# Chapter 6
# Impact of Communication and Swallowing Dysfunction

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A diagnosis of cancer is a frightening reality fraught with physical, financial, and psychosocial implications for patients and their loved ones. For those diagnosed with advanced head and neck cancer, the likelihood of permanent functional impairment relating to communication and/or swallowing is an additional challenge to confront. At the time of diagnosis and onset of treatment, the primary concern of most patients and care providers is survival. However, treatment advances and the rise of human papilloma virus (HPV)-associated malignancies are leading to prolonged lifespan and increased survival, elevating the importance of functional considerations and quality of life.

Head and neck cancer includes cancers of the oral cavity, nasopharynx, oropharynx, hypopharynx, and larynx. These structures are vital to the ability to communicate and swallow. As we will discuss in this chapter, head and neck tumors and their treatment can have acute and lasting effects on communication and swallowing, potentially impacting quality of life. Quality of life (QOL) is a broad term relating to the complex interplay of a patient's expectations, perceptions of functioning or ability, and satisfaction or happiness. It encompasses the psychosocial and, notably, something referred to as psychological well-being [1]. Psychological well-being is described as being composed of six dimensions: self-acceptance, positive relations with others, autonomy, environmental mastery, purpose in life, and personal growth [2]. Patients who are low-functioning in any of these dimensions prior to diagnosis of their cancer are more likely to experience difficulties in adjusting and adapting to functional changes they may experience during and after treatment, thus experiencing a decline in QOL. However, even patients with a positive sense of well-being

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prior to treatment may experience a reduction in psychological well-being and quality of life as a result of speech and swallowing impairment. Functional impairment that impacts even a single aspect of psychological well-being can have a compounding effect that leads to problems in other aspects of well-being, creating a cycle of psychosocial effect (see Fig. 6.1).

Impaired verbal communication can impact all six aspects of psychological well-being. Verbal communication is at the center of our social/family life and, for most, integral to work as well. It is through verbal communication that most people express their wants, needs, thoughts, and ideas. It is how we connect and relate with others around us. It is our primary mode of expression, thus, deeply connected to identity.

> *"The human voice is the organ of the soul."* – Henry Wadsworth Longfellow

Verbal communication is also necessary for the most mundane of daily activities such as making phone calls, asking for help, answering questions, finding what you need at the store, and ordering in a restaurant. Verbal communication is often the workhorse that gets the "business" of life done.

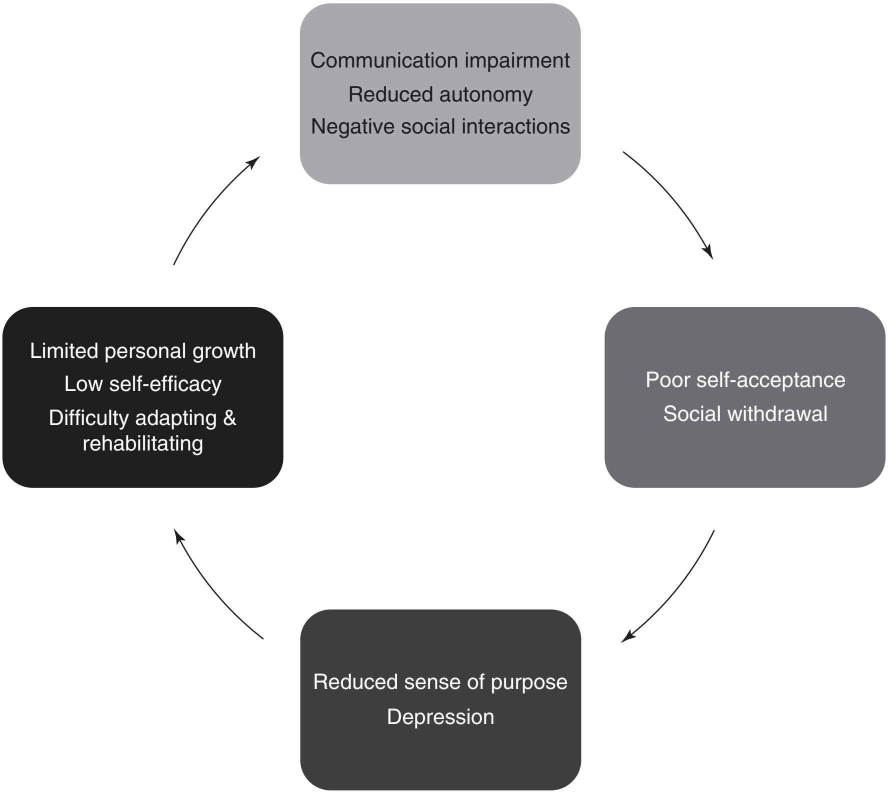

**Fig. 6.1** Cycle of impairment, well-being, and psychosocial effects

Equally fundamental to the quality of our daily lives is the enjoyment we derive from eating and drinking. While, technically, we may eat in order to stay alive, the experience of eating and drinking is a source of pleasure mapped within the reward networks of our pre-frontal cortex [3]. We become hardwired to enjoy and desire certain foods and beverages.

> *"Nothing would be more tiresome than eating and drinking if God had not made them a pleasure as well as a necessity." –Voltaire*

Furthermore, eating is fundamental to social interaction. Holidays, celebrations, and times of mourning often include meals. In fact, it is difficult to imagine a social or family gathering where the sharing of food and beverage is not central to the event. Eating and communicating are fundamental to our autonomy, our sense of self, and to connecting positively with others. Changes in these functions require an ability to cope and adapt on the part of the patient: redefining themselves with respect to where they find pleasure, how they go about getting things

**Table 6.1** Case examples: impact of communication/swallow dysfunction

| Occupational impact | Psychosocial impact |
|---|---|
| 50-year-old male | 70+-year-old female |
| Occupation: Railroad supervisor<br>Needs to be understood on a walkie-talkie<br>s/p RT for vocal fold cancer<br>Has raspy, breathy voice<br>Cannot be heard over walkie-talkie<br>Despite voice therapy and use of amplifier<br>Employer felt safety was at risk<br>Unable to return to work | Long-term survivor of HNC<br>s/p RT for unknown primary<br>She is very active in philanthropic causes Attends frequent cocktail parties<br>Must use sour cream to facilitate eating<br>Embarrassing to ask for<br>Sometimes has to bring her own |
| 40-year-old male | 60-year-old male |
| Occupation: High school math teacher<br>s/p TL for recurrent laryngeal cancer<br>Uses esophageal speech for communication<br>Voice is soft/weak<br>Despite use of an amplifier, unable to be heard in classroom setting<br>Unable to work as a teacher | s/p hemiglossectomy with floor of mouth resection, free flap reconstruction, and post-operative chemo/RT for advanced tongue cancer.<br>Severe dysphagia post-operatively<br>PEG tube dependent<br>His wife feels guilty for eating in front of him and having friends/family over<br>He feels guilty for putting her in that situation |
| 50+-year-old female | 40+ year old male |
| Occupation: SLP, works with stroke patients<br>s/p hemiglossectomy with free flap reconstruction and post-operative chemo/RT for a large tongue cancer<br>Unable to meet occupational speech demand<br>Cannot model precise speech due to dysarthria<br>Unable to return to work | Has two young children at home<br>S/P subtotal glossectomy with free flap reconstruction and post-operative chemo/RT for an advanced tongue cancer<br>Children prefer their mother reading to them at night as they have a difficult time understanding him |

done, and how they connect with others. Table 6.1 provides brief case examples highlighting the impact of communication and swallowing problems on work and psychosocial dynamics.

## Overview of Normal Physiology

### *Communication*

There are many aspects to human communication, with verbal communication (i.e., speech) being our most readily accessed and utilized in everyday life. Speech production is the outcome of two separate neuromotor processes: voice production and articulation. Voice production includes multiple systems: respiratory (lungs), phonatory (larynx), and resonating (upper aerodigestive tract). Voicing begins with the intent to speak, followed by rapid inhalation and then exhalation of air from the lungs. The vocal folds are quickly closed, creating subglottic pressure. When this pressure reaches the minimum necessary threshold, the vocal folds are blown open and begin vibrating. The vocal folds vibrate rapidly (up to 150/second for men, and 230/second for females when speaking normally) and in perfect symmetry. This vibration creates a buzz-like sound which is shaped and amplified (via resonance) as it travels through the cavities of the upper airway (throat, mouth, and sinuses). The voice also creates the supra-segmental features of speech. These include prosody, stress, duration, loudness, intonation, and pitch. Suprasegmentals convey emotions – anger, sadness, and excitement – which are essential to verbal communication. You can change the meaning behind a sentence simply by changing the suprasegmental properties. Any changes in the vocal folds size, shape, or flexibility can affect how they vibrate, altering vocal pitch, intensity, or quality. Changes to the oropharynx or oral cavity can alter resonance, also affecting voice quality or intensity.

We then use our lips, teeth, and tongue to shape those sound waves into words via articulation. Articulation has three primary features used to differentiate phonemes (the individual sounds that make up words): place, manner, and voicing. Place refers to the location where the sound is produced within the vocal tract (e.g., tongue between the teeth, tongue tip to roof of mouth). Manner refers to the way in which the structures contact one another (e.g., stop vs, fricative vs. glide), reflecting the degree of friction and pressure used to create the sound. And finally voicing, which refers to whether the sound is produced with voice or without voice. The differentiating factor between most phonemes is one of these three categories. So, for example, the phoneme /d/ is a voiced, alveolar (tongue tip to alveolar ridge), stop consonant. This is in contrast to the phoneme /t/ which is a voiceless, alveolar, stop consonant. And, it is also in contrast to /z/ which is a voiced, alveolar, sibilant (forcing air through a narrow channel) consonant. Thus, when a person is unable to effectively generate these differentiating phonemic features during articulation, speech becomes difficult to understand as the sounds become less distinguishable (i.e., dysarthria).

## *Swallowing*

Safe and efficient swallowing involves more than 30 nerves and muscles and is dependent on speed, force, and coordination of movements [4]. Swallowing can be characterized as having four stages: oral preparatory, oral propulsive, pharyngeal, and esophageal. The oral preparatory and oral propulsive stages are voluntary. In the oral preparatory stage, food and drink are brought into the mouth and contained within the oral cavity by the lips. The salivary glands are stimulated; saliva is mixed with food as it is chewed, facilitating taste and the creation of a bolus (i.e., a cohesive mass of chewed food or liquid that is ready to be swallowed). The bolus is positioned on the cupped surface of the oral tongue. The oral cavity is sealed anteriorly by the lips and posteriorly by the soft palate and tongue. In the oral propulsive stage, anterior-posterior transfer of the bolus occurs (i.e., lingual stripping wave), with no pocketing or residual of the bolus remaining within the oral cavity. Saliva is an important component of the oral stages as it assists with food breakdown, bolus formation, and oral clearance. Also, adequate jaw range of motion is necessary for biting and rotary mastication.

The pharyngeal stage encompasses two important factors: airway protection (safety) and pharyngeal clearance (efficiency). This stage is involuntary and begins with the bolus head triggering the swallow reflex. The soft palate elevates, closing the nasopharynx, as the tongue base pushes the bolus through the pharynx. The pharyngeal constrictor muscles contract from top to bottom, pushing the bolus downwards. The larynx closes and elevates to prevent aspiration. In rare instances when food or drink enters the laryngeal vestibule, the normal response is a strong cough or throat clear reflex [5].

The esophageal stage is also involuntary. It begins with passage of the bolus through the upper esophageal sphincter (UES). The UES includes the inferior pharyngeal constrictor, the cricopharyngeus, and the cervical esophagus. UES opening is dependent on three factors: neurochemical relaxation of the cricopharyngeus muscle, mechanical forces pulling the UES open (hyolaryngeal excursion), and the driving force of the bolus itself (intrabolus pressure). Once the bolus has entered the esophagus, one to two proximal to distal peristaltic waves move it into the stomach. Clearance should be complete without hold-up, reflux, or regurgitation.

## Risk Factors for Dysfunction and Reduced QOL

Identifying risk factors for physical dysfunction and reduced QOL early may allow care teams to identify and assist those who need increased support during and after their cancer treatment. Communication and swallowing dysfunction is largely dependent on cancer location and stage (size, how advanced the cancer is) as well as the treatment modality employed. At the highest risk for significant dysfunction are those who have advanced tumors of the oral cavity, tongue base, larynx, or hypopharynx. In many cases, communication or swallowing dysfunction is the harbinger of the cancer, triggering work-up and diagnosis. Pre-treatment dysfunction is a reliable predictor of the likelihood for post-treatment dysfunction [4]. Treatment-based risk factors for dysfunction also include multimodality treatment, the intensity of radiation treatment, the specific RT dose to the upper esophageal sphincter, superior pharyngeal constrictors and suprahyoid musculature, and nil per os (NPO) intervals [6–11]. Patient-based factors have also been identified as being associated with increased risk for physical dysfunction; these include active or distant ETOH, living in a rural setting, and advanced age [6–8].

Risk factors for reduced quality of life after HNC treatment include both the presence and severity of physical dysfunction as well as patient-based psychosocial factors. In fact, pre-morbid psychosocial variables may be more influential than physical impairments in predicting reduced QOL [12]. Pre-morbid patient attitudes (e.g., pessimism), coping ability (i.e., poor resilience), mood (e.g., depression), and social support factors influence how a patient conceptualizes and copes with chronic physical impairment after HNC treatment [12, 13]. Those who do not cope well may be less engaged in rehabilitation and less able to adapt. Similarly, the literature reports that as many as 50% of HNC patients present with baseline mild cognitive impairment, and this cognitive impairment is associated with reduced treatment adherence and poorer QOL [14]. Finally, some dimensions of well-being have been found to be age sensitive, making the patient's "stage of life" an important consideration. Autonomy and environmental mastery tend to be more important to younger adults [15–27], while purpose in life and personal growth are more significant for middle-aged and older adults. However, the dimensions of self-acceptance and positive relations with others have been found to be significant components of well-being across all life stages [2].

Over the course of treatment, QOL issues can develop. While clinicians should be sensitive to this, issues surrounding QOL should always be identified by the patient. Patient surveys are useful clinical tools to quickly identify patients with developing functional impairment or QOL issues/concerns. Patient responses on these surveys can be a great springboard for further discussion, intervention, and/or counseling. Table 6.2 lists a variety of validated QOL and functional impairment surveys that may be useful in this population.

## Physical Dysfunction and Their Impact on QOL

### *Dysphonia*

Dysphonia is defined as altered voice quality, pitch, loudness, or vocal effort that impairs communication as assessed by a clinician and/or affects quality of life [37].

Dysphonia typically involves an abnormality in one or more of the following: acoustic-perceptual quality (e.g., roughness, strain, breathiness), vocal intensity (ability to get loud), resonance (hyper/hypo-nasality), and/or vocal endurance. Most

**Table 6.2** Validated functional impairment and quality of life scales

| Scale | # Items | Function | Author |
|---|---|---|---|
| Voice-Related Quality of Life (V-RQOL) | 10 | Voice | Hogikyan and Sethuraman, 1999 [28] |
| Voice handicap Index-10 (VHI-10) | 10 | Voice | Rosen et al. (2004) [29] |
| Quality of Life in the Dysarthric Speaker (QOL-DyS) | 40 | Dysarthria | Piacentini et al. (2011) [30] |
| Swallowing Quality of Life Questionnaire (SWAL-QOL) | 44 | Dysphagia | McHorney et al. (2002) [31] |
| The MD Anderson Dysphagia Inventory- Head and Neck (MDADI-HN) | 20 | Dysphagia | Chen et al. (2001) [32] |
| Eating Assessment Tool (EAT-10) | 10 | Dysphagia | Belafsky et al. (2008) [33] |
| Functional Assessment of Cancer Therapy – Head and Neck (FACT H&N) | 40 | Six subscales: physical, social, family, emotional, functional, and other | List et al. (1996) [34] |
| Vanderbilt Head and Neck Symptom Survey (VHNSS) | 28 | Five subscales: nutrition, pain, voice, swallow, mucous/dry mouth | Murphy et al. (2010) [35] |
| European Organization for Research and Treatment of Cancer Quality of Life – Head and Neck 35 (EORTC QLQ-H&N 35) | 35 | Seven subscales: pain, swallowing, senses, speech, social eating, social contact, sexuality | Bjordal et al. (2016) [36] |

patients who undergo radiation (RT) of the head and neck experience acute dysphonia during treatment. Acute RT-induced dysphonia is typically characterized by a harsh, rough, and strained voice quality resulting from stiff, edematous, and dry vocal folds. Painful voicing (odynophonia) may also be present, limiting verbal communication during treatment. At the peak of treatment, sometimes no sound is able to be produced (aphonia), requiring dependence on others to communicate on the patient's behalf during treatment. These symptoms are usually self-limited, slowly resolving once RT is completed. However, patients with laryngeal cancer are likely to have permanent changes to their voice quality. This often begins prior to treatment, as a result of a glottic malignancy on one or both of the vocal folds. A laryngeal tumor may also invade the recurrent laryngeal nerve, causing impaired motion of a vocal fold (i.e., paralysis or paresis). Vocal fold motion impairment can result in incomplete glottic closure, leading to a breathy, weak (or asthenic) voice quality, poor vocal stamina, and an inability to shout. Treatment of laryngeal cancer may also cause or contribute to voice dysfunction. Vocal fold excision, cordectomy, partial laryngectomy, and/or RT may result in a strained, hoarse, and possibly asthenic voice due to subsequent scarring and/or loss of vocal fold bulk. Finally, in some instances, dysphonia can occur in patients with other cancers of the head and neck. Surgical removal of all or part of the soft palate or maxilla leads to significant changes in vocal resonance and articulatory precision, as the oral cavity now communicates with the nasal cavities. A prosthodontic device (i.e., an obturator; see Fig. 6.2a, b) is typically made to fit the defect and normalize intraoral resonance and pressures. In HNC survivors treated with chemoradiation, lower peripheral cranial nerve palsy can develop years after treatment, leading to global vagus nerve impairment and significant dysphonia.

Dysphonia is widely recognized as leading to negative impacts on QOL. Dysphonic patients experience social, lifestyle, and employment difficulties as a direct consequence of their voice disorder [15, 38, 39]. The psychosocial and QOL impact of dysphonia is determined in large part by the severity of the dysphonia, with those experiencing severe dysphonia most likely to experience impairment and subsequent psychosocial and QOL impacts. However, patients with mild or moderate dysphonia will experience negative impacts if their occupation is contingent on heavy voice use [16]. Similarly, if a patient's wife is hard of hearing, the impact of even a mild reduction in voice volume or clarity could have a detrimental

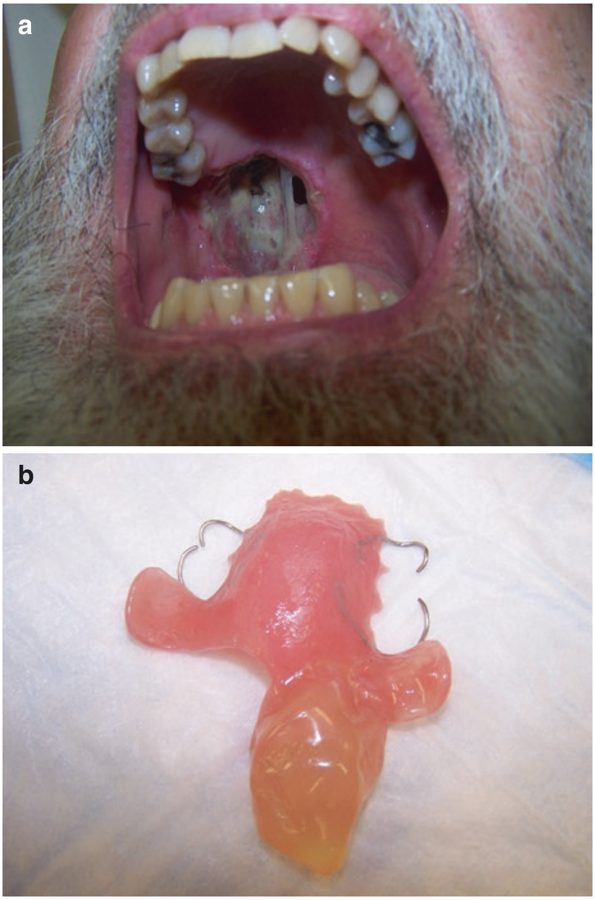

**Fig. 6.2** This defect of the maxilla (**a**) is a result of surgery to remove a maxillary sinus tumor. This defect leads to sound and air pressure leakage out the nose during speech attempts and food and liquid leakage out the nose during eating/drinking. A maxillary obturator (**b**) is made by a prosthodontist. It attaches to the maxilla (via hooking to the teeth in this case) plugging the surgical defect and establishing normal speech and swallowing. The obturator and defect site have to be cleaned/flushed after each meal

impact on his ability to communicate effectively with her, leading to a string of downstream problems in their relationship. Now imagine he is her primary caregiver – the problems compound. Thus, special attention must be given to understanding the voice use/needs and occupational demand in patients at risk for (or with) dysphonia. Both elements (need/use and severity) must be considered in order to understand the psychosocial impact.

## *Total Aphonia*

In very advanced disease, in cases of larynx cancer recurrence (RT failure), or if the larynx becomes completely non-functional (organ failure), the whole larynx is removed (i.e., total laryngectomy). This leads to permanent voice loss (total aphonia) and the need for a permanent tracheostoma (Fig. 6.3). Life can be markedly changed after total laryngectomy (TL). TL requires a form of permanent disfigurement via the creation of a tracheostoma, leading to the potential for feelings of stigma (Fig. 6.4) [17, 18]. Furthermore, patients and their families must adapt to significant changes in pulmonary and respiratory function (e.g., increased coughing and sputum, diminished sense of smell and taste). An alternative sound source must be selected (i.e., alaryngeal voice), resulting in drastic changes to voice quality, as well as a flattening of suprasegmental features (prosody, stress, intonation, and pitch). The overwhelming majority of patients report that loss of voice is the most important QOL factor after TL [19]. In addition, patients report increased feelings of solitude, withdrawal from social conversations and activities, barriers to fulfilling relationships with others, and perceived stigmatization related to their anatomical and functional changes [19].

There are three methods of alaryngeal speech: electrolarynx (EL), esophageal speech, and tracheoesophageal puncture (TEP) with voice prosthesis. All three provide a sound source, which is then shaped by the existing articulators to create

**Fig. 6.3** Pictured is a gentleman following total laryngectomy who now has a tracheostoma. This patient had some difficulties healing immediately after surgery and has some visible scar tissue formation. He also has significant submental lymphedema, altering his appearance. He will require a lot of rehabilitation for his lymphedema and for alaryngeal voice restoration

**Fig. 6.4** This patient is wearing a special filter over her tracheostoma. This filter helps preserve pulmonary function. Learning about and obtaining these devices is a part of the rehabilitation process. Some patients also prefer the appearance of their tracheostoma with this device (rather than an open stoma). These devices are not always covered by insurance and can be costly

speech. The EL is an electronic, battery-operated device with a vibrating head that transmits a buzz-like sound into the throat and/or mouth where it is then shaped into words. The EL is quite easy to learn and a very dependable form of alaryngeal voice. However, the robotic/mechanical sound quality, unwanted attention or perceived stigma, and inability to be hands free (in most situations) may deter people from utilizing this mode of communication.

Esophageal speech (ES) is the most natural of the three forms of alaryngeal voice. The advantages of ES include being hands-free and not requiring a prosthesis or machine; one simply uses their existing anatomy to create speech. ES is generated by using oral and pharyngeal muscles to quickly push air into the cervical esophagus where it is then released in a manner that vibrates the pharyngoesophageal (PE) segment: creating sound. ES speakers report less stress and reduced voice handicap than EL or TEP speakers [20]. However, learning this method of voicing is time-intensive. Also, vocal intensity (volume) may be limited in some patients, which may not be functional or may necessitate the use of a portable amplifier.

Lastly, TEP is a procedure in which a prosthesis, containing a one-way valve, is inserted into the tracheoesophageal wall. This valve allows air from the lungs to enter the esophagus, vibrate the PE segment, and produce sound. The one-way valve also prohibits food/drink from the esophagus to leak into the trachea. As TEP voicing is produced by air coming from the lungs (rather than the oral cavity), TEP speakers can modulate intensity better than ES speakers. TEP voice is also extremely easy to generate. The patient simply takes a breath, occludes the tracheostoma (either with a finger or with a special "hands-free" device that sits atop the stoma), and speaks! The literature supports TEP as providing the best perceptual voice quality, fluency, ease of production, and volume [21–23]. However, as TEP utilizes a prosthetic device seated between the esophagus and the trachea, daily care is required and complications can arise. At best these can be costly and inconvenient for the patient; at worst they can lead to life-threating outcomes (enlarged fistula, aspiration pneumonia, need for a feeding tube). Patient selection is an important factor in optimizing outcomes and limiting risk [24, 25].

Speech-related QOL is lowest immediately after surgery and improves significantly 1 year post-operatively, irrespective of alaryngeal voice method [26]. Also, those who participate in speech therapy tend to report higher QOL when compared to those who do not [27]. Older or retired persons tend to report better QOL following laryngectomy than those in the middle stage of life (where work and financial demands are higher) [40]. Poor or avoidant coping strategies (cognitive and behavioral) are also predictive of poorer QOL in TL patients [41]. Education and counseling is critical in this patient population, as choosing a speech method is a joint decision-making process between the patient and the multidisciplinary team. Furthermore, given the degree of anatomic and physiologic change these patients must adapt to, it is important for clinicians to inquire about and address patients' feelings about these changes. By understanding the patient's psychosocial status and needs, clinicians can facilitate adjustment and help the patient, and their family, develop effective coping strategies.

## *Dysarthria*

Dysarthria is a motor speech disorder associated with disturbances of respiration, laryngeal function, airflow direction, and articulation resulting in difficulties of speech quality and intelligibility [42]. Adequate mobility, sensation, and strength of the articulators are necessary for clear, intelligible speech. Head and neck cancers, surgery, and RT can impact the above and result in dysarthria (Fig. 6.5). Articulation disorders are frequently associated with tumors of the oral cavity, including the lips, floor of mouth, tongue, mandible, buccal mucosa, retromolar trigone, and palate. Dysarthria can be present at diagnosis (pre-treatment) or as the result of surgery and/or RT.

**Fig. 6.5** This woman had a very large tumor of the tongue and anterior floor of mouth requiring subtotal glossectomy with free flap reconstruction. Without a freely mobile anterior tongue, normal articulation is very challenged, particularly for sounds that require the tongue to contact the alveolar ridge or between the teeth

Primary surgery is the typical treatment for oral cavity tumors, with many also undergoing adjuvant RT. Post-operatively, patients may present with reduced intelligibility and clarity secondary to surgical pain/edema, surgical defect, as well as reduced strength, range of motion, and sensation of the articulatory structures. These dysfunctions are highly responsive to rehabilitation, with most patients acquiring intelligible speech. Post-surgical scar contraction, surgical defects, or nerve injury can lead to chronic dysarthria. Dysarthria can also occur as a result of RT and presents differently in the acute vs. chronic stage. During and immediately after RT, the acute effects of RT (mucositis, pain, thick secretions) can result in altered articulation that resolves spontaneously as treatment effects resolve. Chronic RT effects that can influence articulation include fibrotic changes to the articulatory musculature, reduced jaw mobility (trismus), and xerostomia. Patients with xerostomia may find they need to sip water regularly in order to comfortably speak, as their tongue may stick to oral structures during articulation. Very mild changes to sound production can also occur. Severe trismus can affect vowel shaping and reduce the precision of articulatory contacts. Late RT effects include lower cranial nerve palsy (most commonly affecting the hypoglossal nerve and palatal branch of the vagus nerve) resulting in severe dysarthria years after treatment.

Mild-to-moderate dysarthria is most common with patients often having to speak more slowly (with effort) and choose their words more carefully and occasionally having to repeat themselves in order to be understood. These changes can be frustrating and reduce one's motivation to engage others in conversation. Situations where there is elevated background noise (such as parties, social events, restaurants, concerts) compound these difficulties and may lead to reduced willingness to participate in premorbid social activities. When this occurs, psychological well-being is affected, and a reduction in QOL is likely. Similar to dysphonia, special attention must be given to understanding the speech use/needs and occupational demand in patients at risk for (or with) dysarthria. A salesman in his middle years with a mild dysarthria may experience a decline in QOL equivalent to that of a retired, widower with a moderate dysarthria. Both elements (use and severity) must be considered in order to understand the psychosocial impact.

Severe dysarthria represents speech that is unintelligible in most contexts and typically requires use of an oral prosthetic or alternative communication method. This may be writing, utilization of a communication board, or utilization of a computerized system (i.e., type to talk). Patients with poor coping skills may decline all of these options, becoming further isolated. Supporting these patients can be challenging, as, when counseling is attempted, it can be frustrated by the patient's difficulty communicating their thoughts and feelings.

## *Dysphagia*

Dysphagia occurs when someone has difficulty with any one or more of the anatomic or physiologic components of the oral, pharyngeal, or esophageal stages of the swallow [43]. Dysphagia can be present at cancer diagnosis or can be a result of surgery and/or RT. Dysphagia symptoms and severity may progress across survivorship due to progressive fibrosis and/or diminished sensation. HNC treatment can have impacts on all four stages of swallowing: oral preparatory, oral transit, pharyngeal, and esophageal.

Oral stage dysphagia is commonly associated with cancers of the oral cavity including the lips, mandible, tongue, palate, and buccal mucosa (Fig. 6.6). Treatment for HNC can result in loss of dentition, incomplete labial closure, reduced tongue mobility, reduced intraoral sensation, xerostomia, and reduced mouth opening. These dysfunctions can lead to difficulty with bolus containment, formation and transport, and pocketing of foods in the oral cavity. Xerostomia is one of the most common oral stage complaints and occurs as a result of RT. Insufficient saliva can lead to excessive mastication, oral retention of portions of the bolus, and diminished taste and alters the perception of texture.

Pharyngeal stage dysphagia is typically associated with oropharyngeal, laryngeal, and hypopharyngeal tumors. Treatment for HNC can result in poor swallow efficiency (secondary to motor weakness, structural defects, xerostomia or fibrotic stiffness) and reduced swallow safety (secondary to reduced airway protection and/or reduced laryngeal/pharyngeal sensation). At best, these dysfunctions make eating/drinking slow and effortful (e.g., needing to swallow multiple times per bite to clear the pharynx). At worst, they can lead to chronic tracheal aspiration or the need for a feeding tube. The potential for "silent" aspiration (aspiration that does not elicit a cough response) exists in patients who have undergone RT, complicating survivorship, as these patients usually do not recognize that they have dysphagia and so do not report it. For this reason, routine objective instrumental swallow testing (video fluoroscopic swallow study or flexible endoscopic evaluation of swallowing) is necessary for these patients. Chronic aspiration is tolerated in many HNC survivors without complication for many years. This is most true for survivors who are otherwise healthy. However, those who develop complications from chronic aspiration (i.e., chronic aspiration pneumonia) are faced with difficult choices surrounding QOL.

**Fig. 6.6** This gentleman has severe trismus, with maximal mouth opening at less than 10 mm (pictured). As a result, he has difficulty fitting a spoon or fork in his mouth, biting, or chewing. He consumes mostly liquids and some pureed foods. Oral care and oral examination (for recurrence) are also very limited, increasing the risk of dental caries and undetected cancer recurrence

Esophageal dysphagia after HNC treatment is most commonly associated with esophageal stricture. Esophageal stricture can result in food/liquid hold-up above the level of stricture and can result in aspiration, malnutrition, food impaction, and discomfort with eating and drinking. The incidence of esophageal stricture after treatment for HNC has been reported to be between 5% and 24% [44, 45]. That number may be higher with late survivors [46]. Several risk factors have been identified with increased risk of stricture formation: hypopharyngeal and unknown primary tumors, T4 disease, and use of concurrent chemotherapy [47]. The use of a PEG, particularly if the patient is taking nothing by mouth, increases the risk of esophageal stricture, perhaps as a result of disuse of swallow musculature during treatment [48, 49]. Esophageal stricture is generally managed with dilation, although serial dilations are often required and treatment is not always effective.

Dysphagia after advanced HNC typically requires the use of modified food textures (soft and moist), liquid assist for swallowing solids, and slow intake with several swallows needed per bite. Patients may not appear to be having difficulty, but are certainly working harder to consume food. This increased effort, along with changes to taste and appetite, makes eating less enjoyable. When greater dysfunction is present, frequent coughing may occur with meals, a postural strategy may be necessary (e.g., head turn, chin tuck), liquids may need to be thicker, whole food groups may need to be avoided (e.g., dry foods, breads, sandwiches), or anterior leakage may occur (i.e., leakage of food/liquid out the mouth from between the lips) during meals. Those with severe dysphagia often require feeding tubes in order to maintain adequate nutrition. As a result of any or all of these possible changes, the dysfunction is more readily apparent to others and eating/drinking is more likely to be done in private. The experience of eating may lose much of its social and personal capital, becoming simply a means to an end (weight and nutrition). Conversely, some patients are unwilling to sacrifice the pleasure of eating or of sharing food with others socially. They may continue eating without following prescribed measures to prevent aspiration, potentially leading to chronic lung injury or a serious choking event. A choice such as this, to favor QOL over safety/longevity, can lead to strain or even conflict between a patient and his or her family. Family members often want the patient to follow the recommendations made by the healthcare providers in an effort to keep the patient safe and are frustrated by the patient's choice. They may perceive the patient as stubborn or short-sighted when in fact the patient is simply responding to very difficult choices.

Dysphagia is the leading cause of reduced QOL after HNC treatment and is reported in >70% of advanced HNC patients [50]. Dysphagia after HNC treatment has been associated with higher rates of depression in patients [51]. Presence of a feeding tube, penetration/aspiration noted on MBS, and xerostomia were all found to be associated with reduced QOL in dysphagia patients after HNC treatment [52, 53] While the majority of patients report dysphagia, only a minority report satisfaction with the amount of clinical time dedicated to it [54]. This highlights the importance of addressing dysphagia throughout HNC treatment and survivorship. Patients and family members should be counseled regarding the likely impact of dysphagia on their lives. The patient should be encouraged to express how these changes make him or her feel and given an opportunity to clarify what is important to him or her in this context.

## Treatment

This chapter described the effects HNC treatment can have on communication and swallowing function and, subsequently, psychological and psychosocial well-being. Thus, in striving to treat the person, not just the disease, multidisciplinary care is essential. The multidisciplinary care team includes head and neck surgery, plastic surgery, radiation oncology, medical oncology, speech pathology, physical therapy, lymphedema therapy, occupational therapy, social work, psychiatry, psychology, pain management, and nursing. Each member of the team plays a vital role in caring for the patient: treating the disease, the symptoms and effects of the disease and its treatment, and the psychosocial impacts of all of the above.

Speech-language pathologists (SLPs) specialize in the diagnosis and rehabilitation of communication and swallowing disorders and work closely with patients with HNC. SLPs are trained to not only diagnose dysfunction but to identify any resulting impairment that may lead to a reduction in the quality of life. The purpose of rehabilitation is to reduce impairment rather than resolve dysfunction per se. Rehabilitation interventions can be preventative, restorative, compensatory, or palliative in nature. Evaluation and treatment are often lifelong for people with HNC and should begin prior to initiation of cancer treatment. Pre-treatment evaluation can assist in decision making and help predict post-treatment function. Pre-treatment evaluation should include functional assessment of oral motor function, speech, and swallowing. Instrumental swallowing assessment is preferred, particularly for those with cancers of the oropharynx, larynx, or hypopharynx. Screening for cognitive impairment is also very useful. Pre-treatment counseling provides the clinician opportunity to give patients and families realistic expectations for recovery, identify support needs and coping challenges, and reinforce the need for patient engagement in rehabilitation throughout and after their cancer treatment.

Speech/swallowing therapy is usually initiated “prophylactically,” i.e., before initiation of RT and immediately following surgery and/or RT. A treatment plan is developed by the clinician based on input from the patient regarding their goals. Due to the potential for sensory impairment and “silent” aspiration during and after RT, instrumental swallow testing should be utilized in any patient at risk for dysphagia. Treatment of communication and swallowing disorders often include range of motion and strengthening exercises, manual therapies, neuromotor re-education activities (e.g., motor drills), compensatory strategies, and education and counseling related to dysfunction. Long-term survivors of head and neck cancer often face difficult decisions many years after diagnosis, including the need for a feeding tube, tracheostomy, or total laryngectomy for end-stage dysphagia. Education, counseling, and access to all members of the multidisciplinary team throughout survivorship can empower patients to make educated decisions if/when these difficult situations arise.

Support groups can also have a profound impact on patients in all stages of their HNC treatment. Simply connecting and interacting with others who share an understanding of the life-changing effects of their treatment can be empowering. These peer-driven groups offer tremendous information and support for patients and their families. This is portrayed in the patient testimonial excerpts below:

> *"Since meeting with the support group my attitude has changed completely. When I wake up in the morning my first thoughts are: thank you for another day and I am going to make the most of it." – Head and Neck Cancer Support Group member*
>
> *"It made me feel that being alone in this situation was not the loneliest feeling in the world. It made me realize that other people were also going through the feelings I was having, but dealing with them much better than I was. They were living their lives, not just existing." –Laryngectomy Support Group member*

## Conclusion

Head and neck cancer, as well as the treatment for head and neck cancer, can result in communication and swallowing dysfunction throughout survivorship. Determining the impact of these dysfunctions on an individual patient's psychosocial well-being and QOL requires that clinicians understand the degree to which these functions are necessary to the patient's activities of daily living and the patient's baseline ability to cope and adapt with change. Multidisciplinary teams are best positioned to deliver the care necessary to identify and address the impact this disease and its treatment has on a patient's quality of life. Furthermore, the effects of cancer treatment are lifelong – and the medical paradigm should attempt to reflect this.

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