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Investigating quality of life and coping resources after laryngectomy

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Abstract Surgical procedures and in particular laryngectomy can become a life-saving treatment for patients with laryngeal or hypopharyngeal cancer, but can result in permanent damage. Clinical observation suggests that patients vary considerably in their ways of dealing with this new situation and in their ability to cope. The aim of our interdisciplinary group was to investigate the quality of life of laryngectomy patients and learn about their perceptions, situation and coping mechanisms. The development of an appropriate study design and a measurement strategy is presented. We investigated 29 laryngectomized patients who had joined the local self-help group. The patients were free from tumour disease and were mostly married with children, retired from work and had not graduated from high school. Assessment of the quality of life was performed with the European Organization for Research on Treatment of Cancer questionnaires QLQ-C30 and H+N35 and additional open questions. Analysis of the acquired data showed that family support was judged most important for overcoming the problems of disease and treatment. Deficits in this area were highly correlated with a low overall quality of life. Financial problems resulted because of the high percentage of retirement before or after therapy. We suggest that perioperative support taking these facts into consideration can result in an improved coping process. Further prospective studies are needed to reveal the effect of such measures.

Keywords Laryngeal cancer · Laryngectomy · Quality of life · Coping mechanisms

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Introduction

Laryngeal cancer is the most frequent malignant disease of the upper aerodigestive tract, while hypopharyngeal cancer often affects the larynx because of its anatomical position and late diagnosis [13]. The main goal of cancer treatment is to cure the patient of disease. Recurrences after failure of treatment, with the consequent necessity for a further enlarged approach will result in frustration and the need for new coping processes by the affected individual. Incurability has to be considered the worst possible outcome of a therapeutic trial. Functional impairment has to be kept to a minimum without decreasing the chances of survival. In our institute laryngectomy is the main therapeutic option in cases of laryngeal or hypopharyngeal cancer when tumour growth does not allow organ preservation to cure the patient of disease. In order to avoid permanent loss of voice function, tumours are resected without total laryngectomy whenever this is oncologically justifiable. Primary radiotherapy with or without chemotherapy can be an alternative to surgical procedures.

Treatment of laryngeal and hypopharyngeal cancer has a strong impact on a person's life. In particular laryngectomy affects crucial functions such as breathing, swallowing and speaking [10]. Experience suggests that reactions to illness and treatment not only depend on the patient's physical situation but also vary according to factors such as personality, profession, age, cultural environment and social status, even when patients undergo the same therapeutic procedures and gain a similar functional outcome [3]. Patients can show a very positive attitude towards a situation we might consider tragic, while they can also suffer greatly from the slightest change in their voice. Individuals who use their voice frequently, e.g. for work, are more affected than others. As a consequence, all aspects of daily life are affected and the patient experiences the sum of these impairments.

The concept of quality of life has its roots in the behavioural sciences, especially in sociology and social psychology [15]. It is defined as an individual's sense of well-being in the somatic, emotional and social domains

and has become a major topic in the interface between research in medicine and psychology [15]. The multidimensional construct of quality of life is usually assessed by questionnaires that have been validated for this purpose in earlier studies [1, 8, 12, 17, 19, 21, 22]. Acquired data are analysed statistically and the results are interpreted. So far an increasing number of descriptive studies have been published, most of which do not point to particular goals for the assessment. Consequently proposals for concrete practical implementation of the results are rare. In the literature the quality of life (QOL) assessment has often been used comparatively to detect the advantages and disadvantages of different therapeutic options [5, 18, 23, 24]. This procedure is problematic because vast numbers of variables have to be considered. Earlier studies have found surprisingly great similarities in patients' subjective responses to different treatment regimens [5, 9, 23]. Recent investigations have shown that a careful evaluation of variables not directly linked to health or treatment can have a strong influence on a patient's report regarding the health-related quality of life [11, 15, 16]. This may lead to counterintuitive results, for instance when patients after functional and radical surgery report the same QOL status. It becomes increasingly clear that QOL questionnaires alone do not solve the research problem: the research setting has to be more clearly specified [15].

The overall goal of the Giessen project is to find a way to improve the QOL of patients with head and neck cancer. The aim is a detailed knowledge of the particular needs and problems in regard to the general situation as well as according to the differences between affected individuals. Therefore multiple steps in a series of investigations will be necessary (Fig. 1). The aim of the present first step was to learn how patients who are presumably relatively well-off face their fate and to evaluate their QOL and how they experience their illness and treatment. These patients should be able to assess the whole process of diagnosis and treatment. Coping mechanisms are supposed to be an important strategy for dealing with the situation after cancer therapy. Knowledge of the problems expected and the mobilization of coping capabilities will help to optimize patient satisfaction. So far, coping resources have not been investigated systematically in patients after treatment for head and neck cancer.

University of Giessen QL Research Program

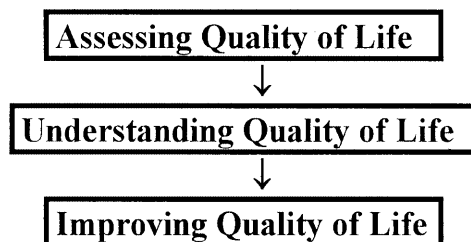


Fig. 1 University of Giessen quality of life (QOL) research programme as a stepwise procedure aiming to yield practical implementation of investigation results

As a first step we decided to explore patients who had undergone laryngectomy for laryngeal or hypopharyngeal carcinoma and had joined a self-help group. As mentioned above, laryngectomy is frequently used to manage extended disease and represents a mutilation with serious consequences for the daily life of the affected person. After participation in some of the group's meetings we gained the impression that the members had found a way of getting along surprisingly well with their handicaps. It can be assumed that this is a group of patients who have actively confronted their illness, who have found a way of getting along with their situation, and who are able to provide useful information on quality of life and coping resources. The goal of this study was to assess these patients' current quality of life status by means of standardized questionnaires, to analyse the most prominent problem areas, and (using qualitative methods) to investigate their worst experiences and the most helpful resources in the course of treatment and their illness.

Patients and methods

Study design

This is a prospective cross-sectional study with one point of measurement and without a comparison group. No direct hypotheses were formulated. It was planned to investigate the frequency ranges of responses and the interrelation of variables in an exploratory manner [7].

Patient recruitment and course of the study

The patients in the sample of interest were members of the local self-help group who had undergone surgery for laryngeal or hypopharyngeal carcinoma. We met the patients either in the clinic during their regular follow-up visit or at their homes. Patients filled out the standardized quality of life questionnaires themselves. In addition, the detailed medical history was recorded. The whole procedure took about 1 h.

Patient characteristics

The local self-help group of laryngectomized patients in Giessen consists of 32 members, three of whom refused to participate (recruitment rate 91%). The average age of the participants was 62 ± 8 years and there were 27 men and two women. The reasons for laryngectomy were glottic carcinoma in three patients, supraglottic carcinoma in 13 and hypopharyngeal carcinoma in the remaining 13. Radiotherapy was performed postoperatively in 22 patients. On average, the time since therapy was 6 years (range 1 to 11 years). Twenty-five of the group were married, two unwed, one divorced and one widowed. Twenty-four had children (average number 2.1). All patients lived in their own households, and 26 were living with a partner. Only three were working full-time, while 18 were old-age pensioners and eight had retired early. Just two patients had graduated from high school (13 years of school in Germany). The others had attended primary school ($n = 15$) or secondary school without high school graduation ($n = 11$); one patient did not indicate the education level.

Quality of life assessment

Assessment of quality of life was performed using the European Organization for Research on Treatment of Cancer (EORTC)

QLQ-C30 questionnaire and the head and neck-specific EORTC HN35 module. The EORTC QLQ-C30 is a cancer-specific multi-dimensional questionnaire incorporating five functional scales (physical, role, cognitive, emotional, and social), three symptom scales (fatigue, pain, nausea and vomiting), a global health status/QL scale, five questions assessing additional symptoms (dyspnoea, loss of appetite, insomnia, constipation, and diarrhoea), and the perceived financial impact of the disease. All scales and single items are scored on a four-point Likert scale except physical function and role-function (dichotomous response choice) and the global health status/QL (seven-point scale).

The EORTC H+N-35 module contains seven symptom scales and six symptom items concentrating on head and neck disease. We also applied the KLQ H+N-R1 questionnaire developed in Kiel with 19 other head and neck-specific questions. None of these tools is specific for laryngeal cancer, while the EORTC questionnaires concentrate on a radiotherapeutic approach rather than on the problems of surgical management.

In order to get qualitative information in addition to the quantitative data obtained by the questionnaires we asked our sample members to answer freely some open questions dealing with their current evaluation of perioperative experiences [7]. These questions were:

- What helped you most to deal with your illness?
- What would you advise other patients to do to achieve a rapid recovery?
- What do you remember as your worst experience?
- What would you advise a young person to do in life?
- What would you do differently after the operation, given your present knowledge?

Statistical methods

Data analysis included aggregating single questionnaire items into quality of life scores ranging from 0 (worst score) to 100 (best score). Single laryngectomy-specific symptoms were correlated with a global quality of life score (Pearson correlations). In addition, descriptive statistics (means, standard deviations, percentages, ranges) were calculated. Responses to open questions were analysed in a qualitative manner [7]. All analyses were performed using the SPSS software package.

Results

Problematic QOL domains

All quantitative QOL scores ranged from 0–100 and were uniformly scored so that 0 represented the worst and 100 the most favourable value. From a pragmatic point of view it can be argued that values under 50 can be considered ‘problematic’ [14]. Table 1 lists the top problematic domains as well as the less problematic ones.

Table 1 Problematic quality of life (QOL) domains with quantitative scores below 50 on a 0–100 scale. Less problematic QOL domains: physical function, role function, cognitive function, appetite, pain

Problematic QOL domains [percentage of patients ($n = 29$) scoring < 50 on a 0–100 scale, 0 = very bad to 100 = very good]	
Emotional function	45
Social function	45
Fatigue	41
Financial situation	38

Table 2 Pearson correlations (r) between postoperative head/neck symptoms and global quality of life. Negative correlations indicate decrease in global QOL due to specific problem

Problem areas	r
Talking on telephone	–.58
Talking to other people	–.56
Getting along with family	–.55
Coughing	–.52
Enjoying meals	–.49

Table 3 Qualitative information about the patients’ condition obtained by analysing the results of the open questions (% responses)

“What was the worst experience in the course of illness?”	
Cancer diagnosis	41
Surgery and sequelae	34
Radiotherapy	10

Table 4 Qualitative information about the patients’ condition obtained by analysing the results of the open questions (% responses)

“What helped you most to get along with your illness?”	
Family	75
Patient self-help group	31
Doctor’s support	21
Rehabilitation cure	14

Specific symptoms and quality of life

As a second step we investigated which specific head and neck symptoms were associated with a low overall QOL status. The correlations are presented in Table 2 and it was found that problems with talking on the telephone, talking to other people, getting along with the family, coughing and enjoying meals were correlated with a low global QOL.

Disease and coping experiences

We had a special interest in the freely formulated answers to the open questions requiring qualitative information about the patients’ condition. To our knowledge, such data have not been assessed in previous studies. The results for two of the questions are shown in Table 3 and Table 4.

Discussion

As it provides the closest social environment the family is considered most important for coping with the cancer diagnosis during and after treatment. Nevertheless, many patients felt the self-help group to be an important aid in overcoming their problems. Obviously contact with other people sharing their fate can be helpful. The members were very well informed about the possibilities of voice rehabilitation. They also made use of devices needed for swimming with a tracheostoma. The study group was surprisingly homogeneous, with most of the members being married, with children, retired and without advanced school education.

The majority of patients regarded the diagnosis of cancer, with uncertainty about the near future, as the worst

experience in the course of their disease. The financial situation was rated difficult by many patients, probably due to the high percentage of retirement after treatment. DeSanto et al. [4] reported similar rates of retirement for patients after total and near-total laryngectomy, with no significant differences between the two groups, showing that tracheostomy as the common characteristic may be the limiting factor for working rehabilitation. Herranz and Gavilan [9] pointed out that after treatment only 27% of patients went back to work after cordectomy and 11% after supraglottic laryngectomy. Significantly higher percentages were reported in Norway and France, indicating that cultural and socio-economic factors may have an important impact. Interestingly, worse adaptation regarding psychological distress after surgery was found for patients who did not go back to work.

We conclude that coming to terms with a laryngectomy is largely a social phenomenon. This interpretation is underscored by the close association between voice and global QOL; for example, impaired communication abilities (e.g. on the telephone) were highly correlated with a low level of global QOL. A patient's situation may be improved by involving the family in the treatment and rehabilitation process from the moment of diagnosis. Family members should not only be informed about the diagnosis and treatment but also made fully aware of possible problems in dealing with a laryngectomized husband or father and of the importance of their cooperation for the affected individual. Postoperative speech therapy support could be combined with social therapy within the scope of postoperative care programmes. Opportunities to go back to work may help to boost the self-esteem of patients.

The present project provided useful information about a subgroup of laryngectomy patients who had joined a self-help group. The generalizability of these findings should be explored in future studies utilizing other samples and additional assessment strategies. In particular, patients who did not join the self-help group after laryngectomy probably show other characteristics and they should be surveyed. The time from diagnosis and therapy should be considered as a variable in order to record the dynamics of coping processes [2]. Furthermore, evaluation by family members and health care providers has to be examined [6, 9, 20]. Finally, the importance of specific psychosocial intervention programmes should be the subject of prospective controlled randomized trials.

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