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Original research article

Key problems of the quality of life of patients after total laryngectomy

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ABSTRACT

Introduction: Laryngeal cancer is the most frequent cancer in the head and neck area. Approximately one third of patients are treated by total laryngectomy (TL). The rate of the patient's adaptation to new conditions is crucial to the quality of his or her future life. Some patients survive tens of years after this operation. The preparation for TL is a complicated process that affects a patient's cooperation in postsurgical time. The patient is informed of the essence of the disease, treatment possibilities, the process of preoperative preparation, as well as the operation itself. Great emphasis is put on awareness of the postoperative development, the patient's good cooperation, as well as good prognosis of the disease. Losing one's voice and the cosmetic defects caused by the tracheostoma are a great problem for the patient. The aim of this study was to show the main problems that patients after total laryngectomy deal with in common life.

Material: In the group, there were 102 patients who had been operated on between 2003 and 2013, 62 of which met the classification criteria.

Methods: This prospective study was statistically evaluated. The frequencies of responses were processed in tables.

Results: During the early postoperative period, the greatest problem of patients after total laryngectomy is their adaptation to new principles of breathing, which is subsequently followed by the adaptation to a new and different way of communication. The best option for the patient is to communicate using esophageal voice. Only 55% of operated patients use one of the verbal forms of alternative voice communication in their future lives.

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Introduction

Laryngeal cancer is the most common cancer in the head and neck area [1, 2]. Through surgical treatment – by removing the larynx total laryngectomy (TL) – we save patients' lives, but simultaneously, we deprive them of the possibility of verbal communication forever [3]. However, the prognosis of this disease is good, primarily in the early stages [4, 5]. Some patients survive tens of years after this operation.

Laryngeal cancer occurs significantly more frequently in men, the highest incidence is in the category between 40 and 70 years of age [6, 7]. This type of laryngeal tumor has its own typical etiology. The most common patient is a low-status man who is less health-conscious and has bad habits; smoking cigarettes and alcoholism (low level or high level) rank first. The Czech Republic differs greatly in terms of age, level of education and the financial status of its inhabitants. Preventive activities are realized with low-impact. Barriers are often given by patients themselves, but also by medical staff. Proof of this state may be the percentage of smokers in the Czech population [8]. In the statistics of patients with laryngeal cancer, up to 94% of them are smokers [9]. The connection between laryngeal cancer and herpesviruses, EB virus and human papillomavirus is proven [10, 11]. Other less significant cofactors are malhygiene of the oral cavity, unsuitable alimentary habits, or malnutrition and chronic gastroesophageal reflux disease [12, 13].

The preparation for TL is a complicated process that affects a patient's cooperation in postsurgical time. After the patient is informed of the diagnosis of tumor disease, we can see obvious psychological changes in him or her. The medical staff's task is to help patients get to the phase of active cooperation and reconcile themselves to the tumor disease.

Smokers' and alcoholics' diet can be very poor and monotonous, which is why it's possible for a nutritional therapist to solve deficiencies. The patient's malnutrition can influence the results of postoperative healing in a negative way [14, 15]. During the early postoperative period (postoperative days), the patient receives nutrition via nasogastric tube.

Within psychological preparation, we try to moderate the patient's fear of operation. The patient is informed of the essence of the disease, treatment possibilities, the process of preoperative preparation, as well as the operation itself. Great emphasis is put on the awareness of the postoperative development, the patient's good cooperation, as well as good prognosis of disease.

The patient is repeatedly informed of the tracheostomy tube (TCHS-tube) he will breathe through after TL. He learns how to use the signaling device, which he can find next to his bed. The loss of his or her voice and the cosmetic defects caused by the tracheostoma is a great problem for the patient. By removing the larynx and the subsequent loss of the ability of verbal communication, the patient's social relations are broken and the patient is eliminated from usual everyday life. After TL, the patients mostly isolate themselves from their surroundings and

become withdrawn. That is why psychological support and help leading to an increase in patients' self-confidence (which has been disturbed) are significant for them. It is important for patients not to lose their appetite for life due to the loss of vocal cords. During the recovery period, they are constantly encouraged.

Before TL, we discuss options of alternative voice communication with the patient. Methods of voice rehabilitation in which the voice is created in different ways other than by vocal cords are termed "alternative voice mechanisms". There are three basic ways the original voice can be substituted for after TL: esophageal voice, an electromechanical method (electrolarynx) and tracheoesophageal fistula [16, 17].

The best option for the patient is communication by using esophageal voice. Esophageal voice should be trained as soon as possible after the operation [18, 19]. This way of communication is closest to the original voice. However, only 30% of patients succeed in learning socially usable esophageal voice [20, 21], while 30% never manage to acquire it.

Patients who did not learn the esophageal voice most often communicate by the so-called pseudo-whisper, which is not sufficient for common communication. Most of these prefer using electrolarynx [22, 23]. The patient has to master the device manipulation technique and to understand how to phrase sentences so that his speech will be understandable to those surrounding him. From the patient's point of view (and those who surround him), the limitation of electrolarynx is a mechanical voice timbre, due to which some patients refuse to use it [24, 25].

In postoperative care, we put emphasis on analgesia of a high quality. The minimization of pain moderates postoperative stress and increases the patient's appetite for cooperation. A significant moment in the adaptation process is the tube exchange itself, performed by the patient. During the first postoperative days, stoma care is performed by the nurse. The patient is educated about the tracheostomy tube change in front of a mirror when he or she is sufficiently psychically and physically ready. Nevertheless, it has to be done very early so that the patient can get closer to doing common things without assistance.

Before discharge, it is right to inform some of the family members of the tube exchange, too. In most cases, this is the patient's wife [26, 27]. By informing her thoroughly, we prevent possible complications.

In order to be successfully reintegrated into common life, the patient should be psychically supported, not only by the medical staff, but also by his family and the surroundings. Some patients use the possibility to cooperate with psychologists; others just prefer cooperation with their families. The aim of all these activities is to get closer to the patient and to achieve the active use of the patient's time by means of a creative activity.

These activities are closely connected with social rehabilitation, which is very arduous in most cases. After TL, the majority of people shun their surroundings and reject contacts (aside from their family members). Here, the cooperation of the family is significant again.

Materials and methods

Material

We chose a group of 62 patients (from 102 patients), who had had a TL operation in the University Hospital in Pilsen from 2003 to 2013, and were expected to cooperate. 62 patients met the inclusion criteria, of which there were 58 men (94%) and 4 women (6%). Age at surgery was 59.1 ± 5.6 (see Table 1).

Methods

The prospective study was created with subsequent statistical evaluation. Relative frequencies are stated in parentheses after the observed sample, frequencies were calculated with respect to the total of 62 patients included in the study. The patient's personal data was accessed only by authorized medical staff and was completely anonymized before evaluation.

The Ethics Committee of the Faculty Hospital Pilsen granted approval of the data analyses.

Table 1 – Studied sample of patients

Number of operated patients		102	
		Number	Age at surgery (mean $\pm$ SD)
Included in study		62	59.1 ± 5.6
Men		58 (94%)	59.0 ± 5.7
Women		4 (6%)	61.0 ± 2.4
Time after surgery	1 year	1–5 years	5–10 years
	24 (39%)	23 (37%)	15 (24%)
Smoking	Yes	No	
	56 (90%)	6 (10%)	
Education	University	High school	Elementary
	2	3	39

Inclusion criteria: carcinoma laryngis, state after total laryngectomy, quality cooperation. Exclusion criteria: a patient's non-cooperation.

Results

All of the patients in the sample were satisfied with the medical care (see Table 2). Information of the TCHS-tube change was classified as sufficient in 100%, and of the TCHS-tube care in 87%. The first year after TL, 100% of patients were wearing the TCHS-tube, but more than five years after TL the percentage of tube-wearing patients dropped to 33% (see Chart 1). None of the patients reported a permanent problem with tube-care or tube-exchange.

More frequent infections of the upper airways than before TL were observed in 36% of the respondents.

Table 2 – Characteristics of care (patients' evaluation)

n = 62	Yes	No
Sufficient information of the TCHS-tube change	62 (100%)	0 (0%)
Sufficient information of the TCHS-tube care	55 (88%)	7 (11%)
Wearing the TCHS-tube (details see Chart 1)	50 (81%)	12 (19%)
TCHS-tube is exchanged by the patient themselves	60 (97%)	2 (3%)
TCHS-tube – the care is no problem	62 (100%)	0 (0%)

Chart 1 – Wearing of the TCHS-tube. Personal adaptation to new conditions of respiration, development in time

Temporary swallowing difficulties disappeared in 41 patients (68%) after several weeks, while in the other 21 patients (32%) they disappeared after a few months. Nobody had a permanent problem (see Table 3).

Table 3 – Health complications connected with tracheostomy

n = 62	Yes	No
Frequent upper airway infections	23 (36%)	39 (64%)
Permanent swallowing difficulties	0 (0%)	62 (100%)
Increased fatigue (in the life after TL)	7 (11%)	55 (89%)

The fundamental findings are presented in the social case history (see Table 4). Permanent tracheostomy is no problem for 97%, but 53% of respondents covered their tracheostomy with a scarf or veil. All of the respondents (45% of patients with a preference for nonverbal communication) reported problems in interpersonal communication for the first year after the surgery, but in the next 4 years this problem nearly disappeared (see Chart 2).

No problems with patients' communication were observed at home (in 90% of patients). It was a little worse in ENT clinics (66%), but in the other medical institutions it was nearly the same as in non-medical offices (about 25%). TL only has a clear impact on patients' economic situation in 15%, and partially in 32%. In our group, 19% of patients kept working as they had before. 63% say that laryngectomy did not have an impact on their hobbies.

Discussion

Considering a good prognosis of this disease, the main task is to provide patients with the possibility of their reintegration into life as early as possible after TL, and to make their lives as close to their pre-surgery standard as possible. This is a kind of "a race against time" – the earlier the patient gets involved in life again, the better the achieved result [28, 29].

Tracheostoma care and tracheostomy tube care are especially important. The significance of this topic for the patient's good feeling is proved by the results of our research in accordance with the results of other

Chart 2 – Personal adaptation to new conditions in communication, development in time

Table 4 – Social case history

n = 62	Yes			No
Tracheostomy is a problem (social, visual, etc.) for people who come into contact with the patient	2 (3%)			60 (97%)
Covered tracheostomy	33 (53%)			29 (47%)
Communications problem	62 (100%)			0 (0%)
Prevailing way of communication	oesophageal	electrolarynx	non-verbal	
	15 (24%)	19 (31%)	28 (45%)	
The family's behaviour changed	8 (13%)			54 (87%)
Changes in job or disability pension	50 (81%)			12 (19%)
Impact of disease on interests and hobbies	23 (37%)			39 (63%)
Change of economic situation	29 (47%)			33 (53%)

works [30, 31]. The patient has to be properly informed, because communication is the most difficult in the early postoperative period. Not all patients in our group were satisfied with the acquiring of this information or the completeness of it (see Table 2).

All patients realize the necessary stoma care and everybody is fundamentally afraid of changing tubes, as some of the works that deal with a similar topic show [32, 33], and these are in compliance with our results. According to our experience, some of the patients are even afraid of touching the tube after the operation. If the approach is right and the exchange is repeatedly shown, these problems are mostly solved very quickly and all patients of our group confirmed that stoma and tube care is eventually no hindrance (see Table 2 and 4). To learn to be self-reliant in care is the only way to prevent further complications. After discharge, the patient's family partially participates in the care. Our results show that less than 3% of patients need longer-term help from their families after the operation (this is mostly help with the tube exchange), whilst the other patients are self-reliant.

The social environment in the family plays an essential role, mainly during the first year after the operation. After that, the patient is usually partially adapted [34, 35]. In patients with no family environment, this help is provided by home care in the Czech Republic.

The fundamental fact is that 45% of patients in our group use non-verbal communication. According to some literature, about 50% of patients are able to verbally communicate with the use of oesophageal speech [36, 37]. One of the factors that cannot be influenced is the mentality of patients. Above all, low-status patients feel no need to cooperate in their own learning. They want to learn nothing and do not like to return to hospital, even to be examined.

Communication problems brought another interesting finding. At ENT Clinics, there are no communication difficulties in 66% of patients. However, only 25% of patients do not have a problem with communication at other medical or public centres. This fact is probably related to insufficient experience of the medical staff of different specializations with communication with the patients after laryngectomy, and the results being the same as in the nonmedical environment are subject to rectification. Our data, as well as our experience, inspired us to summarize the principles of communication of the patient after laryngectomy (see Table 5).

These principles are synoptically summarized in a brief manuscript for patients and their family members, which is given to the patient during the consultation about the operation with a physician.

The adaptation to the new way of breathing and swallowing was in accordance with generally published results [38, 39]. 90% of patients in the group stated that they feel trouble-free at home, and 32% of these do not even consider tracheostomy to be a handicap. The others feel limited at least in some way. Masking of tracheostoma is performed by 53% of patients in some manner. These complications can cause "shame" and inhibit the patient from training alternative voice communication or reintegrating into society. Our results show that patients

Table 5 – Principles of alternative voice communication

Principles of easier communication after laryngectomy:

- Draw the addressed person's attention to the fact that you're talking to him or her.
- Speak face-to-face.
- Look for a quieter environment for communication.
- After finishing your speech, give the addressed person a signal that he or she can speak.
- Be patient with yourself and your surroundings.

stop feeling fear of tracheostoma and the tube some time later. Over the course of years, some of them even stop wearing the tube if the stoma is not closing spontaneously.

Long-term dispensarization is performed approximately once a year. The necessity of postoperative check-ups does not originate only from the required check-ups of wound healing, but also from the consultation and verification of the patient's handling of the new situation. We try to find out the patient's opinion, as well as the opinions of their closest family members and friends. Their view of their life situation changes gradually and, according to that, we have to adjust the approach to help the patient [40, 41].

Patients subjectively say that their fear of TCHS-tube and stoma care disappears more quickly than their fear of communication (social and emotional problems). In our group, all patients mention at least partial communication problems, even if all of them finally adapted within 5 years after operation. Our results show that the TCHS-tube is worn by 66% of operated patients in the 5 years after operation. However, in general the data show that all patients put great emphasis on both problems and they consider their solution to be essential.

Conclusion

Good nursing care influences the rate and quality of the patient's adaptation to new life conditions. Key points in this process are the maintenance of the stoma and tracheostomy tube, as well as the quality of "alternative voice communication". The study shows that it is possible to achieve an acceptable quality of life if there is a good cooperation between the medical team and the patient.

Conflict of interests

The authors declare no conflict of interests in this article.

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