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## Research Article

# Development and preliminary validation of the questionnaire "Evaluation of the constitution of social circles (ECSC)" in patients treated for cancer of the upper aerodigestive tract

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## Abstract

**Purpose:** The constitution of social circles around patients treated for cancer of the upper aerodigestive tract (UADT) has a major influence on factors that affect Quality of Life (QOL) but is poorly assessed, mainly due to a lack of tools. The objective of this study is to develop a questionnaire that assesses the constitution of social circles in a population treated for UADT cancer and to analyze the construct (structural and clinical) and criterion validity.

**Methods:** The Evaluation of the Constitution of Social Circles (ECSC) questionnaire was developed in French by a committee of experts. Structural validity was analyzed using inter-item correlations. The scores of a group of patients treated for UADT cancer were compared with those of a group of healthy subjects (clinical validity). For criterion validity, the ECSC scores were compared to those from various questionnaires that assess social functioning (QFS), psychological status (HAD), perceived speech impairment (PHI) and QOL (EORTC QLQ-H&N35) in patients.

**Results:** Structural validity shows low to moderate inter-item correlations which is consistent with the construction of the questionnaire not assessing underlying concepts. Clinical validity was satisfactory regarding the frequency of contact ( $p=0.01$ ), satisfaction with the frequency of contact in the private circle ( $p=0.03$ ), and the size of the social circles of family and friends ( $p\leq 0.01$ ). Criterion validity was adequate with moderate correlations between the ECSC scores and the QFS sub-scores of interest ( $r_s > 0.56$ ,  $p < 0.05$ ). Anxiety (HAD) had a low correlation ( $|r_s|=0.46$ ,  $p < 0.05$ ) with satisfaction with exchanges and the frequency of contact with family. Satisfaction with exchanges with the private circle was moderately correlated with the EORTC QLQ-H&N35 score ( $r_s=0.56$ ,  $p=0.01$ ) and showed a negative trend on the PHI ( $r_s < -0.39$ ,  $p \geq 0.05$ ).

**Conclusion:** While the test-retest reliability is yet to be evaluated and the sample size should be increased, this preliminary study shows that the ECSC is a valid tool for assessing the constitution of social circles in patients treated for UADT cancer. It highlights the links between social circles and their functional impact on communication and QOL.

## 1. Background

The International Classification of Functioning, Disability and Health developed by the World Health Organization in 2001 [1] suggests looking beyond the impairment to the functional (activity limitations) and psychosocial consequences (participation restrictions) of pathologies. In this classification, personal and environmental factors can impact functional and psychosocial levels. Social support is one of these environmental factors. Social circles (family, friends, caregivers, etc.) have a facilitating or degrading role on the dynamics of activities and participation. Moreover, care strategies now require considering activity limitations and participation restrictions. Caregivers are increasingly involved in the therapeutic protocol, and therapeutic strategies must be adapted to the chronicity of the disease.

In 1995, Wilson [2] presented a bio-psycho-social model through which the different levels involved in functional and psychosocial dynamics can be clarified, and any causal relations that may exist between biological and physiological factors, symptomatic status, functional status, general health perceptions and overall Quality of Life (QOL) can be established.

Overall QOL is defined as overall general well-being and personal development assessed objectively and subjectively in physical, material, social and emotional dimensions, weighted by a set of personal values [3,4]. Health-related QOL refers to how one functions in life and perceives well-being in the physical, mental, and social domains of health specifically [5–7]. Therefore, the characteristics of individuals and their environment, such as the patient's values or social support system, can modify functional status and the general perception of health, which are intermediate factors between biological and physiological variables and QOL.

Many subjective tools have been developed to allow patients to self-assess their symptomatic or functional status (e.g. Voice Handicap Index [8] or Speech Handicap Index [9]) and the perception of QOL (EORTC QLQ-C30 and H&N35 [10,11] and FACT-G [12]). However, the characteristics of the patient's social environment are less explored in healthcare contexts.

In upper aerodigestive tract (UADT) oncology, many studies focus on the QOL of patients [13] in terms of associated impairments, treatment [14] or peer-to-peer support [15]. However, few consider the influence that the constitution of social circles around the patient can have on the relationship between cancer and QOL, with regards to social support [16] or social well-being [17]. A social circle is defined as a set of people with connections, "common ground" and norms that are mutually recognized as shared [18].

Although the relationships within the different social circles and with QOL are complex as shown by the biopsychosocial models [2], psychological, cognitive and general health factors (associated diseases, cancer risk factors and the functional impact of ENT cancer pathology on communication) must be included in the determination of activity limitations and participation restrictions.

Psychological status is linked to the formation of social circles [19]. Weak social relationships increase the level of psychological distress and decrease the motivation to take care of oneself [20]. Social isolation increases the risk of depression, while this risk is decreased by social support [21].

Fratiglioni [22] showed that at the cognitive level, the risk of developing dementia is higher in isolated individuals and those who live alone and are unmarried.

General health is perceived differently depending on the size of the formal support network and the individual's satisfaction with this network [23]. For instance, the risk of colds is increased in individuals with a reduced social network [24]. Even exposure to the risk factors of ENT cancer is linked to the individual's social network. Smoking [24] and alcohol consumption [25] are also higher in individuals with reduced social circles.

With regards to functional limitations, perceived social support affects patients' ability to communicate with their peers [26]. Speech and communication also impact on social dynamics and social isolation is positively correlated with withdrawal from situations involving communication due to poor speech intelligibility, especially for laryngectomized patients [27].

Finally, socially isolated women report a lower QOL (age-adjusted models and multivariate-adjusted models) [28]. In ENT oncology specifically, social support is positively correlated with speech-related QOL [29].

Therefore, it seems to be essential to consider the constitution of social circles of patients in oncology. Social circles can have an impact on functional limitations which include communication skills on one hand, and QOL on the other.

Various questionnaires are available to assess social network. For example, there are questionnaires on supportive behavior in anxiety situations in university students [30], on the satisfaction and availability of social support in healthy adults (such as the SSQ6) [31], and on social adjustment [32]. Another focuses on the frequency with which different relationships are used to fulfill the functions of three behavioral systems; attachment, care and affiliation, in 200 adolescents [33]. Other questionnaires, such as Blackstone's Communication inventory, provide information about the social environment of people with communication needs but are not developed as tests [34]. Finally, one questionnaire measures the frequency of participation and satisfaction with social behaviors of an adult psychiatric population in different types of daily activities [35].

However, these questionnaires have two limitations. On one hand, they are not validated in a clinical context in diseased populations, except for the Social Functioning Questionnaire [35]. On the other hand, none of them specifically evaluates the constitution of social circles in terms of the size of each circle, the frequency of relations with each circle, and the satisfaction with the frequency and quality of exchanges with each circle. However, not only does the constitution of social circles influence subjects' communication needs, but it also contributes to their psychosocial dynamics in terms of interpersonal relationships [36].

The objective of this study is to develop a questionnaire that assesses the constitution of social circles in a population treated for UADT cancer and to analyze the construct and criterion validity in patients in this population.

## 2. Methods

### 2.1. Design

This is a cross-sectional observational questionnaire validation study, with controls.

The study protocol was approved by the Committee for the Protection of Persons (CPP: Ouest IV, 19/02/2020, reference 11/20\_3) within the framework of the ANR RUGBI project<sup>1</sup>.

This study was conducted in two steps: development and then validation of the Evaluation of the Constitution of Social Circles (ECSC).

### 2.2. Development of the ECSC

An expert committee was formed to develop the ECSC, which included two speech therapists, a phoniatrician qualified in language sciences, two computer science researchers and a social scientist/psychology researcher (see supplementary material). The experts were selected according to their academic disciplines which provide complementary perspectives on the social and clinical aspects of social circles and on data processing. All the experts are also involved in multiple research projects related to QOL in their respective fields of expertise.

Multiple focus groups were led with these experts to reach a consensus on two subjects: (1) the definition of social circles and (2) the criteria to be evaluated for each social circle.

#### 2.2.1. Defining social circles

The definition provided by Bidart et al. [18] was given to the experts initially: a social circle is a set of people, with connections, "common ground" and norms that are mutually recognized as shared.

Based on that definition, six social circles were selected by the expert committee and defined in French. Three were part of the patient's close network: the private circle (people with whom one lives every day), family (family who is not necessarily seen on a daily basis but with whom regular contact is maintained), and friends (people who are liked, whom one knows well, and with whom one has close regular contact). The other three circles are more distant individuals: acquaintances (people one has met, with whom one has regular contact but no special relationship, or about whom one knows little), caregivers

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<sup>1</sup> <https://www.irit.fr/rugbi>

and community (people one knows, whom one greets, with whom one shares common interests but have no special relationship), and strangers.

These definitions are close to those proposed by Blackstone [37], with clarification of some circles. The Family circle proposed by Blackstone is segmented into two separate circles to differentiate between the everyday family and close family who are not seen on a daily basis. The other circles are very similar: Blackstone's Friends, Acquaintances, Paid professionals and Unfamiliar partners correspond respectively to circles of Acquaintances, Caregivers and community, and Strangers according to the ECSC.

## 2.2.2. Choice of ECSC criteria

Four evaluation criteria, based on the QFS questionnaire model [35] in terms of frequency and satisfaction assessment, were also defined by the expert committee. The QFS assesses social functioning in eight dimensions of daily living (activities, daily tasks, hobbies, family and intimate relationships, extrafamilial relationships, financial and administrative management, general health and community life). For each of these dimensions, two questions are asked: one related to the frequency of participation in these dimensions, the other to satisfaction with the participation. Each question is constructed on a Likert-like scale, from 5 to 0 (for frequency, 5 = every day to 0 = never, for satisfaction, 5 = very satisfied to 0 = very unsatisfied).

The objective of the questionnaire was to be able (1) to quantify the size and frequency of contact of each social circle and (2) to establish the satisfaction with the exchanges with the members of these different circles.

Four evaluation criteria were chosen by the experts: two related to the constitution of social circles (number and frequency), the other two related to the satisfaction with the exchanges and contact with the members of these social circles. Therefore, the first criterion concerns the number of people considered to be part of the circle (see column A, supplementary material). The second criterion concerns the frequency of contact (column B). The third concerns overall satisfaction with the frequency of contact (column C). The last criterion concerns overall satisfaction with the exchanges with the people in the different circles (column D).

## 2.2.3. Scoring procedures for the ECSC criteria

Two of the four evaluation criteria were measured on a frequency scale (number of people in each circle and the frequency of contact).

The number of people in each circle (column A) was assessed for the private, family, and friend circles. No quantification was requested for the other social circles due to the difficulty in achieving reliability. For the private circle, four responses were proposed: 0, 1, 2 to 4, or 5 and more. For family and friends, five responses were proposed: 0, 1, 2 to 4, 5 to 9, or 10 and more. The score assigned to this criterion corresponds to the first value of the proposed response (i.e. 0, 1, 2, 5, or 10).

The frequency of contact (column B) was measured for all six circles on a five-point scale: every day (score = 5), several times a week (4), several times a month (3), several times a year (2), once a year or less (1).

The other two criteria were related to perceived satisfaction and were measured for all six social circles. The satisfaction criterion regarding the frequency of contacts with each social circle (column C) was evaluated on an 11-point Likert scale, ranging from -5 (frequency estimated as too low), to +5 (frequency estimated as too high), with 0 considered a neutral value. The more the value deviates from 0, the lower the satisfaction (frequency too low if leaning towards the negative, or too high if leaning towards the positive).

The last criterion, which is related to the satisfaction of exchanges with each social circle (column D), was evaluated on an 11-point Likert scale, from -5 (very unsatisfactory exchanges), to +5 (very satisfactory exchanges), with 0 for neutral. Note that, unlike column C, the change in value is linear.

For the two criteria related to satisfaction, the score assigned for the evaluation corresponds to the value of the item checked by the participant.

## 2.3. Validating the ECSC

### 2.3.1. Participants

To validate the ECSC, patients coming for consultation or hospitalization in an ENT rehabilitation service or in an ENT service were included. They were recruited by the ENT or medical staff. In addition, associations of laryngectomized patients were contacted to distribute the questionnaire to their members who met the inclusion criteria.

The inclusion criteria were: being of legal age (at least 18 years old) and having been treated for cancer of the oral cavity, oropharynx, hypopharynx, or larynx (surgical treatment and/or radiotherapy and/or chemotherapy) for at least six months (stable disorders). Exclusion criteria were: patients with any other associated chronic disease, those who were participating in another research with an ongoing exclusion period, or those who the investigator was unable to provide with information and whose compliance could not be ensured due to impaired physical or psychological health (clinical judgement by the investigator).

Controls were recruited on a voluntary basis. Adult subjects with no history of cancer treatment or, in general, no history of chronic disease, were invited to participate. There was no strict matching with the patient population, but attention was paid to the characteristics of the control subjects, in particular their age (for two groups of patients and controls close in age, this being a factor that can influence the constitution of social circles).

All subjects (patients and controls) who could be included during the inclusion period (October 2019 – December 2020) were asked to participate in this study. The inclusion period corresponds to the inclusion period of the quality of life work package of the main study (RUGBI project).

### 2.3.2. Validation study

The validation study was conducted according to COSMIN recommendations [38].

Construct validity was examined by:

- evaluating the inter- and intra-circle correlations of each item (structural validity);
- comparing performance between patients and controls (clinical validity: hypothesis-testing, i.e, patients with UADT cancer are more likely to be impacted in the constitution of their social circles than healthy subjects).

In the absence of an accurate reference tool to measure the constitution of social circles, several questionnaires were used to examine the criterion validity. All were self-reported.

Four items of the Social Functioning Questionnaire (QFS) [35] (Dimension IV. Family and Couple Relationships: Frequency, Satisfaction; Dimension V. Extra-Familial Relationships: Frequency, Satisfaction) as well as the QFS overall Frequency and Satisfaction scores, were compared to the scores of each ECSC item. The higher the QFS scores, the higher the frequency and satisfaction (same change in score as for the ECSC). In fact, the QFS assesses the frequency and satisfaction of exchanges in two social groups (Family/Couple which corresponds to the Private and Family circles, and extra-familial which may correspond to Friend, Acquaintance, Caregiver and community or Stranger circles). This construction of the QFS enables a comparison of all the items of the ECSC with the QFS. Note that only patients treated for oral cavity or oropharyngeal cancer were asked to complete the QFS due to a deviation in the protocol for laryngeal cancer patients.

Due to the association between social isolation and depression [21], the Hospital Anxiety and Depression Scale [39] was used. This 14-item questionnaire gives a sub-score of anxiety from seven items and a sub-score of depression from the seven other items. The higher the score, the more severe the symptomatology (inverse scoring for ECSC). A moderate correlation is expected between HAD and ECSC at least for the anxiety or depression sub-scores.

The Phonation Handicap Index [40] is a 15-item questionnaire that assesses speech-related symptomatology, speech impairment and psychosocial impact (inverse scoring for ECSC : the higher the score, the more severe the symptomatology). The EORTC QLQ-H&N35 is a cancer-specific health-related QOL questionnaire including a Speech dimension (three items, the higher the score the more

severe the symptomatology, similar to ECSC scoring) [41]. Both were used to analyze the relationship between speech and social support. As speech affects communication, a link between speech impairment and social circle formation is expected [29,42].

Finally, Global Health Status, Physical Functioning, and Role Functioning scores from the EORTC QLQ-C30 [10] were compared to the ECSC scores (inverse scoring). The links between QOL and the constitution of social circles [28,29] led us to use this cancer-specific QOL questionnaire with 30 items.

### 2.3.3. Statistical analyses

The statistical analyses were carried out using Stata 16.1 software (StataCorp. 2019. *Stata Statistical Software: Release 16*. College Station, TX: StataCorp LLC.).

For the descriptive analysis of the patient and control groups, frequency indicators were chosen for the qualitative variables (gender and socio-professional category). Age was described by mean and median as indicators of central tendency, and by standard deviation and interquartile range as indicators of dispersion.

Frequency indicators were also used to describe the distribution of tumor location and treatment in patients.

Due to the sample size ( $n < 30$ ), nonparametric statistical tests were used. The characteristics of patients and healthy subjects were compared using a Mann-Whitney test (for age), and a Chi-squared test (for gender). The analysis of construct validity (structural validity) and criterion validity was based on Spearman's correlation coefficients. For clinical validity, the patient/control comparison was assessed with a Mann-Whitney test.

In all analyses, a level of significance at 5% was chosen. The correlation analysis was performed using the following thresholds [43]: higher than 0.9 (very high correlation), 0.7 to 0.9 (high correlation), 0.5 to 0.7 (moderate correlation), 0.3 to 0.5 (low correlation), below 0.3 (negligible correlation). The correlation coefficients were presented with their p-value.

## 3. Results

### 3.1. Participants

Twenty-two patients treated for UADT cancer participated in this study (participation rate: 100%), most of whom were men (15/22, 62%). The mean age was 65.6 years. Nine patients (41%) were treated for laryngeal or hypopharyngeal cancer, 7 (32%) for oral cavity cancer, and 6 (27%) for oropharyngeal cancer.

Twenty-one controls were also included with a mean age of 60.8 years, including 12 women (57%) (Table 1).

Patients and controls were not significantly different in terms of age ( $p=0.11$ , Mann-Whitney test) and gender ( $p=0.07$ , Chi-squared test).

### 3.2. Construct validity: structural validity

Inter-item correlations (Table 2) were mainly low to moderate. This result is consistent with the structure of our questionnaire which is not built with underlying dimensions.

Nevertheless, a complementary analysis of inter-item correlations seems to reveal three groups of social circles, within which the correlations are higher.

First, moderate to high significant correlations were found between the family and friend circles, particularly regarding the frequency of contact (Family B / Friends B correlation:  $r_s=0.56$ ,  $p=0.02$ ), satisfaction with frequency (Family C / Friends C correlation:  $r_s=0.77$ ,  $p < 0.01$ ), and satisfaction with exchanges (Family D / Friends D correlation:  $r_s=0.84$ ,  $p < 0.01$ ).

Table 1: Characteristics of included subjects in each group (patients and controls)

	Patients (n=22)	Controls (n=21)
<b>Gender – n (%)</b>		
Men	15 (62%)	8 (38%)
Women	7 (38%)	12 (57%)
Missing data	0	1 (5%)
<b>Age</b>		
Mean (SD)	65.6 (9.70)	60.75 (6.51)
Median (IQR)	65 (56; 72)	59.5 (56.5; 66.5)
Missing data	0	1
<b>Socio-professional category – n (%)</b>		
Small employer and self-employed occupations	1 (4%)	0 (0%)
Large employer, higher-grade professional, administrative & managerial occupations	3 (14%)	8 (38%)
Intermediate occupations	3 (14%)	2 (10%)
Clerical workers	4 (18%)	0 (0%)
Blue-collar workers	1 (4%)	3 (14%)
Retired workers	9 (41%)	8 (38%)
Never worked and long-term unemployed	1 (4%)	0 (0%)
<b>Location – n (%)</b>		
Oral cavity	7 (32%)	
Oropharynx	6 (27%)	
Larynx/Hypopharynx	9 (41%)	
<b>Treatment – n (%)</b>		
Surgery	1 (5%)	
Radiotherapy	1 (5%)	
Surgery + Radiotherapy	5 (23%)	
Radiotherapy + Chemotherapy	6 (27%)	
Surgery + Radiotherapy + Chemotherapy	9 (40%)	
<b>Time after treatment (in month)</b>		
More than 6 months, without precision – n (%)	9 (40%)	
Mean (SD)	104.69 (157.41)	
Median (IQR)	18 (8; 168)	

A second group including acquaintance, caregiver and community and stranger circles had high significant correlations between satisfaction with frequency concerning acquaintances and caregivers (Acquaintances C / Caregivers C correlation:  $r_s=0.83$ ,  $p<0.01$ ) and concerning strangers (Acquaintances C / Strangers C correlation:  $r_s=0.93$ ,  $p<0.01$ ). Moderate to high correlations were also found concerning satisfaction with exchanges (Acquaintances D / Caregivers D correlation:  $r_s=0.71$ ,  $p<0.01$ ; Caregivers D / Strangers D correlation:  $r_s=0.55$ ,  $p=0.03$ ).

Finally, the private circle was more transversal. It showed moderate significant correlations between frequency of contact in this circle and the acquaintance circle (Private B / Acquaintances B correlation:  $r_s=-0.51$ ,  $p=0.04$ ). Moreover, satisfaction with frequency in the private circle was highly correlated with this item in the family circle (Private C / Family C correlation:  $r_s=0.74$ ,  $p<0.01$ ) as well as in the friend circle (Private C / Friends C correlation:  $r_s=0.62$ ,  $p=0.01$ ). Satisfaction with exchanges was moderately correlated with satisfaction with the family (Private D / Family D correlation:  $r_s=0.65$ ,  $p=0.01$ ) and friend (correlation Private D / Friends D:  $r_s=0.62$ ,  $p=0.01$ ) circles.



*Table 2: Correlation matrix between the scores of the ECSC items for analysis of construct validity (The number corresponds to a circle: 1—Private, 2—Family, 3—Friends, 4—Acquaintances, 5—Caregivers and Community, 6—Strangers. The letter corresponds to a criterion: A—number of members, B—regularity of contact, C—satisfaction with frequency, D—satisfaction with exchanges; in medium gray with white numbers:  $-0.70 < r_s < -0.50$ , in medium gray with black numbers:  $0.50 < r_s < 0.70$ , in dark gray:  $|r_s| \geq 0.70$ ) – in brackets, p-values of Spearman's correlation coefficients*

	1A	1B	1C	1D	2A	2B	2C	2D	3A	3B	3C	3D	4B	4C	4D	5B	5C	5D	6B	6C
1B	0.58 (0.02)	1.00																		
1C	0.17 (0.52)	0.22 (0.41)	1.00																	
1D	0.20 (0.45)	0.26 (0.33)	0.67 ( $<0.01$ )	1.00																
2A	-0.02 (0.94)	-0.37 (0.16)	0.15 (0.59)	0.21 (0.44)	1.00															
2B	0.23 (0.39)	0.03 (0.92)	-0.15 (0.57)	-0.22 (0.41)	-0.19 (0.48)	1.00														
2C	-0.08 (0.76)	0.04 (0.89)	0.74 ( $<0.01$ )	0.41 (0.12)	-0.14 (0.61)	0.31 (0.25)	1.00													
2D	0.11 (0.67)	0.20 (0.44)	0.55 (0.03)	0.65 (0.01)	0.04 (0.87)	0.25 (0.36)	0.69 ( $<0.01$ )	1.00												
3A	0.06 (0.82)	-0.25 (0.34)	0.27 (0.32)	-0.14 (0.61)	0.18 (0.52)	0.28 (0.29)	0.29 (0.28)	0.07 (0.79)	1.00											
3B	0.25 (0.36)	0.20 (0.47)	0.04 (0.89)	-0.21 (0.45)	-0.07 (0.80)	0.56 (0.02)	0.31 (0.24)	0.31 (0.25)	0.51 (0.04)	1.00										
3C	0.13 (0.63)	0.08 (0.77)	0.62 (0.01)	0.41 (0.11)	-0.21 (0.44)	0.24 (0.37)	0.77 ( $<0.01$ )	0.62 (0.01)	0.03 (0.90)	0.24 (0.37)	1.00									
3D	0.13 (0.62)	0.15 (0.57)	0.49 (0.05)	0.62 (0.01)	-0.17 (0.52)	0.34 (0.20)	0.72 ( $<0.01$ )	0.84 ( $<0.01$ )	0.11 (0.68)	0.31 (0.24)	0.74 ( $<0.01$ )	1.00								
4B	-0.20 (0.46)	-0.51 (0.04)	-0.28 (0.30)	-0.24 (0.37)	-0.20 (0.44)	-0.05 (0.86)	-0.08 (0.74)	-0.13 (0.64)	-0.07 (0.80)	-0.25 (0.34)	-0.05 (0.84)	-0.07 (0.81)	1.00							
4C	-0.30 (0.26)	-0.49 (0.05)	0.01 (0.98)	0.23 (0.38)	0.04 (0.88)	0.31 (0.24)	0.37 (0.16)	0.34 (0.20)	-0.28 (0.29)	-0.15 (0.57)	0.43 (0.09)	0.33 (0.22)	0.36 (0.18)	1.00						
4D	-0.16 (0.56)	-0.53 (0.03)	-0.30 (0.25)	-0.01 (0.98)	0.08 (0.77)	0.22 (0.42)	-0.08 (0.76)	-0.02 (0.93)	0.11 (0.68)	0.18 (0.50)	-0.03 (0.92)	0.03 (0.91)	0.47 (0.07)	0.54 (0.03)	1.00					
5B	-0.21 (0.43)	-0.21 (0.44)	-0.45 (0.08)	-0.30 (0.25)	-0.26 (0.33)	-0.17 (0.53)	-0.30 (0.26)	-0.14 (0.60)	-0.23 (0.38)	0.02 (0.93)	-0.07 (0.78)	-0.04 (0.87)	0.69 ( $<0.01$ )	0.06 (0.82)	0.32 (0.23)	1.00				
5C	-0.48 (0.06)	-0.57 (0.02)	-0.33 (0.22)	-0.06 (0.82)	-0.05 (0.85)	0.32 (0.23)	0.20 (0.46)	0.10 (0.70)	-0.16 (0.56)	0.03 (0.90)	0.13 (0.62)	0.17 (0.52)	0.45 (0.08)	0.83 ( $<0.01$ )	0.73 ( $<0.01$ )	0.28 (0.30)	1.00			
5D	-0.31 (0.24)	-0.38 (0.15)	-0.18 (0.51)	0.22 (0.41)	0.10 (0.71)	0.39 (0.13)	0.22 (0.42)	0.44 (0.09)	-0.12 (0.66)	0.27 (0.32)	0.24 (0.37)	0.47 (0.07)	0.18 (0.51)	0.71 ( $<0.01$ )	0.71 ( $<0.01$ )	0.21 (0.43)	0.77 ( $<0.01$ )	1.00		
6B	0.17 (0.53)	-0.14 (0.62)	0.22 (0.42)	0.25 (0.36)	-0.07 (0.78)	0.03 (0.92)	0.29 (0.27)	0.31 (0.24)	-0.15 (0.59)	0.00 (0.99)	0.50 (0.05)	0.47 (0.07)	0.44 (0.09)	0.34 (0.20)	0.14 (0.62)	0.44 (0.08)	0.15 (0.57)	0.26 (0.32)	1.00	
6C	-0.43 (0.09)	-0.58 (0.02)	-0.01 (0.97)	0.24 (0.37)	0.08 (0.77)	0.23 (0.40)	0.26 (0.34)	0.29 (0.28)	-0.24 (0.38)	-0.28 (0.29)	0.33 (0.21)	0.29 (0.27)	0.41 (0.12)	0.93 ( $<0.01$ )	0.51 (0.05)	0.13 (0.63)	0.75 ( $<0.01$ )	0.68 ( $<0.01$ )	0.26 (0.33)	1.00
6D	-0.26 (0.32)	-0.42 (0.11)	0.13 (0.63)	0.35 (0.18)	0.11 (0.68)	0.11 (0.68)	0.24 (0.38)	0.37 (0.16)	-0.29 (0.27)	-0.28 (0.29)	0.45 (0.08)	0.27 (0.31)	0.27 (0.31)	0.87 ( $<0.01$ )	0.40 (0.13)	0.07 (0.80)	0.55 (0.03)	0.55 (0.03)	0.26 (0.32)	0.93 ( $<0.01$ )

### 3.3. Construct validity: clinical validity (hypothesis-testing)

Details of the scores for each item can be found in Table 3.

Clinical validity was analyzed by testing the hypothesis that the constitution of the social circles of patients with UADT cancer is more likely to be impacted than that of healthy subjects.

On average, patients treated for UADT cancer had smaller social circles than controls. Patients had fewer people in their private circle on average, although the difference is not statistically significant (1 vs. 1.43 for controls;  $p=0.24$ ). The number of members in the family and friend circles was significantly lower in patients: an average of 3.41 members in their family versus 6.29 in controls ( $p<0.01$ ), and 3.5 friends versus 6.43 for controls ( $p=0.01$ ).

Frequency of contact was significantly higher in controls in the private domain ( $p=0.01$ ). For the family ( $p=0.85$ ) and friend circles ( $p=0.43$ ), frequency of contact was also higher in controls but the difference is not statistically significant. However, contact with acquaintances ( $p=0.65$ ) and caregivers ( $p=0.46$ ) was more frequent among patients (but the difference is not statistically significant).

Satisfaction with exchanges showed higher median scores for controls in all social circles. On average, satisfaction with frequency was also higher for controls for private (with significance:  $p=0.03$ ), acquaintance and stranger circles, but was just slightly higher for patients for the three other circles (family: 0.02-point difference; friends: 0.11-point difference; caregivers and community: 0.11-point difference).

Finally, for all social circles, satisfaction with exchanges was higher in controls, although this difference is not statistically significant.

Table 3: Details of ECSC scores for patients and controls, and p-value (Mann-Whitney test) for analysis of clinical validity

		PATIENTS						CONTROLS						p-value
		N	Mean	Standard dev.	Perc. 25	Perc. 50	Perc. 75	N	Mean	Standard dev.	Perc. 25	Perc. 50	Perc. 75	
Private	Number	22	1	0.87	0	1	2	21	1.43	1.08	1	1	2	0.24
	Regularity of contact	20	4.15	1.46	4	5	5	21	4.95	0.22	5	5	5	0.01
	Satisfaction with frequency	20	-0.55	1.82	-1	0	0	21	0.62	1.32	0	0	0	0.03
	Satisfaction with exchanges	19	1.95	2.95	0	2	5	21	2.81	2.52	2	4	5	0.47
Family	Number	22	3.41	3.03	2	2	5	21	6.29	3.50	2	5	10	<0.01
	Regularity of contact	21	3.10	1.09	3	3	4	21	3.14	1.01	2	3	4	0.85
	Satisfaction with frequency	22	-0.5	2.46	-2	0	0	21	-0.48	2.25	-2	0	0	0.95
	Satisfaction with exchanges	21	1.38	3.06	0	2	4	21	2.92	2.44	3	3	4	0.10
Friends	Number	22	3.5	2.79	2	2	5	21	6.43	3.37	5	5	10	0.01
	Regularity of contact	21	2.91	1.18	2	3	4	21	3.1	0.54	3	3	3	0.43
	Satisfaction with frequency	22	-0.68	2.63	-2	0	0	21	-0.57	2.09	-2	0	0	0.80
	Satisfaction with exchanges	21	0.95	3.53	-2	2	4	21	2.48	2.4	1	3	4	0.24
Acquaintances	Regularity of contact	22	3	1.11	3	3	4	19	2.74	0.99	2	3	4	0.43
	Satisfaction with frequency	22	-0.05	1.94	0	0	0	19	0.05	1.87	0	0	0	0.65
	Satisfaction with exchanges	22	0.82	1.87	0	0	2	19	1.58	2.24	0	1	4	0.22
Caregivers—Community	Regularity of contact	22	3.5	1.01	3	3.5	4	19	3.26	0.73	3	3	4	0.46
	Satisfaction with frequency	22	0.27	1.42	0	0	0	19	0.16	0.90	0	0	0	0.99
	Satisfaction with exchanges	22	0.96	1.79	0	0	2	19	1.21	2.04	0	0	3	0.71
Strangers	Regularity of contact	19	3.05	1.51	2	3	5	17	3.47	1.33	3	4	4	0.40
	Satisfaction with frequency	18	-0.39	1.88	0	0	0	17	0.18	0.81	0	0	0	0.46
	Satisfaction with exchanges	18	-0.44	1.79	0	0	0	17	0.53	1.28	0	0	0	0.07

### 3.4. Criterion validity

Criterion validity was analyzed using correlation analyses (bivariate analyses).

The number of members of the private circle was moderately correlated with the frequency of contact ( $r_s=0.64$ ,  $p=0.02$ ) and satisfaction with frequency in family circle ( $r_s=0.54$ ,  $p=0.07$ , not statistically significant) (Table 4).

The frequency of family contacts on the QFS was moderately correlated with the number of members in the family circle ( $r_s=0.57$ ,  $p=0.04$ ) with statistical significance. Inversely, satisfaction with family relations on the QFS was moderately correlated with the frequency of family contacts, but this correlation is not statistically significant ( $r_s=-0.56$ ,  $p=0.07$ ).

The correlation between the frequency of extra-familial relations and the size of the friend circle was significantly high ( $r_s=0.73$ ,  $p<0,01$ ) and moderate for the frequency of contact with caregivers ( $r_s=0.52$ ,  $p=0.07$ , not statistically significant).

Finally, the QFS satisfaction sub-score was moderately correlated (statistically significant) with the size of the family ( $r_s=0.68$ ,  $p=0.01$ ) and friend ( $r_s=0.59$ ,  $p=0.03$ ) circles.

*Table 4: Correlations between ECSC and QFS items for analysis of criterion validity (dark gray  $|rs| \geq 0.70$ ; medium gray  $0.50 \leq |rs| < 0.70$ ; light gray  $0.30 \leq |rs| < 0.50$ ) – in brackets, p-value of Spearman's correlation coefficients; in bold, p-values lower than 0.05*

		QFS					
		Family/Couple— Freq.	Family/Couple— Satisf.	Extra familial rel. —Freq.	Extra- familial rel. —Satisf.	Overall frequency	Overall satisfaction
Private	Number	<b>0.64 (0.02)</b>	0.54 (0.07)	0.35 (0.23)	0.43 (0.16)	0.30 (0.32)	0.36 (0.22)
	Regularity of contact	0.15 (0.65)	0.40 (0.24)	0.23 (0.48)	0.17 (0.64)	-0.06 (0.85)	-0.29 (0.38)
	Satisfaction with frequency	0.36 (0.27)	0.44 (0.20)	-0.21 (0.54)	0.39 (0.30)	0.00 (1)	0.28 (0.39)
	Satisfaction with exchanges	0.37 (0.28)	0.17 (0.65)	-0.21 (0.54)	0.39 (0.30)	0.16 (0.65)	<b>0.51 (0.13)</b>
Family	Number	<b>0.57 (0.04)</b>	0.39 (0.20)	0.33 (0.27)	<b>0.58 (0.04)</b>	0.32 (0.28)	<b>0.68 (0.01)</b>
	Regularity of contact	0.26 (0.40)	-0.56 (0.07)	0.06 (0.85)	<b>-0.66 (0.02)</b>	0.24 (0.44)	-0.04 (0.90)
	Satisfaction with frequency	0.18 (0.54)	0.14 (0.67)	-0.03 (0.93)	0.12 (0.70)	0.04 (0.91)	0.15 (0.63)
	Satisfaction with exchanges	0.39 (0.20)	0.26 (0.43)	-0.21 (0.51)	0.42 (0.19)	0.11 (0.71)	0.42 (0.17)
Friends	Number	0.43 (0.14)	0.42 (0.17)	<b>0.73 (&lt;0,01)</b>	0.42 (0.19)	0.35 (0.24)	<b>0.59 (0.03)</b>
	Regularity of contact	-0.09 (0.77)	-0.17 (0.60)	0.49 (0.10)	0.05 (0.88)	-0.15 (0.63)	-0.20 (0.52)
	Satisfaction with frequency	0.35 (0.23)	0.21 (0.49)	-0.11 (0.70)	0.15 (0.62)	0.05 (0.87)	0.00 (0.98)
	Satisfaction with exchanges	0.47 (0.12)	0.14 (0.66)	0.06 (0.83)	0.31 (0.35)	0.31 (0.32)	0.47 (0.12)
Acquaintances	Regularity of contact	-0.36 (0.22)	-0.13 (0.67)	0.19 (0.52)	0.00 (1)	-0.04 (0.89)	-0.13 (0.65)
	Satisfaction with frequency	0.23 (0.44)	0.00 (0.99)	-0.22 (0.46)	-0.06 (0.85)	-0.04 (0.89)	0.00 (0.99)
	Satisfaction with exchanges	-0.02 (0.93)	0.27 (0.38)	0.01 (0.96)	<b>0.56 (0.05)</b>	-0.41 (0.16)	0.09 (0.75)
Caregivers— Community	Regularity of contact	-0.22 (0.46)	-0.06 (0.85)	<b>0.52 (0.07)</b>	0.10 (0.74)	0.14 (0.63)	-0.05 (0.85)
	Satisfaction with frequency	-0.01 (0.97)	-0.08 (0.78)	0.13 (0.66)	0.00 (1)	-0.07 (0.80)	0.10 (0.74)
	Satisfaction with exchanges	0.18 (0.55)	-0.04 (0.90)	-0.05 (0.87)	0.30 (0.33)	-0.05 (0.85)	0.24 (0.41)
Strangers	Regularity of contact	0.24 (0.48)	0.13 (0.71)	0.05 (0.88)	0.22 (0.54)	0.07 (0.82)	0.02 (0.95)
	Satisfaction with frequency	0.27 (0.45)	-0.07 (0.85)	-0.27 (0.45)	-0.13 (0.73)	0.07 (0.84)	0.00 (1)
	Satisfaction with exchanges	0.22 (0.53)	0.03 (0.92)	-0.30 (0.39)	-0.09 (0.82)	0.01 (0.98)	-0.21 (0.56)

On questionnaires that assess associated impairments (Table 5), the anxiety sub-score had a low correlation with satisfaction with exchanges (family:  $rs = -0.46$ ,  $p = 0.03$ , friends:  $rs = -0.39$ ,  $p = 0.08$ , not statistically significant), as well as with the frequency of contact with family ( $rs = 0.46$ ,  $p = 0.04$ , statistically significant) and satisfaction with frequency with friends ( $rs = -0.33$ ,  $p = 0.08$ , not statistically significant). The depression sub-score of the HAD presented the strongest correlations in the private circle (size:  $rs = -0.30$ ,  $p = 0.16$ , satisfaction with exchanges:  $rs = -0.37$ ,  $p = 0.11$ ) and the size of the family circle which was the only significant correlation ( $rs = -0.41$ ,  $p = 0.05$ ).

Table 5: Correlations between ECSC items and associated deficit scales for analysis of criterion validity (dark gray  $|rs| \geq 0.70$ ; medium gray  $0.50 \leq |rs| < 0.70$ ; light gray  $0.30 \leq |rs| < 0.50$ ) – in brackets,  $p$ -value of Spearman's correlation coefficients; in bold,  $p$ -values lower than 0.05

		HAD		EORTC QLQ-H&N35	PHI			EORTC QLQ-C30			
		Anxiety	Depression	Speech	Impairments	Activities	Participation	Social functioning	Global QoL	Physical functioning	Role functioning
Private	Size	-0.06 (0.76)	-0.30 (0.16)	-0.03 (0.87)	-0.13 (0.53)	-0.06 (0.76)	-0.14 (0.52)	0.20 (0.36)	0.35 (0.10)	<b>0.51 (0.01)</b>	0.30 (0.17)
	Regularity of contact	-0.15 (0.51)	0.10 (0.67)	0.04 (0.84)	-0.09 (0.69)	-0.04 (0.84)	-0.08 (0.73)	-0.01 (0.94)	0.06 (0.78)	0.18 (0.44)	0.17 (0.47)
	Satisfaction with frequency	-0.26 (0.25)	-0.26 (0.27)	-0.39 (0.08)	-0.22 (0.33)	-0.41 (0.06)	-0.30 (0.18)	0.25 (0.27)	0.14 (0.55)	0.16 (0.49)	0.32 (0.18)
	Satisfaction with exchanges	-0.25 (0.30)	-0.37 (0.11)	<b>-0.53 (0.01)</b>	-0.44 (0.05)	-0.39 (0.09)	-0.26 (0.28)	<b>0.56 (0.01)</b>	0.36 (0.12)	0.31 (0.18)	0.42 (0.07)
Family	Size	-0.24 (0.27)	-0.41 (0.05)	-0.10 (0.64)	0.13 (0.54)	0.07 (0.75)	0.15 (0.49)	-0.02 (0.91)	0.04 (0.83)	<b>0.58 (&lt;0.01)</b>	0.12 (0.57)
	Regularity of contact	<b>0.46 (0.04)</b>	0.25 (0.27)	0.42 (0.05)	0.20 (0.37)	0.23 (0.30)	0.32 (0.14)	-0.08 (0.71)	-0.09 (0.69)	-0.08 (0.72)	-0.29 (0.21)
	Satisfaction with frequency	-0.25 (0.26)	0.02 (0.90)	0.03 (0.88)	0.02 (0.89)	-0.09 (0.66)	-0.01 (0.96)	0.005 (0.97)	0.07 (0.75)	-0.06 (0.77)	0.11 (0.63)
	Satisfaction with exchanges	<b>-0.46 (0.03)</b>	-0.12 (0.59)	-0.13 (0.55)	-0.27 (0.22)	-0.27 (0.23)	-0.18 (0.41)	0.18 (0.42)	0.11 (0.63)	0.26 (0.25)	0.18 (0.43)
Friends	Size	-0.04 (0.84)	-0.11 (0.59)	-0.02 (0.90)	-0.009 (0.96)	-0.13 (0.55)	-0.07 (0.73)	-0.33 (0.12)	0.24 (0.26)	0.23 (0.29)	-0.002 (0.99)
	Regularity of contact	-0.04 (0.86)	0.18 (0.41)	0.19 (0.40)	-0.03 (0.87)	-0.06 (0.79)	-0.02 (0.91)	-0.41 (0.06)	-0.04 (0.84)	-0.10 (0.66)	-0.37 (0.10)
	Satisfaction with frequency	-0.33 (0.13)	-0.05 (0.81)	0.02 (0.92)	-0.02 (0.91)	-0.14 (0.52)	-0.11 (0.61)	0.10 (0.65)	-0.09 (0.67)	-0.11 (0.62)	0.15 (0.49)
	Satisfaction with exchanges	-0.39 (0.08)	-0.13 (0.56)	-0.07 (0.75)	-0.18 (0.42)	-0.16 (0.47)	-0.09 (0.66)	0.09 (0.67)	0.13 (0.54)	0.04 (0.84)	-0.009 (0.96)
Acquaintances	Regularity of contact	0.11 (0.61)	0.03 (0.86)	0.004 (0.98)	-0.14 (0.52)	-0.02 (0.92)	-0.20 (0.34)	0.16 (0.47)	0.08 (0.69)	-0.10 (0.64)	-0.09 (0.67)
	Satisfaction with frequency	-0.04 (0.83)	0.05 (0.82)	0.30 (0.17)	0.20 (0.36)	0.26 (0.23)	0.23 (0.30)	0.21 (0.33)	-0.17 (0.42)	-0.05 (0.79)	-0.007 (0.97)
	Satisfaction with exchanges	-0.10 (0.65)	-0.02 (0.92)	-0.05 (0.81)	-0.35 (0.10)	-0.26 (0.24)	-0.33 (0.13)	0.27 (0.21)	0.11 (0.62)	0.07 (0.73)	0.007 (0.97)
Caregivers—Community	Regularity of contact	-0.08 (0.70)	-0.11 (0.62)	-0.06 (0.76)	-0.01 (0.94)	0.07 (0.74)	-0.08 (0.72)	0.02 (0.90)	-0.12 (0.57)	-0.01 (0.94)	-0.02 (0.92)
	Satisfaction with frequency	0.02 (0.93)	0.13 (0.55)	0.29 (0.18)	0.25 (0.25)	0.26 (0.23)	0.31 (0.15)	0.09 (0.67)	-0.03 (0.86)	-0.10 (0.63)	0.06 (0.77)
	Satisfaction with exchanges	-0.18 (0.40)	-0.15 (0.49)	-0.01 (0.95)	-0.17 (0.42)	-0.07 (0.74)	-0.03 (0.86)	0.30 (0.16)	-0.02 (0.91)	0.06 (0.77)	-0.05 (0.80)
Strangers	Regularity of contact	-0.28 (0.24)	-0.13 (0.57)	0.05 (0.81)	-0.14 (0.56)	0.18 (0.45)	-0.10 (0.67)	0.16 (0.49)	-0.02 (0.92)	-0.003 (0.98)	-0.07 (0.75)
	Satisfaction with frequency	-0.08 (0.75)	-0.004 (0.98)	0.20 (0.41)	0.11 (0.64)	0.14 (0.55)	0.09 (0.72)	0.26 (0.29)	-0.34 (0.15)	-0.11 (0.65)	-0.24 (0.35)
	Satisfaction with exchanges	-0.13 (0.60)	-0.02 (0.92)	0.12 (0.61)	0.03 (0.87)	0.06 (0.78)	-0.01 (0.96)	0.28 (0.25)	-0.41 (0.08)	-0.07 (0.75)	-0.14 (0.57)

Satisfaction with exchanges in the private circle was highly correlated with the speech domain of the H&N35 ( $r_s = -0.53$ ,  $p = 0.01$ ), but had only a low correlation with the impairment ( $r_s = -0.44$ ,  $p = 0.05$ ) and functional ( $r_s = -0.39$ ,  $p = 0.09$ , not statistically significant) sub-scores of the PHI. The frequency of contact with the family also had a low correlation with the speech domain of the H&N35 ( $r_s = 0.42$ ,  $p = 0.05$ ) and the psychosocial score of the PHI ( $r_s = 0.32$ ,  $p = 0.14$ , not statistically significant). In addition, in the private circle, satisfaction with frequency had a low correlation with the functional ( $r_s = -0.41$ ,  $p = 0.06$ ) and psychosocial ( $r_s = -0.30$ ,  $p = 0.18$ , not statistically significant) PHI sub-scores. Satisfaction with exchanges with acquaintances had a low correlation with the impairment ( $r_s = -0.35$ ,  $p = 0.10$ ) and psychosocial ( $r_s = -0.33$ ,  $p = 0.13$ ) sub-scores of the PHI.

Finally, only satisfaction with exchanges in the private circle was moderately correlated with social functioning on the EORTC QLQ-C30 ( $r_s = 0.56$ ,  $p = 0.01$ ). Although the correlations were not statistically significant, the EORTC QLQ-C30 "social functioning" was moderately correlated with the size ( $r_s = -0.33$ ,  $p = 0.12$ ) and frequency of contacts ( $r_s = -0.41$ ,  $p = 0.06$ ) in the friend circle.

The relation between ECSC scores and QOL assessed by the EORTC QLQ-C30 was low to moderate for the private circle. The size of the private circle and satisfaction with exchanges were systematically associated with overall QOL and specifically with physical and social functioning ( $r_s \geq 0.30$ ,  $p \leq 0.18$ ). The size of the family circle was moderately correlated with physical functioning ( $r_s = 0.58$ ,  $p = 0.04$ , significant correlation). Frequency of contact with friends showed a low correlation ( $r_s = -0.37$ ,  $p = 0.28$ , not statistically significant) with social role. Finally, satisfaction with frequency and exchanges with strangers had a low correlation with overall QOL ( $r_s \leq -0.34$ ,  $p \geq 0.08$ , not statistically significant).

## 4. Discussion

### 4.1. Development of the ECSC

The questionnaire for the Evaluation of the Constitution of Social Circles respects the psychometric properties evaluated at this point in patients treated for UADT cancer.

A first point of analysis concerns the scoring of criterion C (satisfaction with frequency). We chose to propose a scale ranging from -5 (frequency too low) to +5 (frequency too high), with an intermediate score of 0 (satisfactory). This score construction enables linear evaluation of frequency. But an adaptation of this score by transforming the raw scores into absolute values would give values ranging from 0 (satisfactory) to +5 (unsatisfactory). Therefore, an examination of this adapted score using absolute values would provide additional information by targeting the notion of satisfaction which would be complementary to the notion of frequency (evaluated by the raw score).

In our study, several results show a non-significant p-value because our small number of participants only provides a low power to highlight significant links. Therefore, we chose to analyze the value of the correlation coefficient as a priority because this indicator is stronger than the p-value and offers more perspectives for interpretation. The value of the coefficient gives the strength and direction of the relation, whereas the p-value only gives information on the significance of the relation, considering the constraints due to our limited statistical power.

The analysis of structural validity shows that the items are homogeneous and globally are all related to the evaluated concepts of size, frequency and satisfaction with the constitution of social circles. However, a closer look shows that three groups of social circles appear.

The first group includes the family and friend social circles (close relatives). In these two circles, satisfaction with the frequency of contacts and exchanges is linked.

A second group concerns non-close relatives, with a moderate to strong association between satisfaction with exchanges and frequency of contact for three social circles (Acquaintance, Caregiver and community and Stranger).

Finally, the last group concerns the private circle, which shows the highest correlations between satisfaction with exchanges and frequency of contact in this circle and QOL or limitations on speech.

Consequently, these results seem to reflect a three-level dynamic concerning patients' interactions with members of their social circles. Major importance is accorded to the satisfaction with links with the private circle, a predominant role to the size of the family and friend circles, and less close interactions with the non-close relative social circle. However, family and friend circles remain very different, with specific interactions in each. Nevertheless, the tendency of family and friend circles to present statistical correlation indicators that encourage their grouping in the same social circle could be explained by the fact that in oncology, the links with friends are sometimes similar to those with close family or even much closer [44]. Therefore, a grouping of the family and friend social circles makes sense in the specific context of our study population, i.e. oncology.

The analysis of clinical validity shows a decrease in average scores in patients compared to controls. As expected, cancer pathology negatively altered the constitution of social circles [36], although few results appear significant. This lack of statistical significance may be related to our sample size, resulting in a lack of power.

The inverse correlation between satisfaction with family relationships (QFS) and the frequency of family contacts (ECSC) might be explained by the fact that the family circle is smaller for patients and that contact with family members is more highly appreciated due to the lower frequency.

This is consistent with the fact that patients are more isolated after cancer disease [45]. Therefore, it seems that patients have fewer people in their close circles, while more people are in contact with them without developing strong ties. The structuring of patient follow-up with medical care may increase relations with social circles that are less close to the patient.

Regarding criterion validity, the ECSC shows satisfactory correlations with the reference questionnaires.

Laryngectomized patients did not complete the QFS. Therefore, the criterion validity analysis only included patients treated for oral or oropharyngeal cancer. However, the anatomical and structural changes induced by laryngectomy (tracheostomy and increased pulmonary secretions) could also modify contact and the quality of the patients' exchanges with their peers. The criterion validity of the ECSC with laryngectomy patients remains to be demonstrated.

The correlations with QFS are moderate to high regarding the size of the Private, Family, and Friend social circles. Correlations are moderate on the satisfaction items of the ECSC and the QFS.

While the private circle is best correlated with satisfaction with exchanges and overall satisfaction, only low correlations were found with depression and anxiety, contrary to other studies [21].

Finally, the analysis of criterion validity highlights the need to assess each social circle. The Private, Family, and Friend circles are related to anxiety/depression scores, as well as functional performance (social on the EORTC QLQ-C30, and speech on the H&N35). The satisfaction of exchanges with acquaintances is linked to performance for the perceived speech impairment. Finally, overall QOL is linked to satisfaction with the frequency of contact and exchanges with strangers.

## 4.2. Limitations and perspectives

This study does have some limitations.

First, due to our small sample size, the results of this study can only be considered as preliminary. Although *a priori* there is no consensus on how to calculate sample size in validation studies for questionnaires [46], an increase in the sample size would improve the statistical power. The inclusion of a larger number of subjects would allow better generalization of the results, and would make it possible to ascertain the reliability of the results presented in this article. Moreover, increasing the sample size would also permit stratified analyses according to tumor location. Oral, oropharyngeal and laryngeal tumors have different consequences on subjects' capacity to communicate, and affect the phonemic or nasal aspects of speech or voice production. An analysis of the impact of voice or speech disorders according to tumor location on the constitution of social circles could then be carried out.

Among the factors that can impact the constitution of social circles, age should also be considered. In fact, the constitution of social circles changes with age due to retirement, loss of loved ones, etc. [36] A close link has been found between the constitution of social circles and age-related frailty, which can lead to social isolation [47]. Therefore, beyond the clinical data, it seems relevant to analyze the results

of the ECSC in our population according to age for early detection of frailty which can impact therapeutic follow-up.

We chose not to quantify the number of members among the acquaintance, caregiver and community, and stranger social circles because of the difficulties in providing an accurate or close to accurate quantification. However, further validation of the ECSC could include quantifying members to obtain an estimate of the size of each circle. This quantification could provide information about contacts made with peers at social activities without the establishment of close ties. The limits of the ranges in the ECSC should be carefully chosen so that the estimates are precise enough to be informative, but also broad enough to be reliable.

Focus on the development and examination of the validity of the ECSC would require complementary analyses of the reliability. First, the internal consistency of the items could be examined. Although the ECSC is not constructed in dimensions and therefore does not allow for analysis of the internal consistency by dimension, analysis of the global internal consistency of all the items on the questionnaire seems relevant. It would make it possible to ensure the relevance of the items and possibly to make adaptations, particularly in terms of item formulation.

Moreover, an analysis of test-retest reliability is necessary to ensure the stability of the results over time. Therefore, completion of the ECSC a second time could be proposed after a 7 to 14-day delay if no intervening event that could modify the results has occurred.

### 4.3. Clinical considerations

This study highlights the importance of social circles, especially those closest to the patient (private circle, family, and friends). In fact, the size of these circles is smaller compared to a control population. Moreover, the frequency of contact in the family and friend circles is related to perceived speech impairment (Participation PHI, H&N-35 Speech) and social functioning (EORTC QLQ-C30). The highest correlations, and therefore the strongest links, are between satisfaction with exchanges and perceived speech impairment and social functioning, as well as between global QOL and role functioning.

In this study, all the recruited patients had completed cancer treatment at least six months previously, to ensure stability of the disorders induced by the cancer or the treatment. The variety of treatments and care contexts results in different patient profiles. The objective of the ECSC is to be usable in all patients treated for head and neck cancer. Therefore, the inclusion of these different profiles seems entirely relevant. However, the medical context can impact the constitution of social circles and thereby induce different responses to the ECSC. Therefore, stratified analyses to examine the influence of the type of treatment and the time since treatment on the formation of social circles would appear to be important in order to anticipate the psychosocial repercussions of therapeutic strategies at early stages.

In terms of management, the caregiver and community circles are also essential to consider, as they seem to provide support in the maintenance of patient follow-up, and also in the exchanges between the patient and their circles. Furthermore, it seems important to support social circles at an early stage, at the time of diagnosis and throughout treatment, so that social isolation is minimized as much as possible, and so that the patient can rely on available resources daily (both in the private circle and from close relatives and caregivers). This support from social circles is also essential in the prevention of risk factors for the recurrence of cancer [24,25].

The use of the ECSC in routine clinical practice would provide an inventory of the size of the patient's entourage to be drawn up to identify potential caregivers each day (private circle), as well as to assess the possible supports available and the possible replacements for caregivers (family and friend circles). Moreover, combined with other functional and QOL questionnaires (for example, those already used in routine practice), it could help to explain more precisely each patient's perception of their disability (specifically in terms of communication on the PHI) or psychosocial dimensions of QOL. Therefore, use of the ECSC seems relevant from the very first stages of care (i.e. from diagnosis), but regular use

during follow-up would allow the changes in the patient's social dynamics to be assessed. This is in line with the relevance of assessing the test-retest reliability of this questionnaire.

Finally, research remains to be carried out on the influence of the constitution of social circles on the answers to the psychosocial dimension items of self-questionnaires. Some studies have shown that the evaluation of a psychosocial dimension in the Patients' Concerns Inventory [48] seems to be transversal to the analysis of associated impairments [49]. Therefore, use of the ECSC would make it possible to weight responses to the psychosocial dimension of Patients Concerns Inventory questionnaires, to more precisely target patients' needs and complaints.

Although we explored the links between social circles and functional speech impairment, it would be relevant to study any link that may exist between social circles and the other functions of the aerodigestive tract. In fact, an alteration in the capacity to swallow could be linked to the constitution of social circles as such disorders often hinder food intake. Adaptation of food consistency and coughing sometimes lead to social withdrawal of the patient during mealtimes [50].

Finally, in terms of management, the constitution of social circles can be considered in different pathological contexts. Patients with speech disorders in ENT oncology or patients with neurological pathologies who present with dysarthria or aphasia will have different communication needs according to the strength of their social circles. Therefore, the therapeutic strategy should be adapted to the patient's context of communication so that it is as close as possible to their daily life. Moreover, in these pathological contexts, the extension of this study to the primary caregiver of an aphasic or a Parkinsonian patient would make it possible to evaluate the social dynamics in terms of the dyad and not only at the patient level, as well as allow satisfaction to be measured regarding the constitution of social circles in a bilateral patient/caregiver perspective.

## 5. Conclusion

The preliminary results of this study show that the ECSC presents adequate performances in terms of validity. More analyses on a larger sample, and a reliability study are still required to ensure greater generalizability of the results.

The ECSC can be used in routine clinical practice to assess the social dynamics related to patients in terms of the constitution of their social circles. This would enable the adaptation of therapeutic strategies to the human resources available to the patient, and also to prevent social isolation and functional consequences. Lastly, a broader study should be conducted on the influence of the constitution of social circles on other chronic pathologies, such as stroke and neurodegenerative pathologies.

## 6. Statements

*Acknowledgement:* The authors wish to acknowledge Clémentine Valiente and Anaïs Cance, SLP students, for collecting data.

*Statement of Ethics:*

All procedures were performed in accordance with the 1964 Helsinki declaration and its amendments or comparable ethical standards.

*Study approval statement:*

This study protocol was reviewed and approved by the Committee for the Protection of Persons within the framework of the ANR RUGBI project, approval number [CPP: Ouest IV, 19/02/2020, reference 11/20\_3].  
Consent to participate: Each subject was told in advance of the purpose of this study and was given an information sheet. Subjects gave their written informed consent (non-opposition).

*Conflicts of Interest Statement:* All authors declare that they have no conflict of interest.



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**Author Contributions Statement:**

1. Guarantor of the integrity of the entire study: Mathieu Balaguer
2. Study concepts and design: Mathieu Balaguer, Florence Sordes, Virginie Woisard and Timothy Pommée
3. Literature research: Mathieu Balaguer and Florence Sordes
4. Clinical studies: Mathieu Balaguer, Virginie Woisard and Timothy Pommée
5. Data analysis: Mathieu Balaguer, Julien Pinquier, Jérôme Farinas, Virginie Woisard and Florence Sordes
6. Statistical analysis: Mathieu Balaguer
7. Manuscript preparation: Mathieu Balaguer, Julien Pinquier, Jérôme Farinas, Timothy Pommée, Virginie Woisard and Florence Sordes
8. Manuscript editing: Mathieu Balaguer, Julien Pinquier, Jérôme Farinas, Virginie Woisard and Florence Sordes

**Data Availability statement:** Data and the database are available on request from the corresponding author.

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Supplementary material

## EVALUATION OF THE CONSTITUTION OF SOCIAL CIRCLES ÉVALUATION DE LA CONSTITUTION DES CERCLES SOCIAUX

For each group of people, please indicate:

- The **number of people** you consider to be part of the group (column A);
- The average **frequency** with which you have contact with these people (column B);
- How you rate **the frequency** of your contact with these people: from -5 “too low” (I don’t meet them enough) to +5 “too high” (I see them too often) (column C);
- How **satisfied** you are with the quality of the exchanges you have with these people when you meet them: from -5 “very unsatisfied” to +5 “very satisfied” (column D).

Pour chaque groupe de personnes, veuillez indiquer vous concernant :

- Le nombre de personnes que vous estimez faire partie du groupe concerné (colonne A) ;
- La fréquence moyenne à laquelle vous avez des contacts avec ces personnes (colonne B) ;
- Comment vous jugez la la fréquence de vos contacts avec ces personnes : de -5 « trop faible » (Je ne les vois pas suffisamment) à +5 « trop élevée » (Je les vois trop souvent à mon goût) (colonne C) ;
- Si vous êtes satisfait.e de la qualité des échanges que vous avez avec ces personnes quand vous les voyez : de -5 « très insatisfait » à +5 « très satisfait » (colonne D).

Group Groupe	A	B	C	D
		Frequency of contact (check the box) Régularité moyenne des contacts (cocher la case)	Overall satisfaction with frequency (check the box) Satisfaction globale de la fréquence (cocher la case)	Overall satisfaction with exchanges (check the box) Satisfaction globale des échanges (cocher la case)
<b>Private</b> People with whom I live every day Privé Personnes avec qui je vis au quotidien.	How many people do you live with on a daily basis? (Avec combien de personnes vivez-vous au quotidien ?) <input type="checkbox"/> 0: I live alone (Je vis seul.e) <input type="checkbox"/> 1 <input type="checkbox"/> 2 to 4 (2 à 4) <input type="checkbox"/> 5 and more (5 et plus)	<input type="checkbox"/> every day (tous les jours) <input type="checkbox"/> several times a week (plusieurs fois par semaine) <input type="checkbox"/> several times a month (plusieurs fois par mois) <input type="checkbox"/> several times a year (plusieurs fois par an) <input type="checkbox"/> once a year or less (une fois par an ou moins)	<input type="checkbox"/> -5: too low (trop faible) <input type="checkbox"/> -4 <input type="checkbox"/> -3 <input type="checkbox"/> -2 <input type="checkbox"/> -1 <input type="checkbox"/> 0: sufficient (suffisant) <input type="checkbox"/> +1 <input type="checkbox"/> +2 <input type="checkbox"/> +3 <input type="checkbox"/> +4 <input type="checkbox"/> +5: too high (trop élevée)	<input type="checkbox"/> -5: very unsatisfied (très insatisfait) <input type="checkbox"/> -4 <input type="checkbox"/> -3 <input type="checkbox"/> -2 <input type="checkbox"/> -1 <input type="checkbox"/> 0: neutral (neutre) <input type="checkbox"/> +1 <input type="checkbox"/> +2 <input type="checkbox"/> +3 <input type="checkbox"/> +4 <input type="checkbox"/> +5: very satisfied (très satisfait)

Group Groupe	A	B	C	D
		Frequency of contact (check the box) <i>Régularité moyenne des contacts</i> (cocher la case)	Overall satisfaction with frequency (check the box) <i>Satisfaction globale de la fréquence</i> (cocher la case)	Overall satisfaction with exchanges (check the box) <i>Satisfaction globale des échanges</i> (cocher la case)
<b>Family</b>  <i>Family who is not necessarily seen on a daily basis but with whom regular contact is maintained</i>  <i>Famille</i>  <i>Famille que je ne vois pas forcément tous les jours mais avec qui j'ai des contacts étroits et réguliers.</i>	How many people do you consider to be part of your family? ( <i>Combien de personnes y a-t-il dans votre entourage familial ?</i> )  <input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 to 4 ( <i>2 à 4</i> ) <input type="checkbox"/> 5 to 9 ( <i>5 à 9</i> ) <input type="checkbox"/> 10 and more ( <i>10 et plus</i> )	<input type="checkbox"/> every day ( <i>tous les jours</i> ) <input type="checkbox"/> several times a week ( <i>plusieurs fois par semaine</i> ) <input type="checkbox"/> several times a month ( <i>plusieurs fois par mois</i> ) <input type="checkbox"/> several times a year ( <i>plusieurs fois par an</i> ) <input type="checkbox"/> once a year or less ( <i>une fois par an ou moins</i> )	<input type="checkbox"/> -5: too low ( <i>trop faible</i> ) <input type="checkbox"/> -4 <input type="checkbox"/> -3 <input type="checkbox"/> -2 <input type="checkbox"/> -1 <input type="checkbox"/> 0: sufficient ( <i>suffisant</i> ) <input type="checkbox"/> +1 <input type="checkbox"/> +2 <input type="checkbox"/> +3 <input type="checkbox"/> +4 <input type="checkbox"/> +5: too high ( <i>trop élevée</i> )	<input type="checkbox"/> -5: very unsatisfied ( <i>très insatisfait</i> ) <input type="checkbox"/> -4 <input type="checkbox"/> -3 <input type="checkbox"/> -2 <input type="checkbox"/> -1 <input type="checkbox"/> 0: neutral ( <i>neutre</i> ) <input type="checkbox"/> +1 <input type="checkbox"/> +2 <input type="checkbox"/> +3 <input type="checkbox"/> +4 <input type="checkbox"/> +5: very satisfied ( <i>très satisfait</i> )
<b>Friends</b>  <i>people who are liked, whom I know well, and with whom I have close regular contact</i>  <i>Amis</i>  <i>Personnes pour qui j'éprouve de la sympathie, que je connais bien et avec qui je me sens bien, avec qui j'ai des liens privilégiés et en qui j'ai confiance.</i>	How many people do you consider to be friends?  <input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 to 4 <input type="checkbox"/> 5 to 9 <input type="checkbox"/> 10 and more	<input type="checkbox"/> every day ( <i>tous les jours</i> ) <input type="checkbox"/> several times a week ( <i>plusieurs fois par semaine</i> ) <input type="checkbox"/> several times a month ( <i>plusieurs fois par mois</i> ) <input type="checkbox"/> several times a year ( <i>plusieurs fois par an</i> ) <input type="checkbox"/> once a year or less ( <i>une fois par an ou moins</i> )	<input type="checkbox"/> -5: too low ( <i>trop faible</i> ) <input type="checkbox"/> -4 <input type="checkbox"/> -3 <input type="checkbox"/> -2 <input type="checkbox"/> -1 <input type="checkbox"/> 0: sufficient ( <i>suffisant</i> ) <input type="checkbox"/> +1 <input type="checkbox"/> +2 <input type="checkbox"/> +3 <input type="checkbox"/> +4 <input type="checkbox"/> +5: too high ( <i>trop élevée</i> )	<input type="checkbox"/> -5: very unsatisfied ( <i>très insatisfait</i> ) <input type="checkbox"/> -4 <input type="checkbox"/> -3 <input type="checkbox"/> -2 <input type="checkbox"/> -1 <input type="checkbox"/> 0: neutral ( <i>neutre</i> ) <input type="checkbox"/> +1 <input type="checkbox"/> +2 <input type="checkbox"/> +3 <input type="checkbox"/> +4 <input type="checkbox"/> +5: very satisfied ( <i>très satisfait</i> )
<b>Acquaintances</b>  <i>People I have met, with whom I have regular contact but no special relationship, or about whom I know little</i>  <i>Connaissances</i>  <i>Personnes que j'ai rencontrées, avec qui j'ai des contacts réguliers mais avec qui je n'ai pas de relation privilégiée (que je connais peu).</i>		<input type="checkbox"/> every day ( <i>tous les jours</i> ) <input type="checkbox"/> several times a week ( <i>plusieurs fois par semaine</i> ) <input type="checkbox"/> several times a month ( <i>plusieurs fois par mois</i> ) <input type="checkbox"/> several times a year ( <i>plusieurs fois par an</i> ) <input type="checkbox"/> once a year or less ( <i>une fois par an ou moins</i> )	<input type="checkbox"/> -5: too low ( <i>trop faible</i> ) <input type="checkbox"/> -4 <input type="checkbox"/> -3 <input type="checkbox"/> -2 <input type="checkbox"/> -1 <input type="checkbox"/> 0: sufficient ( <i>suffisant</i> ) <input type="checkbox"/> +1 <input type="checkbox"/> +2 <input type="checkbox"/> +3 <input type="checkbox"/> +4 <input type="checkbox"/> +5: too high ( <i>trop élevée</i> )	<input type="checkbox"/> -5: very unsatisfied ( <i>très insatisfait</i> ) <input type="checkbox"/> -4 <input type="checkbox"/> -3 <input type="checkbox"/> -2 <input type="checkbox"/> -1 <input type="checkbox"/> 0: neutral ( <i>neutre</i> ) <input type="checkbox"/> +1 <input type="checkbox"/> +2 <input type="checkbox"/> +3 <input type="checkbox"/> +4 <input type="checkbox"/> +5: very satisfied ( <i>très satisfait</i> )

Group Groupe	A	B	C	D
		Average regularity of contact (check the box) <i>Régularité moyenne des contacts</i> (cocher la case)	Overall satisfaction with frequency (check the box) <i>Satisfaction globale de la fréquence</i> (cocher la case)	Overall satisfaction with exchanges (check the box) <i>Satisfaction globale des échanges</i> (cocher la case)
<b>Caregivers and community</b>  <i>People I know, whom I greet, with whom I share common interests but have no special relationship</i>  <i>Aidants – communauté</i>  <i>Personnes que je côtoie, à qui je dis « bonjour » et « au revoir », avec qui je partage des intérêts communs sans avoir avec eux de relation privilégiée.</i>		<input type="checkbox"/> every day ( <i>tous les jours</i> ) <input type="checkbox"/> several times a week ( <i>plusieurs fois par semaine</i> ) <input type="checkbox"/> several times a month ( <i>plusieurs fois par mois</i> ) <input type="checkbox"/> several times a year ( <i>plusieurs fois par an</i> ) <input type="checkbox"/> once a year or less ( <i>une fois par an ou moins</i> )	<input type="checkbox"/> -5: too low ( <i>trop faible</i> ) <input type="checkbox"/> -4 <input type="checkbox"/> -3 <input type="checkbox"/> -2 <input type="checkbox"/> -1 <input type="checkbox"/> 0: sufficient ( <i>suffisant</i> ) <input type="checkbox"/> +1 <input type="checkbox"/> +2 <input type="checkbox"/> +3 <input type="checkbox"/> +4 <input type="checkbox"/> +5: too high ( <i>trop élevée</i> )	<input type="checkbox"/> -5: very unsatisfied ( <i>très insatisfait</i> ) <input type="checkbox"/> -4 <input type="checkbox"/> -3 <input type="checkbox"/> -2 <input type="checkbox"/> -1 <input type="checkbox"/> 0: neutral ( <i>neutre</i> ) <input type="checkbox"/> +1 <input type="checkbox"/> +2 <input type="checkbox"/> +3 <input type="checkbox"/> +4 <input type="checkbox"/> +5: very satisfied ( <i>très satisfait</i> )
<b>Strangers</b>  <i>Inconnus</i>		<input type="checkbox"/> every day ( <i>tous les jours</i> ) <input type="checkbox"/> several times a week ( <i>plusieurs fois par semaine</i> ) <input type="checkbox"/> several times a month ( <i>plusieurs fois par mois</i> ) <input type="checkbox"/> several times a year ( <i>plusieurs fois par an</i> ) <input type="checkbox"/> once a year or less ( <i>une fois par an ou moins</i> )	<input type="checkbox"/> -5: too low ( <i>trop faible</i> ) <input type="checkbox"/> -4 <input type="checkbox"/> -3 <input type="checkbox"/> -2 <input type="checkbox"/> -1 <input type="checkbox"/> 0: sufficient ( <i>suffisant</i> ) <input type="checkbox"/> +1 <input type="checkbox"/> +2 <input type="checkbox"/> +3 <input type="checkbox"/> +4 <input type="checkbox"/> +5: too high ( <i>trop élevée</i> )	<input type="checkbox"/> -5: very unsatisfied ( <i>très insatisfait</i> ) <input type="checkbox"/> -4 <input type="checkbox"/> -3 <input type="checkbox"/> -2 <input type="checkbox"/> -1 <input type="checkbox"/> 0: neutral ( <i>neutre</i> ) <input type="checkbox"/> +1 <input type="checkbox"/> +2 <input type="checkbox"/> +3 <input type="checkbox"/> +4 <input type="checkbox"/> +5: very satisfied ( <i>très satisfait</i> )