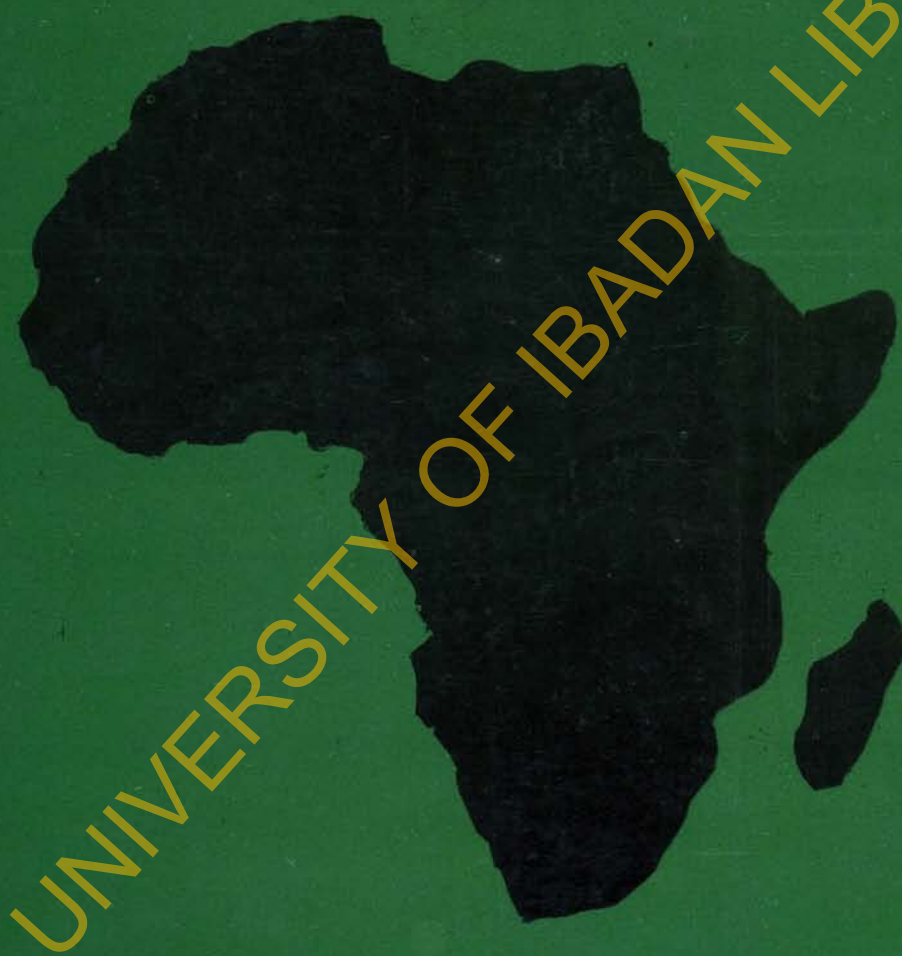


AFRICAN JOURNAL OF MEDICINE and medical sciences

VOLUME 36 NUMBER 1

MARCH 2007



Editor-in-Chief
YETUNDE A. AKEN'OVA

Assistant Editors-in-Chief
A. O. OGUNNIYI
O. D. OLALEYE

ISSN 1116—4077

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The role of support group and duration of infection in HIV/AIDS patients' knowledge and attitudes to their illness

BO Olley

Department of Psychology, Faculty of the Social Sciences, University of Ibadan, Nigeria

Summary

To assess the association between support group membership, socio-demographic and HIV related factors including knowledge and attitude of illness in people living with HIV/AIDS (PLWHAs). Seventy-six participants with HIV who were on follow-up management at three non-governmental care and treatment agencies in south western, Nigeria were asked to complete a questionnaire detailing their demographic characteristics, duration of awareness of HIV status, medication status, membership of a support group, HIV-related knowledge (including number of workshops/seminars attended, reading of literature), and attitude toward their illness and treatment. Compared to those who did not belong to a support group, (34, 45%), those who did (42, 55%) were significantly more knowledgeable about HIV-related ($t=4.02$, $p=0.00$) and also reported more favorable attitudes toward the illness and its treatment ($t=3.38$, $p=0.005$). A multiple regression analysis indicated that group membership and a longer period of awareness of HIV infection contributed significantly to illness knowledge and attitudes. Age, sex, years of education, medication status, and employment status did not contribute significantly to these outcome variables. Individuals living with HIV/AIDS who belonged to a support group and had availed themselves of relevant literature were more knowledgeable and positive about their illness than those who did not belong to support groups. HIV/AIDS support group membership is an important component of psycho-social care in HIV/AIDS patients in Nigeria and should be encouraged.

Keywords: *Support groups; HIV-related knowledge and attitude, antiretroviral therapy*

Résumé

Le but de cette étude était d'évaluer l'association entre le groupe de des supportaire, la sociodémographie et les facteurs liés au VIH inclus la connaissance et l'attitude à la maladie chez les patients ayant le VIH/SIDA (PLWHA). Soixante patients ayant le VIH étaient eu les soins dans trois

organisation non-gouvernemental (ONG) au Sud Ouest du Nigéria, conscient de leur statut du VIH, de leur médication, appartenant au groupe de supportaire, laconnaissance liés au VIH appartenaient (ateliers / séminaires atteint, littéraire) et leur attutide vis-à-vis de la maladie et du traitement. 34.45% appartenaient au groupes sans supportaire et 42.5% des suportaires étaient significativement plus conscient du VIH ($t=4.02$, $P=0.000$) et une attitude plus favorable à la maladie et aux traitements ($t=3.38$, $P=0.005$). Une analyse de régression multiple indiquait que le groupe des supportaires et une longue période de campagne sur l'infection contribuée significativement à la connaissance de la maladie et l'attutide de ces patients. L'age ; le sexe, les années d'éducation ; le traitement et l'emploi ne contribuaient pas significativement aux résultats de ces variables. Les individus vivant avec le VIH/SIDA appartenant aux groupes des suportaires et exposés à une littérature étaient plus conscient et positive a la maladie que autres. Ces supportaires forment une partie importante des soins psychosociale aux patients HIV/SIDA au Nigéria et doivent être encouragés.

Introduction

Nigeria still has the second highest burden of HIV infection in Sub-Saharan Africa, recent declining rate of 4.4% notwithstanding. It is estimated that about 2.9-3.3 million people are living with HIV/AIDS in Nigeria and over 400,000 will require antiretroviral treatment [1]

Health literacy has been reported as an important factor in the health and treatment of people living with HIV/AIDS (PLWHAs) [2]. Consequently inadequate knowledge on the part of these patients and lack of compliance with medical management may impact the course of HIV and lead to faster progression to AIDS. For example, in a community-based sample of 339 people living with HIV/AIDS (PLWHAs) in Atlanta Georgia, United States, it was found that a quarter of them demonstrated lower health knowledge about simple routine medical instructions and this was associated with lower CD4 counts, higher viral loads and less adherence to antiretroviral medications [2].

Inadequate knowledge about HIV/AIDS illness for example may reflect a lack of exposure to information and/or inability to absorb the information because of attitudes to the illness [3]. In certain instances where information is made available, details over time may be forgotten due to coping styles characterized by denial. This behavioral pattern on the part of the patients can reduce the likelihood of adherence to medications [4,5] and increase susceptibility to high risk sexual behaviors [6].

It has been indicated that among PLWHAs there is a relatively low level of adherence to antiretroviral therapy (ARV) [4]. The most commonly expressed reasons for non-adherence include insufficient knowledge about the efficacy of treatment [7] unpleasant side effects, complex and rigid drug routines, lack of acceptance of the seriousness of the illness and the need for treatment and low level of education [7]. However, with the advent of the highly active antiretroviral therapy (HAART), attitudes toward HIV treatment have in some instances been more favorable [8,9]. This notwithstanding, accessibility to HAART is limited especially for PLWHAs in developing countries like Nigeria.

Educating patients about medication regimens, side effects and drug resistance can enhance favorable attitudes toward and therefore adherence to HIV/AIDS treatment. In many instances, PLWHAs have limited access to information and resources. The involvement of HIV support and care groups in many communities though with limited effect on behavior change [9], have filled this gap of information impoverishment [10,11,12]. For example, in a study of 46 seropositive gay men support group participants in United States, Martin *et al* [12] found that patients who participated in support group activities reported less unprotected receptive anal sex at follow-up compared with a control group. However literature on the effect of support group membership on treatment in PLWHAs is sparse and requires further study, particularly in Nigeria with the increasing rate of new infections [13] even with recent reported decline in national prevalence [1].

In this study, we report on the findings of a cross sectional survey investigating the association between support group membership, HIV/AIDS-related knowledge (including workshop attendance, reading literature) and attitudes toward antiretroviral drugs (ARV). We chose to study attitudes toward ARV rather than adherence because of restricted

access to ARV. The majority of patients in Nigeria who were commenced on ARV through the national government ARV initiative program in 18 designated centers in the country did not receive the drugs for several months and owing to the high cost of the drugs could not afford obtaining an alternative supply. In addition, we investigated the influence of sociodemographic variables on HIV/AIDS related knowledge and attitudes towards treatment. We hypothesized that membership of support group and workshop attendance would positively influence knowledge of HIV/AIDS as well as a attitude towards illness and treatment.

In Nigeria several support groups such as Positive Life Association of Nigeria (PLAN) and non governmental organizations for care and support such as Medecin sans Frontieres (MSF) have emerged to meet the needs of individuals living with HIV/AIDS. These groups are facilitated by members themselves with support from several non-governmental and governmental agencies both internationally and locally. For example, PLAN in Ibadan, Nigeria has been involved in several programs aimed at alleviating the distresses associated with living with HIV/AIDS among members. They have an advocacy function. Lectures by experts are organized on occasion. Preventive strategies for re-infection, living a healthy life, and access to ARV form part of the issues discussed at such meetings. Skills in coping with various psychosocial and emotional consequences of HIV/AIDS are also taught.

Method

Procedure

Seventy-six consecutive participants with HIV/AIDS who were attending follow-up management in three non-governmental care and support agencies in Ibadan, Ilesha and Lagos, all in the South Western Nigeria were sampled. After written, informed consent was obtained; they completed self-report questionnaires detailing their demographic characteristics, duration of illness, knowledge of HIV/AIDS and treatment, exposure to workshops/lectures on HIV/AIDS or literature relevant to their illness, and membership of a support group. Part of the questionnaire elicited data on respondents' knowledge of HIV/AIDS and antiretroviral drugs, attitudes with the 18-item version of the HIV Knowledge Questionnaire (HIV-KQ-18) developed by Carey and Schroder [14]. Participants were required to indicate

whether a statement is "true" or "false" or they indicate they "don't know". Items include: "*coughing and sneezing do not spread HIV*", "*a person will not get HIV if she or he is taking antibiotics*" "*there is a vaccine that can stop adults from getting HIV*", "*showering, or washing one's genitals/private parts after sex keeps a person from getting HIV*". This measure has demonstrated good internal consistency (coefficient alpha=0.73, $p < 0.0001$).

Attitudes toward the illness and treatment were assessed with a questionnaire containing 11-items (devised by the author) generated through initial group discussions on 8 PLWHA patients enlisted on the Nigerian government antiretroviral drug initiative. *The patients were drawn from one of the centers designated to administer ARV in Nigeria.* In the ensuing transcription, 15 themes with varying practical and cultural relevance to the attitudes and treatment of HIV/AIDS emerged.

The concurrent validity of the 'attitude' section was examined by getting a physician with more than five years experience in the treatment of HIV/AIDS and who was also blind to the purpose of the study to agree with the items generated and rate them in order of importance. The kappa coefficient (i.e. level of agreement) between physician and patients was +0.90 ($P < 0.001$). Further reliability of the scale was established by pre-testing the 15 items by asking 16 PLWHAs to complete the scale on two occasions (2 weeks apart). Item total correlation of the 15 items ranged from 0.87 to 0.21. Items that had a low correlation were discarded leaving 11 items that constituted the attitude towards HIV/AIDS illness and treatment scale (A-HIV/AIDS). A test-re-test reliability of 0.86 was established. In terms of the internal consistency of responses, the alpha coefficient was 0.68 ($p < 0.0001$).

Items included: "*I do not like the excessive restrictions imposed by taking antiretroviral drugs*". "*People who know I have HIV/AIDS would not want to eat with me for fear of transmission*". "*Antiretroviral drugs are often difficult to access in hospitals*". "*Having HIV/AIDS illness affects whether people want to be friends with me*". "*My physical appearance is beginning to fade away due to taking of antiretroviral drugs*" "*HIV/AIDS has limited the type of food I eat*" "*People living with HIV/AIDS should involve a family member or close friend in taking their antiretroviral drugs*". "*Government programs toward provision of antiretroviral drugs are quite cumbersome*".

The items were scored on a scale of 0 (not at all) to 4 (certainly) with higher scores indicating more negative attitudes toward the illness and treatment.

Biographical details collected were age, sex, medication status, employment status, number of years of formal education, and duration of the knowledge of the illness. Chi-square tests for categorical variables and student t-tests for continuous variables were used to compare differences in socio-demographic characteristics, HIV-related knowledge and attitudes in HIV patients belonging or not belonging to a support group. An average of 14 consecutive days was spent at each location. All patients were reimbursed 150 Naira an equivalent of 1 US dollar.

Data Analysis

Data were analysed with SPSS software version 10 for Windows. First, several univariate tests of association for categorical variables (chi-square tests) and continuous variables (student's t-tests) were done to look for associations between demographic, clinical variables and knowledge or attitudes towards HIV/AIDS. To examine the differences in knowledge and attitudes scores between patients who belong to a support group and those who do not belong, a series of t-tests was done. To examine variables predicting knowledge and attitude, first, a univariate analysis was done using Pearson Product moment correlation. Variables identified as statistically significant were then entered into linear regression models, with both knowledge and attitudes as dependent variables. All statistical tests were two-tailed, using p values of < 0.05 to denote significance and 95% confidence intervals.

Results

Characteristics of the Sample

Of the 81 PLWHAs who were approached to participate in the study, all did so. In the final analysis, five of the questionnaires were discarded as they were substantially incomplete. As presented in table 1, forty-two females (55.2%) and 34 males (44.8%) were included. Their mean age was 28.7 years, S.D. = 6.6 years. The mean duration of knowledge of infection were 4.2 years (S.D = 2.1) (range 6 months to 7 years). The mean year of education was 12.9 (SD= 6.3) (range 8 years to 15 years). Fifty-nine patients (78%) were on 3-combination antiretroviral treatment but stopped owing to lack of access. Twelve

(16%) were at the time of study on various combinations of antiretroviral drugs and antibiotics, while, 5 (6%) were not on any antiretroviral drugs. Forty-two patients (55%) belonged to and had attended at least two or more support group meetings. Of these, 39 (93%) had attended a workshop/seminar discussing HIV/AIDS related issues and had also read the literature, while 3 patients (7%) had not attended any workshops/seminars but had read literature on HIV/AIDS. Of the 34 patients (44.8%) who did not belong to any support group, 13 (38%) had attended a workshop/seminar on /AIDS related issues and had also read some literature, while 21 (62%) had read literature on HIV/AIDS but had not attended workshops/seminars and lectures.

Table 1: Demographic characteristics of 76 patients with HIV infection

Variables	N	%
Male	34	(44.8)
Female	42	(55.2)
<i>Marital status</i>		
Single	39	(51)
Married	31	(41)
Widowed	6	(8)
<i>Support group membership</i>		
Yes	42	(55)
No	34	(45)
<i>Religion</i>		
Christianity	37	(49)
Islam	21	(28)
Others	18	(23)
<i>Drug taking</i>		
Three ARV drugs		
Combinations	59	(78)
ARV/Antibiotics	12	(16)
No ARV drug	05	(06)
<i>Employment status</i>		
Employed	24	(32)
Unemployed	39	(51)
Never employed	13	(17)
	Mean	(SD)
Mean Age	28.7	(6.6)
Mean Years of Education	12.9	(6.3)
Mean duration of infection	4.2	(2.1)

The mean age of support group members was 25.2 years (SD=2.4) and non- members were 24.7 years (SD=3.1). The female/male ratio was 1.04 for the support groups and 1.46 for non-members and the mean duration of knowledge of HIV serostatus was 3.3 and 4.8 years, respectively.

Overall, approximately one-third of the patients were employed with 39(51%) and 13(17%) unemployed and never employed respectively. The employment status among support group members was as follows: - employed 5(12%); unemployed 28(67%) and never-employed 9(21%) and among non-members: employed 19(56%); unemployed 11(32%) and never-employed 4(12%).

HIV-related Knowledge and Attitudes: Compared to those who did not belong to a support group, those who belonged were significantly more knowledgeable about HIV-related matters (23 ± 4.3 vs. 17 ± 2.4 ; $t=4.02$, $p=0.00$), and also reported more favorable attitudes to the illness and its treatment (38 ± 3.7 vs. 35 ± 2.1 ; $t=3.38$, $p=0.005$). Bivariate analysis of the entire sample ($n=76$) found an association ($r=0.78$, $p=0.001$) between greater HIV-related knowledge and more positive attitudes.

Multiple Regression Analysis: Table 2 shows the predictor's of the outcome measures.

Having checked that the data was normally distributed, multiple regression analysis was carried out on the two outcome variables: HIV/AIDS-related knowledge, and attitude towards HIV/AIDS illness and treatment, using the following predictor variables: support group membership, medication status, age, sex, number of years of formal education, employment status, and duration of knowledge of infection. These variables were 'stepped in' if they added statistically significant ($r=0.05$) variance and added at least 1% to the explained variance (r^2). From the table support group membership was the most effective contributor in the explained variance of HIV/AIDS-related knowledge, and attitude towards HIV/AIDS illness and treatment respectively. Of the 21% variance on HIV/AIDS-related knowledge, support group membership accounted for 17% with duration of infection and age contributing 3% and 2% respectively. The R^2 value (adjusted) for attitudes towards illness was 8%, and only membership of support group with 6% explained variance and

duration of infection with 2% explained variance contributed significantly to this outcome variable ($P < 0.05$).

particularly when it has been found that recently diagnosed PLWHAs are more likely to attend support group meetings than longer diagnosed PLWHAs [10].

Table 2: Regression of independent variables on HIV/AIDS knowledge and attitudes towards illness

Independent variables	β	R ² change	Significance
HIV/AIDS knowledge	R ² _{Adj} .21	F=5.54	<0.05
Support group membership	.17	0.09	<0.05
Duration of infection	.03	0.03	<0.05
Age.	.01	0.02	<0.05
Attitudes towards illness	R ² _{Adj} .08	F=3.57	<0.05
Support Group Membership	.06	0.04	<0.05
Duration of infection	.02	0.02	<0.05

Discussion

These findings suggest that those individuals who belonged to and had attended at least two or more support group meetings, were more knowledgeable and held more positive attitudes about the illness (HIV/AIDS) and its treatment than those who did not belong to a support group. These findings support the study by Kalichman and Rompa [2] that found an association between knowledge and attitude toward treatment and illness. In the aforementioned study, an association between knowledge and adherence to antiretroviral drugs was found and not attitudes to treatment. The majority of participants in the present study had had treatment interrupted, thus adherence could not be measured. As this was a retrospective, non-random study, firm conclusions cannot be drawn. While the findings indicate that exposure to specific educational material and support groups is associated with enhanced knowledge and attitudes, it may be that well motivated patients who are keen to learn are more likely to attend groups and avail themselves of information compared with non-members. In other words, it could be argued that it is individual motivation rather than environmental exposure that is more crucial to HIV illness knowledge and attitudes. However, it is worth noting that patients who were better informed and had more positive attitudes were also those who had more recent knowledge of infection. One would have expected an inverse pattern; although feelings of uncertainty about course of illness might have been a motivational factor for seeking information through group membership,

Demographic characteristics did not explain differences in HIV-related knowledge and attitude scores between the groups. Support group members had a higher likelihood of being unemployed than non-members. This finding appears incidental, though; it could reflect the time availability for unemployed PLWHAs to attend support group meetings. Almost all support group members had attended workshops/seminars compared with non-members. Membership may have made access to workshops and seminars easier. It might be suggested that attending workshops/seminars is mainly effective in a group context. It is likely that information obtained from workshop attendance is expanded on and explored in support groups contributing to higher attitude and knowledge scores. We did not confirm previous finding of a positive relationship between higher educational attainment and support group membership [10].

Certain limitations are apparent from this study; firstly, this was a small and highly selective sample that may not be a representative of individual's persons living with HIV/AIDS in Nigeria. While factual knowledge and attitudes appeared to be enhanced by support group membership, it does not infer that group membership alone was contributory. Small sample size of these patients precludes independent analysis of these other confounding variables. Further, the support group educational programme described in here needs to be investigated in a prospective controlled trial before it can be adopted as a recommended therapeutic intervention. Educating patients about illness and treatment involves more than an exchange of information. Increasing patients'

knowledge does not necessarily increase therapeutic compliance unless patients' are taught implementation of this knowledge in their daily routine. These notwithstanding, the present study may serve as reference point for a further investigation of the effect of differential sources of information available to HIV/AIDS patients and their attitudes to illness. HIV/AIDS support groups may serve as an adjunct component of psychosocial care in HIV/AIDS illness in Nigeria.

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Received: 02/01/06

Accepted: 09/10/06