

# **Ethical Perspectives Regarding Human Immunodeficiency Virus (HIV) Positive Children in Childcare Centres**

by  
Sadiya Fatima Adams

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Supervisor: Dr. Susan Hall

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To my mother, father and brother I dedicate this thesis. Their unwavering love, support and encouragement enabled me to stay motivated and pushed me to persevere this achievement.

## **ABSTRACT**

The human immunodeficiency virus (HIV) pandemic gives rise to a vast array of moral and ethical issues. The enrolment of HIV positive children in childcare facilities, in particular, presents a unique set of ethical issues and concerns, including dilemmas with regard to status disclosure, and ethical guidance is required in this regard. The main objective of this study is to argue in favour of a controlled means of disclosure in childcare institutions. However, status disclosure and stigmatisation present a complex relationship that needs to be examined in detail. Against the background of this relationship, this dissertation will attempt to provide a principlist analysis of various ethical considerations with regard to status disclosure, taking into account the perspectives of the guardians of the HIV positive child, the childcare director of the facility, the other children attending the facility, and the HIV positive child him/herself. Finally, this dissertation will attempt to provide a framework for status disclosure of HIV positive children in childcare settings, with specific reference to the Namibian context.

## ABSTRAK

Die menslike immuuniteitsgebrekswirus (MIV)-pandemie lei tot 'n magdom etiese en morele vraagstukke. Die opname van MIV positiewe kinders in kindersorg-inrigtings is, by uitstek, 'n tekenende toonbeeld van wat hierdie dilemma behels. Dit sluit kwessies ten opsigte van MIV-status openbaarmaking in, wat etiese riglyne vereis. Die hoofdoel van hierdie verhandeling is om 'n saak te beredeneer ten gunste van die beheerde openbaarmaking van jong kinders se MIV-status in openbare kindersorg-inrigtings. Die openbaarmaking van MIV-status en daaropvolgende stigmatisering verteenwoordig egter 'n komplekse verhouding wat nader beskouing verg. Teen die agtergrond van hierdie verhouding, poog die verhandeling dan ook om 'n analise, gebaseer op beginselmatigheid (*principlism*), te voorsien. Dit neem verskeie perspektiewe in ag: die ouers/voogde van die MIV-kind, die hoof van die kindersorg-sentrum, die ander kinders wat die sentrum bywoon, en die MIV-kind self. Ten laaste, die verhandeling bied 'n raamwerk aan vir status onthulling van MIV positiewe kinders in kindersorg omgewings, met spesifieke verwysing na die Namibiese konteks.

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## **List of abbreviations, initialisations and contractions**

AIDS – acquired immunodeficiency syndrome

ART – antiretroviral therapy

BCG - Bacillus Calmette-Guérin

CDC – Centers for Disease Control and Prevention

HIV – human immunodeficiency virus

ICRW - International Center for Research on Women

MoHSS – Ministry of Health and Social Services

MTCT – mother-to-child transmission

PEP - post-exposure prophylaxis

UNAIDS – Joint United Nations Programme on HIV and AIDS

USA – United States of America

WHO – World Health Organization



## Definitions

“caregiver” refers to any individual other than a guardian or parent, who takes primary responsibility for the day-to-day care of a child and includes –

- (a) A foster parent;
- (b) A primary caretaker
- (c) A kinship care-giver;
- (d) An individual who cares for a child while the child is in a place of safety;
- (e) The head of a facility where a child has been placed; and
- (f) The child who is the head of a child-headed household;

(Republic of Namibian 2015: 11).

“childcare director” refers to an individual who manages and leads the staff at a child care centre. A childcare provider provides guidance and support to the educational staff and cultivates an environment in which parents and their children can feel secure, safe and well-educated. The childcare director is responsible for everything that goes on at the facility; (Great sample resume n.d.).

“guardian” refers to a parent or other individual who has guardianship of a child; (Republic of South Africa 2005: 22).

“parent”, in relation to a child, refers to a man or woman in respect of whom parentage has been acknowledged and includes the adoptive parent of a child, but excludes –

- (a) The biological father of a child who has been conceived through the rape of or incest with the child’s mother;
- (b) An individual who is biologically related to a child by reason only of being a gamete donor for artificial fertilization; or
- (c) A parent whose parental rights and responsibilities in respect of a child have been terminated;

(Republic of Namibia 2015: 14).

## **Chapter 1: Introduction**

### **1.1 Significance and motivation of a discussion of ethical issues relating to HIV positive children in childcare centres.**

The human immunodeficiency virus (HIV) and acquired immunodeficiency syndrome (AIDS) pandemic has generated a considerable amount of research, due to its profound effects worldwide. According to data obtained by the Joint United Nations Programme on HIV and AIDS (UNAIDS), in 2018, an estimated 37.9 million people were living with HIV, of which 1.7 million were children below the age of 15. (UNAIDS.org 2019a). It is evident from these statistics that the HIV and AIDS pandemic is one of the most pressing global issues of our age. Additionally, the HIV pandemic has presented a vast array of moral and ethical issues pertaining to human life and dignity. The enrolment of HIV positive children in day-care establishments and primary schools, in particular, presents a unique set of ethical issues and concerns.

One of these concerns relates to the reduced capacity of children to make autonomous and competent decisions, specifically pertaining to their health. One can ask whether a child infected with HIV and AIDS is truly capable of comprehending the seriousness of the disease, if they are aware of their status at all. Studies show that parents usually delay status disclosure to their children until they are at least 10 years old (Klitzman, et al. 2008: 31).

Children and adults have different sets of needs, and this also pertains to the management of their medical care. The optimal management of a child's chronic illness requires intensive adult involvement, which would ideally include not only parental supervision, but could also extend to the involvement of childcare providers and/or school nurses. Juvenile diabetes, for example, is a serious illness, which requires extensive adult involvement to ensure optimal medical management. Information about such a condition is usually expected to be shared with childcare providers. An article published by the American Diabetes Association states that young children "often lack the fine motor control, cognitive development, and impulse control necessary to be...active participant[s] in most aspects of diabetes care." Although the management of HIV and AIDS would observably differ from that of juvenile diabetes, the underlying principle remains the same (Silverstein, et al. 2005: 190). In the absence of a

parent or guardian who would usually undertake medical and health decisions, one may therefore ask whether it is possible for a substitute caregiver who is unaware of a child's status to provide the best care, both to the HIV positive child as an individual, as well as to other children attending a particular facility.

In such circumstances, one might reason that it would be beneficial for all parties if the centre director or nurse of the relevant childcare facility were aware of cases of HIV in children attending the facility. However, parents are understandably reluctant to disclose the positive status of a child for fear of stigmatisation and discrimination, which might have harmful effects for the child. What is more, in the unfortunate event that the community at large were to find out about their status, it might provoke an inordinate amount of emotional suffering and lead to isolation due to possible negative treatment (Kimani-Muragea, et al. 2013: 745).

The literature which exists on this topic responds to these concerns on the basis of the current understanding of HIV transmission. Nonsexual household transmission of HIV is unlikely and casual contact between children should not be considered a risk for transmission of the disease. Moreover, the HIV status of a child is confidential information that is not expected to be disclosed. As it stands, educational staff are expected to apply universal precautions and basic hygiene practices to contain the spread of infectious diseases, including HIV (Renaud, et al. 1997: 26; Taras 1998: 451). No documented cases exist in which HIV transmission was found to have occurred in the context of a day-care centre.

However, open skin lesions, injuries that lead to bleeding, biting behaviours and uncontrolled body secretions still pose a risk for HIV transmission. While the risk of HIV infection following a human bite from an HIV infected individual may be epidemiologically insignificant, it is still biologically possible. Human bites may possibly transmit bloodborne pathogens, such as HIV and hepatitis C, by exposing the biter's oral mucosal to the bitee's blood, and the bite wound to the saliva of the biter. Hepatitis C and HIV transmission requires "visible blood" exposure, and as saliva is usually bloodfree, the risk of transmission from biter to bitee is generally small. However, biters may require Hepatitis C and HIV testing after bloody saliva bites, as they may be exposed to the bitee's blood (reverse exposure) (Lohiya, et al. 2013: 92). Moreover, there are existing cases in which HIV transmission was found to have occurred as a result of a human bite from untreated HIV positive individuals to HIV negative individuals, particularly in scenarios where saliva was

mixed with blood (Bartholomew and Jones 2006: 631; Deshpande, Jadhav and Bandivdekar 2011: 1; Shirley and Ross 1989: 425;). In addition, scientists have detected the transmission of HIV from one child to another in the same household. Although the exact cause of infection in this specific case is unknown, the most likely possibility is that the virus was transmitted through blood exposure (Wahn, et al. 1986: 694).

However, one should take note of the fact that the introduction and widespread availability of antiretroviral therapy (ART) has altered the state of affairs with regards to HIV transmission. HIV transmission is much less likely if the infected individual is on effective ART. Evidence shows that an undetectable viral load due to ART means that HIV is not transmittable to offspring and sexual partners (Siedner and Triant 2018: 173). However, in the scenario which I wish to focus on in this thesis, one cannot know with certainty whether an HIV positive child is on necessary ART. In addition, maintaining an undetectable viral load requires good adherence to a prescribed treatment regimen, which may necessitate that all caregivers are informed as to the optimal management of this treatment in children in their care.

HIV and AIDS is an incredibly delicate issue which needs to be sensitively addressed, paying particular attention to the individual physical and psychological struggles of those affected by it. However, one cannot dismiss the fact that HIV and AIDS also affects society at large. Therefore, from this angle, HIV infection should not necessarily be viewed as a strictly private matter. A utilitarian approach, for example, would encourage decision-making that would ultimately maximize the greatest good for the greatest number of people, and would therefore take all affected by a particular decision into account. However, one may ask whether this argument is relevant in contexts where the likelihood of harm occurring is extremely low, even if the magnitude of that possible harm is great. This seems to be the case with regard to the risk of HIV infection in day-care facilities.

As educators are trained to apply universal precautions to contain the spread of infectious diseases, and parents are reluctant to disclose their child's positive status due to fear of stigmatisation, no alternative guidelines or strategies have been explored with regard to this matter. It is for this reason that I was inspired and motivated to investigate whether the existing status quo is satisfactory by means of a philosophical discussion. Major ethical issues raised in this study concern those pertaining to privacy and confidentiality, status

disclosure, stigmatization and harm. Considering the alarming number of paediatric HIV cases worldwide, there is a pressing obligation to gain greater insight into the complexities involved in these circumstances, and to develop adequate guidance to manage these complexities.

As a Namibian citizen, I have decided to focus this study specifically in the Namibian context. Namibia has proven to be highly efficient in their approach to the management of HIV and AIDS. Recent data reveals that around 95% of women living with HIV in Namibia now have access to ART. This has resulted in a 71% reduction in new HIV infections among Namibian children (UNAIDS.org 2019b). Namibia has demonstrated a commitment to confront the HIV epidemic, and I wish to potentially make a contribution to these efforts. Moreover, I further believe that policy makers in the country have proven to be open minded with regard to possible improvements or advancements to existing policy based on research outcomes. However, as other Southern African countries present similar statistics to Namibia where HIV is concerned, it is to be hoped that the arguments presented here, that will be informed by the Namibian context, can also be applied to other countries in the region, and may also be of relevance more globally.

## **1.2 Stating the problem**

There is a need to develop clear ethical guidance specifically directed towards the management and care of HIV positive children in childcare facilities, with specific reference to status disclosure. As is evident from the above discussion, there are certain ethical complexities that arise in this regard. The aim of this study is therefore to investigate ethical issues related to HIV positive children in childcare facilities. Two main questions will be investigated, one of which concerns the interests of the HIV positive child as an individual, and one of which concerns other children in such facilities. Firstly, I will ask whether existing policies or guidelines can ensure that an HIV positive child receives optimal (medical) care from a substitute caregiver. Status disclosure would seem to benefit the child in this respect, but, as mentioned earlier, the fear of stigmatisation is a complicating factor. Secondly, I will ask whether the mere possibility of HIV transmission in a childcare setting, despite the very low probability of such an event occurring, is sufficient grounds for considering alternative measures or policies regarding status disclosure in such contexts.

In this thesis, I aspire to assemble a thought-provoking argument which might inspire policy-makers to review methods that are currently in practice, as well as to present a possible outline as to how this can potentially be attained. This study will adopt the theoretical framework of principlism, and will specifically consider the import of the principles of autonomy, beneficence, non-maleficence and justice for issues around status disclosure in HIV positive children. By breaking down the ethical elements entangled in this matter, the argument I present here may provide insight into the different dimensions surrounding the issue of disclosure and the fear of stigmatisation it provokes, with a view to determining whether stigmatisation is a hurdle that can be overcome.

The ultimate objective of this study is to argue in favour of a controlled means of status disclosure. Due to the relationship between status disclosure and stigmatisation, any pro-disclosure argument needs to be sensitive to the complex issues at stake. I will therefore argue that the best way to gradually implement any pro-disclosure measures would be to use controlled means. I emphasise the word “controlled” as although I will argue for status disclosure in childcare settings, my contention will be that only the most relevant parties should be informed, these being the childcare director of the facility and/or the centre nurse or healthcare coordinator. The childcare director will then be obligated to continue protecting the confidentiality of the child’s HIV status at the centre, with the guidance and support of the facility’s nurse. I will also argue that status disclosure to these significant parties should be exceptionally well-organised by the childcare facility. In addition to this, the relevant parties that have been informed of a child’s positive HIV status, need to be trained to address and manage the needs of an HIV positive child as discreetly as possible, so as to avoid other children at the facility and their parents from noticing any changes in how an HIV positive child is being treated.

### **1.3 The plan of the study**

In order to provide a background to the study, it is imperative that current policies and legislation, specific to Namibia, are examined in greater detail, as the Namibian context is the background against which I wish to explore this topic. In Chapter 2, I will therefore discuss relevant policies in this regard. The main policies of focus will include *The National Policy on HIV/AIDS* (2007), as well as *The Namibian HIV/AIDS Charter of Rights* (2002).

Other Namibian policies that will be examined, which specifically address children with HIV and AIDS include:

- The National Policy on Orphans and Vulnerable Children (December 2004)
- The National Policy on HIV/AIDS for the Education Sector (2003)
- The Education Sector Policy for Orphans and Vulnerable Children (August 2008)

Chapter 2 will also briefly assess the most recent survey reports, which will provide greater insight into the current statistics and prevalence data regarding HIV positive children.

Only once a greater sense of clarity has been achieved on current policies, can we proceed to explore alternative measures that can be implemented with regard to HIV positive children in childcare facilities. However, before turning to the particular ethical dilemmas that are the topic of this study, it will be necessary to provide an overview of the ethical issues raised by HIV and AIDS in general, the ethical issues related to HIV positive children, disclosure, stigmatisation and confidentiality in Chapter 3. Stigmatisation ensues when differences are connected to negative labels, and individuals are branded as outcasts, such that discrimination is the end result (Van Bogaert and Ogunbanjo 2011: 606). When a highly controversial disease such as HIV is thrown into the equation, those who are affected by this illness may also be subjected to victimisation or rejection by the community. This resultant discrimination is a major concern and is inextricably linked to all ethical discussions around HIV. The complexities surrounding stigmatisation immensely complicate matters pertaining to the management of HIV. Examining the ethical and moral aspects surrounding disclosure and stigmatisation in intense detail is essential as it is the core hindrance to possible status disclosure within a childcare setting. As confidentiality provides an opportunity by means of which status disclosure can be promoted and stigmatisation can be reduced, this will therefore also be discussed in Chapter 3.

Once the central concepts surrounding stigmatisation, disclosure and confidentiality have been discussed, Chapter 4 will further elaborate on the ethical considerations which arise with regard to status disclosure within childcare settings. These considerations will be analysed and evaluated by means of a principlist approach. This argument will consider the perspective of the HIV positive child as an individual, as well as the perspective of the guardians, the childcare director the facility and other children attending the facility.

Chapter 5 will seek to suggest strategies by means of which stigmatization can possibly be reduced, as well as to recommend a framework as to how this can potentially be achieved in childcare settings.

Lastly, Chapter 6 will conclude the thesis, and will emphasise the need to focus greater attention on managing HIV discrimination. As Michel Sidibé, the Executive Director of UNAIDS states: “Whenever AIDS has won, stigma, shame, distrust, discrimination and apathy was on its side. Every time AIDS has been defeated, it has been because of trust, openness, dialogue between individuals and communities, family support, human solidarity, and the human perseverance to find new paths and solutions” (Avert 2017b).

## **Chapter 2: Namibian legislation**

### **2.1 Introduction**

In order to proceed with this study, it is imperative to examine current Namibian policies and legislation in greater detail, as well as to assess the most recent survey reports. It is only once these policies have been closely reviewed, that we can proceed to investigate alternative measures that can be implemented regarding HIV positive children in childcare facilities.

The UNAIDS study conducted in 2018 estimated that 11 000 children aged 0 to 14 were living with HIV in Namibia. Furthermore, less than 500 child deaths are estimated to have occurred in the country in 2018, while 37 000 children between the ages of 0 to 17 were found to be orphans, as a direct result of the HIV and AIDS epidemic (UNAIDS.org 2018). One should note that the population of Namibia is approximately 2.5 million, and therefore these figures represent a fairly significant portion of the total population (Worldometer 2020). These statistics indicate that Namibian children living with HIV and AIDS is a momentous issue in the country.

In this chapter, the policies that will be reviewed include:

- The National Policy on HIV/AIDS (2007)
- The Namibian HIV/AIDS Charter of Rights (2002)



- The National Policy on Orphans and Vulnerable Children (December 2004)
- The National Policy on HIV/AIDS for the Education Sector (2003)
- The Education Sector Policy for Orphans and Vulnerable Children (August 2008)

## **2.2 The National Policy on HIV/AIDS (2007)**

The aim of *The National Policy on HIV/AIDS* is to provide an overall reference framework for all HIV and AIDS related policies and procedures, as well as to guide the national HIV and AIDS response of all divisions in society. This policy encourages the establishment of a supportive environment whereby individuals living with HIV and AIDS enjoy equal rights in a culture of open discussion and empathy (Namibia 2007: 4).

Furthermore, the policy aims to reduce stigma and discrimination against those living with HIV and AIDS. It also notes that stigma and discrimination act as barriers towards effectively addressing the epidemic. Therefore, efforts should be made to develop ways to reduce stigma and discrimination. The policy notes that those affected by HIV and AIDS have the right to settle in a culture that cultivates acceptance (Namibia 2007: 4). Acknowledgement is made of the fact that as scientific and medical knowledge about HIV continually changes, our response to the epidemic will evolve from time to time (Namibia 2007: 6).

With regard to incidents involving blood, the policy indicates that all individuals are expected to follow universal precautions in case of accidental HIV exposure (Namibia 2007: 22). Antiretroviral prophylactic treatment can be given to an HIV negative person upon accidental exposure. This will reduce the risk of HIV infection significantly. Moreover, adhering to ART treatment is imperative, as irregular use can increase the risk of drug-resistant HI viruses developing, which will ultimately threaten treatment success for all (Namibia 2007: 23).

## **2.3 The Namibian HIV/AIDS Charter of Rights (2002)**

*The Namibian HIV/AIDS Charter of Rights* places further emphasis on outlawing discrimination and stigmatisation on the basis of one's HIV status, and contends that a rights-

based approach is necessary as part of an efficient public health response to this epidemic. Furthermore, this policy states that the prevention of HIV transmission is the responsibility of Namibian society as a whole, and is not restricted only to those living with HIV and AIDS. Transparency and openness concerning the disease is also promoted (Namibia 2002: 1).

The policy makes a firm distinction between the promotion of open discussion about HIV and AIDS and non-discrimination as a community, and the necessity of personal confidentiality on the other. Confidentiality in the context of the AIDS pandemic is a notion that is, according to this policy, not very well understood, and is often “quite incorrectly labelled as a veil of secrecy that undermines efforts to control the spread of HIV.” (Namibia 2002: 2).

The policy emphasises that both confidentiality and the promotion of open discussion contribute positively to public health with regard to HIV prevention, as well as the provision of support. Namibian legislation stresses that each individual living with HIV and AIDS has the right to confidentiality and privacy regarding their HIV status and health, but that open discussion should be encouraged by means of education and counselling, in order to optimise treatment. This right extends to children and adolescents (Namibia 2002: 2).

A special section in this policy highlights that media programmes should aim to challenge and reduce HIV stigmatisation and discrimination, and that specific attention should be paid to human rights and sensitivity concerning individuals affected with HIV (Namibia 2002: 6).

#### **2.4 The National Policy on Orphans and Vulnerable Children (December 2004)**

*The National Policy on Orphans and Vulnerable Children* aims to promote the well-being of orphans and vulnerable children, including children infected by HIV and AIDS. It enforces the importance of providing treatment, care and support for orphans and HIV-infected children, as well as alleviating the effect of HIV and AIDS on these children (Namibia 2004: 4).

It also acknowledges that discrimination creates conditions that increase the vulnerability of orphans, in terms of receiving proper treatment, care and support, should they be infected

(Namibia 2004: 4). This policy further emphasises the need for government to promote and reinforce programmes that effectively address the issue of discrimination and stigmatisation on the basis of HIV status in children (Namibia 2004: 9).

## **2.5 The National Policy on HIV/AIDS for the Education Sector (2003)**

*The National Policy on HIV/AIDS for the Education Sector* again emphasises that the compulsory disclosure of a child's HIV status to educational facility authorities is not permitted, although voluntary disclosure is encouraged. A supportive environment should be created whereby confidentiality is maintained, and discrimination towards HIV infected individuals is not tolerated (Namibia 2003: 2). This is further emphasised in *The Education Sector Policy for Orphans and Vulnerable Children*.

In the event of injuries or bleeding occurring at the educational institutions, good hygiene practices are to be practiced and universal precautions should be taken. All individuals should be regarded as possibly infected with HIV (Namibia 2003: 2). Furthermore, students should be taught to safely and effectively manage their own bleeding or injuries. Pre-primary or primary school learners should be taught never to touch open wounds, sores, grazes, and skin lesions. They should be taught to call for assistance in such events, and never to handle injuries on their own (Namibia 2003: 6).

Similarly, the rights of all learners and educational sector employees should be protected equally. In the event that an appropriately qualified individual recognises that a child or student poses a significant health risk to others, necessary action should be taken in order to eradicate that risk. Such risks in the context of HIV include uncontrolled bleeding, unmanageable wounds, and the presence of untreatable contagious diseases, or sexual or physically aggressive behaviour which might increase the possible risk of HIV transmission (Namibia 2003: 2).

Students who are infected with infectious diseases such as measles, German measles, tuberculosis, whooping cough, chicken pox and mumps ought to be kept away from the educational facility until they have recovered from the disease in order to protect others, particularly those affected by HIV and AIDS. Educational facilities are required to inform

parents or guardians about vaccination programmes that might affect the wellbeing of HIV infected students (Namibia 2003: 2). Furthermore, heads should allow flexibility in matters such as school hours, erratic attendance, responses to being late, age norms and assistance with homework for learners who are infected or affected by HIV and AIDS (Namibia 2003: 5).

Learners who develop HIV and AIDS related behavioural problems or mental or physical impairments should be accommodated within the educational system, insofar as reasonably possible. Teachers and educational sector employees should be supportive towards the needs of HIV positive children and should safeguard their rights (Namibia 2003: 4).

As with the previous policies, this policy recognises that stigma and discrimination towards people infected with HIV make it difficult for people to voluntarily disclose their HIV status. As a result, this creates secrecy around the HIV epidemic. This secrecy, in turn, creates denial about HIV, which reinforces discrimination and further challenges any efforts undertaken to prevent the spread of HIV. The policy further states that the principle of confidentiality plays an essential role in this regard, not only to respect human rights, but to aid in the prevention and control of HIV and AIDS. Most individuals will only seek HIV-related counselling and treatment if confidentiality is assured (Namibia 2003: 5).

## **2.6 The Education Sector Policy for Orphans and Vulnerable Children (August 2008)**

*The Education Sector Policy for Orphans and Vulnerable Children* extends the rights of orphans and vulnerable children to the education sector. This policy goes hand in hand with *The National Policy on Orphans and Vulnerable Children*, as well as *The National Policy on HIV/AIDS for the Education Sector*. As a result, these policies overlap with one another.

The policy recognises that orphans and vulnerable children require adequate healthcare and nutritional support. Orphans and vulnerable children are at an increased risk of not having their health needs adequately taken care of, which will in turn hamper their ability to optimally benefit from education (Namibia 2008: 8). These needs include proper nutrition, as well as the provision of adequate treatment of diseases. In this regard, the policy states that

teachers shall assist children with taking medication, should the parent or guardian wish them to do so (Namibia 2008: 8).

Universal precautions are to be followed in case of bleeding incidents in an educational setting, as described in *The National Policy on HIV/AIDS for the Education Sector* (Namibia 2008: 8).

As mentioned in previous policies, the Namibian Constitution acknowledges that children have the right to a safe and non-discriminatory environment and that they ought to be protected from any form of abuse or discrimination, and this policy reiterates this (Namibia 2008: 9). Any teacher or education sector employee that fails to protect the confidentiality of a child's HIV status, shall have disciplinary action taken against him/her. All education sector employees are required to be sensitive to the special needs of children that are affected or infected with HIV and AIDS, and all matters pertaining to these needs are to be handled with the utmost compassion (Namibia 2008: 10).

## **2.7 Conclusion**

Upon review of the Namibian policies, the main topics of focus with regard to HIV positive children are:

- Stigmatisation and discrimination will not be tolerated and should be targeted for reduction.
- No adult or child is required to disclose their HIV status.
- Should one's status be disclosed, confidentiality ought to be maintained.
- An environment of acceptance should be cultivated.
- Universal precautions should be adhered to in cases of bleeding.
- As medical knowledge surrounding HIV is constantly improving, national responses towards the epidemic may change.

One can clearly observe that the Namibian constitution commendably advocates the rights of all members of society, whether they are HIV positive or not.

Upon carefully reviewing the Namibian legislation that is currently in place, it became apparent that the idea of controlled disclosure of a child's HIV status to the childcare director of an educational facility, which this thesis will advocate for, does not necessarily clash with what is already in practice. *The Namibian HIV and AIDS Charter of Rights*, in particular, strongly supports the promotion of open discussion and the need for confidentiality. The policy that I will argue for here can be viewed as a mere extension of what is already being implemented in this regard.

Although acknowledgement will be made of the fact that nobody can forcefully be expected to disclose their HIV status, this study will argue in detail as to why disclosure to the childcare director of an educational facility would be optimal and ideal. If stigma and discrimination can be effectively reduced, perhaps a more explicit commitment to a controlled means of disclosure in childcare centres can carefully and gradually be implemented in Namibia.

In the next chapter, I will analyse various ethical issues that arise in the context of HIV and AIDS, including disclosure and stigmatisation, and discuss the profound consequences that occur as a result of these issues.

### **Chapter 3: Literature review: Ethical issues related to HIV**

#### **3.1 Introduction**

HIV and AIDS is undeniably one of the most profound issues that impacts society in this day and age. The epidemic gives rise to a multitude of moral and ethical issues in a number of areas. Although this study is concerned with the ethical issues raised by the enrolment of HIV positive children in childcare institutions, with specific focus on the question of status disclosure, it is important that this discussion is informed by an acquaintance with the broad spectrum of ethical issues regarding HIV and AIDS in general, as well as challenges and ethical issues related to children and HIV and AIDS in particular. This chapter will therefore attempt to provide an overview of some of these issues, before discussing issues related to stigmatization, status disclosure, and confidentiality in particular, as these are of critical importance to this study.

## **3.2 Public health versus individual rights**

Many of the biggest ethical debates with regard to HIV and AIDS have to do with the tension between the rights of the public to protect themselves against the spread of the disease and the individual rights of HIV infected persons to liberty, autonomy, and confidentiality. In essence, conflict emerges when we attempt to protect members of society from infection via control mechanisms that will ultimately restrict the individual rights of those infected. In the case of other infectious diseases, such as leprosy, utilitarian judgements have in the past justified the restriction of individual rights to confidentiality, autonomy, and informed consent, in order to protect the general public (Cambrea, Arghir and Halichidis 2012: 196: Legal and Ethical Issues in HIV Disease n.d.: 136).

When the HIV and AIDS epidemic began, a wide range of public health strategies were attempted such as the implementation of mandatory screening and testing, reporting the names of infected individuals to public health registries and the quarantining of infected individuals. As expected, these methods created a great deal of controversy (Bayer 2007: 1100).

In theory, these appear to be strategies worth considering. However, in practice, these extreme measures have a tendency to fuel stigmatization, and to further isolate those who are already suffering from the disease. Many argue that the best means of prevention is instead to ensure the provision of knowledge, education and information, as well as to encourage voluntary cooperation and HIV testing (Cambrea, Arghir and Halichidis 2012: 196: Legal and Ethical Issues in HIV Disease n.d.: 136). In what follows, I will discuss conflicts that may arise between individual rights and the promotion and protection of public health with specific reference to HIV testing and HIV transmission.

### **3.2.1 HIV Testing and Consent**

HIV testing gives rise to a number of moral issues, particularly with regard to consent and autonomy. Autonomy refers to the individual's capacity to make their own rational and informed decisions<sup>1</sup>.

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<sup>1</sup> The concept of autonomy will be more thoroughly discussed in Chapter 4.

In order to acquire access to the healthcare system and to attain necessary HIV care, an individual needs to be tested. Many would argue that it is an absolute necessity for HIV positive individuals to be aware of their status, as this would directly contribute towards the control of the epidemic, as well as enable the vital preventive measures that must be taken to prevent its further spread. Ultimately, this would improve public health, and testing therefore plays a major role in the management of HIV. Testing also has benefits for the patient.

The issue of HIV testing is complicated as many individuals refuse to be tested. The disease is not only incurable, but also exposes individuals to extreme social, personal and economic consequences (Cambrea, Arghir and Halichidis 2012: 196). Patients may refuse to take the test for a number of reasons, including anxiety about taking the test, fear of stigmatization and fear of loss of confidentiality (Cambrea, Arghir and Halichidis 2012: 196). Marzuk and his colleagues researched suicide among men in New York, and found that an HIV positive status could possibly be associated with a modest elevation in the risk of suicide (Marzuk, et al. 1997: 1723). It should be noted, however, that these data are dated and from a period before effective ART became generally available, probably affecting the outcomes of the study. Moreover, a study in China found that most HIV infected people who were suicidal had attempted suicide immediately after their diagnosis with the virus (Zarei and Joulaei 2018: 4), suggesting that the distress experienced by some individuals who received a positive diagnosis may be so severe that it can lead to suicide.

Generally, in order to perform laboratory tests for HIV, a patient would be required to provide their consent. In an ethical context, the principle of informed consent is based on the understanding that individuals are autonomous beings who have the right to make decisions on matters that affect their own health and wellbeing, free of any form of force, coercion, persuasion or manipulation. Upholding this principle also respects the requirement that no patient should be forced to undertake any medical treatments, procedures or tests that directly pertain to their health, and that complete and sufficient information should be provided to them. Taking the principle of consent into account, some argue that implementing routine obligatory testing for HIV can never be justified, even though it would greatly aid the management of the epidemic from a public health standpoint (Cambrea, Arghir and Halichidis 2012: 194; Omonzejele 2014: 15).



According to Omonzejele (2014: 14), some ethicists argue that there are no truly significant benefits that can be achieved from implementing obligatory testing for HIV, as it ultimately falls into the category of an incurable condition, thus rendering knowledge thereof futile.. The logic behind this argument is that if there is no cure for the disease and infected individuals are destined for death regardless of the outcome, then the motivation for testing is unclear. However, one can counter argue that, since all human beings (whether they are HIV positive or negative) are destined for death and have no knowledge of when or how they will die, one cannot assume that HIV would indeed have made an impact on the timing of an individual's death, since no person is certain when death will occur. Therefore, since HIV infection may not even be the cause of death of an individual, all persons should be aware of their HIV status to aid in the management and control of the disease. More importantly, the advent of ART has changed the landscape entirely. ARTs are increasingly effective in the management and control of HIV infection and in prolonging life. Although these medications do not deliver a cure, they can allow HIV positive people to live long and healthy lives, and can reduce the risk of transmission to others. However, treatment is only possible if people are aware of their HIV status.

It is fair to argue that we are required to respect the obligation to allow individuals to make their own decisions where their health and happiness is concerned, as this has implications for their wellbeing. This upholds the principle of respect for autonomy. Autonomy states that we all possess a moral duty to uphold and respect the autonomous decisions made by other persons (Beauchamp and Childress 2013: 101). However, we cannot ignore the fact that HIV and AIDS is an epidemic that may have negative consequences for all members of society. There are scenarios in which knowledge of one's HIV status holds direct implications for others, and one could argue that in these cases, the obligation to respect autonomy must be weighed against potential harms to others and concerns with regard to public health, and could justifiably be limited under certain circumstances.

An example of such a scenario includes an infected individual who can potentially endanger their sexual partner by engaging in unprotected sex with him/her, and who would thus need to take precautions to prevent transmission of HIV. The transmission of the HIV disease depends largely on the behaviour of members of society, and in most cases, it is transmitted accidentally. Thus, the effective management and prevention of the disease depends largely on people becoming aware of their status by getting tested.

Another example would include that of a pregnant woman, who runs the risk of vertical transmission of HIV to her baby. One may argue that she is morally obligated to prevent this from occurring insofar as possible, especially since there are drugs that could significantly reduce this possibility<sup>2</sup>. It is for this reason that many individuals argue that pregnant women should be required to undergo mandatory HIV testing (Omonzejele 2014: 14). The counter-argument is that forcing women to undergo HIV testing is a violation of their rights, regardless of any good consequences that result (Omonzejele 2014: 14).

In a clinical scenario, an example where testing without direct consent may be acceptable is that of a healthcare worker who has accidentally been exposed to a patient's blood. In the event that an existing blood sample is available and the patient has either refused to consent or is unable to consent, testing may still be carried out provided that the patient is informed, insofar as possible, that the test is being conducted and that the respective healthcare worker will receive the results, which will remain confidential (Medical Protection 2019).

From another viewpoint, it can be argued that measures undertaken to protect individual rights can also protect society as a whole. Thus, it is possible to protect all members of society, rather than to eliminate or disregard the rights of individuals infected with HIV (Legal and Ethical Issues in HIV Disease n.d.: 136). At the end of the day, respecting individual rights could, in many ways, enhance public health where HIV management is concerned.

An example of a public health HIV initiative with regard to HIV testing which both protects individual rights and promotes public health is an opt-out approach to testing, as opposed to an opt-in approach. The opt-in approach is known as the human rights approach, and allows individuals to voluntarily decide for themselves whether they wish to be tested for HIV. Under this approach, individuals are usually counselled and encouraged to disclose their HIV positive status where necessary, although the decision to do so lies with the individual him/herself. This policy places strong emphasis on an individual's right to make their own decisions, as well as on the right to dignity and liberty (van Bogaert and Ogunbanjo 2011: 605).

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<sup>2</sup> I will discuss this issue further when I turn to ethical issues that specifically relate to HIV and AIDS and children.

The opt-out approach, on the other hand, supports “universal” testing, also known as the routine testing of individuals. More specifically, this policy suggests that all persons who attend a healthcare facility should be offered an HIV test. Although this policy is considered to be a public health approach, it still allows an individual the right to decline testing should they wish to do so, thereby protecting and respecting their individual rights (van Bogaert and Ogunbanjo 2011: 606).

The motivation to implement an opt-out approach, as recommended by the World Health Organization (WHO) in 2007, is that whilst recognizing that HIV and AIDS has a profound impact on the lives of those affected in physical, professional, financial and emotional terms, acknowledgement also needs to be given to the fact that HIV and AIDS affects society at large, for example, by impacting the economy and the workforce, or by placing the sexual partners of infected persons at risk. Therefore, taking this into consideration, the epidemic cannot be viewed as a strictly private matter only, and public intervention to encourage HIV testing is therefore justified (van Bogaert and Ogunbanjo 2011: 606).

The biggest benefit that emerges from the opt-out approach is that infected persons who had previously been unaware of their status are given the opportunity to know their status, and are therefore enabled to make lifestyle changes, initiate HIV treatment, and to disclose their status where necessary. It further provides the possibility that infected individuals will be diagnosed at an earlier stage, thereby improving the prognosis of the patient. When the opt-out approach was implemented in Uganda, it was found that approximately half of all persons undergoing testing tested positive for HIV, of which 83% were completely unaware of their status (Nakanjako, et al. 2007: 753). The advantage of this is that positive cases were diagnosed at an earlier stage, with higher CD4 counts. It appears that the opt-out approach is a strategy well-suited to curb the epidemic (van Bogaert and Ogunbanjo 2011: 606).

The opt-out approach serves as an example of the fact that even though public health initiatives are undertaken, they can still be implemented in such a way that all members of society benefit and have their fundamental rights considered and respected; both HIV positive individuals and HIV negative individuals alike (van Bogaert and Ogunbanjo 2011: 606).

### 3.2.2 Moral obligations with regard to HIV transmission

In the previous section, it was mentioned that the autonomy of patients may be justifiably limited when their decisions hold direct implications for the wellbeing of others. In the HIV debate, this is especially relevant where sexual partners and promiscuity are concerned.

There is a general assumption that all persons have a moral duty to avoid imposing harm on others insofar as possible. However, where HIV transmission is concerned, there has been some debate as to whether this obligation falls on the HIV positive individual alone, or on all persons to ensure that they protect themselves against transmission (Bennett, Draper and Frith 2000: 10). Even if we were to argue that all persons in society are responsible for preventing the transmission of HIV, do HIV infected individuals possess a stronger obligation in this regard?

When the principle of autonomy is taken into consideration, and as previously noted, we generally uphold the rights of individuals to make their own decisions where their wellbeing is concerned. Prevention strategies that have been undertaken in order to control the epidemic on a global scale include HIV education and the mass promotion of measures to protect ourselves and others from HIV transmission. Taking this into consideration, we can assume that the majority of individuals who live in urban areas are aware of the risk that unprotected sex holds. Due to the fact that so many individuals are not aware of their status, one may argue that the responsibility to manage the HIV epidemic lies with all members of society, and not only those who are infected with the disease, by following preventive measures that will reduce the spread of the virus. The ethical question that is presented, is whether these autonomous persons have the obligation to protect themselves, when they are aware of the potential risks that their actions hold? When the principle of autonomy is upheld unequivocally, it allows individuals the choice to engage in risky activities, and any repercussions that might result thereof are viewed as a direct consequence of their own choice (Bennett, Draper and Frith 2000: 10).

The counter argument is that individuals who engage in unprotected sex without any knowledge or forewarning of that person's status, have not truly made an informed decision, as they were not warned upfront of all the true threats that the activity held. Therefore, the principle of informed consent is not upheld from this viewpoint, as the consent to engage in

sexual activity with someone is not necessarily the same as consenting to the potential risk of contracting HIV. Only when an individual is fully informed, can an individual be held accountable for their own contraction of HIV, and the harm is then considered to be self-inflicted (Bennett, Draper and Frith 2000: 11).

Some bioethicists hold that HIV infected individuals have an absolute duty to forewarn their sexual partners of their status, and that this moral obligation overrides the obligation of the prospective partner to protect themselves from the probability of contracting the disease. If individuals are aware of their HIV status and still engage in unprotected sexual practices without forewarning their respective partners, then their failure to uphold their obligation to prevent harm might result in devastating consequences, and this responsibility falls solely on them. The argument here, is that consent where a partner is potentially infected, is significantly different from consent where the partner is in fact infected with HIV, particularly if the respective sexual partner is aware of their positive HIV status. On a larger scale, the failure of HIV positive individuals to forewarn their partners could significantly impede the prevention and management of the disease (Bennett, Draper and Frith 2000: 12).

It is also argued that even if an HIV positive individual forewarns their sexual partner of their positive status, and the partner makes the informed decision to take the risk, the HIV positive individual still remains an accomplice with respect to the risks involved. This scenario can be compared to an individual granting another permission to shoot him/her. Even though consent was given, the decision to follow through with the harmful actions, constitutes maltreatment (Bennett, Draper and Frith 2000: 13). Therefore, it is argued, the HIV infected individual holds the responsibility to not only inform their partner of their status, but also to practice safe sex. Some argue that this responsibility is so profound that it even justifies criminalization of deliberate or reckless HIV transmission. I discuss this argument in the next section.

### **3.2.2.1 Criminalisation of deliberate or reckless HIV transmission**

The criminalization of certain forms of HIV transmission has been undertaken in many countries as a public health intervention, and has received much criticism. The criminalization of the act of an infected individual having sexual intercourse without disclosing their status has been implemented in more than half of the states in the United

States of America (USA), as well as a number of West African states (van Bogaert and Ogunbanjo 2011: 607). Moreover, parts of Asia, Latin America, the Caribbean and Europe have also have criminalized the act of HIV transmission (Jürgens, et al. 2009: 163).

“Criminalisation of HIV” refers to the legal penalties that are imposed where HIV positive individuals are proven to be responsible for the deliberate or reckless transmission of HIV to another individual. Criminal laws are implemented to attempt to safeguard the general public from harm and maltreatment, as well as to seek justice against the perpetrator of the harm. Criminalization of deliberate or reckless HIV transmission is justified on the basis that people who are aware that they pose a significant and potential risk to another, are ultimately accountable for either removing that risk, or to at least providing the opportunity for the other individual to consent to the risk (Burriss and Weait 2011: 3).

Many countries have resorted to the criminalisation of these forms of HIV transmission, because it is clear that certain infected persons are not prepared to get tested for HIV, or refuse to disclose their positive status to their sexual partners, regardless of the considerable amount of time, education and resources that are invested in measures to control HIV and AIDS. Reasons for this type of behaviour may include ignorance, substance abuse, violence, denial, anger, financial and economic obligations, and an inability to change behaviour or a lack of concern for other persons (Legal and Ethical Issues in HIV Disease n.d.: 137).

What is more, individuals who are infected by other persons who were aware of their HIV status and failed to disclose it, undergo an immense amount of physical, emotional, financial and psychosocial trauma that HIV transmission brings. These harms, which could have been prevented, are the fundamental reasons for considering criminalisation. As other HIV prevention initiatives do not appear to produce the desired results, criminalisation was proposed in order to provide an alternative means of HIV prevention (van Bogaert and Ogunbanjo 2011: 608).

Unfortunately, the criminalisation of such behaviour poses many problems where the implementation and enforcement of this law is considered. In the event that someone is to be held legally liable for HIV transmission, it would be difficult to establish whether a sexual partner had or had not been sufficiently forewarned of their respective partner’s HIV status, or if consent had been officially given before the parties engaged in unprotected sexual

practices. Moreover, it is difficult to prove whether the offender in fact had prior knowledge of his or her positive status, or whether he or she had deliberately intended to transmit the infection. It is also hard to establish whether the victim was HIV positive beforehand, or whether transmission had indeed occurred as a result of the specific incident (van Bogaert and Ogunbanjo 2011: 608).

Moreover; even if an HIV infected partner were to forewarn their sexual partner and disclose their status, disclosure in itself does not prevent transmission. HIV transmission can only be prevented by practicing safe sex, and one does not need to be informed of a prospective partner's HIV positive status to practice safe sex. This point is related to the argument that the responsibility for HIV prevention falls on society as a whole, and not solely on HIV infected persons. Considering this, if the obligation of self-protection also falls on those who become infected, then the criminalization of HIV transmission may be inappropriate and morally unjustified (Burriss and Weait 2011: 12).

Moreover, some argue that the fact that certain behaviour is wrong is not an adequate justification for legal action, especially since unforeseen and unintended harms might result (Burriss and Weait 2011: 3). Such unintended harms may include stigmatization of the infected, and the further marginalization of vulnerable populations. Criminalization might also lead to people who engage in high risk sexual behaviour deliberately evading knowledge of their status, in order to avoid prosecution, thus contributing to reluctance to undergo HIV testing, as discussed earlier. There is therefore speculation that criminalization could possibly increase the risk of becoming infected (Burriss and Weait 2011: 3; van Bogaert and Ogunbanjo 2011: 608).

In summary, a small number of well-publicized cases of HIV infected persons who purposefully and recklessly infected others have evoked a robust emotional response, and have led to demands to implement criminalization in order to prevent such instances from reoccurring. However, there are a number of problems attached to criminalization, as discussed above, and some argue that these laws have created a false illusion of protection against transmission, as these preventive measures would only apply to a small minority of individuals (Legal and Ethical Issues in HIV Disease n.d.: 137).

In the preceding sections, I have discussed ethical issues related to HIV and AIDS, with specific reference to the tensions between individual rights and public health in the context of HIV testing and HIV transmission. In the next section, I turn to a discussion of challenges faced by children affected by HIV and AIDS, as well as the ethical issues that may arise in this context.

### **3.3 HIV and AIDS and children**

The focus of this section is to gain a deeper understanding of the challenges and ethical issues related to HIV and AIDS and children in general, before we can address those specific to the enrolment of HIV positive children in childcare institutions. The topics that will be discussed in this chapter include caring for an HIV infected child, psychosocial wellbeing and development, child stigmatisation, disclosure to children and mother-to-child transmission (MTCT) of HIV.

#### **3.3.1 Caring for an HIV infected child**

HIV infection places a tremendous amount of psychosocial stress on familial dynamics, both for HIV infected parents caring for their HIV infected child, as well as for the HIV infected child who is affected by the status of his/her parents.

From a parental standpoint, the knowledge that their child is infected places a heavy emotional burden on parents. Depression and misery may result and lead to difficulties in responding to the advice and options given to them by healthcare workers. The compliance of a parent is also largely affected by their ability to accept the HIV status of their child. Feelings of guilt, blame and remorse might ensue, if the child acquired the virus through vertical transmission or via a case of rape. Where caring for their HIV infected child is concerned, feelings of loss, loneliness, fear and hopelessness about the future might ensue (Brouwer, et al. 2000: 536).

A close correlation has also been established between the acceptance of the HIV status of a child and the readiness of a parent to provide the required care for their child. This is because a parent can only be motivated to comply with adequate healthcare guidelines and advice if



they acknowledge and emotionally register the severity of their child's HIV positive diagnosis. Denial of a child's HIV status can prevent parents from seeking appropriate care for their infected child (Brouwer, et al. 2000: 537).

Sadly, the psychological status of the parent might be negatively affected, and parents who are depressed may find that their ability to provide the necessary care for an HIV infected child is compromised. Parents often become exceptionally anxious during periods of illness of the child, and some have stated that they feel helpless in these circumstances (Brouwer, et al. 2000: 538).

Frequently, in cases of MTCT, the infected parent may become ill or die when the child is still very young. Witnessing the suffering of an ill parent can result in a great deal of agony. Moreover, children may often start playing roles in the household that are usually expected of adults. When their parents fall ill, many children play some part in nursing and directly look after their parents. If there are younger siblings, an older child might also undertake a parental role towards them. When a parent or guardian falls ill, it may result in the health and emotional needs of an HIV positive child being neglected. In such circumstances, HIV infected children may get insufficient emotional support. Sadly, this is one of the most devastating side effects that the HIV epidemic has burdened children with (Amzel, et al. 2013: 5; ETU.org.za 2019).

Often, parents are also worried about leaving their children when they die, especially since an HIV infected child requires additional emotional and health support, and faces potential financial strains due to the need for chronic medication and healthcare. The fear that their child might not be adequately cared for can create an immense amount of stress and anxiety. Therefore, parents frequently attempt to prepare for this by saving money (Brouwer, et al. 2000: 538).

Even though ART has allowed infected individuals to maintain their health and to live longer, a significant number of children still experience trauma and suffering when an HIV infected parent dies. If the child is infected with HIV themselves and they are aware of it, they might experience supplementary fears and worries regarding their own mortality and life expectations. In such cases they may require sufficient support in order to feel more confident and optimistic where their own prospective survival and wellbeing is concerned.

When an HIV positive child loses a parent, they experience additional difficulties that go together with HIV-associated grief and mourning. Mourning the death of a guardian is predicted to illicit detrimental and unfavourable effects on the psychosocial state of any child in general. When death was the result of HIV and AIDS, additional hardships may ensue, including financial challenges, disturbances in the provision of adequate healthcare, and stigmatization (Amzel, et al. 2013: 5).

When both their parents die, these children become orphans and are faced with the dilemma of who will look after them. It is best for children to be taken in by people who they know and who make them feel safe, but sadly, this is not always possible. Often, small children are taken in by their families and relatives. Unfortunately, this is not necessarily the case with older children, who are often neglected and might drop out of school in order to look after their younger siblings. Occasionally, orphans stay on alone in their family when their guardians die, and might look after younger siblings whilst attempting to find a means to survive. An exceptionally large number of children are living in unacceptable poverty in these child-headed homes. Other orphans might end up living on the streets, in orphanages, in foster care or in underprivileged homes, where they are more vulnerable to abuse, crime and sex trafficking. Additionally, some children are placed in hospices or in specific homes which cater to children who are very ill or possibly dying. Sadly, poorer communities do not always possess the necessary resources in order to provide adequate institutional support to orphans or children whose parents have fallen ill (Brouwer, et al. 2000: 536; ETU.org.za 2019).

Furthermore, separating children from their siblings by placing them with different families when they have lost their parents is not ideal, as it is better to keep them as close as possible to their natural support system. Taking into account the anxiety and grief they experience, moving them to an unfamiliar environment away from their known school, friends and community, may only intensify their distress. Adoption is also a complicated and lengthy process that is difficult to arrange, especially where older children are concerned and even more so when a family learns of a child's HIV positive status (ETU.org.za 2019).

Small children who are infected with HIV possess a different set of needs which differ significantly from those of an adult who is infected. Often, they depend on their guardian or parent and are not capable of accessing the necessary services or helping themselves. Should

they be very young, they will most likely not have attained the level of psychosocial and emotional development that is required to comprehend their disease, which will hamper their ability to take the precautionary measures necessary to maintain their health and to protect other persons from contracting the virus. Moreover, when children living with HIV become older they may question the necessity of sustained treatment, whether their HIV status is known to them or not. Therefore, as the parent or guardian is often the sole provider of care for the child, it is vital that they provide the proper support and are equipped with the necessary knowledge and training in order to provide optimal care for their child. As far as possible, additional support should be received from childcare committees, support groups, local clinics or relevant HIV organizations (ETU.org.za 2019).

Where financial matters are concerned, an adult suffering from AIDS will severely affect the household income as their physical capability to work may be reduced. In addition to this, transport fees and medical expenses to treat family members affected by HIV or AIDS increase. This decrease in household income coupled with an increase in expenses in order to provide for HIV care, is often the reason why some families affected by HIV find themselves in a state of poverty. This further negatively affects children in terms of nutrition, HIV treatment, education, health status and emotional support. Statistical data reveal that the monthly household income in HIV affected Cambodian families is 47% lower than that of families not affected by HIV. Correspondingly, the monthly income in the majority of HIV affected households in China decreased by more than 30% post diagnosis (ETU.org.za 2019). From this standpoint, we can see that the HIV and AIDS epidemic has the potential to affect others beyond an infected individual. Over a period of time, HIV and AIDS may affect entire sectors of the economy due to a reduced capacity in the workforce. Additionally, resources will be required to provide for the escalating number of HIV infected persons, as well as for the care of the growing number of orphans.

Parents that find themselves in a state of poverty may struggle to regularly visit healthcare institutions or clinics, due to a lack of money or transport. Additionally, the parent him/herself may be too ill and weak to travel, or their HIV infected child may be too weak (Brouwer, et al. 2000: 538).

Some HIV positive children might also find themselves in difficult family environments which could expose them to domestic violence, parental alcohol abuse, or hostile parenting

which can be brought on as a result of HIV infection, decreased income or death in the family (Amzel, et al. 2013: 9).

### **3.3.2 Psychosocial wellbeing and development**

The adverse life challenges that HIV positive children experience and confront as they age, such as losing parents and family members, comprehension of their own disease, HIV-related illnesses, stigma and discrimination, possible bullying, challenges regarding disclosure, and not understanding the necessity of treatment adherence, are believed to affect their psychosocial wellbeing by evoking feelings such as depression, self-esteem issues, loneliness, and hopelessness. These negative psychological effects can potentially affect their future development (ETU.org.za 2019; World Health Organisation 2011: 34).

Strong evidence suggests that HIV negatively affects the cognitive development and performance of HIV infected children. HIV infection has also been linked to a higher risk of developing mental health problems. This data signifies the necessity for early childhood intervention to minimise these risks (Amzel, et al. 2013: 2).

Children who are infected with HIV are also at a greater risk of developing behavioural problems and engaging in high-risk activities when they reach puberty, such as teenage drinking, smoking, poor school performance and engaging in unprotected sex. This may ultimately affect treatment adherence and outcomes and increase the likelihood of transmission to others (Amzel, et al. 2013: 2; World Health Organisation 2011: 34).

### **3.3.3 Child stigmatisation**

Stigmatisation, although potentially experienced by all HIV infected individuals, whether they are an adult or child, may be experienced differently by children. Children who are HIV positive are just as exposed to the probability of stigmatization as adults, but sadly this is often combined with the additional challenge that they are not as able to defend themselves. Thus, they are more likely to face more severe consequences (ETU.org.za 2019).

As mentioned above, when children undergo a tremendous amount of distress and trauma brought on by HIV, this potentially negatively affects their future psychosocial wellbeing. Similarly, HIV related stigma and discrimination against children has also been proven to be more likely to lead to poor mental health, exclusion, social isolation and negative impacts upon education. Where community members are aware of a parent's HIV status, then stigma-by-association might occur against the child, and this has also been linked to negative mental health outcomes. Stigma against children can take the form of household neglect and abandonment, decreased social support, verbal abuse, physical assault, bullying and victimization (Amzel, et al. 2013: 5).

When an HIV infected child anticipates stigma and discrimination, they may react to the situation in different ways. They may become secretive and socially withdrawn, and opt to spend their free time only with their relatives, who might even encourage them to further isolate themselves. Yet, this type of behaviour can breed poor self-esteem and depression. Conversely, some children may wish to disclose their status amongst peers, which can result in either improved support or lead to social isolation (Klitzman, et al. 2008: 31).

What is more, a study conducted in a poor, rural South African setting, found that whilst a number of household parents disclosed the HIV status of their child to close relatives, approximately half of the sampled parents wished to keep it undisclosed, for fear of stigmatisation, discrimination and perceived harmful effects on the development of the child. This is problematic, as early disclosure is important for prompt provision of healthcare. There is also a belief amongst the parents that confidentiality would be broken by health workers who handle the care and treatment of those children, and they were therefore reluctant to present their child for medical care. Parents further reported that they had received negative treatment from healthcare professionals (Kimani-Muragea, et al. 2013: 745). This study revealed that the fear of stigmatisation and discrimination against children is one of the main critical barriers as to why ART uptake remains low amongst children, even though a national ART programme has been implemented in South Africa (Kimani-Muragea, et al. 2013: 744).

### 3.3.4 Status disclosure to children

As discussed previously, disclosure is an important subject in the HIV and AIDS debate. Disclosure in this context usually refers to disclosure of an adult's positive status to his/her sexual partners, relatives, close friends or any other individuals to whom they wish to disclose. However, the disclosure of a child's HIV positive status, from the guardian of the child to the child him/herself is an area that is not as widely discussed. This topic is a rather complex one from which multiple ethical issues follow.

When HIV and AIDS was first discovered, infected children had short life expectancies. Therefore, guardians often never reached the stage at which it was necessary to disclose their disease status to them. Since then, however, the availability of ART has improved the health status of HIV positive children and increased their life expectancies, enabling them to live longer, healthier lives, often well into adolescence, young adulthood, and beyond. As children are living longer with HIV, this means that they are in a position to attain a higher level of cognitive development, which now enables them to eventually understand and comprehend their HIV diagnosis. Moreover, as these children grow into teenagers and young adults, issues regarding safe sexual practices become a concern, as the risk of transmission of the virus increases. As a result, guardians are now faced with the challenging task of eventually disclosing the child's positive HIV status to him/her (Klitzman, et al. 2008: 31).

However, disclosure of a child's HIV status is complicated by the fact that small children do not possess the cognitive development or emotional capacity to comprehend and understand HIV as a disease, as well as its implications. In such cases, disclosure potentially harms the child. Many children who are under the age of 10 have not yet developed the ability to understand abstract concepts related to chronic illness, let alone HIV and AIDS (Klitzman, et al. 2008: 31).

The disclosure of a child's positive HIV status includes informing them that they have a life-threatening illness that is prone to stigmatization and that can be sexually transmitted. This has proven to be an immensely difficult undertaking for guardians.

Many guardians of HIV infected children delay disclosure for various reasons. They may be uncertain about the timing and appropriateness of disclosure, or concerned about HIV related stigma, the emotional capacity of a child to comprehend their diagnosis, and the child's neurocognitive development. They may also experience guilt regarding transmission, be concerned about the psychosocial effects disclosure would have on the child, and fear difficult questions from the child and negative reactions such as blame, sadness and anger (Amzel, et al. 2013: 4; Global and regional trends 2018; Klitzman, et al. 2008: 3). Disclosure to a child is not as simple as telling them of their diagnosis, as guardians must also respond to other worries that children may have (World Health Organisation 2011: 16).

Disclosure to children is advocated due to the potential psychological and health benefits for the child. Public health is also a matter that needs to be taken into account, especially where the possibility of transmission to sexual partners becomes increasingly likely (Klitzman, et al. 2008: 31).

Although many guardians are reluctant to disclose their child's positive status to them, it has been proven that disclosure at the appropriate time might have a positive impact on the emotional and mental well-being of the child (Amzel, et al. 2013: 4). Often, non-disclosure can generate feelings of isolation and increase the likelihood of accidental disclosure in an unsupported and inappropriate setting, creating greater emotional turmoil. Therefore, planned, appropriate disclosure can potentially be beneficial and reduce harm. HIV positive children who have not yet had their status disclosed to them may experience anxiety and associated emotional tribulations, sensing that "something is wrong" with them. Therefore, disclosure could ease and lessen this anxiety, and also presents children with the opportunity to contribute to their own healthcare and to openly ask questions in order to gain a better understanding of their condition. As a result, these anxieties can be eased, as fears of a suspected, unknown disease can have a greater emotional impact than awareness of a known disease (Amzel, et al. 2013: 4; Klitzman, et al. 2008: 31).

Even though many children experience feelings of anger or sadness, these emotions will most likely eventually be replaced by feelings of calm, comfort, relief and improved understanding where their health needs are concerned, such as reasons for taking medication. Research that was conducted in Namibia also suggests that children who are given reasons as to why they

take medication, are much better equipped to adhere to their treatment regimen, improving viral suppression (Amzel, et al. 2013: 4; Avert 2017a).

Another factor to consider is that status disclosure does not always take place in a single setting or in one time and place. Often, disclosure to children takes place over the course of a certain period of time, through numerous conversations, in different environments, potentially with different persons and in response to different events (World Health Organisation 2011: 11). For this reason, it is important to assemble various means of support from sources such as family, friends, peers or school teachers, to deal with challenges related to disclosure that might occur in unforeseen scenarios. Incremental and process-oriented disclosure occurs over many conversations and may call for planning. Incremental disclosure that increases with a child's age is better suited to a child's developmental capability to comprehend and understand the information that is being relayed to them. This has proven to have positive effects on a child's physical and psychosocial wellbeing (Amzel, et al. 2013: 4; World Health Organisation 2011: 27).

One of the major factors as to why parents are reluctant to disclose a child's HIV status, is that doing so frequently amounts to disclosure of stigmatized behaviours that are linked to transmission routes. For example, family secrets such as infidelity and extramarital sexual relationships, bisexuality in a father or parental drug use might be considered part of the family's secrets which parents may wish to keep private from their children. Furthermore, a parent may be fearful of the child disclosing his/her status, or those of family members, to other individuals outside of the family (Klitzman, et al. 2008: 31; World Health Organisation 2011: 16).

Often, disagreements ensue regarding the appropriate timing and setting of disclosure. These disagreements usually occur between healthcare workers who recommend disclosure to the child, and guardians that may disagree and refuse to disclose. Consequently, a multitude of ethical considerations surface in these circumstances. Even in cases where both healthcare workers and guardians agree that disclosure should take place, they may disagree on the best means of doing so.

In the event that parents refuse to disclose the positive status of a child to them at an appropriate time, doctors, psychologists and other healthcare workers are often faced with



ethical issues. How does a third party balance the rights of a parent, versus those of a child, and does the balance of these rights shift as the child grows older? (Klitzman, et al. 2008: 31). Ethical questions that arise in this regard include whether the child has an absolute right to know about his/her positive status, or whether a parent has the absolute right to refuse status disclosure in an attempt to protect the child. Even in the event that a parent does disclose a child's status to them, does the parent then have a right to their own privacy regarding their own personal history of HIV transmission? Do third parties ever hold the right to intervene in the event that a parent refuses to disclose a child's HIV status to them?

One might argue that a child would only require knowledge of their HIV status in the event that they become sexually active, and that since children should be abstinent regardless, there are no moral grounds that necessitate disclosure to children. Even if one were to accept this argument, complexity arises when children reach adolescence and sexual maturity. As sexual education is often an uncomfortable conversation between children and parents, this may further deter parents from telling their child or adolescent about their status (Klitzman, et al. 2008: 31). In cases where a child/adolescent may learn of their status at a later age, such as 18, the child may resent his/her parents for not disclosing their status earlier. However, even children as young as 10 or 11 may resent their parents for not telling them earlier. These circumstances further complicate the question as to the correct time and age for disclosure. Moreover, differences in personality, mental health status and resilience levels further complicate disclosure processes, as each process should essentially be tailored to each child specifically according to his/her needs. As this cannot be determined in advance in accordance with universal criteria, it leaves a lot of grey areas as to the appropriate method of disclosure from parents to children.

In general, parents can be relied upon to make the best decisions for their children. This is why parents and guardians are generally given the right to make decisions about the healthcare of their child, and to exercise their autonomy as surrogate decision makers. However, good intentions on behalf of the parent do not necessarily constitute acting in the child's best interest, especially in cases where their fears and anxieties could hamper their objectivity in making decisions (Klitzman, et al. 2008: 31). In addition, as a child increases in age, their cognitive development gradually increases their ability to act as autonomous agents. Although the benchmark to be considered autonomous is usually 18 years, it is questionable whether parents should be allowed to withhold disclosure until then, even if

they would wish to do so (Klitzman, et al. 2008: 31). While, one could argue that children should be protected from the potential emotional burdens that HIV disclosure can bring, disclosure could potentially empower children and enable them to participate in decisions about their healthcare (Klitzman, et al. 2008: 31), particularly because the age of medical majority is 14 in Namibia.

### **3.3.5 Mother-to-child transmission (MTCT) of HIV**

The final topic that I will discuss here with regard to HIV and AIDS and children relates to MTCT, and raises similar issues to those previously discussed under HIV testing and consent, and HIV transmission. MTCT of HIV is a major public health issue, and constitutes up to 90% of childhood HIV infections (Haruna, Assenga and Shayo 2018: 1). Although there has been improvement in the number of children becoming newly infected with HIV, the statistics still remain high. In 2016, 24% of HIV positive pregnant women did not have access to ART in order to prevent transmission to their infants. In the same year, approximately 160 000 children became infected with HIV (Avert 2020a).

Due to the fact that HIV has such a momentous impact on maternal and child health, it is vital that we attempt to prevent MTCT as early as possible during pregnancy. The prevention of MTCT is dependent on the pregnant woman pursuing and adhering to antenatal care, undertaking an HIV test and agreeing to necessary medical treatment and care (Schuklenk and Kleinsmidt 2007: 1179).

However, there is no guarantee that pregnant women will accept treatment and follow through with ART, even after testing positive. A study that was undertaken in South Africa, Zambia, Cameroon and Cote d'Ivoire found that only 36% of the research sample of 976 pregnant women completed every necessary step of the prevention of MTCT process. Of the remaining 621 women, 4% did not pursue antenatal care and 17% did not take an HIV test (Chi, et al. 2015: 1)..

Should a pregnant woman fail to undergo necessary testing and treatment, the effects of MTCT on an HIV infected newborn, is grave. The average life expectancy of an HIV positive newborn who does not obtain advanced medical care is approximately 2 years. For the

duration of this time, the newborn suffers from a variety of life-threatening diseases (Schuklenk and Kleinsmidt 2007: 1180).

In this context, an important ethical issue arises, that has to do with the moral obligations of pregnant women and governments in the reduction of MTCT, particularly in high prevalence countries where necessary preventive ART is readily accessible to HIV infected mothers (Schuklenk and Kleinsmidt 2007: 1180). Many argue that mandatory testing and treatment are justified in public health emergencies, such as that of HIV and AIDS (Schuklenk and Kleinsmidt 2007: 1180). This standpoint prioritizes the rights of the newborn above that of the pregnant woman's right to privacy and autonomy. The proposition from this viewpoint is that the newborn's life holds greater importance than the right of a pregnant woman to have control over her body and emphasizes that the mother should hold some accountability for the well-being and health of her newborn (Schuklenk and Kleinsmidt 2007: 1180).

What is more, the probability of a newborn contracting HIV as a result of a pregnant woman not adhering to ART gives rise to a risk of significant harm to the newborn. Therefore, purposefully choosing to not prevent this harm when one could have easily done so, without imposing significantly high sacrifices or costs to oneself, can, according to Schuklenk and Kleinsmidt, be viewed as similar to deliberate actions that produce the same magnitude of harm (2007: 1182).

The counter argument made by others is that forcing women to undergo HIV testing is a violation of their rights, regardless of any consequences that result therefrom (Omonzejele 2014: 14). This standpoint places emphasis on the violation of women's privacy and the possible risk of them being exposed to stigmatization (Schuklenk and Kleinsmidt 2007: 118). In particular, some feminist groups have argued against mandatory testing and treatment, arguing that mothers should not be expected to be self-sacrificial and need not put the interests of their children above their own. This view is flawed according to Schuklenk and Kleinsmidt, in that adhering to ART not only decreases the risk of MTCT, but also promotes the physical wellbeing of an HIV infected mother herself, which undermines the idea that this act should be considered as "self-sacrificial" (2007: 1181).

In essence, the ethical issues around MTCT have to do with the conflict between the rights of a pregnant woman to autonomy and privacy and the prevention of harm to the fetus or newborn (Schuklenk and Kleinsmidt 2007: 1180).

In this section, I have provided an overview of the challenges and ethical issues related to HIV infected children, with a view to providing a background to the specific application of this discussion to HIV infected children who are enrolled in childcare institutions. Discussing the topics of caring for an HIV infected child, the psychosocial wellbeing and development of infected children, stigmatisation of children, status disclosure in children, and MTCT, has provided a deeper understanding as to how the lives of children are affected by HIV in general. The next section will proceed to discuss disclosure and stigmatisation at length, as both topics hold critical relevance for this thesis.

### **3.4 Disclosure and stigmatisation**

This section will primarily assess the challenges around disclosure and stigmatisation, as well as the detrimental effects that can often result from fear in the context of HIV and AIDS. This discussion is essential, as the potential for stigmatization is the foremost obstacle to possible status disclosure, with particular reference to childcare settings.

Disclosure refers to the process whereby one's HIV positive status is communicated to a third party, by the HIV positive person him or herself. As discussed in the previous section, disclosure may also refer to communicating a child's own positive status to him/her, or parents disclosing their child's status to third parties. It usually involves a gradual process of disclosing one's status to an increasing number of individuals over a period of time. Disclosure is linked to better health treatment, healthier lifestyles, less social isolation and the positive maintenance of romantic relationships (Thapa, et al. 2018: 1; Wessman, et al. 2017: 142).

#### **3.4.1 Complexities surrounding disclosure**

As previously discussed, instances of negligent transmission have led to the criminalisation of HIV transmission in a number of countries. However, these legal repercussions do not necessarily take into account the actual reasons as to why many people do not disclose their status. The fear of stigmatization and discrimination can make HIV disclosure a very difficult task to carry out (Avert 2017b).

For many women, disclosure may hold severe consequences. In some cases, status disclosure may lead to physical violence and domestic abuse towards women, providing a reasonable and valid justification for non-disclosure (Colombini, et al. 2016: 1).

Responsible HIV disclosure has always been a complex issue, and a decision to disclose should always be well-informed, as those revealing their positive status cannot predict or control the actions of those they are disclosing their status to. This means that there is anxiety linked to each disclosure process as the response or consequences thereof can never truly be foreseen (Chidrawi, Greeff and Temane 2014: 3). Other complexities involved in the HIV disclosure process include considering factors such as when, how and whom to share this information with. Often, individuals start disclosing their status to a limited selection of persons, and may then gradually extend their disclosure publicly, should they wish to do so (Thapa, et al. 2018: 1).

The disclosure of an individual's positive HIV status to their sexual partners presents a few factors worth considering. Individuals have varying expectations with regard to honesty, trust, intimacy and fidelity within relationships. These factors are further dependent upon the duration and nature of the respective relationship (Burriss and Weait 2011: 6). Often, infected individuals are reluctant to disclose at the beginning stages of a relationship, while trust and emotional connection is still being established. In casual and unofficial relationships, infected individuals are less likely to feel that it is necessary to disclose their status, as trust and a high-level of intimacy has not necessarily been established within these relationships (Smith, Cook, and Rohleder 2016: 5).

Counsellors have expressed frustration at the low rates of HIV positive individuals who do disclose their status to their partners. This may lead to a hindrance in the prevention of new infections, as well as a failure to access HIV care for both patients and their partners (Njozing, et al. 2011: 2).

### **3.4.2 Stigmatisation**

The word "stigma" originally comes from the Greek word for "mark". This "mark" is linked to lower societal classes, shame and disgrace. It is an observation of "differentness" and

originates from a person's association with a group of people who presumably hold undesirable and unpleasant traits. People who are stigmatised are often rejected, feared and shunned by other members of the community, resulting in feelings of unworthiness. Fundamentally, discrimination ensues and results in the mistreatment of a person. This often leads to social isolation, as these individuals habitually shy away from others (World Health Organisation 2011: 35).

In the context of HIV, stigma often derives from the observation that the disease is contagious and dangerous, as well as the assumption that an infected person often ends up infected due to behaviours perceived as immoral and shameful by certain sectors of society, such as homosexuality, drug use, sex work or infidelity (Avert 2017b). For example, in a study conducted by the International Center for Research on Women (ICRW), it was discovered that becoming infected with HIV and AIDS was perceived to be the respective person's own fault, since they had decided to partake in immoral actions of their own accord (ICRW.org 2006: 4). To further complicate this matter, religion, cultural norms, gender roles, and belief systems are indissolubly entangled in the HIV debate, and may be implicated in stigmatization (van Bogaert and Ogunbanjo 2011: 607).

Most unfortunately, disclosure is often linked to stigmatisation. According to UNAIDS and the WHO, the main reason why people are reluctant to disclose their HIV status is due to an intense fear of stigmatisation and discrimination. Moreover, they are also hesitant to get tested, for fear of a positive result, as well as to start ART should they test positive, for similar reasons. Even if HIV positive individuals enter treatment, they may be less likely to continue taking scheduled medication or keep appointments for fear of stigmatisation from healthcare personnel, as well as due to fear that members of the public might notice (Avert 2017b; van Bogaert and Ogunbanjo 2011: 607).

In addition to this, HIV stigmatisation may also lead to isolation and exclusion from social networks and the community, loss of income and livelihood, depression, decreased self-confidence, poor and inadequate care within the health sector, a negative effect on reputation, loss of marriage and decreased childbearing options, as well as bullying, insults and gossip (ICRW.org 2006: 5; Thapa, et al. 2018: 6; World Health Organisation 2011: 34). As noted previously, stigmatisation appears to affect children as well.

HIV stigma can be categorised as either real, perceived, internalised or stigma by association. An HIV positive individual may fall victim to rejection, mistreatment, avoidance, hostility, gossip and abuse by others who are aware of their HIV status. These circumstances are known as real stigmatisation (van Bogaert and Ogunbanjo 2011: 67). Stigma is perceived when HIV positive individuals hold the false assumption that others will discriminate against them, when in fact, this is not true. In essence, it is the awareness of negative attitudes regarding HIV, and the fear thereof. Perceived stigma occurs as a result of previous real stigmatisation, and the notion that societal views are incapable of evolving or changing. However, a study conducted in Denmark by Maria Wessman in 2007 discovered that the majority of HIV positive individuals experienced mostly positive reactions once they had disclosed their status, showing evidence of perceived stigmatisation. In this study, more than two thirds of all participants expressed fear of rejection and discrimination as reasons for non-disclosure. Experienced stigma was still present, as 7% of participants had experienced unpleasant reactions upon status disclosure (Wessman, et al. 2017: 143).

Internalised stigma refers to the negative self-judgement and social withdrawal one feels or imposes on oneself. This can drastically lower self-confidence and can result in feelings of worthlessness, shame and blame. Moreover, internalised stigma also has detrimental effects on the mental wellbeing of HIV positive individuals and ultimately decreases quality of life and adherence to self-care and treatment (Avert 2017b; Wessman, et al. 2017: 140). In the study conducted by Maria Wessman mentioned above, internalised stigma was apparent in nearly 30% of participants. Nevertheless, 75% of participants felt better able to make life decisions after they had disclosed their status, implying that disclosure had an overall positive effect on the individual's ability to take action where life decisions are concerned (Wessman, et al. 2017: 143).

Internalised stigma is also present in South Africa. A recent survey reported that some participants expressed feelings of guilt, shame, low-self-esteem and self-blame. These feelings of self-stigma sometimes lead to participants isolating themselves from friends and family, as well as avoiding social gatherings. In some instances, it even lead to the development of a substance abuse problem (The people living with HIV stigma index 2014: 11).

Stigma by association occurs when an individual is stigmatised because they are related or linked to a known HIV positive individual. For example, a child might be stigmatised because his/her parent is known to be HIV positive (World Health Organisation 2011: 35).

In 2015, WHO released new treatment guidelines that reveal the need to address stigmatisation and discrimination as a barrier to accessing HIV treatment, putting into perspective the severity of the issue at hand (World Health Organisation 2015: 29).. Removing this barrier is fundamental to ending the HIV epidemic (Avert 2017b).

In this section I have discussed status disclosure, and its challenging relationship with stigmatisation. This discussion revealed that HIV stigmatisation, and the relationship between a reluctance to disclose and stigmatization, presents an enormous impediment to adequate management of HIV care. This is of particular relevance in a childcare setting, as we can only attempt to improve care of HIV positive children through the promotion of status disclosure and HIV stigma reduction efforts. Fundamentally, the appropriate usage of laws, policies and social norms to avert stigmatisation may play an essential role in the promotion of disclosure and ultimately, the improvement of HIV management.

Of further importance in promoting status disclosure to third persons is respect for confidentiality, particularly in contexts where stigmatization remains prevalent. The next section will therefore discuss the concept of confidentiality in more detail.

### **3.5 Confidentiality and disclosure to third parties**

The previous section shed light on the relationship between HIV-related stigmatisation and the reluctance of individuals to disclose their positive status, or, in the context of this study, their child's HIV status. This hinders the efficient management of the HIV epidemic. However, confidentiality provides an opportunity to promote status disclosure and reduce stigmatisation, as confidentiality engenders trust between parties. Unfortunately, problems may arise in instances where confidentiality is breached. In this section, I will reflect upon these themes.



### 3.5.1 The principle of confidentiality

Confidentiality refers to the principle governing situations in which a healthcare professional or counsellor has been entrusted with a patient's personal and private information, such as information about their HIV status, and requires that the medical professional will ensure that this information will remain private and will not be discussed with other persons, without the consent of the particular patient (Cambrea, Arghir and Halichidis 2012: 194). Confidentiality may also apply in other settings where a trusted individual is appraised of private information relating to a person which they undertake not to share with others (for example, a lawyer who is entrusted with certain information about their client). Confidentiality provides a means of security against private information becoming public knowledge. In a healthcare context, the preservation of a patient's confidentiality maintains trust within the healthcare system, assists in the promotion of HIV testing and increases adherence to HIV treatment (Njizing, et al. 2011: 4). By maintaining trust and confidentiality, counsellors, clinicians and other healthcare professionals are placed in a position to encourage positive behaviour, which in turn, enables the infected individual to gain access to the healthcare system, and reduces the risk of HIV transmission to other persons. In essence, confidentiality promotes open communication and the positive development of trust between a healthcare professional and their patient (Cambrea, Arghir and Halichidis 2012: 194).

One should take note, however, that the principle of confidentiality is not absolute, and some instances may occur where it is not strictly maintained. Essential and relevant information may be shared amongst healthcare workers who are responsible for the medical care of a patient, in order to ensure the effective treatment of that particular patient. Although personal information, such as a patient's positive HIV status, may sometimes be shared, confidentiality is still maintained within this group of medical professionals (UNAIDS Best Practice Collection 2000: 12).

Other cases where confidentiality may be breached without an individual's prior consent, is when there is a risk of a third party being harmed. When an identifiable third party is at risk, the principle of confidentiality comes into conflict with the ethical principle "to do no harm." In these situations, an ethical weighing of the possible benefits and possible harms should be

considered in order to decide on the appropriate course of action. This will be discussed in more detail in the next chapter (UNAIDS Best Practice Collection 2000: 11).

It is essential to differentiate between confidentiality and “secrecy,” as many individuals hold the belief that the two concepts are interrelated. Secrecy often stems from shame, fear, denial and vulnerability and may harm individuals infected and affected by HIV and AIDS, by undermining their ability to cope positively with the disease. Conversely, the principle of confidentiality promotes healthcare. Confidentiality advocates that an individual has a right to privacy of their most personal information. It further promotes an effective relationship between a patient and his/her clinician or healthcare provider, as individuals only feel safe to come forward and share critical, yet personal information, when they are assured that their information will be kept private. Thus, confidentiality plays a fundamental role in the effectiveness of many public health measures through the establishment of these trusted relationships (UNAIDS Best Practice Collection 2000: 11).

### **3.5.2 Conflicting principles**

As previously mentioned, healthcare professionals and counsellors frequently encounter the ethical dilemma whereby the right of the infected individual to confidentiality can be in conflict with the right of the sexual partner to be warned in order to protect them from the risk of infection. This occurs when an infected individual discloses their positive status to their doctor, but refuses to disclose their status to their sexual partner. Whether a healthcare practitioner has an obligation to protect third parties by breaching their patient’s confidentiality, or whether he/she should respect the confidentiality of their patient and risk the possibility of third parties being infected, presents a momentous ethical dilemma in which both obligations should be carefully considered (Klitzman, et al. 2008: 31). When these dilemmas arise, ethical considerations, and particularly the principles of autonomy, beneficence and non-maleficence, should be carefully weighed in order to come to a moral judgement (Cambrea, Arghir and Halichidis 2012: 195).

On the one hand, some believe that the doctor or counsellor may violate confidentiality, purely with the intention of avoiding possible harm. The principle of autonomy requires confidentiality and forbids the disclosure of private information to other persons. However,

respecting this duty could potentially have dangerous consequences where third parties are considered, and maintaining confidentiality may therefore violate the principle of non-maleficence (Cambrea, Arghir and Halichidis 2012: 195).

Various standpoints exist regarding this matter. Firstly, many individuals believe that respect for autonomy should be absolute, suggesting that individuals should not be forced to disclose their private information solely for the benefit of others (Njizing, et al. 2011: 5). It is also important to remember that the decision in favour of non-disclosure does not always stem from the intention to harm, or a blatant refusal to consider another individual's wellbeing. A patient may refuse disclosure due to fear of blame, verbal or physical assault, violence, admitting to promiscuity or divorce (Njizing, et al. 2011: 5). From a Kantian approach, non-disclosure in this given scenario may not be morally wrong as no harm is intended. However, a utilitarian approach would regard non-disclosure in such a case as morally wrong, as it may essentially cause harm to others.

In the event that a breach of confidentiality leads to marital disharmony or divorce, it would ultimately impose harms on both the infected patient and his/her partner (Njizing, et al. 2011: 7). This gives rise to the question as to whether one can justify imposing these harms in order to potentially protect a spouse from contracting HIV. One could possibly justify this by arguing that the potential to contract a deadly disease is much more severe than the potential harm of marital disharmony. In retrospect, we would need to determine the severity and possibility of all outcomes that might ensue.

In this regard, some argue that although a patient's autonomy should be safeguarded, the duty to protect the patient's sexual partners from the risk of HIV exposure, and to give them the opportunity to seek prompt treatment and medical care should they already be infected, still has weight. This view does not necessarily support the breach of confidentiality, but rather promotes encouraging the patient to disclose their status to their sexual partner. This course of action maintains the principle of autonomy and confidentiality, and the duty to protect third parties has, to a degree, been addressed. However, the risk still exists that an infected partner may refuse to disclose their status, thus imposing a significant harm on their partner (Njizing, et al. 2011: 5).

The final standpoint is to support the breach of confidentiality, and to protect the sexual partners by warning them of the HIV risk, in order to allow them to protect themselves and to seek prompt medical treatment if necessary. The moral argument presented here is that patients who refuse to disclose their status to their sexual partners are behaving selfishly by not bearing in mind the health and wellbeing of their sexual partners (Njosing, et al. 2011: 7).

Where partner notification is concerned in Namibia, counsellors and healthcare workers are required to maintain confidentiality of an individual's positive HIV status (Namibia 2002: 2). However, *The Namibian HIV/AIDS Charter of Rights* states that disclosure should only take place to an identifiable sexual partner who is at risk, according to the following criteria:

- The respective HIV infected individual has been comprehensively counselled as to the need for partner notification.
- The respective HIV infected individual has refused to notify or consent to the notification of his/her sexual partner.
- A genuine risk of transmission to the respective partner exists.
- The HIV infected individual is given a reasonable advance notice of the intent to notify their partner.
- A follow-up is made to provide support to the involved parties, as required.

(Namibia 2002: 2).

Ultimately, a number of factors need to be taken into account in deciding whether it is justifiable to breach confidentiality, including the likelihood of transmission to an identifiable third party (which could depend on the viral load of the patient and whether they are already taking precautionary measures to avoid infection), and the likely impact of a failure to maintain confidentiality in a specific set of circumstances.

### **3.5.3 The role of confidentiality in reducing stigmatisation and promoting status disclosure**

As discussed above, deciding whether it is justifiable to breach confidentiality is a complex matter. It must, however, also be noted that confidentiality generally plays a vital role in the

reduction of discrimination and the promotion of status disclosure. Firstly, HIV related stigmatization puts diagnosed individuals at significant risk of discrimination in the event that their positive status becomes public knowledge (Fishman 2013: 214). In order to prevent this from occurring, keeping that personal information private would be necessary.

Confidentiality allows HIV infected individuals to protect that private information, thus providing a valuable avenue for preventing public discrimination and stigmatisation.

Secondly, individuals are often reluctant to get tested for HIV, and will only do so if they can be assured that their HIV status will be kept private, due to the fear of stigmatisation (Fishman 2013: 214). Thus, confidentiality in HIV related matters encourages testing.

Moreover, individuals will only come forward and share personal information, such as their HIV status, if they are assured that their healthcare provider will keep their information private. As a result, confidentiality promotes status disclosure by providing a safe space whereby open communication and the development of trust can be achieved between a healthcare professional and their patient, which in turn leads to better access to treatment (Cambrea, Arghir and Halichidis 2012: 194).

The aim of this chapter was to provide an overview of the background against which the specific topic I wish to address in this thesis, namely, ethical issues related to HIV positive children in childcare facilities, should be considered. In order to sketch this background, I began by discussing general ethical issues related to HIV and AIDS, with specific focus on the conflict that often arises in this context between individual rights and public health. I then moved on to discuss common challenges faced by HIV positive children, as well as ethical issues that arise with respect to children and HIV and AIDS. Finally, I discussed the relationship between a reluctance to disclose one's HIV status and stigmatization, as well as the role which the principle of confidentiality can play in combatting this fear of stigmatization and promoting status disclosure. However, as aforementioned, the principle of confidentiality is not always absolute and may occasionally be breached to prevent harm to others.

In the next chapter, I will proceed to the central focus of this thesis, and via an ethical analysis which takes into account the perspective of all parties involved, and informed by the discussion above, argue that status disclosure would be beneficial within a childcare setting.

### **3.6 Conclusion**

## **Chapter 4: Ethical Perspectives and Considerations for Disclosure**

### **4.1 Introduction**

Thus far, I have presented general background information regarding HIV positive children in childcare centres, and sketched the problem that I wish to address, in Chapter 1. Chapter 2 then proceeded to assess Namibian policies and legislation, in order to gain insight into current practices that are in place as far as childcare for HIV positive children in Namibia is concerned. In Chapter 3, I provided an overview of ethical issues raised by HIV and AIDS in general, considered challenges and ethical issues related to HIV and AIDS and children, and discussed status disclosure, its relationship to stigmatisation, and ethical complexities with regard to confidentiality. This chapter will argue in favour of status disclosure in childcare settings via a principlist ethical analysis which will consider the perspective of all parties involved.

### **4.2 Principlism in Bioethics**

Every day we are challenged with moral and ethical choices, particularly in healthcare, in a society that is diverse and multicultural. To complicate matters, oftentimes many variables exist in each individual clinical case, making a consistent approach to decision-making difficult. Taking diversity into consideration, how can we arrive at applicable guidelines which all persons, regardless of their religious or cultural backgrounds, can adhere to? Principlism is a practical approach to moral decision-making in medical ethics that has been developed by a number of prominent figures, and particularly Beauchamp and Childress, in the last 25 years. This system of ethics is based on the moral principles of respect for autonomy, beneficence, non-maleficence and justice. Principlism is an appealing approach to moral decision-making as it is extensive and broad enough to be shared by all rational persons, regardless of their background or individual religious and cultural beliefs (Strong 2000: 323). Principlism helps to deal with diversity in that it can be universally applied, as it justifies moral reasoning on the basis of a common morality that is acceptable in all civilisations, and not specific customary or cultural rules (Beauchamp and Rauprich 2015: 1).

The principles are as follows:

#### **4.2.1 The principle of respect for autonomy**

The principle of respect for autonomy refers to allowing patients to make their own health and medical decisions. Autonomous agents are seen as rational and ought to be well-informed of their choices and options when making decisions. Patients are considered to be autonomous when they possess the capacity to act intentionally, with understanding, and when they are free from controlling influences that could potentially compromise a voluntary decision. The principle of respect for autonomy serves a morally useful purpose as it allows an individual to attain what he/she regards as the “goods” of life. We have a moral obligation to respect the autonomy of other individuals, as it enables them to make decisions according to their own perception of what they value in life, as opposed to our own subjective values and beliefs. As discussed earlier, this principle forms the foundation for the importance of “informed consent” where healthcare is concerned (Beauchamp and Childress 2013: 102).

#### **4.2.2 The principle of non-maleficence**

The principle of non-maleficence stipulates that we should not intentionally cause harm or injury to others. Harm can be perpetrated through either acts of commission or omission. More specifically, we are obligated not to cause avoidable harm. However, in the event that a harm cannot be avoided, then we are required to, at the very least, minimize the harm. Moreover, it is considered negligent if one inflicts an unnecessary or thoughtless risk of harm upon another individual. This principle also establishes the need for medical competency (Beauchamp and Childress 2013: 150).

#### **4.2.3 The principle of beneficence**

The principle of beneficence entails the obligation to benefit a patient. This duty further obligates us to take positive steps to prevent or to remove harm. The term beneficence refers to actions of kindness, mercy and charity. It is indicative of love, humanity, selflessness and promoting the good of others. Where healthcare is concerned, this principle implies that a

patient enters into a relationship with a physician, trusting that their main goal is to provide help and care (Beauchamp and Childress 2013: 202).

#### **4.2.4 The principle of justice**

The principle of justice refers to the fair distribution of goods and services within society and requires that all individuals should be treated equally and fairly (Beauchamp and Childress 2013: 249). Distributive justice, in particular, refers to a fair means of allocating scarce resources, taking into account that some goods and services are in short supply. In essence, justice in the context of healthcare is often equated to fairness (Beauchamp and Childress 2013: 250). In order to uphold the principle of justice, this thesis attempts to address the idea that HIV is indeed equal to other chronic diseases which are not stigmatised. This is further discussed in section 5.3 *AIDS exceptionalism and treating HIV and AIDS as any other disease*, as it is more applicable to that chapter.

#### **4.2.5 Weighing and balancing of principles**

Although all of the above principles are taken into account when they are considered in a clinical case, we may find that two or more principles come into conflict (DeMarco and Ford 2006: 483). When these conflicts arise, the weighing and balancing of principles is necessary (DeMarco and Ford 2006: 495). Beauchamp and Childress emphasise that the principles are not ordered hierarchically – we cannot determine in advance which principle will take priority in any given situation. As each individual clinical case presents different variables, these principles can be applied by understanding and appreciating the unique features relevant to each case. While on the one hand this flexibility can be seen as a strength of principlism, some argue that this could also be problematic. A failure to stipulate a fixed method of assigning priorities to these principles in instances where they come into conflict with one another may lead to uncertainty about how to proceed (Strong 2000: 323).

### **4.3 Weighing and balancing of principles with respect to status disclosure in childcare facilities**

Given the complexity of the issues surrounding HIV and AIDS, children and childcare, it is expected that a variety of ethical principles will come into conflict in decision-making in this



context. Ethical principles that are prominent with regard to this topic include autonomy, beneficence, non-maleficence, and I will focus on these principles primarily. Respect for autonomy, for example, is associated with the right to confidentiality and privacy, and the right to access information which could have implications for one's health. Beneficence and non-maleficence, on the other hand, are associated with the duty to promote public health and to protect against stigmatisation.

In addition, there are a number of parties whose interests must be considered when applying these ethical principles to this issue. These parties include the parents or guardians of the child, the HIV positive child him/herself, other children attending the facility, and the childcare director of the facility. Each of these parties will be considered with regard to the ethical dilemmas that specifically affect them.

#### **4.3.1 Weighing and balancing of principles pertaining to the perspective of the HIV infected child's parents or guardians**

The parents or guardians of the HIV positive child are ultimately responsible for making the decision as to whether to disclose their child's status or not – they exercise surrogate decision-making on behalf of their children. Individuals are deemed competent to make decisions if they have the capacity to understand the presented information, to make a judgement about it, to anticipate a particular result or consequence, to understand the alternatives, to grasp the degree and likelihoods of harm and benefits, and to express their wishes (Beauchamp and Childress 2013: 116). Many children do not yet have this decision-making capacity and therefore require a proxy to make medical decisions on their behalf. Preschool children, in particular, have not yet developed the significant cognitive skills that would enable them to partake in decision-making in any meaningful manner. Adults are assumed to possess such decision-making capacity. Therefore, a relative (usually a parent) will generally act as a proxy decision maker.

In general, two types of proxies exist: substitutes and surrogates. Substitute decision makers are appointed in order to support a patient's previously expressed wishes, when a patient has either permanently or temporarily lost the capacity for autonomous decision-making that they previously possessed. Conversely, surrogate decision makers do not make decisions based on previously expressed wishes, but rather form their judgements on the basis of the

best interests of the patient. Parents or guardians are usually surrogate decision makers for their children, because children have not yet developed the capacity to express their wishes in a reasoned way (Harrison, et al. 2004: 100). From a legal perspective, the Child Care and Protection Bill of Namibia states that a parent, guardian or care-giver may make medical decisions on behalf of a child if the child has not yet reached the age of 14 years (Namibia 2010).

Present rationalisations as to why parents or guardians are the best persons to make these decisions include the following:

- Parents or guardians ultimately hold the responsibility for bringing up their children in a way that they see fit. This responsibility necessitates the right to make decisions on behalf of the child.
- Parents or guardians are most likely the ones who will need to handle any consequences that these decisions might give rise to.
- Parents or guardians have a privileged understanding of the child and his/her personality and/or best interests.
- Parents or guardians generally have the child's best interests at heart, as a direct result of the family ties, love and affection they have for that child.

Under principlism, we have a moral duty to uphold and respect the autonomy of other individuals, which entails respecting the opinions and decisions made by other individuals concerning their own lives. The autonomous person acts freely according to a self-chosen plan. To respect someone's autonomy, means not interfering with the decisions of competent persons. Therefore, truly valuing the autonomy of an individual would respect the fact that he/she has chosen not to disclose their personal information to anyone. Furthermore, forcing them to disclose their HIV status would compromise their right to make their own choices (Beauchamp and Childress 2013: 101; Wengerd, Hill and Konieczka 2014: 6). By extension, respecting the rights of parents or guardians to make medical decisions for their children, and to exercise surrogate decision-making on their behalf, seems to require that we respect the decision of parents or guardians not to disclose the HIV status their child.

On the other hand, principlism also requires that we uphold the duty of beneficence towards the individual patient him/herself, as well as to other persons involved (Crisp 1989: 68). The principle of beneficence connotes a moral obligation to act for the benefit of an individual, and promotes acts of kindness and mercy. It also necessitates the need to take positive actions in order to help an individual, often by removing a possible harm (Beauchamp and Childress 2013: 202).

In this case, beneficence and autonomy come into conflict. In the event that a guardian refuses to disclose the HIV status of their child, it is most likely due to a fear of stigmatization, as discussed in Chapter 3. In order to uphold the principle of autonomy, this refusal should be respected. However, disclosure has been linked to many positive outcomes, as also discussed in Chapter 3, and as will be further discussed in this chapter. As a result, status disclosure may very well uphold the principle of beneficence. This might mean disregarding a guardian's refusal to disclose their child's status. The principle of autonomy recognises the rights of persons to self-government and independence, whilst that of beneficence promotes actions that serve the best interests of the individual. In this case, we are required to balance the demands of these principles by deciding which carries more weight

On the other hand, one could also argue that the principle of beneficence could also support non-disclosure in order to protect the child from possible harm, such as stigmatization. However, in the event that status disclosure occurs, one cannot predict with absolute certainty whether stigmatisation or the positive outcomes associated with status disclosure will be the end result. In essence, these outcomes can only be measured in terms of "possibilities", and an evaluation of the likelihood of these possibilities should take into account the particular circumstances of the specific case.

Although the rights of parents or guardians to make decisions on behalf of their children is widely accepted, it is not absolute or unlimited. It should also be noted that the right to autonomy is limited in as far as it affects another person. The US Supreme Court states, "Parents are free to become martyrs themselves. But it does not follow that they are free, in identical circumstances, to make martyrs of their children before they have reached the age of full and legal discretion when they can make that choice for themselves," (Cummins and Mercurio 2017: 11). This implies that should the state observe any unfit parental decision-making, then by law, they are entitled to intervene. These instances usually occur in severely

questionable ethical circumstances, such as a competent adult refusing lifesaving medical treatment for his/her child (Cummings and Mercurio 2017: 11). Similarly, the Child Care and Protection Bill of Namibia allows medical interventions by the Minister or a court in circumstances where a parent or guardian unreasonably or irrationally refuses medical treatment and care (Namibia 2010).

Taking these laws into consideration, does any harm inflicted onto the child as a result of parental decision-making around HIV status disclosure present similar ethical grounds for intervention? In order to answer this question, we need to evaluate the likely harms and benefits that will be experienced by the child. I will discuss this further below in the section concerning the perspective of the HIV positive child.

One should also note that children who are infected with HIV often have a parent who is HIV positive as well, as a high percentage of child HIV transmission is known to occur via vertical transmission, or MTCT. In developed countries, the prevalence of vertical HIV transmission in the absence of ART is between 13-32%, whilst in developing countries this increases to 25-48% (Guevara, et al. 2000: 390). More current research reflects similar data; the prevalence of vertical HIV transmission in the absence of ART is between 15-45%, globally. However, ART can reduce this likelihood to below 5% (Avert 2020b).

As HIV infection is known to be accompanied by psychosocial difficulties and stress, one can presume that the parents and guardians of HIV positive children are often exposed to these stressors as well. In the previous chapter, I discussed how a parent's positive HIV status might influence their ability to make decisions with regard to the care of their child. In summary, the knowledge that their child is infected puts a heavy emotional burden on parents. Feelings of guilt, blame, remorse and misery might ensue and a close correlation has been observed between the acceptance of the HIV status of a child and the compliance of a parent to provide the required care for their child (Brouwer, et al. 2000: 536).

I have also previously discussed how experiencing real stigmatisation may lead to perceived stigmatisation. In effect, a parent who has previously fallen victim to mistreatment or abuse due to their positive status, might be reluctant to disclose the HIV status of their child for fear that their child might experience the same ill treatment (van Bogaert and Ogunbanjo 2011: 67). Taking this into consideration, one may ask whether this enhances or diminishes

effective parental decision-making. As mentioned previously, perceived stigmatisation does not take into consideration whether societal views are capable of changing or evolving, or that as time progresses, individuals are becoming more open-minded with regard to HIV-related matters as a result of improved access to information. It is vital to emphasise the importance of patience and empathy when working with parents whose lives have been so profoundly affected by HIV and AIDS, and how their state of mind could potentially influence their ability to work through the decision-making process.

One can also argue that parents or guardians themselves might benefit from disclosing their child's status to the childcare director of the facility, who would then be required to maintain the confidentiality of the child's HIV status. Thus, the principle of beneficence might also need to take into account the potentially positive impact on the parents or guardians, as they would be in a position where they could attain additional help to optimally manage their child's illness, and the burden of secrecy that a positive HIV status can impose would be lessened (Klitzman, et al. 2008: 42). Parents and guardians of HIV positive children often experience burnout, especially as the disease progresses and the burden of care becomes more challenging and demanding, and sharing this burden through disclosure could be beneficial (ICRW.org 2006: 6).

The principle of non-maleficence necessitates the obligation not to intentionally harm or impose risk upon another person, whether it be through acts of commission or acts of omission. Moreover, if a harm cannot be avoided, then we are at the very least required to minimize the harm that we do inflict on another individual (Beauchamp and Childress 2013: 151). If one were to take up an attitude pro-disclosure, two possibilities exist: mandatory disclosure and the encouragement of disclosure. In the case of mandatory disclosure, an immense amount of harm may potentially be inflicted on those affected. It should be noted that mandatory disclosure may likely be forced disclosure, which has been linked to negative outcomes, whereby HIV infected individuals who have experienced forced disclosure often feel a sense of dishonour and disgrace related to their status (Thapa, et al. 2018: 6).

What is more, although one may argue that benefits in the form of additional support and optimal childcare may result from disclosure, the potential for stigmatisation to ensue is still a risk, thus imposing an additional potential harm. Although both forms of disclosure present the potential harm of stigmatisation, mandatory disclosure confers the additional harm of

being linked to negative outcomes as noted above, thus rendering the encouragement of disclosure a more suitable option.

Perhaps one of the biggest ethical debates that seems to consistently arise in medical and clinical settings, is that of beneficence versus non-maleficence. From the perspective of the HIV positive child's parents and guardians, a great deal of harm is possible if the situation is handled poorly. If childcare directors were to unjustly break confidentiality and inform others of the child's HIV status, the child and his/her parents or guardians will likely face stigmatisation and discrimination from the community. Consequently, the parents and guardians will be the ones to deal with this backlash. On the other hand, the disclosure of a child's HIV status could potentially benefit the parents and guardians as well by reducing the burden of secrecy and providing additional help and support for the care of the child, as aforementioned. Are these benefits worth risking the potential harm of stigmatisation which may result from a breach in confidentiality? Once again, a weighing and balancing of potential harms and benefits, taking into account the specific circumstances of the case, is required.

#### **4.3.2 Weighing and balancing of principles pertaining to the perspective of the childcare director of the facility**

As previously mentioned, the term beneficence refers to the obligation to bring about good, and to positively contribute to an individual's welfare. It also entails taking positive steps in order to prevent or to remove a harm from an individual (Beauchamp and Childress 2013: 202). The childcare director of the facility would appear to benefit from being aware of the HIV status of children in their care, upholding the principle of beneficence, as this would better equip them to fulfil their professional duties. Conceivably, one of the greatest benefits would be to better understand the position of the child and his/her parents or guardians. Reasoning from this fact, in cases of frequent absenteeism and health complications, the childcare director would be better equipped to manage and handle these circumstances. The childcare director would also be able to improve the standard of care to the child, as well as to provide help and support, specifically tailored to the child's needs.

One can argue that if universal precautions are followed correctly, HIV status disclosure need not play such a significant role. However, if childcare directors are aware of positive statuses, they would be in a better position to keep an eye out for rough playing or blood spills, provided it is done in a respectful and discreet manner.

It is vital that parents and guardians of all children within the facility should be urgently informed if there has been any exposure to chickenpox, cytomegalovirus, cryptosporidiosis, diarrhoeal disease, tuberculosis, measles, parvovirus or any other infectious diseases within the childcare facility, and this is especially important for HIV infected children (Caring for our children: National health and safety performance standards; Guidelines for early care and education programs 2011: 324). Children who are immunocompromised and who have not been exposed to chickenpox or measles should instantaneously be referred to their healthcare provider in order to receive suitable preventative measures after exposure. Immunocompromised children may also need to be removed from the childcare facility until the outbreak has passed in order to protect them from infections that could potentially cause more serious complications for them in particular. Infection with measles is known to be a more serious disease for HIV positive children than for those who are not infected. In the USA, the first documented deaths that were reported to the Centers for Disease Control (CDC) after 1985, were of HIV positive children who had contracted measles (Caring for our children: National health and safety performance standards; Guidelines for early care and education programs 2011: 325).

It would therefore be beneficial for childcare providers and teachers of the facility to know when a child has an immunodeficiency, regardless of the cause, so that they can reduce the likelihood of transmission of infection to that child. However, the California Childcare Health Program states that this does not require the disclosure of a child's HIV status, as knowledge of a child's compromised immune system does not require knowledge of the cause thereof (California Childcare Health Program, n.d.; Caring for our children: National health and safety performance standards; Guidelines for early care and education programs 2011: 324).

Moreover, the immunisation schedule for HIV infected children also differs slightly from those of other children. HIV positive children should receive the usual vaccines such as diphtheria-pertussis-diphtheria vaccine, measles-mumps-rubella vaccine and Haemophilus

influenza type b conjugate vaccine. They should also receive additional vaccines, such as the pneumococcal vaccine and influenza vaccine. The type of polio vaccine that is administered to most children differs to the one that an HIV positive child should receive. The HIV infected child should receive shots of the inactivated polio vaccine, as opposed to drops by mouth of the live polio virus vaccine (California Childcare Health Program, n.d.; Wise 1991: 9).

Although this immunisation schedule is followed by the USA, Namibia also has its own National Immunisation Schedule. *The National Guidelines for Antiretroviral Therapy* recommends that HIV positive children on ART should be given vaccines according to the national vaccination schedule. This includes the Bacillus Calmette-Guérin (BCG) vaccine, unless the infant has already displayed signs of tuberculosis or immunodeficiency (Ministry of Health and Social Services 2014: 82). Moreover, the *The National Policy on HIV/AIDS for the Education Sector* advises that educational institutions should inform parents or guardians about vaccination programmes and their possible significance for the well-being of children living with HIV or AIDS (Namibia 2003: 2).

Although parents are usually responsible for adhering to their child's vaccination schedule, occasionally schools offer school-based vaccination programmes. Considering this, being in a position to improve the physical care of HIV infected children in terms of protection from other infectious diseases and not deviating from their prescribed vaccination programme, can be considered a benefit, as it promotes the ability of the childcare director of the facility to fulfil their obligations to the children in their care, supporting the principle of beneficence for both the childcare director of the facility and the HIV infected child. Although some might argue that these benefits mostly accrue to the child, the childcare provider also benefits in that they are in a position to perform their job tasks in an easier and more efficient manner, should a child's status be disclosed to them.

Informing the childcare director of the childcare facility about the HIV status of a child in their care could also be argued to promote autonomy, as the principle of respect for autonomy requires that autonomous agents are provided with sufficient information to allow them to make truly informed decisions. The capacity of the childcare director of the facility to make decisions about the best way to provide for the needs of children in their care would be



enhanced by knowledge of the specific circumstances of a child that may require particular accommodations.

One can argue that the parents and guardians of the HIV infected child can still be in a position to ensure that their child is properly taken care of by taking on these responsibilities themselves. However, this will add further strain onto parents and guardians. Moreover, open communication between all persons taking care of a child can be considered the best method to follow in terms of the provision of care.

#### **4.3.3 Weighing and balancing of principles pertaining to the perspective of other children attending the facility**

Beneficence also plays an important role from the viewpoint of the other children in the facility. One could argue that it might provide their parents and guardians with peace of mind if they know that the childcare director of the facility is aware of any serious infectious diseases that might be present in the institution.

On a more serious note, an important issue presents itself in a scenario in which blood comes into contact with an open wound, or if a bite results in blood exposure to either child involved. In such instances, the U.S. Public Health Service recommends post-exposure follow up, which would also require post-exposure prophylaxis (PEP) to be considered (Caring for our children: National health and safety performance standards; Guidelines for early care and education programs 2011: 324).

PEP is the ART that is taken after potentially being exposed to HIV in order to prevent any possible infection from occurring. PEP is recommended only for emergency situations, and must be taken within 72 hours of possible HIV exposure (Centers for Disease Control and Prevention 2018). According to guidelines set up by the CDC, PEP is also recommended in cases where the HIV status of the source of the body fluids is not known, and the incident presents a potential risk for transmission, in case the source was infected with HIV (Centers for Disease Control and Prevention 2016: 9). PEP treatment should be prescribed for a 28 day course, consisting of a 3-drug regimen (Centers for Disease Control and Prevention 2016: 9). In addition to this, a number of side effects are known to possibly occur when PEP is taken,

including nausea, vomiting, diarrhoea, headaches and fatigue among others (Centers for Disease Control and Prevention 2016: 16). Other serious, but less common side effects such as hepatitis and nephrolithiasis have occasionally been reported.

In the unfortunate event that an accident occurs whereby PEP might have to be taken, it would be crucial for the caretaker of the facility to be aware of this possible necessity, especially since there is a critical time frame to take into consideration. Should a child have to undergo PEP treatment due to uncertainty and as a precautionary measure, it would cause harm to the child since they would be at risk of side effects, and subjected to 28 days of a strict treatment regimen. Similarly, if a child does not undergo necessary PEP treatment, it can likely lead to devastating consequences of possible HIV infection, although this may not be likely. In both cases, the principle of non-maleficence plays a vital role, as ultimately, a child undergoing unnecessary PEP treatment, or a child not undergoing necessary PEP treatment, poses a significant risk of harm.

It is important to be aware of the fact that HIV transmission is much less likely if the respective individual is on ART. As stated in Chapter 1, evidence suggests that an undetectable viral load due to ART means that HIV is not transmittable to offspring and sexual partners (Siedner and Triant 2018: 173). However, in this given scenario, one cannot know with certainty whether an HIV positive child is on necessary ART or not, unless this is explicitly disclosed.

#### **4.3.4 Weighing and balancing of principles pertaining to the perspective of the HIV infected child**

Perhaps one of the biggest reasons in support of HIV disclosure in a childcare facility, would be the extended support system that the child could receive. Small children who are HIV positive have a different set of needs than those of HIV positive adults. They are usually too young to care for themselves, and also do not understand the disease. They would therefore depend on their parents or guardians. When that care is handed over to the childcare director of the facility, the support received at the facility should preferably be on par with that received at home. An example to mention would be treatment adherence. Small children would require help and supervision to take their medication at the correct dosage, and at the

correct time. Furthermore, children who suffer from side symptoms after starting ART, may not want to continue. They would therefore need an adult to encourage them to continue their treatment, and to stick to their prescribed regimen (ETU.org.za 2019).

In Chapter 1, I stated that the optimal management of any chronic illness possessed by a child would require intensive adult involvement, which would ideally be extended to that of the childcare providers and/or school nurse. I further provided diabetes as an example of a disease that is usually expected to be made known to childcare providers, in order to provide the best possible care and medical treatment for the child at the institution. Guardians of diabetic children are more likely to share this information with school staff, since diabetes is not considered to be a disease which is stigmatised. This situation differs for guardians of HIV positive children, who are likely to be afraid of disclosing the positive HIV status of their child. One could argue that stigmatization renders the circumstances surrounding these two different chronic diseases unfair and unequal where status disclosure is concerned, and may compromise the possible benefits which would accrue to the HIV positive child as a consequence of disclosure in a way that would not apply to children with other chronic diseases. Stigmatization therefore raises concerns with regard to the principle of justice, which requires that all individuals should be treated equally and fairly (Beauchamp and Childress 2013: 250), which underlines the need to take measures to combat stigmatization.

Moreover, children infected with HIV often face additional challenges, other than the management of their disease, suggesting that support should not only be concerned with their physical health requirements, but also their psychosocial needs. Many children who are HIV positive also have an HIV infected parent, as aforementioned. The parent might be very ill, or may even be dying. These factors could add further stress to the wellbeing of the HIV positive child, and can impede educational progress in terms of enrolment, attendance, performance and future academic prospects (Amzel, et al. 2013: 8; Wise 1991: 11).

The negative impact HIV infection has on the psychosocial well-being of a child has also been linked to an increased chance of developing mental health problems, hampered cognitive development, behavioural problems and partaking in high-risk activities as they grow into teenagers. This might negatively affect future treatment adherence, possible HIV transmission to others and overall mental health. On the other hand, positive psychosocial wellbeing has been associated with improved health and a better quality of life. These

findings suggest the need to improve the psychological wellbeing of HIV positive children, so as to potentially enhance their quality of life as they grow older (Amzel, et al. 2013: 2). A research study which investigated the importance of resilience in HIV affected children found that a supportive and tolerant environment can aid in the development of resilience by alleviating the negative effects HIV infection can generate (Amzel, et al. 2013: 3).

Schools have been identified as one of the fundamental environments in which children may develop resilience, and are considered an essential place to deliver interventions. It has also been discovered that disclosure in educational settings may result in positive outcomes, supporting the principle of beneficence. A study that was conducted in Botswana discovered that two thirds of parents and guardians had disclosed to school staff (Amzel, et al. 2013: 9). In response to disclosure, the guardians received support, tolerance and comfort from the school staff, indicating that schools may possibly serve as environments in which HIV positive children can receive extended psychosocial support.

Unfortunately, schools settings are also capable of becoming an environment in which stigma is present, and HIV positive children may experience isolation or bullying. If these harms result, this would be counter to the principle of non-maleficence (Amzel, et al. 2013: 9). Taking this into consideration, it should be noted that the responsibility to uphold the principle of non-maleficence is usually more stringent than the duty to uphold the principle of beneficence, and non-maleficence tends to override beneficence in most moral dilemmas (Beauchamp and Childress 2013: 150). However, “do not deprive others of the goods of life” is also a rule specifying the principle of non-maleficence (Beauchamp and Childress 2013: 154), and thus failing to provide HIV positive children with the opportunity to be facilitated and supported in childcare institutions can essentially be viewed as a harm. The principle of beneficence further emphasises that not only should we refrain from harming others, but that we should also attempt to contribute to their well-being (Beauchamp and Childress 2013: 202). For this reason, it is crucial that school management creates a non-stigmatising environment for these children, where they can receive support and tolerance instead.

#### **4.3.5 Discussion of the weighing and balancing of principles with respect to status disclosure in childcare facilities.**

When weighing various principles, it is important to establish a balance between acting in the best interests of a person, and taking into account the welfare of others. Ideally, the best course of action would be the one that minimizes the harm and maximizes the benefits for all persons involved in the respective issue, without compromising other important duties such as respect for autonomy.

It should be noted that the findings described above are limited in that the harms and benefits that have been assessed in terms of beneficence and non-maleficence can potentially be interpreted in different ways that can be subjective and possibly lead in different directions. Non-maleficence often overrides other principles, yet the weight of these moral principles varies in different scenarios, and their balancing may be subjective, as individual persons all hold different opinions and perceptions with regard to an assessment of the relative importance of harms and benefits.

Upon reviewing the perspectives of all parties involved in the disclosure process, it appears that more benefits accrue from disclosure, although this general judgement would have to be assessed in specific circumstances, taking into account the particular features of the case. In the context of status disclosure in a childcare setting, the potential harm of HIV stigmatisation and the violation of autonomy in the case of mandatory disclosure are the main concerns that need to be addressed.

Where mandatory disclosure is concerned, the direct violation of autonomy and potential harm that would result would significantly outweigh any potential benefit that could be gained from status disclosure. Therefore, this study does not seek to promote mandatory disclosure, ruling this option out.

Where the likelihood of stigmatisation is concerned, the potential harm presented is assessed in terms of a “potential” and not a “definite” harm. Taking this into account, and given the fact that significant benefits have been identified, beneficence takes precedence over non-maleficence, and disclosure is advised. However, this judgement should again take into

account the particulars of the case, as the likelihood of stigmatization may differ in different contexts.

In terms of the potential harms and benefits for the childcare director of the facility and the other children attending the facility, no potential harms have been identified, making it easier to conclude that beneficence takes precedence over non-maleficence. However, where the potential harms and benefits for the HIV infected child and their parents or guardians are concerned, the potential for stigmatization and discrimination suggests that in some contexts, the harm of stigmatization could outweigh the many benefits that come with status disclosure. Therefore, this study aspires not only to promote status disclosure within childcare settings, but also recommends that the issue of stigmatisation be forcefully addressed to reduce these risks. I will return to this point in the next chapter.

#### **4.4 Conclusion**

In this chapter, I provided an ethical analysis from the perspective of all parties involved in this ethical dilemma; namely the HIV infected child's parents or guardians, the childcare director of the facility, the other children attending the facility and the HIV infected child him/herself. This was done in an attempt to gain insight into how HIV status disclosure affects all parties involved, as well as to establish that status disclosure is desirable in general. As this study advocates encouraging disclosure, as opposed to mandatory disclosure, Chapter 5 will provide more clarity as to the reasons for this. Moreover, Chapter 5 will also discuss what a controlled means of status disclosure would entail.

HIV disclosure can be encouraged by gradually changing the current mindset that exists regarding this controversial topic, and can alternatively be motivated by means of empowerment. This will also be further addressed in Chapter 5, where recommendations for the implementation of disclosure will be addressed.

## **Chapter 5: Recommendations and prescribed framework**

### **5.1 Introduction**

This chapter will seek to suggest a means by which stigmatization can potentially be reduced, as well as to recommend a framework as to how this can possibly be attained with specific reference to childcare settings.

Upon reviewing Namibian legislation<sup>3</sup>, the central concepts of stigmatization and disclosure, and the benefits that a controlled means of disclosure might bring about, the concluding observation of this study is that Namibia commendably advocates the rights of its citizens, and that the recommendations provided in this chapter are in line with Namibian policy and law with respect to HIV and AIDS. Namibia already places a firm emphasis on stigma reduction efforts and judges the breach of confidentiality to be punishable. Therefore, these recommendations can be observed as an extension of laws that are already in force. The provided framework aspires to implement a slow but gradual change in our current system, with the aim of gradually and more prominently focusing efforts on encouraging voluntary disclosure within childcare settings. Ultimately, this approach aims to work towards encouraging a more sympathetic and supportive attitude towards HIV positive children.

### **5.2 Self-disclosure versus mandatory disclosure**

Although the main argument of this thesis supports HIV disclosure, acknowledgement is made of the fact that this cannot be attained through mandatory disclosure, as this would ultimately be a violation of human rights and would directly undercut respect for autonomy. Importantly, mandatory disclosure is usually associated with negative outcomes, such as the exclusion of HIV infected individuals from the community, whilst self-disclosure is more commonly associated with positive outcomes, such as access to treatment and medication (Thapa, et al. 2018: 9). As argued throughout this study, the findings have been that as stigma

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<sup>3</sup> Legislation reviewed in Chapter 2 is specific to Namibia, as this is the context in which I wish to consider the questions raised in this study. However, it should be noted that the Namibian legislation that was discussed is similar to many international laws, and that the recommendations made in this chapter may be relevant in other countries as well.

reduces, the rates of HIV disclosure might potentially increase, and therefore that this should be the aim.

Thapa et al conducted a study in Nepal whereby they used a grounded theory design to research HIV disclosure processes in vulnerable populations. The study was conducted by interviewing health workers, HIV positive individuals, HIV negative community members and a development worker. Their study identified two systems that attempt to control the transmission of HIV within the community; a community self-coping system and a public health system. Although these systems share a common goal, the action taken to achieve that goal, differs (Thapa, et al. 2018: 2).

A community self-coping with HIV, as defined by Thapa et al (2018), refers to the actions undertaken by a specific community in order to manage HIV and the perceived threat it presents. These actions include identifying, labelling, degrading and separating HIV positive individuals from the community in an attempt to decrease the rates of HIV transmission, which often occurs in communities where HIV is extremely stigmatized. A community that is self-coping with HIV would aim to control HIV transmission by attempting to enforce mandatory disclosure, which would eventually lead to the exclusion of people living with HIV from the community (Thapa, et al. 2018: 6).

HIV infected individuals who have experienced mandatory disclosure often feel a sense of dishonour and disgrace related to their status, which further isolates them from the community. HIV negative members of the community who have observed mandatory disclosure exhibit a higher likelihood to perceive HIV as a threat to be isolated, thus increasing the probability of them engaging in actions that further ostracize HIV positive individuals (Thapa, et al. 2018: 6). HIV negative members might view stigmatizing HIV positive individuals as normal practice, in order to control transmission. By doing so, individuals infected with HIV are essentially distanced from the rest of the community (Thapa, et al. 2018: 6). Thus, a community self-coping system is not the recommended approach, but rather that of a public health system.

A public health system refers to the public health initiatives that are put in place in an attempt to combat the HIV epidemic, thereby ensuring health and promoting the general wellbeing of HIV infected individuals. These initiatives comprise of healthcare provision, as well as the



delivery of incentives that allow individuals to gain access to medical services. This approach further promotes an increase in HIV knowledge, the evolution of perceptions regarding HIV issues, and the establishment of good relationships with healthcare workers. A public health system attempts to control the transmission of HIV by empowering individuals affected by HIV, and promoting self-disclosure. An increase in self-disclosure rates has been linked to a reduction in HIV transmission rates (Thapa, et al. 2018: 7).

In essence, a community self-coping system is driven by perceived threats, whilst a public health system is driven by perceived benefits. A public health system also plays a role in reducing stigmatization. The rise in self-disclosure rates and the increase in the prominence of strong HIV infected individuals in the community can increase knowledge and challenge pre-existing HIV-related notions, misconceptions and taboos (Thapa, et al. 2018: 9).

WHO and UNAIDS also support a human rights approach by encouraging “beneficial disclosure” of infected individuals’ HIV status. Beneficial disclosure is regarded as voluntary disclosure, and allows HIV positive individuals to have control over if, how and when they decide to disclose their status. Beneficial disclosure supports autonomy and results in increased openness in the community where HIV and AIDS is concerned. It also meets ethical obligations, maximizing good for both the infected and uninfected individual (UNAIDS 2000: 6).5.3 AIDS exceptionalism and treating HIV and AIDS as any other disease.

### **5.3 AIDS exceptionalism and treating HIV and AIDS as any other disease**

As the next section *5.4 Recommendations regarding disclosure in childcare facilities* encourages treating HIV and AIDS as any other chronic disease within a childcare setting, it is important to discuss AIDS exceptionalism beforehand. This section attempts to address the idea that HIV is indeed equal to other chronic diseases which are not stigmatised, thereby upholding the principle of justice.

AIDS exceptionalism is the idea that AIDS requires a different approach in law and policy to that of other communicable diseases. It is the notion that HIV and AIDS require a response that exceeds those of “normal” health interventions. HIV and AIDS is distinct in the way that

it is transmitted and how it manifests within the body, as well as its long-term demographic, economic, social and political consequences. “Exceptionalism”, means to give something the status of being exceptional. It had originally began as a Western response to the frightening and deadly nature of the virus, which disproportionately affected vulnerable and marginalized groups. The first activists believed that the HIV and AIDS epidemic required an exceptional response in order to protect the rights of infected individuals, as well as to generate resources to aid in the management of the disease. More recently, AIDS exceptionalism came to refer to the international response and the resources devoted to manage the disease. This generation of resources exceeded those of any other health issue (Smith and Whiteside 2010: 1).

In the 1980s, AIDS presented itself when young, previously healthy, mostly homosexual men began dying. The unknown cause and increasing number of deaths combined with homophobia created a response of fear and blame. Extremely religious individuals believed that this was a result of divine punishment for “sinful” lifestyles. However, as haemophiliacs, women and children started presenting the same symptoms, it became apparent that the cause of illness was not related to homosexuality. In 1983, HIV was recognized as the cause of AIDS. The understanding that HIV could spread to the general public through sexual intercourse caused increased panic. Even as information regarding transmission became more accurate, the original stigma and fear remained (Smith and Whiteside 2010:2).

Eventually, HIV and AIDS became more than a health condition, but also a social matter that required a medical and political response. AIDS exceptionalism came to emphasise the human rights of people living with HIV and AIDS with particular concern to their rights to confidentiality, protected privacy, counselling and autonomy (Smith and Whiteside 2010: 2).

The arrival and availability of ART transformed HIV and AIDS from a deadly illness into a manageable, treatable chronic disease. These advancements created a strong case for moving beyond AIDS exceptionalism and managing HIV antibody tests like any other blood tests (Smith and Whiteside 2010: 3). This brought about the “normalisation” of HIV public health practice (Fisher 2009: 11).

Due to the medical advancements in the treatment of HIV, researchers, clinicians and policy makers at institutes such as the CDC have made policy, social, institutional and legal discourses that have categorised HIV and AIDS in the same group as other chronic diseases. The aim of these discourses is to eventually integrate HIV-related patient care into a

generalised clinical setting, to decrease requirements for consent and counselling, and to reduce stigmatisation (Philbin 2014: 2).

Upon reviewing data, Fisher et al. found that over time, victim blame, prejudice and fear of contagion decreased with the reframing of HIV as a treatable chronic disease, indicating that the normalisation of HIV might be an achievable objective. Social psychological forces no longer prevented change and the normalisation of HIV public health practice developed (Fisher 2009: 17).

HIV infected individuals who have access to ART are now in a position to maintain viral suppression indefinitely, sometimes for decades. As a result, the current clinical situation has significantly changed since it started in the early 1980s. The median age of HIV positive adults on ART is steadily rising. By the year 2030, 3 out of every 4 HIV infected individuals are expected to be aged 50 years or older in a number of countries (Serrano-Villar et al. 2016: 1).

However, Peter Piot, former UNAIDS Executive Director, stated that it is a myth that it is time to normalise AIDS and that AIDS is just like any other disease. He further explained that it is ideally what we should aspire to achieve. In order to achieve this, Piot stated that we first need to normalise ART as part of a normal system, that we need to normalise mother to child transmission and that we also need to normalise the rights of people with HIV (Piot 2008).

One of the main reasons as to why HIV and AIDS is not treated as any other disease, is due to the metaphors that are used in association with HIV and AIDS. Susan Sontag addresses this issue in great detail in *Illness as Metaphor* and *AIDS and it's Metaphors*.

*Illness as Metaphor* and *AIDS and its Metaphors* by Susan Sontag are dedicated to a discussion of the myths surrounding the paradigmatic diseases of current times and the use of metaphors that turn physical disease into a moral issue that leads to societal shaming of those affected by it (Garage 2016).

In *Illness as Metaphor*, she makes reference to the metaphorical uses of tuberculosis in the nineteenth century (then incurable) and then cancer in the twentieth century. Sontag formulates her argument from the perspective of a cancer patient, being one herself. She discusses how the use of language has warped the reality of both diseases. Cultural myths about cancer tended to estrange and isolate cancer patients. They suffered without reason

because of the “meaning” ascribed to their illness by society. In the case of cancer patients, it even kept patients from seeking necessary treatment and medical care (Robinson 1989).

A decade later, she wrote *AIDS and its Metaphors*. She observes that the attitudes towards cancer have evolved to be more truthful and open. However, a new illness (AIDS) has become the illness targeted by metaphors (Coulehan 1989). Similarly, in *AIDS and its Metaphors*, Susan discusses how the way we think and talk about AIDS makes the disease even worse than it actually is. The metaphors used increases the suffering of those affected by AIDS, whilst creating needless anxiety within society (Robinson 1989).

Military metaphors, she argues, are particularly aggressive and have negative consequences. We say that the enemy (AIDS) invades and destroys you from within; that the body assembles its immunological defences; that those with the disease are under assault and attack (Kovan 1989).

Sontag attempts to convince people to consider cancer and AIDS as just illnesses, albeit serious ones. She emphasises that they should not be seen as punishment, curse, embarrassment or even death sentence.

This observation brought about by Sontag demonstrates that the metaphors used within society are to blame for the negative associations that existed with TB, cancer and now AIDS. As TB and cancer have progressed to become less of a taboo, perhaps the same can be attained with AIDS.

#### **5.4 Recommendations regarding disclosure in childcare facilities**

Taking into account all of the above, a framework which advocates for disclosure in a childcare setting would need to encourage voluntary disclosure, with emphasis placed on the motivations for disclosure, by empowering HIV infected individuals within the community. HIV positive individuals can be empowered by arming them with knowledge, confidence and an understanding of the ignorance that drives societal fears of HIV.

Ideally, a national policy should exist in Namibia whereby the disclosure of HIV positive children is encouraged in childcare institutions in order to standardise recommended practices and procedures at the national level. The recommendations that should ideally be included in the policy will be discussed further below.

A controlled means of disclosure is advocated in this study, which entails that the only staff that would need to be informed of a child's HIV status would be the childcare director of the facility and/or the centre's nurse or health coordinator. As stated in Chapter 1, the centre director will then be obligated to continue protecting the confidentiality of the child's HIV status at the centre, with the guidance and support of the facility's nurse. The childcare director of the facility would be in the best position to protect the confidentiality of the child's HIV status, and would be able to ensure optimal care with the guidance and support of the centre's nurse (Wise 1991: 6). If fewer staff members are informed, it limits the possibility of confidentiality being broken and also maintains respect for the privacy of the child and his/her family. Although it might reduce the likely benefits if fewer staff are aware of the child's HIV status, it would ultimately allow gradual implementation of a system change with regard to HIV disclosure, which has remained a controversial topic to date. As status disclosure in a childcare setting receives more positive feedback over time, more staff members can possibly be involved. This study further recommends that the disclosure process should be protected by means of a contract safeguarding the confidentiality of the child's HIV status. In the unfortunate event that confidentiality is broken, then this breach shall be punishable by law. By placing more emphasis on the rights of the child, we are essentially empowering him/her, which is what we fundamentally wish to achieve, as previously mentioned in this chapter. This might motivate parents and guardians to move away from a mind-set that perceives HIV disclosure as a threat, and to rather perceive disclosure as a mean of accessing an extended support structure. Ideally, HIV should be regarded as just another illness, such as diabetes or epilepsy. If we can shift the focus of HIV from being seen as a highly secretive disease, to a perception of it as any other chronic disease that individuals are more likely to speak about openly, then a positive shift in levels of stigmatization can be expected.

The age range for children in childcare centres generally falls between the ages of 0-6. As discussed in section 3.3.4, disclosure of a child's HIV status is complicated by the fact that small children do not possess the emotional capacity or cognitive development to comprehend and understand the complex nature of HIV and AIDS and its consequences. The Namibian Ministry of Health and Social Services (MoHSS) recommends that children should be enrolled into specific activities that initiate partial disclosure processes when they reach the age of 6 (Ministry of Health and Social Services 2014: 77). Taking these recommendations into account, many children only begin to partially learn of their HIV

positive status at the age of 6. Moreover, as many children who are under the age of 10 have not yet developed the ability to understand abstract concepts related to chronic illness (Klitzman, et al. 2008: 31), this study would not recommended directly involving the child in decisions about disclosure. However, this study would encourage parents and guardians to communicate and explain the nature of the disease insofar as possible (taking the child's cognitive development into consideration) in a nurturing and supportive way.

It is also essential that the reasons that support the disclosure of a child's HIV status are communicated to the parents or guardians of the child before enrolment in a facility, and could perhaps be stated in the school's policy or verbally communicated to them. It is also imperative that parents and guardians understand their child's rights, and that the duty to uphold confidentiality is legally enforced.

Ideally, any allergies, ailments and diseases affecting a child should be included in the application form during the initial enrolment of the child. This can be done by providing a list of the most common illnesses on the application form, allowing the applicant to select what is relevant and applicable to them. It is important that HIV is included in this list. By including HIV on the list of diseases, we are essentially treating it as any other chronic illness. If it were to be left out, however, we would indirectly stigmatise those affected by HIV by labelling the disease as one that is "not spoken of." It is essential to limit the amount of staff members handling the application forms to only the childcare director of the facility and/or the nurse or medical coordinator of the facility, so as to prevent a breach in confidentiality.

Furthermore, it would be ideal for all people working at childcare facilities to regularly attend anti-stigma training programmes, so as to ensure that knowledgeable, supportive and empathetic individuals are placed in such crucially important positions in society. These training programmes would also equip them with the knowledge to provide optimal care for an HIV infected child, both physically and psychosocially.

It should be noted that people are generally very astute at picking up any changes in how others are treated. Should status disclosure be made known to a childcare director or nurse, they may potentially treat an HIV positive child differently. As a result, this study is limited in that other parents and children at the facility might notice an HIV positive child being treated differently, thus negating any hope of confidentiality. In order to prevent this, the

relevant parties that have been informed of a child's positive HIV status, need to be trained to address and manage the needs of an HIV positive child as discreetly as possible.

### **5.5 Prescribed framework regarding disclosure in childcare facilities**

Taking the above recommendations into consideration, the framework would consist of the following:

- The encouragement of disclosure within a childcare setting should be supported by government and formally communicated in a national policy. Government should then communicate to all childcare institutions as to what the policy entails, which should include a description of the framework detailed below.
- The application form of the school should include a written section where they encourage open communication regarding a child's allergies, ailments and chronic diseases, particularly HIV. This section should further elaborate as to why status disclosure would be beneficial, which could include reference to the provision of tailored care to the child, the appropriate management of blood spills, and informed decision-making around the initiation of ART. This section should also state what the confidentiality agreement would entail, should status disclosure be made. Moreover, parents and guardians should also be informed that a controlled means of disclosure will be undertaken, in other words, that only the childcare director of the facility and/or the nurse or medical coordinator of the facility will be informed about a child's positive status. Lastly, this section should further elaborate on the rights of the child, and emphasise that their wellbeing is ultimately protected by law.
- The application form will then provide a list of all the most common illnesses, allowing the applicant to select what is relevant and applicable to them. HIV should be included within the list. Any medication that the child might be taking should also be included within this section.
- In the event that parents or guardians do decide to disclose the HIV status of their child, a confidentiality contract should be signed immediately upon the enrolment of

the child, or as soon as disclosure was made, so as to ensure that the child's privacy is legally protected as soon as possible.

- Once status disclosure has been made, the school should correspond regularly with the parents or guardians of the child regarding his/her wellbeing. This can be done either via e-mail, or verbally, depending on the preference of the parent or guardian. Alternatively, if the guardians do not wish to correspond with the school thereafter, they can simply indicate this on the application form.

## **5.6 Stigma reduction efforts**

As HIV stigmatization is known to affect communities on a large scale, the recommendations provided here are generalizable to the country as a whole, and not limited to childcare settings specifically. The argument is that if we can continue to reduce stigmatization in the country as a whole, then we can hope that these efforts will also encourage the disclosure of HIV statuses in appropriate settings, such as childcare facilities. Namibia already places strong efforts on stigma reduction programmes, and therefore it is recommended to continue doing so, and to place further emphasis on their implementation. The reduction of stigmatization can also be achieved through the following:

- Developing initiatives to sensitise and improve attitudes of health workers towards HIV infected individuals. Healthcare settings have been found to be common sites for stigma and discrimination against those who are HIV positive (Stringer, et al. 2016: 116). As healthcare workers are seen as role models, this might create wider communal benefits.
- Empowering HIV individuals by making them aware of their rights. Stigma can be reduced if HIV infected individuals are aware that they can take action if their rights are violated (Avert 2017b).
- Designing interventions that can access individuals at all levels within the community, including workplaces, school settings and healthcare practices. Proven effective interventions fall into the following categories: information provision, skills development, counselling and therapy, and testimonials from individuals who are HIV



positive. These interventions should seek to increase awareness about stigmatization, specifically (World Health Organisation 2011: 35).

- Attempting to improve the social integration of HIV positive children within the community. It is important to ensure that these children are aware that they are accepted and contributing members of society (Amzel, et al. 2013: 6).
- Continuously building on stigma reduction efforts and constantly evaluating, adapting and improving on current interventions that are in place (ICRW.org 2006: 12).
- Involving HIV infected members of society in the community has proven to be an effective means of stigma reduction. Those who are infected have the knowledge and life experience that is necessary in order to design and implement suitable stigma reduction reactions. They are also in a position to combat the ignorance that accompanies HIV stigma, by, for example, educating others about the fact that HIV cannot be transmitted via casual contact, and dispelling the perceptions that HIV dooms one to instant disability and death, and that HIV infected members of society are different from the rest of the community (ICRW.org 2006: 7).
- Working together with the media and providing guidelines that should be used in order to communicate messages related to HIV and AIDS education. This should take into account language use, the delivery of correct and factual information (about transmission, prevention, risks and treatment), as well as how HIV infected individuals should be portrayed and represented by the media (ICRW.org 2006: 11).
- Encouraging HIV infected individuals to partake in support groups might also aid in the reduction of stigmatization. Pham Thi Hue, a young, HIV positive woman who has created a support group for other HIV positive women who reside in Hai Phong, expressed that she felt great relief when she disclosed her positive status and no longer wanted to maintain the burden of secrecy. She further stated that the disclosure process had enabled her to overcome self-stigma, and that it made her feel self-assured and confident (ICRW.org 2006: 7).

- Implementing a concerted and dedicated program aimed at educating other parents and guardians whose children are enrolled in childcare facilities. This program should educate parents and guardians about HIV and AIDS, the nature of stigmatisation as a form of discrimination, and why children living with HIV should be and have a right to be treated like all other children. The aim of this program would be to eventually create a shift in societal thinking and doing where the wellbeing of HIV infected individuals are concerned.

## **5.7 Conclusion**

In this chapter, I have suggested a framework for HIV status disclosure in childcare facilities, and also proposed means by which stigmatization can possibly be reduced. Although this study was concerned with HIV status disclosure, stigmatization reduction efforts are also important as these would indirectly encourage infected individuals to disclose their status in appropriate settings. Chapter 6 will proceed to provide a conclusion to this thesis.

## Chapter 6: Conclusion

This study has attempted to shed light on the ethically complex topic of status disclosure of HIV positive children in childcare centres, and to develop guidelines on how to appropriately manage these scenarios. This study has addressed the topic specifically in a Namibian setting. Upon reviewing Namibian legislation relevant to this case, we then proceeded to gain a deeper understanding of the general ethical complexities regarding HIV, before addressing those specifically pertaining to HIV positive children. Thereafter, the complex relationship between disclosure and stigmatisation was addressed, before the necessity of confidentiality was discussed. The main problem of the study was then addressed, by assessing the ethical perspectives of all parties involved in terms of how status disclosure affects them by means of a principlist analysis. This was followed by a proposal of recommendations and a suggested framework by means of which this dilemma can possibly be addressed.

Since the HIV and AIDS epidemic has devastatingly made its presence felt worldwide, the main focus of global attention has been on prevention and treatment. Although HIV stigmatization and its complex relationship with disclosure have gained more recognition recently, it is arguably of equal importance to “prevention and treatment” measures, if not more.

This study has attempted to bring attention to the detrimental effects that HIV stigmatization and discrimination can have on HIV management, and how by aiming to reduce these factors, we can create a future in which harmonious disclosure is made possible. In turn, by creating an environment that encourages appropriate disclosure, we can hope to establish more supportive and tolerant communities, in which HIV infected individuals can thrive.

HIV stigma interventions as early as pre-school are necessary, as this is usually the first site of interaction that an HIV infected child experiences with society outside the family context. At this crucial stage of emotional and cognitive development, an HIV positive child should be made to feel accepted, appreciated and valued, as opposed to feeling like an outcast, and government should also consider empowering teachers by training them to maintain confidentiality, as well as to prepare an HIV infected child for wider society on an equal basis to other children.

As this study's area of focus has been disclosure within childcare settings, the study recognizes that it only covers a fraction of a very broad range of issues related to HIV and AIDS, and that further studies are needed in order to gain more insight into the complexities involving HIV stigmatization and disclosure.

Given the growing number of cases of HIV infected children worldwide, there is an increasing need to improve the standard of care, and to place more efforts on the global reduction of HIV stigmatization. As there is a need for greater guidance and understanding regarding these issues, it is imperative that we constantly seek alternative measures that can be explored, in order to profoundly improve our chances of managing the epidemic of HIV and AIDS to the best of our ability as a global community.

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