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The impact of HIV/AIDS on families and children -a study in China

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Abstract

Objective—The goal of the study was to understand the needs of families and children affected by HIV/AIDS.

Design—This study used a mixed method combining qualitative and quantitative approaches.

Methods—Focus groups were conducted with local health workers, local schoolteachers, village leaders, persons living with HIV/AIDS, and caregivers for children affected by HIV/AIDS in Anhui, China. Face-to-face interviews were conducted with 154 caregivers of HIV-affected children.

Results—The majority of the caregivers interviewed in the quantitative study were parents (84%), 80% were HIV-positive, and 58% were female. About 54% of the caregivers rated quality of life as poor and 85% reported frequent negative feelings. The annual income per person for HIV/AIDS affected families was much lower than the provincial average. HIV also impacted family relations and family economic situation. The impact of HIV on children was reflected in children's school performance. Children's nutrition and health were also compromised.

Conclusions—Interventions that address the challenges that families face, build families' coping skills, and form supportive local community networks, are needed.

Keywords

HIV; China; family; child; family relationship

Introduction

There are an estimated 650 000 people living with HIV/AIDS (PLHA) in China [1]. HIV infection impacts not only PLHA but also their whole family [2]. Given the family-oriented structure of Chinese society [3], HIV can have a devastating effect on Chinese families. Many PLHA are parents and caregivers who are supposed to attend to the needs of their child; they have to cope with their own physical health symptoms, complex medication regimens [4], stigma [5], and fear of AIDS-related death, and must also care for their families [6,7]. The psychological burden and stress affect their overall mental health, and depression is common among parents and caregivers as they struggle with financial limitations [8]. Many caregivers find that they can no longer work as the disease progresses and their health deteriorates, and unemployment leads to extreme economic hardships [9].

HIV can also have an effect on relationships between family members. Chronic illness in the parent can change family roles causing anger or guilt. Family members can become isolated

[10]. The ability of HIV-positive parents and caregivers to care for their children is also impaired, as poverty induced by HIV/AIDS increases the risk of illness and death among children [11].

HIV/AIDS can also affect children's normal childhood. Children from families living with HIV/AIDS often have to deal with psychosocial stress, an ill caregiver, reduced parenting capacity, a shift in family structure, financial deprivation, and stigma and discrimination. These challenges can lead to emotional and behavioral changes in children, such as depression and delinquency. Previous studies have documented that children from HIV-affected families are more prone to developing disorders [12], such as social adjustment and attention problems [13], and depression [14].

The goal of this pilot study was to understand the needs of children and families affected by HIV/AIDS. The study provides a first look at relationships inside a household with caregivers and children affected by HIV/AIDS in China. We believe that life-threatening illnesses negatively impact caregiver's quality of life and family relationships, leading to unwanted behaviors and poor health in their children.

Methods

The study was conducted in Anhui province, a region in China with a high prevalence of HIV/AIDS. In 2005, it was estimated that there were between 10 000 and 49 999 HIV infected people living in this area [15]. Over two-thirds of the existing HIV infections in Anhui were caused by paid plasma donation [16,17]. As the spread of HIV through plasma donation primarily occurred in the early 1990s, many HIV-infected individuals in this province currently have children aged 6–18.

This study combined quantitative and qualitative research methods [18–20]. The study was approved by the Institutional Review Boards (IRB) of the University of California, Los Angeles (UCLA) and the Anhui Center for Disease Prevention and Control (CDC).

Qualitative methods

The qualitative study involved five focus groups conducted separately with: (1) local health workers; (2) local schoolteachers; (3) village leaders; (4) PLHA; and (5) caregivers of children from families affected by HIV/AIDS. Each group consisted of six to nine people.

Recruitment of local health workers was done in cooperation with local Chinese health officials. Village leaders were referred by county and township administrative officials, and local schoolteachers were referred by village leaders. Participants for the PLHA and caregiver focus groups were recruited from the clinics or hospitals where they normally received primary care services. Only those PLHA that disclosed their status to the community were asked to participate in the focus group. Some of the PLHA and caregivers involved in the study were referred by participants already enrolled in the study. Field staff obtained informed consent from all participating members prior to the discussion. Each participant received an incentive of 40 Yuan (US\$5) in cash for participation in the focus group.

All focus groups were transcribed and crosschecked by two different staff members for quality control. Transcripts were analyzed to identify the most frequently occurring themes and grouping them in the context of other information given by the respondents.

Quantitative method

The study population for the quantitative study consisted of caregivers of children aged 6 to 18 years from families affected by HIV/AIDS. They were HIV positive or negative parents or

grandparents. Unlike the qualitative study, the quantitative study participants were not required to have disclosed their family HIV status to the community. Children were considered to be affected by HIV/AIDS if one or more family members had died from or was living with HIV/AIDS. Informed consent was obtained from all participants prior to the interview. Study participants were given 56 Yuan (US\$7) for participation.

Each consenting caregiver took part in a face-to-face interview lasting approximately one hour. The semi-structured interview contained 147 questions that assessed the caregivers' and children's demographics, caregiver's quality of life, family relationships, and the children's school performance, health and nutrition. Caregiver's quality of life and family relationships were measured using the question 'how would you rate your quality of life?' and 'how are current family relations?', respectively. Participants could choose from 1 (very poor) to 5 (very good). A total of 154 caregivers participated in the interviews between December 2005 and June 2006. The data were analyzed using SAS statistical software (version 9.1; SAS Institute Inc., Cary, North Carolina, USA). Descriptive analyses were conducted for caregiver, family and children's characteristics, respectively.

Results

Qualitative study findings

Four major themes were identified: (1) HIV-related stigma isolates families and children; (2) Poor economic conditions make coping more difficult; (3) Children's education and school performance are in jeopardy; and (4) Children's health and nutrition are compromised.

HIV-related stigma isolates families and children—HIV-related stigma and discrimination are important issues for HIV/AIDS-affected families. Discrimination is directed towards both PLHA and their family members. Sometimes children from HIV/AIDS affected families have difficulty understanding why people treat them badly. They feel different from other children, leading to avoidance and isolation.

“If a PLHA borrows utensils from people, after they return the utensils, people will discard the utensils without the PLHA's knowledge.” - Village leader

“People ask their children to stay away from the children from HIV/AIDS families... some people transferred their children to a different school because they don't want their children to study together with children from HIV/AIDS families.” - Caregiver

“Sometimes children don't look happy when they come back from school because they feel that they are different from other kids... The children stay at home all day long because they are afraid of being discriminated against.” - PLHA

Poor economic conditions make coping more difficult—Many HIV-affected families do not have a stable income, and often there are no family members who can work to support the family. Most of these families have a much lower standard of living than households not affected by HIV.

“The living conditions are poor. Both parents are HIV positive. Nobody earns any money. The living condition is so much worse compared to unaffected families.” – PLHA

[HIV/AIDS-affected children's] parents can't work, so their quality of life is worse than unaffected children. - Schoolteacher

Children's education and school performance are in jeopardy—Many HIV/AIDS-affected children cannot continue to go to school because their families cannot afford school.

Their families need them at home or need them to work to contribute to the family's income. For those children who can attend school, their family situation makes it difficult for them to perform well.

"...sometimes they have to cut class to take care of their sick parents and do the housework, so their studies are affected." – Caregiver

"Some of the children's grades are affected by their family. Some dropped out of school in junior high because they have to make money for their parent's treatment."
- Village health worker

Children's health and nutrition are compromised—Most HIV/AIDS-affected children do not have enough nutritious food and suffer from malnutrition. They mainly eat rice, noodles, and pickles because of poverty. Their health and nutrition are often ignored.

"The [HIV/AIDS-affected] children's nutrition is not as good as the [unaffected] kids. The parents have to save money for treatment, so they have no money left to buy food for the kids." - PLHA

"For example, a ten-year-old child's parents were both dead and he got hepatitis, but he had no money to see a doctor. He had to live by himself and take care of himself."
- Caregiver

Quantitative study findings

The caregiver and family's demographics are presented in Table 1. Most caregivers in this study were parents, with a mean age of 44.3 years. Caregivers had very low levels of education, and almost half of the caregivers were illiterate (48%). The majority of caregivers were married (77.3%), were farmers (73%) and were HIV-positive (80%).

Most of the interviewed caregivers were not satisfied with their quality of life, with 53.9% reporting that their quality of life was 'very poor' or 'poor', 45.5% reporting they were dissatisfied or very dissatisfied with their health status and 51.9% reporting that they very often or always felt negative feelings such as sadness, despair, anxiety and depression.

Most families (66.9%) had two to three children and 21.4% had one child. Nearly 40% of the participating families had one HIV-positive parent and one HIV-negative parent, while in 37.3% of families both parents were HIV-positive. In 15.0% of families, at least one parent had died. While the average annual net income per person in Anhui Province was 2641 Yuan (US\$330) in 2005 [20], the families in this study only had an average reported annual income of 606 Yuan (US\$75.8).

The majority (87.7%) of the interviewed participants rated their family relationship as 'poor' or 'very poor'. Most of them reported that family relationships had not changed because of HIV. The percentage of change for the worse (14.3%) was greater than that of change for the better (9.1%) because of HIV. Less than half (47.4%) of the caregivers had disclosed their or their family member's HIV status to others. Although disclosing HIV status to a child is difficult, 81% of caregivers had disclosed this information to their child.

Table 2 summarizes the basic characteristics of HIV/AIDS affected children in this study. Slightly more than half the children were male (55.8%) and the mean age was 13. Children between the ages of 6–12 represented 26% of the sample. Only two (1.3%) of the children in this study sample were HIV-infected.

Although all the children were at school age, 11.7% of the children were not attending school. While only 16.9% of caregivers reported poor performance in school, 34.0% of the children

had repeated grades. About one-fifth (19.4%) were reported to be less physically active than other children. More than two third (68.9%) of the caregivers rated the children's health status as 'good' or 'excellent,' however, 31% of the children had not eaten fruit in the past month and 14% of the children had no protein in their diet. Some children went hungry because there was not enough food.

Discussion

China is a strongly family-oriented society [21]. Thus HIV could have a severe impact on the stability of families and on the next generation. This pilot study used a mixed method to examine the impact of HIV/AIDS on family and children in China. Both qualitative and quantitative studies demonstrated that most of the HIV/AIDS affected families are living in poverty. Poverty deprives people of access to health services, schooling, information and education. When HIV appears in an already impoverished family, there are limited means for response, so the impact is severe and the pressures and pain of poverty are exacerbated. PLHA and family members also have to deal with societal discrimination and isolation, which can be tremendous psychological burdens.

Aside from the impact HIV has on individual family members, HIV/AIDS also poses special challenges for families to function in accordance with this cultural expectation, making it difficult for HIV-affected families to hold together as a unit. In this study, almost 90% of the caregivers rate their relationships with their family members as poor or very poor, but only a small percent indicated a change due to HIV. Apparently the majority of the families in this poor area of China suffer from poor family relationships. The impact of HIV on the family radiates to individual family members including the PLHA who feel shame and, subsequently, less integrated into his/her community.

The struggle to survive everyday overshadows attention and concern about children's education. In Chinese families, the typical role of an adult is to be an independent, productive person who cares for children and aging parents. Chronic illness reverses this culturally-prescribed role, requiring the children to care for the ill adult [22]. Children become the decision makers, which may explain why most of the caregivers disclose their HIV serostatus to their children. When parents are not capable of contributing to housework or providing a stable income for the family because of chronic illness, further burden rests on the children. The loss of support from an adult exposes children to the distress which results from lack of affection, insecurity, fear, loneliness, grief or despair. More importantly, children's nutrition and health is ignored, which limits the possibility of a successful childhood; in our study, one third of the HIV/AIDS affected children had to repeat a grade. Poor performance in school will in turn affect their future as adults.

There are some limitations to this study. It was conducted in a poor area with a large proportion of former plasma donors. It may not be appropriate to generalize the results from these HIV-positive individuals to families with members who were infected through other transmission routes, or other areas with different economic situations. In addition, only families that had children between the ages of 6 and 18 were included in the study. Families with children younger than 6 may face different challenges and HIV/AIDS may play a different role in family member's quality of life and family functioning.

Conclusion

The results of this study have implications for future HIV interventions in China. Programs and interventions that address the challenges that PLHA and their families face, provide information, build families' coping skills, form supportive local community networks, and that

build and strengthen family relations, especially between adult and child are needed. More attention should be paid to parents living with HIV and the healthy development of their offspring.

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Table 1

Description of caregiver and family's characteristics.

	Number	%
Gender		
Male	64	41.6
Female	90	58.4
Age		
30–40 years old	58	37.7
41–50 years old	57	37.0
51 years or older	39	25.3
Education		
Illiterate	51	48.1
Elementary not finished	35	33.0
Elementary school or higher	20	18.9
Marriage		
Married/living as married	119	77.3
Separated/divorced/widowed	34	22.1
Never married	1	0.7
Current occupation		
Full time farmer	112	72.7
Others	42	27.3
HIV serostatus		
Positive	123	79.9
Negative	31	20.1
Relationship with the child		
Father	56	36.4
Mother	74	48.0
Grandparent	24	15.6
Self-rated quality of life		
Very poor or poor	83	53.9
Neither poor nor good	59	38.3
Good or very good	12	7.8
Self-rated health status		
Very dissatisfied or dissatisfied	70	45.5
So-so	26	16.9
Satisfied or very satisfied	58	37.7
Have negative feelings		
Very often or always	80	51.9
Quite often	51	33.1
Seldom or never	23	14.9
Family size		
Less than four people	114	74.0
Four to six people	26	16.9

	Number	%
More than six people	14	9.1
Number of children in the family		
One	33	21.4
Two to three	103	66.9
More than four children	18	11.7
Average income per person per year		
Less than 400 Yuan	55	38.7
401–700 Yuan	42	29.6
More than 700 Yuan	45	31.7
Family HIV status		
Both parents HIV	13	8.5
Only one parent HIV+, both alive	60	39.2
Both parents HIV+, both alive	57	37.3
At least one parent died	23	15.0
Family relations		
Poor or very poor	135	87.7
So-so	14	9.1
Good or very good	5	3.3
Change of family relations because of HIV		
No change	118	76.6
Changed for the better	14	9.1
Changed for the worse	22	14.3
Disclosure of HIV status to others		
Yes	73	47.4
No	81	52.6
Disclosure of HIV status to child		
Yes	124	80.5
No	30	19.5

Table 2

Description of children's characteristics.

	Number	%
Gender		
Male	86	55.8
Female	68	44.2
Age		
6–12 years old	40	26.0
3–18 years old	114	74.0
HIV serostatus		
Negative	152	98.7
Positive	2	1.3
Attending school		
Yes	136	88.3
No	18	11.7
School performance		
Well	53	34.4
Average	68	44.2
Poor	26	16.9
Repeated grade		
Yes	50	34.0
No	97	66.0
Activity level compared to other children		
More physically active	7	4.6
About the same	117	76.0
Less physically active	30	19.4
Health status rated by caregiver		
Very poor or poor	10	6.5
Fair	38	24.7
Good or excellent	106	68.9
Frequency of eating fruit during the past month		
Didn't eat at all	47	30.9
1–2 times per month	58	38.2
More than 1–2 times per week	47	30.9
Frequency of eating protein during the past month		
Didn't eat at all	21	13.7
1–2 times per month	61	39.9
More than 1–2 times per week	81	46.4
How often child go hungry b/c of no enough food		
Never or rarely	90	59.2
Sometimes	41	27.0
Most of the time or always	21	13.8