

Diagnosis Disclosure in HIV-Infected Thai Children

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Background: Increasing number of children with perinatally acquired HIV-infection are now surviving into school age and adolescence. Disclosure of diagnosis to these children has become an important clinical issue. Clinical reports and studies from other countries suggest that a significant number of these children have not been told of their HIV status. The objective of this study was to assess diagnosis disclosure status of perinatally acquired HIV-infected Thai children.

Material and Method: Primary caregivers of 96 HIV-infected children aged 5 years and older were interviewed to assess the child disclosure status and the caregivers reasons to disclose or not to disclose the diagnosis to the child. The disclosed children were also interviewed to assess perception of their illness.

Results: Nineteen of 96 children (19.8%) had been told of their HIV diagnosis by their caregivers. The mean age of the disclosed children was 9.6 years. Eighty-four percent of the disclosed children reported perception of their illness as having HIV infection or AIDS. Common reasons for non-disclosing were concerns that the child was too young, that the child might be psychologically harmed, and that the child could not keep the secret. Of 77 non-disclosing caregivers, 54 reported that they plan to disclose HIV status to the children in the future.

Conclusion: This study demonstrates that diagnosis disclosure was made in only 1/5 of HIV-infected children, and that most of the caregivers were reluctant in disclosing serostatus to the child. Development of an appropriate guideline for assisting the caregivers and the children to deal with the difficult disclosure process is needed.

Keywords: HIV, Children Disclosure Psychological impact

J Med Assoc Thai 2005; 88(Suppl 8): S100-5

Full text. e-Journal: <http://www.medassocthai.org/journal>

With the advancement of the treatment of human immunodeficiency virus (HIV) infection, increasing number of children with perinatally acquired HIV infection and acquired immunodeficiency syndrome (AIDS) are surviving into their school-age years and adolescence⁽¹⁻³⁾. As these children are growing older, more treatment issues become clinically important, including medication adherence and prevention of transmitting virus to other people. Therefore, the child's participation and understanding of his/her health

condition is essential^(4,5). However, telling children that they have a chronic, potentially life-threatening and stigmatizing condition is not an easy task. Many caregivers and providers are reluctant to inform children about their HIV infection status⁽⁶⁻⁷⁾. Research and clinical reports suggest that significant number of older children do not know their full diagnosis. Studies from the United States indicate that between 25% and 45% of school-age children with HIV infection/AIDS have not been informed about their HIV diagnosis⁽⁸⁾. The number is higher, with up to 83% in the United Kingdom and other European countries^(1,9). Common reasons given by caregivers for not disclosing HIV infection status to their children include concerns about the negative psychological impact on the child, fears

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that the child cannot keep the secret, concern about the child's ability to understand, and fears that the child would be discriminated^(5,6). Infected biological parents are facing more difficulty as disclosing the child's diagnosis would involve simultaneous disclosure of their HIV status and a sense of guilt for transmitting the disease to the child⁽¹⁰⁾.

American Academy of Pediatrics Committee on Pediatric AIDS makes a number of recommendations on disclosure of HIV diagnosis to children and adolescents, emphasizing the individualized approach to the child's development, clinical status, and social circumstances⁽¹¹⁾. They strongly encourage disclosure of HIV infection status to school-age children, particularly those requiring hospitalization, as the likelihood of inadvertently disclosure in a hospital setting is high. They also state that adolescents should know their HIV status and should be fully informed of the consequences in many aspects of their health, including sexual behavior.

Studies in children with cancer indicate that children who are informed about the nature and consequences of their illness exhibit better coping skills and fewer psychosocial problems^(12,13). However, many differences exist between cancer and HIV infection, e.g., stigma and multigenerational aspect of the infection. The impact of HIV disclosure in children has been scarcely studied.

In Thailand, as with several other countries in which the highly active antiretroviral therapy is available, the issue of diagnosis disclosure to surviving perinatally acquired HIV-infected older children and adolescents is pressing. At Siriraj Hospital, we have developed multidisciplinary team service for biopsychosocial caring of HIV-infected children and their families. As part of this service, we assessed disclosure status of these children and the caregivers' reasons to disclose and not to disclose the child's HIV status. The ultimate goal for this assessment was to better understand the situation in Thai families in order to better assist HIV-infected children in the disclosure process and to develop appropriate diagnosis disclosure guideline in Thailand.

Material and Method
Sample

The sample consisted of 96 HIV-infected children older than 5 years old and their primary caregivers who attended the Pediatric Infectious Clinic at Siriraj Hospital, a large pediatric HIV center in Bangkok, between June and September of 2004. Caregivers were

explained of the purpose of the assessment and all gave consent for the interview.

Interview

Caregivers were interviewed by the psychologist (UK) or the counselor (YU) using a semi-structure interview inquiring whether HIV serostatus had been disclosed to the child, and their reasons for having disclosed or not having disclosed the diagnosis.

The interview took place at the clinic visit on the children and the caregivers convenience. The children and the caregivers were interviewed separately.

Statistical Analysis

Data was analyzed by descriptive statistics using SPSS program (Chicago, IL).

Results

Sample description

Of the 96 caregivers who were interviewed, 47 were biological parents, 44 were relatives, and 4 were non-related caregivers of the HIV-infected child. Of the 96 children, the mean age was 8.6 years (range 5-15 years), and 52 (54%) were males.

Disclosure Status

Nineteen of 96 children (19.8%) had been told of their HIV diagnosis by their caregivers. The mean age of the disclosed children was 9.6 years, which was not significantly different from that of 8.5 years in non-disclosed ones. The age and gender distribution of disclosed and non-disclosed children is shown in Table 1.

Disclosure was made by biological parents in 10 of the 19 disclosed children (7 by mothers, 3 by fathers). In the rest of the group, disclosure was made by grandmothers in 3 cases, by step-parents in 5 cases,

Table 1. Age and gender distribution of children

	Disclosed N=19	Non-disclosed N=77
Gender		
Male	9	43
Female	10	34
Age (years)		
5-7	6	35
8-10	4	30
11-13	8	11
14-15	1	1

Table 2. Reasons for disclosure

Caregivers reasons for disclosing	Number (N=19)
1. The child would take better care of him/herself	4
2. The child is old enough to know	3
3. The child asked	3
4. The child is being teased of having AIDS	3
5. The child might have known by someone else	3
6. The child would know someday	2
7. The child could prevent transmitting virus to others	1

Table 3. Reasons for non-disclosure

Caregivers' reasons for not disclosing	Number (N=77)
1. The child is too young or unable to understand	45
2. Fear of psychological impact on the child	27
3. Concern that the child could not keep secret	22
4. See no need to disclose	15
5. Feel guilty or afraid of being hated	6
6. Don't know what/how to say	3
7. Other	3

and by a sister in one case. Most of the disclosure took place at home. In only one case, the biological mother disclosed to the child in the clinic with an assistance of a physician.

Reasons for disclosure and non-disclosure

Disclosing caregivers reported a variety of reasons for having disclosed HIV diagnosis to the child. These included having been asked by the child, the child being teased at school, the child might have already known, the child was mature enough to know, the child would take better care of him/herself, the child would eventually know someday, and the child could prevent transmitting virus to others. (Table 2)

When non-disclosing caregivers were asked about their reasons not to disclose, the majority reported that they thought the child was too young or unable to understand (n=45). Other common reasons included fear of negative psychological impact on the child (n=27), concern that the child could not keep secret (n=22), and seeing no need to disclose (n=15). Six reported that they felt guilty or were afraid of being hated; and three did not know how to talk to the child (Table 3).

When asked of what explanation was given to the child why he/she had to come to the clinic, the majority (n=45) of the caregivers reported that they just told the child that he/she need to come or need to take medications, 24 reported they informed the child of his/her illness using variety of names, e.g., weakness, blood disease, low white blood cells, allergic disease, liver disease, splenic disease, lung disease, tuberculosis, and lymph nodes disease.

Of the 77 non-disclosing caregivers, 54 (70%) reported that they would disclose someday in the future, 16 reported they would not plan to disclose at all, and 7 reported that they were uncertain.

The child's perception

When the disclosed children were asked of what they thought their diagnosis were, 16 (84.2%) children reported that they had HIV/AIDS, 3 (15.8%) reported they had an infection or a virus in their bodies without naming it.

Discussion

This is the first report of the diagnosis disclosure status of perinatally HIV-infected children in Thailand. The finding from this study reveals that majority

(80%) of HIV-infected children older than 5 years have not been told of their HIV status. This is consistent with studies from other countries, in which the reported percentages of non-disclosed children ranged from 25 to 83%⁽⁸⁻⁹⁾. The findings from this study reflect the caregivers' unwillingness or uneasiness in letting the child aware of this potentially life threatening and stigmatized illness. This might also reflect the providers' reluctance on encouraging caregivers to disclose HIV status to the child, as there were no clear guidelines in Thailand at the time the study was done.

Similar to other studies^(9,14), the persons who disclosed the diagnosis were the child's primary caregivers. All but one disclosure were done by the caregivers without preparation or assistance from the health care team. This might be due to the necessity assessed by the caregivers to have to tell the child, prompting by certain circumstances. These indicated that the caregivers need guidance for appropriate preparation for this process.

The mean age of children whose diagnosis was disclosed in this study was 9.6 years old, consistent with other studies' findings that most disclosed children are told of their diagnosis by their caregivers between 5 and 10 years old⁽¹⁴⁾. However, the mean age of the disclosed and non-disclosed group was not significantly different. This suggests that the child's age may not be an important determinant for disclosure in this population. Moreover, there were a significant number (12 of 21) of children older than 10 years old to whom diagnosis was not disclosed.

The reasons behind the caregivers' decision not to disclose HIV status to the child in this study are similar to those of Weiner et al and Waugh's studies^(6,10). This indicated that the caregivers' concerns of potential negative consequences are universal across cultures. However, there are some differences in the findings from this study when compared to other studies. For instance, while the most common reason for not disclosing in the Weiner et al report was the fear of the child being psychologically harmed⁽⁶⁾, in the present study, concern that the child was not mature enough to understand was more common. This might reflect cultural differences between Thai and American culture in that Thai parents might tend to view their children as being mature at later ages than those of American's.

The explanations given to the non-disclosed children as to why they had to come to the clinic reflect the caregivers' temptation to keep secrecy on HIV status by not talking about the child's diagnosis or

hiding it under other medical conditions. The fact that only 84% of the disclosed children reported perception of their diagnosis by using the name HIV or AIDS indicates that, besides the caregiver's attempt to conceal the diagnosis, there was also denial in some of the children whose illness status were told. We did not interview the non-disclosed children, as we were concerned that the child's diagnosis might be accidentally disclosed by the interviewing process. Therefore, we do not know what the children in this group perceive about their illness and whether they simply believed in what they were told.

Another interesting point in present findings is that 70% of caregivers who had not disclosed illness status to the child indicated that they would do so in the future. This suggests that most caregivers of HIV-infected children realized that they should, but were not ready to, disclose the diagnosis to the child; while a significant number of them were not willing to or not certain. Therefore development of an appropriate guideline for providers to assist the family and the child with the difficult disclosure process is needed.

There are a number of limitations in this study. As we gathered information in a limited period of time, not all the patients in the clinic were included. This study was performed in a teaching hospital. Therefore the findings might not represent HIV-infected children in other settings. Moreover, the findings might only represent the status at the time study was done, because more children might be disclosed as the time passes. Nevertheless, this study elucidated preliminary data on the status of diagnosis disclosure to HIV-infected Thai children that is important for future study plan and development of an appropriate guideline. Further studies, particularly on the impact of disclosure to the child and family, are needed.

Acknowledgement

We thank the children and their families who participated in the study, the Pediatric Infectious Diseases Clinic's staff at Siriraj Hospital for facilitating the study process, and Dr. Chulaluk Komoltri for data analysis.

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การเปิดเผยผลการวินิจฉัยแก่ผู้ป่วยเด็กไทยที่ติดเชื้อ HIV

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หลักการและเหตุผล: ในปัจจุบันมีผู้ป่วยเด็กที่ติดเชื้อ HIV จากมารดาจำนวนที่รอดชีวิตมากขึ้น และกำลังเติบโตเข้าสู่ช่วงวัยเรียนและวัยรุ่น การให้เด็กได้รู้การวินิจฉัยโรคของตนเองจึงเป็นอีกประเด็นหนึ่งที่มีความสำคัญในการดูแลรักษา รายงานการศึกษาจากต่างประเทศได้แสดงว่าเด็กในกลุ่มนี้จำนวนไม่น้อย ที่ยังไม่ได้รับการบอกผลการวินิจฉัย การศึกษานี้ จึงมีวัตถุประสงค์เพื่อประเมินสถานการณ์ของการเปิดเผย ผลการวินิจฉัยแก่เด็กไทยที่ติดเชื้อ HIV เพื่อเป็นข้อมูลในการวางแผนช่วยเหลือผู้ป่วยและผู้ปกครอง ในการเผชิญกับปัญหานี้ต่อไป

วัตถุประสงค์และวิธีการ: ได้ทำการสัมภาษณ์ผู้ปกครองของผู้ป่วยเด็กที่ติดเชื้อ HIV ที่มีอายุตั้งแต่ 5 ปีขึ้นไป 96 คน โดยใช้การสัมภาษณ์กึ่งโครงสร้าง (semi-structure interview) ประเมินการได้รับการบอกการวินิจฉัยโรคของเด็ก และเหตุผลของผู้ปกครองที่ได้เปิดเผยหรือไม่เปิดเผยผลการวินิจฉัยแก่เด็ก และได้สัมภาษณ์เด็กที่ได้รับการบอกแล้วถึงการรับรู้การวินิจฉัยโรคของตน

ผลการศึกษา: มีเด็ก 19 (ร้อยละ 19.8) คนจาก 96 คนที่ได้รับการบอกผลการวินิจฉัยจากผู้ปกครอง อายุเฉลี่ยของเด็กที่ได้รับบอกผลการวินิจฉัยคือ 9.6 ปี ร้อยละ 84 ของเด็กที่ได้รับการเปิดเผยการวินิจฉัย บอกว่าตนมีภาวะติดเชื้อ HIV หรือ AIDS เหตุผลส่วนใหญ่ที่ผู้ปกครองยังไม่เปิดเผยผลการวินิจฉัยแก่เด็กได้แก่ เห็นว่าเด็กยังไม่โตพอ กลัวเด็กได้รับการกระทบทางจิตใจ และกลัวว่าเด็กไม่สามารถรักษาความลับ ในกลุ่มผู้ปกครอง 77 คนที่ยังไม่เปิดเผยผลการวินิจฉัยแก่เด็ก มีจำนวน 54 คนคาดว่าจะบอกเด็กในอนาคต

สรุป: การศึกษาครั้งนี้แสดงให้เห็นว่ามีผู้ป่วยเด็กที่ติดเชื้อ HIV เพียงหนึ่งในห้าที่ได้รับการบอกให้ทราบถึงผลการวินิจฉัยโรค และผู้ปกครองส่วนใหญ่ยังมีความไม่มั่นใจที่จะเปิดเผยผลการวินิจฉัยแก่เด็ก ดังนั้นจึงควรมีการพัฒนาแนวปฏิบัติในการช่วยเหลือผู้ปกครองและผู้ป่วยเด็กที่ติดเชื้อ HIV ในการเผชิญกับภาวะยากลำบากของกระบวนการเปิดเผยผลการวินิจฉัย
