

/SEX DIFFERENCES IN THE COUNSELING NEEDS OF LARYNGECTOMEES
AND THEIR SPOUSES/

by

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This project is dedicated to laryngectomees and their spouses with the express hope that counseling needs will be met for all.

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INTRODUCTION

The counseling needs of laryngectomy patients have been studied to understand better the pre- and post-surgical impact of the operation. Investigators have found that laryngectomees are not informed fully about the surgery and its consequences (Blanchard, 1982; De Buele and Damste, 1972; Johnson, Casper, & Lesswing, 1979; Minear & Lucente, 1979; Salmon, 1979). Also, laryngectomees reported unanticipated postoperative difficulties and periods of adjustment of up to two years (Johnson et al., 1979).

Investigations of this type have demonstrated the need for pre- and post-surgical counseling for laryngectomees. Little information, however, was available regarding the counseling needs of female laryngectomees. It was assumed that the counseling needs of female patients would be different in some ways from male patients.

The sex ratio of laryngectomy patients has been reported at approximately five males for every female (Boone, 1983). Traditionally, studies of laryngectomees have reported responses of a significantly larger percentage of male patients or have not identified the sex of the subjects. Of the investigations reporting on the counseling needs of laryngectomees (Blanchard, 1982; Gates, Ryan, & Lauder, 1982; Johnson et al., 1979; Keith,

Linebaugh, & Cox, 1978; Kommers, Sullivan, & Yonkers, 1977; Natvig, 1983; Salmon, 1979), none of the results distinguished between male and female subjects. To date, few studies (Gardner, 1966; Stack, 1979) have identified the unique problems encountered by female laryngectomees.

Specific knowledge about how sex differences might influence the counseling needs of laryngectomees is unknown. Obviously, the counseling process would be enhanced if such sex differences could be identified.

Kutner and Kutner (1979) have reported sex differences in patients' attitudes concerning their disabilities. The patients in this investigation were not laryngectomees, but it seemed reasonable to assume that similar attitudes may exist in the laryngectomee population. Male patients emphasized the perception of the loss of independence and the inability to make and spend money. Female patients were more concerned with the effects of their disability on their personal relationships and responsibilities. Kutner and Kutner linked the perceived losses due to disability to the prevailing societal sex role prescriptions.

In addition to the investigations on the counseling needs of laryngectomees, similar research has been conducted on laryngectomees' families, particularly their spouses (Johnson et al., 1979; Kommers et al., 1977; Kommers & Sullivan, 1979; Natvig, 1983; Salmon, 1979).

Gardner (1961) stated that a patient's home environment was a critical motivating factor in the rehabilitation process. Members of the rehabilitation team cannot follow each patient home, therefore, the spouses must be made aware of all the physical and psychological changes that occur following laryngectomy and be prepared to deal with them. Spouses that are prepared adequately for the changes in home life can help the patient adjust to the barrage of unfamiliar affairs such as the loss of speech, the loss of taste and smell, a permanent tracheostoma, the accumulation of mucus around the stoma, the loss of audible laughing and crying, and the change in bathing and swimming (Gardner, 1961). Gibbs and Achterberg-Lawlis (1979) reported that the laryngectomee's spouse plays an important role in facilitating successful esophageal speech.

Several investigators have demonstrated the need for more extensive pre- and post-surgical counseling for laryngectomees' spouses (Keith et al., 1978; Kommers et al., 1977; Kommers & Sullivan, 1979; Salmon, 1979). Counseling the spouse should be done not only in conjunction with the patient, but separately as well. Thus, spouses would be free to express any thoughts and feelings without harming the patient.

Family members of laryngectomees also are important to the rehabilitative process. Gates et al. (1982)

emphasized the importance of family counseling (including spouses) during the early postoperative stage. They stated that the support of the family by the rehabilitation team should continue after the patient is discharged. In another study (Johnson et al., 1979), family members of laryngectomees stated that they could not be overinformed. In addition, the laryngectomees stated that further preoperative counseling was needed, not only for themselves, but for their families as well.

The literature has been consistent in stating the need for more and better counseling of laryngectomees' spouses although few studies have concentrated solely on counseling needs. Those studies that have been completed on laryngectomees' spouses have been based primarily on females. Data specifically on laryngectomees' husbands apparently were unavailable.

Specific knowledge about how sex differences might influence the counseling needs of laryngectomees' spouses is unknown. Yet, there are important sex differences in the way husbands and wives interact, which has implications for the way males and females are counseled.

Vanfossen (1981) has described two themes concerning sex differences in marital interactions. One theme speculated about supportiveness in relationships and suggested that women were more supportive than men. The second theme speculated about power in relationships.

That theme suggested that women were more likely than men to be powerless, whether the powerlessness was actual or perceived. Vanfossen also revealed that more husbands than wives reported having appreciative, affirming, affectionate, and reciprocating spouses.

The literature has suggested differences between males and females in their relationships with each other and in their perceptions of a disability. Certainly, the entire counseling process for laryngectomees might be improved with further knowledge of the general counseling needs of the participants, including both the patient and the spouse. At this time, little information is available on how the counseling needs of males and females involved in laryngectomy rehabilitation might differ.

The counseling needs of laryngectomees and their spouses must be met by qualified professionals. Speech-language pathologists have the necessary knowledge and exposure to laryngectomees needed for counseling purposes (Killarney and Lass, 1979; Salmon, 1979). Many laryngectomees and their spouses have reported the efficaciousness of speech-language pathologists to the rehabilitation process (Keith et al., 1978; Minear and Lucente, 1979; Natvig, 1983).

The purpose of this study was to survey the distinct counseling needs of male and female laryngectomees and male and female spouses of laryngectomees. Laryngectomees

and their spouses from across the nation were surveyed.

The following research questions were explored:

1. What are the differences between the counseling needs of male and female laryngectomees?
2. What are the differences between the counseling needs of male and female spouses of laryngectomees?
3. What are the differences between the counseling needs of laryngectomees and their spouses?

REVIEW OF THE LITERATURE

Introduction

Speech-language pathologists have served an important role on the laryngectomy rehabilitation team and have participated actively in the counseling process. The counseling needs of laryngectomees and their spouses have been investigated to understand better the impact of the operation and to improve the rehabilitation process. Because of the high incidence of male, as compared to female, laryngectomees, investigations have focused primarily on the male laryngectomee and the female spouse. Little information was available on the differences between the counseling needs of male and female laryngectomees and male and female spouses of laryngectomees. Of the information available, some was obtained from laryngectomees only, some from spouses only, and some from both laryngectomees and their spouses.

Investigations of the counseling needs of laryngectomees

De Beule and Damste (1972) surveyed 140 laryngectomy patients. The authors reported a male-female ratio of slightly higher than 18:1, but sex was not investigated as a variable. The patients were asked questions regarding preoperative and postoperative information. Thirty-six percent met with a laryngectomee before the surgery, and

54% met with a laryngectomee after surgery. Fourteen percent reported a negative reaction to both a preoperative and postoperative visit. Of those surveyed, 57% believed that they were prepared preoperatively for the surgery. Fourteen percent reported not being at all informed. Twenty-three percent knew that they would no longer speak nor breathe through the nose. Seventy-three percent of the patients were informed about the surgery by the surgeon, whereas, 17% were informed by the surgeon and also by a nurse, speech-language pathologist, or social worker. Seventy-two percent believed that the information they received was adequate; only seventeen percent reported the information as insufficient. The authors stressed the fact that rehabilitation following laryngectomy should not focus only on speech teaching, but also physical, psychological, and social factors as well.

Keith, Linebaugh, and Cox (1978) conducted a survey on the presurgical counseling needs of laryngectomees. Fifty-nine males and 13 females completed the questionnaire, but sex was not investigated as a variable. Seventy-nine percent of the patients reported adequate counseling preoperatively. Forty-nine percent of the subjects reported that they were unsure of the physical changes. Eighty-eight percent of the respondents said that the physical changes following laryngectomy should be explained more clearly.

Although 85% of the subjects reported that they had enough time to ask questions preoperatively, 52% reported that they did not have the background needed to ask relevant questions. Fifty-seven percent stated that emotions interfered with question-asking.

The respondents reported that reading materials were especially helpful. Unfortunately, only 44% received any reading materials. Of those that did not receive reading materials, 77% reported that they would have liked to have received some.

The questionnaire surveyed respondents' opinions on what information should be covered presurgically. Patients wanted to know about the following: physical, emotional, and lifestyle changes of the laryngectomee, methods of alaryngeal speech, how the speech-language pathologist and laryngectomee work together, causes and treatment of laryngeal cancer, community help resources, and the emotional adjustment of the family (Keith et al., 1978).

Ten percent of the patients felt that full preoperative disclosure of the laryngectomy's consequences was undesirable. Ninety percent of the laryngectomees felt that a hospital visit by a fellow laryngectomee would have been helpful. When asked who should provide presurgical counseling, the patients responded with the following individuals and percentages: physician (82%),

speech-language pathologist (54%). laryngectomee (50%). chaplain (15%), and psychiatrist or psychologist (6%).

Certain questions related to the role of the spouse were asked. Ninety-three percent of the respondents said that the spouse should receive separate, private counseling to provide the spouse with an opportunity to speak more freely and to discuss emotional adjustment problems. Those respondents opposed to separate counseling "alluded to the fact that rehabilitation must be a joint effort of the patient and the spouse, and therefore, communication with professionals must be shared" (Keith et al., 1978, p. 1664). Ninety-three percent of the respondents reported that preoperative counseling can ease the adjustment of both the laryngectomee and the family.

Although only laryngectomees were asked to respond to the questionnaire, the authors (Keith et al., 1978) discussed the family's need for counseling as well. They stated that the needs of the family are two-fold. First, the family would have their own adjustments to make as they accepted the patient's changes resulting from the disease and its treatment. Second, the family must be counseled because they are essential in assisting the patient through the rehabilitation process. The patient would need his family's support and acceptance.

Minear and Lucente (1979) interviewed and sent

questionnaires to 53 male and seven female laryngectomy patients. Again, sex was not investigated as a variable. The study focused on the patients' attitudes and their impressions of the adequacy of pre- and post-operative visits by physicians, speech-language pathologists, social workers, and other members of the rehabilitation team. The percentage of patients reporting satisfactory preoperative counseling with the following individuals was: other laryngectomee, 85%, physician, 77%, speech-language pathologist, 72%, social worker, 64%, and nurse, 30%. The percentage of patients reporting satisfactory postoperative counseling with the following individuals was: speech-language pathologist, 91%, physician, 82%, social worker, 82%, nurse, 80%, and other laryngectomee, 78%.

The survey of patients revealed that a comprehensive team effort is needed to rehabilitate effectively the laryngectomy patient. The authors stressed that a multidisciplinary team effort is crucial to assist the laryngectomee in leading a productive life. The study indicated that something was lacking indeed in the rehabilitation team's efforts. If the patients were not informed fully, then no doubt the spouses were uninformed also, thus hampering their ability to help the patient.

Stack (1979), a female laryngectomee, composed a survey which concentrated on problems experienced by

female laryngectomees. Twenty-nine female laryngectomees completed the questionnaire. Twenty-four percent replied that they had difficulty coping with being a laryngectomee. Ten percent said that the laryngectomy had a negative effect on their marriages. Seven respondents reported an inactive social life. Twenty-three women said that they would be interested in educational programs for laryngectomees. The author concluded that although problems were inevitable, they were not insurmountable.

None of previously-mentioned investigations specifically studied the differences in counseling needs between male and female laryngectomees. Stack's (1979) article demonstrated the need to investigate female laryngectomees as a special sub-population of laryngectomees. In general, the investigations supported the view that more and better counseling was needed for laryngectomees.

Investigations of the counseling needs of laryngectomees spouses

The literature regarding counseling needs associated with laryngectomy generally concentrated on the patients, not the spouses, yet most of the authors recognized the spouse as a decisive motivating factor in the laryngectomee's rehabilitation. Gardner (1961, p. 17) stated that "success or failure depends on the attitude of the wife towards her husband's handicap and his effort to

12114. Recognizing this fact, Kommers, Sullivan, and Yonkers (1977) conducted a survey that concentrated solely on the wives of laryngectomees who evaluated the adequacy of their preparation for the surgery and type and severity of ensuing problems. A list of questions was sent to wives of laryngectomees in Nebraska, Iowa, and Kansas. The responses were arranged systematically and examined. Most questions were open-ended to eliminate biases.

The ages of the respondents fell between 38-72 years (Kommers et al., 1977). The mean age was 56.58 years. The husbands were between 47-76 years of age with a mean age of 62.24 years. The outcome of the questionnaire was associated directly with the wives' preparation for surgery, their opinions as to the kind and quality of counseling, and their real understanding of the laryngectomy procedure and its consequences.

Seventy-five percent of the wives stated that the husband's physician had been the primary source of explanation about the details of the upcoming surgery and its consequences. Seventy-eight percent of the wives were with their husbands when the men found out that they had cancer. Eighty-seven percent of the wives were included in counseling sessions with their husbands, but only 29% were counseled alone. Fifty-six percent of the wives thought that they were prepared at least fairly well for the surgery. Some wives reported that they were not able

to understand fully the consequences preoperatively due to high emotionality or that they understood what they had been told, but they did not want to accept it. Over 10% of the wives stated that they were not prepared for the postsurgical consequences. About 30% of the wives stated that adjusting to the husband's loss of voice was more difficult than they had expected.

Preoperatively, over two-thirds of the wives admitted that their greatest fear was that their husbands would not survive the surgery. The others stated that they were afraid that their husbands would not be able to deal with the surgery's outcome, that the future of the family was uncertain, and "that their husbands would never speak again" (Kommers et al., 1977, p. 1963).

Wives were unaware of the possible causes of laryngeal cancer and its effects following laryngectomy. Forty-two percent of the wives denied that a relationship between smoking and laryngectomy existed despite the fact that 98% of the husbands smoked at least one pack of cigarettes a day and 36% smoked two or more packs a day.

Preoperatively, 98% of the wives understood that their husbands would no longer speak after surgery, but 29% were not aware that their husbands would no longer breathe through the nose. Prior to the husbands surgery, 80% of the wives never came into contact with a laryngectomee. Only 60% of the wives met a laryngectomee

in the hospital either preoperatively or postoperatively.

Many wives conceded to the fact that they had physical and/or psychological complaints following the husband's surgery. Forty percent of the wives noticed increased nervousness and depression or higher blood pressure which they believed resulted, at least in part, from the husband's surgery.

Forty-seven percent of the wives stated that their spirits were lowest postsurgery (Kommers et al., 1977). The range of wives' optimism differed substantially in two groups, those whose husbands were 57 years and older and those whose husbands were under 57 years of age. In the older aged group, 15% of the wives were optimistic before the surgery. This figure surged to 50% postoperatively. Of the younger group, 45% of the wives were optimistic before surgery. This figure fell to 30% after the surgery.

Forty-five percent of the wives reported a decrease in communication between husband and wife after surgery. Twenty percent of the wives "agreed that the laryngectomy had robbed their husbands of some of their manhood" (Kommers et al., 1977, p. 1964). Twenty percent of the wives reported that their marriages were affected negatively, primarily due to decreased communication, changed sex life, and the husband's increased unwillingness to go out socially with his wife. The wives

who reported the negative influence were younger than the total mean age. All of the wives, except one, also noted that other negative factors influenced their marriages, such as, family catastrophes, pre-laryngectomy heavy drinking, problems since retirement, and other enfeebling medical and/or mental problems.

The results emphasized the need for increased and broader presurgical and postsurgical counseling (Kommers et al., 1977). The kind of counseling should vary according to the age of the patient. In older patients, the laryngectomee and his wife needed the greatest support before surgery when their greatest fear was death. A younger wife may not comprehend fully the impact of surgery on daily living until some time postoperatively. She might become depressed if there was not a comprehensive rehabilitation plan for her husband to regain his expressive communication skills.

"Time spent counseling alone with the wife might be exceedingly important" (Kommers et al., 1977, p. 1964). One example for the need of such counseling was observed when one initially-successful esophageal speaker ceased training because his wife was repulsed by this method of speech (Kommers et al., 1977). She had been counseled only in conjunction with her husband and did not express openly those views at that time. She might have felt more free to express herself had she been counseled alone.

The authors found four important factors that adequately prepared the patient and family preoperatively for the surgery itself and the successful adjustment and rehabilitation afterwards. The factors were (Kommers et al., 1977, p. 1964):

- 1) initial explanation of the diagnosis of laryngeal cancer and its probable causes.
- 2) recommendations for management and discussion of consequences after surgery with the important extension of hope,
- 3) referral to a speech-language pathologist before surgery to assure the patient that methods exist for the production of alaryngeal speech, and
- 4) family counseling separate from the patient."

A team including the family physician, surgeon, speech-language pathologist, nurses, and vocational rehabilitation counselor needed to be involved from the outset to prevent feelings of isolation and despair. A visit by a talking laryngectomee was recommended. Whether the visit should occur preoperatively or postoperatively depended upon the personalities involved.

Kommers et al. (1977) reported that postoperative counseling by all members of the rehabilitation team must continue. Information stated preoperatively must be given again, due to the fact that many of the wives could not understand what was said initially, because of high levels of emotionality during the crisis period. The authors suggested that guidance should be provided for all rehabilitation services, particularly for the younger patients who needed to continue supporting their families.

They also suggested that a continued follow-up for all family members to discuss problems should enhance chances for a successful adjustment by the laryngectomee and the family.

There were no available investigations that studied male spouses of laryngectomees. The available information suggested that female spouses needed more and better counseling. Information regarding the counseling needs of spouses seemed important to the overall success of the rehabilitation team's efforts. For example, Gibbs and Achterberg-Lawlis (1979) reported that the laryngectomees' spouses (predominantly wives) were important in the facilitation of successful esophageal speech in their mates.

Investigations of the counseling needs of both laryngectomees and their spouses

Johnson, Casper, and Lesswing (1979) separately interviewed 21 male and four female laryngectomees and their families. Sex was not investigated as a variable. Each laryngectomee who was interviewed had developed a successful means of communication. Each patient readily consented to the interview and many were located by virtue of their membership in the Central New York Laryngectomee Club. Their major preoperative concern was loss of speech. Twenty percent of the sample had met with a laryngectomee preoperatively and were glad that they did.

Those laryngectomees that had not met with another laryngectomee reported that they had wanted to meet with one. Over 25% of the respondents met with a speech-language pathologist (only one was not glad that he did so). The majority of those that had not met with a speech-language pathologist wished that they had.

Twenty percent of those interviewed considered refusing surgery (for a time) because of the resulting loss of voice. Two laryngectomees did not return to work because they felt awkward and inadequate. Two-thirds of the sample believed that their social life had either improved or remained unchanged. One-third of the sample believed that their social life had decreased. Those laryngectomees that reported a decrease in social activity cited social embarrassment and easy fatigability as the reasons. There was no change in marital status for the sample studied. The majority reported no change in sexual activity and one individual, in fact, reported an increase.

All but one laryngectomee received some explanation from their physicians of what the surgery would entail and of the resulting physical changes (Johnson et al., 1979). All of the respondents reported unanticipated postoperative difficulties but the majority stated that they were either on the road to adjustment or had adjusted. The period of adjustment took from three months

to two years. Each laryngectomee stated that further preoperative counseling was needed not only for themselves but for their families as well. Only three respondents believed that full preoperative disclosure would be too much for the patient to handle. All but one would undergo the surgery again if it was deemed necessary.

Seventeen family members (predominantly spouses) also were interviewed (Johnson et al., 1979). Their answers paralleled those of their loved ones. They were informed preoperatively about the laryngectomy procedure and its consequences, but they were prepared inadequately to deal with the patient postoperatively. The anticipated difficulties that family members had to cope with focused on psychological changes in the patient's attitude and mood, problems in communicating, and family reactions (particularly with younger children). The family also had to face the patient's physical changes and the social embarrassment due to the patient's speech, stoma, and coughing.

All 17 family members believed that they could not be overinformed. They said that if necessary they would go through the trauma again. It was important to realize that this study was conducted on well-adjusted patients and their families, who nevertheless stated the need for further pre- and post-operative rehabilitation support.

Salmon (1979) compiled survey results received from

66 laryngectomees and 53 spouses of laryngectomees. The questionnaire concentrated on pre- and post-operative counseling of laryngectomees and their spouses. The responses of 12 female and 54 male laryngectomees, and seven male and 46 female spouses of laryngectomees, were reported, but sex was not investigated as a variable. Preoperatively, 98% percent of the laryngectomees and 77% of the spouses saw a physician, 45% of the laryngectomees and 17% of the spouses saw a nurse, and 32% of the laryngectomees and less than 20% of the spouses saw a speech-language pathologist, laryngectomee, or spouse of a laryngectomee. The above figures emphasized the neglect of the spouse by members of the rehabilitation team.

Sixty-eight percent of the laryngectomees reported that they learned about the surgery itself only from their physicians. Laryngectomees who saw a speech-language pathologist, laryngectomee, or spouse of a laryngectomee were informed minimally about the rehabilitation and its consequences by these individuals. Thirty-three percent of the laryngectomees reported feeling "well prepared" (Salmon, 1979; p. 384), however, only 13% of the spouses reported feeling similarly. Twenty-three percent of the laryngectomees and 15% of the spouses responded that they felt "adequately-prepared" (p. 384). The remaining 44% of the laryngectomees and 45% of the spouses responded that they felt either "poorly prepared" or "not prepared at

all" (p. 364).

The questionnaire asked laryngectomees and their spouses to list, in order of preference, individuals they wished to see before surgery. Laryngectomees listed the following individuals: a laryngectomee, an esophageal speaker, a counselor, a speech-language pathologist, a New Voice Club member, and an American Cancer Society representative. Spouses listed the following individuals: a laryngectomee's spouse, a laryngectomee, a surgeon, an esophageal speaker, a speech-language pathologist, and a minister. These results exemplified the different counseling needs of laryngectomees and their spouses.

The respondents were asked to list, in the order of frequency, the preoperative information that they would have liked to have had. They listed: "1) different methods of communication postsurgery; 2) the surgical procedure; 3) the prognosis; and 4) the anatomical and physiological changes associated with laughing, coughing, the feeding tube, swallowing, the stoma, mucus, the impaired sense of taste and smell, the inability to blow one's nose or sneeze, and the altered physical appearance" (Salmon, 1979; p. 385). Spouses believed that information concerning changes in physical appearance was of prime importance. They also would have liked information to help them deal with the patient's physical and psychological changes following surgery. Both

laryngectomees and spouses would have liked to have been informed on the survival rate.

Preoperatively, 64 laryngectomees and 40 spouses met with a surgeon, 57 laryngectomees and 30 spouses met with a nurse, and more than half of the laryngectomees and almost half of the spouses met with a speech-language pathologist, an esophageal speaker, an artificial larynx speaker, and/or a spouse of a laryngectomee. Twenty-five percent of the spouses reported that they received no postoperative information.

Laryngectomees felt that postoperatively they should be told about their chances for survival, different methods of communication, where to go for speech therapy and its cost. Spouses believed that postoperative information should concentrate on the physical care involved after surgery (e.g., the feeding tube and the suction machine), coping with their own and the laryngectomees' psychological reactions, and how to ease communication difficulties with the laryngectomee.

Salmon (1979) concluded by stating that both the laryngectomee and the spouse should realize that: 1) the patient will lose the larynx and breathe through a permanent tracheostoma, thus, s/he will have to learn a new method of voice; 2) a naso-gastric tube is necessary, the stoma requires care (e.g., suctioning), and neck and head swelling will result immediately after surgery and

for some time thereafter; 3) alaryngeal speech is indeed possible; and 4) the speech clinic staff will be available and will make a postoperative visit.

Blanchard (1982) surveyed 89 male, 20 female, and six unknown sex laryngectomees regarding their pre- and post-operative counseling. Laryngectomees stated that surgeons and speech-language pathologists were the main informational sources. Nine percent of the laryngectomees reported no counseling services from a physician, and 12% reported no contact with a speech-language pathologist. Ten percent of the respondents felt that the operation was not explained fully. Nineteen percent received no information regarding alaryngeal speech. Thirty-one percent were not informed about how to obtain an artificial larynx. Thirteen percent stated that they received no information about supportive services (e.g., New Voice Club). Speech therapy was recommended for 111 of the subjects, however, specific information on where to obtain this service and its cost was not provided.

Eighty-nine spouses also were surveyed. Fifteen percent of the spouses received no counseling from the surgeon. Sixteen percent of the spouses had not been counseled by a speech-language pathologist.

The author stated that pre- and post-surgical counseling must progress to meet the needs of both the patient and spouse. Evidently, important information

(e.g., alaryngeal speech methods and community services) was omitted, therefore, a better coordination of the rehabilitation team's efforts was needed.

Natvig (1983) interviewed laryngectomees and their spouses in Norway. Preoperative counseling was divided into two phases, the initial explanation of cancer and advice on the operation. Sixty-seven percent of the 131 laryngectomees rated the initial explanation of the cancer as satisfactory; 74.5% rated the advice on the operation as satisfactory. The patients also rated their satisfaction with the counselors. The following percentages were obtained: laryngectomized person, 82%, speech-language pathologist, 73%, and physician, 82%.

Fifty-five percent of the sample was dissatisfied with postoperative training. Thirty-one percent reported feeling unprepared for self-care duties. Natvig (1983) stated "that there is a great discrepancy between the counseling assumed to have been offered and that positively perceived by the patients" (p. 253). A proper counseling program, therefore, was essential to assist the future quality of life for laryngectomees.

Seventy percent of the 98 spouses claimed that pre- and post-operative counseling was nonsatisfactory. Most respondents said that they had experienced grave mental trauma at the first postoperative visit. The problems that continued at home were more difficult to deal with

than they had imagined. Silent, snoreless sleep, feeling of disgust aroused by the noisy cough, and the expulsion of crusts and mucous secretions led the spouses to refer to the laryngectomees' first days home as a harrowing period.

Nineteen percent of the respondents rated the spouses' loss of speech as their greatest problem postoperatively. Stomal care was rated as the spouses greatest problem by 34% of the sample. Anxiety over stomal breathing caused the biggest worry for 16% of the spouses. Only 8.5% of the respondents said that they had few or no problems. The remainder of the spouses stated various other problems such as diseases, patient depression, and insecurity as their largest preoccupations.

Natvig (1983) stated that pre- and post-operative counseling certainly could be improved. He stressed the importance of encouraging the spouse to attend counseling and training programs with the patient.

None of the previously-mentioned investigations studied the specific differences between the counseling needs of laryngectomees or their spouses. The results of the investigations, however, confirmed the need for more and better counseling for both the laryngectomee and the spouse. Further, the spouses' counseling needs were different than the laryngectomees' counseling needs. The

laryngectomy rehabilitation team must be aware of the differences in counseling needs between the patient and the spouse.

The role of the speech-language pathologist as counselor

Killarney and Lass (1979) surveyed speech-language pathologists, social workers, and rehabilitation counselors about their knowledge, exposure, and attitude toward laryngectomees. The authors found that speech-language pathologists knew more about the problems of laryngectomees than the other two groups. Therefore, the authors stressed that pre-service training programs for social workers and rehabilitation counselors be improved since they come into contact with laryngectomized persons. The results of this study supported speech-language pathologists as the most capable counselors of laryngectomees.

Square (1979) reported the results of a panel discussion concerning the rehabilitation team's role in the counseling of laryngectomees, their families, and friends. The participants shared their varied ideas. All agreed that "counseling of the laryngectomee, his family, and his friends is vital to the total rehabilitation process" (Square, 1979, p. 113). The author stated that the only rehabilitation team individual with "a broad enough knowledge to arrange, organize and administer such

counseling programs and seminars" (p. 113) may be the speech-language pathologist.

Information on sex differences

Kutner and Kutner (1979) interviewed men and women in a rehabilitation center located in a southeastern metropolis. They examined sex as a variable affecting reactions to disability. The results showed that perceived losses between the sexes differed. Men were more concerned with the loss of independence and the inability to make and spend money. Women were more concerned with the effects of their disability on their personal relationships and responsibilities. The authors linked the differences in perceived losses to the prevailing sex role prescriptions.

Vanfossen (1981) examined sex differences in the mental health effects of spouse support and equity. The author found that more husbands than wives felt affirmed by their spouses and their marriages, and that their spouses reciprocated equally in the marital relationship. Each husband who reported symptoms of depression indicated that he did not share intimacy with his wife, and that his wife neither appreciated him nor helped him become the person that he wished to be. It was found that more wives than husbands engaged in adult nurturing. Wives found affirmation ("the expressive support a person can give to

another by affirming that the other person is the kind of person s/he wants, and by appreciating what s/he already is; Vanfossen, 1981, p. 133) most missing.

Vanfossen (1981) described two themes concerning sex differences in marital interactions. One theme speculated that women were more supportive than men. The other theme suggested that women were more likely to be powerless, whether the powerlessness was actual or perceived. This study provided evidence that the kinds of support provided by spouses varied according to sex.

Neither of the previously-mentioned investigations used laryngectomees and their spouses as subjects. Based on the results of these investigations, however, differences should be expected in the counseling needs between the laryngectomee and the spouse. The available literature also suggested that female laryngectomees might perceive their disability differently than male laryngectomees. The counseling needs of a female patient, therefore, might be expected to be different than those of a male patient. Likewise, the counseling needs of a male spouse might be expected to be different than those of a female spouse.

Summary

In summary, the existing body of literature has provided information on the counseling needs of primarily

male laryngectomees and female spouses. It generally was agreed that more and better counseling of laryngectomees and their spouses was needed. No available investigations, however, have studied the differences in counseling needs based on sex.

The literature has reported that sex differences exist between spouses in their interactions as well as in patients' attitudes regarding their disability. It seemed necessary, therefore, to identify if there were differences between the counseling needs of male and female laryngectomees, male and female spouses of laryngectomees, and laryngectomees and their spouses. Thus, speech-language pathologists and other health-care professionals could ameliorate their counseling services to all individuals involved in the rehabilitation process.

METHODS

Introduction

The rehabilitation of laryngectomees requires a lengthy time beginning preoperatively and extending well into the postoperative period. The pre- and post-operative counseling that a laryngectomee received was reported to be an integral part of the rehabilitation period. Laryngectomees have reported the need for more and better counseling, not only for themselves, but for their spouses and families as well. Investigators have found that family members, particularly spouses, played an important role in the rehabilitation process. Spouses of laryngectomees also have reported the need for more and better counseling.

The existing body of information on the counseling needs of laryngectomees has focused primarily on the male laryngectomees and their female spouses. Yet, sex differences have been reported in the way spouses interact with each other and in patient's attitudes toward their disability. To provide effective counseling to laryngectomees and their spouses, more information was needed to identify potential sex differences in their counseling needs.

The purpose of this study was to identify the differences in counseling needs between male and female laryngectomees, male and female spouses of laryngectomees,

and the laryngectomees and their spouses. A survey was developed to obtain the pertinent information.

Subjects

Laryngectomees and their spouses attending the 1985 International Association of Laryngectomees (IAL) Convention in Atlanta, Georgia were selected randomly to participate in this investigation. In addition, members of New Voice Clubs in California, Georgia, Kansas, Maryland, Oklahoma, and New York participated. All subject participation was voluntary.

Development and distribution of the survey

A 25-item survey was developed to obtain the pertinent information from laryngectomees. A similar 25-item survey was developed to obtain the pertinent information from laryngectomees' spouses. The survey items were copied on both sides of an 8 1/2 X 14 inch form. Surveys were distributed to each subject with written information (see Appendix A) concerning the nature of the investigation.

Two forms of each survey (i.e., laryngectomee and spouse) were available to reduce the possible effects of item order. The laryngectomees completed either Form A or Form B (see Appendix B). The spouses completed either Form C or Form D (see Appendix C). Equal numbers of each

form were distributed and counterbalanced among each group of subjects receiving the survey.

The surveys were distributed in a variety of ways to facilitate their completion by subjects of varied backgrounds and locations. Surveys were either hand delivered to subjects by the investigator or mailed to key individuals who distributed them. The key individuals were members of New Voice Clubs and agreed in advance to the responsibility of distributing the surveys. These key individuals were provided written and verbal (by telephone) instructions by the investigator regarding the procedures for participation in the investigation.

When appropriate, the investigator collected the surveys from the participants in person. At other times, the subjects mailed the surveys directly to the investigator to protect their privacy. In some cases, several members of New Voice Clubs, by choice, collectively mailed their surveys directly to the investigator.

Five randomly-selected items from the each of the laryngectomees' and spouses' surveys were analyzed to determine if there were differences in responses based upon the type of survey delivery. For the laryngectomees' survey, the randomly-selected items were numbers 5, 11A, 12, 14B, and the fourth response for item 17 on Form A or the equivalent items on Form B. The results of a chi

square analysis (Siegel, 1956) for each item revealed nonsignificant differences for the type of survey delivery (#5, $X^2=11.9$, $df=8$, $p>.05$; #11A, $X^2=6.3$, $df=10$, $p>.05$; #12, $X^2=7.7$, $df=6$, $p>.05$; #14B, $X^2=11.4$, $df=8$, $p>.05$; #17, $X^2=12.7$, $df=8$, $p>.05$).

For the spouses' survey, the randomly-selected items were numbers 5, the fifth response for item 9, 16B, 18, and 21 or the equivalent items on Form D. The results of a chi square analysis for each item revealed nonsignificant differences for the type of survey delivery (#5, $X^2=9.8$, $df=8$, $p>.05$; #9, $X^2=12.1$, $df=8$, $p>.05$; #16B, $X^2=6.7$, $df=8$, $p>.05$; #18, $X^2=15.6$, $df=12$, $p>.05$; #21, $X^2=11.0$, $df=8$, $p>.05$). For the purposes of data analysis, therefore, all survey responses for each group were pooled regardless of the type of delivery.

On each form of the survey, all subjects were requested to provide identifying and background information. Table 1 reveals the response types for each of the identifying categories. For data analysis, this information was coded for easy manipulation. Only laryngectomees were requested to provide the date of their laryngectomy, whether they were retired, and their method of communication. Place of residence and occupation were coded according to the categories developed and used by the U.S. Census Bureau (1980).

Table 1. The response types for each of the identifying categories on the survey.

Sex	Male/Female
Age	Under 57 years 57 years and over
Place of residence	Northeast North Central South West Other
Educational level	Some high school High school graduate Some college College graduate Other
Employment status	Employed/Unemployed
Occupation	Executive Professional Technical support Sales Administrative support Private household Protection service Other service Farming, forestry, fishing Precision production Transportation Laborers Machine operators Other
Retired	Yes/No
Date of laryngectomy	Less than 2 years 2 to 5 years 5 to 10 years Greater than 10 years
Method of communication	Writing Mouthing words Electrolarynx Esophageal speech Prosthesis Other Combination

The 25 items on each survey followed the identifying and background information and were listed randomly on each form. Twenty-two of the 25 survey items were experimental items. The remaining three items on each form of the survey were used as a reliability check of the subjects' responses. Of the 22 experimental items, four items surveyed the subjects' lifestyle changes, eight items surveyed the subjects' informational needs, and ten items surveyed the subjects' feelings. Table 2 reveals the specific item numbers in each category for Form A and Form C. In addition to the 25 survey items, subjects were given the opportunity to comment in writing at the end of each form on any aspect of the laryngectomy procedure or rehabilitation.

Reliability

Reliability items were selected randomly from the 22 experimental items and rewritten in slightly different terms. The three reliability items for Form A were 19, 21, and 24 or the equivalent counterparts for Form B. The reliability items for Form C were 5, 12, and 22 or the equivalent counterparts for Form D.

The gamma statistic (Loether and McTavish, 1980) was used to measure the extent of association between the subjects' responses for the two similarly-worded items. A z-score was obtained by dividing the gamma statistic by

Table 2. Survey items by category for Forms A and C.

FEELINGS

Form A: 1, 3, 10, 13, 14, 16, 18, 20, 22, 23

Form C: 2, 8, 11, 15, 16, 18, 19, 21, 23, 24

INFORMATIONAL NEEDS

Form A: 4, 5, 7, 9, 11, 15, 17, 25

Form C: 1, 4, 6, 9, 10, 14, 17, 25

LIFESTYLE CHANGES

Form A: 2, 6, 8, 12

Form C: 3, 7, 13, 20

RELIABILITY

Form A: 19, 21, 24

Form C: 5, 12, 22

its standard error. The z-score was calculated to determine the significance of the extent of association.

Each of the three reliability pairs in the laryngectomees' survey revealed a significant association (#19, $z=7.3$, $p<.0001$; #21, $z=18.3$, $p<.0001$; #24, $z=16.4$, $p<.0001$). Each of the three reliability pairs in the spouses' survey revealed a significant association (#5, $z=5.0$, $p<.0001$; #12, $z=3.3$, $p<.001$; #22, $z=18.9$, $p<.0001$). These results indicated that subjects were responding to different items, similarly worded, in the same manner. Thus, based on these data, the subjects' responses on the survey were deemed reliable.

Validity

Forty-seven (22%) of the total number of subjects were selected to be interviewed by the investigator as a validity check of subject responses. These subjects were selected randomly from those subjects with whom the investigator made personal contact. Open-ended questions regarding the subjects' counseling needs relating to laryngectomy were asked of each of these subjects.

The investigator made written notes of the information provided by the subjects. Interviewees were not tape recorded because an early evaluation of the interview procedures revealed that some subjects were uncomfortable having their remarks recorded. Further,

some laryngectomees were difficult to understand from audio recordings.

The interview results were reviewed independently by two speech-language pathologists (i.e., the investigator and her advisor). For each of these subjects, responses to interview questions were compared to responses on the survey. The speech-language pathologists compared responses looking for consistency between the two methods of obtaining information. Both reviewers determined that the written notes from the interview corresponded closely to responses on the survey for each subject. Hence, the survey responses were deemed sufficiently valid for the purposes of this investigation.

RESULTS

A total of 423 surveys were distributed to individuals in 19 states and Canada. Of the total number of surveys distributed, 161 (38%) were returned. Fifty-four laryngectomees returned Form A; 66 returned Form B. Twenty-two spouses returned Form C; 19 returned Form D. The differences in the numbers of subjects returning each form were attributed to the failure of some subjects to complete and return the survey.

Subject Characteristics

All of the laryngectomees were members of New Voice Clubs in various regions of the United States, except one, who was from Canada. All of the spouses were mates of New Voice Club members.

Table 3 lists the numbers of subjects (laryngectomees and spouses) in each category of identifying and background information. Table 4 lists the numbers of subjects in each category of identifying and background information collected only for laryngectomees.

Survey responses by laryngectomees

The specific responses by laryngectomees to each survey item are reported in Appendix D. Generally, the results revealed the following trends for each

Table 3. The number of subjects in each category of identifying and background information.

Categories	Laryngectomees	Spouses
Sex		
Male	68	20
Female	50	21
Unknown	2	0
Age		
Under 57 years	30	12
57 years and over	83	24
Unknown	7	5
Educational level		
Some high school	25	6
High school graduate	30	14
Some college	36	7
College graduate	21	8
Other	5	4
Unknown	4	1
Place of Residence		
Northeast	43	9
North Central	24	12
South	34	16
West	18	4
Other	1	0
Employment status		
Employed	34	14
Unemployed	84	26
Unknown	2	1
Type of Employment		
Executive	16	2
Professional	10	4
Technical support	5	0
Sales	6	6
Administrative support	21	10
Protection service	1	0
Other service	13	2
Precision production	8	4
Transportation	2	0
Laborers	4	5
Machine operators	22	2
Other	22	2
Unknown	16	2
Method of Delivery (distribution/collection)		
In person/In person	49	6
In person/by mail	15	7
By mail/by mail	56	28

Table 4. The number of subjects in each category of identifying and background information collected only for laryngectomees.

Category	Number of laryngectomees
Date of laryngectomy	
Less than 2 years	26
2 to 5 years	33
5 to 10 years	23
10 years or greater	33
Unknown	5
Method of communication	
Writing	1
Electrolarynx	16
Esophageal speech	54
Blom-Singer device	3
Other	1
Combination of methods	45
Retired	
Yes	69
No	35
Unknown	16

experimental item.

1. The largest percentages of laryngectomees reported the following feelings after surgery: strong feelings of acceptance (45%), no feelings of anger (34.2%), strong feelings of fear and anxiety (33.3%), and strong feelings of depression (27.5%).

2. The majority of laryngectomees (64.2%) reported that there was no change in the spouse's health as a result of the laryngectomy.

3. The largest percentage of laryngectomees (42.5%) reported that the spouse had no specific reaction to the cost of the laryngectomy.

4. The majority of the laryngectomees (66.7%) reported that they had ample opportunity to ask questions before the surgery.

5. The largest percentage of laryngectomees (43.3%) reported that counseling "helped me a lot". On the other hand, 40% of the laryngectomees reported that they received no counseling.

6. The majority of laryngectomees (55%) reported no significant change in social life since the laryngectomy.

7. The largest percentages of laryngectomees reported that the following individuals definitely were effective in helping them to adjust to the consequences of the surgery: the spouse (50.1%), other family (50%), the speech-language pathologist (50%), the physician (45%), another laryngectomee (39.2%), and friends (38.3%).

8. The majority of the laryngectomees (50.1%) reported that the amount of communication with the spouse was the same before as after the operation. Only 26.7% reported less communication with the spouse after surgery.

9. The majority of laryngectomees (82.5%) reported that they understood that they would no longer speak after the surgery.

10. The largest percentage of laryngectomees (30.8%) reported always being optimistic about the surgery and its consequences. Only 10% were never optimistic. Otherwise, 27.5% were least optimistic before surgery; 22.5% were least optimistic after surgery.

11. The largest percentage of laryngectomees (47.5%) reported not being exposed to alternate modes of communication before surgery. The individual most instrumental in making them aware of the alternate communication modes was the speech-language pathologist (38.3%).

12. The majority of laryngectomees (55.8%) reported that the surgery had no significant effect on the marriage.

13. The largest percentage of laryngectomees (40%) repeated themselves when they were misunderstood by the spouse.

14. Before surgery, the largest percentages of laryngectomees reported anxiety about survival (39.2%), loss of speech (25.8%), or fear of the future (21.2%). After surgery, loss of speech (45.8%) caused the most anxiety.

15. The majority of laryngectomees (60%) reported that their spouses were not counseled alone.

16. The majority of laryngectomees (87.5%) reported that they cared for their own stomas and found stoma care to be a non-laborious task (67.5%).

17. The largest percentages of laryngectomees reported that the following individuals definitely provided helpful information about the surgery and its consequences: the physician (54.2%), the speech-language pathologist (38.3%), and another laryngectomee (32.5%).

18. The majority of laryngectomees (52.5%) did not meet another laryngectomee before the surgery. Meeting a laryngectomee before surgery was a positive experience for 37.5% of the respondents.

19. The largest percentage of laryngectomees (40.1%) was counseled by a mixed group of individuals. A large percentage of respondents (35.8%) also reported being counseled by only the physician.

20. A majority of laryngectomees (52.5%) reported no feelings of embarrassment associated with their new method of speech.

21. The largest percentage of laryngectomees (45%) reported that they were not disabled as a result of the laryngectomy. Of those remaining, 45.1% reported being only moderately or slightly disabled.

22. The largest percentages of laryngectomees reported that their first reaction to the stoma was: distaste (27.5%), no reaction (22.5%), or curiosity (20.8%).

Survey responses by spouses

The specific responses by spouses to each survey item are reported in Appendix E. Generally, the results revealed the following trends for each item.

1. The largest percentages of spouses reported the following strong feelings after surgery: fear and anxiety (48.8%) and acceptance (46.3%).

2. The majority of spouses (90.2%) reported that their health was unchanged as a result of the laryngectomy.

3. The majority of spouses (58.5%) did not have to

work extra as a result of the surgery.

4. The majority of spouses (56.1%) reported that they had ample opportunity to ask questions before the surgery. Thirty-nine percent reported they did not have ample opportunity to ask questions.

5. The majority of spouses (51.2%) reported they received no counseling. Of the remaining spouses, 41.5% reported that counseling "helped me a lot".

6. The majority of the spouses (51.2%) reported no significant change in social activity since the surgery.

7. The largest percentages of spouses reported that the following individuals definitely were effective in helping them to adjust to the laryngectomy and its consequences: their spouse (i.e., the laryngectomee; 48.8%), the physician (41.5%), another laryngectomee (41.5%), other family (39%), and the speech-language pathologist (36.6%).

8. The majority of spouses (51.2%) reported no change in the amount of communication with the laryngectomee, however, 36.6% reported that they communicated less.

9. The majority of spouses (85.4%) understood that the laryngectomee would no longer speak following surgery.

10. The largest percentage of spouses (36.6%) was least optimistic before the surgery; 24.4% was always optimistic.

11. The majority of spouses (51.1%) reported not being exposed to the alternate modes of communication before surgery. The speech-language pathologist (28.8%) and the laryngectomee (26.8%) were the individuals most instrumental in making the spouse aware of alternate modes of communication.

12. The majority of spouses (65.9%) reported that the laryngectomy had no effect on the marriage.

13. The majority of spouses (58.5%) reported that when they do not understand the laryngectomee, the laryngectomee typically repeats until understood.

14. Before surgery, the patients' survival caused the most anxiety for the spouses (61%). After surgery, fear of the future (31.7%), loss of speech (31.7%), or the patients' survival (26.8%) caused the most anxiety for the spouses.

15. The majority of spouses (85.4%) reported not being counseled alone.

16. The majority of spouses (63.4%) reported that they did not care for the laryngectomee's stoma. Most of the remaining spouses (19.5%) reported that stoma care was not a laborious task.

17. The largest percentage of spouses reported that the following individuals definitely provided helpful information about the surgery and its consequences: the physician (56.1%), another laryngectomee (31.7%), and the

speech-language pathologist (26.8%).

18. The majority of spouses (82.9%) did not meet a laryngectomee's spouse before the surgery.

19. A large percentage of spouses was counseled by the physician (39%) or by a combination of individuals (26.8%).

20. The majority of spouses (82.9%) was not embarrassed by the laryngectomee's new mode of communication.

21. The largest percentage of spouses (41.5%) reported that the laryngectomee was not disabled as a result of the surgery. Of those remaining, 31.7% and 22% considered the laryngectomee mildly or moderately disabled, respectively.

22. The largest percentages of spouses reported that their first reaction to the stoma was: anxiety (24.4%), distaste (24.4%), or curiosity (17.1%).

Sex differences in the survey responses

Male versus female laryngectomees. The differences between the survey responses of male and female laryngectomees are reported in Appendix D. A chi square (Siegel, 1956) was calculated for each of the experimental items. Two subjects of unknown sex were not included in the analyses (n=118).

Ten of the experimental items revealed significant differences. Six of the items corresponded to the category of feelings and four to the category of informational needs. The general trends of the results were discussed for each significant item. Only general trends were reported, because the nature of the statistic did not allow for a posteriori evaluations.

Significant sex differences were revealed for the item (#1) concerning the amount of fear and anxiety

following surgery ($X^2=9.9$; $df=4$; $p<.05$). Many female laryngectomees (48%) reported strong feelings of fear and anxiety following surgery as compared to the males (23.5%). More male laryngectomees (27.9%) reported moderate feelings of fear and anxiety as compared to the females (12%).

Sex differences also were revealed for the item (#5) regarding the effectiveness of counseling ($X^2=11.9$; $df=4$; $p<.05$). More male laryngectomees (51.5%), as compared to females (32%), reported that counseling "helped me a lot". More female laryngectomees (22%), as compared to males (4.4%), reported that counseling "made little or no difference". Interestingly, a large percentage of male (41.2%) and female (38%) laryngectomees reported they received no counseling.

Sex differences were revealed for the item (#7) regarding the effectiveness of the family in helping the laryngectomee to adjust to the surgery's consequences ($X^2=11.2$; $df=4$; $p<.05$). More female laryngectomees (66%), as compared to males (36.8%), reported that the family (other than the spouse) definitely was effective in helping the patient during the adjustment period following surgery. More male laryngectomees (29.4%), as compared to females (10%), reported that the family was not effective.

Similarly, male and female laryngectomees differed in their opinions regarding the effectiveness of friends

during the adjustment period (item #7; $\chi^2=9.7$; $df=4$; $p<.05$). More female laryngectomees (52%), as compared to males (26.5%), reported that friends definitely were effective. More males (22.1%) than females (12%) reported only moderate effectiveness for friends during the adjustment period. Further, more males (26.5%) than females (12%) reported that friends were not effective.

Male and female laryngectomees also differed in their opinions regarding the effectiveness of another laryngectomee in helping them to adjust postsurgically (item #7; $\chi^2=11.0$; $df=4$; $p<.05$). Although many male (36.8%) and female (40%) laryngectomees reported that another laryngectomee definitely was effective during the adjustment period, a large percentage of males (20.6%), as compared to females (4%), reported another laryngectomee was not effective. Another important difference was revealed in the "no response" category. More females (32%) than males (19.1%) did not respond. Perhaps, these individuals did not have another laryngectomee available to help them adjust following surgery.

Sex differences were revealed in the item (#17) regarding the degree to which the physician provided helpful information about the surgery and its consequences ($\chi^2=9.8$; $df=4$; $p<.05$). More males (60.3%) than females (46%) reported that the physician definitely provided helpful information. More females (18%) than males

(7.4%), however, reported that the physician provided no helpful information. More females (12%) than males (1.5%) did not respond to this item. It was not clear why females were less likely to respond.

Similarly, sex differences were revealed for the item (#17) regarding the laryngectomee as a source of helpful information ($X^2=10.6$; $df=4$; $p<.05$). Many males (32.4%) and females (34%) reported that another laryngectomee definitely provided helpful information. More males (33.8%) than females (14%), however, found the laryngectomee provided no helpful information. More females (10%) than males (2.9%) reported that the laryngectomee "slightly" provided helpful information. Again, more females (32%) than males (16.2%) did not respond.

Females were more likely than males to be embarrassed by their mode of communication (item #20; $X^2=13.9$; $df=4$, $p<.01$). When asked if the mode of communication was an embarrassment, more females than males responded: definitely (14% to 4.4%), moderately (20% to 10.3%), and slightly (32% to 17.7%). The majority of male laryngectomees (66.2%) reported no embarrassment as compared to only one-third (34%) of the females.

Male and female laryngectomees differed on the item (#23) regarding the first reaction to the sight of the stoma ($X^2=15.8$; $df=6$; $p<.05$). More males than females

reported feeling anxiety (11.8% to 4%) or having no reaction (27.9% to 14%). More females (44%) than males (14.7%) reported that they found the stoma distasteful.

Sex differences were revealed for the item (#2) concerning the individuals who counseled the respondents about the surgery and its consequences ($X^2=18.7$; $df=5$; $p<.05$). More female laryngectomees (24%) than males (1.4%) responded to the "other" category. On closer inspection, these results showed that these female subjects were counseled by their husbands. The results also showed that more males (42.7%) than females (36%) were counseled by several individuals. Further, more females (10%) than males (1.5%) failed to respond to this item.

Male versus female spouses of laryngectomees. The differences between the survey responses of male and female spouses of laryngectomees are reported in Appendix E. A chi square was calculated for each experimental item.

Three of the experimental items revealed significant differences. Two items corresponded to the category of feelings and one corresponded to informational needs.

Significant differences ($X^2=11.6$; $df=4$; $p<.05$) between the sexes were revealed for the item (#1) regarding feelings of relief postsurgically. More males than females reported strong feelings (30% to 14.3%),

moderate feelings (20% to 9.5%), and no feelings (30% to 4.8%) of relief. More females (19.1%) than males (5%) reported mild feelings of relief. Interestingly, a majority of females (52.4%) did not respond to this item. Only 15% of the males failed to respond.

Significant differences ($X^2=10.1$; $df=4$; $p<.05$) between the sexes were revealed for the item (#1) regarding feelings of acceptance following surgery. More male than female spouses reported strong feelings (65% to 28.6%) or no feelings (15% to 4.8%) of acceptance. More females than males reported moderate feelings of acceptance (33.3% to 5%) or did not respond (28.6% to 15%).

Sex differences were revealed for the item (#11) concerning the individual most instrumental in exposing the spouse to alternate modes of communication ($X^2=21.2$; $df=5$, $p<.001$). Males were exposed to the alternate modes by the physician (40% to 0%) or the nurse (10% to 0%). The majority of females (52.4%), as compared to none of the males, were exposed to the alternate modes by the speech-language pathologist.

Differences in survey responses between laryngectomees and spouses

The group responses of laryngectomees were compared directly to those of the spouses and are reported in Appendix F. A chi square was calculated for each

experimental item.

Nine of the experimental items revealed significant differences. Five of the items corresponded to the category of feelings, three to lifestyle changes, and one to informational needs.

Significant group differences were revealed for the item (#2) referring to the effect of the laryngectomy on the spouse's health ($X^2=12.7$; $df=3$; $p<.01$). A majority of spouses (90.2%) and laryngectomees (64.2%) reported no health changes. Only laryngectomees (4.2%) reported that their spouses' health improved. The other difference between group responses appeared for the no response category. More laryngectomees (25%) than spouses (2.4%) did not respond. This difference was attributed to the fact that the laryngectomee group included both married and unmarried subjects.

Significant group differences were found for the item (#3) concerning the spouse's reaction to the cost of the laryngectomy ($X^2=87.5$; $df=4$; $p<.0001$). The major difference for this item seemed to be explained by the large difference in no responses. More laryngectomees (24.3%) than spouses (4.8%) did not respond.

Group differences were reported for the item (#8) regarding the amount of communication between laryngectomee and spouse as a result of the surgery ($X^2=17.4$; $df=3$; $p<.001$). More spouses (12.2%) than

laryngectomees (1.7%) reported an increase in communication following the surgery. Similarly, more spouses (31.9%) than laryngectomees (26.7%) reported a decrease in communication. Approximately half of the subjects in each group (50.8% for laryngectomees and 51.2% for spouses) reported no change in communication. The number of no responses also influenced the results on this item. About one-fifth of the laryngectomees (20.8%) did not respond. All spouses responded to this item.

Significant group differences were found for the item (#12) regarding the effect of the laryngectomy on the marriage ($X^2=11.3$; $df=3$; $p<.05$). The major differences seemed to be explained by two factors. First, 20.8% of the laryngectomees did not respond, whereas all spouses responded to the item. Second, almost twice as many spouses as laryngectomees (19.5% to 10%) reported a positive effect on their marriages. Clearly, the majority of subjects in both groups reported that the laryngectomy had no effect on their marriage (55.8% for laryngectomees and 65.9% for spouses).

Group differences were revealed for the item (#13) referring to the laryngectomee's behavior when not understood by the spouse ($X^2=12.0$; $df=5$; $p<.05$). More spouses (14.6%) than laryngectomees (7.5%) reported that the laryngectomee becomes frustrated and ceases talking. Further, more spouses (58.5%) than laryngectomees (40%)

reported that the laryngectomee repeats until understood. The other major difference between the groups was for no responses. Laryngectomees did not respond more often than spouses (23.3% to 2.4%).

Laryngectomees and spouses differed on what caused the most anxiety after the surgery (item #14; $X^2=9.7$; $df=4$, $p<.05$). More spouses than laryngectomees were anxious about the survival of the patient (26.8% to 17.5%) and a fear of the future (31.7% to 16.7%). More laryngectomees (45.8%) than spouses (31.7%) were anxious about the loss of speech.

Significant differences were revealed for the item (#15) relating to whether the spouse was counseled alone ($X^2=11.2$; $df=2$; $p<.005$). The major difference between the groups appeared to be explained by the number of no responses. Laryngectomees did not respond more often than spouses (25% to 2.4%). Otherwise, more spouses (85.4%) than laryngectomees (60%) reported that the spouse was not counseled alone. The differences in these percentages were not as great when the no responses were eliminated (87.5% for spouses compared to 80% for laryngectomees).

Significant group differences were reported for the item (#16) concerning stoma care ($X^2=98.1$; $df=5$; $p<.0001$). The major difference between the groups was revealed by the large percentage of spouses (63.4%) who do not care for the stoma. Otherwise, the results showed

that spouses reported stomal care was more laborious than the laryngectomee. More spouses (12.2%) than laryngectomees (7.5%) reported that stomal care definitely was laborious. More laryngectomees (67.5%) than spouses (19.5%) reported that stomal care was not laborious.

Significant differences were revealed for the item (#20) relating to the amount of embarrassment associated with the laryngectomee's mode of communication ($X^2=13.1$; $df=3$; $p<.005$). More laryngectomees than spouses reported being moderately (15.8% to 4.9%) and slightly (23.3% to 4.9%) embarrassed by the mode of communication. More spouses (82.9%) than laryngectomees (52.5%) reported no embarrassment.

Differences in survey responses based on other variables

Age. Only one of the experimental items responded to by laryngectomees was significant for the age variable. Significant differences were revealed for the item concerning the difficulty of stomal care ($X^2=16.7$; $df=8$; $p<.05$). The majority of the younger (less than 57 years) and the older (57 years and older) groups found stomal care to be not laborious (75.7% and 67.5%, respectively). More older, than younger, laryngectomees, however, found stomal care to be definitely (9.6% to 3.3%) or moderately (10.8% to 0%) laborious. More younger, than older, laryngectomees found stomal care to be slightly laborious

(20% to 10.8%).

Five of the experimental items responded to by spouses of laryngectomees were significant for the age variable. Age differences were revealed for the item concerning feelings of depression postsurgery ($X^2=16.2$; $df=8$; $p<.05$). More younger, than older, spouses of laryngectomees reported strong (41.7% to 20.8%) and mild (33% to 0%) feelings of depression. More older, than younger, spouses reported no feelings of depression (29.2% to 0%) or did not respond at all (33.3% to 8.3%).

Significant differences were found for the item referring to the spouse's reaction to the cost of the laryngectomy ($X^2=22.0$; $df=8$; $p<.01$). The majority of the older spouses (75%) did not have to work extra as a result of the laryngectomy. Fewer younger spouses (41.7%) did not have to work extra. The other major differences between the age groups showed that more younger, than older, spouses were happy to make the sacrifice of extra work (33.3% to 16.7%) or resistful of the sacrifice (16.7% to 4.2%). The latter differences were influenced by the large percentage of older spouses who did not have to work extra and might have been an artifact of the analysis.

Age differences were revealed for the item regarding the amount of communication with the spouse since the surgery ($X^2=14.2$; $df=4$; $p<.01$). Older spouses (70.1%) were more likely to report no change in the amount of

communication than younger spouses (25%). Younger spouses were more likely to report changes. More younger, than older, spouses reported more communication (9.8% to 4.2%) or less communication (41.7% to 25%) with the laryngectomee following surgery.

Age differences were revealed for the item regarding the effect of the laryngectomy on the marriage ($X^2=21.2$; $df=4$; $p<.0005$). Older spouses (83.3%) were more likely to report no effect on the marriage than younger spouses (16.7%). Younger spouses were more likely to report either positive (58.3% to 4.2%) or negative (25% to 12.5%) effects of the laryngectomy on the marriage.

Significant differences were reported for the item concerning the physician as a source of helpful information about the surgery and its consequences ($X^2=25.9$; $df=8$; $p<.005$). More older spouses (75%) reported the physician was a definite source of helpful information as compared to the younger spouses (25%). Younger spouses reported the physician was less helpful. More younger, than older, spouses reported that the physician was a moderate (16.7% to 4.2%) or a slight (25% to 8.3%) source of helpful information, or not a helpful source at all (33.3% to 4.2%).

Educational level. One of the experimental items responded to by laryngectomees was significant for the educational level variable. Significant differences were

revealed for the item concerning the nurse as a source of helpful information about the surgery and its consequences ($\chi^2=32.4$; $df=20$; $p<.05$). This difference was difficult to explain because of the large number of response categories with few or no responses.

None of the experimental items responded to by spouses of laryngectomees were significant for the educational level variable.

Place of residence. Nine of the experimental items responded to by laryngectomees were significant when residence was examined as a variable. Significant residence differences were found for the items regarding postsurgical feelings of fear and anxiety ($\chi^2=20.0$; $df=16$; $p<.05$), depression ($\chi^2=34.9$; $df=16$; $p<.005$), relief ($\chi^2=26.6$; $df=16$; $p<.05$), and acceptance ($\chi^2=33.1$; $df=16$; $p<.01$). No clear trend of feelings based on place of residence, however, could be determined from the results.

Significant residence differences were revealed for the item regarding the effect of the laryngectomy on the spouse's health ($\chi^2=38.7$; $df=12$; $p<.0001$). Over seventeen percent of southern respondents reported the spouse's health was worse after the laryngectomy. This percentage was four times greater than the next highest percentage (4.2%) based on place of residence. Southerners also manifested the lowest percentage of no responses (8.8% as compared to the next lowest percentage, 25%). These

trends were the major differences in the responses.

Significant differences also were revealed for the item regarding the effectiveness of the spouse in helping the laryngectomee adjust to the surgery and its consequences ($X^2=30.0$; $df=16$; $p<.05$). The major differences were manifested in the definitely effective category. The majority of individuals from the south (73.5%) and north central states (50%) reported the spouse definitely was effective. Smaller percentages of individuals from the northeast (37.2%) and west (44%) reported similarly.

Significant differences also were found for the item regarding the effectiveness of another laryngectomee in helping the respondent adjust to the surgery and its consequences ($X^2=30.2$; $df=16$; $p<.05$). Only individuals from the northeast (18.6%) and the south (23.5%) reported that another laryngectomee was not effective. In each region of the country, except the west, the largest percentage of respondents reported that another laryngectomee was effective during the adjustment period. In the west, the largest percentage of respondents (50%) did not respond.

Residence differences were revealed for the item regarding the factors that contributed to the communication decrease between the laryngectomee and spouse ($X^2=32.0$; $df=20$; $p<.05$). The majority of

respondents did not report a decrease in communication with the spouse. Of those that did, there was not a clear trend in the responses based on place of residence.

Significant residence differences were found for the item regarding the degree to which the speech-language pathologist was a source of helpful information about the surgery and its consequences ($\chi^2=35.3$; $df=16$; $p<.005$). Two major differences in responses were revealed. First, the majority of individuals from the northeast (53.5%) found the speech-language pathologist a definite help. The next highest percentage was 37.5% by individuals from the north central U.S. Second, over one-third of the southerners (35.3%) found the speech-language pathologist was not a helpful source of information. The next highest percentage was 16.7% by westerners.

Seven of the experimental items responded to by spouses of laryngectomees were significant when place of residence was examined as a variable. Significant residence differences were revealed by spouses for the item concerning feelings of acceptance following surgery ($\chi^2=23.9$; $df=12$; $p<.05$). Westerners reported greater feelings of acceptance than individuals from other parts of the country. No other strong trends were revealed.

Significant differences were revealed for the item regarding the spouse's reaction to the cost of the laryngectomy ($\chi^2=22.1$; $df=12$; $p<.05$). Two major

differences in responses were revealed. First, a large percentage of individuals (41.7%) from the north central U.S. reported being happy to sacrifice for the laryngectomy. The next highest percentage was 18.8% by southerners. Second, only northeasterners (33.3%) reported being somewhat resistful of the sacrifice.

Residence differences were revealed for the item concerning the effectiveness of the physician ($\chi^2=33.4$; $df=12$; $p<.001$), the family ($\chi^2=21.0$; $df=12$; $p<.05$), and friends ($\chi^2=24.1$; $df=12$; $p<.05$) in helping the spouse adjust to the laryngectomy's consequences. The physician was not effective for the majority of northeasterners (66.7%). The majority of individuals from the north central states (66.7%) and the west (75%) reported the physician definitely was effective.

Two major trends were seen in the results regarding the effectiveness of the family during the adjustment period. First, the majority of individuals from north central states (58.3%) found the family definitely effective. The next highest response was 33.3% by northeasterners. Second, one-half of the westerners did not respond.

Three major trends were seen in the results regarding the effectiveness of friends during the adjustment period. First, 66.7% of the northeasterners reported that friends were either slightly effective or not effective. Second,

66.7% of the individuals from the north central U.S. reported that friends definitely were effective. Third, one-half of the southerners did not respond.

Significant differences were found for the item concerning factors contributing to a decrease in communication between the laryngectomee and spouse ($\chi^2=28.6$; $df=15$; $p<.05$). Three major trends were revealed in these results. First, only northeasterners (33.3%) reported that embarrassment contributed to a decrease in communication with the spouse. Second, a majority of westerners (50%) listed "other" factors (e.g., hearing problems of both the laryngectomee and spouse) as contributing to the decrease in communication. Third, a majority of individuals from the south (56.3%) and north central states (91.7%) did not respond.

Spouses revealed residence differences for the item regarding the effect of the laryngectomy on the marriage ($\chi^2=18.1$; $df=6$; $p<.01$). The majority of individuals from the north central states (66.7%), the south (75%), and the west (100%) reported no significant effects. A majority of northeasterners (55.7%) reported that the laryngectomy had a negative effect on the marriage.

Employment status. Three of the experimental items responded to by laryngectomees were significant for the employment status variable. Significant differences were revealed for the item concerning the effect of the

laryngectomy on the spouse's health ($\chi^2=17.7$; $df=6$; $p<.01$). The majority in both groups reported no changes in the spouse's health. Only individuals that were employed (14.7%) reported better health in the spouse postsurgically. Only individuals unemployed (9.5%) reported worse health in the spouse postsurgically.

Significant differences were found for the item referring to the effectiveness of counseling ($\chi^2=20.4$; $df=8$; $p<.01$). Two major factors for the differences were revealed in the results. First, only individuals that were employed (5.9%) reported that counseling made them feel worse. Second, the distribution of no responses may have increased the significance of this item. The results of this item, therefore, might be an artifact of the type of analysis.

Significant differences also were found for the item relating to the cause of the most anxiety postsurgically ($\chi^2=20.0$; $df=8$; $p<.05$). A larger percentage of those individuals that were employed (26.5%), than those unemployed (13.1%), reported that fear of the future caused the most anxiety. On the other hand, more individuals that were unemployed (51.2%), as compared to those employed (35.3%), reported that loss of speech caused the most anxiety after surgery.

Four of the experimental items responded to by spouses of laryngectomees were significant for the

employment status variable. Significant differences were revealed by spouses for the item concerning the effectiveness of family members (other than the laryngectomee) in helping the spouse adjust to the laryngectomy and its consequences ($X^2=16.3$; $df=8$; $p<.05$). Two trends were seen in the results. Only individuals unemployed (38.5%) did not respond to this item. Further, a larger percentage of individuals that were employed, as compared to those unemployed, reported that the family was moderately (21.4% to 3.9%), slightly (14.3% to 7.7%), or not (21.4% to 11.5%) effective.

Similarly, significant differences were revealed for the item regarding the effectiveness of the speech-language pathologist in helping the spouse to adjust to the surgery and its consequences ($X^2=16.7$; $df=8$; $p<.05$). Two major trends were noted. First, a larger percentage of individuals unemployed (46.2%), than employed (21.4%), reported that the speech-language pathologist definitely was effective. Second, only individuals that were employed reported the speech-language pathologist was slightly (7.1%) or not (21.4%) effective.

Statistical differences were revealed for the item concerning the effect of the laryngectomy on the marriage ($X^2=13.4$; $df=4$; $p<.01$). A trend was revealed for unemployed individuals to report no effects on the marriage and employed individuals to report some type of

effect. For example, 84.6% of unemployed individuals reported that the laryngectomy did not affect the marriage as compared to only 28.6% of those employed. On the other hand, more employed individuals, than unemployed, reported positive (42.9% to 7.7%) or negative (28.6% to 7.7%) effects on the marriage.

Finally, significant differences were reported for the item regarding the experience of meeting with a laryngectomee's spouse before surgery ($X^2=14.1$; $df=4$; $p<.01$). A large majority of respondents did not meet with a laryngectomee's spouse. The differences for this item can be explained by the responses of those who did. A larger percentage of spouses that were employed (14.3%), than those that were unemployed (7.7%), reported a positive experience. Only spouses that were unemployed (7.7%) reported a negative experience.

Type of employment. Two of the experimental items responded to by laryngectomees were significant for the type of employment variable. Significant differences were revealed for the items concerning the degree of helpful information provided by the speech-language pathologist ($X^2= 73.0$; $df=48$; $p<.05$) and the social worker ($X^2=60.0$; $df=48$; $p<.05$). No clear trends were seen in the results of these items because of the large number of response categories with few or no responses.

Two of the experimental items responded to by spouse:

were significant for the type of employment variable. Once again, explaining these results proved difficult because of the large number of response categories with few or no responses. No clear trends were evident based on the type of analysis performed. Significant differences, however, were revealed by spouses for the following items:

1. Did you have ample opportunity to ask questions before the surgery? ($\chi^2=29.2$; $df=18$; $p<.05$)

2. How has your social life changed as a result of the laryngectomy? ($\chi^2=44.0$; $df=27$; $p<.05$)

3. How effective were other family members in helping you adjust to the laryngectomy's consequences? ($\chi^2=52.8$; $df=36$; $p<.05$)

4. How effective was the speech-language pathologist in helping you adjust to the laryngectomy's consequences? ($\chi^2=54.9$; $df=36$; $p<.05$)

5. How effective were "other" individuals in helping you adjust to the laryngectomy's consequences? ($\chi^2=29.4$; $df=18$; $p<.05$)

6. If you communicate less with your spouse than before the surgery, what factors do you attribute to the decrease? ($\chi^2=72.4$; $df=45$; $p<.01$)

7. Who was most instrumental in making you aware of the alternate modes of communication? ($\chi^2=61.8$; $df=45$; $p<.05$)

8. To what degree did the physician provide helpful information about the surgery and its consequences? ($\chi^2=52.9$; $df=36$; $p<.05$)

9. Was meeting a laryngectomee's spouse before the surgery a positive experience? ($\chi^2=29.2$; $df=18$; $p<.05$)

10. Does your spouse's mode of communication embarrass you? ($\chi^2=45.9$; $df=27$; $p<.05$)

Date of laryngectomy. Two of the experimental items responded to by laryngectomees were significant for the date of laryngectomy variable. Only laryngectomees' responses were analyzed based on this variable.

Significant differences were revealed for the item regarding postsurgical feelings of fear and anxiety

($\chi^2=30.3$; $df=16$; $p<.05$). Two major trends were revealed in the results. First, strong feelings of fear and anxiety lessened with time. The highest percentage of strong feelings corresponded to the group, less than two years postsurgery, and progressively lowered across the four groups to the group, ten years or greater postsurgery (53.9%, 39.4%, 26.1%, and 21.2%, respectively). Second, the group, less than two years postsurgery, reported a much larger percentage of no feelings of fear and anxiety (23.1%). The next highest percentage (9.1%) was manifested by the group, ten years or greater postsurgery. No other clear trends were revealed.

Significant differences were revealed for the item regarding whether the spouse was counseled alone ($\chi^2=35.0$; $df=12$; $p<.0005$). The most obvious differences between the groups resulted from the responses of the individuals with the shortest time postsurgery (i.e., less than two years). This group revealed the largest percentage of responses (80.1% as compared to the next highest percentage, 63.6%) reporting that the spouse was not counseled alone. No one in this group (0% as compared to the next lowest percentage, 13%) reported that the spouse was counseled alone.

Method of communication. Six of the experimental items responded to by laryngectomees were significant for the method of communication variable. Only

laryngectomees' responses were analyzed based on this variable. Explaining the significant differences based on the method of communication variable was difficult because of the large number of response types with few or no responses. Clear trends in the results were not obvious and few responses per response category made generalizing the results a risky proposition. The significant items, however, were as follows:

1. What feelings of relief were you aware of following surgery? ($\chi^2=33.9$; $df=20$; $p<.05$)
2. How effective was your counseling? ($\chi^2=42.7$; $df=20$; $p<.005$)
3. How effective were other family members in helping you adjust to the laryngectomy's consequences? ($\chi^2=32.5$; $df=20$; $p<.05$)
4. Before authorizing surgery, did you understand that you would no longer speak after the operation? ($\chi^2=25.9$; $df=10$; $p<.005$)
5. What typically happens when your spouse does not understand you? ($\chi^2=64.8$; $df=25$; $p<.0001$)
6. Was your spouse ever counseled alone? ($\chi^2=25.4$; $df=15$; $p<.05$)

Comments made by the respondents

Laryngectomees. Thirty-five laryngectomees wrote additional comments on the survey form (item #26). Feelings listed by laryngectomees were: satisfaction, inconvenience, betrayal, and dread. One laryngectomee stated that he would have preferred death. He felt that he would be shunned by the public for the rest of his life.

The majority who wrote comments stated that counseling needs to be improved a great degree. Six of the respondents stated that a fellow laryngectomee should

provide the counseling and information about the surgery and its disadvantages. Thirteen of the laryngectomees stated that they would have felt a lot more relief had they been visited preoperatively by a talking laryngectomee. Three of the respondents stated that they had to get information on their own. One laryngectomee stated that she was researching supra-laryngectomy only to find out after the surgery that she no longer had a larynx. Another female laryngectomee was told the night before the surgery that she would lose her larynx. She stated that she did not know what questions to ask and that she was interrupted by hospital personnel (e.g., the anesthesiologist and blood lab personnel), therefore, did not have the time to ask questions.

Five laryngectomees stated that the spouse and family need to be counseled more than the patient because their attitudes can "make or break" the patient. A female laryngectomee stated that her husband helped her the most and kept her from losing her sanity. Another laryngectomee stated that her six boys were the biggest asset to her rehabilitation.

Laryngectomees gave advice to rehabilitation team members. One laryngectomee stated that the physicians and their staff should use layman's terms in explaining the operation and in counseling. A male laryngectomee advised speech-language pathologists to have patience and

understanding and let the patient take his time: do not pressure for fast results.

Ten laryngectomees reported that their attitudes had improved since the surgery and that they were better people as a result of the laryngectomy. One laryngectomee stated that stoma care was a cross to carry, but the surgery has forced him to change his priorities and get a better outlook on life.

Four laryngectomees stated that they had returned to work, but quit within two days to a month, because of unanticipated difficulties (e.g., embarrassment of speaking with the electrolarynx in public, dust in the workplace, and a noisy environment). A female laryngectomee said that speaking in public caused her to become extremely depressed.

Five laryngectomees expressed their delight with the New Voice Club. They stated that being able to talk with fellow laryngectomees was important to their sense of well-being. One of the laryngectomees added that he did not know of any such support group until 10 years after the surgery.

Spouses. Ten spouses made additional comments. Spouses stated that patience and understanding were essential in dealing with the pending surgery. A female spouse stated that she still is depressed (two and one-half years postsurgery) because she feels the cancer will

recur. She said that close friends have snubbed the couple because they are afraid of "catching the cancer".

Spouses also reported that counseling was poor. A female spouse stated that when she sought counseling at the hospital she was told that there was none for spouses. She stated that her husband only received group therapy. They finally received counseling services from a psychiatrist after six months of searching for appropriate help. She added that the first six months had been "hell". A male spouse stated that he was introduced to a laryngectomee who could not speak, therefore, he believed that his mate was doomed to a life of silence.

Five spouses stated that the laryngectomy caused the family to examine itself, thus, become stronger. Two spouses stated that their mates have become more extroverted since the surgery.

Summary. The results revealed that some of the counseling needs of laryngectomees and their spouses were not being met adequately by health-care professionals. Significant differences were found between male and female laryngectomees, male and female spouses, and laryngectomees and their spouses for some of the survey items. Further, differences were found for each of the three categories of survey items: feelings, informational needs, and lifestyle changes. In addition, other

variables, such as age and whether the individual was employed, played a role in the subjects' perceptions of their counseling needs.

DISCUSSION

The results obtained from the survey items revealed important differences between male and female laryngectomees, male and female spouses of laryngectomees, and laryngectomees and their spouses. These results were obtained from laryngectomees and their spouses who were involved with New Voice Clubs across the country. The fact that the subjects were active in support groups indicated their motivation to adjust to the surgery and its consequences. Yet, even though the subjects were motivated and involved in a support group, the results showed that the counseling process generally was inadequate to meet each individual's specific needs. The experiences of these motivated subjects could be assumed to be more positive than the laryngectomees and spouses who failed to seek out a support group. The results of this investigation, therefore, might show the laryngectomy counseling process in a more positive light than if a random sample of all laryngectomees and their spouses could have been obtained.

The speech-language pathologist and other rehabilitation team members must be aware of the differences in counseling needs to be effective and educated to respond to the unique needs of each individual. By understanding the group differences revealed in this and similar investigations, the speech-

language pathologist should be able to anticipate the needs of individuals and modify the counseling process on a continual basis, tailoring it to each specific individual.

The primary differences in the results of this investigation can be evaluated by examining the three categories of information obtained: feelings, informational needs, and lifestyle changes.

Differences based on subjects' feelings

The results revealed that the strong feelings about the laryngectomy differed between the sexes and between the laryngectomee and the spouse. For example, female laryngectomees tended to report more fear and anxiety than males postsurgery. Successful rehabilitation would depend upon reducing these strong emotions and building an adequate support system.

Female laryngectomees also reported more feelings of embarrassment by their mode of communication than males. Laryngectomized females experienced a greater change in voice quality than males. The low pitch of an electrolarynx or esophageal speech has been described as unfeminine. Adequate pre- and post-surgical counseling, especially by the speech-language pathologist, might ease some of these negative feelings toward the new voice.

For spouses, females tended to be less relieved than

males postsurgery. Traditionally, the male is the provider of the family and female spouses may be more concerned about the loss of the provider than male spouses. Male spouses may be less affected in this way, therefore, they feel more relieved after the threat of death has been lifted.

Age differences also were important to the the strong feelings experienced by spouses. These results supported those of Komers et al. (1977). Younger spouses tended to be more depressed than older spouses. Again, the counselor must take this factor into consideration. Support groups, such as New Voice Clubs, might play a crucial role in counseling younger spouses and helping them meet the future with determination rather than fear.

Many professionals (e.g., Keith et al., 1978; Komers et al., 1977; Salmon, 1979) have indicated the value of pre- and/or post-surgical visits by another laryngectomee to the patient and a laryngectomee's spouse to the patient's spouse. The results showed that a majority of laryngectomees and spouses did not meet with a laryngectomee or a laryngectomee's spouse, respectively. Hospital visitations by laryngectomees or their spouses should be encouraged and health-care professionals should make appropriate arrangements for such visitations to occur. To emphasize this point, the American Cancer Society (1985) recently published a manual instructing

laryngectomees on hospital visitations. It was not clear why such visitations were not being made in light of the generally-held belief by health-care professionals, the laryngectomees, and the laryngectomees' families that such visits are beneficial.

Differences based on subjects' informational needs

Sex differences and differences between laryngectomees and spouses also were revealed for items regarding informational needs. For example, sex differences were revealed for the various individuals who helped the laryngectomee adjust to the surgery's consequences. Female laryngectomees found help from family members (other than the spouse) and friends definitely effective. Females might go outside of the home for support more often than males, because they might not find the support that they need at home with the male spouse. As Vanfossen (1981) found, husbands were less supportive than wives. Male laryngectomees, on the other hand, might not need the support of family and friends because of the strong support provided by the female spouse. Counselors should be aware of the emotional needs of female laryngectomees and guide them to appropriate support sources, if spouse support is inadequate.

Sex differences were revealed by laryngectomees for the individuals they considered to be the most helpful

sources of information postsurgery. Physicians were regarded as less helpful sources by female laryngectomees than males. Physicians must be aware of and provide for the unique needs of female laryngectomees. Many female laryngectomees were not provided professional counseling at all.

The unique needs of female laryngectomees apparently have been overlooked or neglected by health-care professionals. As the ratio of male to female laryngectomees diminishes, counselors must be prepared to meet the unique needs of each and every individual. Of those who were counseled, most reported being helped a lot. Obviously, counseling (including counseling of the spouse) must be part of the total rehabilitation of the laryngectomee.

For spouses, females tended to be counseled by a mixed group of individuals. Male spouses tended to be counseled by the physician. Wives of laryngectomees might have believed that the physicians did not provide them with sufficient information. Wives may need more counseling because of the strong negative emotions of fear and anxiety and slight feelings of relief and acceptance postsurgery. Based on the different emotional responses reported by male spouses, they might have felt that the physician counseled them adequately. They exhibited strong emotions of relief and acceptance postsurgery and

might not have needed extra attention. These strong positive emotions might have resulted in a lesser need for counseling. Another possible explanation was that physicians provided male spouses with more attention and counseling than females based on the traditional societal values of the male as "head of the household".

Other important trends were revealed for items surveying subjects' informational needs. Laryngectomees and spouses reported not being informed about the alternate modes of communication before surgery. Yet, loss of speech was one of the main concerns of laryngectomees before surgery, and of laryngectomees and spouses after surgery. The speech-language pathologist was the individual best qualified to discuss communication needs. More adequate preoperative counseling about alternate communication modes was warranted by these results.

Researchers (Keith et al., 1978; Kommers et al., 1977) also have indicated that spouses should be counseled alone. Unfortunately, in practice, spouses rarely were counseled alone. In addition, fewer spouses reported ample opportunities to ask questions before the surgery than laryngectomees. As one of the major participants in the laryngectomee's rehabilitation, this oversight of the spouses' needs has the potential of hampering the entire rehabilitation process.

Finally, 40% of the laryngectomees and 51.2% of the spouses reported receiving no counseling. These results revealed a major failure of the health-care system.

Differences based on the subjects' lifestyle changes

More spouses than laryngectomees reported a change postsurgery in the amount of communication with their respective spouses, whether that change was a decrease or an increase. Perhaps these results might be explained by the fact that the laryngectomees' major concern postsurgically was communication. The laryngectomees' efforts to communicate might have influenced their perceptions that there were no changes in communication. As the receiver of the communication, the spouse might be in a better position to evaluate changes in the amount of communication. Support services should be recommended to those individuals that report a decrease in communication. A reduction in communication with the spouse has the potential of influencing many aspects of the laryngectomee's daily life.

Age was a factor for the spouses regarding the effect of the laryngectomy on the marriage. Older spouses tended to report no effects on the marriage. Younger spouses reported either a positive or negative influence. Counselors must prepare spouses, particularly the younger ones, for potential changes that will affect the marriage.

These changes might include employment opportunities (i.e., a change in the major provider), strong negative emotions, and changes in sex life and personal hygiene habits.

Differences in responses based on other variables

It was difficult to evaluate and draw conclusions from the other variables investigated. Even though some significant results were computed for each variable, no specific generalizations about the counseling process were apparent. Further, the interactions between variables were not investigated. Certainly, some significant results might have been revealed because of variable interaction. The type of analysis also influenced the results because of the categorical nature of the data. Based on an inspection of the raw data, it was doubtful that educational level, type of employment, and laryngectomees' method of communication played a significant role in the responses of the subjects. A few interesting observations, however, were made from the remaining variables.

The data from the spouses revealed that only northeasterners were resistful of the sacrifice resulting from the surgery. Many northeastern spouses reported that the physician and their friends were not effective in helping them adjust to the surgery and its consequences.

Finally, only northeastern spouses cited embarrassment as a contributing factor to an overall decrease on communication with the laryngectomee.

A large percentage of individuals from the north central states, on the other hand, were happy to make the sacrifice that resulted from the surgery. North central spouses also found the physician, family, and friends definitely effective in helping them adjust to the laryngectomy and its consequences.

These responses corresponded in a general way to the public's perceptions of each part of the country. Northeasterners, for example, often are perceived as more independent and less friendly people. Individuals from the north central states often are perceived as more open and friendly.

The differences between employed and unemployed subjects also were interesting. If adjustment problems occurred, there was a trend for those problems to occur for the unemployed laryngectomees. Employed laryngectomees seemed to have fewer adjustment problems. More employed spouses, than unemployed, reported changes in the marriage following laryngectomy. If the spouse had to work or work more as a result of the laryngectomy, additional pressures on the marriage might surface. On the positive side, working often brings a sense of self-worth to individuals which may enhance a marriage.

Finally, some interesting observations were made based on the date of laryngectomy variable. The results revealed that the strong emotional feelings of laryngectomees subsided over time. These results were confirmed by some subjects' comments. It also was interesting that the largest percentage of responses that the spouse was not counseled alone came from recent laryngectomees (less than two years postsurgery). Counseling the spouse alone has been recommended by professionals for many years. The results showed, however, that spouses still were not being counseled and, more importantly, the problem apparently was not decreasing.

Specific suggestions for the counselor of laryngectomees and their spouses

The counseling process of laryngectomees and their spouses must be ameliorated to meet the specific needs of those involved. The following specific suggestions for counseling laryngectomees and their spouses should enhance the counselors' effectiveness.

1. Pre- and post-surgical counseling should be provided to all laryngectomees and their spouses. Spouses should be counseled separately and jointly with the laryngectomee.

2. Health-care professionals involved with laryngectomy rehabilitation, particularly physicians, should provide adequate information and appropriate time for laryngectomees and their spouses to ask questions. Special consideration must be given to the unique needs of the female laryngectomee.

3. Speech-language pathologists must inform

laryngectomees and their spouses about alternate modes of communication presurgically. Special attention should be given to the female laryngectomee postsurgically as they tended to feel embarrassment by their new mode of communication.

4. Participants in laryngectomy rehabilitation need strong support systems. The individuals comprising the support systems might differ for males and females. Further, the support systems for laryngectomees might be different than those for spouses.

5. Younger spouses of laryngectomees need special consideration by counselors. They tended to be more depressed and experienced more changes in their marital relationships than older spouses.

6. Pre- and post-surgical hospital visitations by another laryngectomee and the laryngectomee's spouse should be encouraged. Not all laryngectomees nor their spouses, however, have found hospital visitations by a laryngectomee or a laryngectomee's spouse to be beneficial. Special consideration must be given by the counselor to each patient and to each hospital visitor. In this way, the chances of a positive and beneficial experience for the patient and spouse is enhanced.

Summary

In summary, differences in counseling needs were revealed between male and female laryngectomees, male and female spouses of laryngectomees, and laryngectomees and their spouses. These differences must be understood and dealt with by all members of the rehabilitation team to rehabilitate effectively the laryngectomy patient.

The results made it apparent that the counseling needs of laryngectomees and their spouses were not met adequately by qualified professionals. This study provided evidence of the neglect of both the laryngectomee and spouse by the rehabilitation team. Further, this study has identified unique counseling needs of male and

female laryngectomees and male and female spouses of laryngectomees and suggested ways to improve the counseling process.

Health-care professionals must make a concerted effort to meet the unique needs of each patient or spouse. The goal is to rehabilitate successfully the laryngectomy patient. The spouse has been shown to enhance or retard the laryngectomee's rehabilitation, therefore, counseling of the spouses to optimize their contribution to rehabilitation is vital.

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APPENDIX A

WRITTEN INFORMATION FOR SURVEY COMPLETION

SEX DIFFERENCES RELATED TO ATTITUDES, NEEDS, AND FEARS OF
LARYNGECTOMEES AND THEIR SPOUSES

This study is undertaken to identify the distinct needs, fears, and attitudes between male and female laryngectomees and their spouses. The study will focus on differences between male and female laryngectomees and between male and female spouses of laryngectomees in order that all individual needs may be met during the rehabilitation process.

Caroline Salva, primary investigator, can be reached at:

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Jackson Heights, N.Y. 11370
(718) 672-2081

Dr. Ken Kallail, project supervisor, can be reached at:

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Speech and Hearing Center
Leasure Hall 107
Manhattan, Ks. 66502
(913) 532-6879

Both are willing to answer any questions or supply additional information.

All identifying information will be kept confidential; anonymity of all participants is assured.

You are under no obligation to participate. Should you consent to participate by filling out the survey, you may choose to withdraw your participation at any time.

APPENDIX B
SURVEY FORMS A AND B FOR LARYNGECTOMES

Please complete the following background information.

PLACE OF RESIDENCE (City and State): _____
 DATE OF BIRTH: _____
 DATE OF LARYNGECTOMY: _____
 SEX: _____ MALE _____ FEMALE
 EDUCATION: _____ SOME HIGH SCHOOL _____ HIGH SCHOOL GRADUATE
 _____ SOME COLLEGE _____ COLLEGE GRADUATE
 _____ OTHER (specify) _____
 ARE YOU EMPLOYED? _____ YES _____ NO
 ARE YOU RETIRED? _____ YES _____ NO
 WHAT IS/WAS YOUR OCCUPATION? _____
 HOW DO YOU COMMUNICATE? (CHECK ALL that apply)
 _____ WRITING _____ MOUTHRING WORDS _____ ELECTROLARYNX
 _____ ESOPHAGEAL SPEECH _____ ELON-SINGER DEVICE
 _____ OTHER (specify) _____

Please answer the following items to the best of your knowledge by CHECKING the most appropriate answer.

- 1) What feelings were you aware of following surgery?
 a) FEAR/ANXIETY _____ STRONG _____ MODERATE _____ MILD _____ NONE
 b) DEPRESSION _____ STRONG _____ MODERATE _____ MILD _____ NONE
 c) RELIEF _____ STRONG _____ MODERATE _____ MILD _____ NONE
 d) ANGER _____ STRONG _____ MODERATE _____ MILD _____ NONE
 e) ACCEPTANCE _____ STRONG _____ MODERATE _____ MILD _____ NONE
 f) Other STRONG feelings (specify) _____
- 2) How has your spouse's health been effected by your laryngectomy?
 _____ BETTER _____ WORSE _____ NO CHANGE
- 3) How has your spouse reacted to the cost of the laryngectomy?
 _____ SEEMS HAPPY TO SACRIFICE FOR ME
 _____ SEEMS SOMEWHAT RESISTFUL OF THE SACRIFICE
 _____ NO NOTICEABLE REACTION
- 4) Did you have ample opportunity to ask questions before the surgery?
 _____ YES _____ NO
- 5) How effective was your counseling?
 _____ HELPED ME A LOT _____ MADE LITTLE OR NO DIFFERENCE
 _____ MADE ME FEEL WORSE _____ RECEIVED NO COUNSELING
- 6) How has your social life changed as a result of the laryngectomy?
 _____ GO OUT/ENTERTAIN MORE _____ GO OUT/ENTERTAIN LESS
 _____ NO SIGNIFICANT CHANGE
- 7) How effective was EACH of the following individuals in helping you adjust to the laryngectomy's consequences?
 PHYSICIAN _____ NOT EFFECTIVE _____ SLIGHTLY _____ MODERATELY _____ DEFINITELY
 SPOUSE _____ NOT EFFECTIVE _____ SLIGHTLY _____ MODERATELY _____ DEFINITELY
 OTHER FAMILY _____ NOT EFFECTIVE _____ SLIGHTLY _____ MODERATELY _____ DEFINITELY
 FRIENDS _____ NOT EFFECTIVE _____ SLIGHTLY _____ MODERATELY _____ DEFINITELY
 LARYNGECTOMEE _____ NOT EFFECTIVE _____ SLIGHTLY _____ MODERATELY _____ DEFINITELY
 SPEECH-LANGUAGE PATHOLOGIST _____ NOT EFFECTIVE _____ SLIGHTLY _____ MODERATELY _____ DEFINITELY
 OTHER (specify) _____ NOT EFFECTIVE _____ SLIGHTLY _____ MODERATELY _____ DEFINITELY
- 8a) How has the surgery affected the amount of communication with your spouse?
 _____ COMMUNICATE MORE _____ COMMUNICATE LESS _____ COMMUNICATE THE SAME
- b) If you now communicate less with your spouse than before the surgery what factors do you attribute to the decrease?
 _____ SPEAKING IS DIFFICULT _____ SPOUSE CAN'T UNDERSTAND ME
 _____ EMBARRASSED _____ OTHER (specify) _____
- 9) Before authorizing surgery, did you understand that you would no longer speak after the operation?
 _____ YES _____ NO
- 10) When were you least optimistic about the laryngectomy and its consequences?
 _____ BEFORE SURGERY _____ AFTER SURGERY
 _____ ALWAYS OPTIMISTIC _____ NEVER OPTIMISTIC
- 11a) Check EACH type of alternate communication to which you were exposed before surgery.
 _____ ELECTROLARYNX _____ ESOPHAGEAL SPEECH
 _____ ELON-SINGER DEVICE _____ OTHER (specify) _____
 _____ NONE

- b) Who was most instrumental in making you aware of the alternate modes of communication?
 _____ PHYSICIAN _____ NURSE _____ SPEECH-LANGUAGE PATHOLOGIST
 _____ SOCIAL WORKER _____ OTHER (specify) _____
- 12) What has been the effect of the laryngectomy on your marital relationship?
 _____ POSITIVE _____ NEGATIVE _____ NO SIGNIFICANT EFFECT
- 13) What typically happens when your spouse does not understand you?
 _____ I BECOME FRUSTRATED AND CEASE TALKING
 _____ I REPEAT UNTIL HE/SHE UNDERSTANDS
 _____ I COMMUNICATE IN WRITING
 _____ OTHER (specify) _____
- 14) What evoked the most anxiety for you? (Check ONE for BEFORE and ONE for AFTER SURGERY)
- | | |
|-----------------------------|-----------------------------|
| a) BEFORE SURGERY | b) AFTER SURGERY |
| _____ SURVIVAL | _____ SURVIVAL |
| _____ FEAR OF FUTURE | _____ FEAR OF FUTURE |
| _____ LOSS OF SPEECH | _____ LOSS OF SPEECH |
| _____ OTHER (specify) _____ | _____ OTHER (specify) _____ |
- 15) Was your spouse ever counseled alone?
 _____ YES _____ NO
- 16a) Who cares for your stoma?
 _____ I DO _____ SPOUSE _____ SOMEONE ELSE
- b) Do you consider caring for your stoma to be laborious?
 _____ NO _____ SLIGHTLY _____ MODERATELY _____ DEFINITELY
- 17) To what degree did each of the following individuals provide helpful information about the surgery and its consequences?
- | | | | | |
|-----------------------------|----------------|----------------|--------------|------------|
| PHYSICIAN | _____ DEFINITE | _____ MODERATE | _____ SLIGHT | _____ NONE |
| NURSE | _____ DEFINITE | _____ MODERATE | _____ SLIGHT | _____ NONE |
| SPEECH-LANGUAGE PATHOLOGIST | _____ DEFINITE | _____ MODERATE | _____ SLIGHT | _____ NONE |
| SOCIAL WORKER | _____ DEFINITE | _____ MODERATE | _____ SLIGHT | _____ NONE |
| A LARYNGECTOMEE | _____ DEFINITE | _____ MODERATE | _____ SLIGHT | _____ NONE |
- 18) Was meeting a laryngectomee before the surgery a positive experience?
 _____ YES _____ NO _____ DID NOT MEET A LARYNGECTOMEE
- 19) Which of the following individuals counseled you about the surgery and its effects? (CHECK ALL THAT APPLY)
- _____ SOCIAL WORKER _____ NURSE _____ SPEECH-LANGUAGE PATHOLOGIST
 _____ PHYSICIAN _____ OTHER (specify) _____
- 20) Does your mode of communication embarrass you?
 _____ NO _____ SLIGHTLY _____ MODERATELY _____ DEFINITELY
- 21) Has the laryngectomy reduced communication between you and your spouse?
 _____ YES _____ NO _____ DON'T KNOW
- 22) How disabled do you consider yourself to be as a result of your laryngectomy?
 _____ SEVERELY _____ MODERATELY _____ SLIGHTLY _____ NOT DISABLED
- 23) What was your first reaction to the sight of your stoma?
 _____ ANXIETY _____ CURIOSITY _____ FOUND IT DISTASTEFUL
 _____ NO REACTION _____ OTHER (specify) _____
- 24) How much of a handicap do you consider your laryngectomy to be?
 _____ SEVERE _____ MODERATE _____ MILD _____ NOT A HANDICAP
- 25a) Who counseled you about the surgery and its consequences? (CHECK as many as apply)
- _____ PHYSICIAN _____ NURSE _____ SPEECH-LANGUAGE PATHOLOGIST
 _____ SOCIAL WORKER _____ OTHER (specify) _____
- b) If your spouse was present during the counseling session, PLACE A SECOND CHECK by the professionals listed in #25a.
- 26) Please add any comments that you feel are important. If necessary, use the back of this page.

QUESTIONNAIRE

Form B

Please complete the following background information.

PLACE OF RESIDENCE (City and State): _____
 DATE OF BIRTH: _____
 DATE OF LARYNGECTOMY: _____
 SEX: MALE _____ FEMALE _____
 EDUCATION: _____ SOME HIGH SCHOOL _____ HIGH SCHOOL GRADUATE
 _____ SOME COLLEGE _____ COLLEGE GRADUATE
 _____ OTHER (specify) _____
 ARE YOU EMPLOYED? YES _____ NO _____
 ARE YOU RETIRED? YES _____ NO _____
 WHAT IS/WAS YOUR OCCUPATION? _____
 HOW DO YOU COMMUNICATE? (CHECK ALL that apply)
 WRITING _____ HOUSING WORDS _____ ELECTROLARYNX
 ESOPHAGEAL SPEECH _____ SLOW-SINGER DEVICE _____
 OTHER (specify) _____

Please answer the following items to the best of your knowledge by CHECKING the most appropriate answer.

- 1) How has your social life changed as a result of the laryngectomy?
 _____ GO OUT/ENTERTAIN MORE _____ GO OUT/ENTERTAIN LESS
 _____ NO SIGNIFICANT CHANGE
- 2) Has the laryngectomy reduced communication between you and your spouse?
 _____ YES _____ NO _____ DON'T KNOW
- 3) How has your spouse reacted to the cost of the laryngectomy?
 _____ SEEMS HAPPY TO SACRIFICE FOR ME
 _____ SEEMS SOMEWHAT RESISTFUL OF THE SACRIFICE
 _____ NO NOTICEABLE REACTION
- 4) How effective was your counseling?
 _____ HELPED ME A LOT _____ MADE LITTLE OR NO DIFFERENCE
 _____ MADE ME FEEL WORSE _____ RECEIVED NO COUNSELING
- 5) What was your first reaction to the sight of your stoma?
 _____ ANXIETY _____ CURIOSITY _____ FOUND IT DISTASTEFUL
 _____ NO REACTION _____ OTHER (specify) _____
- 6) How much of a handicap do you consider your laryngectomy to be?
 _____ SEVERE _____ MODERATE _____ MILD _____ NOT A HANDICAP
- 7) When were you least optimistic about the laryngectomy and its consequences?
 _____ BEFORE SURGERY _____ AFTER SURGERY
 _____ ALWAYS OPTIMISTIC _____ NEVER OPTIMISTIC
- 8) What feelings were you aware of following surgery?
 a) FEAR/ANXIETY _____ STRONG _____ MODERATE _____ MILD _____ NONE
 b) DEPRESSION _____ STRONG _____ MODERATE _____ MILD _____ NONE
 c) RELIEF _____ STRONG _____ MODERATE _____ MILD _____ NONE
 d) ANGER _____ STRONG _____ MODERATE _____ MILD _____ NONE
 e) ACCEPTANCE _____ STRONG _____ MODERATE _____ MILD _____ NONE
 f) Other STRONG feelings (specify) _____
- 9a) Who counseled you about the surgery and its consequences? (CHECK as many as apply)
 _____ PHYSICIAN _____ NURSE _____ SPEECH-LANGUAGE PATHOLOGIST
 _____ SOCIAL WORKER _____ OTHER (specify) _____
- b) If your spouse was present during the counseling session, PLACE A SECOND CHECK by the professionals listed in 9a.
- 10a) Who cares for your stoma?
 _____ I DO _____ SPOUSE _____ SOMEONE ELSE
- b) Do you consider caring for your stoma to be laborious?
 _____ NO _____ SLIGHTLY _____ MODERATELY _____ DEFINITELY
- 11) What has been the effect of the laryngectomy on your marital relationship?
 _____ POSITIVE _____ NEGATIVE _____ NO SIGNIFICANT EFFECT
- 12a) Check EACH type of alternate communication to which you were exposed before surgery.
 _____ ELECTROLARYNX _____ ESOPHAGEAL SPEECH _____ NONE
 _____ SLOW-SINGER DEVICE _____ OTHER (specify) _____
- b) Who was most instrumental in making you aware of the alternate modes of communication?
 _____ PHYSICIAN _____ NURSE _____ SPEECH-LANGUAGE PATHOLOGIST
 _____ SOCIAL WORKER _____
 _____ OTHER (specify) _____

- 13) Does your mode of communication embarrass you?
 NO SLIGHTLY MODERATELY DEFINITELY
- 14) To what degree did each of the following individuals provide helpful information about the surgery and its consequences?
 PHYSICIAN DEFINITE MODERATE SLIGHT NONE
 NURSE DEFINITE MODERATE SLIGHT NONE
 SPEECH-LANGUAGE DEFINITE MODERATE SLIGHT NONE
 PATHOLOGIST DEFINITE MODERATE SLIGHT NONE
 SOCIAL WORKER DEFINITE MODERATE SLIGHT NONE
 LARYNGECTOMEE DEFINITE MODERATE SLIGHT NONE
- 15) Before authorizing surgery, did you understand that you would no longer speak after the operation?
 YES NO
- 16) Was your spouse ever counseled alone?
 YES NO
- 17) Did you have ample opportunity to ask questions before the surgery?
 YES NO
- 18) How effective was EACH of the following individuals in helping you adjust to the laryngectomy's consequences?
 PHYSICIAN NOT EFFECTIVE SLIGHTLY MODERATELY DEFINITELY
 SPOUSE NOT EFFECTIVE SLIGHTLY MODERATELY DEFINITELY
 OTHER FAMILY NOT EFFECTIVE SLIGHTLY MODERATELY DEFINITELY
 FRIENDS NOT EFFECTIVE SLIGHTLY MODERATELY DEFINITELY
 LARYNGECTOMEE NOT EFFECTIVE SLIGHTLY MODERATELY DEFINITELY
 SPEECH-LANGUAGE NOT EFFECTIVE SLIGHTLY MODERATELY DEFINITELY
 PATHOLOGIST NOT EFFECTIVE SLIGHTLY MODERATELY DEFINITELY
 OTHER (specify) NOT EFFECTIVE SLIGHTLY MODERATELY DEFINITELY
- 19a) How has the surgery effected the amount of communication with your spouse?
 COMMUNICATE MORE COMMUNICATE LESS COMMUNICATE THE SAME
- b) If you now communicate less with your spouse than before the surgery what factors do you attribute to the decrease?
 SPEAKING IS DIFFICULT SPOUSE CAN'T UNDERSTAND ME
 EMBARRASSED OTHER (specify) _____
- 20) How disabled do you consider yourself to be as a result of your laryngectomy?
 SEVERELY MODERATELY SLIGHTLY NOT DISABLED
- 21) What evoked the most anxiety for you? (Check ONE for BEFORE and ONE for AFTER SURGERY)
- | | |
|--|--|
| a) BEFORE SURGERY | b) AFTER SURGERY |
| <input type="checkbox"/> SURVIVAL | <input type="checkbox"/> SURVIVAL |
| <input type="checkbox"/> FEAR OF FUTURE | <input type="checkbox"/> FEAR OF FUTURE |
| <input type="checkbox"/> LOSS OF SPEECH | <input type="checkbox"/> LOSS OF SPEECH |
| <input type="checkbox"/> OTHER (specify) _____ | <input type="checkbox"/> OTHER (specify) _____ |
- 22) What typically happens when your spouse does not understand you?
 I BECOME FRUSTRATED AND CEASE TALKING
 I REPEAT UNTIL HE/SHE UNDERSTANDS
 I COMMUNICATE IN WRITING
 OTHER (specify) _____
- 23) How has your spouse's health been affected by your laryngectomy?
 BETTER WORSE NO CHANGE
- 24) Was meeting a laryngectomee before the surgery a positive experience?
 YES NO DID NOT MEET A LARYNGECTOMEE
- 25) Which of the following individuals counseled you about the surgery and its effects? (CHECK ALL that apply)
 SOCIAL WORKER NURSE SPEECH-LANGUAGE PATHOLOGIST
 PHYSICIAN OTHER (specify) _____
- 26) Please add any comments that you feel are important. If necessary, use the back of this page.

APPENDIX C
SURVEY FORMS C AND D FOR SPOUSES

QUESTIONNAIRE

Form C

Please complete the following background information.

PLACE OF RESIDENCE (City and State): _____
 DATE OF BIRTH: _____
 SEX: MALE FEMALE
 EDUCATION: SOME HIGH SCHOOL HIGH SCHOOL GRADUATE
 SOME COLLEGE COLLEGE GRADUATE
 OTHER (specify) _____
 ARE YOU EMPLOYED? YES NO
 WHAT IS/WAS YOUR OCCUPATION? _____

Please answer the following items to the best of your knowledge by CHECKING the most appropriate answer.

- 1a) Who counseled you about the surgery and its consequences? (CHECK as many as apply)
 PHYSICIAN NURSE SPEECH-LANGUAGE PATHOLOGIST
 SOCIAL WORKER OTHER (specify) _____
- b) If your spouse was present with you during the counseling sessions, PLACE A SECOND CHECK BY THE PROFESSIONALS LISTED IN QUESTION 1a.
- 2) Does your spouse's mode of communication embarrass you?
 NO SLIGHTLY MODERATELY DEFINITELY
- 3) How has your health been affected as a result of your spouse's laryngectomy?
 BETTER WORSE NO CHANGE
- 4) How effective was EACH of the following individuals in helping you adjust to the laryngectomy's consequences?
- | | | | | |
|-----------------------------|--|-----------------------------------|-------------------------------------|-------------------------------------|
| PHYSICIAN | <input type="checkbox"/> NOT EFFECTIVE | <input type="checkbox"/> SLIGHTLY | <input type="checkbox"/> MODERATELY | <input type="checkbox"/> DEFINITELY |
| SPOUSE | <input type="checkbox"/> NOT EFFECTIVE | <input type="checkbox"/> SLIGHTLY | <input type="checkbox"/> MODERATELY | <input type="checkbox"/> DEFINITELY |
| OTHER FAMILY | <input type="checkbox"/> NOT EFFECTIVE | <input type="checkbox"/> SLIGHTLY | <input type="checkbox"/> MODERATELY | <input type="checkbox"/> DEFINITELY |
| FRIENDS | <input type="checkbox"/> NOT EFFECTIVE | <input type="checkbox"/> SLIGHTLY | <input type="checkbox"/> MODERATELY | <input type="checkbox"/> DEFINITELY |
| LARYNGECTOMY | <input type="checkbox"/> NOT EFFECTIVE | <input type="checkbox"/> SLIGHTLY | <input type="checkbox"/> MODERATELY | <input type="checkbox"/> DEFINITELY |
| SPEECH-LANGUAGE PATHOLOGIST | <input type="checkbox"/> NOT EFFECTIVE | <input type="checkbox"/> SLIGHTLY | <input type="checkbox"/> MODERATELY | <input type="checkbox"/> DEFINITELY |
| OTHER (specify) | <input type="checkbox"/> NOT EFFECTIVE | <input type="checkbox"/> SLIGHTLY | <input type="checkbox"/> MODERATELY | <input type="checkbox"/> DEFINITELY |
- 5) Which of the following individuals counseled you about the surgery and its effects? (CHECK ALL that apply)
 SOCIAL WORKER NURSE SPEECH-LANGUAGE PATHOLOGIST
 PHYSICIAN OTHER (specify) _____
- 6) Did you have ample opportunity to ask questions before the surgery?
 YES NO
- 7a) How has the surgery affected the amount of communication with your spouse?
 COMMUNICATE MORE COMMUNICATE LESS COMMUNICATE THE SAME
- b) If you now communicate less with your spouse than before the surgery, what factors do you attribute to the decrease?
 SPOUSE APPEARS TO BE STRUGGLING TO SPEAK
 I CAN'T UNDERSTAND MY SPOUSE
 MY SPOUSE IS EMBARRASSED TO SPEAK
 OTHER (specify) _____
- 8) If you have had to work extra as a result of the cost of the laryngectomy, how do you feel about it?
 HAPPY TO MAKE THE SACRIFICE
 RESISTFUL OF THE SACRIFICE
 NO SIGNIFICANT REACTION
 DO NOT HAVE TO WORK EXTRA
- 9) To what degree did each of the following individuals provide helpful information about the surgery and its consequences?
- | | | | | |
|-----------------------------|-----------------------------------|-----------------------------------|---------------------------------|-------------------------------|
| PHYSICIAN | <input type="checkbox"/> DEFINITE | <input type="checkbox"/> MODERATE | <input type="checkbox"/> SLIGHT | <input type="checkbox"/> NONE |
| NURSE | <input type="checkbox"/> DEFINITE | <input type="checkbox"/> MODERATE | <input type="checkbox"/> SLIGHT | <input type="checkbox"/> NONE |
| SPEECH-LANGUAGE PATHOLOGIST | <input type="checkbox"/> DEFINITE | <input type="checkbox"/> MODERATE | <input type="checkbox"/> SLIGHT | <input type="checkbox"/> NONE |
| SOCIAL WORKER | <input type="checkbox"/> DEFINITE | <input type="checkbox"/> MODERATE | <input type="checkbox"/> SLIGHT | <input type="checkbox"/> NONE |
| A LARYNGECTOMY | <input type="checkbox"/> DEFINITE | <input type="checkbox"/> MODERATE | <input type="checkbox"/> SLIGHT | <input type="checkbox"/> NONE |
- 10a) Check EACH type of alternate communication to which you were exposed before surgery.
- | | |
|---|--|
| <input type="checkbox"/> ELECTROLARYNX | <input type="checkbox"/> NASOPHARYNGEAL SPEECH |
| <input type="checkbox"/> ELDO-SINGER DEVICE | <input type="checkbox"/> OTHER (specify) _____ |
| <input type="checkbox"/> NONE | |

- b) Who was most instrumental in asking you aware of the alternate modes of communication?
 _____ PHYSICIAN _____ NURSE _____ SPEECH-LANGUAGE PATHOLOGIST
 _____ SOCIAL WORKER
 _____ OTHER (specify) _____
- 11) How disabled do you consider your spouse to be as a result of the laryngectomy?
 _____ SEVERELY _____ MODERATELY _____ MILDLY _____ NOT DISABLED
- 12) Has the laryngectomy reduced communication between you and your spouse?
 _____ YES _____ NO _____ DON'T KNOW
- 13) How has your social life changed as a result of the laryngectomy?
 _____ GO OUT/ENTERTAIN MORE _____ GO OUT/ENTERTAIN LESS
 _____ NO SIGNIFICANT CHANGE
- 14) How effective was your counseling?
 _____ HELPED ME A LOT _____ MADE LITTLE OR NO DIFFERENCE
 _____ MADE ME FEEL WORSE _____ RECEIVED NO COUNSELING
- 15) What typically happens when you don't understand your spouse?
 YOUR SPOUSE: _____ BECOMES FRUSTRATED AND CEASES THE ATTEMPT TO SPEAK
 _____ REPEATS UNTIL I UNDERSTAND
 _____ TRIES TO COMMUNICATE BY WRITING
 _____ OTHER (specify) _____
- 16) What feelings were you aware of following surgery?
 a) FEAR/ANXIETY _____ STRONG _____ MODERATE _____ MILD _____ NONE
 b) DEPRESSION _____ STRONG _____ MODERATE _____ MILD _____ NONE
 c) RELIEF _____ STRONG _____ MODERATE _____ MILD _____ NONE
 d) ANGER _____ STRONG _____ MODERATE _____ MILD _____ NONE
 e) ACCEPTANCE _____ STRONG _____ MODERATE _____ MILD _____ NONE
 f) Other STRONG feelings (specify) _____
- 17) Were you ever counseled alone?
 _____ YES _____ NO
- 18) What was your first reaction to the sight of your spouse's stoma?
 _____ ANXIETY _____ CURIOSITY _____ FOUND IT DISTASTEFUL
 _____ NO REACTION _____ OTHER (specify) _____
- 19) Was meeting a laryngectomee's spouse before the surgery a positive experience?
 _____ YES _____ NO _____ DID NOT MEET A LARYNGECTOMEE'S SPOUSE
- 20) What has been the effect of the laryngectomy on your marital relationship?
 _____ POSITIVE _____ NEGATIVE _____ NO SIGNIFICANT EFFECT
- 21) What were you least optimistic about the laryngectomy and its consequences?
 _____ BEFORE SURGERY _____ AFTER SURGERY
 _____ ALWAYS OPTIMISTIC _____ NEVER OPTIMISTIC
- 22) How much of a handicap do you consider your spouse's laryngectomy to be?
 _____ SEVERE _____ MODERATE _____ MILD _____ NOT A HANDICAP
- 23) If you care for your spouse's stoma, do you consider it to be a laborious task?
 _____ NO _____ SLIGHTLY _____ MODERATELY _____ DEFINITELY
 _____ DO NOT CARE FOR SPOUSE'S STOMA
- 24) What evoked the most anxiety for you? (Check ONE for BEFORE and ONE for AFTER SURGERY)
 a) BEFORE SURGERY b) AFTER SURGERY
 _____ SURVIVAL _____ SURVIVAL
 _____ FEAR OF FUTURE _____ FEAR OF FUTURE
 _____ LOSS OF SPEECH _____ LOSS OF SPEECH
 _____ OTHER (specify) _____ OTHER (specify)
- 25) Before your spouse authorized surgery, did you understand that your spouse would no longer speak following the operation?
 _____ YES _____ NO
- 26) Please add any comments that you feel are important. If necessary, use the back of this page.

QUESTIONNAIRE

Form D

Please complete the following background information.

PLACE OF RESIDENCE (City and State): _____

DATE OF BIRTH: _____

SEX: _____ MALE _____ FEMALE

EDUCATION: _____ SOME HIGH SCHOOL _____ HIGH SCHOOL GRADUATE

_____ SOME COLLEGE _____ COLLEGE GRADUATE

_____ OTHER (specify) _____

ARE YOU NOW EMPLOYED? _____ YES _____ NO

WHAT IS/WAS YOUR OCCUPATION? _____

Please answer the following items to the best of your knowledge by CHECKING the most appropriate answer.

- 1) See the laryngectomy reduced communication between you and your spouse?
 YES NO DON'T KNOW
- 2a) Check EACH type of alternate communication to which you were exposed before surgery.
 ELECTROLARYNX ESOPHAGEAL SPEECH
 BLOW-SINGER DEVICE OTHER (specify) _____
 NONE
- b) Who was most instrumental in making you aware of the alternate modes of communication?
 PHYSICIAN NURSE SPEECH-LANGUAGE PATHOLOGIST
 SOCIAL WORKER
 OTHER (specify) _____
- 3) Was meeting a laryngectomy's spouse before the surgery a positive experience?
 YES NO DID NOT MEET A LARYNGECTOMY'S SPOUSE
- 4) How effective was EACH of the following individuals in helping you adjust to the laryngectomy's consequences?

PHYSICIAN	<input type="checkbox"/> NOT EFFECTIVE	<input type="checkbox"/> SLIGHTLY	<input type="checkbox"/> MODERATELY	<input type="checkbox"/> DEFINITELY
SPOUSE	<input type="checkbox"/> NOT EFFECTIVE	<input type="checkbox"/> SLIGHTLY	<input type="checkbox"/> MODERATELY	<input type="checkbox"/> DEFINITELY
OTHER FAMILY	<input type="checkbox"/> NOT EFFECTIVE	<input type="checkbox"/> SLIGHTLY	<input type="checkbox"/> MODERATELY	<input type="checkbox"/> DEFINITELY
FRIENDS	<input type="checkbox"/> NOT EFFECTIVE	<input type="checkbox"/> SLIGHTLY	<input type="checkbox"/> MODERATELY	<input type="checkbox"/> DEFINITELY
LARYNGECTOMEE	<input type="checkbox"/> NOT EFFECTIVE	<input type="checkbox"/> SLIGHTLY	<input type="checkbox"/> MODERATELY	<input type="checkbox"/> DEFINITELY
SPEECH-LANGUAGE PATHOLOGIST	<input type="checkbox"/> NOT EFFECTIVE	<input type="checkbox"/> SLIGHTLY	<input type="checkbox"/> MODERATELY	<input type="checkbox"/> DEFINITELY
OTHER (specify) _____	<input type="checkbox"/> NOT EFFECTIVE	<input type="checkbox"/> SLIGHTLY	<input type="checkbox"/> MODERATELY	<input type="checkbox"/> DEFINITELY
- 5) How has your social life changed as a result of the laryngectomy?
 GO OUT/ENTERTAIN MORE GO OUT/ENTERTAIN LESS
 NO SIGNIFICANT CHANGE
- 6) What feelings were you aware of following surgery?

a) FEAR/ANXIETY	<input type="checkbox"/> STRONG	<input type="checkbox"/> MODERATE	<input type="checkbox"/> MILD	<input type="checkbox"/> NONE
b) DEPRESSION	<input type="checkbox"/> STRONG	<input type="checkbox"/> MODERATE	<input type="checkbox"/> MILD	<input type="checkbox"/> NONE
c) RELIEF	<input type="checkbox"/> STRONG	<input type="checkbox"/> MODERATE	<input type="checkbox"/> MILD	<input type="checkbox"/> NONE
d) ANGER	<input type="checkbox"/> STRONG	<input type="checkbox"/> MODERATE	<input type="checkbox"/> MILD	<input type="checkbox"/> NONE
e) ACCEPTANCE	<input type="checkbox"/> STRONG	<input type="checkbox"/> MODERATE	<input type="checkbox"/> MILD	<input type="checkbox"/> NONE

 f) Other STRONG feelings (specify) _____
- 7) When were you least optimistic about the laryngectomy and its consequences?
 BEFORE SURGERY AFTER SURGERY
 ALWAYS OPTIMISTIC NEVER OPTIMISTIC
- 8) Which of the following individuals counseled you about the surgery and its effects? (CHECK ALL that apply)
 SOCIAL WORKER NURSE SPEECH-LANGUAGE PATHOLOGIST
 PHYSICIAN OTHER (specify) _____
- 9) To what degree did each of the following individuals provide helpful information about the surgery and its consequences?

PHYSICIAN	<input type="checkbox"/> DEFINITE	<input type="checkbox"/> MODERATE	<input type="checkbox"/> SLIGHT	<input type="checkbox"/> NONE
NURSE	<input type="checkbox"/> DEFINITE	<input type="checkbox"/> MODERATE	<input type="checkbox"/> SLIGHT	<input type="checkbox"/> NONE
SPEECH-LANGUAGE PATHOLOGIST	<input type="checkbox"/> DEFINITE	<input type="checkbox"/> MODERATE	<input type="checkbox"/> SLIGHT	<input type="checkbox"/> NONE
SOCIAL WORKER	<input type="checkbox"/> DEFINITE	<input type="checkbox"/> MODERATE	<input type="checkbox"/> SLIGHT	<input type="checkbox"/> NONE
A LARYNGECTOMEE	<input type="checkbox"/> DEFINITE	<input type="checkbox"/> MODERATE	<input type="checkbox"/> SLIGHT	<input type="checkbox"/> NONE
- 10) Before your spouse authorized surgery, did you understand that your spouse would no longer speak following the operation?
 YES NO

- 11) Were you ever counseled alone?
 YES NO
- 12) What evoked the most anxiety for you? (Check ONE for BEFORE and ONE for AFTER SURGERY)
 a) BEFORE SURGERY b) AFTER SURGERY
 SURVIVAL SURVIVAL
 FEAR OF FUTURE FEAR OF FUTURE
 LOSS OF SPEECH LOSS OF SPEECH
 OTHER (specify) _____ OTHER (specify) _____
- 13a) Who counseled you about the surgery and its consequences? (CHECK as many as apply)
 PHYSICIAN NURSE SPEECH-LANGUAGE PATHOLOGIST
 SOCIAL WORKER OTHER (specify) _____
- b) If your spouse was present with you during the counseling sessions, PLACE A SECOND CHECK BY THE PROFESSIONALS LISTED IN QUESTION 13a.
- 14) Did you have ample opportunity to ask questions before the surgery?
 YES NO
- 15) What typically happens when you don't understand your spouse?
 YOUR SPOUSE: BECOMES FRUSTRATED AND CEASES THE ATTEMPT TO SPEAK
 REPEATS UNTIL I UNDERSTAND
 TRIES TO COMMUNICATE BY WRITING
 OTHER (specify) _____
- 16) Does your spouse's mode of communication embarrass you?
 NO SLIGHTLY MODERATELY DEFINITELY
- 17) If you have had to work extra as a result of the cost of the laryngectomy, how do you feel about it?
 HAPPY TO MAKE THE SACRIFICE
 RESISTFUL OF THE SACRIFICE
 NO SIGNIFICANT REACTION
 DO NOT HAVE TO WORK EXTRA
- 18) What has been the effect of the laryngectomy on your marital relationship?
 POSITIVE NEGATIVE NO SIGNIFICANT EFFECT
- 19) How effective was your counseling?
 HELPED ME A LOT MADE LITTLE OR NO DIFFERENCE
 MADE ME FEEL WORSE RECEIVED NO COUNSELING
- 20) How disabled do you consider your spouse to be as a result of the laryngectomy?
 SEVERELY MODERATELY MILDLY NOT DISABLED
- 21) What was your first reaction to the sight of your spouse's stoma?
 ANXIETY CURIOSITY FOUND IT DISTASTEFUL
 NO REACTION OTHER (specify) _____
- 22) How has your health been effected as a result of your spouse's laryngectomy?
 BETTER WORSE NO CHANGE
- 23) If you care for your spouse's stoma, do you consider it to be a laborious task?
 NO SLIGHTLY MODERATELY DEFINITELY
 DO NOT CARE FOR SPOUSE'S STOMA
- 24a) How has the surgery effected the amount of communication with your spouse?
 COMMUNICATE MORE COMMUNICATE LESS COMMUNICATE THE SAME
- b) If you now communicate less with your spouse than before the surgery, what factors do you attribute to the decrease?
 SPOUSE APPEARS TO BE STRUGGLING TO SPEAK
 I CAN'T UNDERSTAND MY SPOUSE
 MY SPOUSE IS EMBARRASSED TO SPEAK
 OTHER (specify) _____
- 25) How much of a handicap do you consider your spouse's laryngectomy to be?
 SEVERE MODERATE MILD NOT A HANDICAP
- 26) Please add any comments that you feel are important. If necessary, use the back of this page.

APPENDIX D

DIFFERENCES IN SURVEY RESPONSES BETWEEN MALE AND FEMALE LARYNGECTOMEES

The percentage of responses for each survey item by males (M) and females (F) are presented below. All percentages were rounded to the nearest tenth. A "no response" by a subject was denoted by "NR".

1) What feelings were you aware of following surgery?

	STRONG	MODERATE	MILD	NONE	NR
FEAR/ANXIETY					
M	23.5%	27.9%	17.7%	14.7%	16.2%
F	48.0%	12.0%	14.0%	8.0%	18.0%
DEPRESSION					
M	19.1%	17.7%	23.5%	19.1%	20.6%
F	38.0%	14.0%	14.0%	14.0%	20.0%
RELIEF					
M	23.5%	26.5%	11.8%	16.2%	22.1%
F	30.0%	14.0%	6.0%	22.0%	28.0%
ANGER					
M	16.2%	10.3%	11.8%	39.7%	22.1%
F	24.0%	4.0%	14.0%	26.0%	32.0%
ACCEPTANCE					
M	42.7%	23.5%	13.2%	10.3%	10.3%
F	48.0%	8.0%	8.0%	10.0%	26.0%

2) How has your spouse's health been affected by your laryngectomy?

	MALES	FEMALES
BETTER	4.4%	4.0%
WORSE	8.8%	4.0%
NO CHANGE	66.2%	62.0%
NO RESPONSE	20.6%	30.0%

3) How has your spouse reacted to the cost of the laryngectomy?

	M	F
SEEMS HAPPY TO SACRIFICE FOR ME	26.5%	28.0%
SEEMS SOMEWHAT RESISTFUL OF THE SACRIFICE	7.4%	6.0%
NO NOTICEABLE REACTION	47.1%	38.0%
NO RESPONSE	19.0%	28.0%

4) Did you have ample opportunity to ask questions before surgery?

	MALES	FEMALES
YES	69.1%	64.0%
NO	27.9%	34.0%
NO RESPONSE	2.9%	2.0%

5) How effective was your counseling?

	MALES	FEMALES
HELPED ME A LOT	51.5%	32.0%
MADE ME FEEL WORSE	1.5%	2.0%
MADE LITTLE OR NO DIFFERENCE	4.4%	22.0%
RECEIVED NO COUNSELING	41.2%	38.0%
NO RESPONSE	1.5%	6.0%

6) How has your social life changed as a result of the laryngectomy?

	MALES	FEMALES
GO OUT/ENTERTAIN MORE	10.3%	6.0%
NO SIGNIFICANT CHANGE	29.4%	40.0%
GO OUT/ENTERTAIN LESS	57.4%	52.0%
NO RESPONSE	2.9%	2.0%

7) How effective was EACH of the following individuals in helping you adjust to the laryngectomy's consequences?

	NOT EFFECTIVE	SLIGHTLY	MODERATELY	DEFINITELY	NR
PHYSICIAN					
M	14.7%	10.3%	25.0%	44.1%	5.9%
F	18.0%	8.0%	12.0%	46.0%	16.0%
SPOUSE					
M	5.9%	7.4%	10.3%	50.0%	26.5%
F	6.0%	4.0%	12.0%	52.0%	26.0%

7) How effective was EACH of the following individuals in helping you adjust to the laryngectomy's consequences?

	NOT EFFECTIVE	SLIGHTLY	MODERATELY	DEFINITELY	NR
OTHER FAMILY					
M	29.4%	4.4%	13.2%	36.8%	16.2%
F	10.0%	4.0%	8.0%	66.0%	12.0%
FRIENDS					
M	26.5%	8.8%	22.1%	26.5%	16.2%
F	12.0%	8.0%	12.0%	52.0%	16.0%
LARYNGECTOMEE					
M	20.6%	4.4%	19.1%	36.8%	19.1%
F	4.0%	12.0%	12.0%	40.0%	32.0%
SPEECH-LANGUAGE PATHOLOGIST					
M	7.4%	1.5%	17.7%	55.9%	17.7%
F	14.0%	4.0%	18.0%	42.0%	22.0%
OTHER					
M	0.0%	0.0%	0.0%	11.8%	88.2%
F	0.0%	2.0%	0.0%	10.0%	88.0%

8a) How has the surgery affected the amount of communication with your spouse?

	MALES	FEMALES
COMMUNICATE MORE	2.9%	0.0%
COMMUNICATE LESS	20.5%	32.0%
COMMUNICATE THE SAME	55.9%	44.0%
NO RESPONSE	17.7%	24.0%

8b) If you now communicate less with your spouse than before the surgery what factors do you attribute to the decrease?

	MALES	FEMALES
SPEAKING IS DIFFICULT	7.4%	2.0%
EMBARRASSED	.5%	8.0%
SPOUSE CAN'T UNDERSTAND ME	1.5%	8.0%
OTHER	8.8%	10.0%
NO RESPONSE	76.5%	68.0%
FIXED	4.4%	4.0%

9) Before authorizing surgery, did you understand that you would no longer speak after the operation?

	MALES	FEMALES
YES	82.4%	82.0%
NO	13.2%	14.0%
NO RESPONSE	4.4%	4.0%

10) When were you least optimistic about the laryngectomy and its consequences?

	MALES	FEMALES
BEFORE SURGERY	26.5%	28.0%
AFTER SURGERY	20.6%	24.0%
ALWAYS OPTIMISTIC	35.3%	26.0%
NEVER OPTIMISTIC	10.3%	10.0%
NO RESPONSE	7.4%	12.0%

11a) Check EACH type of alternate communication to which you were exposed before surgery.

	MALES	FEMALES
ELECTROLARYNX	5.9%	8.0%
ESOPHAGEAL SPEECH	25.0%	24.0%
BLOM-SINGER DEVICE	1.5%	2.0%
NONE	47.1%	48.0%
MIXED	20.6%	14.0%
NO RESPONSE	0.0%	4.0%

b) Who was most instrumental in making you aware of the alternate modes of communication?

	MALES	FEMALES
PHYSICIAN	11.8%	12.0%
NURSE	1.5%	2.0%
SPEECH-LANGUAGE PATHOLOGIST	45.8%	30.0%
OTHER	17.7%	28.0%
MIXED	19.1%	26.0%
NO RESPONSE	4.4%	2.0%

12) What has been the effect of the laryngectomy on your marital relationship?

	MALES	FEMALES
POSITIVE	10.3%	10.0%
NEGATIVE	14.7%	12.0%
NO SIGNIFICANT EFFECT	57.4%	54.0%
NO RESPONSE	17.7%	24.0%

13) What typically happens when your spouse does not understand you?

	M	F
I BECOME FRUSTRATED AND CEASE TALKING	4.4%	12.0%
I REPEAT UNTIL SPOUSE UNDERSTANDS	50.0%	28.0%
I COMMUNICATE IN WRITING	7.4%	2.0%
OTHER	11.8%	12.0%
MIXED	8.8%	18.0%
NO RESPONSE	17.7%	28.0%

14) What evoked the most anxiety for you?

	a) BEFORE SURGERY	b) AFTER SURGERY
	SURVIVAL	SURVIVAL
M	38.2%	22.1%
F	42.0%	12.0%
	FEAR OF FUTURE	FEAR OF FUTURE
M	22.1%	8.8%
F	22.0%	28.0%
	LOSS OF SPEECH	LOSS OF SPEECH
M	29.4%	47.1%
F	20.0%	46.0%
	OTHER	OTHER
M	5.9%	10.3%
F	6.0%	6.0%
	NO RESPONSE	NO RESPONSE
M	4.4%	11.8%
F	10.0%	8.0%

15) Was your spouse ever counseled alone?

	MALES	FEMALES
YES	19.1%	10.0%
NO	58.8%	62.0%
NO RESPONSE	22.1%	28.0%

16a) Who cares for your stoma?

	MALES	FEMALES
I DO	85.3%	90.0%
SPOUSE	7.4%	4.0%
SOMEONE ELSE	0.0%	0.0%
MIXED	5.9%	4.0%
NO RESPONSE	1.5%	2.0%

16b) Do you consider caring for your stoma to be laborious?

	MALES	FEMALES
NO	75.0%	58.0%
SLIGHTLY	8.8%	26.0%
MODERATELY	7.4%	10.0%
DEFINITELY	8.8%	4.0%
NO RESPONSE	0.0%	2.0%

17) To what degree did each of the following individuals provide helpful information about the surgery and its consequences?

	DEFINITE	MODERATE	SLIGHT	NONE	NR
PHYSICIAN					
M	60.3%	19.1%	11.8%	7.4%	1.5%
F	46.0%	16.0%	8.0%	18.0%	12.0%

NURSE

M	22.1%	23.5%	5.9%	27.9%	20.6%
F	18.0	14.0%	2.0%	20.0%	46.0%

SPEECH-LANGUAGE PATHOLOGIST

M	39.7%	7.4%	5.9%	19.1%	27.9%
F	36.0%	6.0%	6.0%	20.0%	32.0%

SOCIAL WORKER

M	4.4%	4.4%	5.9%	45.6%	39.7%
F	6.0%	2.0%	4.0%	30.0%	58.0%

LARYNGECTOMEE

M	32.4%	14.7%	2.9%	33.8%	16.2%
F	34.0%	10.0%	10.0%	14.0%	32.0%

18) Was meeting a laryngectomee before surgery a positive experience?

	MALES	FEMALES
YES	42.7%	30.0%
NO	10.3%	6.0%
DID NOT MEET A LARYNGECTOMEE	45.6%	62.0%
NO RESPONSE	1.5%	2.0%

19) Which of the following individuals counseled you about the surgery and its effects?

	MALES	FEMALES
SOCIAL WORKER	1.5%	2.0%
PHYSICIAN	39.7%	32.0%
NURSE	0.0%	4.0%
SPEECH-LANGUAGE PATHOLOGIST	2.9%	2.0%
OTHER	2.9%	22.0%
MIXED	48.5%	30.0%
NO RESPONSE	4.4%	8.0%

20) Does your mode of communication embarrass you?

	MALES	FEMALES
NO	66.2%	34.0%
SLIGHTLY	17.7%	32.0%
MODERATELY	10.3%	20.0%
DEFINITELY	4.4%	14.0%
NO RESPONSE	1.5%	0.0%

21) Has the laryngectomy reduced communication between you and your spouse?

	MALES	FEMALES
YES	19.1%	30.0%
NO	58.8%	44.0%
DON'T KNOW	8.8%	0.0%
NO RESPONSE	13.2%	26.0%

22) How disabled do you consider yourself to be as a result of your laryngectomy?

	MALES	FEMALES
SEVERELY	8.8%	8.0%
MODERATELY	16.2%	26.0%
SLIGHTLY	25.0%	26.0%
NOT DISABLED	50.0%	38.0%
NO RESPONSE	0.0%	2.0%

23) What was your first reaction to the sight of your stoma?

	MALES	FEMALES
ANXIETY	11.8%	4.0%
CURIOSITY	23.5%	18.0%
FOUND IT DISTASTEFUL	14.7%	44.0%
NO REACTION	27.9%	14.0%
OTHER	13.2%	12.0%
MIXED	8.8%	6.0%
NO RESPONSE	0.0%	2.0%

24) How much of a handicap do you consider your laryngectomy to be?

	MALES	FEMALES
SEVERE	11.8%	10.0%
MODERATE	13.2%	36.0%
MILD	27.9%	24.0%
NOT A HANDICAP	47.1%	28.0%
NO RESPONSE	0.0%	2.0%

25a) Who counseled you about the surgery and its consequences?

	MALES	FEMALES
PHYSICIAN	50.0%	28.0%
SOCIAL WORKER	0.0%	0.0%
NURSE	0.0%	2.0%
SPEECH-LANGUAGE PATHOLOGIST	1.5%	0.0%
OTHER	4.4%	24.0%
MIXED	42.7%	36.0%
NO RESPONSE	1.5%	10.0%

b) Was your spouse present during the above counseling sessions?

	MALES	FEMALES
PHYSICIAN	25.0%	14.0%
SOCIAL WORKER	0.0%	0.0%
NURSE	0.0%	2.0%
SPEECH-LANGUAGE PATHOLOGIST	4.4%	0.0%
OTHER	0.0%	0.0%
MIXED	14.7%	10.0%
NO RESPONSE	55.9%	74.0%

APPENDIX E

DIFFERENCES IN SURVEY RESPONSES BY MALE AND FEMALE SPOUSES
OF LARYNGECTOMEES

The percentage of responses for each survey item by males (M) and females (F) are presented below. All percentages were rounded to the nearest tenth. A "no response" by a subject was denoted by "NR".

1) What feelings were you aware of following surgery?

	STRONG	MODERATE	MILD	NONE	NR
FEAR/ANXIETY					
M	50.0%	5.0%	15.0%	15.0%	15.0%
F	47.6%	19.1%	4.8%	0.0%	28.6%

DEPRESSION

M	25.0%	20.0%	10.0%	25.0%	20.0%
F	28.6%	14.3%	14.3%	9.5%	33.3%

RELIEF

M	30.0%	20.0%	5.0%	30.0%	15.0%
F	14.3%	9.5	19.1%	4.8%	52.4%

ANGER

M	15.0%	10.0%	10.0%	40.0%	25.0%
F	28.6%	14.3%	4.8%	14.3%	38.1%

ACCEPTANCE

M	65.0%	5.0%	0.0%	15.0%	15.0%
F	28.6%	33.3%	4.8%	4.8%	28.6%

2) How has your health been affected by the laryngectomy?

	MALES	FEMALES
BETTER	0.0%	0.0%
WORSE	5.0%	9.5%
NO CHANGE	95.0%	85.7%
NO RESPONSE	0.0%	4.8%

3) What was your reaction to the cost of the laryngectomy?

	M	F
HAPPY TO MAKE THE SACRIFICE	20.0%	23.8%
SOMEWHAT RESISTFUL OF THE SACRIFICE	15.0%	0.0%
NO REACTION	5.0%	9.5%
DO NOT HAVE TO WORK EXTRA	55.0%	61.9%
NO RESPONSE	5.0%	4.8%

4) Did you have ample opportunity to ask questions before surgery?

	MALES	FEMALES
YES	60.0%	52.4%
NO	40.0%	38.1%
NO RESPONSE	0.0%	9.5%

5) How effective was your counseling?

	MALES	FEMALES
HELPED ME A LOT	40.0%	42.9%
MADE ME FEEL WORSE	0.0%	0.0%
MADE LITTLE OR NO DIFFERENCE	5.0%	4.8%
RECEIVED NO COUNSELING	55.0%	47.6%
NO RESPONSE	0.0%	4.8%

6) How has your social life changed as a result of the laryngectomy?

	MALES	FEMALES
GO OUT/ENTERTAIN MORE	5.0%	19.1%
NO SIGNIFICANT CHANGE	35.0%	33.3%
GO OUT/ENTERTAIN LESS	55.0%	47.6%
NO RESPONSE	5.0%	0.0%

7) How effective was EACH of the following individuals in helping you adjust to the laryngectomy's consequences?

	NOT EFFECTIVE	SLIGHTLY	MODERATELY	DEFINITELY	NR
PHYSICIAN					
M	20.0%	0.0%	15.0%	40.0%	25.0%
F	19.1%	9.5%	9.5%	42.9%	19.1%
SPOUSE					
M	5.0%	5.0%	15.0%	55.0%	20.0%
F	19.1%	4.8%	14.3%	42.9%	19.1%

- 7) How effective was EACH of the following individuals in helping you adjust to the laryngectomy's consequences?

	NOT EFFECTIVE	SLIGHTLY	MODERATELY	DEFINITELY	NR
OTHER FAMILY					
M	10.0%	10.0%	10.0%	45.0%	25.0%
F	19.1%	9.5%	14.3%	33.3%	23.8%
FRIENDS					
M	25.0%	10.0%	5.0%	25.0%	35.0%
F	19.1%	14.3%	19.1%	28.6%	19.1%
LARYNGECTOMEE					
M	10.0%	5.0%	0.0%	35.0%	50.0%
F	4.8%	0.0%	14.3%	47.6%	33.3%
SPEECH-LANGUAGE PATHOLOGIST					
M	10.0%	0.0%	10.0%	25.0%	55.0%
F	4.8%	4.8%	14.3%	47.6%	28.6%
OTHER					
M	0.0%	0.0%	0.0%	10.0%	90.0%
F	0.0%	0.0%	4.8%	19.1%	76.2%

- 8a) How has the surgery affected the amount of communication with your spouse?

	MALES	FEMALES
COMMUNICATE MORE	0.0%	23.8%
COMMUNICATE LESS	45.0%	28.6%
COMMUNICATE THE SAME	55.0%	47.6%
NO RESPONSE	0.0%	0.0%

- b) If you now communicate less with your spouse than before the surgery what factors do you attribute to the decrease?

	MALES	FEMALES
SPEAKING IS DIFFICULT FOR SPOUSE	5.0%	0.0%
SPOUSE IS EMBARRASSED	10.0%	4.8%
I CAN'T UNDERSTAND SPOUSE	5.0%	4.8%
OTHER	15.0%	19.1%
NO RESPONSE	50.0%	66.7%
MIXED	15.0%	4.8%

9) Before authorizing surgery, did you understand that your spouse would no longer speak after the operation?

	MALES	FEMALES
YES	90.0%	81.0%
NO	10.0%	19.1%
NO RESPONSE	0.0%	0.0%

10) When were you least optimistic about the laryngectomy and its consequences?

	MALES	FEMALES
BEFORE SURGERY	30.0%	42.9%
AFTER SURGERY	5.0%	9.5%
ALWAYS OPTIMISTIC	20.0%	28.6%
NEVER OPTIMISTIC	30.0%	9.5%
NO RESPONSE	15.0%	9.5%

11a) Check EACH type of alternate communication to which you were exposed before surgery.

	MALES	FEMALES
ELECTROLARYNX	0.0%	9.5%
ESOPHAGEAL SPEECH	20.0%	28.6%
BLOM-SINGER DEVICE	0.0%	0.0%
NONE	60.0%	52.4%
MIXED	15.0%	4.8%
NO RESPONSE	5.0%	4.8%

b) Who was most instrumental in making you aware of the alternate modes of communication?

	MALES	FEMALES
PHYSICIAN	40.0%	0.0%
NURSE	10.0%	0.0%
SPEECH-LANGUAGE PATHOLOGIST	0.0%	52.4%
OTHER	30.0%	25.8%
MIXED	15.0%	19.1%
NO RESPONSE	5.0%	4.8%

12) What has been the effect of the laryngectomy on your marital relationship?

	MALES	FEMALES
POSITIVE	10.0%	28.6%
NEGATIVE	25.0%	4.8%
NO SIGNIFICANT EFFECT	65.0%	66.7%
NO RESPONSE	0.0%	0.0%

13) What typically happens when you don't understand your spouse?

	M	F
S/HE BECOMES FRUSTRATED & CEASES TALKING	20.0%	9.5%
S/HE REPEATS UNTIL I UNDERSTAND	50.0%	66.7%
S/HE COMMUNICATES IN WRITING	5.0%	4.8%
OTHER	15.0%	0.0%
MIXED	5.0%	19.1%
NO RESPONSE	5.0%	0.0%

14) What evoked the most anxiety for you?

	a) BEFORE SURGERY	b) AFTER SURGERY
	SURVIVAL	SURVIVAL
M	45.0%	20.0%
F	76.2%	33.3%
	FEAR OF FUTURE	FEAR OF FUTURE
M	20.0%	30.0%
F	14.3%	33.3%
	LOSS OF SPEECH	LOSS OF SPEECH
M	20.0%	35.0%
F	9.5%	28.6%
	OTHER	OTHER
M	5.0%	0.0%
F	0.0%	0.0%
	NO RESPONSE	NO RESPONSE
M	10.0%	15.0%
F	0.0%	4.8%

15) Were you ever counseled alone?

	MALES	FEMALES
YES	10.0%	14.3%
NO	90.0%	81.0%
NO RESPONSE	0.0%	4.8%

16) Do you consider caring for your spouse's stoma to be laborious?

	MALES	FEMALES
NO	5.0%	33.3%
SLIGHTLY	0.0%	4.8%
MODERATELY	0.0%	0.0%
DEFINITELY	20.0%	4.8%
DO NOT CARE FOR SPOUSE'S STOMA	70.0%	57.1%
NO RESPONSE	5.0%	0.0%

- 17) To what degree did each of the following individuals provide helpful information about the surgery and its consequences?

	DEFINITE	MODERATE	SLIGHT	NONE	NR
PHYSICIAN					
M	65.0%	0.0%	10.0%	10.0%	15.0%
F	47.6%	14.3%	14.3%	14.3%	9.5%
NURSE					
M	15.0%	15.0%	0.0%	20.0%	50.0%
F	9.5%	4.8%	23.8%	19.1%	42.9%
SPEECH-LANGUAGE PATHOLOGIST					
M	20.0%	5.0%	5.0%	20.0%	50.0%
F	33.3%	4.8%	4.8%	23.8%	33.3%
SOCIAL WORKER					
M	5.0%	0.0%	0.0%	30.0%	65.0%
F	9.5%	0.0%	0.0%	33.3%	57.1%
LARYNGECTOMEE					
M	30.0%	5.0%	0.0%	10.0%	55.0%
F	33.3%	9.5%	9.5%	9.5%	38.1%

- 18) Was meeting a laryngectomee's spouse before surgery a positive experience?

	MALES	FEMALES
YES	5.0%	14.3%
NO	10.0%	4.8%
DID NOT MEET A LARYNGECTOMEE'S SPOUSE		
	85.0%	81.0%
NO RESPONSE	0.0%	0.0%

- 19) Which of the following individuals counseled you about the surgery and its effects?

	MALES	FEMALES
SOCIAL WORKER	0.0%	0.0%
PHYSICIAN	45.0%	33.3%
NURSE	10.0%	0.0%
SPEECH-LANGUAGE PATHOLOGIST	0.0%	0.0%
OTHER	20.0%	23.8%
MIXED	10.0%	42.9%
NO RESPONSE	15.0%	0.0%

20) Does your spouse's mode of communication embarrass you?

	MALES	FEMALES
NO	80.0%	85.7%
SLIGHTLY	5.0%	4.8%
MODERATELY	0.0%	9.5%
DEFINITELY	15.0%	0.0%
NO RESPONSE	0.0%	0.0%

21) Has the laryngectomy reduced communication between you and your spouse?

	MALES	FEMALES
YES	40.0%	28.6%
NO	60.0%	71.4%
DON'T KNOW	0.0%	0.0%
NO RESPONSE	0.0%	0.0%

22) How disabled do you consider your spouse to be as a result of your laryngectomy?

	MALES	FEMALES
SEVERELY	0.0%	9.5%
MODERATELY	35.0%	9.5%
SLIGHTLY	30.0%	33.3%
NOT DISABLED	35.0%	47.6%
NO RESPONSE	0.0%	0.0%

23) What was your first reaction to the sight of your spouse's stoma?

	MALES	FEMALES
ANXIETY	25.0%	23.8%
CURIOSITY	20.0%	14.3%
FOUND IT DISTASTEFUL	30.0%	19.1%
NO REACTION	10.0%	14.3%
OTHER	5.0%	9.5%
MIXED	10.0%	14.3%
NO RESPONSE	0.0%	4.8%

24) How much of a handicap do you consider your spouse's laryngectomy to be?

	MALES	FEMALES
SEVERE	0.0%	9.5%
MODERATE	30.0%	19.1%
MILD	30.0%	28.6%
NOT A HANDICAP	40.0%	42.9%
NO RESPONSE	0.0%	0.0%

25a) Who counseled you about the surgery and its consequences?

	MALES	FEMALES
PHYSICIAN	50.0%	47.6%
SOCIAL WORKER	5.0%	0.0%
NURSE	0.0%	0.0%
SPEECH-LANGUAGE PATHOLOGIST	0.0%	4.8%
OTHER	25.0%	14.3%
MIXED	15.0%	33.0%
NO RESPONSE	5.0%	0.0%

b) Was your spouse present during the above counseling sessions?

	MALES	FEMALES
PHYSICIAN	25.0%	38.1%
SOCIAL WORKER	10.0%	0.0%
NURSE	0.0%	0.0%
SPEECH-LANGUAGE PATHOLOGIST	0.0%	0.0%
OTHER	0.0%	0.0%
MIXED	10.0%	23.8%
NO RESPONSE	55.0%	38.1%

APPENDIX F

DIFFERENCES IN SURVEY RESPONSES BETWEEN LARYNGECTOMEES AND SPOUSES

The percentage of responses for each survey item by laryngectomees (L) and spouses (S) are presented below. All percentages were rounded to the nearest tenth. A "no response" by a subject was denoted by "NR".

The survey items presented below were taken from Form A for laryngectomees. The spouses' survey was similarly worded to obtain appropriate responses from spouses. See Appendix E for the wording of specific items on the spouses' survey.

1) What feelings were you aware of following surgery?

	STRONG	MODERATE	MILD	NONE	NR
FEAR/ANXIETY					
L	33.3%	20.8%	15.8%	12.5%	17.5%
S	48.8%	12.2%	9.8%	7.3%	22.0%

DEPRESSION

L	27.5%	15.8%	19.2%	17.5%	20.0%
S	26.8%	17.1%	12.2%	17.1%	26.8%

RELIEF

L	26.7%	20.8%	9.2%	18.3%	25.0%
S	22.0%	14.6%	12.2%	17.1%	34.2%

ANGER

L	20.0%	7.5%	12.5%	34.2%	25.8%
S	22.0%	12.2%	7.3%	26.8%	31.7%

ACCEPTANCE

L	45.0%	16.7%	10.8%	10.0%	17.5%
S	46.3%	19.5%	2.4%	9.8%	22.0%

2) How has your spouse's health been affected by your laryngectomy?

	L	S
BETTER	4.2%	0.0%
WORSE	6.7%	7.3%
NO CHANGE	64.2%	90.2%
NO RESPONSE	25.0%	2.4%

3) How has your spouse reacted to the cost of the laryngectomy?

	L	S
SEEMS HAPPY TO SACRIFICE FOR ME	27.5%	22.0%
SEEMS SOMEWHAT RESISTFUL OF THE SACRIFICE	6.7%	7.3%
NO NOTICEABLE REACTION	41.7%	7.3%
SPOUSE DOES NOT HAVE TO WORK EXTRA	0.0%	58.5%
NO RESPONSE	24.2%	4.9%

4) Did you have ample opportunity to ask questions before surgery?

	L	S
YES	66.7%	56.1%
NO	30.8%	39.0%
NO RESPONSE	2.5%	4.9%

5) How effective was your counseling?

	L	S
HELPED ME A LOT	43.3%	41.5%
MADE ME FEEL WORSE	1.7%	0.0%
MADE LITTLE OR NO DIFFERENCE	11.7%	4.9%
RECEIVED NO COUNSELING	40.0%	51.2%
NO RESPONSE	3.3%	2.4%

6) How has your social life changed as a result of the laryngectomy?

	L	S
GO OUT/ENTERTAIN MORE	8.3%	12.2%
NO SIGNIFICANT CHANGE	34.2%	34.2%
GO OUT/ENTERTAIN LESS	55.0%	51.2%
NO RESPONSE	2.5%	2.4%

7) How effective was EACH of the following individuals in helping you adjust to the laryngectomy's consequences?

	NOT EFFECTIVE	SLIGHTLY	MODERATELY	DEFINITELY	NR
PHYSICIAN					
L	16.7%	9.2%	19.2%	45.0%	10.0%
S	19.5%	4.9%	12.2%	41.5%	22.0%
SPOUSE					
L	5.8%	5.8%	10.8%	50.8%	26.7%
S	12.2%	4.9%	14.6%	48.8%	19.5%

- 7) How effective was EACH of the following individuals in helping you adjust to the laryngectomy's consequences?

	NOT EFFECTIVE	SLIGHTLY	MODERATELY	DEFINITELY	NR
OTHER FAMILY					
L	20.8%	4.2%	10.8%	50.0%	14.2%
S	14.6%	9.8%	12.2%	39.0%	24.4%
FRIENDS					
L	20.0%	8.3%	17.5%	38.3%	15.8%
S	22.0%	12.2%	12.2%	26.8%	26.8%
LARYNGECTOMEES					
L	13.3%	7.5%	15.8%	39.2%	24.2%
S	7.3%	2.4%	7.3%	41.5%	41.5%
SPEECH-LANGUAGE PATHOLOGIST					
L	10.0%	2.5%	17.5%	50.0%	20.0%
S	7.3%	2.4%	12.2%	36.6%	41.5%
OTHER					
L	0.0%	0.8%	0.0%	10.8%	88.3%
S	0.0%	0.0%	2.4%	14.6%	82.9%

- 8a) How has the surgery affected the amount of communication with your spouse?

	L	S
COMMUNICATE MORE	1.7%	12.2%
COMMUNICATE LESS	26.7%	36.6%
COMMUNICATE THE SAME	50.8%	51.2%
NO RESPONSE	20.8%	0.0%

- b) If you now communicate less with your spouse than before the surgery what factors do you attribute to the decrease?

	L	S
SPEAKING IS DIFFICULT	5.0%	2.4%
EMBARRASSED	4.2%	7.3%
SPOUSE CAN'T UNDERSTAND ME	4.2%	4.9%
OTHER	9.2%	17.1%
NO RESPONSE	73.3%	58.5%
MIXED	4.2%	9.8%

9) Before authorizing surgery, did you understand that you would no longer speak after the operation?

	L	S
YES	82.5%	85.4%
NO	13.3%	14.6%
NO RESPONSE	4.2%	0.0%

10) When were you least optimistic about the laryngectomy and its consequences?

	L	S
BEFORE SURGERY	27.5%	36.6%
AFTER SURGERY	22.5%	7.3%
ALWAYS OPTIMISTIC	30.8%	24.4%
NEVER OPTIMISTIC	10.0%	19.5%
NO RESPONSE	9.2%	12.2%

11a) Check EACH type of alternate communication to which you were exposed before surgery.

	L	S
ELECTROLARYNX	6.7%	4.9%
ESOPHAGEAL SPEECH	25.0%	24.4%
BLOM-SINGER DEVICE	1.7%	0.0%
NONE	47.5%	56.1%
MIXED	17.5%	9.8%
NO RESPONSE	1.7%	4.9%

b) Who was most instrumental in making you aware of the alternate modes of communication?

	L	S
PHYSICIAN	12.5%	19.5%
NURSE	1.7%	4.9%
SPEECH-LANGUAGE PATHOLOGIST	38.3%	26.8%
OTHER	22.5%	26.8%
MIXED	21.7%	17.1%
NO RESPONSE	3.3%	4.9%

12) What has been the effect of the laryngectomy on your marital relationship?

	L	S
POSITIVE	10.0%	19.5%
NEGATIVE	13.3%	14.6%
NO SIGNIFICANT EFFECT	55.8%	65.9%
NO RESPONSE	20.8%	0.0%

13) What typically happens when your spouse does not understand you?

	L	S
I BECOME FRUSTRATED AND CEASE TALKING	7.5%	14.6%
I REPEAT UNTIL SPOUSE UNDERSTANDS	40.0%	58.5%
I COMMUNICATE IN WRITING	5.0%	4.9%
OTHER	11.7%	7.3%
MIXED	12.5%	12.2%
NO RESPONSE	23.3%	2.4%

14) What evoked the most anxiety for you?

	a) BEFORE SURGERY	b) AFTER SURGERY
	SURVIVAL	SURVIVAL
L	39.2%	17.5%
S	61%	26.8%
	FEAR OF FUTURE	FEAR OF FUTURE
L	21.7%	16.7%
S	17.1%	31.7%
	LOSS OF SPEECH	LOSS OF SPEECH
L	25.8%	45.6%
S	14.6%	31.7%
	OTHER	OTHER
L	6.7%	8.3%
S	2.4%	0.0%
	NO RESPONSE	NO RESPONSE
L	6.7%	11.7%
S	4.9%	9.8%

15) Was your spouse ever counseled alone?

	L	S
YES	15.0%	12.2%
NO	60.0%	85.4%
NO RESPONSE	25.0%	2.4%

16b) Do you consider caring for the stoma to be laborious?

	L	S
NO	67.5%	19.5%
SLIGHTLY	15.8%	2.4%
MODERATELY	8.3%	0.0%
DEFINITELY	7.5%	12.2%
NO RESPONSE	0.8%	2.4%
DO NOT CARE FOR SPOUSE'S STOMA	0.0%	63.4%

- 17) To what degree did each of the following individuals provide helpful information about the surgery and its consequences?

	DEFINITE	MODERATE	SLIGHT	NONE	NR
PHYSICIAN					
L	54.2%	17.5%	10.0%	11.7%	6.7%
S	56.1%	7.3%	12.2%	12.2%	12.2%
NURSE					
L	20.0%	19.2%	4.2%	24.2%	32.5%
S	12.2%	9.8%	12.2%	19.5%	46.3%
SPEECH-LANGUAGE PATHOLOGIST					
L	38.3%	6.7%	5.8%	19.2%	30.0%
S	26.8%	4.9%	4.9%	22.0%	41.5%
SOCIAL WORKER					
L	5.0%	3.3%	5.0%	38.3%	48.3%
S	7.3%	0.0%	0.0%	31.7%	61.0%
LARYNGECTOMEE					
L	32.5%	12.5%	5.8%	25.0%	24.2%
S	31.7%	7.3%	4.8%	9.8%	46.3%

- 18) Was meeting a laryngectomee before the surgery a positive experience?

	L	S
YES	37.5%	9.8%
NO	8.3%	7.3%
DID NOT MEET A LARYNGECTOMEE/SPOUSE	52.5%	82.9%
NO RESPONSE	1.7%	0.0%

- 19) Which of the following individuals counseled you about the surgery and its effects?

	L	S
SOCIAL WORKER	1.7%	0.0%
PHYSICIAN	1.7%	4.9%
NURSE	2.5%	0.0%
SPEECH-LANGUAGE PATHOLOGIST	35.8%	39.0%
OTHER	10.8%	22.0%
MIXED	40.8%	26.8%
NO RESPONSE	6.7%	7.3%

20) Does your mode of communication embarrass you?

	L	S
NO	52.5%	82.9%
SLIGHTLY	23.3%	4.9%
MODERATELY	15.8%	4.9%
DEFINITELY	8.3%	7.3%
NO RESPONSE	0.0%	0.0%

21) Has the laryngectomy reduced communication between you and your spouse?

	L	S
YES	23.3%	34.2%
NO	52.5%	65.9%
DON'T KNOW	5.0%	0.0%
NO RESPONSE	19.2%	0.0%

22) How disabled do you consider yourself to be as a result of your laryngectomy?

	L	S
SEVERELY	8.3%	4.9%
MODERATELY	20.8%	22.0%
SLIGHTLY	25.0%	31.7%
NOT DISABLED	45.0%	41.5%
NO RESPONSE	0.8%	0.0%

23) What was your first reaction to the sight of your stoma?

	L	S
ANXIETY	8.3%	24.4%
CURIOSITY	20.8%	17.1%
FOUND IT DISTASTEFUL	27.5%	24.4%
NO REACTION	22.5%	12.2%
OTHER	12.5%	7.3%
MIXED	7.5%	12.2%
NO RESPONSE	0.8%	2.4%

24) How much of a handicap do you consider your laryngectomy to be?

	L	S
SEVERE	10.8%	4.9%
MODERATE	23.3%	24.4%
MILD	25.8%	29.3%
NOT A HANDICAP	39.2%	41.5%
NO RESPONSE	0.8%	0.0%

25a) Who counseled you about the surgery and its consequences?

	L	S
PHYSICIAN	40.8%	48.8%
SOCIAL WORKER	0.8%	2.4%
NURSE	0.8%	0.0%
SPEECH-LANGUAGE PATHOLOGIST	0.0%	2.4%
OTHER	12.5%	19.5%
MIXED	39.2%	24.4%
NO RESPONSE	5.8%	2.4%

b) Was your spouse present during the above counseling sessions?

	L	S
PHYSICIAN	20.0%	31.7%
SOCIAL WORKER	0.8%	4.9%
NURSE	2.5%	0.0%
SPEECH-LANGUAGE PATHOLOGIST	0.0%	0.0%
OTHER	0.0%	0.0%
MIXED	12.5%	17.1%
NO RESPONSE	64.2%	46.3%

SEX DIFFERENCES IN THE COUNSELING NEEDS OF LARYNGECTOMEES
AND THEIR SPOUSES

by

Caroline Teresa Salva

B.A., Queens College, 1984

AN ABSTRACT OF A MASTER'S THESIS

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MASTER OF ARTS

Department of Speech

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SEX DIFFERENCES IN THE COUNSELING NEEDS OF LARYNGECTOMEES AND THEIR SPOUSES

This study investigated the counseling needs of laryngectomees and their spouses. The specific research questions addressed the differences in the counseling needs between three groups: male versus female laryngectomees, male versus female spouses of laryngectomees, and laryngectomees versus spouses.

A 25-item survey was developed to obtain the pertinent information. Two forms of each survey (i.e., laryngectomee and spouse) were developed to reduce the possible effects of item order. The surveys were distributed to New Voice Club members and their spouses in California, Georgia, Kansas, Maryland, New York, Oklahoma, and at the 1985 International Association of Laryngectomees Convention in Atlanta, Georgia. Four items surveyed lifestyle changes, eight items surveyed informational needs, 10 items surveyed subjects' feelings, and three items were used as a reliability check of subject responses.

One hundred and twenty laryngectomees (68 males, 50 females, and two of unknown sex) and 41 spouses of laryngectomees (20 males and 21 females) completed the survey. The subjects exhibited a wide range of ages, methods of communication, education, and employment characteristics.

The results revealed that ten of the experimental

items were found to be significantly different between male and female laryngectomees. Six of the items corresponded to subjects' feelings and four to their informational needs.

Four of the experimental items were found to be significantly different between male and female spouses of laryngectomees. Two items corresponded to subjects' feelings and two to their informational needs.

Ten of the experimental items were found to be significantly different between laryngectomees and spouses of laryngectomees. Six items corresponded to subjects' feelings, three to their lifestyle changes, and one to their informational needs.

Other significant differences were found for some of the experimental items when analyzed according to age, educational level, place of residence, employment status, type of employment, date of laryngectomy, and the laryngectomees' method of communication.

The results emphasized the need for improvement of counseling by the laryngectomy rehabilitation team for both the patient and the spouse. Rehabilitation team members should change their counseling strategies to meet the unique needs of all individuals involved in the total rehabilitation of the laryngectomy patient. Counselors should be sensitive to the different counseling needs of males and females as well as those of laryngectomees and spouses.