

Disclosure and Assent in Pediatric HIV

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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 surveyed providers who were involved with the care of children/adolescents with HIV/AIDS. Survey questions assessed provider demographics, average age of assent to treatment and research, average age of disclosure of HIV, factors that 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 agreed 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 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 most effective when done in a step-wise manner that includes multiple practitioners and counseling with families.

Introduction

Pediatric assent is the process where child patients, who legally do not have authority to consent to treatment, participate in medical decision making. By the American Academy of Pediatrics (AAP) definition, assent involves participating in decision making according to their developmental level when reasonable. In a condition such as HIV, which carries a stigma, disclosure can be a complicated process with many factors. The purpose of this study was to describe how clinicians approach and experience assent and disclosure with HIV-positive children in their practice, with a focus on the process of disclosure, barriers to disclosure, how treatment changes with regards to disclosure, and explore provider opinions regarding disclosure and assent in their practice.

Methods

A survey was distributed to 200 clinicians involved in the care of pediatric HIV patients in the United States electronically using SurveyMonkey.com. The survey was designed to map to aims identified through literature review: the process of disclosure, barriers to disclosures, techniques for the process, and practitioners' attitudes surrounding the disclosure process. After data collection was completed, the results were analyzed via SPSS using frequencies procedures to determine mean, median, and mode. Cross-tabs were used to examine relationships between responses.

Results

Forty-six providers completed the survey, and thirty-six completed it in full. Physicians were the most prevalent survey responders (n=31, 67.4%), and most responders lived in a large city (n=38, 82.6%). Most providers (n=30, 83.3%) endorse preliminary counseling and planning between the providers and parents as a part of the disclosure process. Physicians prefer to name HIV/AIDS on average around 6-7 years, with most common response being 4-5 years (44.4%, n=16), and 38.9 percent responding 8-10 years (n=14), and 8.3 percent responding 6-7 years (n=3).

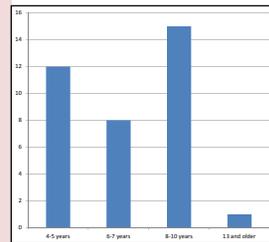


Figure 1: Provider opinion of the developmentally appropriate age for discussion and disclosure of the HIV/AIDS illness.

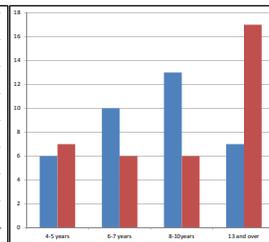


Figure 2: Age reported by physicians for assenting HIV+ children to research studies (blue) and treatment (red)

Results (continued)

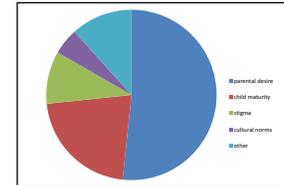


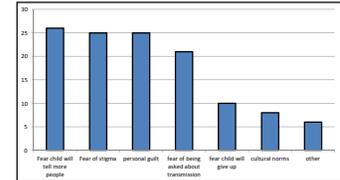
Figure 3: Reasons physicians give for delaying disclosure in a child who is otherwise developmentally mature

In general, providers felt there is a difference in the ages of disclosure and assent, with fifty percent (n=18) answering patients had somewhat of a variable knowledge of their disease state, when they assented to treatment or trials, and 27.8 percent (n=10) felt there is a conflict and patients often assent to research and treatment when they are unaware of their status. Providers gave varying reasons why they delay disclosure (Fig. 4), with the most common answer being parental desire.

Ninety-four percent of providers feel that delaying disclosure negatively effects a child (n=34) and only 2.2 percent of providers (n=1) felt that there were no benefits to early disclosure. Benefits that were identified were better attitude, (n=24, 52.2%) medication adherence (n=22, 46.8%), better provider-patient relationship (n=21, 45.7%), and improved patient relationship with family (n=15, 32.6%). Harms that were identified were 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%) and the child will stop taking their medication (n=7, 15.2%).

Content analysis was performed and 7 themes were identified. 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.

Figure 4: Reasons physicians feel that parents delay disclosure (vertical axis is number of positive responses)



Discussion and Conclusions

Variation in providers' responses and experiences within their practices highlight the complexity of this issue, but over three-quarters (n=28, 77.8%) of providers do feel there is at least sometimes a conflict between the age of disclosure and the age of assent with pediatric HIV.

These survey responses are consistent with previous research suggesting that disclosure gets more complex when parents and providers disagree on the age at which disclosure should occur, and while the experience differs for everyone, many survey participants commented on starting the process early with discussion and planning with the parents, disclosing information in a step-wise manner as the child-patient matures to facilitate communication.

- 77% (n=28) of providers have a child-patient over the age of 13 years unaware of their status, suggesting that while rare, this is an issue that most pediatric HIV providers will encounter.
- Providers note both benefits and harms to delaying disclosure, 94.4% of providers report that delaying disclosure negatively affects a child.
- The age when most providers report that disclosure should take place is older school-age, consistent with previous studies and AAP guidelines as to when children should assent.

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