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INFLUENCE OF HOME-BASED CARE ON THE QUALITY OF LIFE OF PEOPLE LIVING WITH HIV/AIDS IN CROSS RIVER STATE, NIGERIA

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ABSTRACT

HIV/AIDS is a chronic progressive disease which threatens the quality of life of the infected and affected. Home based care is seen as one of the strategies to enhance the quality of life of PLWHA. Therefore, the main purpose of the study was to ascertain the relationship between home-based care and quality of life of PLWHA in support groups in Calabar South Local Government Area. A correlational design was utilized and a purposive sample of 74 PLWHA participated in the study. A self developed and well validated questionnaire was used for data collection. Descriptive statistics was used to analyze socio-demographic characteristics and Pearson Product Moment Correlation was used to test hypotheses. The result obtained showed that most of the respondents 31 (41.89%) were between the ages of 20-30, followed by those below the age of 20 which had 22 (29.73%) respondents. Majority of the participants were females 50(67.57%). Regarding education, majority of the respondents 31(41.89%) had attended secondary school while 20 (27.03%) had no formal education. Furthermore, the results showed a significant positive relationship between home-based psychosocial care and psychosocial quality of life of PLWHA (r cal =.40; r crit =.302; df =72; p< 0.01) and home-based nursing care and physical quality of life of PLWHA (r cal =.47; r crit =.302; df 72; p<0.01). It was therefore concluded that home- based care could promote the psychosocial and physical quality of life of PLWHA. The recommendation was that home based care should be encouraged and given priority by stake holders in the management of PLWHA.

KEY WORDS: home-based care, quality of life, basic nursing care, psychosocial care.

INTRODUCTION

HIV/AIDS is a chronic progressive disease which threatens the quality of life of the infected and the affected. UNAIDS estimated that at least 33.3 million people lived with HIV/AIDS in 2009, with 1.8 million HIV/AIDS related deaths, and 2.6 new infections (Joint United Nations Programme on HIV/AIDS (UNAIDS), 2010). Opiyo (2008) also stated that many African countries have a prevalence rate of over 15%. Nigeria had 2.98 million infected people with adult prevalence rate of 3.6 and orphans were 2,175,760 as at 2009 (United Nations General Assembly Special Session (UNGASS) 2010; UNAIDS, 2010). Actually, countries with high prevalence have overstretched health systems, lack resources and have the lowest level of hospital bed and health worker per person which overburdens the health care delivery system (John, Ndebbio, Duke, Essienumoh & Robinson-Bassey, 2008; Avert 2009).

HIV/AIDS is accompanied by some manageable symptoms such as fatigue, anorexia, weight loss, depression, agitation and anxiety, nausea and vomiting, diarrhea, cough, dyspnoea, fever, sweats and pruritis (Selwyn & Rivard, 2003; Fantoni, Ricci & BelBorgo et al 1996) as well as inadequate pain control (Breitbard, Mc Donald, Resenfeld et al, 1996) at all stages of HIV/AIDS. These symptoms suffered by PLWHA negate the performance of their day to day tasks and enjoyment of life and wellbeing. In a report from Malawi just 15% of PLWHA were able to live as if they didn't have the disease. More than one third needed help with washing and walking, and 28% needed help to go to the toilet (Bowie et al 2006). Similar results were reported from studies in South Africa (Steinerg et al 2002).

Furthermore, HIV related tasks include purchasing, administration and supporting adherence to Anti Retro Viral drugs and medication for pain if the infected person is receiving such treatment, as well as helping with nutrition, as the person's diet may differ from other members of the house-hold. Monitoring and recording progress, making notes of events such as toilet visits, fluid intake and symptom occurrence are also other task that can be undertaken by family, friends neighbours and home-based care workers and volunteers (HIV/AIDS Treatment in Practice, 2000; Avert, 2009). These very practical measures are in addition to meeting the person's psychosocial needs, which are often broader and more severe with HIV/AIDS infection.

Actually, the care for HIV infected is multidisciplinary in approach which should progress on a continuum from the hospital to palliative care at home and the community (John et. al, 2008). However, because of high cost of institutionalized care for PLWHA and sometimes discriminatory attitude of health care workers towards HIV infected persons, many people living with HIV infection prefer to stay at home and treat themselves with traditional and home remedies rather than go to the hospital (John et al, 2008; Ogden et al 2006). Sometimes long distance and cost of transportation to the health facility including fear of

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stigmatization by the public may also hinder the utilization of institutionalized medical care, thus implying the need for home-based care (HBC) for PLWHAs. In Nigeria, according to John et. al (2008) three quarter of PLWHA prefer to be cared for at home in order to avoid discrimination, abandonment, and taunting by health care workers in the health facilities. However, the numbers of home care organizations are few; with the above mentioned challenges is there any relationship between home-based care and quality of life of PLWHAs? This poser can only be unraveled at the end of this study. This study will add to the current literature on home-based care and PLWHA. It will also create awareness on the impact of home care organization activities. It will help planners to know the impact of home-based care on the quality of life of PLWHA, thereby designing intervention to meet their needs.

The main aim of the study is to ascertain the influence of home-based care on the quality of life of PLWHA. Specifically, the objectives are:

(1) To assess the type of care received by PLWHA from home-based care organizations
(2) To ascertain the influence of psychosocial care on psychosocial quality of life of PLWHA
(3) To determine the relationship between basic nursing care and physical quality of life of the PLWHA
(4) To measure some aspects of health-related quality of life of PLWHA receiving home-based care.

LITERATURE REVIEW

HBC is defined as the provision of consistent high quality care for a period of six months and beyond for PLWHA and the care consist of psychosocial and spiritual counselling, provision of basic care kit (ITN, water guard, painkillers (paracetamol or aspirin), calamine lotion, antiseptic soap, disinfectant, oral rehydration solution (ORS), bandages cotton wool, gloves, vaseline, pail etc); provision of basic nursing care where applicable (oral toilet, wound dressing, bed bathing, preparation of ORS, giving of medications, tepid sponging and treatment of pressure areas, provision of nutritional and drug adherence education). HBC is given by Non-Governmental Organization (NGO) or Faith-Based Organisation (FBO), trained health workers or volunteers linked to hospitals. The care givers make visits to PLWHA's homes 2-3 times a week for perhaps one or two hours to render the above mentioned care.

Ogden et al (2006) asserted that maintaining regular contact with a home-based care giver will also relieve a sense of isolation that the ill persons and their families may be facing. Furthermore, a home-based and PLWHA's relationship can serve as a gateway to accessing avenues of psychosocial support during patient's illness and following death.

Quality of life (Qol) is defined as individual's perceptions of their positions in the life context of the culture and value system where they live, and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept, incorporating in a complex way a person's physical health, psychological health, level of independence, social relationships, personal beliefs and relationship to salient features of the environment (World Health Organization, 1996; Elisabete, Morandi, Ivan, & Fermanda, 2007). In this study, QoL is the perception and satisfaction by PLWHA of their overall health in relation to the care given by a home based organization

In a review of 17 studies on the relationship between a home based care and quality of life of patients, the results demonstrated that home-based palliative care significantly improved patients' outcomes in the domains of pain and symptoms control, anxiety, insight and spiritual well-being and these outcomes related to physical, emotional and spiritual quality of life (Harding, Karus, Easterbrook, Raveis, Higginson & Marconi, 2004).

Indeed, achieving a better quality of life is a major goal in the care of patients with terminal diseases including HIVAIDS. In a related study on the quality of life of cancer patients receiving in-patient and a home-based palliative care, the result affirmed that patients receiving a home-based palliative care had statistically significantly less symptom severity and distress, lower depression scores and better physical health and quality of life than those receiving in-patient care (Peters & Sellick, 2006). Further results from the study showed that home-based care patients also reported statistically significantly more control over the effects of their illness, medical care and treatment received, and the course of the disease. Additional results revealed a better general physical health, greater control over the effects of cancer and lower depression score being statistically significant predictor of higher quality of life (Peters & Sellick, 2006).

The benefits of a home-based care are numerous: permits care in familiar environment, increases ownership of the problem, increase longevity of life, reduces frequency of infection, reduces both macro and micro cost of health care and has the potential of offering emotionally satisfying palliative care to PLWHA thereby improving the quality of life and assisting them cope with depression and stigma (WHO, 2001; Layzell & Mc Carthy, 1992; John, 2001; Ogden et al, 2006; Tanzania Commission for AIDS, 2008; Waran, 2002).

Though home-based palliative care is one of the most important forms of care for individuals with progressive or far advanced illness, millions do not have access to HBC because few organizations offer these services, so they continue to endure pain or psychosocial and spiritual sufferings and reduced quality of life. Millions more struggle to care for their sick and loved ones or grieve their loss. However, the few NGOs or FBOs that offer home based care are faced with challenges such as work overload, complaints of short stay from the clients, infrequent home visits, lack of funding, lack of materials such as food, inadequate supplies in the home care kits, deteriorating physical health of the caregivers: such as headaches, body pains, back aches and exhaustion (Orner, 2006). These challenges tend to influence the type of care received by the clients thereby negating the quality of life of the patients.

Statement of the problem

The institutionalized palliative care usually has positive impact on the health of PLWHA but this care lacks continuity at home. Therefore, observation and interaction with PLWHA revealed that they normally look healthy and feel happy before discharge implying a better quality of care while in hospital.

However, records reveal that about 38 to 54 per cent of PLWHA usually come back for readmission and a few even die. Indications from hospital records in the setting of the study showed that 5 out 8 PLWHA are re-admitted within a period of six months. The re-admissions add to the burden of the health care system which already has minimum resources. In addition, family members and significant others are affected because of the needed support during hospitalization.

Investigation into the cause of readmissions revealed that a few who do not come back have a continuum of care and support from family members and home-based care organizations. Evidence in developed countries abound that being cared for at home is an important determinant of the quality of life (Waran, 2002; Peter& Sellick, 2006; Harding et al 2004; Inter Press Services, 2005; Marconi, 2005). Unfortunately, there are no studies in the setting of the study on the impact of home-based care on the quality of life of PLWHA, therefore, the need to carry out this study.

Theoretical framework

Orem Self Care theory was used as the theoretical framework to study the relationship between a home-based care and the quality of life of PLWHA. Orem's theory consists of three related concepts: self care, self care deficit and nursing systems (Berman & Snyder, 2008). The ability of the PLWHA as a self care agent to carry out self care activities relates to and impacts on their quality of life. The home-based care organization is regarded as the dependent care agent that renders care when PLWHA are weakened by disease or are disabled. The home-based care organization's ability to render care also relates to the quality of life of PLWHA.

Therapeutic Self Care demands are directed at meeting the self care requisites or self care needs of PLWHA resulting in maintenance of health and wellbeing, which also relates to the quality of life of PLWHA. In this case of self care deficit, home-based care providers use five methods of helping: guiding, teaching, supporting, providing an environment that promotes individual's abilities, current and future needs. The three nursing systems: wholly compensatory, partly compensatory and supportive educative could also be used by home based care givers to improve the quality of life of PLWHA.

METHODOLOGY

A correlational design was utilized to establish the relationship between home-based care and quality of life of PLWHA. The study area was Calabar South Local Government Area which is one of the local government areas out of 18 in Cross River State. Its headquarter is Anatigha and it is made up of 12 wards. There are 10 HIV/AIDS support groups in Calabar South, PLWHA Operated by an NGO.

The total number of clients in these 10 HIV/AIDS support groups was 168. Three support groups out of 10 were purposefully selected for the study because of their regularity and consistency in attending meetings. The sample size was 74, this constituted 44% of the total population of the study: group I = 30, group 2 = 18, group 3 = 26.

The instrument for data collection was a well developed structured questionnaire with 33 items. Section A consisted of 8 items on socio-demographic data of the respondents; section B was made up of 10 items: while section C had 8 items and D had 7 items which covered the indicators of the quality of life as stated in the WHOQOL-BREF with regards to physical and psychosocial quality of life respectively (WHO, 1997). Additionally, National Center for Chronic Disease Prevention and Health Promotion (CDC) Health-Related Quality of Life Instrument which has 4 items was used to measure the health related quality of life (CDC, 2005). Section B of the questionnaire was rated from 1-5 of which 5 signified the highest score. Sections C and D were rated as 0-1 of which one signified the higher score. Higher scores signified better care from HBO and higher quality of life. A test retest reliability of the instrument showed a correlation coefficient (r) of .72. Descriptive statistics was used to analyze the socio demographic characteristics while Pearson Product Moment Correlation (r) was used to test the hypotheses used in the study.

A written permission to carry out the study was sought from the NGO rendering the home-based care to PLWHAs and consent was given. A verbal consent was also obtained from the participants. Anonymity was ensured by not writing names on the copies of the questionnaire.

RESULTS

Table I: Socio-demographic Characteristics of Respondents

Characteristics	Number	Percentage
Sex: Male	24	32.4%
Female	50	67.6%
Age : < 20	22	29.7%
20-30	31	41.9%
30-40	15	20.3%
50 & above	6	8.1%
Marital status: Single	25	33.8%
Married	21	28.9%
Divorced/separated/widowed	28	37.5%
Occupation: unemployed	32	43.2%
Trading	20	27.%
Farming	12	16.%
Civil servant	10	13.5%
Religious: Christianity	38	51.%
Islam	21	28.9%
Traditional religion	15	20.3%
Qualification: No formal education	20	27.%
Primary	17	23.%
Secondary	31	41.9%
Tertiary	6	8.11%
Ethnicity: Efik	12	16.%
Ibibio/Anang	16	21.6%
Ekoi/Ejagam	12	16.%
Igbo	14	18.9%
Others	20	27.%
Monthly income: Less than N20,000.00	28	37.8%
N21,000.00 – N30,000.00	15	20.%
N31,000.00 – N40,000.00	13	17.6%
N41,000.00 – N50,000.00	10	13.5%
N50,000.00 and above	8	10.8%

The results presented in Table 1 shows socio-demographic characteristics of 74 respondents who participated in the study. Majority of the respondents were females 50(67.6%). Thirty one respondents (41.9%) were between the ages 21-30, which constituted the majority in the group. The respondents were predominantly unemployed 32(43.2) with secondary education being 31(41.9%) followed by no formal education 20 (27%), only 6(8.1%) had tertiary education. Most of the respondents were Christians 38 (51.45%). As regards income level, a majority of the respondents earned less than N20, 000.00

The results in Table 2 showed that more than 37 (50%) of the respondents rated the care they received from a home-based care organization from good to excellent. Such care included psychological/spiritual counseling, nursing care, promotion of safer sex, referral to hospitals and support groups, nutrition and drug education among others.

In Table 3, the results highlighted the influence of home-based care on the quality of life of PLWHA. The results revealed that more than 46 (62%) of the respondents affirmed that home-based care influenced their lives positively.

The result in Table 4 showed a weak positive relationship between psychosocial care and psychosocial quality of life of PLWHA. The calculated r-value of .40 is greater than the crit-r-value of .302 needed for significance at the 0.01 level of significance with 72 degrees of freedom. It therefore implies that there exists a significant relationship between psychosocial care and psychosocial quality of life of PLWHA. Hence the null hypothesis is rejected at 0.01 level of significance.

Table 2: Respondents' assessment of the quality of home-based Care in Calabar, Cross River State.

S/N	Items	Excellent	Very good	Good	Bad	Very bad	total
	Please rate the following home-based care accordingly:						
1	Psychological counseling	41 (55.4%)	20 (27%)	13 (17.6%)	0 (0%)	0(0%)	74 (100%)
2	Spiritual counseling	40 (54.1%)	16 (21.6%)	15 (20.3%)	3(4.1%)	0 (0%)	74 (100%)
3	Referral to support groups	34 (45.9%)	21 (28.4%)	15 (20.3%)	4 (5.4%)	0 (0%)	74 (100%)
4	Advocacy to fight stigma	37 (50%)	17 (23%)	19 (25.7%)	1 (1.4%)	0 (0%)	74 (100%)
5	Raising awareness on HIV/AIDS	43 (58.1%)	21 (28.4%)	8 (10.8%)	2 (2.7%)	0 (0%)	74 (100%)
6	Referral to hospital for treatment	38 (51.4%)	21 (28.4%)	6 (8.1%)	7 (9.5%)	2(2.7%)	74 (100%)
7	Provision of nursing care	37 (50%)	17 (23%)	19 (25.7%)	1 (1.4%)	0 (0%)	74 (100%)
8	Drug education	32 (43.2%)	13 (17.6%)	19 (25.7%)	10(13.5%)	0 (0%)	74 (100%)
9	Nutrition education	33 (44.6%)	16 (21.6%)	21 (28.4%)	2 (2.7%)	2 (2.7)	74 (100%)
10	Promotion of safer sex	37 (50%)	24 (32.4%)	12 (16.2%)	1 (1.4%)	0 (0%)	74 (100%)

***Figures in parentheses are percentages**

Table 3: Influence of Psychosocial and nursing care on quality of life of PLWHA in Calabar, Cross River State.

S/N	Statement	Agree	Disagree	Total
	Psychosocial care has helped me in achieving the following :			
1	Freedom from anxiety	58 (78.4%)	16 (21.6%)	74(100%)
2	Absence of depression	55(74.3%)	19 (25.7%)	74(100%)
3	Enjoyment of a sound sleep	57 (77%)	17 (23%)	74(100%)
4	Freedom from self stigmatization	52 (70.3%)	22 (29.7%)	74(100%)
5	Acceptance of HIV status	52 (70.3%)	22 (29.7%)	74(100%)
6	Freedom from guilt	46 (62.2%)	28 (37.8%)	74(100%)
7	Having faith in God	59 (79.7%)	15 (20.3%)	74(100%)
8	Increased participation in church activities	59 (79.7%)	15 (20.3%)	74(100%)
	Nursing care rendered has helped me in achieving the following :			
9	Wound healing within 6 weeks	46 (62.2%)	28 (37.8%)	74(100%)
10	Adhere to my drugs	52 (70.3%)	22 (29.7%)	74(100%)
11	Adhere to my diet	52 (70.3%)	22 (29.7%)	74(100%)
12	Maintain intact skin	52 (70.3%)	22 (29.7%)	74(100%)
13	Work effectively for livelihood	52 (70.3%)	22 (29.7%)	74(100%)
14	Conserve energy for daily activities	52 (70.3%)	22 (29.7%)	74(100%)
15	Live independently	54 (73%)	20 (27%)	74(100%)

***Figures in parentheses are percentages**

Table 4: Pearson Product Moment Correlation Coefficient Analysis of the relationship between psychosocial care and psychosocial quality of Life of PLWHA

n = 74

Variable	x —	SD	n	r - cal	Remarks
Psychosocial care	24.64	5.70	74	.40	Significant
Psychosocial quality of life	5.92	3.03	74		

P<0.01; df=72; crit r =.302

Table 5: Pearson Product Moment Correlation Coefficient analysis of the relationship between basic nursing care and physical quality of life of PLWHA

Variable	Mean x	SD	n	r - cal	Remarks
Basic nursing care	15.66	4.15	74	.47	Significant
Physical quality of life	4.86	2.78	74		

P<0.01; df=72; crit r =.302

The result in table 5 showed that the calculated r-value of .47 is greater than the critical r-value of .302 required for significance at 0.01 alpha level with 72 as degree of freedom with this result the null hypothesis is rejected. This implies that there is a significant relationship between basic nursing care and physical quality of life of PLWHA.

The result from table 6 shows that with regards to general health, a majority of the respondents had good general health. Majority also had good physical health, but when it came to mental health, fair and poor mental health was observed. The result also showed that poor physical health prevented the respondents from carrying out their usual self care activity of daily living.

Table 6: Some aspects of health-related quality of life of the respondents who received home-based care in Calabar, C.R.S.

n = 74

	Items			**Responses**		
		1-6 days (Excel-lent)	**7-12 days** (Very good)	**13-18 days** (Good)	**19-24 days** (Bad)	**25-30 days** (Very bad)
1	Generally what will you think about your health	3 (4.05)	7 (9.46%)	30(40.54)	20(27.03)	14(18.92)
2	Now, thinking about your physical health which includes physical illness and injury, for how many days during the past 30 days was your physical health not good?	5 (6.76)	9(12.16%)	28(37.84)	22(29.75)	10(13.51)
3	Now, thinking about your mental health, which includes stress, depressions, and problems with emotions, for how many days during the past 30 days was your mental health not good?	2 (2.70)	5 (6.76)	24(32.43)	30(40.54)	13(17.57)
4	During the past 30 days, for about how many days did your physical or mental health keep you from doing your usual activities, such as self-care, work or recreation	10(13.51)	16(21.63)	30(40.54)	10(13.51)	8 (10.81)

***Figures in parentheses are percentages**

DISCUSSION

The findings from the socio demographic characteristics indicated that a majority of the respondents were between 20-30 years with minimal education and were unemployed. These imply that the participants were within the ages of high sexual activity with no means of livelihood which exposed them to HIV infection; and these might have impacted negatively on their quality of life. The results also showed that the majority of the respondents rated the home-based care they received from good to excellent which also confirmed their enjoyment of better quality of life as shown in the results.

The result of the study also showed a statistical significant relationship between psychosocial care and psychosocial quality of life of PLWHA. The above findings is supported by Ogden (2006) who asserted that home based care relieved a sense of isolation by the client (PLWHA) and enhanced access to psychosocial support during illness which positively impacted on the psychological quality of life. In a related study by Peter and Sellick (2006) on the quality of life of cancer patients receiving in-patients and home-based palliative care, the result affirmed that patient receiving home-based palliative care had statistically significant less symptom severity and distress, lower depression scores and better physical health and quality of life than those receiving in-patient cares.

Additionally, Harding *et al* (2004) review of 17 studies also supported the above results of the study that there is a positive relationship between a home based care and the quality of life, be it physical or psychological. The relationship between self care, health deviation care which may be given by HBO and overall health is also supported by Orem's self care theory. The

HBO can use the three nursing systems with five methods of helping: guidance, teaching, support, provision of an environment to promote individual's abilities, current and future needs.

Another finding that the study showed was a significant relationship between basic nursing care and physical quality of life of PLWHA. This finding was supported by Harding et al (2004) results which demonstrated that home-based palliative care significantly improved patients' outcomes in the domains of pain and symptoms control, anxiety, insight and spiritual well-being and these outcomes relate to physical emotional and spiritual quality of life. The improved patients' outcomes will depend on the type of care including nursing care that are received by the patients from HBO as a dependent care giver as stated in Orem's self care deficit theory (Berman & Snyder, 2008).

Peter and Sellick (2006) also affirmed the findings of the study that patients receiving HBC reported statistically significant control over the effects of their illness, medical care and treatment received, and the course of the disease. Further analysis revealed a better global physical health, greater control over the effects of cancer and lower depression score were statistically significant predictor of higher quality of life. The above result is also supported by the CDC population health related quality of life which showed that a majority of the respondents had good general and physical health. Probably, indicating that the home based care has positive impact on the physical health of the respondents.

Actually, one of the requirement for minimum package of home based care services by (WHO, 2002) include nursing care to promote and maintain good health through hygiene, nutrition, pain control, comfort and end of life care. Studies by John *et al*, (2008) have showed that those clients that received home based care were free from discrimination, abandonment and taunting by health workers in health facility. Based on the above, home based care is advocated for all PLWHA because it reduces the frequencies of injection, increases ownership of problem, increases longevity and help to better the quality of life of PLWHA.

CONCLUSION/RECOMMENDATIONS

This study has yielded important information on the relationship between home based care and the quality of life of PHWHA. It was discovered that the proportion of PLWHA who claimed to enjoy physical well-being was greater than those who enjoyed emotional wellbeing. This may be an indication of the need for intervention to enhance emotional quality of life. Another study in the entire state to assess the impact of home based care on quality of life of PLWHA is recommended.

It was recommended that home-based care should be encouraged by stake holders and this strategy should be given priority in the management of PLWHA. The results further revealed that age and income level of PLWHA receiving home-based care are also indicators of the need to address unemployment and poverty which would enhance better quality of life.

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