The Woman Who is Laryngectomized: Parallels, Perspectives, and Reevaluation of Practice

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ABSTRACT
This review centres primarily on clinical perspectives related to women who have been diagnosed and treated for laryngeal cancer and issues that impact clinical practice for women. Traditional care of the laryngectomized individual has been defined by the fact that the majority of affected individuals are male. However, demographics have changed in the past two decades and the occurrence of laryngeal cancer in women has increased dramatically. Thus, new concerns are emerging. It is for this reason that clinical practice must be reevaluated in order to address issues that may not previously have been a primary concern for males who are treated for laryngeal cancer. In order to facilitate a reevaluation of issues that may have particular impact on the female who undergoes laryngectomy, it is proposed that other literature, in particular that related to breast cancer, may offer important parallels that will serve such considerations.

KEY WORDS: laryngectomy • rehabilitation • laryngeal cancer • quality of life

Individuals with life-threatening illnesses may be affected in many ways by such an experience. Despite a general belief that illness may be perceived (and perhaps responded to) differently by men and women, and that some treatment forms may have a more significant long-term impact based on one's gender, little is known about such issues. In the case of malignant disease, certain changes may have a dramatic influence on one's recovery and ultimate rehabilitation outcome. The attitudes of others, and of society at large, will often bear significantly on this process. In this regard, a majority of women who have survived breast cancer are reported to have come away from the experience with a positive and optimistic outlook, despite the many hardships endured (Ganz et al., 1996). These women found life richer and were "energized to look for changes in our environment and the future" (p. 198). The ability to see light following what would appear to be an overwhelming cascade of darkness may foreshadow many successful clinical outcomes. Attitudes of both the individual patient and that of others may play a considerable role in long-term rehabilitation efforts. The purpose of this review is to address several broad issues related to laryngectomized cancer and gender in order to facilitate a reevaluation of issues that may have particular impact on the woman who undergoes laryngectomy. It is proposed that other literature, in particular that related to breast cancer, may offer important parallels. The potential impact of these conceptual changes on clinical practice and suggestions regarding emerging considerations are discussed.

Illness, Rehabilitation, and Clinical Care
Those who participate in the care and treatment of seriously ill or disabled persons have the responsibility and the opportunity to contribute in a positive way to the person's outlook on life. Accomplishing this is a formidable challenge, particularly given the diversity of individuals' responses when treatment choices are presented (e.g., McNeil, Reic-Tabbaa, & Pauker, 1988). The removal of the larynx in individuals di-
agreed with laryngeal cancer is a treatment which causes profound changes in anatomy, physiology, and verbal communication, and these changes will persist for the remainder of the individual's life. Using the World Health Organization's definitions, the pivotal or total removal of the larynx results in varying levels of physical impairment, functional disability, and social handicap (Doyle, in press). Based on the work of Goffman (1963), Doyle (1994) described the risk of being socially penalized due to the subtle (or sometimes obvious) stigma of the diagnosis of cancer, as well as the likely departure from society's standards of normality in voice, speech, and appearance following treatment for laryngeal cancer. Given that society's standards and expectations are not the same for men and women1, it seems important to more closely examine women's rehabilitation needs and to consider specific obstacles that they may face postlaryngectomy. This is particularly true when one considers the increasing number of women undergoing laryngectomy.

Gijsbers Van Wijk, Van Vliet, and Kolk (1996) discussed gender bias as a potential contributor to inadequate health care in several realms including the management of serious, life-threatening diseases. They drew upon the Fourth International Conference on Women in Beijing and the women's health care movement in the Netherlands to formulate some general recommendations for achieving more adequate (gender-sensitive) and appropriate (nonmedicalizing) health care for women. These issues are clearly relevant to all health care workers, with specific importance for physicians, speech-language pathologists, nurses, social workers, and counsellors relative to the treatment and rehabilitation of women with laryngeal cancer. Gijsbers Van Wijk et al. discussed the importance of considering the different social and cultural roles, expectations, and constraints placed on men and women by virtue of their gender (Richardson, Graham, & Shelton, 1989). They pointed out that women, when affected by the same health problems as men, may experience them differently. Consequently, women have different fears and expectations from health care services. Further, Gijsbers Van Wijk et al. provided evidence that women are stereotyped in medical practice as "suffering disproportionately from [...] vague", medically unexplained physical complaints and ailments as well as from emotional problems" (p. 711). Gijsbers Van Wijk et al. explained how sex stereotypes such as these may influence clinical decision-making, with physicians more likely to attribute women's health problems to emotional causes, rather than to physical ones. There is support for this view of gender bias in clinical decision-making with respect to laryngeal cancer (Brown, 1998; Laksmanis, 1997). Hence, speech-language pathologists and other professionals must seek to make carefully structured rehabilitation protocols following treatment for laryngeal cancer by respecting emotional, as well as other needs. As part of this reevaluation process, clinicians should seek to reduce the potential influence of gender on potentially problematic a priori assumptions by seeking direct information from the individual. If such information is obtained, a program of rehabilitation may be tailored to each individual's needs. Similarly, those who conduct research in the area of laryngectomy, as well as other types of head and neck cancer rehabilitation, should seek to obtain information across a broad area of issues (e.g., self-perception of body image and disfigurement, quality of life measures, etc.) for both men and women. By doing so, gender stereotyping may be avoided. Should gender-specific aspects emerge, these areas can be targeted for special attention.

Gijsbers Van Wijk et al. (1996) advocated that health care must become more sensitive to gender differences regarding how one experiences health problems, the individual's response(s) to and implications of treatment resulting from socialization processes, and the social positions and social roles men and women occupy in society. They recommended three main guidelines with respect to the education of health care workers. These guidelines are clearly applicable to the care of individuals who must undergo treatment for head and neck cancer. The first is the principle of self-determination. Health care providers should be taught to take women's health complaints seriously (Laksmanis, 1997) and to do everything in their power to strengthen women's ability to make decisions concerning their own health (see Gunderson, 1999). Secondly, diversity in women's interests, health care needs, and views about quality of care may vary depending on age, socioeconomic and cultural background, ethnicity, religion, etc. Thirdly, there must be adherence to a holistic approach. Health and illness must be viewed in their social context, with consideration of physical, psychological, and societal aspects. This requires direct exploration of how the issues of self-determination, diversity, and the holistic approach differentially affect men and women. In this regard, it is likely that unique considerations will emerge for women that require modifications to existing programs of clinical care.

Gender and Laryngeal Cancer

There is a relative scarcity of information about the particular needs and concerns of the growing population of female laryngectomized women. (The American Cancer Society's publication Cancer Facts and Figures - 1996 reported a 67% increase in death rates due to cancer of the larynx among females when statistics from 1960 to 1962 are compared with those of 1990 to 1992. Over the same thirty year period, the corresponding data for males indicate a 7% decrease in mortality due to cancer of the larynx. The same publication reported the estimated number of new cases of laryngeal cancer in the United States in 1996 as 9,200 males and 2,400 females (1 female for every 3.8 males). In Canada, the ratios are similar; the 1996 estimated incidence rates of laryngeal cancer were 1,100 males and 260 females (1 female for every 4.2 males) according to the National Cancer
Institute of Canada's publication *Canadian Cancer Statistics 1996*. In contrast, 10 years ago *Canadian Cancer Statistics 1987* reported that the incidence of laryngeal cancer was 953 males and 149 females (1 female for every 6.4 males). Clearly, the trends in the data point to the need for clinicians and researchers to focus a more concerted effort on understanding how the experience of treatment for laryngeal cancer in general, and for total laryngectomy in particular, affects women.3 There is a need to explore further the many psychosocial, communicative, vocational, and cultural issues which surround the planning of a comprehensive treatment program and successful rehabilitation strategy for women. It seems clear that requirements in such areas cannot be assumed to be the same for males and females in North America. Gardner (1966) was one of the first to write about the problems of women who have undergone laryngectomy. Both the pre- and postoperative periods were described with respect to the reactions and problems of the patient, and the behaviour of family and friends. Both positive and negative experiences were reported. For example, Gardner (1966) found that many of the female patients reacted unfavourably to their disfigurement. Clearly, the effects of disfigurement (even if relatively minor) in a society that places significant value on physical appearance cannot be disregarded. It does not seem unreasonable to assume that issues of disfigurement may carry more social penalty and impact for women than for men. The level of support from families and friends in relations to perception of disfigurement was reported to be mixed. Relative to communication, Gardner reported a broad range of attitudes among the women he surveyed with respect to their confidence about learning to speak postlaryngectomy. These women reported problems with learning esophageal speech, particularly with the difficulty of being understood, and with being mistaken for men over the telephone. A major recommendation of these women was to improve education of the patient, family, employers, and the public. The primary complaint from many of the women was that they had not been informed of the problems they would face. The lack of information about what to expect contributed to their fears about their disfigurement and about returning to their premorbid vocational, recreational, and household activities. The lack of such information, both in the pre- and postoperative contexts, threatens adaptation to issues and problems that must be confronted. Not knowing what to expect was thought to make it more difficult to cope with learning esophageal speech and contributed to self-blame when verbal communication was difficult. In addressing the Gardner (1966) study, Snidecor (1969) concluded that "we must consider the laryngectomee as a whole person excepting only his (or her) lack of vocal cords" (p. 175). Snidecor discussed the role of the speeco-language pathologist in initial speech training, and in counselling the patient and family members, and advocating for the laryngectomee to his or her employer. In fact, advocacy for all patients treated for laryngeal cancer must be best provided by the speech-language pathologist (Doyle, 1994). It appears that Snidecor understood that speech training is of little value without psychosocial adjustment, and that both areas of the individual's life must be addressed within the comprehensive therapeutic process. Consequently, the complete program of postlaryngectomy rehabilitation, regardless of one's gender, will benefit from a multidisciplinary team approach. Minimally, one hopes that if questions arise, professionals will be able to provide necessary and appropriate referrals to address such concerns.

Gilmore (1994) has presented an extensive review of the literature concerning the psychosocial aspects of laryngectomy. He suggested that studies have not been consistent or conclusive in documenting the adjustment of the laryngectomized population to their circumstances. Further, Gilmore stated that the studies reviewed have not explained why theses individuals do or do not succeed in adjusting, notably in acquiring postlaryngectomy speech. He suggested one reason for this was the use of assumptions which "have almost become dogma" such as "failure implies problems with motivation," "use of an artificial larynx inhibits learning esophageal speech," and "premorbid personality traits are the primary determinants of success." Data in the more recent literature support rejection of these harmful dogmas. Gilmore pointed out that acceptance of this dogma may increase clinical failure by reducing the clinician's openness to other possible factors, physical or psychosocial, which may be blocking progress. When clinical failure occurs, clinicians should focus their efforts on ameliorating the cause(s) rather than assigning blame. This is particularly true when factors such as depression may influence clinical performance. In the late 1990s we have the ability to rapidly access information from other disciplines and literature from other perspectives (e.g., nursing, psychology, etc.) that may shed light on such concerns. Thus, although limited information on the female who undergoes laryngectomy is available, data from other illnesses and diseases may offer valuable insights for improving patient care.

Gilmore (1994) also identified an implicit assumption prevalent in much of the literature that the laryngectomized population is a homogeneous group. He rejected this notion and emphasized that the recognition of individual difference was an essential prerequisite for responsible clinical management. This belief has also been stressed by Gates, Ryan, and Lauder (1982) who implemented clinicians to cast aside this faulty assumption. Several other authors have also stressed the necessity of dealing with laryngectomees as flexible and individualized manner and the need to acknowledge heterogeneity in this population (Doyle, 1994; Gates et al., 1982). Thus, faulty logic and perhaps lack of sound information may predispose some clinicians to exclude from their consideration more
individualized components when structuring post-laryngectomy rehabilitation programs. If the speech-language pathologist does not consider individual differences in structuring programs of care, maximum rehabilitation success may be challenged and postoperative rehabilitation failure increased. Therefore, considering the increasing number of females who will be diagnosed and treated for laryngeal cancer, it is essential that clinicians and researchers explore the psychosocial, communicative, vocational, and other areas that potentially have a direct impact on recovery and rehabilitation.

Cancer Treatment, Body Image, and Related Problems

The emotional upheaval associated with a diagnosis of cancer is further intensified in treatment, particularly treatments associated with alterations in bodily appearance and function. The individual's ability to cope effectively with his or her disfigurement and with any associated physiological changes has begun to emerge as a critical factor affecting not only their response to treatment but the quality of the individual's life as well (Dropkin, 1989). Dropkin stressed that although head and neck cancer comprises only 3% to 6% of diagnosed cancers, it may be described as more emotionally traumatic than any other neoplasm.

The individual's anxieties concerning treatment and survival are compounded by fears of facial disfigurement and related functional impairment. Specifically, Dropkin noted that "Postoperative defects may be visible, may impair self-expression, or may reduce communication with others" (p. 213). These concerns have the potential to negatively and significantly impact the individual's body image and feelings of sexuality and desirability, including self-perceptions of femininity or masculinity. Similarly, Rohe (1994) determined that, in many cases, laryngectomy has a negative effect on body-image, social interaction, and sexuality. Ganz et al. (1982) have stressed the need for an increased awareness of the potentially broad-ranging effects of laryngectomy on the person's well-being. Based on these concerns, there appears to be a clear and obvious need to gather a new body of information in multiple areas (e.g., psychological, psychosocial, communicative, etc.) in order to better serve and address these emotional sequelae more effectively.

Ganz et al. (1999) conducted a follow-up study of breast cancer survivors, both two and three years after their primary treatment. Overall, these women were found to function fairly well compared to patients with other chronic diseases, often continuing to work and to perform normal roles. Despite these generally positive findings, it was determined that many physical, psychosocial, and sexual functioning problems affecting breast cancer survivors persist or even worsen over time. While the physical problems were not necessarily serious or disabling, many women wished they had received more detailed information about the physical recovery after breast cancer, and the persistence of many problems. Parallel considerations for women who have been diagnosed and treated for laryngeal cancer appear to be reasonable. There are similar findings in other problem areas such as body image concerns, fear of recurrence, decreased feelings of sexual attractiveness (Gardner, 1966), and ability to communicate with doctors. Ganz et al. suggested that interventions to address these common problems could be developed, which might lead to further improvement in the individual's quality of life beyond the first year after treatment.

Reassessing components of longer-term counselling (see Doyle et al., 1994, pp. 247-251) may be of benefit, particularly if specific areas of information are built into different phases of a given rehabilitation program. Although further study is required, different approaches based on gender considerations may provide valuable insights into how existing programs of intervention can be modified. The importance of highly structured counseling cannot be overstressed.

Dow (1995) discussed the many work-related adjustments necessary to accommodate cancer survivors. She reported that women, who make up an ever-growing percentage of the workforce, already experience discrimination, fear of losing important benefits, and stigma in the workplace. Dow talked about the "glaring absence of resources and support to assist in work reentry and management of social stigma" (p. 132) as being major concerns. Cancer survivors may have difficulty discussing health problems with coworkers, and have problems in asking and receiving assistance, which further limit reentry into the workplace. These concerns are clearly exacerbated in the case of laryngectomy where the individual may use an alternative, alaryngeal mode of speech communication (whether intrinsic - esophageal or extrinsic - artificial laryngeal device). Because work may serve as a primary source of meaning to the individual, work reentry issues are considered to be major concerns for both women and men who have experienced cancer. Dow suggested that future research about cancer rehabilitation should focus on (among others): incorporating quality of life measures into protocols of clinical trials, and developing interventions to decrease vocational problems associated with cancer. She concluded that physical, psychosocial, and spiritual late effects of cancer are common among...
women, that they may be both positive and negative, and that more studies are needed in order to determine the clinical implications of this information.

Clearly, Dow’s work has strong implications for the rehabilitation of women who have undergone a laryngectomy and where contemporary data are sorely lacking. She reported concern about body-image changes, uncertainty over the future, concern over intimate relations, and developing new friends. Age was suggested to be a major factor in determining the psychologic late effects. Younger women were reported to be more concerned about body-image and intimacy issues, while older women were said to face issues of losing social supports, becoming incapacitated, and lacking financial resources. Dow also reported that the degree of perceived social support and the nature of relationships prior to cancer are considered to be the best predictors of long-term adjustment after cancer. Thus, a healthy psychosocial adjustment is central to the successful rehabilitation of women who have a history of cancer. This suggests that the loss or reduction in one’s ability to verbally communicate may place women at greater risk for psychosocial difficulty with subsequent effects on adjustment and rehabilitation success.

Laryngeal Cancer, Laryngectomy, and Quality of Life

Doyle (1994) has discussed at length the potential for reduced quality of life in those who undergo laryngectomy due to the socially penalizing effects of the diagnosis of cancer, the disfigurement, the deviant speech characteristics, and the loss of the most natural communicative means for addressing and relieving emotional stress. Based on the work of Prutting (1982), Doyle further asserted that communication is the essence of a person’s personal and social identity, so that rehabilitative efforts must consider the social consequences of the disorder. Individuals undergoing therapy must be encouraged to confront their limitations, and therapy must include not only traditional therapeutic regimens, but also focus on activities which will support re-entry into society (see Ferrans, 1990). As stated by Doyle (1994, p. 259), “If re-entry does not occur, quality of life will certainly be diminished.” Consequently, and whenever possible, implementation of a multidisciplinary approach to rehabilitation is encouraged so as to address the multifaceted needs of each individual.

Taylor (1993) discussed the importance of a sense of meaning in life to the successful adjustment of patients with recurrent cancer. Her study confirmed that an individual’s sense of meaning is closely associated with the physical and psychosocial effects of cancer. She found that both high symptom distress and increased dependence were associated with a low (or unclear) sense of meaning, and that an unclear sense of meaning is associated with poor adjustment to illness. Taylor further suggested several strategies which may be helpful to promote a clear sense of meaning in one’s life. Examples of such strategies include encouraging patients to tell their life story, helping them to create legacies, facilitating social support, and exploring cognitive strategies. Taylor’s study was consistent with the view that treatment of individuals with recurrent cancer “must address the whole person – the physical, social, psychological, and spiritual dimensions of being” (p. 1403). Clearly, an important dimension of every person’s being is his or her verbal communication. Thus, for individuals who have experienced total laryngectomy, rehabilitation efforts must focus on the potential psychosocial and communicative effects of their surgery, including but not limited to their altered speech mechanism.

Dibble, Padilla, Dodd, and Mikowski (1998) explored gender-specific differences and similarities in the dimensions of quality of life (QOL) in a sample of 254 women and 222 men with diagnoses of cancer. Significant gender-specific differences were indeed found, leading Dibble et al. to suggest that gender-specific measurement tools need to be used to evaluate QOL. Dibble et al. stated that this study was the first to make this suggestion. Interestingly, the essential dimensions of QOL may be the same for those with and without a diagnosis of cancer. Acknowledging that it would be premature to infer practice implications from this study, Dibble et al. suggested that there should be research support for clinicians who “individualize their care and are sensitive to the ways in which men and women express changes in the quality of their lives as a result of cancer or its treatment” (p. 582). They also stressed the need for cultural sensitivity when considering gender differences and similarities.

Tate, Riley, Perna, and Roller (1997) assessed the relative importance of various QOL dimensions to overall QOL and life satisfaction among women with physical disabilities and breast cancer, and evaluated gender differences by comparing their QOL and life satisfaction scores to those of men with similar conditions. The sample included 99 women and 117 men with physical disabilities or cancer. QOL was defined to be a multidimensional construct including physical, psychological, social, and economic dimensions. Life satisfaction was a more individualized, subjective, and global assessment of QOL according to the person’s chosen criteria. There were no significant differences found between men and women with respect to their quality of life or life satisfaction; however, some differences were observed with respect to factors that best predict QOL and life satisfaction for women versus men. Women tended to be particularly concerned with the impact of their overall health on their ability to function independently and perform daily tasks. Conversely, the QOL and life satisfaction of men were significantly correlated with their social well-being, suggesting to the authors that men may be more concerned with their overall health with respect to how it affects their ability to enjoy life. Tate et al. suggested that the differing perceptions of men and
women wish respect to the impact of health changes should be considered in planning rehabilitation. There were also some differences between women with traumatic conditions versus chronic conditions. For women with chronic conditions, life satisfaction was best predicted by age, education, and spiritual well-being. Tate et al. concluded that gender, psychosocial factors, and type of diagnosis need to be considered when attempting to predict the impact of a physical condition on one’s quality of life and life satisfaction. Thus, the more widespread use of quality of life (QOL) measures is encouraged with a particular focus upon those issues that are common to both men and women, as well as those that distinguish between gender (Allen & Doyle, 1997).

Conclusion

This paper has addressed issues related to women who are treated for laryngeal cancer. The thrust of this presentation has centered on providing an introductory framework from which one can understand, to some extent, the impact cancer has on the individual. An additional focus has attempted to provide parallels between laryngeal and breast cancer in regard to the physical disfigurement and change in body-image, as well as the potential stigma associated with such a disease and its treatment. Based on the information presented, it appears that much of the information from the literature on breast cancer may provide a valuable framework from which we might improve our understanding of the female who undergoes laryngectomy. Given the increasing incidence of women diagnosed with laryngeal cancer, the ability to evaluate the impact of the disease and treatment on the patient in general, and on women in particular, may offer insights into how to modify counselling and treatment programs. With such information at hand, it is suggested that an improved understanding of the female who undergoes laryngectomy that is close to that which existed before treatment is dependent upon numerous factors. Outcomes may be affected by: demographics such as gender, age, or culture; the degree of social and communicative competence; psychological factors including sense of meaning in life and strategies for coping with emotional pain; and, perhaps most importantly, the complex combination of characteristics that makes each individual unique. Rehabilitation programs for those who have undergone a laryngectomy must broaden the area of focus to include multiple dimensions that may influence rehabilitation. This can be done effectively only with a better understanding of the needs and concerns of those who are diagnosed and treated for laryngeal cancer and women will comprise a steadily in-...


