

## KNOWLEDGE AND ATTITUDES OF TERMINALLY ILL PATIENTS AND THEIR FAMILY TO PALLIATIVE CARE AND HOSPICE SERVICES IN NIGERIA

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### ABSTRACT

**Background:** A palliative care and Hospice service is a neglected aspect of medical discipline especially in a developing country like Nigeria. With the global increase in incidence of cancer and HIV/AIDS and 70% of them presenting late, coupled with limited resources, for effective symptom control, palliative care therefore remains the only option left to improve the quality of life of the patients.

**Objective:** To assess the knowledge and attitudes of patients and their relations to palliative care and hospice services (PC&H) and to fashion out appropriate services for the patients.

**Materials and methods:** A total of 130 participants were studied using a questionnaire which comprised of three parts: Socio-demographic variables, Information about Knowledge and Attitudes towards PC&H.

**Results:** Sixty nine were patients while 61 were family members. Ninety four [72.3%] had no knowledge of PC&H regardless of level of education and social status. 109 [84%] agreed that symptoms of the terminally ill patients should be treated to improve their quality of life and 75% of the participants agreed that this will be better done in a Hospice. 106 [83%] participants desire to have hospice established in every community, this again was regardless of tribe.

**Conclusion:** There is a gross lack of knowledge about PC&H in our community as evidenced among the participants studied. However, there is a positive attitude towards PC&H suggesting a general acceptance, since there is presently no well established Hospice in Nigeria; we recommend that government and Non governmental organizations should assist in this area. A hospital based Hospice might be a starting point.

**Keywords:** Knowledge, Palliative care, Hospice.

### INTRODUCTION

The word "palliative" in Latin means "caring". Palliative Care is the management of pain and other symptoms in terminally ill patients in order to improve the quality of their remaining life. This is usually an organized care, which can be given in a hospital setting, hospice or in the home of the patients'. the term 'hospice' (which in modern context is now accepted as a philosophy of care) is used to describe an organized institution, either within or outside the hospital setting, where holistic care is given to patients dying from whatever cause. Holistic means that the patient is viewed as a person with physical, psychological, social and cultural gifts and needs which are special to that person. Hence the care involves a team consisting of various professionals'.

In Nigeria Cancer and HIV/AIDS are two important diseases associated with severe suffering before eventual death. The incidence of cancer is on

the increase worldwide, and it is estimated that some 60% of new cases will occur in the less developed parts of the world. Unfortunately less than 10% of resources committed to cancer control are available to patients in the developing world where the biggest increase in cancer is taking place (WHO, 1986).

Most cancer patients in Nigeria present late and over 70% have pain. The terminal stage is usually associated with frustration when treatments like surgery, chemotherapy and radiotherapy have failed to produce the much desired cure. HIV/AIDS, virtually unknown two decades ago has spread with ferocious intensity and is now a leading cause of death in Sub-Saharan Africa. The epidemic has also brought a great increase in cancers, especially Kaposi Sarcoma. Pain and symptoms control are priorities recommended by WHO. in particular for the care of patients living with advanced cancer and AIDS. For majority of these patients in Nigeria, cure is no longer an option and palliative care is applicable to all patients who are dying from whatever cause.

About 70% of cancer patients present at late stages (III & IV) with few of the patients having access to the limited treatment facilities<sup>2</sup>. palliative care and Hospice services have become the only way to improve the quality of life of these terminally ill patients. The escalating cost of treating cancer in a depressed economy like ours could also be contributing to increasing number of patients presenting late when cure is usually almost impossible. The traditional extended family system in Africa, where support is usually provided is gradually being lost to western civilization<sup>3</sup>. The resultant effect of this is neglect of terminally ill patients. Organized palliative care therefore seems to be the last hope of this group of people.

The study was conducted to assess the knowledge and attitude of patients and relations to palliative care and also, to assess various challenges facing palliative care in order to fashion out an appropriate palliative care and hospice services for Nigerians patients, thereby reducing the stress and burden of caring on their relations.

## MATERIALS AND METHODS

Over a 10-month period September 2002 and June 2003, consecutive patients and their relations attending the Radiotherapy Dept of University College Hospital, Ibadan who had advanced stage disease were interviewed by a research assistant, trained in the use of a set of questionnaires. The questionnaire was made up of 3 sections:

Section A: Socio-demographic variables, such as age, sex, marital status, religion, ethnicity, educational level, occupation, employer and income per-month.

Section B: Knowledge of Palliative/Hospice Care. Consists of questions such as, Have heard of palliative and Hospice care? Is there any in your community? Have you visited any, Have ever made use of its facilities? Mention types of services provided by Hospice you are familiar with? Where is the Hospice located? Where will you like an Hospice to be located?

Section C: Attitudes towards Palliative Care/Hospice. The questions asked are as in Table 4. The research assistant was trained to recognize patients with cognitive function impairment and they were excluded from the study. Subjects who could not understand English had the questionnaire translated to their native language. Participation was voluntary, and confidentiality was assured.

## RESULTS

A total of 130 subjects were interviewed consisting of 48 males (36.92%) and 82 females

(63.10%) with male to female ratio of 1:1.8. 52 (40%) of the subjects were over 48 years.

Thirty-four were single, 14 widowed and 82 married. All subjects agreed to have their relation as care givers. Majority of the subjects had some form of education while only 7 subjects were illiterate.

Sixty nine (53%) of the participants had cancer while 61(47%) were family members. Most of the participants were employed, only 17 (13.08%) were unemployed as shown in Table 2 A review of their income to assess their socio-economic status, as evident on Table 3 showed that 84 (64.6%) earned less than N20, 000 per month, 27 (20.8%) earned between N20, 000 to N30, 000 per month while only 19 (14.6%) earned above N30, 000.00 per month. Among the participants, 16 (12.13%) were health workers while 101 (77.69%) were Non-health workers, There were 13 (10%) non-respondents to the question about their occupation.

While assessing the participants' knowledge about palliative care and hospice, 94 (72.31%) had no idea of what it means, while only 30 (23.1%) had an idea of a hospice. Majority therefore had not visited any hospice anywhere while 14 participants claimed to have visited hospice. Since no well established hospice was available in Nigeria as at the time of the study, these participants must have done so outside the country. The services these 14 participants claimed they received at the hospice visited ranged from pain management - 3, nursing care - 5, physiotherapy and social support. The hospice they visited were all hospital based. When asked about their preference for where hospice should be located, 50 (38.45%) preferred hospital based while 65 (50%) preferred a community-based hospice.

While assessing the attitudes of participants towards palliative and hospice care as shown in Table 5, 114(87%) participants agreed that hospice should be established in Nigeria for effective pain control among terminally ill patients. Seventy-eight (60%) believed that palliative care is compatible with Nigerian culture and expressed willingness to be cared for in the hospice, while 52 (40%) were not sure. As regards preference for home care over hospice care, majority 74 (56%) still preferred hospice care to home care. (See Table 5.)

Table 1: Respondents' Employment Status

	NUMBER	PERCENTAGE
Government	48	37
NGO*	13	10
Self Employment	52	40
Unemployed	17	13.0

\* Non-Governmental Organization

TABLE 2: Respondents' Income per Month

INCOME IN NIGERIA	NUMBER	PERCENTAGE
< N20, 000	84	64.6
N20, 000 – 30, 000	27	20.8
N31, 000 – 40, 000	5	3.8
N41, 000 – 50, 000	4	3.1
N51, 000 – 60, 000	5	3.8
> N60, 000	5	3.8

TABLE 3: Age Distribution of Respondents

AGE GROUP	NUMBER	PERCENTAGE
< 20 years	1	0.8
21 – 27	15	11.5
28 – 37	36	27.6
38 – 47	26	20
> 48	52	40

TABLE 4: Responses to Attitudes towards Palliative Care &amp; Hospice.

	S.A	A	NS	D	SD	Total
I favor establishment of Hospice in Nigeria	85	33	11	1	-	130
Symptoms of terminally ill patients to be relived	41	68	15	6	-	130
Pain relief best in Hospice	30	68	25	5	2	130
Pall. Care will guarantee quality of life of terminally ill patient and their relations	37	66	25	1	1	130
Pal care Compatible with Nigeria culture	22	61	36	10	1	130
Hospice care should be in every community	52	56	21	1	-	130
Willingness to be cared for in Hospice	38	60	22	6	4	130
Home care preferred to Hospice care	14	32	39	29	16	130

## Key to abbreviations:

Strongly agree= SA

Agree = A

Not sure= NS

Disagree= D

Strongly Disagree = SD

TABLE 5: Tribes of Respondents

Tribe	Number	Percentage
Yoruba	75	57.6
Igbo	31	23.8
Hausa	6	4.8
Others	18	13.8
Total	130	100

## DISCUSSION

In the developed community, demographic evolution and scientific progress in treatment of fatal diseases have brought about a large number of disabled old persons and of greatly dependant persons. Nowadays the dying process in such conditions is slower though irreversible and it has created a new form of medical care, known as palliative medicine, which is a widely accepted care for the dying. In the developing countries, palliative care as a specialty is still rudimentary except in some few African countries like Uganda, Kenya, South Africa and Tanzania where there is a relatively high level of awareness<sup>4</sup>.

From our results, it is obvious that in our environment there is a gross lack of knowledge about the importance of palliative and hospice care, as 94 (72.3%) of the participants have never heard of this type of care, regardless of their level of education.

Improved quality of life is of paramount importance to all patients with incurable disease, especially HIV/AIDS and cancer<sup>5</sup>. The need for the establishment of palliative care services in Nigeria is most desirable at this time, based on the available alarming data on the number of people living with cancer and AIDS. Also the cost in Nigeria is enormous and the average income of Nigerians is so poor<sup>6</sup>. There is high level of poverty, as evident on Table 2.

Hospice Africa Uganda makes care available to patients with minimal cost of about 5000 Ugandan shillings (<3 USD) per week, with this affordable amount, terminally ill patients in Uganda can buy liquid morphine (for pain control), antibiotics, steroids and other essential medications. Most of the time, these patients could not afford these meager fees and they have to be cared for free of charge. Uganda a developing country has taken palliative care initiative, seriously having included it in her 5 year health plan (2001 – 2006)<sup>7</sup>. Other African countries need to emulate Uganda. Since these services can be provided relatively simply and inexpensively, they should be given the high priority it deserves, especially in Nigeria where cure of the majority of people living with cancer and AIDS is likely to remain beyond reach for years to come.

One hundred and nine participants (84%) agreed that symptoms of terminally ill patients should be treated in order to improve the quality of their life. Pain, which is usually the major symptom of the terminally ill, was agreed upon by (75%) participants to be best relieved in a hospice where facilities and expertise would be available. It was the desire of 106 (83%) participants that Hospice be established in every community, this was regardless of tribe, because three tribes in Nigeria were represented in the study group.

Majority 84 (64%) of the participants prefer hospice care to home care, this was in contrast to a study done in Uganda where home care was preferred to hospice care<sup>8</sup>. This might be attributed to cultural differences. Among Nigerians, people tend to hide the nature of their sickness from friends and even from some of their relatives; hence receiving care from a hospice is applicable to our society, since it will at least keep them away from people.

Home care is undoubtedly more cost effective than conventional care (Hospitals) and inpatient hospice care. Its advantage is said to be more evident in the last 3 months of life due to shorter hospitalization and non-utilization of high technology intervention and high cost of drugs<sup>9</sup>. Increasing public awareness on the advantage of home care will be necessary to convince people in our society to embrace home care.

The study has shown the need to organize palliative care and Hospice services in our communities and it is obvious that Nigerians will be willing to have their terminally ill patients cared for in these centers if made available. To have a broader perspective of palliative care needs, a national community-based survey will be necessary for an effective planning.

## CONCLUSION

Palliative care which is relatively inexpensive, non-invasive care, must be made available for all terminally ill patients. Since majority of cancer patients present very late to the hospital, after they might have spent all their resources elsewhere, utilizing unproven remedies, the care they receive at the hospital need to be inexpensive, because at this stage, the patients have little or no economic power.

Nigerian government should also subsidize palliative care treatment, so as to enable terminally ill patients access these important services, in our hospitals. The government should also give financial support to NGOs rendering palliative care services in Nigeria. So as to increase coverage, Nigerian government should emulate other African countries providing palliative care services such as Uganda, which has a well-established hospice (Hospice Africa) Uganda, which is a model hospice in Africa.

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