

## Original Article

# African Livelihood; An Impetus to the Care of Children Living with HIV in Nigeria: A Qualitative Analysis

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### Article Metrics

Date submitted: 06/09/2020

Date Accepted: 25/09/2020

Date Published: November, 2020



 <https://doi.org/10.46912/wjmbs.26>

## ABSTRACT

*The cultural framework of African livelihood can influence the care given to the children living with HIV. The study aimed to analyze how African way of life in clan vials tend to influence the care of children living with HIV in the Nigerian context. A grounded theory approach was adopted for this study with Strauss and Corbin's sequential analysis. Nurse practitioners, children living with HIV and their caregivers, and stakeholders practicing within the confines of HIV care participated in this study. Focus group discussions and interview methods were involved in the process of data collection. Strauss and Corbin's analytical sequence was adopted in the data analysis in a bid to project the codes and the emerging concepts. Major themes that emerged among the findings which positively impacts care include: Influence of communal living in healing the minds; children's integration in the cultural setting; friends/neighbors helping the sick and shared neighborly interaction and mutual help while the ones posing challenges to the care include: heightened poverty and inadequacy of resources within community structures; uninformed socio-cultural context with illiteracy and ignorance; and social stigma within the cultural framework. The study concluded that communal living is a crucial element in the parameters of assistive care provision to the children living with HIV on the African continent.*

**Keywords:** African livelihood, Care, Children, HIV/AIDS, Cultural context, Impetus.

## INTRODUCTION

The value of clan vials in the African socio-cultural context cannot be underestimated in the general care of the sick as it offers psychological and physical benefits to the members of the communities and gives a sense of identity and security; the interests of the community members are protected within the cultural framework, and in the rich African cultural setting there is an underlying

philosophy of sharing problems with one another as well as supporting oneself.<sup>1,2</sup> Understanding the cultural context of HIV and AIDS among children and their families in traditional African societies is crucial in the provision of care support for those infected with the virus as it reflects their belief system as well as their response to the treatment options.<sup>3</sup> Disruptions within the African socio-cultural context has a negative impact upon the lives of children infected with HIV and AIDS which affects their integration

into the community.<sup>4</sup> The fragmented nature of some African societies has negative emotional impact on the care of children living with HIV and this affects their integration within the community setting.<sup>5</sup> Preserving the communal ethical culture of the African people in relation to paediatric HIV care in sub-Saharan Africa, enables rural communities to work together in addressing the challenges and changing the dynamics of care for HIV-infected children within the community structures.<sup>6</sup> In this regard, the Education Training Unit, reflecting on the importance of African community structures in response to the care needs of children infected with HIV and AIDS seeks to bring together stakeholders at the local levels to collaborate in strategic plans to establish comprehensive HIV care for these children through a multi-disciplinary approach.<sup>7</sup> HIV-infected children are affected in various dimensions of their health, and the effects are especially pronounced in the way that childhood development is affected by physical, emotional and social deprivation, invariably affecting their behavior and causing adjustment problems which warrant interventions for a desired health outcome<sup>[8]</sup>. Stigmatization of people carrying the AIDS virus, being ostracized within the cultural context and labelling them as suffering from an incurable ailment, has grave implications (relating to the cultural framework) that have not been adequately ascertained in African societies.<sup>9,10</sup> Stigma and discrimination continue to be a major concern among children living with HIV in Nigeria and in the wider African context, and the challenges involved in seeking to assimilate them into the community settings make it urgently necessary to ascertain the parameters of cultural variation that could help to promote their care.<sup>[11] [12]</sup> Against this backdrop, the needs of vulnerable children orphaned by AIDS and their caregivers in African settings need to be addressed at a societal and community levels, and these includes economic strengthening, emotional support, and prevention of stigma and discrimination. In most African countries, lack of commitment among community members is another constraint to contend with in seeking to assimilate HIV-infected children into the community in a bid to combat the effects of the scourge of HIV infectivity.<sup>13</sup> Lack of commitment with inadequate collaborations hampers inter-governmental and organizational support in integrating the children living with HIV in the African societies.<sup>14</sup> In this regard, attitudinal change among populations on their commitment to care at the societal level has shown positive results in alleviating the problems of HIV-affected children.<sup>15</sup> Against this background, the study was conducted to analyze how

African livelihood influence the nature of care given to children living with HIV in Nigeria with a view to establishing an appropriate philosophy of care and improving the quality of care given to them.

## MATERIALS AND METHODS

The study adopted a qualitative research method with focus group discussions and individual interviews. Nurse practitioners working in the HIV clinic, children infected with HIV and their caregivers as well as stakeholders in health were among the participants for this study. The research was conducted in one government hospital, one faith-based health institution and two agencies for the control of AIDS in Kogi State, Nigeria. Nurses and caregivers were engaged in separate focus group discussions, while the stakeholders were engaged in individual interviews. Data collection and analysis were done simultaneously, in line with the grounded theory research approach, to ascertain emerging themes and codes with a view to attaching labels in the analytical sequence, and at a point where no further themes emerged (theoretical saturation) data collection process was brought to an end.

### Design and Participants

A grounded theory approach was adopted for the study in a bid to explore how the cultural influences of African lifestyle affect the care of children living with HIV in the Igala cultural context, and an initial sampling was made of four members among nurse practitioners, children living with HIV and their caregivers from each of the hospitals which was built to theoretical saturation of ten and eight members respectively in the focus group discussion sessions, while two stakeholders from agencies for the control of AIDS were engaged through individual interviews, making a total of 54 participants. The research subjects gave their informed consent before participating in this study and their participation was voluntary, with every effort being made to ensure confidentiality and anonymity to protect them from any risk or harm during the study period.

### Sample inclusion criteria

Child must be between 11 and 14 years and accessing ARV care in health care setting. Nurse practitioners must be working in the HIV clinic and doing home visitation, and must be directly involved in the care of these children to participate in this study. Caregivers must be either

biological or foster parents taking care of these children and accompanying them to the HIV clinic to participate in this research. Stakeholders must be volunteers working in a non governmental organization or a government social service worker to participate in this research.

### Data collection

Data collection was based on mutual agreement between the researchers and the research participants on a secure and confidential venue within the healthcare settings. The faith-based health institution was tagged as Hospital A (Grimard Hospital Anyigba); the government health institution was tagged as Hospital B (General Hospital Ankpa); and the two agencies were Kogi State Agency for the Control of AIDS (KOSACA) and Diocesan Action for the Control of AIDS (DACA). The nurses, caregivers and their children were engaged in focus group discussions within the hospital settings on a monthly basis until theoretical saturation was reached, while the stakeholders were engaged in two separate individual interviews within the aforementioned agencies. The duration of data collection process was approximately six months.

### Data Analysis

Data collection and analysis were done simultaneously, as per the method of Strauss and Corbin grounded theory analytical sequence, to ascertain emerging concepts for attachment of labels for open, axial and selective coding<sup>[16]</sup>. Thematic analysis reflected categories and sub-categories in the conceptualization of the phenomenon of care for these children living with HIV and (communal living influences integration of children in the cultural settings, and people within the community settings, such as friends and neighbors helping the children). The categories and sub-categories were related sequentially until a consensus was reached in the analytical process for the discussion of the research findings, and these were supported by other research work to validate the findings.

### Ethical consideration

Ethical approval was given by the relevant Ethics committee of the institutions before the commencement of the study, together with gatekeepers' permission from the various health institutions and agencies. Adequate information was given by the researcher in regard to the relevance of the study and individual participants gave their consent for voluntary participation

### Findings

Major themes extracted from the sub-categories relating to positive influences on care within the cultural context include the following: healing of minds through communal living and helping one another; children's integration in the cultural settings; friends and neighbors helping the sick child within the cultural setting; and shared neighborly interaction and mutual help. Themes identified as posing a challenge to care within the cultural context of communal living include the following: heightened poverty and inadequacy of resources within community structures; uninformed socio-cultural context with illiteracy and ignorance; and social stigma within the cultural framework.

#### Theme 1: Healing of minds through communal living and helping one another

Nurse practitioners (NPs) and caregiver participants suggested that communal living is beneficial in the sense that it tends to heal the minds of people in keeping with the African culture of caring for one another. In this regard, neighbors can be very helpful in rendering assistance to the sick; they often rally round to support the sick child and the family of the child by gifts of food and other financial assistance.

*The communal living in our place here, I mean Igala land, tends to heal the mind...in oyibo land (western world) when somebody is sick, they can just take the person to the hospital and drop money for the person to be taken care of, but in our African setting, we live in clans and the family members usually take care of the sick ones...(NP Participant 1; Hospital A)*

*Our living in the community helps so much, because sometimes, things might not be easy with me, and the things might be easy for my neighbor...she can give me food to eat. So our communal living together helps; at times your child is sick, and you want to take him to the hospital, your neighbors can give you a helping hand before you go to the hospital; or at times, your clinic day has come and you don't have money to go to the hospital, your neighbors can give you transport money... (Caregiver Participant 7; Hospital B)*

#### Theme 2: Children's integration in the cultural setting

The stakeholders and other caregivers indicated that the children are encouraged to remain in the cultural setting as it helps to integrate them into the community and aids them in accessing care within that community setting; this is because the caregivers for these children understand the

cultural perspectives of child caring patterns which is seen as an advantage in giving appropriate care to the children.

*We encourage them not to move out of the cultural settings because this will help them to integrate better, in short, our lifestyle of living together helps in the care of these children...people around them tend to give them help from time to time... (Individual interview – KOSACA)*

*...Our culture in Igala land encourage us to stay with our sick ones and take care of them, so that belief helps a lot in the care of these children...(Caregiver Participant 1; Hospital B)*

### **Theme 3: Increased poverty and inadequacy of resources for children's care within the community**

Though most of the participants attested that these children are being catered for within the communal structures, some of the caregivers and NPs indicated that inadequate resources in resource poor-settings could pose a problem in rendering care to these children within the network of vulnerable children orphaned by HIV and AIDS.

*This, my child has no father again, so if they can help me in supporting him to continue his schooling and also give him food...we want the community members to help us in terms of food, money and clothes for the children to wear, in any way they can help us, we will be happy... (Caregiver Participant 7; Hospital A)*

*My main problem and pain is my children that have this disease, if not, my own is no longer a problem, if these two children can be spared for me, I will thank God...my problem now is how God will help me to have enough money to give them food... (Caregiver Participant 8; Hospital B)*

*Some of these children, they are orphans, they don't have father and mother, so they need help so that they can go to better schools so that they can become better people in future (NP Participant 3; Hospital A)*

### **Theme 4: Friends and neighbors helping the sick child**

A number of participant responses indicated that the African culture of communal living is advantageous as friends and neighbors are eager to help out during ill-health, especially when you have a sick child and you are not able to give a comprehensive care. It also tends to help the caregivers for these children in their coping mechanisms as they interact with one another and share their problems. By implication, children can also interact freely with their peers and adapt to living with their HIV condition.

*As we live together, when you are not around and your child suddenly breaks down and begins to have stomach*

*problems, other people around will come to help you in taking care of her... (Caregiver Participant; Hospital B)*

### **Theme 5: Uninformed cultural context coupled with illiteracy and ignorance**

Contrary to the opinions of some of the caregivers about friends and neighbors helping the sick within the community structures, some of the nurse practitioners indicated that when people in this cultural context are uninformed, with some levels of illiteracy and ignorance about the HIV condition, children's integration and care can be compromised causing infringements of their rights in relation to the standard of care expected at this level.

*Illiteracy is a problem, they don't even know what this HIV/AIDS means and eeh...denial, some people deny that it cannot happen to them, they cannot have HIV and it is really causing a lot of problem in the care in this our locality... (NP Participant 5; Hospital B)*

*Well, eeh eeh...I want to say that illiteracy is part of the problem we are having, though the constitution say they can access care at a certain age, but constitution is a western thing, so also is the HIV, so if the children have the opportunity to have western education, that it can be helpful in improving the awareness, they will also know that there are certain rights they have as children at their age; that will go a long way to improve this thing... (NP Participant 8; Hospital B)*

### **Theme 6: Shared neighborly interaction and mutual help**

The caregivers and nurse practitioners indicated that the culture of living communally in African societies is beneficial in the sense that when you are away from home (for example, travelling to another place) you can easily leave the care of your sick child in the hands of your neighbors and they will always be willing to help out if you cannot take the child along. The respondents also confirmed that people living in the same cultural settings can relate freely and share things in common which is a great help in taking care of the sick.

*This staying together we are discussing has really helped me, especially when sudden journey takes me out of the town, and my child is sick, and I cannot carry the child along; I will quickly commit the care of the child in the hands of my neighbors...and they always take good care of the child before I come back...(Caregiver Participant; Hospital B)*

*They can mix-up and relate with one another even with their neighbors, they share things commonly and when one*

*of the children of the neighbors is sick, others will rally round to take care of the child... (NP Participant 1; Hospital B)*

### **Theme 7: The problem of stigma in the care of children with HIV and AIDS**

Stigma was reported by some nurse practitioners, stakeholders and caregiver participants as posing a challenge to the care of these children; people around them tend to ostracize them and in addition erroneous cultural beliefs about HIV infectivity is seen as affecting the care being rendered to the children because people see HIV and AIDS as different from any other chronic or long-term disease condition.

*Sometimes, mothers and their children are being stigmatized, so it becomes difficult for us to achieve our goals of caring for these clients... (NP Participant 2; Hospital B)*

*Sometimes, stigma and discrimination affect the care you are giving to the children as some may not report at the right time, especially when they are sick... (Individual interview–KOSACA)*

*The only thing bothering me in the care of this child is the way people look down on us...so many people discriminate against us...they even speak to our faces that we are carrying HIV and AIDS...uko chuu... (derogatory remark), so this usually weakens my spirit in the care of this child...(Caregiver Participant 1; Hospital B)*

## **DISCUSSION**

Most of the nurse practitioners and caregiver participants reported that living communally within the cultural setting was advantageous in healing the minds and helping one another during ill health, as African people value the culture of caring for the sick; in this regard, they asserted that neighbors could be of assistance when you are impoverished financially. Africans live as brothers and sisters in small clusters in the community, which helps to foster mutual interest as they share their problems, and these values tend to heal the minds of the people when there is crisis and/or ill-health.<sup>17</sup> Reflecting on the right mix in indigenous social concepts in Africa, Jaycox and Uche state that there is a strong sense of taking interest in one another when you live with friends and neighbors in indigenous societies as the communal way of life provides a supportive network that can help the community members, which is crucial in the care of the sick.<sup>18,19</sup>

The stakeholders and caregivers indicated in their

submission that when children stick to the cultural settings, they are better integrated as the caregivers will have a better understanding of the caring pattern in the cultural perspective, thus enhancing appropriate care for the children. The culture of the Igala people encourages this aspect of the belief system as they live within clusters in the community. The culture of the African people also promotes harmonious living, the network of relationships among the people is deep and extended, and because of this trend of relationships, people tend to help one another during ill-health because the interest of one becomes the interest of all.<sup>19,20</sup> Kabiza further corroborating this finding, indicated that in giving supportive care to African children who are sick, the caregivers must understand their cultural background and the problems of the child for the care to be appropriated.<sup>21</sup> Children with HIV and AIDS are unique in their caring patterns, therefore the caregivers and stakeholders involved in their care must understand their specific needs in the cultural perspectives as this forms the basis of care.

Against this backdrop, some of the participants asserted that inadequate resources coupled with poverty could pose a challenge to the care of these children at the community level with the growing number of vulnerable children orphaned by HIV and AIDS.<sup>22</sup>

Caregiver participants also submitted that friends and significant others around them are eager to help the sick child, reflecting the cultural context of communal living. Africans are hospitable in the real sense of the word as they accommodate strangers and help the sick and helpless, and also provide shelter to the homeless.<sup>17</sup> The finding of this study further corroborates the submission of Aid for Africa which reported that, supportive care for children living with HIV and AIDS by virtue of the African socio-cultural context of communal living will enhance counseling and various forms of assistive care; hence, members of the community understand the language and culture of the children, and based on this premise, children's need can easily be communicated and assistance given within the circuit of the community.<sup>23</sup>

Contradicting this view, some nurse practitioner participants made the point that the uninformed socio-cultural context, coupled with illiteracy, ignorance and denial, affects the standard of care expected for these children. The uninformed socio-cultural context in African cultural settings, coupled with harsh economic conditions, can be detrimental to the complex livelihood situation of people infected with HIV and AIDS within the community.<sup>24</sup> Further to this, it is reported that, when people

are insensitive to the cultural indices that could ensure the social integration of children living with HIV in African settings, the integration could be compromised by disruptions which will threaten their access to treatment and care support.<sup>25</sup>

The cultural variation of communal living was also clearly reported by other nurse practitioners and caregiver participants who reported that members of the same community mingle freely and share things in common, and through this network of relationships, they are able to leave the sick children under the care of their neighbors if they are away from home. Physical, spiritual and psychosocial benefits could stem from supportive care given in terms of food provision and assistive care given to children within the medical facility.<sup>26</sup> The poor and the vulnerable families in African communities could also benefit from the supportive care to be given to the children by community-based workers and philanthropists.<sup>27</sup> Financial assistance by these groups are important to caregivers providing supportive care to these children, who often lack the necessary economic resources to take good care of them.<sup>28</sup> Community members serving as volunteers in the care and treatment support of these children might also help them to access educational and other physical support.<sup>29</sup>

Some of the participants reported that stigma among the children and their caregivers poses a challenge in the administration of care within the community structures, as they are often ostracized as people carrying the AIDS virus. Studies have clearly shown that caregivers and their children living with HIV are often ostracized by peers, neighbors and community members due to their status, which causes withdrawal syndrome with resultant isolation, and these affects the holistic care given to the clients at the care settings.<sup>30</sup> In Southern African societies, children infected with HIV and AIDS were often ostracized by society members because of their status and other factors relating to stigma and discrimination.<sup>31</sup> Stigma related to HIV and AIDS can give rise to exploitation of young children and their families when the parameters of care for the orphans are defined without effective integration of those affected within the African settings.<sup>32</sup>

## CONCLUSION

The study highlighted communal living as an important factor in seeking to understand the parameters of care among the caregivers, nurses and other stakeholders taking care of children living with HIV in the Igala cultural

context. The findings indicate that people living within the same cultural environment provide assistive care to the children and their families in the form of health care, financial assistance, food supplementation and other physical support. An emergent theory of empathic supportive care is therefore advocated to cushion the care of these children.

## Limitations of the study

The understanding of these children as per cultural context influencing their care was low, so they did not respond to questions being asked under this variable; therefore, this is a limitation as their voices were not fully captured to support this aspect of the study. This study was carried out in Nigeria, other African countries were not included; this is also a limitation.

## Implications for practice

The implications for practice are projects that health care workers and other stakeholders in care should encourage the children to remain within the cultural settings where their parameters of care are more clearly defined within the cultural framework as their care is easily appropriated in this context. In this way, stigma and discrimination would be addressed and respite provided to cater for the needs of vulnerable children orphaned by HIV and AIDS. Caregivers should also take cognizance of the fact that when these children are taken care of within the confines of the cultural environment, they will integrate better than if they are put into hospices.

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