

# Patient, Caregiver, and Surgeon Perceptions of Quality of Life Following Anterior Skull Base Surgery

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**Objective:** To estimate the agreement between surgeons' and lay caregivers' quality-of-life (QOL) perceptions of patients undergoing major skull base surgery.

**Design:** Cohort survey of patients who had undergone anterior skull base tumor excision.

**Setting:** University-affiliated medical center.

**Participants:** Thirty-five patients and their lay caregivers participated in the study.

**Main Outcome Measures:** A triple survey was performed: each patient and his or her caregiver were asked to answer 35 questions related to 6 distinct QOL domains: role of performance, physical function, vitality, pain, specific symptoms, and effect on emotions. The composite health-related QOL of the patients was also rated on an ordinal scale by 3 surgeons who participated in the operation and follow-up.

**Results:** An overall significant agreement was found between patients' and caregivers' scores at the group level (mean scores of each domain) and individual level (patient-caregiver pairs) ( $r=0.76$ ,  $P<.001$ ). There was a minor correlation in the effect on emotions domain and no correlation in the pain domain. We found no correlation between the surgeons' and patients' ratings. The operating surgeons tended to overrate their patients' QOL.

**Conclusions:** The study results show that the surgeon's perception of his or her patient's QOL is not sufficiently accurate to correctly estimate patients' QOL status. These judgments should come from the patient or from the caregiver, whose perception can be used in clinical trials as a proxy for estimation of a patient's QOL.

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**T**HE IMPORTANCE OF TOPICS addressing quality-of-life (QOL) issues of patients with cancer has gained increasing attention during the past 10 years. Quality of life is assessed in an effort to promote restoration of a patient's daily functions and to accelerate his or her return to normal life following surgery. Understanding the effect of surgical procedures on QOL can assist decision making regarding the appropriate medical treatment of a given patient and can be used to identify specific impediments as early as possible during follow-up.<sup>1</sup>

A multidimensional evaluation of QOL involves retrieving information on the physical, emotional, social, and economic aspects of patients' activities of daily living, as well as on specific symptoms associated with their disease.<sup>2</sup> Generally, these investigations focus on the subjective perception of QOL by the patient alone<sup>3,4</sup>; however, lay caregivers and health professionals can also

play an important role in rehabilitation and day-to-day care of patients before and after surgery. The perception of a patient's condition by the surgeon and caregiver is particularly important following complex surgical treatments with significant morbidity, for which multidisciplinary medical treatment and rehabilitation efforts are required for long periods.

Who should measure QOL of patients? The primary source of information regarding a patient's QOL is the patient.<sup>5,6</sup> Proxy assessment of QOL may, however, be important as an adjunct to a patient's rating for several reasons: (1) it improves compliance and allows more accurate evaluation of the patient's condition, in particular for those whose medical conditions are poor<sup>7,8</sup>; (2) it allows proper evaluation of patients with neuropsychologic dysfunction who may be incapable of providing QOL information themselves<sup>8</sup>; and (3) it serves as complementary data to increase score reliability and prevent potential bias.<sup>9</sup>

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Quality-of-life evaluation in patients with anterior skull base tumors is particularly challenging for several reasons. First, many of these patients have intracranial extension of their tumor (ie, the patients are prone to brain injury during surgery and subsequently to cognitive dysfunction).<sup>10</sup> Second, the medical treatment of these patients necessitates extensive surgical intervention, prolonged hospitalization, and long periods of rehabilitation. Third, many of these patients require multiple surgical treatments.<sup>11</sup> All these factors may eventually lead to problems with the accuracy of patients' self-reporting.<sup>12,13</sup>

Little is known about the perceptions of QOL following major head and neck surgery among patients with cancer, their families, and the operating surgeon. The prevailing opinion of the limited ability of caregivers and oncologists to correctly assess patients' QOL<sup>14</sup> was challenged by recent studies<sup>9,15</sup> that found good agreement between patient and proxy ratings. In this study, we performed a triple survey in an effort to elucidate lay caregivers' and surgeons' perceptions of patients' QOL. The aims of this study were (1) to assess the effect of surgery for extirpation of anterior skull base tumors on patients' QOL, (2) to describe to what extent lay caregivers are able to accurately assess the patients' condition following surgery, and (3) to characterize surgeons' perceptions of the effect of surgery on patients' QOL. The psychological, social, and physical well-being of this group of patients was assessed using a disease-specific multidimensional questionnaire.

## METHODS

### STUDY DESIGN

A cohort survey of patients who had undergone anterior skull base tumor excision was performed. Each patient's QOL was evaluated by the patient, by his or her caregiver, and by 3 surgeons who followed up the patient on a regular basis. The study was approved by the institutional Declaration of Helsinki committee.

### STUDY SAMPLE

The hospital charts of 69 patients (76 consecutive operations) operated on between 1994 and 2002 for extirpation of anterior skull base tumors at our institution were reviewed. Extirpation of anterior skull base tumors was performed via the subcranial approach in all patients, using the same surgical technique.<sup>16,17</sup> Inclusion criteria dictated that at least 3 months had to have passed since surgery. The patients were at least 18 years old, were able to read and write, had no severe psychopathologic or cognitive impairment, and gave their informed consent to participate in the survey. Of the 69 potential study candidates, 13 died of various causes, 5 did not reside in Israel, 5 were unavailable for follow-up, 9 were operated on less than 3 months before the study was activated, 1 did not have a caregiver, and 1 was noncompliant. Therefore, 35 patient-caregiver pairs completed the questionnaire. The demographic and clinical data of the patients are shown in **Table 1** and **Table 2**, respectively. The patients were followed up every 1 to 3 months for a mean of 26 months.

Each patient was asked to recruit an informal lay caregiver for proxy rating of his or her QOL. An individual was

**Table 1. Demographic Features of the Patients**

Demographic Feature	No. (%)
Sex	
Male	20 (57)
Female	15 (43)
Age, y	
≤60	27 (77)
>60	8 (23)
Mean	44
Comorbidity*	
Yes	8 (23)
No	27 (77)
Radiotherapy	
Yes	7 (20)
No	28 (80)
Months after surgery	
3-6	9 (26)
>6-24	10 (29)
>24	16 (46)
Type of surgery†	
A	12 (34)
B	23 (66)

\*Comorbidities include myocardial infarction, chronic lung disease, heart failure, peripheral vascular disease, stroke syndrome, liver dysfunction, chronic renal failure, diabetes mellitus, and other malignancies.

†Type A surgery includes osteotomy and removal of the anterior frontal sinus wall and the nasal frame in one block, and type B surgery includes osteotomy and removal of the anterior and posterior frontal sinus wall and the nasal frame.

**Table 2. Tumor Distribution in the Study Population**

Pathological Finding	No. (%)
Malignant tumors	
Squamous cell carcinoma	3 (9)
Esthesioneuroblastoma	2 (6)
Malignant melanoma	1 (3)
Malignant schwannoma	1 (3)
Sarcoma	1 (3)
Plasmocytoma	1 (3)
Adenocarcinoma	1 (3)
Benign tumors	
Meningioma	9 (26)
Mucocoele	5 (14)
Inverted papilloma	3 (9)
Osteoma	3 (9)
Meningoencephalocele	2 (6)
Epidermoid cyst	1 (3)
Angiofibroma	1 (3)
Fibrous dysplasia	1 (3)
<b>Total</b>	<b>35 (100)</b>

considered a caregiver if he or she had a close relationship to the patient and was an active participant in postoperative care. Patients who did not have a caregiver were not included in the study. Most lay caregivers were the patients' children (n=23), and the remaining ones were spouses or partners (n=12).

### STUDY MEASURES

All patients completed the anterior skull base tumor questionnaire<sup>18,19</sup> after a short interview with an independent health

**Table 3. Distribution of Patient, Caregiver, and Surgeon Scores\***

Domain	Patient	Caregiver	Surgeon	r Value	
				PC	PS
Role of performance	2.6 ± 0.6	2.6 ± 0.7	...	0.76	...
Physical function	2.6 ± 0.1	2.8 ± 0.4	...	0.70	...
Vitality	2.6 ± 0.7	2.7 ± 0.7	...	0.75	...
Pain	2.8 ± 0.3	3.0 ± 0.8	...	0.50	...
Specific symptoms	2.7 ± 0.7	2.8 ± 0.7	...	0.71	...
Effect on emotions	2.6 ± 0.7	2.7 ± 0.7	...	0.55	...
Overall†	2.8 ± 0.6	2.6 ± 0.4	3.1 ± 0.6	0.76	0.23

Abbreviations: PC, correlation coefficient between patients and caregivers; PS, correlation coefficient between patients and surgeons.

\*Data are given as mean ± SD quality-of-life scores unless otherwise indicated. All analyses were performed with paired *t* test, except as noted.

†Analyses performed with 1-way analysis of variance.

worker. The participants were instructed not to discuss the questions or answers with each other before completion of the questionnaire.

All questions were phrased to detect differences in QOL between the preoperative and postoperative periods. The answers were given on an ordinal scale with 5 levels indicative of the QOL change relative to the period before surgery. All questions had an identical level of importance.

Relevant QOL questions were generated from review of the literature, interviews with health professionals, and interviews with patients and their caregivers. The initial multidimensional questionnaire included 80 items and was reduced using standard psychometric criteria.<sup>18</sup> Six relevant domains were identified using factor analysis with varimax rotation: role of performance (6 items), physical function (7 items), vitality (7 items), pain (3 items), specific symptoms (7 items), and effect on emotions (5 items). Internal consistency of each domain was evaluated by means of the Cronbach  $\alpha$  coefficient. The Cronbach  $\alpha$  of each domain was greater than 0.8.

The internal consistency of the instrument had a correlation coefficient of 0.8 and reliability coefficient (test-retest reliability) of 0.9. Construct validity of the instrument was assessed by testing whether the clinical variable of the patient affected his or her QOL domain score as hypothesized. Patients older than 60 years had significantly poorer scores in the role of performance and physical function domains than younger patients ( $P < .05$ ). Patients with malignant tumors had significantly poorer scores in the domains of specific symptoms, effect on emotions, physical function, and role of performance compared with patients with benign tumors ( $P < .05$ ). Radiotherapy was associated with poorer scores in the domains of specific symptoms and effect on emotions ( $P < .05$ ). Comorbidity was associated with poor physical function scores ( $P < .05$ ). To further test the usefulness and validity of the instrument, we prospectively evaluated the QOL of 12 additional patients before they underwent surgery and then 5 to 6 months following the operation. Significantly poorer QOL scores were recorded for patients with malignant neoplasms ( $P < .05$ ). These patients were not included in the patient-caregiver-surgeon evaluation study.

The overall QOL as rated by the patient and caregiver was calculated as the mean score of the 35-item instrument. The composite QOL of each patient was also evaluated by 3 surgeons who followed up the patients on a regular basis from the initial office visit to the last follow-up. The surgeons were asked to rate the composite QOL of the patients on a 5-level ordinal scale. The surgeons were blinded to the results of the patients' questionnaire responses.

## STATISTICAL ANALYSIS

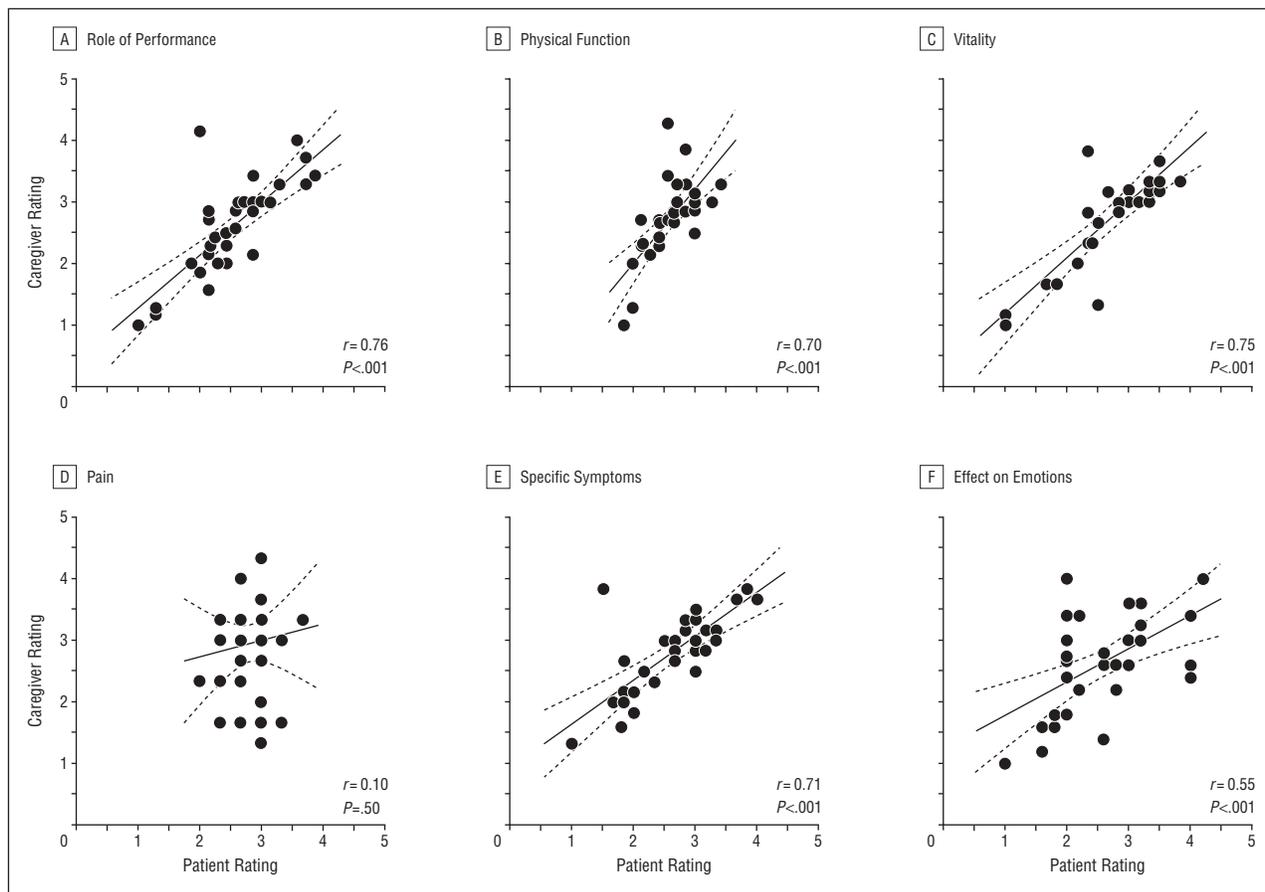
Paired *t* test,  $\chi^2$ , analysis of variance, and Mantel-Haenszel tests were applied as appropriate.  $P < .05$  was considered significant. The Ryan-Einot-Gabriel-Welsch multiple-range test was used to determine significant differences between pairs of groups. Multiple comparisons for the adjusted means were carried, using the studentized maximum modulus method. A correlation between patient and proxy scores was performed using a multiparametric correlation coefficient test (Origin, Version 5; Microcal Software, Inc, Northampton, Mass). We considered a correlation coefficient of  $r > 0.70$  and  $P < .05$  to be statistically significant.

## RESULTS

**Table 3** summarizes the mean QOL scores of each domain as reported by the patients, their lay caregivers, and surgeons. At the group level (mean scores of each domain), there was global agreement between the scores reported by the patients and their caregivers. Only in the specific symptoms domain did the caregivers overrate the patients' scores ( $P < .05$ ).

At the individual level (patient-caregiver pairs), we found an overall significant agreement between patients' and caregivers' perceptions of QOL ( $r = 0.76$ ,  $P < .001$ ). There were significant patient-caregiver correlations in the vitality, physical function, role of performance, and specific symptoms domains (**Figure 1** and **Table 3**). A minor correlation was found in the effect on emotions domain and no correlation in the pain domain.

We analyzed the QOL scores of patients with primary disease and compared them with the scores of patients with tumor recurrence (ie, patients who underwent at least 1 previous operation). Caregivers of patients with primary disease showed a trend to underrate patients' QOL and had weak agreement with the patients' ratings ( $r = 0.51$ ). In contrast, patients with recurrent disease reported similar scores and had strong agreement with their caregivers ( $r = 0.94$ ). No statistical significance was found in age distribution between the different groups ( $P = 0.5$ , Mantel-Haenszel test). The demographic and clinical effects on patient-proxy scores are shown in **Table 4**.



**Figure 1.** Relationship between patients' ratings (x-axis) and caregivers' ratings (y-axis) regarding patients' health-related quality of life (QOL). Each point represents one patient-caregiver pair. Some of the points overlap. The graphs (A-F) show the scores of 6 specific QOL domains. Solid lines indicate the best-fit straight lines to the measured points; dashed lines, 95% confidence intervals.

**Table 4. Demographic and Clinical Effects on Patient-Proxy Scores\***

Variable	Patient	Caregiver	No. of Patients	r Value†
Age, y				
≤60	2.8 ± 0.5	2.7 ± 0.4	27	0.59
>60	2.5 ± 0.7	2.5 ± 0.6	8	0.95
Sex				
Male	2.7 ± 0.5	2.7 ± 0.4	20	0.74
Female	2.8 ± 0.7	2.6 ± 0.5	15	0.71
Tumor				
Malignant	2.5 ± 0.5	2.4 ± 0.4	10	0.75
Benign	2.9 ± 0.6	2.8 ± 0.4	15	0.74
Reoperation				
No	2.8 ± 0.5	2.6 ± 0.4	22	0.51
Yes	2.7 ± 0.6	2.7 ± 0.6	13	0.94

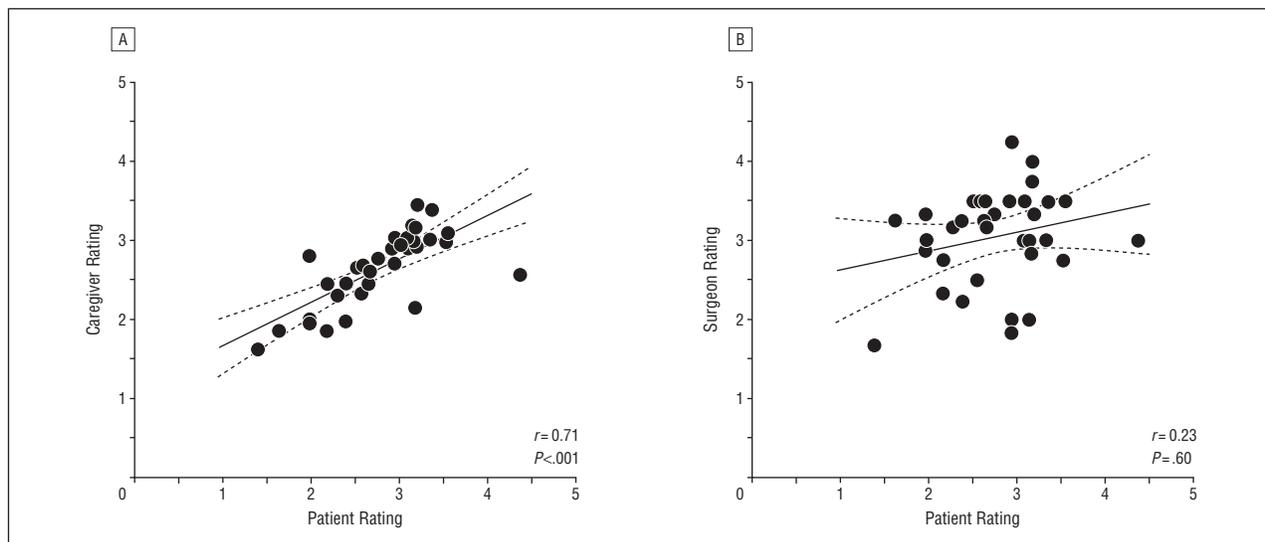
\*Data are given as mean ± SD quality-of-life scores unless otherwise indicated. No statistical significance was found in age distribution between the sex, tumor, and reoperation variables (Mantel-Haenszel test).

†Correlation coefficient between groups.

We then evaluated the correlation between the patients' and surgeons' QOL ratings at the individual and group levels (**Figure 2**). In most cases (24 of 35 cases), the surgeon had overestimated the health-related QOL of his or her patients ( $P < .007$ ). Furthermore, we found no significant correlation between the patients' and the surgeons' scores at the individual level ( $r = 0.23$ ).

## COMMENT

The medical and surgical treatment of head and neck neoplasms in general and of skull base tumors in particular can carry significant morbidity.<sup>20</sup> For example, complications that can affect the activities of daily liv-



**Figure 2.** Correlation between patient-caregiver (A) and patient-surgeon (B) ratings of patients' health-related quality of life. Each point represents one patient-proxy pair. Solid lines indicate the best-fit straight lines to the measured points; dashed lines, 95% confidence intervals.

ing of patients undergoing anterior skull base surgery include recurrent meningitis, long-term cerebrospinal fluid leak, osteoradionecrosis, mucocele, and visual disturbances.<sup>21</sup> The principal goal of this study was to estimate the agreement between patients', surgeons', and lay caregivers' long-term QOL rating following anterior skull base surgery. The patient's perception of his or her QOL was used as a reference. The overall results of the study show a close agreement between the patient's and the lay caregiver's perception of the patient's health-related QOL. Indeed, a significant correlation was found between patient-caregiver ratings in most of the QOL domains (physical function, role of performance, vitality, and specific symptoms domains), as well as in the overall QOL score. Similar results were reported among outpatients with cancer,<sup>22</sup> patients with head and neck cancer,<sup>15</sup> and patients with malignant brain tumors.<sup>23</sup> Our results do not support earlier reports of poor agreement between patients' and lay caregivers' perceptions of QOL.<sup>14,24</sup> Our finding of no correlation in the pain domain is also in agreement with the works of Miaskowski<sup>25</sup> and Redinbaugh<sup>26</sup> and their colleagues on the perception of pain.

We did not find overrating of patients' bodily pain by their caregivers as previously reported by others.<sup>15,27</sup> In our study, 27 patients (77%) reported that the surgical procedure improved or did not interfere with their overall QOL. The discrepancy between our results on the perception of pain and the results of others may stem from the good QOL and minor body pain reported by our patients compared with other patients with cancer.<sup>26</sup> Our finding of a moderate patient-caregiver correlation in the effect on emotions domain is also in agreement with the findings of Sneeuw et al,<sup>9</sup> who reported lower levels of agreement in private domains such as feelings and social function.

The fact that patient-caregiver pairs for patients with recurrent disease had a significantly higher agreement regarding the overall QOL compared with those for pa-

tients with primary disease was also reported by Deschler et al.<sup>15</sup> Such correlation may represent growing knowledge about the patient's disease process, better acquaintance with the medical system, and awareness of the patient's requirements and desires by the patient and caregiver.

Examination of the patient-surgeon agreement at the group and individual levels revealed overrating of patients' QOL by the surgeon. This confirms the findings of others who examined whether a physician or other health professional can make a valid assessment of his or her patients' QOL.<sup>14,27</sup> Similar investigations on the perception of cancer-related fatigue also found close agreement between patient-caregiver scoring, whereas a weaker correlation was found between patient-oncologist rating.<sup>28,29</sup> In essence, the surgeon believes that the patient has a better QOL than what the patient perceives. Our study demonstrates that the surgeon's perception of patients' QOL is not sufficiently accurate to postulate the physical, emotional, social, and economic status of his or her patients and suggests that health care professionals need to work with patients and caregivers simultaneously to facilitate communication and discussion about expectations and medical treatment.

Several limitations of our study need to be noted. First, it involved a single group of patients operated on by one group of surgeons in the same medical institute. Therefore, our results may be applicable for this selected population alone, while the effect of other surgical approaches to the anterior skull base on patient QOL needs to be established. Second, our study involved a retrospective analysis of patients with different types of neoplasms operated on during an 8-year period, factors that may yield considerable variability among the study population. Third, we have not examined the responsiveness to changes over time, which might alter scores during follow-up. Further prospective, multicenter studies are warranted to more accurately assess patient-proxy perception of QOL following skull base tumor resection.

## CONCLUSIONS

Our study provides information on the feasibility of using proxy estimation of a patient's QOL following major head surgery. This study shows that caregivers, at the group and individual levels, can be used in clinical trials as proxies for the estimation of a patient's QOL. Caregivers cannot, however, accurately estimate individual domains, such as bodily pain and effect on emotions. Recurrent disease may lead to growing knowledge about the patient's status and to a better awareness of his or her condition. Our data also show that the surgeon's perception of his or her patients' QOL is not sufficiently accurate to assess their status following surgery. Therefore, QOL data should be based on the patient's questionnaire and not on the surgeon's perception of the patient's condition. In cases of patients at risk for considerable cognitive impairment (ie, intracranial tumor involvement or very old age) for whom poor self-reporting capabilities can be expected, a caregiver's rating can be used as an adjunct to the patient's report.

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