

# Assessment of Quality of Life in Palliative Care

## *Psychometric Properties of a Short Questionnaire*

Bertil Axelsson and Per-Olow Sjöden

From the Department of General Surgery (B. Axelsson), Östersund Hospital, Östersund and Centre for Caring Sciences (P.-O. Sjöden), Uppsala University, Uppsala, Sweden

Correspondence to: Dr Bertil Axelsson, Department of Surgery, Östersund Hospital, S-831 83 Östersund, Sweden. Tel: +46 63 15 30 00. Fax: +46 63 15 45 37.

---

Acta Oncologica Vol. 38, No. 2, pp. 229–237, 1999

The psychometric properties of a short but comprehensive quality-of-life instrument, developed especially for cancer patients in the palliative care setting are presented. Items from physical, psychological, social and existential domains are included. The findings suggest that the AQEL (Assessment of Quality of Life at the End of Life) instrument is both valid and reliable, but further trials with more patients are needed.

*Received 9 February 1998*

*Accepted 28 September 1998*

---

In recent decades the concept of quality of life has emerged as an area of increasing interest in medical care as well as for research. At the same time, palliative care has evolved as one of the few areas within modern medicine that is still expanding despite the economic depression. Since all patients receiving palliative care eventually die, morbidity and mortality are not useful endpoints in attempts to evaluate palliative care programmes. Quality of life is the fundamental endpoint in palliative care, as improved quality of life is the ultimate objective of all forms of palliative treatment (1–3).

Although the concept of quality of life has been defined in various ways by different authors (4–8), there seems to be a growing consensus that quality of life is a multidimensional entity (1, 9, 10) and that it should reflect the patient's own perception of his/her situation (9–12). Even if a generally accepted definition is ultimately adopted, it is likely that different instruments will still be used to measure quality of life in different contexts. In the case of patients with incurable cancer, symptom-related items are mandatory, but items dealing with various aspects of well-being (11) should not be excluded. Freedom from symptoms is unlikely to be either necessary or sufficient for an optimal quality of life in all cases.

Most of the early quality-of-life instruments, such as the Karnofsky Performance Status (13) and the scale proposed by Zubrod (14), focused solely on the physical performance of the patient. During the 1970s and 1980s, psychological and social dimensions were increasingly accepted as

indispensable components of the quality-of-life concept (7, 10, 11, 15, 16). Some authors recommended the inclusion of a global question asking about patients' experience of their overall quality of life (10, 17). Others emphasized spiritual dimensions, such as the meaning of life, as being of particular importance, especially in studies of patients confronted with imminent death (3, 18, 19).

The assessment of quality of life in palliative care is difficult because of the absence of a generally accepted instrument for this specific category of patients (1, 3). During recent years, new quality-of-life instruments have emerged. The Functional Assessment of Cancer Therapy, FACT (20) and the Cancer Rehabilitation Evaluation System, CARES (21) are not developed specifically for terminally ill cancer patients but may be useful depending on the questions one wants answered. Instruments developed for and practicable in the palliative setting are the short version (20 items) of MacAdam's assessment of suffering in terminal illness (22), the McMaster Quality of Life Scale (= MQLS; (23)) with 32 items, the McGill Quality of Life Questionnaire (24) with 17 items and the Hospice Quality of Life Index (25) with 25 items. The MacAdam questionnaire was originally intended to be completed by staff, and the other instruments were published between 1994 and 1996, i.e. after the start of the present study. Neither of them has so far achieved the status of being a generally recommended instrument.

In 1990, when our search for and development of an evaluation tool started, we decided to develop a short but

comprehensive questionnaire in Swedish, designed for cancer patients with an incurable disease. In order to adapt to the growing consensus, the questionnaire should cover physical, psychological, social and existential aspects, i.e. a substantially broader scope than ordinary symptom measurement. It should be simple to use for the patients, having a limited number of questions and a uniform response format in order to increase the likelihood that patients would accept repeated assessment. We also wanted a questionnaire sensitive to changes in patients' condition over time.

The purpose of this paper is to describe the questionnaire and its psychometric properties, namely reliability and validity.

## METHOD

The primary reason for developing a quality-of-life instrument was the need to evaluate the effects of a programme aimed at improving palliative care for terminally ill cancer patients in the County of Jämtland, Sweden. The general aim of the programme was to improve the quality of life of these patients at a cost not exceeding that of conventional care.

### Patients

Three groups of patients, all of them with symptomatic incurable cancer disease, participated in the different phases of the questionnaire development. The first group (A) consisted of 30 consecutive patients (20 males, 10 females) with incurable cancer treated at the Department of General Surgery, median age 67.5 years (41–86). Their Karnofsky Performance Status (KPS) median score on completion of the first questionnaire was 70 (range 30–90, mean 62.3, S.D. = 20.3). Patients diagnoses reflected the panorama within general surgery, such as cancer of the breast (4 patients), the gastrointestinal tract (14), and the urological system (12). This group participated in the initial testing of the response format and the legibility of the questionnaire items. Later on, they were involved in the testing of reliability and validation against the KPS.

A second group (B), which participated in the development process at a later stage, included another 28 patients (18 males, 10 females) who received support from a hospital-based palliative team and were willing to answer another, more extensive quality-of-life questionnaire, a Swedish version (26) of the Cancer Inventory of Problem Situations (CIPS) (27). As they also agreed to complete our newly designed questionnaire, the AQEL (Assessment of Quality of Life at End of Life), once a month for the remainder of their lives, we could validate the CIPS against the AQEL in this group. Their median age was 65.5 years (31–76). Their Karnofsky median score at inclusion was 70 (30–90) and the diagnoses were cancer of the breast (5 patients), the gastrointestinal tract (12 pa-

tients), and the urological system (11 patients). Patients eligible for this support had to fulfil the following criteria: (i) they had to have a symptomatic, incurable cancer disease; (ii) the cancer disease had to be within the realm of general surgery; (iii) the patient had to live within a 40 km radius of the County Hospital; (iv) the patient had to express a wish to live at home; (v) a principal caretaker had to be ready to support the patient at home.

Group C consisted of 13 patients (9 males, 4 females) fulfilling the criteria for support from the palliative team but who lived too far away from the hospital (> 40 km). They completed at least one AQEL questionnaire. Their answers were used for factor analysis together with the data from the first completion of the AQEL in groups A and B. Their median age was 70 years (44–88), their median Karnofsky score was 70 (30–80), and the diagnoses were cancer of the gastrointestinal tract (7 patients) and of the urological system (6 patients).

### Questionnaires

*CIPS (Cancer Inventory of Problem Situations)*. At the time of this investigation the Swedish version of CIPS was the most established questionnaire and had been used extensively by the second author. The CIPS is a self-administered questionnaire with 131 statements, developed by Ganz et al. (27) for documentation of specific disease-related problems. It has been translated and adapted for use with Swedish cancer patients (26). Patients rate the extent to which each problem has applied to them during the preceding month by grading their responses on a 5-point scale ranging from 'not at all' to 'very much'. It took approximately 20 min to complete.

*Development of the AQEL (Assessment of Quality of Life at End of Life)*. The questionnaire included 19 quality-of-life questions and 3 complementary questions. The time frame chosen for all questions was the preceding week. This choice was based on the literature (1, 10, 17) and on the clinical experience that these cancer patients nearing the end of life can have 'good' days and 'bad' days alternatively, but that the overall trend is deterioration. Thus, a time frame of one or a few days may by chance cover only one extreme.

The response format of the quality-of-the-life questions was a modified visual analogue scale, the modification being that the line was interrupted by all integers between 1 and 10. The extreme values were defined verbally, e.g. regarding pain, 1 was defined as 'no pain' and 10 as the 'worst possible pain'. This particular modification of the visual analogue scale was recently recommended by Cohen & Mount (3) as the ideal for palliative care. It combines a high sensitivity to change with an ease of occasionally assisted completion, e.g. when the patient is too weak to hold the pencil, a spouse or a member of staff can read the questions and the patient can answer with a number.

Depending on how the question was formulated, high quality of life corresponded to a high or a low number. This format was chosen to counteract any tendency to response bias.

The items were selected to represent the physical, psychological, social, existential, and global aspects of quality of life (17) as well as an estimation of the accessibility of medical care (see Fig. 1). The quality-of-life questions were classified as follows on the basis of their content: 6 physical items (hours recumbent during the day, need for help with hygiene and dressing/undressing, physical strength, pain, nausea, trouble with bowel movements), 5 psychological items (memory, anxiety, insomnia, depression, ability to concentrate), 2 social items (sharing worries with any family member, regarded as usual by friends), 3 existential items (ability to do what one wants, meaningfulness, ability to feel joy), 2 medical care items (possibility to reach staff, receive adequate care) and one global item (how has your quality of life been during the past week?). The choice of items within each domain was guided by recommendations in the literature (2, 10, 15, 28) and our clinical experience of this specific group of terminally ill cancer patients.

#### Summary of items

*Physical items.* The item 'hours recumbent during the day' deviates from the rest by focusing on the number of hours rather than the grading of a symptom or an experience. We included it as a reflection of the deterioration of bodily functions toward the end of life which may be expressed by the amount of time spent reclining. This assumption is probably more valid in the home-care setting than in institutional care. 'Need for assistance with hygiene and dressing/undressing' is an attempt to condense an ADL assessment (11) into a single item. 'Trouble with bowel movements' is a fusion of questions on diarrhoea and constipation, but also avoids the problem of defining these concepts (11, 29).

*Psychological items.* 'Insomnia' (Have you had difficulty sleeping?) seeks to summarize different sleep disturbances in one item. 'Memory' and 'Ability to concentrate' were used to capture cognitive functions.

*Social items.* Serious illness often leads to a shrinking sphere of social interaction. The kinds of interactions with family or friends that most strongly affect quality of life are insufficiently studied at the end of life. The items 'How many of your worries have you shared with any member of your family' and 'Have your friends regarded you as usual' are attempts to capture dimensions of these interactions.

*Existential items.* In many review articles on quality-of-life instruments for cancer patients, the authors stress the need to include existential items when dealing with incurable cancer (3, 18, 19, 30). They also point out that most of the available comprehensive instruments do not have

even a single item representing this dimension. The item that has been most frequently suggested is 'meaning' (3, 18, 31), which we expressed as 'Has your day felt meaningful?' 'Not at all' to 'completely'. 'Ability to feel joy' (11) and 'Ability to do what one would like to do' (11) capture other aspects of the existential dimension.

*Medical care items.* Items of this kind are not included in traditional questionnaires, but have been proposed by Cella (20) and Aaronson (32). In palliative care, where patients have very frequent contact with staff, even when at home, quality of care received and ability to reach different members of staff are both essential.

*Global item.* Some authors highlight the importance of a global question to get an idea of the patient's own evaluation of all the different aspects of quality of life. This item could reflect the impact of other factors not covered by specific questions in the instrument (10, 33). The inclusion of a global item makes it possible to identify the specific items that are most strongly related to the global dimension.

*Complementary questions.* Three general questions were included at the end of the questionnaire as a complement that may help to explain sudden variations in the quality-of-life scores. Such variations can be caused by co-morbidity or factors outside the patient-carer relationship that usually remain unknown to researchers. Wenger (34) has stressed this as an important entity when interpreting quality-of-life data in clinical studies. No existing instrument seems to gather this kind of information systematically.

The questions deal with whether or not the patient has been hospitalized during the week, whether the questionnaire was completed in hospital or at home, and whether anything especially pleasant or unpleasant had happened in the past week regarding the cancer illness, the family, or among friends.

#### Procedure

*Reliability.* We asked the patients in group A ( $n = 30$ ) to complete the questionnaire twice, with a 3-day interval. This rather short interval was chosen because of the imminent risk of sudden changes in the status of this group of patients. Fifteen patients completed the questionnaires in hospital and 15 at home. The questionnaires were collected immediately after completion in order to eliminate the risk of patients checking the first questionnaire when completing the second.

As the distribution of scores did not conform with the normal distribution, the Spearman's rank correlation was calculated. This non-parametric method was used throughout this study.

*Validity.* Concurrent validity was examined by computing correlations between our questionnaire and the CIPS. CIPS statements that corresponded regarding content to individual AQEL items were selected for this analysis.

Last week:

1. Approximately how many hours per day (8 a.m. to 8 p.m.) have you been lying down?  
1 ---- 2 ---- 3 ---- 4 ---- 5 ---- 6 ---- 7 ---- 8 ---- 9 ---- 10  
One hour at the most 10 hours or more
2. How much help have you needed with dressing and hygiene?  
1 ---- 2 ---- 3 ---- 4 ---- 5 ---- 6 ---- 7 ---- 8 ---- 9 ---- 10  
No help at all Help with everything
3. How has your bodily strength been?  
1 ---- 2 ---- 3 ---- 4 ---- 5 ---- 6 ---- 7 ---- 8 ---- 9 ---- 10  
None As healthy persons of the same age
4. How much pain have you had last week?  
1 ---- 2 ---- 3 ---- 4 ---- 5 ---- 6 ---- 7 ---- 8 ---- 9 ---- 10  
Painfree Worst possible pain
5. How much nausea have you had?  
1 ---- 2 ---- 3 ---- 4 ---- 5 ---- 6 ---- 7 ---- 8 ---- 9 ---- 10  
None Worst possible nausea
6. Have you had any trouble with your bowel movements?  
1 ---- 2 ---- 3 ---- 4 ---- 5 ---- 6 ---- 7 ---- 8 ---- 9 ---- 10  
None Worst possible
7. Have you been able to do what you would like to do last week?  
1 ---- 2 ---- 3 ---- 4 ---- 5 ---- 6 ---- 7 ---- 8 ---- 9 ---- 10  
Not at all Yes, completely
8. How has your memory been for things happening lately?  
1 ---- 2 ---- 3 ---- 4 ---- 5 ---- 6 ---- 7 ---- 8 ---- 9 ---- 10  
Have had great difficulty in remembering No problems in remembering
9. Have you felt worried?  
1 ---- 2 ---- 3 ---- 4 ---- 5 ---- 6 ---- 7 ---- 8 ---- 9 ---- 10  
Not worried at all Very worried
10. Have you had difficulty sleeping?  
1 ---- 2 ---- 3 ---- 4 ---- 5 ---- 6 ---- 7 ---- 8 ---- 9 ---- 10  
None at all Very difficult
11. How has your ability to concentrate been?  
1 ---- 2 ---- 3 ---- 4 ---- 5 ---- 6 ---- 7 ---- 8 ---- 9 ---- 10  
Very bad Very good
12. Have you felt depressed/ low in mood?  
1 ---- 2 ---- 3 ---- 4 ---- 5 ---- 6 ---- 7 ---- 8 ---- 9 ---- 10  
Not at all Very depressed/ low in mood
13. How much of your worries have you shared with any member of your family?  
1 ---- 2 ---- 3 ---- 4 ---- 5 ---- 6 ---- 7 ---- 8 ---- 9 ---- 10  
Nothing Everything
14. Have your friends regarded you as usual?  
1 ---- 2 ---- 3 ---- 4 ---- 5 ---- 6 ---- 7 ---- 8 ---- 9 ---- 10  
Not at all Completely as usual
15. Has your day felt meaningful?  
1 ---- 2 ---- 3 ---- 4 ---- 5 ---- 6 ---- 7 ---- 8 ---- 9 ---- 10  
Not at all Completely
16. Has anything made you happy last week?  
1 ---- 2 ---- 3 ---- 4 ---- 5 ---- 6 ---- 7 ---- 8 ---- 9 ---- 10  
Nothing A lot
17. How easy/hard has it been to get hold of medical staff who know you when it has been needed?  
1 ---- 2 ---- 3 ---- 4 ---- 5 ---- 6 ---- 7 ---- 8 ---- 9 ---- 10  
Very easy Very hard
18. Have you received the medical care you have needed?  
1 ---- 2 ---- 3 ---- 4 ---- 5 ---- 6 ---- 7 ---- 8 ---- 9 ---- 10  
Not at all Completely
19. How has your quality of life been last week?  
1 ---- 2 ---- 3 ---- 4 ---- 5 ---- 6 ---- 7 ---- 8 ---- 9 ---- 10  
Very poor Best possible
20. How many days during the past week have you spent in a hospital/nursing home?  
\_\_ None, \_\_ one day, \_\_ two days, \_\_ three to six days, \_\_ the whole week.
21. Are you at home or in hospital when you answer this questionnaire? \_\_ At home \_\_ In hospital.
22. Has anything especially pleasant or unpleasant happened during the last week? In your family? Among your friends? With your disease? Write a couple of lines to explain.  
\_\_\_\_\_  
\_\_\_\_\_

Fig. 1. The AQEL questionnaire for assessment of patient's quality of life in palliative care.

Twenty-eight patients (group B) completed both questionnaires within two weeks.

It was hypothesized that corresponding items from the two different questionnaires should correlate highly (i.e. convergent validity) and that 'memory' (AQEL) should correlate highly with 'concentration' (CIPS) as should 'physical strength' (AQEL) inversely with 'sitting/lying' (CIPS). On the contrary it was hypothesized that 'memory' (AQEL) should have a low correlation with 'eat/dress/wash independently' (CIPS) as should 'physical strength' (AQEL) with 'pain' (CIPS), i.e. discriminant validity.

Correlations were also computed between Karnofsky Performance Status (KPS) scores and AQEL items for patients in group A. The KPS ratings were carried out by the first author at the time when the patient completed the first AQEL questionnaire.

Factor analysis (orthogonal varimax transformation) was used to examine the extent to which the instrument yielded factors with a logical composition. The criteria for inclusion of an item in a factor were a factor score of  $>0.50$  and a correlation within a factor between the included items of  $>0.30$ . Factors included had an eigenvalue  $>0.75$ . Responses from patients in groups A, B and C were included in the factor analysis, i.e. 71 patients in all.

The ability of the instrument to detect change over time was investigated by allowing the patients in group B to complete a questionnaire every month until they died or withdrew from participation.

## RESULTS

### Reliability

The test-retest correlations ranged between 0.52 and 0.90 for each of the 19 questions and 13 values were  $>0.70$ . Exact values are shown in Table 1. Factor analysis yielded seven independent factors. Test-retest correlations for the factors were computed on the basis of data from group A. These correlations ranged between 0.63 and 0.94 (Table 2).

### Validity

Correlations were calculated between selected CIPS statements and corresponding AQEL items (Table 3). In general, there were moderate to strong correlations in the areas of physical and psychological problems. For social aspects of quality of life, the correlation was weak. The CIPS does not contain any questions about existential dimensions, quality of medical care, or global quality of life. It is noteworthy that the sum total of the questionnaires correlated rather strongly (0.80).

Convergent validity was illustrated by the correlation of 0.49 between 'memory' (AQEL) and 'concentration' (CIPS) and  $-0.62$  between 'physical strength' (AQEL) and 'sitting/lying' (CIPS). The very low correlation values of 0.11 between 'memory' (AQEL) and 'eat, dress, wash

independently' (CIPS) and 0.18 between 'physical strength' (AQEL) and 'pain' (CIPS) support discriminant validity.

Further validation was performed by computing correlations between AQEL items and the KPS score (median = 70, range 30–90, mean = 62.3, S.D. = 20.3; Table 1). The item 'physical strength' had a correlation of 0.66 and the total QoL (quality of life) score had a correlation of 0.63 with the KPS, thus illustrating adequate convergent validity. Other items such as 'anxiety', 'insomnia', 'pain', and 'sharing worries with any family member' had low correlations (0.05–0.23) also suggesting adequate discriminant validity.

Sensitivity to change was investigated by testing the extent to which scores declined when approaching death. Fig. 2 illustrates the distinct decrease in mean total score (sum of 19 items) over time. The scores during the last 6 weeks of life were significantly lower than those in weeks 7–30 (mean 90.5; S.D. = 20.0 compared with mean 112.5; S.D. = 23.6;  $p = 0.0001$ ; Mann-Whitney-U test). Details on individual patients' development over time are presented in a separate article (35).

In two cases, extraordinary dips in the overall QoL score could be related to answers to the last open question: Has anything especially pleasant or unpleasant happened during the past week? In one case the patient's mother had

**Table 1**

*Test-retest correlations and correlations with Karnofsky (KPS) scores for all AQEL items (n = 30)*

	Test-retest correlation	Correlation to KPS
Hours recumbent during the day	0.72	0.49
Need for help with hygiene/dressing	0.84	0.33
Physical strength	0.78	0.66
Pain	0.65	0.23
Nausea	0.73	0.36
Trouble with bowel movements	0.75	0.38
Ability to do what one wants	0.52	0.22
Memory	0.86	0.46
Anxiety	0.67	0.09
Insomnia	0.70	0.05
Ability to concentrate	0.69	0.46
Depression	0.80	0.34
Sharing worries with any member of family	0.90	-0.09
Regarded as usual by friends	0.83	0.08
Meaningfulness	0.74	0.56
Make you happy	0.64	0.53
Ability to reach staff	0.81	0.53
Receive appropriate care	0.68	0.24
Global quality of life	0.75	0.61
Total score	0.78	0.63

**Table 2**

Factor analysis (orthogonal varimax transformation;  $n = 71$ ). All positive values  $> 0.40$  are shown. Loadings in parentheses indicate that items are not included in the respective factor

Item	Symptoms	Life content	Friends	Cognitive	Family	Medical care	Existential
Hours recumbent during the day	0.54						
Help with hygiene/dressing	0.61						
Physical strength		0.79					
Pain	0.75						
Nausea	0.72						
Trouble with bowel movements	0.62						
Ability to do what one wants		0.86					
Memory				0.89			
Anxiety	0.86						
Insomnia	0.86						
Ability to concentrate				0.84			
Depression	0.87						
Share worries with family					0.93		
Regarded as usual by friends			0.63	(0.43)			
Meaningfulness		(0.59)					0.62
Make you happy							0.89
Reach staff						0.89	
Receive appropriate care			(0.54)			0.53	
Global quality of life		0.65					(0.52)
Test-retest correlations ( $n = 30$ )	0.85	0.86	0.77	0.81	0.94	0.68	0.63

died and in the other, the patient was hospitalized due to extensive bleeding from an ulcerating rectal carcinoma.

In the 101 questionnaires analysed, there were only 14 missing values out of 1919 (0.7%).

## DISCUSSION

The results indicate that the AQEL questionnaire for the assessment of quality of life in palliative care may be sufficiently reliable and valid.

Test-retest correlation values  $> 0.70$  are recommended by Selby et al. (28) as strong indicators of adequate reliability. The 0.70 cut-off was reached or exceeded by 13/19 items. For six of the items, test-retest values ranged between 0.52 and 0.70. The 0.70 cut-off was surpassed by 5/7 factors, the remaining two being rather close, 0.68 and 0.63. These somewhat higher figures for factor reliability compared with individual items are in line with expectations. However, the fact that 6/19 items did not exceed 0.70 is no reason to dismiss them as there are 10 options with which to answer each item. Ware (36) emphasizes that the greater the number of response alternatives, the more difficult it is to attain high test-retest correlations. On the other hand, the test-retest interval was as short as 3 days, which may have inflated the values. The choice of such a short period is, however, motivated by possible rapid changes in patient status.

The finding that the factor analysis yielded factors with a rather logical composition strengthens the validity of the questionnaire. On the other hand, the factors were not exactly the same as the dimensions used when designing

the questionnaire. This demands attention during the further development of the instrument. Whether this discordance is an expression of insufficient validity of the questionnaire, or a sign of heterogeneity within the postulated dimensions is difficult to say. The fusion of items from the physical domain with items from the psychological domain may seem strange. On the other hand, it seems reasonable that 'insomnia', 'anxiety', and 'depression' are enhanced by increased physical symptoms. The two cognitive items stick nicely together. 'Physical strength' seems

**Table 3**

Correlations between selected CIPS items and corresponding AQEL items ( $n = 28$ )

CIPS item (number)	AQEL item	Correlation
Sitting/lying (1)	Hours recumbent	0.66
Eat, dress, wash independently (9-12)	Ass. with hygiene/dressing	0.79
Pain (51-52)	Pain	0.78
Leisure difficulties (20-21)	Ability to do what one wants	0.64
Memory (50)	Memory	0.62
Insomnia (22-24)	Insomnia	0.81
Concentration (49)	Ability to concentrate	0.63
Depressed (44, 47, 48)	Depression	0.54
Talk with partner about feelings, future, illness (113-115)	Share worries with family	0.07
All (questions included above)	Total score	0.80

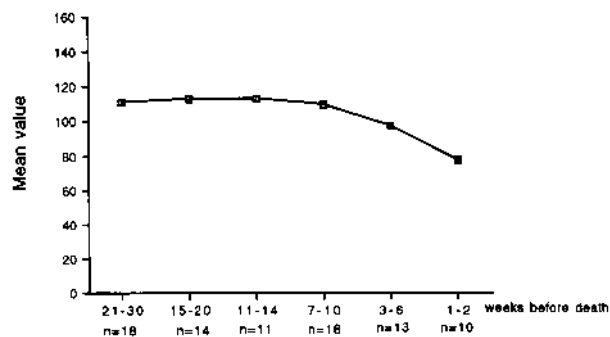


Fig. 2. Total AQEL score over time.

related more to 'ability to do what one wants' and 'global quality of life' than to other physical symptoms, which in turn seems rather reasonable.

Most items loaded onto only one factor and with a reasonable pattern. The fact that the items 'meaning' and global 'quality of life' loaded onto both 'life content' and 'existential' may well be understandable. The item 'get appropriate care' loaded onto 'Friends' and 'Medical care', and the item 'regarded as usual by friends' loaded onto 'Friends' and 'Cognitive'. This is more difficult to explain. However, these four items were the only ones that loaded onto more than one factor.

The most intriguing result in the factor analysis was that the two items from the social dimension ended up completely separated.

The factor analysis was based on the replies from only 71 patients, which strictly speaking is too small a number. Although the present results in general indicate logical factors, the question of factor structure has to be addressed again in future investigations with more patients.

Concurrent validity in relation to corresponding CIPS items was moderate to strong in all cases but one, namely 'sharing worries with any member of family' that was compared with 'talk with partner about feelings, future and illness'. Possible explanations may be that many patients preferred to share their worries with another family member rather than with their partner, or that 'family' to some people means a wider circle of persons than the nuclear family. This item will need rephrasing in future trials.

Correlation values adhered nicely to the hypothesized pattern when comparing the 'physical strength' item from AQEL with 'pain' and 'sitting/lying' from CIPS, and the 'memory' item from AQEL with 'concentration' and 'eat, dress, wash independently' from CIPS. In both cases strengthening the impression of convergent as well as discriminant validity.

Comparisons with the KPS score also revealed a pattern of correlations supporting both convergent and discriminant validity. Correlations between the KPS score and the item concerned with physical strength were in the same

range as has been reported for items in the Functional Living Index-Cancer (37) and by Selby (28). The fairly high correlation between the KPS score and the global item stresses the importance of physical capacity to experienced quality of life. Discriminant validity was illustrated by the low correlations between the KPS score and the items 'insomnia', 'anxiety', and 'sharing worries with any member of family', well in line with expectations.

The decline in many quality-of-life items during the terminal three weeks has been described earlier by Morris et al. (38), Higginson et al. (39) and Hinton (40). Our results agree well with their findings and illustrate that the questionnaire is sensitive enough to detect changes over time, at least in the terminal phase. The number of patients assessed varied between different observation points in Fig. 2. The impact of this on the results is probably an underestimation of the terminal decline in AQEL scores. Arguments in favour if this assumption are that we found a general decline in AQEL scores when approaching death in individual patients, and that it is conceivable that the drop-outs were patients with the poorest quality of life.

The overall impression is that patients with incurable cancer at the end of life have found this questionnaire acceptable for repeated assessments. One illustration of this is the very low number of missing values. It was more difficult to overcome a certain reluctance among the staff involved to trust the patient to decide whether to complete the questionnaire or to withdraw from participation. Clearly, strictly formalized routines are necessary to prevent staff members from depriving patients of the right to decide whether or not to complete similar assessments.

The format of the questions is easy to grasp and facilitates occasional assisted completion. The items are rather evenly distributed between some of the most widely accepted dimensions of quality of life. The questionnaire is brief and comprehensive, which facilitates routine use. When used with breast cancer patients, an item on dyspnoea should be added as dyspnoea is a fairly common symptom and, when it occurs, is frequently the predominant problem.

The AQEL fulfils almost all of the criteria for an ideal instrument proposed by Donovan et al. (19) and Cohen & Mount (3) in their reviews. The only criterion proposed by Donovan et al. (19) that was not fulfilled is that we did not use patient responses to generate the initial items. Cohen & Mount (3) emphasize the advantages of the employed response format, the need for inclusion of items capturing the spiritual dimension as well as the physical, psychological and social dimensions, and a brief completion time both with individual and assisted administration. In some respects, the criteria of Cohen & Mount (3) differ from the principles applied when devising the AQEL instrument. They suggested a time frame of 2-3 days; we chose one week. They suggested a uniform response format where 10 consistently denotes best or worst quality of life; we chose to alternate to avoid a 'yea-saying/nay-saying' bias (31).

The wording of the items and the response format are very important. We sought to focus on the patient's perceptions as much as possible. For instance, we avoided asking 'how often' but rather 'how much' pain and nausea they have had, the extreme being 'worst possible' pain or nausea. We suggest that the wording of most items should focus on the patient's experience of a specific problem rather than just being a simple rating of a symptom, and by doing this it will at least partially comply with the criterion emphasizing the experience of the respondent.

At this stage of instrument development, we deemed it relevant to use either the total score or individual item scores when reporting the results. We advocate caution in using subscale scores until further trials have been conducted.

As a complement to existing instruments, the AQEL is now available for assessment of quality of life at the end of life. The results suggest that the AQEL is reliable and valid, but further investigations are needed to verify these findings. Its brevity and comprehensiveness make it much more practical for regular use than, for example, the extensive CIPS instrument (131 items). Through the complementary questions, the AQEL provides possibilities to detect factors other than the actual disease that influence quality of life. As it is the first quality-of-life instrument specifically developed for palliative cancer care that is available in both English and Swedish, it may prove helpful in future work investigating quality of life within palliative medicine.

#### ACKNOWLEDGEMENTS

This study was funded by a grant from the Swedish Cancer Foundation.

#### REFERENCES

1. Finlay IG, Dunlop R. Quality of life assessment in palliative care. *Ann Oncol* 1994; 5: 13–8.
2. Gough IR, Furnival CM, Schilder L, Grove W. Assessment of the quality of life of patients with advanced cancer. *Eur J Cancer Clin Oncol* 1983; 19: 1161–5.
3. Cohen SR, Mount BM. Quality of life in terminal illness: defining and measuring subjective well-being in the dying. *J Palliative Care* 1992; 3: 40–5.
4. Viney LL, Walker BM, Robertson T, Lilley B, Ewan C. Dying in palliative care units and in hospital: a comparison of the quality of life of terminal cancer patients. *J Consult Clin Psychol* 1994; 62: 157–64.
5. Dupuis G. International perspectives on quality of life in cardiovascular disease: the quality of life systemic inventory. Presented at the Workshop on Quality of Life in Cardiovascular Disease, Winston-Salem, N.C., June 1988.
6. Fowlie M, Berkeley J. Quality of life—a review of the literature. In: *Family Practice* 1987; 4: 226–234. Oxford: Oxford University Press.
7. Cella DF, Tulsky DS. Quality of life in cancer: definition, purpose, and method of measurement. *Cancer Investigation* 1993; 11: 327–36.
8. Frankl VE. *Man's search for meaning*. New York: Pocket Books, 1963.
9. Hopwood P. Progress, problems and priorities in quality of life research. *Eur J Cancer* 1992; 28A: 1748–52.
10. Aaronson NK, Bullinger M, Ahmedzai S. A modular approach to quality-of-life assessment in cancer clinical trials. *Recent Results Cancer Res* 1988; 111: 231–49.
11. Ferrel BR, Wisdom C, Wenzl C. Quality of life as an outcome variable in the management of cancer pain. *Cancer* 1989; June (Suppl).
12. Slevin ML, Plant H, Lynch D, Drinkwater J, Gregory WM. Who should measure quality of life, the doctor or the patient? *Br J Cancer* 1988; 57: 109–12.
13. Karnofsky DA, Burchenal JH. The clinical evaluation of chemotherapeutic agents against cancer. In: McLeod CM, ed. *Evaluation of chemotherapeutic agents*. New York: Columbia University Press, 1949: 191–205.
14. Zubrod CG, Schneiderman M, Frei E, et al. Appraisal of methods for the study of chemotherapy of cancer in man: comparative therapeutic trial of nitrogen mustard and triethylene thioposporamide. *J Chronic Dis* 1960; 11: 7–33.
15. Selby P, Robertson B. Measurement of quality of life in patients with cancer. *Cancer Surveys* 1987; 6: 521–43.
16. Siegrist J, Junge A. Conceptual and methodological problems in research on the quality of life in clinical medicine. 1989 In: *Quality of life in clinical medicine*. UK: Pergamon Press, 1989: 463–468.
17. McMillen Moimpour C, Feigl P, Metch B, Hayden KA, Meyskens FL, Crowley J. Quality of life end points in cancer clinical trials—review and recommendations. *J Natl Cancer Inst* 1989; 81: 485–95.
18. Warner SC, Williams JJ. The meaning in life scale: determining the reliability and validity of a measure. *J Chronic Dis* 1987; 49: 503–12.
19. Donovan K, Sanson-Fisher RW, Redman S. Review article—measuring quality of life in cancer patients. *J Clin Oncol* 1989; 7: 959–68.
20. Cella DF, Tulsky DS, Gray G, et al. The functional assessment of cancer therapy (FACT) scale: development and validation of the general measure. *J Clin Oncol* 1993; 11: 570–9.
21. Ganz PA, Schag CAC, Lee JJ, Sim M-S. The CARES: a generic measure of health-related quality of life for patients with cancer. *Qual Life Res* 1992; 1: 19–29.
22. MacAdam DB, Smith M. An initial assessment of suffering in terminal illness. *Palliative Med* 1987; 1: 37–47.
23. Sterkenburg CA, Woodward CA. A reliability and validity study of the McMaster quality of life scale (MQLS) for a palliative population. *J Palliative Care* 1996; 1: 18–25.
24. Cohen SR, Mount BM, Strobel MG, Bui F. The McGill Quality of Life Questionnaire: a measure of quality of life appropriate for people with advanced disease. A preliminary study of validity and acceptability. *Palliative Med* 1995; 9: 207–19.
25. McMillan SC, Mahon M. Measuring quality of life in hospice patients using a newly developed hospice quality of life index. *Qual Life Res* 1994; 3: 437–47.
26. Glimelius B, Birgegård G, Hoffman K, et al. A comprehensive cancer care project to improve the overall situation of patients receiving intensive chemotherapy. *J Psychosoc Oncol* 1993; 11: 17–40.
27. Heinrich RL, Schag CC, Ganz P. Living with cancer: the cancer inventory of problem situations. *J Clin Psychol* 1984; 40: 972–80.
28. Selby PJ, Chapman JAW, Etazadi-Amoli J, Dalley D, Boyd NF. The development of a method for assessing the quality of life of cancer patients. *Br J Cancer* 1984; 50: 13–22.

29. McCorkle R, Young K. Development of a symptom distress scale. *Cancer Nurs* 1978; 1: 373–8.
30. Bullinger M. Quality of life assessment in palliative care. *J Palliative Care* 1992; 8: 34–9.
31. Kaasa S, Mastekaasa A, Stokke I, Naess S. Validation of a quality of life questionnaire for use in clinical trials for treatment of patients with inoperable lung cancer. *Eur J Cancer Clin Oncol* 1988; 24: 691–701.
32. Aaronson NK. Methodological issues in psychological oncology with special reference to clinical trials. In: Ventrafridda V, Dam FS, Yancik R, et al., eds. *Assessment of quality of life and cancer treatment*. Amsterdam: Elsevier Science, 1986: 29–41.
33. de Haes JCJM, van Knippenberg FCE. The quality of life of cancer patients: a review of the literature. *Soc Sci Med* 1990; 20: 809–17.
34. Wenger NK. Discussion. *Eur Heart J* 1988; 9: 232–4.
35. Axelsson B, Sjöden P-O. Quality of life of cancer patients and their spouses in palliative home care. *Palliative Med* 1998; 12: 29–39.
36. Ware J. Measuring functioning, well-being, and other generic health concepts. In: Osoba D, ed. *Effect of cancer on quality of life*. Boca Raton: CRC Press, 1991.
37. Schipper H, Clinch J, McMurray A, Levitt M. Measuring the quality of life of cancer patients: the functional living index-cancer: development and validation. *J Clin Oncol* 1984; 2: 472–83.
38. Morris JN, Suissa S, Sherwood S, Wright SM, Greer D. Last days: a study of the quality of life of terminally ill cancer patients. *J Chronic Dis* 1986; 39: 47–62.
39. Higginson IJ, McCarthy M. A comparison of two measures of quality of life: their sensitivity and validity for patients with advanced cancer. *Palliative Med* 1994; 8: 282–90.
40. Hinton J. Can home care maintain an acceptable quality of life for patients with terminal cancer and their relatives? *Palliative Med* 1994; 8: 183–96.