

## **Disclosure and Assent in Pediatric HIV**

A Thesis submitted to the University Of Arizona College of Medicine Phoenix  
in partial fulfillment of the requirements for the Degree of Doctor of Medicine

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## **DEDICATIONS**

I would like to dedicate this to my family and the many friends who have provided unbending support for me throughout my medical school career.

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## **ABSTRACT**

The purpose of this study was to examine health care providers' experiences regarding the processes of disclosure and assent in pediatric HIV/AIDS patients. The study population included providers who were involved with the care of pediatric HIV/AIDS. A survey was distributed through email and asked questions to explore provider demographics, the average age of assent to treatment and research, the average age of disclosure of HIV, what factors determine the age of disclosure, barriers to disclosure, provider opinions, and provider perceptions of conflict within the disclosure process. While results showed that there are wide variations among individual patients and providers, most providers agree that disclosure should occur in older school age children (between ages 6-10 years), which is also the time that they typically are able to assent to treatment and clinical trials. Providers often agreed that there is a conflict between the ages of disclosure and assent. Parental concerns (fear of stigma, inappropriate disclosure, and personal guilt) were most often the reason for delays in the disclosure process. The disclosure process was felt to be most effective when done in a step-wise manner that includes multiple practitioners and counseling with families.

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## 1. INTRODUCTION/SIGNIFICANCE

### Background

Informed consent can be complicated in pediatrics, as the person with whom the legal authority lies is not the patient. By definition, informed consent can only exist when patients have “both appropriate decisional capacity and legal empowerment,” so in most cases, children possess no legal decision making authority.<sup>1</sup> The American Academy of Pediatrics states in its guidelines on pediatric assent that child patients should be able to *participate* in medical decision making according to their development level, and they should be able to provide assent when reasonable. When children participate in medical decision-making, the disclosure process benefits the patient and the physician-patient relationship. The CAAP Committee on Bioethics definition for disclosure will be used for this study. This committee defined disclosure as giving the child patient a developmentally appropriate explanation of the disease process and the need for treatment. Assent is understood as the process by which children participate in their treatment. Parental permission is both encouraged and legally required in most cases, but the focus must be the provision of the best care possible for the patient. Therefore, the basic model for medical decision making in pediatric populations is that parents or surrogates provide informed permission which then leads to the child’s assent.

According to the Committee on Bioethics report in 1995, proper informed consent in clinical care should include 4 steps<sup>1</sup>. These steps are as follows:

1. Helping the patient achieve a developmentally appropriate awareness of the nature of his or her condition.
2. Telling the patient what he or she can expect with tests or treatment
3. Making a clinical assessment of the patient’s understanding of the situation and the factors influencing how he or she is responding (including whether there is inappropriate pressure to accept testing or therapy)
4. Soliciting an expression of the patient’s willingness to accept proposed care.

The age at which most children should be able to assent to both their own treatment and to clinical trials is suggested to be 7-8 years, or older school age children.<sup>1,2</sup> The first part of the assent process is for the patient to have a developmentally appropriate awareness of the nature of his or her condition. This implies that a physician has a moral and ethical obligation to discuss health and illness with the child patient.<sup>2</sup> In addition, the physician–child patient relationship is stronger when the physician is able to be open and honest with the child. Pediatric health care often improves when the child is involved, and allowing a child to assume the role of health partner leads to better rapport and understanding of (and possibly adherence to) the medication regimen.<sup>2</sup>

Despite the guidelines on assent, sometimes parents are hesitant to disclose a child’s medical condition to them. In cases where children are not made aware of their diagnosis, this often does not prevent the young patient’s understanding of their prognosis. In the Bluebond-Langner study, terminally ill children as young as 3 were aware of their diagnosis and prognosis without ever being told.<sup>3</sup> Children who are deliberately kept in the dark about difficult information often feel isolated and attempt to “protect the adult.” As a result, both parties end up hurt by the secrecy.<sup>2</sup>

When it pertains to clinical research, children should be offered the opportunity to participate. In these cases, older school age children are often required to give assent before proceeding. If the definition of assent is understood as the child having a developmentally appropriate understanding of their illness and agreeing to participate in treatment or research, then children would not technically be able to assent without disclosure of their disease. Capacity and authority are also required to consent to legally medical treatment, and while older children (identified in this article as 9 and older) have the capacity, they do not have the authority, leading to informed assent rather than consent.<sup>4</sup>

Some unique problems arise with disclosure of the diagnosis of HIV/AIDS, mostly due to the stigma that surrounds the disease. The process of disclosure to and respect for autonomy of a child patient must be weighed against the concept of protection for the patient and patient’s family. The stigma associated with HIV infection leads people to believe they are protecting

their child by not divulging their diagnosis. Families fear negative circumstances when a child will tell a friend or a teacher their diagnosis and then experience being treated differently out of misunderstanding of the disease. In the attempt to avoid these consequences by delaying disclosure, parents run the risk of denying their child's rights to participate in medical decisions impacting their care. This contradiction between law and ethics has led to a practice where cases are addressed on an individual basis, without clear guidelines.<sup>5</sup> This gray area can potentially lead to ethical conflicts between physicians, hospitals, patients, and even legal authorities.

Since patients with HIV/AIDS and their families have the right to privacy, but minor patients also have the right to participate in their medical decisions, specific procedures must be involved to ensure the family's privacy is protected when disclosure happens. In addition, some caregiver decisions must be made regarding how to determine decisional capacity, as age alone will not allow for developmental and cultural differences. Age has been the parameter used most frequently in the past, and may be the best practical guideline in use currently, but this is an imperfect system due to developmental and maturity variability among children of the same age. If age is used as a benchmark, ethicists have agreed around the age of seven years for pediatric assent, but this will vary based on the status of the individual child-patient.<sup>1</sup>

The concept of death is something that may arise when discussing HIV/AIDS, particularly in children who have lost family members to the disease, or are becoming non-compliant with their treatment. The nature of the disease is also a key area of discussion that may arise with young HIV/AIDS patients. While many physicians give the name of the disease to older children and adolescents, younger children are often told they have "an infection in their blood," or simply that they are sick and need medication. The AAP suggests that younger children do not necessarily need to know their diagnosis, but should know about their illness if symptomatic, and furthermore strongly encourages disclosure of HIV status to school age children.<sup>6</sup> Disclosure of an illness can be an important step in the treatment process, but it is a complex issue that must be individualized to the child.

There are many benefits to disclosure, and some negative outcomes for non-disclosure. Respecting a parent's decision for non-disclosure may cause the child-patient/doctor relationship to decline. Children for the most part want to be informed, and secrets can lead to personal distress for both the child and the parent.<sup>4</sup> For children with chronic disease, medication adherence may be closely tied to understanding of the disease, and children often understand more about their condition than parents and their medical team tell them anyway.<sup>4</sup>

When it comes to risks of disclosure, there are several fears that parents and physicians may hold. Physicians fear that a poor attitude could affect their patient's treatment, and parents often think their child's mental health will worsen when they learn difficult news, but this has been seen as typically untrue.<sup>7</sup> Parents are often also scared of the stigma from the community, and fear that the child will not be able to keep the secret. Since the secret may affect multiple family members, as the parents or siblings are often HIV positive themselves, the issue is further complicated.<sup>7</sup> Finally, parents often hide the diagnosis out of guilt that they were the ones to transmit their disease to the child. In addition, the results of disclosure to a child may vary based on cultural norms, and may in fact lead to more harm than good in unique situations.

One idea that providers as a group generally support is anticipatory dialogue, as speaking with the parents and children early on about issues that may arise later can help ease the process of decision making about disclosure when the child is old enough. The AAP suggests that parents should be counseled and the process for disclosure discussed, potentially multiple times, before it takes place. Parents and physicians should also be prepared for a change in circumstances, such as with clinical status, as an older hospitalized patient has a high chance of learning his or her status from health care workers or personal visitors during an inpatient stay.<sup>6</sup> Most current articles on the ethics pertaining to assent and disclosure suggest that in extreme cases where a conflict is insurmountable by the physician and parents, an ethics committee should be utilized.<sup>4</sup>

## Impact

Primary studies have been limited regarding this particular issue surrounding HIV, and in the recent years have primarily come out of resource-limited areas that may not be relevant to the population in the United States. In one study based in Western Kenya, qualitative analysis of interviews showed that caregivers felt that disclosure had benefits such as improved ART adherence and social support in addition to negative psychological side effects on the children and discriminatory effects for the entire family.<sup>8</sup> Studies like this are enlightening and draw comparisons to what is reported by families in the United States, but are also carried out in a very different cultural landscape and may not be applicable in the setting of a United States HIV/AIDS clinic. One study performed in the United States is a longitudinal analysis based on data from the Pediatric AIDS Clinical trial group which examined the age of disclosure and the pre-disclosure and post-disclosure impact on quality of life scores. These researchers found no significant change in quality of life post-disclosure. However, this study did not look further into the disclosure process.<sup>9</sup> The current AAP guidelines do not address a potential conflict between assent and disclosure, and as can be expected in many aspects of bioethics, leave much room for interpretation. Given the lack of primary research surrounding the issue of HIV/AIDS, we designed a study to address not only how disclosure occurs, but how clinicians feel about many aspects of the disclosure process. We focused primarily on tensions surrounding the right to assent and a parent's right to delay disclosure.

## **Aims**

The purpose of this study was to describe how clinicians approach and experience assent and disclosure in HIV and to determine if the age and role of provider is related to preferred age of disclosure. This study explored how practitioners view a pediatric patient's right to informed assent and the parent's right to delay disclosure of diagnosis. Specifically we aimed to:

- a. Describe the process of disclosure.
  - i. When does disclosure and assent occur?
  - ii. Who is involved (providers and family)?
  - iii. Where does disclosure occur?
- b. Describe barriers/reasons for postponement, issues related to disclosure and provider techniques for assisting families with disclosure.
- c. Describe treatment changes in response to the developmental appropriateness of a child's understanding of his/her disease.
- d. Describe attitudes about disclosure and disclosure outcomes.
- e. Describe practitioners' awareness of inadvertent disclosures to children.
- f. Test the hypothesis that practitioner demographic variables (age, profession, and size and setting of clinic) are related to attitudes toward disclosure.

## **Hypothesis**

Based on current ethical guidelines about assent and disclosure, children should be able to know their diagnosis in developmentally appropriate settings. Physicians should use, and likely already support anticipatory dialogue. Bioethics committees may also be utilized when necessary in times of conflict between providers and the parents. In the very rare case of complete disagreement, the physician or provider must recall that his or her primary duty is to the child patient and work to create a solution that will be in the child's best interest. We hypothesized that providers would be similar in the desire to disclose HIV status before assenting to studies and treatment, and that older school age (7-9) would be the age at which most providers preferred to disclose the name HIV/AIDS. We also hypothesized that providers

would in general support anticipatory guidance and that there would be wide variation in techniques and preferences regarding disclosure.

## **2. RESEARCH MATERIALS AND METHODS**

### **Setting of the Project**

This project was based in Phoenix, Arizona at the Bill Holt Pediatric HIV Clinic at Phoenix Children's Hospital. A survey was sent out to 200 clinicians involved in the care of pediatric HIV patients in the United States. The survey was sent out electronically through SurveyMonkey.com to keep costs and the need for physical resources low.

### **Procedures involved in the project**

The survey specifically addressed the aims described above and was designed after careful literature review of research involving pediatric disclosure and assent. It was carefully evaluated to map specific questions to the aims we had described, was evaluated by two pediatric HIV experts and the Scientific Review Committee from Phoenix Children's Hospital and subsequently revised to address recommendations from both groups. The study was ultimately approved by the Phoenix Children's Hospital Institutional Review Board. Once the approval was obtained and the questions were considered complete, the survey was formatted into SurveyMonkey.com to prepare for distribution.

*The survey questions were mapped to the specific aims as outlined below:*

1. Describe the process of disclosure.
  - i. When does disclosure and assent occur?
    - a. Questions 8-9, 16
  - ii. Who is involved (providers and family)?
    - a. Questions 20,22
  - iii. Where does disclosure occur?
    - a. Question 21
2. Describe barriers/reasons for postponement, issues related to disclosure and provider techniques for assisting families with disclosure.
  - i. Questions 17,18, 19, 27, 28

3. Describe treatment changes in response to the developmental appropriateness of a child's understanding of his/her disease.
  - i. Question 14
4. Describe attitudes about disclosure and disclosure outcomes.
  - i. Questions 10,11, 12, 13, 24, 25, 26
5. Describe practitioners' awareness of inadvertent disclosures to children.
  - i. Question 23
6. Test the hypothesis that practitioner demographic variables (age, profession, and size and setting of clinic) are related to attitudes toward disclosure.
  - i. Questions 1-5, questions 10,11, 12, 13, 25,26

The survey link was emailed to pediatric HIV care providers. The email addresses were obtained through internet search engines (obtaining contact information directly from hospital and clinic web sites) and Ryan White funded HIV clinics that provided pediatric care. The link was not email address specific as to allow for a snowball effect where appropriate (asking participants to send the study information and survey link to other providers of pediatric HIV care they know). The email was sent to approximately 200 email addresses. We allowed more than one provider per clinic in order to gain a variety of perspectives from different members of the health care team. To facilitate responses, a reminder email was sent three weeks after the initial survey invitation.

## Methods of analysis

Once the survey was closed, the data was exported from SurveyMonkey into Microsoft Excel, and then formatted into SPSS. Survey results were analyzed using the frequencies procedures to determine mean, median, and mode. Cross-tabs were subsequently used to examine relationships. Details of how the analysis was carried out are stated below.

1. Describe the process of disclosure.

i. When does disclosure and assent occur?

Frequencies were used to identify the most common age of disclosure of disease, including when the name HIV/AIDS is used, and the age of the oldest patient the provider had that was unaware of the disease. (Questions 8-9, 16)

ii. Who is involved (providers and family)?

Frequency counts were used to determine what practitioners are often involved (question 22), and the preparation involved before the actual disclosure (question 20). Crosstabs were then used to define relationships between which providers participate and how they carry out the disclosure process (question 19, 20, 22).

iii. Where does disclosure occur?

Frequency counts were used to determine where the disclosure most often takes place (question 21).

iv. Describe barriers/reasons for postponement, issues related to disclosure, and provider techniques for assisting families with disclosure.

Mean and median were used to analyze the most common responses to why practitioners postpone disclosure (question 17), the common reasons parents give for delaying disclosure (question 18), in addition to the most common methods used to determine if a child is developmentally competent for disclosure (question 19). Questions 27 and 28 will be analyzed as free-text comments; any common themes will be further explored as detailed below (item number 4).

Frequency counts (mean and median) were used to look at how often ethics committees are involved (question 24). Cross-tabs were then used to evaluate the responses that involved ethics committees (there were 4 positive answers) to see if there were any relationships to the variables mentioned above, such as profession of providers (question 22), the age of the patient at disclosure (questions 7,8), and parental reasons given to providers for delaying disclosure (question 18).

2. Describe treatment changes in response to a developmental appropriateness of a child's understand of his/her disease.
  - i. Frequencies were used to analyze mean, median, and mode regarding how providers feel disclosure affects their treatment plans (question 14) and any changes that may arise due to a child's understanding of the disease.
3. Describe attitudes about disclosure and disclosure outcomes.
  - i. Mean and median were used to analyze age of assent to research studies and treatment (questions 6, 7), in addition to provider preference of age of disclosure (question 10), and providers perception of discrepancy between age of disclosure and age of assent (question 10).
  - ii. Frequency counts were used to analyze how providers feel disclosure affects children (questions 12, 13), and how often providers feel that a conflict arises (question 10).
4. Describe practitioners' awareness of inadvertent disclosures to children.
  - i. Frequency counts will be used to analyze how often providers report inadvertent disclosures to children (question 23).
5. Test the hypothesis that demographic variables are related to practitioner attitudes toward disclosure.
  - i. Frequencies were used to look at demographic information of the providers who completed the survey. Cross tabs were then used to evaluate relationships between the pre-survey demographic information(type of provider, size of clinic, age of provider)(questions 1-5) and provider opinion on appropriate age for disclosure, changes made to treatment plans based on disclosure, and what

physicians feel are benefits and harms of disclosure seen in their respective practices. (questions 10,11,12,13,25,26)

Comments made by respondents were examined to understand the problems that physicians and their multidisciplinary health care teams are addressing. Content analysis was used to analyze the narrative comments throughout the survey.<sup>10</sup> This process involved transferring narrative comments to a word file. The files were reviewed and common themes were picked out and major categories determined. Definitions of the major categories were developed. Then phrases and sentences were coded or classified according to the major themes and categories. An independent coder utilized the definitions of the categories to recode the data. Discrepancies were discussed and resolved.

### **3. RESULTS:**

#### **Survey population demographics**

The demographics of survey responders are as follows. Forty-six providers (23%) of the 200 people emailed the link started the survey and completed the demographics information, and 36 (18%) people answered every question and completed the survey in full. The number of pediatric HIV/AIDS patients in the practice of the providers was most commonly 20-50 patients (43.5%, n=20) or 50-150 patients (41.3%,n=19). Approximately 11% of the providers saw less than 20 pediatric HIV/AIDS patients, with 4.3% seeing over 300. As for the setting of the clinic, 82.6% (n = 38) of providers reported working in a large city. Fifteen percent (n = 7) of providers worked in small cities, 2.2% in suburban settings, and no respondents were in rural settings.

Physicians were the most common survey responders (n = 31, 67.4%). The composition of respondents was as following: 17.4% (n = 8) were social workers, 8.7% (n = 4) were mid-level providers and 6.5% (n = 3) were research coordinators. Free-text responses regarding clinic roles were significant for program directors. The ages of the survey responders varied. Of the responders, 65.2% (n = 30) were between 45 and 60 years. Approximately 24% (n = 11) were between 36 and 45 years of age, 8.7% (n = 4) were over 60 years, and 2.2% (n = 1) were between 26 and 35 years.

#### **SECTION A: DESCRIBE THE PROCESS OF DISCLOSURE**

##### *WHEN DOES DISCLOSURE OCCUR?*

The age at which disclosure most frequently occurs appears to be in older school age children, with the mean of respondents reporting giving developmentally appropriate understanding of the HIV/AIDS process status at an age between 6-7 and 8-10. The most common choice was 8-10 years, with 41.7% (n = 15) responding. The next most likely was 4-5 years (33.3 %, n=12) followed by 6-7 years (22.2%, n=8). Only 2.8% (n = 1) of providers felt that 13 and older was the average age for developmentally appropriate understanding.

The mean age when providers felt the name HIV/AIDS should be given to the child was lower than the age providers felt children had a developmental understanding of their disease state, closer to 6-7 years than to 8-10 years. Over half of the respondents said children were made aware of the name HIV/AIDS at 4-5 years (n = 20, 55.6%). Twenty-five percent (n = 9) responded with 8-10 years, followed by 13.9% (n = 5) at 13 years and over, and 5.6% (n = 2) at 6-7 years.

When providers were asked the oldest patient they had seen that was unaware of their status, almost half (n = 17, 47.2%) responded 13-15 years, while 30.6% (n = 11) selected 16 and over. However, 19.4% (n = 7) selected 4-5 years, none selected 6-7 years, and 2.8% (n=1) selected 8-10 years.

#### *WHO IS INVOLVED IN DISCLOSURE?*

Most providers responded that preliminary counseling was part of the disclosure process, with 83.3% (n = 30) stating that parents and providers work together to formulate the plan. Among providers, 2.8% (n = 1) also state that parents talked with providers and then carried disclosure out on their own. Approximately 11% (n = 5) stated it would vary from patient to patient. No one stated that preliminary counseling was not part of the process of disclosure.

Who is present during the actual disclosure seemed to vary widely among providers. Parents were the most common answer (n = 33, 71.7%). The next most likely were physicians and social workers at 60.9% (n = 28, n=28). Nurses were involved 50% of the time (n=23). Nutrition was not involved, and siblings only participated 4.3% (n = 2) of the time. A small number of responders (n = 12, 26.1%) stated other providers, which included mid-levels, child-life specialists, and psychologists.

When cross-tabs were used to look at the relationship between the providers who were present at the disclosure and if preliminary counseling was involved, there were no significant differences between providers present and the use of preliminary counseling (p-values ranged from .321 to 10.571, df=2). In addition, there were no significant differences among which

providers were present during disclosure and the location where disclosure took place (p-values ranged from .459 to 2.498, df=2). (Table 1)

#### *WHERE DOES DISCLOSURE OCCUR?*

Disclosure occurs in outpatient clinics 77.8% (n = 28) of the time. Precisely 19.4% (n=7) of respondents stated that disclosure occurs wherever families preferred, and 2.8% (n = 1) responded that it occurred in the hospital.

#### **SECTION B: BARRIERS TO DISCLOSURE**

When asked reasons why providers delayed disclosure, the most common answer was parental desire (n = 31, 67.4%). The next most common answer was that the child was not mature enough at 28.3% (n = 13), followed by stigma (n = 6, 13%), and cultural norms at 6.5% (n = 3). Thirteen percent (n = 7) of providers responded “other”, with the most common free-written answer being the “patient’s global developmental delay”.

According to providers, parents delay disclosure for the following reasons: fear that child will tell more people (n = 26, 56.5%), fear of community stigma (n = 25, 54.3%), personal guilt (n = 25 54.3%), fear of being asked by child how it occurred (n = 21, 45.7%), fear that the child will give up (n = 10, 21.7%), and cultural norms (n = 8, 6.5%). Other reasons (n = 6, 13%) included fear that the child will become depressed, parent perception that the child isn’t developmentally mature, and the fear of child blaming the parent.

When asked what methods were used to determine developmental competency for disclosure in a child with HIV/AIDS on a scale of importance (numerically valued 1-5), findings suggested that the most important was mental capabilities (M = 2.78, SD = 2.0), followed by grade level (M = 2.39, SD = .934), health status (M = 2.28, SD = 1.162), parental opinion (M = 2.11, SD = 1.617), individual health knowledge (M = 2.06, SD = 1.286), and the patient’s age (M = 2.0, SD = 1.309). The answers varied greatly among respondents, as 44.4% (n = 16) stated that mental capabilities were the most important, while 55.6% (n = 20) stated mental capabilities were not at all important. Grade level was somewhat important to 52.8% (n = 19) of respondents, most

important to 2.2% (n = 1) of respondents, not very important to 22.2% (n = 8), and not at all important to 22.2% (n = 8). Health status was not at all important to 38.9% (n = 14) of respondents, not very important to 5.6% (n = 2) of respondents, somewhat important to 50% (n = 18) of respondents, and the most important to 5.6% (n = 2). Parental opinion was not at all important to 63.9% (n = 23) of respondents, most important to 19.4% (n = 7), and then somewhat important to 16.7% (n = 6). Health knowledge was not at all important to 52.8% (n = 19) of responders, somewhat important (n = 12, 33.3%), the most important determinant to 8.3% (n = 3), and not very important to 5.6% (n = 2). Age was not all important to 58.3% (n = 21), followed by somewhat important to 33.3% (n = 12), and the most important to 8.3% (n = 3).

Eleven percent (n = 4) of providers have used an ethics committee in a conflict regarding disclosure, while 88.9% (n = 32) of respondents deny the use of an ethics committee. The free-text answers asking for details in this question are as follows:

- Another hospital disclosed a mother's HIV status to the state health department after she delivered a baby because they believed she was wrong in not telling her partner that she was HIV positive. We requested an Ethics Consult to discuss further.
- When the minor is over 13, and in situations of severe illness

Since only 4 participants responded to ever having used an ethics committee, cross-tabulations were not performed because there was not enough power to show any relationship between the use of an ethics committee and survey responders' demographics as originally planned.

### **SECTION C: TREATMENT CHANGES**

When providers were asked how they changed their treatment plans in response to the child being unaware of their status, 75% (n = 27) of respondents felt that they only changed their language. Precisely 19.4% of providers reported hesitation in allowing patients to enroll in research trials, and 5.6% (n = 2) reported hesitation in using more aggressive treatment.

## SECTION D: PROVIDER ATTITUDES

### AGE OF ASSENT, PERCEPTION OF CONFLICT:

When asked when patients first assent to research, the mean age reported was between 6-7 years and 8-10 years. The most common answer (n = 13, 36.1%) was 8-10 years, followed by 6-7 years (n = 10, 27.8%), 13 years and older (n = 7, 19.4%) and finally 4-5 years (n = 6, 16.7%).

In regards to assent to treatment, the mean age was much older (between 8-10 years and 11-12 years), as 47.2% (n = 17) stated 13 years and older, 19.4% (n = 7) stated 4-5 years, and 6-7 years and 8-10 years 16.7% (n = 6), respectively.

Physicians preferred to name HIV/AIDS at around age 6-7 year (M = 2.19, SD = 1.261). The most common response was 4-5 years at 44.4%. Precisely 38.9% (n = 14) responded 8-10 years, 8.3% (n = 3) responded 6-7 years, and 8.3% (n = 3) responded 13 years and older.

When providers were asked if there is a difference in the ages of disclosure and assent, the most common answer (n = 18, 50%) was “somewhat”, which suggests that patients are assenting to treatment and research with variable knowledge of their disease process and HIV status. Another 27.8% (n = 10) stated that there is a conflict where patients often assent to treatment/research when they are unaware of their status. Approximately twenty-two percent of respondents felt that there was no conflict, because if a patient is old enough to assent, generally he or she is aware of his or her HIV status.

### DISCLOSURE EFFECTS:

When providers were asked if delaying disclosure positively affects a child, 75% (n = 27) responded “false” and 25% (n = 9) responded “true”. When asked if delaying disclosure negatively affects a child, 94.4% (n = 34) responded “true”, with 5.6% (n = 2) responding “false”.

Specific benefits to disclosure identified by the responders are as follows: better attitude from the patient was the most common answer (n = 24, 52.2%), followed by medication adherence (n = 22, 47.8%), better provider-patient relationship (n = 21, 45.7%), and patient’s improved

relationship with family (n = 15, 32.6%). Approximately 30.4% (n = 14) identified provider's relationship with family as an additional benefit. Thirteen percent (n = 6) of responders wrote free-text benefits that included: open and honest communication, knowledge about transmissibility, less anger. Precisely 2.2% (n=1) of respondents felt that there were no benefits to early disclosure.

The following were identified as potential harms from early disclosure: inappropriate disclosure by child (n = 25, 54.3%), the child being angry with the family (n =13, 28.3%), child becoming depressed (n=9, 19.6%). Approximately 15% (n = 7) stated the child will stop taking their medication, and 6.2% (n = 3) identified other harms in free-text (child has felt isolated, child worries about their mother's health). On average, 15.2% (n = 7) of respondents felt there were no harms to disclosure.

#### **SECTION E: INADVERTENT DISCLOSURES**

Providers reported encountering HIV/AIDS patients who they felt were developmentally mature enough yet unaware of their HIV status at different rates. The most common response was less than once a year (n = 16, 44.4%). The next most common response was 2-5 times a year (n = 12, 33.3%), with 22.2% (n = 8) reporting this occurred 6-12 times a year. Providers also endorsed that inadvertent disclosures occur: less than once a year (n = 22, 61.1%), 1-3 times a year (n = 13, 36.1%), and more than once a month (n = 1, 2.8%).

#### **SECTION F: DEMOGRAPHICS AND PROVIDER ATTITUDES**

When demographics of the providers were looked at with cross-tabs against the ages providers preferred to disclose, perception of conflict between disclosure and assent, and the perception of benefits and harms of early disclosure, there were no statistical significant differences between any demographic groups (p=.215-14.5, df=1-9).(Table 2).

#### **SECTION I: QUALITATIVE ANALYSIS**

When the comments were analyzed by content analysis, 7 themes became apparent. These themes were: 1)disclosure as a multi-step process, 2) describing the illness without using the

name HIV), 3) complexity of this issue and its variation between different families, 4) contingency on children's developmental status and maturity, 5) parental influence, guilt, and fears of stigma, 6) questions surrounding the definition of assent, and 7) preparation for the disclosure process. While some of the comments pertinent to individual questions were mentioned above, some themes merit discussion on their own. One of the most common themes expressed by survey responders was how complicated the issue is, and how much disclosure varied between families. The parents' desires and the maturity of the child were all very important aspects of the disclosure process and therefore led to differing experiences based on different families. The mental development and maturity level of the child were mentioned multiple times by survey responders, and the age at which disclosure takes place, as seen in the survey responses above, is dependent on "mental development" and the "maturity" of the child. A specific aspect of this is if the parents and providers "get a sense that the child understands what should be kept private versus public."

The next theme that was explored was that disclosure is often a multi-step process. This was something echoed in comments regarding multiple questions, in addition to suggestions as to how to disclose. One responder commented that "information is built upon as the patient develops," and another stated they use terms that parents and provider "have discussed beforehand, which varies substantially family to family in terms of naming HIV." One responder highlighted "an incremental process where we talk about blood disorder, then about the disease without the name, and then the disease with the name." Counseling was mentioned many times, and multiple respondents highlighted the idea of a step-by-step process.

Preparation for disclosure was also discussed by multiple providers. Some of the ideas brought up by responders included "providing literature," "conversations with parents," "role play," "help with wording," and "planning meetings." Setting up education meetings with the parents before the process seems to also be a common theme from many of the providers who wrote in free-text responses.

Parental guilt and fear was another issue brought up multiple times. One provider stated that "the parent's main concern is telling the child how they got the virus—this is never easy and

requires a lot of supportive counseling.” Multiple providers state that parents will delay disclosure due to their problems with their own HIV status, and one even elaborated that “uninfected parents are much more likely to disclose to their children.” Multiple providers echoed that many parents perceive negative effects regarding stigma, and the necessity of keeping things secret. Parents also “fear the child will blame the parent.”

The definition of assent and when it was necessary were also themes that arose. One response asked if assent is “conscious consent-awareness and agreement with the plan,” or the child patient “just doing what they are told.” One responder stated that “if research is of direct benefit to child, assent is not necessary,” and another stated that if a new treatment was needed due to resistance, “necessity and guardian/parent permission trumps child assent.”

Responders also provided suggestions and described personal experiences regarding disclosure processes. Many of the previous themes were echoed, and some unique suggestions are highlighted below.

- Disclosure is often required prior to participation in HIV summer camp
- Disclosure workshop for groups of parents
- Role playing with family
- Handing out education materials for family to take home
- Repeatedly discussing risks of non-disclosure
- Patience, working with parents over an extended period of time
- Team based methods, have multiple providers speak with families

#### 4. DISCUSSION

Major findings of the study highlight the complexity of this issue. While the age of disclosure and assent on average are not drastically different (older school age children between 6 and 10 years), the variation in providers' responses and providers' different experiences with different families demonstrate that conflicts do arise. In addition, providers noted that children were more likely to assent to research studies at a younger age (between 6-10 years) than treatment (8-12 years). Over three quarters (n = 28, 77.8%) of providers that responded felt that there is sometimes a conflict between the ages of full disclosure and assent, with fifty-percent (n = 18) felt that patients assent with variable knowledge of their disease, and 27.8% (n = 10) stated that patients assent when they are unaware of their status), suggesting that this issue continues to arise in most practices that deal with HIV/AIDS in pediatric populations. In addition, 77% (n = 28) of providers reported having a child-patient over the age of 13 years who was unaware of their status, suggesting that while a majority of providers in the field of HIV/AIDS have encountered patients who are unaware of their status.

The process of disclosure varies between patients and providers, but most commonly involves parents, physicians, social workers and nurses, and takes place in clinical settings. Parental desire is the most common reasons providers delay disclosure. The reasons parents give for wanting to delay include fear that the child will disclose inappropriately to others, fear of the stigma, and personal guilt.

Providers noted both benefits and harms to delaying disclosure, though most providers (n = 34, 94.4%) felt that delaying disclosure negatively affects a child. Twenty-five percent (n = 9) of respondents also stated that delaying disclosure can positively affect a child. Specific benefits include better attitudes, medication adherence, and better provider-patient relationships. The most common harms included inappropriate disclosures, the child is angry with the family, and fear the child will become less compliant with medication.

These findings revealed that there is still great variability without any clear guidelines as to the timing of assent and disclosure when it comes to a disease like HIV/AIDS, where stigma and

social factors come into play. In addition, this study showed that most providers will encounter inadvertent disclosure in their practice although, this rarely occurs. Furthermore, providers seemed confident that the benefits of disclosure outweigh the harms of child telling their status inappropriately, or the child becoming angry with their family. Finally, some of the comments showed that assent is not always perceived by clinicians as that defined by the AAP Committee on Bioethics, as multiple clinicians stated that assent was not necessary when there were clear benefits to the child.

According to previous studies, the age at which most children should be able to assent to their own treatment and clinical trials is 7-8 years or older school age, which is similar to the ages identified by the providers surveyed in this study.<sup>1,2</sup> In addition, the variability not only between providers, but by the same provider within his or her practice confirms that most cases regarding disclosure and assent in HIV/AIDS are addressed on an individual basis.<sup>5</sup> While it is very important to individualize the disclosure process for families based on their own preferences, a systematic practice for preparing for disclosure may be beneficial.

When providers were asked about benefits and harms regarding disclosure, most providers agreed that benefits outweigh the harm of disclosure, and feel that medication adherence may be closely tied to the understanding of disease.<sup>4</sup> The harms identified are also echoed by Wiener and colleagues (1996), who stated that the issue of disclosure is further complicated by parents who themselves are infected.<sup>7</sup> Findings in this study closely aligned with findings in a Western Kenya study, despite the population differences. Researchers in this study identified improved ART adherence and social support as benefits of disclosure. Negative psychological effects for the children and discrimination were identified as harms related to disclosure.<sup>8</sup> Children in the Western Kenya study were often much more angry and experienced more negative side effects when disclosed late as they were angry that their diagnosis was kept a secret for so long.

A survey such as this requires simplifying a very complex issue into multiple choice questions. The definition of "assent" was intentionally left vague for the purposes of the study and providers' responses indicated that there is no consensus as to what assent truly is.

The questions asked in this survey continue to remain relevant particularly in cases where parents and providers disagree. Some of the most valuable information to come out of the survey is the suggestions providers made as to how to improve the disclosure process, particularly some of the suggestions regarding disclosure workshops, education materials, and role-playing with the family prior to disclosure, and recommendations regarding carrying out the disclosure process in a step-wise manner. While this will, and should, continue to be a very individualized process, more resources and information should be available to providers to facilitate the disclosure process.

### **Limitations**

The study was limited by its sample size, which can be attributed by a very small population of pediatric HIV/AIDS providers. The survey was sent out by email to approximately 200 providers identified through provider databases and internet searches, and of those only 36 completed the survey in full. In addition, the survey was not linked to email addresses in order to insure anonymity and to allow for forwarding of the survey to more colleagues, but this also allows for the possibility of someone answering the survey more than once. This was controlled for in part by checking for any identical survey responders, but this is not a perfect process. Since the definitions of disclosure and assent were left vague intentionally, survey responders may have answered the questions differently based on their own personal understandings of the issue, given just how complex and personal HIV/AIDS disclosure is.

## **5. FURTHER STUDIES AND CONCLUSIONS**

Further studies that may provide more information regarding the disclosure process include looking at the relationship between the rate of older children unaware of their status, and how often inadvertent disclosures occur are needed. It would also be beneficial to look further into the impact of disclosure on medication adherence, as many of the prior studies have been contradictory. Another direction would be to evaluate the effectiveness and availability of education materials pertinent to disclosure. In addition, a study regarding disclosure from the parents and children's' perspectives are much needed to bridge the gap between the physicians' perspective and that of the parent and child.

This study revealed a paucity of knowledge regarding the many complex factors that play into the process of disclosure and assent pertaining to HIV/AIDS in a pediatric population. While there are wide variations among individual patients and providers, most providers agree that disclosure should occur in older school age children, which is also the time that they typically are able to assent to treatment and clinical trials. This is often done in a step-wise manner that includes multiple practitioners and counseling with families, and when it is delayed is usually due to parental guilt and fear of stigma.

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## **APPENDIX A: Survey invitation**

Dear healthcare professional,

My name is Morgan Greene and I am a medical student at the University of the Arizona College of Medicine- Phoenix. I am doing an IRB-approved research project through the Bill Holt HIV/AIDS Clinic at Phoenix Children's Hospital. I am looking into the issues surrounding disclosure of HIV/AIDS diagnoses in children, and the process of informed assent in the context of HIV/AIDS. I am requesting that you complete the short survey attached to this link, and assure you that your responses will be confidential.

If you are a research coordinator and/or administrator in a clinic that serves HIV/AIDS patients, I would greatly appreciate your assistance in forwarding this email to health care workers in your clinic. In addition, please forward this survey to any of your colleagues (including mid-level providers, nurses, and social workers) who also work with children with HIV.

Please refrain from using personal identifiers if you utilize comment boxes, and please complete the survey only once. Participation in the survey will constitute as informed consent, and all answers will remain both anonymous and confidential. Once the survey is completed, it will be disseminated as a thesis at the University of Arizona College of Medicine-Phoenix, and submitted for a journal article and/or a poster presentation at a professional meeting.

I greatly appreciate your time and energy. Please feel free to contact me with any questions, comments or concerns at [mgreene@email.arizona.edu](mailto:mgreene@email.arizona.edu).

\*\*\*\*Survey Link\*\*\*\*

Very respectfully,

Morgan Greene

MD Candidate, Class of 2014

University of Arizona College of Medicine-Phoenix

## **APPENDIX B: Survey reminder**

Dear healthcare professional,

My name is Morgan Greene, and I am a medical student at the University of the Arizona College of Medicine- Phoenix. I am requesting your input for a research project that I emailed you about previously. If you have already completed the survey, thank you tremendously for the effort that you have already made on my behalf. Your perspective is central to the research that I am currently pursuing, and I appreciate the time you have taken out of your busy schedule. I am doing an IRB-approved research project through the Bill Holt HIV/AIDS Clinic at Phoenix Children's Hospital. I am looking into the issues surrounding disclosure of HIV/AIDS diagnoses in children, and the process of informed assent in the context of HIV/AIDS. If you have not already responded, I am requesting that you take the time to complete the short survey attached to the link below.

In addition, please forward this to any colleagues (including mid-level providers, nurses, and social workers) who also work with children with HIV/AIDS. I greatly appreciate your time and energy, and just ask that you refrain from including any personal identifiers if you utilize the comment boxes.

Participation in the survey will constitute informed consent, and all answers will remain both anonymous and confidential. Once the survey is completed, it will be disseminated as a thesis at the University of Arizona College of Medicine-Phoenix, and submitted for a journal article and/or a poster presentation at a professional meeting.

I greatly appreciate your time and energy. Please feel free to contact me with any questions, comments or concerns at [mgreene@email.arizona.edu](mailto:mgreene@email.arizona.edu).

<https://www.surveymonkey.com/s/Q8SH2DF>

Very respectfully,

Morgan Greene

MD Candidate, Class of 2014

University of Arizona College of Medicine-Phoenix

## Appendix C: Survey Contents

**Instructions:** Please answer each question to the best of your ability. There is no right answer. Your participation in this survey constitutes informed consent to participation. All of your answers will remain confidential and anonymous. Please refrain from mentioning patient or practice/clinic identifiers if you choose to complete the free comment boxes. Thank you for your participation!

1. Are you involved with the care of pediatric HIV/AIDS patients?
  - Yes
  - No
2. Approximately how many pediatric HIV/AIDS patients does your clinic see?
  - Less than 20 HIV/AIDS patients under 18
  - 20-50 HIV/AIDS patients under 18
  - 50-150 HIV/AIDS patients under 18
  - 150-300 HIV/AIDS patients under 18
  - 300+HIV/AIDS patients under 18
3. What kind of community does your clinic primarily serve?
  - Large city
  - Small city
  - Suburban
  - Rural
4. What is your professional role in the clinic?
  - Physician
  - Nurse-practitioner/other mid-level provider
  - Research coordinator
  - Nurse
  - Social worker
  - Other (please specify)

5. Please select your age group:

- 18-25
- 26-35
- 36-45
- 45-60
- 60 and up

6. At what age do children typically first assent to research studies?

- 4-5
- 6-7
- 8-10
- 11-12
- 13 and older

7. At what age do children typically first assent to treatment?

- 4-5
- 6-7
- 8-10
- 11-12
- 13 and older

8. At what average age are the children in your clinic given a developmentally appropriate explanation of the HIV/AIDS disease process (with or without naming HIV/AIDS)?

- 4-5
- 6-7
- 8-10
- 11-12
- 13 and older

COMMENTS:

9. At what average age are children made aware of the name HIV/AIDS as the name of their illness?

- 4-5
- 6-7
- 8-10
- 11-12
- 13 and older

10. At what age would you prefer to name HIV/AIDS as the name of their illness to your child-patient?

- 4-5
- 6-7
- 8-10
- 11-12
- 13 and older

COMMENTS:

11. In your practice, do you feel there is a difference between the age of disclosure and the age of assent in your HIV/AIDS patients?

- Yes, often patients assent to treatment/research when they are unaware of their status.
- Somewhat, patients are assenting to treatment/research with variable knowledge of their disease process and HIV status
- No, if a patient is old enough to assent, generally he or she is aware of his or her HIV status

COMMENTS:

12. Delaying the disclosure of HIV to a developmentally competent child positively affects the child.

- True
- False

COMMENTS: Please describe positive effects you have observed in your practice:

13. Delaying the disclosure of HIV to a developmentally competent child negatively affects the child.

- True
- False

COMMENTS: Please describe negative effects you have observed in your practice:

14. Do you change your treatment plan in any way for an older school- age child who does not have a developmentally appropriate understanding of his or her disease?

- Yes, because I am hesitant to allow their participation in research studies.
- Yes, I am hesitant to use more aggressive treatment.
- No, I only change my language.
- No, I do everything exactly the same

15. How often do you see HIV/AIDS patients that you consider old enough to assent to participate in research studies, but who are unaware of their state of HIV status?

- Less than 1 time a year
- 2-5 times a year
- 6-12 times a year
- More than once a month

16. What is the age of the oldest patient you have seen who is/was unaware of their status?

- 4-5
- 6-7
- 8-10
- 11-12
- 13 and older

17. For what reasons do you postpone disclosure for some patients? (Please check all that apply)

- Parental desire
- Child is not mature enough
- Cultural norms
- Stigma
- Other: \_\_\_\_\_

18. If parents are the reason behind delaying disclosure, what reasons do they give?

Please check all that apply, and only answer if you checked "parental desire" in question

- Personal guilt
- Cultural norms
- Fears that the child will "give up"
- Fears that the child will tell more people
- Fear of being asked by child how they got HIV
- Fear of community stigma
- Other (please specify)

19. How do you determine if a child is developmentally competent for disclosure? (please rate each value on a scale of importance)

Not at all important<Not very important<Somewhat important<very important< the most important

- Age
- Mental capabilities
- Grade level
- Health knowledge
- Health status
- Parental opinion
- Other (please specify)

20. Is preliminary counseling/planning with the family typically a part of the disclosure process?

- Yes, the parents and I/other health care providers work together to formulate a plan for disclosure together
- Yes, the parents discuss disclosure with me/other health care providers, and then most often carry out the process on their own.
- Yes, as the child is asking questions.
- No, it typically occurs within the context of one visit.
- It varies from patient to patient
- Other (please specify)

21. In what location do you typically disclose a child's HIV status?

In an outpatient clinic

- At a patient's home
- In a neutral setting (coffee shop, restaurant, park)
- At the family's preferred place
- Other (please specify)

22. Who participates (in addition to the patients) in the disclosures? (Check all that apply)

- Parents
- Siblings
- Nurse
- Physician
- Social worker
- Nutrition
- Disclosure will involve different people in different settings, at different times
- Other (please specify)

23. How often are you aware of inadvertent disclosures that occur, where the patient becomes aware of their status due to a member of the health care team, family member, school teacher, caretaker, etc. discussing the problem in any setting?

- Less than once a year
- 1-3 times a year
- 4-5 times a year
- 6-12times a year
- More than once a month

24. Have you used an ethics committee in a conflict directly regarding disclosure?

- Yes
- No

If yes, please describe when you have used an ethics committee.

25. What are some benefits to early disclosure seen in your practice? (Select all that apply)

- Provider has better relationship with patient
- Patient has better relationship with family
- Provider has better relationship with family
- Patient has better attitude towards disease
- Patient has better medication regimen adherence
- I do not feel there are benefits
- Other: Please specify

26. What are some harms seen from early disclosure? (Select all that apply)

- Child discloses his or her status in an inappropriate setting or against parental wishes)  
(to neighbors, teachers, etc.)
- Child becomes depressed
- Child stops taking medication
- I do not feel there are harms
- Other (please specify)

27. What are some techniques to assist with families who are hesitant to disclose? Please elaborate.

28. Based on your experience working with families of children with HIV/AIDS, can you provide any other information that will help the researchers understand the issues related to disclosure to children who are HIV-positive?

**APPENDIX D: Table 1: Significance of providers present at disclosure and how the process is carried out.**

**Chi-Square analysis of role of providers involved with disclosure versus how disclosure process occurs (preliminary counseling & location involved)**

	<b>Counseling</b>	<b>Location</b>
<b>Parents</b>	p=1.091, df=2	p=.468, df=2
<b>siblings</b>	p=.424, df=2	p=.6005, df=2
<b>nurse</b>	p=10.571, df=2	p=2.098, df=2
<b>Physician</b>	p=.321,df=2	p=.459, df=2
<b>Social Work</b>	p=1.286, df=2	p=.666, df=2
<b>Differs</b>	p=2.40, df=2	p=2.498, df=2
<b>Other</b>	p=3.600, df=2	p=.643, df=2

**APPENDIX E: Table 2: Significance of survey responder demographics and their opinions regarding disclosure**

**Chi-square analysis of survey responder demographics and opinions regarding disclosure (age prefer to disclose, difference perceived between age of disclosure, and assent, positive effects/benefits, negative effects/harms, and treatment changes)**

	<b>Prefer</b>	<b>Difference</b>	<b>Positive</b>	<b>Negative</b>	<b>Tx Changes</b>
<b>Number of pts</b>	p=10.359, df=9	p=3.346, df=6	p=.638, df=3	p=.407, df=3	p=9.120, df=6
<b>Community</b>	p=1.479, df=3	p=2.800, df=2	p=.267, df=1	p=1.694, df=1	p=.495, df=2
<b>Professional role</b>	p=7.102, df=9	p=4.738, df=6	p=6.463, df=3	p=.814, df=3	p=4.410, df=6
<b>Responder Age</b>	p=14.500, df=9	p=7.091, df=6	p=5.564, df=3	p=1.367, df=3	p=6.268, df=6

<b>Benefits1</b>	<b>Benefits2</b>	<b>Benefits3</b>	<b>Benefits4</b>	<b>Benefits5</b>	<b>Benefits6</b>	<b>Benefits 7</b>
p=1.919, df=3	p=.854, df=3	p=.868, df=3	p=.588, df=3	p=.366, df=3	p=1.329, df=3	p=2.729, df=3
p=.907, df=2	p=.580, df=2	p=3.10, df=2	p=6.180, df=2	p=1.058, df=2	p=.215, df=2	p=1.850, df=2
p=1.789, df=3	p=433, df=3	p=3.180, df=3	p=1.281, df=3	p=4.211, df=3	p=10.733, df=3	p=3.149, df=3
p=4.089, df=3	p=3.666, df=3	p=5.259, df=3	p=1.139, df=3	p=1.868, df=3	p=10.733, df=3	p=.808, df=3

<b>Harms1</b>	<b>Harms2</b>	<b>Harms3</b>	<b>Harms4</b>	<b>Harms5</b>	<b>Harms6</b>
p=2.063, df=3	p=.106, df=3	p=1.302, df=3	p=8.877, df=3	p=3.880, df=3	p=3.525, df=3
p=.403, df=2	p=.4256, df=2	p=.421, df=2	p=.194, df=2	p=1.738, df=2	p=6.596, df=2
p=2.543, df=3	p=1.789, df=3	p=1.238, df=3	p=2.203, df=3	p=.901, df=3	p=4.375, df=3
p=3.454, df=3	p=4.639, df=3	p=1.50, df=3	p=6.658, df=3,	p=4.333, df=3	p=.469, df=3