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Perspectives on quality of life following total laryngectomy

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ABSTRACT. *Quality of life (QOL) considerations are uniquely important in head and neck oncology outcomes research due to the multidimensional impact of these tumors and their treatment. The impact of a head and neck cancer diagnosis on the person and the consequences of its treatment cross multiple functional domains that have a clear and direct influence on one's post-treatment well-being and associated QOL. Total laryngectomy can result in significant alterations in the physical, psychological, social, and emotional domains with an ultimate influence on the individual's judgment of his or her own QOL. Loss of voice, altered swallowing and a permanent tracheostoma, together with the uncertainty of cure, have a profound effect on the patient's physical and psychological rehabilitation. The evaluation of QOL and performance outcome in laryngectomees remains critical to optimal patient care, comprehensive evaluation of treatment alternatives, and the development of informed rehabilitative services and patient education.*

Key words: *Quality of life, laryngectomy, head and neck cancer.*

RIASSUNTO. Considerazioni sulla qualità di vita (Qdv) sono individualmente importanti tra gli esiti nella ricerca oncologica per cancro alla testa e collo considerato l'impatto multidimensionale di questi tumori e del loro trattamento. L'impatto di una diagnosi di cancro alla testa e di collo sulla persona e le conseguenze del suo trattamento interessa domini funzionali multipli che hanno un'influenza chiara e diretta su proprio benessere e sulla qualità di vita associata. L'intervento di laringectomia totale può dare luogo a modifiche significative nel fisico, e nei domini psicologici, sociali, ed emotivi con una cruciale influenza sul giudizio dell'individuo rispetto alla propria qualità di vita. La perdita della voce, il deglutimento alterato ed un tracheostoma permanente, congiuntamente all'incertezza connessa alla ripristino della salute, hanno un intenso effetto sulla riabilitazione fisica e psicologica del paziente. La valutazione di qualità di vita e degli esiti sulle attività della persona che ha subito un intervento di laringectomia resta decisivo per prendersi cura in modo ottimale del paziente, per la valutazione ampia e completa di alternative di trattamento, e lo sviluppo di servizi riabilitativi multidisciplinari e di adeguate educazione al paziente.

Parole chiave: Qualità di vita, laringectomia, cancro alla testa e collo.

Perspectives on quality of life following total laryngectomy

Quality of life (QOL) is a multidimensional construct that minimally includes broadly-defined assessments of the physical, psychological, and social domains of functioning. Patients with head and neck cancer are rendered vulnerable to psychosocial problems because social interactions and emotional expression depends to a great extent upon the structural and functional integrity of the head and neck region. The impact of a head and neck cancer diagnosis on the person and the consequences of its treatment cross multiple functional domains that have a clear and direct influence on the patient's post-treatment well-being and associated QOL. The study of outcome using validated voice measures have demonstrated that patients, regardless of age, gender and disease type, can reliably identify the degree of handicap and that treatment of these handicaps demonstrates significant changes, although not necessarily a return to normal (1, 2). A myriad of QOL outcome scales for head and neck cancer exist and have been briefly described in Table I (3-15) Results from the use of QOL scales highlight the fact that although treatment of the cancer is successful, individuals continue to experience difficulties in daily activities and social participation, regardless of the type of treatment (i.e. radiation therapy, conservative or radical surgery, chemotherapy, or a combined treatment protocol). This is particularly true when cancer treatment requires a total laryngectomy (TL) operation. Here the obvious loss of vocal function is not the only consequence of a total laryngectomy. Due to the disconnection between the upper and lower airways, patient breath in and out through the tracheostoma and the nasal functions during breathing (heating, moisturizing and filtering) as well as the sense of smell, are lost. Loss of voice, altered swallowing and a permanent tracheostoma, together with the uncertainty of cure, have a profound effect on the patient's physical and psychological rehabilitation.

Principle complaints of laryngectomized patients are daily sputum production (98%), cough (68%), the need for frequent forced expectoration (57%) and frequent stoma cleaning (37%) (16). Other frequently mentioned problems are fatigue (30%) and sleeping problems (24%). Fortunately, few patients exhibit clinically relevant levels

Table I. A brief description of some of the commonly used QOL instruments in Head and Neck Cancers

Instrument	Self-administered	Items	Domains (items)	Response type	Comments
EORTC-QoL-HN53 ^{23, 24}	yes	35	Pain (4) Swallowing (4) Senses (2) Speech (3) Social eating (4) Social contact (5) Sexuality (2) 11 single items	Likert (4 pts) and binary (yes/no)	Together with core module (EORTC-QLQ-C30), time consuming, RT oriented but comprehensive
FACT-HN ¹⁰	yes	11	Composite (11)	Likert (4 pts)	Together with core module (FACT-G), global score quick
HNQOL ^{7, 8}	yes	20	Pain (4) Emotion (6) Communication (4) Eating (6)	Likert (4 pts)	Global score but incomplete
UW-QOL ^{7, 8}	yes	12	Disease-specific (9) General (3)	Guttman (3-5 pts)	Global score, comprehensive but surgery oriented
QOL-RTI/H and N ⁸	yes	39	Functional (9) Emotional (7) Family and SE (6) General (3) HN module (14)	Likert (4 pts)	Comprehensive but time consuming and RT oriented
HNRQ ⁸	yes	22	Skin Throat Oral stomatitis Digestion Energy Psychosocial	Likert (4 pts)	RT oriented
PSS ⁸	no	3	3 single items	Guttman (3-5 pts)	3 questions; each item is scored individually
VHI ⁸	yes	30	Physical (10) Functional (10) Emotional (10)	Likert (5 pts)	Global score, Long form, comprehensive
VR-QOL ⁸	yes	10	Social-emotional Physical	Likert (5 pts)	Global score, short-form
MDADI ¹	yes	20	Physical (8) Functional (5) Emotional (6)	Likert (5 pts)	Global score, comprehensive

of anxiety (5%) and depression (7%). Relations are found between respiratory symptoms, voice rehabilitation and several aspects of daily life, such as fatigue, sleeping problems, lack of social contacts and psychological distress. Efforts have been made to solve the respiratory problems. The use of a Heat and moisture exchanger (HME) has been shown to improve pulmonary function and, thereby, also psychological functioning of laryngectomized patients (17-19). In these studies, it could be shown that the consistent use of an HME has a significant positive influence on the QOL of the patient and also improves voice quality by diminishing pulmonary complaints.

In a study by Ackerstaff et al. (1994), 95% of patients reported a reduced sense of smell and 44% reported a reduced sense of taste. Other complaints concerned daily

nasal discharge (38%), serious problems swallowing food (25%) and eructation (32%) (20). Recently, efforts have been made to investigate olfactory problems in more detail (21). Olfactory tests showed that approximately one-third of the patients were able to smell. The patients that were able to smell used a greater variety of methods of olfaction. In most patients the method consisted of active use of the facial muscles. The observations from this study led to the development of a so-called Nasal Airflow Inducing Manoeuvre ("Polite Yawning") (22). With this method, patients learn to create an underpressure in the oral and nasal cavity by lowering the jaw, tongue and floor of mouth to pull air into the nose.

Although loss of speech is an obvious disability after laryngectomy, many individuals do not rank speech as the most important contribution to their overall QOL. Despite

altered communication abilities in laryngectomized individuals, the relationship between voice and speech after laryngectomy and QOL outcomes remains unclear. Finizia et al. (1998) studied the voice and QOL of 14 laryngectomized patients versus 14 irradiated patients using the EORTC QLQ C-30 and H and N 35 and the Hospital Anxiety and Depression scale (23). Also, the patients' own perceptual ratings of their voices were compared with the perceptual ratings of a group of listeners. Speech intelligibility, voice quality, and speech acceptability of the irradiated patients were rated higher by both the patients and the listeners. Laryngectomized patients scored significantly better on the question about hoarseness than patients treated with radical radiotherapy. No other significant differences were found for the QOL functions and symptoms. The authors suggested including irradiated patients in the voice rehabilitation program as well. Zotti et al. (2000) used a validated Italian version of the EORTC QLQ-H&N35 and found similar results as obtained with other linguistic versions of the questionnaire (24). Stewart et al. (1998) analyzed the voice and QOL in patients with laryngeal cancer (total laryngectomy (n=17); radiotherapy (n=24); both (n=39) by means of the short-form health status (SF36) and the Voice Handicap Index (VHI) (25). They found that global health status scores and the physical voice handicap scores did not differ among the different patient groups. Laryngectomized patients scored significantly worse on the emotional and functional handicap index. The results also showed considerable overlap in voice handicap scores, with many laryngectomized patients showing less voice handicap than irradiated patients. They concluded that global health status is affected by other factors than voice handicap (26-28).

Individuals learn to adapt and cope with their health condition, what they consider important in their lives changes. For example, in the first year after laryngectomy, individuals often report difficulties with speech, swallowing and eating, and stoma care. As time after laryngectomy increases, survivors may adapt to their new anatomy and mode of communication and may subsequently place more value on social relationships. For example, Hillman et al. (1998) assessed functional outcomes related to communication, swallowing and eating, and employment status for individuals who received one of two treatment modalities: induction chemotherapy and radiotherapy versus total laryngectomy and radiotherapy. They found that at 2 years after treatment, individuals who had undergone laryngectomy reported more difficulty with functional communication and speech scores than those who had received radiotherapy (29). In a follow-up study, Terrell et al. (1998) investigated the long-term QOL in survivors with advanced laryngeal cancer (30). As in the study of Hillman et al. (1998), patients were randomly assigned to one of two treatment groups: radiotherapy plus chemotherapy versus radiotherapy and total laryngectomy (30). They found that individuals who had preserved larynges (radiotherapy plus chemotherapy) had significantly better mental health QOL scores and better pain scores than those in the surgery group.

DeSanto et al. (1995) suggested that individuals who undergo TL are more concerned with the presence of the tracheostoma and interference with social activities than impaired communication (30). In this regard, Gritz et al. (1999) noted that variables often not considered in typical QOL instruments, such as self-perceived disfigurement, self-image, and coping style, may contribute to health functioning of individuals who are treated for HNC (32). Tanya and Doyle (2005) reported in their series that although physical function and role physical were impaired after total laryngectomy, this impairment was not reflected in the physical summary score (28).

Total laryngectomy can result in significant alterations in the physical, psychological, social, and emotional domains with an ultimate influence on the individual's judgment of his or her own QOL. Outcomes after laryngectomy are influenced by several factors, such as an individual's age, gender, economic status, and family support; psychological factors such as coping strategies and adjustment; and time elapsed after laryngectomy. However, when QOL has been assessed with multi-domain questionnaires, the results surprisingly seem to indicate that functional limitations caused by a laryngectomy do not necessarily result in a lower overall QOL (27). The evaluation of QOL and performance outcome in laryngectomees remains critical to optimal patient care, comprehensive evaluation of treatment alternatives, and the development of informed rehabilitative services and patient education.

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