

## ■ The Relationship Between Communication and Quality of Life in Alaryngeal Speakers

## ■ La relation entre la communication et la qualité de vie chez des locuteurs alaryngés

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### Abstract

A national mail survey was conducted to evaluate the relationship of communication and quality of life (QOL) in alaryngeal speakers. Subjective impressions of QOL were ascertained with regard to physical, social, emotional, functional well-being, and disease-specific concerns. Demographic variables which correlated with increased QOL included income and years postsurgery. The number of postoperative symptoms had a strong negative correlation with QOL. There were no differences by gender or partnership status but employment was associated with higher QOL. Results also showed that frequent communicators and those who perceived their communication as successful rated their QOL as significantly higher than those who communicated less often and those who rated themselves as less successful. The abilities to breathe, eat, and communicate showed the strongest significant relationships with overall QOL. Of these three abilities, the ability to communicate was most strongly associated with better QOL. The ability to communicate showed an inverse relationship with feelings of social isolation. A positive relationship was found between the ability to communicate and feelings of pride, acceptance, and enjoyment of life. There was also a positive relationship between communication and functional abilities, such as the ability to perform work- or household-related tasks and the ability to eat. Results are discussed relative to other studies that have examined QOL in head and neck cancer survivors. Implications for future research are discussed.

### Abrégé

Un sondage évaluant la relation entre la communication et la qualité de vie (QDV) auprès de locuteurs alaryngés, a été effectué à l'échelle nationale, par envoi postal. Des impressions subjectives concernant la qualité de vie ont été établies en fonction des aspects physiques, sociaux, émotionnels, fonctionnels, ainsi qu'en fonction de l'état de bien-être et de la maladie. Les variables démographiques en corrélation avec une augmentation de la QDV étaient : le revenu et les années post-chirurgie. Le nombre de symptômes était en forte corrélation négative avec la QDV. Il n'y avait pas de différence entre les genres et l'état civil, mais le fait d'occuper un emploi était associé à une QDV plus élevée. Les résultats obtenus ont aussi montré que les personnes qui communiquent souvent sont celles qui perçoivent bien réussir leur communication et rapportent une QDV significativement plus élevée que celles qui communiquent moins souvent et qui croient moins bien réussir leur communication. Les trois fonctions suivantes : respirer, manger et communiquer ont montré la plus forte relation significative avec la QDV générale. De ces trois dernières, l'habileté à communiquer était celle associée plus significativement avec une meilleure QDV. L'habileté à communiquer était en correspondance réciproque avec l'impression d'isolement social. Une relation positive a été observée avec l'habileté à communiquer et la sensation de fierté, d'acceptation de soi et l'impression de profiter de la vie. Il y a aussi une relation positive entre la communication et les habiletés fonctionnelles telles que réussir des tâches reliées au travail ou à l'entretien ménager et de pouvoir manger. Une discussion des résultats en relation avec d'autres études portant sur la qualité de vie chez les personnes ayant survécu au cancer à la tête ou au cou apparaît à la fin de l'article ainsi que les implications pour les futures recherches.

**Key Words:** alaryngeal speech rehabilitation, communication, head and neck cancer, laryngectomy, quality of life

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In recent years there has been a growing consensus among the medical community that it is not sufficient to measure objective variables alone in determining the efficacy of a particular treatment for cancer (Calman, 1984; Cella, 1994b; de Haes & van Knippenberg, 1985). Formerly, the two most important criteria for measuring success were mortality rate and life expectancy, but there is now a move to consider qualitative as well as quantitative variables. In particular, the concept of quality of life (QOL) was embraced as a means of gauging the impact of treatment on individuals with cancer. The U.S. Food and Drug Administration, National Cancer Institute, and the World Health Organization have advocated the use of QOL assessment in cancer clinical trials (Grant & Rivera, 1998). In addition, the International Society for Quality of Life Research and the European Organization for Research and Treatment of Cancer have engendered an international exchange of information and research on the subject.

When applied to the medical field, QOL assessment combines the two research traditions of investigations into the adjustment of cancer patients with determinants of QOL in the population as a whole (Baltrusch & Waltz, 1987). Using a typology developed by Hornquist (1982), de Haes and van Knippenberg (1985) compared which domains were evaluated by published instruments and studies dealing specifically with the QOL of cancer patients. The key areas investigated included measures of physical, psychological, social, functional (i.e., activities), material (i.e., financial well-being), structural (i.e., participation in the democratic process), and global (i.e., an overall index) well-being. There were not only inconsistencies as to which areas were covered, but also with regard to the definition of each domain. Despite the widespread differences, however, there is a gradually emerging consensus amongst the medical community with regard to several key aspects of QOL (Cella, 1994a). There is now considerable agreement that QOL is subjective and, therefore, best measured from the patient's perspective. There is also agreement that QOL is multidimensional, most commonly incorporating physiological, psychological, and sociological domains, although there is some support for the inclusion of the spiritual also. Finally, many authors agree that an individual's perception of their well-being changes over time, even in the absence of any change in the individual's circumstances, as a result of individual adaptation or changes in personal priorities or goals (Baltrusch & Waltz, 1987; Calman, 1984, 1987; D'Antonio, Zimmerman, Cella & Long, 1996; Hinds & King, 1998; Vallerand, Breckenridge & Hodgson, 1998). In one model QOL represents the gap between one's expectations of how life should be and one's perception of how it actually is (Calman, 1987; Padilla, Grant, & Martin, 1988).

After total laryngectomy, researchers have emphasized the impact of psychosocial factors on postsurgical recovery (Mathieson, Stam, & Scott, 1990;

Richardson, Graham, & Shelton, 1989). Although it is generally accepted that communication is a critical element in psychosocial functioning, the relationship has rarely been studied explicitly, nor has the impact of the failure to develop communicative competence often been documented. Since postsurgical communication is one of the greatest challenges facing an individual after laryngectomy, an understanding of which factors related to communication promote better QOL is vital for rehabilitation. As the authors of one study (Jones, Lund, Howard, Greenberg, & McCarthy, 1992) argue, investigating factors that influence long-term QOL is of great value for improving rehabilitation and the prospects of survival.

One of the most critical aspects of rehabilitation after total laryngectomy is the development of a new method of communication. Estimating success rates remains problematic due to changes in alaryngeal speech options, improved management of certain complications, and differences in recruitment of subjects (Graham, 1997). Historically, studies which looked at the acquisition of esophageal speech (ES) estimated failure rates at between one-fifth to three-quarters of all laryngectomees (Bagshaw, 1967; Gardner & Harris, 1961; Horn, 1962; Martin, 1963; Putney, 1958). Some authors have estimated the true value as being close to 60% (King, Fowlks, & Pierson, 1968). More recently, tracheoesophageal speech (TES) has been an increasingly common method of alaryngeal speech rehabilitation (Iversen-Thorburn & Hayden, 2000). At some facilities, the success of this method has been documented as being over 90% in selected patients (Blom, Singer, & Hamaker, 1981; Izdebski, Reed, Ross, & Hilsinger, 1994; Kao, Mohr, Kimmel, Getch, & Silverman, 1994; Op de Coul, et al., 2000; Singer & Blom, 1980; Wood, Rusnov, Tucker, & Levine, 1981). With regard to the number of individuals who may remain voiceless after laryngectomy, there is considerable variation in data published for different medical centers or geographic regions, with data ranging from 2-23% (Carr, Schmidbauer, Majaess, & Smith, 2000; Clements, Rassekh, Seikaly, Hokanson, & Calhoun, 1997; Terrell, Fisher, & Wolf, 1998). It is also clear that many patients experience significant communication difficulties for up to 6 months after treatment. Several prospective studies have demonstrated that 40% or more of patients still using writing as their primary method of communication at this point, and continue to experience significant, socially-limiting communication difficulties (Armstrong et al., 2001; Gates et al., 1982a; List et al., 1996). Moreover, while TES has gained ground as a method of alaryngeal speech rehabilitation, it is not universally available. In a national survey of speech-language pathologists involved in alaryngeal speech rehabilitation, the majority said that less than 50% of the otolaryngologists in their community offered tracheoesophageal puncture (TEP) procedure routinely (Culton & Gerwin, 1998). Surveys of surgeons prominent in the field of head and neck cancer have indicated that approximately one-third of their patients

were TEP users (Lopez, Kraybill, McElroy, & Guerra, 1987; Webster & Duguay, 1990). In those patients who receive a TEP, success is far from assured as demonstrated by the fact that 44 of 168 patients discontinued use in a retrospective study at the Cleveland Clinic (Lavertu et al., 1996). Likewise, the importance of routine follow-up to ensure continued communication use was underscored by the study of Australian patients by Frowen and Perry (2001) in which only 26% were successfully using their TEP a year after it was placed. It seems clear that, although there has been much progress in the field of alaryngeal speech rehabilitation, for some patients the development of functional verbal communication remains a significant challenge.

With regard to factors that are associated with negative speech outcomes, findings to date have been somewhat equivocal. In some studies, increased age has been shown to be a negative factor for the development of ES (Brusis & Schoning, 1984; Dabul & Lovstedt, 1974; Mjones, Olofsson, Danbolt, & Tibling, 1991) and TES (Jacobson, Franssen, Birt, Davidson, & Gilbert, 1997; Schultz & Harrison, 1992), although this is not always the case (Ackerstaff, Hilgers, Aaronson, & Balm, 1994). Postoperative employment status was the only surgical, biographical, or social factor that correlated with ES proficiency in another study (Frith, Buffalo, & Montague, 1985). Social and motivational differences do not differentiate good esophageal speakers from poor ones (Dabul & Lovstedt, 1974). Several socioeconomic factors (preoperative employment, income planning for recovery period, and dependency status) and physiological factors (postoperative complications, postoperative dysphagia, and lingual mobility) were associated with the development of esophageal speech in Volin's analysis (1980). Treatment variables are not consistently predictive for the determination of who is most at-risk. One study found no correlation between the development of ES with extent of surgery, radiation field, or the presence of dysphagia (Mjones, et al., 1991). Another study found no relationship between intelligibility, upper esophageal speech (UES) pressure, and the presence of dysphagia (Roed-Petersen, Joergensen, & Larsen, 1979). Negative factors associated with unsuccessful outcomes after TEP have included overall patient health (Shultz & Harrison, 1992), poor vision, reduced manual dexterity, and history of radiation treatment (Cantu, Ryan, Tansey, & Johnson, 1998), preoperative communication status (Jacobson et al., 1997), or the presence of pharyngeal stricture (Lavertu et al., 1996). Although the focus has often been on patient characteristics, the skill of the surgeon and rehabilitative team are also critical variables. A correlation between improved speech outcomes after TEP and increased clinician expertise was reported by Shultz and Harrison (1992). The importance of the medical/surgical and rehabilitative teams' efforts to maximize voice quality is reinforced by the finding that voice quality for TEP users correlates with voice use, and the speech method may be

abandoned entirely if good vocal quality is not achieved (Lavertu et al., 1996).

Early studies of the relationship between communication and rehabilitation outcomes attempted to establish the degree to which characteristics of the speaker determined his or her proficiency (Gardner, 1961; Goldberg, 1975; Shanks, 1986; Stoll, 1958). Although associations were observed, it is difficult to determine whether a more positive attitude was the cause or the effect of better speech. Attempts to predict speech outcomes based upon internal characteristics have been largely unsuccessful.

There has been similar disagreement in the studies of postoperative adaptation and speech quality. One study (Amster et al., 1972) found no correlation between social adjustment and speech intelligibility. In contrast, other studies have reported modest positive correlations between adjustment and objective speech measures (Dabul & Lovstedt, 1974; Goldberg, 1975). Individuals who rate their voice more negatively have also been shown to have greater fatigue, reduced frequency of phone-use, greater communication anxiety, and fewer friends (Ackerstaff et al., 1994). In an evaluation of coping and adjustment after laryngectomy, the authors found a correlation between listeners' perceptions of voice quality and the subjects' postoperative adjustment, self-esteem, and general well-being (Blood, Luther, & Stemple, 1992). There was no difference in any of these domains by alaryngeal speech method. The authors posit a reciprocal relationship in which poor postoperative adjustment interferes with participation in rehabilitation, or in which poor progress in therapy contributes to worse adjustment. The importance of psychological state on functional rehabilitation is reinforced by the knowledge that the decision to terminate therapy is often the result of feelings of discouragement (Heaver, White, & Goldstein, 1955).

A review of the literature on psychosocial outcomes after laryngectomy revealed that long-term rehabilitation was multidimensional in nature (Mathieson et al., 1990). In this review the seven key variables which had been most extensively documented were: extent of surgery; preoperative visits by a laryngectomee; illness variables; changes in lifestyle following surgery; patient satisfaction with social support; chronic pain; and ability to communicate. According to this model, the impact of communicative ability may not be distinguishable from that of the other seven variables which shape the successful postsurgical adjustment of the individual.

The current study was undertaken to gather comprehensive information on a randomized, national sample of individuals who had undergone a laryngectomy. As a result it would be possible to examine correlations between variables believed to be related to improvements in overall QOL for survivors of laryngeal cancer. The present study was designed to investigate the impact of communication on adjustment after laryngectomy by (a) investigating the relationship between frequency of

communication and QOL, (b) analyzing the relationship between self-perceived success of communication and QOL, (c) determining how strongly other disease-specific concerns relate to overall QOL, (d) examining if there was a difference in communicative frequency or success by alaryngeal speech method, and (e) identifying which demographic variables were associated with better or worse QOL.

## Method

### Questionnaire

*Demographic variables.* A comprehensive questionnaire was developed by the study authors, based upon a review of the literature relating to the typical experiences of head and neck cancer patients and the factors considered important to psychosocial rehabilitation. Feedback obtained from a pilot group of alaryngeal speakers in the Alaryngeal Speech Clinic at San Francisco State University prompted the rewording of ambiguous questions and the insertion of additional answer options. No scoring of the questionnaire responses was necessary. Answers to close-ended questions were coded numerically and entered to permit the analysis of correlations.

*Frequency of communication.* Respondents were asked, *On the average how often do you communicate with other people?* The ordinal scale allowed six possible answers ranging from *many times per day* to *never*.

*Communicative Success.* Item 10 of the Functional Assessment of Cancer Therapy-Head and Neck Survey (FACT-HNS) (*I am able to communicate with others*) was used to assess respondents' evaluation of their ability to communicate by any means. Answers on the Likert scale ranged from 0 (*not at all*) to 4 (*very much*). In addition, respondents were asked to analyze their typical communicative success with both familiar and unfamiliar listeners using their primary method of communication. The ordinal scale allowed five possible answers ranging from *always* to *never* in response to the question: *How frequently are you successful in expressing your needs and opinions to familiar/unfamiliar adults using your primary method of communication?*

*Quality of Life.* The Functional Assessment of Cancer Therapy-General Measure (FACT-G) was used to measure overall QOL. This instrument was developed to ascertain the combined impact on survivors of both the cancer itself and its treatment (Cella et al., 1993). The FACT-G was designed to measure the QOL of the general population of cancer patients, regardless of type. The protocol uses a 5-point Likert scale for 28 statements on the questionnaire. By tallying the scores from the domains of physical, emotional, social, and functional well-being, the FACT-G provides a global index of the patient's perception of his or her QOL.

*Disease-Specific Concerns.* The FACT-HNS was developed to provide supplementary information

regarding disease-specific concerns of head and/or neck cancer patients (Cella, 1994a). The FACT-HNS has demonstrated good correlations with other disease-specific measures, such as the University of Washington Quality of Life Scale and the Performance Status Scale for Head and Neck Cancer (D'Antonio et al., 1996). The second instrument is composed of 11 items, 9 of which can be summed to provide an overall index of head-and-neck-specific QOL.

### Subjects

The mailing list of the International Association of Laryngectomees (IAL) was obtained with permission from that organization. The original purpose of the investigation was to examine whether there were significant differences between males and females in their patterns of adjustment after laryngectomy, and therefore the list was subdivided into males and females prior to sampling. From these two lists, the names and addresses of 520 individuals, 260 men and 260 women, were randomly selected using the method of systematic sampling with a random start. Of the 520 questionnaires mailed to potential subjects, 361 were returned or accounted for, representing a 69% response rate. Of these, 49 (9%) were returned marked *non-laryngectomee* by the recipient, 40 (8%) were returned marked undeliverable, 29 (6%) were returned by a friend or family member who indicated the individual was deceased, and 4 (1%) were returned by the individual because he or she was unwilling or unable to complete it. Consequently, of the 361 returns, 239 were complete and could be used for analysis. The results of this comparison have been published elsewhere (Graham & Palmer, 2002).

For the purposes of this study a more representative sample was created. Thus of the original 239 complete responses, an initial 13 surveys were discarded because the respondents had undergone only a partial laryngectomy or did not indicate what type of surgery they had received. Of the remaining 226 complete questionnaires, random selection enabled the creation of a gender-balanced survey. The original IAL mailing list was composed of 4,284 males to 1,903 females or a ratio of 2.25:1. By selecting alternate female respondents with a random initial start, a total of 52 female subjects was selected. Thus, our final sample was composed of 170 individuals, 118 males, and 52 females in order to maintain the proportion of our original database. The demographic characteristics and treatment variables of the sample as a whole are summarized in Table 1.

### Statistics

The individuals who comprised the study were described using frequencies and percentages with regard to demographic variables, such as gender, age, income, ethnicity, marital status, and occupational status. Their responses on the questionnaire were entered into an Excel spreadsheet which automatically generated scores for the FACT-G and FACT-HNS. As the FACT-G and FACT-HNS are not currently norm-referenced, all scores were

**Table 1**  
**Background Characteristics of the Sample**

		n	%
<b>Gender</b>	Male	118	69
	Female	52	31
<b>Age</b>	Under 59	30	18
	60-69	57	34
	70-79	68	40
	80 and over	15	9
<b>Partner status</b>	Single	5	3
	Married/partner	120	71
	Widowed/divorce	43	26
<b>Education (highest level completed)</b>	Elementary/middle school	25	15
	High school	61	36
	Some college courses	62	37
	Bachelor's degree or higher	21	12
<b>Employment</b>	Employed (full- or part-time)	32	20
	Volunteer	3	2
	Retired	105	66
	Unemployed	20	13
<b>Income</b>	Less than \$5,000	11	8
	\$5,001 - \$15,000	39	28
	\$15,001 - \$25,000	31	22
	\$25,001 - \$35,000	19	14
	\$35,001 - \$45,000	16	11
	\$45,001 or more	24	17
<b>Number of years postop</b>	1-2	21	16
	3-5	28	22
	6-9	34	27
	10-15	19	15
	16 or more	26	20
<b>Treatment variables</b>	Radical neck dissection	32	19
	Radiation	115	68
	Chemotherapy	11	7

converted to transformed scores for ease of interpretation using the formula: (raw score/maximum possible raw score) x 100. Thus all subscales are reported as a percentage from 0-100%, with lower scores representing worse overall adjustment.

To identify relationships between these variables and measures of QOL, independent measures *t*-tests or Spearman rank-order correlations were calculated to ascertain whether the differences were statistically significant ( $p < .05$ ). Spearman rank-order correlations were also calculated to identify which items on the FACT-HNS corresponded most closely with the overall scores on the FACT-G, and to ascertain whether communicative variables were more closely associated with overall QOL. The relationship between communication and QOL was further analyzed by utilizing an independent measures *t*-test to identify significant differences ( $p < .05$ ) in the mean QOL scores for groups differing in communicative frequency or communicative success. Equality of variance was calculated for each set of data using the Levene Test. Where population variances were not equal, significance data was calculated accordingly.

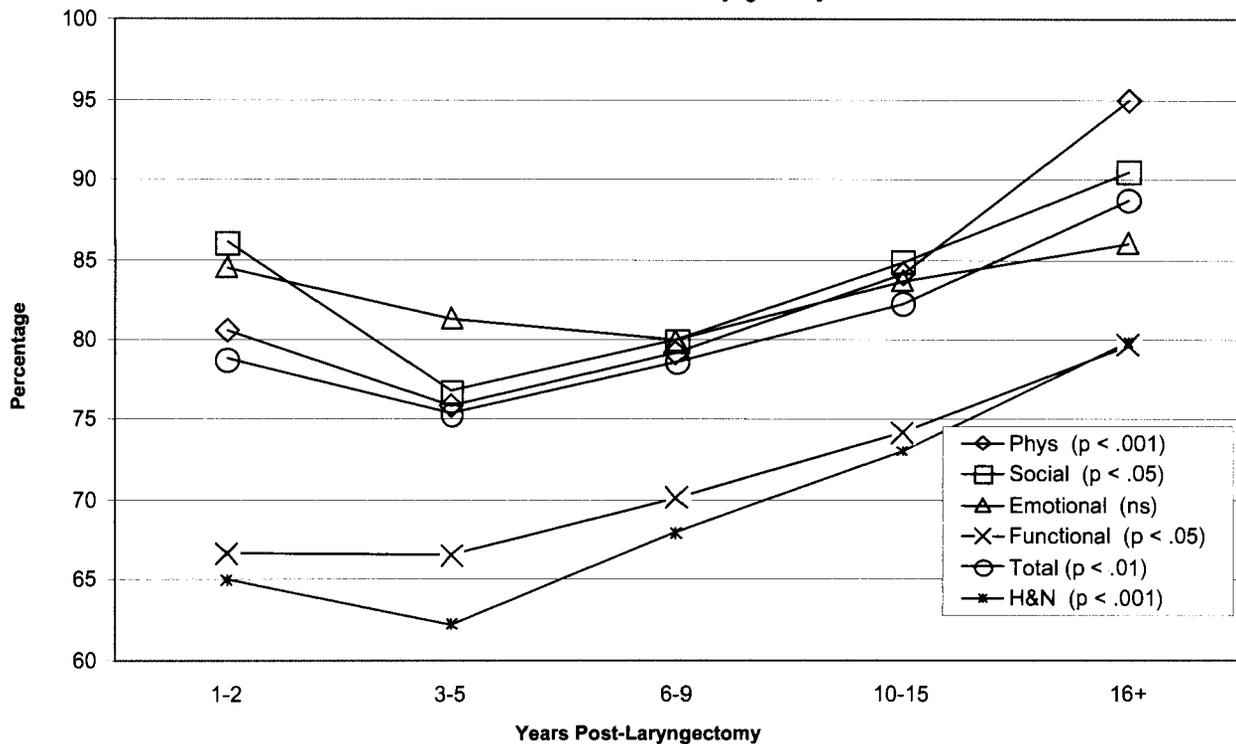
## Results

### Reliability Data

All of the FACT scores were automatically calculated by a scoring program created in Excel for this purpose. Comparison of computer-generated scores with a random sample of questionnaires scored by hand revealed 100% agreement.

The average scores for all of the subscales of the FACT-G and FACT-HNS are listed in Table 2. Comparing these results with those obtained in the development of the FACT-G (Cella et al., 1993), the standard deviations of each of the subscales are roughly equivalent. The mean score was consistently higher than that of the 151 patients with head and neck cancer who were part of the original validation of the instrument (Cella, 1994a). Consistent with the standardization information published by the authors, the FACT-G and FACT-HNS demonstrated instrument reliability. Using Cronbach's alpha, each of the subscales demonstrated good to excellent internal reliability with .74 to .92.

Figure 1.  
FACT Subscale Percentages by  
Number of Years Post-Laryngectomy



### Demographic Variables and Quality of Life

In a previous article (Graham & Palmer, 2002) it was demonstrated that the responses of men and women were more similar than dissimilar, although there were significant differences on individual items of the FACT, as well as demographic differences between these two groups. Differences in mean subscale scores for men and women on the FACT-G were not significant using *t*-tests at the  $p < .05$  level of significance (Table 3). Surprisingly, there was also no difference in the subscales of the FACT-G when comparing respondents based upon the presence or absence of a life partner. There were noted to be differences on several individual items on the questionnaire. In particular, those with a partner reported significantly more difficulty meeting family needs on the Physical subscale (*I have trouble meeting the needs of my family*,  $t(108.27) = 2.38, p < .05$ ), but also greater emotional support (*I get emotional support from my family*,  $t(65.28) = 2.46, p < .05$ ; *My family has accepted my illness*,  $t(47.50) = 2.38, p < .05$ ). In contrast, however, postoperative employment status did show a significant difference in terms of overall QOL. Individuals who were employed part-time or full-time ( $n = 35$ ) demonstrated a significantly higher overall QOL ( $t(139) = -2.51, p < .05$ ) than those who were retired or unemployed ( $n = 128$ ) as summarized in Table 3.

Spearman correlations were investigated to determine relationships between QOL and age, postoperative

income, postoperative employment status, education level, and number of years since the total laryngectomy operation (Table 4). Age showed no significant relationship with overall QOL, although there was a small relationship with Physical Well-Being ( $r = .17, p < .05$ ). Interestingly, this was a positive relationship indicating that our sample reported slightly increased satisfaction with their physical status as they aged. Education level similarly showed no significant relationship with overall QOL but small positive relationships with Emotional Well-Being ( $r = .19, p < .05$ ) and Functional Well-Being ( $r = .17, p < .05$ ). The number of years of preoperative smoking showed a negative correlation with both Physical Well-Being ( $r = -.18, p < .05$ ) and Functional Well-Being ( $r = -.16, p < .05$ ). Neither pre- nor postoperative alcohol consumption showed any significant relationship with any subscale. Postoperative income showed a significant positive relationship with all subscales as summarized in Table 4.

The number of years since surgery also demonstrated a number of significant relationships using Pearson's correlation. Positive relationships were noted for all but the Emotional Well-Being subscale (Table 4). The number of years since total laryngectomy of our respondents ranged from 1 to 38 years, with a median of 7 years. The average for each subscale was plotted for each group of survivors according to the number of years postsurgery (Figure 1). Given the fact that this information was not collected on a

**Table 2**  
**FACT-G and FACT-HNS Subscale Scores**

	Mean (SD)	Range
Physical Well-Being	84.15 (± 20.13)	4-100
Social Well-Being	80.38 (± 19.01)	15-100
Emotional Well-Being	83.43 (± 19.87)	5-100
Functional Well-Being	70.53 (± 27.19)	0-100
FACT-G Total (PWB+SWB+EWB+FWB)	80.40 (± 15.87)	36-100
FACT-HNS	68.80 (± 19.24)	19-100

The FACT is not currently norm-referenced. All subscales provide a raw score which was then transformed to provide a score from 0-100% with lower scores representing a poorer sense of well-being.

**Table 3**  
**Differences in QOL by Gender, Partnership and Employment Status**

	FACT-G total score Mean (SD)	Mean difference	t-value
Male (n=98)	81.43 (± 14.81)		
Female (n=44)	78.11 (± 17.98)	3.46	ns
Married/Partner (n=105)	81.21 (± 16.01)		
Single/Widowed/ Divorced (n=36)	78.89 (± 14.91)	2.42	ns
Employed (n=35)	85.99 (± 13.9)		
Unemployed/ Retired (n=128)	78.38 (± 16.0)	7.61	-2.51*
0-3 Postoperative Symptoms (n=76)	88.23 (± 11.9)		
4+ Postoperative Symptoms (n=89)	73.41 (± 15.8)	14.82	-6.36***

\*p < .05 \*\* p < .01 \*\*\* p < .001 ns= not significant

single cohort of patients over time, it could be hypothesized that each subscale would show an increase over time due to the survivor effect, as sicker individuals would be expected to succumb to their disease or other co-morbidities thus biasing the sample. Interestingly, however, there appeared to be no gain or even a small decline in all subscales for the 3 to 5 years postoperative group, while there were small increases in all but one subscale subsequently. The Emotional Well-Being subscale, however, demonstrated no significant difference postsurgery. It was also clear that the two areas which remained most negatively affected were the Functional Well-Being and the disease-specific concerns of the FACT-HNS.

### ***Disease-Specific Concerns and Quality of Life***

To investigate the relative impact of functional deficits on overall QOL, we examined whether different treatment variables, postoperative symptoms, and other disease-specific concerns influenced perceptions of well-being. Respondents were asked to indicate which symptoms they experienced based on a list (Table 5). The five most common symptoms which were experienced by a third or more of our sample were: increased mucus (62%), difficulty swallowing solids (43%), fatigue (39%), shortness of breath (39%), and gas/bloating/indigestion (33%). The number of symptoms individuals reported ranged from 0 to 15 with a median of 4. To determine whether there was an impact on QOL from the number of symptoms a person experienced, the FACT scores were compared for those who reported three or fewer symptoms in contrast to those who reported four or more. Those with more symptoms reported significantly lower overall QOL than those who had fewer, as summarized in Table 4.

Comparisons were additionally made based upon the treatment modalities that respondents underwent in addition to their surgery. As can be seen from Table 1, the majority of our sample respondents (68%) received radiation treatment (XRT) as part of their cancer treatment, while only 19% underwent radical neck dissection (RND) and 7% were treated with chemotherapy. A comparison of the subscales of the FACT revealed no significant differences between any treatment groups, although this may be attributed in part to the small size of the chemotherapy and RND groups. There were some differences on individual items, however. Those who had undergone XRT reported increased difficulty breathing (*I have trouble breathing*,  $t(86.7) = 2.77$ ,  $p < .01$ ). There were also functional deficits reported by the RND groups who reported more pain (*I have pain*,  $t(39.33) = -2.48$ ,  $p < .05$ ) and a reduced ability to eat (*I am able to eat as much food as I want*,  $t(160) = 2.44$ ,  $p < .05$ ). It may be

hypothesized that those who underwent RND represent a group with more advanced disease, spreading to the lymph nodes. Interestingly, however, respondents from the RND group also reported higher well-being on the Social scale in terms of emotional support from their family (*I get emotional support from my family*,  $t(124.38) = -4.24$ ,  $p < .001$ ), familial acceptance of their disease (*My family has accepted my illness*,  $t(155.54) = -3.13$ ,  $p < .01$ ), and increased closeness with a partner (*I feel close to my partner (or main support)*,  $t(49.16) = -2.18$ ,  $p < .05$ ).

**Table 4**  
**Correlations Between Sociodemographic Variables and Quality of Life**

	Physical Well-Being	Social Well-Being	Emotional Well-Being	Functional Well-Being	FACT-G Total	FACT-HNS
Age	.17*	ns	ns	ns	ns	ns
Education level	ns	ns	.19*	.17*	ns	ns
Preoperative smoking (years)	-.18*	ns	ns	-.16*	ns	ns
Preoperative daily alcohol	ns	ns	ns	ns	ns	ns
Postoperative daily alcohol	ns	ns	ns	ns	ns	ns
Postoperative income	.24**	.20*	.27**	.30***	.31**	.26**
Number of postoperative symptoms	-.62***	-.20**	-.41***	-.38***	-.52***	-.58***
Years postoperative	.32***	.22*	ns	.20*	.26**	.32***

All statistics are Spearman correlations with the exception of Years PostOperative (Pearson's correlation)  
 \* $p < .05$  \*\*  $p < .01$  \*\*\*  $p < .001$  ns = not significant

To determine the strength of the relationship between individual areas of concern on the FACT-HNS and overall QOL on the FACT-G, Spearman correlations were calculated for each of the 11 individual items on the FACT-HNS and for the FACT-HNS total score (Table 6). It is generally accepted that correlation coefficients below .40 are of little practical importance in demonstrating a relationship (Fraenkel & Wallen, 1996). Of the items on the FACT-HNS, three items showed statistically significant relationships for which  $r$  is at least .40 with overall QOL: item 3 (*I have trouble breathing*), item 10 (*I am able to communicate with others*), and item 11 (*I can eat solid foods*). Of these three, the single strongest correlation was between the ability to communicate (item 10) and overall QOL (FACT-G Total) ( $r = .54, p < .001$ ). It is also noteworthy that perceived voice quality showed a weaker correlation with overall QOL ( $r = .36, p < .001$ ) than that observed between QOL and communication.

### **Method of Communication and Quality of Life**

Asked about their primary method of communication, the majority of respondents listed the artificial larynx (AL) as their main mode of expression (Table 7). The AL was used primarily by 95 (56%) of the individuals in this sample. ES was the next most common method, with 36 individuals (21%) listing it as their primary communication method. TES was used as a primary method by 28 individuals (17%). In addition, writing ( $n = 5$ ) or a combination of methods ( $n = 5$ ) was listed as the primary method.

The responses of the communication groups were compared with regard to their frequency of success. As indicated previously, respondents answered two questions about their frequency of communication with both familiar and unfamiliar listeners (*How frequently are you successful in expressing your needs and opinions to familiar adults using your primary method of communication*, and *How frequently are you successful in expressing your needs and opinions to unfamiliar adults using your primary method of communication*). Results are summarized in Figure 2. As demonstrated, users of all three alaryngeal communication methods considered themselves successful with both types of listener groups at least 70% of the time. Those who depended primarily on writing were similarly successful (80%) for familiar listeners but were successful only 55% of the time with unfamiliar listeners.

With regard to familiar listeners, TES users rated themselves most highly. They considered themselves successful 91% of the time with familiar listeners ( $SD = 15.54$ ), while ES users were successful almost 87% of the time ( $SD = 14.00$ ) and the AL group reported 82% success ( $SD = 15.84$ ). Frequency of success with unfamiliar listeners was slightly lower. TES users were, on average, successful 86% of the time ( $SD = 17.32$ ) followed by ES users ( $M = 77.78, SD = 15.56$ ) and AL users ( $M = 71.58, SD = 14.86$ ). A one-way ANOVA reached the level of significance for both the question relating to familiar ( $p < .05$ ) and unfamiliar adults ( $p < .001$ ). A post-hoc comparison using the Scheffé test indicated that TES users consistently rated themselves as more successful than AL

**Table 5**  
**Postoperative Physical Symptoms in Order of Frequency**

	n	%
Increased mucus	106	62
Difficulty swallowing solids	73	43
Fatigue	66	39
Shortness of breath	66	39
Gas/bloating/indigestion	56	33
Difficulty sleeping	53	31
Shoulder pain	52	31
Neck/throat pain	48	28
Lack of saliva	43	25
Loss of teeth	40	24
Loss of appetite	37	22
Constipation	32	19
Bleeding from stoma	32	19
Other	32	19
Difficulty swallowing liquids	22	13
Nausea	19	11
Difficulty concentrating	15	9
Fistula	8	5
Difficulty staying awake	7	4

users with both familiar ( $p < .05$ ) and unfamiliar ( $p < .001$ ) listeners. No significant differences were observed between ES users and either of the others.

It should also be noted, however, that there were notable demographic differences between the TES users and the other two alaryngeal speech groups. The group of TES users included more younger members, more employed individuals, and more individuals with higher incomes, than in the other two groups. Since individuals who undergo the TEP procedure are often screened for candidacy it was expected that there would be qualitative differences between this and the other groups for which it would not be possible to control. Consequently we did not analyze differences in overall QOL by speech method.

It should also be noted that the majority of individuals used more than one communication method. Only 19% of our respondents used one method exclusively, while the majority (56%) used two, and the remaining 25% used

three or more. Asked to indicate all of the methods they utilized, the most frequently cited options were AL (72%), followed by writing (41%), and gestures (39%) as summarized in Table 7. Asked to list all of the methods of acquiring their primary method of communication, respondents commonly listed a speech-language pathologist (68%), self-instruction (53%), another laryngectomy (17%), or a book/pamphlet (17%).

### **Frequency of Communication and Quality of Life**

In response to the question, *On the average, how often do you communicate with other people?*, the majority of individuals (67%) reported communicating with others many times per day. An additional 27% ( $n = 46$ ) communicated with others several times per day. Only 9% ( $n = 9$ ) of the respondents indicated they communicated less frequently than this, with 1% ( $n = 2$ ) interacting with others once per day, 4% ( $n = 6$ ) several times per week, and 1% ( $n = 1$ ) almost never. No one indicated they never communicated with others.

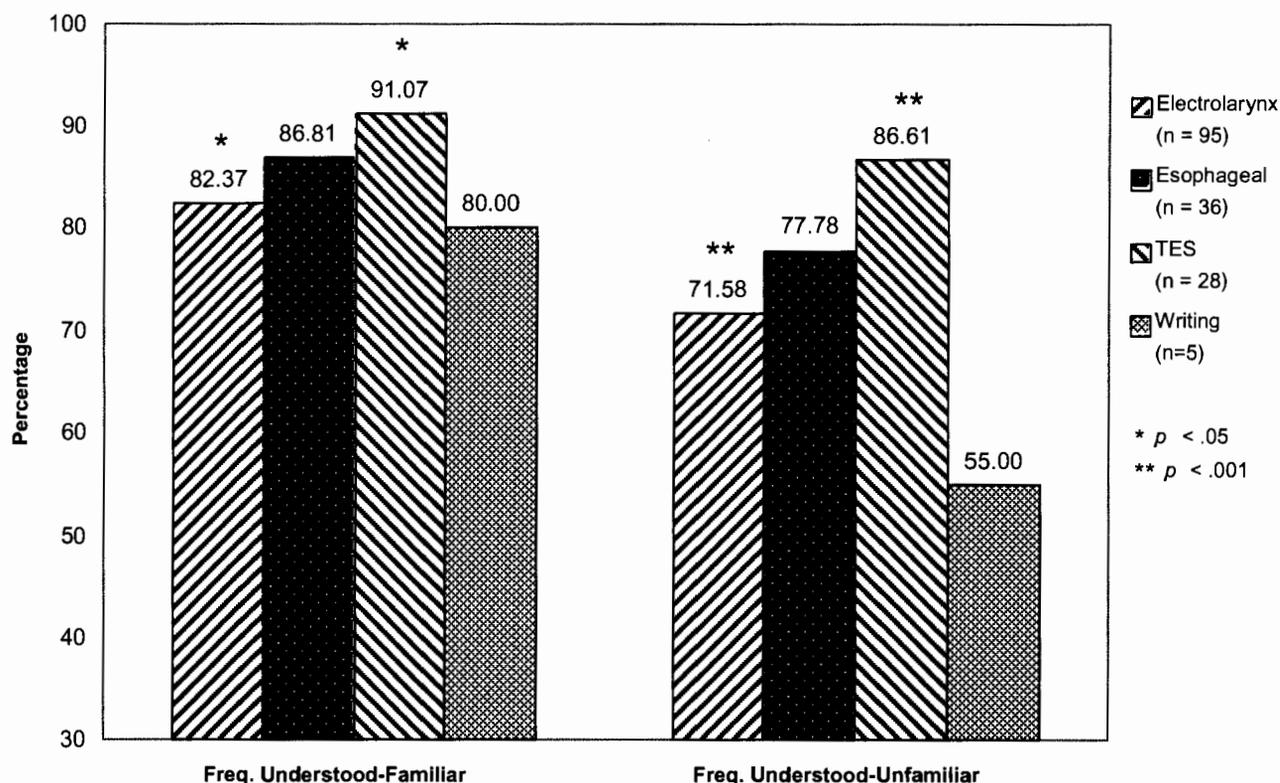
Individuals were divided into Frequent Communicators and Infrequent Communicators based upon their responses (Table 8). Those who answered *many times per day* were included in the Frequent Communicators group and those who answered *several times per day to almost never* were placed in the Infrequent Communicators group. The mean scores of the two groups on the FACT-G were found to differ significantly ( $t(139) = -3.06, p < .01$ ) between Frequent Communicators ( $M = 82.92, SD = 15.20$ ) and Infrequent

Communicators ( $M = 74.08, SD = 16.16$ ). These data are graphically represented in Figure 3.

### **Successful Communication with Familiar Listeners and Quality of Life**

Individuals were asked, *How frequently are you successful in expressing your needs and opinions to familiar adults using your primary mode of communication?* Approximately 45% ( $n = 76$ ) of our sample indicated they were *always* able to express their needs and opinions using this method. Another 49% ( $n = 82$ ) were slightly less successful in that their needs and opinions were *almost always* understood by familiar adults. Communication was successful only *sometimes* for 6% of the sample ( $n = 10$ ) and there was only one individual in the category of *almost never*. No one indicated they were *never* able to make themselves understood by a familiar adult.

**Figure 2.**  
Communicative Success by Speech Method



Individuals were divided into two groups based upon their response to this question (Table 8). Those who answered *always* were included in the Successful Communicators-Familiar group. Those who answered *almost always* to *never* were placed in the Unsuccessful Communicators-Familiar group. Differences in the mean score on the FACT-G were found to be significant ( $t(139) = -4.62, p < .001$ ) between Successful Communicators ( $M = 86.79, SD = 13.65$ ) and Unsuccessful Communicators ( $M = 75.34, SD = 15.52$ ). These results are presented visually in Figure 3.

**Successful Communication with Unfamiliar Listeners and Quality of Life**

The same question was asked with regard to unfamiliar adults. In this circumstance, the number of individuals who were *always* able to make themselves understood dropped to 38 (22%). Most individuals ( $n = 93$ ) regarded themselves as *almost always* being successful, while an additional 37 individuals (22%) reported only *sometimes* being successful. There was only one individual who was *almost never* able to express her needs and opinions to unfamiliar adults using her primary communication method.

As above, individuals were divided into two groups based upon their response to this question (Table 8). Those who answered *always* were included in the Successful

Communicators-Unfamiliar group. Those who answered *almost always* to *almost never* were placed in the Unsuccessful Communicators-Unfamiliar group. No one in the survey indicated they were *never* understood by unfamiliar listeners. Once again, the two groups differed significantly ( $t(139) = -3.32, p < .001$ ) in their perceptions of QOL on the FACT based upon whether they perceived they were Successful ( $M = 88.16, SD = 12.88$ ) or Unsuccessful ( $M = 78.23, SD = 15.83$ ). These data are presented in Figure 3.

**Communication Ability and Individual Quality of Life Concerns**

To examine the interrelationship between the ability to communicate and other factors which contribute to an overall sense of QOL, Spearman rank correlations were calculated for FACT-HNS item 10 (*I am able to communicate with others*) and the 28 items of the FACT-G. A significant correlation at  $p < .05$  or less was noted for 23 of these items. Of these, there were seven items which showed a strong relationship (i.e.,  $r$  was at least .40). There was a significant negative correlation with one of the items on the Social Well-Being subscale relating to feelings of social isolation (*I feel distant from my friends,  $r = -.42, p < .001$* ) and a positive correlation with social support (*I get support from my friends and neighbors,  $r = .42, p < .001$* ). A negative correlation was noted with

**Table 6**  
**Spearman Correlations Between FACT-HNS Items and Overall QOL**

	FACT-G Total
1. I am able to eat the foods that I like.	.36***
2. My mouth is dry.	ns
3. I have trouble breathing.	-.44***
4. My voice has its usual quality and strength.	.36***
5. I am able to eat as much food as I want.	.36***
6. I am self-conscious about how my face and neck look.	-.34***
7. I can swallow naturally and easily.	.30***
8. I smoke cigarettes or other tobacco products.	ns
9. I drink alcohol (e.g., beer and wine).	ns
10. I am able to communicate with others.	.54***
11. I can eat solid foods.	.43***
FACT-HNS Total Score	.59*

\* $p < .05$  \*\*  $p < .01$  \*\*\* $p < .001$  ns=not significant

feelings of anxiety on the Emotional Well-Being subscale (*I feel nervous*,  $r = -.44$ ,  $p < .001$ ). The remaining items were all on the Functional Well-Being subscale and related to the ability to work or perform household duties (*My work [including work at home] is fulfilling*,  $r = .40$ ,  $p < .001$ ), to feelings of acceptance about the disease (*I have accepted my illness*,  $r = .46$ ,  $p < .001$ ), and to feelings of enjoyment of life (*I am able to enjoy life in the moment*,  $r = .48$ ,  $p < .001$ ; *I am content with the quality of my life right now*,  $r = .41$ ,  $p < .001$ ).

## Discussion

### Gender Differences and Quality of Life

Of continued interest to cancer rehabilitation professionals are the physical, social, emotional, and functional factors that shape the individual's perception of QOL, influence recovery, and contribute to better patient outcomes (Blood et al., 1994; Cella, 1994b; Gates, Ryan, Cantu, & Hearne, 1982b; Mathieson et al., 1990; Mohide, Archibald, Tew, Young, & Haines, 1992). Recent studies report an increase in the number of women diagnosed with laryngeal cancer (Brown & Doyle, 1999; Parkin, Pisani, & Ferlay, 1999; USDHHS, 2001). The implication is that in addition to the need to investigate how the disease, treatment, and rehabilitation efforts impact the patient in general, it is important to determine whether there are gender difference considerations requiring modification of specific clinical strategies.

In what is now considered a classic study of women's perspectives following laryngectomy, Gardner (1966) reported on women's lifestyle changes, informational needs, and emotional support systems during rehabilitation. In Gardner's and subsequent studies, the success of alaryngeal speech rehabilitation appears interrelated with a positive attitude, the retention of friends, and the ability to return to work. A greater number of women fell into the younger age group at the time of surgery (Bagshaw, 1967; Gardner, 1966; Graham & Palmer, 2002; Wallen & Webb, 1975), and a higher percentage underwent more extensive surgical procedures than did the men (Bagshaw, 1967; Graham & Palmer, 2002). Pre- and postoperative fear and anxiety were reported by the majority of the women (Gardner, 1966; Salva & Kallail, 1989). The women indicated they were less likely than the men to have obtained important information about the surgery and its consequences from their physician or surgeon (Graham & Palmer, 2002; Salva & Kallail, 1989). Women tended to identify more physical complaints

postoperatively than the men, i.e., increased mucus, difficulty swallowing solids, shortness of breath, fatigue, gas/bloating/indigestion, shoulder pain, insomnia, stomal bleeding, reduced salivation, loss of teeth, and loss of appetite (Graham & Palmer, 2002). Frequently reported unfavorable reactions by women include aversion to the stoma (Bagshaw, 1967; Gardner, 1966; Salva & Kallail, 1989), feelings of unattractiveness due to postoperative scarring (Bagshaw, 1967; Gardner, 1966; Wallen & Webb, 1975), and self-consciousness about the pitch and quality of esophageal speech (Bagshaw, 1967; Salva & Kallail, 1989; Wallen & Webb, 1975). The support of husbands, relatives, and friends was valued by women (Gardner, 1966; Salva & Kallail, 1989) and they were less likely than men to engage in group therapy or attend Lost Chord Club meetings (Wallen & Webb, 1975).

In this study the majority of the individuals were male (69%), as this was controlled for during the selection process based upon the demographic make-up of the original IAL mailing list. This is in keeping with the gender ratio reported in other studies (Iversen-Thorburn & Hayden, 2000). Overall, no significant differences were found in overall QOL by gender. In a previous analysis (Graham & Palmer, 2002) it was concluded that the most noteworthy differences between the men and women in the study were that women identified almost one-third more postoperative physical complaints than did the men. Women did not name the physician or surgeon as a key provider of important information postoperatively

**Table 7**  
**Communication Data**

		n	%
<b>Primary Communication Method</b>	Artificial Larynx (AL)	95	56
	Esophageal Speech (ES)	36	21
	Tracheoesophageal Speech (TES)	28	17
	Writing	5	3
	Other (Multiple Methods)	5	3
<b>All Means of Learning Method</b>	Speech Pathologist	116	68
	Self-Instructed	90	53
	Another Laryngectomee	29	17
	Book or Pamphlet	29	17
	Other	9	5
	Video or Audiotape	7	4
<b>All Communication Methods</b>	AL	122	72
	Writing	69	41
	Gestures	66	39
	ES	56	33
	TES	33	19
	Sign Language	7	4
	Other (Multiple Methods)	5	3
	Telecommunications Device for the Deaf	3	2

The conclusion based on these studies confirms that laryngectomized men and women share many similar experiences, treatments, communication needs, and perceptions of support. The standardization of most of the basic information (regarding operative factors, physical factors, communication options, alaryngeal speech therapy and other rehabilitative services) offered to individuals and their families is supported. However, it appears that some laryngectomized women do have unique concerns regarding their physical condition, informational needs, and emotional support systems during rehabilitation. In anticipation of these individual differences, the rehabilitation specialist should ask specific questions and identify appropriate resources and referrals. It is the responsibility of the rehabilitation team to provide the appropriate services and to include the family in the therapeutic process.

#### *Demographic Data and Quality of Life*

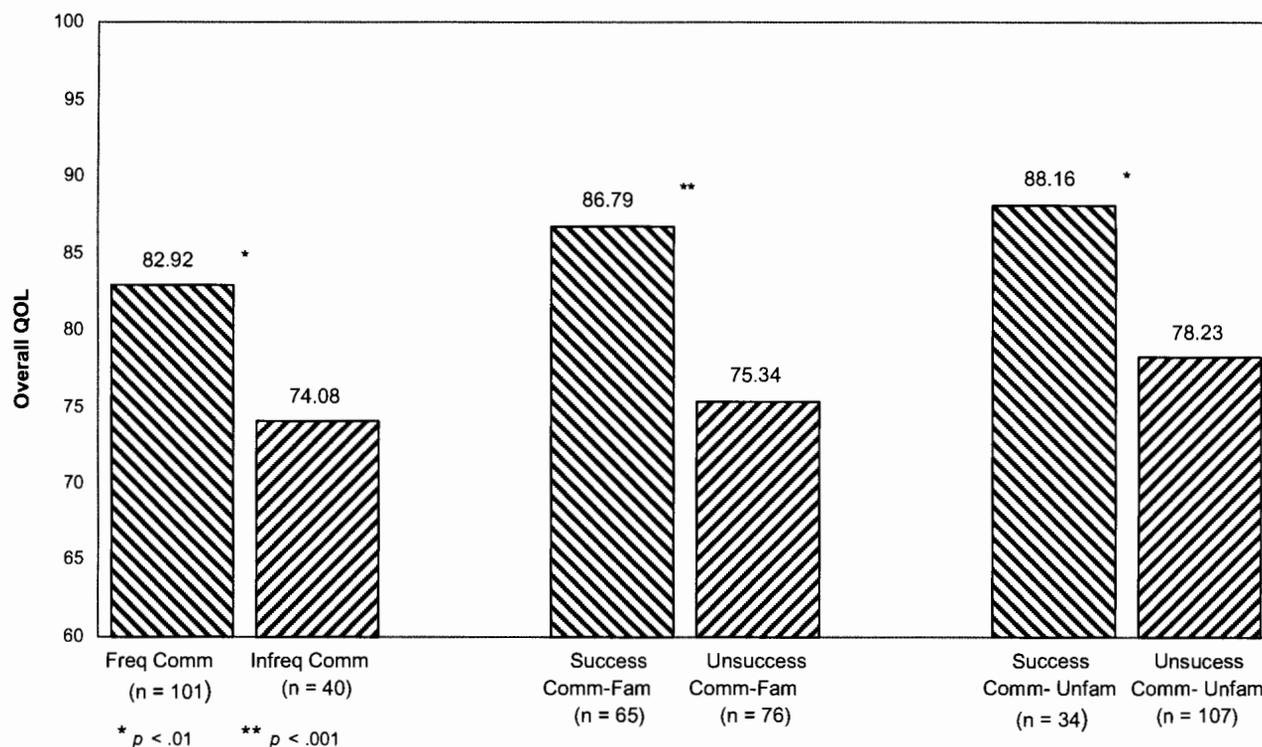
With regard to age, the largest group was in the 70 to 79 year range (40%) which is higher than that in other retrospective surveys (Bagshaw, 1967; De Beule & Damsté, 1972; Gates et al., 1982a; Terrell et al., 1998; Wallen & Webb, 1975). Overall there was no significant relationship with overall QOL, although there was a modest positive relationship with Physical Well-Being indicating that individuals were more satisfied with their physical abilities as they aged, perhaps due to decreased demands or due to the process of adaptation. Most respondents in our survey were retired (66%) which is similar to the findings of other surveys (Carr, 2000; King et al., 1968; Richardson, 1983; Wallen & Webb, 1975) but higher than that of several others (Amster et al., 1972; Gates et al., 1982a; Horn, 1962). As this study gathered information on many long-term survivors, this finding was not unexpected and may be related to the demographic characteristics of members of a support group, such as the IAL. The amount of time since surgery in this survey ranged from less than 1 year to 38 years with a median of 7 years and a mean of 9.3 years. This is higher than that reported by Carr et al. (2000) whose survey revealed their alaryngeal speakers were on average 3.7 years postsurgery but closer

to that reported by De Beule and Damsté (1972). Comparing groups by number of years postsurgery revealed there was a difference in adjustment for overall QOL and all subscales with the exception of Emotional Well-Being.

With regard to education, most individuals had completed either high school (36%) or some college courses (37%). This figure is somewhat higher than that

as frequently as the men did. Women were more likely than men to depend on friends who were not laryngectomized for their adjustment to life after surgery. Finally, with regard to the types of activities that were helpful in adjustment after surgery, women preferred family gatherings, reading, church services, and non-laryngectomized social groups while men benefited from Lost Chord Club meetings, their work setting, and reading.

Figure 3.  
Overall QOL by Frequency &  
Success of Communication



of some other studies (Carr, et al., 2000; Wallen & Webb, 1975). There was no relationship between educational status and overall QOL. In terms of income, most individuals were earning between \$5,000 and \$15,000. There was a positive correlation between income and overall QOL. Employment status was also found to be a factor that was associated with differences in overall QOL. It may be hypothesized that this is the result of a number of factors including age, income, communication status, and degree of disability. Other studies have found that those individuals who are able or choose to return to work also demonstrate better outcomes in other areas (Herranz & Gavilan, 1999).

The majority of our respondents were married or with a partner (71%). Despite suggestions in the literature that family environment may be a critical motivating factor for rehabilitation (Diedrich & Youngstrom, 1966) and the frequent observation of the importance of family support for adaptation (Blood et al., 1994; Relic, Mazemda, Arens, Koller, & Glanz, 2001), there was no significant difference in overall QOL. One possible explanation might be that the respondents in this survey had other means of social support other than those of a partner. Alternatively, this might be the result of the phenomenon observed by Gibson and McCombe (1999) in their prospective follow-up of patients after laryngectomy in which the individuals who were most

independent also had the least reported psychological morbidity, regardless of partnership status.

### *Alaryngeal Speech and Quality of Life*

There have been many studies on the characteristics of alaryngeal speech and the characteristics of the alaryngeal speaker (e.g., Blom, Singer, & Hamaker, 1998; Curry & Snidecor, 1961; Doyle, 1994; Robbins, Fisher, Blom, & Singer, 1984; Weinberg & Bennett, 1972). The characteristics of alaryngeal speech have been analyzed and described in terms of its rate, intensity, and fundamental frequency, using methods such as spectrographs, airflow measures, and manometry (e.g., see reviews by Doyle, 1994; Weinberg, 1986). Similarly, alaryngeal speakers have been categorized based upon age, education level, motivation, and problem solving aptitude and coping skills, in order to determine their potential for regaining functional speech (e.g., Amster et al., 1972; Dabul & Lovstedt, 1974; Gates et al., 1982b; Natvig, 1983; Volin, 1980). These investigations are extremely valuable, in that they highlight the problems faced by the individual after laryngectomy, and they can be used to focus rehabilitation efforts. Nonetheless, the failure to develop functional communication is a negative postoperative outcome regardless of the motivation level of the individual or the acoustic properties of his or her speech. Consequently, the present study was focused

**Table 8**  
**Differences in QOL by Frequency of Communication and Perceived Communicative Success**

	FACT-G Total score Mean (SD)	Mean difference	t-value
Frequent communicators (n=101)	82.92 (± 15.20)		
Infrequent communicators (n=59)	74.08 (± 16.17)	8.84	-3.06***
Successful communicators - familiar (n=65)	86.79 (± 13.65)		
Unsuccessful communicators - familiar (n=76)	75.34 (± 15.52)	11.46	-4.62***
Successful communicators - unfamiliar (n=34)	88.16 (± 12.88)		
Unsuccessful communicators - unfamiliar (n=107)	78.23 (± 15.83)	9.93	-3.32**

\* $p < .05$  \*\*  $p < .01$  \*\*\* $p < .001$  ns=not significant

on the ability to communicate, rather than on specific characteristics of alaryngeal speech. A mutual relationship is posited whereby improved communication is fostered by the physical, social, emotional, and functional recovery of the individual, and it in turn fosters recovery in some of those same areas. This is similar to the model proposed by Maas (1991). Moreover, to the extent that QOL is a measure not just of how well individuals function but how well they have adjusted to altered circumstances, it is suggested that the ability to communicate fosters that process of adaptation.

The nature of QOL research is that it is subjective, and is judged exclusively from the patient's perspective. Thus, one of the criticisms of any study using a QOL protocol is that it is essentially measuring respondents' self-esteem or general level of optimism. There is evidence to support this view. Blood et al. (1994) found that subjective measures of voice did not correlate with the evaluations of voice proficiency by external judges and concluded that there may a tendency for some individuals to "perceive themselves as 'good in everything.' In other words, their voices may be similar to other patients', but their self-esteem is better" (p. 43). Evidence for the opposing point of view was provided by Dabul and Lovestedt (1974) who found that good speakers (measured objectively) tended to respond more positively to all questions about their life postoperatively than those whose speech was judged to be poor. Inevitably, the truth may lie between these two absolutes. More optimistic or outgoing individuals may, in fact, adapt better postoperatively due to their general outlook and they may also judge their proficiency more positively. In this study, we would have predicted strong correlations among all types of functions if Blood's hypothesis had been sufficient to explain the results. The tendency to judge themselves as good in everything would have resulted in overall positive or negative responses with resultant correlations among all items. While there were correlations among many of the items of the FACT,

most of these were small and not strong enough to have any predictive value (i.e., less than  $r = .40$ ). While the influence of the individual's outlook should not be discounted, the results are varied enough to support the notion that the respondents did not consistently judge themselves as good or bad with regard to every ability.

In terms of patient satisfaction with voice quality, it is reported that between 60- 80% of TES users are satisfied with the quality of their voices (Ackerstaff et al., 1994; Silverman & Black, 1994). Both TES and ES users show moderate to low levels of communication apprehension (Byles, Forner, & Stemple, 1985). One comparison of satisfaction showed that TES users reported the highest levels of satisfaction with their communication method (Clements et al., 1997). There have been shown to be no significant differences subjectively between ES and TES users when comparing self-assessments of voice quality (Ackerstaff et al., 1994), although when measured objectively the TES group has been shown to have better intelligibility (De Maddalena, Pfrang, Schohe, & Zenner, 1991).

It is clear that the criteria by which individuals rate their own voices are not the same as those used by other listeners, and that familiarity with the method of alaryngeal voicing also affects judgements of quality. Untrained listeners tend to judge the intelligibility of alaryngeal speech more negatively than experienced listeners (Cavalot et al., 2001; Deschler, Doherty, Reed, & Singer, 1998; Doyle, Swift & Haaf, 1989), although one study found the reverse to be true (Finizia, Lindstrom & Dotevall, 1998). Comparison of perceptual evaluations of the speech of a group of TES users revealed that the evaluations of speech-language pathologists were consistently higher than those of the patients themselves or their significant others (Cantu et al., 1998). In a comparison of the voice of individuals using TES with that of individuals after radiotherapy (Finizia, Dotevall, Lundstrom, & Lindstrom, 1999; Finizia, Lindstrom, &

Dotevall, 1998), there was some degree of correlation between the judgements of the speakers and their listeners. The TES group's ratings of their own intelligibility were, on average, lower than those of the radiation group and this agreed with listener perceptions. The listeners also rated the TES group lower in terms of voice quality and speech acceptability than the TES users did themselves. Another comparison of outcomes after radiotherapy for laryngeal carcinoma versus total laryngectomy found that the latter group had more significant voice problems by self-assessment (Harwood & Rawlinson, 1983), although their means of alaryngeal speech is not reported.

A study by Terrell et al. (1998), perhaps the most significant to date with regard to the question of treatment modalities for this population, found almost no difference between the chemoradiation and surgery-radiation groups in terms of their speech scores. Using the University of Michigan Head and Neck Quality of Life instrument (Terrell et al., 1997), the mean scores for the speech domain of both groups were almost identical. In an attempt to account for this surprising result, the authors suggested three possible explanations. First, it was possible that the individuals who underwent laryngectomy had learned a new mode of communication that "allowed them to communicate reasonably well." Another explanation might be that, by 2 years postoperatively, those who underwent laryngectomy had had "substantial time to readjust to their new condition." Finally, it is possible that both groups had "substantial problems with voice", (Terrell et al., 1998, p. 969) which was supported by the finding that both groups scored lower than head and neck cancer patients with tumors in sites that did not affect speech. This conclusion was also reached by De Santo, Olsen, Rohe, Perry, and Keith in their study (1995).

While some judgements of voice quality may be correlated with acoustic measurements, others do not. Attempts to show correlations between acoustic measurements and perceptual judgements have been somewhat equivocal. In one study listener judgements of voice quality showed a weak positive correlation with perturbation (Finizia et al., 1999) and a similar weak correlation with perturbation, amplitude, and the ability to sustain a phonation in another study (Sanderson, Anderson, Denholm, & Kerr, 1993). Subjective and objective measures have been shown to have strong correlations after partial laryngectomy (Crevier-Buchman et al., 1998). In a group of patients after partial laryngectomy correlations were found between subjective assessments of intelligibility and objective measurements of intensity and pitch (Ptok & Maddalena, 1990), but the acoustic variables did not correlate with the subjects' assessments of their degree of vocal disability. Comparing the TES voice of individuals who undergo laryngopharyngectomy with those of individuals who undergo total laryngectomy (TL) alone, poorer voice quality and intelligibility have been demonstrated according to subjective and objective measurements

(Deschler et al., 1998; McAuliffe, Ward, Bassett, & Perkins, 2000; Mendelsohn, Morris, & Gallager, 1993). Nonetheless, despite the fact that these individuals reported a greater level of disability, one study found that the individuals who had undergone laryngopharyngectomy did not differ significantly from the TL group in terms of their impressions of handicap or well-being (McAuliffe et al., 2000). They also continued to use TES for communication despite the fact that their voice quality and intelligibility were poorer.

In this study, the AL was the most common method of alaryngeal speech (56%) followed by esophageal speech (21%), TES (17%), and writing or a combination of methods (6%). These proportions are similar to those reported in other follow-up studies in which subjects were recruited through laryngectomee support groups (Carr, et al., 2000), although others have reported a comparatively higher utilization of ES (Iversen-Thorburn & Hayden, 2000). Prospective studies through a single medical center generally report a higher level of TES use. However, Mendenhall et al. (2002) report that at 2-3 years postoperative the relative usage rates in 118 patients followed prospectively were AL (50%), TES (27%), ES (1%), and nonvocal (17%). Similarly, in a prospective study of veterans, the majority of 104 alaryngeal speakers 1 year post-surgery were using AL (63%), followed by TES (23%), ES (7%), and an additional 7% were nonverbal (Hillman, Walsh, Wolf, Fisher, & Hong, 1998). In general, our respondents were well-rehabilitated with regard to their communication. Most (67%) communicated with other people many times a day in contrast to only 4% who communicated with others less than daily. Success was generally high with most individuals being either *always* or *almost always* successful in communicating with familiar adults (93%) and unfamiliar adults (78%). It was also noted that the communicative frequency and success of individuals who were using TES was higher than that of the AL group in contrast to the findings of some other studies (Carr et al., 2000).

### ***Functional Deficits and Quality of Life***

Significant functional deficits have been shown to persist beyond the postoperative period. Treatment-related side-effects and disease-specific problems have been reported 3 years after treatment in long-term head and neck cancer survivors (Hammerlid & Taft, 2001). Comparing patients treated for laryngeal cancer according to three modalities, the patients in the total laryngectomy group continued to show significant deficits 6 months postsurgery (List et al., 1996). The 34 laryngectomees in another study (Armstrong et al., 2001) continued to show persistent communication and swallowing problems 6 months postsurgery and their overall sense of health was poorer than that of individuals of the same age, and also poorer than that of individuals with other serious medical conditions. This conclusion is similar to that of another study (Gritz et al., 1999) in

which 105 patients treated for laryngeal cancer showed small improvements in eating, diet, and speech by 12 months postdiagnosis but they were not statistically significant. The impact of intervention for functional deficits on overall QOL is underscored by the results of studies of pulmonary rehabilitation which suggest that improvements in respiratory status are associated not only with decreased coughing, expectoration, and stoma cleaning, but also with reduced levels of anxiety and depression (Ackerstaff et al., 1993). In Natvig's (1984) survey of Norwegian laryngectomees the presence of the stoma and problems with respiration were the most troubling current problem for 25% of his subjects. De Santo et al. (1995) found that the single most important factor determining postoperative QOL was the presence of a stoma and argued that the respiratory difficulties of the neck breather may have been underestimated. This finding is also supported by a study in which the QOL of individuals who underwent laryngeal preservation with supracricoid partial laryngectomy was compared to that of individuals who underwent a total laryngectomy with TEP (Weinstein et al., 2001). This study demonstrated that the first group had better functioning in most of the domains of the Short-Form-36 and had fewer disease-specific complaints.

These views are complementary to the conclusions of this study. Average scores for the domains of the FACT-G were also high on average. Responses on the Physical, Social, and Emotional Well-Being subscales, as well as overall QOL, were at least 80%, indicating positive postoperative adaptation. The respondents in this study were noted to have slightly lower mean scores for both Functional Well-Being (72%) and the disease-specific concerns of the HNS (68%), indicating residual problems in some functional areas.

In addition to surgery, most of our respondents had had radiation treatment (68%). A minority had had a radical neck dissection (19%) or chemotherapy (7%). No overall differences in QOL were noted for the different treatment variables of radiation treatment, chemotherapy, or neck dissection, although this may be due in part to the relatively small numbers of individuals in each of the other groups. Some studies have reported no overall difference in QOL based upon the presence or absence of radiotherapy (Finizia & Bergman, 2001; Finizia, Hammerlid, Westin, & Lindstrom, 1998), although studies of long-term head and neck cancer patients treated by radiation alone demonstrate significant psychosocial morbidity even 7 to 11 years after treatment (Bjordal & Kaasa, 1995).

Thus, while communication is central to postoperative rehabilitation, it is not sufficient in and of itself. Other items on the FACT-HNS that correlated to overall QOL related to eating and breathing. The total rehabilitation of the individual after laryngectomy, therefore, cannot consist solely of speech rehabilitation. While the latter has received the most attention in the

literature, difficulties related to eating/swallowing and respiration also need to be addressed to promote positive long-term outcomes. After their review of the literature, Mathieson et al. (1990) suggested that long-term rehabilitation after laryngectomy was shaped by multiple variables, including the ability to communicate. This study supports that conclusion, and emphasizes that successful rehabilitation after laryngectomy involves addressing the total needs of the individual. Since the concerns of the individual who has undergone a laryngectomy may be different from those of patients who have been treated for other conditions, the importance of using a disease-specific measure is reinforced. This was the conclusion of the authors of two studies (Gliklich, Goldsmith, & Funk, 1997; List et al., 1996) who found that disease-specific domains, such as eating/swallowing, speech/communication, and appearance, were not well-correlated with general health domains on one QOL measure. The results of this study support the notion of communication as central to rehabilitation. This is of course a correlational study and therefore it is not possible to conclude definitively that better communication fosters better QOL. It may be more appropriate to regard communication as an index of overall rehabilitation, influenced as it is by physical, social, emotional, vocational, and functional factors as in the typology suggested by Maas (1991). Thus the role of the speech-language pathologist is even more central to the overall well-being of the patient. Based upon the findings of this study, in addition to efforts for psychosocial and vocational rehabilitation, intervention should focus on three key concerns that are specific to the head and neck cancer patient: communication, eating/swallowing, and respiration.

### ***Suggestions for Further Research***

The names and addresses of individuals for this study were obtained from the IAL, a support and advocacy group operated by the American Cancer Society. Of the estimated 50,000 laryngectomees in the United States, approximately 7,200 are members of this organization (IAL, 2000). This method of recruiting subjects for a study has been used by other researchers (e.g., Blood et al., 1994; Wallen & Webb, 1975) as a means of obtaining subjects from a variety of geographic locations without compromising confidentiality, as would be necessary if names were provided by a medical facility. It is important to consider the impact of this sampling method on potential results. It may be conjectured, for example, that membership in a support group of this type promotes better outcomes and therefore that the individuals on the IAL mailing list may be better rehabilitated than other laryngectomees. This was the speculation of Blood et al. (1994). It may also be possible that many individuals who choose not to join a support group do so because they are functioning well without it. Thus, it is also theoretically possible for the population of laryngectomees at large to be as well-rehabilitated or

better rehabilitated than IAL members. This question remains for future research.

Finally, the demographic characteristics of this sample differ from those that are known to be prevalent in the population of laryngectomees as a whole. To date, there has been little investigation of the specific problems after laryngectomy of individuals who are of different ethnic or racial backgrounds, despite the fact that African-Americans are more likely to develop cancer than any other racial or ethnic group. Over the period of 1990-1997, the incidence of all types of cancer was higher for African-Americans (445 per 100,000) than for white Americans (402 per 100,000), and the mortality rate was likewise significantly higher: 222 per 100,000 versus 167 per 100,000, respectively (American Cancer Society, 2001). Likewise, the 5-year survival rate for laryngeal cancer was 66% for white Americans from 1992-1997, but only 53% during the same period for African-Americans (American Cancer Society, 2002). Despite this statistic, however, the majority of studies of head and neck cancer report data on samples that are overwhelmingly Caucasian. This bias may be due to the methods of sampling, as most studies tend to draw on individuals who either belong to support groups or who receive regular follow-up care at medical centers. Investigation of how other races cope and adjust postoperatively is long overdue.

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