Pediatric HIV Disclosure in Kenya: Resources and Support that are Available and Needed

Katrina Bennett
Lampert Fellow 2015
Lampert Institute for Civic and Global Affairs
Colgate University
Class of 2016
# Table of Contents

Title Page ............................................................................................................. 1

Acronyms and Abbreviations .............................................................................. 4

Operational Terms ............................................................................................... 5

Acknowledgements .............................................................................................. 6

Abstract ................................................................................................................. 7

CHAPTER I: DESCRIPTION OF STUDY ................................................................... 8
   1.1 Background ..................................................................................................... 8
   1.2 Statement of the Problem ................................................................................ 11
      Research Issue .................................................................................................. 13
   1.3 Objectives ....................................................................................................... 15
      1.3.1 General Objective .................................................................................... 15
      1.3.2 Specific Objectives .................................................................................. 15
   1.4 Research Questions ........................................................................................ 16
   1.5 Conceptual Framework .................................................................................. 18
   1.6 Justification .................................................................................................... 18

CHAPTER II: LITERATURE REVIEW ...................................................................... 20
   2.1 Types of Disclosure ........................................................................................ 20
   2.2 Differing Opinions on Nature of Pediatric HIV Disclosure ......................... 21
   2.3 Benefits and Barriers Associated with Pediatric HIV Disclosure ............... 22
   2.4 Characteristics Associated with Increased Pediatric HIV Disclosure ......... 24
   2.5 Pediatric HIV Disclosure in KNH CCC in Nairobi Kenya ......................... 24
   2.6 Existing Guidelines ......................................................................................... 26

CHAPTER III: METHODOLOGY ............................................................................. 27
   3.1 Study Design ................................................................................................... 27
   3.2 Study Area ...................................................................................................... 28
      Justification for using KNH CCC as study area ............................................... 28
   3.3 Study Population ............................................................................................ 29
      3.3.1 Inclusion Criteria .................................................................................... 30
      3.3.2 Exclusion Criteria ................................................................................... 30
   3.4 Sample size and sampling method ................................................................ 30
   3.5 Recruitment Strategy ...................................................................................... 31
      3.5.1 Subject Approach .................................................................................... 31
      3.5.2 Non-Coercive Contact ............................................................................ 31
      3.5.3 Subject Compensation .......................................................................... 32
      3.5.4 Participant Costs .................................................................................... 32
   3.6 Risks, Benefits and Adverse Events ............................................................... 32
3.61 Nature and Degree of Risk 32
3.62 Minimization of Risk 32
3.63 Benefits 33
3.7 Data Collection 33
3.8 Data Management and Analysis 34
  3.81 Confidentiality of Research 35
3.9 Study Limitations 35
3.10 Ethical Approval 36

CHAPTER IV: RESULTS 36
  4.1 Resources and Support Available at the CCC 36
    4.11 Health workers trained in pediatric HIV disclosure 37
    4.12 Health workers advice to perform disclosure as a process 37
    4.13 Health workers providing individualized solutions 38
    4.14 Peer Mentors 38
    4.15 Support Groups 39
    4.16 Health workers empowering caregivers 40
  4.2 Resources and support that are needed 40
    4.21 Education to primary school aged children to reduce HIV stigma 40
    4.22 More counselors in Kenya 41
    4.23 Guidelines that explain how to disclose based on development stages
       of children 42
    4.24 Increased facilitation of conversation/ communication between
       caregivers and their positive child(ren) 43
  4.3 Caregiver characteristics influencing resources and support need for
     disclosure 43

CHAPTER V: DISCUSSION 45
  5.1 Stigma 45
  5.2 Peer Mentors/ HIV+ Role Models 47
  5.3 Counselors 48
  5.4 Future Directions 49

CHAPTER VI: CONCLUSION 50

References 52

APPENDICES 55
  Appendix A: Certificate of Informed Consent 55
  Appendix B: Interview Scripts/ Questions 57
Acronyms and Abbreviations

AIDS- Acquired Immune Deficiency Syndrome
ART- Antiretroviral Therapy
CCC- Comprehensive Care Centre
HIV- Human Immunodeficiency Virus
IRB- Institutional Review Board
KNH- Kenyatta National Hospital
KNH ERC- Kenyatta National Hospital Ethic and Research Committee
PLHA- People Living with HIV/ AIDS
NACC- National AIDS Control Council
NASCOP- National AIDS and STD Control Program
Operational Terms:

**Caregiver**- An individual who provides primary care to a child/ youth or multiple children/ youth who are HIV+.

**Disclosure (Pediatric HIV Disclosure)**- Explaining to a child/youth that they have an illness known as HIV and explaining what this illness means for health outcomes in the future.

**Peer Mentor**- A type of health worker who is going through, or has gone through the same struggles that the patients they are helping care for are currently going through. At the CCC, peer mentors are HIV+ patients who now work a paid job that is mainly to provide support to other HIV+ positive patients who are struggling with various issues.
Acknowledgements

This research would not have occurred without the help and support of many individuals and organizations. Therefore I would like to first thank the Lampert Institute for funding this project, my travels, and more generally, a once in a lifetime experience. My faculty advisor, Professor Ellen Percy Kraly, was also integral to the success of this research. Her thoughtful and well-meaning advice was crucial in getting me over many large hurdles in the research process. Grace Gachanja, a fellow scholar passionate about pediatric HIV disclosure in Kenya, provided me with support, guidance, connections and so much more throughout my research journey. My project would not have happen without her expertise, belief in me, and simple kindness; thank you Grace.

In Nairobi, I met some of the most giving individuals I have ever come into contact with, and am still in awe of their generosity towards me. I would like to thank the staff of St. Lawrence University’s Kenya Program for welcoming me so warmly and ensuring that my accommodations were more than I could ask for during the time I was collecting data. Those at the Comprehensive Care Center of Kenyatta National Hospital were beyond hospitable to me, both during my research in their center, and before my arrival. David Mtabari was essential to making my research happen, and without him I never would have been able to get research approval from the Kenyatta National Hospital Ethics and Research Committee; thank you David, your help was so much more than appreciated. Nelly Opiyo kindly agreed to be my in country advisor without even ever having met me; thank you Nelly, for having faith in me.

To every single individual, group and organization that helped me along the way, I am so grateful. Thank you.
Abstract:

The number of individuals, particularly youth, living into adulthood with HIV is rising in Kenya. This is due to the fact that individuals living with HIV are being enabled to live longer with help from increased access to medication and care. In light of this increasing number of HIV+ youth in Kenya, there is a new need to focus on the care of this growing group of individuals.

One aspect of this care is disclosure of HIV status, or explaining to youth that they are HIV+ and what that diagnosis means. Pediatric HIV disclosure is associated with increased adherence to medication, more social support for youth and better and more informed health decisions. However, pediatric HIV disclosure in Kenya is still very low among most populations studied, and caregivers often worry about factors such as stigma and negative mental health effects for youth if they receive disclosure of their status. Detailed guidelines are not widely available to explain the best way and time at which to give children or youth disclosure in the Kenyan setting. This study aims to discover what resources and support are currently available to aid in this difficult process, what resources and support are needed to improve disclosure in the Kenyan setting, and whether personal HIV status acceptance of caregivers affects the resources they desire to provide children and youth with disclosure.

This study is a grounded theory study gathering qualitative interview data from 11 caregivers of HIV+ youth and 10 health workers working with HIV+ youth at the Kenyatta National Hospital Comprehensive Care Centre in Nairobi, Kenya. In total, 21 interviews were conducted.

Overall, this study revealed that a variety of resources and support are available at the CCC, and that still others could be useful at the CCC and in Kenya more generally. First and foremost resources and support need to be put in place to reduce stigma surrounding HIV and that help caregivers and HIV+ children cope with the stigma that surrounds them in Kenya. One important way to do this would be to change and improve HIV education in primary schools in Kenya. Although stigma remains a difficult obstacle to pediatric HIV disclosure, the use of peer mentors and other HIV+ role models is very important to facilitating disclosure and increased usage of this type of resource could prove to be extremely valuable. Finally, counselors are priceless support systems during the pediatric HIV disclosure process and the continued growth and specialization of counseling in the Kenyan setting will no doubt have a positive effect on pediatric HIV disclosure in the nation.
1. CHAPTER I: DESCRIPTION OF STUDY

1.1 Background

HIV/AIDS is a persistent and multifaceted global epidemic. Kenya currently has 1.4 million adults and 200,000 children living with HIV (NACC, 2012). Mortality rates for HIV-1 infected children have decreased with the result that more HIV+ children are moving into adolescence and adulthood. The positive result creates a new need to focus on treatment and care strategies for this growing group of individuals (Brady et al., 2010).

In Kenya as of 2012, 43% of the population was under the age of 15, making preventing and treating HIV in this population group crucial for lowering the prevalence and spread of the epidemic in the nation. In 2011, it is estimated that 12,894 children became infected with HIV and most of these infections occurred during pregnancy or as a result of breastfeeding (NACC, 2012). Therefore, many children in Kenya are still contracting HIV at birth and need care and resources specific to the situation of their illness.

Properly caring for children who have HIV from birth is a very complex issue, however. One large issue surrounding caring for this population is the fact that globally, there is a lack of data on youth infected with HIV from birth who are over the age of 15 years. These children are not being tracked into adulthood, and so it is very difficult to know the needs of these children, their opinions on the care they received while growing up, the outcomes of their treatments and whether or not they are retained in care (Sohn and Hazra, 2013).
Another challenge with this growing number of youth who are infected with HIV from birth and are living into adulthood centers on ARTs. Children infected with HIV from birth often have complicated clinical histories, have taken many drug treatments and may even have a drug resistant virus, causing their care to be more complex and the options for their treatment to be more limited. Not only is finding a treatment that will be effective a challenge for this group of youth, but ensuring adherence to this effective treatment is a challenge as well. Adherence often becomes an issue during adolescence among these individuals who are infected from birth (Agwu and Fairlie, 2013).

Mental health issues among children and adolescents infected from birth are another concern in the care of this population. Youth infected from birth often have a high rate of psychiatric symptoms such as depression and attention-deficit disorder. Many components of living with HIV could contribute to these poor psychiatric outcomes such as the treatment, possible loss of parents, poverty, stigma and rejection by peers and others. This increased prevalence of mental illnesses leads to increasingly complicated care (Mellins and Malee, 2013). The successful care of youth infected with HIV from birth involves much knowledge, time and many different components and strategies.

A crucial component of care for HIV+ children and youth who are positive from birth is their knowledge and understanding of their illness. The act of telling a child of their illness is formally known as disclosure. Disclosure is not limited to the exchange between a messenger and an HIV+ child, but can come from one sexual partner to another, from an infected individual to family members or friends and can occur among any mix of individuals when one individual is explaining their HIV status to another individual or group of individuals. Disclosure is a complex, and still largely misunderstood behavior,
and it is not completely clear why some individuals choose to disclose and why some do not. Two popular theories that attempt to explain why disclosure occurs are the disease progression theory and the theory of competing consequences. The disease progression theory posits that individuals would choose to disclose the status of an illness once it becomes increasingly serious and it is no longer possible to hide and death may even be imminent. The consequence theory explains that disclosure is likely to happen once the rewards of disclosure outweigh the associated costs (Serovich, 2001).

Pediatric HIV disclosure can come in several different types and these types are defined differently by different sources. Most commonly though, pediatric HIV disclosure is described as either being “full” where children have been given an explanation of their illness so that they completely understand that they are sick and exactly what is causing their sickness (HIV) or as “partial” disclosure where children have been told something is wrong with them but they either do not know what is wrong, or they do not know or understand what their illness is, even if they know the name of it (Kidia et al., 2014).

Disclosure of HIV status interacts with many of the complexities involved with treating children and adolescents that are infected with HIV from birth that were discussed above. Research has shown that children who have received disclosure of their HIV+ status show much better adherence to their medication (Bikaako-Kajura et al., 2006; Vreeman et al., 2014; John-Stewart et al., 2013). Disclosure of HIV status also leads to better access to social support for children (Vreeman et al., 2014) and overall better quality of life (John-Stewart et al., 2013). Besides being beneficial to the child, disclosure of HIV+ status to youth is crucial for prevention for the greater population.
HIV+ youth could spread the illness easily if they were unaware of their status prior to their sexual debut (Turissini et al., 2013). Adolescents who have been received disclosure of their status at a young age by caregivers are in fact much more likely to have intentions to self disclose to their own sexual partners (Santamaria et al., 2011). Furthermore, within the Kenyan healthcare system, adolescents are often moved to adult care systems in which the assumption is knowledge of HIV status. Being abruptly notified of a positive status in an unfamiliar and uncomfortable setting holds the likely potential to be traumatizing to the adolescent (Turissini et al., 2013).

1.2 Statement of the Problem

In resource poor settings, Kenya included, the disclosure rate to HIV+ children is almost always less than 50%, and many have documented disclosure rates as low as 19 and 21% among large groups of children (Kallem et al., 2011; John-Stewart et al., 2013; Vreeman et al., 2014; Warui et al. 2013). Older Kenyan youth, between 11 and 14 are more likely to have full disclosure of their status than younger children, but this rate almost always remains at less than 50% (Vreeman et al., 2010; Vreeman et al. 2014). Literature has shown that disclosing to children at a younger age is better, due to the fact that younger children who are receive disclosure of their status show hardly any negative emotions in response to the news they learn (Gachanja, 2014).

The main reasons caregivers in Kenya give for delaying the disclosure process to children are (a) anxieties and fears about the process and (b) worries about the mental and emotional states of the children. Emotions that some caregivers in Kenya have before disclosure to their children are fear and worry of stigma, judgment, rejection and the
reactions of their children (Gachanja, 2014). Often the caregivers themselves, including parents to the children, have not disclosed their own HIV status to the children. Disclosing the child’s HIV status often leads to the disclosure of the parent’s HIV status and if parents have passed the illness to their children, parents worry that children will lose respect for them and apply blame to them. Many caregivers have not come to term with their own HIV+ status, making it difficult to properly deal with that of a child (John-Stewart et al. 2013).

Concern about the social, emotional and mental state of the child is also a crucial component of the disclosure decision. A fear of many caregivers is that children will not keep the diagnosis private after disclosure, and that this will lead to stigmatization of the child from peers (John-Stewart et al., 2013; Vreeman et al., 2010). Prior studies have shown that children who are affected by HIV in any way experience bullying from peer groups due to stigma and are even sometimes forced to drop out of school (Skoydal et al., 2012). In addition to stigma, caregivers describe fears of children developing personal mental health problems as a result of disclosure. Caregivers do not want children to be caused to “think and think” and refuse to play with friends, eventually withdraw from others and develop depression (Vreeman et al., 2010; John-Stewart et al., 2013). Some research in Kenya has shown that after disclosure, children feel shock, disbelief, anger, sadness, worry, depression, confusion, but also catharsis (Gachanja, 2014). Accordingly, caregivers in Kenya are largely right to worry about their child’s mental state with knowledge of their positive status.

Such low rates of disclosure reported in previous studies conducted in Kenya highlights the fact that one, or several factors are holding caregivers back and impairing
the crucially important pediatric HIV disclosure process. It is highly likely that more resources and support are needed in addition to what is already available to help caregivers with conducting pediatric HIV disclosure.

**Research Issue**

In 2011, the World Health Organization released guidelines on disclosure counseling for children up to 12 years of age, to ensure that disclosure happens and that it happens smoothly. Some of the recommendations included adequate preparation of the child and continued support, primary caregiver accepting his or her own HIV status, child-friendly counseling tools, and adequate social support (World Health Organization, 2011). Support for these activities though, is often not widely available in Kenya.

The mental health of both the caregiver and the child are huge factors in deciding whether or not to disclose HIV+ status to a child and as highlighted by the World Health Organization guidelines, all different types of mental and psychological support are crucial for a positive pediatric disclosure process. Unfortunately, as is the case in many settings around the globe, in Kenya there is very limited access to mental health services. There are only 54 psychiatrists, 418 trained psychiatric nurses and 10 medical social workers for a population of around 43 million within the country (Marangu et al., 2014). Moreover, general health worker trainings are severely lacking in mental health content (Jenkins et al., 2013). Therefore, it is possible that both caregivers and children are not receiving adequate mental support from health services, centers and workers during the disclosure process, and that this deters other caregivers from wanting to disclose HIV+ status to their children.
In addition, the guidelines released by the World Health Organization in 2011 only specify recommendations for disclosing to children who are below the age of 12, while children in resource-poor settings often do not receive disclosure of their status until after the age of 12. In Kenya, caregivers report receiving varying information from healthcare professionals concerning when to disclosure to children and how to best support them. Caregivers in Kenya also find that information about the process is difficult to find and is extremely spread out in dispersed sources (Gachanja et al., 2014). Documentation of what resources are available to aid caregivers in this process is inexact, but extensive public health research suggests that more resources and support are needed to facilitate and improve the process of disclosure to youth in resource poor settings, and in Kenya specifically. In addition, the fact that the World Health Organization guidelines for children under 12 years identifies the caregiver’s acceptance of their own status as being crucial for a smooth pediatric disclosure process indicates that different resources and support may be needed for different caregivers to disclose to children depending on their level of acceptance of their own HIV status.

According to the National Guidelines for Testing and Counseling in Kenya, parents, guardians and caregivers are solely responsible for disclosure to their children. However, besides this, only very general instructions for the disclosure process are provided, such as ensuring that age appropriate information is given as early as possible to children, and making sure that service providers are there to offer assistance when necessary. No specific instructions or help is given in the document as to how to go about the difficult and complex process of pediatric HIV disclosure in the Kenyan setting (NASCOP, 2008).
1.3 Objectives

1.31 General Objective

To discover what resources and support health workers and caregivers of HIV+ youth think is needed to increase disclosure of HIV+ status to HIV+ youth in the setting of Kenya.

1.32 Specific Objectives

(i) To determine what types of resources and support are currently available to caregivers of HIV+ youth and health workers who have already or are wishing to disclose to HIV+ youth in Kenya.

(ii) To determine what types of resources and support are currently lacking and are desired by caregivers of HIV+ youth and health workers who have already or are wishing to disclose to HIV+ youth in Kenya.

(iii) To determine whether or not the availability of mental health services in Kenya for HIV+ youth is a crucial part of the choice of whether or not caregivers feel comfortable disclosing HIV+ status to youth.

(iv) To determine whether or not the HIV status of the caregiver of the HIV+ youth affects their willingness, concerns and thoughts on what resources are needed for disclosure of HIV+ status to youth in Kenya.

(v) To determine whether personal acceptance of HIV status and willingness to disclose status to others affects what resources and support caregivers need when disclosing HIV+ to youth in Kenya.
1.4 Research Questions

(i) What guidelines and resources are available to caregivers in Kenya when disclosing HIV+ status to children;

(ii) What other resources and services, particularly mental health services, would make caregivers more likely to disclose an HIV+ status to a child in Kenya;

(iii) Do certain characteristics of caregivers, such as personal HIV status and personal acceptance and level of comfort with personal HIV status effect what resources and support caregivers need when disclosing to HIV+ children?

1.5 Conceptual Framework

The conceptual framework of this proposal is supported by the theory of self-efficacy. The theory of self-efficacy explains that increasing self-efficacy increases the likelihood of performing a behavior. Self-efficacy, as used here, refers to perceived capability for performing tasks at designated levels. Self-efficacy can be impacted by individuals’ interpretations of their own performances, modeled experiences (seeing others perform the same behavior), social persuasion and physiological or emotional factors such as stress. To increase self-efficacy, individuals must interpret their own actions to be a success, they must see modeled experiences that are successes, must have social persuaders who are trusted, capable, and make success look attainable, and have positive thoughts and feelings about their capabilities of performing a specific action. Possessing skill for a certain action is also positively correlated with increased self-efficacy. Individuals typically engage in activities that they believe will result in positive outcomes and the belief in these positive outcomes stems largely from an individual’s
self-efficacy (Schunk and Pajares, 2009). Guidelines, support, and additional resources could serve to increase caregivers’ perception of their ability to fully disclose HIV status to the children that they care for. Guidelines, support and other resources would lower anxieties and stresses about the situation, as caregivers would know that there are places they can turn to for help and that there are structures in place to make the process easier for them and the children they care for. Guidelines, support and other resources would also increase knowledge about disclosure making caregivers more confident in their personal abilities to disclose and additionally would provide a form of social persuasion to caregivers to disclose to children. All of these effects would serve to lead to increased self-efficacy in performing the behavior of full pediatric HIV disclosure and ultimately increasing the likelihood that that behavior will be completed.

Background factors of the conceptual framework of this study, those that influence the decision to give pediatric HIV disclosure for caregivers are fears about the physical and mental health outcomes of the child, social factors, knowledge about the disclosure process and caregiver characteristics. The outcome variable is the disclosure or nondisclosure of HIV status to youth by caregivers. The intervening variables are guidelines, support and additional resources, as they influence the background variables by increasing knowledge about disclosure, creating a closer to equal playing field for all caregivers, and providing more help, support and knowledge for issues of stigma and possible negative health outcomes. Due to their influence on the background variables, guidelines, support and other resources also ultimately influence the outcome variable.
1.6 Justification

After surveying current literature, it is unclear what types of guidelines, support and resources exist in Kenya for disclosing HIV+ status to youth and what types of guidelines, support and resources could improve this process and are desired by the
parties involved. In addition, it is unclear how much the availability of mental health support services impacts a caregiver’s decision to disclose or not disclose to youth. Finally, it is possible that caregivers at different stages of acceptance of their own HIV status, or caregivers with different statuses could require different resources and support when disclosing to HIV+ youth but this has not previously been greatly expounded upon in the Kenyan context.

To prevent and control HIV, providing adequate care and support to those currently living with the illness is crucial. If individuals do not fully understand their own HIV+ status and what it means and how to best care for themselves, then their illness will not be properly managed. In addition if individuals do not fully understand their HIV+ status then they will be more likely to spread it to others in the surrounding population. Therefore, continued growth of the literature surrounding pediatric HIV disclosure is crucial to providing knowledge to prevention and control efforts.

This study hopes to contribute to the literature surrounding the proper management and prevention of HIV in Kenya by identifying ways in which the pediatric HIV disclosure process can be improved and made easier for all parties involved. This study hopes to add to the literature that already exists on pediatric HIV disclosure in Kenya. Therefore, this research is primarily academic in nature and hopes to contribute new knowledge, especially concerning what guidelines and support are desired by caregivers and health workers in Kenya, to the already existing academic discussion on the topic. However, this research could have operational implications and provide advice to hospitals and NGOs working with HIV+ children and their caregivers on the topic of how to best provide support and knowledge during the disclosure process and ultimately help
to give these organizations a solution to the issues currently surrounding pediatric HIV disclosure in Kenya. This is turn could lead to the establishment of new guidelines or resources specific for disclosing to HIV+ youth in the Kenyan context which could ease the jobs of primary caregivers and health workers, and improve the lives of Kenyan HIV+ youth for years to come.

2. CHAPTER II: LITERATURE REVIEW

2.1 Types of Disclosure

As stated above, pediatric HIV disclosure is a crucial step towards individuals being able to effectively manage and care for their illness. Despite this though, studies report pediatric HIV disclosure remaining low in many settings around the globe, with many caregivers being scared, reluctant and unsure of how to completely tell children or youth of their HIV status (Mellins et al., 2002).

Different levels of pediatric HIV disclosure are possible. Often studies define these different levels of disclosure as “full” or “partial”. These types of disclosure are defined slightly differently in different studies. Often though, “full” disclosure refers to giving an individual all information about his or her HIV status and ensuring that he or she fully understands the ramifications of this status (Kidia et al., 2014). Another study defined the different types of disclosure as “complete parental” disclosure or as “partial” disclosure. Complete parental disclosure was defined as a situation in which both the caregiver and the child would agree that the primary caregiver has told the child about his/her HIV disease and drugs associated with this disease. Partial disclosure in this case refers to a case in which a child or adolescent is not fully aware of his or her disease but
is suspicious and asks many questions of the caregiver concerning the possible disease and the drugs being taken (Bikaako-Kajura et al., 2006).

There are many ways in which caregivers will go about partially disclosing or trying to avoid disclosure as much as possible. In one study, caregivers used methods such as deception, where children were told they had an illness but were not correctly told what it was, or children were told their visits to the clinic were just routine checkups, or children were not told of all the complications that went along with their status (Arun et al., 2009).

2.2 Differing Opinions on Nature of Pediatric HIV Disclosure

The best way to give a child or adolescent a complete disclosure of their HIV status is something that greatly differs around the globe and also among different parties involved in the care and treatment of the youth or adolescent. A study from Zimbabwe highlighted the fact that adolescents and health workers feel very differently about how and where disclosure should occur. Health workers felt that caregivers, in the comfort of their homes, should disclose to adolescents. These health workers felt that they did not have the adequate amount of time to spend with youth during and after disclosure and liked to be available simply to correct any incorrect information that was given. Adolescents, on the other hand, wished they could be told of their status in a healthcare setting due to the fact that they could be sure they were getting all of the correct information and liked being in the clinic space because it made the illness a reality (Kidia et al., 2014). In a study containing data collected from Ghana, this same type of difference of opinion was observed. Healthcare providers overwhelmingly believed that disclosure should be done by caregivers while a large portion of caregivers who had not
yet disclosed believed that healthcare workers should be responsible for disclosure (Kallem et al., 2011).

The age at which children or adolescents should receive disclosure of their HIV status is likely the most debated aspect of the nature of pediatric HIV disclosure. Over time, it seems that the age at which children are being disclosed has slowly decreased (Butler et al., 2009), although this finding came from a study representative of resource rich countries and so may not be generalizable to locations around the globe. In a study coming from India, over half of caregivers interviewed felt that age 14-18 was the correct time to disclose HIV status to youth (Arun et al., 2009). Another study, this one coming from Ethiopia echoed this result of disclosing to youth at a later age, finding that a majority of caregivers thought that youth should be told of their HIV status when they are older than age 14 (Biadgilign et al., 2011). Several other sources though, including large health organizations, such as the World Health Organization and the American Academy of Pediatrics recommend that disclosure should ideally be done at a much younger age, between the ages of 6 to 12 to be specific (World Health Organization, 2011; American Academy of Pediatrics, 1999).

2.3 Benefits and Barriers Associated with Pediatric HIV Disclosure

Disclosing HIV status to youth has been reported to be beneficial to the youth. One large benefit of disclosing HIV status to children is increased adherence to medication. One study in Uganda found that youth who had received complete disclosure of their status never frequently missed a dose of their medication but those who had not been disclosed to or who had partially been disclosed to often missed doses of their medication on several occasions. When complete disclosure had occurred in this case,
children looked at their medication much more positively, as less of a chore and were able to develop their own independent adherence strategies (Bikaako-Kajura et al., 2006). Pediatric HIV disclosure also leads to increased access to social support, as there are individuals a child can knowingly communicate with about going through a similar experience, or simply can have individuals to confide in (Vreeman et al., 2014).

Just as there are benefits, there are also perceived barriers associated with disclosing HIV status to youth. One of these barriers is the fear from parents that youth who receive disclosure of their status will have increased mental health problems (Vreeman et al., 2010). However, literature has actually often shown an opposite trend, in which there are very few statistical differences in mental health outcomes between children who do and do not know their HIV status. In fact, children who had disclosure of their status were less depressed than children who did not know their status to in one instance (Mellins et al., 2002). Another study, this one from the United States, noted that quality of life was not shown to be statistically different in any way when comparing pre-disclosure and post-disclosure quality of life for youth (Butler et al., 2009).

Another barrier to pediatric HIV disclosure is caregivers’ fear of the stigma associated with living with HIV. Caregivers often fear that youth receive disclosure of their status will tell many about their HIV+ status. Caregivers fear that there could be potential negative effects for the child and the entire family from this action. It was a concern that from the child self-disclosing to others, the mother’s HIV status could become known and this would result in discrimination and isolation for the entire family including causing children to ‘be alone’ and the family to ‘receive no help’. Caregivers also worried that from telling others of their HIV status, children would be told things
such as ‘they were going to die’ or that ‘HIV came from your parents’ (Vreeman et al., 2010). Experiencing stigma was positively correlated with a child receiving disclosure of their status according to the data of a study conducted in Kenya (Vreeman et al., 2014).

2.4 Characteristics Associated with Increased Pediatric HIV Disclosure

Many studies note certain characteristics that are associated with increased rates of disclosure. A study coming from Kenya noted that children who received disclosure of their status were often older, had older caregivers and were more likely to have an uninfected caregiver or an infected caregiver who had disclosed their own status to the child. In addition if a child had been hospitalized in the past year or if both parents were deceased, it was less likely that the child had received disclosure of their status (John-Stewart et al., 2013). Another study from a different location in Kenya also found that disclosure levels were greater among older children, and that children on ART were much more likely to know their status than children who were not and that disclosure was much more likely at rural clinics studied than urban clinics (Vreeman et al., 2014).

2.5 Pediatric HIV Disclosure in KNH CCC in Nairobi, Kenya

Several studies have recently been conducted concerning pediatric HIV disclosure at Kenyatta National Hospital (KNH) Comprehensive Care Centre (CCC) in Nairobi, Kenya, the study area for the study at hand. One study at this location found that when parents are preparing to disclose to their children, a great deal of time and effort is put into the process. Activities in this disclosure preparation process included making disclosure plans, reading information, teaching children about the disease before disclosure, doing religious activities such as praying and seeking counseling and attending support group meetings. Overall, those interviewed at KNH CCC expressed the
fact that preparing for disclosure is a long and complicated process, requiring many different elements (Gachanja et al., 2014).

Not only is the actual preparation complex, but many complex emotions span the experience of pediatric HIV disclosure according to parents and children at KNH CCC. Before HIV disclosure, parents explained feelings of fear and other negative emotions concerning the anticipation of how their child or children would react to receiving disclosure of their status. Before disclosure, HIV positive children suspected there were secrets in their lives and their family’s life and worried about these. Parents expressed feeling relieved but also feeling shocked, guilty and panicked when their children reacted to the news negatively. Children who received their positive status disclosure felt somewhat relieved but also felt a wide variety of very negative emotions. Younger children who received disclosure though, hardly showed any emotions at all. In the weeks following the disclosure, parents developed feelings of depression and guilt as they witnessed how their children reacted and HIV positive children who received disclosure experienced withdrawal and self-hate among other emotions. (Gachanja, 2014).

Another study investigated the experiences of HIV positive and negative children at KNH in a more in depth manner following the disclosure of their status. Mainly, the children interviewed discussed their acceptance of their illness, the stigma and discrimination that went along with their illness, consuming and adhering to their medications, their levels of sexual awareness and the various coping mechanisms that they had. Getting HIV disclosure left these children with many difficult feelings and decisions (Gachanja, 2015).
2.6 Existing Guidelines

Currently a variety of different guidelines and recommendations exist pertaining to pediatric HIV disclosure around the globe. The American Academy of Pediatrics is one of the sources that provide recommendations. The American Academy of Pediatrics first recommends that caregivers should be counseled by a knowledgeable healthcare professional during the disclosure process. These recommendations also state that the disclosure should be very individualized to each child and that as younger children are most interested in what will happen to them it is crucial to have continuous discussion with younger children about their illness and what is happening. Overall, the American Academy of Pediatrics recommends that disclosure of HIV infection status should occur when children are school-age and that adolescents should fully know of their status so that they can make appropriate decisions and understand the consequences of their actions (American Academy of Pediatrics, 2002).

As was mentioned previously, the World Health Organization also released guidelines of pediatric HIV disclosure for children up to 12 years old. These guidelines are developed for health workers and were created due to the fact that health workers around the globe seem uncertain on how to counsel individuals about the disclosure process. This document recommends that children of school age, or a normally developing 6 to 12 year old, should be told of their HIV status and that children of school age should be told of their parent or guardian’s HIV status. In addition, other key recommendations from this document state that the decision on who will disclose to the child should be guided by the desire to improve the child’s welfare and minimize the risk to his or her well being and that policy, laws and norms should be put in place through
initiatives to prevent discrimination against those living with HIV and make the disclosure of HIV status easier (World Health Organization, 2011).

Another set of recommendations for pediatric HIV disclosure, which is based on making the disclosure process a drawn out and continuous, following stages of child development and readiness, is also available. This is known as a process-oriented disclosure and stresses the importance of the ongoing education process leading to an eventual full disclosure of diagnosis and the ability to adjust. First is the initial assessment stage of disclosure where health care providers discuss the development stages and the child’s learning style with the caregiver. The child and caregiver are then educated on topics ranging from blood cells to medications and how these things interact. During the second part, the assessment stage, the child’s progression with the education is assessed to determine whether the child is at the correct development phase to move forward in the disclosure process, and the caregivers are also assessed for their readiness. If ready, the child is informed that their blood is unhealthy, that they have a virus inside of them, and finally once they understand everything else, that they have HIV and that privacy and confidentiality must be taken into consideration because of this. Finally, during the reassessment stage, the emotions of both the caregiver and the child are reassessed and then the transmission process of HIV starts to be explained. This particular framework is currently used at the HIV clinic at St. Jude Children’s Research Hospital in the United States (Cantrell et al., 2013).

3. CHAPTER III: METHODOLOGY

3.1 Study Design
This study is a grounded theory qualitative research study composed solely of data collected from semi-structured interviews with caregivers of HIV+ youth and health workers who work with HIV+ youth. The data collection was conducted over a 4-week period and consisted of one-on one or two-on-one interviews. Interviews ranged in length from ten to forty minutes. Interview participants were given a consent form prior to beginning the interview.

3.2 Study Area

The study was carried out in Kenyatta National Hospital (KNH) in Nairobi, Kenya. Specifically, interview participants were recruited from the Comprehensive Care Center (CCC) of the hospital. The CCC, which started operations in 2004, offers a variety of services for HIV+ individuals. These services include basic medical services and check-ups for HIV+ patients, counseling and psychological services, nutrition services, lab facilities, a pharmacy, a variety of support groups, on-site artists who interact with the children, fun social events for patients and staff and many other services. Different types of professionals make up the staff of the CCC, including clinicians, nurses, doctors, counselors, a psychologist, a nutritionist and others. In 2013 the CCC had 31,981 total visits and saw 12,490 patients and in 2014 the CCC had 41,160 total visits and saw 16,065 patients. The CCC currently has 981 active youth patients, or those from infancy to 21 years of age. The interviews took place in private offices of staff members or in the public waiting/social area of the clinic.

Justification for using KNH CCC as study area
Kenyatta National Hospital is a national referral hospital and therefore serves a wide range of communities composed of individuals from diverse backgrounds. The sample of individuals interviewed from KNH CCC is therefore more likely to be heterozygous and representative of more of the Kenyan population as a whole than other study areas may be. In addition to serving a wide range of individuals, a large and diverse staff either occupies or passes through the KNH CCC, making this an ideal location to gather interviews from health workers as well as primary caregivers of HIV+ children.

3.3 Study Population

The study population included female primary caregivers to HIV+ children being treated at the KNH CCC and also male and female health workers at the KNH CCC or who were passing through the KNH CCC. 11 of the participants were female primary caregivers of HIV+ positive children. These caregivers cared for an average of 2 to 3 children, and an average of 1 HIV+ child. 5 of the caregivers had disclosed to their HIV+ children and 6 had not. Of those caregivers who did express an age that was the ideal age to disclose to a HIV+ child, between 11 and 12 was the average.

10 health workers at the CCC were also included in the study population. In this group there was 1 male and 9 females and there were 2 doctors (1 pediatrician), 1 clinician, 3 counselors, 1 psychologist and 3 peer mentors. On average, these health workers had been working in the positions they currently held at the CCC for an average of almost 5 years. Of those health workers who did express a specific age that was the ideal age to disclose to a HIV+ child, between 9 and 10 was the average, but many stressed the importance of disclosure occurring as early as possible.
3.31 Inclusion Criteria

(i) Female primary caregivers of HIV+ youth (8-15 years of age).

(ii) Health workers of any type with experience working with HIV+ youth (8-15 years of age).

(iii) Must be willing to participate in the study and sign an informed consent form.

3.32 Exclusion Criteria

(i) Individuals not willing to consent to be in the study.

(ii) Health workers not having experience working with HIV+ (8-15 years of age).

(iii) Male primary caregivers of HIV+ youth (8-15 years of age).

3.4 Sample size and sampling method

Evidence from literature suggests that small sample sizes are often acceptable, and even important for qualitative studies in order to understand a complex human issue in-depth (Marshall, 1996). Purposive samples are the most common type of samples in qualitative research and are samples that are selected based on a set of predetermined criteria created in order to reach a specific research objective. Often, for a grounded theory study, different individuals have recommended having between twenty to thirty interviews when employing purposive sampling (Guest et al., 2006).

Therefore, to understand the resources for pediatric HIV disclosure currently available and those that are needed from the perspective of primary caregivers of HIV+ youth and health workers, purposive sampling was employed. A sample size of at least
twenty interviews was established, meeting the minimum suggested for a grounded theory study by the literature. At least ten of these interviews were to come from primary caregivers of HIV+ youth and ten of these interviews were to come from health workers who have experience working with HIV+ youth.

3.5 Recruitment Strategy

Interview participants were recruited through direct approach from principal investigator, with help from KNH CCC staff. Staff provided introductions to other staff members as well as to caregivers who were waiting for their next appointment or for their medication during their visits to the CCC. In addition caregivers who were waiting were simply approached by principal investigator without introduction from clinic staff and were asked about their willingness to participate. Recruitment occurred at the CCC between 8 am and 3 pm on weekdays.

3.51 Subject Approach

Either the principal investigator or staff members of the CCC approached potential participants. Potential participants that were approached were greeted in a friendly manner and introduced to the principal investigator. Following this, the general nature of the study was explained and potential participants were given a consent form so that they could read more about the study if they wished to before deciding whether or not to participate.

3.52 Non-Coercive Contact

Any contact with potential subjects concerning participation in the study included a conversation stating that participation in the study is completely voluntary and that the
decision to participate or not will not affect their care, career, or care of their family members/ youth that may be cared for at the CCC. This fact was additionally made abundantly clear in the informed consent form and in this form it was also made clear that participants could withdraw or ask questions whenever they felt uncomfortable or unsure, even if they would like to do so after their individual interview had finished.

3.53 Subject Compensation

Each participant was given 150K Sh to go towards possible bus fare or transportation fees associated with getting to KNH.

3.54 Participant Costs

Interview participants may have needed to pay for transportation to KNH if the interview was not during a time they would normally be at KNH. The subject compensation helped to cover this cost if it did exist.

3.6 Risks, Benefits and Adverse Events

3.61 Nature and Degree of Risk

The main risk in this study is that participants could have been emotionally or psychologically uncomfortable during the course of the interview and after the interview was completed. Discussing topics relating to HIV disclosure to children could surface traumatic feelings associated with personal HIV status disclosure for caregivers or even health workers. In addition, the questions asked in the interview could have surfaced uncomfortable memories of negative experiences HIV+ youth have gone through.

3.62 Minimization of Risk
To minimize risks, the subjects first received an explanation of the exact nature of the interview when they read and signed the informed consent form prior to being interviewed. Second, subjects were informed that the CCC’s psychologist Nelly Opiyo had agreed to be available during this study to anyone who had uncomfortable feelings surface and felt as though they needed to talk to a professional. All participants were given Dr. Opiyo’s contact number and were encouraged to ask questions of the investigator whenever the questions arose.

3.63 Benefits

No real, direct and immediate benefits were offered to participants of the study. The results of the study provide insight into what types of resources and support could be needed to increase and ease the process of pediatric HIV disclosure in the Kenyan setting. This is turn will contribute to the academic literature currently surrounding this topic, possibly leading to the improvement of the facilitation of the process in the future.

3.7 Data Collection

A semi-structured interview questionnaire was used to collect qualitative data. This questionnaire was used in English. The interviews were conducted in English due to the limited language skills of the principal investigator who conducted each of the interviews. If potential participants expressed that they did not speak English or that they were not comfortable speaking English then they were not able to be included in the sample for this study. Interviews were recorded using a voice recorder if participants consented to this and if consent was not given to this the investigator took written notes during the course of the interview. The tape recordings of the interviews were the
primary means of data collected. Participants did not have a copy of the interview script to fill out like a questionnaire and gave their responses in a conversational type of interview. Options for responses were given under many of the questions in the interview script but responses were not limited to these options. These options provided a starting point for the principal investigator to suggest to participants if they were confused about the question or were unsure of what to answer. The principal investigator held the questionnaire the entire time during all interviews and used it as a point of reference to guide the interview, but allowed the interview to drift away from the specific topics in the questionnaire if the participants had more to say on one topic versus another.

Questions in the interview questionnaires for caregivers and health workers differed slightly. Both questionnaires began with general, less personal questions to encourage the participant to warm up and become comfortable in the interview setting. Both interviews forms then transitioned to questions pertaining to participants’ personal experiences with illness and disclosure, specifically relating to HIV+ status among youth. At the end of both interviews, questions were asked pertaining to participants’ opinions and beliefs about how the pediatric HIV disclosure process could be made easier/ if it needs to be made easier/ whether or not it is important.

3.8 Data Management and Analysis

Interview data was transcribed into typed scripts after being recorded or taken written notes about. Following transcription, the data was read to pull out emerging themes. Following the collection of emerging themes the data was read again to pull out and highlight specific participants’ quotes in support of the various themes that emerged.
3.81 Confidentiality of Research Data

Interview subjects gave their name on the informed consent form. If subjects wished to receive a copy of the final results they gave their address and phone number. On the top of each informed consent form, subjects were given a number identification and was used to identify subjects on audio recordings and in the qualitative data transcriptions. Informed consent forms containing subjects’ names and contact information were only viewed by the principal investigator. The principal investigator only viewed interview data that was transcribed and analyzed.

As soon as interviews were transcribed to a digital, typed format, the audio recordings were deleted or the notes taken during the interview were destroyed. Informed consent forms will be kept in the safe and private care of the principal investigator until after the completion of the final product of the study. This is to ensure that results can be sent to the participants who wished to receive them.

The data collected during this study will not be used for any future studies. In addition a copy of the consent form or data collected from participants will not be kept in the participant’s personal or medical record. It is not likely that the interview will have a significant effect on the participant either personally or medically.

3.9 Study Limitations

The study is limited to the opinions of caregivers and health workers at KNH CCC on the topic of pediatric HIV disclosure. In addition only female caregivers are in the study further limiting the study results due to possible gender biased data and opinions.
The participants that the study was able to recruit were also limited due to the limited language abilities of the principal investigator. Many of the potential participants who were approached were unable to participate in the study due to the fact that the principal investigator was unable to speak the language that they spoke and communicate with them.

3.10 Ethical Approval

The methods of this study were approved by Colgate University’s Institutional Review Board (IRB) under the proposal number ER-S15-43. The methods of this study were additionally approved by the Kenyatta National Hospital Ethic and Research Committee (KNH ERC) under the proposal number UP403/06/2015.

4. CHAPTER IV: RESULTS

4.1 Resources and Support Available at the CCC

Through interviews, it became clear that there are many valuable resources and support systems available at the CCC to aid caregivers in the process of pediatric HIV disclosure. However, it also became clear that the CCC is not representative of all HIV clinics in Kenya as many health workers and caregivers expressed the fact that the CCC was the best clinic they had ever been exposed to in Kenya. The main resources and support systems that became apparent at the CCC for pediatric HIV disclosure were health workers who are trained in disclosure, health workers advice to perform disclosure as a process, health workers taking the time to listen to individual problems and provide
individualized solutions, peer mentors, support groups and the empowerment of caregivers by health workers.

4.11 Health workers trained in pediatric HIV disclosure

Counselors, peer mentors and clinicians expressed that upon coming to their positions at the CCC and throughout their time as health workers, they received various trainings on specific issues that they may encounter when dealing with HIV+ patients such as adherence difficulties, administering drugs, side effects of drugs and also disclosure. These trainings are specific for the CCC employees. Peer mentors expressed that they gained basic counseling trainings upon the start of their positions and were also constantly learning from the counselors at the CCC, all of which helped them to aid caregivers in issues associated with HIV disclosure.

4.12 Health workers advice to perform disclosure as a process

Health workers all expressed that pediatric HIV disclosure should be a process and that it should be advised like this to caregivers. Caregivers expressed the fact that counselors who were or had helped them through pediatric disclosure had explained to them that disclosure was a process. The main goal of this “process” was to ensure that both the caregiver and the child were completely ready for the child to be told that they have HIV before the disclosure is done. The exact ‘process’ that is advised was described slightly differently by different health workers but in general consisted of first, counselors checking with caregivers to see if they are ready to disclose to their child and also checking with children to see what their maturity level is and also how much they know about their status. After that health workers generally explained that the next step in the process is to give children information about germs and other related topics to
provide them with a background for understanding HIV. Finally once all involved parties are ready and fully prepared, health workers explained that full disclosure would then commence.

4.13 Health workers providing individualized solutions

Health workers explained the value of providing individualized solutions and taking time to listen to the problems and concerns of each caregiver during the pediatric disclosure process. One health worker explained that if strict guidelines were put in place mandating that all caregivers disclose to their children by a certain age, then the outcome would be that many patients would be lost. The health worker stated that many caregivers would not be ready to disclose at this mandated time and knowing that they would be forced to if they came to the clinic, they would instead choose to stop coming to the clinic and so they would stop receiving important care and medications for themselves and their child. Therefore, providing individualized support and solutions rather than one standard solution or type of support is very important to health workers at the CCC.

4.14 Peer Mentors

The CCC has many peer mentors on staff who provide support to patients of the clinic. These peer mentors are all HIV+ themselves and started out being seen at the CCC as patients. They then began volunteering at the clinic and performing duties such as giving educational ‘health talks’ in the mornings or helping and talking to patients who “seemed down”. After a volunteering period, these individuals were invited to become part of the staff and receive training to become peer mentors and be available to help patients who either are referred to them by doctors, clinicians or counselors or who simply look like they need someone to talk to. These peer mentors provide caregivers
with insight into the pediatric disclosure process based on their own experiences receiving disclosure of their status, their own experiences disclosing, or their own experiences interacting with friends who had disclosed to children. As a peer counselor at the CCC explained, “Actually, right now the best person to help another person with the problem is the one who wears the same shoe. So I understand them and at least I understand what they are going through so it is easy for me to get a rapport with them.”

4.15 Support Groups

The CCC offers a variety of support groups to patients. There are support groups for youths, adults, caregivers who have disclosed and caregivers who have not given disclosure of status to the child(ren) they care for. In the two different support groups for caregivers, participants are able to share their experiences of what has and has not worked in terms of disclosure to the children the caregivers care for. One health worker explained that once some caregivers hear other caregivers explaining that they have just disclosed or that they are about to disclose, they realize that the process is not as difficult as they previously perceived it to be.

In addition to these formally constructed support groups, informal support groups exist at the CCC as well, mainly for children and youth. There are a variety of spaces such as waiting areas and playgrounds where children and youth talk, play and interact during their visits. The CCC also offers ‘fun days’ and outings where the children and youth can interact with each other and also staff in a comfortable and enjoyable environment. These informal support groups facilitated by the CCC for children and youth provide a support system for these individuals so that they can have someone, or
multiple people to turn to for help after possible difficult life events such as receiving disclosure of their status.

4.16 Health workers empowering caregivers

Health workers described a large impediment in the pediatric HIV disclosure process is fear from caregivers of the unknown outcomes that disclosure could lead to. Caregivers fear that children who are receive disclosure of their status will get stressed or sad and that they could blame the caregivers. Therefore, to calm these fears, health workers explained that they empower caregivers. They explain to them the advantages of disclosing and talk them through their fears of negative or unknown outcomes.

4.2 Resources and support that are needed

The interviews revealed that in addition to there being resources and support that are available to help caregivers in disclosing pediatric HIV+ status, there are still many resources and types of support that are needed at the CCC and throughout Kenya that could serve to make the process easier and more likely to occur. The main types which emerged are education to primary school aged children to reduce stigma surrounding HIV, increased number of counselors throughout Kenya, guidelines that explain steps to disclose based on developmental stages of children and increased facilitation of conversation/communication between caregivers and positive children.

4.21 Education to primary school aged children to reduce HIV stigma

Countless caregivers and health workers expressed the sentiment that the social environment must first change in order for pediatric disclosure to become easier and more frequent. Interview participants explained that “Africans hear that HIV is immoral”
and that from the time HIV became a focus in Kenya, the propaganda surrounding it has been nothing but negative. Often, posters about it showed a “very thin individual” looking “very bad”, and that is the image that Kenyans associate with HIV+ individuals. In addition, many families reportedly think that the HIV illness comes only to those who are promiscuous. All of this creates stigma around HIV in Kenya.

The education surrounding HIV in schools described by interview participants plays an important role in creating the stigma surrounding HIV in Kenya. Participants explained that when discussing HIV, teachers usually say that when you get HIV you will die, that it is a deadly disease, that you cannot perform once you have it and that it is immoral. One caregiver and one health worker expressed that the education in schools was not too bad; indicating that education on HIV may be improving in some schools.

Despite this though, an overwhelming majority of caregivers and health workers expressed the sentiment that if “the right information” were being given in schools and at a grassroots level, then there would not be such a large problem with pediatric HIV disclosure. Interviewees explained that if people were educated that HIV is just another disease, that not only immoral people can get it and that it is not an immediate death sentence, then other children would not look upon HIV+ children as negatively, and HIV+ children would not think of themselves as negatively. If this were the case then caregivers would not be as fearful of their child(ren)’s reactions to disclosure, and the process would be much smoother and easier overall.

4.22 More counselors in Kenya

Although there were 5 counselors at the CCC, it was explained that this is not a uniform occurrence at HIV clinics across Kenya. A majority of caregivers expressed that
the counselors at the CCC had either already been very helpful to them or that they wanted the counselors to be there with them or help them through the pediatric HIV disclosure process. Before children are ready to receive disclosure of their HIV status, they often start to refuse to take their medication, and caregivers interviewed explained that counselors walk them through how to deal with this issue. After disclosure occurs, caregivers come with the child(ren) immediately to see the counselor and the counselor ensures that the process has gone well and continues to go well.

4.23 Guidelines that explain how to disclose based on developmental stages of children

From the interview data, it is abundantly clear that pediatric HIV disclosure must be an individualized process and that it depends largely on the maturity of the child at hand. One caregiver of a 10-year-old HIV+ boy explained that she had to disclose to him when he was 9 because he was asking so many questions. Another mother of an 8 year old HIV+ girl though, explained that her daughter had no idea she was positive, would not understand if she was told, and was currently too talkative so would not know when was not an appropriate time to talk about her status to others and when was not.

A variety of health workers stated that they could not name a specific age that was good for all children to receive disclosure of their status because it truly depended on the child and whether or not they were ready to hear about their status and understand its implications, the socialization of the child, their shortcomings and other individual characteristics. One health worker suggested a tool be created which guides health workers and caregivers through what steps of disclosure to proceed to based on checklists of characteristics that a child exhibits.
4.24 Increased facilitation of conversation/communication between caregivers and their positive child(ren)

Health workers described many scenarios in which caregivers believed their children knew nothing of their HIV+, when in reality they almost entirely knew that they were positive but were waiting to hear it from the caregiver so that the two could talk about it. Caregivers are often so fearful of the unknown outcomes of disclosure that they refuse to see that it is likely that their child already knows something about their illness.

Many caregivers interviewed expressed that it was impossible for younger children (younger than teenagers) to understand their status, even though health workers discussed many examples in which younger children received disclosure of their status and reacted very well and were able to comprehend and even picked up about their status before being told. Therefore, more frequent structured conversations facilitated by health workers could serve to make disclosure easier if caregivers realized what their child already knew and what they were truly able to understand about being HIV+.

4.3 Caregiver characteristics influencing resources and support needed for disclosure

Both health workers and caregivers conceded that characteristics of caregivers impacted the support that the caregiver needed throughout the pediatric disclosure process. First, it was expressed that caregivers who have more social support at home, from other family and friends, have an easier time disclosing and need less support and guidance from health workers. It was also explained numerous times that it is very common to have families where, for example, the mother and one child are positive, and
another child and the father are negative, and the only person that knows is the mother. In this situation, the mother has a very difficult time disclosing to the child as she is in fear that the rest of the family will find out. This mother would need more support and guidance and resources when disclosing to her child due to the lack of support that she has in her home life.

Caregivers who have already told others in their lives about their own HIV status, if it happens to be positive, and gotten positive reactions were also more likely to tell children and less nervous to do so. They saw that explaining an HIV status was not so difficult and that the outcome was not so negative.

In addition to this, the personal HIV status of the caregiver also makes a difference in the resources and support that they need when they are disclosing to a child. One caregiver, the only HIV negative caregiver that was interviewed, stated that she thought it was more difficult for a negative caregiver than a positive caregiver to disclose to an HIV+ child. She felt that when she disclosed she was breaking the child’s heart and she could not bring herself to explain that she was negative. This caregiver explained that having an HIV+ caregiver disclose also gives the child hope by showing them that someone else who has HIV is surviving and doing well, so that they know that they will not die right away. She expressed that she needed very specific steps as to how to disclose as she had no idea how to deal with the issue. However, this caregiver was the only HIV negative caregiver interviewed and therefore may not be representative of all HIV negative caregivers in Kenya.
5. CHAPTER V: DISCUSSION

Pediatric HIV disclosure is a very difficult process in Kenya. While the CCC does offer many types of resources and support to caregivers and children throughout the process, the CCC is not representative of all of the HIV clinics in Kenya and it could even benefit from the offering of other types of resources and support. Stigma appeared to be the largest impediment to pediatric HIV disclosure, and while it would be impossible to eradicate stigma completely, through the implementation of certain resources, or types of education to children, stigma could be reduced. One of the most valuable resources available appeared to be offering peer mentors and showcasing others who have successfully gone through difficult experiences such as disclosing to children. This served to calm fears of caregivers and had an ability to persuade disclosure to happen. In addition to this, the value of counselors through the process of pediatric disclosure was shown to be incredibly large, highlighting the fact that mental issues must first be dealt with to deal with important problems that arise in HIV management. Without the help of counselors, it did not appear that many of the caregivers interviewed would have disclosed or even considered disclosing to their children in the future.

5.1 Stigma

The results of this study indirectly showed that stigma is one of the biggest, if not the underlying cause for all, barriers to pediatric HIV disclosure in Kenya. The stigma surrounding HIV in Kenya causes caregivers not wish to disclose HIV status to children, due to the fact that children could become depressed due to stigma from peers, children could be forced to drop out of school due to stigma from peers, children could disclose the status of caregivers to other peers leading to stigmatization, and stigmatization in
general is feared among caregivers in Kenya (Mellins and Malee, 2013; Gachanja, 2014; John-Stewart et al., 2013; Vreeman et al., 2010; Skoydal et al., 2012; Vreeman et al., 2014).

As was reported by caregivers and health workers alike, stigma is still a large concern in Kenya today, and stems largely from the type of education that primary school aged students are receiving pertaining to HIV/AIDS. Much of this education teaches children to believe that HIV is obtained only through immoral acts and that it is an immediate death sentence. These words about HIV seem to follow Kenyan individuals throughout their lives and stick in their minds well into adulthood. Although completely changing this atmosphere of stigma towards HIV in Kenya would be very difficult and would take a long time to achieve, it is possible to begin to start making changes in schools. Several past studies have shown that education to communities and youth can serve to reduce stigma against HIV/AIDS and people living with HIV/AIDS (PLHA). A study in Jamaica targeting youth found that providing information through peer education, workshops, pre-workshop assignments, interviews to examine fears and one on one conversations with PLHA significantly increased youth attitudes towards PLHA and decreased the percent of youth wanting PLHA to be isolated. Another study, based in Tanzania, aimed to increase correct education to primary school children concerning HIV and increase their tolerance towards PLHA. Factual information was provided to the children and they were then tasked with creating songs, performing plays and doing a variety of other tasks with the information they received. This intervention resulted in a significantly increased attitude to PLHA for the children (Brown et al., 2003).

With the evidence of these interventions, it is clear that correct education can be
significantly effective in reducing stigma surrounding HIV/AIDS in certain environments. Much research would need to be done though to find the correct ways to educate primary school children to reduce the stigma in the Kenyan environment though.

Providing resources, namely improved and increased education in primary school, to change the social atmosphere is a crucial step in changing behaviors of many caregivers to encourage pediatric HIV disclosure. If stigma were decreased, pediatric HIV disclosure would not be nearly as much of a challenge as it currently is in the Kenyan atmosphere.

5.2 Peer Mentors/ HIV+ Role Models

The peer mentors at the CCC proved to be one of the most effective resources and sources of support for patients. Interviewees reported that it is very comforting seeing someone else who is also HIV positive succeeding and surviving as patients often assume that they will die very soon after becoming positive, due to the current stigma and propaganda surrounding HIV in Kenya. Furthermore, having support groups for caregivers who were all going through the issues surrounding disclosing to a child proved to be an effective resource. It was clearly easier for patients to take advice from individuals who were also positive as they had personally felt the feelings patients were going through and had also gone through the same struggles.

Due to the sentiments that were expressed towards peer mentors and HIV+ role models during interviews, even more HIV+ role models being available to guide caregivers through the disclosure process seems as if it would be an extremely useful resource. Although the benefits of peer mentors were spoken of often, they were not often
mentioned specifically in guiding caregivers through pediatric HIV disclosure based on personal experiences of peer mentors or other HIV+ caregivers. Recruiting willing caregivers who have gone through disclosure with their child to guide other caregivers who have not yet disclosed to their child would likely be a novel and valuable tool for those aiming to complete pediatric HIV disclosure in Kenya. For caregivers who have not yet disclosed, fear of unknown outcomes due to the stigma in the culture is one of the biggest barriers to beginning the process. However, having constant access to someone who has already gone through the process would make the outcomes of the process less unknown, and therefore less terrifying to caregivers. A specific peer-mentoring program for pediatric HIV disclosure would likely be highly useful.

5.3 Counselors

According to caregivers interviewed, counselors at the CCC play a crucial role in the process of pediatric HIV disclosure. As a health worker explained during her interviewed, HIV is largely a mental process, and it is a disease that is not easily acceptable, and so to accept the disease and take all the necessary steps for care, counseling is very important for patients. In addition, having counselors available at clinics is crucial in the establishment of other resources and support systems that are needed according to the results of this study. For one, creating and utilizing guidelines similar to the process-oriented guidelines, currently being utilized in various places, including the St. Jude Children’s Research Hospital in the United States (Cantrell et al., 2013), that would recommend steps of disclosure based on the maturity and development stages of the child would require the help of a trained counselor. Creating and utilizing
this type of guideline effectively would require being able to correctly assess the
cognitive abilities of children and also to tie specific cognitive abilities with specific parts
of HIV disclosure that can be handled. Successfully using this resource would require
knowledge of cognitive abilities, mental abilities and emotional responses and counselors
would have this knowledge. In addition, interviewees indicated that improved
facilitation of communication between caregivers and HIV+ children could ease the
disclosure process. Facilitating this communication would also go much smoother with
the expertise of a trained counselor.

Trained counselors are invaluable for facilitating pediatric HIV disclosure. Although health workers interviewed explained that counselors and psychologists are not
widely available in Kenya, evidence shows the counselors are expanding in the country.
In recent years, professional associations have begun to be formed in Kenya for
counseling, and increasing numbers of universities are offering counselor preparation
programs. However, counselors are still by no means available to all communities in need
in Kenya. In addition, counseling research is largely not grounded in local Kenyan
cultures and the types of counseling practices that work best in these cultures (Okech &
Kimenia, 2013). Continued growth of the profession of counseling and continued
incorporation of practices and occurrences specific to Kenyan culture will be important
for improving the process of pediatric HIV disclosure across the nation.

5.4 Future Directions

The results of this study produce a variety of further questions about how to
improve the process of pediatric HIV disclosure in Kenya. First, answering the question
of what the best way to educate primary school aged children in Kenyan about HIV is in order to reduce stigma and the question of whether or not schools employing different types of education produced caregivers of children in the schools who are more likely to disclose to them would be important. Second, as individualized care and solutions for pediatric HIV disclosure are abundantly important, looking at whether or not specific characteristics of children who need to receive disclosure of their status, such as gender, dictate the types of support and resources that are needed to help through their disclosure process would be interesting and potentially helpful. Last, creating a process oriented framework for pediatric HIV disclosure in Kenya which moves in incremental steps based on the child’s development stages and testing this framework in various clinics throughout Kenya could provide an answer to the question of whether or not this type of resource could ease and improve the process of disclosure in Kenya.

6. CHAPTER VI: CONCLUSION

After conducting interviews at the CCC in Nairobi, Kenya, it can be concluded that a variety of resources are available to caregivers when planning to disclose HIV+ status to their children. These resources are health workers who are trained in disclosure, health workers advice to perform disclosure as a process, health workers taking the time to listen to individual problems and provide individualized solutions, peer mentors, support groups and the empowerment of caregivers by health workers. The main resources and support systems that are still needed to help with pediatric HIV disclosure at the CCC and in Kenya as a whole are education to primary school aged children to reduce stigma surrounding HIV, increased number of counselors throughout Kenya,
guidelines that explain steps to disclose based on developmental stages of children and increased facilitation of conversation/communication between caregivers and positive children. In addition to this, through the interviews it became clear that all caregivers do not require the same resources and support and that the resources and support needed depend on the caregivers’ social support, personal acceptance of HIV+ status and ability to disclose this status to others, and also the HIV status of the caregivers.

Overall, this study revealed that resources and support first and foremost need to be put in place to reduce stigma surrounding HIV and that help caregivers and HIV+ children cope with the stigma they find in schools. One important way to do this would be to change and improve HIV education in primary schools in Kenya. Although stigma remains a difficult obstacle to pediatric HIV disclosure, the use of peer mentors and other HIV+ role models is very important to facilitating the disclosure and increased usage of this type of resource could prove extremely valuable. Finally, counselors are priceless support systems during the pediatric HIV disclosure process and the continued growth and specialization of counseling in the Kenyan setting will no doubt have a positive effect on pediatric HIV disclosure in the nation.

There are still many barriers to pediatric HIV disclosure in Kenya, making the process very difficult. However, there are also wonderful resources and support systems in place, at least in some areas of the country, and there are many clear ways that these resources and support systems can be improved, individualized and expanded in the future.
References


Behavior, 15(6), 1121-1127.


Appendix A: Certificate of Informed Consent

Certificate of Informed Consent

Overview and Procedure:
My name is Katrina Bennett and I am a student at Colgate University in New York in the United States. I am looking to gather information for a focused research project here at Kenyatta National Hospital Comprehensive Care Center. You are being invited to participate in this study. This is a form to help you understand this search for information before you give any information you have on this topic.

This study looks at the process of telling children and explaining to children that they are HIV+. The purpose of this study is to (1) find out what resources and support systems are currently provided to caregivers when telling children they care for that they are HIV+ and (2) find what resources and support systems are needed for the process of telling and explaining to children that they have HIV and (3) finding out whether or not what is needed for telling children they are HIV+ is different for different caregivers.

If you agree to sign this consent form, I will meet you in Kenyatta National Hospital Comprehensive Care Center for a talk that will last about 30 minutes to an hour and a half. I will ask you questions about yourself and your life, your health history if you are a caregiver of an HIV+ child, your experiences with telling children of HIV+ status, what information you know is available to help with this process and what information you wish was available to help with the process.

Risks and Benefits:
The questions asked during the talk are very personal and could cause you to have bad feelings. The information you give from your experiences will be important for informing caregivers how to best tell children about their HIV+ status and also in guiding the health care system in how to best support care givers through this difficult process. Your participation would be very useful to improving the process of telling children of their HIV+ status in Kenya and internationally. However, you will not receive any real or direct benefits from your participation.

Confidentiality:
The information you share with me during the talk will be kept private. I will consult with an outside source concerning what you tell me during the interview only if you tell me that your life is being immediately threatened. I will identify you in the study only by a random number that I give you and your name will never be used. During the talk, if you give permission, the conversation will be recorded so that I can remember what was discussed exactly. After the data from the talk is recorded it will be typed up so that it can be analyzed. After it is typed up, all notes and the recording of the talk themselves will be deleted forever. The information you share with me will be used for research and I will share it with those at Kenyatta National Hospital, those at local Kenyan organizations working to help with the care of HIV+ individuals, my school in the United States, and possibly other national and international sources for health information so that many others can benefit from the information you provide me with. If you wish, and if you provide your address on this form, I can send you the results of this study.

Compensation:
For participating in this study, you will receive compensation for your bus fare and a snack after the talk is completed.
Your Rights:
You do not have to participate in this study and it will not interfere with your job if you are a health worker, or your treatment or the treatment of the child (children) you care for that is received from this clinic if you choose not to participate. At any time that the study is occurring and you wish to have your statements from this talk taken out of the data, you can contact me and let me know this and you will still be able to keep the small compensation. If you do choose to participate and at any time have uncomfortable feelings because of the personal questions I am asking you, you can contact the clinic’s psychologist, Nelly Opiyo for no cost and talk with her, at 0722-313697.

Contact Information:
If you want to contact me with any questions or concerns, my email address is kabennett@colgate.edu and my phone number is (0701 948 057). The advisor for this project, Ellen Kraly, can be contacted at ekraly@colgate.edu.

By signing below, you are agreeing 1) to participate in this study, and 2) that you have read and understand all of the information provided on this form.

Participant Name (please print)            Researcher Name (please print)

Participant Signature                      Researcher Signature

Date                                          Date

By signing below you are agreeing to have your interview recorded by a voice recorder.

Participant Signature                      Date

If you wish to receive the results of the study please provide your mailing address below:

______________________________________________________________________________

______________________________________________________________________________

______________________________________________________________________________
Appendix B: Interview Scripts/ Questions

Pediatric HIV Disclosure Interview Script/Questions for Caregivers

Thank you for agreeing to participate in this study. As I explained, I hope to generate good information about telling children about their HIV+ status. So your responses will be very helpful to recommend the types of guidelines and support that are needed to help health workers and caregivers like you tell HIV+ children about their status.

Let’s begin with some information about yourself and your accessing of health care.

Can you tell me about yourself, where you access health care and your personal history of illness?

Probes:
1. What is your age?

2. Where do you live?

3. Do you get treated here at this clinic?
   Yes_______ No_______

4. How often do you come to this clinic for yourself or your family?
   1 week _______  2 weeks_______  3 weeks _______  Monthly _______

5. Where else might you seek health care for yourself or your family?
   Other clinics _______ Other hospitals _______ Healer _______

6. If you don’t mind, can you tell me if you have faced a serious illness?
   Yes serious illness_______ No serious illness_______

7. What experience have you had telling others that you have an illness?
   None_______ Some_______ A lot _______

8. Are there places for adults to go to get help with telling others about illnesses that they have?
   Yes_______ No_______
Now I would like to learn a little more your experience in caring for children who are HIV+, and also your own health experiences.

**Can you tell me about your personal experience caring for a child who is HIV+ and telling them or not telling them that they are HIV+?**

Probes:
1. How many HIV+ children do you care for?
   1 2 3 4 5 6 other

2. How old is the child (children) that you care for?
   8 9 10 11 12 13 14 15

3. How long have you cared for this child (children)?
   1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 (in years)

4. Have you or anyone else told the child (children) you care for that they are HIV+?
   Yes_______ No_______

5. Tell me about whether or not you have talked to health workers about telling the child (children) you care for they are HIV+?
   Yes_______ No_______

6. What services or information do you know is available to help you tell your child(ren) they are HIV+?
   Guidelines or rules telling you how to do it_______ Counseling services_______
   Books_______ Support Groups_______ Health Workers_______
   Classes_______ Other_______

7. Have you witnessed children be upset after learning of their HIV+ status?
   Yes_______ No_______

8. (if so) can you tell me more about that experience?
9. What help can children get after they learn about their HIV+ status?
   Counseling_______ Support Groups_______ Learn about HIV_______
   Other_______

I would really like to learn your thoughts about telling children their HIV status…

Can you tell me what you think about the importance and difficulty of telling children they are HIV+?

Probes:
   1. Do you think telling children about their HIV+ status is important?
      Yes_______ No_______

   2. What age do you think is right to tell children that they are HIV+?
      1   2   3   4   5   6   7   8   9   10   11   12   13   14   15   16   17   18   19   other

   3. What information should be told to children when they are told they are HIV+?
      They are sick_______ They have HIV_______ What HIV is_______
      What others think about HIV_______
      How others will treat them because of their sickness_______
      What help is there for them_______ Other_______

   4. Do you think bad things happen/ will happen when children are told that they are HIV+?
      Yes_______ No_______

   5. Tell me what you think about the help that you can get to tell children they are HIV+.
      It is good enough_______ It is not good_______
      It is okay but could be better_______ Other_______

   6. What do you think would make telling children they are HIV+ easy?
      Guidelines or rules telling you how to do it_______
More counseling support

More general information about disclosure

Practicing disclosure before doing it

More peer support groups Other

More counseling support for children

Thank you so much for talking with me. Your responses will be very helpful and if you indicated wanting the final results, I will get them to you as soon as they are completed. Please let me know if you have any questions for me and thank you again!
Pediatric HIV Disclosure Interview Script/Questions for Health Workers

Thank you for agreeing to participate in this study. As I explained, I hope to generate good information about telling children of their HIV+ status. So your responses will be very helpful to recommend the types of guidelines and support that are needed to help caregivers and health workers tell HIV+ children about their status.

Let’s begin with some information about yourself and your experience as a health worker.

**Can you tell me about your current and past experience as a health worker?**

Probes:
1. What is your position?
   - Physician_______ Nurse_______ Psychologist_______ Peer Counselor_______
   - Other_______

2. How long have you worked at your current position?
   - 1 2 3 4 5 6 7 8 9 10 other (in years)

3. What past healthcare working experiences have you had?

Now I would like to learn about your experiences working with HIV+ adults and children in your position as a health worker.

**Can you tell me about your past experiences working with HIV+ adults and children as a health worker?**

Probes:
1. What experience have you had working with HIV+ individuals? Children?
   - With adults: None_______ Some_______ A lot_______
   - With children: None_______ Some_______ A lot_______

2. What experiences have you had with telling children of their HIV+ status?
   - None_______ Some_______ A lot_______

3. What help is available for caregivers when telling children they are HIV+?
   - Guidelines_______ Counseling services_______ Books_______
Finally, I am really interested in learning your thoughts about telling HIV+ children of their status.

Can you tell me what opinions you have about the importance and difficulty of telling children they are HIV+?

Probes:
1. Do you think telling children they are HIV+ is important?
   Yes_______   No_______

2. Do you think that telling children they are HIV+ is difficult?
   Yes_______   No_______

3. Do you think enough help is offered for children and caregivers when caregivers tell their children they are HIV+?
   Yes_______   No_______

4. If enough help is not offered for children and caregivers when caregivers tell their children they are HIV+, what other help should be offered?
   Guidelines telling how to disclose_______   More counseling support_______
   More general information about disclosure_______
   Practicing disclosure before doing it_______
   More peer support groups_______   Other_______
   More counseling support for children_______

Thank you so much for talking with me. Your responses will be very helpful and if you indicated wanting the final results, I will get them to you as soon as they are completed. Please let me know if you have any questions for me and thank you again!