
A Case Study of the Burden of Care among Caregivers of HIV/Aids Patients in Jos Prison, Nigeria

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ABSTRACT

This study investigated the burden of care among caregivers of people living with HIV/AIDS in Jos prison. Emphasis was placed on the challenges that caregivers face in providing care and health services to prisoners who are living with HIV/AIDS. The study employed a case study research method to investigate the subject matter. The purposive sampling technique was used to select 15 caregivers who were used for this study. The Zarit Burden Inventory (Zarit, Reever and Bach-Peterson, 1980) and a structured interview schedule were used to collect data for this study. Results showed that the caregivers burden were severe. Also, the study found out that lack of health facilities, qualified health professionals, logistics among others are some of the challenges that caregivers face. Recommendations were made on how to ameliorate the burden of care among caregivers of prisoners living with HIV/AIDS.

Key words: Burden; care; prisoners; caregivers; HIV/AIDS; patients

Introduction

In Nigeria and many parts of the world, HIV/AIDS has become a very serious public health concern, and has posed a challenge to the world at large. According to Asuquo, Adejumo, Etowa and Adejumo (2013), AIDS has become one of the greatest public health challenges of our time. It is estimated that globally over 35 million people are living with HIV at the end of 2014 with the vast majority of these people living in sub-Saharan Africa (World Health Organisation-WHO, 2014). In Nigeria, over 3.4 Million people representing 2.7 percent are presently living with the virus, with a greater number of them in the age range of 15 and 49 years (UNAIDS, 2015).

According to UNDOC (2007), about 668,000 people are incarcerated in sub-Saharan Africa

with South Africa having the highest prison population of 157,402 people incarcerated. Other African countries have high prison population, though West African countries have the lowest prison population. According to the Nigerian prisons Service 2014 statistics report, there are about 55 Million prisoners in Nigerian prisons, and about 95% of them are in the age range of 18 to 49. Therefore, it can be said that the prison population in Nigeria is vulnerable to HIV/AIDS. A prevalence of 8.7 % had been previously reported among Nigerian prison inmates in (Iwogh, 2004). According to a Survey of some prisons in Nigeria, there is a seemingly high level of homosexual activities among prison inmates in Nigerian prisons (Olayide, 2001). This sexual behavior may be as a result of the lack of conjugal visits for the inmates. Hence, most

prisoners discharge their sexual energies through homosexuality. Again, homosexual activities among inmates occur either voluntarily because of lack of other ways of channeling sexual energies, or through threats and coercion (Joshua and Ogboi 2008).

Prisoners living with HIV/AIDS are often confronted with the problem of lack of liberty, poor health care system in the prison, poor feeding and sanitation, stigmatization, amongst others. The stigma associated with HIV/AIDS makes many prisoners reluctant to admit they are infected or seek care, and can make health workers reluctant to provide care (WHO, 2006). For AIDS patients in prison, caregiving is not always available from their families and friends. Most often the care for AIDS patients in prisons falls on prison staff and fellow inmates (Olenja, 1999). This poses enormous responsibilities, stress and burden primarily on the staff and inmates of the prison. Furthermore, the prisoner who has AIDS has to deal with the burden related to the illness and also with the stigma surrounding it. AIDS patients in prison and their caregivers will have to contend with the stigma surrounding HIV infection and management (Kalondo, 1996). Stigma often leads to social isolation and loneliness not only for AIDS patients in prison, but also for their caregivers who are prison staff and inmates. According to Casaux and Reboredo (1998), this further adds on their burden of care for the prisoner with the chronic and lethal condition such as AIDS. Again, HIV/AIDS dramatically increases the burden on health services, especially since most victims are young adults who otherwise would require little health care. At the same time, stress and AIDS-related deaths among health care

personnel reduce the number of health workers available to care for patients (Ainsworth and Over, 1997).

According to Asuquo et al., (2013), HIV/AIDS patients are faced with social, physical, psychological and emotional problems which often increase the level of burden of caregivers and portray them as targets of HIV-related prejudice and discrimination. There is a widespread of stigmatization against people living with HIV/AIDS and this causes them social problems. Stigmatization limits the social ability of people living with HIV/AIDS. Case studies indicate that the burden of care increases with the impairment in functional activities and the duration of care and a significant correlation exist between the number of caregiving tasks and caregivers burden (Asuquo, et al., 2013).

Theoretical Background

The present study adopted the coping theory for this study. Fineman (1984), stress is a state of tension felt in the presence of an object or a task that is perceived as presenting a challenge to a person's safety or self-esteem. Stress emanates from perceived discrepancy between environmental demands and the person's ability to meet those demands; hence presenting psychological, emotional and even physical distress. Therefore, many people have coping techniques against stress such as denial of stress or avoidance of stress depending on the sources of stress. Coping attempts either to reduce the demands of the stress, to reduce the effects of the stress, or to help the person change the way he or she thinks about the demand of the stress. It could be stimulus-directed coping, where an attempt is made to eliminate or ameliorate the

initial sources of the stress reactions; or cognitive coping which involves changing the way the stressor is perceived; or response directed coping which involves the reduction of the magnitude of the stress response. For caregivers of AIDS patients both the internal factors such as knowledge and external factors such as finance and friends are necessary to help them cope with stressful events (Kangethe, 2009).

The increased burden on caregivers of AIDS patients in prison may develop feelings of anger, grief, loneliness, burnt-out and resentment, which may lead to poor quality of care and ill health of the caregivers. This is typical in caring for patients with AIDS who may be in the terminal stage of HIV infection. HIV/AIDS in prison is a growing concern and information emanating from prisons in Nigeria indicates that there are large numbers of HIV-infected prisoners; hence the prison population is at-risk. The present study will investigate the plight of caregivers of HIV/AIDS patient in Jos prison, and the challenges faced by the caregivers. This will provide information which will be used to formulate evidenced based interventions in prisons, so as to reduce the challenges faced by the caregivers.

METHODOLOGY

This study was conducted in the Maximum Security Prison, Jos, Plateau state, Nigeria. The prison is a convict prison that holds all classes of prisoners and has a capacity of 1149 inmates. As at the time this study was conducted, there were 766 inmates locked up in the prison with 19 (2.48%) of them living with HIV/AIDS.

The study participants were medical staff working in the Clinic of the prison. A purposive sampling technique was used to select the caregivers who are health professional from diverse fields: nurses, community health

workers, psychologists and social workers. All these health professionals had been involved in care giving of prisoners living with HIV/AIDS. About 15 participants who were working in units that cater for HIV/AIDS participated in the study. Permission was sought from the authority of the Nigerian Prisons Service to conduct the study, of which approval was given. The participants were debriefed, and informed consents were obtained following full description of the purpose of the study.

The study adopted a case study research design and data was obtained through structured interview and the Zarit Burden Interview (Zarit, Reever and Bach-Peterson, 1980). A 7-item structured interview was used to elicit information from the participants. The interview sought for the challenges the caregivers faced in the course of caring for AIDS patients in prison. During the interview schedules with the participants, follow-up questions were asked for clarification and better understanding.

The Zarit Burden Interview (ZBI) was used to measure caregiver burden. It is a 22-item, self-report questionnaire that evaluates the caregiver's health condition, psychological well-being, finances, and social life in the context of the caregiver-patient relationship. Responses are on a 5-point Likert-type scale ranging from 0 (never) to 4 (nearly always), and item scores are summed to obtain a total score that ranges from 0 to 88. Higher scores indicate greater levels of caregiver burden. The following categories have been developed to identify little to severe caregiver burden: 0-20 indicates little or no burden, 21-40 reflects mild to moderate burden, 41-60 moderate to severe burden, and 60-88 severe levels of burden (Zarit et al., 1980). This instrument has been previously used on Nigerian

subjects by Yusuf, Nuhu and Akinbiyi (2009), instrument.
hence, there is no need for revalidation of the

RESULTS

Socio-demographic Characteristics of the Participants

The socio-demographic data of the participants is represented in the table below:

Table 1: Demographic Characteristics of Participants

Characteristics	Frequency	Percentage (%)
SEX		
Male	6	40
Female	9	60
RELIGION		
Christianity	12	80
Muslim	3	20
Others		
PROFESSIONAL QUALIFICATION		
SSCE/Diploma/NCE	3	20
RN/BSC	10	67
MSC	2	13
MARITAL STATUS		
Single	2	13
Married	12	80
Widowed	1	7
Divorced	0	0
AGE		
18-35	4	26
36-49	10	67
50-above	1	7
BURDEN OF CARE		
No Burden	0	0
Mild	1	7
Moderate	2	13
Severe	12	80
Total	15	100

Source: Field study, 2015

Table 1 shows that the majority 9 (60%) respondents were female, 10 (67%) in the age range of 36 - 49 years. Twelve representing 80% were Christians by religion, and about 80% (12) were married, while 67% (10) had a first degree and/or are qualified nurses. The table also shows that from the scores of the participants in the Zarit Burden Inventory (ZBI), 12 participants representing 80% have severe burden.

Challenges of caregivers

From the interview conducted, the following challenges were highlighted by the respondents:

1. **Lack of health facilities:** When asked about their challenges, 12 (80%) out of the 15 participants listed the lack of health facilities as their major challenge. Though, there is 10-bed clinic in Jos prison, there are little or no equipments for the management of prisoners living with AIDS. They are not equipped with Anti-retroviral drugs for the management of AIDS patients; hence, they have to make referral to other hospitals outside the prison. The following excerpt from the in-depth interviews with the Officer in Charge of the Prison clinic of Jos prison revealed some challenges which they go through as a consequence of this; *“We are faced with the constraints of health equipments. Normally, we are supposed to screen every admitted inmate, but we are not provided with the testing kits and other materials that aid us in that regard. Infact, we have to seek external support from APIN in Jos University Teaching Hospital, as well as the Plateau State Specialist Hospital, in the area of testing and anti-retroviral drugs.” (The Superintendent of Prison in-charge of the Prison Clinic)*

The lack of medical facilities has impeded the effective management of prisoners living with HIV/AIDS in the prison, as it has increased the burden of care of these caregivers. Though, the

caregivers are doing well in the areas of counselling/psychotherapy and rendering orientation to the inmates on how to live positively with the illness, the lack of medical equipments and drugs has greatly affected their burdens negatively.

2. **Lack of professional Medical personnel:** This is another challenge facing the caregivers. Only 15 medical personnel are working in the prison clinic. They are to attend to the 19 HIV/AIDS patient and over 850 others. With a ratio of one medical personnel to attend to about 50 inmates, the caregivers are burnt out in the long run. The prison clinic is bereft of a medical doctor. Only four registered nurse, two (2) Psychologists, one (1) social worker and a handful of community health worker. This is grossly inadequate in a large prison like this.
3. **Lack of Logistics:** The movement of inmates to attend clinic in referral hospital is usually hampered by the lack of logistics. The prison clinic has no ambulance to convey inmates to and fro clinics outside the prison. The following excerpt from the officer whose schedule is to take the AIDS patients to and fro clinic reveals that funds are not provided for this purpose;

“One of the major challenges I have is logistics problem. Often times, I usually use my hard earned salary to pay for logistics to and fro JUTH where we normally get drugs and screen our patients. The government has not

provided us with ambulance or any form of logistics. Hence, I have to compromise by using my salary to pay for transportation fare to and from JUTH.”

4. **Poor remuneration:** Most of the health workers interviewed complained of poor remunerations. They are not paid their allowances, and other entitlements as at when due. 14 of the participants complained that they have not been promoted in the past 12 years. The Superintendent of Prisons in charge of the prison clinic stated that:

“I have not been promoted since 2002. I have remained on this rank since 2002. My colleagues who are my contemporaries have all been promoted ahead of me. I feel bad for this because I have no record of indiscipline. This predicament is none of my fault!”

5. **Lack of funding:** Thirteen (13) of the respondents pointed out that the medical unit and the Nigerian prisons Service as a whole suffers from poor funding. They complained of lack of proper funding from government, as they have to depend on Non-governmental organisations and other charity groups for some of their needs.

Discussion of Results

The findings of this study have revealed some information about the burden of care among caregivers of prisoners living with HIV/AIDS in Nigeria prisons. It has been able to expose the loopholes in the Nigerian prisons system that impedes the handling of inmates living with the illness.

From the foregoing, results show that caregivers of HIV/AIDS patients in prison are faced by a myriad of challenges which bug down their operations. From table 1 above, 80 percent of the participants scored very high on the Zarit Burden Inventory, showing a severe burden of care. This may be due to the challenges they face in the course of providing care. From the analysis above, it is clear that the caregivers work under very stressful conditions. Hence, their severe burden of care.

The results also revealed the challenges faced by the caregivers. They include the lack of facilities for the provision of healthcare and services to the prisoners. They are left to compromise on certain needs. They go to extremes to fund some of the needs from their personal earnings. This is a serious challenge. The respondents also complained of the lack of logistics, lack of funding, and poor remunerations. All these may have contributed to the high scores in the Zarit Burden Inventory.

Finally, the result revealed that the prison clinic is bereft of medics. From the results, about 15 medical personnel are to attend to over 750 inmates; a ratio of one personnel to more than 50 inmates. This is grossly inadequate. The results also exposed the fact that the prison clinic has not medical doctor attached to it. These causes a great deal of burden on the available caregivers, making them exposed to more stress. The findings of this study has gone a long way to provide information on the abnormalities happening behind the four walls of Jos prison, and by extension, other prisons in Nigeria.

Conclusion/ Policy implications

The ability to provide quality care for HIV/AIDS prisoners requires caregivers that are endowed with professional skills. HIV infers death to many irrespective of retroviral drugs used and caregivers are well aware of the seriousness of this deadly disease. Therefore, the level of

burden of caregivers caring for prisoners living with HIV/AIDS increases due to some challenges which are the lack of medical facilities, lack of funding, lack of medical professionals, poor remuneration, among others.

Consequent upon these, the following recommendations are made for the effective healthcare of prisoners living with HIV/AIDS in Nigeria.

1. The Nigerian Prisons Service should, as a matter of urgency, recruit more medical staff. Increasing the number of healthcare personnel in the prison will reduce their workload and lessen the level of burden.
2. All the prison clinics and sick bays in Nigeria should be made provided with antiretroviral drugs and other kits that will help in the testing and treatment of the prisoners living with HIV/AIDS.
3. Routine and periodic HIV testing and counselling services should be introduced in prisons nationwide. This will identify HIV positive inmates early and further enroll them into care and support before advanced stages of the disease.
4. The level of knowledge on HIV and AIDS is low in Jos prison, so intensive and correct information on HIV /AIDS should be routinely made available to all inmates by introducing a well-designed HIV / AIDS information, education and communication sessions in prisons at least twice a year so as to increase their knowledge base on HIV and AIDS.
5. Prisons in Nigeria should be properly funded to meet up with their mandates of reformation, rehabilitation and reintegration of the legally interned.

REFERENCES

[1] Ainsworth, M. and Over, C. (1997) *Confronting AIDS: Public Priorities in a Global*

Epidemic. Oxford: Oxford University Press for the World Bank (1997).

[2] Asuquo, E. F., Adejumo, P., Etowa, J., and Adejumo, A. (2013) Fear of HIV Susceptibility Influencing Burden of Care Among Nurses in South-East Nigeria. *World Journal of AIDS*, 2013(3): 231-238.

[3] Casaux, M., and Reboredo, G. (1998). Empowerment of Patients with HIV Infection, Family and Social Networks for Better Assistance and Quality of Life for all of them. XII International Conference on AIDS, Abstract Book 12, 249, abstract no. 24268.

[4] Fineman, S. (1984) *Social Work: Stress and interventions*. USA: Gower Publishers.

[5] Kangethe, S. (2009) Critical Coping Challenges Facing Caregivers of Persons Living with HIV/AIDS and other Terminally Ill Persons: The Case of Kanye Care Program, Botswana. *Indian Journal of palliative care*, 15 (2): 115-121.

[6] Iwoh, I. (2004). "HIV/and the Workplace: Preventing Low Productivity among Personnel of Nigerian Prison Service." Paper Presented at the 15th International Conference on AIDS, Bangkok, Thailand.

[7] Kalondo, D. (1996). *Care counseling model provides support in resource poor families*. XI International Conference on AIDS, Abstract Book, abstract no. Mo.D.233.

[8] Joshua, I .A & Ogbo, J.S (2008) Sero-prevalence of Human Immunodeficiency Virus. *SWJ*: 17-19

[9] Olayide, A. (2001). HIV/AIDS in Nigeria: The Policy and Policies 3-13.

[10] Olenja, J.M. (1999). Assessing community attitude towards home-based care for people with AIDS (PWAs) in Kenya. *Journal of Community Health*, 24(3), 187-99.

[11] United Nation Office on Drugs and Crime (UNODC-2007). HIV and prisons in sub-Saharan Africa: Opportunities for Action. Vienna.

[12] UNAIDS (2015). *AIDS Epidemic Update: December 2000*. Geneva: UNAIDS and WHO.

[13] WHO (2014), “*Global Health Observatory (GHO)*,” Federal Ministry of Health (FMOH).

[14] WHO (2006), “*Global Monitoring Framework and Strategy for the Global Plan towards the Elimination of New HIV Infections among Children by 2015 and Keeping Their Mothers Alive (EMTCT)*: IATT M&E WG M&E Working Group of the Interagency Task Team on the Prevention and Treatment of HIV Infection in Pregnant Women, Mother, and Children.”

[15] Zarit, S. H., Reever, K. E., and Bach-Peterson, J. (1980) “Relatives of the Impaired Elderly: Correlates of Feelings of Burden,” *Gerontologist*, Vol. 20, 1980, pp. 649-655.