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## ■ Quality of Life in Patients with Hemiglossectomy: Comparison of the EORTC QLQ-H&N35 and a semi-structured interview

## ■ La qualité de vie chez les patients ayant subi une hémiglossectomie : comparaison des résultats entre le questionnaire QLQ-H&N35 de l'OERTC et une entrevue semi-structurée

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### Abstract

Quality of life questionnaires are often used as a measure of outcomes in the head and neck cancer literature. Semi-structured interviews are rarely used and results are not well documented. The current study was designed to compare and contrast quality of life outcomes assessed by a standardized questionnaire and a semi-structured interview. A semi-structured interview and the EORTC QLQ-H&N35 questionnaire were administered to eight patients with hemiglossectomy and reconstruction using an innervated radial forearm free flap. Whereas some of the responses to questions in the semi-structured interviews confirmed EORTC QLQ-H&N35 results, other responses yielded more detail on functional outcomes and quality of life not captured in the standardized instrument. The EORTC QLQ-H&N35 serves as a good screening tool for identifying quality of life issues, but does not adequately assess the breadth or depth of factors related to quality of life outcomes following intervention for head and neck cancer.

### Abrégé

Dans les publications sur le cancer de la tête et du cou, les questionnaires sur la qualité de vie servent souvent à mesurer les résultats. On a rarement recours à des entrevues semi-structurées et on ne documente pas les résultats de manière exhaustive. La présente étude compare les résultats obtenus par un questionnaire normalisé et une entrevue semi-structurée sur la qualité de vie. On a fait passer une entrevue semi-structurée et on a administré le questionnaire QLQ-H&N35 de l'Organisation européenne de recherche sur le traitement du cancer (OERTC) à huit patients ayant subi une hémiglossectomie et une reconstruction avec du tissu de l'avant-bras innervé par le nerf radial. Certaines des réponses données en entrevue semi-structurée ont confirmé les résultats du questionnaire, mais d'autres ont fourni davantage de renseignements sur l'évolution fonctionnelle et la qualité de vie que ne l'a fait l'outil normalisé. Le questionnaire constitue un bon outil de dépistage des enjeux touchant à la qualité de vie, mais il n'évalue pas correctement l'ampleur ou la profondeur des indicateurs liés à la qualité de vie après une intervention de lutte contre le cancer de la tête et du cou.

**Key words:** head and neck cancer, microvascular tongue reconstruction, quality of life

In Canada, 4,600 new cases of head and neck cancer were diagnosed in 2008 (Canadian Cancer Society, 2008). Treatment for head and neck cancer can result in functional complications, which may include difficulty with deglutition, mastication, and speech (Magdycz, 2002). These functional complications can be further exacerbated when the patient enters into a social realm that includes food and the associated social communication as a core focus. The inability to participate in social eating during family dinners and outings with friends and colleagues has the potential to dramatically impact quality of life (Sherman et al., 2000). The changes in quality of life from treatment of head and neck cancer may be apparent especially in patients with cancer of the tongue because of its critical role in producing normal speech and in eating functions. According to the literature, quality of life, as one measure of outcomes for treatment of head and neck cancer, is being applied commonly to assess speech and swallowing function. As such, quality of life measurements are becoming more important when informing medical–surgical interventions that are applied to this population. Although the use of quality of life questionnaires to assess functional outcomes may seem like a readily available and easy solution, these standardized questionnaires provide only cursory information about speech and swallowing function.

An alternative to quality of life questionnaires is the use of semi-structured interviews. A semi-structured interview is a commonly used qualitative research and clinical method for gathering information from a participant or patient. Unlike a structured interview, where the examiner is limited to a set of questions, a semi-structured interview is flexible and provides opportunity for the interviewer to bring up new questions as they relate to what the patient says. In a semi-structured interview, the interviewer will have a general set of pre-established questions or topics they wish to explore with the patient. Follow-up questions are used as probes to gain a more detailed description of salient or related topics. Although this type of assessment has been used to assess pain as it relates to head and neck cancer (Whale et al., 2001), it has been used infrequently to document functional outcomes.

The development of reliable measures of quality of life through disease-specific quality of life questionnaires such as the EORTC-H&N35 has provided researchers with an objective and standardized assessment method. However, because quality of life questionnaires often are used to inform clinical practice regarding functional outcomes, it is important to evaluate their strengths and weaknesses. Can standardized questionnaires capture the essence and multidimensional nature of functional impairments after treatment for head and neck cancer? On the other hand, little is known about the potential added value that semi-structured interviews may provide in the assessment of functional outcomes following surgical intervention in patients with head and neck cancer. Ultimately, it is important to know whether or not the extra time and effort required to conduct a semi-structured interview will

yield significantly more information relevant to treatment outcomes.

## Purpose

This study was designed to compare and contrast information obtained on functional outcomes via a disease-specific quality of life measure to information obtained using a semi-structured interview. Specifically, we were interested in understanding how well the quality of life questionnaire reflected what patients who had reconstructive surgery after hemiglossectomy said in a semi-structured interview about general life changes following treatment, specific changes in social/emotional status, and specific changes in function (e.g., eating, speech, sensation).

## Methods

### Patients

The patients in this study have been described previously (Loewen et al., in press). A total of 68 patients with oral cancer were assessed between May 2000 and December 2004 at the Institute for Reconstructive Sciences in Medicine (iRSM) at the Misericordia Community Hospital in Edmonton, Alberta, Canada. Of these patients, 14 were identified as having resection and reconstruction limited to the oral tongue (i.e., the anterior two-thirds of the tongue) without the involvement of surrounding structures such as the mandible, maxilla, cheek, and base of tongue. Some patients had involvement of the floor of mouth in addition to the tongue. These patients were sent an information letter approved by the Health Research Ethics Board at the University of Alberta requesting their participation in this study. Eight of these patients agreed to participate in this study. Of the six patients that did not participate, five were unable to be contacted and one declined participation. All patients in this study were diagnosed with squamous cell carcinoma and had approximately 50% of the anterior two-thirds of their tongue resected and reconstructed as determined by the operative report, postoperative photos, and clinician assessment at the time of testing. All patients had reconstruction with an innervated radial forearm free flap. Of the eight patients who participated, four received adjuvant radiation therapy (see Table 1).

## Procedures

### EORTC QLQ-H&N35

The EORTC QLQ-H&N35 survey (EORTC Protocol 15941, 1999; Bjordal et al., 1999) was selected for use in the current study to assess quality of life because of its common use with head and neck cancer patients. EORTC QLQ-H&N35 scores are frequently reported in the literature, making it possible to compare and interpret data across studies and patient groups. Moreover, the EORTC QLQ-H&N35 has established global norms, contains questions related to quality of life specific to this patient population, and has established face validity. The EORTC QLQ-H&N35

was administered to all eight patients. The questionnaires were then scored using standardized procedures. The EORTC QLQ-H&N35 questionnaire results in 18 quality of life summary scores. These 18 areas include: pain, swallowing, difficulties with senses, speech problems, trouble with social eating, trouble with social contact, less sexuality, trouble with teeth, difficulties opening mouth, dry mouth, sticky saliva, coughing, illness, pain killers, nutritional supplements, feeding tube, weight loss, and weight gain.

### Semi-Structured Interview

After completion of the quality of life questionnaire, semi-structured interviews were conducted using an interview guide. Questions were designed to elicit information from patients about: (a) general life changes following treatment, (b) specific changes in social/emotional status, and (c) specific changes in function (e.g., eating, speech, sensation) due to surgically induced physical or structural alterations. Follow-up questions were used for seeking clarification or as probes to obtain more detailed information. Follow-up questions varied from patient to patient. The semi-structured interviews were audio recorded and transcribed verbatim. Three investigators independently analyzed each interview. One researcher was a trained clinical psychologist and the others were both trained speech-language pathologists. The interpretation structure involved a modified thematic apperception approach as originally outlined in Bellak (1975). Each patient response to the open-ended questions was identified in terms of the main theme or gist of the response, the main needs and drives of the patient, and the main coping strategies (defence mechanisms) used by the participant. Each investigator further identified specific themes related to psychological impacts, functional impacts (eating, speech, sensation), and coping mechanisms. Relationships between the functional and psychological impacts following treatment were explored. These themes and coping mechanisms were noted in the margins on the

transcripts, and corresponding phrases that were thought to be reflective of these themes and coping mechanisms were underlined. For the purpose of the current study, a three-way concurrence was necessary for a theme or coping mechanism to be identified and counted as a quality of life construct for an individual patient. Once these themes and coping mechanisms were determined, the primary investigator went through the transcripts and tallied the number of patients that were found to have common psychological themes, functional themes, and coping mechanisms.

### Comparison of Semi-Structured Interviews and EORTC QLQ-H&N35

The results from the semi-structured interviews were compared with the results from the EORTC QLQ-H&N35. As a first step, common psychosocial themes, functional themes, and coping mechanisms that were identified from the semi-structured interviews were matched to subcategories from the EORTC QLQ-H&N35. For example, descriptions of problems with speech were a common theme in the semi-structured interview; this theme was matched with the "speech problems" subcategory on the EORTC QLQ-H&N35. The primary author then categorized all thematic comments made by each patient during the semi-structured interviews into the corresponding EORTC QLQ-H&N35 subcategory. Each patient's representative comments were listed next to their score on the corresponding EORTC QLQ-H&N35 subcategory. For example, a comment from patient #1's interview that reflected the common theme of "speech" was: "People don't understand me as well." All comments made regarding speech in patient #1's interview were listed next to his score of 44 on the "speech problems" subcategory of the EORTC QLQ-H&N35. These representative comments from the semi-structured interviews were independently judged by two of the study's authors and classified as either "in coherence" or "in conflict" with the standardized subcategory score. To determine coherence or conflict, the

authors first calibrated themselves to the composition of a *good* versus *bad* score on the EORTC QLQ-H&N35. There were no published guidelines to assist in this process, so the authors created fictional scenarios of possible responses on the questionnaire to act as a guide. For example, if a patient were to report having "quite a bit" of a problem on each question that comprised the speech subscale on the EORTC QLQ-H&N35, they would obtain a score of 67; whereas, an individual who only reported a "little bit" of difficulty would have a score of 33 (scores range from 0 to 100, where a higher score indicates a poorer quality of life). Coherence

**Table 1**  
Subject demographics

#	Age	Gender	T-Stage	Reconstructed side	Months postoperative <sup>a</sup>	Radiation therapy
1	59	M	T2	R	54	N
2	69	M	T2	L	26	N
3	44	M	T2	R	63	N
4	62	F	T3	R	20	Y - 5810 cGy (IMRT)
5	58	F	T2	R	38	Y - 5740 cGy (IMRT)
6	45	M	T2	R	29	N
7	61	M	T3	R	30	Y - 6000 cGy
8	45	F	T2	L	32	Y - 6120 cGy

Note: <sup>a</sup>Months postoperative represents the time between the date of surgery and the assessment date for this study.

M = male; F = female; R = right; L = left; Y = yes; N = no.



or conflict was determined by comparing the nature of the representative comments made by patients in the semi-structured interviews (i.e., this is or is not a problem) and the severity of the comment (i.e., this is a large or small issue) to the EORTC QLQ-H&N35 score for the matching subcategory. If the authors thought that the EORTC QLQ-H&N35 score reflected the comments made by the patients, then a verdict of coherence was applied; if the score on the EORTC QLQ-H&N35 appeared to be in opposition to the comments made in the semi-structured interview, then the two were considered to be in conflict. After scoring each comparison independently, the two authors compared their ratings of coherence and conflict. If the two authors disagreed on whether the representative comments from the interview were in coherence or conflict with the EORTC QLQ-H&N35 results, the specific judgement was discussed, transcripts consulted, and further discussion continued until agreement was reached. Before discussion to reach consensus, the two authors who assessed conflict or coherence were in agreement 100% of the time for speech, 88% of the time for swallowing, 63% for trouble with social eating, and 75% of the time for trouble with social contact. Overall, the two authors were in agreement 81% of the time.

## Results

### Semi-Structured Interviews

#### Psychosocial Themes

Three main psychosocial themes were identified across patients. All eight patients identified the need for social acceptance; seven of the eight patients identified generalized feelings of frustration, and six of the eight patients identified some form of anger or resentment related to their treatment. Other less common themes included: depression (3 of 8), physical limitations other than with speech or eating (3 of 8), self-consciousness (3 of 8), and fear of cancer recurrence (2 of 8).

Comments representative of the need for social acceptance include: “Yeah I...I do find it annoying because, uh, you...you feel very self-conscious and uh, other people they have a tendency to watch you. They pick you out of a crowd because you eat different than normal...And uh, you feel everybody is staring at you” and “And then another thing that’s maybe changed is, uh, the speaking, and how people look at me, you know...a lot of people that, you know, they probably don’t realize it or they can’t help it, but as soon as I start to talk then it’s almost like, oh, and — you’re not what we thought you were.”

Comments representative of frustration with outcomes include: “you know you’re not going to have a hamburger and be able to eat it with your mouth...to have to cut it with a fork and knife...so it’s frustrating that way,” and “It’s just hard to eat salad, and I can eat a whole salad but then if I go and eat, like for a meal, but if I go the next day to eat a another salad for a meal I’m just just is it’s too much work to eat another salad that day.”

Comments representative of anger or resentment with their treatment include: “In fact it makes it so you hate the thought of eating,” and “Why did it happen to me...you know...why couldn’t it have been somebody else or, you know...”

#### Functional Themes

Two main functional themes were identified across patients. Seven of the eight patients identified eating and five of the eight identified speech as being major issues. Other less common functional themes identified were xerostomia (3 of 8), change in taste (2 of 8), poor saliva control (2 of 8), reduced neck/shoulder range of motion (2 of 8), and change in appearance (2 of 8).

Comments indicating issues with speech include: “People don’t understand me as well” and “And also when you’re speaking – because normal people do not want to sit and wait for me to try to say things.”

Comments indicating concerns about eating include: “...and probably eating bread too...finding that it would get stuck on the top of my mouth was tough,” and “Like ground up meat is just, it’s too dry even if I put it with um...it makes me choke.”

#### Coping Mechanisms

A number of coping mechanisms were identified from the semi-structured interviews. Of the eight patients, seven displayed evidence of denial, five included self-isolation, and four minimized their disability. Avoidance also was a common coping mechanism, as evidenced by steering clear of: (a) situations requiring oral communication, (b) eating certain foods, and (c) social settings that required eating and engaging in face-to-face conversation.

An example of denial as a method of coping was seen in one patient when he was asked how he felt about having to be more careful when he eats or drinks. His response was, “Well just that...it doesn’t bother me at all.” This was said even though this patient also discussed how dry foods would elicit a cough and that he no longer eats in public.

Comments indicating self-isolation as a coping mechanism include: “I’ve ignored basically my family and...and uh, socializing you know. It’s not there anymore,” and “you know, you can’t really go anywhere. Like I don’t even like to go to a person’s house for a meal.” An example of a patient minimizing his or her disability was: “So I’ve gotta be a little bit more careful, but that’s nothing really.”

### Semi-Structured Interviews and EORTC QLQ-H&N35

The subcategories on the EORTC QLQ-H&N35 that were found to correspond with the common themes in the interviews were speech, swallowing, trouble with social eating, and trouble with social contact. The EORTC QLQ-H&N35 results for these subcategories for each patient are displayed in Figure 1. Conflict between the results on the EORTC QLQ-H&N35 subscales and the semi-structured interview is indicated in Figure 1 by an asterisk above each subscale in which a conflict was noted for each patient.

Conflict between data derived from the semi-structured interviews and the four EORTC QLQ-H&N35 subcategories was observed in five of eight patients for the speech category, in five of eight patients in the swallowing category, in four of eight patients in the social eating category, and in four of eight patients in the social contact category. Within patients, conflict was present in at least one subcategory score for seven of eight patients. Three of the eight patients had conflict in all four subcategories between their EORTC QLQ-H&N35 score and what was reported in the semi-structured interview. One patient had conflict in three of the subcategories, three patients had conflict in one subcategory, and one patient had no conflict.

Of the conflicts found, the EORTC QLQ-H&N35 score suggested a lesser impairment than the responses in the semi-structured interview in 17 of 18 instances. There was only one instance where the conflict was because the EORTC QLQ-H&N35 score suggested a greater impairment than the statements made by the patient in the semi-structured interview.

When the results were compared with the patient demographics (Table 1), it was noted that three of the four patients who had conflict in three or more subcategories were female. In addition, all four of the patients who had conflict in three or more subcategories had radiation therapy as part of their treatment. The one patient with no conflict had very good functional outcomes and did not report any issues in the four subcategories.

## Discussion

A study by Mehanna and Morton (2006) reported that 60% of head and neck cancer patients found quality of life questionnaires useful for communicating issues to their doctors and focusing on their problems. The EORTC

QLQ-H&N35 is a standardized quality of life questionnaire that is often used as a measure of functional outcomes in the head and neck cancer population. This study aimed to compare and contrast quality of life outcomes on the EORTC QLQ-H&N35 with semi-structured interview responses in patients with hemiglossectomy and reconstruction with an innervated radial forearm free flap. The current study revealed both coherence and conflicts between the data derived from semi-structured interviews and the scores derived from the EORTC QLQ-H&N35. A conflict between the two measures appeared at least once in approximately 50% of patients in the current study. Interestingly, it was found that conflict or coherence between the semi-structured interviews and the EORTC QLQ-H&N35 appeared to be related more to individual patients rather than to specific subcategories on the EORTC QLQ-H&N35. When there was coherence, one could assume that the EORTC QLQ-H&N35 captured true patient perceptions. When there was conflict between the quality of life measure and the semi-structured interview, it may have been that the standardized questionnaire had not allowed the patients to completely express their feelings. Statements derived during the semi-structured interviews allowed the interviewer to probe deeper for the patient's self-assessment of their situation. Similar findings were reported in the study by Whale et al. (2001). These investigators used the EORTC QLQ-C30 and the EORTC QLQ-H&N35 questionnaires along with a semi-structured interview to assess pain and pain management in head and neck patients following treatment. The authors reported that whereas the questionnaires provided some description of severity and impact, the semi-structured interviews provided more detailed information on the individual aspects and the variety of experiences in terms of pain location and characteristics.

In the current study, two other circumstances may help explain the conflict found between the two forms of measurement. The first may relate to the finding that all four of the patients who had three or more conflicts between their EORTC QLQ-H&N35 score and their semi-structured interview were the same four patients that had undergone radiation therapy in addition to the surgery. The patients who underwent a course of postoperative radiation therapy reported poorer quality of life scores in the EORTC QLQ-H&N35 and identified more issues in the semi-structured interviews when compared to the patients who did not have radiation therapy. The negative influence of radiation therapy on quality of life also was described in a study by Epstein et al. (1999). Oral complications are common after radiation therapy and have a negative effect on quality of life. Specifically,

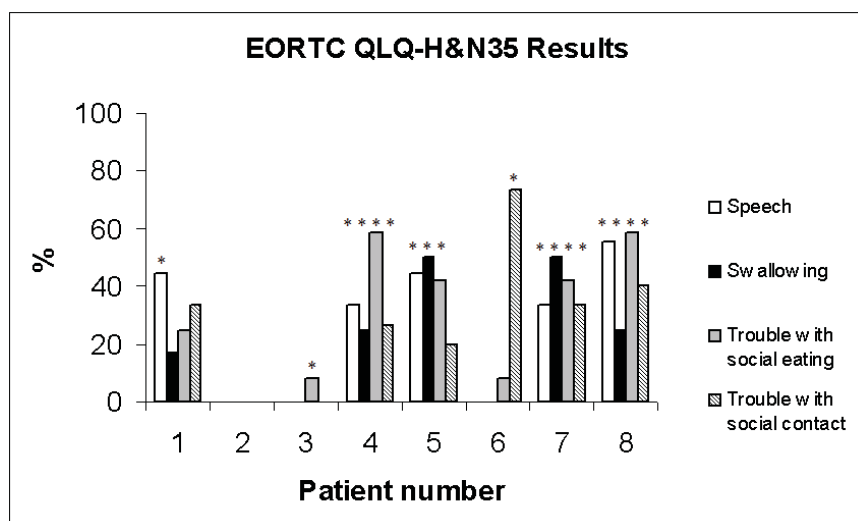


Figure 1. Results for the subcategories of speech, swallowing, trouble with social eating, and trouble with social contact for each of the eight subjects. A higher score on the EORTC QLQ-H&N35 represents a poorer outcome in that area of the quality of life questionnaire. Note: \* indicates a conflict between the EORTC subcategory result and the semi-structured interview.

patients report difficulty chewing or eating, dry mouth, change in taste, dysphagia, altered speech, difficulty with dentures, increased tooth decay, and pain. Fang et al. (2005) found that problems with swallowing, dry mouth, and sticky saliva become more serious one year after radiation therapy. In the present study, the conflict found between the responses in the EORTC QLQ-H&N35 and the semi-structured interview in patients with radiation therapy suggest that quality of life measures may not be sensitive enough to capture all of the nuances of functional problems in patients with poorer outcomes.

The second circumstance that may explain conflicts found between the two forms of measurement may relate to gender differences. Three of the four patients with three or more areas of conflict were women. The women and men in the study may have responded to the interviewer in different ways. All patients in this study were interviewed by female interviewers, which also may have influenced patient responses.

Also from this study, it was evident that when there was conflict, the EORTC QLQ-H&N35 tended to underestimate the magnitude of the issues. This may stem from the inherent psychometric properties associated with Likert scales. Patients responding on Likert scales tend to avoid the extreme ends. Since the EORTC QLQ-H&N35 uses a 4-point Likert scale, patients may have been disinclined to choose 4 (*very much*). When the data were examined subsequently, of all the questions evaluated in the four sub-categories for all eight patients, only 3 of 128 answers were rated with 4, and 54 of 128 answers were rated with 1 (*not at all*). It is possible that 1 was chosen more often because this indicated no problem at all. In contrast, patients who were experiencing issues may have been hesitant to choose the extreme high end of the scale, and the Likert scales used in the EORTC QLQ-H&N35 may have contributed to an underestimation of the severity of the psychological or functional issues. Since the semi-structured interviews revealed that avoidance and minimization of post-surgical disabilities were common coping mechanisms, this may have contributed to the response patterns observed.

A study by Aarstad, Aarstad, and Olofsson (2008) found that an avoidance-focused coping style is inversely related to health-related quality of life. However, the inverse relationship between coping and quality of life is not always evident. Calman (1984) proposed the theory that quality of life is a representation of the gap between reality and an individual's hopes, dreams, and ambitions. The author suggests that if this gap is reduced, it will lead to an improved quality of life, either by improving the patient's reality (i.e., improved function) or by modifying the individual's expectations and ambitions. For some patients included in this study, the coping skills identified in the semi-structured interview may lead to improved quality of life. For example, an individual with reduced function whose coping style is characterized by avoidance will only be able to improve subjective quality of life by adjusting his or her expectations and ambitions. One patient avoided

using certain difficult words as a way of coping with an articulation disorder. To ensure that his listeners could understand him, he avoided words that had previously lead to a communication breakdown. By lowering his expectations regarding the intelligibility of his own speech, he reduced the gap between his expectations and reality. On the other hand, a different patient in the study had isolated himself from all social contact. Nevertheless, he maintained the expectation towards himself that he should be able to participate fully in social events, thereby widening the gap between his reality and expectations.

The current study highlights some areas that may be overlooked when using a quality of life questionnaire. Even though the EORTC QLQ-H&N35 has been developed as a disease-specific tool, the questionnaire is still designed for use with a wide range of lesion sites in head and neck cancer patients and, consequently, there are a wide range of outcomes. For example, the current study examined a homogeneous group of hemiglossectomy patients, but the subcategory of "speech" on the EORTC QLQ-H&N35 includes a question "Have you been hoarse?" This question relating to voice quality may be applicable to other head and neck cancer lesions such as those of the larynx. However, lesions restricted to the oral tongue rarely result in obvious voice changes. Therefore, relying solely on the speech subcategory score of the EORTC QLQ-H&N35 for lesions restricted to the oral cavity may be misleading relative to the impact a speech disorder has on the patient's quality of life.

### Limitations

This study's primary limitation was its small sample size, which is a common problem in studies of patients with head and neck cancer. The patient population was chosen from a convenience sample of patients who were treated at the iRSM and was based on strict criteria which limited the population to patients with partial resection of the oral tongue only and reconstruction with radial forearm free flap. The strict criteria allowed for elimination of other confounding factors and therefore provide a description of quality of life specific to the resection of the oral tongue. The use of a homogeneous group of patients likely outweighs the small sample size. Further research in this topic would benefit from multi-site collaboration to increase patient numbers.

### Conclusion

The current study found that although the EORTC-QLQH&N35 is useful as a tool to objectively assess quality of life, a semi-structured interview provides more breadth and depth of patient concerns regarding function. Therefore, questionnaires such as the EORTC QLQ-H&N35 are best used as a screening tool rather than a comprehensive functional outcomes measure. By adding a semi-structured interview and taking the time to evaluate the responses, a clinician will develop a more in-depth appreciation for the issues facing individuals after treatment. This will lead

to more informed therapies and also more extensive data on outcomes, which ultimately can inform medical and surgical procedures. Because of the disparity between what the majority of patients reported regarding speech and swallowing function on the quality of life questionnaire and what they revealed in a semi-structured interview, the EORTC-QLQ-H&N35 should not be used as the sole assessment of functional outcomes for these parameters. The possibility of underestimation of outcome severity should be considered when using the EORTC-QLQ-H&N35. Other factors to be considered include the patient gender, radiation therapy, and the rapport between the clinician and patient.

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