

## **EFFECTIVENESS OF HIV/AIDS-HEALTH LITERACY PSYCHO-EDUCATIONAL INTERVENTION ON PSYCHOLOGICAL WELL-BEING OF INFORMAL CAREGIVERS OF PLWHAs IN IBADAN**

**BY**

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### **Abstract**

*Caregiving to PLWHAs causes burden and bring risks to informal caregivers. In Nigeria, majority of informal caregivers carry out their activities at home lacking sufficient information leading to increased burden, poor psychological wellbeing and loss of confidence among caregivers of PLWHAs. This study therefore developed a training package for the formal training of informal family caregivers and assessed the effectiveness of the psycho-educational strategy intervention on psychological well-being of informal caregivers of PLWHAs in Ibadan. The study adopted the 2 x 2 pretest-posttest control group quasi –experimental design. One hundred (100) informal caregivers of PLWHAs were selected using multi-stage sampling technique from the population of informal caregivers attending two (2) Non-governmental approved HIV/AIDS support and counseling centers formally screened using Zarit Burden interview. Fifty (50) participants each were randomly assigned into psycho-education and control groups. A questionnaire containing Psychological wellbeing ( $\alpha.75$ ) and socio-demographic profile was utilized in the study. Data were analyzed using the descriptive statistics and Factorial Analysis of Covariance (ANCOVA) at 0.05 level of significance. Results demonstrated that there was significant effect of psycho-educational intervention on the psychological wellbeing [ $F_{(1,97)}=68.90, \eta^2 = .43$ ] of PLWHAs caregivers. Psycho-education group expressed better psychological wellbeing and higher caregiving self-efficacy than the control group. Gender differences and the moderating role /effect of caregiving stress were not significant in the study. Psycho-educational strategy intervention was demonstrated to improve psychological well-being and caregiving self-efficacy of caregivers of PLWHAs in Oyo State. The study recommends that caregivers' based psycho-education training be inculcated in HIV/AIDS care services across Nigeria for informal caregivers of PLWHAs.*

**Keywords: PLWHAs caregivers, HIV/AIDS, Psychological wellbeing, Psycho-education, Psycho-educational strategy**

### **Introduction**

Informal caregivers are central to HIV/AIDS care which addresses medical, emotional, adherence, nursing, nursing and financial, spiritual, psychological and material needs of People living with HIV/AIDS (PLWHAs) (Abera Areri, 2019; Wood, Zani, Esterhuizen & Young, 2018). Informal caregivers for PLWHAs are responsible for the provision of high-level activities such as financial management, transportation, communication, shopping, decision making and so on (Wood, et al., 2018). As the disease advances, they render help on more basic activities such as dressing and eating. Families constitute the bulk work force that provides the major proportion of support for

the millions of people living with HIV/AIDs. The parents, spouses/partners, confidants, children, grandchildren, relatives, and friends are the informal care-givers (IOM-US, 2011).

PLWHA's brain, nervous system, intestines and the blood are often damaged by HIV infection. Care required varied for different disease stages and the level of care required varies for different stages of the disease. Cell damages in PLWHAs often results in severe impaired motor functions which brings about body weakness. PLWHA may experience limitations in self-care (Asuzu & Nwangwu, 2012; Schulz, & Eden, 2016; Stellenbosch University, 2017). In recent times, there has been preference for care of the PL WHAs to commence from the hospital to home-based care. Governments in Africa have shifted away from hospital to home-based care to ease the burden on the already strained medical facilities in Africa (Asuquo, Etowa & Akpan, 2017; Okeke, 2016; Wood et al., 2018). Existing infrastructures are totally inadequate to provide in-hospital care. There is great pressure on hospital personnel to discharge AIDS patients quickly with little or no treatment (Okeke, 2016). Thus, patients were often sent back into their communities where their families took on caregiving duties without formal education, training, much preparations or support (Agbonyitor, 2009; Okeke, 2016). As such, HIV/AIDS caregivers' experiences care burden they are unprepared for and witness to the decline in health and traumatic experiences of their loved ones. The multiplicity of the problem of social and financial support, coupled with taboos and stigmatization associated with HIV/ AIDS pose unique challenges for them (Agbonyitor, 2009; Okeke, 2016). These activities often denigrates and affects their wellbeing (Okeke, 2016; Van den Heuvel, Levin, Mpango, Gadow, Patel, Nachega et al., 2019). Poor caregiving can lead to pre-mature death among caregivers. The PLWHAs can quickly progress to the advanced stage of AIDs thus increasing the need for more care for PLWHAs (Okeke, 2016; Van den Heuvel et al., 2019).

Psychological well-being is the physical, mental health, the social participation and financial disposition of caregivers that enable them to carry out care tasks appropriately. It is influenced by individual biological and psychological factors. It laid emphasis on caregivers' deep sense of wellness, vitality, enthusiasm, self-coherence, logical reasoning, competence and feeling fully functioning in care service delivery. There are five components of psychological well-being: career, social, financial, physical and community (Rath & Harter, 2010; Kruger, 2010). Research findings revealed that larger percentage of family caregivers are doing well in only one aspect of the listed areas (Kruger, 2010; Schulz & Eden, 2016; Sherman, Austin, Jones, Stimmerman, & Tamayo, 2016). Struggling in any of these domains damages informal caregivers' psychological well-being and wear out their lives (Gajraj-Singh, 2011; Schulz & Eden, 2016). Those who are thriving well in all the domains experience strengthened psychological wellbeing and better caregiving service delivery and self-efficacy (Schulz & Eden, 2016). However, stressful conditions often lead to familiar overload with problems reconciling familial, parental and working activities (Otis-Green & Juarez, 2012). These physically and psychologically stressful conditions limit caregivers' active engagement, their well-being and indirectly affect the patient who receive care (Otis-Green & Juarez, 2012). In all the status of the care recipients' cognition and mental health predicts caregivers' burden (Huang, et al, 2012). Under the conditions of sound psychological wellbeing studies, lack of preparedness and poor decision making was found to be due to low level of health literacy in HIV/AIDS. These in turn were associated with poor

caregiver psychological wellbeing, poor prognosis and poorer outcome for HIV/AIDS patients (Mukumbang, Knight, Masquillier, Delpont, Sematlane, Dube, Wouters, 2019).

Literacy is the cognitive ability to understand, interpret and implement written or spoken information about health (Cunha, Galvão, Pinheiro & Vieira, 2017). Studies show that the use of educational strategies that take into account functional literacy in health are essential for patients to have appropriate follow-up health guidelines (Cunha et al., 2017). The significant impact of limited health literacy on health outcomes makes health literacy a crucial area for health professionals. Health literacy is considered a multidimensional construct comprised of individual capacities, interpersonal elements as well as broader healthy-tem, and community factors (Yuen, et al., 2016). Low health literacy among people with chronic health conditions has been associated with poorer disease self-management, poorer health out-comes and mortality (Yuen, et al., 2016). Low health literacy has also been associated with gender, lower educational level, race and older age as potential moderators.

However, informal caregivers require large sum of effort, knowledge, and skills to care for PLHWAs and caregiving researches have revealed that caregivers' who is prepared to deliver care have fewer burdens. In caregiving literature, it is obvious that the physical, mental and psychological well-being of caregivers requires health literacy to succeed. Therefore, if effective care and safe caregiving is to be provided, caregivers need be in a state of perfect well-being physically, socially, mentally, psychologically and possess sound literacy about. In addition, if adequate caregiving services are to be provided for PLWHAs, certain needs of the caregivers must be met and addressed. However, health-professionals often fail to identify, treat and refer family caregivers to the appropriate resource centers for emotional or any other kind of support. They do not engage in promotion of healthy life styles among informal caregivers (Family Caregiving and Public Policy, 2006). To fill the missing gap, the development of comprehensive intervention that target the needs of caregivers is helpful. Intervention strategy that focuses on psychological and educational needs of caregiving and of the caregivers themselves are very essential and beneficial (Mukumbang et al., 2019).

Psycho-education refers to the education and psychological counsel offered to the People living with HIV/AIDS and the informal caregivers of people living with chronic ailment such as HIV/AIDS in order to alleviate their caregiving distress (Lukens & McFarlane, 2004) while HIV/AIDS literacy-Psycho-educational package is the composition of carefully selected educational and psychological counsel offered to PLWHAs as well as their informal caregivers in order to alleviate their caregiving distress. HIV/AIDS literacy-Psycho-educational intervention is a feasible intervention that can be employed for decreasing the levels of anxiety and distress of both the care recipients and informal caregivers of people living with any chronic ailments of which HIV/AIDS is inclusive. However, empirical evidence on its efficacy is stilly scanty in sub-Saharan Africa, including Nigeria. This study, was therefore, designed to develop a Psycho-educational Training Package (PeTP) for the informal caregivers of PLWHAs as well as determine its effectiveness on their psychological well-being in Ibadan, Nigeria.

### **Hypotheses**

The following hypotheses were tested at 0.05 level of significance.

- H<sub>01</sub>: There is no significant main effect of treatment on psychological well-being of informal caregivers of PLWHAs
- H<sub>02</sub>: There is no significant main effect of gender on psychological well-being of informal caregivers of PLWHAs
- H<sub>03</sub>: There is no significant interaction effect of treatment and gender on psychological well-being of informal caregivers of PLWHAs.

### **Methodology**

The study adopted the pretest-posttest and control group quasi-experimental design of 2 x 2 factorial matrix. There was an experimental group and a control group. The population for this study consisted of all family caregivers of PLWHAs that were accessing care from FAHPAC and NELAHS' non-governmental HIV/AIDS support and counseling centers. They are the choice of this study because care for PLWHAs are accessed for free and many PLWHAs patronized the centers thereby making it easy for the researcher to have access to large number of informal caregivers of PLWHAs for the study. 100 out of 600 informal caregivers who scored high on caregiving burden but low on caregiving competence and confidence were randomly assigned to psycho-educational package group (50) and the control group (50). The experimental groups were hosted at FAHPAC while the control group were hosted at NELAH. Inclusion Criteria include being 18 years and above be caregivers providing care for individuals experiencing chronic illness of HIV/AIDS. Some informal caregivers were excluded or those less than 18 years, obtained high index score of 70 and above in the screening exercise.

The research instruments used in this study included obtain information on the participants' socio-demographic characteristics such as center code, identification code, religious affiliation, age, sex, state of origin, local government, family type (monogamy or polygamy) family status (intact or broken), birth order (position among other children), level of education and position of caregivers among family members. Goldberg, Gater, Sartorius, Ustum, Piccinelli, Gureje and Reuter (1997) health questionnaire was used to measure psychological well-being: symptoms of social dysfunction, depression, anxiety and insomnia in order to cushion the emotional disturbances of informal care-givers. It has Better than usual (0); Same as usual (1); Worse than usual (2); and Much worse than usual (3) four point likert scale. Reliability coefficient, internal consistency, and test re-test reliability of the instrument were 0.78 to 0.95, 0.93, and 0.94 respectively (Jackson, 2007; López-Castedo & Fernández, 2005) while expert validate the content. Care-giver burden was measured with instrument developed by Zarit et al. (1980) and Bedard et al. (2001). It is designed to measure caregiver burden that is the presence of depression, anxiety and traumatic symptoms of informal caregivers with chronic ailment such as HIV/AIDS. It is the instrument of choice for this study because it is used as a screening tool for caregivers' burden. High burden is seen by higher scores and vice versa and content validity was used for its validity.

Permission to use the public HIV/AIDS facilities was obtained through a letter from the Head of Department of Adult Education, University of Ibadan. The researcher discussed the aim and gain of the intended psycho-educational training package with them. The facilitator's manual developed specifically for the study was collected by each CEO of the two NGO centers for preview. The Family Health and Population Action Committee (FAHPAC) and the NELAH.

After permission had been granted, the researcher met the Executive Officers (CEO) of the two organizations on different occasions at their centers. PLWHAs were asked to identify their HIV/AIDS -Support person who is herein referred to as the patient's informal or family caregiver. The informal caregivers' psychological wellbeing were determined through questioning and the administration of Zarit Burden Interview (Screening Scale Version). The screening exercise lasted for a duration of two weeks in each of the two centers. The screened eligible informal caregivers after the screening exercise were randomly assigned to the experimental group and the informal caregivers that were qualified after screening at the NELAH center were purposively chosen as the control group. An initiation information was collected from participants in the experimental and the control groups. Thereafter, the experimental group was exposed to a psycho-educational package programme.

Curriculum for treatment in the experimental Psycho-educational package group.

- Introduction , Pre-treatment Briefing, General Orientation and Pretest
- Facts about HIV/AIDS
- The role of caregivers
- Challenges of caregiving
- Training on self - mastery of skills for managing infections and AIDS related conditions through modeling .
- Safety precautions for prevention of infection for caregivers, symptom management and care procedures.
- Stress reduction techniques and how to counteract burnout.
- Revision of all session objectives and conclusion of treatment objectives: revision and conclusion of treatment, post treatment testing.

The experimental group was exposed to six instructional period of 1 hour each. In all, the treatment lasted for six weeks. The treatment utilized participatory education techniques such as lectures, role-plays, small group, large group, discussions, brainstorming and individual assignments. The control groups were not given any packages. Post-test data was obtained from experimental and control groups with the use of Psychological Well-being Questionnaire. Data collection from the bio-data questionnaire was collated and analyzed using the descriptive statistics. The hypotheses were computerized and analyzed using a 2 x 2 Analysis of Covariance (ANCOVA) at 0.05 level of significance.

## **Results**

### **Hypotheses testing**

The data collected from the respondents on this were subjected to Analysis of Covariance (ANCOVA), descriptive statistics of mean and standard deviation as well as graphical representation. Results obtained are presented in Tables 1 followed by a detailed discussion.

**Table 1: 2x2 ANCOVA showing the interaction effect of Treatment and gender on psychological well-being of caregivers of PLWHAs**

Source	Type III Sum of Squares	df	Mean Square	F	Sig.	$\eta^2$
Corrected model	9166.697 <sup>a</sup>	7	1309.528	57.075	.000	.813
Pretest	35.601	1	35.601	1.552	.216	.017
Main Effect:						
Treatment	1580.893	1	1580.893	68.902	.000	.428
Gender	64.483	1	64.483	2.810	.097	.030
2 way interaction Effect:						
Treatment * Gender	1.895	1	1.895	.083	.774	.001
Error	2110.863	92	22.944			
Corrected Total	11277.560	99				

\* Significant at  $p < 0.05$

**H<sub>01</sub>:** There is no significant main effect of treatment on psychological well-being of caregivers of PLWHAs. The result in Table 1 reveals that the effect of treatment is significant ( $F_{(1,97)} = 68.90$ ,  $p < 0.001$ ,  $\eta^2 = .43$ ). Therefore, there is a significant main effect of treatment on psychological well-being of caregivers of PLWHAs. To determine the severity of the mean psychological well-being of caregivers of PLWHA scores of participants in each of the groups (treatment and control group), the post hoc is shown in Table.2.

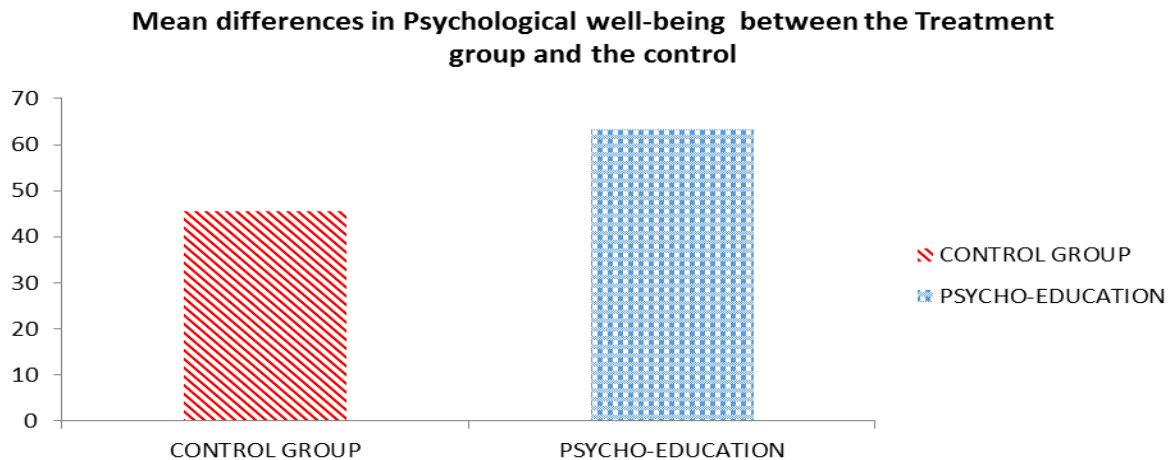
**Table 2: LSD Post Hoc Analysis Showing Mean Differences in Psychological well-being among the treatment Groups**

Treatment group	Mean	S.D	LSD	Sig.
Control group	45.44	1.12		
Psycho-education group	63.41	.93	17.96*	<.001

The covariates appearing in the model were evaluated at the following values: Pretest = Psychological well-being = 43.7400

\*\* mean differences Significant at  $p < 0.01$

As shown in Table 2 the result of the post hoc analysis on the level of differences between the Psycho-education and the control group ( $LSD = 17.96$ ,  $p < .01$ ). The hypothesis was rejected. There was significant main effect of treatment on psychological well-being of caregivers of PLWHAs.



**H<sub>0 2</sub>: There is no significant main effect of gender, on psychological well-being of caregivers of PLWHAs.**

To test the main effect of gender on psychological well-being of caregivers of PLWHAs, the main effect of gender was not significant ( $F_{(1,91)} = 2.81, p > 0.05$ ), on the post-test scores of subjects on psychological well-being of caregivers of PLWHAs. The null hypothesis is thus accepted and the alternate hypothesis rejected.

**H<sub>0 3</sub>: There is no significant interactive influence of Treatment and gender on psychological well-being.**

The data collected from the respondents on this were subjected to Analysis of Covariance (ANCOVA), descriptive statistics of mean and standard deviation as well as graphical representation. Results obtained are presented in Tables 1 demonstrated that there is no significant interactive influence of treatment and gender on psychological well-being of caregivers of PLWHAs in the study was accepted ( $F(1, 92) = .08, p > .05$ ). The null hypothesis is thus accepted and the alternate hypothesis rejected.

**Discussion**

There first hypothesis stated that there will be significant main effect of treatment on psychological well-being of caregivers of PLWHAs was rejected.. This finding supports the previous finding of Okeke (2006) who investigated the effectiveness of social support and self-Efficacy. Findings revealed that both strategies improved the welfare of informal care-givers of HIV/AIDs patients. The findings is also similar to a meta-analysis of 13 studies which asserted that respite interventions on care-givers reduce burden, depression and enhance well-being (Sorensen, 2002; Dellasega & Zerbe, 2002).

The second hypothesis stated that there would be no gender differences in psychological wellbeing in study stated was supported as the current study did not find gender differences in PLWHA caregivers' psychological wellbeing. This finding is in contrast to earlier studies which

have demonstrated that gender play significant role in caregiver's well-being and caregiving outcome. This findings contrasted earlier reports which suggested that women experience more depression and stress than men when caring for HIV patients in United States, Africa, and Thailand (Lindsey et al., 2003; Songwathana, 2001; Wight et al., 2007).

This finding also disagrees with the study of Akintola, (2004) and Orner, (2006) which have demonstrated that caregiving affect women more than men. This is because women or the male caregivers are sometimes found to be playing double role during caregiving activities. Though the impact is greater on the females than male due to gender role expectations. In addition, the third hypothesis stated that there is no moderating influence of gender on the impact of psycho-education on psychological wellbeing was confirmed.

This findings is in agreement with studies which have shown that gender may not affect psycho-educational outcome as most inclusive studies did not disclose gender differences in final outcome for caregivers' wellbeing (Amoateng, Kalule-Sabiti, & Oladipo, 2014; Chi et al., 2019). That is an informative finding in the sense that tertiary and secondary HIV-Care centres should provide health literacy psycho-educational interventions for caregivers of PLWHA that will help them cope better, possibly due to lack of knowledge about the care and prognosis of HIV/AIDS. Therefore the role of the trained counsellors and mental health in assisting providers with their problems needs to be improved among caregivers. HIV-related literacy psycho-educational interventions should be inculcated into service delivery for HIV/AIDS care.

### **Conclusion**

Occurrence of caregiving stress amongst caregivers of PLWHAs is known to affect both the carers and well as the patients. Consequent upon which caregivers experience poor psychological wellbeing. From the results of the present study, it is quite obvious that psycho-education package is an effective intervention for the enhancement of psychological well-being of informal caregivers of PLWHAs.

### **Recommendations**

This study recommends that:

1. Health literacy intervention package of this nature be organized for informal caregivers of PLWHAs to address issues of care, prescription, where to get drugs, drug adherence, nutrition and safety practices would be addressed.
2. Issues of where care givers could get help and seek information about their patients should be addressed. Thus, Counseling Caregivers or providing education is of great importance to a successful caregiving experience of PLWHAs. Information gained from psycho-educational package will put the caregiver in a better position to cope with stressors.
3. The concern of the informal caregivers should be embedded in policies and the difficulty associated with caregiving should be considered too. In doing this, the family unit should be regarded as indispensable. The study had certain limitations.



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