

Special Issue | Social and development concerns in Africa (c)
 Special Issue on Social Work During COVID-19: Article 12 | March 2021
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 (An International Publisher for Academic and Scientific Resources)

INSTITUTIONALISED CHILDREN WITH HIV AIDS DURING COVID 19 PANDEMIC: A CASE STUDY

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<p>Special Issue Editors ¹Norvy Paul ²Johnson Mavole ³Arya Chandran</p> <p>¹The Catholic University of Eastern Africa, Nairobi ²St. Augustine University of Tanzania, Mwanza City ³Bharathamatha School of Social Work, Kochin, India</p> <p>Chief Editor Web: www.ijfdc.org Email: info@ijfdc.org</p> <p>Editing Oversight Impericals Consultants International Limited</p>	<p>Abstract: <i>Children infected with HIV/AIDS are susceptible to untold problems, which worsen their biological, psychological and social functioning. The chronic medical conditions in children pose a range of potential challenges to the child and the family members and health care providers, especially during a pandemic. COVID has brought about a severe threat to their subsistence and, to no small extent, existence in this world. This study intends to identify various social work interventions necessary for these children during this pandemic situation. The study was conducted among some institutions providing care for children with HIV/AIDS in South India using Case study method. Data was collected from institutional caregivers of the children using telephonic interviews, generating themes and drawing conclusions from it. This study brings about innumerable challenges faced by those institutions providing adequate care, protection, and necessities for those children. The current pandemic situation prevents them from acquiring the necessary treatment and assistance for infected and affected children and obtaining desirable social support forms. Various governmental and non-governmental institutions must focus on social work intervention among these children, utilising necessities like food, clothing, medicines, regular medical check-ups, counselling, motivation, life skill training, etc. Dedicated efforts of various organisations during recent years have resulted in a decline in HIV prevalence and number of people living with HIV/AIDS. We cannot change the virus, but we can change inequalities, power imbalances, marginalisation, taboos and stigma, and discrimination. We can change behaviours and societies.</i></p> <p>Keywords: HIV AIDS, COVID, Children, Institutionalization, Social Work Intervention</p>
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Introduction

Children infected with HIV/AIDS are susceptible to untold problems, negatively impacting their biological, psychological, and social functioning. Chronic medical conditions in children pose a range of challenges to them and the family members and health care providers (Vranda & Mothi, 2013). This is even more critical during a pandemic like COVID, which has developed a grave threat to their well-being. This study aims to assess the challenges faced by Institutionalised children with HIV/AIDS in the pandemic situation. The objectives of this paper include a) response of child caregivers and institutional heads towards COVID pandemic, b) highlight the problems and challenges faced by the institutions in providing adequate care, protection, and necessities of children, c) constraints in acquiring necessary treatment and assistance for infected as well as affected children, and obtaining desirable forms of social support, and d) precautionary measures to be planned before the recurrence of any other disaster.

1. Methods of the Study

The study was conducted among institutions providing care for children infected with HIV/AIDS in South India, namely States of Kerala, Tamil Nadu, Karnataka, and UT of Puducherry using the Case study method. Data was collected from institutional heads/caregivers of children (Table 1) using telephonic interviews, generating themes and drawing conclusions. An Interview Guide consisting of ten items about the study objectives was prepared and sent to respondents who expressed their consent.

Table No.1: Data Collection Sources

State/UT	Management	Samples	Total Samples
Kerala	Private	Institutional Head-1	1
Tamil Nadu	Private	Caregiver-1	1
Karnataka	Private	Caregiver-1	1
Puducherry	Private	Institutional Head-1	1
			4

One respondent permitted to record the telephonic conversation, while the other one rejected permission. One respondent gave answers typewritten in document format, while another one gave audio messages through WhatsApp. The lockdown restrictions of COVID 19 created some difficulties regarding the data collection. The respondents have explained the purpose of the study, their right to participate in / withdraw from the study, confidentiality of data and details of

institutions, willingness of the researcher to share the results and findings of the study with the respondents, and sought permission for using it for academic purposes.

2. Case Profiles

Case 1

The respondent was the head of a private institution in the State of Kerala, which provides care and support for children infected with HIV/AIDS for the last five years. They are actively participating in community awareness programs to reduce stigma and discrimination in society, thus enabling the infected and affected to live worthy of human dignity. They provide medical services of a team consisting of a doctor, a clinical psychologist, a medical social worker, and a nurse with a nearby hospital. The counsellor provides counselling and psychosocial support for children too. Regular blood tests, cd4 count monitoring, Antiretroviral therapy (ART), and medicines are also arranged for the children.

During the COVID pandemic, children were instructed to wear masks, and not allowed to go outside and interact with others to avoid possible infection chances, as a part of the guidelines and regulations given by the Government and Health authorities. The children were provided with recreational activities, games, and tasks as a part of their daily fixed timetable. Moreover, the children were engaged in preparing, packing, and delivering food for those in need during the COVID crisis and making masks to provide it to hospitals.

As a part of the rehabilitation of children who have completed 18 years, they started a supermarket which provides provision, even home delivery, by which they did not face any shortage of provisions. They also had the availability of agricultural products from their farm where children engage, in groups, for these works.

Even though the visit of well-wishers was restricted, and their sister institutions' income declined, they could manage the financial situations with their local resources' help. They ask for the government to identify these children as vulnerable and provide services for them at the door; they should be given attention and provide the necessary support by the general public during a crisis.

Case 2

The respondent was the head of a private institution in the Union Territory of Puducherry, which provides homely care and attention for children with HIV/AIDS for the last 15 years. They began as a hospice for AIDS patients, who often came to live out the end of their lives, supported by the sisters and brothers' help and prayers. Many children with AIDS came with their mothers

before being left orphaned. Then they started a home for those children too.

During the COVID pandemic, children were not allowed to visit their family during the holidays and strictly adhered to the confinement challenges and stopped all outside visits. The entry of outsiders was restricted except for those providing essential services. They had announced clearly that no one would be allowed to come or leave the campus till the lockdown is lifted. They planned a very early self-confinement and stocked provisions two months ahead and avoided many transactions during the early days of lockdown.

The children were engaged in various activities through the organised schedule. Some of the activities the children engaged are taking care of cows, mulching and feeding them, rear goats, feed hens and maintaining their coops, taking care of dogs, tilling and getting the soil ready for plantations, growing and maintaining vegetable and fruit gardens, starting and developing nurseries, cooking the meals for everyone, participating in the storeroom and kitchen maintenance activities, reading and practising mathematics, cleaning their buildings, learning to dance and sing and draw, assisting in the carpentry and masonry, playing football and prison ball, taking time to pray and meditate, do yoga and Kalari.

With the social welfare department's support, they had sufficient availability to medical requirements throughout the lockdown. They had good financial support from their sponsors and benefactors too. They would appreciate some kind of farming volunteer programs, as they have a big cultivable area and could use any professional farm solutions as the kids will benefit from an unpolluted environment that's nature-oriented.

The institution undergoes triple therapy, which gives an almost standard immune system. Regular physical exercise – including yoga and martial arts – and a balanced diet (supplemented with multivitamin supplements) help keep the children in good health. In addition to the teaching received at school, each child can participate in extracurricular activities to develop their creativity and capabilities, like painting, drawing, dance (Bharatanatyam), yoga, kalarippayattu (traditional martial art of Kerala), football, and more.

Case 3

The respondent was a caregiver at an institution in Tamil Nadu, which provides basic care, education, medical facilities, and vocational rehabilitation for children infected with HIV/AIDS. During the initial stage of the pandemic, they took necessary precautions, restricted the entry of outsiders and family members of children. Children were given awareness regarding COVID and

its related aspects; masks, sanitiser, and soap were used as needed. Welfare officers were giving guidelines and came twice for inspection. They gave videos for disinfecting the institution.

One of the inmates studying at Chennai was quarantined in another building and then accommodated as per quarantine instructions set by the State. Medicines for three months were collected earlier by staff from Chennai had to halt at around 25 places before reaching the institution. Provisions were supplied without any problem. They have a poultry farm that provides milk, egg, and vegetables. This helped them to manage the shortage of necessary commodities. Students appearing for the 10th board exam were anxious about exams being postponed. Other students enjoyed the lockdown period as the educational institutions were closed.

Children were provided with an activity-based timetable, providing games, watching television, gardening, music, and yoga. Separate portions of land were allotted to them as groups for the vegetable garden, having their name board. Moreover, they started making candles, rearing ducks and hen, cultivating grass for cattle and cattle-feed. The children in the institution were enjoying an extended vacation.

Case 4

The respondent was a caregiver of an institution in the State of Karnataka. The institution was started as a centre for helping uninfected children of HIV-infected parents. Later, it started to provide care and protection for HIV infected children also. It also provides rehabilitation for the children and conducts awareness programs for school, college, and nursing students who visit the institution about discrimination against HIV/AIDS.

During the COVID pandemic, they followed an activity-based timetable for the children like watching TV, cooking, art, and crafts according to their interest. They arranged for video-calling for interacting with their family members, as they could not go to their homes during vacation. The children were provided with online classes on YouTube, tuitions as their schools were shut down during this period. The health and nutrition of the children were given top priority. The management was tensed at the beginning of the lockdown period regarding the availability of provisions. Gradually, they became confident enough to manage the situation.

Health issues were of concern for them as even a usual viral fever is very dangerous for the children. They have a hospital nearby which provided necessary medical services; medicines were also given as needed. Counsellor's service was provided to help deal with the problems that they face.

During the early period of lockdown, the government had instructed them to retain the institution's staff and not allow them to go home. Later, the rules were relaxed and allowed to go home but not to public functions and gatherings. The institution arranged for their travel; picked them up and dropped them back. They face a financial crisis; the higher-paid staff was convinced about the crisis, and their salaries were reduced by 50%; minimum wages staff were paid full.

They felt some difficulty following lockdown restrictions within the institution during prayer gatherings and other routine activities; they managed to have prayers and meals in different batches to maintain these norms. They used masks and sanitisers. According to Government norms, outsider interactions were stopped entirely. They ensured that if anyone had to go out, one had to sanitise one's hands and legs and take a bath before meeting the inmates. All vegetables and milk packets were washed in saltwater.

3. Results

The thematic analysis of case studies of the respondents resulted in generating the following themes and are summarised as follows:

1) Response to COVID Pandemic

Children were happy at the institution amid devastating epidemic around the globe, not much worried about it. They enjoyed as in a vacation being able to appreciate much free time, unlike their schooling days. They were provided with the medical services consisting of a doctor, a clinical psychologist, a medical social worker, and a nurse with the help of a nearby hospital. Medicines were arranged with the help of caregivers or government/health/welfare authorities.

Regular blood tests, cd4 count monitoring, etc. were adjourned, but we could provide their ART medicines by arranging a caregiver to collect from nearest government hospital/ ART centre.

Children were not allowed to go outside or even to their homes and interact with others to avoid possible infection chances. They were instructed to wear masks, use sanitisers, soap but did not follow social distancing inside the campus because of practical difficulty and ensured safe living inside the campus. Those who went outside were either quarantined or sanitised before meeting the inmates. Preventive measures included the restricted entry of outsiders and family members of children. Children were given awareness regarding COVID and its related aspects. Government and health authorities provided necessary guidelines and conveyed information to children regarding the pandemic situation. District child welfare committee members visited the

institutions for inspection and providing instructions regarding children and staff.

The child welfare committee members came in for a couple of visits to make sure we are all doing fine, and they instructed us on general awareness and usage of masks and sanitisers. They also insisted on the confinement rules to keep our kids' safe inside.

2) Problems and Challenges

Shortage of provisions to maintain the children's health and nutrition was a concern for an institution, while the other stored it well in advance. Medicines were collected in advance with much difficulty. Due to a low level of immunity, they have a high risk of infection, which affects their physical health. As the number of inmates was high, they find it challenging to follow government instructions inside their campus. One of the institutions faced financial difficulty, while others managed it.

The financial crisis is there for sure. It still exists. Higher paid staff was convinced about the crisis, and their salaries were reduced by 50%. Minimum wages staff were paid full. Children were not bothered about their schooling, but tenth standard students were anxious about exams being postponed. They had emotional disturbances as they were not allowed to visit their family during the holidays and enjoy leisure activities. Some children become angry towards caregivers and even refuse to have food.

The real challenge was only seeing the children get sad without going for a swim to beat the hot days.

3) Managing the Crisis

Children were provided with a video calling facility to interact with family members and arranged online tuition classes as the schools were shut down. Activity-based timetable, having provision for games, watching television, vegetable gardening, music, yoga, candle-making, animal husbandry gave them enough time to learn new things, deal with friendship and isolation issues, and in a way, rediscover nature and God.

It was an activity-based timetable that we followed. We gave them activities to be involved in like watching TV, cooking, art, and crafts.... according to their interest.

The children also helped prepare, packing, and deliver food for those in need during the COVID crisis. Also, they helped in making masks for providing it to hospitals. One of the institutions gave vocational rehabilitation to inmates by starting a provision store that provided necessary commodities to their sister institutions and helped manage the shortage of provisions during the

lockdown period.

All institutions produce their vegetables and fruits in their agricultural land with their human resources and children's support. Animal husbandry is an added advantage to have additional income for their needs. As a part of government restrictions, staff members were not allowed to leave campus at the earlier stage but then allowed to go home but not to public functions and gatherings.

4) Lessons and Future Plans

During the pandemic, the children had good health contrary to earlier experiences of being infected with cold/fever. The use of masks prevented any chances of infection of any kind within the community. This period provided an opportunity to introspect, analyse and make efforts to grow in areas that they were lagging. They focused on basics like eating habits, sleeping routines, cleanliness, sports, arts, reading and computing, farming, and gardening. A feeling of togetherness has largely evolved among them, having put up with everyday chores without any feeling of obligation, having to work, eat and play together. It allowed reconciling with nature to deal with future pandemics, being self-sufficient, and having a sustainable ecosystem that can contribute to the unpolluted environment.

We don't have any plans for currently unseen future pandemics. Rather we teach our kids to face the challenges as they appear while appreciating and embracing nature and living a healthy life physically, socially, and psychologically.

The crisis necessitated a self-sufficient economy by focusing on farming volunteer programs, cultivating own land to the full extent, and exploring the possible chance of using any professional farm solutions. Efforts should be made to reach out to government authorities to ensure they identify these children as vulnerable and provide services for them at the door. During a crisis, they should be given attention and provide the general public's necessary support.

4. Discussion

In this study, we brought about the response of child caregivers and institutional heads towards the COVID pandemic and the problems and challenges faced by the institutions in providing adequate care, protection, and necessities of children during the pandemic. The institutions offer a holistic approach, thereby ensuring the children's physical, psychological, educational, and spiritual growth using an activity-based/organised timetable. (Brown et al., 2000), in a study, it outlines the need for multidisciplinary treatment to effectively reduce the treatment burden on the infected, their families, and health care providers and decrease the incidence of

transmission to the uninfected.

Children are prepared for integrating back into society by enabling them to socialise with their peers. They learn skills, are educated, and receive life skills training to support themselves after they leave institutional care. Owens (2020) gives importance to this approach, which can change the quality of their life. By living healthier and close to nature brings out the human body's potentialities to develop immunity against opportunistic infections, which benefits the children who are vulnerable to an epidemic.

HIV-infected children attended fewer school days (Anabwani et al., 2016; Cohen et al., 1997; Mayes et al., 1996), dropped out of school more frequently (Bele et al., 2011; Parchure et al., 2016), were more likely not to be in the correct grade for their age or to have repeated a grade, and had low grades while in school (Bandason et al., 2013; Henning et al., 2017). These results indicate that physical illness is the main barrier to HIV-infected children's schooling. The limited education greatly increases the vulnerability of children living with HIV (CLHIV) as they transition to adolescence and adulthood and needs to be urgently addressed (Parchure et al., 2016). Educational performance of these children can be improved by addressing their health issues and providing tuition classes.

Anabwani et al. (2016) found that HIV-infected children's absenteeism from school was mainly due to frequent medical appointments and illness. One solution to this issue may be to increase access to Antiretroviral (ARV) treatment and extra lessons for HIV-infected children (Zinyemba et al., 2020). This could not be readily available while at home, instead provided by an institution at large. Every institution ensures that the children are provided with triple therapy, which gives them an almost standard immune system. Optimal nutrition, an essential therapy for HIV-infected children, has the potential to provide adjunct immune-modulatory therapy, thus improving care and outcomes of children with HIV/AIDS (Hussein et al., 2019).

According to Charles et al. (2012), ensuring high-quality, comprehensive services at the Antiretroviral treatment (ART) centres and a high level of social support for the People living with HIV/AIDS (PLHA) is vital and would lead to an increase in the Quality of Life (QOL). The institutions ask for the government to identify these children as vulnerable and provide services for them at the door; they should be given attention and provide the necessary support by the general public during a crisis. Identification as a vulnerable group is essential to provide the necessary social support when needed.

Conclusion

Governmental and non-governmental institutions need to address the pivotal needs of Children living with HIV/AIDS like food, clothing, medicines, regular medical check-ups, counselling, motivation, life skill training. In recent years, the dedicated efforts of various organisations have resulted in a decline in HIV prevalence and the number of people living with HIV/AIDS. We cannot change the virus, but we can address their problems and ensure better living conditions. This research experience aimed to highlight and bring out findings on the same based on field realities.

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APPENDIX

Interview Guide

1. What is the general feeling of Children with HIV/AIDS during COVID Pandemic?
 - (a) Physiological (b) Psychological (c) Social
2. What are the problems Children with HIV/AIDS are facing during COVID pandemic?
 - (a) Family (b) Schooling (c) Outsiders
3. What are the challenges faced by institutions in providing care for them?
 - (a) Availability of provisions (b) finance (c) medicines (d) Any other
4. How are you managing COVID restrictions like Social distancing, using sanitiser and mask, etc.?
5. What are the various guidelines given by government authorities and how it helped in managing the crisis?
6. Do you think there is any need for professional social work intervention during this period and why?
7. What are the programs/activities organised by you during this epidemic and what role do children play in them?
8. What are the various social work interventions applied for overcoming these challenges?
9. What are your tentative plans to face future pandemics like COVID?
10. What are your expectations from other stakeholders - Government, Ngo, Civil Society etc.....?