

Philip C. Doyle, PhD
 Department of
 Otolaryngology Head
 and Neck Surgery
 Schulich School of
 Medicine and Dentistry
 The University of
 Western Ontario
 Voice Production and
 Perception Laboratory
 Rehabilitation Sciences
 University of Western
 Ontario
 London, ON, Canada

Adam M. B. Day, MSc
 Voice Production and
 Perception Laboratory
 Rehabilitation Sciences
 University of Western
 Ontario
 London, ON, Canada

Heather D. Whitney, MSc
 Voice Production and
 Perception Laboratory
 Rehabilitation Sciences
 University of Western
 Ontario
 London, ON, Canada
 Currently affiliated
 with School District 67,
 Okanagan Skaha, British
 Columbia, Canada

Candace Myers, MSc
 Cancer Care Manitoba
 Winnipeg, MB, Canada

Tanya L. Eadie, PhD
 Department of Speech
 and Hearing Sciences
 University of Washington
 Seattle, Washington,
 United States

■ The Utility of Symptom Checklists in Long-Term Postlaryngectomy Follow-Up of Tracheoesophageal Speakers

■ L'utilité d'une liste des symptômes pour le suivi à long terme après une laryngectomie chez les locuteurs ayant recours à la parole trachéo-œsophagienne

Philip C. Doyle
 Adam M. B. Day
 Heather D. Whitney
 Candace Myers
 Tanya L. Eadie

Abstract

This study evaluated the application and clinical utility of the Rotterdam Symptom Checklist (RSCL) in the long-term follow up of individuals who had undergone total laryngectomy. The RSCL provides an index of physical, psychological, and activity status in those who experience illness and/or disability. Twenty-four adults (12 men and 12 women) served as participants. All 24 speakers used tracheoesophageal (TE) speech as their primary mode of alaryngeal communication. Based on the data obtained, substantial variability was observed for both women and men who participated. While extensive deficits were not noted for some areas of assessment addressed in the RSCL, this symptom assessment instrument appears to be sensitive to a variety of concerns that may exist in the more extended postlaryngectomy period. Such evaluations are not typically considered in the long-term period postlaryngectomy after regular medical surveillance has been completed. Thus, the findings of the present study suggest that the use of such symptom checklists could provide an ongoing baseline measure across the three domains represented in the RSCL. The value of this type of continuous baseline over the course of long-term follow up by speech-language pathologists would seem to offer considerable value to evaluating rehabilitation and the process of monitoring both short- and long-term postlaryngectomy outcomes.

Abrégé

La présente étude a évalué l'utilisation et l'utilité clinique de la Liste des symptômes de Rotterdam pour le suivi à long terme des personnes ayant subi une laryngectomie totale. Cette liste fournit un index de l'état physique, psychologique et du niveau d'activités des personnes malades ou ayant une incapacité. Vingt-quatre adultes (12 hommes et 12 femmes) ont agi comme participants. Les 24 locuteurs avaient principalement recours à la parole trachéo-œsophagienne comme mode de communication alaryngée. Selon les données obtenues, il existe une variation substantielle pour les femmes et les hommes ayant participé à l'étude. Bien que l'on n'ait pas relevé de déficits considérables pour certains aspects contenus dans la liste, cet outil d'évaluation des symptômes semble être sensible à un éventail de préoccupations qui peuvent se faire sentir dans la période prolongée suivant la laryngectomie. De telles évaluations ne sont généralement pas prises en compte pour une période prolongée à la suite de la laryngectomie et une fois que le suivi médical régulier a pris fin. Ainsi, les résultats de la présente étude montrent que l'utilisation d'un tel outil peut servir de mesure de base permanente pour les trois aspects évalués par la Liste des symptômes de Rotterdam. La valeur de ce type de mesure de base permanente dans le cadre d'un suivi à long terme effectué par des orthophonistes semble considérable pour évaluer la réadaptation et faire le suivi des résultats à court et à long termes après une laryngectomie.

Key words: laryngectomy, head and neck cancer, quality of life, laryngeal cancer, symptom checklists, rehabilitation

Based on current statistics provided by the Canadian Cancer Society (2009), the diagnosis of laryngeal cancer represents approximately 1% of all new cancer sites in men and less than 0.5% in women. Despite the infrequent occurrence of laryngeal cancer relative to more widely recognized sites of malignancy (e.g., breast, prostate, lung, etc.), the consequences of laryngeal cancer are indeed dramatic. The diagnosis of laryngeal cancer and its treatment clearly may produce adverse physical and psychological effects on the individual (DeSanto, Olsen, Perry, Rohe, & Keith, 1995; Devins et al., 1994; Doyle, 1994, 1999, 2005). More specifically, a variety of changes secondary to the treatment of laryngeal cancer will cross anatomic, physiologic, psychological, social, and emotional boundaries. Changes across these domains will ultimately influence the individual's ability to participate fully in a variety of activities that frequently took place with ease prior to cancer treatment. Although such concerns cross a wide range of head and neck cancers (Rieger, Zalmanowitz, & Wolfaardt, 2006), the focus within the present treatise is specifically related to laryngeal malignancy and treatment via total laryngectomy. When considered collectively, the impact of these types of changes will have a corollary influence on the individual relative to one's general well-being (Doyle, 2005) and overall "quality of life" (QOL; Hassan & Weymuller, 1993). Further, it is well documented that verbal communication and swallowing are significantly influenced in those who are treated with radical surgical procedures such as total laryngectomy (Ackerstaff, Hilgers, Aaronson, & Balm, 1994; List et al., 1996; Ward, Bishop, Frisby, & Stevens, 2002). Taken together, a diagnosis and subsequent treatment of laryngeal cancer is likely to have a direct influence on one's general activity level and well-being, as well as creating the potential for physical and psychological symptom distress. The presence of distress broadly defined at any point in the post-treatment period (regardless of treatment modality) is an essential dimension to monitor and document. Thus, the ability to easily and efficiently identify and monitor such changes in the postlaryngectomy period may be viewed as an essential and necessary component of the short- and long-term rehabilitation process.

It is well-recognized in the communication disorders literature that the speech-language pathologist (S-LP) often plays a critical role in the care of those individuals who are diagnosed with laryngeal cancer (Doyle, 1994; Doyle & Keith, 2005; Edels, 1983; Myers, 2005; Salmon & Mount, 1991; Snidecor, 1968; and others). Although the primary role of the S-LP has traditionally focused on seeking to provide voice and speech rehabilitation, as well as dysphagia and diet management, the role of the S-LP is often more extensive. Frequently, the responsibilities assumed by the S-LP extend considerably beyond communication, eating, and swallowing in this clinical population. The duties and responsibilities of the S-LP are indeed multidimensional in many health care settings. The role of the S-LP in direct patient care often begins in close proximity to the time of diagnosis with preoperative counseling (Doyle, 1994;

Salmon & Mount, 1991). The continued involvement of the S-LP will then most likely involve the formal aspects of voice, speech, and dysphagia rehabilitation with subsequent broad-based counseling occurring in the early postoperative period. In many cases, rehabilitation extends into the months and even years following surgery (Doyle, 1994). However, a frequently unacknowledged yet critical aspect of the S-LP's responsibility often rests with long-term follow up issues. For example, in many instances it is not unusual for the S-LP to have close, regular, and long-term professional contact with those who have been treated for laryngeal cancer. As a result, post-treatment clinical visits with the S-LP provide an easy and valuable opportunity for regular assessment of not only the individual's general communication, but, perhaps more importantly, of the individual's general physical and psychological status and well-being (Doyle, 2005; Myers, 2005).

Ideally, postlaryngectomy clinical visits involve regular appointments with the S-LP after "formal" communication and swallowing treatment has been completed. For example, these sessions may involve aspects of tracheoesophageal prosthesis management, troubleshooting with an electrolarynx, or answering questions related to dietary restrictions and associated management. These clinical appointments with the S-LP often provide the opportunity to directly address any problems that have been encountered over the course of recovery and rehabilitation and provide information and resources as needed (Doyle, 1994; Doyle & Keith, 2005). Many experienced clinicians will attest to the wide array of concerns that emerge within such contacts. In such circumstances, the S-LP may be able to provide information, recommendations, and solutions to specific problems, or if the concerns are out of their professional domain, the S-LP can serve a valuable role in seeking appropriate referral(s) for the individual and his or her specific problems or concerns (Doyle, 1994, 1999). Thus, with exception of regular medical follow-up for those who have been treated for laryngeal cancer, the S-LP may have the greatest opportunity for the most regular and longest term contact with the individual in the post-treatment period. Consequently, the S-LP may be in an ideal position to identify problems that might require more expedient levels of consultation with other health care professionals.

If the S-LP maintains regular contact with the individual who is laryngectomized, this may suggest that the individual's general health status, and perhaps better stated, one's functional status and health related QOL (Trew & Maguire, 1982), could be easily and effectively monitored in a longitudinal fashion. Because laryngeal cancer and its treatment hold the potential for changes in one's level of distress and associated levels of physical and psychological symptoms that may certainly change over time (List et al., 1996; Nalbadian et al., 2001; Terrell, Fisher, & Wolf, 1998), we believe that the S-LP might be in the best position to assess related areas of change or concern over the longer term of recovery, rehabilitation, and ideally, social re-entry. One method that could prove to be a valuable addition to

post-treatment clinical follow-up visits to the S-LP would be through the use of simple “symptom” checklists (Myers, 2005). The use of checklists to monitor an individual’s health and functional status in the presence of a disease or following curative treatment has been reported in a number of works that have focused on issues underlying QOL (Bruera et al., 1991; de Haes, van Knippenberg, & Neijt, 1990; Myers, 2005) and indeed appears to be gaining wider acceptance in a variety of clinical venues that address concerns of those with cancer.

Over the years, several instruments have been designed to specifically measure symptom clusters, including the Edmonton Symptom Assessment Scale (ESAS), the M. D. Anderson Symptom Inventory (MDASI), the Memorial Symptom Assessment Scale (MSAS), the Symptom Distress Scale (SDS), the Rotterdam Symptom Checklist (RSCL), and others. The general goal of such tools is to address one’s abilities (or reductions in ability) within specific domains of function. It is common to see several areas addressed in an effort to identify changes in physical and psychological symptoms and/or alterations in one’s physical abilities or activities. It is, however, generally agreed that measurement instruments of this type can serve to reliably identify, and perhaps index, one’s functional status for a given time period.

In this regard, it may be suggested that such a checklist also might provide a measure of the individual’s status over the post-treatment period. Thus, if problems were identified in a timely fashion, they could then be addressed in a more expedient manner and could have an impact on the success of the rehabilitation process (Paice, 2004). For example, it has often been reported that concerns related to speech and swallowing impairments diminish as an individual learns to adapt to his or her condition post-treatment for laryngeal cancer (Nalbadian et al., 2001), yet concerns related to physical pain and psychological well-being may continue to exist even 10 years after treatment (Terrell et al., 1998). In addition, concerns related to speech or swallowing in every day activities may remain (Ward, Koh, Frisby, & Hodge, 2003). In such cases, the benefits of using symptom checklists would be twofold: (1) results could be used to identify areas of concern for referral to other health care professionals and (2) if other areas of concern were treated (e.g., mental health, pain), this could benefit areas within the scope of practice for the S-LP (e.g., social participation and communication; sharing mealtimes with friends and family). Thus, the purpose of this preliminary study was to assess the utility of a well-established symptom checklist that is designed to address physical, psychological, and activity status for a fixed interval of time. By undertaking this preliminary assessment, we reasoned that areas of concern addressed within the symptom checklist potentially could be used as a method of indexing the overall status of individuals who completed this simple tool. It was reasoned that the symptom checklist could serve as an ongoing measure of rehabilitation status, and possibly provide an efficient,

yet relatively concise measure of QOL in the postlaryngectomy period. These data might then support the use of such symptom checklists as a simple yet valuable tool in on-going assessments of those who have been treated for laryngeal cancer. Thus, while the primary objective of this study was directed at providing descriptive data for TE speakers relative to symptom report across physical, psychological, and activity domains, several specific research questions were posed: (a) Do differences in the report of postlaryngectomy symptoms exist between men and women? (b) Do demographic factors correlate with symptom outcome? and (c) Does self-perception of speech performance correlate with symptom outcome?

In considering our desire to evaluate the potential application and clinical utility of symptom checklists as a means of assessing long-term postlaryngectomy outcomes, we sought to eliminate a potentially primary confounding variable related to one’s chosen method of alaryngeal speech. In doing so, the present study included only individuals who had undergone tracheoesophageal (TE) voice restoration (Singer & Blom, 1980). The selection of only those who used TE speech was undertaken for two reasons. First, because TE voice restoration has been shown to be a generally viable and successful method of postlaryngectomy “alaryngeal” communication for more than 25 years, these participants may be perceived as experiencing fewer overall communication difficulties relative to their counterparts who use esophageal speech or the artificial larynx (Ward et al., 2002). As such, we felt that by reducing the overall potential for explicit communication difficulties related to inadequate acquisition of some mode of alaryngeal speech (e.g., esophageal and/or electrolaryngeal speech), questions posed in the present study could be addressed in a more independent fashion. Second, because TE is widely employed today in North America, we felt the present data might have more widespread initial application (Iverson-Thoburn & Hayden, 2000). Thus, it was anticipated that “communication” issues would be less likely to influence the responses they would provide to the symptoms addressed.¹ Additionally, recent work by Day, Dzioba, Beaudin, Eadie, & Doyle (2008) and Moukarbel, Doyle, Yoo, Franklin, Day, & Fung (2008) suggests that those who use TE speech may experience less voice-related disability relative to other alaryngeal methods. Hence, we believed that evaluation of TE speakers would reduce, at least to some extent, the potential negative influence of vocal disability on the measures gathered in this evaluation of long-term functioning and symptoms.

¹It should be noted that no questions directly related to communication status were included as part of the measurement tool evaluated in this investigation. However, communication limitations might have had some influence on several areas explored in the *psychological* and *activity* domains, thus our desire to reduce the potential influence of overall communication problems by using TE speakers.

Methods

Participants

The participants for this preliminary study were 24 adults who had undergone total laryngectomy. All participants had undergone TE puncture voice restoration (Singer & Blom, 1980) and currently used TE speech as their primary method of alaryngeal verbal communication. Participants included 12 males (mean age = 65 years 3 months; range = 49–81 years) and 12 females (mean age = 54 years 8 months; range = 39–60 years). Participants selected for inclusion were required to be at least 36 months postlaryngectomy. The mean period postlaryngectomy was 49.9 months for males and 57.5 months for females. The population assessed in the present study involved participants who were matched by gender relative to time postlaryngectomy; most participant pairs (male/female) were matched within one year, but no difference exceeding 18 months existed for any participant pairing. Table 1 presents demographic characteristics of the 24 individuals who participated in this study.

Additional Participant Demographics

Of the 24 participants, the males had used TE speech for a period ranging from 1 year 11 months to 5 years, 6 months; females had used TE speech from two years to 7 years, 6 months. Three males and six females had undergone primary TE puncture, with the remaining participants undergoing secondary puncture postlaryngectomy. Eleven males received radiation therapy as part of their cancer treatment; six males received preoperative radiation treatment and five males received postoperative treatments. In contrast, six females received radiation therapy, three preoperatively and three postoperatively.

Finally, as one component of the study, all participants were asked to provide a self-assessment of their own overall TE (communication) speech ability. No definition was provided other than a request for categorical identification of self-assessments. For males, three rated their speech as *excellent*, three assessed their speech as *above average*, and six assessed their speech as *average*. For females, six judged their TE speech as *excellent*, two assessed their speech as *above average*, two assessed their speech as *average*, and two assessed their speech as *below average* (see Table 2).

Procedure

All participants who agreed to participate in this preliminary investigation were contacted by an independent third party and asked if they would be interested in completing a brief questionnaire that focused on postlaryngectomy health issues. The contacting agent was a distributor for TE puncture voice prostheses and associated laryngectomy supplies (InHealth Technologies, Carpinteria, CA). The procedure that took place was as follows: When an individual contacted the distributor via phone to place a prosthesis order, the agent asked that person if they would be interested in completing a questionnaire as part of a study being conducted by an independent,

Table 1
Demographic Information for Male and Female Participants

Sex	Age ¹	Period PL ²	TE speech ³	Rad Tx ⁴
Male	65.3	49.9	44.2	Pre-op = 6
	(49–81)	(29–72)	(23–66)	Post-op = 5
				None = 1
Female	54.7	57.5	54.5	Pre-op = 3
	(39–68)	(24–90)	(24–90)	Post-op = 3
				None = 6

Notes: ¹Mean age is in years and months (range); ²period postlaryngectomy is in months (range); ³mean time using TE speech is in months (range); ⁴radiation therapy received (yes/no, pre-op/post-op).

Table 2
*Self-Ratings of Speech Proficiency for Female and Male Participants**

	Poor	Below average	Average	Above average	Excellent
Females		2	2	2	6
Males			6	3	3

*No descriptions other than the categorical labels for proficiency identified above were provided to participants.

external research group. If the individual agreed, the questionnaire, a letter of information, a consent form (in accordance with the ethical approval for the study), and a pre-addressed, postage-paid envelope was forwarded to the potential participant along with their order. Those who responded to this solicitation represented multiple geographic locales across North America. From the larger pool of TE participants who responded ($n > 90$), the gender- and time postlaryngectomy-matched group assessed in the current project was selected based on the previously outlined selection criteria.

Measurement Tool

The measurement tool employed in this investigation was the Rotterdam Symptom Checklist (RSCL) developed by de Haes and colleagues (1996) at the Northern Centre for Health Care Research in the Netherlands. The RSCL is a 38-item self-assessment instrument that requires the participant to identify one of four categories of response for a series of questions in three domains of inquiry. The ratings provided by the respondent to each area of inquiry represent a judgment of the degree to which the respondent experiences the presence of the given "symptom" within the past week (de Haes, Van Knippenberg, & Neijt, 1990). Of the 38 questions posed, 23 addressed symptoms in the *physical* domain, seven addressed *psychological* symptoms, and eight addressed symptoms dealing with *activity*. Each of the questions is then rated by the respondent with one

of four response choices that represent the presence or frequency of the symptom in question: *not at all*, *a little*, *quite a bit*, and *very much*. Once the respondent has completed the symptom checklist, the clinician/experimenter assigns a score of from 1 to 4 for each response (1 = *not at all*, 2 = *a little*, 3 = *quite a bit*, and 4 = *very much*). According to the authors of the RSCL (de Haes et al., 1996), a higher score for any question is seen to reflect a "higher level of burden or impairment." Examples of symptoms addressed in the physical domain include lack of appetite, sore muscles, headache, etc. In the psychological domain, symptoms included irritability, worrying, etc. Finally, in the activity level domain, areas addressed included care for myself, go shopping, etc. Additionally, an overall valuation of life question is posed at the end of the RSCL to assess the individual's perceived QOL (using a 7-point scale ranging from *extremely poor* [7] to *excellent* [1]). Finally, in addition to the RSCL, each participant was asked to complete a brief personal history questionnaire that provided demographic information in order to better define their status within their peer group of TE speakers. Thus, the RSCL may be viewed as a simple, composite instrument that seeks to capture the individual's functional performance across the domains noted

Data Analysis

From the 24 RSCL instruments gathered in the present study, the response data were calculated using the method described in the RSCL guidelines (de Haes et al., 1996). First, the sum of scores for all questions in each of the three symptom subscales (i.e., physical, psychological, and activity) was calculated and an overall raw score was generated. As stated by de Haes and colleagues, a higher score on any given symptom addressed in the physical or psychological content areas, or in any respective domain of evaluation, can be associated with a greater "level of burden or impairment." In contrast, a higher numeric response in the activity level is associated with lesser burden or impairment. This is also true for the responses provided in the respondent's overall valuation of life. Once a raw summation of item scores in each of the three domains included in the RSCL was completed, additional analyses were performed on the data. The individual scores within each of the three domains were then converted into a standard score using the following procedure recommended by de Haes et al. (1996). The analyses involved the generation of what the authors of the RSCL have called "transformed" scores (de Haes et al., 1996). The transformation of raw scores is undertaken in order to comparatively evaluate the level of impairment in one domain to that of another. This transformation involves applying the following procedure to an individual's score in any of the three domains:

$$\frac{\text{raw scaled score} - \text{minimum raw score}}{\text{maximum score} - \text{minimum score}} \times 100 = \text{transformed score}$$

The transformation of raw scores that are initially generated allows the clinician or experimenter to represent

a transformed score of 0 with no identified impairment and a score of 100 with the greatest impairment.

Results were calculated independently for each male and female participant. Normalized data scores were then analyzed for differences due to gender and other demographic variables using both parametric and nonparametric statistics. The relationship between RSCL domains to any demographic variables were determined using Spearman correlation coefficients with the exception of gender, which was calculated with rank-order biserial correlations because of its nominal nature. A predetermined level of statistical significance ($p < .05$) was used for all analyses.

Results

RSCL Scores

Based on RSCL data obtained, a composite picture of the male and female participants was generated for each specific symptom domain of interest. Specifically, the individual participant physical symptom raw scores were found to range from 23 to 50 for females and from 24 to 51 for males (the possible scores ranged from a low of 23 to a high of 92)². The transformed physical scores for women ranged from a low of 0 to a high of 39.13 and the range for was men from 1.45 to 40.58. In the psychological domain, the scores ranged from 7 to 19 for females and from 7 to 22 for males (range of possible scores: 7 to 32). The transformed psychological scores for women were determined to range from a low of 0 ($n = 3$) to a high of 48; for men, these scores ranged from 0 ($n = 2$) to 60. Finally, within the activity domain, the total score was found to range from 19 to 32 for females and from 26 to 32 for males (range of possible scores being 8 to 32). Transformed activity scores for women ranged from 4.17 to 100 ($n = 6$) and for men ranged from 16.67 to 100 ($n = 5$). Taken together, these scores indicated substantial variability across both women and men who participated.

The final data analyzed as part of this investigation related to the participants' overall valuation of life requiring a single numeric response from a 7-point equal appearing interval scale. The overall mean score for women participants was 1.42 (falling between *excellent* and *good*) and for men it was 2.08 (*good*). The means and standard deviations for all normalized scores of the RSCL domains and overall valuation of life for all 24 participants can be found in Table 3.

Differences between the RSCL domain scores and overall valuation of life scores for men and women were not found to be significantly different from one another.

²Assuming that a score of 1 is provided for all possible symptoms addressed within the subscale pertaining to this domain, a score of 23 would be achieved; conversely, if a score of 4 is provided for all symptoms, a maximum score of 92 would be achieved. The minimum and maximum scores for the other domains of inquiry would be generated in the same manner.

Table 3
Mean and SD for Domains of RSCL for Male and Female Participants

RSCL domain	Male		Female	
	Mean	SD	Mean	SD
Physical	18.00	12.01	13.65	11.47
Psychological	20.67	18.20	13.33	17.75
Activity	14.24	13.23	10.76	16.23
Overall valuation	2.08		1.42	

Notes: Transformed RSCL scores may range from 0 to 100 with higher scores reflecting poorer functioning or more substantial symptoms (i.e., greater levels of potential disability).

SD = Standard Deviation

Relationship between RSCL scores and demographic factors

Relationships between RSCL domain scores and demographic variables were calculated using Spearman correlation coefficients. Based on these analyses, no significant relationships were found. One significant relationship was found between presence/absence of radiation and scores on activity domain of the RSCL ($r = .620$), with those who had radiation showing worse activity scores. Overall valuation of life showed two significant relationships, the first to number of months since laryngectomy ($r = -.697$) and the second to time that the individual had used TE speech as their primary mode of communication ($r = -.620$); both relationships were found to be significant at a probability level of $< .05$.

Relationship between RSCL scores and self-rated speech scores

Each of the RSCL domain scores were significantly related to self-rated speech (physical, $r = -.580$; psychological, $r = -.694$; $r = -.635$, $p < .05$). However, overall valuation of life scores were not found to be significantly related to self-rated speech scores.

Discussion

The purpose of this preliminary study was directed at assessing the utility of a commonly used symptom checklist in the monitoring of individuals who had received a total laryngectomy as treatment for laryngeal cancer. All participants currently used TE speech as their method of alaryngeal communication. The specific measurement tool used, the *Rotterdam Symptom Checklist* (RSCL), was designed to evaluate the individual's status within physical, psychological, and activity domains, as well as obtaining a simple measure of one's overall valuation of life. Prior to conducting this preliminary study, it was believed that the three domains addressed within the RSCL could be useful in indexing the overall health-related QOL status of these individuals. We also believed that such measures could serve as a simple but valuable index of one's symptom status at a relatively fixed point in time (i.e., based upon

assessments of the symptom over the previous week). It was anticipated that symptom concerns as represented by questions included within the RSCL would emerge if information was solicited as part of this project. If true, it was anticipated that the RSCL or a similar type of symptom checklist instrument could serve as an ongoing, longitudinal measure of one's health status and/or health-related QOL over the extended course of the postlaryngectomy period. Results are discussed relative to RSCL group data, individual differences, and clinical implications of the utility of symptom checklists.

RSCL Group Data

From the standpoint of the "symptoms" assessed and the domains represented using the RSCL, the present data suggest that few symptoms were identified as being problematic at the time these participants completed the RSCL. These results are consistent with those found by previous studies, in that individuals who use TE speech as their primary mode of communication generally report good overall quality of life scores, particularly when this is evaluated many years postlaryngectomy (Eadie & Doyle, 2005; Hanna et al., 2004; Nalbadian et al., 2001; Weymuller et al., 2000). These results also are supported by the correlation that was found between time since surgery and the one question related to overall valuation of life ($r = -.697$). These results indicated better self-rated valuation of life as more time had passed since the individual had undergone surgery and had begun using TE speech as the primary mode of communication. Interestingly, no significant relationships were found between time variables and any of the domain scores. These results could have been masked by the fact that most participants in this investigation were between 4 and 5 years postlaryngectomy. Further investigation into these results is warranted, with the use of prospective studies. However, it should also be pointed out that while few symptoms were identified in the present group of participants, some symptoms were noted by some individuals, and when identified, the assessed magnitude of those symptoms was quite variable.

An additional significant relationship was found between presence of radiation and activity scores ($r = -.620$). That is, individuals who had radiation therapy, either pre- or postoperatively, reported reduced RSCL activity scores more often than did those individuals who did not receive radiation therapy. Although one might speculate that there were long-term effects of radiation that affected participation in activities, one might also expect that this might be generated through reduction in physical functions. Since the correlation with physical functioning was not significant, it appears that this was not the case. Instead, this result might be a reflection of the increased severity of disease in individuals who received both radiation and surgical therapy as opposed to surgery alone. It is clear that radiation does have side effects that are persistent throughout the life of the individual, and subsequently, the ability to monitor an array of symptoms that persist over time is clear. Further, as more aggressive treatment

protocols such as chemoradiation become the standard of care for some cancers, it would seem obvious that the ability to assess longer term outcomes is necessary. We are currently engaged in a prospective longitudinal study of such concerns and the progression of symptoms (either increases or decreases) over time.

Individual Differences Among RSCL Data

Although group mean values for the RSCL indicated high levels of functioning, it was anticipated that the checklists would be sensitive to individual differences and that some symptoms would emerge as problematic for some participants but not for others. That is, we believed that while these 24 participants would not identify a substantial number of symptoms or associated distress as a group, individuals would be able to document the presence of isolated symptoms that are represented within one or more of the three domains of the RSCL. These results are reflected in the variability and range of observed scores, demonstrating the sensitivity of the tool to various difficulties. Clearly, the present work was descriptive. However, we cannot stress the importance of considering the individual within the context of the present work (Doyle & Keith, 2005). While group performance and/or functioning specific to symptoms may not emerge explicitly, it is incumbent upon clinicians to understand that unique individual profiles will be observed and may change over time. Thus, although we pursued the present study as a pseudo-group design, we do not wish to degrade the critical importance of the individual in the context of our desire to monitor symptoms over an extended post-treatment period of time.

As noted, no group differences were found between male and female participants for domain scores. These results are similar to those found by previous researchers who used a disease-specific quality of life instrument (Eadie & Doyle, 2004). However, it was interesting to note that when the entire body of raw data was evaluated to determine if any particular symptoms clearly stood out within any given domain evaluated, some commonalities across men and women were observed, as well as some unique patterns of symptom identification. Namely, men consistently identified increased levels of symptomology in their responses to the symptoms of decreased sexual interest and acid indigestion, both symptoms being represented in the physical subscale. Distress associated with the symptom of acid indigestion also was reported for the women participants. In contrast to men, however, women reported that they experienced increased levels of distress associated with the physical symptoms of shortness of breath and dry mouth.

Despite the small sample from which these data were obtained, it may be suggested that as a result of the symptoms identified by some respondents, some clinical attention would be considered both at a group level and at the individual level. For example, the prevalence of concern about decreased sexual interest expressed by men indicates that issues of sexuality in the postlaryngectomy period cannot be discounted. This suggestion becomes even

more significant as one considers the potential for younger individuals undergoing treatment for laryngeal cancer, in addition to the increasing life expectancy despite cancer diagnosis and treatment (American Cancer Society, 2003). It is not unreasonable to assume that concerns about sexual interest and performance would be acknowledged given the importance of such behaviour in personal relationships. Doyle (1999) has recommended that while discussions of sexuality often have been avoided as part of counseling in those who are laryngectomized, such discussions are a mandatory component of comprehensive clinical care for those with laryngeal cancer, in that the impact of such changes are often dramatic with subsequent reductions in one's QOL. Although it is clear that such discussions may not fall within the expertise of the S-LP, the responsibility to ensure that an appropriate referral is provided cannot be overlooked.

Similarly, the concern raised by women regarding shortness of breath should be carefully evaluated in order to determine if such a physical symptom may relate, at least in the present sample, to the use of a TE puncture voice prosthesis in the presence of a tracheal airway with a typically smaller cross-sectional area relative to men. The impact of such symptoms reported by women is clear in that reductions in breathing likely may have an impact on the performance of other physical activities, and hence may limit one's ability to perform activities of daily living or those related to employment. Again, although group trends from this preliminary evaluation of the RSCL lack external validity, the concerns raised may be common concerns that likely merit follow-up and possible referral to other health professionals. For example, if issues related to breathing were addressed, this could increase general levels of activity, thereby reducing fatigue and increasing independence (Ackerstaff et al., 1993, 1995). This also could increase social participation, which has been reported to be the most important concern among those who undergo total laryngectomy (DeSanto et al., 1995). Similarly, when collective information on the presence and severity of symptoms is reported by individuals, this information may form a comparative base from which potential patterns of difficulty may be discerned.

Utility of Symptom Checklists

Through such comparative assessments of ongoing symptom checklists, symptoms that persist may suggest that appropriate action be pursued by the S-LP. Thus, use of such symptom checklists may affect rehabilitation success by removing barriers to clinical assessment of symptoms. Paice (2004) indicates that there are three kinds of barriers to assessment of symptoms: (a) those related to the health care professional; (b) those related to the patient; and (c) those related to the health care system. Health care professional barriers include the subjectivity of cancer-related symptoms and the assumption that patients will voluntarily report these sensations. Patient-related barriers include many of these shared assumptions, for example, the patient may assume that the health care professional

will anticipate problems, making reporting unnecessary. Patients are further reluctant to report symptoms because they do not want to bother their physician or family member. Finally, the health care system produces barriers, including time limits on the health care professional. Thus, the use of standardized symptom assessment tools would make it easier for otherwise unreported symptoms to be treated by appropriate members of the health care team (Myers, 2005).

The findings of the present study suggest that the use of such symptom checklists could provide an ongoing baseline measure across the three domains represented in the RSCL. The value of this type of continuous baseline over the course of long-term follow up by S-LPs would seem to offer considerable value to the monitoring process. Specifically, if changes are noted over time within or across any of the three domains represented on the RSCL, the clinician could then seek further clarification from the individual patient and make recommendations and/or referrals as deemed appropriate under the circumstances. Minimally, the clinician can solicit additional information from the person about the level and or severity of the symptom(s). Obviously, of greatest interest here is the fact that if changes are observed, the clinician could then perform a re-assessment, if necessary, prior to making any type of decision about follow-up. However, because S-LPs frequently develop substantial professional relationships with those who are diagnosed and treated for head and neck cancer, the method of evaluating whether such changes are caused by less significant reasons (e.g., patient was at the end stages of a cold, etc.) or by more significant reasons (e.g., potential disease recurrence or developing pathology) seems quite realistic. As with any type of high-quality clinical care, the clinician and patient must enter into a dialogue in order to fully evaluate problems and hopefully provide prompt suggestions and/or referrals for further help.

Results derived from symptom checklists also may provide reasons for success/lack of success with speech and/or swallowing outcomes. For example, results from the present study indicate significant results between self-rated speech and all domains of the RSCL. These results are consistent with those found by others, who have highlighted the importance of communication and social and psychological well-being. Previous results also indicate that coping strategies, adjustment, social support, social well-being, and psychological issues are positive predictors of post-laryngectomy outcomes (Blood et al., 1992, 1994; Doyle, 2005; Doyle & Keith, 2005; Palmer & Graham, 2004). Thus, use of symptom checklists also could inform the S-LP of possible causes of problems in their own scope of practice (Myers, 2005). Referrals to psychosocial programs also could bolster comprehensive speech and/or swallowing outcomes. For example, even when no dysphagia is indicated, individuals may still report distress (Ward et al., 2002).

Based on the present data, we feel that the use of symptom checklists such as the RCSL, or tools that are similar in their design and intent, could prove as a

valuable adjunct for the S-LP who works with individuals who are laryngectomized. Although the present work centered on those laryngectomized persons who used tracheoesophageal speech as their primary mode of verbal communication, the present data also may be reflective of other alaryngeal speaker groups. The important issue here is the desire to monitor individuals and if a problem emerges, to seek to remedy the problem in a timely manner and through the most appropriate means. The primary finding of the present project focuses clearly on the ability to monitor individual patients in an efficient and consistent fashion. Therefore, the present findings support the potential utility of symptom checklists as a simple and viable means of documenting issues that may underlie the health related QOL in individuals who are treated for laryngeal cancer, and perhaps those who are treated for other types of head and neck cancer, and who may be followed by speech-language pathologists (Doyle, 2005; Myers, 2005).

Conclusions

This preliminary study assessed the utility of a commonly used symptom checklist in the monitoring of individuals who had undergone total laryngectomy as treatment for laryngeal cancer. All participants currently used TE speech as their method of alaryngeal communication. The Rotterdam Symptom Checklist is designed to evaluate the individual's status within physical, psychological, and activity domains, as well as to obtain a simple measure of one's overall valuation of life. The underlying premise of this work centers on the fact that S-LPs may be in an ideal position to monitor health related changes, particularly those that could be addressed through use of a simple symptom checklist. The viability of this approach has been documented in the current project. Based on the information gathered, the utility of symptom checklists as part of the regular follow-up protocol for individuals treated for laryngeal cancer appears to be supported. Although further and larger scale research is required, these preliminary data support use of tools similar in construct to that of the RSCL. We are continuing to explore this important area of clinical outcome in those who have been laryngectomized and use a variety of alaryngeal voice and speech options.

References

- Ackerstaff, A. H., Hilgers, F. J. M., Aaronson, N. K., & Balm, A. J. (1994). Communication, functional disorders and lifestyle changes after total laryngectomy. *Clinical Otolaryngology*, 19, 295-300.
- Ackerstaff, A. H., Hilgers, F. J. M., Aaronson, N. K., Balm, A. J., & van Zandwijk, N. (1993). Improvements in respiratory and psychosocial functioning following total laryngectomy by the use of a heat and moisture exchanger. *Annals of Otolaryngology and Rhinology*, 102, 878-883.
- Ackerstaff, A. H., Hilgers, F. J. M., Aaronson, N. K., De Boer, M. F., Meeuwis, C. A., Knegt, P. P., et al. (1995). Heat and moisture exchangers as a treatment option in the post-operative rehabilitation of laryngectomized patients. *Clinical Otolaryngology and Laryngology*, 20, 504-509.
- American Cancer Society. (2003). *Cancer facts and figures - 2003*. Atlanta, GA: American Cancer Society.
- Blood, G. W., Luther, A. R., & Stemple, J. C. (1992). Coping and adjustment in alaryngeal speakers. *American Journal of Speech-Language Pathology*, 1, 63-69.
- Blood, G. W., Raimondi, S. C., Dineen, M., Kauffman, S. M., & Stagaard, K. A. (1994). Social support in laryngeal cancer survivors: Voice and adjustment issues. *American Journal of Speech-Language Pathology*, 3, 37-44.

- Bruera, E., Kuehn, N., Miller, M. J., Selmser, P., & Macmillan, K. (1991). The Edmonstron Symptom Assessment System (ESAS). A simple method for the assessment of palliative care patients. *Journal of Palliative Care*, 7(2), 6-9.
- Canadian Cancer Society, Statistics Canada, and Public Health Agency of Canada. Canadian Cancer Statistics (2009). Incidence and Mortality by Cancer Site (pp. 11-15). www.cancer.ca.
- Day, A. M. B., Dzioba, A., Beaudin, P., Eadie, T., & Doyle, P. C. (2008, November). Voice disability secondary to total laryngectomy and use of alaryngeal speech. Presented at the Annual Convention of the American Speech-Language, Hearing Association, Chicago, IL.
- de Haes, J. C. M., Olschewski, M., Fayers, P., Visser, M. R. M., Cull, A., Hopwood, P., et al. (1996). *The Rotterdam Symptom Checklist: A manual*. The Netherlands: Northern Centre for Healthcare Research (NCH), University of Groningen.
- de Haes, J. C. M., Van Knippenberg, F. C. E., & Neijt, J. P. (1990). Measuring psychological and physical distress in cancer patients: Structure and application of the Rotterdam Symptom Checklist. *British Journal of Cancer*, 62, 1034-1038.
- DeSanto, L. W., Olsen, K. D., Perry, W. C., Rohe, D. E., & Keith, R. L. (1995). Quality of life after surgical treatment of cancer of the larynx. *Annals of Otolaryngology, Rhinology and Laryngology*, 104, 763-769.
- Devins, G. M., Stam, H. J., & Koopmans, J. P. (1994). Psychosocial impact of laryngectomy mediated by perceived stigma and illness intrusiveness. *Canadian Journal of Psychiatry*, 39, 608-616.
- Doyle, P. C. (2005). Rehabilitation in head and neck cancer. In P. C. Doyle & R. L. Keith (Eds.), *Contemporary considerations in the treatment and rehabilitation of head and neck cancer: Voice, speech, and swallowing* (pp. 737-754). Austin, TX: ProEd.
- Doyle, P. C. (1999). Postlaryngectomy speech rehabilitation: Contemporary considerations in clinical care. *Journal of Speech-Language Pathology and Audiology*, 23, 109-116.
- Doyle, P. C. (1994). *Foundations of voice and speech rehabilitation following laryngeal cancer*. San Diego: Singular Publishing Group.
- Doyle, P. C., & Keith, R. L. (2005). *Contemporary considerations in the treatment and rehabilitation of head and neck cancer: Voice, speech, and swallowing*. Austin, TX: ProEd.
- Eadie, T. L., & Doyle, P. C. (2005). Quality of life in male tracheoesophageal (TE) speakers. *Journal of Rehabilitation Research and Development*, 42, 115-124.
- Eadie, T. L., & Doyle, P. C. (2004). Auditory-perceptual scaling and quality of life in tracheoesophageal speakers. *Laryngoscope*, 114, 753-759.
- Edels, Y. (1983). *Laryngectomy: Diagnosis to rehabilitation*. Rockville, MD: Aspen Press.
- Hanna, E., Sherman, A., Cash, D., Adams, D., Vural, E., Fan, C. Y., et al. (2004). Quality of life for patients following total laryngectomy vs. chemoradiation for laryngeal preservation. *Archives of Otolaryngology - Head & Neck Surgery*, 130, 875-879.
- Hassan, S. J., & Weymuller E. A. (1993). Assessment of quality of life in head and neck cancer patients. *Head and Neck Surgery*, 15, 485-495.
- Iverson-Thoburn, S. K., & Hayden, P. A. (2000). Alaryngeal speech utilization: A survey. *Journal of Medical Speech-Language Pathology*, 8, 85-99.
- List, M. A., Ritter-Sterri, C. A., Baker, T. M., Colangelo, L. A., Matz, G., Pauloski, B. R., et al. (1996). Longitudinal assessment of quality of life in laryngeal cancer patients. *Head & Neck*, 1, 1-10.
- Moukarbel, R., Doyle, P. C., Yoo, J., Franklin, J. H., Day, A., & Fung, K. (2008, June). Voice-related quality of life (V-RQOL) following laryngectomy. Paper presented at the 67th Annual Meeting of the Canadian Otolaryngology Society, Jasper, AB.
- Myers, C. (2005). Quality of life and head and neck cancer. In P. C. Doyle & R. L. Keith (Eds.), *Contemporary considerations in the treatment and rehabilitation of head and neck cancer: Voice, speech, and swallowing* (pp. 697-736). Austin, TX: ProEd.
- Nalbadian, M., Nikolaou, A., Nikolaidis, V., Petridis, D., Themelis, C., & Daniilidis, I. (2001). Factors influencing quality of life in laryngectomized patients. *European Archives of Otorhinolaryngology*, 258, 336-240.
- Paice, J. A. (2004). Assessment of symptom clusters in people with cancer. *Journal of the National Cancer Institute Monographs*, 32, 98-102.
- Palmer, A. D., & Graham, M. S. (2004). The relationship between communication and quality of life in alaryngeal speakers. *Journal of Speech-Language Pathology and Audiology*, 28(1), 6-24.
- Rieger, J. M., Zalmanowitz, J. G., & Wolfaardt, J. F. (2006). Functional outcomes after organ preservation treatment in head and neck cancer: A critical review of the literature. *International Journal of Oral and Maxillofacial Surgery*, 35, 581-587.
- Salmon, S. J., & Mount, K. H. (1991). *Alaryngeal speech rehabilitation: For clinicians by clinicians*. Austin, TX: ProEd.
- Singer, M. I., & Blom, E. D. (1980). An endoscopic technique for restoration of voice after laryngectomy. *Annals of Otolaryngology, Rhinology and Laryngology*, 89, 529-533.
- Snidecor, J. C. (1968). *Speech rehabilitation of the laryngectomized* (2nd ed). Springfield, IL: Charles C. Thomas.
- Terrell, J. E., Fisher, S. G., & Wolf, G. T. (1998). Long-term quality of life after treatment of laryngeal cancer. The Veterans Affairs Laryngeal Cancer Study Group. *Archives of Otolaryngology - Head & Neck Surgery*, 124, 964-971.
- Trew, M., & Maguire, P. (1982). Further comparison of two instruments for measuring quality of life in cancer patients. In J. Beckman (Ed.), *Quality of Life*. Proceedings of the Third Workshop of the EORTC Study Group on Quality of Life (pp. 111-127). Paris, France.
- Ward, E. C., Bishop, B., Frisby, J., & Stevens, M. (2002). Swallowing outcomes following laryngectomy and pharyngolaryngectomy. *Archives of Otolaryngology - Head & Neck Surgery*, 128, 181-186.
- Ward, E. C., Koh, S. K., Frisby, J., & Hodge, R. (2003). Differential modes of alaryngeal communication and long-term voice outcomes following pharyngolaryngectomy and laryngectomy. *Folia Phoniatrica et Logopaedica*, 55(1), 39-49.
- Weymuller Jr., E. A., Yueh, B., Deleyiannis, F. W. B., Kuntz, A. L., Ramsey, A., & Coltrera, M. D. (2000). Quality of life in patients with head and neck cancer. *Archives of Otolaryngology - Head and Neck Surgery*, 126, 329-335.

Author Note

Correspondence concerning this article should be addressed to: Philip C. Doyle, PhD, Voice Production and Perception Laboratory, Rehabilitation Sciences, Elborn

