

Quality of life, life satisfaction and benefit finding...is it possible to experience positive growth after treatment for head and neck cancer?

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Key Words: Head and neck cancer, quality of life, life satisfaction, benefit finding, positive growth

INTRODUCTION

Head and neck cancer (HNC) commonly includes cancers arising in any part of the mouth, tongue, lips, throat, salivary glands, pharynx, larynx, sinus and other sites located in the head and neck area (International Classification of Disease (ICD) 10 codes C00-C14, C30-32, C73). In the UK, the major sites are the larynx, oral cavity, hypopharynx and oropharynx, which together account for 90% of HNC squamous cell carcinomas. Approximately 7800 new cases are diagnosed in the UK each year (Office for National Statistics, 2006; NHS National Services: Scotland, 2009; Welsh Cancer Unit, 2009). There have been minimal improvements in 5 year survival rates for the majority of HNCs diagnosed in England, with the lowest 5 year relative survival rate evidenced for hypopharyngeal cancer (26%) and highest for thyroid cancer (87%). The 5 year relative survival rates for oropharyngeal, oral and nasopharyngeal cancer in England remain at approximately 50% (Oxford Cancer Unit, 2010).

Treatment for curative intent often involves a combination of treatments such as surgery, radiotherapy and chemotherapy each with their own physical side-effects. Psychologically, patients commonly report a range of emotions from anxiety (De Boer *et al.*, 1999) and anger (Julkunen *et al.*, 2009) to depression (Hammerlid *et al.*, 1999). These emotions are reported from diagnosis to many years after treatment.

In the context of adaptation, patient reported outcomes (PROs) such as quality of life are of importance both clinically and academically. Understanding the nature of adaptation following a diagnosis of cancer is important if mechanisms to promote adjustment and reduce negative emotional effects are to be developed for patients.

The main objectives of this paper are to firstly, describe common patterns of quality of life after diagnosis with HNC. Secondly, to discuss in the context of adaptation the recent move away from measures of 'deficit' to the application of more *positive* PROs such as life satisfaction, with illustrative data from patients treated for HNC. Lastly, the paper will discuss the concept of 'benefit finding' amongst patients with HNC in the context of the growing literature on positive growth.

WHAT DO WE KNOW ABOUT THE QUALITY OF LIFE IN PATIENTS WITH HNC?

There is wide variation in what is meant by Quality of Life (QoL). The World Health Organisation (WHO) has defined a high QoL as a "state of complete physical, mental and social well-being and not merely the absence of disease or infirmity". Assessing global QoL generally provides a broader picture of the impact of disease on an individual's life. In clinical practice, however, QoL usually refers to health related QoL (HR-QoL) which seeks to measure multi-dimensional aspects of QoL thought to be impacted by a change in health status or disease. QoL measurement is included in the minimum dataset of the British Association of Head and Neck Oncologists (BAHNO) and the British Association of Otorhinolaryngologists-Head and Neck Surgeons (BAO-HNS) and is thus recognised as having implications for patient well-being.

One of the main difficulties with measuring HR-QoL in patients with HNC is the heterogeneous sites involved. Many of these cancer sites will have vastly differing symptom profiles, treatment plans and thus differing side-effects and consequences to each other. Depending on the nature of the information sought, HNC site specific HR-QoL measures are often applied in addition to more global HR-QoL measures. Although it may seem intuitive to stratify patients on the basis of their cancer site, in reality this is rarely done due to the relatively small numbers involved (oral and larynx cancers aside) moreover, even within subgroups, there are a number of confounders such as stage of disease and treatment modality which makes conclusions difficult. It is beyond the scope of this paper to include details of every primary study published to date in this vastly expanding field, (see: Rogers *et al.*, 1999; Lederboer *et al.*, 2005; Llewellyn *et al.*, 2005; Rogers *et al.*, 2007; Llewellyn, 2010; for review articles) however, there are a number of general patterns that have been documented in patients with HNC.

Unsurprisingly, the majority of studies have found a temporary deterioration in HR-QoL in the first three months after treatment particularly in the roles of physical and role functioning, most probably caused by treatment itself (de Graeff *et al.*, 1999; Rogers *et al.*, 2000). Prospective studies have shown that generally, in those that survive, the majority of HRQoL domains return to pre-treatment levels within 12 months with minimal change after this period (de Graeff *et al.*, 2000). It

must be acknowledged that a return to pre-operative levels does not necessarily equate to functional levels prior to diagnosis which explains why in some cases HR-QoL eventually exceeds baseline levels. It is also worth noting that incremental changes in HR-QoL do not necessarily equate with clinically meaningful differences.

In the longer term, despite initially high levels of depression, there is a gradual improvement in psychological functioning and global QoL over the next few years, although this is less consistent in the literature. However, there is a subgroup of patients who continue to experience high levels of psychological morbidity years after treatment which is not wholly related to physical functioning. Although a patient's characteristics are clearly important, there is no clear evidence for the impact of disease and treatment on outcomes such as QoL and many studies have reported that somatic symptoms and dysfunction are not associated with emotional distress or QoL. To date there has been little attempt to explain these discrepancies in QoL and although factors such as stage, site of disease and type of treatment have some impact on HR-QoL, it is unclear from these mainly heterogeneous studies, what additional factors account for the variation evidenced in PROs.

SUBJECTIVE WELL-BEING AND LIFE SATISFACTION

Despite obvious physical dysfunction, some patients come to terms (emotionally adapt) with the effects of treatment and are satisfied with their life and subjective well being (SWB). The latter is increasingly recognised as an important outcome factor following illness or injury that is disparate to QoL. SWB as a construct is thought to contain both an emotional component and a cognitive judgement component which is often referred to as life satisfaction (Andrews and Withey, 1976). Research has focused on the assessment of emotional well-being (such as through the use of anxiety and depression measures) but how 'life satisfaction' is affected by illness is poorly understood. Life satisfaction has been defined as a judgemental process, in which individuals assess the quality of their lives by their own unique set of criteria (Shin and Johnson, 1978).

Clinical experience shows that some patients live a fulfilling life with which they are satisfied, despite considerable physical disability as a result of treatment. Subjective well-being allows a patient to make a judgement on their situation and may be a more relevant outcome indicator after survival. Intuitively one would expect that patient satisfaction or subjective well-being would reduce as the magnitude of treatment and disability increases. Studies with HNC patients have shown that the relationship is complex and that subjective well-being is not directly related to treatment or clinical factors (Llewellyn *et al.*, 2008). A Norwegian study of long term head and neck cancer (HNC) survivors and matched controls, reported significantly worse levels of life satisfaction and physical health in their patient sample (Bjordal *et al.*, 1993). The authors explain the lack of consistency between these results and that of the cancer literature (Kreitler *et al.*, 1993) by hypothesising that re-appraisal and other processes of adaptation 'may not be applicable for a population

with considerable side-effects, including physical limitations and changes of appearance after treatment, which are constant reminders of their disease' (Bjordal *et al.*, 1993). Other research has indicated that life satisfaction in oral cancer patients is related to pain, speech difficulties and dysphagia (Morton, 1995). Other results suggest, however, that despite worse physical HR-QoL reported by oral cancer samples, compared to healthy controls, there is no difference with regards to life satisfaction (Llewellyn *et al.*, 2008). This demonstrates that physical limitations do not automatically lead to worse perceptions of life satisfaction. Few studies have been published reporting the levels of life satisfaction in patients with oral cancer; indeed fewer still have assessed the patterns of life satisfaction over a longer period of time. It has been hypothesised that time would have an effect on levels of cognitive and emotional adaptation for many reasons, not least in terms of healing after treatment and diminishing levels of pain, however, levels of life satisfaction or emotional adaptation were not found to be effected by time (Llewellyn *et al.*, 2008). This may be because the median time to assessment was four years by which time adaptive changes may have taken place and compensatory processes plateaued. Although these particular study data were cross-sectional, and thus cannot indicate whether life satisfaction had changed over time, previous studies have reported that life satisfaction undergoes significant improvement between diagnosis and 12 months post-treatment (Morton, 1995; Morton, 2003). It is, therefore, plausible to assume that life satisfaction decreases around the time of diagnosis and treatment and therefore any subsequent increase could be taken as an indicator of cognitive adaptation.

WHAT ARE POSITIVE OUTCOMES/BENEFIT FINDING IN RELATION TO HNC?

As previously discussed, it does seem plausible that despite the experiences of diagnosis and treatment which are often distressing, life satisfaction and subjective well-being is comparable to that of healthy controls or other non-cancer patient groups. Research with patients with non-HNC cancers has further demonstrated that there are often aspects that patients view as *positive or beneficial* (Sears *et al.*, 2003; Carver and Antoni, 2004; Schulz and Mohamed, 2004; Stanton *et al.*, 2006).

According to Saakvitne and others, this positive growth occurs due to "*cognitive restructuring mechanisms which translate traumatic experiences into the gaining of wisdom, personal growth, positive personality changes and more meaningful and productive lives*". These positive changes which could also result from a traumatic experience such as a cancer diagnosis, are also termed '*benefit-finding*' (BF) (Saakvitne *et al.*, 1998) or the '*identification of benefit from adversity*' (Tennen and Affleck, 1999). Much of the research in this area has been concerned with women with breast cancer (Carver and Antoni, 2004; Helgeson *et al.*, 2004), however, qualitative data from male and female patients with HNC has demonstrated that benefits such as improved personal resources, enhanced sense of purpose, closer relationships with others and changes to life priorities can be identified (Thambyrajah *et al.*, 2010). It has been suggested that those that initially find benefit during difficult situations may be

emotionally better off in the future (Carver and Antoni, 2004; Urcuyo *et al.*, 2005). Relationships have been demonstrated between BF and adaptive coping strategies in cancer (Urcuyo *et al.*, 2005) and coping strategies in turn have been found to have positive effects on adaptation and QoL in relation to patients with HNC (Llewellyn *et al.*, 2007a; Llewellyn *et al.*, 2007b).

The ability to mobilise resources may be a central mechanism driving adaptation (Hobfoll, 1998). Similar to concepts of resilience, internal or personal resources, such as personality, that can be activated independently of external resources, may mediate the association between physical symptom distress and psychological morbidity (Hou *et al.*, 2010). People who have more positive expectations of life events and an effective armoury of coping skills may be better able to buffer the negative effects of a cancer diagnosis. Results with patients with HNC have indicated that coping may play an important role and that it may be possible to predict at an early stage those who are more likely to suffer negative psychological outcomes at a later stage (Harrington *et al.*, 2008). It has also been noted that BF is unrelated to QoL, anxiety or depression and is therefore conceptually different to these types of PROs (Llewellyn *et al.*, 2011).

Qualitative research with patients with HNC has also added to the post-traumatic growth literature by documenting the positive impact of lifestyle changes, such as healthier eating, and reduction of alcohol and nicotine (Thambyrajah *et al.*, 2010), which has implications for recovery and recurrence.

IMPLICATIONS AND CONCLUSIONS

PROs such as HRQoL and Life Satisfaction, appear to be promising for use in clinical practice as they are quick and simple to complete. However it has been recognised that the majority of HNC clinics in the UK do not undertake routine assessment of even HRQoL (Mehanna *et al.*, 2006). The biggest impediments to use in clinical practice appear to be related to the perceived lack of clinical relevance and the lack of resources for data collection, analyses and interpretation.

Patient outcomes are to some extent influenced by personality, which may not be directly amenable to intervention. However, the extent to which an individual responds to a health threat may be improved by targeting coping strategies. Previous feasibility research has demonstrated that interventions to improve coping can lead to better QoL and less depressive symptoms in patients with HNC. The impact is enhanced when problem-focused coping styles are taught rather than emotion focused ones (Allison *et al.*, 2004). Interventions to directly target positive outcomes such as posttraumatic growth have been developed. Cognitive behavioural based writing interventions have been shown to significantly increase posttraumatic growth in a generalised group of participants suffering from posttraumatic stress (Knaevelsrud *et al.*, 2010). These types of interventions may be relevant for those who are severely distressed after a cancer diagnosis and/or treatment.

Research into PROs, such as those discussed in this article, have benefitted our knowledge and understanding of patient adaptation in a theoretical sense and have been invaluable in the routine evaluation of clinical trials. It would not necessarily

be useful to suggest that all individuals must find positive outcomes after a diagnosis for HNC, as there may be significant grief processes at work. However, common research findings support the utility of developing tailored interventions based on fostering better resilience for those that would benefit most.

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