An Integrated Approach to HIV Disclosure for HIV-Affected Families in Thailand

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Abstract

Disclosure of HIV status to family members could improve communication, relationship, and cohesion. We evaluated the impact of a family-centered program designed to increase the readiness/willingness of parents to disclose HIV status to their children. People living with HIV (PLWH) with children \geq 8 years were surveyed regarding HIV knowledge, family relationship, attitudes, willingness/readiness to disclose, and they were then invited to participate in group education and family camps. Of 367 PLWH surveyed, 0.8% had disclosed, 14.7% had not yet disclosed but were willing/ready to disclose, 50.4% were willing but not ready, and 33.2% did not wish to disclose. The educational sessions and camps led to significant improvements of HIV knowledge and disclosure techniques, and readiness/willingness to disclose. Given the benefits of group education and family camps in supporting PLWH to improve their communication with their families and disclose their HIV status, these supporting activities should be included in HIV programs.

Keywords

HIV, disclosure, children, willingness, readiness

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Introduction

Research has demonstrated that family support for people living with HIV (PLWH) is an important contributor to improved quality of life, better perceived health, fewer symptoms of depression, and greater antiretroviral therapy (ART) adherence.¹⁻⁷ However, rates of self-disclosure of HIV status are reported to be lower for family members than partners and friends.⁷⁻⁹ Reasons for nondisclosure are cited as the desire to protect others from distress and harm, fear of discrimination, exclusion, abandonment, accusations, conflict, abuse, and assault.^{2,7,8,10-17}

It has been suggested that in some cultures there may be additional barriers to disclosure for PLWH.⁷ In Asia, the cultural values of harmony and avoidance of conflict may contribute to the reluctance of PLWH to disclose their diagnosis since these beliefs are associated with a desire to protect family from shame or obligation to help, and an aversion to communicating highly personal information.¹⁸

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What Do We Already Know about This Topic?

Disclosure to parental HIV status to their children can be either beneficial or harmful or both. No one really knows what is the best way to disclose.

How Does Your Research Contribute to the Field?

The result from this study could publicize our experience from the HIV disclosure project by the workshop, HIV disclosure handbook, broadcast over the national TV stations, newspapers and website. We can conclude that the project could generate the interest of the local governmental and non-governmental organizations as well as civil society.

What Are Your Research's Implications toward Theory, Practice, or Policy?

Due to sharing a diagnosis of HIV may be difficult under the best of circumstances, and discussing HIV/AIDS with children poses additional challenges. HIV-infected parents invariably struggle with questions of whether, when, and how to tell their children that they are infected with HIV irrespective of the HIV status of their children. Experiences with paediatric HIV disclosure have shown that supports from counselors and clinicians and the shared experiences of other parents can be of great help to parents. Therefore, HIV Disclosure knowledge and counseling skills for healthcare workers and PLWH volunteers to facilitate HIV disclosure by HIV affected parents. This requires effective practical training and the HIV disclosure model for HIV-affected families in Thailand.

For mothers living with HIV (MLWH), disclosure of HIV status to family members can be a daunting and emotional task accompanied with the potential for both support and rejection.^{7,14,18} Children can be a major motivator to increase MLWH's longevity but are also their greatest worries in regard to children's health and future.^{19,20} The mother's judgment of their child's maturity and ability to handle the information and not be psychologically harmed are key in deciding whether to disclose their HIV status.^{3,7,14,17,19}

Parents are more likely to disclose their HIV status to older children and those who are likely to keep the information confidential; mothers are likely to disclose earlier than fathers and more likely to disclose to daughters than sons.^{5,14,19,21} Disclosure has been found to be more common among parents with poor health, stressful life events, larger social networks, and where children were perceived to be experiencing HIV-related stigma.^{14,21}

Some have reported problematic child behavior following disclosure; however, these may be attributable to maternal sensitivity in assessment and expectation of a disruptive impact.^{21,22} The majority of the literature demonstrates HIV disclosure as having benefits for both parent and child including improving communication, relationships, and cohesion among family members.^{3,5,12,14,19,23} In addition, children of MLWH have been reported to have better self-esteem and less aggressive behavior when they are made aware of their mother's diagnosis.^{3,14}

In most cases, it would appear that MLWH believe that they should be the one to disclose their diagnosis and do not regret doing so after the fact.^{12,14,17} However, some report wishing they had planned better and prepared themselves to communicate this information to their children.¹⁴ In one study, all forms of education (whether self-education, conferences or speaking with a health professional) were helpful and empowering for MLWH; enabling them to better share their HIV status with their children and supporting a need for assistance at this critical time.¹⁴

Family-centered HIV care models suggest that support for parental disclosure should happen at a household level, engaging, where possible, all family members.¹⁹ Positive family relationships trust and effective communication skills are essential for disclosure to be constructive.²⁴⁻²⁷ Cognitive behavioral therapies to improve mother-child communication and parenting skills have been found to be effective in achieving higher rates of successful disclosure.²⁵ One such program, Teaching, Raising and Communicating with Kids (TRACK), explores the mothers' concerns, assesses children's readiness to receive the news, plans, and practices disclosure.²⁵ Children participating in the TRACK program, whose mothers disclosed their HIV status, were happier and exhibited fewer symptoms of depression and anxiety. Family camps, that provide an opportunity for families to spend time together and participate in recreational activities, have also been educational and empowering for families of PLWH.28-30

Disclosure of HIV status to family members is challenging in Thailand, with particularly low rates of disclosure in some provinces, such as the North East.^{11,21,31} There have been, to date, no interventions or models in Thailand to support PLWH in disclosing their HIV status to their family members. There is a need for health care providers to be client- and family-centered, tailoring both timeline and processes for HIV treatment and counseling to the needs of the individual and their family.^{11,19,32} Parents living with HIV require support to plan the disclosure of their HIV status so that they in turn may better support their children. This study evaluates the impact of group educational and family camp activities on parental disclosure of HIV status to their children, family relationships, and attitudes toward disclosure including readiness and willingness to disclose.

Methods

Participants

After gaining approval from the relevant institutional review boards, HIV-affected families, with children aged 8 years or older, were recruited from the Thai Red Cross AIDS Research Centre in Bangkok and the Queen Savang Vadhana Memorial Hospital in Chonburi, between January 2011 and May 2012. Study objectives and procedures were explained to the participants and written informed consent was obtained prior to screening for study eligibility. To be included in this study, the parent with HIV had to be a Thai citizen and aged 18 years or older; with an HIV-affected or HIV-infected child of at least 8 years of age unaware of maternal HIV status. The child was also asked to sign an assent form for the study. Participants were excluded from the study if they had reported having a severe illness and/or mental health problems.

Procedures

Participants were surveyed in face-to-face interviews to determine their willingness and readiness to disclose their HIV status to their children. The interview questions were validated by disclosure experts and in a pilot test of 30 PLWH. Participants were also questioned regarding any supportive factors and/or barriers affecting their readiness to disclose. Children were assessed for their understanding of their parent's health status and their readiness to receive more information on their parent's health on another day outside the clinical environment.

The parents living with HIV were then given the opportunity to participate in group education sessions and family camps, coordinated by facilitators (nurses, nutritionists, counselors, and peer educators) trained in disclosure techniques. The facilitator training, provided by the Communication Skills Training Centre of the Paediatric Department of Chulalongkorn University, included attention to the counseling process, HIV disclosure, disclosure techniques, and a skill-building workshop.

Three group educational sessions were held over a period of 12 months with parents being given the option of how many to attend and whether to bring their children. The educational sessions provided practical information on HIV including modes of transmission and treatment as well as psychosocial support. The sessions discredited the myths that PLWH are dangerous or are "bad" people and recognized that PLWH could live full and active lives. There was considerable discussion of disclosure of HIV status to others including the associated advantages and disadvantages, techniques for disclosure, and how to prevent or mitigate potential problems arising from disclosure. Role play was utilized to practice disclosure and address response scenarios. Following the sessions, a questionnaire was used to assess HIV knowledge, attitudes and readiness to HIV disclosure, and experiences of HIV disclosure.

Additional group sessions provided an opportunity for parents living with HIV to share experiences of disclosure, how disclosure occurred, and the consequences. These sessions provided further opportunity to address concerns particularly those related to parent-child relationships. Once again a short selfadministered questionnaire was given following the sessions to assess attitudes and readiness of participants for HIV disclosure.

Following the group sessions, parents who indicated that they were ready to disclose their HIV status and whose children indicated a certain level of readiness to receive the information were given the opportunity to attend family camps. These camps aimed to strengthen relationships and improve communication between family members, increase their understanding of HIV, motivate and empower attendees, and improve their quality of life. Camp activities included icebreakers and team building exercises, healthy living and eating, stress management and exercise, adherence to care and medication, and "Buddha at home" sessions, which included mindfulness and meditation. When parents were ready to disclose their HIV status, the family was taken to a private room with trained staff. The staff provided moral support to increase parents' selfconfidence and intervened to enhance communication if the disclosure process did not proceed smoothly.

Prior to attending camps, participants' knowledge about HIV, readiness and willingness to disclose, and the quality of the family relationships were assessed during questionnaire interviews. Self-administered questionnaires were also provided to parents and children at the end of the camp to assess participants' satisfaction, and to grade each camp activity regarding whether it assisted with HIV disclosure or improved healthy living skills. Following the camp, researchers visited the families twice, after 3 and 6 months, using a similar questionnaire to assess the parent's knowledge and skill regarding HIV disclosure, whether they had disclosed their HIV status, either directly or by implication, and the impact of the interventions on family communication and relationships.

Data Analysis

The willingness and readiness for HIV disclosure, as well as the disclosure rate, were calculated, with the 95% confidence intervals (CIs). Comparisons were made using a χ^2 test. The associated factors of attitudes, willingness, and readiness of HIV disclosure were evaluated using a series of logistic regression models. Covariates tested included age, gender, educational level, income, children's age, and lifestyle factors.

Ethical Approval and Informed Consent

This study was approved by the institution review board of the Faculty of Medicine, Chulalongkorn University (approval no. 308/53 and 208/54) and the ethics committee of Queen Savang Vadhana Memorial Hospital (approval no. 12/2553 and 13/2554). All participants provided written informed consent prior to enrollment in the study.

Results

Three hundred and sixty-seven HIV-infected parents (18.8% male and 81.2% female) from 325 families together with 125 children (47% boys and 53% girls) participated in this survey. Median (SD) age of the parents was 37.5 (\pm 5.2) years, median (SD) age of HIV-infected children (n = 31) was 12.0 (\pm 3) years, and median (SD) age of HIV-uninfected children (n = 94) was 11.5 (\pm 4.3) years. The proportion of participants, who were married, widowed, or separated, were 70.6%, 24.5%, and

Variables	Disclosed Group	Willing and Ready to Disclose Group	Willing But Not Ready to Disclose Group	Didn't Want to Disclose Group	Didn't Respond Group	All Group	P Value
Number (%)	3 (0.8)	54 (14.7)	185 (50.4)	122 (33.2)	3 (0.8)	367 (100)	
Age, mean (SD), years	37 (32-43)	39 (36-44)	37 (34-40)	37 (34-4I)	41 (30-47)	37 (34-41)	.0249
Male, n (%)	0 (0)	4 (7.4)	40 (21.6)	24 (19.7)	l (33.3)	69 (18.8)	.0826
Marital status, N (%)	I (33.3)	28 (51.9)	133 (71.9)	96 (78.7)	l (33.3)	259 (70.6)	.0034
Education: less than high school, n (%)	2 (66.7)	44 (81.5)	132 (71.4)	73 (59.8)	2 (66.7)	253 (68.9)	.0777
HIV duration: > 5 years	3 (100)	45 (83.3)	144 (77.8)	92 (73.8)	l (33.3)	285 (77.7)	.1110
Receiving ART	3 (100)	51 (94.4)	161 (90.1)	99 (91.7)	2 (100)	293 (90.2)	.0756
Duration of ART: >1 year	2 (66.7)	45 (88.2)	145 (90.I)́	99 (91.7)́	2 (100)	293 (90.2)	.0756

Table I. Demographic Data and Proportion of the Willingness and Readiness.

Abbreviations: ART, antiretroviral therapy; SD, standard deviation.

Table 2. Demographic Data amon	g Infected versus Uninfected Children.
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Variables	Total Group	Infected Children	Uninfected Children	
Number	125	31	94	
Age mean (SD), years	-	12.0 (3.0)	11.5 (4.3)	
Male, n (%)	59 (47.2)	14 (45.2)	45 (47.8)	
Have been to hospital with parent, n (%)	35 (28.0)	31 (100)	4 (4.3)	
The reason to go to the hospital of parent, n (%)	(),			
Checkup	78 (62.4)	19 (61.3)	59 (62.8)	
Drug receiving	30 (24.0)	6 (19.4)	24 (25.5)	
Illness	19 (15.2)	6 (19.4)	I3 (I3.8)	
Other reasons	22 (17.6)	0 (0)	22 (23.4)	
Wondering about parent health status, n (%)	64 (51.2)	15 (48.4)	49 (52.I)	
Notice that their parent taking medicine, n (%)	101 (80.8)	10 (32.3)	91 (96.8)	
Understanding about kind of their parent drug, n (%)		· · · ·		
Antiretroviral therapy	6 (4.8)	2 (6.5)	4 (4.3)	
Some kind of medicine	61 (48.8)	24 (77.4)	37 (39.4)	
Not know	48 (38.4)	5 (16.I)	43 (45.7)	
Impact of parental medication on child, n (%)	(),			
Anxiety regarding their parent's health	55 (44.0)	8 (25.8)	47 (50.0)	
Want their parent's health to improve	II (8.8)	0 (0)	II (II.7)	
Believe their parent is sick	16 (12.8)	8 (25.8)	8 (8.5)	
Eager to understand and/or concern regarding parent's health	7 (5.6)	0 (0)	7 (7.4)	
Impassive regarding parent's health status	34 (27.2)	13 (41.9)	21 (22.3)	
Believe their parent's health status is the same as their own	2 (1.6)	2 (6.5)	0 (0)	
Eager to know about their parent health status, n (%)	(),			
Yes	100 (80.0)	20 (64.5)	80 (85.1)	
No	16 (12.8)́	9 (29.0)	7 (7.5)	
Already known	5 (4.0)	2 (6.4)	3 (3.2)	
Others	4 (3.2)	0 (0)	4 (4.3)	

Abbreviation: SD, standard deviation.

4.9%, respectively. The majority (88.6%) of parents living with HIV were receiving ART (Tables 1 and 2).

The initial survey of HIV-infected parents found that 3 (0.8%) of the participants had previously disclosed their HIV status to one or more of their children; 54 (14.7%) had not yet disclosed but were willing and ready to do so; 185 (50.4%) were willing to disclose but did not feel ready; 122 (33.2%) did not wish to disclose their HIV status; and 3 (0.8%) did not respond (Table 1). All of the children who had been told of their parent's HIV status were themselves not infected with HIV (Table 2).

Parents' major concerns regarding HIV disclosure included fears that the child was too young to understand HIV (47%); the child may fear contracting HIV (19%) from their parent; and the child may consider their parent to be a bad person (9%). Families with uninfected children had significant higher willingness and readiness to disclose than families with infected children (P = .03; Table 3). Predictors of willingness to disclose were determined by multivariate analysis and included parents aged 31 to 35 years (odds ratio [OR] = 3.06, 95% CI: $1.01-15.66, P \le .01$), parent being male (OR = 5.06, 95% CI: $1.55-16.50, P \le .01$),

Group		Number (%)						
	Disclosed	Willing and Ready to Disclose	Willing but not Ready to Disclose	Do Not Want to Disclose	Do Not Respond	All		
Disclosure survey	3 (0.8)	54 (14.7)	185 (50.4)	122 (33.2)	3 (0.8)	367 (100)		
Group Education	3 (3.8)	17 (21.7)	19 (24.3)	3 (3.8)	_	78 (100)		
Camp	I (3.0)	8 (24.2)	10 (30.3)	I (3.0)	-	33 (100)		

Table 3. Willingness and Readiness to Disclose: Comparing Data from Disclosure Survey—Group Education and Camp.

Table 4. Comparing Results from Follow-up at Months 3 and 6.

Month (Total Number of Families)	Number of Families (%)						
	Improved Family Relationship	Improved Family Communication	Increase HIV Disclosure Knowledge	Increase HIV Disclosure Skill	Imply HIV Status	Disclosed HIV Status	
3 (27) 6 (22)	22 (81.5) 19 (86.4)	22 (81.5) 19 (86.4)	5 (55.6) (50.0)	(40.7) 8 (36.4)	4 (5 .9) 7 (3 .8)	8 (29.6) 5 (22.7)	

and children aged >17 years (OR = 31.48, 95% CI: 10.71-92.57, $P \le .001$). Readiness to disclose was associated with age 31 to 35 and ≥41 years (OR = 5.33, 95% CI: 1.33-21.36, and OR = 5.18, 95% CI: 1.27-27.11; P = .02), higher education (OR = 2.26, 95% CI: 1.26-4.04, $P \le .01$), having ≥3 children (OR = 3.15, 95% CI: 1.37-7.23, P = .02), and children aged >17 years (OR = 2.75, 95% CI: 1.47-5.14, $P \le .01$; Table 1).

The survey of children's readiness to receive information regarding their parent's health revealed that 3.2% of children were already aware of their parent's HIV status; 80.8% had observed their parent taking medication and were eager to understand their parent's health status; 44.0% felt anxious regarding their parent's health; 12.8% believed their parent was sick; and 8.8% indicated they wanted their parent's health to improve. Approximately half of the children (48.8%) were aware that their parent was taking some kind of medication while 4.8% of the children knew their parent was taking anti-retroviral treatment (Table 2).

Of the initial 367 HIV-infected parents surveyed, 78 participated in group education and a total of 36 families, 60 PLWH, and 47 children attended 2 family camps. The survey following group education sessions revealed improvements in the attitudes to and knowledge of PLWH regarding HIV, their family communication and relationships. In addition, participants reported a better understanding of disclosure issues and techniques.

The group sessions and family camps were both associated with an apparent increase in the readiness and willingness of parents to disclose their HIV status to their children with 14.7% of initial survey participants being willing and ready to disclose compared to 21.7% following the group education and 24.2% after the family camps (Table 3). A total of 4 families undertook disclosure following these interventions, 3 following group education with 1 family disclosing while in family camp. There was also a reduction in the proportion of parents who "did not want to disclose" or were "willing but not ready to

disclose" from 33.2% and 50.4%, respectively, in the initial survey, to 3.8% and 24.3% of PLWH following the group education, respectively. Following the camp, only 1 family of the 33 participating (3%) did not wish to disclose and 10 families (30.3%) were willing but not ready to disclose. Discussions from the family camp indicated that the readiness of parents to disclose their HIV status is related to their attitudes to HIV, communication skills, family relationships, and the knowledge of techniques for HIV disclosure.

During the follow-up visits, at 3 and 6 months following the education group and camp, researchers observed continued strengthening of family relationships and communication as well as improvements in knowledge and skill regarding how to disclose one's HIV status (Table 4). Improved family relationships and improved communication were reported by 81.5% and 86.4% of PLWH at 3 and 6 months, respectively. A greater level of care and concern, by the children, for parents living with HIV was also noted in families where disclosure had taken place. Further PLWH disclosed their status to their children at 3 and 6 months, with 8 (29.6%) of the 27 reporting disclosure at 3 months and 5 (22.7%) of 22 at 6 months. In some instance, PLWH reported having not disclosed but implied their HIV diagnosis, to their children, 14 (51.9%) at 3 months and 7 (31.8%) at 6 months.

Discussion

Findings from this study confirm that it is very uncommon for Thai parents living with HIV to independently disclose their diagnosis to their children. Indeed, the rate of disclosure to children appears lower than those reported in other studies.^{3,33,34} However, the main reasons for nondisclosure, including the child's immaturity, possible loss of confidentiality or accusations of poor character, and protecting the child from distress, were consistent with those cited in the literature. And, despite these apprehensions, nearly two-thirds of the parents surveyed were willing to disclose their HIV status to their children. In instances, where the father was HIV negative and mother was HIV positive, the fathers tended to encourage disclosure with the hope that the child would be supportive in caring for their mother. However, when parents both were living with HIV then they often indicated a preference not to disclose but rather care for each other.

Parents were also less likely to be willing and ready to disclose their HIV status if the child was diagnosed with HIV. This finding may reflect the parental guilt for the child's infection and concerns that the child will consider them a "bad person" and blame them for the infection. As in other studies, parents were more willing and ready to disclose if the child was older, for example over 17 years of age.^{19,21,35} However, unlike other reports, fathers were more willing to disclose their status than mothers. This may be related to fathers seeking the child's support in care as compared to the maternal need to protect children. Parents with higher education were also found to be more likely to be ready, which may be in keeping with a better understanding of HIV and/or social-psychological factors associated with education such as a greater sense of control over their lives and health, and a higher levels of social support.³⁶ PLWH with 3 or more children were also more likely to be ready to disclose. This may be related to having older children and/or the increased pressure from multiple children to reveal their HIV status.

The majority of children reported having observed parental medication and expressed a desire to better understand their parent's health. Almost half indicated that their parent's health caused them some anxiety. Disclosing information about a parent's illness has been found to reduce levels of anxiety among the children with terminally ill parents while parental HIV disclosure has been associated with better self-esteem and lower levels of aggression in children.^{14,37} These potential benefits for the child and their interest in their parent's health are strong supporting factors for disclosure.

Attendance at group education and family camps was associated with improvements in HIV knowledge, understanding of disclosure techniques, as well as family communication, and relationships. There was also an apparent increase in the readiness and willingness of parents to disclose their status with 4 additional families disclosing. These improvements in family relationships and communication echo the outcomes of other disclosure studies.^{3,5,12,14,19,23} Improved family relationships will likely provide increased support for PLWH which in turn, according to other researchers, may result in improved ART adherence, quality of life, and perceived health, as well as fewer symptoms of depression.¹⁻⁷ In addition, it is suggested that children's behavior self-esteem and anxiety may improve.^{14,37}

Limitations

This study represents pragmatic research in a health care setting. Participants self-selected to attend the interventions, group education, and family camps, as is the case in routine practice. As such, the study suffers from selection bias as the participants were likely more willing and ready to disclose than those who did not participate. This study does not measure disclosure rates and attitudes in those who did not elect to participate in the interventions, nor does it specifically compare changes in the attitudes of individuals attending the education and camps prior to and following the interventions. In addition, it does not include quantitative measures of quality of life or perceived health or consider changes in maternal clinical outcomes or behavior and anxiety in children following disclosure. Finally, there was drop out of families available for follow up at 3 and 6 months.

Conclusion

In Thailand, there are currently very low rates of parental disclosure of HIV status to children. This study confirms that family-centered interventions provide improvements in the family relationships of PLWH and to their willingness and readiness to disclose their HIV status. There is a need for further studies to explore the barriers and supporting factors for parental disclosure to children, in order to develop programs to better support PLWH in disclosure, and improve the quality of life of families living with HIV.

Authors' Note

The views expressed are those of the authors and should not be construed to represent the positions of the U.S. Army or the Department of Defense.

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Declaration of Conflicting Interests

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