

Need for a paradigm for application of outcome measure (QOL scales) in head and neck cancer patients in India

ABSTRACT

Quality of life (QOL) is a multidimensional construct that minimally includes broadly defined assessments of the physical, psychological, and social domains of functioning. However, measuring this QOL is complicated by the fact that there are many different validated questionnaires available. In India, with people now wanting self-directed care and greater autonomy, we must direct increased efforts towards QOL and its assessment. We propose the Assessment, Translation & Validation, Application and Audit method to increase the use of QOL scales in our country.

KEY WORDS: Head-neck cancers, instruments, outcome measurement, quality of life, scales

Quality of life (QOL) is a multidimensional construct that minimally includes broadly defined assessments of the physical, psychological, and social domains of functioning.^[1] When determining treatment for head and neck cancer, different therapeutic options may provide a similar prognosis or chance of cure, but with very different quality of life (QOL) outcomes. The evaluation of QOL and performance outcome in HNC is critical to optimal patient care, comprehensive evaluation of treatment alternatives, and the development of informed rehabilitative services and patient education.

However, measuring this QOL is complicated by the fact that there are many different validated questionnaires available.^[2] In addition, QOL is an individual perception that can be affected by health status, as well as by disease. When quantifying QOL, we must consider the influence of numerous factors and their potential interdependence if accurate representations of QOL status are to be gathered.^[3] Outcome measurement using validated questionnaires and research have been a topic of discussion among the medical fraternity, the government, and insuring agencies in the West for past many years. In the case of laryngeal cancer, results from the use of QOL scales highlight the fact that although treatment of the cancer is successful, individuals continue to experience difficulties in daily activities and social participation, regardless of the type of treatment (i.e. radiation therapy, conservative or radical surgery, chemotherapy, or a combined treatment protocol).^[4-6] There is evidence

that with time patients adjust and learn to cope with the disease and treatment sequelae.^[3,5-8,12] QOL outcome measurement is, largely, subjective and highly individualized.^[9] In India, with people now wanting self-directed care and greater autonomy, we must direct increased efforts towards QOL and its assessment.

We propose the Assessment, Translation & Validation, Application and Audit (ATAA) method to increase the use of QOL scales in our country [Figure 1]. For far too long, we have neglected this important domain citing an over-burden on our healthcare infrastructure. However, if we want to move forward, we must incorporate this model. Stage 1 of this paradigm includes a rigorous assessment (A) and evaluation of the existing head, neck QOL scales/instruments. In the literature, as many as 20 health-related outcome measurements have been described. Most questionnaires involve the judicious combination of disease, treatment and site along with generic measures to assess the QOL. These scales can be classified as: general head, neck QOL scales like the EORTC H & N 35, UWQOL v4, HNQOLQ, FACT-H&N v4, HNCI and symptom-specific ones like the MDADI, LASA and DSHNC.^[10-19] It is easy to get confused with the semantics of all these scales but it is imperative to check their quality and content prior to use. All existing scales vary widely in respect of their development and validation and information to this end must be gathered.

Once an appropriate scale is identified and selected,

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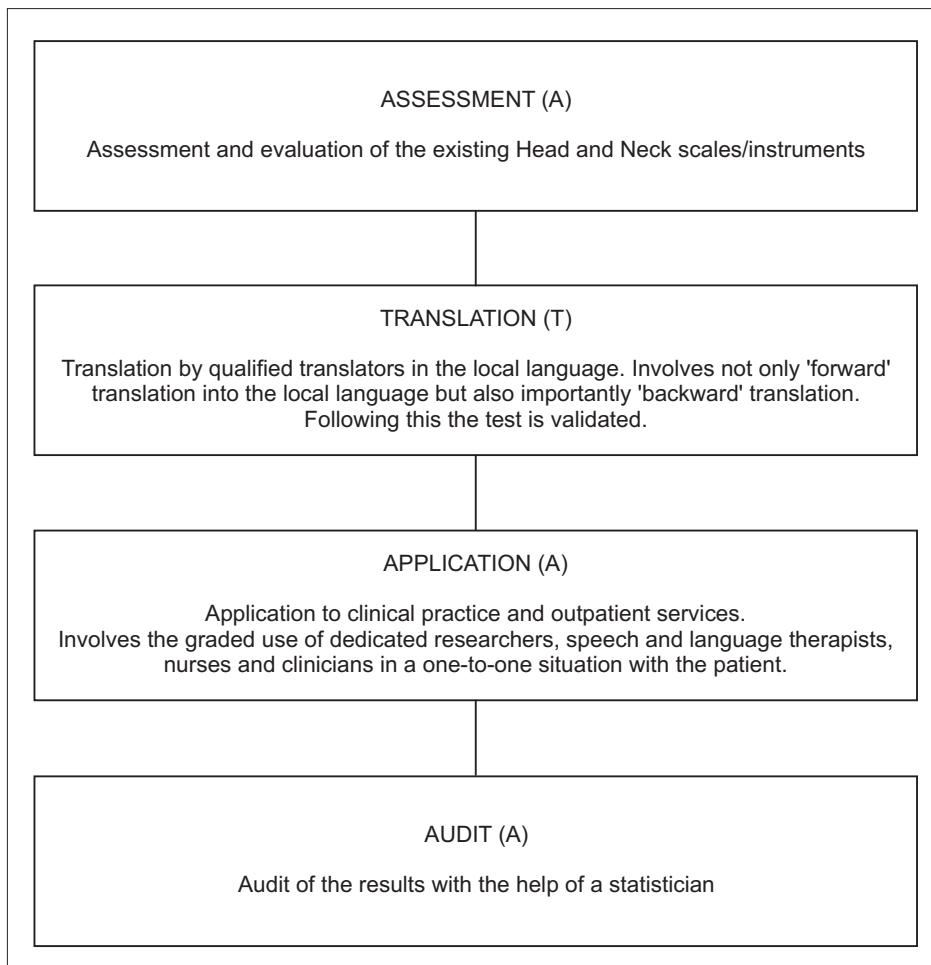


Figure 1: Flowchart depicting the ATAA (Assessment, Translation and Validation, Application and Audit) method

stage 2 is the translation (T) by qualified translators to the local language. This is a lengthy process that involves not only 'forward' translation into the local language but also importantly 'backward' translation. This is crucial to ensure that final scale/questionnaire compares favorably to the original English version not only in the translation but logically as in the nuances of the meaning. Following translation, the scale must be then validated in a study that assesses both the reliability (internal consistency and test-retest) and validity (content, construct and criterion) domains.

The third stage is that of application (A) to clinical practice and outpatient services. This should involve the graded use of dedicated researchers, speech and language therapists, nurses and clinicians in a one-to-one situation with the patient. Although this is not the ideal way and the self-administered route is best, the prevailing low literacy may make the self-administered approach challenging. But this problem can be solved by using methods like reading out questions verbatim to the patient and noting down the response. This procedure will require training those who will be assisting patients with questionnaire completion very carefully to avoid biasing

results. To aid us in patient evaluation, validated instruments like EORTC and FACT are available in regional languages viz. Hindi and Marathi.^[20]

The last stage (4) of the exercise involves an honest and independent audit (A) of the results with the help of a statistician. Only then can we elucidate meaningful directions for future research and clinical care for our patients. Finally, mention has to be made of longitudinal data (follow-up) of the patients, which may prove to be a daunting task. But the principle of the patient acting as their own control, over time, collecting their own history pertaining to symptoms/ complications is a critical point. The use of such a role-model/ paradigm with due emphasis at every stage will ensure that valid and reliable data is collected to bridge the gap between treatment and QOL outcomes in this country.

REFERENCES

1. Jones E, Lund VJ, Howard DJ, Greenberg MP, McCarthy M. Quality of life of patients treated surgically for head and neck cancer. *J Laryngol Otol* 1992;106:238-42.
2. Ringash J, Bezzak A. A structured review of quality of life instruments

- for head and neck cancer patients. *Head Neck* 2001;23:201-13.
3. Vilaseca I, Chen AY, Backscheider AG. Long-term quality of life after total laryngectomy. *Head Neck* 2005;132:948-53.
 4. Kazi R, Singh A, De Cordova J, Clarke P, Harrington K, Rhys-Evans P. A new self-administered questionnaire to determine patient experience with voice prosthesis (Blom-Singer valves). *J Postgrad Med* 2005;51:253-8.
 5. Tanya EL, Doyle PC. Quality of life in male tracheoesophageal speakers. *J Rehab Res Dev* 2005;42:115-25.
 6. Stewart MG, Chen AY, Stach CB. Outcomes analysis of voice and quality of life in patients with laryngeal cancer. *Arch Otolaryngol Head Neck Surg* 1998;124:143-8.
 7. Deleyiannis FW, Weymuller EA Jr, Coltrera MD, Futran N. Quality of life after laryngectomy: Are functional disabilities important? *Head Neck* 1999;21:319-24.
 8. Finizia C, Hammerlid E, Westin T, Lindstrom J. Quality of life and voice in patients with laryngeal carcinoma: A post treatment comparison of laryngectomy (salvage surgery) versus radiotherapy. *Laryngoscope* 1998;108:1566-73.
 9. Morton RP. Studies in quality of life of head and neck cancer patients: Results of a two-year longitudinal study and a comparative cross-sectional cross-cultural survey. *Laryngoscope* 2003;113:1091-103.
 10. Hassan SJ, Weymuller EA Jr. Assessment of quality of life in head and neck cancer patients. *Head Neck* 1993;15:485-96.
 11. Weymuller EA, Yueh B, Deleyiannis FW, Kuntz AL, Alsarraf R, Coltrera MD. Quality of life in patients with head and neck cancer: Lessons learnt from 549 prospectively evaluated patients. *Arch Otolaryngol Head Neck Surg* 2000;126:329-35.
 12. Vartanian JG, Carvalho AL, Yueh B, Priante AV, de Melo RL, Correia LM, *et al.* Long-term quality of life evaluation after head and neck cancer treatment in a developing country. *Arch Otolaryngol Head Neck Surg* 2004;130:1209-13.
 13. Terrell JE, Nanavati KA, Esclamado RM, Bishop JK, Bradford CR, Wolf GT. Head and neck cancer specific quality of life: Instrument validation. *Arch Otolaryngol Head Neck Surg* 1997;123:1125-32.
 14. D'Antonio LL, Zimmerman GJ, Cella DF, Long SA. Quality of life and functional status measures in patients with head and neck cancer. *Arch Otolaryngol Head Neck Surg* 1996;122:482-7.
 15. Funk GF, Karnell LH, Christensen AJ, Moran PJ, Ricks J. Comprehensive head and neck oncology health status assessment. *Head Neck* 2003;25:561-75.
 16. Chen AY, Frankowski R, Bishop-Leone J, Hebert T, Leyk S, Lewin J, *et al.* The development and validation of a dysphagia-specific quality-of-life questionnaire for patients with head and neck cancer: The MD Anderson Dysphagia inventory. *Arch Otolaryngol Head Neck Surg* 2001;127:870-6.
 17. Llewellyn-Thomas HA, Sutherland HJ, Hogg SA, Ciampi A, Harwood AR, Keane TJ, *et al.* Linear analogue self-assessment of voice quality in laryngeal cancer. *J Chronic Dis* 1984;37:917-24.
 18. Katz MR, Irish JC, Devins GM, Rodin GM, Gullane PJ. Reliability and validity of an observer-rated disfigurement scale for head and neck cancer patients. *Head Neck* 2000;22:132-41.
 19. Pusic A, Liu J, Chen C, Cano S, Davidge K, Klassen A, *et al.* A systematic review of patient-reported outcome measures in head and neck cancer surgery. *Otolaryngol Head Neck Surg* 2007;136:525-35.
 20. Chaukar DA, Das AK, Deshpande MS, Pai PS, Pathak KA, Chaturvedi P, *et al.* Quality of life of head and neck cancer patient: Validation of the European organization for research and treatment of cancer QLQ-C30 and European organization for research and treatment of cancer QLQ-H and N 35 in Indian patients. *Indian J Cancer* 2005;42:178-84.

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