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Quality of life research in head and neck cancer: A review of the current state of the science

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Abstract

Quality of life (QOL) has become an increasingly important outcome measure for patient's undergoing treatment for a wide array of illnesses. QOL is a global construct that reflects a patient's general sense of well being. It is by definition multi-dimensional and reflective of the patient's point of view. Health related issues are among the many factors that may influence QOL. Since head and neck cancer (HNC) affects structures that are critical for normal functions such as speech and swallowing, and treatment may lead to deformities that adversely impact psychosocial functioning, there is particular interest in assessing QOL in this cohort of patients. In order to interpret the HN QOL literature, it is important to have an understanding of the significance and limitations of QOL assessments in the head and neck patient population as well as an appreciation for the currently available measurement tools. Unfortunately, the HNC QOL literature has many limitations including: small sample size, lack of prospective data and poor study design. None-the-less, important insights can be obtained by review of the current literature. First, it is important that QOL studies be reported in such a way as to provide clinically meaningful data to clinicians. Linking measurements with clinical benchmarks is one way to accomplish this goal. In addition, both general and HNC specific measures are needed in order to provide a comprehensive assessment of global health and tumor specific issues. In general, QOL declines immediately after therapy and returns toward baseline by 1 year. Several factors have been identified that may predict for worse QOL outcomes including: the presence of a feeding tube, co-morbid disease, tracheotomy, site and stage. Data correlating QOL with functional outcome and symptom burden fails to demonstrate a consistent relationship. This may be attributed to methodological issues in study design or the patient's ability to adapt to functional and symptom control problems. Whether routine use of QOL measures in the clinical setting is beneficial to patients has yet to be determined. Further studies are warranted as currently available instruments may not be valid for repeated clinical use.

Keywords: Quality of life; Tumor; Paranasal sinuses; Head and neck cancer; Function preservation; Symptom control

1. Introduction

Head and neck cancer (HNC) patients are unique with regards to the potential adverse impact of tumor and its treatment on quality of life (QOL). HNC refers to primary tumors arising out of the larynx, pharynx, oral cavity, paranasal sinuses and the salivary glands. Thus, they arise in areas which are structurally complex and functionally imperative for critical activities such as speech and swallowing. Furthermore, head and neck deformities that result in loss of facial integrity may have profound emotional and social effects. Thus, evaluation of the biopsychosocial sequellae of HNC and its treatment is of great importance [1]. By understanding these effects, we can potentially design interventions that lessen the adverse impact of this disease process.

Concerns about the acute and late effects of combined modality treatment have provided impetus for the recent flurry of studies evaluating QOL and symptom outcomes in patients treated for advanced head and neck cancer [2,3]. Despite this, the failure to use a consistent definition of QOL and inconsistent use of measures to assess outcomes in HNC patients has led to numerous problems. These include: (1) a lack of consensus of the importance of QOL in managing HNC patients, (2) a debate on how to best assess QOL in HNC patients, and (3) a lack of understanding of how to interpret data [4]. Thus, it is important for clinicians to understand the meaning of QOL, how it is measured, and how it can be used. In the following review, we will begin by defining quality of life and distinguishing it from symptom control outcomes. We will then discuss the psychometric measures and available tools to assess both QOL and symptom control in the head and neck population. We will summarize what we have learned from current studies. Finally, we will use the research to provide recommendations for clinical practice.

2. Defining QOL and symptom control

QOL is a global construct that has developed over the past three decades in response to the perceived need to assess the patient's overall sense of well-being and how it relates to disease and disease treatment [5–7]. QOL is affected by intrinsic characteristics of each individual patient including: beliefs, expectations and experiences [6]. Thus, QOL must be evaluated from the patient's perspective. This view has been supported by the World Health Organization which defines QOL as "an individual's perception of their position in life, in the context of the culture and values systems in their life, and in relation to their goals, expectations, standards, and concerns" [8], QOL measures seek to obtain a comprehensive, multi-dimensional picture of the patient's "total health related experience." In order to achieve this goal, QOL measures evaluate broad domains including emotional, physical, functional, social, financial and spiritual well-being [7,9].

An important issue in QOL research is the relationship between symptoms and the domains of QOL. A symptom may be defined as a perceived alteration in sensation. Because symptoms contribute to the physical and functional domains, most QOL tools incorporate questions regarding common disease or treatment related symptoms. However, a distinction must be made between symptom assessment as a component part of a validated QOL tool and studies conducted specifically to assess a symptom or symptom cluster. Evaluation of a symptom can provide important information, but it does not place that symptom in the context of global well being. Symptom assessment may be undertaken using symptom surveys or objective measures. One of the major areas of confusion in the head and neck QOL literature is the failure to distinguish symptom surveys and quality of life measures.