



# Caretakers' barriers to pediatric antiretroviral therapy adherence in Vietnam – A qualitative and quantitative study



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## ARTICLE INFO

### Article history:

Received 4 August 2016

Revised 16 October 2016

Accepted 1 February 2017

Available online xxxx

### Keywords:

Antiretroviral therapy adherence

Caretakers' barriers

Children

## ABSTRACT

**Background:** Poor antiretroviral therapy (ART) adherence leads to drug resistance and treatment failures. The options for second and third line ART regimens, particularly for pediatric patients, are very limited in low and middle-income countries. HIV-infected children are mostly passive drug-takers, thus caretakers play a very important role in assuring ART adherence. Pediatric ART adherence is still a challenging problem in Vietnam since non-adherence is the major risk factor for treatment failure. Our study explores and measures caretakers' barriers in order to improve pediatric ART adherence in future.

**Methods:** Exploring caretakers' barriers was conducted through a qualitative study with Focus Group Discussion (FGD) on two topics: 1. Current society – family support and difficulties in taking care children under ART; 2. Stigma experience. Based on the finding from the qualitative study a quantitative study measuring caretakers' barriers was conducted through a designed questionnaire. Study methods strictly followed the consolidated criteria with 32-item checklist for interviews and focus groups.

**Results:** In total eight FGDs with 53 participants were conducted. Common caretakers' barriers to children's ART adherence, were financial burden, lack of ART KP (Knowledge-Practice), stigma, depression, shifting caretaker, drug taste and side effects, lack of family support, fixed health check-up schedule and HIV non-disclosure. In the questionnaire study a total of 209 caretakers participated. The most commonly reported caretakers' barriers were: financial burden (144; 69%), KP burden (143; 68%), depression (85; 41%) and stigma (30; 14.8%). Some caretakers' characteristics that significantly associated with reported barriers ( $p < 0.05$ ). Rural caretakers reported significantly more financial burden (OR = 2.26) and stigma (OR = 3.53) than urban. Caretakers with under high school level education reported significantly more financial burdens (OR = 2.08) and stigma (OR = 4.15) compared to caretakers with high school education or over.

**Conclusion:** Financial burden, KP burden, depression and stigma were common reported caretakers' barriers to pediatric ART adherence. Family residence, caretaker's education level and job were considered as the key factors determining caretakers' barriers related to financial burden and stigma. These findings may be important for policy makers and researchers in order to develop effective interventions regarding to caretakers' burdens and associated factors. Furthermore, a tool for nurses in monitoring caretakers' barriers to pediatric ART adherence was developed first with FDG, and then interview questionnaire. This tool could be applied and modified easily in any pediatric ART clinic settings in accordance to economic, social and cultural circumstances.

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## 1. Background

HIV/AIDS epidemic is still a burden, especially in resource-limited settings. In the world, there were 36,9 million people living with HIV and around 2 million people were newly infected with HIV and 1.2 million people died of AIDS-related illnesses in 2014 (UNICEF report, 2015). In Vietnam 230,000 people were living with HIV in 2015 (Vietnam Administration for AIDS Control: Report, 2015).

Pediatric ART adherence is still a challenging problem in Vietnam since non-adherence is the major factor for ART first line treatment failure in children (V.T. An, 2011). ART adherence in pediatric patients is different depending method of assessment; highest when interviewing caretakers but lower when analyzing patients' records (M.D.A. Nhu, Diep, & Khanh, 2009).

Caretakers' difficulties are very diverse when depending on children's status such as age, health status; psychology; or on their own financial capacity (J. Haberer & Mellins, 2009). In Vietnam, caretakers' barriers to pediatric ART adherence have not been explored by any qualitative and/or quantitative studies. Our study aims to explore

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and measure the caretakers' challenges and barriers in taking care HIV-infected children during ART.

## 2. Methods

### 2.1. Study settings

The study was conducted in 2014–2015 at the HIV/AIDS out-patient clinic (OPC) in 3 main pediatric hospitals in Vietnam. Vietnam National Children Hospital manages HIV-infected children from the northern regions, Hanoi and surrounding provinces. Children's hospital 1 and 2 manage patients from the southern areas, Ho Chi Minh City and surroundings.

### 2.2. Study method

The consolidated criteria of 32-item checklist for interviews and focus groups were strictly applied in this study.

The two topics [1. Current society – family supports and difficulties in relation to taking care of children with ART; 2. Stigma experience] were mentioned in FGD (see Appendix 1). The number of FGDs was determined by the data saturation point i.e. no other ideas obtained.

### 2.3. Participant enrollment

In qualitative study, all caretakers arriving at the OPC on every Tuesday from 8 to 9 am were asked to participate in the study and recruited after giving consent to participate. The number of participants for each FGD was from 6 to 8 to assure the engagement of all participants. There were in total 53 caretakers joining the 8 FGDs. FGDs were conducted once weekly in a private room and lasted 45–60 min. Discussions were conducted in Vietnamese and were moderated by the first author and another trained FGD moderator, both native Vietnamese speakers.

In quantitative study, questionnaire interviews, caretakers were enrolled by the same means as the qualitative study (all caretakers arriving at the OPC Tuesday 8 to 9 am were asked to participate in the study and recruited after giving consent), but excluded if they had joined FGD. There were 209 caretakers joining the interviews performed by OPC nurses.

### 2.4. Data collection and analysis

Qualitative data were recorded and transcripts were processed by content analysis (previously described by Elo & Kyngas, 2008; Graneheim & Lundman, 2004). All the transcripts were read through at least 3 times before coding and categorizing manually and inductively, in stages. The first stage consisted of identifying meaning units, where phrases in the transcript were underlined and then restated in the margins as codes. In second stage, categories were developed from codes and then further compared and merged into a theme. This work was done real-time after each weekly FGD in order to determine the data saturation point.

Quantitative data were collected by questionnaire and analyzed by Stata v.12 for proportion of variables and association factors with univariate analysis.

## 3. Results

### 3.1. FGD's

Of the 53 caretakers (8 men and 45 women), 58% were biological parents and 45% were employed (“employed one” means “one earns money from any kind of employment”). Among them, 53% were HIV positive (see Table 1).

**Table 1**  
Demographic characteristics of caretakers.

Caretakers' characteristic	53 caretakers [n (%)]	209 caretakers [n (%)]
<b>Sex</b>		
Male	8 (15.1)	32 (15.3)
Female	45 (84.9)	177 (84.7)
<b>Age</b>		
≤29	23 (43.4)	34 (16.3)
30–39	12 (22.6)	115 (55.0)
≥40	18 (34.0)	60 (28.7)
<b>Job</b>		
Employed	24 (45.3)	166 (79.4)
Unemployed	29 (54.7)	43 (20.6)
<b>HIV status</b>		
Positive	28 (52.8)	146 (69.9)
Negative	25 (47.2)	63 (30.1)
<b>Educational level</b>		
Under high school	39 (73.6)	128 (61.3)
High school or above	14 (26.4)	81 (38.7)
<b>Relationship to the child</b>		
Biological parents	31 (58.5)	134 (64.1)
Others	22 (41.5)	75 (35.9)
<b>Family residence</b>		
Urban area	n/a <sup>a</sup>	90 (43.1)
Rural area	n/a <sup>a</sup>	119 (56.9)

<sup>a</sup> n/a: not available.

The overarching theme of 2 topics was caretakers' stories on difficulties and society and/or family supports when taking care children under ART adherence and their experiences of HIV-related stigma. Results relating to this theme will be presented in 3 themes: difficulties, risky non-adherence issues and stigma.

#### 3.1.1. Caretakers' difficulties in relation to taking care children under ART

Most caretakers brought up poverty as a major barrier. There was no money support from society, only small amount given from their families.

*“I'm old, so I can't earn for living. The child's parents are all dead. I'm getting money from his uncle. It's not much, just enough for daily meals. I don't have enough money to buy any drugs for my grandchild. All drugs are being supported by this OPC”.*

[(A grandma)]

The OPC is located in the city center. Meanwhile, most caretakers live in rural areas, so they are facing many difficulties to arrange transport to the OPC, including high travel cost and time consuming losing time for work causing decreased income. Furthermore, health check-up schedules are fixed and mostly on school days, so some children are not able to present at the OPC for health check-up and receiving drugs, in order to get the medication the children need to be present at the OPC visit.

*“I live far from this OPC. Sometimes, I'm on my errands near OPC, I want to receive ARV drugs but I can't. I must go back home or school to bring her to OPC. So the most difficulty for me is to receive ARV drugs without my child”.*

[(A father)]

#### 3.1.2. Risky non-adherence issues

Participants who are not primary caretakers stated that they had no ideas on the child's treatment. So they might not have essential knowledge and experience of taking care of children with ART.

*“His parents died. The hospital sent him to this OPC for treatment. I don't know anything about his disease or his treatment. I just follow OPC instructions to give him drugs daily on time. Whenever he has any symptoms, I bring him to OPC for health check-up”.*

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