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Community-based family-style group homes for children orphaned by AIDS in rural China: an ethnographic investigation

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As the number of children orphaned by AIDS (Acquired Immunodeficiency Syndrome) has reached 17.3 million, most living in resource-poor settings, interest has grown in identifying and evaluating appropriate care arrangements for them. In this study, we describe the community-based family-style group homes ('group homes') in rural China. Guided by an ecological framework of children's wellbeing, we conducted a series of ethnographic observations, in-depth interviews and group discussions in the rural areas of Henan Province, which has been severely impacted by the AIDS endemic through commercial blood collection. Based on our observations and discussions, group homes appear to provide stable and safe living environments for children orphaned by AIDS. Adequate financial support from non-government organizations (NGOs) as well as the central and provincial governments has ensured a low child–caregiver ratio and attention to the basic needs of the children at group homes. The foster parents were selected from the local community and appear to have adequate qualifications and dedication. They receive a monthly stipend, periodical evaluation and parenting consultation from supporting NGOs. The foster parents and children in the group homes have formed strong bonds. Both children and foster parents reported positively on health and education. Characteristics of community-based group homes can be replicated in other care arrangements for AIDS orphans in resource-poor settings for the optimal health outcomes of those vulnerable children. We also call for capacity building for caregivers and communities to provide sustainable and supportive living environment for these children.

Keywords AIDS orphans, care arrangements, China, family homes, group homes

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KEY MESSAGES

- In rural central China, community-based family-style group homes provide stable and safe living environment for children orphaned by AIDS.

- Sufficient financial support from local government and NGOs and qualified and dedicated foster parents recruited from nearby villages have contributed to the positive outcomes of group homes but also raised concerns on sustainability of such care model.

> • Caring for children orphaned by AIDS involves more than providing stable living environment; a continuum of care and safety net with capacity building in communities is necessary for long-term care and development of these vulnerable children.

Introduction

The loss of parents during childhood has far-reaching and lasting consequences on the development and wellbeing of children. Compared to non-orphans, orphans are more likely to experience malnutrition, poor physical and mental health, educational disadvantages and exploitation for child labour (UNICEF 2004; Sherr *et al*. 2008). As of 2013, the number of children orphaned by AIDS (Acquired Immunodeficiency Syndrome) worldwide has reached 17.3 million, and most of these children live in resource-poor settings (UNICEF 2013). In addition to the negative experiences by orphans, children orphaned by parental AIDS may suffer from more stigma, bullying and social exclusion than other orphans (Cluver *et al*. 2008; Cluver and Orkin 2009; Chi and Li 2013). How to care for a large number of AIDS orphans effectively remains a significant global public health and social concern (UNICEF 2004).

Two main care models for AIDS orphans are practised in most low- and middle-income countries. One is institutional care (e.g. orphanage), which is often criticized for lack of capacity to meet children's emotional needs and is therefore generally less favoured than other care models (Subbarao and Coury 2004; Ahmad *et al*. 2005; Ford *et al*. 2007). The second model is foster care, including adoption into new families and care by members of the community or extended family. Owing to the AIDS-related stigma, adoption of AIDS orphans by non-family members is limited in many settings; and most AIDS orphans are cared for by their extended family members ('kinship care'). Data on kinship care have shown that it often cannot meet the essential needs of orphans, especially in households headed by widows, the elderly or youths (Oleke *et al*. 2005; Zimmerman 2005; Howard *et al*. 2006; Oleke *et al*. 2007; Boris *et al*. 2008). Mental and physical health problems of caregivers in kinship care have also been observed (Oburu 2005; Ice *et al*. 2010; Kuo and Operario 2011; Kuo *et al*. 2013). A small proportion of orphans live in communities and are cared for in family-style group homes, or 'children's homes' (Subbarao and Coury 2004), in which paid and usually trained foster parents (community members or social workers) live with a group of orphans (usually 4–10) in an ordinary house (instead of an institutional building) in the community (Subbarao and Coury 2004). The hope was that by providing children with a family-like setting, these homes would adequately meet orphans' basic material, safety and psychosocial needs (Zimmerman 2005). However, the reliance of this model on external financing and its lack of supervision and support of social workers potentially undermine its quality of care and sustainability (Kidman *et al*. 2007; Kidman and Heymann 2009).

Although much research has been conducted on the psychosocial wellbeing of children orphaned by AIDS (Steele *et al*. 2007), studies focused on the particular care model for these vulnerable children are scarce. Furthermore, most studies on care arrangements for AIDS orphans were conducted in sub-Saharan Africa, where more than 80% of AIDS orphans live. In recent years, however, the increasing number of AIDS orphans

in Asia has drawn global attention. For example, China hosts an estimated 260 000 AIDS orphans (He and Ji 2007; Zhao *et al*. 2007). A large number of AIDS orphans are concentrated in the rural areas of central China, including Henan, Anhui and Shanxi provinces, where an outbreak of AIDS endemic occurred in the 1990s as a result of unhygienic commercial blood collection, leaving many children orphaned (Ji *et al*. 2007; Zhao *et al*. 2007). Owing to the stigma and fear associated with HIV/AIDS, few AIDS orphans were adopted into non-family households in China (Zhao *et al*. 2009). For quite a long time, most AIDS orphans in rural China were cared for by members of their extended families.

Not until 2004 did the Chinese government initiate emergency measures in response to the growing crisis of AIDS orphans and mounting international criticism (Wu *et al*. 2004; Wu *et al*. 2007). Under the Chinese government's 'Four Free One Care' policy, children orphaned by AIDS were provided free schooling and economic assistance. In Henan Province, a number of 'Sunshine Houses' (orphanages for AIDS orphans) and 'Sunshine Families' (family-style group homes) were built by the government with financial support from some non-governmental organizations (NGOs) and private donors for the increasing number of AIDS orphans (Zhao *et al*. 2007; Zhao *et al*. 2009); however, kinship care continues to be the major care arrangement for a large majority (about 80%) of orphans in the area, followed by institutional care and family-style group homes (Zhao *et al*. 2009).

The group homes care model is hypothesized to represent a step further towards 'normal' family life for orphans, but data on the characteristics and function of such community-based family-style group homes from China have been virtually non-existent. Our recent study in Henan compared health outcomes of AIDS orphans in the three care models and showed that children in group homes were doing better in all aspects, including a lower level of traumatic symptoms, better physical health and superior school outcomes compared to children in orphanages and kinship care; furthermore, such differences sustained after controlling for potential confounds (Hong *et al*. 2011). As the reasons for such superior outcomes from the group homes remain unclear from the quantitative investigation, we thus conducted a series of ethnographic investigations, seeking to improve understanding of the characteristics and function of these group homes in rural China.

Based on Bronfenbrenner's ecological system of human development (1979) and our ethnographic investigation, a multilevel conceptual framework was developed to guide the data collection and analysis of this study (Figure 1). This framework places the children's wellbeing at the centre of a number of concentric rings, each representing increasingly distal influences on the child. At the most proximal level, children's family environment, caregivers and neighbourhood exert the most direct influences on children's physical health and psychosocial wellbeing. A stable home provides food, clothing, school supplies, financial stability and a safe living condition; qualified and dedicated caregivers give children a
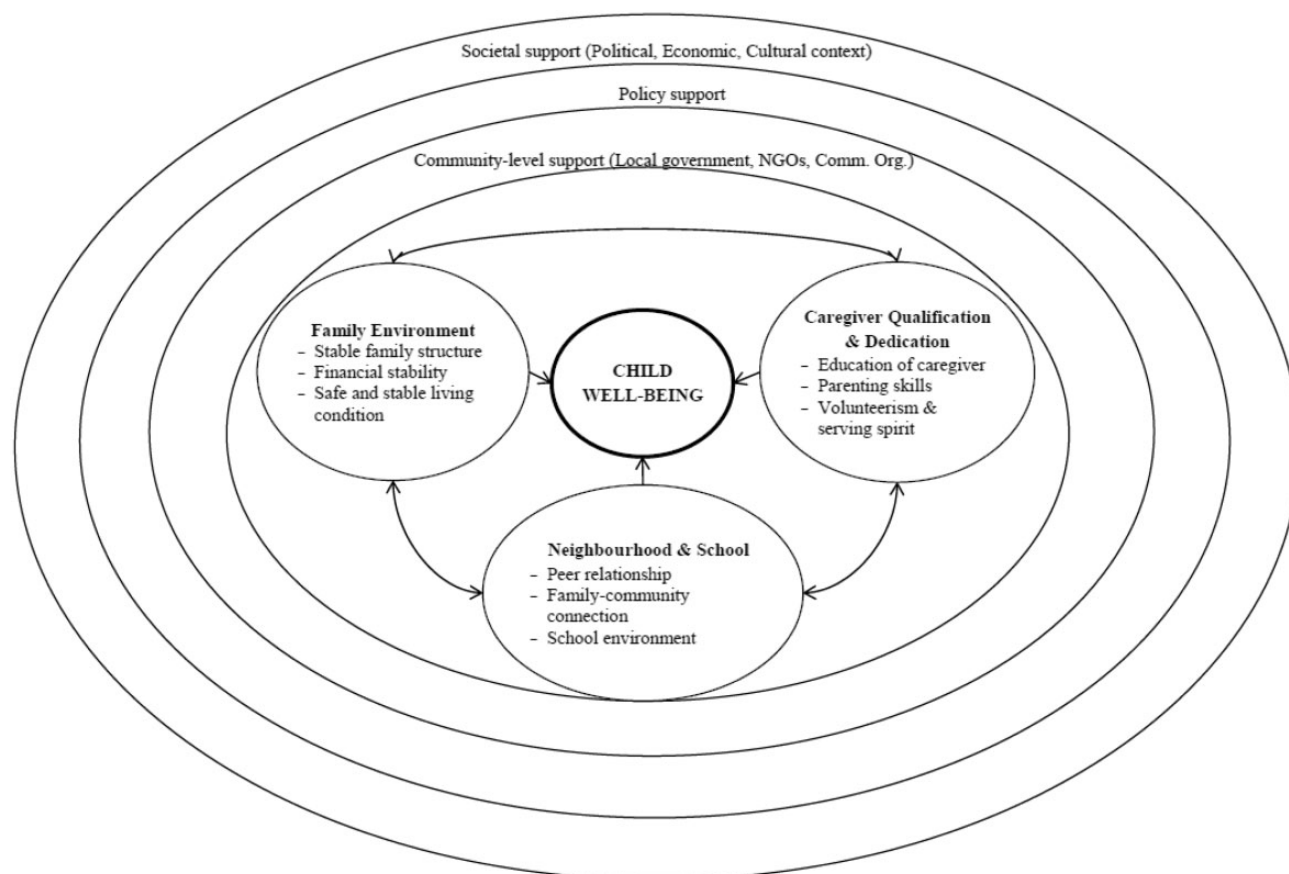
Figure 1 Theoretical framework on the care of children orphaned by AIDS in resource-poor settings

warm family atmosphere and enhance positive communication and educational aspiration among children; a supportive neighbourhood fosters a nurturing community and shields children from stigma and isolation. The three interpersonal-level domains are interconnected and reciprocal; they provide an immediate and closely knit safety net for children. At the community level, support for these vulnerable children comes from local government, NGOs and community organizations. At the policy level, the legislature as well as government regulations and policies regarding the support and welfare of children and families affected by AIDS, treatment and care of HIV-infected individuals, and efforts to reduce the AIDS-related stigma all impact orphans directly and indirectly through many components of their socioecological system (e.g. local government, community organization, their schools and caregivers). These complex interactions of policy, community, caregivers and children do not occur in a vacuum; instead, a society facilitates them by providing social, cultural, political and economic contexts within which they take place. The relationships at different levels or rings are reciprocal. For example, children receive peer support while at the same time providing support to their peers; families receive support from the community while also serving the community; and the policies made at the government level affect the wellbeing of children, whose development and feedback also affect future policy-making.

Methods

Study site

The current study was conducted in Henan province, an agricultural province in central China with a population of 100 million, 60% of whom live in rural areas. In 2007, the rural per capita income in Henan was about 4000 Yuan ($650) (China Bureau of Statistics 2011). All ethnographic work was conducted in two rural counties of Henan Province, where a large number of rural residents (mostly farmers) were infected with HIV from unhygienic blood and plasma collection between the late 1980s and middle 1990s (West and Wedgewood 2006). Although accurate epidemiological data are not available to the public, both counties are generally believed to have the highest prevalence of HIV infection in central China. The two counties also had similar demographic and economic profiles; both were designated by the central government as 'National Level Poverty-Stricken Counties'.

Ethical approval

Our study protocol was approved by the Institutional Review Boards (IRB) at the Wayne State University in USA as well as Beijing Normal University and Henan University in China. The study also received approval from local authorities in Henan Province.

Data collection procedure

The current study was embedded in a large study involving the longitudinal assessment of the psychosocial wellbeing of children affected by AIDS in China (Li *et al*. 2009). From 2006 to 2010, our research team made numerous visits to the study site, developing a strong rapport with local communities and local leaders (both formal and informal). From 2008 to 2010, we conducted ethnographic observations in the villages, communities, schools and families. We also engaged in informal discussions with community members and local leaders. We did not take notes during the site visits; instead, recollection and field notes were recorded upon return to the research office or hotel room at night. In 2010, we conducted individual in-depth interviews with family members of eight group homes in one rural county. We interviewed one caregiver and one or two children from each group home, and in total, we interviewed eight caregivers and 12 children from the eight group homes. According to the study protocol approved by IRB, we did not conduct HIV testing or ask for children's HIV status; therefore, we did not know whether any child in the group homes was HIV-positive.

Prior to the interview, a semi-structured interview guide was developed based on the literature and previous fieldwork. The interview guide consisted of open-ended questions and covered the domains of family environment, living and financial conditions, caregiver–children relationship, caregivers' and children's attitudes towards the current care arrangement, and children's relationship with peers, schools and communities. The interviews took place inside the group homes, where only the interviewer and participant were present. Appropriate consents were received from parents and children prior to the interview. No financial incentive was provided to the participants, and the children received small gifts, such as pencils and notebooks, upon the completion of the interview. Each interview lasted 30–45 min and was audio-taped and later transcribed verbatim.

Data analysis

All interview transcripts and field notes were entered into Atlas.ti 6.0. Data analysis was informed by constructivist grounded theory (Charmaz 2000) and framework analysis (Ritchie and Spencer 2002) and followed the procedures outlined by Ryan and Bertrand (2000): identifying themes, building codebooks, marking texts, constructing models (relationships among codes) and testing these models against empirical data. Preliminary coding commenced with the reading and rereading of transcripts by research team members. Coding themes were developed from the conceptual framework as reflected in the domains of the interview guide as well as new themes emerging during the interview and coding process (Silverman 1993; Rubin and Rubin 1995; Le Compte and Schensul 1999). In the second stage of data analysis, two research team members independently coded all transcripts and inter-rater reliability was 80%. All coding disagreements were reconciled successfully after discussion among all research team members. Detailed summaries with substantial retention of original quotes were prepared to facilitate further discussion and elaboration. Quote excerpts and summaries were then categorized by participant characteristics and the coding domains; they were further compared and reviewed for inter-relationships and correspondence with coding and conceptual framework (Ryan and Bertrand 2000). The findings presented in this manuscript reflect the range of responses with some indication of the more consistent responses.

Results

Characteristics of the community-based family-style group homes

Living environment

At first sight, the villages where we conducted the current study looked like ordinary villages in central China; but when we entered the villages, we saw many graves and tombs along the country road, which were particularly prominent in winter (see Picture 1). Many people who died as a result of commercial blood collection were buried on their own farms. Most houses in the villages were one-room huts; some were huts of three or more rooms. The 'Sunshine Families' (i.e. the group homes) were located in the centre of a village in a one-story brick building consisting of eight connected dwellings (see Picture 2). Each dwelling had a small front yard, used as a family garden where seasonal vegetables were grown; each house was also equipped with a solar water heater (see Picture 3). Each home was about 1000 square feet with a kitchen, a bathroom, a living room and three small bedrooms. Inside the house, each family had a TV and some essential furniture. The parents had one bedroom and 2–4 children shared a bedroom. All children and their parents said they were satisfied with their living conditions.

Family structure

A group home consisted of a father, a mother and 5–8 children (see Figure 2). These children might have come from different AIDS-affected families, but they called each other brother and sister and their caregivers mother and father. All the parents and children were from the same village or nearby area. The parents' biological children were typically grown and had left for college or work. The father usually worked in the vicinity, and the mother was the primary caregiver.

Financial support

Financial support for the group homes came from the following three sources: first, each mother at a group home received 700 Yuan each month from the local government as a stipend; and each child received an additional 200 Yuan as living allowance from the local government. So a family of five children could receive 1000 Yuan ($180) each month, higher than the average family income in the area. This allowance covered all the household expenses. Many mothers reported that because of increasing living expenses, especially food and other essentials, they often used their own stipend for the household expenses. Second, each child received a small amount of pocket money from the local government. For children under 18 years of age, the bank card was retained by the mother, but the children had the passwords. If the children wanted to use the pocket money, they would need to discuss it with their mother. Third, children received 40 Yuan per month as pocket money from an NGO. All the financial support, including pocket money, ended once the

Picture 1 Village scene in an 'AIDS village' in rural Henan Province

Picture 2 Family-style group homes for AIDS orphans in rural China

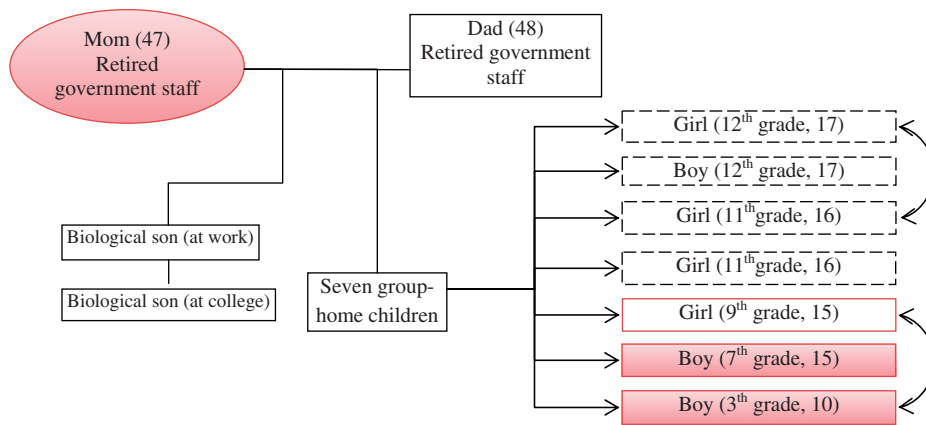**Picture 3** A typical group home in rural Henan Province, China

Figure 2 Typical family structure in a group home
Note: Gray colour indicates they were our informants and double arrows indicate they are biological siblings.

children reached 18 years unless the children attended high school, vocational school or college. Similar support would be provided until they graduated from colleges.

Caregivers' qualification and dedication
Caregiver selection
Caregivers in group homes were identified through a dual process of volunteering and selection. All caregivers in the

group homes must have met the following criteria: first, they were legally married couples from local areas. Secondly, they passed physical examinations—having no infectious diseases and physically capable of taking care of children. Thirdly, one of the parents had completed middle school. And finally, they were willing to take care of the children orphaned by AIDS. In our interviews, at least one-third of the group homes had a parent with a post-secondary education. Fathers typically worked as government staff, accountants, healers or janitors;

mothers were typically retired. Three mothers were former caregivers in the orphanages. The age of the mothers ranged from 40 to 54 years.

Dedication of caregivers

All the parents we talked to expressed their compassion towards these orphans. A tearful mother shared her daughter's story:

> This girl had a miserable life. Her father and mother died, followed by the death of her young brother. Only her grandma was left to take care of her, but her grandma was in her 80s . . . . I would like to give her love.

Some parents had to face misunderstanding and stereotyping from families and friends, especially regarding their motivation for this caregiver's job. A mother with a college degree was often asked why she would take a nanny's job. Nevertheless, after some time in the group homes, most mothers reported that they received support and understanding from families and friends. Their biological children often came back to visit their siblings in group homes. A mother shared her recent experience of celebrating the birthday of a child in her group home with other family members:

> My oldest daughter [her biological child] bought a birthday cake for one of her siblings in the group home. They were all happy and had a good birthday party.

Training and support of caregivers

Ongoing training and evaluation of caregivers were provided by an NGO in collaboration with the local government. After being selected as caregivers, all mothers were provided training on parenting skills. Prior to moving into group homes, children and mothers attended a 1-week camp to get to know each other and build bonds. The NGO provided group home families with free parenting consultation, and mothers met once a week in a mothers group. Each family was evaluated every 2 years, and one family was selected to receive the Model Group Home Award and a mother was recognized as a Model Sunshine Mother. The NGO provided funding for children's summer vacation; for example, some children visited Hong Kong or Shanghai.

Parent–child relationship

Bonding and trust-building

Parenting several children of different ages and from different birth families is a challenge; it is even more so when these children have experienced trauma. It takes much love, patience and wisdom to build a healthy parent–child relationship. A mother shared with us how she and her daughter built the bond:

> When she arrived here, she looked so timid. We tried to talk to her, but she often looked scared. We often took walks and started with small talk. Slowly but gradually, she became more familiar with us and started talking about her parents and aunts. She has no other family and was cared for by her aunt, whom she feared. We tried our best to love

her and comfort her. It took almost two years. Now she talks a lot at home, and we are very close.

Some older children, especially adolescents, often resisted the idea of entering a new family with new parents. A 40-year-old mother recalled how her older son built trust and bond with her:

> My oldest son [in the group home] arrived when he was in high school. He was old enough to remember his own parents and was too embarrassed to call me mom. One day, he was bullied in school and was sent to a hospital and got 6 stitches on his head. When he was in the hospital, I got up very early and brought fruit and food to visit him. When he first saw me, he simply asked, ''Why have you come so early?'' Other patients in his ward asked, ''Are you his mom?'' I said yes. They were all surprised and asked how I had such an old son. I told them because I got married early and never told people that he was actually adopted. I took care of him in the hospital for a week. After he was out of the hospital, one day he saw me on the street. He waved at me and called me mom for the first time. At that moment, I burst into tears, and I was so happy.

Parenting practices

All parents respected the children as equal contributing family members and included them in household routines. For instance, most mothers asked their children, especially older ones, to help with chores around the house. In their regular get-togethers, mothers also exchanged parenting experiences. Several mothers reported when new children came into the family, the entire family needed to work together to help the members adjust to family routines, including wake-up and bed-time, helping with household chores, and joining family activities. A young child shared her joy with us:

> During the holidays, my father will lead the family dinner. On Chinese New Year's Eve, we'll have a family dinner. Everybody sits around the table, drinks some wine, and talks about the future.

All families attached importance to education, so all of these children went to school. A mother told us that when one of her older sons wanted to drop out of school and follow his fellow villagers to work in the city, she talked to him and asked his extended family to join the persuasion effort. Ultimately, the boy remained in school. Another mother worried about her teenage daughter, who had developed a relationship with a boy and let her school grades slip. Communicating with her daughter via mail because the topic was sensitive in the local culture, she encouraged her daughter to focus on schoolwork. Most children we talked to expressed positive expectations for their future: many wanted to attend vocational schools after middle school; others planned to attend high school and then college.

Relationship with the neighbourhood and school

Peer relationships

Children in these group homes developed solid friendships. None of the interviewed children reported being stigmatized in

school because of their status; they all made friends at school. A mother shared the following reasons with pride:

> The children from group homes wear better clothes and have better living conditions and better grades than other children.

Family–community relationships

As group homes were built in the community, children maintained frequent contacts with their relatives, such as grandparents, aunts and uncles. They visited their extended families on weekends or holidays; they also paid tribute to their deceased parents during the annual Tomb-Sweeping Day. Children returned to their extended families to help grandparents with farming during seeding or harvesting time. A 12-year-old boy told us that his most troubling concern was that his grandfather was too old to do farm work and his grandmother was too old to take care of his cousin. He returned to help them every week. Some parents in group homes contacted children's biological family members to seek help with parenting. A mother asked a boy's biological grandmother to join the effort to convince the boy to finish middle school instead of entering the work force. Children continued to live in the same community where they had grown up and never felt like outsiders.

School environment

Both elementary schools and middle schools were located within walking distance of the group homes. Communication between group home parents and school teachers was convenient. Mothers maintained good contacts with the local school teachers, who found it easy to contact parents if children got into trouble in school (e.g. peer conflicts, learning problems). Children reported that school teachers were nice to them. After school, children from group homes often studied together.

Social environment

Over the years of doing fieldwork in Henan, we observed that public campaigns have helped raise awareness and support AIDS orphans. A number of NGOs have reached out to the communities and provided financial support and volunteer services. We also found that the local government officials were less resistant to the label of 'AIDS village'; some indicated that they would try to take advantage of such labelling through potential financial support from the government, NGOs and private donors. At the societal level, stigma against people affected by AIDS persisted, but at the local level, the stigma was less pervasive; and people talked about 'AIDS orphans' openly because almost every family was directly or indirectly affected by the epidemic. In the interviews and conversation with group home family members, several participants observed that the stigma against AIDS orphans appeared to have diminished in the past 10 years. They attributed this change to the high prevalence of HIV infection among local residents, effective public campaigns on HIV transmission routes and better support of families affected by AIDS from the local government and NGOs.

Discussion

Several considerations require attention before we interpret the findings of this study. First, we must be aware of potential bias in ethnographic research and the role of researchers in data collection and analysis. In contrast with previous qualitative studies on AIDS orphans in resource-poor settings, most comments and stories shared by children and caregivers in group homes in the current study involved positive experiences. Our findings may have derived only from experiences the participants *chose* to share with us. It was also possible that we studied only an 'exemplary' group home recommended by the local leaders because we had to get their permission to do the fieldwork; however, our ethnographic observations corroborated our interview data. The children and caregivers in group homes experienced a better quality of life than their counterparts in the villages. For example, they had free housing, the mothers received stipend of 700 Yuan per month and each child received 200 Yuan per month for living expenses. They also had access to many resources unavailable to other children in the village. Secondly, our study was conducted in a rural county in Henan province, where HIV was transmitted through commercial blood collection and transfusion; whereas in other regions, such as Africa, the majority of transmission occurred through sexual contact. These children might have faced different challenges in their lives (Zhao *et al*. 2007). Cultural differences between African countries and China may also influence the caregiving policies and practices. Last but not least, our in-depth individual interviews included only mothers and children in the group homes; fathers and older children attending vocational schools were not included. We have, however, collected data from other sources through ethnographic observation and informal discussion to obtain a more holistic perspective on the group homes.

The data contribute to a general picture of community-based group homes in rural China. These group homes exhibited the following characteristics: first, the group homes received sufficient financial support from local government and NGOs; in addition to free housing, group home parents and children received monthly stipend and living allowances. The children's basic needs, including food, clothing, shelter, medical care and education, were met. Secondly, these group homes were built in the same communities in which the children had lived before they lost their parents. In a familiar social environment, children were less likely to feel isolated and could continue to maintain close ties with their extended families and other social networks. In addition, the group homes were built in a small community; children and caregivers could form their own social networks and support one another. Thirdly, the group home provided the children with a family with a father, a mother and siblings; the low child-to-caregiver ratio also ensured adequate care and attention to the children. Fourthly, caregivers were selected based on their qualification and willingness to ensure they were physically and emotionally capable of taking care of these orphans. They also received continuous training and supervision on parenting and were evaluated periodically.

The features or additional resources unavailable to other AIDS orphans would very likely account for the differences we observed in a previous study. In other words, the children in the group homes in the current study were better off mentally,

physically and educationally in comparison to their counterparts (Hong *et al.* 2011); yet a concern arose about the sustainability of these group homes. As opposed to African countries, where funding for AIDS orphan care comes primarily from international donors, funding for care for these orphans in China comes from the Chinese central government and local government as well as a small number of NGOs. Without commitment and long-term support from the government and the NGOs, the sustainability of group homes, not to mention their scale-up, is questionable. The characteristics of group homes we observed in the current study can be integrated into other care models for AIDS orphans for the optimal development and wellbeing of the children; therefore, instead of advocating for scaling up group homes, we call for integrating the key characteristics of group homes into existing care models for AIDS orphans. Caring for AIDS orphans involves much more than providing a stable living environment (e.g. group homes); instead, it lies on a continuum of care and a safety net (Abebe and Aase 2007). The backbone of care for vulnerable children is economic and organizational capacity building in the local community, which also benefits long-term care and development of these children (Thurman *et al.* 2008). The children's wellbeing is nested in concentric circles of support from family, neighbourhood, community and society (as shown in Figure 1); therefore, support and interventions should not just focus on short-term outputs of direct services or monetary support; instead, programmes should be designed for capacity building at community level (Thurman *et al.* 2008; Kaufman *et al.* 2013). For example, the group homes can be built into a strong small community integrated into the larger community. The group homes also represent effective capacity building and 'investment in' caregivers, including providing parenting training and consultation, periodical evaluation, and interactive communication.

Built upon strong collaborative partnerships between local community and academic institutions, our study provides an in-depth description of community-based family-style group homes in rural China. We learned that children in group homes have received support and care at different levels. Such multilevel support is essential for healthy development of these vulnerable children. Our study also highlights the need for better consideration of care arrangements for AIDS orphans and the effective use of limited resources for the optimal wellbeing of these children. Future researchers should look into continuous monitoring and evaluation of group homes and other care models for AIDS orphans from the perspectives of all key stakeholders in social contexts. Such studies would build evidence for policy-making regarding care arrangement for AIDS orphans and other vulnerable children in resource-poor settings. We also call for capacity building for caregivers and the community to establish strong environments to foster resilient children.

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