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Quality of life among primary liver cell carcinoma patients in Ibadan, Nigeria

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Summary

A descriptive prospective study was conducted to evaluate the quality of life of patients with primary liver cell carcinoma at the University College Hospital, Ibadan, Nigeria. Quality of life (QOL) was evaluated using a modified WHO QOL Field Trial version questionnaire of December 1996. The QOL parameters include body pains, energy and acceptability of bodily appearance among others. Thirty-four patients aged between 23 – 74 years with a mean age of 49.6±13.4 were assessed. There were 28 (82.4%) males and 6 (17.6% females) (M/F = 4.6:1). Only about thirty percent of the patients rated their quality of life as being good or very good, with 70% rating their quality of life as very poor, poor or neither poor nor good. Eighty five percent of the patients were dissatisfied with their health, with 44.1% describing their health as very dissatisfying and only less than 10% enjoying satisfactory health. Eighty two percent of the patients responded that physical pain prevented them from doing what they want to do from moderate to extreme extent. All responders believed they require medical treatment to function in their lives with 22 (64%) requiring it very much. Seventeen (50%) of the patients had not enough energy at all for their daily activities, while 21 (61.7%) found their bodily appearance unacceptable to them. Fourteen (41.2%) did not receive adequate information they required about their day-to-day life. We conclude that our patients with PLCC have a low QOL rating and measures such as pain relief, reduction of bodily disfigurement and information to patients need to be put in place in order to improve their QOL.

Keywords: *Primary liver cell carcinoma, quality of life, Nigeria*

Résumé

Une étude future descriptive a été faite pour évaluer la qualité de vie de malades atteints de carcinome cellulaire primaire du foie au Collège de medecin de l'Université, d' Ibadan, Nigeria. La qualité de vie (QOL) a été évalué utilisant le WHO QOL (qualite de vie de l'OMS) une version de questionnaire modifier d' Essai de terrain de décembre 1996. Les paramètres QOL incluent les couleurs corporelles, la force et l' acceptabilité d'apparence corporelle parmi d'autres. Trente-quatre malades ont de l'age entre 23 - 74 ans avec une moyen d' âge de 49.6±13.4 ont été évalues. Il avait 28 (82.4%) d'hommes et 6 (17.6% de femmes (M/F = 4.6:1). Approximativement trente pour cent des malades ont estimé leur qualité de vie comme etant bonne our tres bonne avec 70% estimant leur qualité de vie comme très pauvre, pauvre ou ni pauvre ni bonne. Quatre-vingts cinq pour cent des malades ont été mécontentés avec leur santé, avec 44.1% décrire leur santé comme très mécontentant et seulement moins que 10% qui decrivent la santé satisfaisante. Quatre-vingts deux pour cent des malades ont répondu cette que douleur physique les empechait de faire ce qu'ils veulent faire ce qu'ils desiraient de l'ampleur modéré à l'extrême. Toutes les persons interrogee croient avoir besoin de traitement medical pour pouvoir vivre avec 22 (64%) l''exigeant beaucoup. Dix-sept (50%) des malades n'avaient assez de force pour leurs activités journalières, pendant que 21 (61.7%) trouvaient que leur apparence corporelle etait inacceptable. Quatorze (41.2%) n'ont pas reçu d' information adéquate qu'ils ont exigé au sujet de leur vie quotidienne. Nous concluons que nos malades avec PLCC ont un QOL bas qui estime et mesure tel que soulagement de la douleur, une réduction de défiguration corporelle et on a besoin des information aux malades pour améliorer leur QOL.

Introduction

Primary liver cell carcinoma (PLCC) is a malignant disease with dismal long-term prognosis worldwide [1]. Recent evidence shows increasing incidence of the disease even in developed countries of the world [2]. Several treatment modalities have not yielded the desired impact on overall survival [3], except for the rare early presentation when surgical resection could effect a cure. In Nigeria PLCC is a very common cancer especially in males and most present in advanced stages of the disease [4,5] and it is also noted to be the commonest killer cancer on the medical wards, where most die within six months of diagnosis [6]. In view of the late presentation, poor response to therapy and little hope for cure, a palliative approach to improve the quality of life will be a desirable approach to managing PLCC.

Quality of life (QOL) evaluation has become essential in all situations where a disease or its management could lead to physical, emotional, cognitive, social, family or professional impairment [7,8] and must be a major consideration in chronic debilitating and incurable diseases such as cancers, and it concerns interventions to maintain the patients symptom-free as much as possible or to reduce the distress of the disease [9]. The objective of this

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study is to evaluate the QOL of patients with PLCC at the University College Hospital (UCH), Ibadan, in order to know the area of care that might improve coping mechanisms.

Materials and methods

Thirty-four (34) consecutive adults (28 males, 6 females) with PLCC seen at the Liver Unit of the UCH, Ibadan, over a 6 month period were enrolled in a descriptive study, after obtaining consent, to participate in the study. Excluded from the study were patients with clinical features of hepatic encephalopathy and other co-morbid illnesses. A modified World Health Organisation Quality of Life Questionnaire (WHO QOL) Field Trial version of December 1996 was administered to collect data relating to selected fourteen parameters such as pain, concentration, acceptance of bodily appearance etc. The questionnaires were filled by literate patients or translated to local dialect for the illiterates who were mainly of the Yoruba stock. Biodata and scoring rating of 1 – 5 on various aspects of quality of life, where 1 = Not at all, 2 = Not much, 3 = Moderately, 4 = A great deal, 5 = Completely, were collected. A descriptive data analysis was done using SPSS statistical software.

Results

Thirty-four patients aged between 23 and 74 years with a mean (± SD) of 49.6±13.4 were assessed. This consisted of 28 (82.3%) males and 6 (17.6%) females. M/F = 4.6:1. Ten (39.4%) of the patients studied rated their quality of life as being good or very good, with an overwhelming 70.6% rating their quality of life as very poor, poor and neither poor nor good. Table 1. Nineteen (85.3%) of the patients were dissatisfied with their health, with 44.1% describing their health as very dissatisfying and only less than 10% enjoying satisfactory health. All the patients responded that pain of various degrees prevented them from doing what they wanted to do with 28 (82.3%) of them experiencing moderate to extreme pains. All responders (100%) believed they required medical treatment to function in their lives with 22 (64%) requiring it very much. Fifty percent (17 patients) had not enough energy at all for their daily activities, while another 17% had just a little. Seven (20.6%) of the patients found their bodily appearance unacceptable to them, with another 14 (41.2%) barely accepting it.

Table 1: Quality of life rating among PLCC patients

Rating	Number (%) N=34	Male (%) N=28	Female (%) N=6
Very Good	2(5.9%)	2	0
Good	8(23.5%)	7	1 (16.7)
Don't know	9(26.5)	8	1 (16.7)
Poor	6(17.6)	4	2 (33.3)
Very Poor	9(26.5)	7	2 (33.3)
	34(100)	28 (100)	6 (100)

NB: The question asked- How would you rate your QOL?

Sixteen (47.1%) found it difficult to concentrate while 12 (35.2%) did not enjoy life at all. On how meaningful life has been with PLCC, 22 (64.7%) patients had moderate satisfaction, while 12 (35.3%) patients had only little satisfaction with their lives. Table 2. When asked how available the information they needed in their day-to-day life was, 14 (41.2%) patients had little or no information they needed for their day-to-day lives. Seventeen (50%)of the patients responded that they had no leisure time.

Table 2: Patients perception of personal life satisfaction

Ratings	Total (%) N =34	Male (%) N =28	Female (%) N =6
Extreme satisfaction	0	0	0
Very much satisfied	14(32.4)	12(42.0)	2 (33.3)
Moderate satisfaction	8(23.5)	7(25)	1 (16.7)
Little satisfaction	12(35.3)	9(32.1)	3 (50)
No satisfaction	0	0	0
	34(100)	28(100)	6 (100)

NB: Question asked - To what extent do you feel your life to be meaningful?

Discussion

Our study clearly shows that most of our patients with PLCC suffer from multiple problems, which are mainly pains, poor concentration, low energy and disfigured bodily appearance among others. It is remarkable that only about one third of the patients rated their quality of life as being good or very good, leaving more than two-thirds with poor quality of life. This is similar to the report of Bianchi et al. in Italy [10], a developed country, and it calls for interventional measures to improve on the other parameters that contribute to the low QOL of these patients.

Most of the patients were noted to be dissatisfied with their health, with many describing their health as very dissatisfying. This suggests that healthcare providers managing patients with PLCC will have to work a lot more on supportive therapy, which could alleviate these identified health problems and improve coping mechanisms. Individualised care, after compiling specific needs and expectations of the patients will also go a long way in improving their quality of life. Further studies addressing expectations of PLCC patients from healthcare providers in our practice need to be embarked upon. Pain, a noxious stimulus is noted for being the commonest symptom determining health seeking behaviour. Bianchi et al in a study of QOL in HCC (PLCC) patients in Italy concluded that pain is a relevant symptom in HCC affecting the QOL and has a definite therapeutic importance in the clinical management of the patients [10]. This study has shown that pain is a major factor affecting the QOL of the patients with a large number claiming that physical pain prevented them from doing what they wanted to do.

In some advanced centers, cancer pains are controlled by patients through on-demand analgesic devices, which patients regulate according to need. Also since most of our patients present in advanced states when chances of cure are remote, liberal analgesia will be a good measure to make passage as peaceful as possible. Pain control may be a factor that will make patients to enjoy a better QOL as it is evident that none of the patients enjoyed life to the fullest. With all respondents believing they require medical treatment to function in their lives, it shows that the patients accept and welcome the use of medications for their condition and such expect some sort of medication from their healthcare provider. This is a point to bear in mind when treating PLCC patients in order to meet at least in part, the expectations of these patients by prescribing relevant drugs to alleviate their sufferings and ultimately improve their QOL.

Palliative care has been a major approach in management of most of the patients at our centre, mainly because of late presentation. Studies are however now showing improvement in the QOL and survival in advanced, unresectable PLCC patients treated with long acting octreotide [11,12,13]. It will be auspicious to embark on clinical trials of this drug and similar remedies in our patient population.

Caloric intake is usually poor in patients with liver disease, usually due to associated anorexia, poor glycogen storage and affectation of the metabolic functions performed by the liver with low energy as a consequence. Half of our patients had not enough energy at all for their daily activities, while a significant number had just a little. This engenders the need for management efforts directed towards high energy/caloric diets that patients could tolerate without compromising liver function and thus averting precipitation of hepatic encephalopathy.

Many patients who develop PLCC have background liver cirrhosis with attendant hypoalbuminaemia and third-spacing of fluid leading to distortion of bodily appearance. Unacceptability of bodily appearance found in a substantial number of the patients, calls for concerted efforts to reduce disfigurement such as leg oedema and ascites, which are known common features of PLCC. Gentle diuresis will therefore be a worthwhile therapeutic measure in these patients. A major aspect of patient management very often neglected in our practice is communication to the patient, due to assumed lack of knowledge of the illiterate patients. It is, however well known that a well-informed patient is more likely to cope better than the uninformed. A large proportion of our patients were not well informed or uninformed. Patients should therefore be carried along in decision-making concerning their management. This, apart from gaining their confidence leads to better understanding and co-operation with the managing team and probable improved outcome.

We conclude that our patients with PLCC have a low QOL rating and measures such as pain relief, reduction of bodily disfigurement and information to patients need to be put in place in order to improve their QOL.

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