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HEAD AND NECK

Evaluation of the information given to patients undergoing total pharyngolaryngectomy and quality of life: a prospective multicentric study

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Abstract

Background Providing cancer patients with adequate information is essential to their confidence and satisfaction regarding medical care. The aims of this study were to evaluate the information given to patients undergoing total pharyngolaryngectomy (TPL) as well as the evolution and predictors of patient quality of life (QoL).

Methods We conducted a prospective multicentric study on patients undergoing TPL for a locally advanced laryngeal/hypopharyngeal cancer. All patients completed the EORTC QLQ-INFO25, QLQ-C30, and QLQ-H&N35 questionnaires, before and after surgery.

Results This study enrolled 46 patients. Between the pre- and post-therapeutic periods, we observed no significant changes in the global QLQ-INFO25 and QLQ-C30 scores. However, we found a significant deterioration in 4 QLQ-INFO25 scales/items and in social functioning, as well as an increase of sense, speech, and social contact problems. N-stage and professional activity were significant predictors of preoperative QLQ-INFO25 scores. Younger age was significantly associated with financial difficulties, whereas professional activity and lower education level were significant predictors of xerostomia and swallowing problems, respectively.

Conclusion In patients undergoing TPL, we observed significant changes in QLQ-INFO25 scores between the pre- and post-treatment periods and, particularly, a deterioration of patient satisfaction with the information received. Several clinical factors were identified as significant predictors of QLQ-INFO25 and QoL scores.

Keywords Information · Satisfaction · Total laryngectomy · Quality of life · Head and neck cancer

Introduction

Despite the advances made in chemoradiation-based organ-preservation protocols, total pharyngolaryngectomy (TPL) still plays an important role in the treatment of patients with

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locally advanced laryngeal/hypopharyngeal cancer [1, 2]. Although some progress has been made in vocal and respiratory rehabilitation of laryngectomized patients, TPL has still a major impact on the patient's life, due to its physical and functional sequelae, as well as its psychosocial consequences [3-5]. Among all head and neck oncologic surgical procedures, TPL is probably the surgical procedure most frequently refused by patients [3]. Thus, patients undergoing TPL certainly have specific information needs. Providing cancer patients with adequate information has many benefits: shared decision-making; greater satisfaction with care; improvement in patients' sense of control; lower levels of affective distress; better communication with the patient's family; and better quality of life (QoL) [6, 7]. Cancer patients do not always report having received sufficient information [8]. Moreover, clinicians' and patients' priorities on information disclosure may not always coincide and patients' wishes may change over time [7, 8].

The aims of this study were to evaluate the information given to patients undergoing TPL as well as the evolution and predictors of patient QoL.

Material and methods

Patients

All patients who underwent primary TPL for a locally advanced laryngeal/hypopharyngeal cancer, between September 1, 2012, and July 31, 2014, were enrolled in this prospective multicentric study (three tertiary care centers: Face and Neck University Institute of Nice, Department of Otorhinolaryngology and Head and Neck Surgery—Public Assistance Hospitals of Marseille, Department of Otorhinolaryngology and Head and Neck Surgery—University Hospital of Strasbourg). Each included patient had to sign a specific consent form. The protocol and all accompanying material provided to patients were reviewed and approved by institutional ethics committees prior to the start of the study (approval reference number: 2012-juin-12918). Postoperative adjuvant radiotherapy, with or without concurrent chemotherapy, was administered, when indicated, based on the patients' general health status, tumor stage and adverse pathological features. Patients were staged according to the 2009 American Joint Committee on Cancer (AJCC) staging system.

Questionnaires

Patients completed the French versions of the European Organization for Research and Treatment of Cancer (EORTC) information module questionnaire (QLQ-INFO25), the EORTC Core Quality of Life Questionnaire (QLQ-C30) and the EORTC Head and Neck Cancer Quality of Life Questionnaire (QLQ-H&N35) before surgery and at 6 months post-treatment. These questionnaires (see electronic supplementary material for the English version) are validated in their French-language version and are available on the EORTC website (https://qol.eortc.org/questionnaires/). Patients who were not fluent in French or who could not answer the EORTC questionnaires for physical, psychological or other reasons were excluded from the study. The 6-month post-treatment questionnaires were not completed in the event of death or tumor recurrence before the sixth post-treatment month.

The EORTC QLQ-C30 (see electronic supplementary material) is a general self-report questionnaire designed to assess QoL in cancer patients. It consists of five functioning scales (physical, role, cognitive, emotional, and social), three symptom scales (fatigue, pain, nausea, and vomiting), a global QoL scale, and six single questions assessing additional symptoms commonly reported by cancer patients. The EORTC QLQ-H&N35 (see electronic supplementary material) is a tumor-specific self-report questionnaire for head and neck cancer patients including seven symptoms scales (pain, swallowing, senses, speech, social eating, social contacts, and sexuality) and six single items (teeth problems, mouth opening, dry mouth, sticky saliva, coughing, and feeling ill). The scales and single-item variables of the QLQ-C30 and H&N35 questionnaires were linearly transformed into a score from 0 to 100. A high score for a functioning scale and for the global QoL scale represents a better level of functioning, whereas a high score for a symptom scale or a single-item scale denotes a high level of symptoms or problems. The EORTC QLQ-INFO25 (see electronic supplementary material) has 25 items organized in four hypothesized scales: information about the disease (4 items), medical tests (3 items), treatment (6 items) and other services (4 items), and eight single items. The response format is a 4-point Likert scale (1—not at all, 2—a little, 3—quite a bit, 4—very much), except items 51, 52, 54, and 55, which have a dichotomous (yes/no) response. The scales and single-item variables of the EORTC QLQ-INFO25 were linearly transformed into a score from 0 to 100. Higher scores mean a higher level of information received, desire for more information and greater satisfaction.

Statistical analysis

We investigated potential differences between the QLQ-INFO25, QLQ-C30, and QLQ-H&N35 scores obtained before surgery and at 6 months post-treatment (including postoperative radiotherapy or chemoradiotherapy, when required) by means of *t* tests on paired measurements. When possible, dimensional consistency was calculated using Cronbach's alpha with its 95% confidence interval

(bootstrapping method). We assessed the potential predictors of QLQ-INFO25 (before and after treatment), QLQ-C30, and QLQ-H&N35 (after treatment) scores among the following factors: age (< vs > 65 years), gender, education level: high school diploma (yes vs no), professional activity (yes vs no), N-stage (< vs ≥ 2a), postoperative adjuvant therapy (yes vs no). Univariate analyses were conducted using Student's *t* tests or Wilcoxon tests. When several significant factors were identified in univariate analyses, multivariate analyses were performed using linear regression models. All statistical analyses were performed at 5% alpha risk or 95% confidence interval by a biostatistician using R.3.0.1 software on Windows.

Results

Clinical characteristics of the patients

A total of 46 patients were included in the study. Their main clinical characteristics are shown in Table 1.

EORTC QLQ-INFO25, QLQ-C30, and QLQ-H&N35 scores before and after treatment

These scores are shown and compared in Tables 2, 3, and 4.

Regarding EORTC QLQ-INFO25 scores, between the pre- and post-treatment periods, we observed a significant decrease in four scales/items (written information; information on CD tape/video; satisfaction with the information received; overall, the information has been helpful). Regarding EORTC QLQ-C30 scores, between the pre- and post-treatment periods, we observed a significant deterioration in two scales/items (social functioning and diarrhea) and a trend towards a decline in two scales/items (cognitive and role functioning). Regarding EORTC QLQ-H&N35 scores, between the pre- and post-treatment periods, we observed a significant increase in three scales/items (sense, speech, and social contact problems) and a trend towards a decrease in one scale/item (coughing).

Table 1 Patients' clinical characteristics

Characteristics	Number of patients (%)
Gender: male/female	40 (87)/6 (13)
Age: < 65/ > 65 years	18 (39)/28 (61)
Educational level: high school diploma: Yes/No	35 (76)/11 (24)
Professional activity: Yes/No[a]	21 (46)/25 (54)
T-stage: T1 or T2/T3 or T4	4 (9)/42 (91)
N-stage: N0 or N1/N2a–c or N3	34 (74)/12 (26)
Adjuvant treatment: None/RT ± CT	25 (54)/21 (46)

RT radiotherapy *CT* concurrent chemotherapy

[a]Including retired patients

Predictive factors of EORTC QLQ-INFO25 scores before and after treatment

Before treatment, patients with a higher N-stage ($N \geq 2$) reported that they had received less information about the disease (50.5 vs 64.6; $p = 0.04$) and medical tests (55.6 vs 66.7; $p = 0.02$), and that, overall, the information had been less helpful (57.6 vs 78.8; $p = 0.004$) than patients with a lower N-stage. Patients with a work activity reported that, overall, the information had been less helpful (65.0 vs 80.0; $p = 0.02$) than patients without a work activity. The impact of N-stage ($p = 0.001$) and work activity ($p = 0.005$) on the helpfulness of the information received was confirmed in multivariate analysis.

We identified no predictive factor of QLQ-INFO25 scores after treatment.

Predictive factors of QLQ-C30 and QLQ-H&N35 scores after treatment

In univariate analysis, younger age (< 65 years, $p = 0.04$) and work activity ($p = 0.04$) were significantly associated with greater financial difficulties. Multivariate analysis confirmed the impact of younger age on financial difficulties ($p = 0.005$), but not of work activity ($p = 0.36$). We identified no other predictive factors of QLQ-C30 scores.

Work activity ($p = 0.04$) was significantly associated with xerostomia (dry mouth). Lower education level (≤ high school diploma) was significantly associated with more swallowing problems. We identified no other predictive factors of QLQ-H&N35 scores.

Discussion

This prospective multicentric study is the first study to evaluate the information received by patients undergoing TPL using the validated EORTC QLQ-INFO25 questionnaire. The reliability of this instrument for assessment of the information given to cancer patients was established in a large international study reported by Arraras et al. showing satisfactory internal consistency, test–retest reliability, and convergent and divergent validity [7]. This study enrolled patients from various countries receiving radiotherapy and/or chemotherapy for all types of cancers including a small proportion of head and neck malignancies (6.9%). More recently, we tested this instrument to evaluate perception of the information received by HNSCC patients undergoing different types of oncologic surgical procedures [9]. Among HNSCC patients, those undergoing TPL represent

Table 2 EORTC QLQ-INFO25 scores before and after treatment

Scales/items	Before treatment					After treatment					*p* value
	Mean	SD	Cronbach's alpha	Lower CI 95%	Upper CI 95%	Mean	SD	Cronbach's alpha	Lower CI 95%	Upper CI 95%	
Info about the disease (items 31–34)	61.3	19.4	0.51	0.83	0.51	55.3	21.7	0.6	0.12	0.81	0.26
Info about medical tests (items 35–37)	61.1	28.4	0.57	0.9	0.57	53.7	29.0	0.92	0.83	0.96	0.31
Info about treatments (items 38–43)	41.7	24.6	0.71	0.88	0.71	44.6	27.2	0.88	0.75	0.94	0.66
Info about other services (items 44–47)	24.8	23.0	0.48	0.81	0.48	33.2	27.1	0.81	0.55	0.92	0.2
Info about different places of care (item 48)	32.6	30.2	–	–	–	43.0	34.7	–	–	–	0.22
Info about things you can do to help yourself (item 49)	33.3	28.9	–	–	–	38.8	32.1	–	–	–	0.48
Written info (item 50)	47.8	50.5	–	–	–	8.7	28.8	–	–	–	*< 0.001*
Info on CD tape/video (item 51)	8.7	28.4	–	–	–	0.0	0.0	–	–	–	*0.04*
Satisfaction with the info received (item 52)	65.9	21.6	–	–	–	44.4	36.3	–	–	–	0.01
Wish to receive more info (item 53)	46.6	50.4	–	–	–	59.0	50.3	–	–	–	0.35
Wish you had received less info (item 54)	0.0	0.0	–	–	–	4.7	21.8	–	–	–	0.33
Overall, the info has been helpful (items 55)	73.1	20.6	–	–	–	53.0	30.2	–	–	–	*0.01*
Global Score (items 31–55)	41.6	12.1	0.87	0.93	0.87	37.2	18.0	0.95	0.91	0.97	0.36

Scores range from 0 to 100. Higher scores mean a higher level of info received, higher info wishes and higher satisfaction. Items 52–55 have a dichotomous answer

Info information, *SD* standard deviation, *CI* confidence interval, *p* value comparison between pre- and post-treatment scores, statistically significant *p* values are underscored; – not applicable

Table 3 EORTC QLQ-C30 scores before and after treatment

Scales/items	Before treatment					After treatment					*p* value
	Mean	SD	Cronbach's alpha	Lower CI 95%	Upper CI 95%	Mean	SD	Cronbach's alpha	Lower CI 95%	Upper CI 95%	
Global quality of life (items 29, 30)	55.2	18.6	0.88	0.71	0.95	57.9	19.8	0.95	0.75	0.99	0.59
Physical functioning (items 1–5)	76.2	22.8	0.82	0.74	0.87	70.0	25.5	0.85	0.74	0.91	0.33
Role functioning (items 6, 7)	73.9	31.5	0.82	0.55	0.93	58.7	32.1	0.81	0.52	0.93	0.07
Emotional functioning (items 21–24)	64.1	23.0	0.71	0.54	0.81	55.0	31.4	0.87	0.71	0.94	0.23
Cognitive functioning (items 20, 25)	84.7	19.5	0.37	0.19	0.68	71.7	32.3	0.84	0.6	0.95	0.09
Social functioning (items 26, 27)	79.3	27.9	0.83	0.61	0.93	55.0	40.6	0.94	0.82	0.97	*0.01*
Fatigue (items 10, 12, 18)	41.7	29.7	0.91	0.85	0.95	44.9	32.7	0.94	0.89	0.97	0.7
Nausea and vomiting (items 14, 15)	12.6	23.3	0.81	0.75	0.85	12.8	20.5	0.73	0.65	0.79	0.97
Pain (items 9, 19)	33.7	29.5	0.74	0.45	0.87	31.1	31.0	0.81	0.36	0.93	0.75
Dyspnea (item 8)	44.2	37.2	–	–	–	53.0	31.9	–	–	–	0.32
Insomnia (item 11)	44.4	38.9	–	–	–	43.4	35.4	–	–	–	0.92
Appetite loss (item 13)	41.3	34.5	–	–	–	27.2	31.9	–	–	–	0.11
Constipation (item 16)	18.8	26.9	–	–	–	27.2	28.4	–	–	–	0.25
Diarrhea (item 17)	7.9	16.0	–	–	–	21.7	29.4	–	–	–	*0.05*
Financial difficulties (item 28)	18.1	32.7	–	–	–	25.7	38.4	–	–	–	0.43

Scores range from 0 to 100. A high score for a functioning scale and for the global QoL scale represents a better level of functioning, whereas a high score for a symptom scale or a single-item scale denotes a high level of symptoms or problems

SD standard deviation, *CI* confidence interval, *p* value comparison between pre- and post-treatment scores, statistically significant *p* values are underscored, – not applicable

Table 4 EORTC QLQ-HN35 scores before and after treatment

Scales/items	Before treatment					After treatment					*p* value
	Mean	SD	Cronbach's alpha	Lower CI 95%	Upper CI 95%	Mean	SD	Cronbach's alpha	Lower CI 95%	Upper CI 95%	
Pain (items 1–4)	27.2	25.3	0.84	0.74	0.91	18.4	24.6	0.89	0.78	0.95	0.17
Swallowing (items 5–8)	32.7	30.6	0.84	0.72	0.91	27.4	29.3	0.8	0.69	0.9	0.48
Senses (items 13, 14)	16.2	28.1	0.9	0.71	0.98	62.3	32.2	0.8	0.49	0.94	*< 0.001*
Speech (items 16, 23, 24)	32.8	28.7	0.7	0.39	0.84	59.9	28.8	0.58	− 0.19	0.8	*< 0.001*
Social eating (items 19–22)	29.1	32.4	0.9	0.8	0.96	40.9	35.0	0.88	0.71	0.95	0.18
Social contact (items 18, 25–28)	14.3	18.3	0.69	0.46	0.85	40.5	34.6	0.94	0.88	0.97	*< 0.001*
Sexuality (items 29, 30)	38.3	38.2	0.94	0.76	0.99	49.2	41.3	0.98	0.93	1	0.32
Teeth (item 9)	16.6	32.5	–	–	–	25.7	32.4	–	–	–	0.29
Opening mouth (item 10)	10.6	24.6	–	–	–	22.2	32.1	–	–	–	0.13
Dry mouth (item 11)	29.5	33.8	–	–	–	23.1	30.8	–	–	–	0.44
Sticky saliva (item 12)	41.6	40.1	–	–	–	45.8	36.5	–	–	–	0.67
Coughing (item 15)	51.5	32.5	–	–	–	36.1	30.9	–	–	–	0.06
Feeling ill (item 17)	17.0	25.5	–	–	–	23.1	32.4	–	–	–	0.44
Pain killers (item 31)	65.1	48.2	–	–	–	47.8	51.0	–	–	–	0.19
Nutritional supplement (item 32)	34.8	48.2	–	–	–	50.0	51.0	–	–	–	0.24
Feeding tube (item 33)	25.5	44.1	–	–	–	20.8	41.4	–	–	–	0.66
Weight loss (item 34)	46.5	50.4	–	–	–	30.4	47.0	–	–	–	0.20
Weight gain (item 35)	30.2	46.4	–	–	–	52.1	51.0	–	–	–	0.10

Scores range from 0 to 100. A high score for a symptom scale or a single-item scale denotes a high level of symptoms or problems

SD standard deviation, *CI* confidence interval, *p* value comparison between pre- and post-treatment scores, statistically significant *p* values are underscored, – not applicable

a particularly relevant population to evaluate information given to cancer patients because TPL is responsible for major functional and esthetic impairments likely to affect patient QoL [5, 10]. Furthermore, a growing number of medico-legal issues are arising related to head and neck oncologic surgery, and insufficient or inappropriate patient information before surgery is acknowledged to be the main source of medico-legal litigation [11].

In the present study, for the EORTC QLQ-INFO25 questionnaire, we found a global score of 41.6 and 37.2 in the pre- and post-therapeutic periods, respectively. This result, which can be considered stable, indicates continuous and appropriate patient information throughout the treatment period. A similar result was reported by Arraras et al. (global score = 43.8) in the above-mentioned study, which included various types of malignancies [7]. Although there was no significant decline of the global score between the pre- and post-therapeutic periods, we can notice, however, that the only significant changes in QLQ-INFO25 scores observed tended to deteriorate over time. The post-therapeutic decrease of the QLQ-INFO25 scores regarding written information and information on CD tape/video is easily understandable since these methods of information are essentially used in clinical practice before treatment to explain the therapeutic procedures and their consequences. However, the deterioration of the post-therapeutic scores regaarding satisfaction with the information and the helpfulness of the information received reflects a disparity between the amount and the adequacy of information given to patients. Patients acknowledged receiving a lot of information and were satisfied with information received pretherapy. Post-treatment, they often suffered from late effects and various functional problems which may, retrospectively, have modified their satisfaction level and their perception of information received during the different phases of care. This is particularly true for patients undergoing TPL, which is always regarded by patients as a mutilating surgery causing a very real individual and social trauma [4, 5].

Regarding QLQ-C30 scores, we observed that the global QoL score remained stable between 55 and 60, as generally reported for patients undergoing TPL [4, 10, 12, 13]. In the present study, we evaluated QoL at 6 months post-treatment, which is a little early. It is likely that this score would have increased slightly until 1 year post-treatment. Indeed, it is widely accepted that, after HNSCC treatment, QoL at 1 year is a reliable predictor of long-term QoL [13, 14]. Higher global QoL scores are generally described for HNSCC patients undergoing conservative surgical procedures or non-surgical therapies [12, 15].

Role and cognitive functioning tended to decline after treatment. However, as expected, the most significant change was the deterioration of social functioning. In contrast, the post-therapeutic score of 70.0 showed that physical functioning was well-preserved. This highlights the main consequences of TPL, which mainly affects communication, physical appearance and, therefore, social life. Emotional functioning, with a post-therapeutic score of 55.0, was also largely impacted but did not decline significantly in comparison with the pretherapeutic period because preoperative emotional functioning was already low. This finding emphasizes the need for appropriate management of patient anxiety and fear during the preoperative period. After therapy, long-term side effects of treatment, changes in physical appearance, deterioration of social life and the anxiety related to cancer and the risk of recurrence and death may all affect patients' emotional status. In a study analyzing psychosocial effects in long-term HNSCC survivors, Holloway et al. showed that both psychosocial and physiologic factors influenced QoL in patients with HNSCC, but that many QoL measures were most strongly influenced by psychosocial considerations [16]. This suggests that multidisciplinary management of patients undergoing TPL should include social and psychological supportive measures.

Regarding head and neck symptoms, sensory and speech problems represented the main post-therapeutic issues for patients. Difficulties involving social eating and social contacts were also rated high. Similarly, in a study analyzing psychosocial QoL, Babin et al. showed that, after therapy, laryngectomized patients reported a significant decrease in eating-out (friends' homes or restaurant) and a significant increase in the time spent watching television [4].

Of note, sexual problems were one of the EORTC QLQ-H&N35 items with the highest scores. In this regard, a recent study on 262 patients with oropharyngeal cancer by Taberna et al. showed significant declines in the frequency of sexual activities at follow-up. A reduced sex life has been reported by several authors in HNSCC patients, irrespective of tumor site and treatment [17, 18]. In an interesting study analyzing intimacy and sexual dysfunction following major HNSCC treatment, Low et al. found that one-third of the patients reported substantial problems with sexual interest and enjoyment, and one-quarter reported problems with intimacy [19]. Little information and support regarding intimacy and sexual dysfunction are generally offered to HNSCC patients and their carers. There is therefore a need to research these issues more extensively.

With the growing interest in more personalized care in cancer patients during recent decades, it seems necessary to provide tailored information to each individual taking into account their tumor and scheduled treatment as well their socio-demographic and psychological characteristics. For this reason, in the present study, we investigated the predictive factors of EORTC QLQ-INFO25 scores. We showed that, before surgery, elevated N-stage was associated with poorer scores. To explain this result, we could suppose that patients with more advanced disease are particularly anxious

and have greater information needs than patients with less-advanced tumors. Interestingly, we also found that working patients reported that the information had been less helpful than non-working patients. Patients working at time of diagnosis have great information demands because they face potentially important decisions for obvious organizational, familial, and financial reasons. The proportion of patients able to return to work after TPL is largely unknown but is probably low, with most patients resuming work requiring quantitative or qualitative changes. In an interesting study evaluating the impact of TPL on return to work, Costa et al. showed that the most important factors in maintaining a work activity were the level of professional qualification and the vocal rehabilitation method [20]. In this study, 80% of patients with intermediate-to-high qualifications maintained their jobs, compared to 35% of those with low professional qualifications, while 70% of patients with voice prostheses resumed work compared to 31% of the patients rehabilitated with an esophageal voice.

Overall, these results indicate that patients undergoing TPL have specific information needs and that, in this particular group of patients, the information delivered has to be tailored to each individual patient. In this regard, Rogers et al. developed and evaluated the Patient Concerns Inventory (PCI-H&N), a holistic, self-reported tool to help HNSCC patients disclose their needs and concerns during consultations [21–23]. They showed that patients with laryngeal cancer tended to select more items in the social care and well-being area, and that those with poor QoL outcomes were significantly more likely to indicate more items of concern [24]. Moreover, the use of this instrument in clinical practice seemed to improve patients' satisfaction with the information that they were given [25]. Thus, this type of instrument could be useful to tailor the information delivered by health-care professionals to the needs of each individual. Interestingly, Laccourreye et al. showed that approximately one half of patients diagnosed with advanced laryngeal cancer amenable to TPL or a laryngeal preservation protocol wanted to receive additional information before making their decision. This proportion increased significantly among patients with a high level of education and among those with a family history of cancer [3].

Finally, we investigated potential predictors of QoL outcomes. Interestingly, we found that younger age was a significant predictor of financial difficulties. It is not surprising that elderly patients, who are generally retired at the time of diagnosis, do not undergo any change of income after surgery, and thus, that they do not suffer from financial hardship. In contrast, for younger patients, the disease and its treatment will oblige them to give up their work activity. In France, the treatment of HNSCC is entirely covered by the national health insurance system, and it is thus the discontinuation of professional activity more than the costs entailed by HNSCC diagnosis and treatment that gives rise to patients' financial problems.

The correlation between professional activity and xerostomia has to be interpreted in subjective terms. Working patients constitute the more active patients in the HNSCC population and those needing most to communicate. A given level of xerostomia will have a greater impact on patients continuing to work due to the obvious effect of xerostomia on swallowing and speech function.

The weaknesses of this study are the relatively low number of patients included and the lack of an objective measurement tool for the information provided to patients. A major strength is the evaluation of the information delivered to a homogeneous population of patients across various reference head and neck cancer centers, using an internationally validated questionnaire.

From a clinical perspective, the findings from this study can be used to help health-care professionals adapt the information delivered to head and neck cancer patients, and particularly to those undergoing TPL. However, in this regard, the main problem is not the lack of information, but even more the postoperative confrontation of patients with the irreversible reality after such surgical procedures. In the light of this study, it would be useful to analyze the effect of a standardized information program or of specific patient information delivery procedures on patients' perception of the information they receive. Indeed, the challenge in clinical care is to take action when patients express dissatisfaction [26]. Our aim should be to use the results obtained from the assessment of patient satisfaction to improve information delivery by implementing specific and personalized measures. This pre-supposes that health-care professionals are able to define the ideal content of the patient information they must seek to deliver. The use of the Patient Concerns Inventory could help to define individual information needs more precisely [23].

Conclusion

In patients undergoing TPL, we observed significant changes in QLQ-INFO25 scores between the pre- and post-treatment periods and, in particular, we noted a significant deterioration of patient satisfaction with the information received. Several demographic and clinical factors were identified as significant predictors of QLQ-INFO25 and QoL scores and these factors could be used to adapt the information delivered to each patient. Awareness of our shortcomings in the areas of patient information and of predictors of patient information needs is a first step to improve patient satisfaction with the information received.

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Compliance with ethical standards

Conflict of interest We have no conflict of interest to declare.

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