

# Clinical Paper Head and Neck Oncology

# The impact of treatment for head and neck cancer on positive psychological change within a year of completing treatment

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Abstract. Head and neck cancer carries a high level of morbidity and mortality. So why could anyone find having such a disease a positive event? The adversity hypothesis of "what doesn't kill you makes you stronger" suggests that people can use adversity to develop as human beings. This positive psychological change has received little attention in relation to head and neck cancer. Responses to the Silver Lining Questionnaire, University of Washington Quality of Life Questionnaire, and Short-Form 12 were collected from a postal survey, 3 to 12 months after the completion of treatment for head and neck cancer. Fifty-two (63%) people returned the survey and were included in the analysis. Time since completion of therapy did not show any relationship with positive psychological change. Tumour stage and treatment regimen both had a relationship with positive change. Participants with lower stage tumours had higher levels of positive change than those with tumours of higher stages. Participants who had surgery alone reported more positive change than those who had surgery with radiotherapy. A social factor related to greater change was being married or living with a partner when compared to living alone. Further research would aid the identification of bio-psychosocial factors that influence the development of positive psychological change and inform the development of rehabilitation interventions.

Key words: positive psychological change; post-traumatic growth; head neck cancer.

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Head and neck cancer (HNC) is a relatively uncommon disease with only 6398 new diagnoses in the UK in 2014; however, it carries a high level of morbidity and mortality (50% at 5 years)<sup>1</sup>. Factors associated

with this disease have traditionally been studied using a biomedical approach, as the investigators have tended to be clinicians. In the last three decades, psychosocial factors such as health-related quality of life (HRQoL) outcomes have emerged as an important addition to the conventional clinical outcome measures<sup>2</sup>. Furthermore, in the last 10 years, the phenomenon of positive psychological change (PPC) following a traumatic experience has sparked the interest of health care professionals working in long-term patient care and interventions.

The construct of PPC has been variously referred to as 'benefit finding' (BF), growth', 'thriving', 'stress-related 'transformational coping', 'post-traumatic growth' (PTG) or 'existential growth', and may concern alterations in the perceptions of oneself, social relationships with family and friends, life priorities, and appreciation of life. The use of these different terms highlights the difficulties in defining processes of growth and conceptualizing the construct. It has been suggested that PTG and BF are distinct constructs that have a conceptual overlap<sup>3</sup>. However, the scales that have been developed may be argued to measure the same thing differently or in different samples. For example, Sears et al. showed that BF was predicted by personal characteristics (i.e., education, optimism, and hope), but PTG was not<sup>4</sup>. It remains unclear how the two concepts relate to each other, but where BF may start immediately after diagnosis and results from challenges to the individual's cognitive representations, PTG could be hypothesized to develop because of the rumination and restructuring of the self/ world relationship that occurs in the weeks, months, and even years following trauma<sup>5</sup>. Because of this temporal and conceptual overlap, it was decided to use PPC as the preferred term in the current study, and it is acknowledged that this study is not differentiating between BF and PTG.

At the time of writing, only five quantitative studies and a systematic review had been published investigating PPC in people who had been treated for HNC<sup>6-11</sup>. These investigated the relationship of PPC with various bio-psychosocial factors related to HNC and that have been investigated in HRQoL studies. Harrington et al. assessed the relationship between PPC and treatment regimen, time since treatment, stage of cancer, and diagnosis of further illness, and failed to find any associations<sup>6</sup>. This pattern was reinforced by the findings of Llewellyn et al.9 and Holtmaat et al. 8. Ho et al. found that people with more advanced cancer (stages III and IV) reported lower levels of PPC, but different treatment modalities did not significantly influence PPC<sup>7</sup>. However, Leong et al. failed to find an association between tumour stage and the development of PPC<sup>10</sup>. These findings suggest that the biological variables are, at least at present, inconclusive and the impact of demographic factors is equally unclear.

No relationship has been found between gender and PPC<sup>6,7</sup>, and no published literature has found an impact of age on PPC in HNC, although it has been found that younger participants with breast cancer report higher levels of PPC<sup>12,13</sup>. Two studies following the treatment for HNC reported a beneficial effect of marriage or stable cohabiting over single status in the reporting of PPC<sup>7,9</sup>.

Harrington et al. found that in people who have had HNC, dispositional optimism and positive reframing could account for 23% of variance in PPC and that higher levels of religious coping was correlated with greater PPC, but that there was no relationship with anxiety or depression<sup>6</sup>. Once again Llewellyn et al. supported the findings of Harrington et al.<sup>6</sup> in regard to reframing, and found that an increased use of emotional support and a decrease in self-blame positively affect PPC. Other psychological factors were investigated by Ho et al. who found that hope, optimism, and PPC are all positively correlated<sup>7</sup>. However, only hope was a significant individual indicator of PPC<sup>7</sup>.

The aim of this study was to further examine the relationships between biomedical variables, HRQoL, social factors, and subjective reports of PPC following treatment for HNC. It was hypothesized that a greater disease adversity overcome (survived), fewer disease and treatment side-effects, and higher HRQoL would be associated with greater PPC.

### Methods

This was a prospective study using self-completion psychometric measures.

### **Participants**

Ethical review was sought and granted. Potential participants were identified through a regional health informatics database. A questionnaire battery was sent via the mail, with a freepost return envelope, to all potential participants. No follow-up letters were sent.

To be approached as a potential participant, the person had to be over the age of 18 years and to have an understanding of English judged by clinical staff to be sufficient to complete a series of questionnaires in English. Their tumour had to have a histological diagnosis of squamous cell carcinoma (SCC) and be sited in the mouth, lip, oral cavity, salivary gland, pharynx, nasal cavity, or sinuses.

Potential participants were between 3 and 12 months post treatment and disease-free. The time frame of greater than 3

months post treatment was selected to allow for the acute effects of treatment to resolve and the demands of treatment (e. g. fatigue, travel, financial burden, family upheaval) to have lessened.

Of the 82 potential participants, 52 (63%; 36 male, 16 female) returned an at least partially completed questionnaire pack. Demographic data included age at time of diagnosis, sex, Index of Multiple Deprivation (IMD; UK government study of deprived areas in local councils based on income, employment, health, disability, education, skills and training, barriers to housing and services, crime, and the living environment)<sup>14</sup>, and family status (married, living with partner, living alone, living with relative/friends). Medical data included tumour stage, date of diagnosis, treatment regimen, and date of treatment completion. Treatment regimen was split into three categories: surgery (n = 16), surgery and radiotherapy (n = 17), radiotherapy with or without chemotherapy (no surgery) (n = 18).

The Mann–Whitney *U*-test was used to compare medical (tumour stage, time since treatment, treatment regimen) and demographic (age at time of diagnosis, gender, family status, IMD) data between responders and non-responders to the questionnaires, and no significant difference was found between them. Table 1 provides demographic information of the respondents.

### Questionnaires

The Silver Lining Questionnaire (SLQ) is a 38-item measure using a five-point Likert scale that examines the extent to which people believe their illness has resulted in a positive psychological change despite the negative consequences of being ill<sup>15,16</sup>. The SLO has not been used to investigate PPC in people specifically with or following HNC. other than in unpublished literature by the present authors. The SLO has been used with mixed cancer cohorts (breast, colorectal, gynaecological, and lung)<sup>17</sup>. An additional strength of the SLQ is that it was developed in the same geographical region of the UK as where this research study was undertaken<sup>15</sup>.

The University of Washington Quality of Life Questionnaire (UW-QOL) version 4, specific for head and neck cancer, has 12 individual domains: pain, appearance, activity, recreation, swallowing, chewing, speech, shoulder function, taste, saliva, mood, and anxiety, and two sub-scales of physical function and social function 18. The UW-QOL has been validated by comparison to the Karnofsky scale and Sickness Impact Profile, demonstrating an average criterion validity of 0.85<sup>18</sup>.

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