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Understanding the Psychosocial Needs of HIV-Infected Children and Families: A Qualitative Study

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Abstract

Objective—This study aims to engage children living with HIV/AIDS and their caregivers in a qualitative assessment to address psychosocial needs pertaining to this population. The purpose is to identify unique situations and concerns they experienced in dealing with the disease and ongoing treatment process.

Material and Method—Individual in-depth interviews using a semi-structured interview guide were employed.

Results—Thirty-four children (12 boys and 22 girls) aged 8–16 and thirty-five primary caretakers (6 males and 29 females) aged 21–66 participated in this study. Results identified some of the common concerns and challenges shared among this population, including impact of the illness on loved ones, disclosure, adherence, behavioural problems, discrimination, treatment affordability, and financial constraints. Certain issues that emerged as important themes specific to this population include unwarranted concerns about certain aspects of the illness, misinterpretation of the nonverbal clues within families, future child guardianship and placement planning, treatment availability during transitional period, and the challenge of maintaining the confidentiality of the diagnosis.

Conclusion—The needs and suggestions of the target groups provided the framework for improving the current services such as the provision of private sessions with children separated from their caregivers (especially for older children and adolescents), disclosure intervention, behavioral screening, life skills building, and empowerment mobilization. Thus, the information gained can be used to facilitate the holistic and humanized health care provision for children living with HIV/AIDS.

Keywords

HIV/AIDS; Children; Families

HIV/AIDS continues to be an escalating health problem throughout the world. The proportion of children and families affected with HIV/AIDS has continued to be a significant public health problem. With the availability of anti-retroviral therapy, HIV disease in Thailand and throughout the world has shifted from one, seen as imminently fatal, to one with a more chronic disease course(1–3). As a result, there are numbers of HIV-

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infected children surviving into adolescence and adulthood. Shifts in the pattern of the HIV/AIDS epidemic require health care providers to recognize and address the needs of this growing population. Furthermore, the epidemiology of pediatric HIV diseases places these children at risk for psychosocial and behavioral problems, for reasons other than HIV disease. The majority of HIV-infected children in Thailand are born to HIV infected parents whose risk factors include intravenous drug use and commercial sex(1). They are typically confronted by daily life stress, poverty, trauma, and family disruption. A high prevalence of substance abuse, psychiatric disorders, and chronic stress has been found in the birth parents of HIV-infected children(4). These important contextual issues need a closer investigation. The present study aims to develop an understanding of the current psychosocial needs, experiences, and perceptions of their current life situations among HIV infected children and their caregivers using an individual in-depth interview approach. Information gained from this study will be used to further improve the current service provision for children living with HIV/AIDS

Material and Method

Targeted participants were HIV-infected children and their primary caregivers attending the infectious disease and immunology clinic at Queen Sirikit National Institute of Child Health (Children's Hospital), Bangkok, Thailand. Eligibility criteria for children included: 1) having a diagnosis of HIV-infection made at Children's Hospital; 2) being aged 8–18 years; 3) never having been diagnosed with a neurological, developmental or psychiatric disorder; 4) having permission from their legal guardian to be interviewed; 5) being able to provide verbal assent. Eligibility criteria for primary caregivers included: 1) having or providing care for an HIV infected child aged 8–18 years; 2) being aged 18 years or older; 3) possessing the ability to provide informed consent; 4) being a native Thai speaker.

These children and families were recruited through provider referrals. Agenda themes for children and caretakers in data collection included their leading concerns about the health problem and/or their current life situation. Semi-structured questionnaires were used. Note taking and audiotape recording were performed for all interviews with the permission of the participants. All transcripts were written and analyzed in Thai. Only selected quotations were translated into English during the later phase of data analysis. Data analysis was performed in Thai using the ATLAS.ti v5.0 software. Two independent raters coded the transcripts to identify and code themes expressed by the participants regarding the above agenda.

Results

Thirty-four children (12 boys and 22 girls) and thirty-five primary caretakers (6 males and 29 females) were ultimately enrolled. All of them were ethnically Thai. Mean age of children was 12.5 ± 2.2 years standard deviation (SD), range 8–16 years. All of them were infected vertically, except for two, who were infected through contaminated blood transfusion. All of them attended a regular school program. For primary caretakers, there was a large range in age of respondents (27–66 years) with a mean ± SD age of 43.1 ± 11.5 years. There were 3 biological fathers, 11 biological mothers, 16 relatives, and 1 foster parent. All of them (100%) had lower than or equal to a high school education. All children and caretakers were interviewed individually (each child was interviewed separately from his/her caregiver).

The themes identified from caregivers included: the ever-present possibility of losing their child; sharing painful information; perceived inability to continue care-giving responsibility; adherence to medication; behavioral problems; ostracism and social isolation; keeping the diagnosis private; and uncertainty of future treatment affordability. Each theme will be discussed.

The ever-present possibility of losing their child

One of the most difficult issues, emotionally, for parents was the prospect of progressive illness with the ever-present possibility of losing their child. As long as a child’s clinical and/or immunologic status was not brought under control, every episode of physical illness became a primary concern for caretakers. This fear was related to the perceived vulnerability of the child as he/she might not recover from the current episode of the symptomatic illness, as illustrated in the following quotes:

> “What I perceived as a major concern is that, whenever he comes down with an illness, I’m always worried that this might be really a serious one….Is he going to make it this time?…”
>
> “I don’t know who will be the first to go: she or me. If she goes first, I will not able to handle it…”
>
> “I wonder whether I would lose my mind if he were to pass away… If I cannot come to terms with it, the only thing I can do is to be ordained…. All of my children are already grown up… I told them that if I lost my mind they would have to chain me up….”
>
> “…I’m afraid that he might have a sudden heart attack… I’m afraid that he will have a heart failure or something like that…since I cannot be with him all the time…”

The last quote belonged to a mother whose child - besides being HIV-infected - had clinically stable congenital heart disease. She was extremely concerned about the possibility of her child having a sudden heart attack, similar to adults with a heart disease. She noted that this fear is related to the unpredictability and life-threatening nature attached to the term ‘heart disease’. Although it was her constant concern, it appeared that she had never discussed this with a physician. Her unwarranted concern was dismissed after a research team member explained that her child’s heart condition was stable and did not have similar implications as adults who have ischemic heart diseases.

This finding suggests that a screening question addressing parental concern should be incorporated into the regular clinic visit. This can help elucidate and mitigate some unthought-of parental concerns caused by simple misconceptions.

Sharing painful information

Some caregivers were mainly concerned about how to tell their child his/her HIV infection, as shown in the following quotes:

> “What concerns me is when he grows up, I’m afraid I will not know what to do… [I] think that I may try to let him know little by little.”
>
> “[It’s] about telling my child [about her HIV status]: I can see that she has grown up; she has started to complain about breast tenderness. But what I fear the most is to see her in pain…”

This theme underlines the need for disclosure intervention service in any treatment centers providing care to HIV-infected children.

Perceived inability to continue care-giving responsibility

In our study, the significant proportion of caretakers was grandparents or elderly relatives. Therefore, their primary concern was related to their perceived inability to continue providing care for their child until he/she becomes self-reliant. Stigma and ostracism towards HIV-infected individuals make it difficult to find someone they can trust who would be willing and able to provide care for their child. This concern is illustrated in the following quotes:

> "I thought that if my child gets really sick, it would be best if she goes before me… because when she gets sick, I'm still able to take care of her… (sobbing)….[But if I go before her] she will be on her own when she gets sick… there will be no one there for her….I will be so worried if I go before her…"

> "I'm just worried that, when she grows up, her chances to continue education will be non-existent. [I] don't know how long she will have someone, paying for her education…"

> "If I am no longer around anymore and if her status will be revealed, how will she be able to live? …"

This theme stresses the importance of early consideration of the child's future child guardianship or future placement plan for those who are under the care of an elderly relative or infected parent. This requires involvement of the appropriate referral to social workers and/or related services for potential solutions.

Adherence to medication

The majority of caretakers were concerned about children's inability to adhere to their own medication schedule. For small children the unpalatable nature of medication is the major barrier to adherence. Also, some pill sizes were so large that children had difficulty swallowing them or keeping from vomiting. The majority of caretakers found this rather troublesome since they could hardly trust someone else, especially those who were not aware of the gravity of the illness to ensure that their child rigorously adheres to the regimen.

In addition to the poor palatability of medication and/or high pill load, two major barriers to adherence are: children's lack of awareness of his/her HIV status and the monotony of the never-ending treatment process. Lack of awareness is a common problem among children who had not yet been disclosed, and thus did not appreciate the importance of taking regular medication as reflected in the following quotes:

> "He has an issue about taking medication. He keeps asking why he has to take medicine. Like….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. For example, sometimes it is about half an hour before 6 and he wants to go to the market, but we aren't able to go because it is too close to the time he needs to take medicine…It bothers him."

> "Before switching to this current regimen she refused to take medication, no matter what…she said she would rather die than take medicine…"

Some of those who got burned out from this never-ending treatment process were found to be adolescents with and without previous disclosure of their HIV status. One 16-year-old girl who was disclosed 3 years ago noted:

> "When my grandfather stresses me out I just don't want to take medicine anymore….if I have to die then just let me die….why I should stay alive if I have to

> live like this…..sooner or later I have to die anyway…when grandma and grandpa scold me, I get so stressed and just don't want to take medicine anymore."

Behavioral problems

In general, there was no major concern about their child's misbehavior being serious. Two caregivers reported incidents of stealing (within their family environment), which were transient and no longer a problem. One caregiver, who was a foster mother at the temporary shelter for abandoned children, reported some serious psychological symptoms of neglect in her 8-year-old HIV-infected child, such as locking herself in the bathroom and beating herself whenever she felt upset. As she noted:

> "When I first came to take care of her in the beginning, she seemed so emotionally deprived and acted like someone who had been severely neglected. Whenever she cried she would scream and lock herself in a bathroom. Sometimes she also banged her head against the bathroom wall"

Enuresis also emerged as a major concern in one family. As one mother noted:

> "[There is] only one problem, she sleeps so deeply and she would pee on the bed every night. When she sleeps, it's just like she is in a coma since there is no way to wake her up and she keeps lying there till the bed becomes dry…"

Another concern is related to their child's expression of interest toward the opposite sex. Among HIV-infected female children, this included acts of flirtation, having a boyfriend and/or expressing their desire to have a boyfriend. A mother of an 8-year-old girl, non-identified, noted:

> "She complained to me that all of her friends had a boyfriend, but no one is ever interested in her."

Another biological mother of a 13-year-old girl, disclosed, said:

> "The neighbors always talk behind her back whenever she does something because she's rather precocious…she likes to dress up to attract attention, and has started dating."

These findings suggest the use of periodic behavioral screening assessment and modification and appropriate referral among those who are at high risk of transmitting the virus to others.

Ostracism and social isolation

Most caregivers considered the communities in which they live as having unsympathetic attitudes towards HIV-infected individuals. One of the common parental concerns for their children, who have some distinctive physical characteristics commonly associated with HIV/AIDS, is ostracism and social isolation. This fear was related to the stigma attached to HIV/AIDS. The common physical symptoms that are subject to discrimination include: sunken cheeks resulting from severe lipodystrophy, emaciated, and extensive skin eruptions as articulated in the following sentiments:

> "It stresses me out when my neighbors and teachers ask why our son is so skinny, why he has to be absent from school so often….it's so obvious from looking at his face, it constantly worries me."

> "Every time when I help him take a shower, he looks more and more unlike what he was before; every time he goes out he is embarrassed about his bony body."

> "Before switching to this current regimen, he looked worse than this…his face had withered. He was so skinny that I didn't want to go on since people began to get

> suspicious. If my husband and I were also skinny, people would think of the disease and we would not be able to continue to live there.”

> “[I’m] worried about the rash, the eruptions; it makes him an outcast in the neighborhood. In our neighbourhood, there is one other child who also suffers from this; he is extremely small for his age… [I’m] afraid that he [her child] will be rejected…”

Some children have a difficult time because of the interminable bullying at school and in the neighborhood as reflected in the following sentiments:

> “When she was going to school back in my home town, 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 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.”

> “When she was still in the school there [where they used to live], the neighbors used to tell the motorbiker not to pick her up because she had AIDS. After that, that motorbiker never picked her up again.”

> “It’s about his friends teasing him, calling him an ‘old man’ because when he smiles, his face shows lots of wrinkles. They call him ‘uncle’. When someone walks by our house, he stares at him as if something is seriously wrong with him.”

This finding suggests the role of life skill interventions and empowerment mobilization among those who are subject to ostracism and discrimination. In addition, peer group support among caretakers with shared experience, especially from those who were able to successfully handle this issue, can be valuable for those who encounter similar situations.

Keeping the diagnosis private

Because of the stigma of HIV-AIDS, families are fearful of disclosing the diagnosis and have limited support systems from both inside and outside their family. This is especially troublesome in maintaining medical adherence when not all family members are aware of the child’s illness. Most of the times, to keep their secret, primary caregivers have to be extremely circumspect in storing, administering, and disposing of the medicine. Furthermore, they also have to come up with a good reason for explaining why they must ensure their child’s adherence to medication and undisrupted clinic visits. The following quotes illustrate caregivers’ concern in keeping the diagnosis private:

> “At first when my mother-in-law saw him continually taking medicine, she secretly threw them away…So I explained that he would die if he doesn’t take it … She can’t throw it away, we can hardly afford it….”

> “Whenever we go somewhere, we have to be very cautious in hiding the medicine and disposing its containers. One time when we just dumped them [the emptied containers] into the garbage can in front of our house, a street dog came and dug through it, something like that. So the medicine containers were scattered all over the place. So every time, we have to remove all the labels and wrap them in a bag and seal them with tape. Because 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.”

> “We have lot of difficulties when I share my apartment with another person…It’s very difficult since I don’t want her to see when I have to give my child medicine….Some medicines have to be kept in the fridge so I have to take out the

> leaflet and wrap it up with gift wrapping paper. I'm afraid that she might look at the label or the leaflet and realize what it is."

This issue is a major challenge for caregivers and health care providers since medical adherence is one of the key factors for treatment success. This sensitive and personal matter may be addressed in a support group through the sharing of experiences under the guidance of a counselor or psychologist. However, guidance and/or individualized strategies are needed in different family situations.

Uncertainty for future treatment affordability

Given that the majority of caretakers seeking care at this center, are from a socio-economic underprivileged group, they generally cannot afford their child's medication. Management costs, including laboratory investigations and medication at this centre, come from the combination of the National Access-to-Care Program, combined with research grants. Therefore, these children have been provided with treatment and follow-up without charge. However, once they become 18 years or older, they are not eligible to continue receiving care at the Children's Hospital. This might become a major barrier for them in terms of access to antiretroviral (ARV) treatment. This is because there are a lot more HIV-infected adults than the available funding for free ARV medication, in contrast to the much smaller number of pediatric patients. In addition, the long-established and comfortable doctor-patient relationship will no longer exist, once they have to start over at other treatment centers for adults. One grandmother noted:

> "I just want to know if she will still be treated for free when she grows up…I'm afraid when she grows up, she will no longer be given treatment…..I want her to continue treatment here, but when she grows up, she will need to move to other place, right?"

This theme suggests that those who are working with children be aware of this unique situation affecting these children and attempt to make this transition as smooth as possible. As a health care provider, we may need to take this issue into consideration and negotiate with all stakeholders including policy makers in order to find a solution for this problem. This is so that they can continue to receive treatment and care as needed.

The themes identified from children included: financial constraints; health of caretakers; the ever-present possibility of dying; ostracism and social isolation; the threat of ill health. Each theme will be discussed.

Financial constraints

The majority of these children came from a socio-economically disadvantaged segment of the population. Some of them had lost their parents or main providers, because of HIV/AIDS. Financial concerns appeared to be a recurring theme for not only caregivers but also children as illustrated in the following quotes:

> "[I'm] worried that I won't be able to go to school…since sometimes we are short of money….It's hard and now we barely have enough money…".

> "[I'm] worried that my dad won't pay for my school…It will hurt my mom a lot….she wants me to get the highest education possible…If I cannot go that far, she will be sad, she told me that."

> "I'm not strong, I'm quite sick… No energy… My grandma doesn't have money to bring me here. She told me that she was scolded by my doctor…the doctor yelled at her telling her to take good care of me, and to give me the medicine"

> "I don't want to be a burden to my grandparents, as he [her grandfather] is also very ill. He has cancer and has to spend lots of money. We barely have anything to eat now…we need money to treat him. I feel like I'm such a burden. I have to come to the hospital and it costs a lot…."
>
> "[I'm] worried about many things… …. When will I get a new pair of shoes? I have to wear the torn ones, and I feel ashamed about it."

The finding reflects that the health and well-being of these children could not be adequately addressed in terms of physical health under the current medical model, when the basic life's needs (*e.g.* food and shelter) are challenged. It requires a much wider involvement and collaboration with various organizations, to find solutions for their intricate and inter-connected problems.

Health of caretakers

When there is a sense of concealment within the family where children have not yet been disclosed of their HIV status, it may mislead them to think that there is something seriously wrong in the family and make them feel helpless. A 14-year old non-disclosed female who contracted HIV infection via a contaminated blood transfusion (*i.e.* her parents were not infected and relatively healthy), was wondering whether her parents might have some form of a serious illness. As she noted:

> "…I'm afraid that something bad will happen to my parents. My mom is not so healthy; I'm not sure whether my dad has cancer or not. I'm quite worried, I don't want to go to school…[I] want to be with them to take care of them …."

This finding suggests that there is a certain communication gap within families, and information about the illness is usually withheld from children. Children are generally perceptive when it comes to non-verbal communication; they can pick up a hidden message indicating something is seriously wrong, that no one dares to bring it up. However, if children are not allowed to talk or ask about the problem, they will not have any opportunity to seek help or obtain emotional support. This finding can be used to communicate with parents and caregivers to avoid unduly delayed disclosure.

The ever-present possibility of dying

It appeared to be relatively common for caregivers to tell children to take medicine, otherwise they would die. While there is no evidence showing that this strategy is effective, it may create some adverse impact on children's emotional well-being. As some of the children noted:

> "I'm afraid that if I don't take the medicine I will die. My mom told me if I stop taking medicine I will die…It worries me."
>
> "I'm afraid that I will die; I'm scared since if I die, I don't know what will happen to me. Those around me will be saddened…."

Among those who are disclosed, certain benign symptoms such as fainting can become a psychological threat that had never been voiced out, let alone properly addressed. As a 9-year-old, disclosed boy noted:

> "I'm only worried about my heart problem [and that I will die of a sudden heart attack]."

This finding underlines the importance of providing private sessions for children to express their deepest fear and worries, so we can help them address it properly.

Ostracism and social isolation

Some of the children experienced different forms of mockery and/or discrimination, ranging from being bullied at school for being orphaned, to attitudes toward people living with HIV/AIDS in general as noted in the following quotes:

> “Other kids like to tease me since I don’t have a mom and dad like them”

> “My friends like to mock me. One friend of mine, a boy, dragged me into the restroom and hit me”

A 13-year-old girl referred to a ‘stereotype’ in the rural community where she lived as being conservative and narrow-minded. She perceived that the people’s hostile and discriminatory attitudes, especially among the older generation, toward HIV-infected individuals were intolerable and unacceptable. She deemed that this mind-set is still prevalent in rural Thailand and expressed her desire to escape the climate of rejection she felt in the community. The following quote is her testimony about the conservative and insular nature of her community:

> “In the village where I live there are mainly elderly people who don’t know about the disease; they were not educated. If someone suffers from AIDS, they tell everyone to stay away from him. They’re really narrow-minded… They never went to school, so they don’t know how the disease is actually transmitted.”

The threat of ill health

Some children - all of them had not yet been disclosed - considered their physical symptoms as their primary concern as in the following quotes:

> “[I’m] concerned about my illness, because when I catch a cold, it’s so difficult to get better”

> “I’m not strong, I’m quite sick… No energy… Sometimes I’m so tired that I can’t even walk…”

> “When I get sick, I am quite stressed and I don’t understand why I have to have this….When will I recover and be like the others?”

Interestingly enough, when asked whether they had ever expressed these concerns, they admitted that they hardly ever brought them up directly with their attending physician. Although they could hardly point out the reason why they had never done so, we speculate that in a busy clinic, caregivers generally assume the role of reporting their perceptions of their child’s health to physicians. Children are not accustomed to communicating directly - and probably not expected to do so - with their physician despite the fact that many of these children are capable of expressing themselves and familiar with their physician. This finding underlines the importance of giving these children the opportunity and encouraging them to voice out their personal concern independently of their caregivers’.

Discussion

Although not all data agrees that these children are at greater risk of psychological distress, much of the data continue to point to a need for psychosocial adjustment and support. Understanding the psychosocial needs among HIV-infected children is critical for improving their mental health and quality of life. Also, given the evidence that mental health problems are associated with poor medication adherence in HIV-infected adults(5–13), improving the mental health of HIV-infected children may have an impact on their physical health as well.

The current data provide support for previous research on the need for psychological assessment and interventions for children and families affected with HIV disease. Despite the variability in their demographic and background social variables which may influence their primary psychosocial needs when dealing with HIV, the current research identifies many important psychosocial concerns common to this population. These concerns include fears about the impact of the illness on loved ones, finances, disclosure, discrimination, behavioral problems, child custodial issue, adherence, treatment availability and affordability. It's imperative that we, as health care providers, appreciate the significance of unmet psychosocial needs on their quality of life, and resort to assess and properly address them. Further, we need to ensure that the intervention we provide adequately meets individual requirement through proper assessment. For example, many issues - such as unwarranted concerns about certain aspects of the illness, misinterpretation of the non-verbal clues within their family (as seen in an HIV-infected child who worried about the health of her uninfected parents), misconceptions about and barriers of disclosure, and the challenges of social isolation and ostracism - are the areas which both children and caregivers are reluctant to openly discuss with each other. As thus, it is important to recognize the need of, not only caregivers, but also children themselves, to have private sessions with health care providers or counselors, where their innermost concerns can be identified and properly addressed. As we can see from our results, many of these matters can be alleviated by providing correct information. These could hardly be achieved if both of them are present with the health care providers at the same time. This study supports the importance of such communication with children and families, a group that has rarely been studied empirically. The areas targeted for improvement of current service, based on our findings, are: doctor-patient communication, provision of private session with children separated from their caregivers (especially for older children and adolescents), disclosure intervention, behavioral screening, life skills building, and empowerment mobilization. Many of these cannot be addressed by health care providers alone. Peer group support and partnership with various parties are some of the potential solutions. This study points to the unique needs of children with HIV disease and emphasize the need for psychosocial intervention and support.

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