AIDS Orphanages in China: Reality and Challenges

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Abstract

With the increasing number of AIDS orphans in China, the government has been building AIDS orphanages since 2004 to accommodate some of those children who have lost both parents to AIDS. However, no data are available regarding the quality of this model of institutional care of AIDS orphans in China. This study, based on qualitative data from children and workers in AIDS orphanages, examines the daily lives, needs, and feelings of orphans and explores the advantages and disadvantages of institutionalized care of AIDS orphans in China. The current study was conducted in 2006–2007 in two rural counties of central China. Data in the current study included individual in-depth interviews with 23 children who lost both of their parents to HIV/AIDS (ages 8 to 17 years) living in AIDS orphanages and 5 AIDS orphanage workers. Findings in this study reveal that children living in orphanages mostly felt that the living conditions were better than the families they lived with after the death of their parents. However, according to the children and orphanage workers, the institutional care has some disadvantages, such as administrative restraints, limited psychological guidance, stigma, lack of education on AIDS, and financial burdens of the operation. Implications for intervention programs include continuing support from the government and nongovernmental organizations, improvements in administrative styles, and the need of incorporating psychological support within the institutions.

Introduction

CHINA HAS APPROXIMATELY 700,000 people living with HIV, with 20,000 individuals developing AIDS in the year 2007.¹ As estimated by the China Ministry of Health in 2004, there are at least 100,000 AIDS orphans in China.² According to UNAIDS/UNICEF, AIDS orphans are children under 18 years of age who have lost one or both parents to AIDS.³ The China Ministry of Civil Affairs has speculated that without effective prevention programs, the number of AIDS orphans will increase to 260,000 by 2010.⁴

The drastic increase in the number of AIDS orphans has stretched the limits of traditional care arrangement for orphans in China. Kinship care has long been a first option in China, but now it is not always available for children orphaned by AIDS, especially in resource-poor regions.⁵ Since 2004, the Chinese government has made some emergency responses to provide support for these children, including building AIDS orphanages in areas hard hit by the epidemic.

One of the unique characteristics of China's AIDS epidemic in the 1990s was that most of those persons infected were concentrated in rural areas in several provinces⁶ including

Henan Province. Henan is an agricultural province in central China with a population of 98.69 million including 64.80 million farmers.⁷ In 2007, the rural per capital net income in Henan was 3852 Yuan (or about \$481.5).⁷

In the late 1980s, some commercial blood stations collected blood in remote rural areas of Henan Province using unhygienic collection procedures, resulting in the rapid spread of the HIV/AIDS epidemic.^{2,4} According to an estimate by the China Ministry of Health (MOH) and United Nations Theme Group on HIV/AIDS in China (UNTG), in the mid-1990s there were at least 3 million commercial blood donors inhabiting China's central and southern provinces including Henan Province.⁸ Many of these donors became HIV positive and have subsequently died resulting in children who have lost one or both parents to AIDS.^{2,4}

On the 2003 World AIDS Day, the China government announced a national AIDS control program, "the China Comprehensive AIDS Responses" or "China CARES." The basic strategies in China CARES were "four frees and one care" programs: free antiretroviral drugs, free prevention of mother-to-child transmission, free voluntary counseling and testing, free schooling for children orphaned by AIDS, and care and

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economic assistance to the households of people living with HIV/AIDS.⁹ One study conducted between 2005–2006 in Guizhou Province showed that China CARES program might have had a positive effect in urban areas in terms of improving knowledge regarding voluntary HIV counseling and testing and reducing discrimination against people living with HIV/AIDS but had little impact in rural areas.¹⁰

The China CARES program has supported local governments to build AIDS orphanages since late 2004. The first of such AIDS orphanage was built in Henan Province.² The government of Henan Province claimed that they spent a total of 17.40 million yuan (or about \$2.18 million) in construction of 20 AIDS orphanages, which admitted 356 AIDS orphans in 2004.¹¹ Eligible children for these orphanages are those who have lost both parents to AIDS (double orphans) and who do not have extended family members who are physically capable of taking care of them.¹² Based on a report from the Department of civil affairs of Henan Province, at the end of 2007, approximately 10% of double AIDS orphans were living in AIDS orphanages, while less than 5% were legally adopted and approximately 85% were taken care of by their extended families.¹³

Research in the Western nations has suggested that the centralized institutional care such as orphanages may be disadvantageous to the mental health of children, and should be avoided if other care arrangements are available.¹⁴ Most studies regarding care arrangements of AIDS orphans have been conducted in sub-Saharan Africa. In many African countries the extended family traditionally forms the basis for orphan care.^{15,16} The model of orphan care in African nations seldom relies on the institutional care,¹⁷ for it is universally assumed to be highly undesirable, if not pathogenic.^{18,19} However, some studies argue that the effects of institutional care may be less negative than previously implied.²⁰ In some resource poor countries, orphanages are often the only viable means of orphan care¹⁴ and more research is necessary to better understand this option particularly in those cases when adoption or other living arrangements are not possible.²¹

In Henan Province, the AIDS orphanages were established by the government following some general guidance. AIDS orphanages were established to meet orphans' basic needs with a long-term goal for children to grow up mentally and psychically healthy. Every orphanage has to have basic utilities (e.g., electricity, hot water), recreation facilities, access to basic medical care, and other daily necessities. Some large orphanages offered on-site schools for younger children (e.g., elementary school children), while middle school and high school children attended nearby village schools or public boarding schools.

The number of children in each orphanages ranges from 20 to 150. The child to worker ratio is between 3:1 to 15:1. Each orphanage has one management team, which includes directors, caregivers, security staff, medical staff, and cooks. A typical AIDS orphanage is operated in dormitory fashion with children living in double-occupancy rooms and following a preestablished daily schedule for meals, bed time, entertainment, and other activities. When a child needs to leave the orphanage, s/he needs to get permission from the management.

The orphanage only admits children between 8 to 17 years of age. As part of the admission process, the children must sign an agreement to comply with all the regulations of the

orphanage. To protect the health and safety of every child living in a collective environment, each orphan admitted has a physical examination (including HIV testing) to make sure that s/he is free of any infectious disease or other major illness.

To date, research regarding the experiences of children affected by AIDS living in orphanages is limited in Asian countries. In order to develop appropriate care arrangement for AIDS orphans, there is a need to evaluate the living conditions of children in AIDS orphanages. Therefore, this study, based on qualitative data from children and workers (their caregivers) in AIDS orphanages, will examine the daily lives, needs, feelings of orphans and explore the advantages and disadvantages of institutionalized care of AIDS orphans in China.

Methods

Study site

The current study was conducted in 2006–2007 in two rural counties in central China which were seriously affected by HIV/AIDS through the unsafe practices of commercial blood collection. Both counties are rural ($\geq 94\%$ rural residents) with a total population of approximately 2.3 million. Both counties are poor with rural residents earning an average annual income of approximately \$393 US in 2005. Both counties reportedly have the highest prevalence of HIV-infection in the region, although the exact number is unknown.

Participants

The participants in our study included 23 double-orphaned children (ages 8 to 17 years) living in 4 orphanages and 5 orphanage workers. The potential participants were informed of the purpose and design of the study and assured of confidentiality. Participants all signed informed consent forms prior to the interviews. The study protocol and consenting procedures were approved by the Institutional Review Boards of both Wayne State University in the United States and Beijing Normal University in China.

Data collection

The current study is based on secondary analysis of qualitative data collected in a larger study examining psychosocial needs of children affected by HIV/AIDS in central rural China.²² In-depth individual interviews in the larger study were conducted using semi-structured interview guides. The guides were developed based on the research objectives and questions related to sociocultural conditions, life events, and potential psychological outcomes for the children. The interview guides provided a means of ensuring that all relevant topics were covered during the interviews. Interviews were conducted in a conversational style, so questions were not always asked in the same order or worded in the same manner. With the appropriate consent of the participants, interviews were audiotaped. Interviewers were local university faculty members and students trained by the U.S. and Chinese investigators with backgrounds in anthropology, psychology, and public health. Interviews were conducted in Mandarin. All the interviews were conducted in private at orphanages. Each interview lasted approximately 1 hour. Each of the participants received a small gift at the end of the interview.

Data analysis

Audiotapes were transcribed verbatim over the course of data collection. Each of the transcripts was translated into English with two rounds of accuracy checks by bilingual staff. Both the U.S. and Chinese investigators conducted data analysis with reading and rereading the transcripts and field notes in English and Chinese. Coding themes were developed based on research objectives and research questions. New themes were identified and added during the coding process. The transcripts were recoded if either a new code was developed or an existing code was revised. Using the open coding technique,²³ the investigators reviewed transcripts to identify themes, develop definitions of themes and subthemes and explore agreement among the investigators. The transcripts were coded using the qualitative data analysis software ATLAS.ti 5.0.²⁴ After the coding and discussion among investigators, searches were conducted using categories of codes. These texts were reviewed for commonalities and themes within single interviews and across interviews.

Findings

Demographics

The children ranged in age from 8 to 17 years with a mean age of 12.7 years; 12 were boys and 11 were girls. The mean age of children when their father died was 8.1 years and the mean age when their mother died was 7.8 years. Five orphanage workers (2 men and 3 women) had a mean age of 28.2 years.

Advantages of orphanage

Most of the children we interviewed felt that the living conditions in orphanages were better than the families they lived with after their parents had died. The improvements include the following aspects.

Stable and improved living environment. The orphanages offer children free living quarters, free meals, and free clothing and the workers in orphanages acted as their guardians in providing care for them. Orphanages afford children not only a place to reside, but also a place to settle for an extended period of time. This was particularly important for those children without relatives to rely on and who were either homeless or caring for themselves prior to coming to the orphanage. One 14-year-old girl had lost her mother to AIDS when she was 7 years old. Her father died 1 year later. After her father's death, she lived with her second uncle but not long afterward he also died. Because she had no other relatives to rely on, she had to live at home by herself. She shared her feeling during the interview:

We [her family] were poor before, Umm . . . my clothing was too tattered . . . too old . . . like a . . . beggar girl. The pants that I was wearing were very short and my legs stuck way out of them. I have nothing to eat at home. I went back and forth and ate meal in one home and another in another home until about half of a year later I came to live at an assisted living center. I stayed in the assisted living center over one year, and then came here [orphanage]. Now I feel the situations here (at orphanage) are very good.

The orphanages employ cooks to prepare meals for children and provide children with seasonal clothes. Most of the children living in orphanages were satisfied with their current

living conditions. They generally thought the living standards in orphanages were better than the local households. One 15-year-old boy living in an orphanage stated:

My life was improved greatly after I came to the orphanage. We ate much better than at home [his original house]. At present [in the orphanage] we have a menu, on the menu, there are several kinds of foods, and the meals are not the same everyday in one week. We are supplied with many free clothes and shoes each year; about two suits of clothes every season.

One 11-year-old girl also stated, "I'm happy living here. I did not live well at home. There were bugs [at home] and I was always being bitten by them. There are no mosquitoes here [in the orphanage] and it's spacious. There are lights in the classroom, too."

A 10-year-old boy compared the general living conditions of the orphanage with those of local villages. "In our village school, the water in our classroom would be 30 cm (12 inches) high [during the rainy days] because the roof is damaged and the rain would drip from the top of the roof. Some villagers live inside of straw houses where there is neither electric fan nor air-conditioner. They can only use manual fans. However we have electric fans and air-conditioners [at orphanage]."

Improved learning environment. A successful child education is based on a combination of good school and home education. The children orphaned by AIDS face not only dropping out of school due to poverty or other family conditions, but they also lack home education. In orphanages, the workers act as the children's guardians including taking care of the children's education. The workers will urge the children to study hard, supervise their homework, and make sure every child gets to school on time. The workers even give children some help on schoolwork. One orphanage worker described her daily routine:

In the morning, I clean up the rooms. When it is time for lunch and dinner, I remind them and help them if necessary. In short, these are all the small things (or tasks). After the meal, I play games with them. Another thing is study . . . I study the materials [that the children learn in school]. If the children have some difficulties in study, I can help them.

Another worker who is managing one orphanage stated how hard they have supported children with their studies.

We buy whatever the children need. We decide not to lag in this regard. Even we have no enough money and have to borrow money, we still buy. We deliver study supplies to the children every Wednesday. They can ask for and get the supplies whenever they need . . . If they have difficulties in study and can't catch up, we invite outside teachers to help them. We invite school teachers [to teach here] if the children needed to make up a missing class.

Because of the better study conditions and close supervision, most of the workers in orphanages thought the children's learning was comparable with that of children in local families. One male orphanage worker stated:

Compared with the children in the city, they may not be better. To tell you the truth, compared with the other children in the rural places they are not too bad. Their parents died and their grandparents can't monitor them. So no one cared about whether they did their homework at home. They (Children) come here (orphanage) and we have disciplines . . . The children's performances with learning are much better now.

During the interview one 12-year-old boy said that it was very convenient living in the orphanage and he mentioned that his grades had improved after he started living at the orphanage.

Improved and timely medical care. Some orphanages are equipped with a medical room where doctors from the County Hospital regularly carry out routine medical examinations and vaccinations of the children. Because of the free medical care provided by the government, every child with an illness is given immediate attention in the orphanage. In the interviews, a 15-year-old boy said, "They are taking good care of us. Even if you suffer from a minor illness and it is in the middle of the night, they would pick you up and send you to the County Hospital for treatment. Once a child broke his finger while playing basketball and needed an operation, and they took him to the County Hospital at night and spent about 6 or 7 thousand Yuan [Chinese currency] on the operation."

A 14-year-old girl also recalled what happened at the time of her illness:

Once I was sick and ate nothing for the whole day. The weather is very hot that day. The director [of the orphanage] learned the situation and picked me up in a car to the County Hospital. He stayed with me until very late in the night. He received a phone call from his family asking him to go home for some urgent. But he decided taking me to the hospital for medical treatment instead of going home.

This young girl felt that the director of the orphanage treated her like her parents had treated her. She cried during the interview and told the interviewers that she could not find a proper word to express her gratitude to him. She said she felt very lucky to be staying in orphanage because the workers loved her and took good care of her.

Psychological support and comforting. Poverty, loneliness, and discrimination have cast a dark shadow on the psychological health of many AIDS orphans. One 13-year-old girl talked to us about her fear after her parents' death:

Every evening, I always feel as if someone is just outside my room. I must open my eyes every night, otherwise, I would feel that someone is walking in my room. Things have been like these for 2 years, I dare not go outdoors on my own when evenings come. I am having a sense of great terror everyday and I am afraid of going into a room all by myself. When I slept with my grandma at home [before she came to orphanage], I often woke up from nightmares. When I just came to live in the Sunshine House [orphanage], I was afraid of going upstairs on my own.

The orphanages have provided the children with a sense of community to help them to overcome their sense of loneliness and fears. As one orphanage worker said, "Even though they are orphans, they live in a big family of affection and friendship where people love and take care of them. They are not lonely." And just because of this, that girl said she is "gradually feeling better now" after coming to the orphanage.

An 8-year-old child stated, "We have various kinds of activities here, such as high-jump and table tennis. And we can also make many good friends. I get along with my classmates very well. We talk about jokes, guess riddles, and play in the rooms. There are a lot of fun here." An orphanage worker talked about the psychological changes she had observed.

An overall impression is that they have made progress in the aspect of self-supporting and self-improving. Their manners and politeness are also remarkable. Their attitudes have changed to become more open and the previous loneliness has disappeared. The children are getting along with each other very well, and the communications between the children and adults are quite normal.

The healthy mental status of the children is typically demonstrated by the fact that most of them have positive expectations for their future, which is often expressed in relation to education. Many children we interviewed stated that they hope to study in the future, to go to a university, and find a good job. Some children expressed hope that they could become doctors to treat AIDS patients. Other wanted to become scientists, businessmen, and soldiers. One 15-year-old boy told the interviewer his hope for the future:

If I can go to a college I will choose a military college in the future. If I cannot make it, I want to study technology, perhaps computer. I prepare to study it in this summer vacation. . . . I learned basketball and computer last year, I want to study computer this year again.

Disadvantages of orphanage

The orphanages indeed have afforded children good living conditions. However, according to the children and workers, there are still some areas that need improvement in the future.

Administrative restraint. In one interview, we asked one 8-year-old girl to draw a picture of whatever she wanted to show us; and she drew a bird. When we asked her why she drew a bird she replied:

Because I want to be a bird to fly freely. I'm not free now because I can only go home [her original house] once a month. We can go back some other times, only when there are some matters [with home]. I want to be free as a bird and let me go home once every 2 weeks. I miss my grandfather and grandmother and aunt [father's sister].

Children at orphanages follow a preset schedule for daily activities: getting up, having meals, going to school, and going to bed. There are daily checks on entering and leaving the orphanage. Most orphanages allow the children to go home once per month, on holidays, or under special conditions, but the children can only leave with the permission of the orphanage staff. During weekends, the relatives of the children can come to visit children.

Some children we interviewed felt that they do not have enough freedom at the orphanages. These feeling may reflect that these children came from the countryside and were used to having a lot of freedom. They may feel uneasy about the change of life style and rules at the orphanages. In addition, the collective, closed style management in orphanages may limit children's physical and emotional space to interact with their relatives and peers outside of the orphanages.

Most of these regulations are based on good intentions for the children's safety. Workers are worried that the children might get into trouble outside of the orphanage. However, such rules are contradictory to many developmental needs of young children such as the opportunity to explore and experience different environments.

Need for psychological guidance. The orphanages are supposed to not only provide orphans with material support,

but also mental or emotional support. Many orphanage workers make a lot of effort in this aspect. However, compared to other children, those at the orphanages have experienced extremely stressful and/or traumatic life events which might have significant psychological and emotional effect. Dealing with mental health problems among this group of children is certainly not an easy task. It is difficult for the orphanage workers to identify these mental health concerns, and generally the workers do not have the necessary training to handle these issues. One young girl described feeling depressed and confused.

Every afternoon after school, I usually stay inside the orphanage or sit in a nice and cool place until it gets dark. . . . I don't know what to play in my spare time so that after class I always go outside the classroom or just sit inside the classroom. I just sit there bending over the desk, without reading any books.

Another 15-year-old boy stated, "Ever since my mother died [after his father's death], I sometimes became bad-tempered and silent. When I first attended the junior high school, I never replied to my classmates when they asked me about my parents. Sometimes when my classmates bullied me by calling me an orphan with no parents, I would get very angry and fight against them."

While the orphanage workers are the supervisors of these children, their "parenting role" is not always recognized. For example, when children sometimes feel sad for missing their deceased parents or have some kind of psychological problems, they would not talk to the workers in the orphanage. An 8-year-old boy told the interviewers, "I don't have the courage to talk about my parents with the workers. I am afraid to do so for fear of being laughed at and looked down upon."

Stigma. While most of the children felt they had a better life in the orphanages, the fact that they are living in orphanages make them easily identified or labeled as "AIDS-related" (or used to live with parents with AIDS). This situation leaves the children subject to stigma associated with AIDS. A 14-year-old boy we interviewed told us his reasons for hiding where he was living from his classmates:

I wouldn't tell my classmates that I was from the Sunshine House [orphanage]. I wouldn't let others know the truth for fear of being looked down upon. Some of my classmates would say that children from the Sunshine houses are also infected with HIV/AIDS. I would tell them my previous home address rather than the Sunshine House.

The stigma against AIDS originates from not only the fear for AIDS but also the lack of knowledge of AIDS. Unfortunately this kind of stigma exists not only among ordinary citizens but also among some government officers and leaders. One 14-year-old girl mentioned her experience:

They all know we were examined for (HIV) several times. I remembered clearly that doctors did twice at my home, after I came here, twice, in school once, altogether up to five or six times, we were all not infected with it (HIV). But the leaders (officials from county, city, or provincial government) had a sense of avoiding us when they came here. . . . If they first put out their hands to shake with us, we would do it too; if they did not want to shake hands, we didn't do it either. It seemed that they feared of us.

Lack of AIDS knowledge. From the interview we found that most children knew little about AIDS except for some

main modes of transmission. The knowledge of AIDS was even more limited among younger children. One reason for the children's lack of knowledge may be related to caregivers or schoolteachers reluctance to discuss HIV/AIDS because of fears of upsetting the children. A 13-year-old girl shared her view during the interview:

AIDS is probably transferred by mothers to infants, and transferred through blood. I am not clear about anything else. I don't know much about AIDS. Perhaps one should be more careful about personal hygiene. Because of our parents, it's difficult for our teachers to tell us the knowledge about AIDS for fear of making us sad.

Another 8-year-old boy stated in response to a question about what he knew about HIV/AIDS, "To prevent from getting infected with HIV/AIDS requires you not to stay with AIDS patients together, and you should also stay away from AIDS virus. I am not clear about the rest of it. This is what I found from the books myself, the teachers here usually wouldn't tell us anything about this, but the children might sometimes talk about this with each other."

Many of children expressed fear of AIDS since their parents' deaths. On the one hand, the children are unwilling to talk about AIDS and their parents with the workers, while on the other hand the workers do not want to talk about it to avoid making the children sad. Overall, this lack of discussion about AIDS inside of the orphanages results in an unwarranted omission of proper HIV/AIDS education and awareness.

Financial burdens. The orphanage workers expressed that the greatest difficulty with their job was related to the shortage of funds. The orphanages receive funds from local governments based on the number of children they have (160 yuan or about \$20 per child per month), which are used to cover all the expenses of child care and operations of the orphanage. The orphanage workers thought that the current funding level was hardly sufficient to provide adequate care for the children. One manager explained expenditures per month as follows:

The difficulty is, in general, lack of money. When someone is sick we take him to see a doctor and pay for the treatment and medicine. The medical expense is huge every month. The government pays 160 yuan per child per month. Of the 160 yuan, only 130 yuan are used on the children directly. The 130 yuan include 100 yuan for living and 30 yuan for clothes; and the other 30 Yuan is supposed to be for electricity. Actually, the 30 yuan for electricity is all the money for service and management. The expenses of office supplies come from the 30 yuan as well.

Discussion

The top priority for AIDS orphan care is to meet their basic needs (food, clothing shelter, medical care, and education). This priority becomes critical in the regions which experience extreme poverty, such as the counties in our study. Our data suggest that AIDS orphanages have mostly served these needs by providing orphans with stable or improved living conditions including medical care and schooling. However, our data also suggested that there are areas that need improvement in these orphanages including use of developmentally appropriate management styles, adequate psychological support, and sufficient funding.

The findings in our study have important policy implications to improve AIDS orphan care in China. First, the central and local governments should continue to support AIDS orphanages for the long-term benefits of the children in these establishments. Domestic and international nongovernmental organizations, community-based organizations and even individuals also should be encouraged to support the orphanages. In the meantime, the relevant government agencies should develop a realistic policy to make sure the financial support from the government and other sources are used for orphans.

Second, the orphanages need to improve their administrative style. The current closed type of administrative methods should be changed so that the children have more opportunities to see their relatives and have more contact with the outside world. For example, it might not be necessary for the orphanages to have their own primary schools but rather that these younger children like the older youth could attend nearby schools. This could serve not only to promote contact and communication between these children and children living in the villages, but also reduce operational costs of the orphanages.

Third, the orphanages need to work with the local community to reduce stigma against children living in the orphanages. Appropriate HIV/AIDS knowledge education may help the local villagers to reduce unnecessary fears associated with HIV/AIDS, and may also reduce the stigmatization against the children whose parents died from HIV/AIDS. A recent study in China suggests that a brief intervention program shows evidence of reducing HIV stigma and discrimination.²⁵

Fourth, the orphanages need greater psychological support. The orphanage workers should receive adequate training to provide basic psychological and emotional support to the children. The workers also need to receive some training in skills to effectively communicate with children about their late parents and HIV/AIDS and to provide children with normal channels to grieve. Providing children with necessary knowledge about HIV/AIDS helps them to better understand the cause of their parents' deaths and is necessary to decrease their own risks for infection in the future.

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