## Patient acceptance and differential perceptions of quality of life measures in a French oncology setting

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A three-part study evaluated French cancer patients' acceptance of self-rated quality of life measures, the predictive value of these measures, and the agreement between patient and health provider ratings of patient quality of life. In part one, 93% of 137 patients indicated a willingness to complete the Qualite de la Vie-Questionnaire (QOL-Q) and Analogues Lineaires pour la Mesure de la Qualite de vie (LA), and 63.6% indicated a willingness to be interviewed by a psychologist. Willingness to complete the scales was related to hospitalization status and treatment modality. In parts two and three, 100 patients were asked to complete the QOL-Q, LA, the Karnofsky Index (KI) and a side-effects checklist, and to undergo a psychological interview. Following interview, a psychologist rated the patients using the QOL-Q, and classified patient level of emotional distress. Oncologists rated the patient using the KI and the side-effects checklist. The results indicate that the patients' ratings of their quality of life were higher than the psychologist's ratings, and that the QOL-Q has predictive value in indentifying severe emotional distress. Low level of patient and physician agreement on the KI was partially explained by patient age and cancer site. A moderate level of agreement was found between patient and physician perceptions of side effects. The study suggests that the QOL-Q, not the LA, may be useful as a screening tool to identify patients with impaired quality of life, and that self-rated measures should be included in quality of life assessments.

Key words: Cancer, France, quality of life.

## Introduction

Quality of life measures are being considered as one of the end-points by which clinicians can evaluate the risks and benefits of cancer treatment.<sup>1,2</sup> For example, the inclusion of quality of life assessments have been recommended in clinical trials of palliative treatment particularly when survival outcomes are equivocal.<sup>3</sup> Similarly, quality of life measures may be used to provide an index of physical and psychosocial distress associated with oncology protocols, and be used to evaluate or justify the existence of psychosocial services within an oncology unit.

Several instruments have been proposed to evaluate the quality of life of oncology patients including the Karnofsky rating,<sup>4</sup> the Linear Analogue Self Assessment,<sup>5</sup> Vitagram,<sup>6</sup> the Symptom Distress Scale,<sup>7</sup> the Cancer Patients Symptom Checklist,<sup>8</sup> the Q-L Index,<sup>9</sup> the Quality of Survival Scale,<sup>10</sup> the Quality of Life Index,<sup>11</sup> the Life Change Scale, <sup>12</sup> the Anamnestic Comparative Self-Assessment (ACSA)<sup>13</sup> and the Functional Living Index-Cancer.<sup>14</sup> The wide range of criteria, or content factors, found within these scales suggests that there is no single theoretical or methodological approach to quality of life.<sup>15</sup> This conclusion is supported by recent reviews<sup>16,17</sup> of clinical studies which, in total, use more than 36 different measures of quality of life. These measures, most of which were developed for non-cancer populations, appear to cluster around four content factors: functional status, treatment complications or discomfort, psychological status, and interpersonal relationships.

## Background of the study

In 1982 our French research team consisting of an oncologist, statistician, psychologist, psychiatrist,

and an oncology nurse assessed available quality of life scales for possible inclusion in clinical trials. We sought to identify a self-administered scale which yielded global measures of physical status, chemotherapy and radiation therapy side-effects, psychological status, social support, sexual functioning, and the ability to continue with professional and leisure pursuits. We also sought a scale which could be administered within 30 min.

Moreover, we sought a reliable and valid quality of life scale which had been administered to a French-language population, and which reflected French cultural values. Sartorius<sup>18</sup> advised that global assessments of quality of life be tested in their culture of application and that cross-cultural relevancy be established for such measures. However, except for the European Organization of Research and Treatment of Cancer Quality of Life Study upon a lung cancer population<sup>19</sup> studies of cultural relevancy with French patients have not been reported. Most of the quality of life scales for cancer populations have been developed in the United States, English speaking regions of Canada or Great Britain, and, as such, reflect North American and Anglican values. Hence, our failure in 1982 to identify a quality of life scale with our specified content factors and our reluctance to use scales with questionable cultural relevancy prompted the development of two French quality of life scales measures, the Qualite de la Vie-Questionnaire (QOL-Q) and the Analogues Lineaires (Linear Analogue-LA). The development and psychometric analysis of these scales are described in detail elsewhere.<sup>20</sup>

French cancer patients have rarely been administered self-rated quality of life measures. More commonly, patients who are identified by their oncologist as having emotional difficulties are referred to a psychiatrist or a psychologist for evaluation and treatment. Our clinical observations suggest, though, that patients are reluctant to accept such referrals for fear of being labelled 'crazy'. Subsequently, the quality of life of most cancer patients is not evaluated unless the patient is referred and is willing to accept the referral. In contrast self-rated measures of quality of life can be used to screen all patients for levels of psychosocial and functional status, and can be used to provide empirical evidence to evaluate psychological assessment and intervention. Accordingly, the purpose of this three-part study was to test the acceptance of self-rated quality of life measures in French oncologic population, to test the predictive value of these measures, and to compare patient and clinical ratings of patient quality of life.

More specifically, three research questions were posed: (1) To what extent are patients willing to complete the QOL-Q and LA compared to their willingness to be interviewed about their quality of life. (2) To what extent do the QOL-Q and the LA correspond with the level of patient emotional disturbance rated by an interviewing psychologist? (3) How do patient self-ratings of quality of life compare to ratings made by an interviewing psychologist and their oncologist? A discussion of the collective results of the research questions is presented following the methods and findings for each question.

## The patient willingness to complete the quality of life scales vs. willingness to be interviewed (Question #1) Method

## Subjects

In June 1985, 137 cancer patients were selected from the Departments of Radiotherapy and Oncology Services of the Centre Hospitalier Regional de Besancon using consecutive sampling techniques. All inpatients and regularly scheduled outpatients were eligible for inclusion provided they had sufficient cognitive capacity to understand the interviewer's questions. The distribution of sociodemographic, disease and treatment characteristics within the selected sample closely approximated the distribution found within the population treated by the radiation therapy and medical oncology services: 65% of the selected cases were female; 35% had a primary diagnosis of breast cancer, 20% had ovarian or uterine cancer, 10% had head and neck cancer, 5% had lung cancer, and 30% had other cancer diagnoses; 65% were outpatients and the remainder were inpatients; and 62% were undergoing chemotherapy only, 27% were undergoing radiation therapy alone, and the remainder were receiving combined treatments. With the exception of 28 patients with recurrent disease, all patients were seen for initial treatment.

## Procedures

During outpatient visits or hospitalizations, subjects were approached by the oncology nurse and

asked if they would be willing to complete selfreport measures of their quality of life, and asked if they would be willing to be interviewed about their quality of life by the department psychologist. The quality of life scales were not actually administered, but psychological referrals were made when specifically requested by the patient.

## Results

Of the 137 patients approached by the nurse, 128 (93.4%) indicated that they would be willing to complete self-measures of quality of life compared with 84 (63.6%) who indicated they would be willing to participate in an interview ( $\chi^2 = 40.4$ , p < 0.001). Among those cases who would be willing to be interviewed, 19 specifically requested psychological intervention and were referred. Outpatients were more likely to express a willingness to complete the scales than inpatients ( $\chi^2 = 5.8$ , p = 0.02). No significant differences were found on patient's willingness to respond to quality of life measures with respect to gender, stage of disease, or treatment modality. However, patients undergoing single treatment modalities were more willing to complete the scales (95%) and undergo a psychological interview (65%) than patients receiving combined treatment (82% willing to complete scale, 36% willing to be interviewed).

## The correspondence between quality of life measures and psychological distress rating (Question #2) The patient vs. clinician ratings (Question #3) Methods

#### Subjects

Between October 1985 and December 1986, a sample of 100 cancer patients were selected from the same oncology setting using quota, stratified sampling techniques to reflect the distribution of cancer site and stage of disease within the patient population (Table 1). The typical patient was 55 years of age, married, and was undergoing treatment for newly diagnosed disease. Consistent with the characteristics of the patient population, nearly twice as many females were sampled than males, and the most common cancers were breast,

 Table 1. Patient characteristics of selected sample for questions 2 and 3

	Male ( <i>n</i> = 30)	Female ( <i>n</i> = 70)	Total ( <i>n</i> = 100)
Age (years) Mean Range	56 30-77	54 30-77	54.6 30-77
Marital Status Single Married Widowed Divorced	1 25 4 0	11 46 11 2	12 71 15 2
Hospitalization Status Inpatient Outpatient	14 16	34 36	48 52
Current Treatment Chemotherapy Radiotherapy	13 17	45 25	58 42
Primary Cancer Breast Melanoma Head and neck Colorectal Lung Hodgkin's disease Uterine and ovarian Bone Prostate Other	1 12 4 2 0 1 2 3	34 3 5 1 3 0 20 0 4	35 4 17 5 7 2 20 1 2 7
Stage of Disease Newly diagnosed Metastatic	25 5	37 33	62 38

ovarian or uterine, and head and neck. All patients were assessed during the fourth or fifth cycle of chemotherapy or near the completion of radiation therapy.

#### Measures

The QOL-Q contains 23 items with each item response placed on a 5-point Likert scale (Appendix A). The items assess physical status (e.g., pain, fatigue, appetite, physical capacity), psychological status (e.g., depression, anxiety, nervousness, worry), social functioning (e.g., relations with family and friends, marital relations), sexual functioning (e.g., sexual desire and activity), impact of treatment, changes in professional life, and ability to maintain hobbies and pursue interests. A total score is derived by summing the raw scores of the items. A previous QOL-Q administration on a different sample selected from the same French population found a standardized internal consistency correlation coefficient of 0.77.<sup>20</sup>

The LA measures five content factors: depression, fatigue, sense of well-being, pain, and self-confidence (Appendix B). Each factor is assessed using a 10 cm line labelled with contrasting endpoints. Item scores are derived by measuring the distance (in centimetres) between the left endpoint and where the patient places him/herself on the lines. The total score is the summing of the item scores. A standardized internal consistency correlation coefficient of 0.70 has been reported based on a study of 43 French cancer patients. Positive relationships measured by Pearson rcorrelation coefficients, were found between QOL-Q, LA and ACSA (concurrent validity).<sup>20</sup> The Karnofsky Index (KI) was developed in 1948 as a measure of nursing dependency among cancer patients.<sup>4</sup> Despite recent criticisms of the index,  $^{21-24}$  it continues to be widely used as a measure of therapeutic effectiveness and as a prognostic indicator, and is regularly used in French oncology settings. The scale consits of a 10-point index of physical status, with responses ranging from "Able to carry on normal activity, no complaints, disease'' no evidence of to "Moribund, fatal processes progressing rapidly". Because moribund patients were unable to participate in our study, and because of concern that the two latter catergories might evoke emotional discomfort, these two categories was deleted in our patient version.

The World Health Organization checklist of treatment side-effects consists of 12 categories: nausea/vomiting, diarrhoea, constipation, haematuria, pulmonary function, fever, allergic reaction, skin reaction, hair loss, infection, neurological effects, and pain. Each category is coded on a 0-4 index, ranging from none, or no status change, to severe complications.<sup>25</sup> Patients have not experienced difficulties in completing the two instruments.

## Procedure

Patients who agreed to participate were administered the QOL-Q, LA, the KI, and the side-effects checklist by the oncology nurse during regularly scheduled appointments, and were scheduled for an interview with the department psychologist during the same day. The  $\frac{1}{2}$ -1 h psychological interview consisted of semi-directed questions which corresponded to the content factors found in the QOL-Q. Following the interview, the psychologist used the QOL-Q to rate each patient, and classified patients as having either minimal to moderate distress, or somewhat severe to severe distress. Classification of severity of distress was based on the extent to which the patient experienced depression, anxiety, loss of self-esteem, ineffective coping strategies, loneliness, loss of emotional control, and reduction or loss of social support.

Following clinical examination, each patient's physician was asked to rate the patient using the KI and the side-effects checklist. Six oncologists participated in this portion of the study.

## Analysis

Weighted kappa coefficients<sup>26,27</sup> and interclass correlation coefficients<sup>28</sup> were used to compare patient and psychologist QOL-Q item scores. A Student's *t*-test was used to compare patient and psychologist QOL-Q total scores. A stepwise multiple regression analysis was used to examine the effects of patient characteristics (age, gender, marital status, hospitalization, cancer site, stage of illness, treatment modality) on patient/psychologist difference (D) scores.

Chi square  $(\chi^2)$  analysis was used to determine which items 'correctly' classified patients into the level of psychological distress assigned by the psychologist. 'Correct' items were entered into a logistic regression analysis as predictor variables with the level of psychological distress as the outcome variable. Significant predictor variables were then entered into a discriminant function analysis. The predictive value of all LA items was also examined in a discriminant function analysis using level of distress as the outcome variable. The comparisons of patient and physician Karnofsky scores and ratings of side-effects were conducted using interclass correlation coefficients and weighted kappa coefficients. Using the D-scores between paired patient and physician KI responses as the dependent measure, stepwise multiple regression analysis was then used to examine the effect of patient characteristics.

## Results

All the hundred patients answered to the questionnaire and LA but only 83 patients completed in their entirety the QOL-Q and 93 the LA. The patient QOL-Q scores ranged from 28 to 72, with a mean of 52.9, a median of 54, and a standard deviation of 9.95. The psychologist QOL-Q scores ranged from 23 to 67, with a mean of 42.8, a median of 43, and a standard deviation of 8.00. Examining QOL-Q total scores, patients consistently rated themselves as having higher quality of life compared to the psychologist's ratings (t = 7.96, p < 0.001). When total scores were compared using an interclass correlation coefficient a relationship moderately low was found (R = 0.227).

Using weighted kappa coefficients, moderate patient/psychologist agreement was found for most of the 23 QOL-Q items. The three items with the highest patient/psychologist agreement were about daily activities ( $\kappa = 0.59$ ), sexual desire  $(\kappa = 0.56)$ , and pain  $(\kappa = 0.57)$ ; the three items with the lowest agreement were about marital relations ( $\kappa = 0.12$ ), nervousness ( $\kappa = 0.09$ ), and anxiety ( $\kappa = 0.11$ ). The four items related to sexual function and type of treatment were eliminated from further analysis because of incomplete patient responses. Forty per cent (n = 33) of the patients were classified by the psychologist as having somewhat severe or severe distress. Univariate analysis found that the QOL-Q items with the highest levels of correct classification were those related to physical status ( $\chi^2 = 17.7$ , p < 0.001), anxiety ( $\chi^2 = 17.8$ , p < 0.001), nervousness ( $\chi^2 = 9.8$ , p = 0.002), ability to overcome worry ( $\chi^2 = 11.9$ , p < 0.003), interest in activities  $(\chi^2 = 8.3, p = 0.004)$ , and desire to cry  $(\chi^2 = 7.6, p = 0.004)$ p = 0.006).

The stepwise logistic regression analysis (forward entry) with the remaining 19 QOL-Q items on the level of psychological distress found three items accounting for most of the variance: household/professional activities (beta coefficient = 0.74,  $\chi^2 = 5.97$ , p = 0.015), physical status (beta coefficient = 0.58,  $\chi^2 = 12.75$ , p < 0.001), and anxiety (beta coefficient = 0.83,  $\chi^2 = 6.30$ , p = 0.012). When these three items were entered into a discriminant function analysis, correct classification of psychological distress occurred in 73.5% of all cases, and in 81.8% of those previously classified as having somewhat severe to severe psychological distress.

The LA scores ranged from 0.48 to 4.9, with a mean of 3.42, a median of 3.51, and a standard deviation of 0.96. A discriminant function analysis of the LA indicated that only one item "Depression", was statistically significant. When "Depression" was examined alone, correct classification of

psychological distress occurred in 70.7% of all cases, and in 51.2% of those cases previously classified as having somewhat severe to severe psychological distress.

All 100 patients and their physicians completed the KI and the WHO side effect checklist as requested. The interclass correlation coefficient for the KI scores was moderate (R = 0.56), with perfect agreement between the patient and physician scores occurring in 25% of the patient/physician pairs. A *post hoc* analysis of the patient/physician pairs using a Pearson correlation coefficient resulted in a higher coefficient (r = 0.633, p < 0.001). Perfect agreement in KI scores was independent of treatment modality (22.5% perfect agreement for radiotherapy cases, 29.5% for chemotherapy cases), but related to hospitalization status (39.6%) perfect agreement for inpatients, 11.5% for outpatients). The Kruskall-Wallis tests demonstrated that the mean difference between the patient and physician KI scores was independent of which physician had performed the rating. The stepwise regression analysis of the D-scores found that low patient/physician agreement was partially explained by patient age and cancer site. The KI scores of younger patients were lower than the physician scores; the scores of older patients were higher than the physician scores (beta coefficient = 0.034, t = 2.57, p = 0.012). Among cases with uterine corpus or breast cancers, the physicians systematically rated the patients higher on the KI than the patients rated themselves; among cases with head and neck cancer, similar scores were observed between patients and their physicians (beta coefficient = -0.14, t = -2.01, p = 0.047).

The level of side-effects most frequently noted by both the patient and physician was grade 1 (mild or absent). The most common side-effects were nausea and vomiting; the least common were haematologic, fever, and allergic reaction. Weighted kappa coefficients to compare patient and physician ratings of side-effects ranged from 0.78 to 0.08, with most coefficients indicating a moderate to poor level of agreement. No systematic pattern of patient/physician D-scores was observed with respect to symptom severity.

## Discussion

As observed in another French study<sup>29</sup> most of our patients expressed a willingness to complete selfrated quality of life measures. We also noted that their willingness to participate was associated with hospitalization status, treatment modality, and physical status. Those patients who were most willing to participate were outpatients, receiving single treatment modalities, and were in satisfactory physical condition. Consistent with our clinical impressions, our findings suggest that patients are more willing to complete quality of life instruments than be interviewed by a psychologist. On the other hand the French psychologists favoured interviews which seem to them more informative.

Based on the psychologist's ratings of psychological distress, it appears that the QOL-Q adequately predicts patient level of emotional distress. Thus, the QOL-Q should be useful as a screening tool to identify patients with physical and/or psychosocial distress, and as an evaluation tool to measure intervention effectiveness. In contrast, the results indicate that the LA does not sufficiently discriminate between levels of distress, and perhaps has limited clinical use.

The moderate level of agreement found between patient and psychologist QOL-Q ratings may be due to several factors. The results of Pearlman and Uhlmann<sup>30</sup> comparing patient and physician ratings of the quality of life of chronically ill elderly patients, suggest that elderly patients have a tendancy to report physical problems, and underreport psychological or social concerns. Patient interviews necessitate a subjective interpretation by the rater, and are, as such, a reflection of the rater's own bias. The consistently lower ratings of the psychologist may be a reflection of her own negative expectations of the quality of life of cancer patients.

Our findings of moderately low patient and physician agreement on the Karnofsky Index support the results of previous studies.<sup>22,23</sup> It appears, though, that our results contradict those of a more recent investigation which found a high Kendall correlation between patients' (n = 100)and physicians' (n = 2) Karnofsky scores.<sup>31</sup> However, when we used a Pearson correlation coefficient in a post hoc analysis, our results (r = 0.63) were nearly identical to those in this latter study. Our findings illustrate the problematic relationship between correlational and concordance statistics: only moderate rates of concordance are obtained despite well-correlated independent ratings. Current statistical methods for analysing rater/subject concordance do not consider multiple subjects/one rater study designs; instead, they assume multiple subjects/multiple raters in which each rater is independent of other raters.

Similar to the systematic bias of the psychologist's ratings, the physicians consistently rated their younger patients and those with breast or uterine cancer as having higher functional status than these patients rated themselves. The physicians also rated their older patients as having lower functional status than the patients rated themselves. As suggested by others who found that patients and oncologists had discordant perceptions on the nature of the disease and the aggressivity of treatment, <sup>32</sup> it appears the differential perceptions may be influenced by such patient characteristics as diagnosis and age. Future research comparing patient and physician perceptions of quality of life might be advised to consider physician characteristics such as age, gender, years of oncological practice, medical speciality, and extent to which time is allocated to discuss patient problems.

In summary, the results of our quality of life study indicate that French oncology patients are willing to respond to self-rated measures of quality of life. The ability of the QOL-Q to adequately predict levels of emotional distress suggests that this scale has validity as a screening tool to identify patients with impaired quality of life. Our findings strongly support the importance of considering patients' self-ratings of quality of life as patient perceptions may significantly differ from the assessments of their health providers.

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Appendix A. Self-rated questionnaire for the measure of	f quality of life of Bes	ançon (QOL-Q)			
During the past week 1. Has your ilhess or treatment had a major impact on your daily life (for example, have you had problem in bathing dressing etc ) 2	Not at all O	A little	Somewhat O	Ouite a bit	Very much O
2. Are you satisfied with your job or your ability to work at home?	0	0	0	0	0
	A great deal for worse	Yes, somewhat for the worse	Not at all	Somewhat for the hetter	A lot for the better
<ol><li>Has your way of life changed because of your illness or treatment?</li></ol>	0	0	0	0	0
4. Has your illness or treatment changed your relation which	÷				
family members?	00	00	00	00	0
friends? spouse or partner?	00	00	00	00	00
5. Has your spouse or partner been affected by vour illness or treatment?	Not at ali O	A little	Somewhat O	Ouite a bit	Very much O
<ol> <li>Has your interest in sex changed?</li> <li>Have you modified your sexual relations?</li> </ol>	A lot less	Somewhat less	Not at all	Somewhat more	A lot more
During the last 3 days	Not at all	A little	Somewhat	Quite a bit	Very much
<ol> <li>B. Have you telt because of your illness or treatment pain?</li> </ol>	00	00	00	00	00
ured r loss of appetite (not hungry)?	C Veny well hetter				
9. How have you felt physically?	than normal	better than normal		than normal	very sick, a lot man normal O
During the past week, because of your illness of	Not at all	A little	Somewhat	Quite a bit	Very much
10. Have you been nervous or irritable? 11. Have vou been anxious?	00	00	00	00	00
<ol> <li>Have you been depressed?</li> <li>Have you felt like crying?</li> <li>Has your treatment control you to feel downcood</li> </ol>	00	000	000	000	000
or blue?					
<ul> <li>a) surgery?</li> <li>b) radiation therapy?</li> <li>c) chemotherapy?</li> <li>c) chemotherapy?</li> <li>15. Have you had interest in doing things you usually do?</li> <li>16. Have you been able to overcome your worries?</li> <li>17. Have your leisure activities changed (for example, hobbies, sports, going to movies, listening to music)?</li> </ul>	೦೦೦೦೦೦	000000	000000	000000	000000

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## Quality of life

Appendix B. Linear analogue for the measure of quality of life of Besançon

These last 3	days
It is not possible to be more depressed	I don't feel depressed at all
It is not possible to be more tired	I feel fit and well
I feel very anxious	I don't feel anxious
It is not possible to have more pain	l don't feel any pain
l've lost all confidence in myself	I still have confidence in myself