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Journal

AIDS Care, 29(6)

ISSN

0954-0121

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Publication Date

2017-06-03

DOI

10.1080/09540121.2016.1227059

Peer reviewed



Published in final edited form as:

AIDS Care. 2017 June ; 29(6): 800–806. doi:10.1080/09540121.2016.1227059.

Living with HIV in West Bengal, India: perceptions of infected children and their caregivers

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Abstract

Children living with HIV (CLH) face several physical and psychological challenges. The impact of the disease is not limited to the affected CLH, but also affects their caregivers and family members. We qualitatively explored the experiences, knowledge, concerns, and perceptions of primary caregivers and triangulated those aspects with those expressed by their CLH. We conducted 34 in-depth interviews (IDI) with primary caregivers of 8- to 15-year-old CLH residing in West Bengal, India. Four focus group discussions (FGD) with CLH were held, two each with children aged 8–12 and 13–15 years. Participants were recruited with the help of a community-based organization providing need-based services to adults and CLH. Five major themes shared by caregivers and children were identified, including concerns about HIV, medications, discriminatory behaviors, having a “healthy mind”, and the advantages and limitations of available HIV-related health services. Two primary themes exclusively from IDI with caregivers were caregiving challenges and concerns about the future of their CLH. Indian CLH and their caregivers face many daily challenges, and there are many unmet but relevant expectations. Caregiving goes beyond the child-caregiver dynamic, and is intertwined with the local community and the healthcare and support system structures. The current study underscores the need for comprehensive care programs focusing on improving support to both CLH and caregivers.

Keywords

HIV; discrimination; qualitative research; caregivers; children

Introduction

Children younger than 15 years comprise approximately 7% of India’s approximately 2.1 million people living with HIV (PLH) (NACO, 2014). Nationwide scale-up of antiretroviral therapy (ART) provision, together with earlier diagnoses, have made it possible for more

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Disclosure statement

No potential conflict of interest was reported by the authors.

Supplemental data for this article can be accessed [10.1080/09540121.2016.1227059](https://doi.org/10.1080/09540121.2016.1227059).

children living with HIV (CLH) to live into adolescence and adulthood. However, this poses new challenges for the limited health resources of India. The major focus of India's HIV program has been "treatment-centric", that is, improving access to ART and other medical care for the infected. Although the importance of caregivers and families for PLH has been highlighted in the literature (Decarlo & Folkman, 1997; Prachakul & Grant, 2003), interventions for families with HIV-infected individuals have been inadequate, and caregivers are often the only source of daily care for CLH (Yeap et al., 2010).

Compared to healthy children, CLH, especially those from resource-limited settings, face many obstacles in their daily lives, including frequent HIV-related illnesses, hospitalization, and poor school attendance (Ferrand et al., 2007; Pridmore, 2008). In addition to physical manifestations (Ferrand et al., 2007), CLH often face various psychosocial and behavioral problems (Punpanich, Detels, Gorbach, & Leowsrisook, 2008; UNICEF, 2004). The emotional impacts of HIV infection affect both CLH and their caregivers. There is enormous stress in caring for CLH, and caregivers may need emotional and social support themselves (Rose & Clark-Alexander, 1998). No Indian study till date has qualitatively explored the constructs of caregiving of CLH. We wanted to understand Indian CLH caregivers' psychosocial needs and inform relevant national HIV programs.

Methods

Study setting and recruitment

Participants were 8- to 15-year-old CLH and their caregivers residing in the districts of Purba Medinipur and Paschim Medinipur, West Bengal. The principal caregivers attended in-depth interviews (IDI), whereas focus group discussions (FGDs) were conducted with CLH. Eligibility criteria for participants are presented in supplementary Table S1. The detailed study methodology has been presented previously (Das, 2015; Das, Detels, Javanbakht, & Panda, 2016).

Results

Participant characteristics

Among the 20 parent-caregivers, 19 were the mothers, whereas non-parent-caregivers consisted of grandparents, uncles, aunts, and neighbors. All CLH participating in FGDs had been infected through vertical transmission, except one 12-year-old thalassemic male child infected by a contaminated blood transfusion. Among FGD participants, 11 (58%) were single-parent orphans, while both parents of three (16%) had either died or abandoned their family. Major characteristics of the participants have been described elsewhere (Das, 2015; Das et al., 2016).

Emerging themes

Findings from content analysis of IDIs and FGDs were organized into two major categories, issues shared by caregivers and children, and issues mentioned only by caregivers. Quotes from the participants, according to themes, are presented in Table 1 (caregivers and children) and Table 2 (caregivers only).

Issues shared by the caregivers and children

Common themes were: (1) concerns about illnesses; (2) medications, (3) HIV-related discrimination; (4) health as a state of mind; and (5) available health services and satisfaction and grievances about them.

Concerns about illnesses

Suffering from a chronic/debilitating disease—Most caregivers (31 of 34, 91%) and CLH (14 of 19, 74%) categorized HIV as a serious health concern, and many considered that the HIV-infected might never lead a “normal” life. Although the participants admitted that they might not always have symptoms, in general they understood the chronic nature of the disease and considered their health to be inferior to the uninfected, especially among caregivers whose CLH had additional serious illnesses. However, there were others who were optimistic in spite of being HIV-infected. They felt that being diagnosed with HIV should not be overly emphasized, and one’s HIV status should not deter them from carrying out their regular activities.

Death-related concerns—Threat to life by HIV was a recurring theme, as many participants considered HIV to be fatal. Death issues were in two contexts, the knowledge of HIV/AIDS being a fatal disease and the prospect of death of the CLH.

Medications

Perceived benefits of ART—Many participants compared pre- and post-ART health scenarios from their own experience. They reported a marked improvement in health following initiation of ART. Some regretted that their CLH was nearly dead before initiating ART, but others were glad their CLH could receive ART from an early stage and have better health. Not everyone was convinced about the benefits of ART. A few caregivers complained that despite taking ART, there were no noticeable improvements in health unless supported by measures such as nutritious diets.

Adherence-related problems—The most commonly cited barrier to adherence was the rigorous medication regimen. It was difficult for the caregivers to persuade their CLH to continue taking medicine, especially when they knew that the drugs must be taken indefinitely. Some participants blamed drug side effects for non-adherence, and some CLH would complain about side effects to avoid taking the drugs.

HIV-related stigma and discrimination

Immediate environment (family)—Participants described facing discrimination from persons they considered close, such as relatives and family members refusing to touch or share food with infected individuals and influencing such misgivings to others. Discrimination within the family might not always be overt, but even subtle forms of discrimination, such as avoidance, caused mental trauma to CLH.

Extended environment (community)—Many participants reported concealing their diagnosis outside their immediate family and friends to avoid discrimination. Caregivers reported warning CLH to avoid inadvertently disclosing their HIV status to others. There

were also concerns that a person with HIV might be labeled as having a “bad” character. Schools (and even private tutors) sometimes refuse to accept CLH, often due to pressure from the parents of other students. Some communities did not allow PLH to bathe in the community pond.

Healthcare settings—Even basic health services are sometimes denied to PLH. Discrimination in healthcare settings was not restricted to any particular group of healthcare providers. One caregiver concealed her daughter’s HIV status from the doctor they visited for other common ailments.

Health as a state of mind

Importance of having a “healthy mind”—Participants recognized that having a positive view of life was important for living a healthy life, especially for PLH. Caregivers said they tried to cheer up their CLH by giving them examples of other “healthy” PLH.

Sources of happiness—Happiness for caregivers was often centered on the health of their CLH. Most respondents, caregivers, and children alike opined that the key to happiness (and health) was in everyday matters such as interacting or playing with friends, not bearing too much stress, going places, etc. However, for orphans, absence of one or both parents often prevented “happiness”.

Available health services – satisfaction and grievances

Satisfaction with services—Respondents were satisfied with receiving free HIV medications, and many would have found it difficult to continue the treatment if they had to pay. A few participants expressed satisfaction with the proactive approach of testing (CD4 and diagnostic tests) adopted by the government health system.

Many praised the services offered by CBOs and their efforts to promote awareness about HIV and giving helpful advice. These organizations have various nutritional and support programs that improved the living conditions of CLH and their families.

Grievances about available services—A common complaint among residents of rural areas was the distance they needed to travel to receive various health services. The cost of transportation to reach health centers was often a deterrent. Inconsistent provision of several HIV-related services and availability of medications were other major grievances. Discourteous services at health facilities often left negative impressions. Unpleasant experiences caused some caregivers to consider stopping ART to avoid future experiences. A lack of basic amenities and poor quality of services at the health facilities were also mentioned as barriers for accessing healthcare. A grievous concern expressed by the mother of a thalassemic child was that the local blood transfusion system had infected her son with HIV.

Issues exclusive to caregivers

Most themes from caregivers of CLH were related to their experiences of raising a CLH, including caregiving challenges and concerns about the child’s future.

Caregiving challenges—Financial constraint was the most common caregiving obstacle. Caregivers who were living with HIV indicated that the disease had worsened their economic situation or made them unable to work. Non-parent-caregivers had the difficulties of raising a child under foster care. They acknowledged that even their best efforts at parenting might not be sufficient.

Concerns about the child's future—Many caregivers, especially those living with HIV themselves, expressed apprehension about the possibility of the CLH losing them as caregivers. Marriage of CLH was a major source of distress for caregivers, with concern about finding a suitable mate for their CLH and the difficulties associated with marriage. They often felt that their CLH, especially girls, needed someone to support them if the caregiver died. Caregivers expressed disappointment that their CLH had little chance of becoming a parent in the future and that the family bloodline might end with them. One mother was so desperate to get her daughter married that she was willing to conceal her daughter's HIV status.

Conclusions

Through triangulation of the views of varied groups of caregivers and CLH, the present study revealed different constructs associated with caregiving for CLH in India. The qualitative methods expanded the study's scope to issues related to caregiving from the perspectives of caregivers and their CLH. Caregiving needs for CLH in a resource-limited setting such as India is a complex problem. CLH and their caregivers face many challenges on a daily basis, and there are many unmet but relevant expectations. Caregiving goes beyond the child-caregiver dynamic, and involves prevailing community, health-care, and support systems. Our findings further emphasize the need for comprehensive care programs that improve support for both CLH and caregivers. Facilitating access and removing barriers associated with health services as well as provision of economic and psychosocial support (counselling, education, etc.) for CLH and caregivers are urgently needed. Involving various nongovernmental support groups for implementing such interventions is recommended.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgment

The study was approved by the institutional review board (IRB) of the University of California, Los Angeles and the Institutional Ethics Committee (IEC) of the National Institute of Cholera and Enteric Diseases (under the Indian Council of Medical Research), the collaborating research institute located in Kolkata, West Bengal.

Funding

This study was supported by NIH/Fogarty International Center [grant D43TW000013 (R.D.)].

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Representative quotes by themes and sub-themes – common issues shared by the CLH and caregivers.

Table 1

Theme	Sub-theme	Representative quotes
Concerns associated with "being sick"	Suffering from a chronic/debilitating disease	"In terms of health, I can give them (his sons) up to 6-7 (out of 10). I'm saying this as I have seen my kids. We say that we are okay, but we can never say we are healthy. We are good at this moment but can become sick any moment. Even a slight mistake can make us sick." [HIV + father of 11- and 14-year-old single-parent-orphaned boys, IDI-1]
		"If you ask about her health ... she is completely healthy, barring a few minor things. Still I would give her 7 out of 10 (on health), I would take 3 away as she has this disease, she has the virus! I can't say she is absolutely healthy. She can be down with illness any moment. As she has this disease, she cannot be as healthy as others." [HIV- uncle of 11-year-old both-parents-orphaned girl, IDI-31]
		"If an adult gets it, he can't work any longer. This disease can also cause so many other types of damages ... " [HIV+ 14-year-old single-parent-orphaned boy, FGD-3]
		"Then (following repeated blood transfusion) the doctor advised for HIV blood test ... he got HIV. It was so shocking! He was already receiving blood for thalassemia, and now this! How can even God save him? How will he survive with so much pain?" [HIV- mother of a 14-year-old thalassemic boy, IDI-16]
		"Once you are born, you have to die someday. The drug (ART) has really helped us have a healthy life...so what's the worry? Others are dying from cancer, sugar (diabetes). If you have sugar (diabetes), there are so many restrictions... can't eat this, can't eat that! This HIV disease... other than this thing between husband and wife, we don't have to worry about anything else. Just take your daily medications, and you're fine! Keep eating whatever you like... even deep fried snacks, samosas... everything. Those suffering from sugar (diabetes) can't eat things like sweets, potatoes and so many other things. They crave for those foods, still can't eat. We are much better." [HIV+ mother of 8-year-old girl, IDI-17]
	Death-related concerns	"The thing that I fear most is that...it (HIV) will slowly drain out all the life energy from you. It'll eat away everything in your body. Then you'll be so sick that nothing will save you. This is what I'm very much afraid of." [HIV+ mother of 15-year-old girl, IDI-12]
		"If anyone gets this disease (HIV), he dies. This disease causes your health to go bad. Then dangers come." [HIV+ 8-year-old single-parent-orphaned girl, FGD-2]
		"I used to be so afraid (of nephew's death). It was because my elder brother and sister-in-law (parents of the CLH) died from this disease. It's very difficult for a person who has this disease to survive." [HIV- uncle of 14-year-old both-parents-orphaned boy, IDI-29]
		"One day she (her daughter) was saying "My parents have it (HIV), I have it, too. Why should we bother about taking drugs? We'll all go (die) together." [HIV+ mother of 15-year-old girl, IDI-12]
Essentiality of medicines	Perceived benefits of ART	"We (parents and son) are taking medicines (ART) and we are doing good. We are not afraid any more. If we were not treated, we would have

Theme	Sub-theme	Representative quotes
HIV-related stigma and discrimination	Immediate environment/within family	<p>become weak. Had we not been taking these medicines, we could have been infected with many other diseases. As we are being treated, we feel good. We are like normal people ... no lack of energy at all." [HIV+ mother of 11-year-old girl, IDI-6]</p> <p>"I take the medicines so that my disease gets cured...so that this HIV disease gets cured quickly." [HIV+ 10-year-old both-parents-orphaned boy, FGD-1]</p> <p>"Talking about benefits, she (daughter) is healthy because of ART. I mean, she has not become so weak like me...like I was before it got diagnosed. I was almost dead (before starting ART). Compared to that she is doing quite well. So, I feel as she was on ART, she never fell so sick." [HIV+ mother of 8-year-old girl, IDI-8]</p> <p>"I get fever, headache, cough and cold, pain in the limbs (without ART)...sometimes I can't even visit the hospital. The drugs they bring me every month (monthly supply of ART) keeps me healthy." [HIV+ 15-year-old both-parents-orphaned boy, FGD-3]</p> <p>"(On benefits of ART) Not yet...he is not very healthy even after starting the medicines (ART). I mean look at other 14-15 year olds who don't have this disease. Compare their health with that of my son's! Since, he has been diagnosed, even after starting the medicines, his health has not changed at all. He is still so skinny! Even after taking the drugs for more than a year, his health has not improved. He eats so little." [HIV+ mother of 14-year-old boy, IDI-23]</p>
	Adherence-related problems	<p>"Regarding health, he (her son) is doing quite well. The only thing is he hates taking those drugs at the designated hours. He does take them occasionally...at other times his frustration shows up and he refuses." [HIV- mother of 12-year-old thalassaemic boy, IDI-7]</p> <p>"I don't like taking medicines. They force me to take those. I feel really bad about it." [HIV+ 13-year-old single-parent-orphaned boy, FGD-4]</p> <p>"There were difficulties at the beginning (of ART intake)... he had to be given blood, had bouts of vomiting. Then his medicines were changed. He did not have any problems thereafter. (At that time) His hemoglobin got very low...about 3." [HIV+ mother of 14-year-old single-parent-orphaned boy, IDI-2]</p> <p>"She (daughter) says that it (ART drugs) gives rise to foul body odor. (She) says, 'I hate taking the medicines. Stop this nonsense.'" [HIV+ mother of 15-year-old girl, IDI-12]</p>
	HIV-related stigma and discrimination	<p>"The day her father died ... she (daughter) did not take a bath or even go to the bathroom ... she was crying so much ... but no one from the family even touched her or talked to her. They said that they would get infected if they touched her." [HIV+ mother of single-parent-orphaned 8-year-old girl, IDI-3]</p> <p>"I have two grandsons - one each from two sons (one of them was HIV+ and died). But the cousins don't mingle freely. (The uninfected grandson says) 'You are not allowed (to play)... get lost'. Then he beats him (the HIV+ grandson). He becomes upset. He comes to me and complains, 'Granny, they won't let me play'" [HIV- grandmother of both-parents-orphaned 10-year-old boy, IDI-20]</p> <p>"As we have this disease, some family members (extended family) hate us. They may speak to us, but as we can feel, they harbor hate within. You know from their body language...and the way they behave. We feel bad about their behavior. We feel bad because they behave this way for</p>

Theme	Sub-theme	Representative quotes
Extended environment/in the community		<p>our disease. Our mind becomes weak. But we have to live ...we have to fight and live.” [HIV+ mother of 8-year-old girl, IDI-8]</p> <p>them about their opinion. (If others knew) It could happen that someone insults you in the middle of the street...you can't stop people from saying things.” [HIV+ father of 11- and 14-year-old single-parent-orphaned boys, IDI-1]</p> <p>“My son's CD4 count report became low and he was keen to tell that to others. I stopped him. There is chance that people may misinterpret (about diagnosis). I asked him not to speak about it to anyone. I told him, 'Don't say these things...people will hate you.'” [HIV+ mother, separated from husband, of an 8-year-old boy, IDI-15]</p> <p>“I haven't told our neighbors about HIV. They may think that I am a bad girl. I got this disease as I didn't have a clean character. That's what I think. So, I haven't told anyone.” [HIV+ mother of 15-year-old single-parent-orphaned girl, IDI-19]</p> <p>“There are some mothers who don't allow their children to play with HIV-infected children.” [HIV+ 14-year-old single-parent-orphaned boy, FGD-3]</p> <p>“...That private tutor refused to teach him (nephew). One of my sister-in-laws informed the tutor about his HIV. Her children were also tutored by the same guy. So she told the teacher that this boy had this disease and nobody should mingle with him or play with him...that if he (nephew) continues to be tutored she (sister-in-law) would not allow her children to take lessons from him.” [HIV- uncle of 14-year-old both-parent-orphaned boy, IDI-29]</p> <p>“When his mother was still alive, people didn't allow her to take baths in the neighborhood pond. After she expired, her son was barred from going to school or taking tuition from special tutor (tutor for speech impaired)...because he had this disease. Also, he was not allowed to use the pond or play with other kids.” [HIV- grandmother of 15-year-old both-parents-orphaned deaf boy, IDI-30]</p> <p>“(Following doctor's advice) So, I admitted her (granddaughter) to the hospital. They kept her in a corner. The doctors would come and see her. The nurses were forever rude...the cleaners would sometimes refuse to clean her place. The ayahs (nurse maids) would come up with all sorts of excuses, because they didn't want to take care of a HIV patient. Then I had to take care of everything on my own. What could I do? I couldn't abandon her, so I wore gloves and decided to do everything myself.” [HIV- grandmother of 8-year-old both-parents-orphaned girl, IDI-26]</p> <p>“See...if we tell the local doctor about this disease (HIV)...that is if I tell the doctor that she (daughter) is HIV positive, she has these complications...that should be the right thing. But what can we do? We keep it (diagnosis) secret. We just tell the doctor she has fever or diarrhea...but we don't say she has HIV! We know she is having diarrhea because of HIV, still we hide it.” [HIV+ mother of 9-year-old girl, IDI-13]</p>
Health as a state of mind	Importance of having a 'healthy mind'	<p>“Only good foods don't make you healthy! She (daughter) needs to have a healthy mind, too. You've got to keep her having fun...we out ways to keep her happy so that she stays healthy. Even after having proper food, one can be down from depression...to keep her healthy we have to keep her cheerful!.” [HIV+ mother of 8-year-old girl, IDI-8]</p>
In healthcare settings		

Theme	Sub-theme	Representative quotes
Available health services – satisfaction and grievances	Satisfaction with available services	<p>“The healthy persons are... those who play regularly, have fun in life are healthy!” [HIV+ 14-year-old single-parent-orphaned girl, FGD-3]</p> <p>“If she gets to play with other children... mingle with kids, be joyful, get about ... These things are essential for happiness... and when she is happy, she is healthy. When she doesn't get these, she gets sick. Her quality of life improves with happiness, her symptoms lessen, too.” [HIV+ mother of 8-year-old girl, IDI-8]</p> <p>“If everyone in the family is disease-free, if they are having fun... that makes a perfectly happy family. Look at us... we are a family of 4. I would say we are good. Although he (son) has a disease, we hope he will be better... We are good!” [HIV – mother of 14-year-old thalassemic boy, IDI-10]</p> <p>“We can think she is normal... but she is not! She doesn't have a father ... however hard we try to keep her in good mood, you can't compensate for the loss (death of father).” [HIV– aunt of single-parent-orphaned 14-year-old girl, IDI-28]</p>
Satisfaction with available services	Satisfaction with available services	<p>“I am happy (about the services). I mean if you get diagnosed (with HIV) and receive the medicines for free, you should be happy. We cannot afford to buy medicines. If I had to buy my own medicines, it would have been impossible for me. I would have died long time back (if free medicines were not given).” [HIV+ mother of 15-year-old single-parent-orphaned girl, IDI-19]</p> <p>“They tested her (granddaughter) immediately after she was born (for HIV). They (doctors) didn't tell me but told my daughter-in-law. The people at hospital spoke to my son and asked them to come back on a particular date. But he didn't care about going back. But the hospital didn't lose track.... when she was one and a half years old, some people from Niritran Hospital (a tertiary care hospital) came to our house for inquiry. They took them to the hospital for testing.” [HIV– grandmother of 9-year-old both-parents-orphaned girl, IDI-25]</p> <p>“We have Calcutta Medical College and Medinipur Medical College in our state. For those who can't buy the medicines ... the state government and Indian government give free medicines to these people from these medical colleges. HIV patients get many kinds of help from these places. I have heard the government bears a lot of cost for HIV patients.” [HIV+ 14-year-old single-parent-orphaned boy, FGD-3]</p> <p>“I am happy about the help they give us (talking about NGO volunteers)... these efforts should continue and the government should also co-operate.” [HIV– grandfather of 8-year-old boy, IDI-11]</p>
Grievances with available services	Grievances with available services	<p>“Treatment facilities... had the (ART) centers been nearer ... if they could open more centers, in small towns, suburbs... then we didn't have to go to Kolkata (capital city). I understand that it might not be possible to provide the CD4 machine everywhere, that's fine with me. I can make a single trip every six months ... but if we can get the medicines at a nearby place, then we can save time, energy... food and transport related expenses (for travelling to ART center) See, I have to get up at three in the morning, take a train... then take a bus. No way can I return home before 10 at night.” [HIV+ father of 11- and 14-year-old single-parent-orphaned boys, IDI-1]</p> <p>“The most important thing is medicines. Sometimes there is dearth of medicines. They (ART center staff) say, 'there is no supply'. Drugs are the basic requirement (for survival). They (children) need it to live. If these (ART) are not available at the hospital, how can we save them?” [HIV–</p>

Theme	Sub-theme	Representative quotes
		<p>mother of 11-year-old thalassaemic boy, IDI-22]</p> <p>„(Sharing her experience at ART center) Sometimes it turns really bad...if some pills from previous month were left in the container... they would use all sort of filthy language... those people who dispense medicines. I feel humiliated...(I ask myself) why do I need to face the girl (niece). They use such nasty words... I feel like not going back there again. But what else can I do?“ [HIV- aunt of 13-year-old both-parents-orphaned girl, IDI-18]</p> <p>“(On how to improve services for PLH) If the doctors and other staff at hospitals stop shouting and quarreling...it will be better.” [HIV + 14-year-old single-parent-orphaned boy, FGD-3]</p> <p>“(About health facility visit) It stinks so bad! The smell is really awful. It is so bad that you don't feel like talking to people.” [HIV+ 11-year-old single-parent-orphaned boy, FGD-1]</p> <p>“My son didn't have any symptoms. He was prescribed blood transfusion...and HIV strikes! ... Because he (son) received blood for thalassaemia, we went for the (HIV) test...and out of ten kids my son was the only one to get infected! People who had regular blood transfusion did not get infected ...and only we got unlucky! ... I hate the blood banks ... what sort of checking mechanism do they have? They (blood banks) are highly irresponsible.” [HIV- mother of 8-year-old thalassaemic boy, IDI-22]</p>

Table 2

Representative quotes by themes - issues exclusive to caregivers.

Theme	Representative quotes
Caregiving challenges	<p>“We no longer have the energy to work. We get tired easily if we try to do some heavy work. So we have to live like this (in poverty). We used to get help from this place (NGO), but that has stopped, too.” [HIV+ mother of 11-year-old boy, IDI-6]</p> <p>“Financially, we are almost ruined. We had to sell whatever land and property that we had...to pay for my husband’s treatment. Then she (daughter) had an accident and the little that was left was gone too [crying]. Now, I have to work really hard for survival of myself and two kids. My son (elder) passed Madhyamik (school board exam) this year and wanted to continue his education ... but I couldn’t afford it ...my daughter is still studying. I don’t know for how long I can continue to bear this burden!” [HIV+ mother of 9-year-old single-parent-orphaned girl, IDI-14]</p> <p>“You know, both her parents are not alive...considering that, I would say she is doing well. On her quality of life, on a scale of 10 I can give her 9 at most. She would always have this vacuum in life...her parents aren’t there. We cannot do much about that... grandparents and uncles cannot fill up that space ... she will always have something missing in her life.” [HIV– uncle of 11-year- old both-parents-orphaned girl, IDI-31]</p> <p>“Sometimes he (nephew) misses his parents...and he starts behaving differently! When my own kids call me daddy... it’s not that he doesn’t talk to me...but, you know, it’s different!” [HIV– uncle of 14-year-old both-parents-orphaned boy, IDI-29]</p>
Concern about child’s future	<p>“We (parents) always think about it...that when we are no longer there. Nothing can be done about us...but that girl (daughter) ...she also has this infection. What will happen to her? We are not worried about us. We got this disease and we may die. But she is just 13, and has this disease...how will she manage (without us)?” [HIV+ mother of 15-year-old girl, IDI-12]</p> <p>“I worry about his (grandson) future. Presently we (grandparents) are both alive...but what would happen if one or both of us die? His parents haven’t left behind a penny for him...or any property...how will the poor child survive? If he was not sick then it might have been possible for him to earn a living and live his own life ... but how can he do that when he is sick with a disease (HIV) like this? His grandfather is doing all he can ... but if someday he is no more ... who will be taking him to the treatment center?” [HIV– grandmother of both-parents-orphaned 10-year-old boy, IDI-20]</p> <p>“As per my knowledge...whoever becomes my son in law...he has to be someone having the same disease. I want her (daughter) to be happy and self-reliant. If her condition (illness) ever becomes like me...she should be able to survive on her own. I have my father to look after me...but she does not have anybody like that in my absence. I am sick, too...I don’t know for how long will I survive. I’ll be gone someday. After I’m gone, her husband needs to look after her.” [HIV+ mother of 8-year-old single-parent- orphaned girl, IDI-3]</p> <p>“See, there is no way I can marry her (daughter) off. Once people come to know about her disease, she can’t get married. She has to live with me...as long as possible.” [HIV+ mother of 15-year-old girl, IDI-12]</p> <p>“See... it’s not possible to arrange her (daughter) marriage if people come to know (about her disease). Now, if I can find a boy who is different (immature)...I’ll request him to marry my daughter and stay with us. I’ll somehow make him understand! I have this plan for my daughter. If it fails she’ll continue to live with me.” [HIV+ mother of 15-year-old single-parent-orphaned girl, IDI-19]</p>