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Caregivers Predicament in helping Orphaned and Vulnerable Children to Cope with HIV/AIDS Stigma in Bauchi metropolis Nigeria

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Abstract

This paper aims to identify the practical issues affecting the role of caregivers in relation to religion as a significant cultural factor. The theoretical lens for the study was the Structuration theory postulated by Giddens (1984). A mixed-method approach was adopted through a descriptive cross-sectional survey. Thus, data were collected within the Bauchi metropolis from 218 caregivers using both questionnaires and interview. The key informant interviews were conducted on officials of Government agencies and NGOs. A Pragmatist world view led to the application of the sequential transformative approach of quantitative and qualitative methodology. Statistical Package for Social Science (SPSS) was used to analyze the quantitative data using descriptive statistics such as frequency, and percentages, while NVivo software was used to analyze qualitative data synthesis and prose thematically. The findings of the study revealed that the influence of cultural factors such as religion, and social Attitude has a significant impact on the role of caregivers in providing help to children with HIV and AIDS to overcome social stigma in Bauchi Metropolis. The study also identified other challenges and difficulties including lack of caregiver education, lack of professional knowledge of the Social casework approach to issues of social stigma, and lack of utilization of consultation and case referral for further inquiry/collaboration with other caregivers. Using the orientation of structuration theory, the study concludes that, what tends to render most caregivers unable to properly handle issues of social stigma in addition to the cultural factors identified, including lack of incentive by governmental structures to support caregivers in working with vulnerable children and HIV/AIDS orphans cope with the social stigma. The study, therefore, recommends the empowerment of caregivers with skills acquisitions, training, workshops and be part of the decision-making structures on programs related to HIV and AIDS.

Keywords: Stigmatization, Discrimination, HIV/AIDS, Caregivers, Vulnerable Children

1.0 Introduction

Globally there is very little known about the plight of caregivers of HIV-positive children (Bani Ismail, L., Hindawi, H., Awamleh, W. et al. 2018, Bajaria, S., 2021). Likewise, in Bauchi state (Metropolis), the cases are the

same where caregivers in Bauchi suffer from right protection, access to support: such as empowerment, training on how to properly care for the HIV-orphaned children, caregivers are not well educated, health systems are poor, etc (Asuquo, E. F. et al. 2017).

This paper presents the challenges caregivers went through for social support on HIV orphans children in Bauchi Metropolis. The main area of concern is on how effectively those caregivers can handle issues related to HIV/AIDS social stigmatization within the community, and how synergy among the active plays could also help on the problems. Studies on caregivers' predicament were scanty and did not take into account differences in terms of culture, religion, and traditions. However, there is little data concerning caregivers' predicament in Nigeria and Bauchi specifically (Osafo, et al. 2017). Therefore, study on this area will go a long way in tackling the predicament of caregiver's plight on HIV-positive children.

It is in this logic that. This study, therefore, focused to examine the social environment influences, community behaviors, attitudes, backgrounds, gender, social class, race, and ethnicity, age, religion, and social network of caregivers that could influence their capacity. Similarly, it also includes various aspects of their class, and status.

Background to the Study

HIV and AIDS prevalence rate around the globe has been a major concern (Avert, 2017). The epidemic has led to a huge number of children being left orphaned and vulnerable with a heavy burden of care and support left for caregivers (PEPFAR, 2017). Globally, about 13.4 million children are living without one or both parents due to AIDS, while a majority of those HIV positive children's are looked after by caregiver's, with over 80 percent of these children living in Sub Saharan Africa (President's Emergency Plan for AIDS Relief [PEPFAR], 2017). This shows that Africa is the part of the world that requires urgent attention on the social stigmatization of HIV/AIDS that will help control issues related to the disease before it gets too late.

In Nigeria, there are more than 1.9 million children orphaned as a result of HIV/AIDS (Tagurum et al., 2015, NACA, 2019), despite a gradual decline in the overall cases of HIV/AIDs across the world, social stigma burden on caregivers remained the same. This indicates that enough has not been done (Avert, 2017). Caregivers are those people whose role is to look after HIV-positive children, where evidence by Avert 2017, clearly shows that there are linkages that must be addressed such as caregivers' rights, social stigmatization, and rights protection on children, among others. Globally there is very little known about the plight of caregivers of HIV-positive children (provide source or justify). Likewise, in Bauchi state (Metropolis), the cases are the same where the caregivers much of their energy, health, finance, where centers around the care of those HIV orphans.

Sociological theories with specific reference to perspectives in medical sociology have explained the relationship between social

background and differential access to quality health care and how the processes of medicalization and de-medicalization shape how society responds to different illnesses negatively or positively. The social stigma attached to HIV infection remains the most serious problem to caregivers that is triggering the spread of the pandemic, and HIV and AIDS orphan-hood exposes children to vulnerabilities that are beyond the coping capacity of caregivers, which caregivers, in turn, make them suffer from loss of shelter (protection), poor health, malnutrition, abuse and above all threat that are harmful due to social stigmatization on children (UNAIDS, 2016).

According to Malcolm et al., (1998) HIV and AIDS social stigma has been conceptualized in two ways; as felt or enacted. Felt social stigma is the imagined fear of societal attitudes and discrimination raised from a particular undesirable attribute, and disease (such as HIV), or association with a particular group. While enacted social stigma is the real experience of discrimination based on one's HIV-positive status. Social stigma to HIV and AIDS increases social differences by labeling individual's into classes, and are part of the realities of the social world which increases ground for the spread of the epidemic, and stopping patients from being tested, searching for help, and adhering to or continuing with treatment (Pinar, 2015).

Caregivers' condition is alarming because of children living with HIV and AIDS encounter different forms of social stigma; verbally, victims experience scolding, taunting, naming, gossiping, blaming; while physically they experience social exclusion. Social exclusion such as separation from families and friends, displacement from home, separation of household tools, loss of identity (hide), rights and status were denigrating; and denied access to many resources, such as employment and health care made for everyone (Lekas et al., 2018).

Caregivers, therefore, have an important role in providing care and support of HIV and AIDS orphaned children, given the status they occupy in their lives, which goes a long way in helping the reduction of HIV and AIDS cases of social stigma and discrimination at the local community-level (Surkan et.al., 2011). Illness like HIV is to some degree socially constructed, which affects certain traits symptoms, and behavior like social stigmatization (Barkan, 2017). Hence, the support given by caregivers to those children orphaned and vulnerable to HIV and AIDS is compromised. This is made worse by the characteristics of those caregivers, and the shortage of antiretroviral (ARV) (WHO, 2020).

This paper, therefore, examined the dilemma caregivers went through in helping HIV and AIDS vulnerable orphaned children to cope with HIV and AIDS social stigma in the area of study Bauchi Metropolis.

Literature Review

The amount of challenges caregivers encounter while helping HIV and AIDS orphaned and vulnerable children were enormous.

The social dimension of illness is when a person's predisposition as ill depends on

how other people react to the disease like HIV/AIDS, where people fear them because of its contagious nature, which might deny them many privileges by the larger society (Bradby, 2009). Umeadi (2014) believes some caregivers have the zeal and firmness to support and care for HIV and AIDS vulnerable orphaned children, but they lack the appropriate skills and knowledge to help them cope with the social stigma.

In essence, people living with HIV social stigma are faced with various challenges: violence, social and physical seclusion, deprived opportunities, and economic discrimination. According to Giddens, (1984) "structuration theory", emphasizes that behaviors and structures are intertwined. Therefore, communal and family cohesion will help in facilitating caregiving.

Acheampong et al, (2015) examined the psycho-social coping experiences among caregivers of people living with HIV and AIDS in some areas of South Africa**.** They asserted that despite existing data on HIV and AIDS problems such as social stigmatization, HIV patients' rights, among other factors bedeviling them are still found in South Africa. This shows that more needs to be done to control the disease which has been more in Africa. The effect of the disease on patients causes financial and income problems which put a serious burden on individuals (caregivers) and households (Barnett & Whiteside, 2002). The psychosocial trauma caregivers and HIV patients go through due to social labeling differences, directly affects families' wellbeing and HIV children's school performance. As well as the general lives in the neighborhood and family's interaction. The ability and motivations of caregivers to look after those children are shattered due to a lack of support from both family and community. However, such negligence might cause caregivers of HIV patients to end up engaging in dangerous actions such as hiding HIV status that might spread the epidemics, engaging patients in substance abuse because they are condemned to refuse to take ARV, and having unprotected sexual behavior (Coombe, 2002).

According to United States Agency for International Development (USAID) report (2013), caregivers in Nigeria are having more difficulty in coping and shouldering the responsibilities of the HIV and AIDS children in various parts of the country including Bauchi State. These difficulties covered areas of health, education, protection, psychosocial, nutritional, and shelter needs, and how best to meet those needs. United Nations Children's Fund (UNICEF) report (2005) shows one of the problems of HIV and AIDS children and their caregivers in Nigeria is poverty. Similarly, the family system and institutions that support and care for HIV and AIDS children with their caregivers in difficult situations such as; social stigmatization and Discrimination, had been tough due to critical economic changes.

Mills' concept of Sociological Imagination establishes that setbacks about the health of an individual are largely blamed on the patient. This is illustrated by the condition of the HIV and AIDS orphaned children: they

are being socially stigmatized for their status. Larger social forces beyond their control also exacerbate the situation and become a problem for caregivers (Barkan, 2017).

Bauchi Metropolitan area has been chosen because the issue of HIV and AIDS stigma seems to have affected caregiver's economic wellbeing, health status, and above all the capacity to care for those orphaned by HIV/AIDS. Therefore, suggesting that the social system has made caregivers lacking proper knowledge and skills in terms of handling children with HIV and AIDS be psychosocially stable, economically viable amongst the enormous challenges caregivers encounter as a result of the HIV disease stigma on children (BASOVCA, 2014).

Osafo, et al. (2017) warns that there is a failure in caregiving which seriously affected HIV children's psychosocial wellbeing that needed to be understood. Thus, there is a need for more studies in the same area particularly in the Northern part of Nigeria. Although some studies have been locally conducted on the theme, such researches are based in the southern part of the country. The northern part remained unstudied. Therefore, is a gap considering differences in terms of geography, religion, ethnics, and the level of cohesion from the people in the areas. Hence, the rationale for this paper.

Theoretical framework

This paper used structuration theory as advanced by Giddens (1984). The central assumptions of this theory are that behavior and organization are intertwined. People go through a socialization process and become hooked on the existing social structure. At the same time, social structures are being transformed by people's actions. In other words, social structures are a medium of human activities as well as the result of those actions. Social structures do not only limit behavior but also create a potential threat to human behaviors. This paper understood the need for a collective response to address the issue of social stigma. Therefore, the theory can help explain the caregiver's situation if the entire society coming together and change the attitude (narratives) of social stigma as a form of social structure to help caregivers support vulnerable children and children with HIV and AIDS.

This theory's application on the study for caregiving will help in a collective response to this menace of social stigmatization. Therefore, the standing social arrangement within the African setting of homogeneous (Ubuntu spirit) collectivity, if it would be practice effectively, the issues of social stigmatization could be minimized to a lower level that will not be a problem to caregivers and the large society. Thus, both the immediate, extended family and community members will more often than not really be all over the place to offer social support and care for the member of their family, community needing care. Therefore, communal living and family cohesion provide and facilitate caregiving. However, even in the lack of such structures, the illness will always induce such a caregiving structure. It will go a long way in helping

caregivers to better care for those HIV orphaned children against all issues of social stigmatization.

Methodology

This paper used research design, area of study, research population, and sample elements, data collecting tools, and analysis strategy and analyzing it to explain their predicament. The paper adopted a descriptive cross-sectional design with the sequential transformative approach of quantitative and qualitative methodology (mixed method) was used. The study used 218 caregivers in the Bauchi metropolis from BASOVCA in 2018. However, a simple random sampling technique was used to sample 136 respondents using Krejcie and Morgan formula. The instrument for data collection was a set of questionnaires for the caregivers, and an interview for the key informant using the purposive sampling technique. Quantitative data was analyzed using Statistical Package for Social Science (SPSS) to produce descriptive statistics such as frequencies, and percentages. While information from interviews and open-ended questions was summarized thematically and coded for analysis using NVivo software. However, the paper followed ethical principles.

Data Analysis and Discussions

Table 1: Demographic information of the caregivers

Category	**Frequency**	**Percent**
Gender		
Male	21	15.9
Female	115	84.1
Totals	136	100
Age (years)		
18 – 30	43	32.6
31 – 65	68	49.3
66 and above	25	18.1
Totals	136	100
Education level		
Primary	12	9.4
Secondary	50	36.2
Tertiary	41	29.7
Others	33	24.6
Total		
136	100	

The table above indicated 84.1% were females, while 15.9% were males. Looking at the gender of caregivers it is shown that this result was expected because of the African culture where women are mostly the ones who take up the roles of caregiver in households. The finding is consistent with UNAIDS 2016, where caregivers of HIV and AIDS vulnerable orphaned children are women. Females are more determined in terms of care for the offspring and united with other female counterparts (Pequet & Per 2017).

The age findings show that 49.3% were within the age of 31-65 years. The study shows that most of the caregivers were middle-aged. This result is a true reflection of what happens when parents die and leave the young ones. In most cases, it is the old who take care of them. Age of caregivers according to this findings agree with Ntozi and Nakayiwa (1999) where they indicated that older parent looks after HIV patients, and they end up suffering from

psychological, economical, and health issues among other problems.

Caregiver's educational level on the table above found that 29.7% have tertiary education, 36.2% have secondary education. The educational background indicates that the caregivers have no specialized education as caregivers of HIV and AIDS children. In order to take care of these vulnerable children facing social stigmatization and discrimination, the caregivers need to be trained to cope with challenges. Thus, People with higher levels of education may have better life opportunities and strong coping abilities when faced with hard circumstances like HIV and AIDS social stigma (UNAIDS, 2018).

Caregiver's challenges experienced while caring for orphaned and vulnerable children with HIV/AIDS in Bauchi Metropolis.

Table 2: Forms of Discrimination Reported

Statement	Frequency	Percent
Family separating domestic items (utensils)	97	73.2
Losing friends after disclosing HIV status	101	70.3
Neighbors warning other children from closely interacting with the child because of their HIV status	52	37.7
Teachers discriminating the child from participating in activities they would wish to at school	0	0.0
Any form of treatment by religious leaders	4	2.9

The table above shows that 73.2% of caregivers perceived the family, friends, teachers, and religious leaders have treated the children living with HIV negatively.

KII from Rahama foundation explained that "most of the caregivers are wrongly handling issues concerning HIV and AIDS. However, social stigma has made them hide and, therefore, failed to enquire measures on handling the epidemic that is alarming in spreading that required all stakeholders involved".

A total of 73.2% of the family members were found to be separating domestic items (utensils).

Up to 70.3% of the children lost friends and neighbors after disclosing HIV status.

Caregivers believed social stigma is a blow to the child, particularly in schools, playgrounds, family, and friends. They only comfort them through emotional and psychological support.

Caregivers suffered challenges from family members due to poverty, lack of awareness, discrimination, and separating domestic items. The study found that most families were ignorant of the HIV/AIDS disease that lead to fear and social stigmatization. Many of the experiences of the fear by the family are just misconceptions on HIV transmission that may leave the family vulnerable to experiencing isolation and social stigma (Sonia et al, 2015).

A KII respondent explained that most family members don't associate themselves with the

HIV family member (patient), and refuse to offer any kind of assistance. It is thus a problem in handling issues of the HIV and AIDS epidemic.

Challenges from the community members (society) - Caregivers believe that discrimination, ignorance, lack of unity (cohesion), aggression where factors that affect them and the HIV children.

KII from BOSOVCA explained, "children's conditions at the community level have been helter-skelter due to ignorance of HIV/AIDS which caused discrimination by depriving the patient right to live and move around like any other person".

The challenges experienced by religious groups were lack of cooperation and support from religious leaders, their belief was HIV/AIDS happen as a result of the sin committed by the person which also affects their children.

The challenges from Government and traditional authority were the lack of legal backing and involvement of all stakeholders including caregivers in sensitizing the public. Poor interventions, meaning that the major problem of caregivers and children are not taking into account to relieve their situation and lack of proper record keeping.

Challenges encountered from the health sector were lack of manpower and unqualified workers, poor attitude toward patients, proximity issue, poor facilities and structure (building). Lack of togetherness in handling the issue of HIV in the society and failure by the government, health sector factors as well as an unchallenged attitude by the religious groups have increased the social stigma associated with HIV/AIDS, caregivers try to hide the status of the children they are taking care of. This may lead to the increase of the disease and make it spread throughout the community because its magnitude will not be realized. The African spirit of togetherness (Ubuntu) could be adopted to address social stigmatization.

Conclusion and Recommendations

The paper indicates that social stigma is one of the major challenges to the caregivers in supporting those children to cope with HIV and AIDS issues. It also affects the management of the disease against spreading and controlling the effect right from the family setting, community cohesion, and key stakeholders like the traditional rulers and government (policies) among others. HIV and AIDS social stigma impacts negatively on caregivers in their course to help those children toward health-seeking behavior among many factors and on the children denial on certain privileges, psychosocial (emotional) and their rights as a human being.

Based on the findings, caregivers need to be empowered and enlighten on prevention, transmission and managing the disease, conversely, not only blaming community, government, religion, and leaders among others. However, well-to-do people (philanthropists) should as well include caregivers by assisting them in every way possible. The relevant government ministries and agencies including NACA, SACA, BASOVCA, and BACATMA as the case may be in Bauchi among others need to

design programs that can effectively deal with social stigma reduction, and it should be reviewed periodically.

The government needs to intensify campaigns in the media and other related bodies by involving religious groups, traditional rulers, NGOs, and international bodies to sensitize the general public aimed at reducing social stigma in communities through quoting verses from a different religious background and traditional leaders by citing some events that replicate cohesions during our forefathers' times. This allows peaceful coexistence in society, unlike now as we are vulnerable just because that togetherness (Ubuntu) is no longer functioning. This study only focused on Bauchi Metropolis. A similar study can be carried but on a bigger scale.

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