REVIEW ARTICLE

Quality of life in head and neck cancers patients: predictive factors, functional and psychosocial outcome

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Received: 10 July 2007 / Accepted: 17 December 2007 / Published online: 11 January 2008 © Springer-Verlag 2008

Abstract The principal endpoints in head and neck cancer are survival with improvement of quality of life (QoL) in cancer patients. Patients treated for head and neck cancer suffer from a number of symptom domains: physical symptoms linked to diet and feeding, communication disorders, pain and their general state of health; psychological symptoms including depression, irritability, loss of selfesteem (occasionally feelings of shame), and social symptoms including relationship difficulties with partner (sexual disorders) or with other family members, loss of work, reduction in salary, and sense of uselessness, resulting in a negative impact on their daily life. At present, most tools

only partially evaluate patient QoL, concentrating on the global impact of disease and its treatment on patients' physical and psychological condition. The "sociability" of individual patients is rarely evaluated, and the development of qualitative studies in this domain will enable improved understanding of the social factors involved in each patient's adaptability to disease, its treatment and aftereffects.

Keywords Quality of life · Oncology · Head and neck cancer · Measurement tools · Sociability

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Introduction

In the past, acknowledgement of treatment efficacy in oncology, through tumour control, global survival, and disease-free survival was the only measured outcome. Physicians were essentially concerned about healing their patients and preserving the "quantity of life", survival being the only measurement tool. Inevitably, the notion of "quality of life" (QoL) has become increasingly important in patient treatment, particularly in oncology where life expectancy is limited and treatment rarely offers total recovery. Consequently, alongside survival or response to treatment, patient QoL is now included as an evaluation criterion in clinical trials. Advances in the field of oncology, changed mentalities, and the transformation of patientcarer relationships have all imposed the study of healthrelated quality of life (HRQoL) in medical research. Even if the main aim of physicians is to increase survival, HRQoL evaluation has firmly established its relevance in oncology.

Over the last few decades, there has been an increasing interest in HRQoL studies. Three assessment methods are used: patient self-completed questionnaires (valuable tools



in HRQoL evaluation), semi-structured interviews, and qualitative approaches (being more difficult to implement).

The aim of this work is to summarise a review of patient-reported outcome measures in head and neck cancer.

Method

First, we searched the keywords "quality of life" and "head and neck cancer" using pubMed. We selected papers among those published over the last 20 years. We excluded case reports and papers limited to ear, nose, lung oesophageal, and thyroid cancer. The search was retaining 35 articles on predictive factors of HRQoL, and patients' functional and psychosocial outcome.

Results

Cancer is both frightening and threatening for patients, and for their families and friends. For the patient, the diagnosis of this serious illness evokes images of suffering and death. Independent of each patient's individual situation, there is always a "before" and an "after" diagnosis, and initial treatment. With the onset of cancer, the patient's life may continue more or less as before; however, more often than not, it enters into a downward spiral.

Predictive factors of HRQoL

Generally speaking, the discovery and treatment of head and neck cancer leads to an alteration in global patient HRQoL with a negative impact on daily life [1].

Age and sex

Female sex and advanced age are said to be predictive factors in the alteration of HRQoL [1, 2], though this theory remains under debate [1, 3, 4]. Patients under the age of 65 and presenting with laryngeal cancer treated by isolated and/or adjuvant radiotherapy, often report ill-being and anxiety [3]. Woodward reports better QoL in patients older than 65 years compared with patients 65 years or younger. Pretreatment functional status is often better in younger patients. Extensive surgical procedure reduces it and perception of QoL decreases [5].

Demographic factors

The influence of demographic factors is in controversy. Smoking and depression affect QoL [6]. The impact of alcohol consumption is variable; it may improve QoL [7] or

have negative effects [8]. Daily life is important: QoL and survival are better for married persons, those not living alone [9], and those who are employed [2]. In Vartanian's study [8], one in three patients became unable to work as a result of disease or its treatment, whilst 42% reported a significant decrease in household income.

Socioeconomic status

Patients with higher economic status, higher educational levels [6] or without comorbidity [10] tend to enjoy better QoL. Distress and low-socioeconomic status have been linked to poor access to a high-quality health care system. These patients have been shown to present with more advanced stages of disease, later diagnosis, together with increased disabilities, complications, and sequelae. Multiple comorbidities are associated with bad functional outcome [5]. Socioeconomic status is therefore significantly linked to HRQoL [8, 10] and should be included as a prognostic factor of morbidity and mortality.

There is a relationship between educational level and disability rate. Patients with higher social, cultural, economic statuses, and level of education are more able to cope with cancer and its consequences. Patients from lower status tend to work in activities requiring more physical strength and are poor candidates for rehabilitation since they are less inclined to accept change. Many of them become disabled after diagnosis and treatment. Loss of work decreases household income, resulting in a reduced quality of daily life [8].

Effect of disease

The impact on HRQoL of tumour localisation, cancer stage, and type of treatment is also a source of controversy [4]. Patients with oro- or hypopharyngeal and oral cavity tumours have worse scores on the HRQoL eating scale compared to patients with cancer in the larynx [11]. In contrast, scores for these three localisations on the speech scale are better than those for patients presenting with cancer of the larynx [11]. Furthermore, in most cases these comparisons deal with heterogeneous cohorts including patients with both early and advanced cancers, thus explaining certain good QoL scores [12]. Nevertheless, advanced cancers are associated with poorer QoL due to increasingly severe symptoms [1, 13].

Effect of treatment

The impact of treatment type on HRQoL is also a source of controversy. HRQoL is low during treatment [1, 13]. The most significant HRQoL changes occur during the first year after diagnosis [13]. Impact on body image appears to more



distinctly affect patients having undergone surgery than those having received alternative treatment [4]. Neck dissection may be associated with shoulder pain, impacting on health status. QoL [11] can be affected by the presence of a tracheotomy [11]. Radiotherapy didn't always have an effect on long-term QoL outcome [5]. In opposite, multimodality treatment decreases QoL [1, 3]. Patients having undergone radiotherapy in association with surgery or chemotherapy have been reported to experience poorer QoL than those treated with radiotherapy alone [1, 3, 14]. Not all authors agree. List reported several phase II studies in Chicago University with equal QoL results in populations 1 year after concomitant chemoradiotherapy [15]. Allal [16] found better QoL results in T3-T4 patients treated with radiotherapy with or without chemotherapy than those treated with surgery. HRQoL alteration is particularly distinct among patients who, after having benefited from an organ preserving protocol, are finally obliged to undergo total laryngectomy [17]. All of the above results are subject of controversy. Both tools used and study designs are heterogeneous. Interpretation of the influence of therapy on HRQoL is difficult since many factors are intrinsically linked. Time lapse since the end of treatment is moderately predictive of HRQoL alterations.

The time

Patients with head and neck cancer treated with intensitymodulated radiotherapy experienced a small drop in QoL, which recovered to baseline by 12 months post-radiotherapy [18]. Generally, longer the time lapse from diagnosis and treatment, better the patient's HRQoL [11]. Improvement appears to stabilise 1 year after the completion of treatment [13-19]. Magné [20] reported outcome symptoms after 5 or 6 years and found a modest change compared to results obtained after the first year. In a recent prospective study of 137 treated head and neck cancer patients, patients with low-QoL at 1 year had a significantly increased risk of death [21]. Time since diagnosis helps patients to adjust to the effects of diagnosis and treatment, and to mobilise their coping strategies. One year after treatment, the appreciation of long-term survival becomes more important than pre-treatment QoL [21].

Functional outcome

Physical complaints

In head and neck oncology, the most affected HRQoL domains are those linked to patients' physical health. Patients with head and neck cancer report difficulties related to diet and feeding, communication, pain and general state of health [22]. Nutritional disorders are due to a

variety of factors: xerostomia (dry mouth syndrome), taste and smell disorders, deglutition and swallowing disorders, difficulty in mouth opening, and dental problems [16, 20], the same symptoms leading to significant deterioration in HRQoL [13]. The immediate effects of radiotherapy cause acute and often very severe mucositis. Long-term effects of radiotherapy are the most common cause of feeding disorders [23, 24]. Nerveless, with intensity-modulated radiotherapy, Scrimger [18] didn't see significant correlation between HRQoL scores and stimulated saliva production rates in the post-radiotherapy period.

Communication difficulties are liable to alter daily life since oral language remains the preferred method of contact among individuals. Dysphonia is a frequent symptom in neoplastic head and neck pathologies, but it is not systematically correlated with alteration in quality of life or associated with perturbed social relationships [25]. This demonstrates that patients can have not only good functional speech but also a positive attitude about their speech [5]. The presence of a tracheostoma or tracheostomy can alter breathing patterns, hence impacting on the ability to undertake various physical activities. Permanent stoma and loss of speech are unquestionably serious disabilities; nevertheless these factors do not always appear to decrease patients' QoL [26]. A potential explanation for this is that, with time, patients learn to cope with tracheostoma and alaryngeal speech.

Pain and fatigue are acknowledged as being major factors in the alteration of HRQoL [27]. After 3 years, pain is less severe than at time of diagnosis [13]. Post-therapeutic pain appears as a significant negative prognostic factor [4], linked with patients' psychological status.

Enteral feeding through catheter limits daily activities and is a major cause of discomfort for patients [11, 27].

Mood disorders

Patients treated for head and neck cancer often suffer from depression, which influences their HRQoL [3, 25]. Longterm, 20-30% of patients with head and neck cancer develop psychiatric pathologies [27]. Several studies have paid particular attention to factors associated with depressive states observed among patients treated for head and neck cancer. Tobacco intoxication or personal histories of depression are acknowledged as factors altering the HRQoL of individuals [6, 28]. Indeed, head and neck cancer patients often present alcoholic and tobacco intoxication for which weaning proves to be difficult. The efforts required to stop these toxic habits can induce or exacerbate depressive states [28], which tend to persist several years after treatment, even among patients in remission [11, 16, 28, 29]. Depression at diagnosis is an independent predictive factor for global QoL at 3 years [13], both being



intimately linked; a depressive state has a negative effect on HRQoL and vice-versa [29].

Global HRQoL appears to be highly correlated with physical dysfunction and the loss of autonomy. Often problems related to a gastrostomy catheter are more of an emotional nature than linked to the actual technical complications that the catheter may induce (such as leakage around the orifice, infections, and diarrhoea). The presence of the catheter poses the problem of eating difficulties in public places and the modification of body image. It creates, in the same way as other intravenous devices, a constant reminder of disease and of the absence of recovery [11, 27].

Psychosocial outcome

Identity change

The impact on body image appears to more distinctly affect patients who have undergone surgery than those who have received radiotherapy [16]. Studies focusing on patients' psychological reactions demonstrate that one of the main problems of surgery is related to physical appearance. Patients with tracheostoma following total laryngectomy, or with extensive neck and face scars, often suffer from depression with a loss of self-esteem, hence influencing their HRQoL [30, 31]. On the whole, all of these dysfunctions often lead to major psychological and social distress among patients [28, 29].

Diagnosis and treatment in head and neck cancer modify the patient's individual and social identity [31]. Many patients suffer from a sense of abandonment, betrayal and identity deprivation induced by cancer, which are all factors favouring individual isolation, marginalisation or even exclusion, inevitably lowering HRQoL [27, 30]. Many "extra-medical" problems experienced by patients treated for head and neck cancer remain poorly explored. Equally, the QLQ-C30 and H&N35 questionnaires remain relatively vague in their evaluation of the practical aspects of daily life, leisure activities and social relationships.

Marital life and sexuality

Certain questions remain taboo, in particular those related to income and to patient sexuality. Certain patients report the absence of perceptible change. Marital life is often modified with an increased number of divorces or, at the least, a more conflictual marital relationship for 46% and changes in sexual activity for 30% of patients [32]. Sexual activity is reduced during the first 6 months following surgery for a quarter of laryngectomees [32]. Sexual satisfaction remains an important factor in the psychological rehabilitation of operated patients, as well as their perception of a familial [2] and social support [33].



Loss of occupation is associated with reduced income and, consequently, impairment of quality of life. Psychological adaptation after surgery has been found to be worse for patients who do not return to work. They also experience a significant decrease in household income. After treatment, 52% of patients remain the primary source of income for the family unit and 23% become non-contributors [8].

Cancer results in a great number of workdays lost through sickness, well above those related to chronic illness [34]. Levels of work incapacity among head and neck cancer patients vary from 34 to 52% [4, 8, 11]. The type of treatment appears to have an impact on the resumption of professional activity. Only 15% of patients undergoing total laryngectomy and 50% of those undergoing supraglottic laryngectomy go back to work after surgery [26]. Individuals treated by chemotherapy and having undergone lymph node curettage have a significantly higher risk of work incapacity [4]. Post-therapeutic pain appears to be a significant negative predictive factor [4]. In the Lee-Preston study, subjects within the professional activity age group are often more anxious, with an unstable emotional state. These individuals appear weakened in their professional situation; job loss is synonymous to a decrease in revenue with an inevitable negative effect on HRQoL [3].

Comments

During the past 30 years, there has been a considerable increase in the awareness of QoL issues in oncology. This awareness is of interest to both patients and physicians. For people suffering from illness, and in particular, those suffering from head and neck cancer, HRQoL is a fundamental concern; not only are these patients faced with a highly potentially lethal illness, but they must also learn to cope with the consequences of such illness and its treatment on their physical appearance, and on essential elementary body functions, such as swallowing, breathing, and speaking [22, 27], together with its psychological and social consequences.

The increased interest in QoL has been reflected in studies published on this topic. Unfortunately, often these studies do not examine all HRQoL domains and results do not offer help in therapeutic decision-making. One can only remark that few studies are well conducted (the majority of published studies use validated questionnaires and the best data quality is obtained with longitudinal studies). Nevertheless, there is no "gold standard" HRQoL to evaluate the specific disturbances caused in head and neck oncology. Only three questionnaires (EORTC Head and Neck Module, University of Michigan Head and Neck Quality-of-life Questionnaire, Head and Neck Cancer Inventory) fulfil



guidelines for instrument development and evaluation as outlined by the Medical Outcomes Trust [35]. The use of alternative methods of psychometric data analysis (such as Rasch) may improve the value of health measurement [35]. Thus, many of the "extra-medical" problems experienced by patients treated for head and neck cancer are subject to very little study. These extra-medical aspects are vitally important to improving our understanding of the difficulties experienced by cancer patients. Thus, from a sociological point of view, HRQoL should focus particularly on: "the integration of disease into daily life, in other words the evaluation of the impact of the satisfaction and dissatisfaction that we experience concerning our life in general, without taking into account the physician's and other health professionals' points of view" [27]. This social health approach remains limited in modern medicine. It refers to the notions of integration and support, in other words, the patient's level of sociability. Sociability should not be interpreted as an intrinsic individual quality enabling us to distinguish "sociable" people from less-sociable ones, but as the relationships that an individual (or a group) maintains with others as a whole, whilst taking into account the form of each relationship. These general social relationships have been largely described and are well-known [27]. Use of such knowledge would enable us to place the cancer patient within society and to appreciate the modifications observed in his/her family, friendly, and social relationships. It appears evident that a social health approach is essential in HRQoL analysis. Patient sociability, with its different links and relationships, has an influence on the way the patient copes with and withstands illness. Therefore, the more isolated patients are from a social or familial point of view, the more vulnerable they are likely to be. Reduced sociability is even said to be a poor prognostic factor in certain pathologies including cancer [27]. Indisputably, social health remains very poorly studied in France, very probably because "serious work on the articulation of the health network and on social support would require complex questioning and considerable time, a concept, given the cold-shoulder by health professionals who remain convinced that, if a choice is to be made, it is far more important to understand the physical perception of symptoms or emotional distress rather than to investigate relational phenomena" [24]. A double approach to HRQoL, that is to say both medical and sociological, is not a conflicting but a complementary notion.

In oncology, survival remains the main objective, but the evaluation of the quality of survival (more than HRQoL) has become indispensable as well as ethically and economically necessary [24]. The progressive introduction of HRQoL measurement tools has transformed medical evaluation of patient situations and their care. HRQoL measurement has already contributed to improved awareness of the

side effects or iatrogenic effects linked to new cancer therapies (alopecia, body transformations, etc.). Subsequently, clinical studies have taken into account these effects and guide therapeutic choices towards different treatments with comparable effects [27].

HRQoL measurement tools emerge as reference tools in the longitudinal follow-up of cohorts of patients treated for head and neck cancer. They offer the advantage of differentiating patient and carer perceptions and enable, in certain cases, to improve treatment adaptation. Finally, HRQoL research focuses on the integration of disease into the patient's daily life and on the relative variability of different QoL dimensions (family relationships, work, etc.) according to different disease stages [11]. A new era is emerging in the organisation of novel principles assessing patient response to disease and its treatment. Predicting long-term survival based on studies of QoL has been conducted in breast [36] and lung [37] cancers, and more recently in head neck cancers [18, 20].

Further progress is necessary. Despite the multidimensional orientations offered by HRQoL scales, their evaluation remains close to that of biomedical models. Psychological and social dimensions are reduced to quantitative studies. HRQoL analysis would certainly be improved by the introduction of qualitative analyses and the development of research in collaboration with other human science disciplines.

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