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## Factors associated with caretaker's readiness for disclosure of HIV diagnosis to HIV-infected children in Bangkok, Thailand

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### Summary

To determine factors associated with caretaker's readiness to disclose an HIV diagnosis to their child, a prospective study was conducted among caretakers of HIV-infected children aged seven to 16 years who were receiving care at two paediatric HIV treatment centres in Bangkok. Caretakers were offered readiness preparation counselling and their perceptions on disclosure were assessed using a semi-structured questionnaire. Among caretakers who had participated in the readiness preparation process for at least one year, 71% (195/273) were ready for disclosure. Using logistic regression analysis, we found that child's age of nine years or older, child's severe immunosuppression, caretakers having prior discussion with their child about the illness, caretaker's perception that their child had the ability to understand the HIV diagnosis and to keep it secret, and caretaker's opinion that the proper age for disclosure is between seven and 12 years old were associated with caretaker's readiness for disclosure. These determinants may be useful for guiding disclosure readiness preparation counselling.

### Keywords

HIV; paediatric; disclosure; caretaker; readiness; Thailand

### Introduction

It was estimated that 6510 HIV-infected children received antiretroviral treatment (ART) in Thailand in 2011.<sup>1</sup> Nearly all of these children acquired the HIV virus through perinatal transmission. As a result of the national prevention of mother-to-child HIV transmission programme, the number of new perinatally acquired HIV infections has been reduced

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### Conflict of interest

The authors declare that there is no conflict of interest

substantially.<sup>2,3</sup> Increased access to ART through the National ART Program has contributed to a substantial decrease in morbidity and mortality rates among HIV-infected children and increasing numbers of children are surviving into their adolescence. As these children are growing up, disclosure of HIV diagnosis to them has become a challenging clinical issue.

According to the American Academy of Pediatrics, as HIV-infected children mature they should be fully informed about their diagnosis so that they are able to take an active role in their self-care and antiretroviral (ARV) adherence, as well as to prevent further HIV transmission through risky behaviour (especially unprotected sex).<sup>4</sup> Nevertheless, disclosing HIV diagnosis to an infected child is not an easy task. Studies indicate that paediatric HIV disclosure prevalence in Europe and North America varied from 10 to 75%.<sup>5</sup> A more recent review reported that the proportions of children who knew their HIV diagnosis were lower in low- or middle-income countries (median = 20.4%) compared to that of industrialised countries (43%).<sup>6</sup>

Studies in Thailand in 2005–2006 found that only 20–30% of HIV-infected children between the ages of five and 16 had been told their HIV diagnosis by their caretakers.<sup>7,8</sup> Common caretaker's reasons for not disclosing included concerns that children were too young, might be psychologically harmed and could not keep the diagnosis secret.<sup>9–11</sup> As caretaker's readiness influence disclosure and many caretaker-related factors were identified as barriers for disclosure, particularly in resource-limited settings,<sup>12</sup> a process of preparing caretakers and assessing caretaker's readiness is very crucial for successful disclosure of diagnosis in HIV-infected children.<sup>13</sup>

Starting in 2005, a group of multidisciplinary professionals involved in HIV care at Siriraj Hospital, Queen Sirikit National Institute for Child Health (QSNICH), and the Thailand Ministry of Public Health-U.S. CDC Collaboration developed a disclosure model to assist caretakers during the process of disclosing HIV diagnosis to infected children and to support these children and caretakers.<sup>13</sup> The model emphasises counselling of caretakers to assess their readiness to disclose and to support them during the decision-making process. This disclosure model has been implemented as a routine service at the two participating clinics since 2005. A previous evaluation of this model showed that substantial time was required for the process of readiness preparation for caretakers.<sup>13</sup> The average time required for preparation, measured from the point of enrollment to the point of disclosure, was 15.2 months. While clinical studies have suggested that caretaker's readiness is crucial for HIV diagnosis to be disclosed to a child successfully, data on predictors of disclosure readiness are limited. This study explored factors associated with readiness for disclosure among caretakers who participated in this programme for at least one year.

## Methods

This study was part of a collaborative project to develop a counselling-based diagnosis disclosure model for HIV-infected children in Thailand. The model was implemented at two teaching hospital-based paediatric HIV treatment centres in Bangkok, Siriraj Hospital and

QSNICH, during 2005–2008. The detail of the model development has been described elsewhere.<sup>13</sup>

The disclosure model comprised four steps: (1) eligibility screening, (2) assessment of the caretaker's and the child's readiness for disclosure, (3) disclosure and (4) post-disclosure follow-up. All caretakers of HIV-infected children aged seven years or older who received care at the two participating clinics were screened. Eligibility criteria included children's HIV status not being disclosed and caretakers willing to participate in the programme. Exclusion criteria for children were significant cognitive impairment, suicidal ideation, psychosis or urgent medical conditions. Exclusion criteria for caretakers were severe medical or psychiatric conditions that preclude participation in the disclosure process. Caretakers of eligible children who were willing to participate in the programme were scheduled for readiness assessment counselling. The counselling was conducted by psychologists, nurses or social workers in the participating clinics who were experienced in caring for HIV-infected children and families.

In the step of readiness assessment (step 2), counsellors interview caretakers separately from their child following the programme guidelines. The guidelines are written as a manual with clear instruction how to conduct counselling (available online at [www.cqihiv.com/ViewDocumentDetail.aspx?ID=3&Title=Pediatric HIV Disclosure Manual](http://www.cqihiv.com/ViewDocumentDetail.aspx?ID=3&Title=Pediatric%20HIV%20Disclosure%20Manual)). During the counselling, a semi-structured questionnaire was used to explore various caretaker's perceptions that might influence their decision to disclose, such as their perception about a child's ability to understand the HIV diagnosis and keep it secret; their expectation that disclosure would improve the child's adherence/self-care; their concern that disclosure would have negative impacts on the caretaker–child relationship and their opinion about the appropriate age at which to disclose to a child. Through the counselling process, counsellors worked with caretakers to determine the caretaker's and the child's readiness. A caretaker was considered ready to disclose if the caretaker (a) perceived that the child was ready and (b) had made the decision to disclose the child's HIV diagnosis to their child. Caretakers made their own decision without being pressed by counsellors. A disclosure session was scheduled when it was determined that the caretaker was ready. If a caretaker was not ready, additional readiness assessment counselling sessions were scheduled. Readiness assessment might be completed in one single session or take multiple sessions, which usually occur every two to three months per regular scheduled follow-up visits.

As this study focused on the caretaker's readiness for disclosure after receiving counselling in step 2, the primary outcomes of interest were factors associated with being ready within one year of participation in the programme among caretakers. The period of one year was selected because it was found in our previous study to be the average time required for caretaker preparation.<sup>13</sup> Counsellor's notes including what was recorded in the semi-structured questionnaire were used for analysing factors influencing caretaker's readiness. In addition, data on children's demographics, disease severity and recent CD4 count were obtained from medical records upon enrollment.

## Data analysis

Mean, standard deviation (SD) and median values were calculated for continuous variables, where appropriate, and frequencies were measured for categorical variables. Univariate analyses were used to compare the characteristics, including the disclosure attitudes and beliefs, of caretakers who were ready for disclosure and those who were not. All correlates from univariate analyses with  $p < 0.05$  were included in a multivariate model using forward stepwise regression. The assumption that the quantitative variables were linear in the logistic model was checked and, if not verified, they were transformed to dummy variables using median value or other well-established cut-off values. All statistical significant testing were two tails with a significance level of  $p < 0.05$ . All analyses were conducted using SPSS Statistics 16 (IBM SPSS, Chicago, IL).

## Human subjects protections

The disclosure model was developed and integrated into routine disclosure counselling services. Data were collected by clinic staff as part of routine services at both hospitals. The study sought informed consent from each child's caretaker to enable the analysis of their clinical data for model evaluation purposes. Human subject research ethics approval for the study was obtained from the U.S. Centers for Disease Control and Prevention, the Thailand Ministry of Public Health and the two participating hospitals.

## Results

Among a total of 438 HIV-infected children seven years and older receiving care at the two participating centres, 398 (89%) children were eligible for the disclosure programme. Reasons for ineligibility included lack of informed consent ( $n = 18$ ); having conditions that precluded effective communication ( $n = 6$ ) and awareness of HIV status ( $n = 16$ ). Of 398 caretakers of eligible children who underwent readiness assessment counselling, 273 caretakers (69%) had participated in the programme for one year or more by the time of this analysis. Among those, 195 caretakers (71%) were determined to be ready for disclosure within one year and 78 caretakers (29%) were not yet ready at the end of one year.

Demographics and clinical characteristics of the 273 children whose caretakers participated in the programme for one year or more are shown in Table 1. One hundred and sixty-five children received treatment at QSNICH and 108 children received treatment at Siriraj Hospital. The children's median age was 10 years (range: 7–16 years). Slightly less than half (46%) were male. About one-third of the children were under the care of biological parents and two-thirds lived with extended family. Children's mean CD4 was 20%. All of the children were receiving ART.

Caretaker's factors relating to disclosing HIV diagnosis to their child obtained using semi-structure questionnaires during the readiness assessment counselling are shown in Table 2. Almost 90% of caretakers had talked with their child about the child's illness or the necessity of taking medications, while not disclosing the child's HIV diagnosis. Eighty-eight percent of caretakers perceived that their child had the ability to understand the diagnosis of HIV. Twenty percent perceived that their child might have been suspicious of their HIV

diagnosis. Sixty percent expected that disclosure could improve the child's adherence and self-care. Only a few caretakers were concerned that disclosure might have a negative impact on the parent-child relationship or create stigma towards their child. Sixty percent thought that the proper age of children for disclosure was between seven and 12 years old, rather than >12 years old.

Factors associated with caretaker readiness for disclosure within one year are shown in Table 3. The results of univariate analyses indicated that caretaker's readiness was significantly associated with receiving care at Siriraj Hospital, the age of a child (>9 years), a child's severe immunosuppression, caretaker having talked with the child about the child's illness, caretaker's perceptions that their child had the ability to comprehend the diagnosis, was able to keep the diagnosis secret, and might have suspected their HIV diagnosis, caretaker's expectation that disclosure could improve the child's adherence/self-care, and caretaker's opinion that the proper age for disclosure is between seven and 12 years old as opposed to older than 12 years. After adjusting for the effect of other variables using logistic regression analysis, seven factors remained significantly associated with disclosure readiness: receiving care at Siriraj Hospital (adjusted OR 2.38; 95% CI 1.01, 5.58); child's age >9 years (adjusted OR 7.23; 95% CI 2.62, 19.95); child with severe immunosuppression (adjusted OR 6.54; 95% CI 1.36–31.36); caretaker having talked with the child about the child's illness (adjusted OR 3.80; 95% CI 1.06–13.70); caretaker's perception that child had the ability to comprehend the diagnosis (adjusted OR 7.05; 95% CI 2.03–24.47); caretaker's perception that the child was able to keep the diagnosis secret (adjusted OR 4.88; 95% CI 2.03, 11.70); and caretaker's opinion that the proper age for disclosure is between seven and 12 years (adjusted OR 5.85; 95% CI 2.33, 14.67).

## Discussion

This study examined factors associated with disclosure readiness within one year among caretakers who received counselling on disclosing HIV diagnosis to their HIV-infected children. We found that caretaker's readiness was associated with the treatment site, child's age, caretaker's having talked with their child about the child's illness, caretaker's perceptions that the child was able to comprehend the diagnosis and to keep the diagnosis secret and the caretaker's opinion on the proper age for disclosure. Consistent with other studies, the most important factor for disclosure readiness was the caretaker's perception of their child's cognitive maturity to comprehend the disease and the implications of their infection.<sup>9,14–17</sup> Caretakers of older children (i.e., nine years or older) in our sample were more likely to be ready for disclosure.<sup>9</sup> It was also found that caretakers who thought that the appropriate child's age for disclosure was between seven and 12, as opposed to more than 12 years old, were more likely to be ready to disclose HIV diagnosis to their child. This suggests that caretaker's perception about the developmental capacity to understand the disease concept among school-age children is a critical factor associated with caretaker readiness for disclosure.

Almost 90% of caretakers in our sample had discussed certain aspects of their child's illness with their child such as the importance of ARV adherence for improved health outcomes without disclosing the child's HIV status. This suggests that caretakers in this study, similar

to those from other reports, were reluctant to reveal the HIV diagnosis and communicated with their child about the child's illness without explicitly naming the disease.<sup>11,18</sup> We found that caretakers who had discussed the child's illness with the child were more likely to be ready for disclosure. In parallel, we also found that caretakers of children with severe immunosuppression were more likely to be ready for disclosure compared to their counterpart. This finding might reflect the caretaker's awareness of the necessity of having open communication with their child in order to maintain his/her positive health behaviour and good ARV adherence. However, existing literature fails to demonstrate a consistent finding regarding an association between disclosure and HIV disease severity.<sup>5</sup> While some disclosure literature has shown that uninfected parents/caretakers disclose to their child more frequently than biological parents who are living with HIV,<sup>19</sup> we did not find caretaker readiness to be associated with being or not being biological mother in our study. In addition, we found that caretakers of children receiving care at Siriraj Hospital, as opposed to at QSNICH, were more likely to be ready for disclosure. Although the two study sites are tertiary paediatric HIV centres in Bangkok and counselling at both sites were done per the same guideline and manual, there might be some differences in socioeconomic backgrounds of the caretakers and in the counsellor's characteristics, as well as differences in care delivering system between the two hospitals, which could contribute to the different results. However, we did not collect this information in this study.

Some limitations were identified in this study. The subjects were limited to two urban tertiary centres where the children received comprehensive treatment by multidisciplinary care teams. Therefore, the results may have limited generalisability to other settings, where children's and caretaker's characteristic, and availability of support for disclosure are different than those of the population in this study. Further, our primary outcome was caretaker's readiness, which is not the same as disclosure itself. There may be other influencing factors on the actual disclosure decision and process that have not been taken into account in this study, such as a child's initiation of risky behaviours. In addition, missing data about the perceptions of caretakers relating to HIV disclosure may have resulted in incorrect ascertainment of predictors for caretaker readiness. Finally, we did not collect data on the details of counselling process or counsellor's characteristics among each counselling session. Therefore, we could not assess the association of caretaker's readiness and the counsellor's characteristics or other programme factors.

Despite these limitations, this study has important implications. First, the awareness of their HIV diagnosis among infected youth in Thailand is low. There is an urgent need to facilitate the disclosure process before these children begin to engage in risky behaviours. Second, there are factors associated with the readiness of caretakers to disclose which may be useful for prioritising the disclosure readiness and preparation counselling process, given the limited personnel for this activity, and for designing counselling messages for caretakers who are not ready to disclose HIV diagnosis to the child under their care.

## Conclusions

We found that the following characteristics assessed during readiness assessment counselling were associated with caretaker's readiness for disclosure: child's age of nine

years or older, child's severe immunosuppression, caretakers having prior discussion with their child about the illness, caretaker's perception that their child had the ability to understand the HIV diagnosis and to keep it secret, and caretaker's opinion that the proper age for disclosure is between seven and 12 years old. These determinants may be useful for guiding the disclosure readiness preparation process. Readiness assessment and preparation for caretaker disclosure are important elements of successful paediatric HIV disclosure interventions.

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**Table 1**

Demographics and clinical characteristics of the children.

<b>Characteristics (N = 273)</b>	
Site: n (%)	
QSNICH	165 (60)
Siriraj	108 (40)
Median age (range): years	10 (7–16)
Male gender: n (%)	126 (46)
Types of primary caretaker: n (%)	
Biological parent	91 (33)
Relative	154 (56)
Other	28 (10)
Family structure: n (%)	
Single	68 (25)
Extended	182 (66)
Foster	23 (8.4)
School attendance: n (%)	253 (93)
Mean CD4 percent (SD)	20.4 (9.3)
Median CD4 (IQR): cell/mm <sup>3</sup>	578.5 (312, 863)
Current severe immunosuppression (CD4 <200 cell/mm <sup>3</sup> ): n (%)	39 (14)

IQR: interquartile range; SD: standard deviation; QSNICH: Queen Sirikit National Institute for Child Health.

**Table 2**

Caretaker's factors relating to disclosing HIV diagnosis to their child.

<b>Ideas and perceptions</b>	<b><i>n/N (%)</i></b>
Caretakers having talked with child about child's illness	240/268 (90)
Caretaker's perception that child had the ability to understand HIV diagnosis	220/249 (88)
Caretaker's perception that child had learning problem	25/273 (9.2)
Caretaker's perception that child was able to keep HIV diagnosis confidential	67/249 (27)
Caretaker's perception that child might have been suspicious of his/her HIV diagnosis	56/268 (21)
Caretaker's expectation that the child's adherence/self-care might be improved after disclosure	91/150 (61)
Caretaker's concern that disclosure might have negative impact on parent-child relationship	7/249 (2.6)
Caretaker's concern disclosure would create stigma to their child	15/249 (6.0)
Caretaker's opinion on the proper ages of children for disclosure	
7-12 years	131/217 (60)
>12 years	86/217 (40)

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Table 3

Factors associated with readiness for disclosure within one year among caretakers who participated in readiness preparation counselling at two paediatric HIV treatment centres in Bangkok, 2005–2008.

Factors	Univariate analysis			Multivariate analysis	
	Caretaker were ready for child's disclosure (N = 195) n (%)	Caretaker were not ready for child's disclosure (N = 78) n (%)	Crude OR (95% confidence interval)	Adjusted OR (95% confidence interval)	
<b>Child's demographic and clinical characteristics</b>					
Site	QSNICH	107 (65)	58 (35)	1	1
	Siriraj	88 (81)	20 (19)	2.39 (1.33, 4.27) <sup>a</sup>	2.38 (1.01, 5.58) <sup>b</sup>
Age	9	76 (56)	60 (44)	1	1
	> 9	119 (87)	18 (13)	5.22 (2.86, 9.51) <sup>a</sup>	7.23 (2.62, 19.95) <sup>a</sup>
Gender	F	109 (74)	38 (26)	1	
	M	86 (68)	40 (32)	0.75 (0.44, 1.27)	
Primary caretaker	Bio-parent	66 (72)	25 (28)	1	
	Relative	107 (70)	47 (30)	0.72 (0.26, 1.98)	
	Else	22 (79)	6 (21)	0.62 (0.24, 1.63)	
Child's not attending school	Yes	181 (72)	72 (28)	1	
	No	13 (68)	6 (32)	0.86 (0.32, 2.36)	
Child with current severe immunosuppression <sup>c</sup>	No	158 (70)	67 (30)	1	1
	Yes	35 (90)	4 (10)	3.71 (1.27, 10.85) <sup>b</sup>	6.54 (1.36, 31.36) <sup>b</sup>
<b>Caretaker's factors</b>					
Caretaker having talked with child about child's illness	No	15 (54)	13 (46)	1	1
	Yes	178 (74)	62 (26)	2.49 (1.12, 10.85) <sup>b</sup>	3.80 (1.06, 13.7) <sup>b</sup>
Caretaker's perception that child had learning problem	No	164 (76)	52 (24)	1	
	Yes	19 (76)	6 (24)	1.04 (0.38, 2.65)	
Caretaker's perception that child had the ability to understand HIV diagnosis	No	14 (48)	15 (52)	1	1
	Yes	162 (74)	58 (26)	2.99 (1.36, 6.58) <sup>a</sup>	7.05 (2.03, 24.47) <sup>a</sup>
Caretaker's perception that child was able to keep secret	No	36 (54)	31 (46)	1	1
	Yes	140 (77)	42 (23)	2.87 (1.59, 5.18) <sup>a</sup>	4.88 (2.03, 11.70) <sup>a</sup>

Factors	Univariate analysis		Multivariate analysis	
	Caretaker were ready for child's disclosure (N = 195) n (%)	Caretaker were not ready for child's disclosure (N = 78) n (%)	Crude OR (95% confidence interval)	Adjusted OR (95% confidence interval)
Caretaker's perception that child might have been suspicious of HIV diagnosis	No	138 (65)	74 (35)	
	Yes	55 (98)	1 (2)	29.46 (4.00, 217.44) <sup>d</sup>
Caretaker's expectation that disclosure could improve the child's adherence/self-care	No	48 (81)	11 (19)	1
	Yes	84 (92)	7 (8)	2.75 (1.00, 7.56) <sup>b</sup>
Caretaker's concern that disclosure might result in negative impact on parent-child relationship	No	171 (71)	71 (29)	1
	Yes	5 (71)	2 (29)	1.04 (0.20, 5.48)
Caretaker's concern that disclosure would create stigma to their child	No	166 (71)	68 (29)	1
	Yes	10 (67)	5 (33)	0.82 (0.27, 2.49)
Caretaker's opinion on the proper ages of child for disclosure	>12 years	59 (69)	27 (31)	1
	7-12 years	110 (84)	21 (16)	2.40 (1.25, 4.60) <sup>d</sup>

All variables with  $p$  value  $<0.05$  were included in the multivariate analysis. The final model resulted factors were shown as in final column.

<sup>a</sup>  $p$  value  $<0.01$

<sup>b</sup>  $p$  value  $<0.05$

<sup>c</sup> Severe immunosuppression: CD4 less than 200 cells/mm<sup>3</sup>.