

Kinship Care at Community is better Model to Ensure Psychosocial and Economic Security to Orphans Living with HIV than from Care Homes

Acharya SL,¹ Pokhrel BR,¹ Ayer R,² Belbase P,² Ghimire M,³ Gurung O⁴

¹Ministry of Health and population, National Center For AIDS and STD Control, Nepal, ²Nepal Health Research Council, Nepal, ³Durham University, United Kingdom, Central department of Sociology and Anthropology, ⁴Tribhuvan University, Kirtipur, Nepal.

ABSTRACT

Background: There were about 24,000 children affected by AIDS living in Nepal in 2010; of these 5,000 AIDS orphans were in need of immediate support. The objective of this study was to investigate which model of care and support is more appropriate for improving psychosocial and economic security of AIDS orphans.

Methods: With the documented 5200 cases of AIDS orphans from 42 districts at National Association of People Living with HIV, we purposively selected five districts – one from each development region, based on the highest number of AIDS orphans reported. From five districts, 56 HIV positive double orphans aged 8-18 years and their 42 caregivers were interviewed to find their psychosocial and economic situation.

Results: Thirty nine (70%) orphans were found living in kinship care, while 17(30%) were living in institutional care homes. Orphans living in kinship were more optimistic, as they were backed by their close relatives 35 (90%), had birth certificates 35 (90%), ensured inherent family property 21 (54%), obtained basic needs like food, education and shelter from grandparents 23 (59%), and had more than five friends who visited their homes 26 (67%). While, the orphans living in institutional care homes 17(30%) had no birth certificates, fewer contacts with siblings 2 (12%), and none had friends outside the care homes.

Conclusions: Kinship care is better model for psychosocial and economic security for AIDS orphans in Nepal, rather than institutional care. Families can provide good protection to AIDS orphans if government provides minimum support to them.

Keywords: AIDS orphans; children affected by AIDS; care homes; institutional care; kinship care.

INTRODUCTION

Nepal hosted around 24,000 children affected by AIDS in 2010; of those 5,000 AIDS orphans were in a need of an immediate support for their social protection.^{1,2} Children affected with HIV are found to be prone to abuses like physical violence, negligence, hatred and harassment and situation is even worse in AIDS orphans. AIDS orphans are stigmatized in social settings and are deprived from their basic rights and social protection which also results in negative health outcomes, social and psychological problems among them.^{3-5,8-11}

Apparently, there have not been any studies to document the situation of AIDS orphans. This study, therefore, has aimed to bridge the gaps in data on the psycho-social and economic status of AIDS orphans; a situation assessment of AIDS orphans which will provide evidence to government, policy makers, international development partners and social activists to better frame their initiatives to address the needs of AIDS orphans robustly.

Correspondence: Mr. Shiva Lal Acharya, Ministry of Health and population, National Centre for AIDS and STD control, GPO Box number: 8974, CPC number: 336, Nepal. Email: shivaachrya@yahoo.com, Phone: 9841369544.

METHODS

A descriptive cross sectional study was carried out to assess the psychosocial and economic situation of the children affected by AIDS in Sunsari, Kathmandu, Kaski, Bardiya and Doti districts of Nepal between August 2011 to June 2012. Both qualitative and quantitative methods were used to collect the data.²

Ethical approval was taken from ethical review board, Nepal Health Research Council. Verbal consent was taken from each participant and their caregivers. Participant who were ill and refused to give consent were excluded from the study.

Firstly, with the documented 5200 cases of AIDS orphans from 42 (out of 75) districts under the support of the National Association of People Living with HIV (NAP+N), five districts - Sunsari, Kathmandu, Kaski, Bardiya and Doti were purposively selected - one from each development region, based on the highest number of AIDS orphans reported in the region. From five districts, 56 HIV positive double orphans aged 8-18 years and 42 caregivers of the orphans were interviewed in-depth to dig out their psychosocial and economic situation regarding care. The primary care givers of the CABA in this study HIV positive double orphans were interviewed with structured questionnaires to reflect the current level of economic situation, education, health seeking behaviours and social participation of children and care givers.

Secondly, from the database, detailed information on double orphans living with HIV, aged of 8 -18 and their caregivers, was identified with local addresses. With the help of structured questionnaires, informal observations and interviews; the qualitative and quantitative data was collected. A structured questionnaire was used to collect the quantitative data that took up to 30 minutes. Children affected by AIDS were observed and interviewed in informal settings using qualitative questions. In addition to this, in-depth interviews were conducted among 10% of care givers from each region.

The study interviewed 56 orphans between the ages of 8 and 18 years of age, and documented their current situation from socio-economic and Psychological perspective. There was one facilitator assigned by PLHA constituency to conduct interviews. Data was analysed by SPSS 16.0 version.

RESULTS

Demographic situation of CABA: Among 56 studied CABA, 35 (62%) were males and 21 (38%) were females from the age group between 8 and 18 years. Majority of them were living in kinship care 39 (70%) and among kinship,

the data showed that, majority of orphans were living with grand parents 22 (56%), brothers/sisters 7 (8%) and uncle/aunts 6 (5%) however those living in PLHIV run carehome make 7 (30%) (Table 1). Similarly, while assessing the proportion of respondents on the basis of their father's sub group, data revealed that majority of respondents belonged to migrant workers family 32 (57%) (Table 2). And also, caste wise, the proportion of Chettries 16 (29%) and Baisya 21 (37%) respondents were higher, indicating greater vulnerability to HIV and AIDS.

Socio economic situation of CABA: Regarding knowledge on HIV and AIDS, treatment, care and support to care givers of children, it was found that 39 (93%) caregivers had a proper knowledge on HIV and AIDS including treatment, care and support. Out of total participants 35 (62%) (Table 3) of children had their birth certificates and also have protected their inherent property and waiting to hadover them, but 21 (38%) had no birth certificate and access to their inherent property. Surprisingly, none of children living in institutional care homes had birth certificate nor they had access to inherent their property. Regarding the enrollment of social security program for the children affected by AIDS in Nepal, 17 (30%) (Table 3) of children were enrolled in social security program like educational support, medicinal support, and nutritional support. However, majority were not privileged.

While assessing their socio-economic situation of children, their access to clean drinking water, sanitation and personal hygienes 33 (59%) of respondents used piped water as major source of drinking water, 6 (11%) used borehole water, 3 (5%) used spring water, none of them used rainwater as a source of drinking water, 4 (7%) used surface water from river as a major source of water, 7 (13%) used stone tap water, and 3 (5%) used bottled water as major source of drinking water. Regarding personal hygiene and cleanliness of children, it was found that 36 (64%) of households have a separate place to clean hand with soap and water, 12 (21%) have water and ash, mud and sand where 8 (15%) of household do not have place to wash hand.

Psychosocial status of CABA: Psychosocial wellbeing of CABA, in this study, was studied in association with stigma and discrimination at school and its consequences. Forty eight (86%) (Table 3) of CABA were found going school regularly whilst 8 (14%) dropped out school and main reasons behind dropping school were school being too far 14 (25%), health condition being poor 14 (25%), due to stigmatized environment in school 14 (25%).

Friendship plays crucial role in determining psychosocial status. This study had assessed the number of friends children have, and 17 (30%) of children had only two friends, 11 (20%) had four friends, 13 (23%) had six

friends, 9 (16%) had eight friends, and 6 (11%) had more than ten friends. The children living in the care homes were not found to have friends outside the carehomes while children in kinship care had more friends and closely associated with thier community, relatives and family members. Fourteen (25%) (Table 3) of children reported psychological problems and within that 14 (25%), 13 (23%) had chosen not to attend social gatherings, 21 (38%) were isolated from friends and families, 4 (8%) avoided taking medicines, 8 (15%) had some kind of sleeping disorders. These complaints were mainly from children living in care homes.

Table 1. Distribution of CABA in relation to caregivers.

Caregivers	n (%)
Grand father	8 (14)
Grand mother	14 (25)
Brother/Sisters	7 (12)
Uncle/Aunts	6 (11)
Close relatives	4 (7)
Institutional Care Homes	17 (30)
Others	

Table 2. Distribution of CABA in relation subgroups of father-MARP wise.

Subgroups of father	n (%)
Migrants	32 (57)
IDU	12 (22)
MSM	3 (5)
None of MARP	9 (16)

Table 3. Distribution of CABA in relation to socio-economic and psychosocial status.

Socio-economic Status	n (%)
CABA with birth certificates	35 (62)
CABA enrolled in social security project	17 (30)
Psychosocial Status	n (%)
School going CABA	48 (86)
CABA reporting psychological problems	14 (25)

DISCUSSION

It is noticed that, large portion of children affected by AIDS are living in their community. There were two care homes, run by people living with HIV in Nepal, focused to children affected by AIDS under the support of Embassy of Denmark in Nepal called Nava Kiran Keta Keti Ashram, which has accommodated 76 children in two care homes - one in Kathmandu and next was in Kailali. The second was already closed and first has downsized and only accommodating 16 CABA. They are also trying to reintegrate them with their family. Besides, there

are few children living in care homes with their single mothers for short period to access treatment, care and support.^{7,8,12}

Very few studies has been conducted in the past to explore the situation of the CABA, one of the studies conducted by HIV and STI control board in 2009 revealed that female CABA received less health care services when they fell sick compared to the male CABA, similar finding was revealed by the same study that female CABA were more stigmatized and discriminated compared to male CABA also regarding to the psychosocial condition female CABA were found to suffer more from Psychological problems than male CABA.⁸

Study showed that, orphans living with HIV in Nepal have not enrolled in any social security project in Nepal. Few are getting minimal support on education, medication and nutrition from different NGO and INGO. Largely, orphans are in care of their grandparents, and siblings and very few care givers has knowledge on the duration of breast feeding, immunization and vitamin intake to CABA. Fifty percent and above have access to clean drinking water and have culture of hand washing with detergent.

More than two third of care gives have knowledge on HIV and its transmission, its treatment and care and support in Nepal, that is inspiring for further social security and reintegration project for orphans living with HIV in Nepal. It is also very necessary to educate the community members including school going children and teachers on easy and free availability of life saving antiretroviral treatment of HIV and AIDS in Nepal. In addition to this, the people living with HIV also need to provide proper counselling on positive living with rights and responsibilities to HIV and AIDS to their community.

Children living in kinship care have birth certificate, where none of children living at care homes have birth certificate and have any connection to their family members. Not only that, they do not have any access to inherent property, which may be very harmful to future life of children to ensure economic and social security in their society. Above 48 (85%) children are going to school and those who have dropped out; one fourth has dropped out due to HIV related stigma.

While assessing psychosocial wellbeing of children, 42 (75%) children have not shown any symptoms where 14 (25%) have reported some kinds of psychological problems. Children living at care homes have more psychological problems comparing to children of kinship care. Children living at care homes do not have more than 2 close friends, who also live inside the care homes. They do not have friends outside the care homes, where

children of kinship care have more than 4 friends in their community and school. They have maintained good relation with their relatives and friends, which has not found in care homes.

CONCLUSIONS

The study has come up with conclusion that, in Nepal, children affected by AIDS in kinship care are psychosocially and economically more secure than children of care homes. Most of the care givers had good knowledge on HIV and AIDS, its transmission and available treatment, care and supports in Nepal, which is very much inspiring to reintegrate orphans living with HIV in their mainstream society. Not only that, big portion of care givers have protected the birth certificate and inherent property of children too. Finally, for better social security of CABA, kinship care has to be promoted rather than institutional care in Nepal. For that, government should come up with financial and technical aid to care givers of CABA to ensure quality of lives and fundamental rights of CABA in Nepal. It is also recommended that all the stakeholders should integrate kinship care in their programs for better care and support of CABA so that they can lead economically and socially productive life.

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