality.
2. Vreeman et al. (2010) also found that the parents involved in the study mentioned that one of the benefits included children taking responsibility for their own medication as they grew older.
3. Another study found that disclosure allows for a child to have greater access to healthcare facilities, candid conversations with members of the family, and greater psychological wellness have all been linked to disclosure (Amankwah-Poku et al., 2021).

Harms

Harms can be categorised as physical, psychological and social.

Physical harm is any action or situation which can lead to harm on the child's body. This can also include illness or lack of good health.

Psychological harm is any situation that leads to the child feeling worried (warranted or unwarranted), being upset, having a depressed mood, feeling embarrassed or shameful, feeling guilty, and/or having some form of loss of self-confidence (University of Virginia, 2022). Deprivation of truth and transparency can be seen as a form of psychological harm.

Social harm would be any actions or behaviour that cause a child to have negative experiences at home, school or in their community. Any event that may negatively impact the relationship between the child and the parent may be a social harm.

There are several risks and potential harms associated with disclosing HIV status to children, particularly if the disclosure is not handled appropriately or if the child is not developmentally or emotionally ready. These include:

1. Emotional Distress

Fear, Anxiety, or Depression: Disclosure may lead to significant emotional distress, including fear, sadness, or depression, as the child grapples with the implications of the diagnosis .

Confusion: If not done in an age-appropriate manner, the child may become confused about their condition, leading to unnecessary stress or misunderstandings about their health.

2. Feelings of Isolation or Stigma

Social Rejection: Children might feel isolated or rejected by peers if they misunderstand their condition or fear being "different." Disclosure may lead them to worry about social stigma or bullying.

Self-Stigma: They may internalize negative perceptions about living with HIV, leading to shame, guilt, or feelings of inferiority.

3. Psychological Trauma

Shock or Betrayal: If the child feels the information was withheld for too long or if the disclosure is abrupt, they may experience feelings of betrayal by caregivers or healthcare providers.

Trauma from Abusive or Traumatic Contexts: Disclosure in the context of ongoing trauma (e.g., abuse, neglect, family crisis) may compound psychological harm and worsen existing emotional challenges.

4. Impact on Development

Cognitive Overload: Children may struggle to process complex medical information beyond their developmental stage, leading to cognitive overload and stress.

Delayed Coping Skills: Some children might not have the necessary emotional or psychological coping skills at the time of disclosure, which could affect their ability to manage the diagnosis in a healthy way.

5. Impact on Behaviour and Self-Esteem

Behavioural Changes: Disclosure may trigger behavioural problems, including withdrawal, aggression, or difficulty in school, as the child struggles to come to terms with their diagnosis.

Lowered Self-Esteem: The child may feel diminished self-worth, particularly if they perceive the illness as a flaw or defect, which can have lasting effects on their self-esteem.

6. Harmful Reactions in Non-Supportive Environments

Inadequate Family Support: If the child does not have a supportive environment, the disclosure could increase feelings of abandonment, insecurity, or even provoke negative reactions from caregivers.

Family Dynamics: In some cases, disclosure may exacerbate tension or dysfunction in families, particularly if caregivers struggle with their own acceptance of the diagnosis.

7. Premature Disclosure

Premature Burden: If disclosure is done too early, children might not fully understand their diagnosis but still feel burdened by it, potentially leading to increased anxiety and responsibility for their own health.

Dependency on External Information: Children might start to seek information from external sources, including peers or the internet, which could lead to misinformation and further confusion.

1. As stated in the NDOH HIV disclosure guidelines "disclosure that takes place during adolescence can result in non-adherence and consequent treatment failure", therefore disclosing later in childhood can have physical harms. According to Van Elsland et al (2019), "parents who had trouble giving their child his or her medicine were less likely to have told the child that they were HIV positive" (Van Elsland et al., 2019). It is possible that the difficulties with medication administration that some parents experienced were caused by non-disclosure (Van Elsland et al., 2019). Van Elsland et al., 2019 found that a high viral load is closely related with non-disclosure (Van Elsland et al., 2019).
2. Furthermore, the NDOH HIV guidelines states that: "Delaying the initiation of the disclosure process is likely to make eventual disclosure an increasingly difficult

process". A South African study found that parents children living with HIV had told the vague information about why the child had to attend regular medical check-ups at the doctor or the healthcare facility, incorrect details about the nature of the illness were given to the child because the parents did not want the child to know that they are living with HIV (Murnane et al., 2017).

3. Disclosure involves making information known to the child about a potentially life threatening, stigmatized and transmissible illness that many parents/caregivers fear that this knowledge may become the start of emotional and physiological harm for the child (Okechukwu et al., 2018)

3.4 Initiating partial disclosure with a child who is between the ages of 6 to 8 years is beneficial to the child.

As human beings and especially as health care practitioners there is a moral obligation to do good to others. This implies, in broad strokes, that one should behave in others' best interests. A health care practitioner should be morally bound to operate in the interests of others, in doing so this includes assisting others in furthering their essential and legitimate objectives, frequently by averting or eradicating any potential harm (Beauchamp, 2008). The quest to maximise utility by producing more benefits for the child, a health care practitioner would be promoting the well-being of the patient through qualities of mercy, acts of kindness, charity and generosity. This means that the actions performed show bring about good outcomes and/or in some cases the actions performed should minimise bad outcomes.

According to American philosopher Tom Beauchamp, beneficence includes all standards, behaviours, and dispositions that are pursued with the intention of advancing the welfare of others (Beauchamp, 2008). Humans have a moral imperative to behave for the good of others in order to maximize utility, which occasionally may involve stopping or eradicating any

potential harm (Beauchamp, 2008). In the healthcare setting, it may also include assessing the extent of harm and finding ways to minimise harm or mitigating harm if it is bound to happen.

Benevolence is a valuable moral trait which encompasses the predisposition to do good and to act for the benefit of others, which makes it a virtue. Beneficent acts are often thought to be coming from a place of moral obligation, but beneficent acts can be non-obligatory. When someone religiously acts for the benefit of other, and their moral aspirations are in line with putting the interest of other first, then they can be considered to be benevolent, which means that they are not always acting from a place of obligation. A person who religiously acts with the intention and motivation to benefit others may be considered to hold the virtue of benevolence. A health care practitioner who's primary purpose is to show kindness and to do well for his or her patients may be considered to be virtuous because they are showing qualities of being benevolent.

3.5 The benefits of initiating partial disclosure outweigh the harms of disclosure.

The principle of non-maleficence is based on the "maxim primum non nocere (first do no harm)". It asserts that there is a moral need to refrain from harming or causing harm to others. It is about the health care practitioner not causing or intending any harm to the patient. "This principle supports several moral rules such as do not kill, do not cause pain or suffering, do not incapacitate, do not cause offense and do not deprive others of the goods of life" (Varkey, 2021).

In the clinical setting, the health care practitioner ought to compare the beneficial outcomes against the burdens of all discussions, treatments and procedures. To discern which of those interventions would be unnecessarily burdensome, and to select the patient's best line of action.

In circumstances in which an HIV positive child is not compliant on medication, their viral load will increase, which will make the child extremely sick. This is a form of physical harm to the child. My stance is that non-adherence to medication is associated with non-disclosure. Furthermore, when a patient is on treatment, but their viral load is very high, it shows that the treatment may not be taken correctly by the patient, or the treatment is failing (Van Elsland et al., 2019). Disclosure of HIV status is important to ensure that the patient changes their behaviour and attitude towards taking treatment, when a patient knows their status they have a better chance at treatment access, and the adherence among HIV-positive patients is better when they have received disclosure (Norman et al., 2007).

Social harm is any form of non-medical bad consequences that can occur due to initiation of partial disclosure, such as any difficulties in the child's personal relationship with their parent(s), loved ones or community such as at school. The social harm that would occur if the child does not receive disclosure is that the child constantly feeling different and isolated from other children without understanding or knowledge of why his or her life is different from other children. This could happen when the child is pulled out of school to attend regular medical check-ups at the healthcare facility. Or if the child is sick and they have to be admitted to the hospital for prolonged periods of time, this causes disruptions in the child's daily routine.

3.6 Application of Benefits Versus Harms.

In an article written by Wayne Waz, he talks about the ethical dilemma and complexities that a health care practitioner faces when they are treating a minor. He discusses a case of a young girl who is diagnosed with AIDS. In the case, the grandmother, being the primary caregiver, does not want the child's positive HIV/AIDS status to be made known to the child. In this case, an ethics consultation is called for assistance. In the two years before the ethics consultation, the 9-year-old girl had had numerous admissions into the hospital for treatment of various

infections and for poor growth. Because of this, her health care practitioners determined that she needed to be admitted again for intravenous therapy and nutritional support (Waz, 2010).

Furthermore, she had developed a lung infection which required treatment intravenously, her disease had also progressed into AIDS nephropathy whereby her kidneys were not working well, because of this she needed to receive regular peritoneal dialysis which is an invasive procedure done to detoxify her blood. Her grandmother who was her primary caregiver requested from the healthcare team that the child not be told about the predicted prognosis or treatment course (Waz, 2010).

In this case, the conflict is between the health care practitioners and the grandmother over the potential harms and benefits of disclosure of the HIV/AIDS status to the child. According to the author, the child knew that she had a chronic illness but was not aware of the diagnosis of HIV/AIDS (Waz, 2010). The child had spent a lot of time in the hospital during those two years and was well aware of how different her life was as compared to her siblings and her friends. The reason the health care practitioners felt that the child did not know that she has AIDS is because she had never asked questions about AIDS or used the terms "HIV" or "AIDS" (Waz, 2010). "When she asked her grandmother, 'What is wrong with me?' her grandmother avoided the use of the terms HIV or AIDS" (Waz, 2010).

Firstly, the health care practitioner should be guided by the best interest principle which states that in all actions affecting children their best interest must be a primary consideration. Secondly, Section 28 (2) of the Constitution which states: "A child's best interests are of paramount importance in every matter concerning the child". This means that a health care practitioner's obligation and intention ought to be doing those actions which will benefit the patient and also relieving the suffering of a patient. A child who is expressing a need to know about her health condition has a right to have disclosure initiated with them. "Children have

the right to get information that is important to their well-being and helps them stay healthy" (The Children's Act of, 2005; Article 17 CRC).

Firstly, a rule utilitarian health care practitioner has to consider that it is beneficial for the child that she knows her HIV positive status because this will empower her with knowledge. That is the first benefit of disclosure being initiated with the child against parental consent. The child is empowered with information that will help him or her understand why they have to take medication every day. This information also benefits the child because the child will understand why they have to attend regular medical check-ups for health monitoring. By maximising the child's knowledge, he or she will be benefited which maximises her well-being psychologically.

Secondly, a benefit of initiation of disclosure is that a child who is adhering to their medication and is cooperative with the regular medical check-ups will be virally suppressed, and their immune system will be stronger. The child's physical well-being will be maximised. Furthermore, the risk of opportunistic infections will be reduced. This child will be able to live a somewhat typical "normal healthy life". Therefore, the child's well-being is overall promoted. If the child is mature enough to understand and appreciate the benefits of being on treatment then they are more likely to feel better knowing that they are taken care of and the medication they are receiving is making their health better this will improve the child's psychological well-being.

A counter argument is that the child may feel sad and depressed knowing that they have a terminal illness that has no cure. This may cause the child to have anxiety and/or depression after disclosure. A rule utilitarian health care practitioner ought to ensure that the disclosure process is to be done in a way that there is pre- and post- disclosure counselling. As stated by the CRC- Article 24 "the child has a right to the highest attainable medical care and has the

right to enjoy the best attainable state of physical, mental and spiritual health". The counselling process will ensure that the child has improved attitudes and an improved standard of life, therefore there harm is mitigated, and the child's well-being is maximised.

Another counter argument is that there is a social harm that disclosure poses to the child. The child may also be sad if they know and understand that this terminal disease was passed from their parent(s) to them. The child may feel disappointed and angry towards their parent(s). Some children may feel that they are being punished because they did something bad. Firstly, my response to this counterargument is that truth and transparency build rapport. Secondly, when the rule is followed, and partial disclosure is initiated the child's well-being is being considered. It is crucial to show children respect, empathy, and honesty in order to establish a rapport. Therefore, by creating a safe space for a child to ask questions it creates an opportunity for the health care practitioner to counsel the child and to reassure the child so that the child does not internalise the stigma they may feel. As stated above, the trust relationship is essential to a rule utilitarian health care practitioner, by establishing trust with the child the child's well-being is maximised.

Possible Harms of initiating partial disclosure

There are cases whereby the disclosure process may get complicated, therefore a counter argument is that disclosure may result in the child experiencing internalized stigma. The Child and Adolescent HIV disclosure guidelines state that following a disclosure session, particularly in cases involving child safety or complicated disclosure problems, a formal referral is required (WHO, 2011). The health care practitioner needs to recognise complicated cases early in the disclosure process and ensure that they involve a multidisciplinary team as is stated the guidelines (NDoH, 2016; WHO, 2013). A social worker or psychologist should be available for disclosures that are complicated. This ensures that there is continuity of care, and that the

child's well-being is taken care of psychosocially. Having scheduled follow -up visits ensures that the health care practitioner is able to monitor the child to ensure that there is understanding of disease and emotional adjustment

3.7 Non-disclosure and delayed disclosure cause the child's overall well-being to be compromised.

In their article Gyamfi et al., 2015, the authors state that the wellbeing of the child will eventually be impacted negatively by lack of disclosure (Gyamfi et al., 2015). The WHO is aware that withholding information may have an impact on a child's health, including access to pediatric HIV care and treatment as well as treatment compliance . In light of this, the WHO advises that children of school age should be informed of their HIV status as part of their long-term management and further advises that younger children should be informed of their status gradually to account for their cognitive abilities and emotional maturity in preparation for full disclosure (WHO, 2013).

Moreover, a child who does not know or understand why they have to take medication every day or has to be taken to the clinic or the doctor regularly may become uncooperative and not adhere to their treatment (Van Elsland et al., 2018). This child may become more prone to opportunistic infections and become extremely sick. This may lead to the child having to stay at home due to the illness or even worse, having to be admitted to hospital. This means that the child will not have a healthy and "normal" lifestyle. Furthermore, the child may end up having to miss school which will delay their education and development.

I argue that it is ethically justified for the child to be partially disclosed to by a health care practitioner if the child has been asking their parent questions about their illness and they are not being given answers, furthermore it is justified for partial disclosure to be initiated when a child is being given misleading information about their health. When a child is being given

misleading information it is a form of deception. The New Horizons Disclosure of HIV status Toolkit for Paediatric and Adolescent Populations describes deception as “ascribing the child’s condition to a different illness” (New Horizons Advanced Paediatric Care, 2016).

I argue that giving a child misleading information about their health is a form of harm. As I discussed previously, an action which may cause the child confusion and mistrust is a form of psychological harm. It is damaging to children's psychosocial development and coping, impairs disease knowledge, and as children grow into adolescence it makes them more susceptible to risky behaviour when there is a lack of open communication about HIV/AIDS (Abadía-Barrero & LaRusso, 2006).

A study of the extent of disclosure to HIV positive children was done in Johannesburg, South Africa by Murnane et al., 2017. They used a similar interview method as described by Funck-Brentano et al., 1997 in their study. Murnane et al., 2017 found that from the parents involved in their study, 25% of the parents had not fully disclosed to the child the child’s HIV positive status.

The parents had told the child vague information about why the child had to attend regular medical check-ups at the doctor or the healthcare facility (Murnane et al., 2017). Less than 5% of the parents told the child about the nature of the illness (Murnane et al., 2017). When the child asked why they needed to take medication they were told that they need to take medication so that it can kill the organism that is making them sick (Murnane et al., 2017). Another reason the parents gave the child for taking medication is that the child is born with an illness (Murnane et al., 2017). Close to 20% of the parents involved in the study had told the child ambiguous details about his or her illness (Murnane et al., 2017).

Some of the parents who had not completely disclosed said yes when asked if they had continuous conversations with the child regarding HIV or sickness (Murnane et al., 2017). This

information suggests that partial disclosure was prevalent in this group (Murnane et al., 2017). The parents who participated in the research decided not to tell the children because they thought they were “too young to understand the information” being given to them about their diagnosis (Murnane et al., 2017).

In the same study they discovered that 20% of the children aged 7 to 9 who had not had full disclosure had inquired about HIV with their parents, which may indicate that the kid is prepared for partial disclosure to be initiated. Another aspect of beneficence is prevention or removal of harm which is similar to the principle of non-maleficence which is “Do no harm”. Based on these two similar ethical principles, my argument is that partial disclosure is justified, and non-disclosure and delayed disclosure are not justifiable because their child’s wellbeing is compromised (Murnane et al., 2017).

Delayed disclosure and non-disclosure cause preventable harm to the child. Madiba and Diko (2020) authored an article that examined the consequences of delayed disclosure in children who are perinatally infected with HIV. They identified these factors: the child refusing to take their treatment, which leads to unplanned disclosure, this leads to anger and resentment towards to parent, there is a risk of possibly transmitting the illness to the partner once the child reaches adolescence and starts engaging in sexual intercourse. If there’s continued disruptions in the treatment course due to non-adherence the child’s viral load may increase which leads to poor prognosis, which they concluded are the consequences of delayed HIV disclosure and adherence to ART.

Having mentioned these consequences of delayed disclosure, I argue that delayed disclosure does not uphold the guidelines of the Convention of the Rights of the child which states that the child’s best interest must be of primary concern.

Mobiba and Diko (2020) they found that one of the main barriers stopping parents from disclosing to the child is that they felt unprepared since they lacked the knowledge of HIV to be the ones to do it. They worried that if the child asked them about being HIV positive, they would not be able to respond. When the health care practitioner discloses to the child that they are HIV positive, they also educate the child on the disease's causes and effects in addition to informing them of their positive HIV infection status. Furthermore, there is a post-disclosure plan which includes continued monitoring and counselling which is beneficial for the child, as opposed to cases in which the disclosure is initiated by the parent alone. Additionally, they found that there is a strong association between non-disclosure and a detectable viral load. A detectable viral load is a clinical indicator of treatment failure for the child. My argument is that non-disclosure and delayed disclosure pose a physical harm to the child and their well-being.

A counter argument is that the benefit of non-disclosure is that the child is protected from experiencing the effects of the stigma that is associated with the diagnosis of HIV.

My response to the counter argument is that there is extraordinarily little literature to support the argument that children who receive disclosure experience anxiety and depression. In an article written by Krauss et al., (2016) they state that children who did not receive disclosure about their HIV positive status did not experience any feelings of depression or anxiety. Furthermore, an article published by Menon et al. (2007) emphasizes that some children who did experience any initial anxiety or depression have these reactions dissipate quickly over time. They further elaborate to say that these “negative outcomes of disclosure” may be over exaggerated by the parents, especially if the parents themselves struggle with anxiety or depression (Menon et al., 2007). Additionally, Menon et al., (2007) found that disclosure of HIV status to children did not have negative effects on the child’s mental wellness. Access to

psychosocial support for the child and the parent may be facilitated through interventions that encourage transparency (Menon et al., 2007). An article on the Pediatric AIDS Clinical Trials Group found that indicators of quality of life, such as how a patient views their own health, how the patients experiences symptoms, the state in which a patient is in psychologically, how they use healthcare facilities, how they function physiologically, and their role in their social environment, were not very different between before disclosure and after disclosure (Odiachi, 2017).

Another counter argument to partial disclosure is that delayed disclosure gives the parent and the health care practitioner a chance to formulate a plan for the disclosure process and to plan for anything else that may go wrong if the child does take the information well. Furthermore, delayed disclosure gives the parent who may not necessarily be the biological parent an opportunity to educate themselves about HIV and ways in which to initiate disclosure with the child. However, according to a few publications, parents' personal worries are more frequently the cause of non-disclosure and delayed disclosure (Funck-Brentano et al., 1997; Wiener et al., 2007). Delaying disclosure due to the parents 'personal worries may not be in the best interest of the child.

Partial disclosure of a child's HIV status to a child against parental consent is ethically justified based on the numerous benefits that it has for the child. Some of the benefits of partial disclosure are beneficial both medically and psychosocially. Arguably, the benefits of non-disclosure and delayed disclosure do not outweigh the benefits of partial disclosure. Therefore, early HIV disclosure in children between the ages of 6 to 8 years is ethically justified.

According to clinical reports, disclosure has benefits such as fostering trust, improving access to support resources, fostering open communication within the family, and improving children's long-term health and mental wellbeing (Wiener et al., 2007).

As stated by Gyamfi et al. (2015), fear of stigma is one of the biggest obstacles to disclosure. My stance is that one of the benefits of disclosure is reduced stigma. The stigma is reduced by having open conversations about HIV, this may be hard to achieve with the older generation, but if we start gradual conversations about HIV with children we will reach a society where HIV is not stigmatised anymore. Finally, reduced HIV stigma not only benefits the child in their family, their place of learning and where they live, but reduced stigma will filter in the greater community and society in general, which means that the greatest good will be done for the greatest number. This will maximise well-being for everyone involved.

Chapter 4: To analyse the dual-loyalty dilemma the health care practitioner faces when the parent(s) refuse to initiate or participate in the HIV status disclosure of the child.

4.1 Introduction

Joseph Goldstein authored an article titled: "Medical Care for the child at risk: On state supervision of parental autonomy." He states that "to be a child is to be at risk, dependent and without capacity or authority to decide what is 'best' for oneself" (Goldstein, 1997). "To be an adult, is to be a risk taker, independent, and with capacity and authority to decide and to do what is 'best' for oneself" (Goldstein, 1997). An adult who is a parent, is assumed by law that he or she has the ability, accountability and responsibility to decide what is the best decisions for one's child (Goldstein, 1997). The law is intended to provide every child the chance to navigate the developmental challenges they will face as they grow into adults and reach the crucial age at which the state will assume they are competent to make decisions for themselves (Goldstein, 1997).

When a child is placed in the care of a health care practitioner, there are three parties involved: the health care practitioner, the child who is the primary patient and the parent(s) who makes decisions on behalf of the child and takes responsibility for the child. For a long time, parents were not only surrogate decision makers for the child based on the child's perceived incompetence to make his or her own decisions, but it was and to a certain extent, it is still believed, that the parent(s) have a right and a responsibility to be involved in the medical decision making of the child (Ross, 1997).

In this chapter, I will look into the relationship that the health care practitioner has with the child as their patient and the relationship which the health care practitioner has with the parent of the child. I will analyse the concept of dual-loyalty and the challenge that the health care practitioner faces when dealing with a parent who refuses to initiate or participate in the child's HIV status disclosure to the child.

The reason for this chapter to be included in my defence of the thesis that health care practitioner ought to be allowed to disclosure the HIV status to some children between the ages of 6 to 8 years who have sufficient mature provided that the disclosure is in the child's best interest is because the parent plays an important role in the disclosure process. The reason I believe there may be a dual loyalty between the health care practitioner and the child, and the health care practitioner and the parent are because it is in the child's best interest that their parent is involved in the healthcare treatment as along as it benefits the child. The disclosure process would be uncomplicated if the parent is cooperative and willing for a child to be receive disclosure of their HIV status. There may be instances in which the parent is not willing for their child to receive disclosure, seeing that disclosure is an ongoing process and that it is not a one-time event, the health care practitioner ought to ensure that they keep the parent's HIV status private while initiating disclosure with the child about the child's own HIV status.

4.2 What is loyalty?

To understand "dual loyalty" as a concept, one ought to first examine what the term loyalty means. The Oxford Dictionary defines loyalty (to/toward somebody/something) as "the quality of being faithful in your support of someone or something" (Oxford, 2023). The Stanford Encyclopaedia of Philosophy describes loyalty as "a practical disposition to persist in an intrinsically valued (though not necessarily valuable) associational attachment, which involves a potentially costly commitment to secure or at least not jeopardize the interest or well-being of the object of loyalty" (Kleinig, 2007).

A person may be loyal to their partner and may also be loyal to a car brand but that does not necessarily mean that the two hold the same value to the person. In many relationships, it is a central aspect which is encouraged and fostered, such as family relationships where loyalty is expected. In organizations, loyalty is often demanded. It is common practice for a health care

practitioner to have loyalty to his or her patient. Loyalty is expected in the relationship between a health care practitioner and his or her patient. It is one of the fundamental qualities that drive the healthcare profession. Loyalty is necessary for transparency, truthfulness, honesty and trust in the care of patients.

4.3 Loyalty as a Virtue

Some people find that loyalty as a virtue is difficult to understand, some argue whether it is a feeling or a verbal expression or an outward expression of actions. Kleinig (2007) explains that loyalty can be measured by how a person behaves instead of how strong their emotions are in favour of a certain person or object. This means that their actions are driven by their devotion to that person or object, and even in circumstances whereby their own interests may be compromised. In the practice of healthcare, loyalty may be measured by conduct and effort on the health care practitioner's side to remain committed to the well-being and the best interests of their patient. Therefore, a health care practitioner may feel compelled to initiate disclosure with a mature child against their parent's consent because they feel an obligation to show loyalty to the child who is their patient.

Aristotle said that a virtue is an admirable character quality which is seen in reoccurring good actions (Rachels & Rachels, 2019). It is imperative that we understand that the action needs to be habitual. One cannot possess the virtue if you only practice it occasionally. In contrast to vices, virtues are good. A virtue is therefore an admirable quality of character that shows via consistent behaviour (Rachels & Rachels, 2019). The Stanford Encyclopaedia of Philosophy states that a virtue is: "an excellent trait of character" (Kleinig, 2007). For example, honesty is considered to be a virtue. This means that an honest person is one who believes in speaking the truth, having honest actions and intentions. The advantage of virtue ethics is that it links to human characters and gives an account for moral motivation (Kleinig, 2007).

Loyalty is shown by actions but the motivation behind the actions is also important. The reason virtue ethics is more advantageous and well-suited for this chapter is because it recognizes the actions and motivations behind the actions of a person who is to be considered virtuous. The aim of this chapter is to assess how virtuous is a health care practitioner who chooses to be loyal to their patient versus being loyal to the patient's parent(s). Rachels and Rachels (2019) give the following example suggested by American philosopher Michael Stocker to explain virtue ethics: You are in the hospital getting better after a protracted sickness (Rachels & Rachels, 2019). Your friend Smith pays you a visit (Rachels & Rachels, 2019). You tell Smith how much you appreciate his visit and what a great friend he is after a long talk (Rachels & Rachels, 2019). Smith claims that he is only carrying out his responsibility (Rachels & Rachels, 2019). You come to understand that Smith is only coming to see you because he thinks it is "the right thing to do," not because he wants to or likes you (Rachels & Rachels, 2019).

Michael Stocker explains that there is nothing wrong with what Smith did. But it is quite clear that there is something that does not live up to a certain moral standard with what Smith did (Rachels & Rachels, 2019). We then have to grapple with Smith's intentions for doing what he did, and whether good intentions are good enough to live up to a required moral standard (Rachels & Rachels, 2019). We cherish friendship, love, and respect as human beings, and we want our relationships to be built on reciprocal respect. According to Stocker, theories that emphasize moral behaviour cannot give a comprehensive explanation of the moral life (Rachels & Rachels, 2019). A theory that stresses personal values like honesty, friendship, love, and loyalty is thus necessary, which is virtue ethics.

"Loyalty involves partiality towards loved ones and friends, beneficence involves equal regard for everyone" (Rachels & Rachels, 2019, p. 181). Non-maleficence requires that there be no harm posed to the parent and the child. My argument is based on the child being the primary

patient, therefore the health care practitioner ought to put the child's interest before the parent's interest. This is especially important given that the parent, who is often assumed to promote the best interests of the child. In this case, the parent is conflicted and does not prioritise the best interest of the child.

When assessing the sort of motivations that would guide a healthcare practitioner's actions as virtuous, Rachels and Rachels (2019) interpret Elizabeth Anscombe's stance that we should rather get rid of words like "morally right action" and focus on using terms like "unjust" or "intolerant" when talking about virtue (Rachels & Rachels, 2019). Virtue ethics will be used to look into the character of a health care practitioner, the different decisions that he or she may take for the child or the parent. Virtue ethics will help guide us to assess what are the motivations behind the different decisions and how this makes him or her a "virtuous" health care practitioner. The hope is that this will help us assess what ought to be done to resolve the dual loyalties that the health care practitioner faces.

In the practice of healthcare, loyalty is complex yet fundamental. Loyalty is based on trust. HPCSA guidelines on ethical practice stated that: "Practice as a health care professional is based upon mutual trust between patients and health care practitioners" (HPCSA, 2019, p. 2). If a patient trusts that their health care practitioner is acting in their best interest, and they have their needs met by their health care practitioner then they will be more inclined to show loyalty to their health care practitioner.

4.4 Dual-loyalty

Dual loyalty may be defined as “a clinical role conflict between professional duties to a patient and obligations, expressed or implied, to the interests of a third party such as an employer, an insurer, or the state (military) that can violate patient’s rights” (Wilson, 2019). Dual loyalty can also happen when a health care practitioner finds themselves in a moral dilemma of having to balance the interest of two parties which they have equal loyalty to. A person in custody can be understood as a child being in the care or guardianship of their parents. Or in other cases- not applicable to the healthcare setting, a person under custody can be when someone is in prison. In both these settings, the health care practitioner has to weigh the interest of their patient with the interest of a third party.

A dual-loyalty case that comes to mind in the South African context is the case of Steve Biko. Steve Biko was a political activist during a period in South Africa called Apartheid. He was detained by security police based on the Terrorism Act of 1967. During this time, a doctor was instructed to examine Biko because he was “acting strange” and refused to answer questions from the police. He was examined by the doctor, in the presence of the police, some abnormal findings were found during the examination such as ataxia, slurred speech and bruises on the body, but the doctor completed his medical certificate and stated that he had found no abnormalities or pathologies on the patient (McLean & Jenkins, 2003).

Biko was examined by the same doctor for the second time but this time his senior doctor was present. Biko complained of a pain on his head and back, which was suggestive of a possible brain injury. A neurologist consulted with Biko at the prison, left-sided weakness and difficulty speaking were found on the examination and abnormalities in his cerebrospinal fluid (Moodley & Kling, 2015). The neurologist referral him to a neurosurgeon. Biko’s district doctor recommended to the security police that Biko be transferred to another hospital, this

recommendation was refused by the security police. The doctor discussed the neurologist's findings with his senior doctor, but no treatment was initiated (Moodley & Kling, 2015).

A neurosurgeon was eventually consulted, he recommended that Steve Biko be closely monitored in a hospital. The district doctor permitted for Biko to be returned to his prison cell where he was left lying on a mat on the floor. Upon further examination, his doctors found that his condition was deteriorating, they recommended that Biko be transferred to a prison in Pretoria, which is 1100km away, by motor vehicle (Moodley & Kling, 2015).

Biko was transported to Pretoria Central Prison, naked, in the back of a police land rover, handcuffed and with no medical escort present. He arrived in Pretoria, was examined by another doctor with no information on his medical history. Biko passed away within 6 hours of arriving at Pretoria Central Prison, he was left alone on the floor of a prison cell on the evening of September 12, 1977 (Moodley & Kling, 2015).

Many human rights were violated in the case of Steve Biko. There is no doubt that there various instances where the doctors chose to abide by the rules that were given by the state police instead of doing what is in their patient's best interest. The principles of beneficence, non-maleficence and justice were absolutely neglected.

The Steve Biko case is one of the many dual-loyalty cases (many are not as extreme) that health care practitioners face in South Africa. In this dual-loyalty dilemma that the health care practitioners faced, they failed to put their patient's interest as their primary concern. My research is based on the dual loyalty dilemma that the health care practitioner faces when he or she has to choose between disclosing to the child their HIV status against their parent's consent or not disclosing to the child because the parent refuses for disclosure to be initiated with the child.

In his article, Wilson (2009) defines dual loyalty as a conflict that divides a health care practitioner's loyalty between two or more patients or parties (Wilson, 2009). On the one hand, the health care practitioner must always work to improve their patient's health since they are obligated by fiduciary duties while ensuring that they do not harm any other person who may be involved (London, 2005). The health care practitioner ought to show loyalty to the child because they feel an obligation to disclose to the child the child's HIV positive status because they believe that it is in the child's best interest to know their own HIV positive status. Simultaneously, the health care practitioner may feel obliged to ensure that they do not intentionally make the parent's HIV positive status known to the child during the disclosure process, as doing so may be seen as infringing upon the parent's right to confidentiality of their own HIV status.

Consequently, four factors must be present for there to be a dual loyalty situation:

1. Concurrent responsibility to the child (the primary patient) and one or more other parties, in this example, the parent(s).

2. The conflict between these concurrent obligations, to initiate disclosure to the child vs to honour the parent's wishes by not initiating disclosure with the child against their consent.

3. The parent(s) exerting any sort of pressure on the health care practitioner, which is measurably significant to the power the child may have. The pressure here is the motivation the health care practitioner has to act in ways that would show loyalty to the child over the parent.

4. The ability to separate the clinical duty of a health care practitioner from their social agent role, such as in cases where a health care practitioner needs to consider if the child being HIV positive may affect other people. Secondly, the health care practitioner having to separate the

child's needs from those of their parent(s) so that he or she may honour the loyalty he or she has to the child.

4.5 Loyalty to the child

When a parent brings their ill child to the hospital or clinic, they are entrusting the care of the child to the health care practitioner, this means that the parent is in a position where they know that they themselves can only do so much to help their ill child. This means that there is a certain degree of trust that the parent has in their health care practitioner, and the parent believes and trusts that the health care practitioner will do what is in the child's best interest.

When a parent refuses for disclosure to be initiated by a health care practitioner with the child about his or her HIV positive status, it creates a dilemma in which the parent believes that he or she is doing what is the child's best interest and the health care practitioner also believes that they are doing what is in their patient's best interest.

Loyalty is shown by actions but the motivation behind the actions is also important. A virtuous health care practitioner ought to maintain loyalty to their patient. In this case, the health care practitioner ought to put the child's interest first, that is one way in which the loyalty between the health care practitioner and the child will be maintained.

In the previous chapter, I argued for the health care practitioner to disclose to the child their HIV status because it is in the child's best interest. I mentioned the benefits of partial HIV disclosure: the child being empowered with knowledge, the child having a growing sense of independence, the child learning to take some responsibility for their own health as he or she grows up, the child being adherent on medication which ensures better health outcomes for the child (Gyamfi et al., 2015).

The health care practitioner's decision to disclose to the child against the parent's consent is aimed at having an age-appropriate discussion with the child about what HIV is, how does one contract HIV, how is HIV passed on from one person to the other, how do you live with or manage HIV, how to protect other people from contracting HIV from you, etc. The disclosure process is aimed at ensuring that the child is empowered with information so that they have knowledge about their own chronic illness.

In this section, I will support my argument with legal and ethical guidelines, starting with the child's right to participation.

My argument is that it is ethically justified for the health care practitioner to put the child's interest before the parent's interest by initiating disclosure with the child against parental consent.

Firstly, I argue that the health care practitioner is ethically justified to disclose to the child their HIV positive status based on the child's right to participate in their own healthcare. The HPCSA ethical guidelines section 5.5 discusses patient participation in their own healthcare. It states that: "health care practitioners should respect the rights of patients to be fully involved in decisions about their treatment and care even if they are not legally competent to give necessary consent" (HPCSA ethical guidelines, p.15). This is particularly important in my dissertation because my focus is not on obtaining consent for treatment, but rather initiation of disclosure, which is a discussion about health status and giving a patient information which may be useful when the time comes to make decisions.

With minors, the challenge that most health care practitioners face when trying to involve them complicated in medical discussions and decisions, is the various degrees of maturity within the children's age groups and the fact that their capability to understand and grasp information develops with age (Rosoff, 2017). My response is that the child's ability to participate in

discussion about their healthcare may also be dependent on the child's previous health-related experiences such as other chronic illness and previous hospital admissions. As I previously defended in my previous chapter, partial disclosure may be initiated with children of various degrees of maturity. Furthermore, it may be assumed that children who grow up with HIV have had more than one encounter with a health care practitioner or healthcare setting whether it be a general practitioner's consulting rooms, a clinic or a hospital, therefore there is some form of exposure from those experiences, therefore the child may expect some form of loyalty from their health care practitioner.

Another counter argument is that when a health care practitioner puts the child's interest before the parent's interests, there may be a disruption in the harmonious relationship the child has with their parent. When it comes to children and family structures, the context is particularly important, and it may not be justified for the health care practitioner to show loyalty only to the child. What may be permissible in one culture may be frowned upon in another culture because family dynamics are important. And this is especially important for a health care practitioner to be mindful of as the parent is in the best position to know what is best for the child.

My response is that in the practice of western medicine, respecting someone involves recognizing the person's ability to make well-informed decisions about their own health treatment. This means that a health care practitioner must provide the person with sufficient information to make the correct choices for themselves. It is justified for the health care practitioner to uphold their loyalty to the child first because the child is their patient and as their health care practitioner one ought to act in ways that shows honesty and integrity. Furthermore, to ensure that trust is maintained between the child and their health care

practitioner, the health care practitioner needs to give the child information that is truthful and accurate.

To ensure that there is loyalty between the child and their health care practitioner, honesty and truth-telling is imperative. My position is that participation in one's healthcare is encouraged by the National Health Act 61 of 2003, therefore it is required that there be honest and open communication between the health care practitioner and the patient. The disclosure of their HIV status against parental consent ensures that they know their own HIV positive status and that they get to practice their right to participation according to the National Health Act 61 of 2003.

4.6 Application of dual loyalty

Do paediatric patients have a right to know? This is the title of an article written by Phillip Rosoff. The ethical dilemma presented in this case is about a medical student named Jenny who is part of the healthcare team that is taking care of a 13-year-old patient suffering from Ewing sarcoma, which is a type of cancer which occurs in bones or the soft tissue around bones. The patient's parents wish to protect the child from knowing the harmful effects of his treatment (Rosoff, 2017).

The patient's name is Adam. "Adam is diagnosed with Ewing's sarcoma of the left distal femur" (Rosoff, 2017). The health care practitioner in charge of Adam's care is Dr. K. Upon discussion of Adam's treatment plan, Dr. K mentions to Adam's parents that there is a cure for Ewing's sarcoma, and he recommends that the treatment be started as soon as possible. Without Adam knowing, Dr. K informs Adam's parents that there is high possibility of Adam becoming infertile and that there is no time for Adam to put some sperm away in the sperm bank. Adam's parents do not want Adam to know about sperm banks, and they inform the doctor to not tell Adam about possibilities of infertility after his treatment (Rosoff, 2017).

Adam's father states that "He's too young to understand" (Rosoff, 2017). Later on, during one of Jenny's conversations with Adam about his future aspirations, Jenny finds out that Adam would like to be a father and have a big family one day when he grows up. Jenny makes an effort to let Dr. K know about Adam's future aspirations. They discuss Adam's anger issues, which they have attributed to Adam feeling some lack of control over his life, which is commonly seen in adolescents battling cancer (Rosoff, 2017).

Jenny asks Dr. K whether it would be appropriate for her to tell Adam about his infertility due to the chemotherapy that he will need. Dr. K tells Jenny not to tell Adam about the infertility risk and that the parents have been told about the risks of the chemotherapy, and they have chosen to go ahead with the treatment. Dr. K also emphasizes to Jenny that the parent's wish needs to be respected and that Adam should not be told about the infertility risk from the chemotherapy (Rosoff, 2017).

Jenny's concern is whether there is a psychological harm that Adam may experience when he survives his cancer but then grows up to find out that he is infertile because of the chemotherapy that he went through as a young adolescent. Jenny is also concerned about whether Adam has a right to know all the information regarding the proposed treatment plan, including the side effects of his chemotherapy (Rosoff, 2017).

Informed consent is one of the foundations of healthcare practice. And for informed consent to come into practice, the patient has a right to have control over their body and the patient has to exercise that right with adequate, relevant, accurate information so that they can make informed choices which are in their best interest (Bester et al., 2016)

For the patient to make the best decision for themselves, the patient ought to have sufficient cognitive function to understand and appreciate the benefits of the treatment and the possible risks of the proposed treatment. The type of information and the amount of information given

to the child at each visit will vary but the information must be accurate and relevant so that the patient can make an informed decision (Rosoff, 2017). “For children, the capacity to engage in informed decision making is a gradually acquired capability, and different young people exhibit varying degrees of ability to make informed decisions as they age.” (Rosoff, 2017).

According to Rosoff, the ability to make decisions about one's health and medical care depends on the development of the parts of the brain that are in charge of complex reasoning and forethought, which do not reach full maturity until one is in their early twenties. Although adolescents may not be able to fully understand all the advantages and disadvantages of a suggested course of action, they may, to some extent, understand the information provided and should be included in the decision-making process since it may benefit them.

The decision-making authority of minors will always rest with their parents or other caregivers in the absence of a court-ordered declaration of emancipation or other legal authorization of decisional autonomy.

The dilemma in this case is that the health care practitioner has to choose between telling the child about the infertility risk and having the child produce a semen sample to be preserved at the sperm bank, versus fulfilling the parent’s wish of not telling the child about the infertility risk (Rosoff, 2017). In this case, the health care practitioner identified the possible risk of infertility as a harm for the child and could have suggested that the child produce a semen sample which could be preserved through cryopreservation for when he has grown up and is ready to have children (Rosoff, 2017).

There are two points to argue for the health care practitioner to act in best interest of the child. Firstly, the pressured matter of initiating the child on chemotherapy as a matter of urgency to stop the cancer from spreading to other regions of the body. Secondly, to ensure that the child grows up to see his aspirations of being a father and having a large family come to life (Rosoff,

2017). A challenge that the health care practitioner faces in this case is that the patient clearly has the capacity to at least partially understand and appreciate what they have been told about their condition and the treatment plan and hence he should be able to participate to a limited extent in the decision-making process (Rosoff, 2017).

The preferred approach to effective and morally acceptable medical decision-making for both adults and children is one that embraces shared responsibility, involving the parents and the children (to the extent that he can or wishes to be involved) in a two-way conversation, which can be difficult at times given the differences in family dynamics, the emotional tension of the situation, and so on (Rosoff, 2017.)

The argument is that if Adam were assessed to have sufficient maturity and he met the criteria for decisional capacity, he could override his parent's decision. The author argues that the potential repercussions of him knowing that the treatment could cause him to be infertile could damage or even completely ruin the trust in this newly forming patient-clinician relationship, this could ultimately mean that Adam does not receive the chemotherapy and dies from cancer (Rosoff, 2017). Counterargument to this is that, in most settings the parents and the patient are more likely to take the course of action that is recommended by their health care practitioner, provided that their health care practitioner gives them all the relevant and appropriate information, reassures them of the benefits of the proposed treatment and puts their fears, misconceptions and misunderstandings at ease.

The response to this counter argument is that, given all the information and efforts of the health care practitioner, some parents may still decide to go against the advice given by their health care practitioner because there are still parents out there who chose to not have their children vaccinated.

In Adam's case, like most cases involving a minor, the degree to which Adam participates in the medical decision-making and the extent to which he is informed about his medical information is largely dependent on his parents. The AAP state that: "Surrogate decision-making by parents or guardians for paediatric patients should seek to maximise benefits for the child by balancing healthcare needs with social and emotional needs with the context of overall family goals, religious and cultural beliefs and values" (Rosoff, 2017). If a patient is at considerable risk of serious harm, health care practitioners have a moral and legal obligation to scrutinize and, if necessary, oppose both the patient's and the surrogate's medical decisions (Rosoff, 2017).

This implies that when a parent makes choices on a child's behalf, they should constantly evaluate how those choices will affect the child's best interests, family input and possibilities of harm, and how harm can be avoided (Rosoff, 2017).

Determining harm from the parent's perspective. Firstly, the parents are worried about the psychological harm that Adam may experience if he is told about the risks of the treatment. The physical harm that the parents are worried about may occur if Adam refuses for the treatment to be initiated once he knows about the risks of the chemotherapy, is that he his cancer may progress, and he will become sicker. It is worth mentioning that Adam may choose to be uncooperative, but his parents are the ones to make the decision for the treatment to be initiated. The parents are less concerned about the psychological harm that may happen in the future if Adam later finds out that the chemotherapy he had as a young adolescent has made him infertile, and he cannot have children because of it.

There are a few ways to determine possible harm to Adam from the health care practitioner's perspective. Firstly, the harm would be if the disclosure of the risks of his chemotherapy is discussed with Adam, and he decides to not go ahead with Chemotherapy. Once again, it is not

his decision to make about whether he has the chemotherapy or not, it is the parent's decision. Without the disclosure, this harm would be avoided, which means that the health care practitioner would have fulfilled the parent's wish to not tell Adam about the side effects of the chemotherapy. Secondly, the psychological harm of Adam not knowing the side effects of chemotherapy and then later finding out that he is infertile. Thirdly, the concern of harming the relationship between Adam and his parents if the health care practitioner chooses to tell Adam the side effects of chemotherapy against his parent's consent.

4.7 Adam's case in the South African Context

The case discussed above is an American case. In the South African context, the case could be analysed legally. Firstly, based on section 15, of The Children's Act of 2005 – "Enforcement of rights"- it highlights that "anyone listed in the section has the right to approach a competent court, alleging that a right on the Bill of Rights or in this Act has been infringed or threatened, and the court may grant appropriate relief, including declaration of rights" (The Children's Act of, 2005).

Based on the Enforcement of rights chapter, the people who are eligible to petition a court, are:

a) "A child who is affected by or involved in the matter to be passed on judicially" (The Children's Act 38 of, 2005)

   A child may approach the court with assistance from another adult and a lawyer, if he finds out that his parents are refusing for disclosure to be initiated with him or her because the parents have not given consent.

b) "Anyone acting in the interest of the child or on behalf of another person who cannot act in their own name" (The Children's Act 38 of, 2005) In this case it would be the health care practitioner.

c) “Anyone acting as a member of, or in the interest of, a group or class of persons” (The Children’s Act 38 of, 2005) Based on the above statements, the health care practitioner may approach the court if the parent refuses for disclosure to be initiated with the child.

d) “Anyone acting in the public interest” (The Children’s Act 38 of, 2005)

It is in cases such as Adam’s case that ethicists find that the best interest standard does not give many conclusive guidelines about what to do in such cases. Ethicists have maintained that the harm principle may be a better construct to use to resolve dual-loyalty dilemmas such as this one. Diekema states: “The harm principle provides a foundation for interfering with parental freedom that more accurately describes an appropriate standard for interfering with parents who refuse to consent to medical treatment on behalf of a child” (Diekema, 2004). He continues by saying that involving the government is appropriate not when a parent's rejection is against the best interests of the child, but rather when the parent's refusal puts the child at a more danger of suffering major avoidable harm (Diekema, 2004).

Most parents feel they are acting in their child's best interest, yet the concept of "best interest" is intrinsically a matter of values (Diekema, 2004). The counter argument is that very often, health care practitioners focus on the benefits of their proposed route of health management without taking into consideration other aspects of the child’s life. This is often another area where the conflict comes in, often the parents have insight on the sort of life the child lives outside of the hospital and the parent may be in a better position to gauge whether the said “benefit” will actually be favourable for the child. All too often, only objective medical interests are considered when determining someone's best interests (Diekema, 2004).

As an illustration, while discussing chemotherapy for a child with leukaemia, medical professionals commonly undersell the drawbacks of cancer treatment in favour of focusing on

how much the medication will improve the child's chances of survival. Some parents could give more weight to the dangers, side effects, discomforts, and interruptions that the child might experience while receiving treatment, possibly concluding that the likelihood of survival is not worth such burdens (Rosoff, 2017).

The health care practitioner may have to weigh between is this harm against the harm that will occur when the child finds out that his parent chose to keep his HIV status a secret from him. Rosoff (2017) seems to agree with Diekema (2004) with the argument that state intervention through the court system is justified when parental refusals place a child's life in danger or the child faces a high chance of suffering serious and considerable morbidity, and the therapy is effective and likely to be successful.

Instead of asking "Is this intervention in the child's best interest?" a health care practitioner should ask "Does the parents' decision significantly increase the likelihood of serious harm as compared to other options?" when a parent refuses to consent to a suggested course of treatment. Parental choices that are not disproportionately more likely to cause substantial harm than the alternatives can be accepted.

In Adam’s case, the omission about the side effects of the treatment is not life-threatening (Rosoff, 2017). But the psychological harm is of concern. Adam has made it clear that he wants to become a father one day when he is an adult. I argue that there is a harm that is posed to Adam by the secrecy that comes with him not being told about the side effects of the medication. The health care practitioner has brought forward a solution that ensures that Adam grows up to become a father one when he grows up because his sperm will be preserved in the sperm bank, and he has a chance to heal from the cancer by having chemotherapy.

My research is not about a parent refusing treatment for the child, my research is about a parent refusing for information to be shared with the child, information that may be of benefit to the

child. Furthermore, my research is based on the dilemma where it is of benefit to the child to know their HIV positive status, but the parent is refusing for the information to be shared with the child.

By being honest with the child about their HIV status, the health care practitioner is acting as a virtuous agent would. Information on healthcare states that "every child has the right to have access to information on health promotion and the prevention and treatment of ill-health and disease, sexuality and reproduction" (Section 13, The Children's Act of, 2005). Each and every child has the right to know about their health condition. Have knowledge on the causes and treatments for their health conditions; Confidentiality regarding their health conditions and the health conditions of any parents, caregivers, or other family members, unless doing so would be against their best interests. In accordance with this part, information given to children must be pertinent and in a form that they can understand (Information on Healthcare, section 13, The Children's Act of, 2005).

Health care practitioners, ought to always act in a way that shows integrity, honesty and loyalty. "Virtues are habits of character that are cultivated through practice that results in actions which are essential for an individual to flourish" (Hawking et al., 2017). Rachels and Rachels (2019) state that honesty is imperative between people because without it the interactions between people would go in many different ways (Rachel & Rachels, 2019). A virtuous health care practitioner knows that honesty is important. The motivation behind the disclosure against parental consent would be ethically justified because the health care practitioner chooses to be honest with their patient.

A counter argument is that if the health care practitioner chooses to disclose against the parent's consent, there will be damage to the trust relationship that the parent has with the health care

practitioner. However, this disclosure is still justified because the health care practitioner ought to remain honest and transparent for him or her to be considered a virtuous person.

4.8 Loyalty to the parent.

Moral character is made by a person's actions. The actions, habits and emotional responses of a person who is virtuous are all united and directed towards the moral and the good.

The success of a relationship between a person and their health care practitioner, or between a parent and the healthcare practitioner he or she chooses to take care of their child is based on trust. In his article titled "can we trust trust?" (1988), Diego Gambetta stated that trust is dependent on the "subjective probability with which an agent assesses that another agent or group of agents will perform a particular function" (Gambetta, 1988). The parent ought to trust that the health care practitioner will do what is in the child's best interest. Having stated this, the dilemma that the health care practitioner finds themselves in is maintaining some form of confidentiality of the parent's HIV positive status.

The HPCSA state that: "health care practitioners should recognise the right of patients to expect that health care practitioners will not disclose any personal and confidential information they acquire in the course of their professional duties, unless the disclosure is made in accordance with the patient's consent" (HPCSA, 2016, ethical guidelines, p. 15). This means that without the parent's consent, it would be infringing upon the parent's right to make known to the child their parent's HIV positive status, whether it is intentional or unintentional.

Furthermore, the ethical guidelines states that: "A health care practitioner should not breach confidentiality without sound reason and without the knowledge of their patients" (HPCSA, 2016, p15). This is where the health care practitioner needs to grapple with the fact that the parent is refusing for the disclosure to the child to occur, even though it has been determined

that it is in the child's best interest to know. Sound reason would be weighing the benefits to the child versus the harm to the parent. In my opinion, it is ethically justified to breach this confidentiality because the child has a right to know their HIV status as long as it benefits the child.

The National Health Act 61 of 2003 has a firm stance on confidentiality. It states that "All information concerning a user, including information relating to his or her health status, treatment or stay in a health establishment, is confidential" (Confidentiality, National Health Act 61, 2003). Subject to Section 15, no person may reveal any information covered by Subsection (1) unless (a) the user gives written consent, (b) a court order or legislation demands disclosure, or (c) failure to disclose the information poses a substantial risk to public health (Confidentiality, National Health Act 61, 2003).

The parent is refusing to have partial disclosure initiated with the child because he or she feels that the child will find out that he or she got HIV from the mother/parents when they were born. The parent does not want the child to know their own HIV status, so this means that there is no consent for disclosure given by the parent. This puts the health care practitioner in a difficult position because if the health care practitioner does disclose to the child the child's HIV status and the child figures out that they have been infected with HIV from the mother through birth then it may be argued that the health care practitioner has led the child to knowing about the parent's HIV status.

An argument can be made that good intentions can coexist with bad outcomes. "Agent-based virtue ethics grounds the rightness of an action in the moral goodness of certain inner features of the agent" (Fink, 2020). Fink (2020) goes on to say that doing the right thing will always be considered to be virtuous, but what determines whether an action is virtuous is determined by the person's motives, intentions and their character traits. A good intention means that a

virtuous health care practitioner has good motives for choosing to disclose to the child their HIV status against parental consent even if there may be a bad outcome after the disclosure.

In his narrative, Michael Slote focuses on an agent's motivations. According to him, "agent-based virtue ethics sees rightness in terms of having excellent motivations and wrongness in terms of having bad (or inadequately good) intentions" (Slote, 2010). Virtuous people evaluate a situation, determine what is correct on all sides, and want to behave appropriately since doing the right thing will benefit them eventually. Honesty, integrity and truth-telling are virtues that we all seek in a health care practitioner. The health care practitioner's decision to disclose to the child their HIV positive status against parental consent is ethically justified because the health care practitioner is choosing to be honest and transparent with the child. By doing this, the health care practitioner is displaying good character and is therefore being virtuous. My stance is that some bad outcomes are predictable, and the health care practitioner ought to have a plan to deal with the bad outcomes or to mitigate the bad outcomes if they do occur. Pre-disclosure counselling and post disclosure counselling for the child as an individual, counselling for the child and their parent(s), family or group counselling (should they choose to) may also be helpful should any bad outcomes happen.

The motivational theory of virtue ethics certainly makes sense in the context of human civilization, where we form unique relationships and alliances that motivate us to act honourably out of compassion, trust, and loyalty (Gardiner, 2003). My argument is that the health care practitioner ought to act so as to promote the child's needs first over the parents. It is not enough for the health care practitioner to simply follow guidelines and laws irrespective of his or her internal beliefs, attitudes and reason. The virtuous health care practitioner has an internal desire to act well for their patients. The unpredictable bad outcomes can only be defensible when one can judge that there is no ill-intent in performing partial disclosure.

Joseph Goldstein states in an interview based on his book titled the best interest of the child: “notions about what information children should have and when is one of the functions parents perform” (Goldstein, 1997). His stance is that there is no right way to raise children, each parent ought to raise their child in a way that best suits them (Goldstein, 1997). My stance is that being truthful and trustworthy is essential for the relationship between the child and the health care practitioner. Trustworthiness is one of the cornerstones of any relationship between a patient and their health care practitioner. It is the responsibility of the health care practitioner to uphold this trust firmly and to honour it by acting honourably.

Thomas Murray contends that while protecting children from harm is crucial, parents are not required to prioritize protecting children's wellbeing above all other goals (Murray, T. 1996; Diekema, 2004). He goes on to say that we do not ask or expect parents to barricade children in their yards to prevent interaction with neighbourhood dogs, bullies, or escaping automobiles. Parents are not obligated to take extreme measures to protect their children from every imaginable risk. (Diekema, 2004). This means that when weighing the benefit of initiating disclosure with the child, against the possible psychological harms of disclosure, the parent believes that the harm is not grossly significant.

I believe that the possible harm to the child such as psychological harm that may occur due to the disclosure of a HIV positive status is justifiable because is it temporary and interventions can be put in place to correct this. Furthermore, if a health care practitioner suspects that the disclosure is making a child sad or depressed then post disclosure counselling should be considered. It may even be beneficial for both the child and the parent to go for post-disclosure counselling (Mahloko & Madiba, 2012; WHO, 2011).

A counter argument is that the health care practitioner ought to act in a way that shows compassion and consideration for the parent’s concerns. Compassion is “an active regard for

another's welfare with an imaginative awareness and emotional response of deep sympathy, tenderness and discomfort at another's misfortune or suffering" (Beauchamp and Childress, 2001). This is particularly important for the care relationship between a health care practitioner and the child. There ought to be a good balance between what is absolutely necessary for the child to know at each phase of the disclosure process and how this information will affect the child. According to Gardiner, it is not enough to have excellent qualities; one must be able to recognize when and how to demonstrate them. As a result, the virtue of a person is determined by their use of reason and practical knowledge (Gardiner, 2003).

My stance is that the health care practitioner shows compassion and consideration by weighting the benefits to the child versus the harms, and then does the same for the parent. But ultimately, the loyalty does not compare with the loyalty that the health care practitioner has to the child. The most important thing for the health care practitioner to do is to ensure that the there is some form of compassion towards the parent, and to advise for the parent to also have counselling sessions.

I do not believe that there will be harm to the parent when the child knows their HIV positive status. My argument is that the parent should have received counselling before his or her own HIV positive status was made known to him or her.

Furthermore, in cases where the parent did not receive pre-disclosure and post-disclosure counselling about their own HIV positive status and he or she has not dealt with their own negative feelings about their own HIV positive status, then this would be an opportunity for the parent and the child to both receive counselling. Therefore, the health care practitioner has mitigated any harm to the parent and has ensured that the harmony between the child and their parent has been preserved.

"A duty is an ethical obligation to do or refrain from doing something" (Whitbeck, 1995). We are obligated to another person in some way and for a certain purpose if we have an obligation toward them. The other party has a right or claim against us that is related to what we owe them (Whitbeck, 1995).

HPCSA guidelines on ethical practice state that "Duties may be ethical, legal or both at once, and operate in the personal, social, professional or political sphere of our lives" (Booklet 1, HPCSA, 2015).

Firstly, the health care practitioner has a duty to do what is in the child's best interest. Having mentioned the benefits of disclosure in my previous chapter, the health care practitioner has a duty to disclose to the child their HIV positive status against their parent's consent if the child wants to know their status, if it is in the child's best interest to know their own HIV status and if there are mitigatable risks or harms involved in the child knowing their HIV status and if there is a possibility of HIV transmission to other people if the child is not informed of their HIV status.

Even though it can be argued that the health care practitioner has a duty to keep the parents' HIV positive status confidential as per the HPCSA guidelines. I argue that it would be justified for the health care practitioner to give the child knowledge about how they may have possibly gotten infected with HIV including possibilities of mother to child transmission. If it means that such knowledge empowers the child and inadvertently reveals the parent's HIV positive status then I argue that the disclosure is justified.

In summary, the virtuous health care practitioner ought to examine the facts of every imaginable scenario. In his review, Donald Vandeveer quotes Brock and Buchanan (1989) where they define best interest as "acting so as to promote maximally the good of the individual" (Vandeveer, 1992). The best interest standard, according to Beauchamp and

Childress, is one in which a surrogate decision maker has to identify the highest beneficial outcome among the available options, applying varying importance to patient interests in each option and excluding or removing inherent risks or costs (Beauchamp & Childress, 2001). In both cases, the requirement is that the parent has to do what they determine is in the child's best interest and the same is expected of the health care practitioner that he or she may decide for the child which is most favourable to the child.

The health care practitioner ought to consider the cultural sensitivities and should conclude that to a virtuous health care practitioner requires one to be honest, trustworthy and compassionate to both the child and the parent involved in this dual-loyalty dilemma.

CHAPTER 5: To argue for conditions under which it would be justified to initiate partial disclosure of a child's HIV status against parental consent.

5.1 It is ethically justifiable for a health care practitioner to initiate partial disclosure with a child who is HIV positive if the child demonstrates curiosity about their HIV status.

Curiosity is a state of being inquisitive or being in wonder. Children are known for asking 'why?' - a question often sparked by the child's need for their question to be answered and their curiosity to be satisfied (Liquin & Lombrozo, 2020). Curiosity is fulfilled by an appropriate explanation once it has been aroused, which is often attained by causal intervention or questioning, both of which become more effective with time (Liquin & Lombrozo, 2020).

Most children are born with an internal desire to explore and learn. It is this built in curiosity that encourages them to seek out new adventures and adapt. Curiosity is deeply linked to all aspects of human development and growth, which foster the process of gaining skills and knowledge. Curiosity is a significant learning motivator for children because it combines the advantages of active learning and an intrinsic desire with the significance of explanatory content, which may reveal the inexplicable and causal structure of the world to enable generalizable knowledge (Liquin & Lombrozo, 2020).

Partial disclosure is appropriate for children between the ages of 6 to 8 years because it will satisfy their curiosity. When a child is given what they perceive to be a sufficient answer, their curiosity might be sated (Liquin & Lombrozo, 2020). Children like explanations that are straightforward and generic in character, as well as those that contain a fair amount of pertinent material for explanatory purposes (Liquin & Lombrozo, 2020). "Children also prefer explanations which appeal to function or purpose and explanations that appeal to properties inherent to the thing being explained, though these preferences decrease across development"

(Liquin & Lombrozo, 2020). So, when a child is informed of the importance of taking medication and the benefits of taking medication then their curiosity will be satisfied.

In his essay, Elias Baumgarten (2001) suggests that the urge to be curious may be a character feature or desire. He continues by defining curiosity as the desire to learn more about various topics or to engage in further activities. “The more one has this character trait, the more often or the more intensely one will on particular occasions experience a desire or urge to investigate and learn more about something” (Baumgarten, 2001). A person's desire or impulse that their curiosity "arouses" may or may not be followed through on (Ross, 2020). When it comes to deciding what types of things are commendable about a person’s level of curiosity as well as the circumstances in which one should or should not act on that curiosity after it has been awakened, we might apply moral standards (Ross, 2020).

My stance is that a child may display signs of curiosity in different ways. Firstly, when the child starts asking the parent or the health care practitioner questions about his or her HIV status then the health care practitioner is ethically justified to disclose to the child. Secondly, if the child has questions about why he or she has to take medication every day. Thirdly, the child may ask why he or she has to attend regular check-ups at the clinic, then disclosure by the health care practitioner may be justified. Furthermore, in cases where the child gets sick frequently, and he or she wants to know why he or she is getting frequent infections, then it would be justified for the health care practitioner to disclose to the child because the child is showing signs of curiosity.

Curiosity is a moral virtue as it means that a person who exhibits it has a character trait of excellence which can be intellectual or moral. Ross claims that “curiosity is a moral virtue, though curiosity is not a necessary feature of any well-lived life, it is a quality that is generally conducive to it” (Ross, 2020). I agree with Ross; a child’s curiosity may prompt a health care

practitioner to initiate disclosure with them. This disclosure may actually lead to the child being empowered with knowledge which benefits the child.

Ross continues by saying that while being curious may inspire one to do acts that advance human happiness, this is not necessary for curiosity to be virtue (Ross, 2020). One of the actions of human welfare being the promotion of health, happiness, and fortune of the child. As I have argued in my previous chapter, there are numerous benefits for the child when disclosure is initiated. My stance is that the child's curiosity is a justifiable condition for their HIV status to be disclosed to them so that they may experience the benefits of disclosure.

The moral importance of curiosity's instrumental value cannot be overstated since it does not depend on its ability to foster other virtues (Ross, 2020). Care and worry are closely related to and frequently linked with curiosity (Ross, 2020). Jordan Stewart-Rozema (2019) emphasizes that curiosity is crucial not only for knowledge acquisition but also for ethical life, arguing that it has the potential to aid both learning and care (Stewart-Rozema, 2019). She proposes expanding the understanding of curiosity to encompass its role in moral development. My stance is that any friendship or close relationship benefits from curiosity because of its link to care and concern. "Curiosity is conducive to the kind of deep caring that characterizes close relationships" (Ross, 2020). This means that the relationship that the health care practitioner has with their patient will be strengthened by the open communication and the understanding that they have.

Lewis Ross (2020) states that a virtuous person will feel a curiosity that is demanding (not readily satisfied), timely (arising in suitable conditions), and correctly discriminating (focused on the right object) (Ross, 2020). My stance is that a child between the ages of 6-8 years should assumedly not have any malicious reason to enquire about their own HIV status. Given the right circumstance (a home where communication is foster and a child feels free to approach

their parent with their own ideas of the world) and the appropriate level of maturity, the child's curiosity is harmless.

The counterargument that may be brought up is that curiosity is not a virtue. This may be argued in the sense that a virtue ought to be an admirable characteristic of excellence. But when one person's curiosity leads to someone else's harm then it is not admirable. When acting out of curiosity, one may endanger others or infringe on their right to privacy (as with the parent, should the child unintentionally learn of the parent's HIV status). However, I have claimed that the need to be curious may be somewhat controlled by us, not the acts that result from it. The health care practitioner ought to try to ensure as far as possible, that the child's curiosity does not cause any harm to anybody else, by ensuring that there is no violation of other person's right to privacy or confidentiality.

Saying that curiosity is a virtue implies, most crucially, that it aids in leading a fulfilling life. There is debate over how to prove the link between any asserted virtue and leading a good life. Some suggestions include proving that the virtue makes people happy or satisfies their desires, proving that it aids in obtaining some of the specific benefits shared by all who lead good lives, or proving that the virtue aids in avoiding a vice, which is a hindrance to leading a good life. My stance is that if the child's curiosity is used as the rule to initiate the disclosure, then it does serve the child well because the child will be empowered with knowledge.

Conversely, children do not all mature at the same pace. There may be children in the age 6 to years who do not show any curiosity of their HIV status, it is the health care practitioner's onus to spark that curiosity so that the child may benefit from the disclosure process. The hope is that this knowledge will help the child stay adherent on their HIV treatment, which in effect will help them to stay healthy, which is one of the many benefits of disclosure. Thus, the idea that the child will be living well is achieved.

5.2. When a child demonstrates the capacity to receive partial disclosure then disclosure of their HIV status should be initiated with them.

A person's capacity is determined by their ability to comprehend the pertinent information that has been offered (such as the discussion's objective anticipated dangers, and potential benefits), as well as their understanding of the possible effects of any decisions they make based on this knowledge (Hawkins et al., 2020). According to Derish and Vanden Heuvel (2000), mental capacity in the context of health refers to a clinical assessment of a person's capability to make justifiable and realistic decisions about their health (Derish & Vanden Heuvel, 2000). This encompasses the choice to accept, decline, or engage in medical care.

There are four qualities listed as necessary for (medical) decision-making: firstly, the ability to communicate a choice; secondly, having some understanding; thirdly, the ability to give reasoning; and finally, demonstrating a level of appreciation (Grootens-Wiegers et al., 2017). "Each ability has a number of associated particular skills and talents that must be properly developed to sustain the capacity" (Grootens-Wiegers et al., 2017). All four capacity requirements must be satisfied for a child to be deemed capable of making a choice.

In order to strike a balance between patient protection and respect for autonomy, medical decision-making requires a certain level of skill. Competence means that the person has a certain level of knowledge and skill to participate or make decisions. According to Grootens-Wiegers et al. (2017), to be adequately competent, one must not only possess the mental ability to make judgments but must also be accountable for those decisions. In other words, even if a person may theoretically possess the mental capacity to make a sensible choice, some circumstances such as a serious illness, stress, or social pressure—can diminish that person's competence (Grootens-Wiegers et al., 2017). The health care practitioner ought to weigh the benefits against the harms of disclosure and make the decision whether to disclose to the child

or not. In cases where the child is admitted for any complications of HIV due to lack of treatment or defaulting, this may lead to HIV encephalitis (when the HIV infection spreads to the brain, causes swelling, possible dementia and other neurocognitive dysfunctions) then the child's capacity may be affected. It may be in the child's best interest to not receive disclosure until such a time then their condition has stabilized, and the infection has subsided.

Virginia Held's defence focuses on the moral significance of genuine, compassionate relationships. When working with a patient, it is crucial for health care practitioners to remember the role that emotions play in helping us comprehend what to do and in driving us to take the ethically right course of action (Held, 2006). Held (2006) maintains that without empathy it may be difficult for a health care practitioner to show care in a way that fits into society's moral standard. Without care, one would not be willing to step up and help people in need (Held, 2006). According to ethics of care, morality is more about the health care practitioner assuming accountability for the other person in need than it is about intellectual recognition (Held, 2006).

In their article titled: "Ten myths about decision-making capacity," Ganzini et al. (2004) claim that decisional making capacity is not an on-or-off phenomenon, they contend that the ability to make decisions depends on the particular choice in a particular circumstance. Drotar et al., (2004) identified four predisposing factors which influence a child's decision-making capacity, namely the child, the parent, the health care practitioner and situational factors (Drotar et al., 2004). In addition to these, a child's cognitive development and some experience with medical treatment may also contribute to the child's capacity to make decisions and be a competence participant in decision making processes (Drotar et al., 2004).

A child's personality and a child's emotional state of mind can affect capacity, these can also be a motivator for information-seeking and for the child to show their preferences (Grootens-

Wiegers et al., 2017). Furthermore, a child's disease severity can affect their understanding of the information provided and the child's ability to concentrate and retain information long enough to communicate a preference (Grootens-Wiegers et al., 2017). Parents and health care practitioners will also influence a child's capacity with their attitude towards the child, the attention they give the child and how supportive they are of the child during the disclosure process. Situational considerations include the nature and degree of the information provided, as well as the occasion and environment of the disclosure. Children's capacity to understand information and, consequently, skills to make decisions, expand as they get older (Grootens-Wiegers et al., 2017).

The African Charter, article 7, "Freedom of Expression" states that: "every child who is capable of communicating his or her own views shall be assured the rights to express his opinions freely in all matters and to disseminate his opinions subject to such restrictions as are prescribed by laws" (African Charter, 1997). As learned from research done on children living with cancer, there are some positive outcomes that have been associated with open communication with children living with cancer about their cancer diagnosis (Cole & Kodish, 2013). Increased survival rates, the growth of the children's rights movement, the rising demand for children to participate in gruelling testing procedures and treatment regimens, and findings from psychological studies suggesting a continuum of cognitions through which kids frame illness and death are some of these outcomes (Cole & Kodish, 2013).

According to international children's law, "a child's right to participate crucially demands the recognition, respect and meaningful engagement of children during decision-making processes relating to all matters concerning them, both in private and in public" (Fokala & Rudman, 2020). The right of children to participate also highlights the necessity of parents encouraging their engagement (Fokala & Rudman, 2020). Adults must routinely evaluate a child's capacity

based on their age, maturity, and potential to significantly contribute to a decision-making process, especially those who have a legal duty to care for a child (Fokala & Rudman, 2020). The significance of this obligation stems from the fact that, in contrast to other rights, the right to participation calls for a child to be actively involved in the decision-making process (Fokala & Rudman, 2020). “The enjoyment or renunciation of this privilege depends on the meaningful engagement—or lack thereof—enabled by the pertinent adult(s)” (Fokala & Rudman, 2020).

5.3. When a child is of sufficient maturity to participate and be heard in decision-making process about his or her own health treatment then partial disclosure ought to be initiated.

“A child is considered to be sufficiently mature when they understand information that is given about their illness, and they are able to act in accordance with appreciation of that information” (The Children’s Act of, 2005). In many contexts, the child’s cognitive development determines how mature they are. Maturity will be displayed through the child’s moral development and their emotional, social and physical growth (Havenga & Temane, 2015; Pillay & Singh, 2017).

During childhood the child’s ability to retain and understand information in specific amounts and depth develops (Grootens-Wiegers et al., 2017). Maturity in orientation and attention develops around the ages of 7–10 (Grootens-Wiegers et al., 2017). “Memory specifically increases between the ages of 6 and 12 and then goes on to slightly increase during adolescence” (Grootens-Wiegers et al., 2017).

Article 12 of the CRC states that: “State Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child” (United Nations, 2019). In a research study conducted by Weithorn and Campbell (1982), the competence of healthy children was evaluated based on their capacity to respond

to hypothetical questions (Weithorn & Campbell, 1982). They found that most children by the age of 9 were able to understand simplified information about health-related issues (Weithorn & Campbell, 1982). “It stands to reason that basic choices regarding the administration and minor surgical interventions are in the abilities of decision making for younger children” (Weithorn & Campbell, 1982, p.5).

Section 130(2)(a) of The Children’s Act 38 of 2005 states that “consent for an HIV test on a child may be given by the child only if the child is 12 years of age or older or under the age of 12 years but is of sufficient maturity to understand the benefits, risks and social implications of such a test” (Section 130, The Children’s Act 38 of, 2005). My stance is that through a series of dialogues between the child and the health care practitioner, a child’s maturity for healthcare decision-making can be developed if the health care practitioner is supportive and willing to help foster the child’s maturity.

Article 24 of the CRC teaches that every child has the right to the best facilities for the treatment of disease and the restoration of health, as well as the greatest quality of health that is reasonably feasible.

The following essential components can be used to deconstruct the idea of health: First, every child can participate in decisions about what happens to his or her body thanks to the child's right to health. This involves the capacity to decide on matters pertaining to one's health. It also implies that, for any reason, no one should deprive her or him of this right.

Second, the right to health encompasses a whole condition of physical, mental, and social well-being and goes beyond simply the absence of disease. Which means that whatever decisions are made to affect the child, their biological, social and psychological needs need to be taken into consideration.

Thirdly, there are several factors that might have an impact on a child's wellbeing. Children can get stronger and happier if they have access to food, water, a safe home, and supportive surroundings. Additionally, in order to make wise decisions regarding your health, information and awareness are essential. The right to health includes all of these factors since, without them, the right to health cannot be realized. This means that the care given by the health care practitioner ought to ensure that these determinants are not disrupted by the disclosure process.

Some responsibilities that we have as humans ought to be aimed at fulfilling the needs of those vulnerable individuals in society (including their need for empowerment). The disclosure process is an on-going step by step journey that the health care practitioner takes with their patient. As Care Ethics teaches, morality demands not once-off actions, but care needs to be an ongoing pattern of actions and attitudes. The disclosure would be justified because it is an act of care. Ethics of care teaches that an act is right if and only if it is a manifestation of the appropriate amount of caring attitudes (Held, 2006).

Care ethics offers an alternative way of deliberation for decision-making with the primary focus being a sympathy approach. This involves appreciating someone else's situation from their perspective and being moved to help them because of what the health care practitioner sees from that perspective. This requires giving full attention to the patient, while attempting to see the world as they see it from their perspective -- not to see the world as you would see it if you were in their situation (Kittay 1997; Noddings 2010; Sevenhuijsen 1998). This perspective allows the health care practitioner to know better what their patient needs or wants, why they need or want that care, and how you might help.

5.4. Preparing the child for decision making on HIV treatment or health.

My stance is that it is ethically justified for a health care practitioner to initiate partial disclosure with a child when preparing the child for decision making on HIV treatment.

To care means that you devote thought, interest and concern for something or someone because you consider it important. Care between people extends across many spheres, bringing people into relations with one another.

Because of the nature of care, it will always involve two or more parties. In the case of my dissertation, one party is the person being cared for (care recipient) and the second party is the person providing the care (the caregiver). The role of a health care practitioner and a parent is to provide care, which means that at different times they will pay the role of caregiver. Care involves maintaining the world of, and meeting the needs of, us and others (Held, 2006). It builds on the motivation to care for those who are dependent and vulnerable such as children.

Caring and being cared for are really important for human flourishing (Held, 2006). This means being engaged in activities and relationships which are meaningful to ensure that there is continued development of one's potentials and living well (UNESCO, 2021). Human flourishing aims to uphold, protect, restore and/or enhance the human experience of living through fundamental elements (VanderWeele, 2017). This means that there is a predisposed cognisance of a care recipient's given need, a willingness to address that need, the competency to effectively address that need by quality care and a well-informed response from the health care practitioner in the event of potential exploitation of care practices (VanderWeele, 2017).

There are four sub-elements of care that can be understood simultaneously as stages, virtuous dispositions, or goals. Firstly, a health care practitioner should be attentive in the sense that they have the ability to pick up what their patient needs. Secondly, they ought to have a sense of responsibility, so as to take care of the identified need. They need to possess the necessary competence and skill set to successfully take care of their patients' needs. And finally, they ought to be responsive enough to be cognisant of their patient's position and not abuse the responsibility given to them to provide a service to their patient (Held, 2006; Maio, 2017).

Caring about someone typically comes with a degree of partiality toward them. To care about someone is to elevate their needs to some degree in your calculation of what matters (Held, 2006). According to Nel Noddings it is impossible to care for everyone. She maintained that while the one caring has an obligation to care for proximate humans to the extent that they are needy and able to respond to offerings of care, there is a lesser obligation to care for distant others if there is no hope that care will be completed (Held, 2006). This means that there is a form of reciprocity that needs to take place in order for care to be realised.

Nonetheless, the emphasis on the moral dimension of relationships and the appreciation of virtues which make relationships more stable are two of the crucial elements at the heart of an ethics of care (Maio, 2017). The recognition and appreciation of virtues such as benevolence, truth-telling, trust and honesty add value to the relationship. Therefore, in situations whereby a child is ill and there is no parent to give consent for disclosure to be initiated, it would be justified to disclose to the child their HIV status and initiate them on treatment so that they are well-taken care of. "Well-being" or living well according to ethics of care is seen as caring for those people who are close, attending to their needs and maintaining their trust (Rachels & Rachels, 2019).

5.5. Child posing risks to themselves because of ignorance (e.g., defaulting)

When a child is posing a risk to themselves because of ignore then it is ethically justified for disclosure to be initiated with the child. First, ignorance entails that the child is unaware of the risk that defaulting has on their health. This means that the health care practitioner ought to initiate disclosure with the child so that the child is not a harm to themselves. The principle of non-maleficence teaches that the health care practitioner ought to ensure that he or she removes harm when they can see that their patient is posing a risk to themselves.

My stance is that for the health care practitioner to show care, they ought to initiate disclosure with the child. In the context of a health care practitioner disclosing to a child their HIV positive status against parental consent, the caring relation can only exist if the child being cared for can interact and receive the care being given by the health care practitioner. At minimum, the care-recipient must be able to receive and acknowledge the care in a personal, one to one encounter (Rachels & Rachels, 2019). This means that a relationship needs to exist between the child and the health care practitioner, outside of the assumed pre-existing relationship between the health care practitioner and the parent.

Normatively, care ethics seeks to maintain relationships by contextualizing and promoting the well-being of caregivers and care-recipients in a network of social relations (Held, 2006). This means that there is some fulfilment that the health care practitioner gains from giving care to his or her patients. And on the other hand, the patient who is the care-recipient benefits from the intervention and measures that the health care practitioner puts in place to help them.

Rachels and Rachels (2019) describe the ethics of care as perfectly suited to the kind of relationship a health care practitioner may have with their patient. They emphasize that ethics of care does not take obligations or duties as fundamental; nor does ethics of care require that we impartially promote the interests of everyone alike. This means that a relationship between a health care practitioner and the child ought to benefit the child regardless of whether there is parental consent or not. My argument is that as long as there is no harm to the child or to the parent, the health care practitioner is ethically justified to disclose to the child their HIV status against parental consent.

Practising care means recognising that each individual lives within a basic structure of dependence, whether or not they are conscious of this dependence (Maio, 2017). This is what makes relationships, the two parties involved needing each other. For the health care

practitioner, it is imperative that they disclose to the child because they know the benefits it will have on the child. Care thus places significantly more value on affective connections and prioritises interactive actions for resolving ethical conflicts (Maio, 2017).

5.6. Child posing risks to other because of ignorance (i.e., if they are sexually active or share needles). These risks of course should consider the age of the children.

Health care practitioners ought to preserve, protect and promote a child's right to health. Every child needs to have access to adequate healthcare and health education to protect themselves and others from HIV.

Care is most often defined as a practice, value, disposition, or virtue. Philosopher Virginia Held (2006) notes that care is a form of labour, but also an ideal that guides normative judgment and action, and she characterizes care as "clusters" of practices and values (Held, 2006). Care is not limited to voluntary or relational efforts and may include paid work (Held, 2006). This means that care can be tied in with a profession or line of work within healthcare, whereby there is an expectation for care to be provided whether it is from the patients or whether it is an intention the health care practitioner has. It is worth mentioning that one may unconsciously care for another, but for the purpose of this dissertation, only conscious care is taken into account. For the healthcare setting, the health care practitioner ought to be in a state of awareness concerning his or her own emotions, intentions, choices and actions when deciding to care for or meet the needs of a care recipient (Kalfoss & Cand, 2016).

Held describes a caring person as one who has appropriate motivations to care for others and who participates adeptly in effective caring practices (Held, 2006). Political scientist Daniel Engster develops a "basic needs" approach to care, defining care as a practice that includes "everything we do to help individuals to meet their vital biological needs, develop or maintain

their basic capabilities, and avoid or alleviate unnecessary or unwanted pain and suffering, so that they can survive, develop, and function in society" (Engster, 2006).

Moreover, care allows for a health care practitioner to have a one-on-one relationship with their patient against parental consent. As Carol Gilligan (1982) states in her book, for care to be realized, the network of relationships which bind us to others needs to be acknowledged, therefore there is a necessity to be there for others for this care to be realized (Gilligan, 1982).

The political scientist, Joan Tronto understands care not primarily as virtue, but rather as practice (Tronto, 1993). She makes it clear that care cannot be achieved through good intentions alone but can only be considered to have been carried out when these good intentions have actually resulted in some kind of effect on the other person (Tronto, 1993).

Based on Tronto's views it would be ethically justified for a health care practitioner to disclose to a child who is posing a risk to others because the intention is good. Good in the sense that the disclosure is to educate and protect the child from re-infection which comes as a risk of needle sharing. The hope is that from this knowledge provided by the health care practitioner, the child will also start making responsible decisions in terms of not sharing needles with other people and thereby protecting them from getting HIV. And more importantly, the child will stop using drugs because they realize the negative impact it has on his or her life.

Therefore, disclosure ought to be initiated with the child to ensure that they do not pose a danger to themselves or those they interact with especially when they grow up and engage in sexual activity or needle-sharing.

In this chapter I argued that there are conditions under which it would be justified to initiate partial disclosure of a child's HIV status against parental consent. Though it may be argued that there are many exceptions to why disclosure should not be initiated, my stance is that

there are significant benefits to initiating disclosure with a child who is living with HIV, and there are procedures and guidelines that can guide health care practitioners to navigate appropriate disclosure where there are exceptions. Furthermore, these exceptions should not prevent a health care practitioner from looking into other ways of initiating disclosure or involving other specialised or allied fields of healthcare. More research into these exceptions is needed.

Chapter 6: Conclusion

The rationale for my dissertation was to emphasize that partial disclosure with a child who is HIV positive is ethically justified against parental consent, when the child has sufficient maturity to understand the information given to them and appreciate the benefits, risks and possible consequences of the disclosure. The aim was to highlight the benefits of disclosure and to argue that the possible harms of disclosure are minimal and mitigatable.

6.1 Overview of arguments

In my dissertation I attempted to answer the research question: "Is it ethically justified for a health care practitioner to initiate disclosure with an HIV positive child against parental consent?" I argued that it is ethically justified for a health care practitioner to initiate partial disclosure with HIV positive children between ages 6 – 8 years, even against parental consent, if it is in the best interest of the child and if the child has sufficient maturity.

To support my claim, I use existing literature and arguments grounded on moral theories. I evaluate the initiation of partial disclosure for children between the ages 6 to 8 years. Given the benefits HIV disclosure to children, I argue that it is ethically justified for a health care practitioner to initiate HIV disclosure with children between 6 to 8 years against parental consent.

Firstly, I discuss the child's age, the concepts of maturity and capacity in chapter 2. I discuss how maturity can be displayed by children even younger the age of 12 years. I argue that capacity and maturity can be developed through different life experiences such as if a child suffers from chronic medical conditions such as asthma, and how previous experience with hospitalization can make a child mature enough to understand HIV disclosure. I discuss the best interest principle and how it applies to disclosure of the child's HIV status through the process of partial disclosure. I argue that partial disclosure is appropriate for children between

the ages of 6 to 8 years because children in this age group are able to understand and appreciate simple information given to them in a stepwise manner. In chapter 3 I compare the benefits and risk of the status quo of non-disclosure and delayed disclosure with partial disclosure of a child's HIV status. I discuss the Principle of Utility and elaborate on how initiation of disclosure maximises the principle of utility. I use rule utilitarianism to argue that if the rule of partial disclosure by a health care practitioner is ethically justified, it maximises well-being for the child.

Secondly, in chapter 4 I analyse the dual loyalty dilemma the health care practitioner faces when the parent(s) refuses to initiate or participate in the HIV status disclosure of the child. In this chapter I develop my argument by explaining loyalty and applying it to the disclosure process for a child. I explain how the health care practitioner has a dual loyalty when he or she is treating a child because the child is under the care of their parents. My stance in this chapter is that the health care practitioner ought to honour his or her loyalty to the child above and beyond any needs the parent may have. I argue that it is possible for the child to receive disclosure of his or her HIV status without disclosing the parent's HIV status.

Finally, in chapter 5 I argue for conditions under which it would be justified to initiate partial disclosure of a child's HIV status against parental consent. I start by emphasising that disclosure is ethically justified when a child shows interest and curiosity about their HIV diagnosis. I make an attempt to explain curiosity as a virtue to living well. I explain the benefits of disclosure and how these can be sparked by the child's curiosity. I explain that it is the health care practitioner's onus to stimulate curiosity because the knowledge gained from initiating HIV disclosure discussions is beneficial for the child. I make provisions to say that the instances where curiosity may not be good, is if there is curiosity about their people's diagnosis or infringement of the parent's confidentiality. I argue that curiosity of the child is

imperative for the child's growth and cognitive development. I also reiterate the concept of capacity and maturity, and how these concepts should be assessed for the disclosure process to be successful and beneficial for the child. I argue that disclosure may be ethically justified in the process of preparing the child for decision making on HIV treatment and health. I make arguments to say that disclosure may be justified on the condition where the child is posing a risk to themself because of ignorance (e.g., defaulting). Furthermore, I argue that another condition where partial disclosure is justified is if the child is posing a risk to others because of ignorance (i.e., if they are sexually active or share needles). I make attempts to respond to any objections whereby disclosure may not be justifiable.

6.2 Final Remarks

A child between the ages of 6 to 8 years is of sufficient maturity to receive disclosure. Children in this age group can understand basic information when it is given in a step wise process. The appropriate form of disclosure for children between the ages of 6 to 8 years is partial disclosure. Partial disclosure is when a child is informed of his or her illness without calling the illness by its name (Van Elsland et al. 2018). Full disclosure means that the child is provided with full information and has knowledge about the illness (Van Elsland et al. 2018). What researchers have found is that delayed disclosure may lead to accidental disclosure whereby the child finds out they are HIV positive without gaining this knowledge from their parent or from a health care practitioner (Van Elsland et al. 2018; Gyamfi et al. 2017). The problem is that often times the child finds out their HIV status in a negative manner whereby there is stereotypes, bullying or stigma attached to the HIV (Van Elsland et al. 2018; Gyamfi et al. 2017). Partial disclosure provides more benefits for the child than harms. Once the child is empowered with knowledge, stigma is alleviated, the child has a more cheerful outlook because they are healthy, and their lives resemble those of their age

mates. Furthermore, children who know their HIV status have better health outcomes and fare well in school because they are not getting recurrent infections form lack of treatment or defaulting treatment (Van Elsland et al. 2016). Clinical reports have indicated positive outcomes associated with disclosure including the promotion of trust, enhanced access to support services, open family communication, and better long-term health and emotional well-being in children (Wiener et al, 2007).

To respect the child's autonomy means that, the health care practitioner has a fundamental obligation to ensure that patients have the ability to choose, as well as the right to ability or decline information (Beauchamp & Childress, 2001). Though there may be differences based on different cases and scenarios, Hawkins et al. (2020) have stated these four elements (understanding, appreciation, reasoning and choice) to make up mental capacity. My argument is that if a child can demonstrate these fundamental elements at any given age, then they have sufficient maturity and capacity to participate in HIV disclosure. Basic comprehension and knowledge or cognition of facts is one minimal interpretation of understanding (Grisso & Appelbaum 1998). Because partial disclosure involves the use of basic terms and a breakdown of information, it is appropriate for children to grasp when disclosure is initiated.

The principle of "the best interest of the child" is implemented in Article 3 (1) Convention on the Rights of the Child (CRC), which states that in all actions concerning children, the best interests of the child shall be a primary consideration. The best interest principle is often associated with consequentialism because of its tendency to lean towards calculating welfare, by balancing benefits and burdens, and aiming to maximise the good. A health care practitioner ought to ensure that they weigh the benefits and harms of each child that they initiate disclosure with this is particularly important because not every child's circumstances will be the same.

Many utilitarians believe that pleasure and pain are objective states and can be, more or less, quantified (White, 2022). The rule that a health care practitioner may initiate HIV disclosure with a child against parental consent is followed, then more and more children can stay compliant on medication and have a better quality of life, therefore a greater good for a greater number will be achieved. I argue that a rule utilitarian would consider partial disclosure as a justifiable rule because initiating partial disclosure with the children, who have capacity and maturity - in this case 6 years and above, will produce more well-being for the child.

Dual loyalty may be defined as a clinical role conflict between professional duties to a patient and obligations, expressed or implied, to the interests of a third party. Loyalty is expected in the relationship between a health care practitioner and his or her patient. It is one of the fundamental qualities that drive the healthcare profession. Loyalty is necessary for transparency, truthfulness, honesty and trust in the care of patients. The health care practitioner ought to show loyalty to the child because they feel an obligation to disclose to the child the child's HIV positive status because they believe that it is in the child's best interest to know their own HIV positive status. Simultaneously, the health care practitioner may feel obliged to ensure that they do not intentionally make the parent's HIV positive status known to the child during the disclosure process, as doing so may be seen as infringing upon the parent's right to confidentiality of their own HIV status. My argument is that it is ethically justified for the health care practitioner to put the child's interest before the parent's interest by initiating disclosure with the child against parental consent. The health care practitioner ought to ensure, as much as possible that they do not intentionally disclose the parent's status.

Curiosity is deeply linked to all aspects of human development and growth, which foster the process of acquiring skills and knowledge. Partial disclosure is when is appropriate for children between the ages of 6 to 8 years because it will satisfy their curiosity. My stance is that the child's curiosity is a justifiable condition for their HIV status to be disclosed to them so that they may experience the benefits of disclosure.

Capacity is a person's ability to understand relevant information presented (e.g., purpose of the information or discussion, foreseeable risks, and potential benefits), and to appreciate the potential consequences of any decision they make based upon this information (Hawkins et al., 2020). This includes the ability to participate, consent to or refuse medical treatment. Children between the ages of 6 to 8 years who show understanding, appreciation, reasoning and the ability to express a choice are ethically justified to receive disclosure.

A child is considered to be sufficiently mature when they understand information that is given about their illness, and they are able to act in accordance with appreciation of that information. As I have argued, most children in my chosen age group can understand basic information about disease and illness. As stated by Weithorn & Camp "children younger than 9 years are capable of making basic choices regarding the administration and minor surgical interventions are in the abilities of decision making for younger children" (Weithorn & Campbell, 1982, p.5).

When a child is posing a risk to themselves because of ignore then it is ethically justified for disclosure to be initiated with the child. Ignorance entails that the child is unaware of the risk that defaulting has on their health. This means that the health care practitioner ought to initiate disclosure with the child so that the child is not a harm to themselves. Non-maleficence teaches that the health care practitioner ought to ensure that he or she removes harm when they can see that their patient is posing a risk to themselves.

Health care practitioners ought to preserve, protect and promote a child's right to health. To prevent HIV in themselves and others, each child needs to have access to quality healthcare and health education. For the healthcare setting, the health care practitioner ought to be "in a state of awareness concerning his or her own emotions, intentions, choices and actions when deciding to care for or meet the needs of a patient in their care" (Kalfoss & Cand, 2016).

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UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

Faculty of Health Science

Division of Postgraduate Academic Management

Declaration of Intention to Submit for Examination

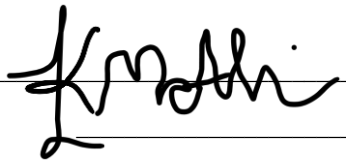
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Name of Candidate:	Kethabile Isaac Matli
Person Number:	705992
Programme:	Master of Science in Medicine (Bioethics and Health Law)
School:	Clinical Medicine- Steve Biko Center for Bioethics
Title of Thesis/Dissertation/ Research Report:	HIV status disclosure to children by health care practitioners against parental consent in South Africa

Name and Surname of Supervisor / Co-Supervisor	Supervisor / Co-Supervisor	School	% of Supervision
Lizeka Tandwa	None	Clinical Medicine- Steve Biko Center for Bioethics	100

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