

**Assessment of Palliative Care Needs of Hiv-positive Clients in a Teaching Hospital in South-eastern Nigeria**

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**Abstract**

Human immunodeficiency virus (HIV) infection is a world-wide epidemic but has disproportionately affected developing countries negatively. Despite the positive impact of antiretroviral therapy (ART), HIV-positive clients do experience various needs that require palliative care. In Nigeria, palliative care is still an emerging service not readily accessible, and under-studied. This study assessed the palliative care needs of out-patient HIV-positive clients in a teaching hospital in Southeastern Nigeria.

Using a survey design, a sample of 387 clients was purposively drawn from a population of 4119 confirmed HIV-positive adult clients on ART. Palliative Care Need Assessment Scale (PNAS) was used for data collection. Data were analyzed using percentages, mean scores for Likert scaled items with decision rule at  $\geq 2.5$  for significant needs, MANOVA and MANCOVA at significant level of  $p \leq 0.05$ .

Respondents scored less than the decision mean ( $< 2.5$ ). Female clients reported significantly more psychological problems ( $P = 0.02$ ), Low CD4 cell count ( $< 200$  cells/mm<sup>3</sup>) was inversely proportional to more physical, psychological and socio-cultural needs. Female gender interaction with low CD4, first line of ART and less than 6 months duration of management were inversely proportional to more problems in the physical and psychological domains.

Respondents' self-assessed palliative care need is low. However, female clients with low CD4 cell count, on first line of ART and less than 6 months duration of management experience significant un-met palliative care needs. This vulnerable group should receive priority attention to meet their palliative care needs.

**Keywords:** HIV-positive, needs, palliative care.

**Introduction**

Increasing population of the world is affected by life limiting illnesses such as human immunodeficiency virus/acquired immune deficiency syndrome (HIV/AIDS). Majority of the cases occur

in the developing countries where there is limited access to prompt and effective treatment for these illnesses (World Health Organization (WHO), 2012). Developing countries therefore has been disproportionately affected with nearly one in every 20 adults (4.9%) living with HIV and accounting for 69% of the people with HIV worldwide (WHO, 2013). Of all people living with HIV globally, 9% (3.4 million) are in Nigeria (United Nations Programmes on AIDs, 2014). Approximately 180,000 people died from AIDS-related illnesses in Nigeria in 2015. Since 2005, the reduction in the number of annual AIDS-related deaths has been minimal, indicative of the fact that only half (51%) of those living with HIV in Nigeria are accessing antiretroviral treatment (ART) (Averting HIV and AIDS. HIV and AIDS in Nigeria, 2017). Even with the widespread adoption of Antiretroviral Therapy (ART) in several countries since 1996, and its profound positive impact on morbidity and mortality of the HIV positive clients, HIV/AIDS is still incurable and people living with HIV (PLHIV) continue to need help with the management of pain and other symptoms that affect their quality of life as well as their ability to adhere to treatment (Harding, et al. 2004 and Green, & Horne, 2012).

A study of patients receiving HIV treatment in South Africa found that all participants had at least one symptom; while the nine most prevalent symptoms were feeling sad (64.68%), and irritable (62.08%), numbness/tingling in hands and feet (61.04%), worrying (61.04%), problem with sexual interest and activity (51.95), pain (51.17%), displeased with physical appearance (48.83%), feeling nervous (40.52%), and lack of energy (40.26%) (Farrant, et al. 2012). Furthermore, the study found a high burden of psychological symptoms; with female gender and current CD4 count as significant contributors to the symptom profile in the physical and psychological domains; while increased number of years ( $\geq 2$  years) on treatment was associated with higher burden in all the domains. As a justification for integration of palliative care into HIV/AIDS care, some other researchers in Africa and Asia found that PLHIV that were primarily on ART reported experiencing between 8-18 symptoms at any giving time with the majority reporting at least one symptom. Furthermore, the greater the number of symptoms, the more the palliative care needs that PLHIV report, and the lower their ART adherence level (Green, & Horne, 2012). Poor adherence can lead to an increase in prevalence and severity of symptoms, treatment failure with increased risk of viral mutation and reduced quality of life (Green, & Horne, 2012). It was also observed that, there were varying symptom clusters of concern reported by respondents at different follow up times with medication reported as the most frequent and effective strategy for management, followed by spiritual care and complementary or traditional treatment (Pelter, 2013). In addition to experiencing varying degrees of symptoms/needs researchers report that some demographic and clinical characteristics of the clients influence the symptoms they experience (Uwimana, & Struthers, 2006, Butters, Higginson, George, & Carthy, 2007, Lee, et al., 2009, Farrant, et al, 2012, and Pelter, 2013). Integration of palliative care into HIV services has also been shown to improve clients adherence to ART and life expectancy, thus improve the quality of life of the clients and families (Harding, Selmen & Agupio., 2012).

Palliative care provides an effective model for integrating many aspects of care that are essential in the management of HIV/AIDS (United Nation Programme on HIV/AIDS, 2000). Palliative care is an approach that improves the quality of life of clients and their families facing the problems

associated with life threatening illnesses, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual (WHO, 2012). Provision of satisfying palliative care begins with effective assessment of clients' in order to render care that will meet clients' and their family needs. Needs are the requisites that are necessary in order to perform well and to achieve certain goals. Palliative care needs are the variations in clients needs throughout the illness trajectory (Department of Health, Western Australia, 2008). They include: high physical symptom burden example pain, diarrhea, vomiting, weight loss, etc, emotional distress, anxiety, hopelessness, discrimination, and unmet information and communication needs (O'Leary, et al. 2009). They pose as challenges to clients' quality of life. HIV infection affects not only the client's physical functioning, but also one's emotions, socio-cultural and spiritual wellbeing, as well as that of one's family. The palliative care needs of PLHIV/AIDS fall into four major spheres namely clinical care, social care, spiritual and psychological support. These are the focus for PLVHIV/AIDS needs assessment. The ability to identify these clients' needs and related/causal factors are essential for rational health decisions and actions to address their health problems (Sebuyria, 2013).

Thus the researchers' focus in this study was to assess the palliative care needs of HIV positive clients guided by Engel's Biopsychosocial (BPS) model of illness (1977) (Santrock, 2007). BPS model states that the biological, psychological and social factors are involved in the causes, courses, manifestations and outcome of health and diseases. Each of these factors is not sufficient to bring about health or illness, but the interaction between them contributes to both health and illness. Assessing all the dimensions together is an action in the right direction towards achieving holistic care of a client (Halligan & Aylward, 2006 and Santrock, 2007). Palliative care need awareness came into Nigeria with the HIV epidemic and increasing prevalence of cancer. It has been recognized by government and other stakeholders as an important component of HIV/AIDS and cancer care in Nigeria. However, palliative care is at infancy stage in Nigeria compared to East and South African regions. Although there are some emerging sites mostly located in tertiary health institutions in Nigeria (Soyannwo, 2013).



Figure i: Emerging Palliative Care Sites in Nigeria– 21 States

**Note: \* indicates States with emerging palliative care services**

The palliative care access is far from adequate in the presence of limited expert human resources (Palliative Care Network Community, 2011). Despite the fact that Nigeria has a very high number of PLHIV, with 820 ART sites (United Nations Programmes on AIDs, 2016). And the need for palliative care entrenched in the Federal Ministry of Health, Nigeria (FMOH) Guidelines for HIV/ AIDS treatment and care for adolescents and adults (2010), there is dearth of empirical work on palliative care need assessment of HIV/AIDS clients in Nigeria. Hence this study assessed the physical, psychological, spiritual, socio-cultural domains of palliative care needs of adult HIV-positive clients on out-patient antiretroviral treatment (ART) at a university Teaching Hospital in Southeastern Nigeria, and determined the influence of some demographic and clinical characteristics on clients palliative care needs.

**Methods**

The survey was conducted at the retro-viral disease (RVD) clinic of the study site. From a total population of 4119 confirmed adult HIV-positive clients, 18 years and above registered and accessing ART services at the RVD clinic, a sample size of 387 clients was determined by power analysis and sample units purposively selected from available, eligible and consenting PLHIV. The study was approved by the Research Ethics Committee of the study Hospital. Informed

consent was obtained from the clients after explanation of the purpose and process of the study, and assurance of confidentiality and anonymity of information given. Also administrative permit from the unit administrators was also obtained. Palliative Need Assessment Scale (PNAS) was a 51 item questionnaire used for data collection. The items were adapted from six existing instruments with known psychometric properties, namely; Memorial Symptom Assessment Scale (MSAS), Hospital Anxiety and Depression Scale (HAD), Beck’s Depression Inventory (BDI), Functional Assessment Chronic Illness Therapy-spiritual (FACIT-Sp), Spiritual Need Survey (SNS) and Need End of Life Screening Test (NEST). The PNAS was organized in two sections: section A has 11 items eliciting clients’ demographic and clinical information (CD4 cell count and line of ART elicited from clients’ case file), while section B with 40 items elicited palliative care needs of the clients (physical, psychological, socio-cultural and spiritual domains). The items were structured on a 5-point rating scale of none (0); rarely (1); occasionally (2); frequently (3) and almost constantly (4), with a mean score of 2.5. Negatively worded items with mean scores  $\geq 2.5$  were identified as clinically significant problems/needs requiring palliative care, while positively worded items with mean scores  $\geq 2.5$  indicate non-significant palliative care problems/needs and vice versa. The instrument was face and content validated by three research experts in medical-surgical Nursing. The divergent validity of the instrument was obtained by pilot test using 38 HIV-positive clients at a Federal Medical Center in another State. The divergent validity of the instrument was computed using Pearson Product Moment Correlation, which gave moderate coefficient values that ranged from 0.59 to -0.051 across the four domains. The reliability of the instrument was established using split half technique and computed using Spearman Brown Correlation formula. The coefficient indexes that ranged from 0.67 to 0.86 were obtained across the four domains. Instrument was interviewer administered to the clients by three trained research assistants after obtaining due ethical consent, administrative permission and informed consent from the respondents. Data generated were analyzed with the aid of Statistical Package of the Social Sciences (SPSS) version 18, summarized descriptively using percentages and mean scores, and presented in tables, while hypotheses were tested using Fisher’s (F) test, Multiple Analysis of Variance (MANOVA) and Multiple Analysis of Covariance (MANCOVA) at alpha level of  $P \leq 0.05$ .

**Results**

**Table 1: Demographic Characteristics of the Respondents. (n = 387)**

Variable	Frequency	Percentage (%)
<b>Age Mean</b> 41.5 ±11.1		
<b>Age (Years) Groups</b>		
18-39	188	48.6
40-59	170	43.9
60-75	29	07.5
<b>Gender</b>		
Male	146	37.7

Female	241	62.3
<b>Place of residence</b>		
Same town as the hospital	67	17.3
Near-by-town	209	54.0
Other States	111	28.7
<b>Living arrangement</b>		
Lives alone	61	15.8
Lives with nuclear family	268	69.3
Lives with another family member	47	12.1
Lives with extended family	11	02.8
Lives with a paid person	00	00.0

The respondents' demographic and clinical data as presented on table 1 showed they were between 18 to 70years old, predominantly between 18 and 59years and mean age of 41.5 years. Majority was females (62.3%), and married (51.9%)

**Table 2: Clinical Information Respondents**

(n = 387)

When confirmed HIV positive	Frequency	Percentage
Less than 1 year	40	10.3
1year < 2years	37	09.6
2 < 3years	55	14.2
3years and above	255	65.9
<b>Duration of accessing care at study site</b>		
Less than 6months	23	05.9
6months <1 year	42	10.9
1 < 1 ½ year	18	04.7
1 ½ < 2 years	18	04.7
2 < 2 ½ years	27	06.9
2 ½ years and above	259	66.9
<b>CD4 cell count (cells/mm<sup>3</sup>)</b>		
500 and above cells/mm <sup>3</sup>	132	34.1
200 - 499 cells/mm <sup>3</sup>	206	53.2
Less than 200 cells/mm <sup>3</sup>	49	12.7
Mean CD4 cell count	432.2 cells/mm <sup>3</sup> ±214.3	
<b>Lines of ART drugs</b>		
First line drugs	333	86.0
Second line drugs	54	14.0

The CD4 cell count ranged from 24 to 1157. Most (87.3%) respondents have CD4 count of  $\geq 200$  cells/mm<sup>3</sup>, their mean CD4 cell count was 432.2 cell/mm<sup>3</sup>, while the median was 386.0 cell/mm<sup>3</sup>.

**Table 3: Respondents' Physical Problems that Require Palliative Care (n=387)**

S/N	Physical problem	No (0)	Rarely (1)	Occasionally (2)	Freq. (3)	Almost Constantly (4)	Mean Score ( $\bar{X}$ )	SD
1	Pain	139	120	107	17	04	1.04	0.95
2	Lack of energy	112	92	136	37	10	1.33	1.07
3	Nausea/vomiting	252	88	42	04	01	0.49	0.75
4	Cough	169	93	101	22	02	0.95	0.99
5	Dizziness	198	75	83	22	09	0.89	1.07
6	Loss of appetite	169	88	103	20	07	0.99	1.04
7	Diarrhoea	216	94	67	08	02	0.67	0.87
8	Constipation	305	58	21	02	01	0.28	0.61
9	Mouth sores	283	75	26	02	01	0.35	0.65
10	Dry mouth	294	77	13	03	00	0.29	0.57
11	Itching	173	111	88	12	03	0.87	0.92
12	Numbness/tingling in hands/feet	304	51	26	04	02	0.32	0.69
13	Hair loss	351	27	09	00	00	0.12	0.39
14	Weight loss	175	81	113	14	04	0.94	0.99
15	Cannot carry out my activities of daily living like bathing, oral care, washing	293	58	28	04	04	0.37	0.75

clothes etc.								
<b>Total</b>	3433	1188	963	171	50	9.90	12.31	

**Table 4: Respondents’ psychological problems that require palliative care. n=387**

S/N	Psychological problem	No (0)	Rarely (1)	Occasionally (2)	Freq. (3)	Almost Constantly (4)	Mean Score (X̄)	SD
16	I am more irritable than usual	178	115	77	15	02	0.83	0.91
17	I feel miserable and sad	123	122	112	27	03	1.13	0.97
18	Worrying thoughts go through my mind	65	102	191	19	10	1.50	0.92
19	I wake early and then sleep badly for the rest of the night	205	86	79	12	05	0.78	0.96
20	I get frightened or have panic feelings for apparently no reason at all	282	64	30	08	03	0.41	0.78
21	I have lost interest in things/people	225	99	49	09	05	0.63	0.88
22	I feel discouraged about the future	177	83	99	22	06	0.96	1.04
23	I feel guilty	227	84	61	10	05	0.66	0.92
<b>Total</b>		1482	755	698	122	39	6.90	7.3

**Table 5: Respondents’ spiritual problem that require palliative care (n=387)**

S/N	Spiritual problem	No (0)	Rarely (1)	Occasionally (2)	Freq. (3)	Almost Constantly (4)	Mean Score ( $\bar{X}$ )	SD
24	I need to review my life	76	95	132	58	26	1.65	1.15
25	I need spiritual or religious community to help me in my personal spiritual going	101	103	106	38	39	1.51	1.26
26	I need someone to talk to about death and dying	272	76	24	08	07	0.45	0.85
27	I need to forgive myself and others	147	81	108	35	16	1.20	1.16
28	I need a quiet space to mediate /reflect/pray	109	62	142	47	27	1.54	1.22
29	I still finds reason for living even during difficult times	16	12	56	82	221	3.24*	1.08
30	I am grateful to God for my life	01	02	13	47	324	3.79*	0.55
	<b>Total</b>	722	431	581	315	660	13.38	7.27

\* means score > 2.5

**Table 6: Respondents' socio-cultural problems that require palliative care. n = 387**

S/N	Socio-cultural problem	No (0)	Rarely (1)	Occasionally (2)	Freq. (3)	Almost Constantly (4)	Mean Score ( $\bar{X}$ )	SD
31	I can make acceptable decisions about my care	03	05	31	57	291	3.62*	0.75
32	I get information about my health status from my professional health care givers	02	00	37	126	222	3.46*	0.71
33	My caregivers help with activities I cannot do myself like bathing, washing my clothes, cooking	216	53	56	19	43	1.02	1.38
34	I am treated as an outcast in my community	346	23	7	8	03	0.19	0.64
35	My family members do not relate freely with me	273	49	54	9	02	0.50	0.86
36	My family and children are avoided in the community	340	30	10	6	01	0.19	0.57
37	I feel ashamed to mix up with people in my work place and community	234	54	76	18	05	0.72	1.01
38	I still maintain my position in my group/community	24	20	62	137	144	2.92*	1.14
39	My caregivers respect me as an individual	14	16	61	129	167	3.08*	1.04
40	My illness poses financial burden on my family/friends	97	171	94	15	10	1.15	0.93
	<b>Total</b>	154	421	488	524	888	16.8	9.0

**\*means score > 2.5**

Each respondent reported at least 2 needs at varying degrees in each domain.(Tables 3;4;5 and 6), but each item mean score was < 2.5. Lack of energy was the most prevalent problem in the physical domain with mean score of 1.33 and 47.3% respondents reporting that the problem occurs occasionally to almost constantly (Table 3). In the psychological domain, worrying thoughts was the most prevalent problem with mean score of 1.50 with 56.8% respondents experiencing the problem occasionally to almost constantly (Table 4). Being grateful to God had the highest score of 3.79 while the need to discuss death and dying with someone had the least score of 0.45 in the spiritual domain (Table 5). The high mean scores of items in the spiritual and socio-cultural domains indicate respondents did not experience problems in these areas as they were positively worded. Lastly, in the socio-cultural domain, the ability to make acceptable decision about healthcare ranked highest (3.62) while being treated as an outcast in the community and children being avoided in the community had the lowest score of 0.19 (Table 6). Analysis of the hypotheses showed that, female respondents reported significantly more psychological problems (P= 0.02) than the males. Respondents with low CD4 cell count (< 200cell/mm<sup>3</sup>) reported significant physical, psychological and socio-cultural needs (P = 0.00, P=0.00; P = 0.01 respectively). MANCOVA analysis showed that, female gender interaction with low CD4 (<200 cell/mm<sup>3</sup>) was related to more physical (P = 0.04) and psychological needs (P = 0.02). Female respondents on first line of ART had more physical (P = 0.02) and psychological needs (P = 0.01). Also female gender interaction with less than 6 months duration of management was inversely proportional to more problems in the physical and psychological domains (P = 0.02; P = 0.00 respectively). Interaction with age as a co-variant showed no significant relationship.

**Discussion**

This study assessed the palliative care needs of HIV-positive clients that will inform appropriate approaches that may help resolve clients' problems and improve their quality of life. However respondents' reported physical, psychological, spiritual and socio-cultural problems that require palliative care services were minimal and not statistically significant. This may be due to the fact that most (73.8%) respondents have been on the ART treatment for more than two years and receiving supports of family members and clinic staff as well as developed some self coping strategies. The homogeneity of the study sample drawn from population of ambulatory HIV-positive clients that access expert tertiary health care services at one retroviral outpatient (RVD) clinic, excluding those that access services at other secondary out-stations of the institution, those not on ART treatment in the communities, those with AIDs or were on admission in the wards may explain the low level of palliative problems/needs identified in this study.

The result showed that majority (69.3%) of the respondents resides with their nuclear families which were supportive. Also the formal health care professionals at the clinic in the process of disclosing clients' HIV status counsel and support them to make decisions/adjustment about their

health care. Similarly, the result revealed that majority of the clients reside in nearby towns to the hospital away from their communities or travel a long distance to access health services, which may be a strategy utilized by the clients to fight against social stigma and discrimination in their communities where people know them.

Although lack of energy was the highest recorded need in the physical domain (mean = 1.3), and worrying thought was the most prevalent in the psychological domain (mean =1.5), respondents were still highly grateful to God for their lives and think they have every reason and desire to continue living (mean score > 2.5) which we believe could be their coping strategies. This finding was consistent with the idea that when people encounter difficulties in life, example being diagnosed of incurables disease as HIV-infection, they report an increase in religious spirituality with belief and hope that God can cure/heal them, and incorporate their understanding of God as a coping strategy (YYYY, Ezeome, Ofi, Nwaneri, & Ogbolu, 2015).

We also found that more females (62.3%) respondents than males (37.7%) reported psychological problems requiring palliative care. This may be due to personality trait of females that makes them to be more likely to complain of symptoms and be depressed (International Communication, Relations and Compatibility, 2014 and Ask Women Net, n.d).

Respondents with low CD4 cell count (< 200cell/mm<sup>3</sup>) reported more physical and psychological palliative care needs. This supports the idea of clinical staging of HIV by World Health Organization (WHO), where CD4 cell count less than 200cell/mm<sup>3</sup> is classified as stage 3, disease during which the client has multiple physical symptoms due to presence of opportunistic infections. Also applying the principle of bio-psychosocial model of illness, the clients' emotional status may also be negatively affected, but the spiritual domain may be enhanced as respondents increase in their religious spirituality behavior as a coping strategy. These observations may explain the female gender interaction with low CD4 cell count, first line of ART and less than 6months duration of care with high significant (P<0.05) prevalence of physical and psychological palliative care needs among the respondents. First six months of therapy is a period of adjustment to ART when early side effects of treatment like fatigue is expected. In other words with low CD4 cell count, first line of ART, less than 6months duration of care and female gender accounted for the highest symptom burden experienced by these respondents. Similar findings have found that female HIV-positive clients reported more symptom burden (Lee, Gay, & Porfillo, 2009 and Farrant, et al, 2016). However, the findings of this research contradicts that of other studies that identified inadequate information to plan for further care and communication with health professionals as the most burdensome needs of HIV-positive clients (Uwimana, & Struthers, 2006 and Butters, Higginson, George, & Mc Carthy, 2007). Also increased number of years on treatment was associated with high burden of symptoms among HIV-positive clients in South Africa. (Farrant, et al, 2016). These differences may be because in our grouping of duration of treatment, respondents with two years and above were lumped together; whereas long term side effects of ART may begin to manifest above five years and are seen more with patients on second line therapy (WHO, 2016). Switching to second line therapy occur in cases of resistance to first line therapy with low CD4 count, increased viral load, increased symptoms (WHO, 2016).Preponderance of the current study respondents were on first line ART.

A major strength of our study was its ability to demonstrate that HIV-positive respondents experience various palliative care needs at different degrees. To achieve this, we used weighted mean scores to compute the degrees of palliative care needs among the respondents. Also, this study adapted an instrument that offered comprehensive/holistic assessment of the major domains of clients' health successfully enabled by the Bio-psychosocial model of illness in order to identify any need that may affect clients' health status, ART adherence and thus clients' quality of life. The study was able to establish that link exists between female gender, CD4 cell count, line of ART and duration of care with degree of palliative care needs of clients.

The non-probability sampling procedure did not give all the clients equal choice of being selected. Hence, clients with much need who may be tired and not interested may not have been captured in the selection process. These limitations inform the limitation of generalization of findings to the study population only and not to the wider population of HIV-positive clients and the recommendation for community based studies.

### **Conclusion**

This study results indicated that the palliative care needs were low among the clients studied. However female clients with low CD4 cell count, on first line of ART, and with less than 6 months duration of care reported significantly more physical and psychological palliative care burdens. HIV-positive clients with similar characteristics should be regarded as high risk and vulnerable group for priority palliative care attention. This study further supports the need for regular comprehensive assessment of HIV-positive clients, with a view to identifying and resolving their needs timely, thus improving their quality of life. There is a need for further studies that can capture clients not on treatment, those with AIDs and in their homes and communities.

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