_____

Instruments/ Questionnaire Tools Used for Assessing Quality of Life Among Oral Cancer Affected Patients

Dr Swati Sharma¹, Dr Rohit Punga²*, Dr M. Siddharth³

¹Phd Scholar, Associate Prof & Staff Incharge, Department of Public Health Dentistry, School of Dental Sciences, Sharda University, Greater Noida.
²*Professor and Head, Department of Oral &Maxillofacial Surgery, School of Dental Sciences, Sharda University
³Phd Guide, Dean, Professor & Head, Department of Periodontology School of Dental Sciences, Sharda University

*Corresponding Author 's E-mail: rohit.punga@sharda.ac.in

Article History	Abstract
    	QOL is largely affected by lot of overlapping facts and domains. Though enormous health care research is going all over the world to improve the survival as well as improve the quality of life in all the cancers of human body. Human being s individual perception for quality of life is one of the most important parameters to enhance the overall wellbeing of cancer patients. During the last decades, this idea of QOL has developed enormously and so are the various available treatment options in health care research to assess the individual's understanding of well-being.

1. Introduction:

Oral cancer belongs to cancer groups which are heterogeneous in nature originating in all and distinct oral cavity parts. It is one of such type of cancer which also comprises of varying prevalence rate, predisposing factor and clinical outcome. Oral cancer includes oral cavity cancer and nearby adjoining anatomical structures.

Globally, oral cancer has 6th position in prevalence rate out of all systematic cancer and rank first out of all cancers among head and neck region with reporting incidence of 300000 clinical annual cases of which 62 % of the burden is shared by developing countries. In India, the age-adjusted incidence rate is approximately twenty in 100000.

Despite advancement and updates pertaining to oral oncology, oral cancer occurrence still shows increase trends. This increased trend is evident among developing countries much more than developed countries. As consequence, both mortality as well morbidity associated with oral cancer will be much more evident in developing than developed nations. Site specific nature and characteristic of oral cancer to typical anatomical structures, its disease process and treatment largely impair physical image of affected patient along with essential functions e.g.: breathing, swallowing, speaking and mastication.

During past few years, huge advancement in outcomes and prognosis of oral cancer has occurred, hardly any change is visible from oral cancer's mortality rate and five-year survival rates. Improved health related quality of life among affected oral cancer individuals would thus be one of main and significant recent thrust area for research which has fetched attention among health care professional community also. Further, assessing quality of life have provided evidence which is essential for assessing patients' living state and also formulating treatment strategies.[1,2]

Standardized instrument/questionnaires are utilized for assessing QOL quality of life.

Various assessing tools for QOL are categorized under 4 broad headings:

1. Broader measure of dimension
2 General cancer measures

3. Region specific Head and neck measures of cancer
4. Performance indicator measures in neck and head region.[3]

Most common and widely used instruments for assessing QOL in oral cancer patients are[3,4]:

1. EORTC (European Organization for Research and Treatment of Cancer)
2. FACT SCALE (Functional Assessment of Cancer Therapy)
3. UW-QOL (University of Washington Head and Neck Measure)
4. FLIC (Functional Living Index Cancer)
5. OHIP -Oral Health Impact Profile

These are few of mostly used questionnaires/instruments for assessing QOL outcomes among Oral Cancer affected individuals. None of above mentioned instruments are generic ones which are specifically designed for QOL assessment among oral cancer affected individuals only. Rather, all of above mentioned questionnaires are just transformed with minor changes from main questionnaire in relation to region of neck and head. On comparing cancer of neck and head region, oral cancer affected individuals experience much significant problems in their mouth like restricted and reduced opening of mouth, difficulty in mastication, phonetics and reduced salivary secretion.

Disabilities in and adjoining areas pertaining to oral cavity cause psychological difficulties among oral cancer affected individuals. Anxiety associated with mainly oral cancer recurrence largely influences QOL. It also may affect their well-being and associated QOL quality of life.

Poor and reduced QOL may even decrease survival rate among affected. Though oral cancer diagnosis in mainly during its early stages and advances among various treatment options have significantly improved its prognosis. Delay observed in detecting oral cancer often is main concern as not just the functional aspects of oral cavity are largely affected but advanced stages treatment options also impacts QOL. [1,3]

Thus, it becomes essential to assist affected individuals showing reduced QOL to help them find solutions so as to improve QOL.

I. EuroQOL -European Organization for Research and Treatment of Cancer is a standardized instrument for describing and quantifying HRQOL:health related quality of life . EuroQOL5D provides a compact single value of index utilized for evaluating clinical parameters. There are 2 sub section as part 1 and part 2.

This questionnaire is self-reported. It uses five-dimensional classification. This classification which includes 5 dimensions are self-care, mobility, regular activities, any discomfort and depression or anxiety. Every dimension further constitutes three more statements which are organized in a ordered manner as per its severity. Patient is then supposed to tick mark the statement which best describes their present feelings i.e. how they feel "today." In all, 243 types of possible states of health could be defined via this strategy. Every heath state can thereafter be transformed as "utility health index" score. EQ-5D user guide consists of values in its tables which provides great help for its calculation. "1" as maximum score denotes best health state. The second section as Part two comprises self-rated evaluation by utilizing visual analogue scale thermometer. In this section, self-reported health state of patient is quantified.100 score would be assigned for best state and 0 score for worst state.

The European Organization for Research and Treatment of Cancer (EORTC) questionnaire also consist of another unique module which is intended to be specifically utilised for assessment of HQOL only for patients of cancer in neck and head region as stated by Bjordal et al in 1994. EORTC variant in neck and head region has 35(thirty-five) questions pertaining to symptoms and also include side-effects relating to treatment. Scoring is based on responses on four-point scale starting from 1 which is utilised for 'not at all' and goes till 4 which is utilised for 'very much'. Initial 18 (eighteen) questions enquire for symptoms like presence of pain or swallowing difficulties or change in taste and appearance. Next twelve questions enquire regarding functional parameters like chewing, speaking, social contacts and also sexuality. Five yes or no questions in last relates to specifically to analgesia, weight and supplemental feeding

II. Oral Health Impact Profile is another sophisticated tool for assessing qol among oral cancer affected individuals. It is used very widely across countries for assessing QOL. Oral Health Impact Profile commonly called as OHIP was introduced first in 1994 Slade et al[5].

The main layout of OHIP follows the framework and benchmark of Locker's modification and adaptability of WHO classification related to disabilities, handicaps and impairments so as to quantify oral health. *Locker, 1998[6]*. All the functional parameters affected from oral health are further noted in an order of their outcomes. This provides us detailed insight owing to multidimensional concept pertaining mainly oral health.

OHIP includes measurements of 49 items. Statements are further subdivided to 7 domains under the headings as: Pain, functional limitation, social and physical disabilities, psychological discomfort, psychological disability and lastly handicap. Likert scale is needed for recording the responses and the problems faced due to bad oral health as follows

0 is never
1 is hardly ever
2 is occasionally
3 is fairly often
4 is very often

Frequency of outcomes are also summed in all 49 items. Huge evidence is gathered to gauge both reliability and validity for OHIP. Evidences show that OHIP shows acceptable and good psychometric features particularly in research of oral health. Slade in 1997 [5]have conducted various attempts to reduce 49 items included in OHIP to 14 items only as OHIP-14. This shorter version of OHIP not just is easy as per administrative norms but also serves as more specific and sensitive tool for assessing typical oral health conditions. OHIP 14 includes fourteen items which also contain similar 7 domains just as in OHIP original version as stated by Slade in 1997[5].

III. Another commonly used measure with respect to cancer among region of neck and head is questionnaire noted as- University of Washington Quality of life questionnaire (Rogers et al., 2002)[4]. The current versions (version 4.0) cover 12 twelve domains: discomfort/pain, esthetics/appearance, physical activity, recreation, eating/chewing, phonetics/speech, swallowing, shoulder function, taste, saliva, mood and anxiety. Each question is scaled and scored as 0 for (worst) going until 100 for best according to the hierarchy of response.

There is inclusion of two 2 global questions, every question is scored on 6 six-point Likert scale ,1 question enquire health related and other one asking about overall quality of life during "the past 7 days."

UNIVERSITY OF WASHINGTON QUALITY OF LIFE SCALE (UW-QOL) has been extensively validated, particularly in oral cancer affected individuals cured and treated mainly from primary surgery.

Hassan and Weymuller[7] first introduced UW-QOL as main and important tool for assessing QOL among oral cancer affected individuals has an advantage as it provide huge usefulness for assessing functional parameters specific to a disease.

It is short questionnaire which is best suitable for patients who undergoes primary surgery. The current version is version 4 comprising domains of anxiety and mood as added ones. This questionnaire is self-administered patient related comprising 15 questions.12 are significant to disease like appearance, pain, activity, swallowing, recreation, eating, phonetics, altered taste, shoulder problems, problems in salivation, mood and anxiety. Three are general issues which measures global HRQOL. This section also rates out of all domains, change in which domain would be most relevant and significant for patients undertaking the questionnaire. Lastly, free section of text writing was also permitted for patients for addressing issues which were not featured in questionnaire. Scoring from 0 which is worst to best scoring of 100 would be scored by Likert like scale.

IV. Another questionnaire which is often utilised for assessing HRQOL following rehabilitation among oral cancer affected individuals post treatment.

Liverpool Oral Rehabilitation Questionnaire (LORQ) is a HRQOL health-related quality of life instrument assessing impact and effect of oral rehabilitation on patients' HQOL following oral cancer post treatment Lot of revisions have been done for this measure. Version 3 is most regularly and frequently used. It has 40 items /symptoms further sub divided in two main sections. First one relates to oral functions, appearance of oro-facial region and lastly social interactions. Second section relates to individual perception related to prostheses satisfaction.[8]

V. The fifth most regularly and often used questionnaire for assessing QOL among oral cancer patients is Functional Assessment of Cancer Therapy Scale; FACT Scale-Head and neck section FACT HNS. FACT-HNS a modified module of FACT G consists of eleven 11 items including topics relating to chewing, appearance, swallowing, breathing, habits of alcohol and smoking. Likert scale from "0 to 4"is used for scoring. FACT HNS is pretty reliable questionnaire which uses principles of sound psychometry along with patients' inputs.[9]

Research Problem

WHO states 'outcome of health upon Quality of life is complex multifactorial largely dependent upon human beings physical state, biological state, psychological state, level of being independent including social interactions &associations affected largely by the environment'. The QOL is multidimensional concept which looks at the way the patients feel about themselves pertaining to prevailing medical condition.[4] There are lot of definitions quoted by various researchers for QOL.WHO defined QOL as "an individual's perception of their position in life in the context of the culture and value systems, in which they live and in relation to their goals, expectations, standards, and concerns." Looking upon &taking into considerations for evaluating oral health-related QOL (OHRQOL) it basically denotes the comfort while doing daily activities like chewing, speaking, engaging in day to day household chores and being socially active, self-confidence and lastly complete satisfaction relating oral health.[7] Oral cancer patients suffer largely not just because they are often associated too few of vital sites but largely because the basic daily needs is extensively affected by involving mouth/ oral cavity &associated structures The main essential role of main anatomical structures and parts of mouth/ oral cavity encompasses very important functions like chewing, swallowing, speaking, taste and salivation. Cancers & thereby various treatment options mouth/ oral cavity & adjoining structures often results in worst outcomes due to impaired functions ultimately detiorating the oral health related quality of life (ORHQoL). Detiorated &compromised oral health largely affects the overall well-being and health of an individual ultimately negatively affecting the health-related QoL (HRQoL) at larger prospects

Though due to more &more advancement pertaining to various treatment options &approaches for treating oral cancer, noticeable improvements are visualized among oral cancer survival rates but still oral cancers at all sites experiences detiorated OHQOL.[5]

QOL assessment is complex composite issue which involves evaluation of overall issues pertaining to clinical condition, treatment effects etc along with specific ones like phonetics pain, mastication etc.

During period of 1980, lots of generic measures for assessing OHQOL were developed for assessing oral health 's specific effect of oral health upon quality of life.

Many patients specific QOL assessment tools are developed but still not much evidence is visible as which assessment tools are preferred for oral health relating specific conditions. Developing and introducing newer measurement tools will definitely help in contributing QOL assessment for varying oral conditions and their treatment regimens. Still, rationale behing use of newer specific assessment tools should be clearly stated by the researcher regarding evaluation strategy, reliability, validity, specificity and utility for newly developed tools**.**

No instrument/questionnaire follows gold standard owing to QOL assessment. An ideal questionnaire should be concise, short, easily understandable, self-assessed, low in cost, and clearly defined psychometric criteria.

Typically for assessing OHQOL among oral cancer patients,4 main subtypes /classification of assessment tools are used. Since QOL includes very broad characteristics and it shows lot of transitions particularly because of interferences by different factors, none among any instruments are capable to fulfil the task for analysing OHQOL completely. Any questionnaire which is subjected to such interference from external variables makes very difficult for conceiving any instrument. Despite being availability of couple of questionnaire for assessing QOL. Elements which show good potential to effect QOL e.g individual's religions, cultural along with historic factors pertaining to every individual subjects are not included among any available questionnaires.[8]

Solutions Found

Oral cancer affected individuals should always be categorized as different entity which are separate from other affected individuals from cancers of region of neck and head. This point is important because mostly all the questionnaires which are developed are modification for cancers of neck and head region.

Varied methods and techniques are used for assessing QOL. Open, semi structure interview format, questionnaires specifically completed by the affected oral cancer individuals are few among practical forms of assessment.

Subjective observations of the clinician are few among the non-standardized way for assessing QOL but they are non-reproducible and can't be quantified. HRQOL assessment can also complement clinician evaluation of function.

Among most of questionnaires used for assessing QOL among oral cancer affected individuals, UW QOL is only questionnaire that questions individual's perception openly regarding his/her QOL. This questionnaire has

12 closed specific questions along with three open general questions. Investigating and evaluating QOL pre and post treatment helps to analyse the dynamics and process of QOL along with time.[10]

Conclusion:

Quality of life thus is main indicator for assessing disease outcomes. It also serves as interpreter tool for assessing disease related survival. QOL is largely affected by lot of overlapping facts and domains. Though enormous health care research is going all over the world to enhance and improve the survival as well as improve quality of life among all the cancers of human body. Human being s individual perception for quality of life is most relevant, important and significant parameter to enhance the overall wellbeing among cancer patients. During the last decades, this idea of QOL has developed enormously in health care research to assess the individual's understanding of well-being.

Increase in success rate owing to treatment of oral cancer, consequent enhancement in patient's survival, need for comprehensive care, thus it becomes very necessary that QOL assessment among patients of neck and head cancer should be imbibed very well into dental clinical practice. Correlation among all questionnaires for assessing QOL among oral cancer affected individuals denotes that every researcher has to be sufficiently cautious enough for the aspect which needs to be evaluated in particular.

Scope For Further Research:

Quality of life QOL among oral cancer affected individuals are profoundly detiorated and affected mainly from difficulties originating from malignancy itself in region of neck and head. Distortion of phonetics, altered taste and loss of appetite, eating difficulties, extreme dryness affecting oral mucosa region are few among these difficulties.

For effectively managing the patient affected from cancers of mouth/oral cavity, cure is one aspect. Quality of life, QOL should be equally considered for assessing and evaluating the treatment outcome. Evaluating and assessing QOL may also lead to multidisciplinary team for being consulted and involved more often thereby helping patients avail improved survival from better quality of life. Present health care systems for affected individuals by oral cancer, has shown enormous interest for assessing effect and impact of overall status of oral health on HRQOL. This is in turn would greatly impact oral care services along with initiatives for improving QOL in dental profession. Ultimately justifying that improved oral health will directly affect general health along with wellbeing. Though QOL measure pertaining to dentistry are available but still there are minimally utilised for clinical practice. Thus, more and more research in all assessment measure for OHQOL is overtly needed.[11]

References:
1. Li-Jen Liao, Wan-Lun Hsu, Wu-Chia Lo, Po-Wen Cheng, Pei-Wei Shueng and Chen-Hsi Hsieh. BMC Cancer ;2019; 19:425.
2. Min Nie, Chang Liu, Yi-Chen Pan, Chen-Xi Jiang, Bao-Ru Li, Xi-Jie Yu, Xin-Yu Wu and Shu-Ning Zheng. Development and evaluation of oral Cancer quality-of-life questionnaire. BMC Cancer 2018 18:523
3. Bahareh Tahan, Sayed Mohammad Razavi, Hamid Emami3 & Fatemeh Alamchi. Assessment of the quality of life of the patients with treated oral cancer in Iran. Oral Maxillofacial Surgery 2017; 21:429–437.
4. C McGrath, S.N. Rogers. Overview of Instruments Used to Assess Quality of Life in Dentistry.
5. Slade GD. Community Dental Oral Epidemiology.1997; 25(4): 284–290.
6. Locker D. Community Dental Health 1998:5(1);3-18
7. Hassan SJ, Weymuller EA: Assessment of quality of life in head and neck cancer patients. Head Neck 15:485, 1993.
8. Gomes EA et al. Head and Neck Cancer Patient's Quality of Life: Analysis of Three Instruments Journal Dent Shiraz University Med Science March 2020; 21(1): 31-41
9. Arun Chandu, Andrew C.H. Smith, Simon N. Rogers. Health-Related Quality of Life in Oral Cancer: A Review. Journal Oral Maxillofacial Surgery 64:495-502, 2006
10. Fabiana Paula de Andrade, Jose Leopoldo Ferreira Antunes, Marcelo Doria Durazzo. Evaluation of the quality of life of patients with oral cancer in Brazil. Brazilian Oral Research 2006;20(4):290-6
11. Shailesh M Gondivkar, Amol R Gadbail, Sachin C Sarode, Shankargouda Patil. Quality of Life Assessment should be Part of Oral Health Evaluations in Day-to-day Practice. The Journal of Contemporary Dental Practice, October 2017;18(10):857-858