The Impact of Total Laryngectomy: The Patient’s Perspective

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Worldwide, about 450,000 new cases of cancer of the head and neck are diagnosed each year, with a high incidence of laryngeal cancer in southern and eastern Europe, Latin America, and western Asia (Donnelly, Gavin, & Comber, 2009). More than 12,000 new cases of laryngeal cancer (9,680 in men and 2,570 in women) were diagnosed in the United States in 2008 (American Cancer Society, 2008). In Ireland, 139 (119 male and 20 female) patients from a total population of 4.2 million were diagnosed with laryngeal cancer in 2005 (Donnelly et al., 2009). Patients whose tumors are not eradicated by radiation generally are subjected to surgery to control the disease (Farrand & Duncan, 2007). Total laryngectomy is undertaken in as many as 50% of those patients (Donnelly et al., 2009). Five-year (age-standardized) relative survival for patients diagnosed from 2000–2004 was estimated to be 52%, with no significant variations by gender (Donnelly et al., 2009). Total laryngectomy is believed to be more emotionally traumatic than any other type of surgery because of the resultant psychological and functional impairment (Farrand & Duncan, 2007; Op de Coul et al., 2005).

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Purpose/Objectives: To describe the experiences of patients who had total laryngectomy from their perspective.
Research Approach: Descriptive, qualitative study.
Setting: Participants’ homes or investigator’s hospital office.
Participants: 10 patients after total laryngectomy.
Methodologic Approach: Data were collected by semi-structured, open-ended interviews during a period of six months, with an interview topic guide built on the framework of the literature review. Data were analyzed with descriptive content analysis. Trustworthiness of the study was enhanced through the use of verbatim quotations, audible data analysis trail, and a reflexive approach.
Main Research Variables: Patients’ experiences of undergoing total laryngectomy.
Findings: Patients who have undergone a total laryngectomy report difficulties and concerns that are largely functional and psychological. The functional difficulties reported included descriptions of altered swallow, excess phlegm, speech difficulties, weak neck muscles, and altered energy levels. The psychological concerns reported included descriptions of depression, regrets, and personal resolve.
Conclusions: As a group, patients experience a broad range of problems well after completion of treatment, reinforcing the need for rehabilitation management for prolonged periods after surgery.
Interpretation: Nurses are suitably positioned to support this group of patients across the disease management trajectory, from the initial preoperative period to the postoperative period and through to the rehabilitative period and beyond.

Functional Difficulties Inherent in Treatment for Laryngeal Cancer

A patient’s functional performance after total laryngectomy is the dimension affected the most because removal of the larynx has a profound impact on fundamental activities of daily living, such as talking, eating and drinking, breathing, and kissing (Davis & Roberts, 1999). Researchers have reported that loss of natural voice is not the most important dimension affecting quality of life after treatment for laryngeal cancer (Herranz & Gavilan, 1999; Llatas et al., 2003; Stewart, Chen, & Stach, 1998) because several potential techniques are
available for voice rehabilitation after total laryngectomy. Interestingly, however, results from a study by Ferrand and Duncan (2007) indicated that improved voice quality does not result in widespread benefits to quality of life. Functional difficulties identified in studies using quality-of-life instruments revealed that patients reported concerns about eating, diet, pain, speech, hobbies, work, and marital and sexual functioning (Campbell, Marbella, & Layde, 2000; De Boer, McCormick, Pruyn, Ryckman, & van den Borne, 1999; de Graeff et al., 2000b; Gritz et al., 1999; Rogers, Hannah, Lowe, & Magennis, 1999; Terrell, Fisher, & Wolf, 1998). de Graeff et al. (2000b) also found that gender and age had little value as predictors of who would experience functional difficulties, whereas depression frequently was correlated with functional difficulties. The impact of total laryngectomy is not limited to functional effects; psychological concerns after total laryngectomy also have been researched.

Psychological Concerns After Total Laryngectomy

Total laryngectomy results in significant levels of change in the psychological well-being of the patient undergoing treatment (Eadie & Doyle, 2005). The relationship between psychological distress and total laryngectomy has been attributed to image disturbance and functional difficulties inherent in the disease and treatment process (Feber, 1996). Other research, however, suggests that unmet information and support needs may contribute significantly to psychological distress (De Boer et al., 1999; Sollner et al., 2001). Research also has identified that psychological distress among patients with head and neck cancer is not limited to the immediate postoperative period (Bjordal & Kaasa, 1995; Hutton & Williams, 2001). The issue of patient participation in decision making being a precursor to reducing anxiety among patients with head and neck cancer also has been addressed in the literature (Craig, 1996; Dropkin, 2001).

The literature pertaining to patients after laryngectomy is based largely on the ideology of the biomedical model, which tends to disregard the significance of the experience and impact of the illness, concentrating instead on symptoms as indicators of disease or tolerance of disease (Ampil et al., 2004; Hall et al., 2003). In addition, most of the studies used fixed quality-of-life categories, which may not capture the individuality of patients’ experiences and interpretation of illness and, therefore, risk omitting important symptoms that patients might express in other ways.

Physical and psychosocial adjustment and rehabilitation require the input of skilled members of a multidisciplinary team. As members of this multidisciplinary team, nurses are in a unique position to act as patient advocates to ensure that patients’ journey through the healthcare system is uncomplicated and results in the best healthcare outcomes, both short and long term. To understand the experiences as expressed by patients after total laryngectomy, healthcare providers should afford patients the opportunity to describe their experiences in their own words. Thus, this study sought to describe the experience of total laryngectomy from patients’ perspectives.

Research Methodology

Design

A descriptive, qualitative design was chosen for this research because it best served the aim of the study. The purpose of the research was to describe the experiences of patients after total laryngectomy. The main objectives of the research were to describe the experiences of patients who had undergone total laryngectomy as treatment for laryngeal cancer and to report the experiences as accurately as possible (in the patients’ own words) from the patients’ perspectives. The final product of qualitative research is lucid descriptions of the participants’ experiences (no reading between or over the lines
Sample

Purposeful sampling was selected as the most appropriate method for the study. The logic behind purposeful sampling lies in selecting information-rich cases for in-depth study (Coyne, 1997; Sandelowski, 1995). The following inclusion criteria were met.

- All participants had a total laryngectomy in the previous seven years or less, but more than six months passed since surgery.
- All participants used similar methods of communication (tracheoesophageal speech).
- All participants were able to communicate their experiences in English.

Based on the inclusion criteria, lists of potential participants were obtained from the speech and language therapist working in the Speech and Language Therapy Department in the hospital where the research was conducted. Permission to access participants was granted by the Hospital Ethics Committee, the consultant otolaryngologist, and the speech and language therapist. The researcher contacted patients by letter, inviting them to participate.

Data Collection

Ten of 12 potential participants consented to participate in the study. An interview date, time, and location of their choosing were arranged, and participants signed a consent form. Two participants preferred to be interviewed in their own homes. The remainder of the participants chose to be interviewed in a quiet room in the hospital, expressing a desire to keep their homes private.

The principal data collection method was an audiotaped, semi-structured interview with an interview topic guide (see Figure 1). The researcher (a lecturer practitioner in the area of head and neck cancer) compiled the interview guide built on the framework of the literature by the researcher) that are understood easily by the lay population and clinicians alike (Sandelowski, 1996).

Main Question 1: Can you tell me how life has been since your laryngectomy operation?
Main Question 2: How would you describe your general mood?
Main Question 3: How do you feel your laryngectomy has affected your general physical health?
Main Question 4: Your life after the laryngectomy, was it what you imagined it to be?

Clarifying and Probing Statements
- So you’re saying . . . Is that what you mean?
- Can you tell me more about that?
- How did that make you feel?
- Can you explain what you mean by that?

Data Analysis

This form of analysis is the least interpretive of the qualitative analysis approaches, in that no mandate exists to represent the data in any other terms but the participants’ own. Ten audiotapes were transcribed verbatim. The researcher read the transcripts several times to become immersed in the data and sensitized to the experiences of each participant, to obtain a sense of the whole (Graneheim & Lundman, 2004). The researcher reads each transcript carefully, highlighting text that appeared to describe important or repetitive comments and writing in the margins of the text keywords and phrases (meaning units) that seemed to capture the participants’ experiences, using the participants’ own words. Therefore, the text was divided into meaning units that then were condensed, which refers to a process of shortening the meaning unit while still preserving the core. The condensed meaning units were abstracted and labelled with codes. Table 1 provides a list of meaning units, condensed meaning units, and codes. Coming up with the codes was like constructing an index for a book or labels for a file system: looking at what was there and giving it a name. Finally, depending on the relationships between subcategories, the researcher combined the larger number of subcategories into a small number of categories, which constituted the manifest content. Table 2 provides a summary of the categories and subcategories. Comparison of categories across the 10 participant interviews led to the development of common categories.

The concepts of credibility, dependability, and transferability were used to ensure the trustworthiness of the study (Berg & Welander Hansson, 2000; Patton, 1990). A coresearcher (a nursing professor with extensive cancer research experience) read the interview transcripts and validated the final categories chosen. The researcher also kept a reflective journal to record the context and process of researcher and participant interaction. To facilitate transferability of findings, the researcher provided a clear and distinct description of selection and characteristics of the research participants, the research process, and the process.
of data analysis. Trustworthiness also was enhanced with verbatim quotations, ensuring the selection of the most appropriate meaning units which make up the individual categories.

**Findings**

Ten participants (eight male and two female) accepted the invitation to be interviewed. Table 3 summarizes participant demographic information.

**Functional Difficulties**

This category incorporates the subcategories of physical symptoms and speech difficulties associated with total laryngectomy from the patients’ perspectives. Some of the major physical symptoms associated with this type of surgery included altered swallow, excess phlegm (also known as sputum), altered nutrition, weak neck muscles, and altered energy levels.

**Physical symptoms:** Participants whose time since surgery ranged from one to four years or more described a number of physical symptoms. Three of the participants had a problem with phlegm. The presence of phlegm impacted communication and most of the participants’ ability to socialize comfortably with friends. This was illustrated by a male patient who found phlegm not only a nuisance but also time consuming: “I’ve to suction twice a day at least because of the phlegm. . . . [Suctioning] takes half an hour in the morning, again in the evening, and I’d always wake in the middle of the night to do it.” He added that because the phlegm is a problem and so time consuming that he “doesn’t see anyone, partially because of the phlegm.”

A patient recognized that although he didn’t suffer from pain, his energy levels were not the same as they were before the operation: “I never had pain, but you wouldn’t have that much energy at all; you’d be inclined to lie down more often and fall asleep.”

One of the female patients’ biggest concerns was her swallowing ability, and admitted that she “must be very careful” when she eats.

I was out for lunch, and there was eight of us there. I decided I’d have roast pork, so I mustn’t have chewed enough, anyway it got stuck, I decided to get water and that might wash it down, and the water came out my nose and out my mouth and everything. . . . So I had to run to the ladies.

Her description was typical of most participants interviewed: “Your swallow is seriously affected. After eating a meal, it can come back up, like if you bend or working or anything, certainly your capacity to keep it down is impacted.” One patient remarked that although most of the time he had no difficulties with eating, it could happen, and when it did, it was potentially an embarrassing situation: “At times, you could get a difficult moment, it could be very embarrassing if it happened in a restaurant now, a bowl of soup or something, and before you know where you are it’s coming down your nose.” As illustrated by these descriptions, the participants’ altered swallowing capacity impacted their comfort when eating in public. In contrast, one explained that “I’m doing alright that way; there isn’t much that I can’t eat or drink.”

No participants described pain, although two experienced difficulties with neck muscles. One’s account indicated some degree of discomfort: “They cut that muscle away there [points to both sides of neck], and it puts an awful lot of pressure on that side.” With a similar sentiment, another acknowledged that the only thing he has to manage is his neck muscles: “Back neck and front neck muscles, I do exercise at home. . . . You got to keep reinforcing and building the neck muscles.”

**Speech difficulties:** Speech difficulties, a subcategory of functional difficulties, were a concern described by all
participants. Issues raised by the participants included their inability to alter speech volume and tone, the awkwardness surrounding speech, leaking valves, and the nonuniformity of their voices. Ultimately, their concerns indicated the high value that they attributed to speech.

One patient believed that the voice from the valve “is not the same as being able to talk clearly. . . . It’s not aggressive enough.” Another believed that speech was “awkward.” One expressed his disappointment with the different speech valve designs: “I’m very disappointed with a lot of designs. I’m five years now, there isn’t one new aid out in that time, the same old thing all the time.” He concluded by stating that he would “like something better than this” in his “throat.” One woman believed that the process of learning speech was “fairly easy” but that it took more than a year to perfect. The only thing that she found frustrating was that she could not “increase the volume” of her voice, as she detailed in light-hearted terms: “I can’t raise my voice, only so much, there’s no more shouting, which some people would say is a good thing.”

One man reflected on an experience when his speaking valve was removed because of an infection, which made him appreciate it: “I think when I heard my voice, I was depressed by it, I thought the quality of it was poor. But then I got an infection, and the valve had to be taken out. It’s only when it’s gone that I really missed it.”

Another woman admitted that her voice “isn’t always good” and that sometimes “it isn’t uniform.” One man conceded that no matter how hard he practiced he “can’t talk like a normal person.” Nonetheless, he admitted that the valve was “his saviour” and that without it he would not have “bothered to carry on with life.”

Psychological Impact of Total Laryngectomy

This category incorporates descriptions from the participants about depression, regrets, and personal resolve. In addition, the subcategory of personal resolve incorporates descriptions of self-determination, optimism, and realism toward the future.

All participants portrayed their lives as being a fine balance between being “up and down.” For one man, the first thing that really hit him was what he called a “horrible depression.” After he went home,

I was still down and anxious, and [the consultant] advised me to go to [a psychiatrist]. I went to him three or four times, and he put me on [an antidepressant]. . . . That did help an awful lot. I’ll be honest, that sorted it out, and I don’t have to take anything now.

He was the only participant to receive formal treatment for his depression. Another had a very different story: “My mood has never improved. There are times I’d ask myself, ‘Was it worth it?’ . . . The fact that you can’t say anything, it really dawned on you that you’re going to be this way for the rest of your life.” One participant admitted that he’d cried “several times.” The same participant vividly described how he felt after the operation: “I felt very down for a while, very fed up. At that stage, I would have nearly thrown myself in the river or something, really depressed, twas depression, I felt so low.” Another admitted that his “humor wouldn’t be too good” and that he would be “down and out a lot of the time.”

Altered mood and symptoms of depression were articulated by eight participants (all men). In contrast, one of the women stated that she was “very content,” which she related to the fact that she could drive.

Intrinsically linked with most participants’ descriptions of depression were expressions of regret. One female patient was of “two minds” afterward whether she did
the “right thing.” Two of the men had many doubtful thoughts: “There would be times when you wish it hadn’t happened and you wish you were involved in work and you wish you could articulate whatever you wanted.” Another said, “I suppose if I thought I had to go through this, I’d have no operation.” One concluded his interview by stating that he was “sorry he got it done.”

Despite the descriptions of depression and regrets, most participants were determined to get on with their lives through a process of self-determination, realism, and optimism toward the future. One of the women recalled how determined she was after the operation: “I said, ‘Sure, I have two girls, and they’ve already lost a father,’” so I was determined to get better, I was very determined; I never thought I wouldn’t get better.” Another believed: “No point in sitting down, lying down, and feeling sorry for yourself. . . . We’re at the right side of summer now. I’m looking forward to the fine weather and the beautiful long days.”

However, one man was realistic about the future and described a percentage analysis of his chances.

I think 90% of the time I do look forward, 10% of the time I’m realistic. You have moments and you have concerns, somebody you know has died. . . . I don’t plan long term. You think you’ll be around next year and the year after, you hope for that. If you didn’t adopt that, you’d probably die of something else.

Two participants emphasized their contentment with life: “I’m at my ease that I am as well as I am, to be honest with you. I wouldn’t let it stop me, like, you might as well be dead otherwise.” Another said, “I’ll be 65 next week. I’m going all day, and I’ll keep it going.”

The participants all expressed specific descriptions in relation to depression, regrets, and personal resolve, all of which had a direct impact on their lives.

**Discussion and Implications**

Ten participants’ experiences of having a total laryngectomy were elucidated through qualitative interviews. Findings from the study provide a unique description in understanding what living with a total laryngectomy is like. The study is one of few that afforded participants the opportunity to speak about their experiences.

Eating problems were reported frequently as problematic consequences of surgery for most participants in the study. Participants reported difficulties chewing and swallowing and limitations eating in public. Hammerlid, Mercke, Sullivan, and Westin (1998) studied a cross-section of patients with head and neck cancer (N = 48) and attempted to determine the functional difficulties that most affected their quality of life. Eating difficulties were common, with 51% of patients reporting difficulties with swallowing. The findings correlate closely with the findings of Campbell et al. (2000), who also found that chewing and limitations eating in public remained significant problems at three years for patients who had undergone total laryngectomy. Inherent in this problem was participants’ concern about excess phlegm, which is not evidenced in the literature. A postulated reason, according to Ziegler, Newell, Stafford, and Lewin (2004), is that the characteristics of functional complications in survivors of head and neck cancer have not been studied extensively. Also, as indicated by the literature review, studies using fixed quality-of-life categories may not capture the individuality of patients’ experiences and interpretations of illness. Findings from the current study show this to be true. One participant described the problem he had from recurrent infections of the speaking valve from *Candida*, a problem that is not described in the literature yet was an obvious concern for this laryngectomy patient.

Pain is considered to be a significant problem for patients after head and neck cancer (Fritz, 2001; Whale, Lyne, & Papanikolau, 2001). This was not replicated in the current study, perhaps because time that had elapsed since surgery ranged from 1.5–7 years. Two participants reported discomfort in neck muscles, similar to findings of the frequent general symptoms experienced by patients with oral and pharyngeal cancer (Langius, Bjorvell, & Lind, 1993). Fatigue is the most common persistent symptom in patients with cancer (Servaes, Gielissen, Verhagen, & Bleijenberg, 2007). Only one

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**Table 3. Sociodemographic Characteristics of Patients Interviewed After Total Laryngectomy**

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<td>Country of origin</td>
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<td>Rural</td>
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<td>Employment status</td>
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<td>Employed</td>
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<td>Marital status</td>
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<td>Single</td>
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N = 10
participant admitted that energy levels were not the same as before the operation. The research studies that have shown fatigue to be a problem after laryngectomy investigated patients who were 9–12 months after laryngectomy (DeSanto, Olsen, Perry, Rohe, & Keith, 1995; List et al., 1996), which may explain the difference in findings.

In the sample as a whole, difficulty with speech was a major concern. Although voice was restored for all of the participants with the alternative method of tracheoesophageal speech, all participants identified the quality of the new communication as not normal, both to themselves and to listeners, captured in the words of one participant as the “inability to lose yourself in the crowd.” Researchers have reported that loss of natural voice is not the most important dimension affecting quality of life after treatment for laryngeal cancer (Herranz & Gavilan, 1999; Llatas et al., 2003; Stewart et al., 1998). The findings from the current research study contrast strongly with previous research studies that used fixed quality-of-life categories. Although speech without a larynx is intelligible, demonstrated by the researcher’s ability to conduct face-to-face interviews, the participants reported many concerns over the quality of their voices: “I can’t raise my voice,” “It isn’t uniform,” “I’d like something better,” “I’m very disappointed,” and “Can’t talk like a normal person,” along with descriptions of difficulties of background noise, indicating a problem that seriously affects participants’ quality of life. One group of researchers (Devins, Stam, & Koopmans, 1994) concurred with the findings when they found that a high proportion of patients who had received laryngectomies felt that their loss of voice had a significant impact on their self-expression and social relations. This was directly related to decreased life happiness and increased emotional distress. Another study by Farrand and Duncan (2007) found that improved voice quality does not automatically result in widespread benefits to quality of life. Nevertheless, descriptions in the current study reveal many concerns over participants’ quality of voice, which ultimately affected their quality of life.

All participants in the study reported psychological difficulties, most commonly depression, which is consistent with other research studies (Bjordal & Kaasa, 1995; De Boer et al., 1999; Hammerlid et al., 1997, 1999). Byrne, Walsh, Farrelly, and O’Driscoll (1993) postulated that depression was associated with poor communication skills and geographical isolation. Although the authors cannot confirm the postulation about geographical isolation, their findings support that depression is associated with poor communication skills. Impaired communication might be a vulnerability factor for depression, as most participants described the difficulty they experienced in learning speech and their disappointment with the quality of it. This emphasizes the importance of early attention to communication skills and suggests that learning to speak as soon as possible can help reduce psychological distress. Byrne et al. (1993) recommended that patients undergoing mutilating forms of surgery should receive psychiatric intervention in the form of counseling, support groups, and antidepressant medication. Interestingly, only one participant in the study received psychiatric counseling and antidepressant medication even though all of the participants displayed symptoms of psychological distress.

Participants also demonstrated through their descriptions that increased time since onset of illness was associated with lessening depression. Several individuals within Hutton and Williams’ (2001) study also reported that distress lessened during the course of their illness. These findings seem to be more consistent with a model of adjustment and reduced distress such as that postulated by de Graeff et al. (2000a) rather than with the model of patient burnout described by Rapoport, Kreitler, Chaitchik, Algor, and Weisssler (1993). de Graeff et al. (2000a) suggested that rather than patients burning out, they tend to adjust to their illness. They found that despite deterioration, a gradual improvement occurred in depressive symptoms during the years after treatment.

Intrinsically linked with most participants’ descriptions of depression were feelings of regret, such as being of “two minds” and “wishing it hadn’t happened.” One participant said that if he had the chance again, he would have no operation. This level of regret appeared to be higher in those participants who reported complications with speech and phlegm. These findings resonate with those of Gamba et al. (1992), who assessed the advantages and disadvantages of surgical treatment for patients with head and neck cancer. Approximately one of three was found to be unsatisfied with the treatment outcome or claimed to have suffered too much from treatment. In this situation, patient willingness to tolerate any form of surgery merely to survive may become secondary once they are cured and have to face the prime objective of psychological and social adaptation.

Findings from this study also indicate that psychological distress among the participants is not limited to the immediate postoperative period, which corresponds with similar findings from the literature (Bjordal & Kaasa, 1995; Hutton & Williams, 2001; Rapoport et al., 1993). Despite these descriptions of concerns from all participants, most still have a strong personal resolve for life and the future. However, this personal resolve is influenced heavily by the participants’ ability to “keep busy” and “not to be idle.” This concept is not discussed in the literature in relation to patients who have had a laryngectomy, perhaps because of the vast amount of fixed quality-of-life studies published.
Limitations

The principal limitation of the study was the small sample size. Nevertheless, generalizability is not a guiding criterion in qualitative research; the expectations for determining whether the findings are transferable rest with potential users of the findings. A methodologic limitation of the study was reliance on data gathered through a single interview. An alternative could be to use two focus groups: one to learn patients’ stories and the second to receive meaningful comments on standards and the process of head and neck cancer care as a whole.

Only two women were included in the sample, limiting insight from the female perspective; hence, a wealth of unexplored data may exist related to this phenomenon. Further study to ascertain patients’ perspectives with an equal male-to-female ratio would allow a comparison between the genders.

Nursing Implications

Nurses are suitably positioned to support this group of patients across the disease-management trajectory, from the initial preoperative period to the postoperative period and through to the rehabilitative period and beyond. Nursing roles in head and neck cancer support (e.g., nurse specialists) should be explored and expanded. Indeed, education from nurses who specialize in head and neck cancer have been identified as best practice by patients themselves (Thorne, Bultz, & Baile, 2005). Based on the descriptions provided in this study, nurses must take time to listen to patients’ concerns and acknowledge their right to express all emotions. Continued work and research to measure the impact of interventions designed to reduce functional disability also are required. Findings suggest a possible role for psychologists as members of the healthcare team to help patients adjust to their new status. Cognitive therapy and referral to support groups are likely to be particularly useful in tackling the hopeless and helpless thinking associated with depression (Hutton & Williams, 2001).

Conclusion

One of the major conclusions of the study is that, as a group, patients who have received total laryngectomy suffer from a broad range of problems. Some are closely related to the disease itself, such as the direct and indirect effects of the surgery and the treatments (e.g., phlegm, discomfort in neck muscles, difficulty eating and drinking). Most problems, however, are largely psychological. Long-term survivors of total laryngectomy experience treatment effects well after completion of treatment. The findings reinforce the need for rehabilitation management for prolonged periods after surgery. Psychological needs and dietetic needs should be addressed in all patients who have received laryngectomy and incorporated into their treatment plans before definitive management commences, namely in the preoperative period. Problems with speech emphasize the crucial role of speech and language therapy.

Living with the functional and psychological difficulties described is a continuous struggle for patients. This study highlights the difficulties and, in so doing, will assist nurses and healthcare staff in developing improved standards of care for patients with laryngeal cancer.

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