

# Chapter 11

## Instruments for Quality of Life and Mental Health Assessment



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Head and neck cancer patients have an incredibly high rate of depression, reported at approximately 40%, and possess the highest suicide rates in the cancer community [1, 2]. It is thus extremely important to know which tools are available to screen for depression and quality of life (QOL) difficulties in this population in order to identify at-risk and suffering patients. In addition, head and neck cancer patients may struggle with a disfigured appearance, altered speech and swallowing abilities, social isolation, and high stress/anxiety. Accurately assessing QOL metrics can assist us in improving our patients' well-being and improve treatment outcomes. This chapter will summarize the tools available for assessing quality of life and will provide an organized and concise reference for head and neck surgeons interesting in utilizing these instruments.

Head and neck cancer patients are faced with a very challenging course as they make their way through treatment and recovery. While survival is the primary focus of treatment, once the initial treatment period ends, the patient usually begins to focus on other physical, functional, and social aspects of their life [3]. As more of our patients are surviving their head and neck cancers, quality of life measures become an increasingly important tool in addressing our patients' well-being. Identifying each patient's specific priorities can help tailor our counseling, specialty referrals, and treatment options.

The diversity of cancer subsites in the head and neck leaves each patient with a unique set of challenges. Most will undergo some degree of alteration in their physical appearance, but the oral cavity, pharyngeal, and laryngeal cancer patients have additional insults to speech and swallowing. All of these factors contribute to com-

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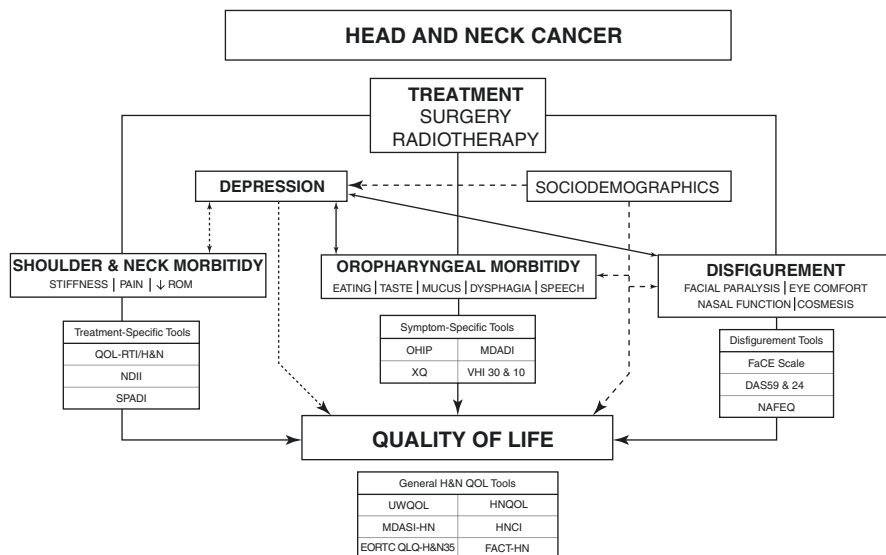
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**Fig. 11.1** Head and neck cancer quality of life assessments. QOL-RTI/H&N, Quality of Life-Radiation Therapy Index/Head and Neck; NDII, Neck Dissection Index II; SPADI, Shoulder Pain and Disability Index; OHIP, Oral Health Impact Profile; XQ, Xerostomia Questionnaire; MDADI, MD Anderson Dysphagia Inventory; VHI 30&10, Voice Handicap Index; FaCE Scale, Facial Clinimetric Evaluation Scale; DAS59 and DAS24, Derriford Appearance Scale; NAFEQ, Nasal Appearance and Function Evaluation Questionnaire; EORTC QLQ-H&N35, European Organization for Research and Treatment of Cancer Quality of Life Head and Neck Modules; UWQOL, University of Washington Quality of Life Questionnaire; FACT-HN, Functional Assessment of Cancer Therapy-Head and Neck; HNQOL, Head and Neck Quality of Life Questionnaire; MDASI-HN, MD Anderson Symptom Inventory-Head and Neck Module; HNCI, Head and Neck Cancer Inventory

plex social and emotional sequelae. Figure 11.1 displays the complexity involved in addressing each aspect of a head and neck cancer patient's quality of life.

Thankfully there are many instruments available to assess our patients' overall quality of life, mental health, and functional impairments. The instruments presented here have been widely studied and have been utilized in clinical trials or other high-level studies as important outcome measures. More importantly, these tools are used in the clinical setting to help the clinician focus on improving the patient's quality of life as they enter the survivorship period.

## Importance of Quality of Life Measures for Head and Neck Cancer Patients

The World Health Organization aptly identifies how complex it is to define quality of life and how individualized this can be to each person. They state that “[quality of life] is a broad ranging concept affected in a complex way by the person's physical

health, psychological state, level of independence, social relationships, and their relationship to salient features in the environment” [4]. With the incredibly high depression and suicide rate in cancer patients, and in head and neck cancer patients specifically, the importance of finding tools to delineate pitfalls in our patients’ quality of life cannot be overstated [1, 2].

Our head and neck cancer patients are notably faced with various degrees of disfigurement and altered appearance. They have significant disturbances in their speech and swallowing, which are essential to social interactions and maintaining relationships. Quality of life measures have thus gained acceptance as integral in assessing a head and neck cancer patient’s overall well-being. There are dozens of scales, all of which have been studied for their validity, reliability or reproducibility, and sensitivity to changes over time. While there are over 75 tools available for cancer patients of any subtype [5], this chapter will focus on those most commonly used for head and neck cancer patients.

Specific to head and neck cancer, quality of life instruments can be aimed to assess a patient’s general well-being versus a more specific symptom-related instrument [6]. Most instruments will assess various domains and combine the results into a single quality of life score; others are validated to provide separate scores for each domain. This may prove to be useful for more targeted therapy. Aside from general quality of life measures, there are also many instruments available to assess each specific symptom a patient may encounter. Some examples are listed in Table 11.1. Most instruments are self-administered by the patient. The most commonly used scoring format is a 5-point Likert-type scale. For example, participants are asked to indicate where they fall from a “strongly agree” to “strongly disagree” range, when asked if they have difficulty swallowing solid foods. The following sections will provide a summary of commonly cited quality of life instruments in the literature, providing the reader a concise and thorough source to reference when selecting which quality of life measure is most appropriate for their patient population.

## Head and Neck-Specific Quality of Life Measures

Each of these measures assesses a variety of dimensions related to head and neck cancer, including, but not limited to, the following: pain, functional performance (speech/swallowing), social well-being, and aesthetics/appearance. In this section we will describe six validated and commonly cited tools that are beneficial to the physician treating a head and neck cancer patient. Table 11.2 summarizes and compares the general format of these six quality of life measures. Each asks the patient to reflect on their feelings and symptoms over a specific time period, which is important to note given that these patients go through a complex healing process and have fluctuating symptoms and concerns during this time.

The two most frequently published questionnaires for assessing overall quality of life in head and neck cancer patients are the European Organization for Research and Treatment of Cancer (EORTC) Quality of Life Head and Neck Module (QLQ-H&N35) and the University of Washington Quality of Life (UWQOL)

**Table 11.1** Summary of the most commonly encountered quality of life instruments

<i>Head and neck-specific measures</i>
EORTC QLQ-H&N35
UWQOL
FACT-HN
HNQOL Questionnaire
MDASI-HN
HNCI
<i>Treatment-specific measures</i>
QOL Radiation Therapy Index
The Neck Dissection Impairment Index
Shoulder Pain and Disability Index
<i>Symptom-specific measures</i>
Oral Health Impact Profile
Xerostomia Questionnaire
MD Anderson Dysphagia Inventory
Voice Handicap Index 30 & 10
<i>Disfigurement-related measures</i>
Facial Clinimetric Evaluation Scale
Derriford Appearance Scale 59 & 24
Nasal Appearance and Function Evaluation Questionnaire
<i>EORTC QLQ-H&amp;N35</i> European Organization for Research and Treatment of Cancer Quality of Life Head and Neck Modules, <i>UWQOL</i> University of Washington Quality of Life Questionnaire, <i>FACT-HN</i> Functional Assessment of Cancer Therapy-Head and Neck, <i>HNQOL</i> Head and Neck Quality of Life Questionnaire, <i>MDASI-HN</i> MD Anderson Symptom Inventory-Head and Neck Module, <i>HNCI</i> Head and Neck Cancer Inventory

**Table 11.2** Head and neck-specific quality of life measures

	Symptoms evaluated	Time frame assessed
EORTC QLQ-H&N35 [7]	7 domains: pain, swallowing, taste/smell, speech, eating in public, social life, sexuality 11 simple items	Past week
UWQOL [8]	12 items: pain, appearance, activity, leisure, swallowing, mastication, speech, shoulder dysfunction, taste, saliva production, mood, anxiety	Past week
HNQOL [9]	4 domains: communication, eating, emotion, pain	Past month
HNCI [10]	4 domains: speech, eating, aesthetics, and social disruption	Past month
FACT-HN [12]	4 domains: physical, social/family, emotional, functional well-being 12 simple items related specifically to the head and neck	Past week
MDASI-HN [13]	3 domains: level of symptom severity in general, impact of symptoms on daily life, and specific head and neck symptom severity	Past 24 hours

questionnaire [6]. Both of these measures provide an overall composite score and assess symptoms specific to head and neck cancer patients. Both ask the patient to reflect on their symptomatology over the last 7 days.

The EORTC QLQ-H&N35 is a 35-item questionnaire with measures specific to pain, swallowing, senses, speech, social eating, social contact, and sexuality. Additional single items are assessed, including pain, dry mouth, and nutritional status. This questionnaire is one of the lengthier available, raising the question of whether patient attention and engagement will effect participation. Validation studies have found the QLQ-H&N35 to be sensitive to radiation exposure and disease site, with radiated patients reporting greater difficulty with pain, swallowing, coughing, dry mouth, and weight loss [7]. Patients with cancer in the oral cavity, oropharynx, hypopharynx, and larynx reported different impairments than those with head and neck cancers in other subsites, with significantly greater difficulty in the swallowing and speech categories. [7]

The UWQOL is a commonly used, concise, 12-question questionnaire that focuses on the patient's sentiments over the last week [8]. Multiple-choice questions are listed regarding the patient's pain, appearance, activity, recreation, swallowing, chewing, speech, shoulder, taste, saliva, mood, and anxiety. The patient is also asked which of those is affecting them the most over the last 7 days (up to 3 may be selected), which can assist the clinician to understand what aspect of a patient's care is most important. The answers are scored with a Likert-type scale, with 0 being no change and 100 being the worst outcome. This tool has been extensively used and has been validated in over 15 languages.

In addition to the EORTC QLQ-H&N35 and the UWQOL, there are other instruments which have been validated to provide separate scores for each domain assessed. Providing these distinct scores per domain can allow the clinician to break down the patient's sentiment on their recovery and quality of life and can help the clinician direct the patient to appropriate resources. These include the Head and Neck Quality of Life (HNQOL) questionnaire, the Head and Neck Cancer Inventory (HNCI), and the Functional Assessment of Cancer Therapy-Head and Neck (FACT-HN). Notably, both the HNQOL and the HNCI assess the patient's symptoms in the last month, while the FACT-HN is focused on the last week of symptoms (Table 11.2). The HNQOL questionnaire measures the patient's score in each of the following domains: communication, pain, eating, and emotion [9]. The HNCI evaluates the following four domains: speech, eating, aesthetics, and social disruption through a 30-item questionnaire [10, 11]. The FACT-HN consists of 27 core items which among them have questions related to 4 domains: physical, social/family, emotional, and functional well-being [12]. There are then an additional 12 items for head and neck-specific symptoms. As with the HNQOL and the HNCI, scores for each domain can be combined or also evaluated separately as subscores.

MD Anderson has also carefully constructed a head and neck-specific questionnaire based on initial focus group meetings with cancer patients and extensive literature review. This head and neck-specific module, called the *MD Anderson Symptom Inventory-Head and Neck Module (MDASI-HN)*, has been tested extensively for internal validity and test-retest reliability and evaluates nine main items: mucus

production, difficulty eating, choking/coughing, difficulty with voice or speech, skin pain/rash, taste disturbances, mouth sores, and dental problems [13]. This questionnaire is unique from the others mentioned in that it asks patients to reflect solely on the last 24 hours. Patients are asked to score their symptoms on a scale of 0 (not present) to 10. This tool has been psychometrically validated in seven languages.

In summary, there are many high-quality QOL measures that have been developed to assess the overall well-being/quality of life in head and neck cancer patients. Deciding which instrument to use depends largely on whether the goal is to assess the patient's symptoms in the past day (MDASI-HN), week (EORTC QLQ-HN35, UWQOL, or FACT-HN), or the last month (HNQOL or HNCI). Furthermore, the clinician must decide whether a short inventory will be easier to deliver and for patients to adhere to or whether more extensive data acquisition is desired. Similarly, clinicians should decide whether one composite score will suffice or if it would be more beneficial to break down the patient's quality of life score for each domain, as is validated and possible with the HNQOL, HNCI, and FACT-HN.

## Treatment-Specific Measures

While comprehensive QOL instruments are useful to gauge a patient's overall experience with head and neck cancer, having specific and concise instruments related to issues with treatment allows the care team the ability to quickly summarize well-being. These measures also provide the clinician or researcher an opportunity to compare different treatment modalities and their effects on QOL. Also, more succinct instruments help prevent data gathering fatigue within all facets. Through this section, we will discuss QOL instruments used specifically for those undergoing radiotherapy and neck dissections in an effort to identify areas that may benefit from focused interventions. These are summarized in Table 11.3.

**Table 11.3** Treatment-specific quality of life measures

	Symptoms evaluated	Time frame assessed
QOL-RTI/H&N [14, 15]	25 general items: functional/health, emotional/psychological, family/socioeconomic 14 HN-specific items: pain, appearance, speech, chewing and swallowing, mucus and saliva, taste, cough	Past week
NDII [19]	10 items: pain, stiffness, range of motion, functional status, ability to lift objects, work, and carry out recreational activities	Past 4 weeks
SPADI [20]	2 domains: pain, disability (ADLs) 13 items	Past 24 hrs

*QOL-RTI/H&N* Quality of Life-Radiation Therapy Index/Head and Neck, *NDII* Neck Dissection Index II, *SPADI* Shoulder Pain and Disability Index

The *QOL-Radiation Therapy Index (QOL-RTI)* has been used widely for evaluation of QOL changes during radiation therapy in general [14]. An adjunct module designed specifically for the *Head and Neck (QOL-RTI/H&N)* was developed after recognition that radiation to this area causes a unique set of changes, unseen in other areas of radiotherapy [15]. Together, the QOL-RTI/H&N survey is a 39-question assessment, with 14 questions specific to evaluating changes over the previous week in mucous, saliva, eating, taste, speech, cough, and local pain in a Likert-type scale. Studies have shown that the H&N adjunct is more sensitive than general QOL tools to identify critical issues in the head and neck radiotherapy patient [15]. This tool has been validated in multiple languages including Spanish, Chinese, German, and Japanese [16–18]. Combined use of a generalized QOL tool and one that is specific to radiotherapy can help provide a more complete picture about how a patient is tolerating therapy, which could influence future clinical decision-making, provide the patient with targeted treatment to abate their symptoms, and hopefully improve their recovery experience.

The Neck Dissection Impairment Index (NDII) and the Shoulder Pain and Disability Index (SPADI) are two tools we recommend to assess a patient's postoperative morbidity in regard to the neck and shoulder in particular. The NDII evaluates disability after neck dissection in the form of pain, stiffness, range of motion, functional status, and ability to lift objects, work, and carry out recreational activities. It is formatted in a 10-question Likert-type scale and is given in the context of the past 4 weeks [19]. With specific regard to shoulder pathology, the SPADI is a well-cited tool to help to narrow the specific shoulder disability and thus help clinicians and therapists provide a more tailored treatment plan [20]. The SPADI evaluates pain and disability on two separate visual analogue scales, with a total of 13 questions, and focuses on impairments in functional status over no specified time frame. Specifically, these two instruments, the NDII and SPADI, can be used to identify patients who may benefit from focused shoulder therapy and to monitor their progression throughout treatment and rehabilitation.

Assessing the patient's perceived dysfunction following these common treatment modalities is incredibly important to patients. Shoulder dysfunction specifically has been reported to persist following neck dissection and also correlate significantly with overall health-related QOL [21]. Furthermore, shoulder and neck disability after treatment for head and neck cancer has been correlated to have significant impact on almost all domains of QOL including limitations of physical functioning, vitality, pain, general health perception, and general mental health [22]. Consideration of the multiple elements that influence QOL including the large impact of treatment-specific sequelae from radiation or neck dissection is vital to understanding a patient's postoperative health.

## Symptom-Specific Measures

While general head and neck quality of life questionnaires also assess symptoms related to speech and swallowing, having separate symptom-specific QOL measures helps assess one very particular area. These symptom-specific instruments are often used by our speech-language pathology colleagues, most commonly pertaining to dysphagia and voice handicap. The most commonly used symptom-specific instruments are summarized below and in Table 11.4.

Oral health is an important area of well-being related to head and neck cancer patients. A majority of head and neck cancers occur in the oral cavity, and evening treatment of cancers outside of the oral cavity often either directly (through surgery) or indirectly (through the sequelae of radiation or chemotherapy) affects the oral cavity. The *Oral Health Impact Profile (OHIP)* is not specific to head and neck cancer alone, but carefully asks patients, in a series of 14 questions, what difficulties they have faced with their teeth, mouth, or dentures, ranging from speech, oral intake, and general satisfaction with their oral health [23]. Despite it not being originally developed for cancer patients, studies including the OHIP for head and neck cancer patients note a significant decline in quality of life in patients who noted oral impairment [24]. Including dental colleagues and dental assessment in the oncologic approach is thus important both for the patient's physical health and also for their mental well-being.

Xerostomia, or dry mouth, is a symptom closely linked to oral health that is extremely important to independently assess. Countless features pertaining to our cancer patients put them at higher risk for xerostomia, particularly their older age, malnutrition, salivary gland ablation, and exposure to chemotherapy/radiation. Interestingly, it cannot be overlooked, as noted in the theme of this chapter, that head and neck cancer patients may also suffer from pain and depression and may therefore be taking narcotics, antidepressants (from anticholinergic effects), and

**Table 11.4** Symptom-specific quality of life measure

	Symptoms evaluated	Time frame assessed
OHIP [23]	14 items: difficulties w/teeth, mouth, dentures, speech, oral intake, and general satisfaction with oral health	Past month
XQ [26]	8 items: talking, eating, swallowing, speech, and sleep	Past month
MDADI [27]	4 domains: global or subscale: emotional, functional and physical 20 items	Past week
VHI 30&10 [28, 29]	VHI-30: global or subscale: emotional, functional, and physical VHI-10: Global only 30 and 10 items, respectively	Unspecified

*OHIP* Oral Health Impact Profile, *XQ* Xerostomia Questionnaire, *MDADI* MD Anderson Dysphagia Inventory, *VHI 30&10* Voice Handicap Index



other potentially xerogenic drugs, which can further exacerbate the patient's dry mouth [25]. The Xerostomia Questionnaire (XQ) is a quick 8-question self-reported tool that evaluates how dry mouth influences talking, eating, swallowing, speech, and sleep [26]. This is performed on a Likert-type scale with higher values indicating worse xerostomia. Through early identification and treatment of xerostomia, we may lessen this burden and improve our patient's QOL as they recover from their cancer treatment.

Oropharyngeal dysphagia as a sequela from head and neck cancer treatment can be particularly injurious to QOL, nutrition, and overall postoperative well-being. The *MD Anderson Dysphagia Inventory (MDADI)* is a well-validated and reliable tool for clinicians to utilize when evaluating the role of dysphagia on QOL, specifically within head and neck cancer patients. This instrument gauges swallowing dysfunction over the past week through 20 questions, divided into 4 subscales of global, emotional, functional, and physical QOL impairment [27]. In combination with a formal swallowing evaluation, assessment of an individual's perception of their dysphagia and its toll on their QOL can help illuminate areas where treatment may provide benefit. Also, an objective measurement of disease-specific QOL changes may provide a means for demonstrating treatment efficacy and identify room for improvement.

With regard to voice impairment, the patient's own perception of handicap or disability is important to evaluate, because each individual's use of their voice in a social and professional context is unique. Therefore, when considering treatment of a laryngeal pathology or the potential role of speech therapy, an objective measure of perceived impairment can be helpful. There are two well-validated measures to evaluate this: the *Voice Handicap Index 30 (VHI-30)* and an abbreviated version, the *Voice Handicap Index 10 (VHI-10)*, that differ primarily by size, with 30 and 10 questions, respectively [28, 29]. While the VHI-30 is more comprehensive and allows subscale evaluation of voice impairment, the VHI-10 is a quick and global way to examine this metric. Intriguingly, many patients are unaware of the severity of their voice impairment until completing the VHI [28], which emphasizes the importance of identification, especially with regard to our voice's influence in QOL. Therefore, recognition and education about voice handicap may be helpful and motivating to patients throughout their therapy.

## **Disfigurement-Related Measures**

Aside from functional deficits in speech and swallowing, the head and neck cancer patient's physical appearance is frequently altered. This can drastically change the way an individual thinks about themselves, the way they approach social gatherings, and the way they perceive their own QOL. While the majority of clinicians focus on functional problems such as swallowing, speech, and pain, many head and neck

cancer patients endure a significant emotional and psychosocial change while healing from the therapies used to fight their disease. Patients may be hesitant to bring up concerns about their appearance, and therefore, clinician awareness of this impact on QOL is important when evaluating the overall health of head and neck cancer patients [30]. There have been few validated tools for evaluation of disfigurement in the head and neck cancer patient; however there are some instruments available to assess outcomes of facial dysfunction, general appearance, and nasal appearance/function (Table 11.5).

Assessment of facial impairment and disability, particularly related to facial nerve paralysis, has been validated with the *Facial Clinimetric Evaluation (FaCE) Scale*. Through 15 Likert-type questions, the FaCE Scale provides information from the past week about social function, facial comfort, facial movement, oral function, eye comfort, and lacrimal control. This patient-reported tool has been shown to be superior to previous physician-graded scales in regard to assessing facial dysfunction [31]. The *Derriford Appearance Scale 59 (DAS59)* and its shorter version, the *Derriford Appearance Scale 24 (DAS24)*, are tools used to evaluate the role of general appearance on self-esteem, psychosocial activities, and patient awareness/satisfaction [32, 33]. While these may help alert a clinician about potential psychosocial changes or a decline in QOL from appearance changes, neither of these questionnaires are specific to head and neck cancer patients. Additionally, both contain questions that may be unrelated to this population. Lastly, the *Nasal Appearance and Function Evaluation Questionnaire (NAFEQ)* is a useful tool designed for use in the perioperative period following nasal reconstructive surgery. This is a Likert-type survey that dedicates seven questions to airway passage, snoring, olfaction, epistaxis, phonation, and dry mucosa and seven detailed questions related to cosmesis [34]. With 50% of this instrument being directly related to cosmetic concerns, the utility of this tool in the head and neck cancer patient is less applicable.

**Table 11.5** Disfigurement-related quality of life measures

	Symptoms evaluated	Time frame assessed
FaCE Scale [31]	15 items: social function, facial comfort, facial movement, oral function, eye comfort, and lacrimal control	Unspecified
DAS59 and DAS24 [32, 33]	59 items and 24 items, respectively Psychosocial activities, patient awareness/satisfaction, sexual and bodily self-consciousness of appearance	Unspecified
NAFEQ [34]	7 functional items: airway passage, snoring, olfaction, dry mucosa, epistaxis, and phonation 7 cosmetic items: overall assessment, item in each part	Unspecified

*FaCE Scale* Facial Clinimetric Evaluation Scale, *DAS59 and DAS24* Derriford Appearance Scale, *NAFEQ* Nasal Appearance and Function Evaluation Questionnaire

## Conclusions

Caring for head and neck cancer patients requires that we focus not only on curing a patient's cancer but also on treatment-related physical symptoms and psychosocial well-being. As detailed in this chapter, many excellent QOL instruments have been developed and studied. The specific instrument chosen will depend largely on clinician preference and also on what specific metric symptoms and time frame are being captured. By utilizing these quality of life measures, the clinician can assess the complete summary of their patients' care. Identifying if the patient's speech, swallowing, appearance, or general well-being is significantly affected can help the clinician proactively intervene and improve their patients' overall well-being and outcomes.

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