



## Research Article

## Experiences of Caregivers in Healthcare for and Social Support of HIV Positive Children Attending Schools in Bangkok

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## SUMMARY

**Purpose:** The study was conducted to explore caregivers' experiences and perceptions of barriers to their children receiving appropriate healthcare and support at schools in Thailand.

**Method:** A qualitative narrative study was conducted to achieve the aim stated above. Twenty caregivers of children living with HIV/AIDS attending schools in Bangkok were interviewed in depth. The interviews were audiotaped, transcribed and analyzed using narrative analysis.

**Results:** The analysis indicated that caregivers fear discrimination, suffer from stigma and most do not reveal their child's HIV status to schools. Obstacles to children living with HIV/AIDS getting appropriate care and support in schools are persistent. Caregivers need to collaborate with the public health sector to provide HIV education and support for themselves and for teachers; community nurses would be well placed to provide this.

**Conclusion:** Our findings can inform the design of systems for educational and social support alongside adequate healthcare for children living with HIV/AIDS attending school. The Thai government needs to establish collaboration between the educational and health sectors to reduce the stigma of HIV, promote acceptance and provide support.

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## Introduction

In 2013, it is estimated that 610,000 people in Thailand are living with HIV, and 23,000 people have died from AIDS-related illnesses in the past 12 months (UNAIDS, 2013). The population of HIV positive children under the age of 15 in Thailand is estimated to be between 12,000 and 17,000 with approximately 4,200 new infections occurring annually (UNAIDS/WHO, 2009; UNICEF, Thailand, 2010). Although the Thai government has launched a healthcare program providing anti-retroviral therapy for pregnant women to prevent mother-to-child transmission of HIV, the prevalence of children born with HIV is still about 3% (UNICEF, Thailand). Healthcare programs focused on reducing the number of HIV-infected children and providing long-term care and educational support for existing children living with HIV/AIDS may be

overlooked by the government despite a much better prognosis with the increased availability of antiretroviral treatment. The Universal Declaration of Human Rights states that all children have the right to survival, protection, development and participation to enable them to successfully achieve the "goals of childhood" (United Nations, 2003). Children living with HIV/AIDS should have equal access to education, as well as access to treatment and care including attention to their special needs, all of which would enhance their physical and emotional well-being and their social and intellectual development (UNESCO, 2000; United Nations, 2013).

Several reports about HIV/AIDS in Thailand have shown that children living with HIV/AIDS are discriminated against and often rejected from school because the parents of other children fear HIV transmission to their own children (Klunklin & Greenwood, 2006; Thailand Division of Communicable Disease Control, 2003). Caregivers, whether or not HIV-positive themselves, suffer from discrimination and as a result families may keep a child's HIV infection a secret (Demmer, 2011). In areas where there are large numbers of HIV/AIDS infected people, other members of the community may fear becoming infected. As a result, some caregivers who have sought help have been rejected or abandoned,

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even by family members, when they disclose their children's illness. Consequently, they receive little support from their communities (Lyons, 2006; Yoktri, 1999). Caregivers and children with HIV/AIDS have experienced such discrimination and hostility from teachers that children had been withdrawn from school (Thampanichwat, 2008). Previous studies of children living with HIV/AIDS in Asia (including Thailand) have reported that the three main impacts of HIV infection are loss of social and family support; stigma and discrimination; and decreased access to education, healthcare, and social services (Wijngaarden, 2001; Wijngaarden & Shaeffer, 2005).

Schools could act as center-points for comprehensive community responses to HIV/AIDS as they are the ideal places to bring teachers, caregivers and others together to help support vulnerable children in a coordinated and effective way (UNAIDS, 2003). However, although the Ministry of Education in Thailand has established regulations to promote access to free education for all children and to provide support to disadvantaged children (Thailand Office of the National Education Commission, 1999), there is very little evidence that the educational system in fact has provided adequate support to children living with HIV/AIDS. In addition, we know very little about what caregivers experience when their children with HIV go to public schools, how caregivers describe their experiences of the healthcare and support and what help they need. Healthcare providers and policy makers need to understand the challenges and obstacles that caregivers experience while looking after school age children with HIV/AIDS and how their children can access free education and elicit support. Thus, the approach of this study, underpinned with principles of narrative analysis, can assist healthcare providers and policy makers to more deeply understand the situation of caregivers of children with HIV/AIDS and so act to improve health care and support for their children.

#### *Aims of study*

This study aims to describe the experiences and difficulties experienced by caregivers of children with HIV/AIDS attending public schools. Narratives of participants provide important information to guide educational organizations in offering appropriate healthcare and support to children with HIV/AIDS in schools (Sakalys, 2003). The research questions were: (a) what do caregivers experience when their children with HIV go to public schools? (b) How do they describe their experiences of the healthcare and support that is made available to them?

## **Methods**

### *Study design*

Qualitative narrative method was used to explore and then depict what happened when family caregivers sent their children to schools. Qualitative study of subjective experiences and common dialogue of caregivers' story-telling was appropriate in this study because it captured with authenticity the opinions and responses of the participants (Atkinson, 2007). Their narratives also described experiences of family caregivers who had themselves provided care for children with HIV/AIDS and the obstacles they faced when they voiced their need for healthcare and support.

### *Setting and samples*

This study took place in Bangkok, the capital of Thailand with a total population of 8.25 million based on the 2010 Census. In addition, the number of people living with HIV was 56,717

(Thailand Division of AIDS, TB and STIs, Health Department, 2011). We recruited a purposive sample of 20 family caregivers of children with HIV/AIDS who joined the activities with HIV/AIDS clubs and organizations in Bangkok. The leaders of HIV clubs and organization were instrumental in providing assistance and advice to low-income caregivers living in communities in inner urban and sub-urban areas of Bangkok. These leaders also referred potential, appropriate participants to the investigators. The criteria for selection required participants to be biological mothers or fathers (or other male or female relatives) who acted as primary caregivers of children with HIV/AIDS. Participants had to be taking care of a child who had attended school for at least 6 months. Participants had to be Thai speakers and were sufficiently healthy to participate in the activities of the HIV clubs.

### *Data collection*

The study was conducted over 18 months from January 2008 to June 2009. The 20 family caregivers of children with HIV/AIDS were introduced to us by an HIV/AIDS organization and invited to participate in the study. In-depth interviews of the 20 participants were conducted in private rooms in their homes. Using their previous related experience, the authors developed a semi-structured series of open-ended questions that allowed them to lead participants into an in-depth interview as follows: Please tell me about your child's illness. How does the teacher take care of your child when he or she gets sick? Do you disclose your child's HIV status to the teachers? Why (or why not)? How did you feel about the teacher's response when he/she knew your child's status? Tell me about a recent bad day in caring for your child when he/she was going to school. Follow-up questions were created to facilitate an in-depth interview with empathic listening and to investigate further the caregivers' experiences in caring for their children. Each interview was tape-recorded and lasted 50–60 minutes. Triangulation technique was used after each interview by means of discussion with peers, and by participants' confirmation. We analyzed the narrative data confirming our understanding by asking comprehensible questions, re-reading the narrative accounts in conjunction with the questions, articulating more explicit questions based on these close readings and creating codes that reflected the narratives discerned in the interviews. After interviewing 20 participants, no new codes or additional data emerged from the narratives. Thus, the data collection was judged to be saturated.

### *Data analysis*

Data were transcribed verbatim with all interview data reconfirmed by the participants. The interviews were conducted and analyzed in Thai language and only the excerpts referred to in the study were translated into English. The accuracy of the English language translation was confirmed by an expert from the Faculty of Arts at Chulalongkorn University. The translation of the excerpts was checked by the authors for accuracy and consistency. Interview data were analyzed using a thematic analysis with multi-staged analysis technique (Riessman, 2008; Stevens 1993; Stevens & Doerr 1997). A multi-staged narrative analysis was devised based on synthesis and extension of narrative techniques articulated by the investigator and experts. These stages were as follows: (a) demarcation of the boundaries of each story in the interview and group transcripts, (b) analysis of story content and context, with attention paid in each case, to obstacles and needs for support and care for children with HIV/AIDS in schools, (c) searching for similarities and differences in children with HIV/AIDS' care and support among the various participants, and (d) the experiences of obstacles as described by all 20 participants when matched and

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