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### ► **To cite this version:**

Guillaume Grandazzi, Lise-Marie Roussel, Florence Cuny, Fabrice Morlais, Ludivine Launay, et al.. Impact of head and neck cancer on partner's sociability. *European Annals of Otorhinolaryngology, Head and Neck Diseases*, 2019, 136 (3), pp.165-168. <10.1016/j.anorl.2019.02.017>. <hal-02285984>

**HAL Id: hal-02285984**

**<https://normandie-univ.hal.science/hal-02285984v1>**

Submitted on 13 Sep 2019

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## **Impact of head and neck cancer on partner's sociability**

### **Abstract**

#### **Introduction**

“Sociability” is defined as the range of experiences linking the subject to others. This is the first study to focus specifically on the impact of head and neck cancer on the sociability of patients’ partners.

#### **Method**

Data were collected via a dedicated questionnaire sent to patients’ partners. The main endpoint was partner's self-assessment of the impact of the patient's disease on the partner's everyday life. The impact on sociability was analyzed with respect to: the circle of friends (friendship environment), unknown environment, known outside environment, necessary environment, and solitary activities.

#### **Results**

Two hundred and seventy partners responded. Their everyday activities were impacted by the patient's disease in 71.5% of cases. The friendship environment was badly affected in 46.4% of cases. The unknown environment was affected in 44.0% of cases. Social practices related to the known outside environment were affected in 67.8% of cases, and the necessary environment in 26.0%; the number of solitary activities increased in 35.6% of cases. Social impact on patients’ partners was thus considerable.

### **Keywords**

Head and neck neoplasms, Quality of life, Partner, Sociology, Sociability

# **1. Introduction**

Sociology is defined as the analysis of social organization and the study of the individual in society [1]. The field is thus very large, ranging from the economy to politics and human sciences. It also concerns the organization of health care [2], [3] and the impact of disease on the quality of life of patients [4] and their family and friends [5].

Impairment of quality of life [6] is especially severe in the ENT sphere due to disorders of communication [7] and swallowing [8] and esthetic blemish [9].

No studies, however, have specifically focused on impact in terms of sociability, which is another field of study in sociology. Sociability is defined as the range of experiences linking the subject to others [10]. It is studied in terms of five distinct environments: circle of friends (friendship environment), solitary environment, known environment, unknown environment, and necessary environment [10].

The questionnaires most often used in ENT are the EORTC QLQC30 and its specific head-and-neck H&N35 module [11], but these deal only partially with disease impact on sociability: 12 out of the 65 questions have this focus. The solitary environment is not assessed and the others only partially. Moreover, these questionnaires apply to the patients but not to his or her partner.

There are no specific validated questionnaires assessing subjects' sociability.

The aim of the present study was to assess the impact of head-and-neck cancer on the sociability of the patient's partner, by means of a dedicated questionnaire.

## **2. Material and Method**

### **2.1. Population**

The study included partners of patients with squamous cell carcinoma of the larynx, hypopharynx, oropharynx or oral cavity, managed between January 1, 2008 and December 31, 2010 in 4 French administrative areas (Calvados, Manche, Nord, and Somme) according to tumor registry data.

Patients (and their partners) with other tumor locations, other serious disease, second head and neck location or recurrence were excluded.

The partners of the selected patients were mailed a questionnaire assessing their social relations 1 month after treatment initiation. Only responses received within 12 months of treatment initiation were included for analysis. Patients' and partners' informed consent was collected at the same time.

Disease characteristics (tumor stage, location, type of treatment) were collected from the tumor registry. TNM stages were dichotomized as early (stages I and II) or advanced (stages III and IV). Locations were classified as supra- or infra-hyoid (Table 1). Treatments were classified as surgery, radiation therapy, or chemotherapy/palliative. Cases in which the patient's partners considered the esthetic sequelae to be serious were noted.

Table 1. Characteristics of patients and partners.

<b>Variables</b>	<b>N(number)</b>	<b>% (percentage)</b>
<i>Disease characteristics</i>		
<b>Location</b>		
<b>Supra-hyoid</b>	156	57.8
<b>Sub-hyoid</b>	114	42.2
<b>Stage</b>		
<b>I-II</b>	97	35.9
<b>III-IV</b>	173	64.1
<b>Treatment</b>		
<b>Surgery</b>	113	41.9
<b>Primary or adjuvant radiation therapy</b>	212	78.5
<b>Palliative care or exclusive chemotherapy</b>	58	21.5
<i>Partner characteristics</i>		
<b>Age</b>		
<b>&lt; 60 years</b>	165	61.1
<b>≥ 60 years</b>	103	38.2
<b>Missing data</b>	2	0.7
<b>Gender</b>		
<b>Male</b>	34	12.6
<b>Female</b>	236	87.4

<b>Variables</b>	<b>N(number)</b>	<b>% (percentage)</b>
<b>Occupation</b>		
None	127	47.0
In work	140	51.9
Missing data	3	1.1
<b>Cumulative monthly income of partner and patient</b>		
≤ €1,099	61	22.6
> €1,099	173	64.1
Missing data	36	13.3

Data were also collected, from the questionnaire, for the partner's age, gender, occupation, and income (Table 1).

The study protocol had institutional review board approvals.

## **2.2. Endpoints**

The main endpoint was disease impact on daily life as assessed by the partner.

To assess sociability, 5 environments were distinguished, with the following groups of questions:

- questions on the friendship environment: friends, family members and members of the close environment;
- questions on the unknown environment: trips to unknown places, involving strangers;
- questions on the known environment: trips to known places, but in presence of strangers;
- questions on the necessary environment: relations within the couple;
- and questions on the solitary environment: activities of the partner alone, including work.

The partner's subjective level of information about the patient's health status and somatic impact (sleep disorder) were also assessed.

## **2.3. Statistics**

The main endpoint (disease impact on partner's daily life), satisfaction with information received (“satisfied” versus “dissatisfied”), and somatic impact (sleep disorder) were reported as percentages.

The other questions were scored – 1 to + 1: i.e., decrease or increase in frequency or quality of the activity in question. Increased frequency corresponded to increased sociability and decreased frequency to decreased sociability, except for solitary activities (reading and watching TV), where the contrary was the case and increased frequency (decreased sociability) was scored – 1 and decreased frequency (increased sociability) + 1. Zero scores indicated no change: “like before”, “the same”, “no change”.

Non-responses were also scored 0, presuming that the partner felt unconcerned by the activity in question and had probably not changed behavior.

For each environment, deterioration was expressed as a percentage.

Univariate analysis was performed with logistic regression, with a significance threshold of 5%, to assess the impact of the various factors (income, treatment type, gender, age, occupation, tumor location, partner's sleep disorder, disfigurement considered to be important) on the probability of deterioration in the five environments.

Analysis used SAS® software version 9.3.

## **3. Results**

### **3.1. Population**

The questionnaire was mailed to partners of 1,525 eligible patients. Two hundred and seventy responded and were included for analysis (Fig. 1).

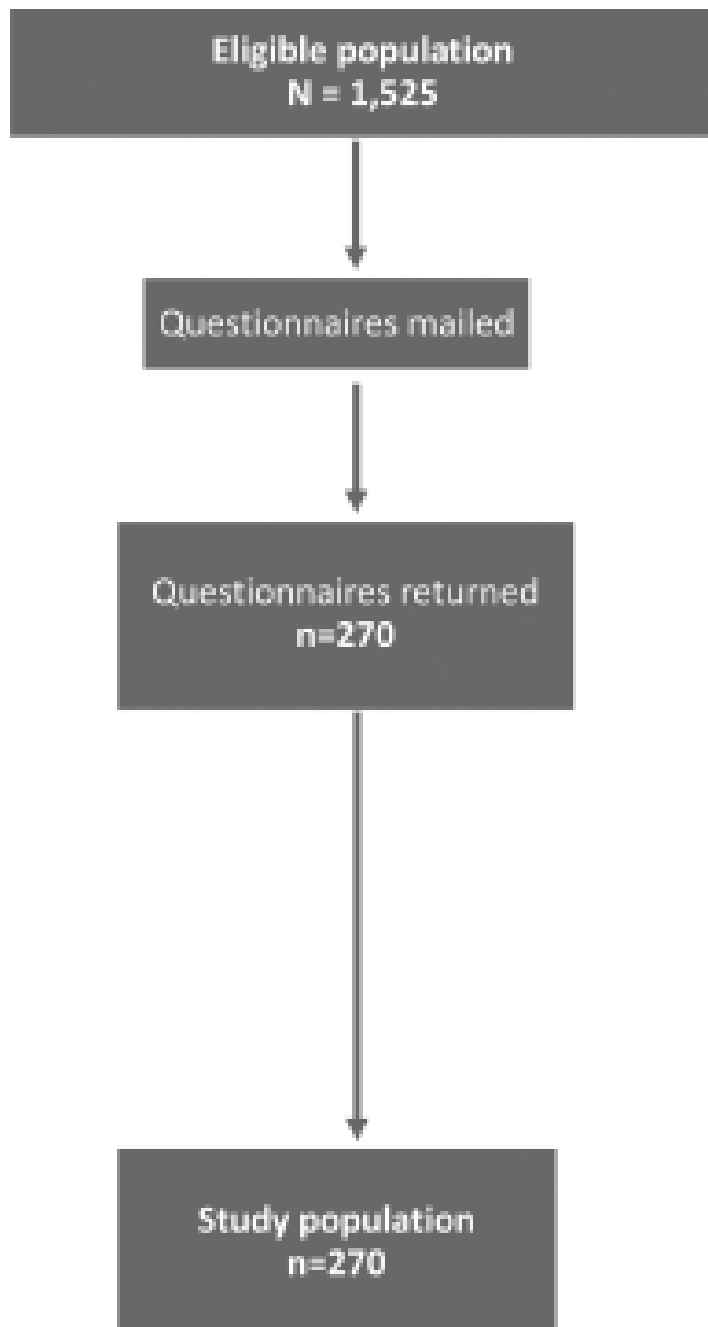


Fig. 1. Study population flowchart.

Respondents comprised 236 women and 34 men, 61.1% of whom were under 60 years of age. Most (51.9%) were in work at the time of study, with cumulative income for the couple exceeding the statutory minimum of €1,099 in 64.1% of cases (Table 1).

Tumor stage was advanced in 64.1% of cases, requiring surgery in 41.9% (Table 1). Disfigurement was considered important in 41.9% of cases.

### **3.2. Main endpoint**

Partners considered their daily activities to be impacted by the patient's disease in 71.5% of cases.

### **3.3. Friendship environment**

The friendship environment was considered to be impaired in 46.4% of cases.

Impairment was significant in case of advanced tumor (OR = 1.88 [1.13–3.13],  $P < 0.05$ ), of important disfigurement (OR = 1.75 [1.07–2.85],  $P < 0.05$ ) or of radiation therapy (OR = 2.46 [1.31–4.60],  $P < 0.01$ ).

Impairment was also significant when joint monthly income exceeded €1,099 (OR = 2.34 [1.26–4.35],  $P < 0.01$ ) or when the partner was male ( $P < 0.05$ ).

Partners' sleep disorder also significantly impaired the friendship environment (OR = 3.26 [1.82–5.82],  $P < 0.001$ ).

The other factors were not significantly associated.

### **3.4. Unknown environment**

Nearly half of the partners (44.0%) reported impact on the unknown environment.

Partners of patients undergoing radiation therapy reported significant impairment (OR = 2.02 [1.09–3.75],  $P < 0.05$ ).

Partners' sleep disorder also significantly impaired the unknown environment (OR = 2.41 [1.36–4.25],  $P < 0.01$ ).

The other factors were not significantly associated.

### **3.5. Known environment**

Social practices in the known outside environment were reduced for 67.8% of partners.

Partners of patients undergoing radiation therapy reported significant impairment (OR = 2.06 [1.13–3.74],  $P < 0.05$ ).

Partners' sleep disorder also significantly impaired the known environment (OR = 1.95 [1.11–3.43],  $P < 0.05$ ).

The other factors were not significantly associated.

### **3.6. Necessary environment**

The necessary environment was impacted for 26.0% of partners.

Partners of patients undergoing radiation therapy reported significant impairment (OR = 2.20 [1.02–4.75],  $P < 0.05$ ).

Partners' sleep disorder also significantly impaired the necessary environment (OR = 2.12 [1.08–4.16],  $P < 0.05$ ).

The other factors were not significantly associated.

### **3.7. Solitary environment**

The number of solitary activities was unchanged for 64.4% of partners and increased for 35.6%.

Partners of patients with important disfigurement showed significant increase in solitary activities (OR = 1.68 [1.01–2.78],  $P < 0.05$ ).

There was significant increase in solitary activities for partners with joint income equal to or exceeding the statutory minimum (OR = 1.99 [1.03–3.83],  $P < 0.05$ ) or aged  $\geq 60$  years at the patient's diagnosis (OR = 2.36 [1.37–4.07],  $P < 0.01$ ).

The other factors were not significantly associated.

### **3.8. Information and somatic impact**

More than three-quarters of the partners (77.1%) reported being well informed about the patient's illness. A total of 68.1% had sleep disorder.

## **4. Discussion**

A total of 71.5% of partners considered that their daily activities were impacted by the patient's disease. All aspects of sociability were affected for at least a quarter of them.

The quality of life of partners of patients with head and neck cancer is known to deteriorate after the diagnosis [12], [13], [14], [15]. The questionnaires used to assess

this, however, do not cover sociability [15]. The present study is the first to show disease impact on partners' sociability.

The environment seemingly least impacted was that of solitary activities, which increased in a quarter of cases. This was counted as impaired sociability, although this is open to debate: it could be seen as necessary "time out". Moreover, the frequency of telephone calls was not counted as part of this environment, as they seem rather to protect the partner from social isolation. Partners of patients with important disfigurement significantly increased their solitary activity, especially in couples with higher incomes. These findings were in agreement with previous studies [16], [17].

The present univariate analysis, however, is open to discussion: there are probably confounding factors, and multivariate analysis would have been more appropriate. The quantity of missing data, however, made this impossible.

Radiation therapy was significantly associated with impairment of the friendship, unknown, known and necessary environments. Again, this may be a confounding factor, associated with advanced tumor stage. Advanced tumor is associated with disfigurement [18], swallowing disorder [8], [19], impaired general health status [20] and vocal impairment [21]. Here again, multivariate analysis would have been useful.

The friendship environment was significantly impaired for male partners. In France, the mean age of head and neck cancer patients is 55 years [22] and, according to INSEE, the National Institute of Statistics and Economic Studies, men in this age groups are more dependent on their partner for household chores and activities of daily life [23]. Having friends home becomes difficult when your partner has a head and neck cancer. The main endpoint was a closed question allowing only a binary qualitative response. To better assess impact on partners' sociability, a question with a quantitative response would have been better.

Disfigurement considered to be important reinforces isolation and impairs sociability. Goffman uses the term "stigma" [24] for an undesirable attribute that renders the individual different from the norm or social group in which he or she lives. Such "stigmatization" is due to an attribute or physical sequela, such as loss of the voice, which is discrediting and acts as a barrier to social interaction. Relations with other

people become difficult, especially when sequelae are visible. Stigmatized patients may feel rejected by people they meet. “Normal” people do not know how to react to stigmatization and a feeling of discomfort or avoidance arises.

Finally, we focused exclusively on partners of patients in the early stages of treatment, between 1 and 12 months after diagnosis, when later treatment side-effects have not all set in. Radiation therapy in particular is liable to induce later side effects [25]. A more long-term study of disease impact on partners could have been performed.

## 5. Conclusion

Although many studies demonstrated the impact of cancer on the quality of life of patients and partners, this is the first to document impairment of partners’ sociability. Health professionals need to be aware of such changes, and multidisciplinary management should be undertaken to improve support.

## Acknowledgments

We thank the patients and partners who filled out and returned our questionnaires, the ENT physicians, maxillofacial surgeons, stomatologists, oncologists, pathologists, health insurance physicians, multidisciplinary team meeting secretaries, medical secretaries and medical records administrators of the Calvados, Manche, Somme and Nord administrative *Départements*. We also thank the Ligue Contre le *Cancer* of Calvados, Manche and Nord for funding (grant number: PRC07/EB).

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