# Tradeoffs between Quality and Quantity of Life:

## Development of the QQ Questionnaire for Cancer Patient Attitudes

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The patient's perspective is of prime concern in weighing the benefits and side effects of oncologic treatment. Little is known about patients' preferences and attitudes. The authors developed a short questionnaire to assess patient attitudes concerning trade-offs between quality of life and length, or quantity, of life (the QQ Questionnaire). The questionnaire turned out to be feasible for use in various groups of cancer patients. In a factor analysis, the questionnaire was shown to consist of two factors, a Q(uality) and a L(ength) factor. Values of Cronbach's $\alpha$ for the Q and L scales (consisting of four items each) were 0.68 and 0.79, respectively. Younger patients and patients who have children assigned relatively more importance to striving for prolonged survival. Contrary to our expectation, no association was found between scores on the two scales and time tradeoff utility scores. The QQ Questionnaire can be used in research settings to study patient attitudes and the stability and determinants of patients' preferences. Key words: oncology; quality of life; side effects; patient preferences; health state utilities. (Med Decis Making 1998;16:184-192)

Tradeoffs between quality of life and length of life are often necessary in decision making in oncology. It is acknowledged increasingly that in this process of weighing the benefits and side effects of treatment, the patient's perspective is of prime concern. Some patients are willing to go to extreme lengths to prolong survival, accepting treatments that severely impair quality of life. Other patients feel that they want to make the most of their remaining years, and are unwilling to risk an inferior quality of life. Little is known about which factors determine whether a patient finds length of life or quality of life is the more worthwhile. Preferences for either quality of life or length of survival, assuming that both are not obtainable simultaneously, have been

shown to depend on perceived prognosis for survival and independent functioning,' and on the minimal acceptable quality of life.' O'Connor' found that preferences for toxic treatment decreased as the probability of survival dropped below 50%. The willingness to accept a treatment with a minimal chance of benefit has also been shown to be related to disease status. Several studies have found that patients are more likely to opt for such treatments than healthy subjects.[3-6] Age and social circumstances, such as having a family or not, might also be expected to influence this tradeoff.

In decision analysis and technology assessment, patient preferences are most often incorporated using utility assessment. Utility is defined as the subjective value that the individual assigns to the outcome of a decision under conditions of uncertainty. Utility-assessment methods have predominantly been used in research settings to calculate quality-adjusted life years (QALYs) or equivalent measures of quality-adjusted survival.' The complicated nature of the methods makes administration by a trained interviewer necessary. Moreover, the assessment methods are quite abstract, and their relevance is not always obvious to patients. Recently, the treatment-preference (or treatment tradeoff ) method has been developed for both clinical and research set-

tings [4,6,8-10] This method has been shown to be simpler to use and more meaningful to patients. However-as is the case with utility-assessment methods-its use is treatment-decision-specific, and modification is necessary for each new condition and decision. It does not assess a more general attitude towards the tradeoffs involved.

An instrument that could be used in a research setting to assess patients' general attitudes toward the tradeoff between quality of life and length of life would be useful. Health-related quality of life and utilities have been found to correlate only weakly." This indicates that the willingness of the patient to trade off, as assessed in utility measurement, depends not only on his or her quality of life, but also on other characteristics of the patient or of the situation. Instruments that measure general attitudes towards the weighing process might provide more insight into this deliberation process and into the assignment of utilities. Such instruments could be used to investigate variations in attitudes, as well as factors that influence the process of weighing of quality and quantity of life. Knowledge of differences in attitudes between specific groups of patients may shed more light on patient decision making. Such instruments might also be used to evaluate the stability of treatment preferences.

We developed a short questionnaire that addressed the attitudes of respondents toward the weighing of benefits and side effects of cancer treatments, th eQ(uality)-Q(uantity )Questionnaire. The questions are based on statements made by patients during interviews in which utilities for cancer treatment were assessed.[12] This paper describes some psychometric properties of the questionnaire: the dimensional structure, the resulting subscales, and their internal consistency. Construct validity has been investigated by assessing the relationships between several patient characteristics and responses to the QQ Questionnaire. We expected attitudes towards weighing quality of life and length of life to be related to sociodemographic characteristics of patients as well as to their disease states and prognoses. Several hypotheses were therefore formulated. Our first hypothesis was that younger subjects would be more willing to opt for length of life than older subjects, and would be more prepared to accept reductions in quality of life. This has also been found by Katz et al.[13] and suggested by the data of Kiebert et al.[2] Our second hypothesis was that subjects who have children might also opt more strongly for length of life.[2] In hypothetical examples, diseased subjects have been found to favor toxic treatment more strongly than healthy subjects. Therefore, our third hypothesis was that this finding might be extended to subjects whose prognoses were poor, who might thus assign more importance to length of life than patients with better prognoses. Our impressions from previous work are indeed

that even though in an early phase of disease patients state that they will not accept treatment at any cost, once the disease has progressed, most patients seem to be prepared to do everything necessary to prolong survival. Fourth, patients who are limited in their functioning or performance may accept reductions in their quality of life (up to their minimal acceptable thresholds) more easily as they will have adapted to some extent to such reductions.' Finally, we expected to find an association between the patients' attitudes and their utilities. Of two patients with similar subjective evaluations of their health states, the one who assigns a higher utility to that state (and is thus less willing to trade) can be expected to assign more importance to length of life.

## Methods

### CONSTRUCTION OF THE QQ QUESTIONNAIRE

The questionnaire was constructed on the basis of semistructured interviews with 30 disease-free testicular cancer patients, held in 1991. The interviews pertained to the patients' experiences with the disease and the treatment, and to their utilities for hypothetical health states related to the disease. Results of the latter have been published elsewhere." These interviews were taped, transcribed, and submitted to qualitative data analysis. The purpose of this analysis was to find formulations, on the basis of the patients' own accounts, suitable for measuring patients' attitudes toward the weighing of costs and benefits of treatment. All remarks made by the patients that referred in some way to this weighing process were noted. In total, 45 such remarks were made. Three investigators (AMS, JCJMH, GMK) independently selected relevant statements to be included in a questionnaire. Reasons for exclusion of statements were: difficult to comprehend, stating the obvious; very extreme opinion; ambiguous; not a strict weighing of quality of life and length of life, but referring to factors that might influence this weighing; too disease- or situation-specific, Some of the statements were reformulated to make them more general (e.g., "treatment" was substituted for "chemotherapy"). Thus, ten statements were selected concerning tradeoffs between quality of life and length of life, quality of life and chance of survival, and the attitude of subjects toward the discontinuation of treatment. Four of the ten items stressed quality of life; six items stressed either chances of survival or duration of survival (see table 1).

Each statement was followed by a seven-point Likert scale on which the strengths of the respondents' agreements could be scored. The scale ranged from 1 "completely disagree" to 7, "completely agree."

Table **1** • **Cancer** Patients' Scores on the QQ Questiannaire, and Factor Loadings (>0.30) after Varimax Rotation (n = 203), in Order of Factor Scores

| | Mean ± SD (n) | Median | Factor 1 | Factor 2 |
|---|---|---|---|---|
| 1. If a treatment can prolong my life, I will always accept it, whatever the side effects may be. (L*) | 5.0 ± 1.9 (209) | 5 | 0.73† | |
| 9. Even though the treatment is difficult to bear, I would accept it If the chance of living longer were increased even by as little as one percent. (L) | 4.0 ± 2.2 (210) | 4 | 0.67† | -0.41 |
| 3. If I reached a point during treatment at which I wanted to stop, then I would probably manage to summon the strength from somewhere to help me to continue. (L) | 5.1 ± 1.8 (208) | 5 | 0.63† | |
| 10. In order to live a bit longer I would clutch at any straw even though that might mean a poor quality of life. (L) | 3.6 ± 2.1 (211) | 4 | 0.63† | -0.46 |
| 5. With a malignant dlsease you try as much as posslble to reduce the chance of dying from it. A couple of months of poor quality of life is the price you have to pay. (L) | 5.7 ± 1.8 (210) | 7 | 0.57 | |
| 7. When It comes to being cured, I would choose the safest way, even though there Is a chance that I will undergo an Intensive treatment for nothing. (L) | 5.5 ± 1.8 (211) | 6 | 0.55 | |
| 8. If you have to endure an intensive treatment for six months in order to live for an extra half year, then I wouldn't bother. (Q*) | 5.0 ± 2.1 (211) | 5 | | 0.73† |
| 4. There can be side effects that are so bad that I would refuse the treatment, even though that would mean a shortened life. (Q) | 4.9 ± 2.0 (209) | 5 | | 0.71‡ |
| 2. If a treatment that prolongs my life results In such complications that I am prevented from leading a normal life, I would not have it. (Q) | 4.9 ± 1.9 (209) | 5 | | 0.68‡ |
| 6. A moment might come In which I would say "I have done my best, I think enough Is enough." (Q) | 5.3 ± 2.1 (209) | 6 | | 0.61‡ |

*L = item that refers to striving for length of life; CI = item that refers to striving for quality of life.
†Item retained in the final L scale.
‡Item retained in the final Q scale.

## PATIENTS AND PROCEDURES

Four groups of patients were asked to complete the QQ Questionnaire. The first group consisted of 59 consecutive testicular cancer patients who were under treatment or who had received treatment in the previous two years in the Daniel den Hoed Clinic, Rotterdam, the Leiden University Hospital, or the Hospital of the Free University, Amsterdam. The second group consisted of 73 consecutive colorectal cancer patients. They were either in the follow-up schedule of the Diaconessen Hospital or the Leiden University Hospital (*n* = 55) or had been diagnosed as having incurable recurrences and treated at or referred to one of the two hospitals (*n* = 18). The third group consisted of 29 patients who were taking part in a randomized controlled study of chemotherapy for breast cancer. The fourth group consisted of a consecutive series of 63 outpatients receiving radiotherapy for a variety of malignant diseases. The patients in the latter group were in the second or third week of radiotherapy.

Patients in group 1 were asked to complete the questionnaire in the outpatient clinic, preceding an interview; patients in groups 2, 3, and 4 were asked to complete the questionnaire at home and return it by mail. In groups 1 and 3 the response rate was 100%. In group 2, 96% returned the questionnaire. Fifty (79%) of the patients in group 4 returned the questionnaire. In total **211** questionnaires were available for analysis, an overall response rate of 93%.

The mean age of the patients was 50.6 (SD 18.5) years. The four patient groups differed significantly with respect to age (table 2). One-hundred and thirty patients were male, 81 were female.

Sociodemographic and treatment information was obtained in addition to the responses to the ten-item questionnaire. The testicular and colorectal cancer patients also filled out the Medical Outcomes Study short-form general health survey (MOS SF-20[14]) and the distress scales of the Rotterdam Symptom Checklist (RSCL[15]) The MOS SF-20 consists of 20 items covering six dimensions: physical functioning, role functioning, social functioning mental health, health perceptions, and pain. The RSCL was developed specifically for cancer patients. It contains a list of 30 items to assess the physical and psychological distress experienced by the patient in the preceding week. Finally, these two patient

Table 2 • Age Distribution by Patient Group

| Patient group | N | Mean* ± SD |
|---|---|---|
| Testicular cancer | 59 | 29.8 ± 6.4 |
| Colorectal cancer | 73 | 65.4 ± 12.6 |
| Breast cancer | 29 | 53.4 ± 10.6 |
| Radiotherapy | 50 | 52.1 ± 15.0 |

*Difference between patient groups statlstically significant, p < 0.001 (one-way ANOVA).

groups rated their overall situations during the preceding week by means of a visual-analog scale (VAS) and a time tradeoff question (TTO). The VAS consisted of a 100-mm rating scale anchored at the extremes by "perfect health" and "death." It can be seen as a global judgment of the quality of life. In the TT0 question, the patient was asked how many years in perfect health he or she considered to be equivalent to his or her remaining life expectancy in his or her own situation during the preceding week.[16]

## DATA ANALYSIS

*Feasibility.* The numbers of missing values were counted, and comments made by the patients were grouped for presentation purposes.

*Distribution ofscores.* We examined the distributions of scores, overall and separately for each patient group, in order to detect possible skewness and answering tendencies.

*Construction of subscales and internal consistency.* We carried out a principal-components analysis to investigate the structure underlying the relationships among the items of the questionnaire. The purpose of this analysis was to derive factors (dimensionsl that represent non-directly-observable constructs from the measurement of directly observable variables "the items of the questionnaire." The factor solution presented here is based on the eigenvalues ($>1.0$). We rotated the principal components to orthogonal simple structure using the varimax method, to facilitate interpretation." Subscales were constructed on the basis of the principal-component analysis by adding the scores of the variables that loaded on a factor. Cronbach's alpha was used to estimate internal consistency, a measure of the reliability of these subscales.[18] Items were deleted from the subscales to improve reliability. Measures with Cronbach's alpha of 0.70 or greater have been recommended for comparing groups."

*Association of subscales with patient characteristics and utilities.* We assessed the associations between the subscales and patient characteristics (age, sex, marital status, having children, patient group, type of treatment, prognosis), health status (MOS-SF20, RSCL), and patient utilities (TTO). The specific hypotheses we had pertained to: age (younger subjects will strive more for length, older subjects more for quality of life); having children (subjects with children will strive more for length of life); prognosis (patients with poor prognoses were expected to strive more vehemently for length of life); health status (those who are limited in functioning or role performance due to disease or treatment, or who have more symptoms, will strive more for length of life); and utilities (for two subjects who similarly judge the qualities of their lives on the VAS, a measure that does not require a tradeoff, the subject

who assigns the lower TTO score-and thus is more willing to trade off life years in exchange for quality of life-can be expected to strive more for quality of life). We had no direct measures of prognosis. The prognoses of the testicular cancer and breast cancer patients were assumed to be good, as were those of the disease-free colorectal cancer patients (all had been treated with curative intent). The prognoses of the colorectal cancer patients whose cancers had recurred was assumed to be poor, as were those of the lung cancer patients in the radiotherapy group. The prognoses of the remaining patients in the radiotherapy group were coded as missing.

Associations between continuous variables were evaluated by means of Spearman's correlation coefficients, and differences between categories were tested by means of t-tests and analysis of variance, as well as by nonparametric tests (Mann-Whitney U-test and Kruskal-Wallis one-way analysis of variance, respectively). None of the associations was expected to be very strong, as no clear association between patient preferences or utilities and patient characteristics has yet been reported.

## Results

### FEASIBILITY

Twenty respondents (9.5%) wrote comments pertaining to the acceptability of the questionnaire. Most of these comments (11) pertained to difficulty: the respondents thought the questions difficult to answer. Two respondents wrote that they thought the questions threatening. One respondent said that the questionnaire had made him think about the problem, and that he did not find it pleasant. He could imagine people whose prognoses were worse than his considering the questionnaire threatening. Another respondent wrote that the questions gave him food for thought but he judged this to be positive. Two respondents referred to their religion. They stated that matters such as these were not in their hands. One quoted a passage from the Bible ("Put your affairs in order, for you are to die," II Rings 20:1). Seven respondents commented on the hypothetical nature of the questions. They stated that they could not answer the questions, or that when confronted with the actual decisions they might revise their judgments.

Eight of the 211 patients did not respond to one ($n = 6$), three ($n = 1$), or four ($n = 1$) items. In total, 0.6% of the possible responses were missing. Four of the patients with missing responses were in the radiotherapy group, two in the colorectal cancer group, and two in the breast cancer group. Three missing responses were seen for item 3, two each for items 1, 2, 4 and 6, one each for items 5 and 9.

**Table 3 •** Association of Age and Education Level with Aquiescence (Number of Times Patient Scored "Agree Completely") on the QQ Questionnaire

| | Number of Times "Agree Completely" | | | | |
|---|---|---|---|---|---|
| | ≤5‡ | 8 | 7 | 8 | ≥9 |
| Age (years)* | | | | | |
| 30 or less | 40 | 3 | | | |
| 31-45 | 31 | 4 | 3 | | |
| 46-60 | 48 | 8 | 1 | | |
| 81-70 | 33 | 3 | 5 | 1 | |
| 71 or more | 28 | 1 | 3 | 1 | 2 |
| Education level† | | | | | |
| Primary school only | 33 | 7 | 3 | 1 | 1 |
| Vocational training (lower) | 50 | 7 | 8 | | 1 |
| Vocational training (intermediate) | 38 | 4 | 1 | 1 | |
| College | 18 | | | | |
| University or professional education | 33 | 1 | | | |
| Unknown | 8 | | | | |
| TOTAL | 178 | 19 | 12 | 2 | 2 |

*Means for the five age categories: 2.7, 2.7, 3.5, 3.9, and 4.6, respectively (p s ,001, one-way ANOVA); correlation between age and acquiescence (both variables treated as continuous); p = 0.30.

†Means for the five education levels: 4.5, 3.75, 3.1, 2.6, and 2.5, respectively (p ≤ 0.001, one-way ANOVA).

‡Subjects "agreeing completely" five times or fewer are considered not to be acquiescent and are therefore grouped together.

## DISTRIBUTION OF SCORES

The distribution of the scores was skewed. The medians were 5 or higher for eight of the ten items (table 2). Only items 9 and 10 had median scores of 4. Such a distribution of scores was counterintuitive, as the items were all framed in the same direction. Subjects who agreed to an item stating that quality of life should prevail were not expected to agree to another item stating that length of life should prevail. We therefore tested our data for acquiescence, a tendency to agree with the item no matter in what direction it was framed." Acquiescence may be expected to be stronger in older and less educated subjects. We constructed a variable that counted the number of times a subject agreed completely (i.e., scored a 7), and tested for its association with age and level of education. The results are presented in table 3. Older patients and patients with lower levels of education did indeed show complete agreement more often than did younger patients and patients with more education.

## CONSTRUCTION OF SUBSCALES AND RELIABILITY

Two factors were found to represent the relationships among the ten items (eigenvalues > 1.0). Factor one explained 37% of the variance and included items 1, 3, 5, 7, 9, and 10, i.e., all items that pertained to "striving for **length of life,** no matter whether the quality of life is impaired." Factor two explained 12% of the variance and contained items 2, 4, 6, and 8. These were all items that pertained to "a limited acceptability of reductions in **quality of life** on behalf of survival." The factor loadings are shown in table 1. Items 9 and 10 loaded on both factors, but more strongly on the first.

When the factor analysis was repeated, deleting from the analysis those 16 respondents who showed high degrees of acquiescence (subjects who scored a 7 more than six times), similar results were obtained. Item 10 loaded slightly higher on the second factor this time (-0.58, whereas its score on the first factor was 0.51). Item 3 loaded on both factors in the same way (0.42 and -0.42, respectively).

Based on the results obtained from the whole group, a "length-of-life" (quantity) subscale and a "quality-of-life" (quality) subscale were constructed by adding the patient's scores on the items loading on the respective factors. A reliability analysis was carried out to estimate Cronbach's a for the two factors, and to evaluate whether α might be 'improved by deleting items. For the first factor ("length of life") α was 0.77. It could be improved to 0.79 by deleting first item 7 and then item 5. We assessed the reliability of the scale with items 9 and 10 excluded, as these items loaded high on both factors. Reliability of this scale (including items 1, 3, 5, and 7) was, however, only 0.61, and could not be improved by deleting other items. The a for factor two ("quality of life") was 0.68. This could not be improved by deleting any of the four items. We therefore ended up with two four-item subscales, which we call the "Q scale" (primacy of Quality of life) and the "L scale" (primacy of treatment, or Length of life). The reliabilities and the distributions of the scores for the four patient groups on these two subscales are presented in table 4. As the original items were scored from 1 to 7 ("disagree completely" to "agree completely"), the scores on the subscales could range from 4 to 28. A high score on the Q scale implies that the respondent felt that there was a limit to the acceptability of reductions in quality of life. A high score on the L scale meant that the subject would strive for length of life, even if this would result in a reduced quality of life.

## CONSTRUCT VALIDITY

*Association of subscales with sociodemographic and disease characteristics. As* hypothesized, a moderately strong association was found between age and the two subscales: Spearman correlation coefficients were 0.44 and -0.23 for the *Q* and L scales, respectively (p ≤ 0.001 for both). This indicated that older patients agreed more often with statements stressing the importance of quality of life, and less often with statements stressing the importance of continuing to strive for prolonged survival. The dis-

**Table 4** • Reiiabiiities Cronbach's α) and Distributions of the Scores of the Four Patient Grouos on the Q and L Scales

| | *n* | ₀l | Mean ± SD* | Median | interquartile Ranae |
|---|---|---|---|---|---|
| Q scale | | | | | |
| Testicular cancer | 59 | 0.67 | 18.2 ± 5.5 | 19 | 8 |
| Coiorectai cancer | 73 | 0.62 | 22.2 ± 5.3† | 22 | 9 |
| Breast cancer | 26 | 0.72 | 20.5 ± 5.1 | 22.5 | 7.75 |
| Radiotherapy | 48 | 0.71 | 19.2 ± 6.1 | 20 · | 7 |
| Ail patients | 206 | 0.68 | 20.1 ± 5.7 | 21 | 9 |
| L scale | | | | | |
| Testicular cancer | 59 | 0.72 | 18.8 ± 5.4 | 20 | 7 |
| Coiorectai cancer | 71 | 0.82 | 15.8 ± 6.9‡ | 13 | 12 |
| Breast cancer | 26 | 0.78 | 18.6 ± 6.2 | 19 | 8.5 |
| Radiotherapy | 48 | 0.80 | 18.8 ± 6.1 | 18 | 10 |
| Ail oatients | 206 | 0.79 | 17.8 ± 6.3 | 17 | 11 |

*Scores could range from 4 to 28.

†Test of difference between groups: $p = 0.0005$ (one-way analysis of variance), $p = 0.0003$ (Kruskal-Wallis nonparametric analysis of variance); colorectal cancer patients scored significantly higher than testicular cancer patients and than the radiotherapy group; when corrected for age: $p = 0.22$ (analysis of variance).

‡As above, $p = 0.02$ (one-way analysis of variance), $p = 0.007$ (K-W); colorectal cancer patients scored significantly lower than the other three patient groups; when corrected for agef $p = 0.25$.

tribution **of scores** for the subscales for each age group is shown in table 5. An effect of having children became apparent for the **L scale,** when correcting for age. Subject8 who had children scored higher, a8 expected, on this subscale ($p = 0.04$). Thus, they would strive for length of life, even if this would entail a reduction in the quality of life. These patients with children also tended to score lower on the Q scale than did the patient8 without children when a correction was made for age ($p = 0.10$). Contrary to our expectation, the score8 of the patients whose prognoses were good (those with testicular cancer, disease-free colorectal cancer, and breast cancer) were not different from those of the patient8 who had poor prognoses (patients with recurrent colorectal cancers, lung cancer patient8 receiving radiotherapy).

*Association of subscales with health status and utilities.* For the testicular and colorectal cancer patients, associations between score8 on the **QQ** Questionnaire and health status and utilities could be assessed. We were especially interested in the association between scores on the *QQ* Questionnaire and patient utilities, since both instruments have been developeqin the domain of preference assessment.

No (age-corrected) association was found between the Q and L scales and the psychological and physical distress scale8 of the **RSCL. For the MOS-SFPO,** an association was found between the role-activities subscale and the L scale: Spearman's $r = -0.25$ ($p = 0.01$). When the role-activities subscale was dischotomized into subjects with and subjects without limitations, the following mean L-scale scores were found: 19.7 (SD 6.1, n = 34) for the group with limitations and 16.2 (SD 6.4, $n = 93$) for the group without limitations. Median score8 were 21 and 15, respectively (p Mann-Whitney = 0.004). Thus, the subjects who were more limited in their role functioning assigned more importance to the effect of

treatment on survival. This wa8 in line with our expectation. Correction for age did not alter the association

We assessed the association between TT0 scores and the subscales, correcting for VAS scores and age. The TTO score reflect8 a subject's willingness to *trade* off **life year8 to obtain remediation of health problems. The TT0 scores were therefore expected to correlate inversely with the response on the Q scale when correcting for the patients' valuations of their health states by means of a VAS, which requires no tradeoff. Partial correlation between TTO scores and the Q scale was -0.11 ($p = 0.22$).**

## Discussion

**The purpose of this study was to assess the psychometric properties of an instrument measuring**

**Table 5** • Distribution of Scores for the Q and L Scales by Age Group*

| | *n* | Mean ± SD† | Median | interquartile Range |
|---|---|---|---|---|
| Q scale | | | | |
| 530 | 43 | 17.2 ± 5.7 | 18 | 7 |
| 31-45 | 38 | 18.3 ± 5.2 | 18.5 | 6.75 |
| 46-60 | 55 | 20.1 ± 5.5 | 22 | 7 |
| 61-70 | 39 | 21.8 ± 5.2 | 22 | 8 |
| ≥71 | 33 | 24.2 ± 4.5 | 26 | 6 |
| L scale | | | | |
| ≤30 | 20 | 18.6 ± 5.7 | 20 | 8.5 |
| 31-45 | 38 | 19.7 ± 6.2 | 20.5 | 11 |
| 46-60 | 53 | 18.0 ± 6.2 | 17 | 11 |
| 61-70 | 40 | 17.3 ± 6.4 | 16.5 | 9.5 |
| a71 | 32 | 14.5 ± 6.6 | 13 | 7.75 |

*For both subscales, differences between age groups were statistically significant (Kruskal-Wallis); $p < 0.001$.

†Scores could range from 4 to 28.

patient attitudes toward the weighing of quality of life and survival in treatment decisions in oncology.

First, some general remarks about the questionnaire can be made. The response rate to our questionnaire was high, and very few data were missing. Some respondents mentioned spontaneously, however, that they had found some of the questions disturbing. The topic of weighing costs and benefits of treatment can indeed seem threatening to patients. Some patients might not be willing, or might not have the psychological resources available, to cope with questions like these. It should be made very clear to patients that they are not obliged to answer the questions, and that they can contact the investigators or their physicians should they afterwards want to discuss the issues raised.

Even though several respondents remarked that they thought the questions difficult, very few data were missing. Subjects who had difficulty with answering some of the questions, however, may have solved the problem by simply agreeing with the statement. This may be in part an explanation for the acquiescence found. The patients may not have wanted to leave. questions unanswered. In developing the questionnaire, we took care to change the directions of the items with regard to quality of life and length of life. However, the questions were all framed in the same direction with regard to agreement. We realized later that some of the items might have been difficult to understand or ambiguous, partly due to their length. We therefore developed a simplified version of the questionnaire for future studies (see appendix). In this version we also used a five-point Likert scale instead of a seven-point scale to make it easier for the respondents to use. As a consequence of the changes, reliability and validity will have to be reassessed. Matters of burden and acquiescence also need future study. Because a separate factor analysis excluding the patients who were acquiescent showed very similar results, we feel confident about the results of our psychometric analyses. The reliability of the L scale was good, while that of the Q scale was moderate. Two items were dropped from the L scale to improve reliability.

The results of the factor analysis were not fully in accordance with our expectations. Two factors were found. One referred to limits to the trading of quality of life for survival. The other stressed the importance of duration or chance of survival, even if this meant a reduction in quality of life. We had indeed selected four items stressing the importance of quality of life and six stressing that of quantity of life. However, when assuming that tradeoffs can be made between quality of life and length of life, we expected to find one factor with opposite signs for the factor loadings of the Q items and of the L items. The finding of two separate factors indicates that what we are looking for in utility assessment may be more complicated than is usually assumed. This

finding is unlikely to be explained by acquiescence bias, since an analysis deleting the responses of the acquiescent patients also resulted in the same two factors. In light of these results, we decided to categorize the subjects in four categories, based on a dichotomization of the Q and L scales at their median values. Such a distinction has been proposed for a two-factor solution" and has been used in quality-of-life research[20,21] Subjects who scored high on both scales would be those aspiring to two outcomes simultaneously. These patients did not want to give up either quality of life or length of life. We consider these patients to be "aspirers." Patients who scored low on both scales we consider to be "resigners." They may have been resigned to not gaining either way.[*] The other two patient groups behaved more clearly in line with our original assumptions: they favored either quality of life or length of life more strongly. The notion of these four groups contradicts the usual approach in utility assessment. For instance, the TTO method is based on the principle that the less preferred a health state is, the higher will be the proportion of life expectancy that a person will be willing to trade off to gain perfect health. Quality of life and length of life are thus seen as two mutually exchangeable commodities. This should result in finding two groups only, those striving for quality and those striving for length: one can't have both at the same time. Our findings are to be replicated in future research, but would raise some interesting theoretical questions.

Associations were found between age and both subscales. The association was stronger for the Q scale. The older the subject, the more quality of life seems a predominant objective. This association with age explained most of the associations found with variables such as patient group, type of treatment, and marital status. For the L scale, a significant association after correcting for age was found with having children. Patients who had children assigned relatively more importance to striving for prolonged survival. The associations with age and having children are in accordance with intuition, and raise our confidence in the validity of the questionnaire. No association between the responses to the QQ Questionnaire and prognosis was found. However, this was hardly surprising, as our classification into good and poor prognoses was very crude. It is also questionable whether the patients themselves were aware of, and did not deny, their poor prognoses.

The only association found between the responses to the QQ Questionnaire and health status was that the patients who reported limitations of their role

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[*]To test whether "resigners" were not merely depressed, we compared the scores on the MOS mental health and the RSCL psychological distress subscales between the four groups. No differences were seen.

**activities** scored higher on the L scale. This implies that they would accept reductions in their quality of life for longer survival. This could be explained by a process of adaption: patients experiencing limitations might have adapted to this situation and might therefore think a reduction in quality of life more acceptable than subjects with no limitation, who answer in a more hypothetical way questions pertaining to quality-of-life reductions. Healthy subjects have often been found to assign lower values to impaired health states than subjects who are in those health states themselves,[4,22] possibly because the latter have adjusted to their situation. However, the correlation we found was low, and if adaption is an explanation for this finding, then it is not clear why no such association was found for the other dimensions of health status. Thus it may have been a chance finding.

Several studies have tried to correlate health-status or quality-of-life measures with utilities (see Revicki and Kaplan[11] for a review), and correlations have been found to be at most weak. This has been explained by the differences in the measurements tasks. We designed our questionnaire explicitly to evaluate attitudes toward the tradeoff involved in utility assessment and absent in health-status assessment. We had therefore expected to find a negative correlation between TTO scores (utilities in which a tradeoff is involved) and the Q scale, when correcting for patients' valuations of their health states by means of a VAS (in which no tradeoff is involved). A subject who is willing to trade off life years in exchange for a specific improvement in quality of life (and who thus has a low TTO score) may be expected to score high on the Q scale. The correlation was low and non-significant, although the direction of the correlation was as expected. An explanation for the lack of correlation between subscales and TTO scores may be that of task incompatibility. In the TTO, the subject is asked explicitly to evaluate his or her health state in the preceding week, while in the QQ Questionnaire a more general attitude toward treatment decisions is assessed. The lack of an association might also reflect a difference between hypothetical and actual situations. The QQ Questionnaire related to a hypothetical situation, while the TTO in our study was related to the actual situation. Just as patients are less willing than healthy subjects to trade off length of life for quality of life,[3-5] patients might be less willing to trade off length of life for quality of life in actual situations than in hypothetical situations. The TTO and the QQ Questionnaire may therefore not be comparable in this patient sample. A correlation may exist for patients for whom the statements in the QQ Questionnaire pertain to choices that actually have to be made, because attitude towards *tradeoff* and time *tradeofl* will coincide. Finally, the lack of a correlation may have been due to a lack in

sensitivity of the TTO in the actual situation. Manv respond&s were not willing to trade off at all (median scores were 98 for testicular and 100 for colorectal cancer patients, data not **shown).†**

To our knowledge, no other attempt has been made to develop a questionnaire (including psychometric testing) to elicit cancer-patient attitudes toward treatment decisions that involve tradeoffs between quality of life and length of life. Studies that have assessed attitudes for specific treatment decisions have used the treatment-preference method or the treatment tradeoff method[4,6,8-10] These methods do not reveal a more general attitude, because they are framed specifically for particular treatment decisions. The QQ Questionnaire is thus a useful supplement to the existing instruments for preference and utility assessment. The next step in the development of this questionnaire is to assess the test-retest reliability. In such a study, matters of burden and acquiescence can also be assessed. Our questionnaire can be used by researchers to study patient attitudes and factors that influence patient preferences. In prospective studies, the method can be applied to learn whether and how patients change their attitudes when faced with the actual decisions.

In conclusion, we found that a very short questionnaire can classify subjects with respect to their willingness to trade off quality of life in favor of prolonged survival. Younger patients and patients who had children assigned relatively more importance to the objective of prolonged survival, while accepting a reduction in quality of life. This finding was in accordance with our expectation and thus supports the validity of the questionnaire.

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**†We indeed found much lower TTO-scores for hypothetical health states in a previous study in testicular cancer patients, indicating more willingness to trade off (see Stiggelbout[12]).**

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# APPENDIX

## *The QQ Questionnaire*

(Version revised on the basis of the study reported here)

Please read the following statements and tell us which best describes your feelings about the consequences of treatment.

Please check one box only for each statement.

|  | I strongly disagree | I disagree | I neither agree nor disagree | I agree | I strongly agree |
|---|---|---|---|---|---|
| 1. If a treatment could prolong my life, I would always accept it, whatever the side effects might be. | ☐ | ☐ | ☐ | ☐ | ☐ |
| 2. If a life-prolonging treatment would prevent me from leading a normal life, then I would rather not have it. | ☐ | ☐ | ☐ | ☐ | ☐ |
| 3. If I reached a point during treatment at which I felt like giving up, I would probably manage to find the strength to continue. | ☐ | ☐ | ☐ | ☐ | ☐ |
| 4. I can imagine some side effects being so bad that I would refuse the treatment, even if that meant a shorter life. | ☐ | ☐ | ☐ | ☐ | ☐ |
| 5. A moment might come at which I would say "I have done my best, this is the limit." | ☐ | ☐ | ☐ | ☐ | ☐ |
| 6. If I had to endure six months of intensive treatment in order to live for an extra half year, then I wouldn't bother. | ☐ | ☐ | ☐ | ☐ | ☐ |
| 7. I would always accept hard-to-tolerate treatment, even if the chance of its prolonging my life was as little as one percent. | ☐ | ☐ | ☐ | ☐ | ☐ |
| 8. In order to live a bit longer, I would clutch at any straw. | ☐ | ☐ | ☐ | ☐ | ☐ |