

# Palliative care needs evaluation in untreated patients with hepatocellular carcinoma in Ibadan, Nigeria

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## ABSTRACT

**AIM** This study aimed to evaluate the physical, psychosocial and spiritual needs of untreated patients with hepatocellular carcinoma, in order to determine effective palliative care approach and therefore improve their quality of life when curative therapy is elusive.

**METHODS** The modified *Needs Evaluation Questionnaire* (NEQ) on pain and psychological assessments, thoughts and feelings and spiritual concerns was administered to 205 consecutive patients with recently diagnosed hepatocellular carcinoma after informed consent. The questionnaire included questions on pain, psychological state of mind, interference of disease with life, family functioning, knowledge of the disease, sexual functions and spirituality, among others. Responses were collated and analysed using simple statistics.

**RESULTS** Abdominal pain, abdominal swelling, and weight loss were the leading clinical features, occurring in 157 (77%), 143 (70%) and 91 (44%) patients respectively. Pain characteristics varied, with 179 (87%) having it at presentation. Most of the patients (116, 57%) used NSAIDs for pain relief. Less than half (98, 48%) wanted to know the cause of the cancer, while 157 (77%) wanted to know treatment options. The majority (189, 92%) were ignorant about anyone with a similar ailment. Sexual function was not perceived as a problem but some expressed fears about sex, feeling that their partners would not find them attractive. Self-esteem was high in almost all respondents. Most (177, 86%) felt God is a "doer" while 28 (14%) felt God is a "supporter" and 162 (79%) would like a therapist or religious leader to talk to them.

**CONCLUSION** Pain was a major concern and spiritual support by religious leaders were desired. Self-esteem of patients should be preserved and reinforced. We recommend that palliative care and end-of-life issues should be made part of multidisciplinary care of cancer patients in our setting.

**Keywords:** Carcinoma, Hepatocellular; Palliative care; Nigeria; Africa; Needs Assessment.

## INTRODUCTION

Hepatocellular carcinoma (HCC) is the commonest liver cancer in Nigeria <sup>1</sup>. The disease has a high fatality rate, with morbidity equating mortality in our environment.

Generally, prognosis and quality of life of HCC in Africa is grim because of late presentation <sup>2-3</sup>, which makes curative care of HCC a lost battle. In developed countries of the world, palliative care

has been well developed and found to contribute immeasurably to improving the quality of lives of patients with diseases requiring terminal and end of life care. Disappointingly, palliative care is still at the rudimentary stage in Africa<sup>4-6</sup>, and limited in scope and practice. It is only recently that a few centres are initiating daycare hospice services to cater for the palliative care needs of a limited number of patients<sup>5-6</sup>.

It is obvious therefore that there is a need for effective palliative care services in resource limited settings, based on the needs as perceived by the patients themselves, who are the consumers of the services provided, even in the face of daunting challenges<sup>7-8</sup>. This study sought to evaluate the physical, psychosocial and spiritual needs of recently diagnosed patients with HCC, in order to determine effective palliative care approach and therefore improve their quality of life when curative therapy is elusive.

## METHODS

This study was carried out between February 2007 and May 2009 on 205 patients with HCC on the Medical wards of the liver unit at the University College Hospital (UCH), Ibadan, Nigeria. HCC was diagnosed by typical clinical features, liver ultrasonography, liver biopsy and or alpha-fetoprotein levels of > 200 IU/ml. The modified *Needs Evaluation Questionnaire* (NEQ) on pain and psychological assessments, thoughts and feelings and spiritual concerns were administered by one of the authors, after obtaining informed consent.

There were 16 questions on pain, which included pain intensity, pattern, site, sleep relationship, and treatment modality. There were questions on psychological assessment, with 4 multiple choices for each, relating to information sought about HCC, interference of disease with life goals, family functioning, and knowledge about the disease. Seven questions on thoughts and feelings included problems with communicating with physicians, fears about sexual functions, and hope of recovery.

Six questions on spirituality centred on "why me?", how to cope, influence of cancer on spirituality, faith in God and religious beliefs, need for religious leader's counseling, etc. Responses were collated and analysed using simple proportions and relevant basic statistics.

## RESULTS

One hundred and forty five (71%) of the patients were male and 60 (29%) were female (M:F ratio 2.4:1). Age range was 14-85 years with average of 44 years. The modal age group was 31-40 years. Abdominal pain, abdominal swelling, and weight loss were the leading clinical features, occurring in 157 (77%), 143 (70%) and 91 (44%) patients respectively.

### PAIN ASSESSMENT

Characteristics of the pain varied, with 179 (87%) having it at the time of presentation while 120 (59%) had the pain present at all times. Pain was intermittent in 75 (37%).

Pain severity also varied, it was mild in 9 (4%), discomforting in 56 (27%), distressing in 66 (32%), horrible in 48 (23%) and excruciating in 6 (3%); Figure 1.

NSAIDs were used by 116 (57%) patients for pain relief, while 87 (42%) used weak opioid analgesics like tramadol, pentazocine and dihydrocodeine. Pain got worse in 83 (40%), got better in 53 (26%), but remained unchanged in 50 (24%) with analgesic medication.

Pain disturbed daily activities in 151 (74%) while sleep and mood were disturbed due to pain in 134 (65%). Other common symptoms associated with pain were anorexia 146 (71%), early satiety 122 (60%) and tiredness 154 (75%). About a third 71 (35%) of patients were satisfied with pain relief while 117 (57%) were dissatisfied.

### PSYCHOSOCIAL ASSESSMENT

Less than half 98 (48%) wanted to know the cause of the cancer, 157 (77%) wanted to know available treatment options and 95 (46%) wanted to know the

recovery rate. Only 43 (21%) of patients felt their cancer slowed them down; 74 (36%) felt frustrated while 86 (42%) felt that cancer set them back completely. Two patients (1%) however felt that the cancer did not affect their normal lives. One-third (63, 31%) felt totally incapacitated, but 19 (10%) were able to cope well, while 123 (60%) could not cope effectively. Most (189, 92%) did not know anyone with similar cancer. While 129 (63%) knew their diagnosis, 76 (37%) did not know what they were being treated for.

Communicating with health care providers was not problematic in 195 (95%) but 10 (5%) that had problems cited incessant tests and poor information concerning the tests. Sexual function was not perceived as a problem as only 5 (2%) expressed fears about sex. All respondents felt their partners would not find them attractive because of their bodily disfigurement, mainly abdominal swelling. The self-esteem of patients was intact as only 9 (4%) had low self-esteem. Fear of death was present in 144 (70%) while 184 (89%) hoped for healing; 107 (52%) very hopeful of recovery, 75 (37%) fairly hopeful and 23 (11%) not hopeful of recovery; Figure 2.

#### SPIRITUAL ASSESSMENT

There were 134 (65%) Christians, 68 (33%) Muslims and 3 (1.4%) patients with no religion. All but 1 (0.5%) patient had religious beliefs that might help them. Most (177, 86%) felt God is a "doer" while 28 (14%) felt God is a "supporter". Many (157, 77%) questioned why the illness occurred to them. While 57 (28%) spoke with no one about their feelings, 114 (56%) spoke with their relatives; 12 (6%) to their religious leaders and 22 (11%) to God about their illness. One hundred and sixty two patients (79%) would have liked a therapist or religious leader to talk to them.

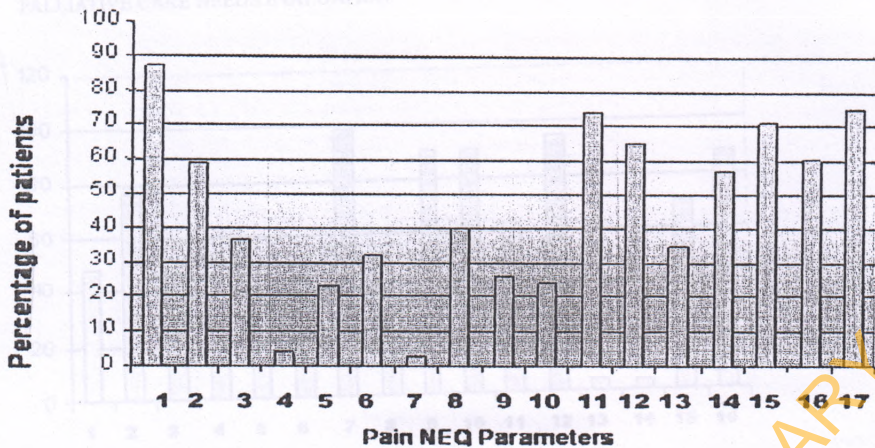
#### DISCUSSION

Recent cancer statistics in the GLOBOCAN report has shown that in 2008 a majority of the 12.7 million new cases of cancer and the 7.6 million cancer deaths worldwide occurred in developing countries, with 56% and 63% of cancer incidence and mortality

respectively<sup>9</sup>. Liver cancer came third among the most common causes of cancer death worldwide accounting for 9.2% and cervical and liver cancers being the commonest in developing countries<sup>9</sup>. This no doubt will increase the cancer burden in developing countries and all efforts need to be put in place to combat the menace. Multidisciplinary approach including palliative and end-of life-care is currently the recommended mode of management. Unfortunately, these areas of medical care are still little developed in Africa

Our study further confirms previous studies which showed male preponderance and younger age trend in the presentation of HCC<sup>10</sup> and the triad of abdominal pain and swelling and weight loss being the commonest clinical features among our patients as previously reported<sup>11</sup>. Evidently, there were varieties of pain types which were mainly intermittent for which the majority used NSAIDs. Access to opioid drugs has been a major challenge for cancer pain control in many developing countries including Nigeria, where for years pethidine and other opioid drugs have been unavailable, irregular or inadequate<sup>12-14</sup>. Recently, oral morphine was made available in some West African countries but still a far cry from the required amount. It is not surprising then that about two-thirds of the patients were not satisfied with pain control, which disturbed daily activities in as high as 74% and is often distressing, excruciating, horrible and disturbs mood and sleep in a significant number of the patients. Efforts therefore need to be stepped up to make opioids available (especially oral preparations) which have been shown to be effective in cancer pain control, as well as making other proven and novel pain control measures available including acupuncture<sup>15-17</sup>, among others.

In developing countries including Nigeria, where the level of literacy is low, explaining the nature of illness to patients is often treated lightly as it is usually assumed that patients would not understand or need not know about the nature of their illness. Our study has shown that, the majority (62%) would like to know the nature or cause of their illness and also 77% would like to know available therapeutic options. This knowledge would help patients to participate in planning and implementation of their



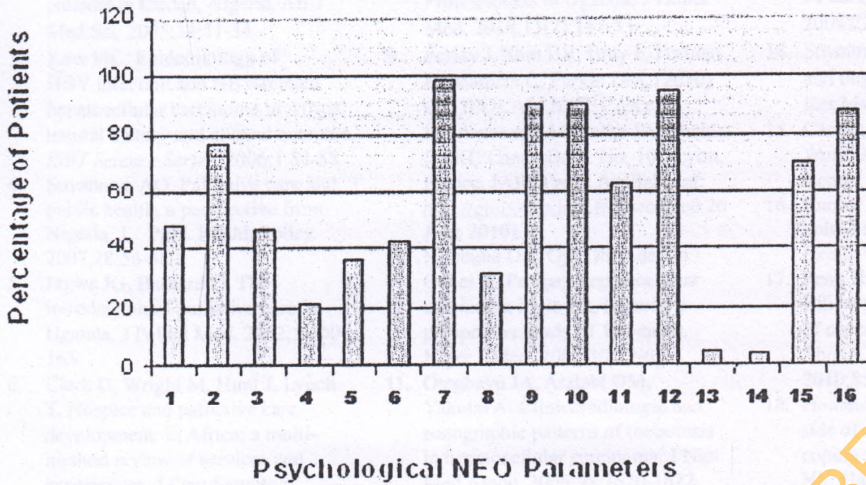
**Figure 1: Characteristics of pain in patients with hepatocellular carcinoma.** Bars represent percentage of patients who had: (1) pain at presentation, (2) persistent pain, (3) intermittent pain, (4) mild pain, (5) distressing pain, (6) discomforting pain, (7) horrible pain, (8) worsening pain, (9) improving pain, (10) static pain, (11) pain that disturbed their daily activity, (12) pain that disturbed their sleep and or mood, (13) satisfaction with pain relief, (14) dissatisfaction with pain relief, (15) anorexia associated with pain, (16) early satiety associated with pain, (17) tiredness associated with pain. NEQ, Needs Evaluation Questionnaire. This figure shows variation in characteristics and severity of pain among study patients but most patients had pain at presentation.

treatment, rather than the doctor just playing the know-it-all role. The knowledge of the nature of illness will further boost treatment compliance when patients are made to be actively involved in selection of therapeutic options.

Coping strategies are definitely important in cancer survival. Sixty percent of our patients were unable to cope well with their disease and therefore would require the support of their family, physicians and a psychologist specifically trained in dealing with patients with cancer. Effective techniques and therapies that have been found to be helpful in some studies include individual and group counselling, cognitive-behavioural techniques (ways of viewing illness that help), relaxation, meditation, prayer and spiritual practices, art and music therapies, creative writing<sup>18</sup>. This has been found to be helpful in some studies. Most of our patients (92%) did not know of anyone with similar cancer like they had. This may be due to beliefs and attitudes that encourage secrecy when illness occurs in a family and of course for the fact that in our part of the world physicians rarely

inform their patients about the nature of the illness and patients also seldom ask physicians questions, though most of the respondents claimed there was no problem communicating with their health care providers.

The self-esteem of most patients was intact and therefore efforts should be made by care givers to always protect patients' self-esteem. In spite of this apparently good self-esteem most patients still felt they were not attractive to their spouses because of bodily disfigurement. Some psychotherapy may therefore be needed to bolster and sustain their self-image. Most of the patients would require repeated assurance and re-assurance and end of life counseling because of *angor animi* (fear of impending death). The efficacy of partner-assisted coping skills training to enhance coping with cancer treatment is also being explored in some studies. One of the primary goals of such intervention is to focus on the relationship between partner and patient and on ways to improve their relationship while dealing with cancer.<sup>19</sup>



**Figure 2: Psychological disturbances in HCC patients.** Bars represent percentage of patients who: (1) wanted to know cause of illness, (2) wanted to know treatment options, (3) wanted to know recovery rate information, (4) felt cancer slowed them down, (5) felt frustrated, (6) felt cancer was a setback; (7) felt their normal lives were affected by cancer, (8) felt totally incapacitated by cancer, (9) were unable to cope well, (10) knew someone with similar illness, (11) knew diagnosis, (12) felt there was good communication with care giver, (13) had sexual fears, (14) had low self esteem, (15) feared death, (16) hoped for healing. NEQ, Needs Evaluation Questionnaire. This figure shows, inter alia, that almost all patients felt that their normal lives were affected by their disease.

It is heartwarming, though, that a similarly high percentage were still hopeful of surviving. This hopefulness will certainly help and should be reinforced, in order to sustain the body-mind dualism that keeps the body going when the spirit is up and could also bring the body down when the spirit is low. The same reasoning goes for beliefs in the supreme being, God, who most believed is a doer and could heal them. This underscores the need for involvement of spiritual leaders of all faiths to pray for and support the patients so as to reinforce their survival instincts.

## CONCLUSION

In conclusion, pain was a major concern and should be addressed in all HCC patients, spiritual support by religious leaders and reinforcement of positive

beliefs should be encouraged. Information about tests, procedures and nature of disease should be made freely available. Self-esteem of patients should be preserved and reinforced. There was less concern about sexual function among the studied population. Angor animi was high and psychotherapy should be offered when noted. Coping strategies need to be devised and advised. We recommend that palliative care and end-of-life issues should be made part of multidisciplinary care of cancer patients in our setting as advanced by Grant et al in a recent publication.<sup>20</sup>

## FOOTNOTES

**Conflicts of interest:** The authors declare no competing conflicts of interest.

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