

Title: A Comparison of Two Quality of Life Measures in the Head and Neck Cancer Organ

Preservation Population: The EORTC QOL-H&N35 and Semi-Structured Interviews

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Short version of Title: Comparing QoL Measures

ABSTRACT

Background: Surgery, followed by radiation and/or chemotherapy, has been a conventional treatment for head and neck cancer (HNC). Organ preservation, a non-surgical option, is increasingly being used to treat HNC. This treatment may influence function and consequently quality of life. Standardized questionnaires, such as the EORTC QOL-H&N35, are commonly used to measure quality of life. Qualitative tools such as semi-structured interviews (SSIs) have been less commonly used to study patient perception of outcomes. This study aimed to determine the coherence between the EORTC QOL-H&N35 and SSIs after organ preservation treatment. Secondary objectives included assessing pre to post treatment changes and determining if tumour location or gender influenced outcomes.

Methods: Eleven HNC patients undergoing organ preservation completed the EORTC QOL-H&N35 and SSIs before and 4-6 months after treatment. The researchers developed thematic categories based on frequently occurring trends in interviews and compared them to subsections of the EORTC QOL-H&N35.

Results: Each tool gave unique perspectives on outcomes. While the EORTC QOL-H&N35 provided more detail regarding function, SSIs gave a more holistic account of patient perception of outcome. Comparison of outcomes from pre to post showed worse outcomes post treatment. Site of cancer and gender had no significant impact on treatment outcomes.

Conclusion: There are changes from pre to post treatment in organ preservation thus, as quality of life is often used to guide clinical practice, it is crucial to fully understand patient perception of treatment success and its impact on everyday life, through the most reliable and comprehensive measurement tools.

INTRODUCTION

Head and neck cancer (HNC) is diagnosed in approximately 650,000 people worldwide each year (Crozier & Sumer, 2010). The structural areas affected by HNC include: the oral cavity, the nasal cavity, the pharynx and the larynx. More specifically, the oral cavity encompasses the mouth, tongue, lips, as well as hard and soft palate. The pharynx can be described as consisting of the nasopharynx, the oropharynx (which includes the base of tongue, pharyngeal arches, tonsils, soft palate and uvula), and the hypopharynx (esophageal inlet and pyriform sinuses). Structures within the larynx that can be affected include the true and false vocal folds, aryepiglottic folds, epiglottis, and the arytenoid cartilages.

Many factors have been identified that increase one's risk for HNC including: tobacco use (especially chewing tobacco), alcohol consumption, chewing betel nuts (high prevalence in Asian populations), and, most recently, the human papilloma virus (HPV) (Crozier & Sumer, 2010). Due to the higher historical prevalence of males consuming alcohol and tobacco, the male to female ratio of patients with HNC is skewed, with males accounting for the majority (Kruse, Bredell, & Grätz, 2011).

According to Cagnetti, Weber, and Lai, (2009) treatment of HNC has been dynamic over the past century. Originally, radiation therapy was considered the best option due to limitations of anesthesia and antibiotics at the time. The authors claim that with advancements in these areas and the initiation of blood banking, surgery became a more viable option. With more advanced staged cancers, primary surgery was followed up with radiation therapy in order to decrease the potential for recurrence. However, in many cases, radical surgery ablated so much tissue that function of the organ was severely compromised. Thus, the authors describe a shift

in focus from that of primarily survival outcomes to survival as well as preserved functional outcomes. This shift was reflected in the literature in the early 1990s when organ preservation via chemotherapy followed by radiation was advocated as a treatment to reduce the devastating functional outcomes associated with surgical laryngectomy (Wolf, Hong, Fisher, & Urba, 1991). Since that time, organ preservation has become a standard of treatment for other types of HNC.

Organ preservation treatment can be administered either as radiation therapy (RT) alone or as concurrent chemotherapy and radiation therapy (CRT) (Cognetti, Weber, Lai, 2009). However, it is important to note that organ preservation does not always result in part or full reinstatement of organ function. For example, as Jacobi and colleagues (2010) found, organ preservation to treat HNC carcinoma of the larynx, oral cavity and pharynx sometimes resulted in impaired voice quality, articulation, and resonance. When the physiology of these areas is considered, it becomes apparent that other functions such as chewing, swallowing, and breathing may be altered. Furthermore, side effects associated with RT and/or CRT include mucositis, radionecrosis, xerostomia, fibrosis, loss of taste, excess secretions, pain, fatigue, trismus, and muscle atrophy (Moore, Chamberlain, & Khuri, 2004; van der Molen, van Rossum, Burkhead, Smeele, & Hilgers, 2009). Therefore, although this treatment may be successful in obliterating the cancer, lingering side effects may result in poor functional outcomes that have the potential to negatively impact quality of life. Consequently, organ preservation treatment may not translate into functional preservation for all patients.

Functional outcomes have the potential to affect a patient's perception of their quality of life. Negative functional outcomes, such as difficulty swallowing due to xerostomia, may

affect a person's willingness to eat in public, and lingering pain or fatigue may affect their ability to return to work following treatment (Moore et al., 2004; Rieger, Zalmanowitz, & Wolfaardt, 2006; van der Molen et al., 2009). In addition, poor functional outcomes can affect social and personal interactions in an undesirable way (Rieger et al., 2006). At the same time, there is evidence that organ preservation treatments tend to be associated with relatively good speech outcomes including few articulation errors or intelligibility issues, and that many negative side effects are temporary (Rieger et al., 2006; van der Molen et al., 2009). Overall, patients have a wide range of functional outcomes following treatment and their resulting quality of life may differ based on their personal experiences. Additionally, social support can influence quality of life in a positive way, highlighting the importance of retaining social interactions for maintenance of quality of life (Semple, Dunwoody, George Kernohan, McCaughan, & Sullivan, 2008). Therefore, how we measure quality of life should be sensitive to differences in personal experiences, access to social support, and the range of functional outcomes experienced by patients.

While functional outcomes and quality of life issues have been extensively studied in the HNC population, more research is needed to ensure the tools used to measure these are sensitive to the experiences of the patient and valid in their results. This becomes ever-more important as quality of life outcomes are often used to guide clinical practice. Thus, it is important to evaluate the strengths and weaknesses of such measures (Loewen, Boliek, Seikaly, Harris, & Rieger, 2009).

Quality of life may be measured on dimensions of physical, psychosocial, and emotional functioning (McCabe, Begley, Collier, & McCann, 2008). One common tool used to measure

quality of life in patients diagnosed with head and neck cancer is the European Organization for Research and Treatment of Cancer – Head & Neck 35 (EORTC QOL-H&N35), a standardized questionnaire that looks at pain, swallowing, senses, speech, social eating, social contact, and sexuality (Pusic et al., 2007). There are a number of challenges, however, in accurately measuring quality of life. For example, previous research has found that standardized questionnaires tend to underestimate the impact of negative functional outcomes on quality of life (Loewen et al., 2009). Therefore, while a questionnaire such as the EORTC QOL-H&N35 offers a quick and standardized probe for information, it may not be able to capture the entire picture. This may be related to inherent problems with the Likert Scale, the lack of qualifiers, the inclusion of questions that are not relevant to all individuals, and the complexity of functional impairment experienced by the patient (Loewen et al., 2009; McCabe et al., 2008).

A less common tool for measuring patient perception of outcomes, the semi-structured interview (SSI), begins with a guide of questions, but allows the interviewer to ask additional questions and probe more deeply based on the responses of the patient. Thus, SSIs allow more depth, detail, and flexibility to explore salient points of interest of current quality of life and functioning (Loewen et al., 2009) than do standardized tests. However, there is a cost of additional time spent by both patient and clinician without the guarantee of gaining more useful and relevant information.

While SSIs may capture the intricacies of functional impairments faced by organ preservation patients, little is known about how they compare to standardized measures of quality of life in this population. Ideally, responses from each tool will mirror one another, proving each tool to be a consistent, reliable, and responsive measure of quality of life (Pusic et

al., 2007). If, however, they do not agree with one another, an analysis of the information provided by each, and its usefulness, must be completed to understand the relative benefits of implementation of either tool in clinical practice.

While research has captured the differences between a standardized quality of life measure and SSIs in patients who underwent surgery and adjuvant radiation therapy for oral cancer (Loewen et al., 2009), little is known about whether these differences apply to patients who underwent organ preservation therapy. This study explores two quality of life measures used with the organ preservation population, specifically the EORTC QOL-H&N35 and SSIs, to determine whether responses from each measure are comparable in terms of information gathered and overall usefulness. Based on previous research done by Loewen and colleagues (2009) on HNC patients who underwent surgery, it is predicted that the measures will not be comparable. More specifically, we expect the EORTC QOL-H&N35 will less accurately report on quality of life, and SSIs will provide a more comprehensive evaluation. This is further supported from clinical observation of the EORTC QOL-H&N35 that some questions are ambiguous in nature and not well understood by the clients and are therefore less likely to be answered in an accurate and/or consistent way. In addition, similar to the results found in a study evaluating voice and speech outcomes in CRT patients (Jacobi et al., 2010), it is predicted that both the EORTC QOL-H&N35 and SSIs will find post treatment outcomes to be worse than those collected prior to treatment. Furthermore, this study will evaluate whether site of cancer will result in different responses to quality of life measures. Lastly, differences between responses of male and female patients will be investigated.

METHODS

Data were collected by speech-language pathologists at the Institute for Reconstructive Sciences in Medicine (iRSM) at the Misericordia Community Hospital in Edmonton, Alberta. Participants completed the EORTC QOL-H&N35 questionnaire and SSIs prior to treatment and 4 to 6 months post treatment. SSIs were recorded by the speech-language pathologists and later transcribed by the researchers. All participants were asked the same three broad questions with additional probing and questions for further clarification or information. Additional questions asked by interviewers varied depending on the situation. The standard questions were: Can you tell me three things that have changed the most in your life since the diagnosis or treatment? Has your social life changed at all? Some people are frustrated with their speech and swallowing after this treatment or with this diagnosis and some people don't notice any difference in this area. How do you feel about your speech and swallow?

Thematic analysis based on Boyatzis's (1998) hybrid approach was used to interpret the data. The interviews were divided between two researchers who listened to the interviews separately and transcribed them verbatim. Next, the researchers listened to the other half of the interviews that they did not transcribe. While listening, they checked over the transcriptions of the other researcher to ensure they were transcribed accurately. Next the researchers identified each patient's recurring feelings and concepts brought out in the interviews. From this, the authors developed five overarching categories and defined themes within them (see Table 1). Each researcher then independently coded the interview transcripts according to the mutual themes and definitions developed in order to determine the presence

or absence of themes and the frequency with which they occurred. Revisions were made to themes as required; for instance, if a theme only had one occurrence in the entire sample, it was deleted from the roster.

Table 1 .Classification and description of themes identified in SSI transcripts

Category	Theme	Definition	Example
Functional	Swallowing	dysphagia, difficulty swallowing	#5: the swallowing that – especially when it’s very dry and what have you and other than that it’s it’s not too bad you just try to force your way through it.
	Speech	intelligibility, ease of speech, articulation	#5: -I-I don’t pronounce near clear enough at times
	Senses	Taste and smell	#7: yes I have some changes in my taste buds
	Eating	Chewing	#1: I am unable to eat
Physical	Appearance	changes in body structure, how the client looks to self/others	#8: I lost my hair
	Pain	pain within structures of the body, achy, hurt, soreness, discomfort	#7: my throat still has a certain soreness to it
	Saliva	xerostomia, too much saliva, drooling	#8: you know, except for the dry mouth
	Fatigue	tiredness, loss of energy, alertness issues	#11: and I am perpetually tired
Social	Work	changes in work status, ability to work, schedule	#7: and also I haven’t gone back to work
	Social support	Family and friends	#4: I’ve got a lot of family support. My grandson shaved his head for cancer
	Social life	relationships with family and friends, activities, going out in public	#7: still golfing lots

Emotion	Frustration/Anger	Negative feeling associated with helplessness	#11: frustrated as hell
	Anxiety/Fear	Tension, worry, uptight	#2: cause if I dwell on these things then I get tense
Personal factors	Outlook/perspective	In what regard do they hold their future	#8: My attitude has changed, it is what it is
	Values and Spirituality	Religion, personal ideals, what is important to the person, belief system	#6: I'm just being positive and optimistic and I pray a lot whenever and believing and not focusing on it

The researchers came to agreement on any discrepancies in the way that patient statements were categorized. Each SSI transcript was reviewed by both researchers. The frequency of same theme coding by the researchers was divided by the total number of theme codes found in the transcripts and multiplied by 100 to ascertain percent agreement. The inter-rater reliability of assigning themes and subthemes was 79.56%. Unanimous agreement was reached through conversation about the discrepancies in coding. The researchers openly considered the views of the other and in the end were able to come to the same decision. No third party was required to break ties or resolve any discrepancies.

The researchers entered data from the EORTC QOL-H&N35 into a spreadsheet to yield scores for each subscale. The EORTC QOL-H&N35 conversion yielded percentages for which a severity rating was applied: 0% indicated that the issue was not a concern; 1-49% indicated a bit of concern; and any percentage greater than 50 indicated significant problems. The scores in each subscale were then compared against the overlapping themes found in the SSIs. The EORTC QOL-H&N35 covered pain, senses, sticky saliva, dry mouth, swallowing and speech, which all directly overlap with SSI themes.

In order to compare the two measures, the EORTC QOL-H&N35 scores for each client pre and post CRT were displayed on 3 graphs that were organized in the following way: pain and senses were grouped in a graph representing senses; sticky saliva and dry mouth were combined in a graph labelled xerostomia; and swallowing and speech were placed together in a graph labelled functional. In the next step, the researchers compared the EORTC QOL-H&N35 scores for each category to the SSI transcripts to judge if the two measures were: in agreement (the symptom severity reported in the SSI correlated to the severity rating on the EORTC QOL-H&N35), in disagreement (SSI statement of symptom severity was rated better or worse on the EORTC QOL-H&N35), or if the category was not mentioned in the SSI transcript at all. One researcher analyzed SSI transcripts and EORTC QOL-H&N35 concordance for patients 1-6 while the other researcher analyzed patients 7-11. Tallies were kept in each of the 3 aforementioned groupings. In cases of disagreement between responses on the SSI and the EORTC QOL-H&N35, an asterisk was placed above the bar of the EORTC QOL-H&N35 graph. Patients displaying multiple instances of disagreement were investigated further to see what factors may have accounted for the discrepancy between measures.

RESULTS

Twenty five participants were recruited into the organ preservation study between August 2007 to September 2011. Pre and post treatment interviews from 11 of these participants were analyzed. Demographic data is shown in Table 2. Fourteen participants were excluded for a number of reasons, including: 1) the post treatment interview for six participants fell after the approved ethics time period; 2) one participant did not show up for their

appointment; 3) three interviews were incomplete due to clinical time constraints; 4) inability to schedule one patient (i.e., could not find a time that would work for them); and 5) three had incomplete interviews for other reasons. All patients in this study were diagnosed with squamous cell carcinoma.

Table 2. *Patient demographics*

Patient Number	Age	Gender	Site of Cancer
1	72	Male	glottic laryngeal area
2	85	Female	supraglottic larynx
3	49	Male	BOT
4	56	Male	BOT and LPW
5	60	Male	BOT and neck
6	65	Female	SP
7	59	Male	neck
8	57	Female	BOT, LPW and epiglottis
9	57	Male	BOT and neck
10	55	Male	BOT
11	64	Male	pyriform sinus

Note: BOT = base of tongue, LPW = lateral pharyngeal wall, PPW = posterior pharyngeal wall, SP = soft palate

Comparison between EORTC QOL-H&N35 and SSI

The correspondence between the patient's pre and post CRT EORTC QOL-H&N35 scores and SSIs was determined by comparing the severity of impairment rated on the EORTC QOL-H&N35 to that reported in the SSI (see Table 3, and Figures 1-4). Generally, it was found that

the categories with the largest agreement between the measures were *sensation* and *dry mouth* while less agreement was found in the *functional* and *social* categories.

Disagreement between the EORTC QOL-H&N35 and SSI measures was observed twice in patient 1 across *functional* and *dry mouth* categories, twice in patient 6 across the *sensation* and *functional* categories, and twice in patients 3, 8, 9, and 10 across the *function* and *social* categories. The remaining patients showed agreement across all of the categories.

Table 3. Correspondence between common themes measured by the EORTC QOL-H&N35 & SSIs

Theme	EORTC QOL-H&N35 and SSIs Agreement (N= number of total agreements)	EORTC QOL-H&N35 and SSIs Disagreement (N= number of total disagreements where b= SSIs reported better outcome and w=SSI reported worse outcome)	Not mentioned in SSIs (N= number of times not mentioned in SSIs)	Percent agreement between EORTC QOL-H&N35 and SSIs (excluding not mentioned counts)
Functional: speech and swallowing	30	12 (b=12, w=0)	2	30/42= 71%
Sensation: pain and senses	25	1 (b=0, w=1)	18	25/26 = 96%
Dry mouth: dry mouth and saliva	27	1 (b=1, w=0)	16	27/28= 96%
Social	15	6 (b=1, w=5)	1	15/21= 71%

Note: Percent agreement was calculated by dividing the counts of agreement by the total number of actual responses ('Not mentioned' were excluded from this calculation); w= instances where patients indicated worse function in the SSIs than on the EORTC QOL-H&N35; b=instances where SSIs reports indicated better function than on the EORTC QOL-H&N35.

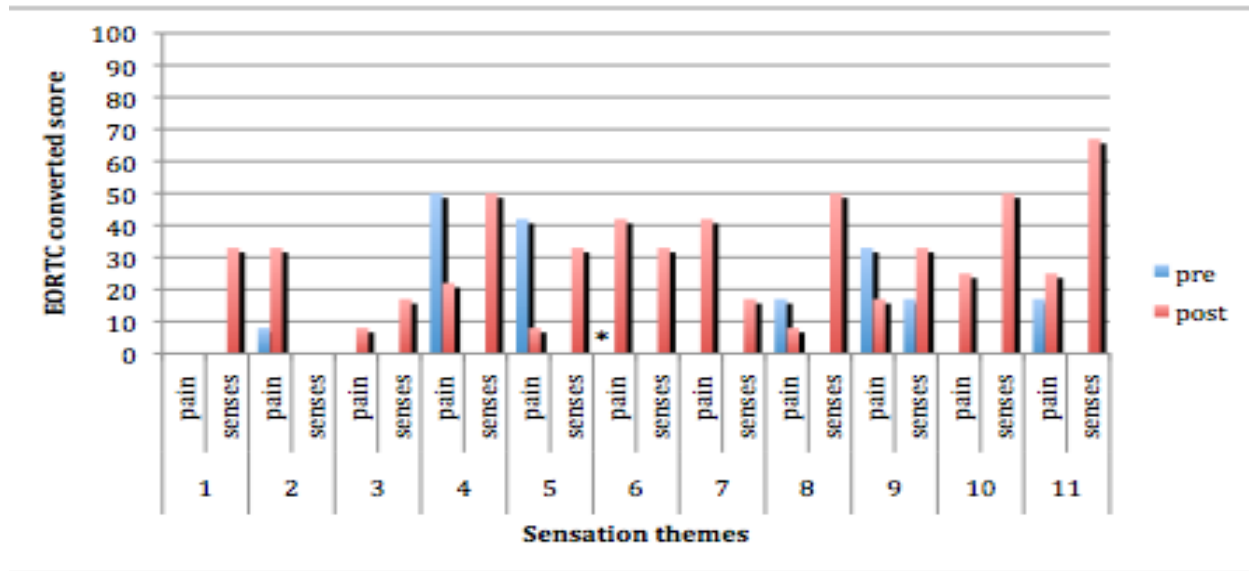


Figure 1. Results for the Sensation themes for each of the 11 patients. Note that high values of the EORTC QOL-H&N35 scores translate to worse outcomes. The * denotes disagreement between the patients' SSI and EORTC QOL-H&N35 responses.

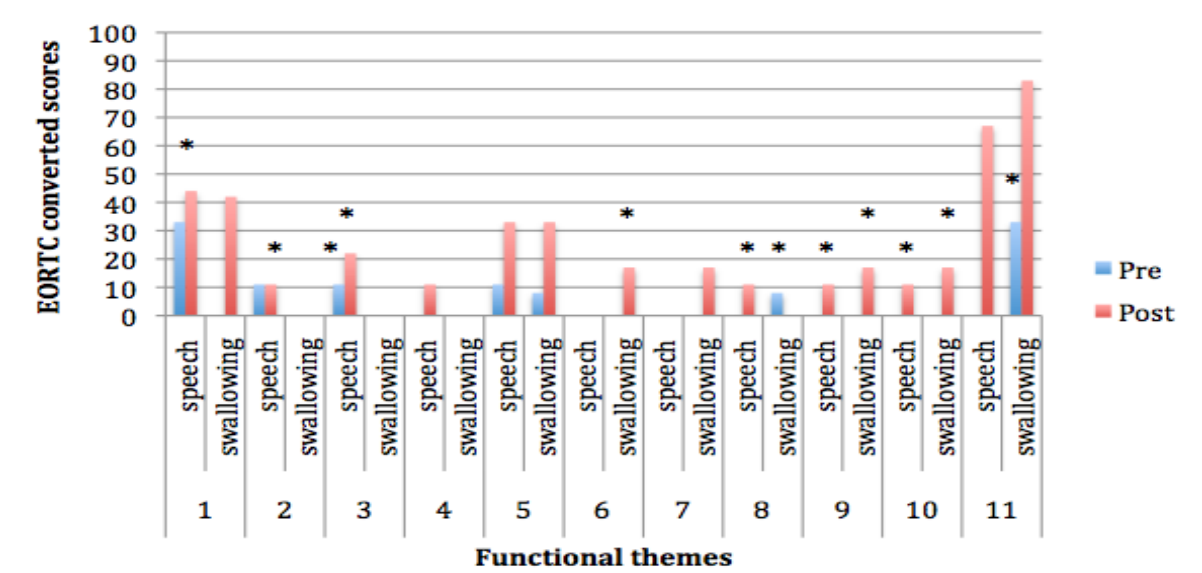


Figure 2. Results for the Function themes for each of the 11 patients. Note that high values of the EORTC QOL-H&N35 converted scores translate to worse outcomes. The * denotes disagreement between the patients' SSI and EORTC QOL-H&N35 responses.

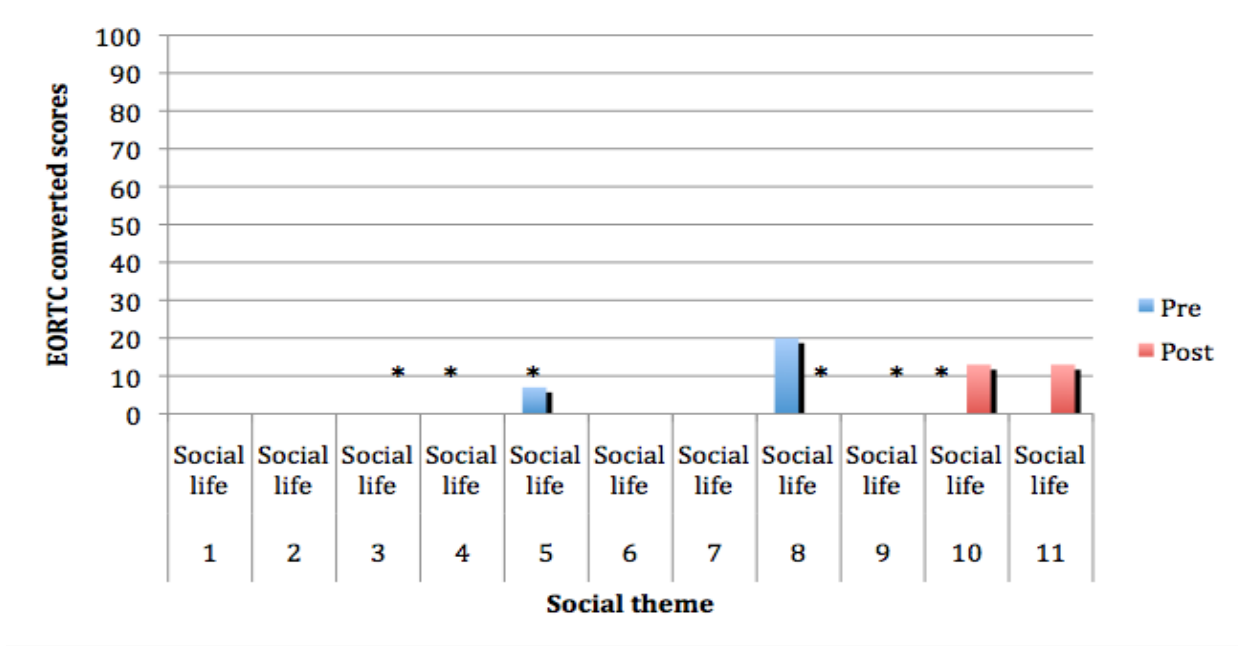


Figure 3. Results for the Social theme for each of the 11 patients. Note that high values of the EORTC QOL-H&N35 converted scores translate to worse outcomes. The * denotes disagreement between the patients’ SSI and EORTCQOL-H&N35 responses.

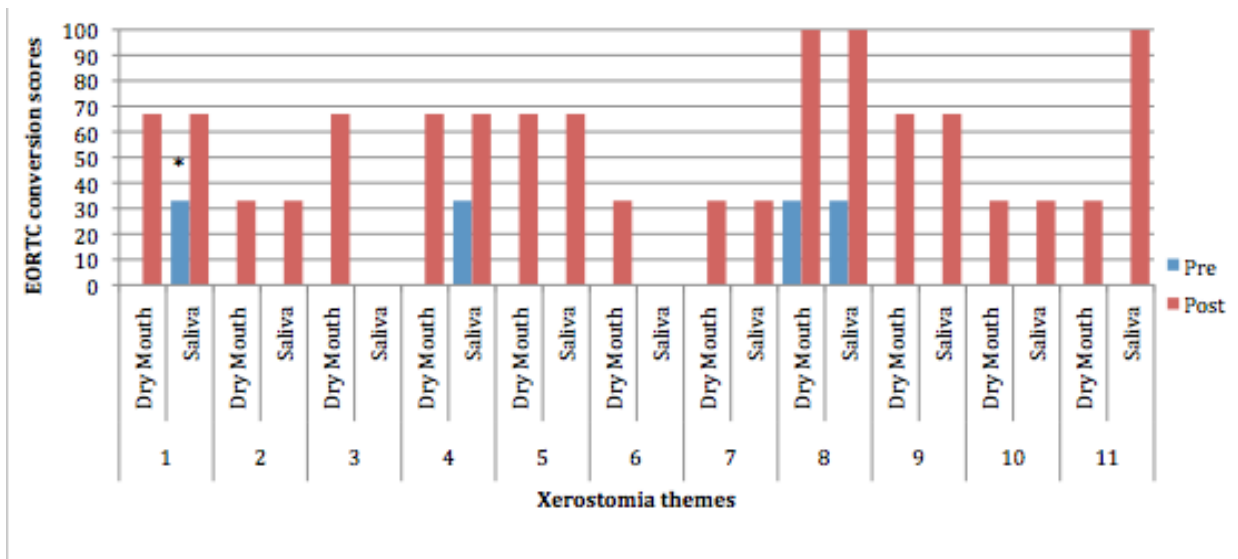


Figure 4. Results for the Xerostomia theme for each of the 11 patients. Note that high values of the EORTC QOL-H&N35 converted scores translate to worse outcomes. The * denotes disagreement between the patients’ SSI and EORTCQOL-H&N35 responses.

Pre-Post changes on the EORTC QOL-H&N35 and SSI***EORTC QOL-H&N35***

To determine if there were any significant differences between pre and post EORTC QOL-H&N35 scores, a Wilcoxon Signed Ranks test was used. The results showed that 4-6 months after treatment, patients experienced significantly worse quality of life as measured by the EORTC QOL-H&N35 in senses ($Z = -2.814$, $p < 0.05$), speech ($Z = -2.636$, $p < 0.05$), swallowing ($Z = -2.410$, $p < 0.016$), dry mouth ($Z = -3.017$, $p < 0.05$) and saliva ($Z = -2.687$, $p < 0.05$). Please refer to figures 1 to 4 for a depiction of pre and post treatment scores on the EORTC QOL-H&N35.

Semi-Structured Interviews

Functional themes. There were 4 themes in the *functional* category. Eight patients had issues with *eating* (8 occurrences: 2 pre and 6 post treatment), 4 patients had problems with *swallowing* (6 occurrences: 1 pre and 5 post), *speech* problems were mentioned by 4 patients (6 occurrences: 3 pre and 3 post) and 3 patients reported changes in *senses* (4 occurrences: 4 post). Two patients mentioned *no change* in any area under the *functional* category.

Physical themes. Four *physical* themes were identified. Of 11 participants, 6 discussed *pain* (7 occurrences: 4 pre and 3 post), 5 mentioned problems with *saliva* (6 occurrences: 1 pre and 5 post), 5 acknowledged *fatigue* (7 occurrences: 2 pre and 5 post), and 4 indicated changes in their *appearance* (5 occurrences: 2 pre and 3 post).

Social themes. Four *social* themes were classified. Out of the 11 patients, 6 reported changes in their *social life* (4 occurrences: 3 pre and 1 post). The other popular subtheme reported by 5 of the patients was changes in their *work* situation (5 occurrences: 2 pre and 3

post), while 4 claimed that they had experienced changes in *social support* (5 occurrences: 4 pre and 1 post) and 1 mentioned issues around *social eating* post treatment. Of all the patients only 1 stated that their social situation had *not changed* before treatment.

Emotion themes. Two themes in the category of *emotions* emerged. *Frustration* was reported by 4 of the 11 patients (4 occurrences: 1 pre and 3 post treatment), while *anxiety/fear* were discussed by 2 patients (3 occurrences, all pretreatment).

Personal factor themes. There were 2 main themes identified under *personal factors*. Issues related to *outlook and perspectives* were mentioned by 9 of the 11 patients (11 occurrences: 6 pre and 5 post). The *values and spirituality* theme surfaced in 3 out of the 11 patients interviewed (4 occurrences: 2 pre and 2 post).

Visual inspection of tables 4 and 5 allowed researchers to detect any trends related to site of cancer and sex. Means for each EORTC QOL-H&N35 category were calculated and then compared pre and post treatment between patients with multiple sites of cancer involvement (the base of tongue plus other sites) versus single sites of cancer (table 4). It appeared that multiple sites of cancer in a patient resulted in more severe functional outcomes pre treatment, especially in regards to pain, and post treatment scores for dry mouth. Furthermore, EORTC QOL-H&N35 mean category scores were compared between male and female patients (table 5). Across the majority of categories, the sexes had similar reports with the exception that males seemed to experience more pain pre-treatment and also a greater impact on function (speech and swallowing) post treatment.

Table 4. Mean EORTC QOL-H&N35 category scores compared across site of cancer

Pre Treatment	Pain	senses	dry mouth	saliva	speech	swallowing	social
Multiple sites of lesion: base of tongue plus other sites	23.7	4.5	5.5	11	3.7	2.7	4.5
Single site of lesion	5	0	0	6.6	8.8	6.6	0
Post Treatment	Pain	senses	dry mouth	saliva	speech	swallowing	social
Multiple sites of lesion: base of tongue plus other sites	14.7	38.3	66.8	55.7	16.5	11.2	2.2
Single site of lesion	28.4	30	39.8	46.6	24.4	31.8	2.6

Table 5. Mean EORTC QOL-H&N35 category scores compared between the sexes

Pre Treatment	Pain	senses	dry mouth	saliva	speech	swallowing	social
Female patients	8.3	0	11	11	3.7	2.7	6.7
Male patients	17.8	3.4	0	8.3	6.9	5.1	1
Post Treatment	Pain	senses	dry mouth	saliva	speech	swallowing	social
Female patients	27.7	27.7	55.3	44.3	7.3	5.7	0
Male patients	18.4	37.5	54.3	54.3	24.9	26.1	3.3

DISCUSSION

Quality of life is an important part of treatment outcome measures. While they do not directly measure function, formal quality of life scores, such as those captured by the EORTC QOL-H&N35, provide insight into life experiences that relate to function. Functional outcomes have an impact on social and health outcomes, especially for head and neck cancer patients because of the importance of head and neck regions for social interactions, emotional expression, communication, movement, nutrition, and respiration (Kazi et al., 2008; Moore et al., 2004). This study aimed to compare and contrast two tools used for measuring quality of life in patients with head and neck cancer who received organ preservation treatments, the EORTC QOL-H&N35 and SSIs. Furthermore, this study explored how outcomes reported by the EORTC QOL-H&N35 and SSIs changed from pre to post treatment. Finally this study looked at differences in responses based on the site of cancer and sex.

Comparison of EORTC QOL-H&N35 and Semi-structured Interviews

The main question in this study looked at how the EORTC QOL-H&N35 and SSIs compared in terms of information gathered about patients' quality of life. The two assessment tools showed both agreement and disagreement, with some categories revealing better coherence than others. The majority of patients showed conflict between SSI and EORTC QOL-H&N35 responses on at least one category. Only patient 7 had complete coherence between the two measures. He indicated no problems before organ preservation treatments and only slight difficulty after treatment. This may be related to personal factors such as outlook on life or personality. Based on his interview he appeared to have a very positive personality (for example, he laughed and made jokes throughout the interview) and focused on what was

improving rather than what was impaired as evidenced through statements such as, “It is getting a little bit better all the time. Every week’s a little bit better than the week before”. Overall, it was generally found that patients reported better outcomes during SSIs than on the EORTC QOL-H&N35 in all categories except social life. This may be related to difficulty matching their personal and unique outcomes to the discrete values on the EORTC QOL-H&N35. On the other hand it also may be related to patients minimizing impacts and maximizing function during conversation (e.g., reluctance to complain, pride, lack of comfort talking about their misfortunes with others, and denial as a coping mechanism). It is also possible that further prompting by the interviewer was not adequate to delve into the full extent of the problem. For example, when patient 1 was asked about her speech and swallowing at 5 months post treatment, she responded, “oh very good compared to what it used to be during treatment”. To this, the clinician responded, “great” and ended the interview. This patient’s EORTC QOL-H&N35 scores show worse function on both speech and swallowing. Therefore, it would have been interesting if her response had been probed further, for example, “What was it like during treatment?” or “Is it back to pre treatment functioning?” to fully capture her current level of function.

Agreement between the EORTC QOL-H&N35 and SSIs varied depending on a number of factors including severity of impact, functional outcome category, whether the category was directly probed during interviews, and interviewer expertise. For example, sensation and dry mouth showed good agreement between the EORTC QOL-H&N35 and SSIs and these areas were highly impacted across patients. Agreement between measures might have been better for these categories because they were not probed directly during SSIs. Therefore, patients only

mentioned them during the interview if they felt it was a significant problem, in which case they were also reported as such on the EORTC QOL-H&N35. If patients felt sensation and dry mouth were not impacted they were generally not mentioned during SSIs and scored “not at all” on the EORTC QOL-H&N35. Because these areas were not directly probed during SSIs, sensation and dry mouth may be more adequately covered by the EORTC QOL-H&N35. On the other hand, areas that were directly questioned in SSIs, such as functional and social categories, showed less agreement between measures. Generally patients minimized the impact of speech and swallowing issues in interviews. This was unexpected, as previous research found that patients tended to underestimate the magnitude of issues on the EORTC QOL-H&N35 and avoid the extreme ends of the Likert scale (Loewen et al., 2009). This may have been partly confounded in the current study because only one question was asked to cover both speech and swallowing. Therefore, during the SSIs some patients responded to one area and not the other or responded to both at the same time, which may not adequately reflect true functioning. For example, when patient 6 was asked if she was frustrated with her speech and swallowing, she responded, “no I don’t - I don’t know”; however, her EORTC QOL-H&N35 scores indicated no problems with speech and moderate problems with swallowing. Furthermore, there was no prompt by the clinician to delve further into the patient’s uncertain response. These two functions were not always affected to the same degree and likely should be addressed separately during SSIs. Differences in the comparison of the EORTC QOL-H&N35 and SSIs may have been further compounded because of inadequate probing by the interviewer during SSIs. While SSIs allow for more depth, detail, and flexibility to capture quality of life and

functional outcomes, they also rely on interviewer skill and comfort to be an effective measurement tool.

SSIs were able to capture relationships between categories that may have been missed by analysis of the EORTC QOL-H&N35 alone. SSIs reflected the inter-connectedness of saliva, swallowing, and eating and the impact that deficits in these areas had on quality of life and functioning. For example, when asked about his swallow, patient 4 responded, “The swallowing is a lot drier and stickier and slower so I choose things a lot more now than I ever did before so it takes me longer to eat a meal”. Furthermore, patient 5 responded post treatment, “I get frustrated at times with the swallowing, especially when it’s very dry. I wish it could be the way it was before, that’s all” and then went on to expand his answer by saying, “My taste is just starting to come back but it’s not nearly what it was before. I can get a general taste now, but nothing really specific”. SSIs revealed that eating can be impacted because of changes in swallowing, dry mouth, and taste and these relationships are not explicitly captured by the EORTC QOL-H&N35.

The EORTC QOL-H&N35 also does not appear to be adequate in capturing the social impact of organ preservation treatment. Based on EORTC QOL-H&N35 results, social life would appear not to be affected; however, SSIs showed significantly more impact than was captured by the EORTC QOL-H&N35. This may be related to the types of questions the EORTC QOL-H&N35 uses to capture social impact such as, “Have you had trouble having social contact with your family?”. This incongruence was highlighted in the case of patient 9, who scored 0% on the social life questions on the EORTC QOL-H&N35 (indicating no problems); however, when asked

if his social life was affected at 5 months post treatment he responded, “oh yes, because I don’t seem to go as many places as I used to. When you go someplace you like to enjoy the food or beverages, and I can’t do that yet”. This also may be related to the restriction of ‘in the last week’ put in place by the EORTC QOL-H&N35 questionnaire. A number of patients reported that their social life had changed early on and during treatment, but had returned to normal by the time treatment was completed. For example, in response to a question of whether her social life had changed, patient 8 responded, “it did at the beginning you know because I got sick and I ended up in the hospital twice from it too so that puts a damper on what you do” and patient 1 replied, “it did for a while because I was just totally tired, but now that I got my strength back, I carry on the same as I did before and I’m back to work again”. However, both patients scored 0% on the EORTC QOL-H&N35 social categories, indicating no problems. Therefore, based on SSI analysis, we can see that social life was impacted more than the EORTC QOL-H&N35 indicated and it may have been impacted more during treatment rather than after its completion. Perceived social support can have a positive influence on quality of life (Semple et al., 2008), however because the EORTC QOL-H&N35 only looks at negative changes in social support it may not adequately capture positive changes.

Both the EORTC QOL-H&N35 and SSIs captured distinctive items (i.e., items were mentioned in the SSI, but not the EORTC QOL-H&N35 and vice versa) and offered opportunities for additional information on some categories. Information on the patient’s level of pain, which is not a specific SSI question, was not always captured in the SSIs, but was always captured in the EORTC QOL-H&N35. On the other hand, the EORTC QOL-H&N35 did not adequately capture the impact the patient experienced on their social and work life. Thus, it may be that functional

and physical themes are easier to rate using a discrete scale whereas social and personal themes are more complex and require more freedom in answering. Overall both the EORTC QOL-H&N35 and SSIs were found to supply useful information on the patient's quality of life.

Analysis of SSIs revealed additional themes that were not covered by EORTC QOL-H&N35 questionnaires and that have a direct impact on quality of life. Patients are complex and their responses are influenced by their experiences, making it difficult to capture the full range of outcomes by analysis of discrete categories like those found in the EORTC QOL-H&N35. Additional themes that emerged in this study included physical themes such as appearance and fatigue, social themes such as work and personal relationships, emotional themes such as frustration/anger and anxiety/fear, and personal factors such as outlook/perspectives and values/spirituality. The themes that most frequently occurred in the SSIs were outlook and life perspectives, eating, pain, social life, changes in saliva, fatigue and change in work situations. For some patients, changes in outlook and life perspectives were seen as a positive side effect of the cancer diagnosis. For example, patient 8 responded post treatment: "It makes me value the time that I have more. I spend it doing things that I really want to do rather than things I should do and I think that changes can be just as good" and patient 5 responded pretreatment, "Mmm change your outlook on life, you think a lot more about not being indispensable like some people think they are". Some patients also indicated that diagnosis and treatment showed them they have more social support than they thought. For example, patient 9 indicated "knowing that I have a lot of support" as one thing that had changed the most in his life and patient 10 indicated that although treatment "alienated some, it brought others closer". Similar positive reframing was found in Semple and colleague's (2004) study of changes

and challenges following treatment for head and neck cancer. While not all patients experienced positive changes in response to their diagnosis and treatment, it is important to note these experiences along with the negative outcomes. On the other hand, experiences with changes in eating, pain, saliva, fatigue, and work situations were seen only as negative outcomes of head and neck cancer. For example, when asked about three things that had changed in his life since treatment patient 11 responded succinctly “can’t eat, can’t drink, and I’m perpetually tired” and patient 9 responded post treatment “probably my eating and sleeping habits definitely because of the fatigue and as far as my social activities definitely yes”. Fatigue has been found to be significantly affected over the long term and has been implicated in negative outcomes such as malnutrition (Molassiotis & Rogers, 2012). SSI was able to capture certain parameters that the EORTC QOL-H&N35 had not revealed due to its closed question structure.

Pre-Post Outcomes

Pre to post comparisons of the EORTC QOL-H&N35 scores and SSIs support the idea that although organ preservation treatment preserves the structures necessary for speech and swallowing, function still suffers. In the post treatment period, patients showed worse outcomes on the EORTC QOL-H&N35 in senses, speech, swallowing, dry mouth, and saliva; and in SSIs in the categories of eating, swallowing, senses, saliva, fatigue, appearance, work situation, and frustration. This finding is similar to other research that showed negative outcomes may continue to persist for over a year post treatment and in some cases may be permanent (Semple et al., 2008; van der Molen et al., 2009). These negative outcomes may directly or indirectly affect quality of life. Patient 5 experienced many of these negative changes

and said, "I get frustrated with the swallowing, especially when it's very dry. You have to force your way through it and I just wish it could be the way it was before, that's all". Patient experiences of pain varied pre to post treatment with some patients experiencing more pain and some patients experiencing less pain. Moore and colleagues (2004) posit that adequate pain control is important to preserving quality of life; however, for many patients in the present study, pain persisted after the completion of treatment. For example, patient 7 said, "My throat still has a certain soreness to it that makes swallowing certain food a little more difficult". Overall, this study shows that organ preservation therapy continues to result in worse post treatment outcomes even though the structures for speech and swallowing remain intact.

Further review of SSIs revealed additional information regarding pre and post social outcomes. For example, in response to a question about changes in his social life patient 4 answered pre treatment, "Maybe some people are a little afraid of me now that I have cancer, I guess, because they don't really know how to approach me", and responded post treatment "I've had a lot of family and friend support during my treatment so I don't think it's changed my social life at all" indicating a positive change. On the other hand, patient 11 responded no change in social life pre treatment but responded "what social life" post treatment indicating a negative change. Overall, social outcomes varied from patient to patient with some patients indicating better outcomes than others. Research has shown that social support and understanding by family and friends are related to better post treatment outcomes (Karnell, Christensen, Rosenthal, Magnuson, & Funk, 2007), therefore this outcome is an important predictor of quality of life following organ preservation treatments.

Other Factors: Site of Cancer and Gender

Based on the sample size in this study, it was difficult to determine how the site of cancer impacted quality of life following treatment. The most common site of cancer was base of tongue. Visual inspection of tables 4 and 5 would lead one to believe patients with cancer in the base of tongue plus other sites showed more impact in the categories related to dry mouth and changes in saliva post treatment than did patients with cancer elsewhere (for example, base of tongue alone, soft palate, or laryngeal areas). Furthermore, patients who had cancer in the base of tongue plus other sites tended to report more impact pre treatment, especially with regards to pain, than did patients with cancer elsewhere. This may be related to the negative impact of multiple site involvement and potentially the more invasive nature of the cancer in those cases.

Similar to other studies of head and neck cancer patients, there were few measurable differences between male and female patient responses (Abendstein et al., 2005). However, it was found that males experienced more pain pre treatment and a greater impact on function post treatment. These differences between male and female patients contradict the findings of Lee and colleagues (2010) who found that male patients had better social adjustment and female patients had higher symptom/impairment levels; however, their results were for patients treated with a total laryngectomy, which reduces the generalizability of their findings to the current study. Differences in male and female responses in the current study may be related to impact of multiple sites of cancer, with males showing more multi-site involvement than females, rather than an impact of gender. At the same time, one commonality among all 3 female patients in the present study was mentioning their outlook/perspectives during the pre

treatment SSI. For example, patient 2 said, “I’m just trying to go along as time goes by and what happens, I guess, happens”, patient 6 said, “I’m just being positive and optimistic”, and patient 8 said, “Well my outlook on life” was one of the three biggest changes she had experienced since diagnosis. Each female patient suggested a personal struggle that accompanied the physical struggle of a cancer diagnosis, whereas only one male patient mentioned their outlook/perspectives during pre treatment interviews. This trend mirrors findings in other studies that females are more likely to experience emotional problems or depression related to health problems (Lee, Gibson, & Hilari, 2010). A larger sample size would be needed to determine if these factors were significant in the current study.

LIMITATIONS

All patients in this study were chosen from a convenience sample of patients treated at iRSM, which resulted in a small sample size. Future research would benefit from collaboration with other sites to increase the patient population size and diversity. The patient population in this study consisted of 8 males and 3 females. While head and neck cancer is traditionally considered a predominately male disease, incidences of female cases are on the rise. Furthermore, data were only examined pre treatment and shortly after treatment (up to 6 months post); therefore, it is not possible to make generalizations regarding how the patients adapt long-term. Also, while there were 3 standard questions asked during SSIs there was no standardized system used to further probe client responses. There were also differences in interviewing techniques between clinicians and consequently not all patient responses were

probed to the same depth. Lastly, researcher bias may have factored into the interpretation of the qualitative data and assigning themes to comments made by patients.

CONCLUSION

The main objective of this study was to determine if coherence exists between two commonly used tools in evaluating the quality of life before and after organ preservation treatment for head and neck cancer. SSIs have the potential to cover a broader scope of outcomes, especially the social impact of diagnosis and treatment, if the clinician not only administers the questions, but also uses responses as an opportunity to probe deeper and gain insight into the underlying and related issues around the topic. If time constraints do not allow the clinician to use an SSI as a means of probing for more in-depth information, there is the potential that they will receive very limited information; in these situations, the EORTC QOL-H&N35 would be a better tool because more areas are directly addressed. Furthermore, most agreement between the measures was found when assessing the topics of sensation and dry mouth while less agreement was found between functional and social outcomes.

It was confirmed that, regardless of outcome measure used, quality of life measures 4 to 6 months after treatment were worse than the pre treatment measures. Comparison of pre and post treatment outcomes between organ preservation therapy and surgical treatment would be one area of future research that could be undertaken to determine whether one option leads to better quality of life outcomes than the other.

Other factors that may impact quality of life measures were investigated as well. Site of cancer, particularly the tongue base plus another region, might result in more negative quality

of life scores and reports just before treatment. In addition, the role that sex plays also was considered, but after evaluation, no conclusions could be reached. In future research, assessment of personality as an influence on quality of life could be considered.

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