Psychology in Spain, 2002, Vol. 6. No 1, 68-76

QUALITY OF LIFE PARAMETERS IN TERMINAL ONCOLOGICAL PATIENTS IN A HOME CARE UNIT

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In this study the quality of life of 42 terminal oncological patients within a home care unit was evaluated using the questionnaire QLQ-C30 and self-report measures. Patients were evaluated at two time points, when they entered in the Unit and after one, two, three or four weeks. Clinical and demographic variables were registered and analyzed using repeated-measures covariance analyses and the Student t-test. Results revealed that only pain evaluated through QLQ-C30 changed significantly after admission to the Unit (p<.45). On the other hand, most of the clinical symptomatology variables, evaluated through the SCS, showed significant decreases (vomiting, p<.003; pain, p<.000; constipation, p<.000; sleep, p<.000). Anxiety and depression levels, which were below clinical levels on admission to the Unit, showed no change at the second evaluation. Nor did the Karnofsky Index show significant changes. The quality of life concept in relation to terminal illness is discussed.

El estudio pretende revisar la metodología y las dificultades asociadas a la evaluación de la calidad de vida en pacientes oncológicos en situación terminal y avanzada. Para ello se evalúa la calidad de vida informada a través de una escala estandarizada, el cuestionario de calidad de vida de la EORTC, el QLQ-C30, y se observa si es sensible a la recepción de cuidados paliativos en el domicilio. Se pretende al mismo tiempo, comparar estos resultados con los posibles cambios reportados por los pacientes sobre sus síntomas físicos, sobre la percepción del apoyo social y sobre los marcadores de ansiedad depresión, tras el ingreso en una Unidad de Hospitalización a Domicilio (UHaD). El trabajo se realizó con 42 pacientes a los que se evaluó en dos ocasiones, al ingreso en la UHaD y al cabo de 1, 2, 3 ó 4 semanas. Se recogen variables sociodemográficas y clínicas, y los datos se analizan mediante análisis de covarianza de medidas repetidas, y a través de t de Student para muestras relacionadas. Los resultados indican que tan sólo la variable dolor del QLQ-C30 cambia significativamente tras el ingreso en la UHaD (p<.045). Por el contrario, la mayoría de las variables referidas a sintomatología clínica y evaluadas por el médico, descienden significativamente tras el ingreso en la unidad (vómitos: p<.003; dolor: p<.000; estreñimiento: p<.000 y sueño: p<.000). Los niveles de ansiedad y depresión, que al ingreso ya revelan ausencia de patología, no se modifican desde los valores iniciales. El índice de Karnofsky no cambia significativamente tras el ingreso en la Unidad. Se discute la adecuación del uso del término calidad de vida en la enfermedad terminal.

A growing interest in the measurement of the "quality of life" concept has given rise to numerous interpretations and some confusion with respect to its definition and objectivity. Quality of life indicators in oncology have ranged from the purely physiological and physical to complex questionnaires based on the psychological repercussions of the illness and the social activities of patients. Some of the first measures used were designed to quantify patients' "health status" from perspectives such as perceived distress (Hunt, McEwen and McKenna, 1985), impact of the illness (Bergner, Bobbitt and Pollard, 1976) physical functioning (Mahoney and Barthel, 1965) and degree of patient satisfaction (Lough, Lindsay, Shinn and Stotts, 1985). Thus, quality of life was evaluated using a variety of indicators, many of which are informative with respect to the life led by patients but not with respect to its quality. In any case, many of the instruments considered appropriate for the assessment of this concept have been applied in the early phases of illness, and there are still no instruments validated with Spanish samples to evaluate quality of life during the terminal stages of illness (Pratheepawanit, Salek and Finlay, 1999; Padierna and Fernández, 2001). As Tierney, Horton, Hannan and Tierney (1999) remind us, studies on the quality of life in terminal patients have basically concentrated on the relief of symptoms, rather than on a formal assessment of patient satisfaction. Furthermore, the evaluations

The original Spanish version of this paper has been previously published in *Psicothema*, 2001, Vol. 13. Nº 2, 310-317

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have more often been carried out by carers than by the patients themselves, due to the belief that the latter were too ill to provide valid information (Carnike and Carey, 1999). Subsequent studies that show these patients to be capable of giving information about their status indicate a low degree of correlation between their assessments and those of their carers (Keizer, Kozak and Scott, 1992; McMillan and Mahon, 1994). The consequence of this and other confusing aspects is that it is often impossible to identify exactly what is being measured and, furthermore, the basic principles of application of some specific measures are not clear.

One of the aims of this study is to review the methodology employed and the difficulties involved in evaluating *quality of life* in terminal cancer patients. For this purpose, the aim is to examine the usefulness of information provided by the QLQ-C30, one of the instruments most commonly used for assessing quality of life in terminal cancer patients, with respect to palliative care in the home. Another objective is to compare these results with possible changes in patients' reports about their physical symptoms and social support, and in anxiety and depression indicators after admission to a home care unit (HCU). Lastly, the suitability of the term *quality of* life in terminal illnesses is discussed, with a view to proposing a different and perhaps more pertinent concept in relation to this issue, that of "degree of comfort", or even " quality of death".

METHOD

Subjects

The sample was made up of 42 oncology patients (12 women and 30 men) with different types of terminal cancer at an advanced stage. Participants' age ranged from 46 to 90, with a mean of 69. In order to be included in the study, participants had to meet the following conditions: Karnofsky Index score ≥ 40, absence of cognitive dysfunction and the verbal consent of both patient and family to participate in the study. All participants were selected from the various departments (internal medicine, medical oncology, urology, emergency and others) within the HCU of the Hospital de Cabueñes (Gijón, northern Spain).

Material

Hospital Anxiety and Depression Scale (HAD, Zigmond and Snaith, 1983). The HAD was designed to evaluate the emotional state of subjects receiving non-psychiatric hospital outpatient attention. With the aim of avoiding false positives in the psychopathological assessment in these contexts, the authors excluded references to physical symptoms. The scale consists of 14 items divided into two subscales of anxiety and depression, each with 7 items. The content of the items refers to the patient's subjective perception in relation to psychological aspects associated with depression and anxiety disorders. Each item has 4 response alternatives rated according to a Likert scale with scores ranging from 1 to 4 measuring the intensity of perceived discomfort on the part of the patient. The authors situated the cut-off zone for the two subscales at between 8 and 10, considering cases for values over 11. Validity coefficient is 0.70, and with respect to reliability, Cronbach's alpha coefficient is 0.80 for each of the subscales.

Functional Social Support Scale (Duke-UNC, Broadhead, Gehlbach, De Gruy, Kaplan, 1988). This is a self-assessment scale made up of 11 items that record people's opinions on the availability of others capable of offering support in times of difficulty, on access to social relationships and on their own possibilities for empathic and emotional communication. This questionnaire evaluates two dimensions of functional social support; *confidant* (items 7, 8, 6, 4, 1 and 10; defined by the possibility of having access to people with whom problems can be discussed) and *affection* (items 11, 9, 2, 3 and 5; defined by the degree of access to people that provide affection). The response to each of these items is evaluated by means of Likert scale of 1 to 5 points. There is a Spanish version of the questionnaire with a reliability of 0.80.

Quality of Life Questionnaire for Cancer (QLQ-C30) European Organisation for Research and Treatment of Cancer (EORTC) (Aaronson et al., 1993; Sprangers, Cull, Bjordal, Groenvold and Aaronson, 1993). This instrument consists of 30 items distributed across 5 functional scales (physical functioning; role; social functioning; emotional functioning and cognitive functioning), and three symptom scales (fatigue, pain and nausea-vomiting). Likewise, the questionnaire incorporates a global health/quality of life scale and some individual items that evaluate different symptoms of the illness and/or treatment (dyspnea, insomnia, loss of appetite, constipation, diarrhoea and financial impact). The questions refer to a time period of one week and use a Likert-type response format (an example of this questionnaire can be seen in Appendix 1) .

Symptom Control Sheet (SCS). This is a register of symptoms designed and applied by the doctors at the HCU. It records some of the commonest and most incapacitating symptoms of terminal cancer (activity or mobility level, vomiting, dyspnea, pain, constipation

and sleep). See Appendix 2 to consult this register and its correction.

Karnofsky Index. (Karnofsky and Burchenal, 1949). Used to evaluate the functional status of patients on a scale of 0-100 (0=death; 100=normal development).

PROCEDURE

All patients were assessed on two occasions – on admission to the HCU and after 1, 2, 3 or 4 weeks after admission. Given that the mean stay of terminal cancer patients in the HCU is around 4 weeks (García, Cueto, Arce and González, 1995), the second evaluation had to be carried out within 30 days of admission. The choice of date for this second evaluation was made on the basis of a random numbers table designed for this purpose. Group size according to time was as follows: 17 patients were re-assessed one week after admission to the HCU, 8 of the 42 were re-assessed after 2 weeks in the HCU, 9 patients 3 weeks after admission and 8 patients after 4 weeks in the HCU.

During the first interview with the subjects, in which they were asked for their consent to participate in the study, they were informed about its objectives and general structure. The verbal consent of patients and their relatives was requested by the doctor, who also introduced both patient and family to the person responsible for applying the psychological and quality of life instruments used. During this initial interview, which took place in all cases on the first day of admission to the HCU, the doctor in charge carried out the first measurement for the SCS, assessed the patient on the Karnofsky Index and determined the palliative treatment appropriate for the case. The HAD, DUKE-UNC and QLQ-C30 were applied by the psychologist on the day the patient was admitted. One, 2, 3 or 4 weeks after admission the patients were re-assessed following the same procedure. Three HCU doctors and a psychologist participated in the study. The latter was trained in and familiar with the application of these tests to terminal cancer patients. Total duration of the study was 18 months, and it was carried out in accordance with the availability of participating patients.

DATA ANALYSIS

A repeated-measures covariance analysis was carried out, in which the covariant was initial score on each of the scales and subscales applied on the day of admission to the HCU. Subjects' scores on each of the scales and subscales on entering the HCU were taken as the WITHIN variable and time elapsed between the date of admission and the second evaluation as the BETWEEN variable (1, 2, 3 or 4 weeks). This analysis was carried out with the aim of detecting changes in the variables evaluated as a function of the time of application of the second evaluation (1, 2, 3 or 4 weeks after admission).

Furthermore, and with the aim of checking for the presence or absence of changes after admission to the HCU in the variables used, the data were analyzed by means of the Student t-test for related samples.

RESULTS

The results are obtained from the total number of patients making up the sample (n=42). The variables considered were: age, indicators of anxiety and depression, perceived social support and the QLQ-C30 with its respective subscales. All those variables controlled by the doctor (SCS) were taken into account: activity level, vomiting, dyspnea, pain, constipation, sleep and Karnofsky Index.

Age

Mean age of the total sample (n=42) was 69.8 years, with a range of 46 to 90 years. By gender, men (n=30) had a mean age of 71.3 years and a range of 48 to 90, and the 12 women in the sample had a mean age of 66.16 and a range of 46 to 83.

HAD-A (Anxiety indicators evaluated by the HAD)

Raw score of the total study sample in the anxiety variable evaluated by the HAD was 7.97 from a maximum possible score of 21. By gender, the women had slightly higher anxiety scores than the men (9.08 and 7.53 for women and men, respectively). This difference was not statistically significant ($p<.409$).

The results indicate the absence of statistically significant differences between the two times of evaluation of the anxiety variable by the HAD ($p<.704$). Also, the repeated-measures covariance analysis indicates that regardless of the timing of application of the second evaluation (after 1, 2, 3 or 4 weeks), differences are not observed with respect to the anxiety levels of the subjects [$F= 1.6654$; $p<.225$].

HAD-D (Depression indicators evaluated by the HAD)

Mean level of depression for the total sample of the study was 7.30 out of a maximum possible score of 21. As occurred for the anxiety variable, the women presented higher levels of depression than the men (10.08 and 6.20 for women and men, respectively), this difference being statistically significant ($p<.001$).

On the other hand, despite the fact that a slight increase in the depression indicators was observed after the period spent in the HCU, these differences were not statistically significant (p<.196). The repeated-measures ANCOVA indicates the absence of significant differences between the different time points of evaluation of this variable.

DUKE-UNC

Perceived social support reported by the total of patients was 50.39 out of a maximum of 55 points. By gender, the women reported a lower degree of social support (48.08) compared to the 51.20 reported by the men. The differences observed were statistically significant (p<.012).

Perceived social support values among the 42 patients in the study did not show significant changes from the initial values at admission to the HCU (p<.714). (see Table 3). The repeated-measures ANCOVA indicated no significant differences between the two evaluation time points for this variable.

QLQ-C30

Detailed information on the mean scores obtained by subjects in the different functional subscales and individual items of the QLQ-C30 can be seen in Table 1. A model of this instrument is shown in Appendix 1.

By gender, the women presented global quality of life levels of approximately 3 points, while the men scored slightly higher (3.51). The difference by gender in this variable was also significant (p<0.54).

After the second evaluation, none of the five functional scales or the other symptom scales or individual items changed after admission to the HCU. Decreases were only detected with respect to the initial values on the scale referred to as *pain* and the individual item *insomnia*, though only those for pain reached statistical significance (p<.045 and p<.062, pain and insomnia, respectively) (see Table 3). The repeated-measures ANCOVA was not significant for any of the subscales or individual items of the QLQ-C30.

SCS-ACTIVITY

With respect to activity or mobility level, the total sample presented a mean activity of 2.07.

The range for this variable was established between 0 (goes out, total autonomy) and 4 (bedridden more than 80% of day) (see Appendix 2 and Table 2).

The variable activity or capacity of movement on the part of the patient also decreases in the second evaluation, though this decrease does not reach statistical significance (p<.065) (see Table 3). The repeated-measures ANCOVA indicates no statistically significant differences between the different evaluation time points for this variable.

SCS- VOMITING

With respect to vomiting reported by the patients before admission to the HCU, the total study sample shows a mean level of 0.80. See Appendix 2.

Vomiting reported on admission decreases significantly in the second evaluation (p<.003) (see Table 3). Statistically significant differences were not detected by the repeated-measures ANCOVA.

SCS-DYSPNEA

With reference to the dyspnea reported by the 42 patients in the study, most are situated at around 0.61, and the range of scores is from 0 (absence of dyspnea) to 4 (inca-

Table 1
Mean values obtained for the total sample in the QLQ-C30

VARIABLES	SCORES	
	Means/d	Range
PHYSICAL FUNCTIONING	1.53/.27	1-2
ROLE	1.46/.17	1-2
SOCIAL FUNCTIONING	1.72/.89	1-4
EMOTIONAL FUNCTIONING	2.25/.77	1-4
COGNITIVE FUNCTIONING	1.69/.72	1-4
FATIGUE	2.89/.79	1-4
PAIN	2.27/1.04	1-4
NAUSEA/VOMITIN	1.79/.91	1-4
DYSPNEA	1.95/1.12	1-4
INSOMNIA	2.14/1.07	1-4
APPETITE	2.90/1.00	1-4
CONSTIPATION	2.61/1.26	1-4
DIARRHOEA	1.19/.59	1-4
GLOBAL SCALE	3.36/.81	1-7

Table 2
Mean values obtained by the total sample in the SCS

VARIABLES	SCORES	
	Means/d	Range
ACTIVITY	2.09/1.12	0-4
VOMITING	0.80/1.27	0-4
DYSPNEA	0.61/1.01	0-4
PAIN	2.11/1.36	0-4
CONSTIPATION	0.61/.49	0-1
SLEEP	1.16/.79	0-2

pacitating dyspnea). See Appendix 2 and Table 3.

Although dyspnea levels fall with respect to the initial values, this decrease is not statistically significant (p<.071) (see Table 3). The repeated-measures ANCOVA was not significant for the dyspnea variable evaluated by means of the SCS.

SCS – PAIN

Mean pain level reported by the total study sample was 2.11 from a maximum of 4. The scoring range was from 0 (absent) to 4 (incapacitating). See Appendix 2 and Table 2.

After the second evaluation, pain decreased significantly with respect to the initial values (p<.000) (Table 3). The repeated-measures ANCOVA indicates the absence of statistically significant differences for the different evaluation time points in the SCS pain variable.

SCS-CONSTIPATION

On admission, the total sample reported constipation levels of 0.61. This variable ranged from 0 (absence) to 1 (constipation). See Appendix 2 and Table 2.

A statistically significant decrease with respect to the initial values was also observed in the constipation variable of the SCS (p<.000) (Table 3). The repeated-measures ANCOVA indicated the absence of statistically significant differences in the different evaluation times for this variable.

Table 3
Pre- and post-evaluation means and differences in the variables assessed

INSTRUMENT	PRE MEAN	POST MEAN	DIFFERENCES
HAD			
Anxiety	7.97	7.69	P<.704
Depression	7.30	8.40	P<.196
Duke-UNC	50.39	49.97	P<.714
QLQ-C30			
Physical Functioning	1.53	1.49	P<.281
Role	1.46	1.51	P<.210
Social Functioning	1.72	1.75	P<.863
Emotional Functioning	2.25	2.14	P<.477
Cognitive Functioning	1.69	1.67	P<.877
Fatigue	2.89	2.84	P<.943
Pain	2.27	1.91	P<**.045**
Nausea/vomiting	1.79	1.71	P<.565
Dyspnea	1.95	1.73	P<.277
Insomnia	2.14	1.76	P<.062
Appetite	2.90	2.80	P<.643
Constipation	2.61	2.42	P<.411
Diarrhoea	1.19	1.11	P<.519
Financial Functioning	1.33	1.19	P<.160
Global Scale	3.36	3.30	P<.761
SCS			
Activity	2.09	1.63	P<0.65
Vomiting	0.80	0.21	**P<.003**
Dyspnea	0.61	0.40	P<.071
Pain	2.11	0.66	**P<.000**
Constipation	0.61	0.23	**P<.000**
Sleep	1.16	0.33	**P<.000**

SCS- SLEEP

An initial score of 1.16 was found in the sleep variable evaluated by the doctor. Possible scores were 0 (well), 1(reasonably) and 2 (badly). See Appendix 2 and Table 2.

A statistically significant decrease with respect to the initial values was also observed in this variable (p<.000) (Table 3). The repeated-measures ANCOVA indicated the absence of statistically significant differences in the different evaluation times for this variable.

KARNOFSKY INDEX

The total sample presented a mean Karnofsky Index value of 52.8 and a range of 40 to 70. No significant changes were observed in the Karnofsky values after the second evaluation in the total sample of patients.

DISCUSSION

One of the objectives of this project involved identifying the demographic characteristics of the study sample with regard to the variables relevant to the terminal process of the illness. Some of these variables, such as the indicators of *anxiety and depression* and the *social support* available to the patient, were assessed using two psychological instruments, the HAD scale (Zigmond and Snaith, 1983) and the DUKE-UNC social support questionnaire (Broadhead et al., 1988) whose utility in the psychological evaluation of physical patients is widely documented in the specialized literature (De la Revilla, Bailón, de Dios, Delgado, Prados and Fleitas, 1991; Caro and Ibañez, 1992; Bredart et al., 1999 Skarstein, Ass, Fossa, Skovlund and Dahl, 2000). Another variable of growing interest in current oncological research is that of *quality of life* with reference to the terminal process of cancer. Despite a lack of consensus upon its definition, quality of life is generally understood as a multidimensional concept that encompasses psychological and social aspects, symptoms generated by both the illness and its treatment and the patient's level of functioning. Although since 1993 improving quality of life has been a priority objective in dealing with patients in the terminal stage of illness, there is still no valid and relia-

ble instrument available for its evaluation within the context of palliative care (Rees, Hardy, Ling, Broadley, A'Hern, 1998). In order to assess quality of life we applied the EORTC questionnaire QLQ-C30, one of those most commonly used in oncology patients (Arrarás, Illaramendi and Valverdi, 1995). Finally, we consider and assess some of the variables related to the physical symptoms frequently presented by oncology patients in advanced stages of terminal illness (pain, dyspnea, vomiting, constipation and sleep) admitted to the HCU (García et al., 1995).

First of all, and with regard to the evaluation of anxiety and depression levels by means of the HAD scale, the results indicate that the sample of our study is halfway between the category "absence of symptoms" (scores of between 0 and 7 for both anxiety and depression) and "doubtful case" (scores of between 8 and 10 for both anxiety and depression), according to the criteria of the authors themselves (Zigmond and Snaith, 1983). In fact, the criteria proposed by Snaith (1983) indicate that for the inclusion or exclusion of a patient from the group with emotional disorders, only scores of between 11 and 21 would be clear indicators of anxiety and depressive disorders. If we bear in mind that, on admission to the HCU, the sample of this study presented mean levels of 7.97 and 7.30 for anxiety and depression, respectively, we can affirm that in our study the cancer patients, despite being in the so-called terminal phase of the illness, are psychologically well adjusted. This finding casts doubt on reports of emotional problems in patients with physical illnesses, and supports the idea that while oncology patients may present symptoms, especially of anxiety and depression, these symptoms should not necessarily be considered as constituting a clinical syndrome as the term is traditionally understood. It is also worth mentioning the differences found between men and women with respect to the evaluation of the two variables. In accordance with published findings over many years (Taylor, 1953; Zung, 1973; Spielberger, 1977; Zigmond and Snaith, 1983; Bredert et al., 1999), anxiety and depression are influenced by socio-demographic factors such as age and sex. These predictions are borne out in our study, in which it can be observed how the group of 12 women in the sample presented higher levels of both anxiety and depression than the men, with the differences in the depression indicators being greater and statistically significant.

The results of this study also indicate that the social support perceived by the total sample was highly positive. Several authors have described how the relationship between social support and terminal illness is associated with extremely difficult and "stressful" situations faced by the patient (symptoms, examinations and prognoses). The data indicate that our patients feel strongly supported by their family and socially, with a mean perceived support score of around 50.39 from a maximum of 55, the mean indicators for the general population being 35.55 (de la Revilla et al., 1991). Obviously, having a sufficient (minimum) level of family support is one of the prerequisites for admission to the home care unit, where the palliative care administered to the patient also requires the attention, time and care of one or more relative(s). It is therefore not surprising that the patients in our sample reported very high levels of social support. If, as the results indicate, the sample of patients report a high and positive degree of social support, this data could be placed alongside the anxiety and depression indicators observed to become another explanatory variable for the acceptance of and adaptation to the illness and its course. Future research should undertake to analyze and confirm this assumption, considering the relationship between the two variables with samples similar to the one used in this study.

A notable and surprising aspect of our results concerns the data on the quality of life variable obtained by means of the QLQ-C30 questionnaire, on the one hand, and the on the various symptoms of the illness as evaluated by the SCS, on the other. According to the EORTC questionnaire, the patients report more problems in relation to symptoms such as *appetite* and *fatigue* than for symptoms such as *constipation* and *pain*. Apparently, the absence of control over these symptoms should have a negative influence on quality of life. However, when patients are asked to assess their *global quality of life*, all of them put it at an intermediate level (neither *terrible* nor *excellent*, i.e., "normal"). On the other hand, the evaluation carried out by the doctor using the SCS revealed that *dyspnea* (what the QLQ-C30 calls *fatigue*) is not precisely the variable that most concerns or incapacitates patients, and that the most incapacitating symptoms would relate *to pain*, *constipation and sleep*, in that order. We can find no explanation for this divergent result, since, despite using different evaluators (the doctor in the checking of symptoms and the psychologist in the QLQ-C30), the patients always answered in the presence of both professionals. In this way we assumed we could discard the presence of different response tendencies depending on whether the evaluation was carried out by a doctor or by another person.

In a similar line, we shall now move on to a discussion

of the differences reported by the patients themselves with respect to the same variables after admission to the HCU. In none of the scales of purely psychological content were any differences observed subsequent to the palliative care administered. The initial levels of anxiety, depression and social support are maintained at the second measurement, regardless of the time period between the two evaluations. This is consistent with what was expected, given that in the initial evaluation we observed no maladjustments susceptible to modification. In contrast, all the symptoms reported by the patients to the doctor (pain, constipation, sleep and vomiting) did change. These changes were in a positive direction, with considerable reductions in all symptoms by comparison with the initial levels. Symptoms such as pain, constipation and sleep changed significantly and clinically in the post-evaluation, regardless of when this was carried out. The data and verbal information provided by the patients bear this out.

With regard to the QLQ-C30, no differences were detected between the evaluations in any of the functional subscales, nor in the majority of the symptom scales. It seems that nothing changes after admission to the unit. Neither does the *global quality of life* subscale change with respect to the initial indicators. The variable defined as activity or mobility in the SCS is deserving of special mention. The decrease in activity level of the patients with respect to the first evaluation, despite not being significant ($p<.065$), indicates how the patients in the study experience progressively lower levels of autonomy and mobility. Nevertheless, this is to be expected, and is in keeping with their prognosis, given that we are dealing with a sample of oncology patients in an *advanced* stage of *terminal* illness. In contrast, the *physical functioning* scale, evaluated by the QLQ-C30 and comparable to the *activity* variable of the SCS, given that it also evaluates the area relating to patients' activity and mobility, does not register any change with respect to initial levels. If we bear in mind the terminal prognosis of the patients and the fact that their Karnofsky Index does not improve subsequent to admission in the HCU, it is not unreasonable to think that the "activity" variable evaluated by the doctor is not only more discriminative but also more pertinent than the "physical functioning" scale of the QLQ-C30, at least in a terminal oncology population. In fact, 3 of the 5 items making up this QLQ-C30 subscale (see Appendix 2) are not applicable to a sample with an initial Karnofsky Index of 40, defined as "requires considerable assistance and frequent medical care" (Karnofsky and Burchenal, 1949).

By way of conclusion, it can be said that the term *quality of life* in terminal illness is a vague concept and has been used with different criteria in very different situations (Enck, 1990; Rosenthal, 1993). One of the most widely used questionnaires for evaluating this concept, the QLQ-C30, does not permit the detection of differences subsequent to admission in the HCU in important terminal process symptoms such as vomiting, constipation and patients' quality/quantity of sleep. Nor does it permit the detection of differences observed and reported by patients with respect to the decrease in their levels of activity/mobility. Some of the items included in the scale are not pertinent to the terminal process (e.g., "Do you have any difficulty in going for a long walk?" or "Are you fully capable of doing your job or performing household tasks?"), while some of those that are indeed relevant ("Do you feel depressed?" or "Do you feel nervous?") are too general to provide appropriate information about the patient's level of anxiety or depression. Finally, it is surprising that the patients situate themselves at an "intermediate point" (neither terrible nor excellent) with respect to their *global quality of life*, especially when one of the items of this subscale ("How would you rate your general physical condition during the past week?") should produce a low score, if we accept the veracity of the prognosis and the initial Karnofsky Index. We thus feel that, rather than speaking of quality of life in terminal cancer, it would be more appropriate to speak of degree of comfort achieved and demanded by patients. According to what can be deduced from this study, it is the symptoms of the illness that most concern and incapacitate terminal patients. It seems that they have accepted their illness – which is consistent with data already published in previous studies (Hinton, 1999) and with the levels of anxiety and depression reported in the study –, and that what they are asking for at this point is not an increase in "quality of life", but rather that they be given the assistance necessary to achieve a dignified death without suffering: Quality of death?

"…For him, all this occurred in an instant and the significance of that instant would never change now. For those present, the death throes continued for two hours more. Something bubbled in his chest and his exhausted body shuddered…

- It's over! - said one of them, standing over him

He heard these words and repeated them in his soul. "Death is over – he told himself…"

Leon Tolstoy, *The Death of Ivan Illich.*

APPENDIX 1
QLQ-C30

We are interested in knowing some things about you and your health. Please respond personally to all the questions by circling the number that best applies to your case. There are no "correct" or "incorrect" answers. The information you provide shall remain confidential.

	No	Yes
1. Do you have any difficulty in doing activities that require considerable effort, such as carrying a shopping bag or suitcase?	1	2
2. Do you have any difficulty in going for a long walk?	1	2
3. Do you have any difficulty taking a short walk outside?	1	2
4. Do you have to spend the greater part of the day in bed or sitting down?	1	2
5. Do you need help with eating, getting dressed, washing or going to the toilet?	1	2
6. Do you have any problem to do your job or carry out household tasks?	1	2
7. Are you totally incapable of working in a profession or doing household tasks?	1	2

DURING THE LAST WEEK

	Notat all	A little	Quite a lot	Alot
8. Have you had asphyxia?	1	2	3	4
9. Have you had pain?	1	2	3	4
10. Have you had to stop in order to rest?	1	2	3	4
11. Have you had difficulty sleeping?	1	2	3	4
12. Have you felt weak?	1	2	3	4
13. Have you lacked appetite?	1	2	3	4
14. Have you felt nauseous?	1	2	3	4
15. Have you vomited?	1	2	3	4
16. Have you been constipated?	1	2	3	4

DURING THE LAST WEEK

	Notat all	A little	Quite a lot	Alot
17. Have you had diarrhoea?	1	2	3	4
18. Have you felt tired?	1	2	3	4
19. Did any pain interfere in your daily activities?	1	2	3	4
20. Have you had difficulty in concentrating on things like reading the newspaper or watching television?	1	2	3	4
21. Have you felt nervous?	1	2	3	4
22. Have you felt worried?	1	2	3	4
23. Have you felt irritable?	1	2	3	4
24. Have you felt depressed?	1	2	3	4
25. Have you had difficulty in remembering things?	1	2	3	4
26. Has your physical state or medical treatment affected your family life?	1	2	3	4
27. Has your physical state or medical treatment affected your daily activities?	1	2	3	4
28. Has your physical state or medical treatment caused you financial problems?	1	2	3	4

In the following questions, please put a circle around the number 1 – 7 that best applies to you.

29. How would you rate your general physical condition during the last week?	1	2	3	4	5	6	7	Terrible	Excellent
30. How would you rate your general quality of life during the last week?	1	2	3	4	5	6	7	Terrible	Excellent

APPENDIX 2
CORRECTION INSTRUCTIONS

In the symptoms section a number from 0 to 4 should be written according to the intensity of the symptom, bearing in mind the following:

Activity
0: Goes out. Total autonomy
1: Goes out but with assistance
2: Limited to the home but with autonomy in going to the toilet and eating
3: Limited to the bed – chair
4: Bedridden more than 80% of the day

Vomiting
0: No nausea or vomiting
1: Sporadic nausea
2: Vomiting once a day and not every day
3: Vomiting more than once a day
4: Total intolerance

Dyspnea
0: No dyspnea
1: Dyspnea on moderate effort
2: Dyspnea on minimal effort
3: Dyspnea at rest
4: Incapacitating dyspnea

Constipation
0: No
1: Yes

Sleep
0: Well
1: Reasonably
2: Badly

Pain
0: None
1: Slight
2: Moderate
3: Severe
4: Incapacitating

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