CAREGIVERS CHALLENGES IN FACILITATING VULNERABLE ORPHANED CHILDREN COPE WITH HIV/AIDS STIGMA IN BAUCHI METROPOLITAN, NIGERIA

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A THESIS SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENT FOR THE AWARD OF THE DEGREE OF MASTER OF ARTS (SOCIOLOGY) IN THE SCHOOL OF HUMANITIES AND SOCIAL SCIENCES OF KENYATTA UNIVERSITY.

OCTOBER, 2021

DECLARATION

I declare that this thesis is my original work and has not been submitted in this form to any other institution for examination. Any quotation has been referenced according to guidelines.

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DEDICATION

I thank almighty Allah for giving me the wisdom to undertake this M.A program in Sociology. I also dedicate this work to my late parents Late Alhaji Ahmed Abubakar (Madakin Bauchi), and Hajiya Hauwa'u Ahmed (Yaya Kaduna).

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ABBREVIATIONS /ACRONYMS

AIDS	Acquired Immune Deficiency Syndrome
AMFAR	American Foundation for Aids Research
BASOVCA	Bauchi State Orphans and Vulnerable Children Agency
BACATMA	Bauchi State Agency in Control of HIV/AIDS, Tuberculosis, Leprosy & Malaria.
CHF	Child Headed Family
CSO	Civil Organization society
FMWASD	Ministry of Women Affairs and Social Development (federal)
HIV	Human Immune deficiency Virus
MDA	Ministries, Department, and Agencies
NACA	National Action Committee on AIDS
OVC	Orphan and Vulnerable Children
SPSS	Statistical Package for Social Science
UN	United Nations
VC	Vulnerable Children
WHO	World Health Organization
GHAIN	Global HIV/AIDS Nigeria

ABSTRACT

The prevalence of HIV and AIDS stigma on children has caused a burden on caregivers, HIV-positive children, and their families. About 17 million children around the world have lost one or both parents due to HIV and AIDS and left to caregivers (UNAIDS, 2019. USAID, 2021). This study explored the range of challenges caregivers encounter in assisting vulnerable children and HIV/AIDS orphans facing issues related to social stigmatization. The main aim was to highlight major challenges encountered by caregivers in the Bauchi metropolis. Specifically, the objectives were set to identify the practical issues affecting the role of caregivers with religion as a significant cultural factor. The majority of caregivers of these children live in sub-Saharan Africa with Nigeria accounting for an estimated 1.9 million cases (UNAIDS, 2019, USAID, 2021). However, despite collective efforts by caregivers, families, and communities aimed towards protecting, caring, and supporting infected affected children, the scourge of stigma has remained high. Reports indicate that more is needs to be done to support caregivers for them to look after those children (UNAIDS, 2019). Therefore, this study focuses on caregivers' predicament while helping HIV and AIDS vulnerable orphaned children in Bauchi Metropolis. The study highlights the challenges caregivers experience as a result of stigmatization reinforce by cultural and religious influence among others, in making children living with HIV and AIDS cope with the epidemic. The purpose of the study was to understand the position of caregiver's characteristics situations and impact culture, and religion's impact on the care of children with HIV and AIDS in Bauchi Metropolitan. The study was guided by two theories, the Stigmatization theory by Goffman, and the Structuration theory by Giddens. The sequential transformative approach of quantitative and qualitative methods (mixed method) was used in this study through a descriptive cross-sectional survey. SPSS was used to analyze the quantitative data using descriptive statistics such as means, frequency, and percentages, while NVivo software was used to analyze qualitative data synthesis and prose thematically. Bauchi metropolis has about 218 caregivers of children orphaned & vulnerable to HIV and AIDS. Data collection questionnaires and interview guides were used. Key informant interviews were conducted on government agencies and NGOs. The findings revealed that caregivers faced challenges and difficulties while dealing with orphaned and vulnerable children with HIV and AIDS. These challenges were mainly due to lack of education from most of the caregivers, lack of knowledge on how to handle stigma cases, and lack of consultation habit (inquiry) that make them unable to properly handle issues of stigma. In addition, the government is not doing enough to support caregivers in helping those HIV children cope with the stigma. The influence of culture, religion, and society has also made it difficult for caregivers to help children with HIV and AIDS to overcome stigma. The study, therefore, recommends the empowerment of caregivers with skills acquisitions, training, and workshops, and to be part of the decision-making on programs related to HIV and AIDS.

CHAPTER ONE: INTRODUCTION

1.1 Background to the Study

Human Immunodeficiency Virus (HIV) and Acquired Immunodeficiency Syndrome (AIDS) pandemic remain a serious global health challenge. The epidemic has led to a huge number of children being left orphaned and vulnerable with the burden of care and support left to caregivers. Globally, about 17 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 90 percent of these children living in Sub Saharan Africa (President's Emergency Plan for AIDS Relief [PEPFAR], 2017). In Nigeria, there are more than 1.9 million children orphaned as a result of HIV/AIDS (Tagurum et al., 2015, NACA, 2019, USAID, 2021), despite the recent statistics revealing that among children aged 0–14 years, HIV prevalence according to new data is 0.2%. Therefore significant efforts have been made in recent years to stop new HIV infections among children (UNAID, 2019). In Bauchi State particularly, there are more than 1482 children orphaned by HIV and AIDS in Bauchi Local Government Area. While Bauchi Local Government Metropolitan Area has over 218 caregivers of HIV and AIDS orphaned and vulnerable children. This means that there is one caregiver for every HIV orphaned child (Bauchi State Orphans and Vulnerable Children Agency [BASOVCA], 2017).

HIV and AIDS prevalence rate around the globe has been a major concern (Avert, 2017). Despite a gradual decline in the overall cases of HIV/AIDs across the world, the 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, stigmatization, and right protections on children, among others. Globally there is very little known about the plight of caregivers of HIV-positive children when it comes to socio-demographic factors (Bajaria et al, 2021).

Sociology discipline and medical sociology, in particular, explain how social backgrounds, social inequality, quality of health care could shape how society responds to different illnesses. The response can be negative or positive. Therefore, risks faced by those taking care of children affected by HIV and AIDS are serious. This, because children's immune systems are not fully developed, children living with HIV/AIDS get sick more frequently hence, inundating the capacity of the caregivers.

HIV-positive children face enormous problems. These problems are a concern to caregivers. These problems range from denial of education, lack of efficient health system that can accommodate the children, there is no proper skill acquisition to engage the children, poor nutrition due to low economic status of the caregivers, emotional and psychosocial effects resulting from the stigma and discrimination (UNAIDS, 2016).

The stigma attached to HIV infection remains the most serious challenge to caregivers. This is because, it leads to feelings of hopelessness, shame, and segregation. Therefore, caregivers of the affected children may be unwilling to ask for help or for treatment for these children. In addition, it may lead to a lack of understanding by family, friends, or others. This may in turn triggering the spread of the pandemic. HIV and AIDS orphan-hood exposes children to vulnerabilities that are beyond the coping capacity of caregivers: such as loss of shelter (protection), non-enrollment in school and drop-out,

poor health, malnutrition, abuse, and above all threats that are harmful due to stigmatization (UNAIDS, 2016).

In the sick role concept of Talcott Persons (1951), a patient being ill is both an embodied and a social experience such as stigma. Stigma-prone diseases like HIV have been historically associated with severe, disfiguring, incurable, and progressive outcomes especially when modes of transmission are perceived to be under the control of individual sexual behavior particularly STDs and STI's (Avert, 2018).

According to Malcolm et al., (1998) HIV and AIDS stigma has been conceptualized in two ways; as felt or enacted. Felt 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 stigma is the real experience of discrimination based on one's HIV-positive status.

Caregivers often find themselves in a dilemma, because children living with HIV and AIDS encounter different forms of stigma. These stigmas come in various forms; verbally, 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 denigrated; and denied access to many resources, such as employment and health care made for everyone (Lekas et al., 2018).

Stigma due to HIV and AIDS increases social differences because it leads to putting individuals into classes. This is part of the realities of the social world which increases ground for the spread of the epidemic by hindering the impact of interventions and

stopping patients from being tested, searching for help, and adhering to or continuing with treatment (Pinar, 2015).

Badahdah (2010) pointed out that stigma causes unfavorable evaluation and treatment of people living with HIV and AIDS (PLWHA) as one of the key troubling features of the epidemic. Shame, lack of awareness, and religiosity are among the major factors in predicting the stigmatization of individuals with HIV and AIDS. Coping, therefore, is determined by the nature and extent of a person's social support. One can go through, anxiety, anger, or depression upon learning his/her HIV status. 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 stigma and discrimination at the local community-level (Surkan et.al., 2011).

Medical sociologists utilize social constructionist theory to highlight the social experience of illness. Social constructionism urges that individuals and groups produce their own conceptions of reality and that knowledge itself is the product of social dynamics (Conrad, and Barker, 2010). Illness like HIV is to some degree socially constructed, which affects certain traits symptoms, and behavior like stigmatization (Barkan, 2017). Hence, the support given by caregivers to those children orphaned and vulnerable to HIV and AIDS is compromised. This situation is aggravated by the characteristics of their caregivers, as well as the shortage of antiretroviral (ARV) (WHO, 2020).

This burden is mostly shouldered by caregivers who are often old, this is particularly so in Africa. These responsibilities and the associated stigma have negatively affected the caregiver's well-being economically, health-wise, physical and psychological. This has led to the caretaker's poor health, physical pain, and depression among others. But if trained early the caregivers could help in dealing with the social stigma issue (Osafo, 2017. Exavery et al, 2021).

The study, therefore, examined the challenges caregivers experience in helping HIV and AIDS vulnerable orphaned children to cope with HIV and AIDS stigma in the area of study Bauchi Metropolis.

1.2 Statement of the Problem

Recent efforts aimed at reducing new HIV infections among children have been effective. This has led to a steady decline in the prevalence of HIV and AIDS among both infected adults and children. However, the number of affected children (0.2%) remains high, this possess a problem for caregivers (UNAIDS, 2019).

Caregivers are burdened with the care and support of children with HIV and AIDS. While these children are stigmatized, caregivers' problems range from poor health, exhaustion, and depression. These problems are the caregivers supporting the children suffering from stigmatization while neglecting their situations. In addition, caregivers lack the necessary skill to handle issues related to HIV stigma due to lack of education or training, poverty, and old age. The ARV is also in short supply.

Moreover, children in Bauchi face the challenge of cultural and religious discrimination. This is because HIV and AIDS are regarded as an abomination in Bauchi. This is because

the people of Bauchi are tied to their cultural and religious inclination. Culture increase stigma, because it is silent on HIV, while religion sees HIV as a curse from wrongdoing "sin" of a person. Most of the time, caregivers have to conceal HIV children's status to avoid stigma and this leads to missing out on some services that would help better the lives of these children. This situation is normally a problem for these old untrained and emotionally exhausted caregivers. This makes it difficult for caregivers to help those children cope with stigma effectively (USAID, 2021).

This study, therefore, focused to examine the challenges caregivers face as they care for HIV and AIDS orphaned children. These challenges are social, economic, cultural, and religious. They include; 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.

Studies on caregivers' situations were scanty and do not take into account differences in terms of culture, religion, and traditions. Therefore, there is little data concerning caregivers' experience in Nigeria and Bauchi. Therefore, a study on this area will go a long way in tackling the condition of caregivers' plight on HIV-positive children.

To carry out this task, the study examined the profile of caregivers of HIV and AIDS vulnerable orphaned children and identified challenges they experienced. The study also tried to find out the support caregivers need to address stigma among vulnerable orphaned children with HIV and AIDS in Bauchi Metropolitan.

1.3 Purpose of the Study

To understand the challenges caregivers in Bauchi (sub-county) Metropolitan, Nigeria go through as they take care of vulnerable orphaned children to cope with HIV and AIDS social stigma.

1.4 Objectives of the study

1.4.1 Broad objective

To examine the challenges caregivers in Bauchi (sub-county) Metropolitan, as they help vulnerable orphaned children to cope with HIV and AIDS stigma.

1.4.2 Specific objectives

1. To examine the demographic characteristics of caregivers of HIV and AIDS vulnerable orphaned children in Bauchi Metropolitan.

2. To identify the challenges experienced by caregivers of HIV and AIDS vulnerable orphaned children in Bauchi Metropolitan.

3. To ascertain the support caregivers need to address stigma among vulnerable orphaned children cope with HIV and AIDS in Bauchi Metropolitan.

1.5 Research Question

1. What problem does a caregiver's individual characteristic play in helping HIV and AIDS vulnerable orphaned children?
2. What challenges do caregivers experience while looking after children vulnerable orphaned by HIV and AIDS epidemic to cope with stigma?
3. How do caregivers of HIV and AIDS vulnerable orphaned children cope or overcome those challenges?

1.6 Significance of the Study

This study sheds light on the problem caregivers encounter due to the stigmatization HIV/AIDS children encounter. The study is important to scholars in the area of medical sociology and especially those specializing in health and illness. It is important because it fills a gap in the literature on the predicament of caregivers of HIV/AIDS children.

The information could be useful to ascertain the plight caregivers are facing that will help inform policymakers on the nature of caregivers' burden on stigma children with HIV go through. It can help in the area of academics learning, policy formulation on the current situation of caregivers along with orphaned children who are HIV and AIDS positive, and provide remedies on how it can be effectively addressed. The findings of this research should, therefore, add new evidence to the already existing knowledge in the literature of the field.

1.7 Justification of the Study

Despite the abundance of research on HIV and AIDS stigma, little has been done on caregivers' situation in helping HIV children on psychosocial wellbeing to cope with stigma. However, most of the studies that were done have left gaps like locations, time, and tools used in their research works which may require further research on the area. Such gaps may include psychosocial wellbeing, lack of sensitization on stigma causes, and management in a structured way to determine responses at individual, community, government levels, empowering caregivers, and reviewing programs/policies among others (BASOVCA, 2014). Understanding HIV and AIDS stigma and measures taking by caregivers in supporting HIV and AIDS could go a long way in controlling the disease from spreading.

1.8 Scope and Limitation of the study

The research was carried out in Bauchi (sub-county) Metropolis. It covered the difficulties experienced by caregivers of children orphaned by HIV and AIDS. It was therefore limited to Bauchi even though the issue could be affecting other areas in Nigeria.

The study focuses on caregivers of HIV and AIDS vulnerable orphaned in Bauchi. Due to stigmatization, the identity of the children and their caregivers is normally concealed, making it difficult for the researcher to locate the caregivers. However, to overcome this problem, their identity and location were found through BASOVCA that has recorded and documented caregivers of HIV and AIDS vulnerable orphaned children in Bauchi State.

1.9 Operational Definitions of Terms

Caregiver

Somebody who provides any form of psychosocial, or nursing support to vulnerable orphans that are HIV and AIDS positive for a given period.

Children with HIV/AIDS

Refers to children who carry the Virus or are HIV-positive**.**

Orphans

An 'orphan' is a child who lost one or both parents. In this case, they lost one or both parents through HIV and AIDS

Vulnerable

Vulnerability is unequal opportunities, social denial. Due to a child's background, he/she might be prone to HIV stigma. Thus, rendering them vulnerable.

Antiretroviral Therapy

The drugs and sensitization treatment that suppress the severity of HIV/AIDS transmission risks.

Epidemic

The epidemic is a widespread occurrence of an infectious disease. For instance, HIV/AIDS under this study. Its patient's condition is regarded as epidemic owing to the potential effect it poses over a given number of people within a larger population.

Stigmatization

Stigma is the seclusion of victims or patients of HIV and AIDS suffered due to its contagious nature.

Discrimination

The deprivation, exclusion, and restriction HIV/AIDS patients are subjected to.

Survey population

Part of the larger population that a researcher aimed at assessing for investigation (research).

Target Population

The population in which the researcher used and generalized the result (findings).

Children Affected by HIV and AIDS (CABA) – "The term Children affected by HIV and AIDS refers to children living with HIV, as well as those whose well-being or development is threatened by HIV because they live in HIV-affected households and communities". The children caregivers under this study support against stigma.

Coping

A patient with HIV and AIDS can handle issues of the diseases effectively, particularly if it is difficult like HIV stigma.

CHAPTER TWO: LITERATURE REVIEW

2.0 Introduction

This section examined studies related to the area of caregiver's conditions in helping HIV and AIDS children who are orphaned and vulnerable against stigma, as well the challenges caregivers undergo during the period of caring for HIV and AIDS children to make them productive and part of the society.

The section is organized in thematic method, through which each objective was reviewed thematically for proper understanding of the phenomenon being studied. The funnel review moves from global to regional, and, then to the local context on each objective.

2.1 Characteristics of Caregivers of HIV and AIDS Vulnerable Orphaned Children

Sociological explanation on illness like HIV and other related issues to it believes that the meaning and experience of such is constructed and shaped by cultural, religious, and social systems (Barkan, 2017). Therefore, caregivers to children with HIV and AIDS around the globe suffer a great burden due to many issues about their conditions in terms of individual and economic characteristics that have a major influence on helping children who are vulnerable orphans due to HIV and AIDS to cope with the stigma (UNAIDS, 2015). Caregivers in Sub-Saharan Africa recorded a higher level of caring challenges to HIV and AIDS children, however many caregivers in Sub-Saharan Africa are too old to look after HIV children, where they need care as well (too). Whereas in the developed countries there is an institution that looks after elderly people, in Sub-Saharan Africa the story is different where the elderly are left with the responsibility of being careers (Osafo, 2017). This is common where in many households, the death of the main breadwinner plunges the family into poverty and leaves grandparents to care for children

(Desai and Potter, 2014). According to UNAIDS 2016, the majority of the caregivers of HIV and AIDS vulnerable orphaned children are looked after by elderly women who lack the necessary skills in supporting them to cope with the stigma and other HIV-related issues. The majority of the caregivers in Sub-Saharan Africa are highly dependent on their siblings in terms of income, shelter, and comfort. Some of them retired and even their pension is not enough to cater for the basic household needs.

Knodel et al, (2000) believe that support of caregiver's particularly older people who are well equipped will help those children in coping with the stigma. In essence, older people play a vital role in looking after people with HIV and AIDS. In Thailand, an older person offers 70% of care to those people infected by HIV. UNAIDS (2006) reports in the same nation show that this could not help these orphans academically as many of these elderly caregivers have a low educational background.

Ntozi and Nakayiwa (1999) in research conducted in six districts of Uganda explained that nearly two-thirds of AIDS patients were looked after by their older parents. Those older parents as HIV caregivers suffered from health and psychological issues, where it also affected them economically as they suffer costs relating to HIV care. Therefore, in that regard non-caregivers to HIV and AIDS do not experience and undergo such difficulties. Hence, there is the need for a longitudinal study of the caregivers for a better understanding of their problem, and the government to intensify their effort in providing ART to be readily available for the HIV patient.

Gloria et al, (2010) studied the socioeconomic differentials between HIV caregivers and non-caregivers among elderly people living in Nairobi city slum, the study shows huge

gaps. According to UN 2009, an adult is a person of around 60 years above, while in Sub–Saharan Africa they are projected at 43 to 44 million and with an expected annual growth rate of 3 to 4%. The living standard of many elderly people had been influenced by the care of orphans and people infected due to HIV and AIDS. This is further exacerbated by the low availability of ART. Only 20% of those in need of a cure in Kenya are on ART.

The emergence of this new role of older people as HIV and AIDS caregivers is arising, especially at the stage of their life course where their economic activity, physical capability, and health. However, it is possible to increase their vulnerability and influence their finances, health is heavily compromised thereby increasing their vulnerability.

Socio-demographic and socio-economic factors of caregivers have a role in patterning HIV and AIDS stigmatization. It is revealed in Maragua district, central province, Kenya that gender, marital status, age, education level, and economic status among others of the HIV positive persons influence internalization of HIV stigma by the children from their caregivers (Kinoti, 2011).

Osafo et al (2017) point out that caregivers of HIV and AIDS in the Niger Delta region of Nigeria were experiencing stress, anxiety, and depression among many issues. Moreover, there is a higher level of stress in caregiving of HIV patients from the caregivers where they require adequate attention to understand and help reduce their stress. Likewise, Bauchi caregivers require the same attention due to their age, gender, and cultural/religious background. According to BASOVCA 2014, caregivers required training to be empowered on issues of HIV and AIDS in Bauchi. HIV children living

with elderly caregivers make them feel alone or lonely. There is a need for a proper plan for institutional-based care, community-based care, and family-based care systems. Such intervention should and ameliorates caregivers' level of care by learning through set policy aiming at eradicating stigma in all spheres by supporting infected children along with their families.

If caregivers could have support, it might help them to cope with the stigma problem children suffered along with their challenges. It means also helps by minimizing the negative effects of the symptoms and to treatment, as well as by minimizing the negative treatment by other people to reduce their impact on their social role and identity, through social rejection (Bradby, 2009).

2.2 Challenges Experienced by Caregivers of HIV and AIDS Vulnerable Orphaned Children to help them cope with stigma

The second objective ascertained the amount of challenges caregivers encounter while helping HIV and AIDS orphaned and vulnerable children.

According to Talcott Parsons (1951), on "sick role" argued that 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 stigma.

In essence, people living with HIV 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.

Family dynamics have affected caregivers on social stigma and discrimination. Because most of the social stigma was widely perpetrated by the immediate family members, due to their reaction on both the caregivers and the children living with HIV/AIDS status with fear, shame, guilt, mocking, and most times threat of suicide. Therefore, the family members' concern is not on the victims, but rather on the shame they brought to the family, fear is contacted with the disease due to ignorance among other factors that extent the social stigma to the society (Atanuriba et al. 2021).

Children with HIV and AIDs suffer an enormous amount of problems due to a lack of proper knowledge and understanding by the caregivers' conditions on how well they can support them (WHO, 2013; Duangkamol & Ankana 2014). Adams (2015) argued that in Africa, most of the caregivers were after the financial support (tipping) given by the international bodies, NGOs, and government. Therefore, it is a problem in caring for HIV and AIDS children, more so those caregivers are not concerned with victims but rather the money was given by donor agencies. Lack of awareness and poor management of HIV at the family level also contribute immensely against fighting stigma. More than 50% of caregivers are elderly women and are more found in Sub-Saharan Africa therefore, is a problem (UNICEF, 2016). In Africa, routine care of the family rests on the shoulders of women. Thereby, caregivers of PLWHA that could not afford hospital

treatment choose to look for spiritual help other than medical or professional treatment from the hospitals to handle the diseases amicably.

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 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; stigmatization and Discrimination, had been tough due to critical economic changes.

In a study by Lucy and Mercy (2015), it is examined that the effect of nutrition on children vulnerable orphaned by HIV and AIDS in Bauchi. It suggested that the failure by caregivers to provide needed food to HIV children has affected their responses to HIV treatment. HIV patient requires food intervention to improve their complete health and nutritional fit to respond to treatment effectively since the caregivers cannot provide. Certainly. It can be achieved especially through government intervention and NGOs as well by inspiring community response and support for caregivers to provide food to HIV and AIDS children for a better life.

Bajaria et al, (2021), show the linkages caregivers encounter, there is a lack of services involvement by the larger society on matters related to HIV/AIDS. While caregivers are a central key in the lives of those HIV children because their capacity could mediate the effect of social stigma. And help in understand fully the plight of those HIV-Positive children, that the policymakers can build on it.

Mills' concept of Sociological Imagination establishes that setbacks pertaining to 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 stigmatized for their

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

2.3 Support needed by Caregivers of HIV and AIDS Vulnerable Orphaned Children to Address Stigma

Objective three (3) shows measures needed by caregivers in their effort with the challenges experienced in helping HIV and AIDS vulnerable orphaned children against stigma in Bauchi metropolitan.

A community approach to disease such as HIV/AIDS will help a long way toward addressing and controlling health challenges experienced by caregivers and HIV/AIDS children encounter, which are entangling to our health care system, coupled with limited resources and corruption to tackle the health needs of the society (Amzat and Razum, 2014). According to Hao and Liu (2015) for almost every 50 people living with HIV and AIDS around the globe, one is Chinese, making it a large universal HIV problem. To them, poor caregiving causes a lot of miseries from the illness on PLWHAs face are enormous which are related to stigma, where caregivers are unable to address.

Stigma makes HIV patients feel socially isolated, depressed, lack self-esteem, denied them looking for social care, health support, and treatment. To them, there is little or no role social networks and media play in supporting caregivers to HIV patients in the level of awareness to properly help them cope with stigma. Social network mechanisms were akin to television, radios, and mobile phones. Its role cannot be overemphasized in addressing stigma by enlightening caregivers' ways and methods in handling issues of stigma (Bradby, 2009).

The connection between the well-being of caregivers and their patients is crucial. Even though the well-being of caregivers could not fully define the well-being of patients, it has been advocated that caregivers' well-being could have an impact on patients' well-being and this may keep caregivers positive and consistently inspired to remain caregiving with the expectation of seeing more development in patients (Kohli et al., 2012). Campbell et al. (2014) observed that many children with HIV are now surviving into adolescence and adulthood due to advancements in medication. Yet HIV remains a serious disease that affects several families because most families never support caregivers of HIV and AIDS patients due to contagious effects and labeling attached to it which affect the psychosocial wellbeing of both caregivers and HIV patients. Furthermore, HIV frequently occurs in the UK and the world through a sexual relationship, pregnancy, delivery, and breastfeeding, etc.; and family serves as the unit in which most HIV children are raised. Thereby, the place they meet their needs both developmentally and medically. Similarly, are affected by the social consequences of HIV, like stigmatization, social exclusion, and lack of support giving to their caregivers.

A study by the Clinton Health Access Initiative in South Africa (2021), reported that for the world to achieve the said target of a generation free of AIDS by 2030 lies on the system and individual effort toward eradicating the epidemic because there is a mixed perception toward AIDS, where the main problem were been ignored and attending the secondary aspect of the disease; like the primary aspect of poverty, education, basic amenities, etc. that would go a long way in tackling the disease.

Empowering the capacity of caregivers as well as protecting and supporting them will go a long way in making them properly and well equipped to support vulnerable orphaned

children by HIV and AIDS against stigma (Osafo et al, 2017). Achema and Ncama (2015) examined the role of Ubuntu as a guiding philosophy that will help caregivers care for children with HIV and AIDS in Nigeria. Based on the African spirit caregiver requires support by all stakeholders and members of the society to help them support children with HIV to cope with stigma. The livelihood among the African people of togetherness can create a tonic setting in creating a sense of belonging and aiding social supportive systems on both caregivers and the HIV and AIDS children. Hence, the collective responsibility of the community can remedy and suppress stigma.

Furthermore, Tshoose (2010) believes the spirit of Ubuntu in the African backgrounds can help caregivers in the care of children living with HIV and AIDS to cope with stigma. Hence, under such, people were taking concrete steps to offer a kind of support and care to whoever needed it. On the other hand, when such a method of Ubuntu is not achieved, then caregivers and families of HIV patients would conceal the status of the HIV child. Thus, it would be a huge challenge for the caregivers, health care system, and society as proper actions to limit the problem of HIV disease spreading and stigma cannot be actualized (WHO/UNICEF, 2010). Achame and Ncama (2015) aim to ascertain caregiving to children living with HIV and AIDS in Nigeria through the said method. Similarly, understand the problem and improve the quality of care using the spirit of Ubuntu among communities could succeed in alleviating difficult times of inadequate resources, economic challenges, rural-urban migration, and changes in family structures for the caregivers.

The spirit of Ubuntu has improved the logic of caring and hospitality by the caregivers for children living with HIV and AIDS in the extended African family. The said method

helps caregivers, nurses, and other stakeholders involved in the care of children infected with HIV and AIDS by embracing or adding Ubuntu as part of medication to caregivers of HIV patients. Bauchi State is taking the same measures to tackle the problems.

To this end, collaboration with international donor agencies (USAID, UNAIDS, etc,) had enhanced the situation of caregivers in Nigeria. Association for reproductive and family health (ARFH) and local non-profit organizations are among the collaborators that help and support caregivers along with the Global Fund Nigeria. ARFH since 1994 had archived a lot on helping caregivers with HIV/OVC through assisting governments to care for vulnerable children through better strategies and improved ways in the support of caregivers to HIV/OVC burden in the country, via training and funding communities to find, locate and protect caregivers and HIV/OVCs and offer both socio-economic support to vulnerable households and make sure that caregivers and HIV/OVC access essential services that include education, vocational training, prevention, treatment, care, psychosocial support, targeted food and nutrition, protection, birth registration, and other means.

Moreover, the international bodies are making sure governments are reviewing their programs to offer effective support to the caregivers of PLWHA by supporting and improving their psychosocial challenges. It may also be important to identify ways they can ameliorate psycho-spiritual challenges for caregivers. In view of their inclination by visiting a spiritual person for those children ailment. This may mean to include the spiritualists by educating them on the danger of HIV and AIDS, and how they can be contained. For instance, through organizing and strengthening community-based

responses, ensuring access to needed services for caregivers, and building the capacity of service providers. (Exavery, et al 2021).

These include the Child Rights Act (2003), which includes the UN Convention on the Rights of the Child and the development of a five year National Action Strategy for caregivers on Orphans and Vulnerable Children by the Federal Ministry for Women Affairs and Social Development (FMWA & SD), 2006). The recent report in 2019 by the Government of Nigeria indicates a significant improvement in national HIV prevalence in Nigeria to 1.4% among adults aged 15–49 years. Such development is significant if compared to the previous scale of 2.8% HIV prevalence. However, improvement is nonetheless needed. UNAIDS and the National Agency for the Control of AIDS showed in 2019 that there used to be about 1.9 million people living with HIV in Nigeria. Comparably, HIV cases among children according to the new data report by NACA is 0.2%. This indicates that major efforts have been made in the past few years to stop new HIV and AIDS infections among children (UNAID, 2019; NACA, 2019).

2.4 Summary of the Gap

Bauchi Metropolitan area has been chosen because the issue of HIV and AIDS stigma seems to have affected caregivers' 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 (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 conducting this study.

2.5 Theoretical framework

In this research, Stigmatization theory By Goffman (1963) and Structuration theory by Giddens (1984) was used as a guide. The reason for using two theories in this research work is to show first how social stigma is been perceive by the society in which it affected not only those been stigmatized along but also people around them like their caregivers, which also would affect the spread of the disease, considering the fact people are looking at HIV/ AIDS patient as a problem to the society, while the theory fails to come up with a solution on how to address such problem of social stigma. While the second theory helps this research work on how the society socially stigmatized HIV/AIDS narratives to change, in such a way the society can come together to fight not only HIV social stigma, but rather the disease and other related matters bedeviling the society on HIV/AIDS.

Stigma theory was developed by sociologist Goffman (1963) is widely used in the area related to stigma. He (Goffman) defined stigma as a profoundly discreditable attribute that could lead a person to be deemed almost sub-human. He also identified three types of stigma: abominations of the body, blemishes of individual character, and tribal stigmas. Abominations of the body are stigmas associated with physical deformations or

deviations from a social norm, such as people with physical challenges, missing limbs, or physical deformities, among others. Blemishes of individual character are stigmas associated with a person's character, identity, or simply his or her particular way of being. Some of these blemishes can be attributed to people in jail, drug users, alcoholics, and people with poor mental health, among others. Tribal stigmas on the other hand refer to the negative evaluation of particular persons because of their association with a given group. Some of these stigmas are related to race, ethnicity, and sexual preference. All of these types of stigma can contribute to the devaluation of people who manifest them.

Therefore, in this study, the theory will help in explaining the stigma surrounding HIV and AIDS in Bauchi Metropolis, considering the settings of people in the area. This study has used "Abominations of the body stigma" to explain how HIV and AIDS patients are stigmatized due to their status, while the nature of the disease is contagious meaning people distance themselves from such category of children.

This study also utilized structuration theory as advanced by Giddens (1984) to assess the role of caregivers on children living with HIV and AIDS in Bauchi. 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 study understood the need for a collective response to address the issue of stigma. However, the theory can help explain caregivers' situation if the entire society

coming together and change the attitude (narratives) of stigma to help caregivers support children with HIV and AIDS.

This theory's application on the study for caregiving is that even if an individual would turn down care for family members or relative's patients, the standing social arrangement within the African setting of homogeneous (Ubuntu spirit) collectivity makes pro-social behavior from family members, regardless of real trauma and problems. In several scopes of African culture, particularly in the family sphere, an individual's problem is a collective problem. Thus, both the immediate and extended family members will more often than not rally all over the place to offer social support and care for the member of their family 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.

2.6 Conceptual framework

A conceptual framework is the understanding of how variables under study connect. It shows the variable conceived in the study, to assist a researcher to develop awareness and understanding of the phenomenon under study (Mugenda & Mugenda 2008). This study looked into the role of caregivers are dealing with children who are living with HIV and AIDS to cope with stigma. The conceptual framework below represents how the variables interrelate in this study.

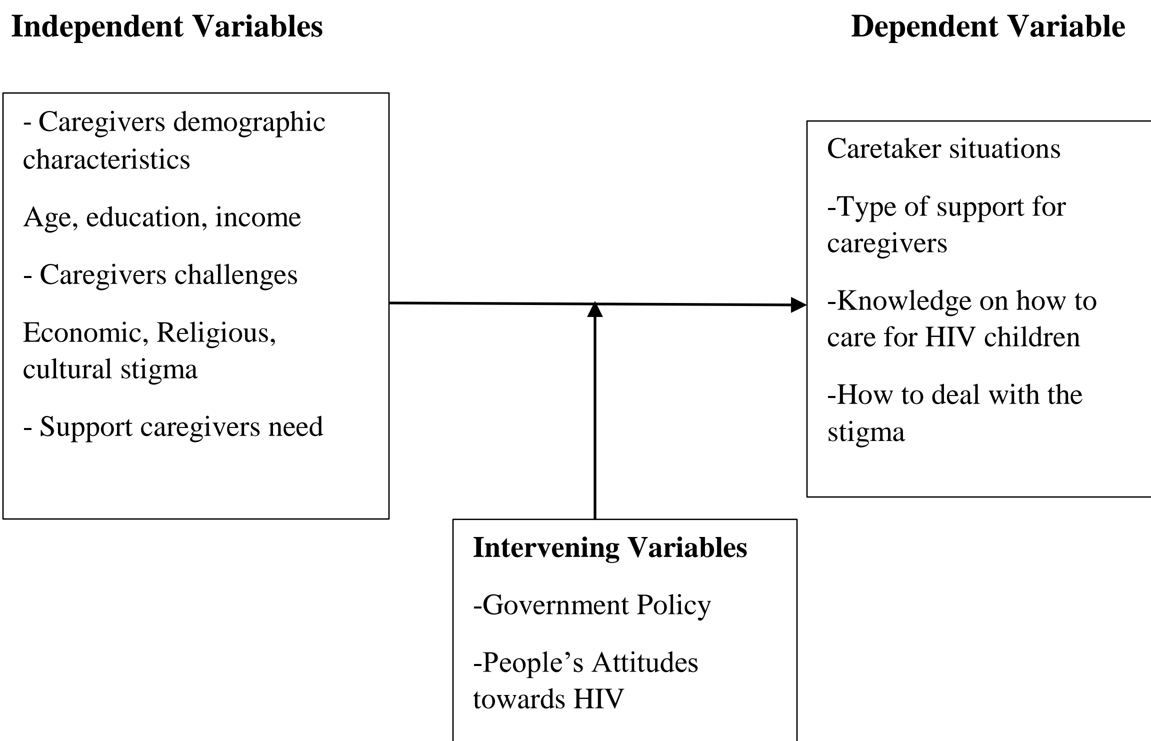

Figure 2.1 Conceptual framework

The above diagram shows the interaction between the dependent and independent variables. The study focuses on caregivers' individual and economic characteristics such as age, gender, cultural setting, religion, occupation, and income among others, also to understand the characteristics of the factors that might cause, along with the little effort those caregivers are offering that needed improvement or adjustment. While the dependent variables are the situation of caregivers in terms of their capacity in handling stigma to children vulnerable orphaned living with HIV and AIDS. The intervening variables constitute factors including traditional institution, NACA, BACATMA, and BASOVCA, the WHO and UNICEF, etc. caretaker situation is the dependent variable. While the independent variables include caregivers' characteristics, as well as the caregiver's challenges. The intervening variables are seen to significantly influence the dependent variable.

CHAPTER THREE

RESEARCH METHODOLOGY

3.0 Introduction

This chapter covers research design, area of study, research population, and sample elements, data collecting tools, and analysis strategy and analyzing it to explain their predicament.

3.1 Research Design

This study adopted a descriptive cross-sectional design with mixed methods. The study answered the questions of who, what, when, where, and how issues associated with the situation of caregivers in Bauchi (sub-county) Metropolitan, Nigeria in helping vulnerable orphaned children to cope with HIV and AIDS stigma.

The strength of the descriptive design is that it yields rich data that leads to useful study commendations. Furthermore, this approach allows the collection of a large amount of data that enable detailed analysis. Moreover, descriptive research may bring out some important variables that could be subjected to further quantitative analysis. Because the study was conducted at one point in time, a cross-sectional survey was best suited because it examined the relationships between variables at one moment in time.

This study used a mixed-method approach in data collection. Both quantitative and qualitative approaches are employed. The quantitative techniques e.g. Key informants enabled a deeper understanding of the predicament of the caregivers of HIV/AIDS-affected children in Bauchi.

A descriptive survey was purely descriptive and used to examine the predicament of caregivers of children affected by HIV and AIDS stigma (Bryman, 2012). The adoption

of mixed-method could help strengthen the credibility and complement the weakness of one method by the other, thereby; ensuring the two methods help to minimize error in the study (Creswell, 2009).

3.2 Study site

The study was carried out in the Bauchi metropolis area of Bauchi L.G.A (sub-county) Bauchi State (county), Nigeria. Bauchi Metropolis consists of five (5) wards: Dankade, Dan Amar, Hardo, Dawaki, and Makama wards. The area has been chosen because it has a higher rate of about 4% of HIV and AIDs in the country as compared to other states with about 2% (BASOVCA, 2018). In addition, Bauchi Metropolis is the most densely populated city in Bauchi State according to census 2006.

Bauchi Local Government Area (L.G.A), a sub-county in Bauchi State, Nigeria, has 3,687 square kilometers of landmass, representing about 5.3% total landmass in Bauchi State, Nigeria. Bauchi State (county) is located in the North-Eastern region of the country with 20 Local Government areas (sub-counties). Bauchi Local Government (sub-county) has a total population of 493,810 (National Population Commission. Census, 2006). It shares boundaries with Toro L.G.A from the West, Ganjuwa L.G.A from the North, Darazo L.G.A from the Eastern part, Dass L.G.A from the Southern part, and Alkaleri L.G.A from the North/Eastern part of Bauchi State. Although there is a presence of a Christian population, Bauchi L.G.A is predominantly Muslim. More than ten (10) different tribes (Hausa, Fulani, Gerawa, Sayawa, Bankalawa, Karekare, Guddarawa, Angasawa, Jarawa, and Kir-Balar) are found in the city.

Bauchi is a tourism state having Yankari Game reserve (wildlife and historical monument), people across the country and abroad come to Yankari Game reserve. However, the rate of HIV is less compared to other states like Akwa Ibom with about 29% of the Nigerian HIV cases, while Bauchi is 4% and there are studies unlike other high cases of HIV and AIDS. However, the rate of stigma is higher compared to other parts of the country due to cultural and religious ties. See Figure 1.2 a, b, c which are the maps of Africa, Nigeria, and Bauchi State for details of the location of the domain.

Map of Africa

Bauchi State

Map of Bauchi

Bauchi Metropolitan

3.3 Target Population

The population is the total universe units from which a sample is to be selected. The study targeted caregivers of vulnerable orphaned children with HIV and AIDS in Bauchi Metropolis. According to BASOVCA (2018) caregivers of children, vulnerable orphaned by HIV and AIDS are 218. Therefore, the study used the figures given by BASOVCA to base the research on this population with a view to generalize findings. BASOVCA helped in identifying the sampling frame, caregivers of children with HIV and AIDS vulnerable orphaned. The study also targets NGOs and government agencies working with HIV and AIDS vulnerable orphaned in Bauchi metropolis (sub-county) served as units of the population.

3.4 Sample Size

The sample size for this study is based on the developed sampling frame of caregivers got from BASOVCA. It was determined using Krejcie and Morgan's (1970) formula. The population of 218 caregivers is from the population of 218 caregivers, a sample of 136 respondents was selected for representation. The sample was chosen from the target population and it had been divided into five wards within Bauchi Metropolis. The sample-size adopted computation formula developed by Krejcie and Morgan (1970). The following formula is:

$$S = \frac{X^2 NP(1-P)}{d^2(N-1) + X^2 P(1-P)}$$

Table 3.1 Sample size

TABLE FOR DETERMINING SAMPLE SIZE FROM A GIVEN POPULATION

N	S	N	S	N	S	N	S	N	S
10	10	100	80	280	162	800	260	2800	338
15	14	110	86	290	165	850	265	3000	341
20	19	120	92	300	169	900	269	3500	246
25	24	130	97	320	175	950	274	4000	351
30	28	140	103	340	181	1000	278	4500	351
35	32	150	108	360	186	1100	285	5000	357
40	36	160	113	380	181	1200	291	6000	361
45	40	180	118	400	196	1300	297	7000	364
50	44	190	123	420	201	1400	302	8000	367
55	48	200	127	440	205	1500	306	9000	368
60	52	210	132	460	210	1600	310	10000	373
65	56	220	136	480	214	1700	313	15000	375
70	59	230	140	500	217	1800	317	20000	377
75	63	240	144	550	225	1900	320	30000	379
80	66	250	148	600	234	2000	322	40000	380
85	70	260	152	650	242	2200	327	50000	381
90	73	270	155	700	248	2400	331	75000	382
95	76	270	159	750	256	2600	335	100000	384

Note: "N" is population size
"S" is sample size.

Krejcie, Robert V., Morgan, Daryle W., "Determining Sample Size for Research Activities", Educational and Psychological Measurement, 1970.

Solution

$$S = \frac{(1.96)^2 \times 210 \times 0.5(1-0.5)}{(0.05)^2(210-1) + (1.96)^2 \times 0.5(10.5)}$$

$$S = \frac{3.8416 \times 210 \times 0.5}{0.0025 \times 209 + 3.8416 \times 0.25}$$

$$S = \frac{201.684}{1.4829}$$

S=136

Table 3.2: Research population, sample element, and selected area

	Population	**Total Sample**
Caregivers	218	136
Total	**218**	**136**

Source (BACATMA, 2018).

While five (5) key informants were used for the study: three (3) from government agencies; and two (2) from NGOs dealing with caregivers and HIV and AIDS orphaned and vulnerable children in Bauchi Metropolitan using Marshall M.N 1996 technique. Key informants can start from 3 and above (Marshall M.N, 1996).

3.5 Sampling Design

This study adopts both probability sampling and non-probability sampling. For probability sampling, the research used cluster sampling and simple random sampling. For non-probability sampling, Purposive sampling was used. Random sampling is a technique where every item in the population has an even chance and likelihood of being selected in the sample. Purposive Sampling helps a researcher to study a certain cultural domain with a knowledgeable expert within a given area (Creswell, 2009).

Bauchi Metropolis consists of five (5) wards: Dankade, Dan Amar, Hardo, Dawaki, and Makama wards. Each ward was treated as a cluster in this study and therefore all the wards were used to generate the study sample. Cluster sampling is a probability sampling technique where a researcher divides a population into smaller groups known as clusters. They then randomly select among these clusters to form a sample.

After getting the sample size of 136 using Krejcie and Morgan’s (1970) formula, the researcher sought to get a proposition of respondents from each of the five wards in Bauchi Metropolis. This was to ensure equal representation. See table 8.

Table 3.3: Number of Selected Riders per PPS Cluster

Ward PPS (Cluster)	**PPS cluster population of caregivers**	**Proportion/sampl e weight %**	**Selected caregivers per PPS cluster**
Dankade	54	25%	34
Dan Amar	43	20%	27
Hardo	37	17%	23
Dawaki	51	23%	32
Makama	33	15%	21
Total	**218**	100%	**136**

Source: Author

The population of each probability proportional to size (PPS) on the cluster was divided by the total cluster population of 218 multiplied by the sample size of 136. For example, the PPS Cluster of Dankade (ward) was calculated as 54/218x136=34. So out of the 54 caregivers found in Dankade, 34 were sampled using simple random sampling. This was 25 percent of the 136 samples. The list of caregivers provided by (BACATMA, 2018) was used in sampling the final individual respondent. For example, Makama had 33 caregivers; out of this 15% were to be sampled (See table 3.3). This meant that 21 caregivers were sampled from 33 in Makama using simple random sampling.

This was done for all the five (5) wards in Bauchi Metropolis. Simple random sampling to get the respondents was done using a table of random numbers. This meant that each case had an equal probability of being selected.

Purposive sampling was used for Key informants from representatives of NGOs and Government agencies that were interview to supplement the interviews. The study had five key informants. Two key informants were from BASOVCA one from BACATMA, one from the Ministry of Health one from Rahama Foundation (an NGO working).

3.6 Pilot Study The

A pilot study allows the researcher to determine the adequacy of instructions to interviewers, or respondents completing a self-completion questionnaire (Bryman, 2012). For this study, a pilot study was carried out as a pretest to check the validity and reliability of the research instruments. Ten respondents from caregivers of HIV and AIDS vulnerable orphaned children were used for the pilot study. This has helped the research corrected some grammatical and wording issues that helped instruments from eliciting wrong interpretations or misinterpretations from the respondents. Besides, it helped the study to check the consistency of the results of the research instruments. The pilot study helped the research identified lapses and made improvements and corrections on the construction of the research instruments. It was carried out in Bauchi Metropolis.

3.7 Validity and Reliability

Validity and reliability of the findings were carried out. Content validity helped measure the instrument by covering all the attributes of the concepts of the research measure. The supervisor guided the entire process. The questionnaire and interview questions were constructed and reviewed according to the instruction of the supervisor.

To test the reliability of the instruments, the researcher used a test-retest method. Moreover, those ten pilot studies were the leaders of the five wards understudy, while this research also used research assistants in data collection. They were well trained on both research procedures and data collection tools.

3.8 Research Instruments

Both primary and secondary data were collected in the research. Primary data were collected using questionnaires for caregivers and key informant interview guides for the key informants. While secondary data were sourced from existing literature including books, journals, publications, among other sources.

This research sourced data through the administration of questionnaires to caregivers of children orphaned and vulnerable by HIV and AIDS on primary data. More so, structured interviews were conducted on the key staff of BASOVCA and other related agencies. While for secondary data, journals, publications, and other statistical records from relevant agencies were used.

3.8.1 Questionnaire

Data were collected through self-administered questionnaires that included closed-ended 5 points Likert scale method ranging from '1' as strongly disagree (SD), '2' as disagree (DA), '3' neutral (N), '4' as agree (A), '5' as strongly agree (SA). The Likert scale has the advantage of making it easy for a researcher to construct and administer the scale and the statement of the questions to make the respondents understand it so easily, and the scale is deemed then to measure the intensity with which respondents feel about an issue (Malhotra, 1994; Bryman, 2012). Yes and No questions, open-ended questions, and boxes to tick the appropriate options were used. Caregivers of children with HIV and AIDS answered questionnaires that were easy to understand and respond to.

3.8.2 Structured interviews

Key staff members are participants from whom data were collected through a well-structured interview to ascertain information could not have from caregivers. Interviews guard against confusing the questions since the interviewer can clarify the questions thereby helping the respondent give relevant responses (Mugenda & Muganda, 2013).

3.9 Data Analysis Procedure

The questionnaire had open and closed-ended questions that generated both qualitative and was qualitative data. Quantitative data was analyzed using Statistical Package for Social Science (SPSS) to produce descriptive statistics such as means, frequencies, and percentages. While information from interviews and open-ended questions was summarized thematically and coded for analysis using NVivo software.

3.10 Data Management and Ethical Consideration:

The research was conducted following ethical principles. All sources of data were acknowledged; consent was sought from the participants and their rights were respected; confidentiality and anonymity were ensured and the purpose and intention of the research were explained. Approval was given from Kenyatta University for data collection and a research permit was obtained for identification from the Bauchi State Ministry of Health. Copies of the approval and permit were attached in the reference section (appendix).

CHAPTER FOUR

DATA PRESENTATION AND ANALYSIS

4.1 Introduction

This chapter presents the findings obtained from data collected through questionnaires from caregivers of children living with HIV and AIDs in Bauchi Metropolis. However, key informants also provided information through interviews that complemented the outcomes of the questionnaires. The findings are discussed based on an analysis of quantitative and qualitative data collected. In this chapter, data obtained through a structured questionnaire to caregivers were subjected to statistical analysis using Statistical Package for Social Sciences (SPSS 22.0). Interviews were first transcribed using NVIVO and analyzed thematically. The findings of this study are presented in the form of figures, tables, and graphs based on the set objectives of the study.

Therefore, findings regarding the first specific objective reflected whether or not caregivers' characteristics would have an impact in helping children living with HIV and AIDS. The second specific objective ascertained the challenges faced by caregivers in handling issues of stigma encountered by HIV and AIDS vulnerable orphaned children. Lastly, the third objective focused on caregivers needed support to better care and handle issues of stigmatizations HIV children suffered.

4.2 Demographic characteristics of the caregivers of HIV children (profile of caregivers)

Objective one of this study sought to find out the profile caregivers of HIV and AIDS vulnerable orphaned children in Bauchi Metropolitan. This included the caregivers'

demographic information and characteristics on gender, age, religious affiliation, ethnic group, educational level, and occupation. See table 4.1,

Table 4.1: 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
Religious affiliation		
Christianity	51	37.0
Islam	80	59.4
Others	5	3.6
Totals	136	100
Ethnic group		
Hausa	37	26.8
Fulani	26	18.8
Gerawa	24	18.1
Sayawa	23	17.4
Others	26	18.8
Totals	136	100
Education level		
Primary	12	9.4
Secondary	50	36.2
Tertiary	41	29.7
Others	33	24.6
Total	136	100
Income per month		
0 = 5000($140)		
5000 = 20000($560)	31	23.2
20000 = 50000($1,390)	20	15.2
50000 and above	2	1.4
No idea/no income	1	0.7
Total	136	40.5
Duration (years)	Frequency (n = 138)	Percent
1 = 5	41	30.4
6 = 10	58	42.8
11 = 15	33	23.9
16 = 20	4	2.9
Total	136	100

Gender of Respondent

The study found that on gender, the majority (84.1%) of the caregivers were females while only 15.9% of the respondents (caregivers) were male. This result was expected because of the African culture where women are mostly the ones who take up the roles of caregivers 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).

Structuration theory by Giddens asserted that cohesion within the society is significant in achieving any goal. Having more females than males shows that those children will have better support to cope with stigma once they have the necessary skills (Osafo, 2017). The results from key informants agreed that the majority of the caregivers were female in Bauchi Metropolitan, Nigeria.

Key informants (KII) said that most of the caregivers of HIV children in Bauchi were female of middle age, who are either full-time housewives or retirees. However, the KII believes that female caregivers take good care of children with HIV particularly in our society (KII-01, 02, 04, 05).

Age of respondent

The caregivers were mainly in the age bracket of 31 – 65 years (49.3%). While 32.6% were aged between 18 – 30 years old and only 18.1% were 66 and above. 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.

The above 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. Osafo et al., (2017) point that caregivers experience mental stress coupled with anxiety, depression among others as a result of taking up the caregiver role for HIV and AIDS children. The study, therefore, shows the need for more support for these caregivers from family, community, and institutional base systems. This will go a long way in ensuring that the caregivers are in a good state both physically and psychologically to adequately support children.

Religion of Respondent

On the religion of the caregivers, the study found that the majority of the caregivers (59.4%) were Muslims. Christians accounted for 37.0% whereas other religions were 3.6% of the total 136 caregivers. The result shows that majority of the patients and caregivers are Muslim. This is consistent with the demographic data of the Bauchi metropolis that shows the predominance of Muslim dwellers. However, both Islam and Christian religions see HIV and AIDS as 'tests' from Allah. But the religions allowed for support and ART intake because both religions believe no disease has no cure (Balogun, 2010). Structuration theory by Giddens opined that behaviors and structures are intertwined. Therefore, religious teaching and Ubuntu spirit would help caregivers support children living with HIV and AIDS victims.

Respondents Ethnic Group

The caregivers belonged mainly to four ethnic groups (Hausa, Fulani, Gerewa, and Sayawa). Many (26.8%) of them belonged to the Hausa group while the others were; Fulani (18.8%), Gerawa (18.1%), and Sayawa (17.4%). The majority of the affected tribe

were Hausa, and Fulani, who have the highest population in the study area. It suggests that they were most affected due to their number as the study has shown. Although caregivers from all across ethnic groups were affected by the stigmatization.

Educational Level of Respondents

The study results indicate that all caregivers had some level of education. A significant portion of the caregivers (36.2%) had secondary education while 29.7% had tertiary education and 9.4% had primary education. Education is an important factor that largely influences knowledge as well as social status. In addition, there is no indication that the caregivers have specialized education as caregivers of HIV and AIDS children. To take care of these vulnerable children facing stigma and discrimination, the caregivers need to be trained to cope. 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 stigma (UNAIDS, 2018).

Therefore, caregivers with low levels of education who were the majority in the study faced more difficulties on how to help children cope with HIV and AIDS stigma.

A KII respondent from the RAHAMA foundation revealed that the majority of the caregiver's most affected families had low levels of education, where they prepare local medication (traditional) to cure ailment (KII-01, 05).

According to Osafo et al., (2017) caregivers need to be empowered to properly support vulnerable orphaned children by HIV and AIDS against stigma. Also, Knodel et al., (2000) believe that the role of caregivers particularly older people who are well equipped (through training) will help those children in coping with the stigma.

Income of Respondents

The caregivers were mainly low-income earners with 59.0% of the caregivers having an income of NGN5000 or less ($140). Fewer of the caregivers (1.4%) had a monthly income of Naira NGN50000 ($140) and above as indicated in table 4.1. Such low income does not incentivize them to dedicate their energies to caregiving.

A KII respondent from the Ministry of Health and Social Development explained that most of the caregivers are dependent. However, caregivers are being trained to be productive rather than being dependent, by empowering them with other businesses (KII-05, 05).

The effort of NACA, various state agencies on HIV and AIDS control, BACATMA as the case may be in Bauchi and International donor agencies such as the Global Fund, USAID, and UNAIDS among others had made major donations to support caregiver and OVC problem in Africa and Nigeria. Similarly, the association for reproductive and family health (ARFH) and local non-profit organizations were part of the working team to address these issues. The study also revealed that caregivers were either dependent that needed interventions or had less than what could cater for the HIV children's challenges.

Duration of Caregiving

Table 4.1 above indicates that the majority (73.1%) of the caregivers have provided care for HIV children for a period between 1 to 10 years. On average, therefore, caregivers have provided 8 years of care. The report shows that caregiver's average number of years in supporting those children could provide them with practical experience, but to Chinedu (2014), many caregivers have that zeal and firmness to support and care for HIV and AIDS orphaned and vulnerable children, but they lack the appropriate skills and

knowledge to help them cope with stigma. However, many caregivers in sub-Saharan Africa needed care too (UNAIDS, 2015). The finding suggests that the majority of the caregivers require sensitizations and enlightenment because despite years of care stigma still exists and affect the children.

Occupation of Caregivers

The study results indicate that most of the caregivers were having other occupations that were not business, farming nor employment and. Some of the respondents were on employment. The result has indicated that most of those caregivers are either unemployed or full-time housewives which are dependent on their husbands to provide.

Caregivers were highly dependent, they got their support from either families or the government. They were always at home which is an indication that most of them were not in gainful employment and a few had already retired and their pension was not enough to cater for domestic needs as well as that of children they were taking care of (KII-01, 04, 05).

The finding is consistent with UNAIDS (2016), which found that the majority of those caregivers to vulnerable orphaned children are highly dependent on their siblings in terms of income, shelter, and comfort. The study also revealed that some of them retired and even their pension was not enough to cater for the household needs including health issues like HIV and AIDS.

In conclusion, the study found that a caregiver is likely to be female, between 31-65 years of age, and a Muslim with low education levels. The caretaker is therefore likely to be a low-income earner or unemployed and would have worked for an average of 8 years as a caretaker of children orphaned due to HIV and aids.

4.3 Challenges faced by caregivers of HIV and AIDS vulnerable orphaned children in Bauchi Metropolitan

The second objective in this study sought to establish challenges caregivers encountered in the course of taking care of children who are HIV and AIDS carriers. The study identified four areas that put the caregivers in a predicament as they took care of these children. These four areas were from; close family members, from members from the larger society (culture), from religious groups, from the local authority or government, and finally from health facilities.

4.3.1 Difficulties Suffered in Handling the Children Living with HIV and AIDS from close Family Members

This question focused on the difficulties caregivers suffered along with the HIV and AIDS children. The study result indicated that the caregivers, as well as the HIV children, suffered mainly from poverty and discrimination

Poverty is among the problems hindering caregivers' efforts in taking care of HIV children from close family members. Poverty made it difficult for caregivers to buy nutritional food, clothes, and medicine, in case the child was suffering from other diseases apart from HIV and AIDS where they were getting the drugs (ARV) free of charge. Most of the family members in the study were poor. Therefore, they could not provide for their needs of supporting the child against his condition. Lack of support from other family members further exacerbates such a situation. From the demographic characteristics (see table 4.1) the study found that most caregivers (59.0%) as low-income earners with caregivers having an income of NGN5000 or less ($140). There was also an

indication that for those who had retired, they had hardly enough for basic needs and medication.

This, therefore, puts the caregivers in a predicament that could lead to stress and therefore psychological problems.

Due to poverty, the caregivers lacked the know-how to effectively deal with/take care of the children living with HIV and AIDS. In addition, most of their family members did not know how to take care of HIV patients. This made it difficult for them to deal with the situation at hand. The caregivers were not optimistic because they knew HIV had no cure and yet they have to take care of these children. Due to lack of knowledge, they thought they were also in danger of being infected because they eat together, play, stay in the same room with the patient. Not knowing that it can only be transmitted through blood, by use of needle, sharp object used by the patient that contained blood on it.

Discrimination is among the challenges caregivers and children with HIV and AIDS suffer from a close family member. Family is where every person gets his/her comfort physically, emotionally, psychologically; but when the ties are distant just because of one's condition (health) all hopes will be gone knowing fully well that when family rejected the child then the whole society will as well turn down on them too. Sometimes they are called names like dead, liability, "you bring shame to the family" and many others. Occasionally the affected children are separated from others in the playing ground.

A KII respondent focal officer from BASOVCA laments that"

There is a lack of Cohesion caring for people living with HIV and AIDS in Bauchi. Typically, family members do not want to 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 (KII-04, 05).

Most of the families of children living with HIV may be or may not be sure of how to protect themselves on measures against the fear of transmission. Like measures related to blood contact, bathroom items, kissing/hugging, and food among others (Burton et al., 2008). The mediums of transmission can only be addressed through enlightening or educating them on how HIV transmission and measures on precaution to reduce the risk of the diseases within the family household. Because 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 stigma (Sonia et al, 2015). The study found that most families were ignorant of the HIV and AIDS disease.

The treatment accorded to children living with HIV and AIDS

This question tried to inquire whether caregivers faced challenges, while the caregivers believed that children living with HIV and AIDS are treated differently in the family and community as shown below.

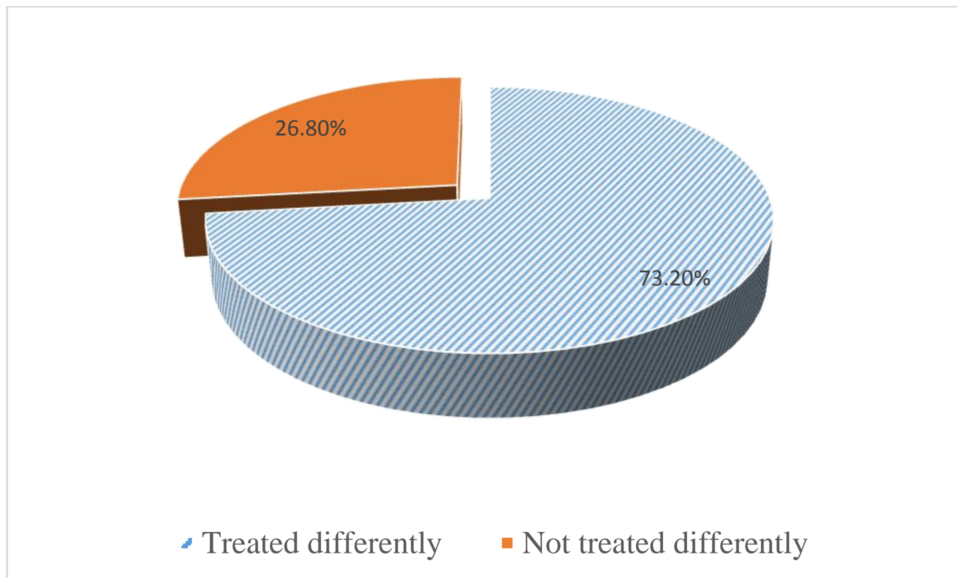

Figure 4.1: Treatment of children living with HIV and AIDS

Caregivers perceived the 73.2% of families, friends, teachers, and religious leaders have treated the children living with HIV negatively due to their HIV status after being disclosed.

A KII respondent believes that caregivers alone cannot handle the issues of care for children living with HIV. They need the intervention of the government and other agencies related to HIV and AIDS to better handle, support, and care for those children's rights against maltreatment from stigmatization and discrimination (KII-03, 05).

This is consistent with Banteyerga et al., (2003), that people living with HIV and AIDS encounter different forms of stigma. To him, issues among the verbal problems experience include scolding, taunting, naming, gossiping, blaming. Physical and social exclusion takes the forms of separation from families and friends, separation, displacement from home, separation of household tools, loss of identity (hide), rights and status were denigrated; and denied access to many resources, such as employment and health care made for everyone. Moreover, it affects the caregivers too by losing focus in supporting those children against stigma. This research also understood that stigma starts right from the family, upward to the community.

4.3.2 Difficulties experienced in Handling the Children Living with HIV and AIDS from Society Members (culture)

This question aimed at understanding how Society perceives HIV and AIDS patients and their caregivers. This is because perception tends to influence a person's attitude towards something. Caregivers were concerned that their HIV children faced a lot of discrimination within the community just like in the family (as already discusses) they had different types of discrimination including being denied playing with their fellow

children of the same age. Similarly, these children could not mingle with others within the community, in some instances, the neighbors constantly toll the affected children to get back home and remain there. Sometimes it was more severe like threatening them with injury if they did not stay home. Hence, out of fear the child would stay at home always. This brought anguish to the caregivers.

Lack of knowledge or ignorance is also another area caregivers expressed concern over the safety and psychological condition of the child. The incurable nature of HIV and the cost of managing it are among the reasons victims are stigmatized in the community. Due to the conservative culture, the caregivers and the infected children are discriminated against. They condemn the disease as taboo and therefore, nobody wants to be associated with the caregiver and the infected child.

In traditional African societies, societal problems were handled collectively or communally but with urbanization and modernization, this aspect has changed. People are becoming more and more individualistic. Because of the lack of togetherness in handling the issue of HIV in society and the stigma associated with it, 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 stigmatization.

The caregivers are concern about how the HIV children are treated because it affects the children psychologically and emotionally. In addition, it affects the children's wellbeing

and socialization and this could affect their trust and productivity. Similarly, caregivers are affected emotionally and psychologically due to the treatment the children they are taking care of go through.

Children's conditions at the community level have been discouraging due to ignorance of HIV and AIDS which causes discrimination by depriving the patients' right to live and move around like any other person (KII-01, 05).

The caregiver's responses shown stigma is alarming on HIV patients. It ruins not only the child and caregivers alone but also the whole community from having a quality life. This is consistent with Goffman's (1963) theory on stigmatization where he explained "Tribal stigma" as the negative evaluation of a particular person's condition because of their association with a given group. Some of these stigmas are related to race, ethnicity, and sexual preference. However, HIV is not left out. The finding revealed that HIV-related stigma has shown a pervasive effect, particularly in the local communities. This is due to disclosure of their status for fear of discrimination.

Reported Cases of discrimination due to stigma by the Children Living with HIV

The question enquired extent of stigmatization of HIV and AIDS carriers reported to caregivers. Table 4.2 indicates the different forms of discrimination due to the stigma that HIV children had to deal with. While these acts lead to anguish among the children, they equally affected their caregivers.

Table 4.2: Forms of Discrimination Reported

Statement	Frequency	Percent
Family separating domestic items (utensils)	97	70.3
Losing friends after disclosing HIV status	101	73.2
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 majority (73.2%) of the Children Living with HIV faced the problem of losing friends. This occurred soon after their HIV statuses were revealed. This act can have adverse effects on a child and on those who are taking care of this child.

Caregivers said losing a friend is an enormous blow to the child particularly in schools, playgrounds, and family friends. About 73.2% agreed and explained how they are able to be there for the child i.e. through emotional and psychological supports offered to the child and making sure that everything is handled so that the child comes to terms with the situation through awareness, and knowing their rights against infringement. Therefore, caregivers comfort the child by monitoring his whereabouts and what the child should do and avoid that would not make him feel the effect of those friends he lost after disclosing HIV status to them. This, therefore, add more burdens to the caregiver compared to if the children had their friends who could comfort them.

The second most reported problem was separating the utensils the HIV children used from the others- this scored 70.3%. This was a clear indication that there was something wrong with them. This was mostly done by family members who did not understand how

HIV is transmitted. Religious leaders rated low in involvement in discrimination with only 2.9% reported. It is only teachers who were reported not to show any form of discriminating the child from participating in activities they would wish to at school

The only way we can avoid stigma is through collective response and sensitizing the public on how HIV can be handled (KII-02, 05).

In line with Badahdah's (2010) findings, stigma causes unfavorable evaluation and treatment of PLWHA as one of the key troubling features of the epidemic. Shame, lack of awareness, and religiosity are among the major factors in predicting the stigmatization of individuals with HIV and AIDS. Stigmatization of HIV and AIDS can increase the ground for the spread of the epidemic. This is manifested in patients not attending tests, and also being aware of how to live with the disease (Pinar, 2015). There is, therefore, a need to be taken to tackle issues of HIV stigma and spreading the disease.

4.3.3 Society's View of Children Living with HIV and AIDS

It was important to understand how society viewed HIV and AIDS children living within their surroundings. In general, society views children living with HIV and AIDS as contagious, only staying away from children living with HIV and AIDS is the best option if not to be infected. Key informant information shows that establishing institutions may not help in reducing stigma.

"Establishing an institution might not help against stigmatization, but rather increase the amount because setting an institution could identify them and show that HIV and AIDS is a disease that patient needs to be quarantined. The public will stigmatize them, but if they

are allowed to intermingle. The public will see that HIV and AIDS are like any other diseases that require only little measures and control to be able to live with the disease (KII-01, 05).

4.3.4 Difficulties Suffered in Handling the Children Living with HIV and AIDS from Religious Groups

This question sought to explore the challenges caregivers experienced along with the HIV and AIDS children taken care up from religious groups. Contrary to what one would expect, religious groups have been key in promoting stigmatization because most of the religious have poor leadership skills. These leaders fail to encourage acceptance, generosity, and charity to the needy. From the demographic characteristics in this study, the majority (84%) are Muslims and one would think that they would embrace those in suffering. The Quran encourages brotherhood in 49:10 it says *"the believers are but brothers, so make settlements between your brothers. And fear Allah that you may receive mercy".* This means that the religious bodies do not regard the HIV-affected caregivers and children as 'brothers'.

Religious leaders also paint the epidemic as a curse from wrongdoings. Because of this, the patient or their parent as the case may be for the children that led to their condition and they should only blame themselves not the God or religious group and leaders. This has therefore exacerbated stigmatization by making it difficult for caregivers to care for those children living with HIV and AIDS. Spiritual support is key for caregivers to help HIV and AIDS children to cope with stigma.

Another problem experienced by caregivers is the lack of unity among the different religious groups. One religious group will encourage support to such a category of people while the other will condemn it totally which has created a gap because nothing can be achieved without cohesion and understanding. Lack of tolerance among the religious groups has created a vacuum that such kind of issue could not be addressed amicably. Thus, there is the need for different religious groups to come together in pursuing a lasting solution to the menace.

Caregivers believe there is a need for those religious leaders from various religious groups to be trained on the danger of HIV and AIDS and how it is transmitted. This could be handled by showing them the problem and if it is not contained holistically, the problem that lies ahead could not be addressed. Such a measure could benefit the whole society.

Caregivers revealed that religious groups and religious leaders are not taking any concrete steps to help fight out stigma. UNICEF (2013), reports that religious bodies failed to contribute against stigma because they may have the impression that getting infected with the disease is a punishment for the 'sinful' behavior, due to having sexual relations either before marriage or being unfaithful to marriage partners as well-behaving in other ways that contradict certain religious teachings.

While it is a belief that religious groups are in a better position to alter the course of the epidemic because they hold a power that can shape social values, they can also promote responsible behavior that respects the dignity of all persons and defends the sanctity of

life, helps public with divine knowledge, encourage charity for spiritual and social care and promoting action from the grassroots (UNICEF, 2003). If such and many more can be harnessed from the religious group the issue of stigmatization and discrimination could be wiped out. The research, however, shows that religious groups contribute seriously to stigmatizations.

4.3.5 Difficulties Suffered in Handling the Children Living with HIV and AIDS from Local Authority/ Government

This question highlighted areas that were challenging to the caregiver and HIV children they were taking care of. There is a lack of legal backing from the government or the authorities concerned about HIV and AIDS. While existing laws provide protections for the rights of the children, the practice among community members is in sustained violation of such laws. Hence, a discrepancy between policy and actions. Some caregivers are appealing to the authorities concerned to have a body that will protect the right of HIV and AIDS person and their caregivers to stop stigmatization.

To a caregiver, the government is not doing enough to stop or reduce stigma. The interventions offered by the government are things even the caregivers can provide to the HIV child. However, on different occasions, the caregivers said they heard from the media that certain relief or supports was given to caregivers from the government, but to them, nothing was given. Therefore, to them, agencies either siphoned the said assistance or it is propaganda by the government in helping caregivers and people with HIV and AIDS in Bauchi.

Furthermore, there is a lack of proper record keeping from the agencies related to HIV and AIDS in Bauchi. Interventions by the government are usually not sufficient. Similarly, the workers are incompetent or they do not want to keep a record that is not realistic, whereby they cannot justify it. They believe there is some form of corruption or mismanagement going on.

Owing to the ineffectiveness of the agencies involved to address the matter, the involvement of stakeholders is necessary. The caregivers have indicated willingness to participate in identifying the depth of the problem as well as possible solutions.

Caregivers believe government and local authorities like traditional rulers are intervening, but it is not enough to address the issue of stigma and discrimination within the society. More efforts need to be made if they want to address stigma. The key informant explanation put it in perspective.

"The Government has intervened in many areas for caregivers of HIV and AIDS children by collaborating with NGOs and other international bodies on HIV and AIDS, governments provide support like vocational skill, food, and nutritional support, areas of health by giving ARV free for the child and caregivers household economic support and child protection, as well as psychological support" (KII-01 to 05).

UNAIDS (2015), explained that for any government to achieve their target, they should be reviewing their programs to offer effective support to the caregivers of PLWHA by supporting and improving their psychosocial challenges. However, it may also be important to identify ways they can ameliorate psycho-spiritual conditions for caregivers. Given their inclination for visiting a spiritual person seeking help from God, instead of

from medical practitioners, psychologists, and counselors. There is the need to include spiritualists in sensitization.

Although there are claims that the government has intervened in supporting the children with HIV the caregivers still complain about their support in this issue. This shows there is a missing link between the government and the caregivers. The government is said to be doing something about HIV but the caretakers claim that the government is not doing much. UNAIDS (2016), reported showing concern over the right and support of children with HIV and their caregivers. They are making sure through reaffirming commitment to end the HIV and AIDS epidemic. Because so many programs were initiated, yet they did not achieve the target result.

Duangkamol and Ankana (2014), Adams (2015), argued that in Africa, most of the caregivers and personnel working with the NGOs and other relevant agencies on HIV and AIDS are not fully equipped to deal with all the HIV cases due to funding problems. This, therefore, leaves the families with a big burden on taking care of all the expenses that come with this situation. Caregivers' responses revealed that the government had failed in supporting (help) caregivers of children living with HIV and AIDS.

In view of the above, the local government needs to involve traditional leaders in the act of sensitizing the general public, because their voice is highly respected and taken seriously. To caregivers, stigma can also be tackled if traditional rulers understand HIV and AIDS and how to handle issues related to the disease would help a long way to

caregivers by helping children cope with the stigma. The effect of stigma could reduce to the barest level, whereby the issue of HIV and AIDS can be handled effectively.

4.3.6 Difficulties Suffered in Handling the Children Living with HIV and AIDS from Health Facilities

The study results show that caregivers of children living with HIV and AIDS experienced challenges in helping HIV-infected children cope and handle issues of stigma from the health sector.

These challenges were due to unqualified workers particularly about issues relating to HIV and AIDS. They lacked manpower in the hospital and clinics which hinders fast services, management skills are also not sufficient through the division of services in the clinics by providing sections and sessions for HIV patients. However, most of the staff lacked a positive attitude towards HIV patients (children) this discouraged caregivers in seeking these significant services for the children.

Furthermore, the caregivers reported that health workers lack the edge in counseling caregivers and their HIV-infected children. They give ARV and could not advise caregivers on how to keep the drugs at home safe. Moreover, what food HIV patients should be taking to help them maintain a balanced diet (nutrition), as well as to advise caregivers on hygienic ways of life at home to keep the child against other related illnesses.

Caregivers reported facing proximity challenges. Most of the health centers that gave ARV were far away. Due to the lack of money for fare and as a result of poverty they are

found it difficult transporting the child to collect the ARV and other checkups. In addition, due to poor coordination, ARV drugs do not reach caregivers, sometimes the ARV drugs are finished while caregivers cannot afford the drugs and the child develops some complications that lead to sickness. Moreover, services particularly in the clinics are not run on 24 hours basis in case of emergency.

Moreover, most of the health centers did not have the necessary facilities to cater for even minor services like blood tests, malaria, and typhoid fever, among other diseases that require simple processes and prompt action. The structures are dilapidated and caregivers are concerned that whenever they took the child to the health center they were asked about their medical history meaning there is poor record-keeping on patients at some point.

In summary, some of the major challenges reported by caregivers were lack of counseling, drug availability, and having qualified doctors or medical personnel as well as proximity issues that seriously affect them. According to WHO (2010), among the major problems suffered by HIV children was malnutrition. In addition, Ifitezue and Sosanya (2015) point out that lack of proper nutrition affects children's growth and development more especially for children with HIV and AIDS. Food intervention to improve their health and nutrition will be an important step. It is understood that caregivers cannot be able to handle the issue of caring for those children alone due to a lack of finances and knowledge. They require professional advice on how to support those children in all areas of life. The finding shows that the health sector is either poorly funded or manage.

4.3.7 Treatment of Children Living with HIV

In trying to find out how HIV-positive children were treated by different categories of people in society, the study found that caregivers reported that the children were generally treated negatively. Table 4.3 shows the treatment of children with HIV.

Table 4.3: Opinion of Caregivers on how HIV Child is Treated Negatively.

Treatment by	SA	A	Neutral	D	SD	Mean response
Family	2 (1.4%)	2 (37.7%)	73 (52.9%)	11 (8.0%)	-	2.67
Friends	28(20.3%)	63 (45.7%)	43 (31.2%)	4 (2.9%)	-	2.05
Teachers	-	-	71(51.4%)	42(30.4%)	5 (3.6%)	3.47
Religious Leaders	1 (0.7%)	2 (1.4%)	2 (1.4%)	76(55.1%)	57(41.3%)	4.35
Total	31	117	189	133	62	

NB: SA-Strongly agree, A-agree, D-disagree, SD-strongly disagree

On a scale of 1 – 5 (1-strongly agree, 2-agree, 3-neutral, 4-disagree, 5-strongly disagree), mean caregivers' feelings on the treatment of children living with HIV due to their status were computed. Caregivers perceive that friends (mean response 2.05) treat children living with HIV negatively due to their status more than the family (mean response 2.67). On teachers (55.1%) caregivers disagreed while 41.3% strongly disagree that religious leaders treat children living with HIV negatively due to their status.

As explained by Sonia et al., (2015), the fear and negative reactions from friends have affected them due to the disclosure of their HIV status. Early disclosure could influence their resilience and future coping mechanisms to stigma. Intervention and support systems can help improve their overall quality of life. Furthermore, stigmatization of HIV

and AIDS increases ground for the spread of the epidemic by hindering the impact of interventions and stopping patients from being tested, search for help, and adhering to continues with treatment (Pinar, 2015). This research finding shows HIV status led to stigmatization due to poor knowledge on HIV management.

4.3.8 Nature of Support Caregivers Offer to Orphaned Children

This question sought to know whether caregivers were able to handle problems faced by children living with HIV and AIDS. About 70.2% of Caregivers believed and highlighted that they separated domestic items which were a result of protecting the child from infections and other diseases that may harm them and, therefore, causes sickness. However, it was done due to advice from health workers and other professionals related to HIV and AIDS where they explained the importance of separating home utensils for a child on health benefits. Sometimes caregivers counseled them with a professional for the child to understand the situation and the rationale behind such actions.

Caregivers believe the neighborhood is key to child growth. It is the place where the child first interacts with the generalized others and it means so much because they first get their peer group. But only 37.7% distance themselves from the HIV child because of their HIV status, to caregivers it also affects them on everything they do within the neighborhood. Therefore, caregivers meet those neighbors and sensitize that the child should not be treated these ways because HIV can be handled if measures and care are taken. To some, they went further and explained to them how they can live without being infected with the disease. However, 0% of cases have been shown by the child to

caregivers. This suggests that teachers are more educated and aware of how to live with HIV and AIDS patients.

Caregivers revealed that very few religious leaders treated their children badly. Only 2.9% of caregivers narrated that religious leaders treated the child differently due to their status. They see it as a cause of their action that led them into this situation including the children. That is their parents' wrongdoing that caused the child to be infected with the virus.

Based on the key informants' responses, it was revealed that caregivers alone cannot handle the issues of care for children living with HIV. It would require the intervention of the government, NGOs, and other agencies related to HIV and AIDS to better handle, support, and care for those children against stigma (KII-01, 02, 03, 04, 05).

Stigma is usually ignited by fear (Malcolm et al., 1998). Felt 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. On the other hand, enacted stigma is the real experience of discrimination based on one's HIV-positive status. That is why many caregivers take measures and advice from professionals to help those children cope with stigma. The study revealed that caregivers were affected too by the stigmatization children with HIV went through.

4.4 Support Needed by Caregivers to Address Stigma among Vulnerable Orphaned Children in Bauchi Metropolis

The third objective of the current research sought to find out the methods used by caregivers in helping children to cope with the problem related to HIV and AIDS stigma.

Under this objective, the study interrogated community support given to the caregivers, how equipped caregivers were to handle the affected children, the caregiver's attitude to their being equipped, and how children are coping.

4.4.1 Community support to caregivers of children with HIV and AIDS

This question ascertained whether there are areas, community-supported caregivers, in helping children cope with stigma. The caregivers were asked to state whether the community gives them support.

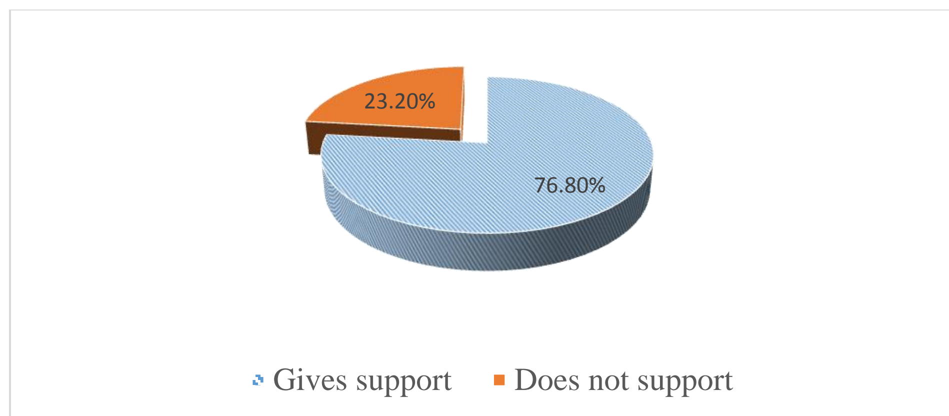

Figure 4.2: Community support to caregivers of children living with HIV and AIDS

The study results indicate that 76.8% of the caregivers received support from the community. Most of the support received by caregivers of children living with HIV and AIDS was verbal like advice, sympathy (without empathy), among others. However, 23.2% of the respondents said they did not receive any form of support from the community. Maybe 23.2% did not consider advice or sympathy to be supported. So they did not feel supported.

BACATMA (2013) reported that HIV/AIDS is regarded as an abomination because of cultural and religious influences. This may lead to low levels of support and a lack of

involvement in anything that has to do with the caregivers as well as the children affected. Without adequate community support, there is a big burden on the caregiver's shoulders, this affects their operations, and the time dedicated to taking care of the HIV children.

4.4.2 Some of the Support Community Offer to the Caregivers

As stated earlier, the study sought to find out whether the community supports caregivers in handling stigmatization of HIV infected and found that 76.8% of caregivers agreed that there are some forms of support from the community. But the support was in form of advice and sympathy. However, some advised the caregivers on seeking local medicine (traditional) for the HIV child, since ARV only manages the disease. To them, traditional medicine could cure the disease. Very few within the community allowed interaction through inquiring the best way possible to be with the HIV child without being infected with the virus. This gives a sense of hope and courage to caregivers and the children living with HIV and AIDS.

On the other hand, caregivers said 23.2% of the community does not help in any way, but rather they cause constant fear on caregivers and the HIV child. They gossip, backbite, and discriminate against HIV patients by calling them all sorts of negative names such as; liability, epidemic, patient a whole lot of other names that cause a threat to the HIV child and their caregivers. To caregivers that have to stop, or otherwise, the life of children living with HIV and AIDS would be in great danger.

"The society or community at large should also understand how to live with HIV and AIDS patient, where the disease will not be spread and government should make sure

laid down laws will help protect the issue of stigmatization and discrimination" (KII-01, 05).

Therefore, the support offered by the community is not really what the caregivers were expecting or needed. Smith et al, (2017) went further to say, caregivers' health status is generally poor because they experienced a great burden from caregiving which lead to depression and being exhausted. Sometimes they don't even bother with their health due to their patient. But little effort is made to support those caregivers by the community in areas like verbal advice, showing concern among others.

4.4.3 Being Equipped to Handle Issues of Stigma Faced by Child

KII from Rahama Foundation explained that most of the caregivers are wrongly handling issues concerning HIV and AIDS. However, stigma has made them hide and felt to enquire measures on handling the epidemic, which is alarming in spreading the disease instead of controlling it (KII-01, 05).

The question seeks to investigate in what ways do caregivers are determined to help HIV and AIDS children to cope with stigma.

Table 4.4: Caregivers Perception on how well they are equipped to handle issues of stigma

This table shows in percentage how skillful caregivers are in caring for HIV and AIDS patients through the Likert scale.

Statement	SA	A	Neutral	D	SD	Mean response
Educated	10 (7.2%)	33 (23.9%)	55 (39.8%)	37 (26.8%)	3 (2.2%)	2.93
Well trained	-	18 (13.0%)	60 (43.5%)	47 (34.1%)	13 (9.4%)	3.40
Practical experience	126 (91.3%)	10 (7.2%)	2 (1.4%)	-	-	1.09
Guided by professional	14 (10.1%)	100 (72.5%)	24 (17.4%)	-	-	2.07

NB: SA-strongly agreed, A-agreed, D-disagreed, SD-strongly disagreed

Caregivers mainly feel that they are equipped with practical experience (mean 1.09) on a scale of 1 strongly agree, 2-agree, 3-neutral, 4-disagree, 5-strongly disagree). Table 4.4 shows that 91.3% of the caregivers strongly agreed that they have practical experience. However, they admitted that they were not well equipped in terms of training (mean 3.40). These show that caregivers were not well supported by the agencies handling issues of HIV through training, workshop, and other forms of enlightenment. It implies that they are using their day-to-day practical experiences to care for the child.

"Most of the caregivers are elderly and low in education. Practical experience will not be enough for them to care HIV child, there is need for constant training and workshops to equip them with what it takes to handle issues of HIV and AIDS" (KII-03, 05).

This is consistent with UNAIDS' (2017) report that caregivers needed support because their mental health and knowledge on how to handle HIV are paramount. They need to be fostered, as this will in turn lead to effective and efficient care of children living with HIV and AIDS. However, their opinions are centered on embracing many ways possible to address issues of the stigma that will be welcomed as long as it is not harmful to the children, caregivers, and the community.

4.4.4 Suggestions on How Caregivers can Adequately handle issues of Stigma

The question focuses on how caregivers suggest the best way possible for them to help children living with HIV and AIDS can cope with stigma. The caregivers recommended that to enable them to adequately handle issues of stigma faced by children as shown bellowed;

Caregivers believe caring for HIV and AIDS children should not be left for them alone. All stakeholders should join hands and be part of the responsibility of not fighting stigma, but caring and supporting them against this menace. Collective responsibilities right from the ward head up to the emir (traditional leaders), religious groups, government, and the general public should rise to the occasion and fight against the epidemic.

Caregivers urged the need for a constant update on the way on handling issues of HIV and AIDS through training and workshops by equipping the caregivers with the necessary skills on helping HIV children to cope with stigma. Caregivers want to be empowered through vocational training and skill acquisition, even the children living with HIV and AIDS need apprenticeship to be productive.

Caregivers should be incorporated in decision-making against the laws and programs set to alleviate the problem caregivers, HIV and AIDS patients, the government, and the general public encountered from the epidemic. However, caregivers' rights need also to be protected like the child right act. Their rights should be taken seriously.

Caregivers' main concern is the involvement of all stakeholders in helping them achieve adequately in handling issues of stigma faced by children. Moreover, Osafo et al, (2017) and Achema and Ncama (2015) see the role of Ubuntu as a guiding philosophy for care to children with HIV and AIDS in Nigeria based on the African spirit which is very important in understanding the form of the sick child. The livelihood among the African people can create a tonic setting in creating a sense of belonging and aiding social supportive systems whereby the needs of others can be established. As such, these will help caregivers to adequately support children against stigma.

4.4.5 Helping HIV Children to Cope with Stigma

Caregivers choose the given methods below among the strategies to help HIV children be able to cope with the stigma threat. The caregivers gave among the options below how they think there is a need for positive thinking, turning to God, joining support, drug adherence, attending regular clinics, and attending empowerment seminars.

Table 4.5: Coping Mechanisms to help HIV Children adopt Mechanism for Stigma

This table shows caregivers' methods used in helping HIV children cope with stigmatization.

Statement	SA	A	Neutral	D	SD	Mean response
Positive thinking	76 (55.1%)	62 (44.9%)				1.45
Turning to God	45 (32.6%)	48 (34.8%)	38 (27.5%)	6 (4.3%)	1 (0.7%)	2.06
Joining support	38 (27.5%)	34 (24.6%)	58 (42.0%)	8 (5.8%)	-	2.26
Drug adherence	121 (87.7%)	17 (12.3%)	-	-	-	1.12
Attending empowerment/seminar	3 (2.2%)	36 (26.1%)	64 (46.4%)	35 (25.4%)	-	2.95
Attending regular clinics	77 (55.8%)	36 (26.1%)	20 (14.5%)	3 (2.2%)	2 (1.4%)	1.67

NB: SA-strongly agree, A-agree, D-disagree, SD-strongly disagree

In helping HIV children to cope with stigma, the caregivers felt that the children should observe medicine adherence (mean 1.12) and have positive thinking (mean 1.45) on a scale of 1-strongly agree, 2-agree, 3-neutral, 4-disagree, 5-strongly disagree. They feel that attending regular clinics would help a long way in helping HIV children adopt stigmatization. Caregivers show their concern on drug adherence, positive thinking because if the child is taking the medicine almost every day while other family or friends are not it could discourage the child to stop taking the drugs. Through utilizing positive thinking, caregivers emphasize to children living with HIV and AIDS the important of regular medication intake and by telling him that they are suffering from other illness that does not involve stigma like heart problem or anemic among others (Amira et al., 2018). However, that is why they are recommending clinical and organizing seminars and

workshops for both the children and caregivers for them to understand the disease and how to live with it professionally.

Children's conditions can be remedied through training on vocational skills and having free education, drugs are given free of charge without paying any amount of money. However, another way to take care of those HIV and AIDS children is to adopt the CHILD RIGHT ACT. Bauchi State government adopted this Child Act where it will protect every child against stigma and discrimination, isolation, and other social vices. So the best way of talking about this issue of HIV is through special consideration (priority) to children with HIV and AIDS because of the trauma of the diseases (KII-03, 04, 05).

4.4.6 Caregivers' Recommendations on the Support Child need to Cope with Stigma

Table 4.8 presents the opinions of caregivers on how they feel HIV children can adapt and cope with stigmatization problems.

Table 4.6: Suggested Support for the Children

The table gives four options from which the caregivers will select how stigma can be tackle.

Statement	Frequency	Percent
Family	136	99.3
Peers/ Friend	124	89.9
Teachers	127	92.0
Religious leaders	136	98.6

Caregivers suggested that family support was important. About 99%, of the respondent, supported it while religious leaders were 98.6% and the teachers 92.0% respectively. However, friends and peers carried around 89.9% that entails that there is the need of involving all the options for the child to handle issues of stigmatization. In terms of the support, caregivers would like given to the children to help them to cope with HIV stigma more effectively, the caregivers recommended important roles families, peers/friends, teachers, and religious leaders will play. As explained by Tshoose (2010), the spirit of Ubuntu in the African backgrounds frequently influences the care of children living with HIV and AIDS; hence, under such, people were taking concrete steps to offer a kind of support and care to whoever needed. Therefore, caregivers believe that a lack of "Ubuntu spirit" could trigger HIV-related issues.

4.4.7 Roles Played by the Government to Support Children Cope with Stigma

This table shows the nature of support offered to HIV and AIDS victims by the government.

Table 4.7: Government Roles in Supporting Children Cope Stigma

Statement	SA	A	Neutral	D	SD
Government regular medical provision (ARVS	67 (48.6%)	70 (50.7%)	1 (0.7%)	-	-
Anti-discrimination Act 2014	11(8.0%)	20 (14.5%)	74 (53.6%)	66 (47.8%)	33(23.9%)
Media is used to show that HIV and AIDS is normal	60 (43.5%)	38 (27.5%)	32 (23.2%)	6 (4.3%)	2 (1.4%)

NB: SA-strongly agree, A-agree, D-disagree, SD-strongly disagree

Table 4.7 shows that 50.7% of caregivers agreed that government supports the children by providing regular medical (ARVS) assistance to vulnerable children with HIV and AIDS. However, 53.6% were neutral, while 47.8% disagreed and 23.9% strongly disagreed that government did not take the anti-discriminating act seriously, only 14.5% agreed and 8.0% of caregivers believed establishing the anti-discrimination Act 2014 had in some ways helped against stigma among vulnerable children with HIV and AIDS. Furthermore, 43.5% of caregivers saw media as being used to show that HIV and AIDS are normal.

The government in its effort to tackle issues of HIV and OVC came up with a plan in providing services in seven (7) thematic areas of OVC/HIV interventions. Among the areas are; education because a child with HIV has the right to acquire education, health, right on food and nutrition, right to shelter, right to psycho-social support, right to protection and legal (child protection and legal), lastly, empower caregivers. This is in line with the national plan of action and national standard of practices (KII-02, 03, 04, 05).

Therefore, this entails that caregivers need more support from the government, because despite those services rendered, still, the issue of stigma exists and seriously affects the wellbeing of the child and for the caregivers (Osafo et al., 2017). However, the study understood that interventions were coming from areas that do not matter most to caregivers and the HIV children due to the lack of involvement of them to ascertain their main conditions.

Generally, societal views on HIV and AIDS children are mainly based on major concerns particularly the spread of the disease due to the age and lack of knowledge on how to

handle and relate with HIV and AIDS patients. UNHCHR (2015), points that many obstacles hinder caregivers' effectiveness in prevention and support due to the lack of support by community initiatives on HIV and AIDS. These are due to cultural/religious, structural, and financial problems. However, it should be anchored based on the African spirit which is very important in understanding the form of the sick child (Achema & Ncama, 2015).

The majority of the key informants were against establishing an institution for HIV and AIDS children because most of the families refused to take their children. However, securing them in a place would still increase the amount of stigmatization rather than stopping it.

PEPFAR (2021), report shows that helping caregivers and orphaned children with HIV require constant review that would accommodate their problem. Where they promise to provides technical assistance and support to various bodies to handle issues related to HIV/AIDS both in the short term as well as long term plans, policies, a modification that will improve the capacity of caregivers and social stigma to children with HIV.

CHAPTER FIVE

SUMMARY, CONCLUSIONS, AND RECOMMENDATIONS

5.1 Introduction

This chapter gives a summary of the study and comes up with the conclusion of what has been found in the study as well as recommendations the study suggests to agencies concerned with handling issues of HIV and AIDS on the possible ways to address problems of an epidemic. The chapter ends with suggestions on further research avenues.

The study focused on how caregivers' experience (characteristic) helped vulnerable orphaned children cope with HIV and AIDS stigma in Bauchi Metropolis, Nigeria. Specifically, the research aimed at establishing the role played by caregivers of children living with HIV and AIDS to help those children cope with stigmatization and discrimination and adopt the various method of supporting them. The influence of caregivers particularly their characteristics can go a long way in helping orphaned and vulnerable children living with HIV and AIDS with different ways of coping with the stigma and methods embraced by caregivers coping mechanisms due to their knowledge and skills to handle stigma issues. Programs and efforts were made by government and international bodies as well as NGOs. Yet it did not archive the required goal in fighting the stigma and helping caregivers to be equipped in handling issues of stigma to children living with HIV and AIDS. Therefore, in formulating any program caregivers need to be part of the policy.

The study was conducted in Bauchi Metropolis, Nigeria. Targeted caregivers of children who are vulnerable orphans living with HIV and AIDS were enrolled in the support groups through BASOVCA. A sample of one hundred and thirty-eight (138) respondents who are caregivers of children living with HIV and AIDS within Bauchi metropolis, Nigeria samples were used among the 218 caregivers in the area under study (BASOVCA, 2019) using Krejcie and Morgan formula. While the key informants used in the study included the staff of the Ministry of health (Bauchi), staff from BACATMA, BASOVCA, and NGOs who collaborate with international agencies on HIV and AIDS using the Marshall formula. For the caregivers of children living with HIV and AIDS, questionnaires with open and close-ended questions were administered through face-to-face interviews, and for the key informants, an interview guide was used. The data were analyzed by the use of Statistical Package for Social Scientists (SPSS) for caregivers, while NVIVO was also used to analyze interviews for key informants.

The study findings indicate that 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 family setting, community cohesion, and key stakeholders like the traditional rulers and government (policies) among others. HIV and AIDS 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.

5.2 Summary

This part presents the summary of the study findings as per the study objectives.

5.2.1 Objective One: Demographic characteristics of the caregivers of HIV children (profile of caregivers)

The study found that a caregiver is likely to be female, between 31-65 years of age, and a Muslim with low education levels. The caretaker is therefore likely to be a low-income earner or unemployed and would have worked for an average of 8 years as a caretaker of children orphaned due to HIV and aids.

The study also found that some of the characteristics of caregivers put them in a predicament as they cared for the HIV children. For example their age, level of education, and their occupations, and lack of income-generating activities. This all influenced the welfare of caregivers as they worked to provide a conducive environment for the children.

On education, only 29.7%, had tertiary education. The majority 84.1% of those caregivers were female. About 73% of the caregivers have provided care for the children between one year 1 to ten years 10. On these notes, there is the need for family, community, religion, and government to join in to help caregivers through enlightenment and support in every way possible to be able to handle issues of HIV stigma going by their characteristics problems.

More than half of the caregivers (59.0%) of caregivers earned less than NGN. 5,000 ($40) agreed that they had difficulties in handling issues of HIV and stigma to those

children, while fewer of the caregivers 1.4% had a monthly income of NGN. 50,000 ($140).

5.2.2 Objective Three: Caregivers' Challenges in Helping HIV and AIDS Children to Cope with Stigma.

According to the findings of the study, caregivers show that 70.3% of the family members were in support of separating domestic items and the majority of the caregivers explained that73.2% of HIV positive children reported that they were not accepted and cherished in the communities they are living because of their status. Also, the respondents (caregivers) confessed that those children were treated differently because of their status by the rest of the community, like religious leaders, traditional rulers, and friends who are not HIV and AIDS positive after disclosure.

Caregivers' response indicated that they sought HIV and AIDS-related health services in hospitals or clinics away from their neighborhood to avoid meeting other people in their community who visit nearby clinics and hospitals. The key informants also explained that caregivers sometimes are the cause of some of the problems because they fail to report any issues they and the children encounter.

Caregivers of children living with HIV and AIDS reported that they encounter enormous challenges right from the close-knit family members to friends and community members, to a religious group, as well as government/local authority, health and the society as a whole has made it difficult in supporting the child against stigma. The family members have a poor misconception of the disease by insisting on separating home items, distance

themselves to interact, and thinking the disease has no cure. While the community aggravated stigma through making sure that their child does not play with HIV child and at times the child is being denied certain privileges due to ignorance and fear of getting in contact with the disease.

Furthermore, religious groups have a role to play in supporting caregivers, but they ignore just because the disease was as a result of their wrongly acted 'sin' that God punished them, while for the children it is not their fault. Whereas it is believed that religious leaders should shape social values, promote responsible behavior that respects the dignity of all persons, and defends the sanctity of life, they should also embrace HIV patients. However, caregivers felt that the government/ local authority was not doing enough to help caregivers support children with HIV against stigma, most of the laws set by the authorities were only on paper but the law does not have any serious effect, while their voice is highly respected, they hardly come out to talk about the ills of stigma.

The health aspect required a lot of improvement by having qualified medical personnel, availability of ARV at all times, and more centers for HIV patients among others. While society, in general, sees HIV as a disease that has no cure, so those children should be quarantined if it can be contained and it affects both caregivers and HIV child, because they have little knowledge on how to handle the disease. Therefore, the risk of spread could increase, because status non-disclosure can also be embraced by the caregivers as a coping mechanism to stigma.

There is the need to have an effective program and policies that will mitigate and impacts caregivers' capacity on stigma.

5.2.3 Objective Three: Supports needed by Caregivers in Helping Children Living with HIV and AIDS to Cope with Stigma.

Family support is paramount to caregivers to enable them to help children cope with HIV and AIDS stigma. Even though the effects of HIV and AIDS-related stigma were severe within the communities where HIV-positive children live. The study found out that 76.8% of the respondents (caregivers) believe they only received verbal support from the community. By and large, the kind of supports some get from the community was nothing more than a piece of advice, word of encouragement, and little financial support.

The study found out that some coping strategies caregivers go through are enough where the practical experience they have (91.3%) believing they are equipped, but a majority of them admitted they were not well trained to handle stigma. While for children to cope with stigma, caregivers felt that drug adherence, attending regular clinics, and empowerment on HIV can help address stigma and positive thinking, turning to God could be achieved through joining support groups as a coping mechanism to stigma. That is why caregivers recommended cohesion if adequately we can handle stigma and a lot of training not only to them as caregivers but also all stakeholders should be involved.

Lastly, caregivers believe the only way to support children from stigma, support should be given (99.3%) from the family, friends (89.9%), while religious leaders (98.6%) and

teachers (92.0%). This entails that cohesion is the key. Government should make sure that the child rights act is effective and media should be an avenue to sensitize people on how to live with HIV and AIDS patients.

5.3 Conclusions

The study explored the predicament caregivers go through in helping vulnerable orphaned children to cope with HIV and AIDS stigma, in Bauchi Metropolis, Nigeria. From the demographic characteristics, caregivers of HIV children seem to be also vulnerable hence putting them in a predicament in dealing with their welfare and that of the children. In addition, the caregivers experience a myriad of challenges from the family, the society, religious leaders, and health care institutions in Bauchi Metropolitan. Moreover, to address stigma among vulnerable orphaned children who cope with HIV and AIDS in Bauchi Metropolitan, the caregivers need different types of support from all the social institutions in Bauchi Metropolis.

5.4 Study Recommendations

Based on the study findings, the following recommendations were made

1. The government and other relevant agencies should empower caregivers through vocational skills and other means of livelihood to address the issue of their income.
2. Caregivers need to be educated on prevention, transmission, and managing the disease, not only blaming community, government, religion, leaders among others. While well-to-do people should as well include caregivers by assisting

them in every way possible, by understanding it is not a violation of norms and values when they help them.

3. The relevant government ministries and agencies including NACA, SACA, and BACATMA as the case may be in Bauchi among others need to design programs that can effectively deal with stigma reduction.

4. The government needs to intensify campaigns by involving religious groups, traditional rulers, NGOs, and international bodies to sensitize the general public aimed at reducing 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.

5. The government should also have ways and manners that can determine the level of stigma experienced in various areas like family level, community, health sectors, and schools, etc. Such surveys may help in coming up with programs that can address issues of stigma with the services caregivers offer to children living with HIV and AIDS can benefit. This implies that there is a need for all stakeholders to be charged with the responsibility of designing programs that will address the issue of stigma through enlightenment campaigns.

6. Government should use media as an avenue and its relevant representatives at the grass-root levels that can help promote the right of the HIV child and also to have certain rights for those caregivers of HIV children and special task force or agencies in which cases of right tempering or encroachment can be reported. The

media sensitization and enlightenment campaign can portray good practices that the general public can do to avoid infection and care for children living with HIV and AIDS orphans and vulnerable.

5.5 Areas of Further Research

1. There is the need to study and understand areas from which stigma is higher i.e. community level to a religious group and health sector as well as government stigma effect and compare with the less stigma area on HIV and AID on how it can be intervened and contained to address stigma and the spreading of the disease.
2. Therefore there is a need to find out what other social issues influence stigma in order to sufficiently address it.
3. This study only focused on Bauchi Metropolis. A similar study can be carried but on a bigger scale.

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APPENDICES

Appendix I: Letter of Introduction

April 2019.

Dear Respondent,

My name is Sulaiman Ahmad, a master's student of the Department of Sociology at Kenyatta University. I am conducting research on the topic **“Role of Caregivers in Helping Vulnerable Orphaned Children Cope with HIV/AIDS Stigma in Bauchi Metropolitan, Nigeria”.** The information to be collected is for academic purposes only and anonymity is ensured. No need for your name or phone number. Kindly support me in this endeavor by providing the required information. The questionnaire items will be read to you were necessary to enable you to respond as accurately as possible.

Thank you for your time and response.

Sincerely yours.

Sulaiman Ahmad

Department of Sociology Kenyatta University

Phone number: +2348028502093, +2348030694284, +254752388099.

Appendix II: Questionnaire for Caregivers

SECTION A: Demographic information

Please tick the appropriate box below ( )

1. What is your gender?

(a) Male ( ) (b) Female ( )

2. What is your age?

(a) 18-24( ) (b) 25 – 34 ( ) (c) 35-45( ) (d) 50 -65( )

3. What is your religious affiliation?

(a) Christianity ( ) (b) Islam ( ) (c) Others………..

4. What ethnic group do you belong to?

(a) Hausa ( ) (b) Fulani ( ) (c) Gerawa ( ) (d) Sayawa ( ) (e) Other……

4. What is your educational level?

(a) Primary level ( ) (b) Secondary level ( ) (c) Tertiary level( ) (d) Other……………

5. What is your average level of income per month?

(a) 0- 5000 (b) 5000-20,000 (c) 20,000-50,000 (d) 50,000 and above Naira.

6. For how long have you been providing care to this child (give number of years or months)? ………..

SECTION B.

The challenges experienced by Caregivers.

8. Do you feel that children living with HIV and AIDS are treated differently in this community?

Yes (   )   No (   )

9. Do you feel the following have treated the child living with HIV negatively due to their HIV status?

Statements	Strongly Agreed	Agreed	Neutral	Disagreed	Strongly Disagreed
Family					
Friends					
Teachers					
Religious leaders					

10. Has any of the following been reported to you by a child living with HIV?

Statements	**Yes**	**No**
Family separating domestic items (utensils)		
Losing friends after disclosing HIV status		
Neighbor's warning other children from closely interacting with the child because of their HIV status		
Teachers discriminating the child from participating in activities they would wish to at school		
Any form of treatment by religious leaders		

If yes, how as a caregiver do you support the child against those problems he/she suffered.

………………………………………………………………………………………………

………………………………………………………………………………………………

11. What are the difficulties suffered in handling children living with HIV and AIDS from close family members……………………………………………………………………………………….

………………………………………………………………………………………………

………………………………………………………………………………………………

12. From community members (culture)…………………………… ………………...

……………………………………………………………………………………………
……………………………………………………………………………………………

13. From religious groups……………………………………………………………
……………………………………………………………………………………………
……………………………………………………………………………………………

14. From local authority/government…………………………………………………
……………………………………………………………………………………………
……………………………………………………………………………………………

15. From health facilities……………………………………………………………
……………………………………………………………………………………………
……………………………………………………………………………………………

16. In general how does society view children living with HIV and AIDS
……………………………………………………………………………………………
……………………………………………………………………………………………
……………………………………………………………………………………

Support is needed by caregivers to address stigma among vulnerable orphaned children who cope with HIV and AIDS.

17. Does the community gives support to caregivers of children living with HIV and AIDS?
Yes ( ) No ( )
If yes; what kind of support they offered……………………………………………
……………………………………………………………………………………………

18. How well do you feel you're equipped to handle issues of the stigma that are faced by a child?

Statements	Strongly Agreed	Agreed	Neutral	Disagreed	Strongly Disagreed
Educated					
Well trained					
Practical experience					
Guided by professional					

19. What would be your recommendations to enables caregivers of children living with HIV and AIDS to adequately handle issues of stigma faced by children………………………………………………………………………………… ………………………………………………………………………………………… ……………………………………………………………

20. Did you think helping HIV children adopt the following as coping mechanisms will help a long way against stigma?

Statements	Strongly Agreed	Agreed	Neutral	Disagreed	Strongly Disagree
Positive thinking					
Turning to God					
Joining support					
Drug adherence					
Attending empowerment/ seminar					
Attending regular clinics					

21. What would be your recommendations in terms of the support that you would like given to the child in order to enable them to cope with HIV stigma more effectively?

Statement	Options
Family	
Peers/ Friend	
Teachers	
Religious leaders	

22. Role played by the government to support children cope with stigma?

Statements	Agree	Strongly Agree	Neutral	Disagree	Strongly Disagree
The government provides regular medical (ARVS) assistance to vulnerable children with HIV and AIDS					
Anti-discrimination Act 2014 help against stigma among vulnerable children with HIV and AIDS					
Media is used to show that HIV and AIDS is normal					

Appendix III: Interview Question Guide for Key Informant (Staff)

1. Please describe some of the government interventions on children living with HIV and AIDS and their caregivers?

2. What are the challenges faced by caregivers of children living with HIV and AIDS encounter?

3. How best do you think the challenges faced by caregivers can be adequately addressed?

4. How the present situation of children living with HIV and AIDS can be best helped or aid?

5. How did you think establishing an institution might help HIV and AIDS children and their caregivers against stigma?

6. What are the demographic information of those taking care of children with HIV and AIDS in the Bauchi metropolis?

Appendix IV: Ethical Clearance

SECRET

GOVERNMENT OF BAUCHI STATE
MINISTRY OF HEALTH

Bello Kirfi Road, Off Murtala Mohammed Way,
P.M.B 065, Bauchi

E-mail: bauchismoh@gmail.com

Reference MOH/GEN/S/1409/I

Date 8th April 2019

PROTOCOL REG N0 BSMOH/REC 01/2019
PROTOCOL APPROVAL N0: NREC/12/05/2013/2019/01

Sulaiman Ahmed,
Department of Sociology,
Bauchi State University,
Gadau.

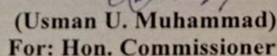
ETHICAL CLEARANCE FOR SUBMITTED PROTOCOL:
"The Role of Caregivers in helping Orphaned and Vulnerable Children to Cope with HIV & AIDS Stigma: A Case of Bauchi Metropolitan, Nigeria"

The Bauchi State Health Research Ethics Committee (HREC) under the State Ministry of Health has received the above named protocol from you for ethical clearance and approval in line with the guidelines set by the Committee. The protocol was reviewed and the committee noted that that the research falls under the low risk Category which does not entails clinical trials or any invasive procedures.

2. Consequently, the Committee has granted expedited approval for the research to be conducted. However, you should share with us your workplan clearly indicating the start date, where and when to visit the research site(s) and also **the final results of your findings**.

3. The Committee therefore requires you to comply with all Institutional Guidelines, Rules and Regulations and with the tenets of the National Health Research Ethics Committee Code including that all adverse events are reported promptly to the Committee. **No changes are permitted in the research without prior approval by the Committee** except in circumstances outlined in the Code. The Committee reserves the right to conduct compliance visit to your research site without prior notice.

4. Thank you.



(Usman U. Muhammad)
For: Hon. Commissioner

SECRET

Appendix V: Research Authorization – Kenyatta University

KENYATTA UNIVERSITY
GRADUATE SCHOOL

E-mail: dean-graduate@ku.ac.ke
Website: www.ku.ac.ke

P.O. Box 43844, 00100
NAIROBI, KENYA
Tel. 020-8704150

Our Ref: C50/31624/2015

DATE: 1st April, 2019

The Honourable Commissioner,
Bauchi State Ministry of Health
Bank Road, Bauchi
NIGERIA.

Dear Sir/Madam,

RE: RESEARCH AUTHORIZATION FOR MR. SULAIMAN AHMED – REG. NO. C50F/33346/14

I write to introduce Mr. Sulaiman Ahmed who is a Postgraduate Student of this University. He is registered for M.A. degree programme in the **Department of Sociology, Gender & Development Studies**

Mr. Ahmed intends to conduct research for a M.A. thesis Proposal entitled, **"The Role of Caregivers in Helping Orphaned and Vulnerable Children to Cope with HIV and AIDS Stigma: A Case of Bauchi Metropolitan, Nigeria."**

Any assistance given will be highly appreciated.

Yours faithfully,

PROF. ELISHIBA KIMANI
DEAN, GRADUATE SCHOOL

JG/cww

Appendix VI: Approval of Research Proposal- Kenyatta University

KENYATTA UNIVERSITY
GRADUATE SCHOOL

E-mail: dean-graduate@ku.ac.ke
Website: www.ku.ac.ke

P.O. Box 43844, 00100
NAIROBI, KENYA
Tel. 020-8704150

Internal Memo

FROM: Dean, Graduate School **DATE:** 1st April, 2019

TO: **Mr. Sulaiman Ahmed**
C/o Department of Sociology, Gender & Development Studies **REF:** C50F/33346/2014

SUBJECT: APPROVAL OF RESEARCH PROPOSAL

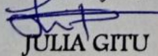
This is to inform you that Graduate School Board, at its meeting on **27th March, 2019**, approved your Research Proposal for the M.A. Degree entitled, **"The Role of Caregivers in Helping Orphaned and Vulnerable Children to Cope with HIV and AIDS Stigma: A Case of Bauchi Metropolitan, Nigeria."**

However, do clearance with the office of the Director, Ethical Committee, Kenyatta University.

You may now proceed with your Data collection, subject to clearance with the Director General, National Commission for Science, Technology & Innovation.

As you embark on your data collection, please note that you will be required to submit to Graduate School completed Supervision Tracking Forms per semester. The form has been developed to replace the Progress Report Forms. The Supervision Tracking Forms are available at the University's Website under Graduate School webpage downloads.

Thank you.



JULIA GITU
FOR: DEAN, GRADUATE SCHOOL

CC. Chairman, Sociology, Gender and Development Studies Department
Supervisors:
1. Dr. George Evans Owino
   C/o Sociology, Gender & Development Studies Dept.
   Kenyatta University
2. Dr. Gladys Nyachieo
   C/o Sociology, Gender & Development Studies Dept.
   Kenyatta University

JG/cww

KU/GS/ARRP/1

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Internal Memo

ROM: Graduate School DATE: 04/03/2019

O: Name: Sulaiman Ahmed

eg. No. C50F/33346/2014

epartment: Sociology, Gender & Development.

JBJECT: ACKNOWLEDGEMENT OF RECEIPT OF RESEARCH PROPOSAL

ιis is to acknowledge receipt of your Research Proposal for your Masters/Ph.D ogramme.

ou will soon be informed of the Graduate School Board Decision, once your Research oposal is considered.

ank you.

HN M. ODONGI
R: DEAN, GRADUATE SCHOOL

Chairman. Department of: