

# DON'T ASK, DON'T TELL? THE ETHICS OF DISCLOSURE OF HIV-STATUS TO PERINATALLY-INFECTED CHILDREN

*A ÉTICA DA REVELAÇÃO DA INFECÇÃO PELO HIV A CRIANÇAS INFECTADAS  
POR TRANSMISSÃO PERINATAL*

*Joseph De Santis<sup>1</sup> & Jessie M Colin<sup>2</sup>*

## ABSTRACT

**Introduction:** The care of children with Human Immune Deficiency Virus (HIV) infection in the United States has become an area of concern for pediatric health care providers. Perinatal, or mother to child infection accounts for about 90 percent of all HIV cases in children. **Objective:** The care of children with Human Immune Deficiency Virus (HIV) infection in the United States has become an area of concern for pediatric health care providers. The objectives of this paper is to identify some of the reasons why parents do not disclose HIV-status to children; to discuss the special challenges for health care providers such as registered nurses (RNs) and pediatric nurse practitioners (PNPs) who provide care for HIV-infected children; and to discuss the ethical challenges which must be addressed by health care professionals. **Methods:** This paper uses a case study approach to present the complex ethical issue of disclosure of the diagnosis of perinatally-acquired HIV to a child against the wishes of the child's parents. **Results:** Based on the ethical principles, RNs and PNPs should adopt a stance that support disclosure at a certain point in the child/adolescent's life. Disclosure of HIV status is a stressful experience for the parent, child, and the healthcare provider who performs the disclosure. Disclosure, therefore, needs to occur as a process. **Conclusion:** Disclosure of diagnosis to an HIV-infected child is a difficult issue for healthcare providers and for parents. Each institution that provides care for HIV-infected children should have a protocol in place for handling this complex issue. Although a variety of other factors besides ethics need to be considered, ethics provide a starting point for grappling with this complex issue. As professionals providing care for children, it is important that the best interest of the child is at the center of the decision-making process.

**Keywords:** HIV, disclosure, bioethics, pediatric nurse practitioner, perinatal HIV infection

## RESUMO

**Introdução:** A assistência a crianças com infecção pelo Vírus da Imunodeficiência Humana (HIV) se tornou uma área de preocupação para os profissionais de saúde pediátrica. A transmissão perinatal, ou transmissão da mãe para o bebê, é responsável por aproximadamente 90% de todos os casos de HIV em crianças. **Objetivo:** A assistência a crianças com infecção pelo vírus da imunodeficiência humana (HIV) nos Estados Unidos tornou-se uma área de preocupação para profissionais de saúde que trabalham com pacientes pediátricos. Os objetivos desse artigo são identificar as razões pelas quais os pais não revelam a soropositividade a crianças; discutir os desafios para os profissionais de saúde, como enfermeiros e profissionais de enfermagem que provêm assistência a crianças HIV positivas; e discutir os desafios éticos enfrentados por profissionais de saúde. **Métodos:** Esse artigo utilizou um estudo de caso para apresentar os aspectos éticos complexos da revelação do diagnóstico de infecção materno-infantil do HIV a uma criança contra a vontade de seus pais. **Resultados:** Com base nos princípios éticos, profissionais de saúde devem adotar uma postura que dê suporte à revelação do diagnóstico em algum momento da vida de uma criança ou adolescente. A revelação do estado sorológico é uma experiência estressante para os pais, para a criança e para o profissional de saúde que faz a revelação. A revelação, desta forma, deve ocorrer como um processo. **Conclusão:** A revelação do diagnóstico a uma criança infectada pelo HIV é um tema difícil para profissionais de saúde e para pais. As instituições que oferecem assistência a crianças infectadas pelo HIV devem dispor de protocolos, para manejar essa complexa situação. Embora muitos fatores, além dos aspectos éticos devam ser considerados, a ética provê um ponto de partida para o enfrentamento desses assuntos. É fundamental que os interesses da criança sejam o centro do processo de tomada de decisão por parte dos profissionais de saúde que lhes prestam atendimento.

**Palavras-chave:** HIV, revelação, Bioética, profissionais de enfermagem pediátrica, infecção materno-infantil do HIV

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## CASE STUDY

Tommy is a 14 year old male who was just recently diagnosed with HIV-infection during his recent hospitalization for pneumonia. Tommy's mother was HIV infected when he was born, but

was not aware of her diagnosis as she was never tested for HIV during her pregnancy. Tommy's mother has a substance abuse problem, so Tommy's elderly grandparents provide care for Tommy and his mother. Tommy has been relatively healthy throughout his life, but was diagnosed with diabetes when he was 8 years old.

Highly active antiretroviral therapy (HAART) was initiated during this hospitalization to control his HIV-infection. The health care team wants to disclose Tommy's diagnosis to him

<sup>1</sup>. Doctoral student in Nursing at Barry University and HIV Educator at Jackson Health System in Miami, Florida.

<sup>2</sup>. Associate Professor - Barry University School of Nursing, Miami Shores, FL.

before discharge. Tommy's mother is ambivalent about the disclosure, but Tommy's grandparents are adamant that they do not want him to know his diagnosis yet. Tommy's grandparents feel that if he knows his diagnosis, he will become depressed and will no longer possess the will to live. Currently Tommy is not sexually active. Tommy is discharged home without knowing his diagnosis, as per his grandparents' wishes.

Tommy is a very introverted adolescent and never asks any questions about his medication regimen or health care visits to either his health care providers or his grandparents. When Tommy becomes ill, the grandparents attribute the illness to his diabetes. With every encounter in the pediatric HIV clinic, health care providers approach Tommy's grandparents in an attempt to persuade them to disclose Tommy's diagnosis to him. Tommy's grandparents continue to refuse to disclose his diagnosis to him.

## INTRODUCTION

The care of children with Human Immune Deficiency Virus (HIV) infection in the United States has become an area of concern for pediatric health care providers. Perinatal, or mother to child infection accounts for about 90 percent of all HIV cases in children. Cumulatively, approximately 9,000 children in the United States less than 13 years of age have been infected with HIV, and with the advent of HAART in the 1990's, the majority of these children will live to reach adolescence<sup>1</sup>. These statistics indicate that as children with HIV live longer, certain issues arise that were not present when the life expectancy of a child with HIV was less than 8 years. One of these issues is the disclosure of HIV-status to perinatally-infected children. Parents and health care providers will be faced with this issue more frequently in the near future.

This issue is a significant issue in pediatric health care. It has been noted that between 41%<sup>2</sup> and 50%<sup>3</sup> of children with HIV infection have not been informed or fully disclosed of their HIV-status. Additionally, the American Academy of Pediatrics (AAP) has developed a position paper on this issue. The AAP believes that there are numerous reasons why parents do not disclose HIV-status to their children. These include the fear that it will impact the emotional well-being of the child; it will affect the child's will to live; the child may express anger at the parent for infecting them; the parents possess guilt over transmission to the child; fear that the child will disclose the diagnosis to others; parental difficulty coping with their disease; and denial that the parent and child are HIV-infected<sup>4</sup>.

## PROBLEM STATEMENT

Since the beginning of the HIV epidemic in the early 1980's, HIV has been a unique disease. Besides fatal, contagious plagues that have afflicted mankind throughout history, no other disease has generated as much social stigma. Unfortunately, this stigma continues as the disease enters the third decade of existence.

Currently, HIV is viewed as a disease that affects those with alternative lifestyles, minority groups, the poor, or citizens of underdeveloped countries<sup>1</sup>. This fact only continues to strengthen the HIV-associated stigma.

Those living with HIV often conceal their diagnosis to avoid being ostracized from their families, partners, and communities. A unique situation arises when an HIV-infected mother bears a child who becomes perinatally-infected with HIV. This situation provides special challenges for health care providers such as pediatric nurse practitioners (PNP's) and pediatric registered nurses (RN's) who care for HIV-infected children. As a member of the health care team, the PNP is involved in encouraging parents to disclose to the child his/her diagnosis at an appropriate time.

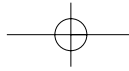
Webster's Dictionary<sup>5</sup> defines disclosure as "the act of making known or revealing what was secret". Since a definition of disclosure can not be located in the literature that is applicable to this discussion, an operational definition was generated. Disclosure is defined as a process whereby a parent is emotionally-ready to inform the child of his/her HIV infection after the child is determined to be developmentally-appropriate and developmentally-ready to receive this information. The disclosure process involves developmentally-appropriate explanations, honesty, open communication patterns, and support<sup>6</sup>. In cases where the parents does not or can not disclose to the child, the PNP can disclose to the child with the support of the health care team, including the social worker and child psychologist.

Parents are often reluctant to disclose the diagnosis to their child. This reluctance places the PNP in a difficult predicament, as one of the PNP's major role functions is to serve as an advocate for both the child and family, ensuring that the best interests of both are taken into consideration at all times. The parent's reluctance to disclose the diagnosis to the child may place the PNP in direct conflict with the parent over this issue. This situation has led to the development of the ethical/philosophical question of what action should the PNP take when the parent refuses to disclose the diagnosis of HIV to a developmentally-appropriate child? Should the PNP support the parents' wishes in an attempt to preserve the parent-PNP relationship, or should the child be disclosed against the parents' wishes in the best interest of the child?

## REVIEW OF THE RESEARCH LITERATURE

In reviewing the literature on disclosure in children, two major categories of articles emerged, research based and non-researched based. Since relatively little research has been written on this topic, some research on parental disclosure of the parents' HIV status to their children has been included. Although a wealth of research literature exists on the disclosure of other illnesses to children, such as cancer, these research studies are not included because of the unique nature of HIV infection.

Armistead, Tannenbaum, Forehand, Morse & Morse<sup>7</sup> conducted a descriptive study of 87 African-American HIV-infected



mothers with HIV-negative children. Using a variety of research tools such as the Physical Symptom Inventory (PSI), the Child Behavior Checklist (CBCL), and the Children's Depression Inventory (CDI) to measure internalized and externalized feelings and behaviors, the researchers concluded that non-disclosure seemed to be the norm for African-American families. Disclosure was more likely to occur in lower income families, when the mother is physically ill with symptoms, and when the child is older or is a female. Disclosure was not related to the mother's age, educational level, marital status, or stage of mother's illness (HIV infection versus AIDS).

Caliandro and Hughes<sup>8</sup> interviewed grandmothers who were primary caregivers of a grandchild who had HIV. Using phenomenological techniques, the researchers were interested in, among other things, the disclosure process. One of the themes that emerged from the study was living in the child-centered present. A sub-theme involved the secrecy of HIV infection. The secrecy involved not only keeping the diagnosis of HIV a secret from the child, but from others as well. The disclosure process and the secrecy surrounding HIV infection was a major source of stress for the grandmothers in the study.

Funk-Brentano, Costagliola, Seibel, Straub, Tardieu and Blanche<sup>9</sup> used both quantitative and qualitative techniques to study 35 HIV-infected French children. The majority of the parents in this study used secrecy to conceal the diagnosis from the child. This resulted in about one-third of the children feeling more healthy than they actually were. Almost 75% of the children reported stress related to their disease process, disease regulation, and the disclosure process.

Instone<sup>10</sup> conducted a qualitative research study with projective drawing interpretation of the perceptions of school age children with HIV about their illness. Twelve children and their guardians were studied, and the study revealed that diagnosis was concealed from children for a period of two to eight years. The study noted that concealing, pretending, and revealing the diagnosis all affected the child's psychosocial adjustment. Regardless of the child's knowledge of the diagnosis, interpretation of the drawings revealed that these children experienced severe emotional distress, disturbed self-image, and social isolation. Parents were not aware that the children were experiencing these issues.

Ledlie<sup>11</sup> conducted a grounded, substantive theory study of 18 families with children who were perinatally-infected with HIV. Only eight families had children who were aware of their diagnosis. A central theme emerged from this study was when the time comes, which means that families will disclose the child's diagnosis when the family is emotionally-ready to disclose. This theme consisted of intervening conditions (such as the child's age), the child's understanding of the illness, the child's growing awareness of the illness, the child's reaction to the diagnosis, developmental issues, family secrets, medications, reactions of others, and reactions of health care providers. This study is vital in understanding this complex issue because it lays the groundwork for nursing interventions to be developed from this theory.

Lee and Rotheram-Borus<sup>12</sup> studied 307 families with HIV with adolescents. Using a randomized, controlled intervention

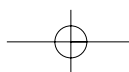
study with a longitudinal design, the researchers concluded that parents are more likely to disclose to older children; mothers disclosed more than fathers; parents disclosed more to boys than girls; disclosure occurs more frequently in the presence of poor health, increased stress, increased social support, and when stigma and problematic coping is present. No differences were found in disclosure in regard to ethnicity, socioeconomic status, self-esteem or mental health.

Nehring, Lashly, and Kay<sup>13</sup> conducted a descriptive, qualitative nursing study to identify whom biological and foster mothers disclose the diagnosis of HIV. Three themes emerged from the study including telling for support, determining who should know, and telling children. Telling children involved the child with HIV, siblings, and foster siblings. This study revealed that a continuum existed in disclosure of illness, ranging from no disclosure to partial to full disclosure. Included in the continuum was deception, or lying to the child about his/her HIV status. Deception included telling the child that he/she had a different, more acceptable diagnosis. The majority of participants did disclose at the age-appropriate time, but the study points out that further research is needed in the area involving the lack of disclosure by dishonesty, as it has the potential for affecting the parent-child relationship.

Pilowsky, Sohler and Susser<sup>14</sup> studied 29 mothers with HIV/AIDS residing in New York City. Using the Parent Disclosure Interview (PDI), 17 of the 29 mothers did not tell any of their children of the mother's HIV infection. The study found that disclosure is more common with older children. Of the mothers who did disclose to their children, they did so because of the child's right to know or because of the mother's declining health. Of the mothers who did not disclose, the majority of these chose not to disclose because of the age of the child.

Silver and Bauman<sup>15</sup> studied 157 African-American and Hispanic mother with HIV living in New York City. The mothers all had at least one uninfected child. The researchers wanted to find if the mother's disclosure of her HIV status had an effect on anxiety scores of the child. The researchers found that the children in the study had lower anxiety scores than average anxiety scores for children their age. Although over a third of the children in the study did had no knowledge of their mother's illness, an analysis of variance (ANOVA) showed no differences in scores for those who were disclosed, those who were partially-disclosed, and those who had no knowledge of their mother's illness. An analysis of covariance (ANCOVA) did reveal, however, that children who were aware of the diagnosis were less anxious when controlling for the health status of the mother.

From the available research knowledge base of this topic a few summary assumptions about disclosure to perinatally-infected children can be noted. First, disclosure of the diagnosis of HIV-infection is a stressful process for the child's caregiver. Second, the diagnosis of HIV is often concealed from the child in an attempt to decrease the child's anxiety. Concealing this diagnosis often creates stressors for the child. Third, there are distinct time periods during the child's life when caregivers are more likely to disclose HIV status to the child, and/or may be more



likely to disclose to the child with encouragement and support by healthcare professionals.

## Two Sides of a Complex Issue

### RESPECTING THE WISHES OF THE PARENTS

Probably the strongest argument for respecting the wishes of the parents involves the rights of children in general and the rights of children in regard to health care. Legally, since children less than 18 years of age can not make any decisions for themselves, children must depend upon their parents to make decisions for them. When examining the concept of the rights of children in regard to healthcare, four distinct arguments exist regarding this issue. The first is that children have no rights as they are the property of their parents, and must depend on their parents to make decisions for them. Second, children only have the right to have their psychological and physiological needs met, but have no rights concerning decision-making in health care. Third, children do have rights, but they are limited based on the child's ability to make a competent decision regarding health care. Lastly, children have full rights that are equal with the rights of adults<sup>16</sup>.

Since children are under the care of their parents, it makes sense that parents would have their best interests in mind, and would make decisions for them based on this. Parents are given autonomy by the legal system to make decisions for their children. Since parents have been given this right by law, parents should be the ones to decide when and how the child's diagnosis of HIV will be disclosed to them.

Dependency issues also are a factor that need to be considered in this issue. As discussed previously with the concepts of children's rights, children are dependent on their parents in all aspects of their lives. If children do not have a responsible adult to make decisions for them, the legal system often appoints a guardian *ad litem* to make decisions for the child. Intricately involved in dependency is informed consent, as children can not give permission for surgery, admissions to hospitals, etc. Therefore, since the child is completely dependent on the parent for decision-making and informed consent, the parents have the final decision-making authority regarding their child.

Parents should have the right to decide when their children find out about the child's HIV diagnosis based on certain aspects of rights-based ethics. Rights-based ethics states that individuals have the right to minimum suffering and maximum freedom of choice. Individuals should have the right to freely choose among options and the right to exercise options. Allowing parents to decide when to disclose to their child is consistent with rights-based ethics.

Allowing parents to decide when to disclose to their children is also consistent with duty-based ethics. Duty-based ethics states that humans have the duty to promote good will at all times. The intentions to do good is more important than actually doing good.

Since the parents may conceal the diagnosis from the child to prevent psychological harm to the child, as long as they have intentions to do good, they are within the constraints of duty-based ethics.

Certain aspects of virtue-based ethics are also important to consider with this issue. Virtue-based ethics is supported by two concepts, objectivism and paternalism. Objectivism is the belief that those in power should not decide what is the best action for another, as all individuals should be free to make their own decisions. Paternalism is when those in power make decisions for others because of the knowledge, wisdom, or rationality of the person in power. When health care professionals disclose to a child against the wishes of the parent, objectivism is violated and the parent is subjected to a paternalistic decision of the health care provider. This violates the concept of virtue-based ethics. Paternalism has been the dominant model in medicine, as the provider feels that the knowledge of health care that the provider possesses surpasses that of the client. In an attempt to make the best possible options for the client, the health care provider makes the majority of decisions regarding health care for the client. This model has been changing recently, however, as a more educated consumer, insurance companies, and a change in attitudes among health care providers have caused a paradigm shift. Clients and families are now viewed as equal partners in health care decision making (17), and should always be included in the decision-making process. To disclose against the wishes of the parents violates their ability to make decisions for their child.

### DISCLOSING AGAINST THE WISHES OF THE PARENT

Parents who are reluctant or who refuse to disclose the diagnosis of HIV to their HIV-infected child at an appropriate time violate certain ethical principles, namely beneficence, autonomy, and veracity. Beneficence is producing good and avoiding harm, or maleficence. In Nursing care terms, good and harm include social, psychological, economic, and religious aspects. Promoting good and minimizing harm includes consideration of the benefits to all involved in the issue, in this case, the parent and the child. The parent who is unwilling to disclose may be producing harm by choosing not to disclose the diagnosis to the child in various ways (18). First, trust in the parent-child relationship may be damaged if the child feels that the parent deliberately deceived him/her in concealing the diagnosis. Secondly, harm can result to others if the child engages in unprotected sexual intercourse and infects another because of the lack of knowledge of the HIV diagnosis<sup>19</sup>.

The principle of autonomy states that individuals should be offered the freedom to participate in decision-making regarding their lives based on personal choices regardless of the outcome of the choices. Children who do not know their diagnosis can not be fully autonomous, as they are not aware of their diagnosis. Being unaware of the diagnosis does not allow the child to make fully-informed decisions regarding health care<sup>18</sup>. Since the child is not

aware of the diagnosis, and may not understand why he/she is required to adhere to a complex medication regimen, the child may refuse to take the medications without understanding the consequences of non-adherence to antiretroviral therapy. A child who is disclosed at an age-appropriate time can participate in decision-making as an equal partner with the parent and health care provider. Participation in this decision-making is an important developmental milestone that will eventually lead to the child's independence from the parent in the transition to adulthood.

Veracity, or truth-telling, is also violated when a parent conceals the child's diagnosis. Veracity is violated in not disclosing the diagnosis to the child, lying to the child, or concealing from the child his/her diagnosis. Those incompetent to make decisions for themselves in the eyes of the law must have an appointed person to make decisions for them. In the case of children, this is their parent or guardian<sup>18</sup>. The PNP could potentially encounter a difficult, unique situation if the parent or guardian asks the PNP to assist in concealing the diagnosis disclosure from the child.

A few philosophical considerations exist that impact the complex issue of disclosure. The first is the topic of biological versus biographical life. Biological life includes all living organisms, including humans, and their anatomical and physiological processes. What differentiates humans from merely existing as a biological organism is the fact that humans possess a purposeful consciousness that includes hopes, frustrations, and expectations for the future. This purposeful consciousness constitutes a biographical existence. Although the concept of biological versus biographical life has been used largely to determine which person would receive scarce, or rationed medical services<sup>20</sup>, it has utility for use with the concept of disclosure. Since children with normal and even slightly subnormal intelligence can have hopes and expectations for the future, children should be viewed as biographical organisms like adults. To deny a child the right to know his/her diagnosis and to make choices and plan for the future would indicate that the child is less than a biographical organism, and not at the same level of development as adults.

Earlier it was discussed that parents are given the legal right to make decisions on behalf of their children. One can not examine this issue unless legal implications are considered. A thorough analysis of the legal aspects of HIV is beyond the scope of this paper, however, it is important to briefly address this issue. Laws regarding HIV/AIDS vary by state in the United States, and by country internationally. In Florida, the AIDS Omnibus Act protects the health care provider who upholds the family's decision not to disclose the diagnosis to the child<sup>21</sup>. The Florida AIDS Omnibus act is currently in the process of being challenged in the Florida courts. The prosecution of this case is pursuing changes that will make health care providers more accountable in disclosing the diagnosis to the child, despite the parent's desire not to disclose the diagnosis<sup>22</sup>. In cases where there is a subjected medical neglect on the part of the parents (such as parents refusing to administer antiretroviral medications to the child), health care providers must report this immediately to the state's child protective services division.

## USING ETHICS TO DEVELOP A POSITION STATEMENT ON THIS ISSUE

Ethical principles should be utilized to guide the PNP to develop a position on disclosure of diagnosis to HIV-infected children when parents are reluctant to or who refuse to disclose the diagnosis to the child. In addition to the ethical principles discussed in the previous section, justice-based ethics, virtue-based ethics, rights-based ethics, duty-based ethics, and virtue-based ethics will be used to develop a position statement on this complex issue.

Although justice-based ethics is not completely applicable to this issue, a small portion of the concept is important to discuss. Justice-based ethics is concerned with what services are due to the client<sup>23</sup>. In this case, the client is both the parent and the child. The child is due an honest explanation of his/her condition and required treatment. To conceal the diagnosis does not allow the child to fully participate in care and to receive the full services due. Most children/adolescents who know their diagnosis can participate in support groups and network openly with other children/adolescents with the same condition. In addition, if the child is having difficulty in dealing with the diagnosis, the child can be referred for psychological counseling. If the child does not know the diagnosis, these services are not available to the child.

One of the PNP's priorities in this difficult issue is the potential independence of the child. To develop this independence in children, children should be encouraged to participate in their health care when they are developmentally-ready to participate. A child who is fully aware of his/her HIV status is free to partner with the family and PNP in planning and implementing his/her health care plan. This planning, implementation, and participation in care and decision-making can not occur unless the child is fully disclosed of his/her HIV status.

Rights-based ethics involves the right to minimum suffering with maximum freedom of choice, allowing the client to freely choose among alternatives and to exercise options<sup>16</sup>. Concealing the diagnosis from the child violates his/her rights to minimum suffering with maximum freedom of choice. Not knowing the diagnosis could result in stress for the child<sup>9, 10, 15</sup> in numerous ways. One of these is fantasizing about the illness. A child who does not know his/her diagnosis often fantasizes about the illness, which often results in increased anxiety for the child. Most children report less anxiety after they are told of their diagnosis<sup>15</sup>. As mentioned previously, concealing the diagnosis does not allow the child to choose among options, mainly whether to become compliant with a medication regimen, which will maintain his/her life.

Duty-based ethics promote good with good intentions and truth-telling, and to promote the greatest good for the greatest number. Concealing the diagnosis from a child or lying about the diagnosis violates truth-telling. Concealing the diagnosis does not promote the greatest good for the greatest number. Being fully informed of the diagnosis not only benefits the child, but the healthcare team as well. Once the child has been fully-disclosed, healthcare team members can engage in more open dia-

logue with the child. Since disclosure will benefit both the child and healthcare team, the only person who would not benefit would be the parents. In this case, disclosure is the right choice because it promotes good for the greatest number.

Another component of duty-based ethics is obligations. The PNP has certain obligations to the client. Since the PNP is aware of the child's diagnosis and is aware of the positive aspects of disclosure, the PNP has an obligation to ensure that the child is aware of his/her diagnosis. The obligations of the child override the obligations to the parent with this issue, as it is the child who stands to be harmed by not knowing his/her diagnosis than the parents.

Virtue-based ethics also need to be considered with this issue. Virtue-based ethics has at its core the belief that people ought to act in ways that produce good and reduce harm. This means that altruism and objectivism need to be incorporated into this process. Altruism is treating others the way that one would ideally like to be treated<sup>16</sup>. Failure to disclose the diagnosis to the child has the potential of producing more harm than good. In addition to the reasons already discussed, a huge concern involves the transmission of HIV infection. A child/adolescent who is not aware of his/her infection status and who engages in sexual activity has the potential of infecting others, and has the potential of contracting sexually-transmitted diseases from sexual partners. If the child/adolescent is fully aware of the diagnosis, steps can be taken to reduce the risk of infecting others and contracting a sexually-transmitted disease. Altruistically, the PNP can argue that, put in a similar situation as the child, the PNP would want to be treated a certain way. This includes being informed of the diagnosis.

## WHAT SHOULD WE DO?

Based on the ethical principles, PNP's should adopt a stance that support disclosure at a certain point in the child/adolescent's life. Disclosure of HIV status is a stressful experience for the parent, child, and the healthcare provider who performs the disclosure. Disclosure, therefore, needs to occur as a process. The authors believe that this process begins at diagnosis. Many children are diagnosed with HIV-infection during the first year of life. Of course, at this point, the child can not understand his/her diagnosis, but the process can begin with the PNP informing the parents after diagnosis that at some point as the child approaches adolescence, it will be important to inform the child of his/her diagnosis. Yearly until the child reaches pre-adolescence, the family should be reminded of their obligation to disclose the diagnosis to the child.

As the HIV-infected child approaches age 10 or 11, an intensive effort by the health care team should be in place to fully disclose to the child. The first step in this process is to review the results of the neuro-developmental evaluation that is conducted by child psychology. This evaluation will determine the child's developmental functioning and will note any neurological deficits or emotional problems. Once the exam is determined

age-appropriate, the psychologist and the PNP can meet with the parents to discuss the exam results and to discuss the need for disclosure.

If the parents are reluctant or refuse to disclose, a multidisciplinary ethics team should be convened immediately to discuss the disclosure process. A team conference provides an excellent opportunity for the team to informally assess the parents' psychological functioning and thought processes. Perhaps the parents are reluctant to disclose because of a mental health disorder or cognitive decline of the parent. With these disorders, it may be possible that the parent is unable to make a rational decision regarding disclosure or any other aspect of the child's care. If this is suspected, an immediate referral to child protective services would be essential to ensure that the child is residing in a safe environment.

The team would be comprised of a social worker, child psychologist, PNP, RN, and the child's parents. The first intervention of the team is to review with the parents the benefits and harms of disclosure. It should be discussed at length in simple, non-medical terminology why it would be more beneficial than harmful for the child to know his/her diagnosis. Research studies could be summarized and presented to the parents, along with anecdotal evidence of past disclosures of other children and families. Social benefits and harms of disclosure, normal adolescent growth and development (including sexual exploration and other risk-taking behaviors) should be discussed. State mandates on disclosure of HIV-status to sex partners needs to be discussed explicitly with the parents. The team should stress the importance of the child knowing his/her diagnosis so that when he/she becomes sexually-active, steps can be taken to prevent transmission of HIV to others. It should be stressed to parents that they are the ultimate decision-maker for the child, but if the team feels that the child could be harmed or could harm others by not knowing his/her diagnosis, a referral to child protective services may be warranted.

A discussion of the family's social situation and cultural issues should also be addressed. Perhaps the parents are reluctant to disclose because of an unstable social environment, and the disclosure may aggravate the situation. The team can develop interventions with the family that are culturally-sensitive and acceptable to the family.

The team must also assess the parents' beliefs and knowledge of HIV. Even today, many deny that they are HIV-infected, and deny that they have transmitted this illness to their children. If parents are experiencing denial, this requires intensive psychological and educational intervention to help the parents overcome this dysfunctional coping strategy.

Lastly, the team should make every effort to understand why the parents are refusing to disclose to the child. An in-depth assessment of their decision must be made to ensure that they fully understand the issues and the consequences of their decision.

Despite the team approach, many family may still refuse to disclose the child's diagnosis. The team has two options at this point: to support the family's decision and continue to encourage

disclosure, or to challenge the family's decision via the legal system with child protective services assistance<sup>24</sup>. At this point in the process, the hospital's ethics committee should also be consulted regarding this case.

At this point if the family refuses to disclose to the child despite the intense education that was provided via the family conference, this author recommends the child protective services should be consulted to intercede on behalf of the child. Since the child need to be disclosed overrides the need of the parent to conceal the diagnosis, this author feels that the healthcare team has the right to ensure that the child is fully informed and aware of his/her condition. Consulting with child protective services is one method to ensure that the healthcare team is compliant with legal requirements, and it also provides an objective opinion of the case. Perhaps the healthcare provider is too emotionally-tied to the issue and can not appreciate the parents' concern. Child protective services provides that objective view of the situation, and child protective services will be the ultimate decision-maker in the case.

In addition to the situations described previously, the team has the option of referring the case to child protective services for a variety of reasons. These include, but are not limited to, when a child is asking his/her diagnosis but the family refuses to provide the information or lies to the child; when there is evidence that the child is sexually-active; or when the child has a behavior change such as depression or anxiety; when the child and family refuse to take antiretroviral therapy to control HIV infection<sup>19</sup>.

In summary, the PNP has the obligation to protect the child at all costs. By supporting the disclosure of the diagnosis to the HIV-infected child, the PNP is advocating for the child and ultimately what is in the best interest of the child.

## OUTCOME OF THE CASE STUDY

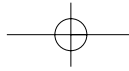
Even though Tommy's grandparents were reluctant to disclose the diagnosis, Tommy was notified of his HIV-status during a hospitalization for diabetes. During the hospitalization, the grandparents were again approached by the health care team. The grandparents gave their consent for Tommy to be informed of his diagnosis. Tommy was quiet during the disclosure, and when asked how he felt upon hearing the news, he replied, "I knew what I had. I looked my medicines up on the internet." Tommy probably maintained his silence to protect his grandparents. Tommy continues to do well to date, and because of his grandparents' devotion and attention to his medical needs, Tommy has an undetectable viral load (less than 200 copies per millimeter of blood) since diagnosis. Because Tommy's grandparents were continually encouraged to disclose his diagnosis, damage to the relationship between the family and health care providers did not occur.

## SUMMARY

Disclosure of diagnosis to an HIV-infected child is a difficult issue for health care providers and for parents. Not every disclosure will occur as smoothly as Tommy's. In fact, many times the relationship and trust between the family and health care providers may be strained or damaged because of this issue. Each institution that provides care for HIV-infected children should have a protocol in place for handling this complex issue. Although a variety of other factors besides ethics need to be considered when tackling this complex issue, ethics provide a starting point for grappling with the issue. As professionals providing care to children, it is important that the best interest of the child is the center of the decision-making process.

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**Correspondence:****JOSEPH DE SANTIS**

Jackson Health System in Miami, Florida.

300 NW 42nd Ave. # 211

Miami, Fl. 33126

E-mail: [jdesantismiami@aol.com](mailto:jdesantismiami@aol.com)

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