Assessing and Improving Quality of Life in Patients with Head and Neck Cancer

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OVERVIEW

Health-related quality of life (QoL) indicates the patients' perception of their health. It depends not only on disease- and treatment-related factors but also on complex inter-relationships of expectations, values and norms, psychologic distress, and comparison with other patients. This article introduces methods and challenges of QoL assessment in patients with head and neck cancer, as well as ways to overcome measurement problems and ways to improve their QoL.

In daily life, we often do not realize how important simple things like swallowing, speaking, and eating are for us. Only if a severe disease, such as a head and neck neoplasm, deteriorates these functions do we appreciate the importance of oral health and the related quality of life (QoL).

Mr. Brown and his wife come to my office at the Psychosocial Counseling Centre for Cancer Patients and Relatives. He moves slowly, his body is very thin, and he nearly loses his trousers. One can see that this patient does not have much time left. The couple takes a seat and, before they start talking, his wife gives him a plastic bag, which he uses put his thick, sticky saliva in. He is not able to swallow it because it is too viscous and his energy too low. It takes a while to empty his mouth. Then he starts crying and says how humiliated he feels because of this scene.

What is QoL? The World Health Organization (WHO) has defined it as "an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns."[1] This concept includes several dimensions of life (i.e., physical health, psychologic well-being, and social relationships). The level of independence from others and features of the environment can be considered additional dimensions.

In the context of oncology, the term "health-related QoL" usually does not indicate that an overall satisfaction with life is of interest, but rather a more specific domain of QoL. For ease of reading, we will only use "QoL" in this chapter when speaking about "health-related QoL."

ASSESSMENT

Because of the multidimensional nature of health-related QoL, most measurement tools are multidimensionally constructed.

Another important conceptual issue is the point of view from which the assessment is made. In most concepts, it is implied that the patient is evaluating his well-being; thus, QoL is considered to be similar to self-perceived health. However, some authors, often implicitly, use the same term for objective measurements, i.e., for an assessment performed by physicians, nurses, or proxies. Often, this is measuring toxicity or function (e.g., performance status). For reasons of comparability, it is recommended to use the term "quality of life" only when self-assessment is meant in accordance with the WHO definition.

A physician who wants to include QoL in his treatment considerations has to decide the aims of the assessment. From a holistic perspective, QoL focuses on the subjective suffering of the patient and on his or her individual needs and wishes, depending on the context in which the patient lives. On the other hand, in the analytic approach, a (virtual) norm is set and the degree of deviance from this norm is assessed. The latter approach is commonly applied in clinical trials, while the former is often used by a physician in practice.

Assessment Tools

The two main methods of psychometric assessment in general are interviews and questionnaires. As a frequent application of QoL instruments is in clinical trials, self-administered questionnaires are used most often because of their brevity and ease of analysis.

TABLE 1. Frequently Used Quality-of-Life Instruments

Title	Developed by	Number of items	Short form	Remarks
Generic				
World Health Organisation Quality of Life Assessment Instrument (WHOQOL)	WHO QoL Group[22] (collaboratively in several culturally diverse areas)	100	WHOQOL-BREF (26 items)	
36-Item Short-Form (SF-36)	Medical Outcomes Study[23]	36	SF-12, SF-8	Computer-administered version available
EuroQol Questionnaire (EQ-5D)	EuroQol Group[24] (collaboratively in several culturally diverse areas)	5 plus visual analogue scale	Not available	Licensing fees are determined by the EuroQol Executive Office on the basis of the information provided
Specific for Cancer				
European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-C30)	EORTC Group[25] (collaboratively in several culturally diverse areas)	30	EORTC QLQ-C15	Free of charge for academic users
Functional Assessment of Cancer Therapy (FACT-G)	FACIT Group[26]	27	Not available	Different version for the general population available
Specific for Head and Neck Cancer				
European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-H&N35)	EORTC Group[27] (collaboratively in several culturally diverse areas)	35	Not available	Free of charge for academic users
Functional Assessment of Cancer Therapy, Head and Neck Module (FACT-HN)	FACIT Group[28]	39	Not available	Free of charge for academic users
University of Washington Quality-of-Life Instruments (UW-QOL-R)	Hassan & Weymuller[29]	10	Not available	
MD Anderson Symptom Inventory–Head and Neck Module (MDASI-HN)	Rosenthal[30]	28	Not available	

The questionnaires can be classified into generic and specific instruments, whereby the former measures general aspects of QoL along the main dimension outlined by WHO (e.g., physical fitness, pain, anxiety) and the latter are developed for specific conditions or problems, such as head and neck cancer, high-dose chemotherapy, or fatigue.

The development of QoL questionnaires is mostly conducted in several phases. First, the relevant issues of a specific health problem are collected and rated regarding their importance. Second, items are formulated from the issues and a provisional questionnaire is tested in a group of patients. Eventually, after rephrasing and shortening, the final questionnaire is validated, preferably in different clinical and cultural settings. The involvement of patients from the first phase on is considered crucial in this process to ensure that the questionnaire validly measures QoL domains that are of

high importance to patients. Some frequently used questionnaires are displayed and described in Table 1.

One of the earliest scales developed to measure QoL is the Karnofsky Performance Status, known as the "Karnofsky Index."[2] This instrument, published in 1949, assesses the patient's physical functioning abilities to care for him- or herself. Although this is one of the most frequently used scales, its reliability and sensitivity to change are poor[3]; therefore, it should be administered only in conjunction with more comprehensive and reliable tools.

Challenges in Assessing QoL

It may be common sense that the perceived quality of our life is an important predictor of satisfaction and thus relevant in health care planning. However, quality of life is still not routinely measured in clinical practice. In clinical trials, assessing QoL is becoming more and more common, but the analysis of these data is often unsatisfactory. Why?

First, it might be that the investigators do not have enough knowledge on how to analyze the questionnaires used. They may be discouraged by the multidimensionality of the instruments, which results in multiple outcomes, something that is usually considered negative in clinical trials. As a consequence, investigators sometimes calculate total scores from different scales that are psychometrically and clinically unrelated, resulting in meaningless outcomes.

KEY POINTS

- Quality of life is a multidimensional construct.
- Measurement of quality of life should always be based on the patient's perspective.
- Understanding psychologic processes of adjustment and coping can help to solve problems in the assessment and improvement of quality of life.

Second, the doctor may be puzzled by the psychologic nature of self-assessments in general. QoL is a conglomerate of expectations, perceptions, and comparisons with other people. Whether we are satisfied in a certain situation or not depends, on the one hand, our expectations and, on the other hand, on the assessment of our reality—the level to which those expectations are fulfilled. If we do not expect to live without suffering, we can bear more health problems than others. In other words, if a patient tells us he or she has no problems with the side effects of a certain treatment, this can mean that there are really no side effects or that the patient does not consider them to be a problem worth mentioning to the doctor. Another facet of the psychologic adjustment process is the comparison with other people. If, for example, a patient who has undergone radiation in the head and neck region that resulted in parotid gland dysfunction meets other patients who have received the same treatment and who are worse off than him or her, that patient might praise fate for having fewer side effects, and will probably indicate a better health status compared to a patient who meets only fellow patients who have fewer problems. This phenomenon is called top-down or bottom-up comparison.

Third, it has been shown that patients tend to report only problems they consider relevant to their disease.[4] For example, a patient with cancer who is asked whether he or she has experienced pain during the past week might consider only the tumor pain to be relevant, but not the migraine he or she suffered the day before. This "selective reporting" can lead to an underestimation of the health problems of patients. Therefore, it makes more sense to compare subgroups of patients rather than patients with general population samples.

The sometimes surprising results of QoL measurement can be understood when all of these psychologic processes are taken together; for example, the so-called "satisfaction paradox," whereby patients with severe diseases indicate better QoL than healthy subjects. These challenges sometimes lead to confusion and frustration on the part of the investigator; however, that does not mean that QoL measurements are invalid. After consulting QoL experts, many of the above-mentioned challenges can be detected, understood, and addressed.

Another methodologic challenge is the compliance of patients in completing QoL questionnaires. It is often assumed that patients are unwilling to do so. However, only a few authors have reported on completion rates in their studies. We performed a systematic review of all publications based on one of the most frequently used QoL instrument in patients with head and neck cancer, the EORTC QLQ-H&N35, and we found that out of 125 papers, only 23 reported on percentages of missing values. The completeness of the questionnaire varied from 66%[5] to 99%.[6] Scales with missing values included Sexuality, Speech, Teeth, and Weight Gain, with average percentages of missing values of 11.5%, 7.0%, 2.7%, and 2.0% respectively. Regarding the Teeth and Sexuality scales,[5-8] some authors reported that it may remain unclear whether a nonanswer was because the patient was unwilling

to answer or because the item did not apply to his or her status.

Another interesting point to consider in the analysis of QoL results is the difference between statistical significance and clinical relevance. Simply speaking, statistical significance is a function of the number of patients included. If a study is large, small differences between groups will become statistically significant; if the study is small, even large differences will not become significant. Therefore, instead of only looking at the p value of a finding, it is also important to interpret the size of the effect (be it a difference or an association). Only an effect size that is clinically meaningful should be used for clinical decision making.[9]

IMPROVEMENT OF QoL IN PATIENTS WITH HEAD AND NECK CANCER

A clinician who wants to improve his or her patients' QoL must consider the following:

1. What are the most important QoL domains for the patient?

2. What domains usually deteriorate because of the treatment or the disease, and for how long?

3. What factors influence the patient's QoL?

TABLE 2. Quality-of-Life Domains of High Priority to Patients

Worry that cancer will come back
Worry that new cancer might develop
Problems swallowing solid food
Problems with sense of taste
Trouble eating
Problems with talking
Problems with articulation/speaking clearly
Voice quality
Problems with chewing
Problems with wound healing
Edema/swelling in head and neck
Problems with sense of smell
Problems swallowing liquids
Sticky saliva
Dry mouth
Soreness in mouth
Trouble enjoying meals
Pain in mouth
Painful throat
Problems swallowing pureed food
Problems because of loss of teeth
Dizziness
Tingling and numbness of feet or hands
Problems with teeth
Rash
Trouble talking to other people

What QoL Domains Are Important for the Patients?

There are three ways to answer this question. First, it is possible to compare mean scores of different QoL domains. The scales with the highest scores (or lowest, depending on the direction of scoring) can be considered the most important. This method is not without problems, because scales are often not constructed to be directly comparable with each other.

The second option is to ask patients, "How important is [QoL domain] for you?" Within the European Organisation for Research and Treatment of Cancer QoL Group, we have done this in a group of 137 patients with head and neck cancer who come from eight different countries.[10] They were asked to indicate, from a list of 92 different issues, the 25 they would prefer to include in a questionnaire. The issues most frequently mentioned are displayed in Table 2. It appeared that fear of tumor progression, swallowing, talking/voice quality, swelling in the neck, and sense of taste are the most important QoL domains. Similar results were found by List et al.[10,11]

The third way is to ask the patients to give their opinion of what constitutes a tolerable level of suffering from symptoms that affect their QoL. This method is a bit more sophisticated and more difficult for the patients. An advantage, however, is that it acknowledges the fact that QoL is changed after an oncologic treatment and that this can imply a certain amount of suffering. Thus, the important question is not which QoL domain is most frequently deteriorated but which deterioration is most problematic for the patient. For example, a moderate increase in pain might be more problematic than a large increase in problems with smelling.

We used this method in a group of patients after total laryngectomy.[13] The results showed that patients are most accepting of sensory impairments, coughing, and dyspnea; constipation, nausea and vomiting, and diarrhea were rated as being the most troublesome symptoms.

Typical Course of QoL in Patients with Head and Neck Cancer

The course of QoL during and after treatment depends, in addition to individual factors, on the tumor entity and on the treatment the patient receives (Fig. 1). There is, however, a common pattern that occurs across different groups of patients: QoL decreases during treatment, improves slowly about 6 months after baseline, and improves again after 12 months. Frequently though, it does not achieve pretreatment levels of QoL. In particular, dry mouth and swallowing problems (especially after radiotherapy) as well as speech problems (especially after surgery) are long-lasting issues (S. Singer, PhD, et al, unpublished data, February 2013).[14-18]

When investigating the course of QoL, clinicians should be aware that differential drop-out is a problem in prospective studies.[19] Patients who drop out of the study because of death or health problems differ from those who continue to participate, and this is true for the baseline scores as well. Therefore, if only the QoL of patients who complete all time points is analyzed, the scores are usually over-optimistic (S. Singer, PhD, et al, unpublished data, February 2013).
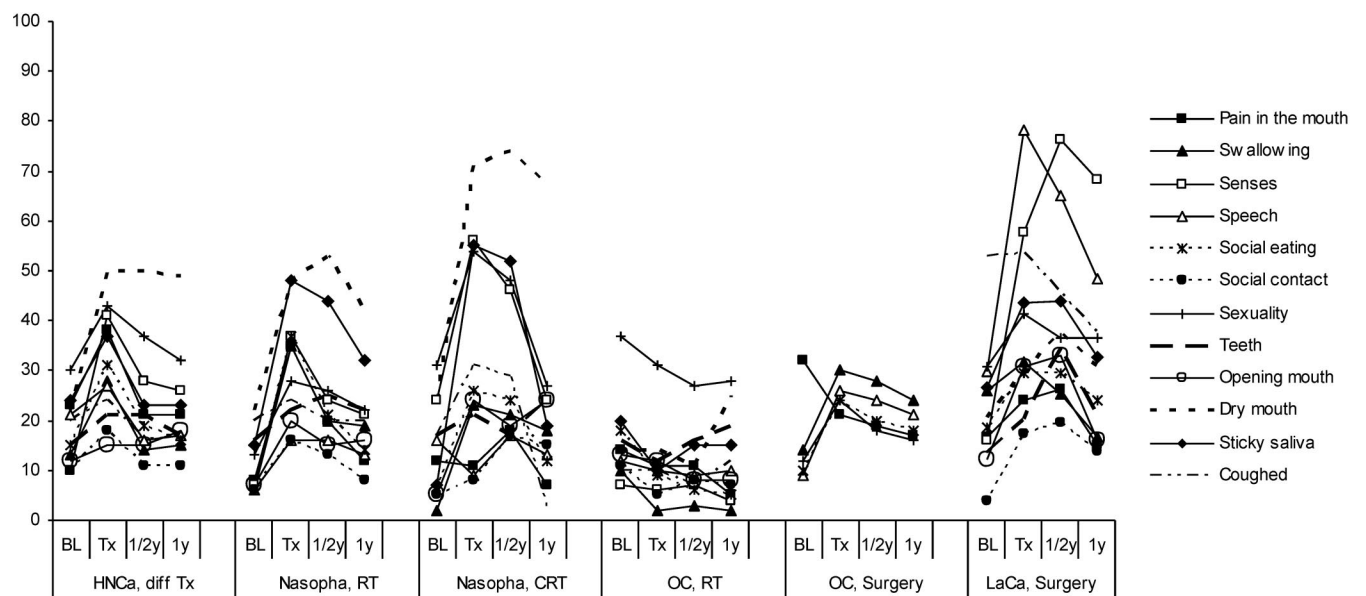
FIG 1.   Quality of life over time in patients with different types of cancer and treatment.

Displayed are the mean scores of the EORTC QLQ-H&N35. Data sources (from left to right): Bjordal et al, 2001 (375 patients, Sweden and Norway)[12]; Fang et al, 2008 (203 patients, Taiwan)[13]; Oates et al, 2007 (14 patients, Australia)[16]; Yoshimura et al, 2009 (56 patients, Japan)[14]; Schliephake et al, 2002 (53 patients, Germany)[15]; Singer et al, 2013 (174 patients, Germany; S. Singer, PhD, unpublished data, February 2013).

Abbreviations: HNCa, heterogeneous group of patients with head and neck cancer; Nasopha, nasopharyngeal cancer; OC, cancer in the oral cavity; LaCa, laryngeal cancer; diff Tx, different treatments; RT, radiotherapy; CRT, chemoradiotherapy; BL, at baseline before treatment; Tx, during treatment; 1/2y, 6 months after baseline; 1y, 1 year after baseline.

Predictors of QoL

Knowledge of factors that can influence the course of QoL after head and neck cancer treatment is crucial for clinicians, especially if these factors can be changed. To date, we know that certain features of the treatment (for example, sparing of the parotid gland during radiation[20]) can improve certain QoL domains (for example, dry mouth and swallowing). There is also good evidence that the course of QoL is highly related to the mental health of the patient (S. Singer, PhD, et al, unpublished data, February 2013).[21] This calls for professional psychologic support in patients with head and neck cancer, which is frequently insufficient.[22,23]

In conclusion, QoL is an important outcome to be considered in clinical trials and in routine treatment. Its assessment can be challenging at times; however, there are reliable and valid tools available and clinicians can use them meaningfully if they know how to apply them and how to interpret their scores.

Disclosures of Potential Conflicts of Interest

The author(s) indicated no potential conflicts of interest.

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