



Health-related quality of life and patient-reported outcome measurement in Head and Neck Oncology

Improvements in head and neck cancer (HNC) care strive to enhance a range of patient outcomes including survival, reduced treatment burden, better shared decision making, more individualised and tailored treatments and health related quality of life (HRQOL). HRQOL is now an established component and represents the patients' physical, psychological, and social response to the disease and therapy (WHOQOL, 1998) (1). There is a range and complexity of the literature on HNC reporting HRQOL outcomes (quantitative and qualitative) and this is reflected in the "Handle on QOL" resource (2). A broader scope of outcomes is addressed through the terms patient-reported outcomes (PROs) or patient-reported outcome measurements (PROMs). These encompass any measures obtained directly from the patient, which include areas of HRQOL, as well as wider concepts such as patient satisfaction with care (3). Over the last three decades, HRQOL has become a significant outcome measure for cancer patients in clinical trials (4). In this setting, patient-reported HRQOL data is commonly required alongside progression-free survival, and overall survival to assess the efficacy of a given therapeutic intervention. In addition, in some units, HRQOL is routinely collected during follow-up and this serves to establish large longitudinal datasets and also provides the opportunity for using the HRQOL data to inform individual patient care (5).

As part of NHS England improving cancer outcomes programme (QOL Metric) all cancer patients are being invited to complete the ED-5d (6) and EORTC-C30 (7) instruments, at 18 months of being told of the diagnosis (8). This data is available on a dashboard as well as for individual patients. Such national initiatives will serve to provide a very useful material to help drive changes in practice and care which will result in improved HRQOL outcomes.

The clinical care of individual patients in oncology clinics is augmented by regular measurement of PRO such as symptoms, functioning, and HRQOL, both before and during treatment (9). This plays an important role in informing clinicians of the degree of dysfunction in specific domains. In addition to HRQOL, it is feasible to monitor symptoms and ask about patient concerns and this helps to disclose potential unmet needs and provide a mechanism through which additional multidisciplinary support can be initiated. A better understanding by the patient, carers and clinicians as to the PRO can aid communication and allow more active treatment decision making. Published evidence indicate that measuring the HRQOL early after the completion of treatment may provide an indication of the likely HRQOL at 12 months post-treatment (10). There are a number of questionnaires currently being used by various health and social care professionals (3) but these are limited in their scope of enquiry by the nature of the number of items included, the format of the measure, such as Likert scale, the wording and formatting. HRQOL can be measured reliably and validly (11) so as to help clinicians gain insights into a patient's perspective of their disease and treatment. One of the key challenges to the use of PRO in clinical care is poor communication and lack of co-ordination between primary and secondary healthcare, social care and third sector providers (voluntary agencies). This results in patients having repeated assessments on their care pathway, repeatedly providing the same information, inefficiencies in terms of untargeted support, resources used in those with low needs and requirement and repetition of already stretched services. The use of disease specific prompt lists allows for a much better opportunity for holistic assessment by virtue of the range of issues covered. One such example is the HNC specific Patient Concerns Inventory (PCI-HN) that has been tested in a randomised control trial (12).

Papers reporting on specific aspects of HRQOL have been published in a variety of journals (2). Clinical teams need time and effort to identify what may be relevant to their practice. The purpose of a special series on HRQOL is to provide an update by bringing together all the important, and often interrelated issues in HNC care. These include holistic needs assessments, identification of unmet needs and their effect on patients and families, functional outcomes as well as the psychological impact of a cancer diagnosis on relationships and sexual wellbeing.

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