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Impact of paediatric human immunodeficiency virus infection on children's and caregivers' daily functioning and well-being: a qualitative study

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Abstract

Background—Human immunodeficiency virus (HIV) infection impacts not only upon the physical health of affected children, but also their psychosocial functions, family relationships and economical status. Caregivers are confronted with complex challenges related to the physical, emotional and financial demands of raising these children. The purpose of this study was to enhance our understanding of the impact of HIV disease on both children's and caregivers' well-being, using a qualitative inquiry approach.

Methods—A total of 35 primary caregivers of HIV-infected children participated in in-depth interviews. The issues discussed included the major negative impacts on children's daily functioning and well-being, and the perceived caregiver/parental burden. Participants included parents (40%), grandparents (22.8%), other relatives (e.g. uncles, aunts) (34.3%) and one foster parent (2.8%).

Results—Qualitative analysis revealed that the major negative impacts of HIV/AIDS included physical symptoms, school performance and relationship changes. The major negative impacts on caregivers' well-being included acceptance of the diagnosis, dealing with the financial burden and keeping the diagnosis private.

Conclusions—Approaches are needed to address these challenges by enhancing families' coping skills and building supportive networks.

Keywords

AIDS; carers; chronic illness; emotional well-being; psychosocial factors; quality of life

Introduction

Paediatric human immunodeficiency virus (HIV) infection presents a range of complex psychosocial challenges, not only to patients, but also to family members and healthcare providers. Existing literature indicates that families play a major role in supporting HIV/AIDS patients in Thai society (Uthis 1999; Knodel *et al.* 2001; Kespichayawattana & VanLandingham 2003). Given that new medical advances are allowing both children and

adults with HIV infection to live longer (Lima *et al.* 2007; Muga *et al.* 2007; Ewings *et al.* 2008; Patel *et al.* 2008), assessing how these families deal with the negative physical, psychosocial and economic impacts of the disease becomes increasingly important.

The majority of existing research on the impact of HIV on affected families focuses on HIV-infected adults, indicating that the burden of HIV on affected families encompasses medical, social and economic issues (Uthis 1999; Wachter *et al.* 2002; Kespichayawattana & VanLandingham 2003). The major negative impacts on caregivers include enormous workloads, physical strain, increased social isolation and depression (Kipp *et al.* 2007a,b). Some of them experience anxiety and frustration associated with inconsistent and irregular support and lack of information (Chambers *et al.* 2001). Similarly, studies conducted in Thailand showed that these caregivers experienced enormous burdens relating to escalating healthcare costs, insufficient support and financial limitations (Suwanagool *et al.* 1997; Burintramart *et al.* 1998). Most of them felt overwhelmed with the caregiving demands of their family members (Phengjard *et al.* 2002).

In comparison with HIV-infected adults, there is little documentation regarding the experiences and perceptions of caregivers of HIV-infected children. Similar to caregivers for children with other childhood chronic, life-threatening illnesses (Ievers-Landis *et al.* 2001), caregivers of HIV-infected children experience fatigue, depression, exhaustion and emotional distress (Pakenham *et al.* 1995; Hackl *et al.* 1997). Overextended caregiving demands diminish their physical stamina and leave many of them inadequate time to care for themselves (Joslin & Harrison 2002). A study in China indicated that the individual income of families affected by HIV/AIDS is much lower compared with that of the provincial average. The major negative impact of HIV on children was reflected in children's school performance, health and nutrition (Ji *et al.* 2007).

HIV impacts upon relationships both within and outside the family (Pakenham *et al.* 1995), as well as livelihoods. The stigma attached to HIV/AIDS prevents many caregivers from seeking out assistance or support for themselves or their families (Joslin & Harrison 2002). A study by Mellins and Ehrhardt showed that HIV-infected parents reported more isolation and fewer financial and support resources. All children were particularly vulnerable to separation and loss, with uninfected siblings reporting resentment for their burden of caregiving (Mellins & Ehrhardt 1994). Furthermore, grandmothers who assume the role of primary caregiver experienced the negative impact of raising HIV-infected children at the expense of their own physical and emotional well-being. They also encountered financial difficulties in raising a sick child and emotional distress resulting from lack of social support (Caliandro & Hughes 1998). The level of social support obtained can vary, depending on the relationship with HIV-infected children. This might be due to feelings of guilt and the level of perceived social isolation of biological parents as compared with non-biological parents. As reported by Martin and colleagues (2004), caregivers who were not related to their charges were more likely to seek out more community resources and support than caregivers related to their charges. Caregivers of children with HIV/AIDS need physical and emotional support themselves (Rose & Clark-Alexander 1998).

The physical and emotional burdens of raising HIV-infected children can exacerbate caregivers' psychological conditions, which, in turn, can affect their perceptions of the child's behaviour. Bachanas and colleagues examined differences in psychological functioning between caregivers of HIV-infected children and caregivers of healthy children. The results identified high rates of psychological distress among caregivers of HIV-infected children (Bachanas *et al.* 2001). However, the rates of psychological adjustment problems were rather comparable between caregivers of HIV-infected and of healthy children. In addition, caregivers who reported more psychological distress also reported more

internalizing (withdrawn and/or depressed) and externalizing behaviour problems in their children, regardless of the child's HIV status (Bachanas *et al.* 2001). Thus, it suggested that caregivers' psychological distress was found to be strongly associated with children's maladjustment. That is, the association between caregivers' psychological distress and children's internalizing and externalizing problems holds, regardless of whether the child is infected with HIV. However, caregivers of children who suffered a greater degree of immune suppression were three times more likely to report their child internalizing borderline/clinical behavioural problems than caregivers of children who were less immunosuppressed (Burgos *et al.* 2007). Therefore, it seems that it was not HIV infection status itself that was associated with children's maladjustment, but instead, the severity of symptomatic illness.

A study by Dowdell (2004) about grandmother caregivers and the burden of caring for HIV-infected children demonstrated that poor physical health of the grandchild correlated with poor health of the grandmother, which correlated strongly with the grandmothers' low level of self-esteem, a strong perception of poor family support, and low financial status.

As existing evidence has pointed out, there is more to treatment and medication when dealing with a serious, life-threatening illness in children. Because of the complexity of psychosocial factors in HIV-affected children and family, it is essential that we take into consideration both individual and family functioning when dealing with the disease. The caregivers' burden and its impact on the family may have a substantial impact on treatment success, which mainly relies on long-term treatment adherence. Improved research in these areas will help us to better understand the impact of HIV/AIDS, and provide better and more humanized health care for this population.

This study is part of a larger study, 'Development of a Culturally-Appropriate Health-Related Quality of Life Measures for HIV-infected Children in Thailand', which was intended to develop a tool to measure and evaluate the health-related quality of life among HIV-infected children. The present study is intended to develop an understanding of the important negative impacts on the daily functioning and well-being of HIV-infected children, as well as their parents'/caregivers' stress and burden. We hypothesized that these families had to deal with not only less than optimal physical health of their child, but also a heightened sense of social isolation and/or stigma. However, we do not have much information regarding the extent to which and how it manifests in their daily living. To obtain such a level of insight, a qualitative method with a semi-structured individual in-depth interview and content analysis were employed. This one-on-one interview approach was chosen in order to get the best available information in certain areas without the interference of a group bias or the drawback of group dynamics, as in a focus group interview. In addition, we were more interested in examining the details of each situation rather than the percentages or the most frequent answers generated, as can be obtained from a quantitative approach. Information gained from this study may be beneficial in further improving current service provision for children living with HIV/AIDS.

Methods

Data were collected through individual in-depth interviews with primary caregivers (main care provider with closest relationship) of HIV-infected children during follow up at an infectious disease and immunology clinic. Eligibility criteria for participants included: (1) being a primary caregiver for an HIV-infected child aged 8–18 years diagnosed at the Queen Sirikit National Institute of Child Health (Children's Hospital), Bangkok, Thailand; (2) being at least 18 years old; (3) the ability to provide informed consent; and (4) being a native Thai speaker. Participants were recruited through provider referral. The interview sessions were

conducted by two paediatric residents who underwent a 1-week training workshop and were supervised during field practice. Agenda themes included the impact of HIV infection on daily functioning and well-being of children and caregivers. The semi-structured interview used the questions and probes below:

1. These questions are aimed directly at getting your perspective, so please tell me, in your own words, how 'the illness' has affected your child's life?

Probe: Tell me what your child does on a typical day?

What can't your child do because of 'the illness'?

How do the main problems of your child's illness impact upon him/her?

How do the main problems of your child's treatment affect him/her?

How does 'the illness' limit your child's daily activities?

How is your child's life similar or different from other children?

2. How does your child's illness affect you and your family?

Probe: Tell me what it's like to take care of a child with this illness.

What's your day like for you? Describe what you do each day.

How do you and your child manage day-to-day with your child's illness?

What can't you do because of 'the illness'?

How do the main problems your child's illness impact upon you?

How do the main problems your child's treatment process affect you?

How does 'the illness' limit your daily activities?

How is your life similar or different from other caretakers?

3. This question deals with your concerns. You may feel it is very personal and sensitive. Please let me know if you don't feel comfortable with the question if you want to move on to the next question without answering this one. I also want to remind you again that this interview is absolutely voluntary; you can stop the interview any time. All of your responses will remain confidential.

What are some major concerns you are dealing with right now?

Probe: What is the most important problem you are facing right now?

What are some of the competing demands you have to face besides caring for your child?

What makes you feel that these concerns are most important for you?

Does the child display appropriate behaviour? If yes, tell me more about that.

Does the child take unnecessary risks? If yes, can you elaborate?

Time spent for each interview was recorded. The interview process examining these particular aspects took approximately 15–25 min. Note-taking and audio-taping were used to record all of the interviews, with the permission of the participants. The interviews were transcribed verbatim, with content analysis carried out in Thai language, using ATLAS.ti v5 software for qualitative analysis. This method was used to analyse words and phrases that reflect important concerns of the interviewees. This method was conducted by looking at text to see what themes emerged, such as what caregivers talked about the most and how these themes were related to each other.

Of the 38 primary caregivers approached for the enrolment, 35 (6 men and 29 women) were enrolled, all of whom were ethnic Thais. The response rate was 92%. The mean age of the respondents was 43.1 ± 11.5 years. There were 3 biological fathers, 11 biological mothers, 16 relatives and 1 foster parent.

All except one had only a high school level education or less. There were 35 children (13 boys and 22 girls) under their care, with a mean age of 12.5 ± 2.2 years, ranging from 8 to 16 years. Table 1 presents participant demographic characteristics.

Results

HIV's major negative impact on children's daily functioning and well-being

The important negative impacts of HIV-related illness on children's daily functioning and well-being, as reported by caregivers, can be classified into four major themes (below). Table 2 contains representative quotes by theme for the major negative impacts of HIV on children's daily functioning and well-being.

Physical health problems—Many caregivers expressed concern about their child's physical health problems. Having a low level of energy was a common finding shared by a few caregivers. One prominent negative feature was the child being easily fatigue or exhausted. One grandmother reported that her child had less physical endurance than children of the same age when participating in sports or exerting herself (quote 1). One aunt reported that after school her child seemed to be extremely exhausted physically, and often if the child did not get an energy boost from a sugared drink (most often a carbonated drink) she would not have any energy to do anything (quote 2). Another caregiver reported that the child was rather slow in carrying out his overall activities, with the most obvious aspect being unable to finish any simple household chore (quote 3). Other types of physical health problems included pain, recurrent infections and distinctive features. Physical aches and pains such as earaches, abdominal pain, headaches, oral ulcers and neural pain from herpes zoster (quote 4) were common complaints reported from caregivers. One caregiver reported her child to be especially susceptible to lower respiratory tract infections (quote 5). Distinctive physical characteristics, such as poor physical growth, being severely underweight, sunken cheeks (quote 6) and extensive pruritic skin eruptions (quotes 7–8), were also commonly reported by both parents and caregivers as a major factor negatively influencing their child's sense of well-being, as these characteristics caused the child to be a target of ridicule or discrimination (quotes 6–8).

School performance—Some parents and caregivers reported that problems regarding study and school had the most negative impact on their child's daily living and functioning. This was manifested in some forms of learning disabilities (quote 9), lack of interest (quote 10) and falling behind in their studies (quote 11). The majority of these children miss school often because of frequent clinic visits and severe illness requiring hospitalization. They are usually unable to catch up with their peers and have poor academic performance, stress, low self-esteem and school avoidance (quotes 12–13).

Adherence to medication—Many families reported that difficulty achieving optimal adherence was mainly the result of the unpleasant taste, high pill load and large pill sizes of the medications, as well as the rigorous medication schedule. One biological mother noted that strict adherence to the schedule prevented her son from living a normal life by interfering with his activities, especially playing with friends. In addition, he could not go out for spontaneous activities if they were close to his medication time (quote 14). Another biological mother whose son was still too young to properly administer his own medication

could not allow her child to engage in certain activities that took him away from home (such as camping overnight) (quote 15). Another caregiver reported being afraid that others would see her child taking the medications, which would reveal that she was HIV-positive (quote 16).

Relationship changes—Relationships within and outside the family are most likely to change after diagnosis of HIV or manifestation of HIV-related symptoms. The changes in relationships we found in this sample were in the form of abandonment by family members and social isolation. While the majority of biological mothers or fathers remained in a stable relationship, one family experienced separation and abandonment. In this family, the father (the main provider), despite being aware of his HIV status, left his wife and daughter for another woman without providing them with any financial support. This greatly affects the child's sense of well-being, both financially and emotionally (quote 17). Other children were affected by being a target of mockery, ridicule and/or discrimination. HIV-infected children of deceased HIV-positive parents are at a higher risk because of the social isolation associated with HIV. This is a particular problem among children whose HIV status becomes public knowledge through the death of their parent(s) (quotes 18–19). Certain caregivers had experienced social isolation from both their own community and their relatives. One biological mother and her infected daughter had left their hometown after years of attempting to cope with bullying and verbal abuse directed at the child. Unfortunately, the situation did not improve after moving to an urban area, as they still had to face their relatives' lack of tolerance and discriminatory attitudes. A blatant show of insensitivity and a deliberate act of narrow-mindedness one mother encountered was described (quote 20). In one family, the child himself was rather young and not directly affected by discrimination, because his caregivers did not allow him to go out to interact with friends or neighbours in order to prevent him from being ridiculed or rejected (quote 21).

The major negative impact of HIV on caregivers' daily lives

This section describes the perceived caregiver/parental burden related to caring for HIV-infected children. Our study indicates that the most negative impacts of the child's illness on caregivers' daily lives can be classified into four different themes (below). Table 3 contains representative quotes by theme for HIV's major negative impact on caregivers' daily life.

Difficulty of accepting the diagnosis—The period following the diagnosis of HIV is generally a time of great personal turmoil for both parents and other caregivers. One aunt had and continues to frequently recount the revelation of the child's diagnosis (quote 22). Despair, confusion, a sense of guilt and prior suicidal thoughts were evident in one biological father who had lost his wife to AIDS. He had a tremendous sense of guilt for transmitting HIV to his loved ones, and had considered taking his own life, but the concern for his child stopped him from doing so (quote 23). Despite years of living with their child's diagnosis, it remains difficult for many of them to come to terms with the illness (quotes 24–25).

Financial burden—Families reported how the burden of treatment occurs in the context of the overall financial challenges for the family. For example, because of the necessity of providing care for her HIV-infected niece, along with other family members, one caregiver reported that her family often had no food to eat (quote 26). With limited financial resources, one grandmother could not afford to send her grandchild to school (quote 27). A biological mother whose child, in addition to being HIV-infected, had many other comorbidities such as congenital heart disease and severe allergic conjunctivitis, reported

general financial hardship (quote 28) and that the expense of caring for a child with HIV is a burden to her family's limited resources.

Protecting confidentiality—One major issue imposing upon caregivers' daily routines was concealing the child's HIV status, which often involves a great deal of effort. For those whose child was relatively healthy, the most wearisome issues concerned dealing with caring but inquisitive friends, neighbours and/or teachers asking about the child's regular school absences for clinic visits. Most caregivers found it difficult to explain why their child was taking long-term medications with a very exacting schedule (quote 29); without a good explanation, they felt it incurred suspicion. Some caregivers experienced difficulty in both administering medication and disposing of empty drug containers (quotes 30–31). Additionally, some caregivers had difficulty providing sound reasons for the child's frequent absences from school. Some caregivers were obliged to make excuses for their child's absences to avoid potential discrimination (quote 32). Because secrecy and fear of ostracism were prominent, most families have limited social and emotional support. One HIV-negative biological father who lost his wife to HIV/AIDS had the sole responsibility of raising his child, while declining any assistance from his relatives in order to conceal the child's HIV status (quote 33).

Discussion

This qualitative exploration was designed to come to an understanding of the impact of paediatric HIV infection on children's and caregivers' daily functioning and well-being. A qualitative method was selected to achieve this objective, as it is the best way to get people to talk about their personal feelings, thoughts, experiences and perspectives without the influence of group dynamics, such as in a focus group discussion. In addition, in contrast to a quantitative method, it also helps us to probe into the participants' thought processes to elicit reasons for and gain an understanding of each answer. This study of caregivers of HIV-infected children in Thailand reveals profound stress and burdens on the families and individuals who care for these children. In addition to the direct effects of HIV infection on the physical health of these children, other important negative impacts include interference with daily functioning, such as schooling/studying, and changes in interpersonal relations both within and outside the family. Many of these children are also severely marginalized because of their illness and/or being an orphan, as well as being financially disadvantaged. Therefore, apart from dealing with the effects of chronic illness, they must also struggle with the hardships of poverty. In the situation where a caregiver is elderly and also the sole provider, the sense of security and concern about survival became a major issue. Furthermore, the family's financial situation is closely correlated with the severity of the disease and the complexity of the treatment process. This worsens when these children suffer from additional comorbidities such as congenital heart disease, allergies and haemoglobinopathy. Thus, they require even more frequent and different specialty clinic visits, resulting in higher travel expenses, parental absences from work and loss of income, leading to a great financial burden. As the children become older, the more potent and expensive their antiretroviral regimens must become. However, there is a ceiling of medical care coverage per visit for those who use the government-subsidized Access to Care Program. Therefore, some children's prescriptions are limited to 1 month for each visit, resulting in relatively frequent visits and higher travel expenses.

Similar to other reports, it is evident that many families are coping not only with HIV-related issues, but also with additional stressors related to their living conditions (Mellins & Ehrhardt 1994; Caliandro & Hughes 1998; Bachanas *et al.* 2001; Chambers *et al.* 2001; Wachter *et al.* 2002; Martin *et al.* 2004; Ji *et al.* 2007; Kipp *et al.* 2007a). The difficulty of accepting a HIV diagnosis, poverty, heightened personal fear that HIV status will be

revealed, and consequent poor perceptions of social support from family members and friends are common psychosocial stressors that caregivers must face daily. Cultural issues may impact upon communication patterns, attitudes about HIV infection, and willingness to access social and psychological support systems. In Thai culture, privacy is not a typical social norm, but getting involved and showing concern is the way that people connect with each other. Telling others 'it is none of your business' would be very offensive when responding to personal questions, and fitting social norms is important for remaining part of the community. Given this cultural context, this issue becomes especially troublesome when caregivers try to keep their child's condition private. In Thailand, the extended family (usually grandparents and other relatives) is the predominant source of alternative care. Other support is available, albeit limited, for assisting these parents/caregivers. Because of limited resources, care settings organized by child welfare services, such as foster care and adoption, are not practical options in Thailand. Most families affected by HIV/AIDS in Thailand are socially marginalized as a result of their poverty, illiteracy and/or parental drug use. These factors may hinder access to both treatment and social support. Therefore, it is important that as more children live longer and reach adolescence, their needs for social care services are met.

Given the multitude of stressors on family members that must be faced daily, the themes identified in this study are particularly relevant. The results of this study indicate the potential areas for intervention by healthcare providers working with HIV-affected families coping with poverty and insufficient resources. A study by Das indicated that despite the multitude of psychological and social stressors/burdens among HIV-infected individuals, there was a marked improvement through supportive counselling, family therapy and psychiatric intervention (Das 1994). Specifically, provision of stress management techniques and problem-focused coping strategies, peer group support and access to resources are likely to benefit many caregivers.

Despite the significant findings of this study, there are limitations that should be noted. Given the nature of cross-sectional studies, method of subject selection and relatively small sample size, generalizability of the results to a broader population is limited to those who had access to the healthcare system. A larger and more diverse sample is necessary to fully understand the complexities and wider range of perceptions and experiences in dealing with HIV/AIDS. Further research should include those who are not in or able to access the mainstream healthcare system. Another limitation was the lack of a control group of uninfected children. Therefore, we do not know to what extent these impacts are attributable to HIV infection. For example, it is possible that among infected children who do not have any distinctive clinical or behavioural problems, caregivers might pay more attention to the academic achievement aspect of the child's life. Furthermore, existing research has pointed out that caregivers' reports of their children's well-being and/or psychosocial adjustment are associated with the level of caregivers' psychological distress. In this study, caregivers' psychological well-being was not assessed or taken into consideration during the analysis. Therefore, we are not certain that the caregivers' perception of the child's well-being is necessarily the same as what the children themselves might report. In addition, taking a longitudinal perspective and considering the different stages of the illness can improve understanding. This is because the impact of the illness and the families' experiences and perceptions are likely to change considerably during the course of HIV-related illnesses and treatment. Also, other stressful life events and related coping strategies were not accounted for in this study. Nevertheless, these limitations are unlikely to alter the primary objective of this study, which was to elucidate the experience-related commonalities among families struggling with HIV/AIDS. The study also provided them not only the opportunity to articulate their perceptions and experiences, but to also realize that their voices are being heard.

In conclusion, HIV/AIDS creates significant mental health needs among HIV-affected families. This appears to persist even in the context of advances in medical treatment. This article is an attempt to help service providers understand the difficulties of families who have HIV-infected children. Interventions that address psychosocial problems are needed to help people and children with HIV reconstruct their lives, especially since HIV-infected individuals are now living longer. Improving coping capacity, building local supportive networks and increasing access to available resources are needed to reduce HIV-related psychosocial distress among in this population.

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Key messages

- HIV infection impacts upon all aspects of health and well-being of both infected children and their caregivers.
- Lower levels of energy, poor school performance, achieving optimal treatment adherence and social isolation are among the major impacts of HIV/AIDS upon infected children.
- Adjustment to diagnosis, financial burden and protecting confidentiality are among the major difficulties encountered by caregivers.
- It is essential that both individual and family functioning be taken into consideration when dealing with HIV infection.

Table 1
Participant demographic characteristics

Mean age (range)	43.1 ±11.5 years
Gender (% male)	6 (17.1)
Type of relationship	
Biological father	3 (8.5)
Biological mother	11 (31.4)
Grandparent	8 (22.8)
Other relative (uncle, aunt, sibling)	12 (34.3)
Foster parent	1 (2.9)
Education – highest level reached	
Less than high school	19 (54.3)
High school	15 (42.9)
College (BA)	1 (2.9)

Table 2
Representative quotes by theme for the major negative impacts of HIV on children's daily functioning and well-being

Theme	Representative quotes (age, gender, interviewee number)
Physical health/low energy	<p>[1] 'She seems to be easily fatigued. For example, after school she looked like she had no energy left.' (65, F, 12)</p> <p>[2] '...she would be so exhausted; she would just sit there crying...' (27, F, 19)</p> <p>[3] '[His main problem is being] too slow... he... like... could not help out with anything at home.' (37, F, 31)</p>
Physical health/pain	<p>[4] 'Headaches [were the big problem] especially when he got shingles.' (F, 47, 18)</p>
Physical health/respiratory infections	<p>[5] '[It's] pneumonia, if he gets wet in the rain, he always catches it.' (66, F, 13)</p>
Physical health/distinctive physical characteristics	<p>[6] 'It's about his friends teasing him, calling him an "old man" because when he smiled his face would show lots of wrinkles. [They would] call him "uncle".' (32, F, 10)</p> <p>[7] 'The worst problem is skin eruptions... she can go out but she always wears long-sleeved shirts.' (27, F, 19)</p> <p>[8] 'The rash was so distinctive that he could not go out. He was quite upset. He wanted to go out and play.' (7, F, 57)</p>
Schooling/studying	<p>[9] 'Her IQ is pretty much the same as a grade 1 student's, even though she is now in grade 4. She can't read. She can only respond verbally, write her name, and do some simple plus and minus operations.' (34, F, 8)</p> <p>[10] 'She was very slow in learning... not at all interested.' (47, F, 34)</p> <p>[11] 'The most stressful thing is schooling; she feels discouraged. She looks so unhappy because she misses school so often.' (55, F, 2)</p> <p>[12] 'She doesn't want to go to school because the teacher often hits her for not being able to read properly or memorize the lesson. She often complains of headaches whenever she is stressed out about school.' (55, F, 2)</p> <p>[13] 'She often lies about the teachers being in a meeting so she doesn't have to attend school. She doesn't want to go to school because she can never catch up with her friends, so they tease her and bully her sometimes.' (34, F, 8)</p>
Adherence to medication	<p>[14] '... when he plays with other kids outside, once it's 6 o'clock, I have to call him to come back home. He gets quite upset. Also, it puts quite a limit on how we do things. When we want to go somewhere, we have to keep an eye on the time. If it's nearly six, we wouldn't be able to go anywhere since we couldn't let anyone see him taking this medicine.' (32, F, 10)</p> <p>[15] 'So far, whenever there have been any activities, he has never been able to attend, since I have to give him his medicine myself, because it's in suspension form and has to be mixed first.' (32, F, 10)</p> <p>[16] 'She could not go somewhere very long because she needs to take the medicine with her. It's quite difficult to take medicine somewhere outside our own home.' (42, F, 34)</p>
Relationship changes/abandonment	<p>[17] 'If there is something that bothers her, it is usually about her dad [who abandoned her].' (32, F, 9)</p>
Relationship changes/social isolation	<p>[18] 'He can't play with other kids. He can't go his a friend's house. If he goes, the neighbours would say things; the way they look and gossip about him... makes him feel ashamed about himself.' (57, F, 7)</p> <p>[19] 'The neighbours used to tell the motorbiker not to pick her up because she had AIDS. After that, that motorbiker never picked her up again.' (27, F, 19)</p> <p>[20] 'The kids there called her "ie kae" [old woman] or "took kae peeh" [ugly gecko], so I brought her here to live in Bangkok with my sisters. But it's even worse. They have an attitude. They don't let her eat with their children. They never let her touch their food. They act as if they don't want to have anything to do with her.' (42, F, 15)</p> <p>[21] 'Our neighbours' wagging tongues cause my grandchild to feel bad about himself. The adults tell the kids to stay away from him. They said, 'He has AIDS, his parents died from AIDS.' He [her grandchild] is afraid that we won't let him go out and play so he doesn't tell us what they say. I don't want him to go out because when he goes out he gets horrible looks from them.' (57, F, 7)</p>

Table 3
Representative quotes by theme for HIV's major negative impact on caregivers' daily life

Theme	Representative quotes (age, gender, interviewee number)
Acceptance of the HIV diagnosis	<p>[22] 'When I first found out, I couldn't stop crying, couldn't eat, and couldn't sleep. During the night, I would wake up and that thought would immediately come to my mind. It was overwhelming.' (47, F, 18)</p> <p>[23] 'I thought about it for years and years... It's all my fault. ...I used to think about taking my own life but I don't know how she can survive without me.' (34, M,3)</p> <p>[24] 'When she sleeps, I cry every night in silence. When someone yells at her and she cries, it would make me cry every time.' (55, F, 2)</p> <p>[25] 'He has no future. Sometimes when I am working, a tear rolls down my cheek whenever I thought about my child. This feeling barely fades away after all of these years.' (35, F, 30)</p>
Financial burden	<p>[26] 'It's mainly about not having enough money to live on. Yesterday, we ran out of money. We had nothing to cook, so we didn't have anything to eat.' (42, F, 34)</p> <p>[27] 'Sometimes we don't have money. If we don't have enough money to pay for transportation, the child can't go to school.' (47, F, 18)</p> <p>[28] 'We barely get by. Our income is so little, but the expense is so high' (35, F, 10)</p>
Protecting confidentiality	<p>[29] 'Sometimes people wonder why he has to take medication on such an exact schedule. No other medicine needs to be that exact.' (52, F, 26)</p> <p>[30] 'We have to be very cautious about hiding the medicine and disposing of its containers.' (32, F, 10)</p> <p>[31] 'Now that these medicine containers are often shown on TV, if someone sees it, we don't know what would happen to us if we didn't take off the labels.' (32, F, 9)</p> <p>[32] 'I have to lie to his teachers by saying we have things to take care of both inside and outside of the province. But I never tell them that I will take him to see his doctors. I'm afraid that they will ask what's wrong with him.' (32, F, 10)</p> <p>[33] 'I could not just leave him with someone else. I don't want my cousins to know. So I have to take care of him, find a school for him, and do everything for him by myself.' (40, M, 21)</p>