



Patient Self-reported and Clinician-rated Quality of Life in Head and Neck Cancer Patients: a Cross-sectional Study

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One to six years after treatment for head and neck cancer, 68 patients were asked to fill in a questionnaire at home with a subsequent examination at the out-patient clinic of the Ullevål University Hospital. 50 patients (74%) both answered the questionnaire (the EORTC QLQ-C30, a diagnosis specific questionnaire module, the GHQ-20, and two questions from a population survey) and presented for examination where the clinician rated side effects after treatment, and filled in the Karnofsky Performance Status and the Spitzer's Quality of Life index. No patients had relapse or second primary tumours at the time of examination but a variety of post-treatment side effects were recorded. The patients appeared to report lower quality of life including more post-treatment side effects compared with the clinician's assessments. The cost-benefit of the standard clinical follow-ups in terms of increased survival may be questioned. Patients seem to need better support in coping with the physical and psychosocial problems which often appear.

Keywords: head and neck cancer, quality of life, survivors, self-report questionnaires, cross-sectional, EORTC QLQ-C30, General Health Questionnaire, Spitzer's Quality of Life index

Oral Oncol, Eur J Cancer, Vol. 31B, No. 4, pp. 235–241, 1995.

INTRODUCTION

EVEN THOUGH many patients with head and neck cancer present with advanced lesions at the time of diagnosis, the disease is potentially curable. Most recurrences occur within the first 2 years post-treatment, but the patients have a persistent high risk of secondary primary cancers [1]. Clinical follow-up after treatment usually focuses on tumour control, i.e. early detection and treatment of recurrences. Other objectives are evaluation of treatment results and major complications, provision of support and help, and detection and treatment of secondary neoplasms. The cost-benefit of such examinations in terms of increased survival may be questioned [1].

Reduced health-related quality of life (QOL) including high level of late side effects and psychological distress, have been found in cured head and neck cancer patients, especially in surgical patients [2–8]. Patients with such problems should ideally be identified at the follow-up visits, but symptoms and psychosocial problems are seldom reported spontaneously by the patients [9]. Standardised clinician-rated QOL instruments such as the Spitzer Quality of Life index (QL-index)

[10] may give important information and facilitate the communication between clinicians and patients. However, researchers within psychosocial oncology agree that the patients themselves, whenever possible, should be the source of subjective data such as health-related QOL. Studies have shown that health-workers and proxy raters often evaluate the patient's problems and worries in a different way compared with the patient him/herself [11]. Several validated instruments are available for self-assessment of health-related QOL in cancer patients [12]. One of these, the European Organization for Research and Treatment of Cancer Core Quality of Life Questionnaire, 30-item version (the EORTC QLQ-C30) [13] has been found valid for QOL assessments in head and neck cancer patients [6, 14].

In the present cross-sectional study we wanted to assess the health-related QOL including side effects of treatment, in addition to tumour control in patients with head and neck cancer, 1–6 years after the start of treatment. Information gained by clinical examinations and the QL-index were compared with the patients' subjective ratings on a standardised self-report questionnaire.

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Received 26 Jan. 1995; accepted 20 Feb. 1995.

PATIENTS AND METHODS

Patient selection

The study was approved by the local ethical committee, and conducted in the period from November 1991 to January 1992 at the Ullevål University Hospital, Department of Otolaryngology, Head and Neck Surgery. Almost all head and neck

cancer patients in Oslo, the capital of Norway, receive their treatment and follow-up in this department. Patients with carcinomas in the oral cavity, pharynx, parotid gland, skin, or with metastasis to neck nodes from unknown origin, receiving primary treatment in the 5-year period from January 1986 to January 1991, were eligible for the study (a follow-up time of at least 1 year). Patients with malignant melanomas, sarcomas, and lymphomas were excluded. Of the eligible 193 patients registered in the hospital files, 68 patients (35%) were alive and received a mailed letter of introduction, with information about the study and invitation for a clinical check-up at the hospital. They were asked to fill in an enclosed self-report questionnaire. The 50 patients (74%) who both filled in the questionnaire and attended the clinical examination will be evaluated in the current paper. The remainder did not fill in the questionnaire ($n=3$), did not meet at the hospital ($n=6$), or both ($n=9$). The reasons for non-attendance were: unable to attend owing to palliative treatment elsewhere for recurrent disease ($n=3$) or secondary cancer ($n=1$); refused to participate ($n=3$); unknown ($n=11$).

Classification of treatment and other clinical data

Data concerning diagnosis, tumour classification, treatment, and side effects were taken from the hospital files by two of the authors: a head and neck surgeon (AF) and an oncologist (JT). The diagnoses and the malignant tumours had been classified at the start of treatment [15, 16]. The surgical interventions were categorised into three groups: (a) no surgery or biopsy only; (b) minor surgery, i.e. local extirpations of tumours without removing bone, or without reconstructive surgery; (c) major surgery, i.e. removal of bone and/or reconstructive surgery. Radiotherapy had been given as 2 Gy per fraction, 5 days a week, up to total doses of 50–70 Gy. Most patients who received radiotherapy were treated by bilateral opposing beams with wide margins towards the primary tumour and upper neck, including unilateral or bilateral anterior fields towards the supra- and infraclavicular regions (50 Gy).

Clinical examination

Without knowing the results from the patient self-report questionnaires, the surgeon performed a standardised clinical examination including inspection of relevant areas and palpation of possible neck nodes. Investigations such as endoscopic examinations, X-rays, or CT scans were to be performed when indicated (not necessary in any patients). Side effects of disease and treatment were classified into different categories (e.g. fibrosis of the neck: “absent” or “present”), or on four point Likert scales (e.g. dryness in the mouth: “not at all” to “very much”). In addition, the surgeon rated the patients on the Karnofsky Performance Status scale [17]. Even though this scale only measures one dimension of the multi-dimensional health-related QOL construct, it has frequently been referred to as a proxy measure of QOL in clinical trials.

Spitzer Quality of Life index (QL-index)

Based on the clinical interview, the head and neck surgeon filled in the QL-index which is one of the first health-related QOL instruments published in the literature [10]. This observer-rated instrument is brief: five questions assess the patients' activity, daily living, health, support and outlook. It is widely used as an outcome measure in clinical studies in cancer patients [11, 18–20]. Each question was scored on a

three point scale (0–2), and an unweighted sum score was calculated (possible range 0–10). Previously, a high inter-rater reliability and validity has been found [21], but systematically higher scores are observed when the patients rate themselves compared with scores obtained by other raters [11].

The patient self-report questionnaire

The questionnaire consisted of standardised instruments or questions; the EORTC QLQ-C30 [13], a 12-item diagnosis specific module for head and neck cancer patients [14], the General Health Questionnaire, 20-item version, (GHQ-20) [22] and two general well-being questions from the Nord-Trøndelag Health Survey [23]. In addition, questions assessing sociodemographic variables were included.

The cancer specific EORTC QLQ-C30 comprises five multi-item function scales (physical, role, social, emotional and cognitive function), one overall QOL scale, three multi-item symptom scales (pain, fatigue, and emesis), and six single questions assessing bowel function, breathing, appetite, sleeping disturbances and economic consequences of the disease. This “core” questionnaire was combined with a *head and neck cancer specific module* developed at the Norwegian Radium Hospital, which assesses disease- and treatment-related symptoms [14]. In the present study we used 12 questions which had a high frequency and variability in previous studies [6, 14]. All scales and single questions are scored on categorical scales, and linearly transformed to 0–100 scales. A high score means a high level of functioning or a high level of symptoms. The clinical relevance of the mean scores are illustrated by the frequency of patients reporting “quite a bit” or “very much” problems on single questions both in the EORTC QLQ-C30 and in the head and neck cancer module.

The GHQ may be used as a screening instrument for psychiatric disorders in non-psychiatric clinical settings [22]. It has also been used as a global measure of QOL, because of the balance of questions assessing both negative and positive aspects of life. Questions about somatic symptoms of anxiety and depression are excluded in the GHQ-20, as compared with the longer version, the GHQ-60. Scores from the 20 single questions in the GHQ-20 (four response categories, score 0–3) are summed, giving a possible scoring range from 0 to 60 (Likert score). An alternative scoring system may be used for “case” identification. This GHQ score has a possible scoring range from 0 to 20 (questions scores of 0 or 1), and the cut-off point for “case” is between 3 and 4. The questionnaire is sensitive to transient disorders, which may remit without treatment. Many patients classified as “cases” probably need support, information and/or someone to talk to, rather than a psychiatric intervention.

The two general well-being questions assess satisfaction with life and physical health on two seven-point categorical scales, ranging from positive (“very satisfied”/“strong and healthy” = 1) to negative (“very dissatisfied”/“tired and worn out” = 7). Results are reported for three scoring groups: the three positive response categories (score 1–3); the “so-so” category (score 4); and the three negative response categories (score 5–7). The questions have previously been used in Norway in a large population survey [23], and in head and neck cancer patients [8].

Statistical analysis

The statistical software SPSS PC+ version 4.0 was used in the statistical analyses [24]. Descriptive statistics are reported.

The association between clinician-rated performance status and QOL, and the patient-rated EORTC scales expected to assess similar dimensions were explored by plots (e.g. Karnofsky Performance Status versus physical function, QL-index sum score versus overall QOL, and the five QL-index dimensions versus role function, physical function, fatigue, social function and emotional function, respectively); results not shown. Multivariate analyses were not performed because of the small study sample.

RESULTS

Patients' characteristics

There were no major differences in patients' characteristics in the study sample (those who filled in the questionnaire and

presented for examination, $n=50$) compared with the total population (all eligible living patients, $n=68$) (Table 1). The mean age of the study sample was 62 years, and 33 were males. Cancer in the oral cavity was the most frequent diagnosis ($n=22$), and the majority of the patients ($n=40$) received surgery as their primary treatment, either alone or in combination with radiotherapy (Tables 1 and 2). 5 patients had been treated for local ($n=3$) or regional ($n=2$) recurrent disease in the follow-up period. Two of the five recurrences were within previous irradiated area. "Minor" and "major" side effects after treatment as reported in the hospital files in the follow-up period are listed in Tables 3 and 4. Myelopathy, or lenticular opacities were not registered in any patients.

Table 1. Patients' characteristics

	Total population n (%) or mean (range)	Study sample n (%) or mean (range)
Number of patients	68 (100%)	50 (100%)
Mean age (years)	64 (20–89)	62 (20–88)
Gender		
Male	44 (65%)	33 (66%)
Female	24 (35%)	17 (34%)
Tumour site (ICD-9)		
Oral cavity (140, 141, 143–145)	32 (47%)	22 (44%)
Parotid gland (142)	11 (16%)	9 (18%)
Pharynx (146–148)	18 (26%)	14 (28%)
Tumour colli/skin (196, 171–173)	7 (10%)	5 (10%)
Stage of disease		
I	18 (26%)	14 (28%)
II	18 (26%)	12 (24%)
III	10 (15%)	8 (16%)
IV	16 (24%)	12 (24%)
T × N +	6 (9%)	4 (8%)
Mean time since start of treatment (months)	40 (13–70)	40 (13–70)
Treatment		
Surgery alone	21 (31%)	14 (28%)
Radiotherapy (RT) alone	12 (18%)	9 (18%)
Pre-operative RT	17 (25%)	12 (24%)
Postoperative RT	17 (25%)	14 (28%)
RT after chemotherapy	1 (1%)	1 (2%)
Mean RT dose: primary tumour (Gy)	59 (44–70)	60 (50–70)
Mean RT dose: neck nodes (Gy)	50 (46–64)	51 (46–64)*
Surgical treatment		
None	13 (19%)	10 (20%)
Minor (primary tumour)†	36 (53%)	27 (54%)
Major (primary tumour)†	11 (16%)	7 (14%)
Only neck node dissection	8 (12%)	6 (12%)
Mean weight change during treatment (kg)	–6 (4––26)	–8 (0––26)
Recurrence after primary treatment	8 (12%)	5 (10%)
Secondary primary cancers	1 (1%)	0

*In patients receiving RT ($n=36$): RT towards supra- and infra-clavicular region; bilateral, 29 patients; unilateral, 5 patients; none, 2 patients.

†+ / – neck node dissection.

The clinical interview and examination at follow-up

39 (78%) patients received the maximum score of 100 on the Karnofsky Performance Status (mean 94, range 40–100). 11 patients (22%) gained weight in the period from the start of treatment to follow-up, 6 (12%) had had a stable weight, 18 (36%) lost 10% or less, and 14 (28%) lost more than 10%. 9 of the 31 patients (28%) who smoked before the start of treatment had stopped smoking. "Major" side effects, besides those registered in the hospital files (Table 3), were not found. Half of the patients ($n=26$, 52%) were rated with "quite a bit" or "very much" of a problem with dryness in the mouth. All of them had received radiotherapy towards the oral cavity (48–68 Gy). 22 of the 34 patients (65%) who received radiotherapy towards neck nodes had a fibrosis of the neck. Fibroses were also registered in 3 patients after neck node dissection. Other "minor" side effects registered at follow-up are listed in Table 4. All patients including those who had been treated for relapse during follow-up were disease free and without pathological neck nodes at the time of examination.

Table 2. Classification of surgery ($n=40$)

<i>"Minor surgery": local extirpations of tumours without removing bone, or without reconstructive surgery</i>	
In the tongue	$n=9$
In the parotid gland	$n=6$
In the hard palate	$n=2$
In the cheek or floor of the mouth	$n=4$
In the tonsils	$n=3$
In the face/ear	$n=2$
In the submandibular gland	$n=1$
Total	$n=27$
<i>"Major surgery": removal of bone and/or reconstructive surgery</i>	
Total parotidectomy	$n=2$
Extirpation of the hard palate and arcus palatine	$n=2$
Laryngectomy	$n=1$
Laryngectomy, glossectomy and hypopharyngectomy	$n=1$
Mandibulectomy with jejunum transplantation	$n=1$
Total	$n=7$
<i>Neck node surgery</i>	
Combined with primary tumour surgery	$n=11$
Without primary tumour surgery	$n=6$
Total	$n=17$

Table 3. "Major" side effects of disease and treatment

Gender/age*	Diagnosis (ICD-9)/stage	Radiotherapy primary tumour/neck nodes (Gy)	Surgery and/or chemotherapy	OR	Thr	Others/comments
M/53	141/II	64/50	Minor (tongue)	—	X†	Thr complicated by infection†
M/44	141/III	54/50	Minor (tongue)	X	—	Re-operations, relapse, suicide after follow-up
F/61	141/III	50/50	Minor (tongue)	—	X†	
F/67	142/IV	64/50	Major (parotid)	—	—	Total facial nerve palsy
M/60	144/IV	70/50	No surgery/chemotherapy	X†	—	
M/59	144/IV	64/50	No surgery/chemotherapy	—	—	Soft tissue necrosis†
F/53	145/II	—	Minor (palate)	—	—	Oronasal fistula†
M/68	146/IV	64/50	Cisplatin + 5FU	X	—	
F/54	148/IV	66/50	Neck node dissection	—	X†	Laryngeal oedema
F/46	148/IV	64/50	Major (larynx)	—	X	Laryngeal oedema
M/42	148/IV	64/50	Major (larynx/pharynx)	—	X	

*Age (years) at time of diagnosis.

†Not present at follow-up.

OR: osteoradionecrosis.

Thr: tracheostomy.

Table 4. "Minor" side effects after disease and treatment (number of patients)

	Listed in the hospital files since start of treatment	Registered at follow-up
Dryness in the mouth	8	26
Nutritional problems	7	17
Oral candidiasis	4	5
Fibrosis/skin problems	4	25
Oedema on the neck	4	7
Personality disorders	3	1
Pain	3	—
Anxiety and depression	2	5
Trismus	2	1
Cosmetic problems	1	7
Partial facial nerve palsy	1	—
Hypothyreosis	1	Not assessed
Need of paracentesis	1	—
Problems with speech	1	5
Problems with teeth	—	4

Each patient can be rated more than one time.

The Spitzer QL-index

The mean sum score of the QL-index as rated by the clinician was 8.4 with a range of 3–10. 21 patients (41%) had a sumscore of 10; 16 patients (31%) scored 8 or 9. Most patients had a high level of activity and daily living. Greater variability was found in the patients' health, support and outlook (Table 5). The clinician's ratings on the QL-index and the Karnofsky Performance Status were highly associated, even though the Karnofsky Performance Status ratings were more skewed than the scores on the QL-index (plot not shown).

The patient self-report questionnaire

The sociodemographic characteristics of the study sample are reported in Table 6. 20 patients (40%) were daily smokers,

with a range of 5–30 cigarettes per day. Only 11 of the 50 patients (22%) had never smoked.

EORTC QLQ-C30 and the head and neck cancer module.

Most patients reported some reduction in function, with the largest impairment in the emotional dimension (Table 7). Various symptoms were also reported, especially fatigue and sleeping disturbances. 19 (38%) and 18 patients (35%) had "quite a bit" or "very much" of a problem with dryness in the mouth and problems with mucous production, respectively (Table 7). Additionally, many patients had problems with change of taste and with swallowing (especially with swallowing sandwiches which are common for breakfast and lunch in Norway).

The GHQ-20 and the subjective well-being questions. The mean Likert score was 21 (median 18, range 8–53), and 17 patients (34%) were classified as "cases". 33 patients (66%) reported that they were "satisfied with their life", 12 patients (24%) were "so-so", 5 patients (10%) were "dissatisfied". Their physical health was more impaired; 24 patients (48%) reported "health and fitness", 16 (32%) "so-so", and 10 (20%) were "tired and worn out".

Associations between patient self-reported QOL and assessments by the clinician. The variance was lower and the "ceiling" effect greater in the clinician's assessments compared with the patients' reports. The agreement was best for the Karnofsky Performance Status versus physical function (plots not shown).

The frequency of symptoms/problems reported were higher in the self-report questionnaires compared with the clinicians ratings. Except for dryness in the mouth and fibrosis of the neck, 14 patients were without any symptoms/problems according to the clinician. Only 7 patients reported none or only a few problems in addition to dryness in the mouth on the questions in the EORTC QLQ-C30 or the head and neck module. However, more symptoms were registered by the

Table 5. Clinician-rated quality of life—Spitzer's Quality of Life index

Dimension	Number of patients (%)		
	Not reduced "2"	Reduced "1"	Much reduced "0"
Activity—ability to work, study or manage house work	43 (86)	5 (10)	2 (4)
Daily living—ability to be self-reliant in daily activities and transport	44 (88)	6 (12)	0
Health—ability to feel well or "great"	31 (62)	15 (30)	4 (8)
Support*—relationship and support from family and/or friends	40 (80)	2 (2)	7 (14)
Outlook—ability to be calm, positive in outlook, and in control of personal circumstances	30 (60)	15 (30)	5 (10)

*One assessment is missing.

Table 6. Sociodemographic characteristics of the study sample

	n (%)
Household type*	
Living alone	11 (22)
Spouse or cohabiter	34 (68)
Other adults	6 (12)
Own children	12 (24)
Full-time resident of an institution	3 (6)
Education	
Compulsory only	27 (54)
Secondary school	15 (30)
University	6 (12)
Unknown	2 (4)
Employment	
Semi/unskilled worker	6 (12)
Skilled, artisan, foreman	9 (18)
Subordinate staff (shop, office, public service)	10 (20)
Lower professional (e.g. nurse, technician, teacher)	3 (6)
Management position in public or private enterprise	9 (18)
Self-employed businessman (industry, transport, trade)	5 (10)
Have not been in gainful employment (because of, e.g. full-time house work, studies, disability pension)	6 (12)
Unknown	2 (4)

*The patients could answer yes more than one time.

clinician in this follow-up examination than for the whole follow-up period according to the hospital files.

DISCUSSION

In the present cross-sectional descriptive study, the cancer patients themselves reported a high frequency of treatment-related side effects (Table 7), and psychological distress 1–6 years after treatment. This confirms results from another study in head and neck cancer patients [6–8]. Compared with patients surviving 7–11 years treatment, the patients in the current study had similar mean scores on all scales in the EORTC QLQ-C30, but a somewhat higher level of sleeping disturbances (mean score 22 versus 33), reduced appetite (mean score 12 versus 22) [6], and "cases" according to the GHQ-20 (30% versus 34%) [7]. The results on the general well-being questions are also remarkably consistent with the results in the population with longer follow-up time—as opposed to results from a gender-/age-matched control group from the general population [8]. The patients were less satisfied with life compared with the general population, in which 82% were "satisfied with life", 16% "so-so", and 2%

Table 7. Patient self-reported quality of life: EORTC QLQ-C30 and the head and neck cancer module, mean scale/item score and frequencies (%) of patients reporting "quite a bit" or "very much" reduced function/symptoms (single items)

n = 50	Mean scores	
	(S.D.)	%
<i>EORTC QLQ-C30 multi-item scales</i>		
<i>Function scales*</i>		
Physical function	84 (23)	—
Role function	84 (30)	—
Social function	79 (29)	—
Emotional function	77 (25)	—
Cognitive function	81 (27)	—
Overall quality of life*	73 (28)	—
<i>Symptom scales†</i>		
Pain	12 (17)	—
Fatigue	26 (26)	—
Emesis	6 (12)	—
<i>EORTC QLQ-C30 single items‡</i>		
Dyspnoea	16 (24)	8
Sleeping disturbance	33 (38)	29
Appetite	22 (36)	22
Diarrhoea	9 (18)	4
Constipation	19 (31)	14
Economical impact	24 (37)	21
<i>Head and neck cancer module, single items‡</i>		
Cough	13 (21)	4
Pain in mouth or tongue	16 (26)	8
Trouble swallowing	27 (33)	22
Hoarseness	15 (23)	6
Trouble talking on the phone	16 (29)	12
Trouble swallowing bread	31 (37)	26
Trouble swallowing liquid	4 (13)	2
Trouble with taste	25 (33)	18
Dryness in the mouth	44 (37)	39
Mucus production	34 (35)	35
Effect of analgesics, when used (n = 13)‡	47 (33)	10

*High score means a high level of function.

†High score means a high level of symptoms.

‡High score means a good effect of analgesics, % refers to the frequencies of patients reporting "quite a bit" or "very much" effect of analgesics.

were "dissatisfied with life". The same pattern was found for the strength and fitness question: 52% of the general population were "strong and healthy", 37% "so-so", and 12% were "tired and worn out".

Clinicians usually focus on tumour control and "major" side effects at the follow-up examinations. In the present study, as expected due to previous studies [1], relapses or secondary primary cancers were not found. Most are detected between regular visits. "Major" side effects after treatment were well documented in the hospital files (Table 4). Only a small proportion of the "minor" side effects reported by the patients in the self-report questionnaires were registered in the same files. These findings support the previous assumption, suggesting that clinicians are not sensitive enough to the patients' problems, especially when they are not encouraged to focus on these problems. The higher prevalence of symptoms registered in the present follow-up examination shows that it is quite easy to improve the clinicians ability to pick up these problems by using standardised examination programmes with assessments of symptoms. Patients with "major" side effects need—and usually get—extensive follow-up and support. The impact of "minor" side effects are often neglected.

The Spitzer QL-index was easy for the clinician to fill in, and he was confident with the accuracy of his ratings. However, the variability on the scale was low (Table 5), and the scale is less sensitive to specific treatment-related side effects compared with the patients' self-report questionnaires used in the present study. The mean score on the QL-index was somewhat lower than scores in two healthy control groups (8.8 and 9.17, respectively) [10], but higher than demonstrated in studies in cancer patients. Loizou and coworkers reported the best post-treatment mean scores of 6.8–7.1 in patients with malignant dysphagia [20]. A strong association between the clinician's ratings on the Karnofsky Performance Status and the QL-index indicates that the patients' physical and functional status are most important for his interpretation of the patients' QOL.

The self-report questionnaires used in the present study are—like most other QOL questionnaires—designed to be used in clinical studies, giving data on a group level. The ability of the questionnaires to give valid information about individuals in clinical practice, or even better, to be used as individual predictors or prognostic factors for events in the future, remains to be shown. However, such questionnaires could be used prior to clinical examinations, in order to improve the clinicians ability to focus on the factors that are important for the patients. Some patients adapt to their situation and cope well despite a number of symptoms. Others deteriorate when the years are passing by, maybe because they give up trying to cope with the situation. When the patients' problems are described, we should try to improve their situation by offering palliation whenever possible, and we must try to prevent the side effects of treatment in new groups of patients. The effect of interventions performed in order to improve the patients' coping abilities and rehabilitation has to be examined in clinical studies.

Many of the patients are still smokers. This is an important risk factor for secondary cancer, which is a constant threat to head and neck patients. A stop smoking programme may give a higher cost-benefit with regard to survival compared with the usual extensive investigations in order to detect relapse or secondary cancer.

The small number of patients in the present study did not allow for subgroup analysis. Nor could we explore risk factors for reduced QOL or psychological distress post-treatment. However, studies like this give useful descriptive information about the level and nature of the patients' problems, which

should be taken into consideration when prospective studies are planned in the future.

CONCLUSION

Clinical follow-up examinations after treatment for head and neck cancer should focus on the patient's QOL, including "minor" side effects due to treatment and possibly also on eventual psychological distress. The patients should be encouraged to stop smoking. Patient self-report questionnaires appear to be more sensitive than clinician-rated questionnaires and could be used as a tool for better communication between clinicians and patients.

- Boysen M, Lövdal O, Tausjö J, Winther F. The value of follow-up in patients treated for squamous cell carcinoma of the head and neck. *Eur J Cancer* 1992, **28**(2/3), 426–430.
- Harwood AR, Rawlinson E. The quality of life of patients following treatment for laryngeal cancer. *Int J Radiat Oncol Biol Phys* 1983, **9**, 335–338.
- Morton RP, Davies ADM, Baker J, Baker GA, Stell PM. Quality of life in treated head and neck cancer patients: a preliminary report. *Clin Otolaryngol* 1984, **9**, 181–185.
- Rathmell AJ, Ash DV, Howes M, Nicholls J. Assessing quality of life in patients treated for advanced head and neck cancer. *Clin Oncol* 1991, **3**, 10–16.
- Jones E, Lund VJ, Howard DJ, Greenberg MP, McCarthy M. Quality of life of patients treated surgically for head and neck cancer. *J Laryngol Otol* 1992, **106**, 238–242.
- Bjordal K, Kaasa S, Mastekaasa A. Quality of life in patients treated for head and neck cancer. A follow-up study 7 to 11 years after radiotherapy. *Int J Radiat Oncol Biol Phys* 1994, **28**(4), 847–856.
- Bjordal K, Kaasa S. Psychological distress in head and neck cancer patients 7 to 11 years after curative treatment. *Br J Cancer* 1995, **71**, 592–597.
- Bjordal K, Mastekaasa A, Kaasa S. Self-reported satisfaction with life and physical health in long-term cancer survivors and a matched control group. *Oral Oncol, Eur J Cancer* (accepted for publication).
- Maguire P, Tait A, Brooke M, et al. Psychiatric morbidity and physical toxicity associated with adjuvant chemotherapy after mastectomy. *Br Med J* 1980, **281**, 1179–1180.
- Spitzer WO, Dobson AJ, Hall J, et al. Measuring the quality of life of cancer patients: a concise QL-index for use by physicians. *J Chron Dis* 1981, **34**, 585–597.
- Slevin ML, Plant H, Lynch D, Drinkwater FJ, Gregory WM. Who should measure quality of life, the doctor or the patient? *Br J Cancer* 1988, **57**, 109–112.
- Cella DF, Tulsky DS. Measuring quality of life today: methodological aspects. *Oncology* 1990, **4**(5), 29–38.
- Aaronson NK, Amedzai S, Bergman B, et al. for the European Organization for Research and Treatment of Cancer, Study Group on Quality of Life. The EORTC QLQ-C30: A Quality of Life Instrument for Use in International Clinical Trials in Oncology. *J Natl Cancer Inst* 1993, **85**, 365–376.
- Bjordal K, Kaasa S. Psychometric validation of the EORTC Core Quality of Life Questionnaire, 30-item version and a diagnosis-specific module for head and neck cancer patients. *Acta Oncol* 1992, **31**, 311–321.
- WHO. *International Classification of Diseases*, 9, version (ICD-9). Geneva, WHO, 1984.
- UICC: Hermanek P, Sobin LH. *TNM Classification of Malignant Tumours*, 4th edition. Berlin, Springer, 1987.
- Karnofsky DA, Abelmann WH, Craver LF, Burchenal JH. The use of the nitrogen mustards in the palliative treatment of carcinoma. *Cancer* 1948, **1**, 634–656.
- Wood-Dauphinee S, Williams JI. The Spitzer Quality-of-Life index: its performance as a measure. In Osoba D, ed. *Effect of Cancer on Quality of Life*. Boca Raton, CRC Press, 1991, 169–184.
- Parker DF, Levinson W, Mullooly JP, Frymark SL. Using the Quality of Life index in a cancer rehabilitation program. *J Psychosoc Oncol* 1989, **7**(3), 47–62.

20. Loizou LA, Rampton D, Atkinson M, Robertson C, Brown SG. A prospective assessment of quality of life after endoscopic intubation and laser therapy for malignant dysphagia. *Cancer* 1992, 70, 386–391.
21. 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(8), 1161–1165.
22. Goldberg D, Williams P. *A User's Guide to the General Health Questionnaire*. Windsor, Berkshire, NFER-NELSON, 1988.
23. Holmen J, Midthjell K, Bjartveit K, et al. *The North-Trøndelag Health Survey 1984–1986. Purpose, Background and Methods. Participation, Non-participation and Frequency Distributions*. National Institute of Public Health, Unit for Health Services Research, Oslo, Norway; National Institute of Public Health, Community Medicine Research Center, Verdal, Norway; Report No. 4; 1990.
24. Norusis MJ. *SPSS/PC+™*. Chicago. SPSS Inc, 1986.

Acknowledgement—This work was supported by the Norwegian Cancer Society Project No. 88283/002.