Head and Neck Cancer, Precision Medicine and Health Related Quality of Life: The Patient Is the Keystone

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Abstract

Precision medicine is nothing new in health context, neither in oncology clinical practice. Although, focusing on the “individual” remains trendy, actual, relevant and opportune either for clinical practice, research purposes and particularly, for patients’ lives. Patient- reported outcomes are multidimensional and subjective measures that can be objectively quantified. They reflect patients’ perceptions about their health-status, symptoms, functioning, satisfaction degree with healthcare, health behaviors and health related quality of life. Patient-reported outcomes can capture the voice and experience during the head and neck patient disease journey favoring communication and shared decision-making and engaging both patients and healthcare providers. This approach can demystify procedures, clarify concerns about future and favors emotional support. Moving towards personalized healthcare in head and neck cancer clinical practice brings us emerging challenges in the next few years. Pharmacogenomics, gene testing, health outcomes measures, and patient-reported outcomes are all crucial tools to find a direction and achieve the common objective: find the best path forward! The patient is the keystone!

Keywords: Head and neck cancer; Oncology; Patient reported outcomes; Precision medicine; Health related quality of life

Abbreviations: HRQoL: Health Related Quality of Life; PRO: Patient Reported Outcomes

Introduction

Over the past six decades, organizational culture and quality of healthcare have been substantially discussed and improved. Analysis, reflection and implementation of strategies, able to optimize quality of products and services, were in focus. Greater responsiveness was promoted, a diversity of development trajectories was favored and personalization in healthcare was highlighted. Such line of thinking meets a global political, economic and social trend observed since the 90’s, when greater pressure is applied in the health sector so that it become challenged with accountability, transparency, equal access to healthcare and optimization of the effectiveness of all related services.

The patient is the keystone: Precision Medicine

During the recent decade, the singularity and uniqueness of the individual have been celebrated and recognized within the media, arts, and sciences - biomedical field included. Person

alized medicine is nothing new in health context, neither in oncology clinical practice. Although, focusing on the “individual” remains trendy, actual, relevant and opportune either for clinical practice, research purposes and particularly, for patients’ lives. Personalized or more recently used, precision medicine, ensures a better, and tailored care for the individual patient by enabling earlier diagnoses, risk assessments, and optimal treatments. Additionally, precision medicine has the potential to increase patient confidence and compliance to the treatment. The patient is the keystone! [1,2]. Health promotion and protection is the first goal in nowadays medicine. Identification of individual disease susceptibility and prediction of individual response to a treatment is closely related to molecular, genetics, physiological profile, environmental exposure and behavioral factors. This global - and at the same time individual understanding - is a complex challenge that involves researchers, clinicians and patients [1].
The patient is the keystone: Patient Reported Outcomes and Health Related Quality of Life

Patient-Reported Outcomes (PRO) are multidimensional and subjective measures that can be objectively quantified. PRO reflect patients’ perceptions about their health-status, symptoms, functioning, satisfaction degree with healthcare, health behaviors and health related quality of life (HRQoL). HRQoL is a multidimensional and subjective concept considered a major issue in the assessment of PRO in head and neck cancer patients. HRQoL research is grounded on patient perceptions. HRQoL has been used both as a concept and as a health outcome measure, related to cancer randomized controlled trials and clinical practice, providing information about treatment risks, benefits and tolerability [3,4]. PRO is traditionally linked to patient symptoms’ and functional assessment, both in current trials and head and neck clinical practice [5,6]. First studies were mainly based on symptomatology and made relevant contributions for our current, broad and deep understanding of the distinct HRQoL impacts caused by different treatments [7].

Head and neck cancer patients often experienced extensive physical, emotional, and social suffering. Confrontation with disease is no longer a passive and absolutely lonely journey, where individuals are merely targets for radiation, or chemotherapy agents that evolved to effectively destroy cancer cells. Because side effects do exist, unfortunately, both individual perception of the disease, and the development of different treatment options contribute to the wide range of HRQoL impacts [8]. PRO that reflect head and neck cancer patient HRQoL and that demonstrated value in oncology healthcare, are being used as helpful metrics to support both politician’s and decision makers in order to establish benchmarks for the quality of care [6,9]. The value of PRO-as prognostic, or stratification factors in research across head and neck cancer-has been highlighted and emphasizing the importance of domains such as physical functioning, global health and global quality of life as significant determinants for prognostic prediction [10].

Research identify some conditions that affects the individual response to disease and that have a direct impact on prognostic: feeling neglected, helpless, intimidated and disempowered by lack of information, having fear and worry for the future, hope, emotional support and encouragement, validated personhood and companionship, safety in trust, right to individual knowledge and choice; control over own life; partnership and respect; capacity for self-management [11]. PRO can capture the voice and experience during the head and neck patient disease journey favoring communication and shared decision-making and engaging both patients and healthcare providers. This approach can demystify procedures, clarify concerns about future and favors emotional support [12,13]. PRO routine assessment revealed to be valuable for the access to important volumes of data and added to HRQoL research the potentiality of making predictions [14,15]. Patients may now, consciously, choose the treatment approach based on predicted outcomes, as well on the knowledge of the most critical moments they may face throughout the disease [16].

Interestingly, the evolution of QoL research and the access to larger databases has allowed greater knowledge beyond the physical domains, clearly the most intensively investigated to date. Indeed, and a number of studies are now particularly focused on emotional domains - such anxiety and depression - and individuality currently gains further importance [17,18]. Despite all advantages of including PRO in head and neck cancer randomized clinical trials and practice, a lack of consciousness concerning analysis and data interpretation has been signalized [19]. Critical literature reviews and structured collaborative process are fundamental. Some challenges are defined: adoption of clear standard research objectives, improve appropriate statistical methods and terminology for PRO analysis, and finally deciding how to manage missing data [4]. Our team is continuous working on PRO analysis and optimization, involved in the development of personalized PRO measures and in the implementation of PRO daily assessment in oncology - head and neck cancer has been our main goal for more than one decade. Moving towards personalized healthcare in head and neck cancer clinical practice brings us emerging challenges in the next few years. Pharmacogenomics, gene testing, health outcomes measures, and PRO are all crucial tools to find a direction and achieve the common objective: find the best path forward! The patient is the keystone!

Conflict of Interest

The authors declare that they have no conflict of interest.

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