The Psychosocial Aspects of Prosthetic Use Scale (PAPUS): Preliminary Data

L'échelle des aspects psychosociaux reliés à l'utilisation de prothèses (PAPUS): données préliminaires

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Abstract

Measurement of quality of life (QOL) has become an increasingly important issue for individuals who undergo treatment for head and neck cancer. It is the individual's posttreatment QOL that contributes to the success or failure of treatment regardless of the survival period. Although multiple tools currently exist for measuring areas that influence QOL, no single instrument is likely to be ideal for any given clinical group. The primary objective of the present project was to gather preliminary data describing the psychosocial impact that intraoral prosthetic devices have on the QOL of a small group (n = 6) of individuals who were diagnosed and treated for orofacial cancer. Selected questions gathered from several currently published articles were compiled into a QOL questionnaire designed for the head and neck population. Data were collected and then grouped by subscale, and preliminary evaluation of data according to sex was performed descriptively. Preliminary data suggest that it is possible to use selected elements of specific measurement tools as a method of determining QOL domains related to speech and swallowing in individuals with oral cancer.

Abrégé

La mesure de la qualité de vie (QDV) est devenue une question très importante pour les individus ayant à subir un traitement pour un cancer au cou ou à la tête. C'est surtout la qualité de vie après le traitement qui détermine le succès ou l'échec d'un traitement et ce, peu importe la période de survie qui s'en suit. Même s'il existe présentement de multiples outils d'évaluation des différents domaines de la qualité de vie, aucun n'est spécifique à un groupe clinique en particulier. L'objectif principal du présent projet était de recueillir des données décrivant l'impact psychosocial des prothèses intraorales sur la qualité de vie auprès d'un petit groupe (n = 6) d'individus ayant été diagnostiqués et traités pour un cancer oro-facial. Des questions ont été tirées de documents publiés sur le sujet et mises ensemble dans un questionnaire de QDV spécifique à la population avec cancer au cou ou à la tête. Les données ont été recueillies et groupées en sous-groupes. Une évaluation préliminaire des données, selon le sexe, a été effectuée de manière descriptive. Les données préliminaires suggèrent qu'il est possible d'utiliser des éléments sélectionnés à partir d'outils de mesure spécifiques, déjà existants, comme méthode de mesure de certains domaines de QDV reliés à la parole et à la déglutition auprès des individus présentant un cancer buccal.

Key words: Psychosocial, head and neck cancer, quality of life, functional measurement, prosthetics

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Head and neck cancer has dramatic effects because it can affect fundamental functions, such as respiration, swallowing, and verbal communication (Doyle, in press; Hassan & Weymuller, 1993). In addition, physical disfigurement and potential functional disabilities can result from this type of cancer and its treatment. Individuals with orofacial cancer are not only fearful of death from malignant disease, but often have significant concerns about the deformities that may occur as a consequence of treatment, and the effects of the disease and its treatment on communication and swallowing. Treatment for orofacial tumours poses the distinct potential for facial disfigurement, changes in body image, loss of efficient verbal communication, and associated social sequelae. These potential effects can impact the manner in which an individual perceives him or herself, as well as how the individual is perceived by others (Doyle, in press; Hassan & Weymuller, 1993; Karnell, Funk, & Hoffman, 2000). Consideration of the psychosocial impact of this disease is an essential component of assessment for such individuals in the posttreatment period (Konstantinovic, 1999; List, D'Antonio, Cella, Siston, Mumby, Haraf, et al., 1996; Rogers, Humphris, Lowe, Brown, & Vaughan, 1998; Rogers, Hannah, Lowe, & Magennis, 1999b; Sharp, List, MacCracken, Stenson, Stocking, & Siegler, 1999). As a consequence of potential facial disfigurement, changes to body image, loss of efficient verbal communication, and associated social sequelae, one's quality of life (QOL) also may be influenced considerably (Doyle, 1999; Kornblith, Zlotolow, & Gooen, 1996; Moroi, Okimoto, & Terada, 1999; Rogers, Fisher, & Woolgar, 1999a, p. 12-15). QOL is an individualized, multidimensional concept that is of great importance to those with oral cancer, and is a potentially valuable measure of treatment success (Rogers et al., 1999a).

As a general rule, medical intervention primarily focuses on the treatment of cancer in terms of increasing an individual's length of survival (Hassan & Weymuller, 1993). Thus, the duration of survival following medical intervention is used as the index of treatment success. However, Hassan and Weymuller (1993) suggest that this type of measure may be incomplete relative to the care of individuals who have been treated for head and neck cancer. These authors explicitly state that:

In the interest of monitoring the impact of treatment, physicians have paid close attention to tumour site, stage, and response to treatment as measured by local regional control and survival. Less attention has been given to the psychosocial well-being of the individual and to what extent the individual has been able to return to preillness function. (Hassan & Weymuller, 1993, p. 485)

On the basis of their statement, it is clear that concerns beyond those of tumour elimination and disease control must be considered when assessing posttreatment outcomes. The individual's posttreatment well-being and associated QOL is an important consideration in all instances. Comprehensive methods of assessing the individual's response to treatment, both short- and long-term, will benefit the ultimate outcome (Creagan, 1999; Cune, de Putter, & Hoogstraten, 1994; de Batt, van Aken, Mulder, & Kalk, 1997; Doyle, in press; Feine, Dufresne, Boudrias, & Lund, 1998; Myers, 2002). In this regard, the literature is limited with respect to the psychosocial impact of treatment for those with orofacial cancer. Nevertheless, broad measures of specific domains underlying QOL have become increasingly important for those who undergo treatment for orofacial cancer (Doyle, 1999, in press; Epstein, Emerton, Kolbinson, Le, Phillips, Steveson-Moore, & Osoba, 1999; Finizia, Hammerlid, Westin, & Lindstrom, 1998; Gliklich, Goldsmith, & Funk, 1997; Jacobson et al., 1997; Karnell, Funk, Tomblin, & Hoffman, 1999; Konstantinovic, 1999; Kornblith et al., 1996; Kuboki et al., 1999; List, Ritter-Sterr, et al., 1996; Moroi et al., 1999; Rogers, Lowe, et al., 1998; Rogers et al., 1999a, 1999b; Terrell, Nanavati, Esclamado, Bradford, & Wolf, 1999; Young et al., 1998).

Current clinical data indicate that for some subgroups of individuals with head and neck cancer, the posttreatment survival period has increased in recent years. In this regard, Moroi et al. (1999) stated, "Recent advances in cancer treatment and early tumour detection have greatly improved the survival rate and various oral prostheses have been found to contribute to the QOL for head and neck cancer patients" (p. 265). In essence, however, it is an individual's QOL that constitutes the success or failure of a treatment independent of the posttreatment survival period. That is, the length of time an individual survives posttreatment is not in and of itself an adequate index of success; it is the quality of the person's life during that survival period that constitutes the best measure of success. Evaluation of QOL, therefore, may offer information about psychosocial well-being in relation to, and within the context of, effects related to disease treatment (Doyle, 1999, in press; Rogers et al., 1999a). The objective of the present project was to gather preliminary data describing the psychosocial impact that oral prosthetic devices have on the QOL of individuals who are diagnosed and treated for orofacial cancer. The specific focus of this preliminary study centred on assessing the QOL status of those individuals who, following treatment for orofacial cancer, were fitted with an oral prosthesis to facilitate improved posttreatment speech and swallowing. To meet this objective, a specific hybrid measurement tool that included questions selected from existing instruments was constructed for use in this study.

Methods

Participants

The participants were six adults, consisting of two men (age range 52-85 years) and four women (age range 54-66 years) who were treated for orofacial cancer. The anatomic sites of malignancy were the maxilla (n = 3), tongue (n = 1), oral cavity not specified (n = 1), and left tear duct (n = 1). All 6 participants received surgery as a primary treatment and 5 of 6 participants also received postsurgical radiation therapy. The primary mode of communication used by all participants was oral communication. Participants utilized a variety of

Table 1
Composition of PAPUS Subscales

PAPUS Subscales	Total number of items in each subscale	Scales used to gerenate subscale question items and number of question items represented from these scales						
		OPFS[a]	SQI[b]	OHIP/NHP/AIMS[c]	UL[d]	VHI[e]	EORTC Core/EORTC/H&N/SQA[f]	SSA[g]
Communication/Speech	15	1	2	2	1	9		
Resonance/Voice/Intelligibility	21	3	1	5		1	10	1
Eating/Swallowing/Diet	29	3	5	15				6
Psychosocial and Emotional	19	1	1	6	6			5
Appearance/Aesthetic/Comfort/Pain	33	6	11	13	1			2

a OPFS: Obturator Prosthetic Functioning Scale
b SQI: Study-specific questions generated by investigators of PAPUS
c OHIP: Oral Health Impact Profile, NHP: Nottingham Health Profile, AIMS: Arthritic Impact Measurement Scale Version 2
d UL: University of Liverpool Quality of Life Questionnaire for Head and Neck Cancer
e VHI: Voice Handicap Profile
f EORTC-Core: European Organization for Research and Treatment of Cancer Quality of Life Core Questionnaire, EORTC-H&N: European Organization for Research and Treatment of Cancer Quality of Life Head and Neck Module, SQA: Study specific questions generated by authors of study
g SSA: Study specific statements generated by authors of study

oral-dental prostheses, including oral maxillo-dental, maxillary, palatal drop, and obturator devices. For 2 of the participants, this was their first oral-dental prosthetic device; the prosthesis was a permanent device for 5 of the participants and temporary for one. At the time of participation, all six individuals reported wearing their device for more than 8 hours daily and reported that they always wore the devices during eating, resting, talking, and moderate exercise activities. Through responses to questions posed in the measurement tool, the majority of participants self-reported being satisfied with the device; 3 participants reported being *very satisfied*, 2 reported being *somewhat satisfied*, and only 1 reported being dissatisfied with the prosthesis. The comfort level of the device was rated as high for all participants; 1 participant reported the device was *very comfortable*. The other 5 participants indicated their devices were *somewhat comfortable*.

Measurement Tool

A specific measurement tool was generated from existing published instruments. As such, the specialized, composite tool designed for use in this evaluation was created using a pre-selected subgroup of questions from multiple instruments (Cune et al., 1994; Finizia et al., 1998; Jacobson et al., 1997; Kuboki et al., 1999; Young et al., 1998). This composite measurement tool, termed the Psychosocial Aspects of Prosthetic Use Scale (PAPUS), was constructed to examine aspects such as: (1) communication/speech, (2) resonance/voice/intelligibility, (3) eating/swallowing/diet, (4) psychosocial and emotional, and (5) appearance/aesthetic/comfort/pain issues (see Appendix). The purpose of the

PAPUS was twofold. First, it was designed to provide more specific information related to the psychosocial aspects and the impact of prosthetic device use in a small population of individuals treated for oral cancer. Second, it was designed to determine the potential feasibility of further evaluation of this preliminary tool or similar types of instruments.

Each subscale of the PAPUS was comprised of selected items from the following eight validated scales: (1) Obturator Prosthetic Functioning Scale; (2) Oral Health Impact Profile (OHIP), Kuboki et al. (1999); (3) Nottingham Health Profile (NHP), Kuboki et al. (1999); (4) Arthritic Impact Measurement Scale Version 2 (AIMS), Kuboki et al. (1999); (5) University of Liverpool Quality of Life Questionnaire for Head & Neck Cancer (UL), Young et al. (1998); (6) Voice Handicap Index (VHI), Jacobsen et al. (1997); (7) European Organization for Research and Treatment of Cancer Quality of Life Core Questionnaire (EORTC-Core), Finizia et al. (1998); and (8) European Organization for Research and Treatment of Cancer Quality of Life Head and Neck Module (EORTC-H&N), Finizia et al. (1998). The majority of items presented in the PAPUS subscales were questions or statements derived from the above cited questionnaires. Previous studies that used the above cited questions/scales presented them in their entirety or as a subset of items. Kuboki et al. (1999) provided questions on the basis of three QOL questionnaires: OHIP, NHP, and AIMS. Finizia et al. (1998) used the EORTC-Core, EORTC-H&N with study-specific questions. Young et al. (1998) developed the UL. Items from the VHI developed by Jacobsen et al. (1997) also were included in the PAPUS. The current authors also generated several additional questions for inclusion in the PAPUS. The PAPUS consisted of 117 questions

in its final form. Information about the breakdown of items in each PAPUS subscale is shown in Table 1.

Procedure

All participants were seen in a university-based outpatient clinic and were followed regularly by the Orofacial Rehabilitation Unit at the London Health Sciences Centre. All participants were volunteers in this preliminary assessment and all provided informed consent. Each participant completed the PAPUS in the clinic immediately prior to a scheduled follow-up appointment or while waiting for their oral prosthesis to be repaired. All assessments were done under the supervision of a certified and registered speech-language pathologist. Participants were able to ask questions if items needed to be clarified. Demographic information also was collected from participants.

Scoring Procedure

Responses to most items were in the form of scaled scores. There also was a subgroup of questions that required a *yes/no* response. Each subscale item on the PAPUS was rated using a 5-point scale (1 = never, 2 = seldom, 3 = occasional, 4 = often, 5 = always). At the beginning of each subscale, participants were presented with the open-ended sentence (*As a result of using my device....*) to assist them in responding to individual subscale items. Depending on the question, a rating of 5 could indicate that the subscale item had a positive or negative impact on the individual. For example, with Question 15 in the Communication/Speech subscale (i.e., *I have been satisfied with my overall ability to talk to others*) a rating of 5 indicated that the prosthesis had a positive influence on the individual's ability to communicate. Alternatively, on the Eating/Swallowing/Diet subscale, Question 1 (*I have difficulty chewing foods*), a rating of 5 indicated that this individual always had difficulty with this activity (see Appendix).

Data Analysis

Data were collected and then grouped by subscale according to the participant's sex. The reason for this was to determine if any obvious difference among the participants' gender might be present. The frequency of scaled scores obtained was documented for each item in each subscale. Then, the range of scaled scores for all 6 participants and the differences between and similarities among sexes in terms of their ratings of items on the PAPUS subscales were evaluated. Descriptive analyses of the data were conducted and are presented. No additional statistical analyses of the data beyond those that were descriptive in nature were undertaken because assumptions of parametric statistical manipulation would have been violated based on the small, feasibility sample studied.

Results

The complete range of possible scores was represented across the 6 participants for all five subscales of the PAPUS. Although the number of participants was small, attempts at identifying the possible sensitivity of the tool and potential differences between male and female respondents were

considered. The results for each subscale of the PAPUS are presented separately.

Communication-Speech Subscale

The scores for the male and female participants for items on this subscale ranged from 1-5. There were very similar ratings for two items by both groups. Question 5 resulted in scores of either a 4 or 5, while Question 9 revealed scores from 1-3 for both male and female participants. In contrast, there were differences in ratings noted between males and females for Question 10 (*I have talked less than usual*). Women scored this question as a 1 or 2, while men scored it a 3 or 4. The pattern raises concerns about gender-based differences relative to communication. Women in this small sample were more positive than men based on scaled scores.

Resonance/Voice/Intelligibility Subscale

The scaled scores for these items ranged considerably. However, regardless of gender, Questions 4, 7, 8, 14, and 19 were rated similarly by women and men. For Questions 4, 8, 14, and 19, scores were 3 or less, while for Question 7 scores were 3 or greater (see Appendix, Subscale B).

Eating/Swallowing/Diet Subscale

Ratings of items in this subscale covered the entire spectrum of scores. However, Questions 19 and 20 were rated similarly across participants with scores consistently at 3 or less. On the basis of the findings from these two questions and given the range of scaled scores noted for items in this subscale, these questions may have some particular sensitivity to the difficulties encountered by individuals with oral cancer.

Psychosocial Emotional Subscale

Ratings of items in this subscale ranged from 1-5 for all participants. There were many similarities in the ratings obtained from participants on this subscale, particularly for Questions 6, 8, 10, and 11. Similarly, for Questions 18 and 19, participants unanimously agreed that life was worth living and that they would make the same treatment choices again if diagnosed with oral cancer.

Appearance/Aesthetic/Comfort/Pain Subscale

Ratings for these items ranged from 1-5. Interestingly, a number of items in this subscale were rated similarly across participants regardless of gender. Specifically, Questions 3, 10, 16, 17, 18, 23, and 25 were assigned scaled scores of 3 or less. There was one difference in the rating of an item in this subscale among participants. For Question 31 (*My appearance affects my self-esteem*), all the female participants rated this question as a 1, with ratings of either 2 or 4 provided by the male participants. The scores spanned the entire range for the additional questions. This result may suggest that the scale is sensitive to individual variability.

Discussion

The objective of this preliminary project was to assess the psychosocial and QOL status of individuals who had been treated for orofacial cancer and who were fitted with an oral prosthesis to facilitate improved speech and swallowing. A specific hybrid measurement tool that included selected

questions from existing, published instruments was developed for use in this study. It was believed that information gathered could serve as an initial descriptive profile of issues that might be addressed in larger-scale follow-up studies at empirical and clinical levels of inquiry. Thus, these preliminary data provide information on the feasibility of using similar hybrid instruments for such clinical assessments. In essence, although numerous tools exist, it is not unreasonable to assume that subscales from particular instruments may have greater clinical utility for a given population, therefore, selected elements of existing tools were explored for use in this study. Nevertheless, it is important to note that generalization of these limited, preliminary data is not possible; the objective of this study was directed at assessing whether composite tools might be of clinical use in such assessments, and if further exploration is warranted and was oriented toward determining the feasibility of similar endeavours.

Overall, the results using the PAPUS with participants who have oral cancer suggest that the participants were satisfied with their prostheses and that this satisfaction positively impacts QOL. These data are based on several participants who use a second prosthesis and appear to be more satisfied as suggested by their comments when asked how the current device compares to their older device. Two participants noted that the second device was *better* than the first. Although having used the device for 8 months at the time of completing the PAPUS (the device results in a *better seal not as good for chewing*), one participant noticed a difference. This information suggests that individuals indeed may be able to sensitively evaluate their own progressive status over a relatively short-term posttreatment period, as well as being able to clarify positive or negative changes related to the prosthesis and its use. Thus, the composite questions chosen appear to be sensitive to such changes.

A full range of scores was observed for several subscales. This observation indicates that there was variability among participant responses in each of the subscales, which, at face value, suggests that the questions comprising the subscales are potentially sensitive to individual differences. Such differential sensitivity also may have been observed relative to gender, although confirmation is not possible given the small sample. For example, one female participant consistently rated PAPUS subscale questions similar to that of the other females, but different from male participants. Similarly, for some items, males scored items differently than females. This finding, although preliminary, supports the feasibility of the PAPUS (or some similar composite measurement instrument) as a potentially sensitive index of functioning for those treated for orofacial cancer.

With regard to consistency in the scores, the greatest degree of similarity among participants was found with the ratings of items in the Appearance/Aesthetic/Comfort/Pain subscale. However, there were differences between males and females that were of particular interest. For example, it was interesting to note that men indicated that their appearance affects their self-esteem more than that indicated by the women. This finding was not anticipated, and, in fact, it was assumed that this question would reveal more about female

participants. Interestingly, this finding does not appear to be directly related to the extent of surgical treatment or the associated degree of posttreatment change in cosmesis. While clearly preliminary in nature, this finding does suggest that similar stereotypic assumptions may be problematic, and therefore, should be avoided in future assessments.

Suggestions for Future Research

Although the present data are preliminary, there is potential to use the PAPUS in novel ways in the future. The most obvious is that future studies with a larger sample size would permit a better understanding of the similarities and differences experienced among men and women. As well, participants could be examined at multiple, but regular time intervals following treatment for oral cancer using a similar composite instrument. Participants could be evaluated initially after they have adjusted to their device (as in the present study), and then could be reevaluated at a later time. This approach would allow for a follow-up that monitors ongoing patient satisfaction and optimal device function (de Batt et al., 1997; Gliklich et al., 1997; Kornblith et al., 1996; Moroi et al., 1999; Rogers et al., 1999a; Terrell et al., 1999; Young et al., 1998). In this regard, if negative changes are observed, appropriate intervention can be offered immediately in an effort to remediate the problem. Though none of the present 6 participants expressed any dissatisfaction concerning the length of the PAPUS, the possible use of a short form of the present composite measurement tool might also be explored in the hope of gathering the most information in the most time-efficient manner possible (Young et al., 1998). We believe that a reduction in the length of the present tool could be achieved without considerable loss of information, despite the small number of participants in the present report. Future work on the PAPUS should explore this option.

The findings of this study clearly suggest the potential for additional exploration of the PAPUS or similar tools in the future. For example, participants in a follow-up study might consist of individuals who have received their permanent devices at a similar point in time posttreatment. Another approach might examine participants with other forms of head and neck cancer, such as those who have undergone partial or total glossectomy or laryngectomy. As more information is gathered, refinements should be made to make the questionnaire as useful as possible, while at the same time being sensitive to having a time-efficient measure covering multiple domains of function that may influence QOL and psychosocial limitations. The goal is to develop an efficient and sensitive QOL measure for this population.

In summary, the present work explored the utility of constructing a hybrid measurement from preexisting QOL tools reported in the literature. Many excellent measurement tools currently exist, although selected questions may be inappropriate for some clinical populations. The present findings suggest that such an approach to measurement may be of value as an informal survey. Despite the small sample of participants, ratings on the PAPUS provided a range of judgments. This sensitivity has been reported in larger studies of individual tools from which questions were obtained for

inclusion in the present tool. The selection of questions from existing questionnaires, similar to those pursued through the PAPUS, may be a more effective and efficient manner of assessing multiple levels of functioning when compared to the development of a new questionnaire altogether. On the basis of the present data, tools similar to the PAPUS appear to hold promise as a method of measuring multiple areas of interest in individuals with head and neck cancer. Nevertheless, further exploration with a larger group of participants is necessary to determine whether the practice of borrowing items result in a valid QOL instrument. It would seem that a careful selection of particular elements from previously established tools may be possible for use as an informal, yet sensitive means of gathering information on a person's clinical status relative to treatment for orofacial cancer. Although standard quantitative scoring would be impossible under such circumstances, application of components of particular measurements or combinations thereof would seem to offer important information without requiring that instruments be completed in their entirety. This application would offer clinicians the opportunity to obtain specific information in a relatively quick and efficient manner. By doing so, problem areas may be identified and rehabilitation programs may be modified accordingly with the goal of optimizing overall rehabilitation outcomes.

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Author Note

For those interested in information on what questions appearing in the PAPUS were selected from the specific tools cited, please contact the senior author for further information. Correspondence regarding this work should be directed to Talya Wolff, M.Cl.Sc., Communication & Writing Aids Service, Bloorview MacMillan Children's Centre, 350 Rumsey Road, Toronto, Ontario M4G 1R8, Canada.

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References

Creagan, E.T. (1999). Attitude and disposition: Do they make a difference in cancer survival? *Journal of Prosthetic Dentistry, 82*(3), 352-355.

Cune, M.S., de Putter, C., & Hoogstraten, J. (1994). Treatment outcome with implant-retained overdentures: Part II - Patient satisfaction and predictability of subjective treatment outcome. *Journal of Prosthetic Dentistry, 72*(2), 152-158.

de Batt, C., van Aken, A.A.M., Mulder, J., & Kalk, W. (1997)."Prosthetic condition" and patients' judgement of complete dentures. *Journal of Prosthetic Dentistry, 78*, 472-478.

Doyle, P.C. (1999). Postlaryngectomy speech rehabilitation: Contemporary concerns in clinical care. *Journal of Speech-Language Pathology & Audiology, 23*(3), 109-116.

Doyle, P.C. (in press).Rehabilitation in head and neck cancer: An overview. In: P.C. Doyle & R.L. Keith (Eds.), *Contemporary Considerations in the Treatment and Rehabilitation of Head and Neck Cancer: Voice, Speech, and Swallowing.* Austin, TX: Pro-Ed.

Epstein, J.B., Emerton, S., Kolbinson, D.A., Le, N.D., Phillips, N., Steveson-Moore, P., & Osoba, D. (1999). Quality of life and oral function following radiotherapy for head and neck cancer. *Head & Neck, 21*, 1-11.

Feine, J.S., Dufresne, E., Boudrias, P., & Lund, J.P. (1998). Outcome assessment of implant-supported prostheses. *Journal of Prosthetic Dentistry,79*(5), 575-579.

Finizia, C., Hammerlid, E., Westin, T., & Lindstrom, J. (1998). Quality of life and voice in patients with laryngeal carcinoma: a posttreatment comparison of laryngectomy (salvage surgery) versus radiotherapy. *Laryngoscope, 108*(10), 1566-1573.

Gliklich, R.E., Goldsmith, T.A., & Funk, G.F. (1997) Are head and neck specific quality of life measures necessary? *Head & Neck, 19*(6), 474-480.

Hassan, S.J., & Weymuller, Jr. E.A.(1993). Assessment of quality of life in head and neck cancer patients. *Head & Neck, 15*, 485-496.

Jacobson, B.H., Johnson, A., Grywalski, C., Silbergleit, A., Jacobson, G., Benninger, M.S., & Newman, C. (1997). The Voice Handicap Index (VHI): Development and validation. *American Journal of Speech-Language Pathology, 6*(3), 66-70.

Karnell, L.H., Funk, G.F., Tomblin, J.B., & Hoffman, H.T. (1999). Quality of life measurements of speech in the head and neck cancer patient population. *Head & Neck, 21*, 229-238.

Karnell, L.H., Funk, G.F., & Hoffman, H.T. (2000). Assessing head and neck cancer patient outcome domains. *Head & Neck, 22*(1), 6-11.

Konstantinovic, V.S. (1999). Quality of life after surgical excision followed by radiotherapy of cancer of the tongue and floor of the mouth: Evaluation of 78 patients. Journal of Craniofacial Surgery, 27(3), 192-197.

Kornblith, A.B., Zlotolow, I.M., & Gooen, J. (1996). Quality of life of maxillectomy patients using an obturator prosthesis. *Head & Neck, 18*, 323-334.

Kuboki, T., Okamoto, S., Suzuki, H., Kanyama, M., Arakawa, H., Sonoyama, W., & Yamashita, A. (1999). Quality of life assessment of bone-anchored fixed partial denture patients with unilateral mandibular distal-extension edentualism. *Journal of Prosthetic Dentistry, 82*(2), 182-187.

List, M.A., D'Antonio, L.L., Cella, D.F., Siston, A., Mumby, P., Haraf, D., & Vokes, E. (1996). The Performance status scale for head and neck cancer patients and the Functional Assessment of Cancer Therapy-Head and Neck Scale. *Cancer, 77,* 2294-2301.

List, M.A., Ritter-Sterr, C.A., Baker, T.M., Colangelo, L.A., Matz, G., Pauloski, B.R., & Logemann, J.A. (1996). Longitudinal assessments of quality of life in laryngeal cancer Patients. *Head & Neck,*18,1-10.

Moroi, H.H., Okimoto, K., & Terada, Y. (1999). The effect of an oral prosthesis on the quality of life for head and neck cancer patients. *Journal of Oral Rehabilitation, 26*(4), 265-273.

Myers, C. (2002). 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* (in press). Austin, TX: Pro-Ed.

Rogers, S.N., Humphris, G., Lowe, D., Brown, J.S., & Vaughan, E.D. (1998). The impact of surgery for oral cancer on quality of life as measured by the Medical Outcomes Short Form 36. *Oral Oncology, 34*(3), 171-179.

Rogers, S.N., Fisher, S.E., & Woolgar, J.A. (1999). A review of quality of life assessment in oral cancer. *International Journal of Oral Maxillofacial Surgery, 28* (2),99-117.

Rogers, S.N., Hannah, L., Lowe, D., & Magennis, P. (1999). Quality of life 5-10 years after primary surgery for oral and oro-pharyngeal cancer. *Journal Craniofacial Maxillary Surgery, 27,* 187-191.

Rogers, S.N., Lowe, D., Brown, J.S., & Vaughan, E.D. (1998).A comparison between the University of Washington Head and Neck Disease-Specific measure and the Medical Short Form 36, EORTC QOQ-C33 and EORTC Head and Neck 35. *Oral Oncology, 34* (5),361-372.

Rogers, S.N., McNally, D., Mahmoud, M., Chan, M.F.W.Y., Humphris, G.M., & Psychol, M. (1999c). Psychologic response of the edentulous patient after primary surgery for oral cancer: A cross-sectional study. *Journal of Prosthetic Dentistry, 82* (3), 317-321.

Sharp, H.M., List, M., MacCracken, E., Stenson, K., Stocking, C., & Siegler, M. (1999). Patients' priorities among treatment effects in head and neck cancer: Evaluation of a new assessment tool. *Head & Neck, 21,* 538-546.

Terrell, J.E., Nanavati, K.A., Esclamado, R.M., Bradford, C.R., & Wolf, G.T. (1999). Health impact of head and neck cancer. *Otolaryngology Head Neck Surgery, 120*(6), 852-859.

Young, P.E., Beasley, N.J.P., Houghton, D.J., Husband, D.J., Currie, M., Chislett, B., & Jones, A.S. (1998).A new short practical quality of life questionnaire for use in head and neck oncology outpatient clinics. *Clinical Otolaryngology, 23*, 528-532.

Appendix
Psychosocial Aspects of Prosthesis Use Scale

Please provide a rating using the following scale for each statement, as it is most suitable to you.

Always	Often	Occasionally	Seldom	Never
5	4	3	2	1

A. Communication-Speech Subscale

As a result of using my device...

___ 1. I have difficulty speaking in public
___ 2. My prosthesis interferes with my speaking
___ 3. I have problems talking on the phone
___ 4. I have problems talking to other people
___ 5. I can make myself understood using speech
___ 6. When I speak in a crowded or noisy room, I am understood
___ 7. I have problems talking at home
___ 8. I have problems talking at my job
___ 9. I have problems talking in my social life
___ 10. I have talked less than usual
___ 11. I have been satisfied with the way I sound when I talk
___ 12. My ability to talk has caused frustration doing tasks outside the home (e.g., at work, grocery store)
___ 13. I have avoided conversations because of the way I talk
___ 14. I have been frustrated getting others to understand me because of the way I talk
___ 15. I have been satisfied with my overall ability to talk to others

B. Resonance/Voice/Intelligibility Subscale

As a result of using my device...

___ 1. My voice is different with this prosthesis
___ 2. My voice is hoarse
___ 3. I experience voice fatigue
___ 4. I am ashamed of my posttreatment voice
___ 5. My voice got worse after treatment
___ 6. My voice got better after treatment
___ 7. My voice is about the same now as before treatment
___ 8. My voice makes it difficult for people to hear me
___ 9. I tend to avoid groups of people because of my voice
___ 10. My voice sounds creaky and dry
___ 11. I feel as though I have to strain to produce voice
___ 12. My voice difficulties restrict my personal and social life
___ 13. I feel left out of conversations because of my voice
___ 14. My voice problem causes me to lose income
___ 15. My voice problem upsets me
___ 16. I feel annoyed when people ask me to repeat
___ 17. My voice makes me feel incompetent
___ 18. My speech is nasal
___ 19. I have difficulty producing speech sounds in words
___ 20. My speech is difficult to understand
___ 21. People misunderstand some of my words

C. Eating/Swallowing/Diet Subscale

As a result of using my device...

___ 1. I have difficulty chewing foods
___ 2. I have leakage when swallowing foods
___ 3. I have trouble swallowing solid foods
___ 4. I choke when swallowing
___ 5. I am producing more mucus
___ 6. I have trouble swallowing pureed food
___ 7. I have trouble swallowing liquids
___ 8. I have leakage when swallowing liquids
___ 9. My prosthesis interferes with eating or swallowing
___ 10. Food gets stuck in my throat when eating
___ 11. I find it uncomfortable to eat any foods
___ 12. I feel that I am clenching my teeth more
___ 13. I feel that my sense of taste has gotten worse
___ 14. I have trouble with taste
___ 15. I have trouble with smell
___ 16. I have an unsatisfactory diet
___ 17. I have lost my appetite
___ 18. I have trouble enjoying meals
___ 19. I have trouble eating in front of family
___ 20. I have trouble eating in front of other people
___ 21. I have been unable to brush my teeth properly
___ 22. I take a nutritional supplement
___ 23. I am fed through a feeding tube
___ 24. I lose weight
___ 25. I am able to eat food that I want
___ 26. I have to avoid eating some foods
___ 27. Because of difficulty eating, I avoid eating in restaurants or other people's homes
___ 28. I have pain in my face when chewing
___ 29. I have difficulty opening my jaw normally

D. Psychosocial Emotional Subscale

As a result of using my device...
1. Do other people around you notice a difference when you are wearing your prosthesis? Who? Describe what differences they notice.

_____

_____

___ 2. I avoid my family and/or social events because of my dental prosthesis
___ 3. I am self-conscious about my prosthesis
___ 4. I avoid smiling
___ 5. I feel tense and irritable
___ 6. I am unable to reveal my teeth
___ 7. I feel the physical stress of the treatment
___ 8. I have trouble with social contact with family
___ 9. I have trouble with social contact with friends
___ 10. I have trouble going in public
___ 11. I have trouble with physical contact with family/friends
___ 12. I feel less sexual enjoyment
___ 13. I feel less sexual interest
___ 14. I feel limited as a result of physical problems from treatment

15. How do you feel you have coped emotionally since your treatment? (please circle one)
Constant anxiety/depression   Average   Well-adjusted, happy, positive
     1   2   3   4   5

16. How has your treatment affected your relationship with friends and family (please circle one)
Very negatively   Not affected at all
     1   2   3   4   5

17. To what extent have you returned to your normal life? (please circle one)
Non-normal life   Normal life
     1   2   3   4   5

18. Since your treatment is life worth living? (please circle one)
Yes   No

19. Knowing what you know now would you still have the same treatment? (please circle one)
Yes   No

E. Appearance/Aesthetic/Comfort/ Pain Subscale
As a result of using my device...

___ 1. My mouth feels dry
___ 2. I am dissatisfied with the way I look
___ 3. The clasps on my front teeth are noticeable
___ 4. My upper lip feels numb
___ 5. My lower lip feels numb
___ 6. I have difficulty inserting/removing the prosthesis
___ 7. My upper lip looks funny (scarred)
___ 8. My prosthesis is uncomfortable (irritating)
___ 9. My prosthesis is unstable (loose, rocking etc.)
___ 10. I have toothaches
___ 11. I have pain in my teeth when I drink or with hot or cold food
___ 12. I have pain when I bite
___ 13. I have painful gums
___ 14. I am fatigued
___ 15. I feel ill
___ 16. I get nauseated
___ 17. I vomit frequently
___ 18. I have dyspnea
___ 19. I have sleep disturbances
___ 20. I use painkillers
___ 21. I am bothered by my appearance
___ 22. I have pains in my face
___ 23. I have pains in my mouth
___ 24. I have pains in my throat
___ 25. I have pains in my jaw
___ 26. I have numbness in my mouth or face
___ 27. I have problems with my teeth
___ 28. I have problems opening my mouth wide
___ 29. My appearance affects my willingness to work or participate in recreational activities
___ 30. My appearance affects how often I see my family or friends
___ 31. My appearance affects my self-esteem
___ 32. My appearance prevents me from participating in social activities

___ 33. Do concerns about your appearance affect your quality of life? (please circle one)
Never go out now   Happy with my appearance
     1   2   3   4   5