

The trajectory of positive psychological change in a head and neck cancer population

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Abstract. A stressful event may be sufficient to challenge a strongly held set of assumptions about the world and the self. In some people this may lead to post-traumatic stress disorder (PTSD) and in others to positive psychological change (PPC), whereby a person's reactions to the challenge are beneficial. Little research has investigated PPC in people who have had head and neck cancer (HNC). The aim of this study was to identify demographic, clinical, and psychological factors associated with PPC over time. A cross-sequential study collected data over 5 years. Participants were sent the Silver Lining Questionnaire (SLQ; a measure of PPC), the University of Washington HNC quality of life measure, and the Medical Outcomes Short-Form 12 each year. Additional data were collected from clinical records. Analysis using linear mixed-effects modelling revealed that participants with lower stage tumours and those who only had a surgical intervention reported greater PPC over time. Multivariable modelling adjusting for psychosocial variables found that PPC had a quadratic relationship with time since diagnosis, increasing initially and levelling off after 18 months. These findings build on the minimal PPC research with people following HNC. In particular it demonstrates a model of trajectories for the development of PPC longitudinally over time.

Key words: positive psychological change; post-traumatic growth; longitudinal.

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A cancer diagnosis is a highly stressful event and may be significant enough to shatter an individual's understanding of themselves. In 1975 Parkes used the phrase 'assumptive world' to refer to a way in which a person views their reality¹. According to Parkes, we are rarely aware of the fundamental elements of our assumptive world; the minor disappointments, challenges, and failures of day-

to-day life seldom bring them to light. It has been said that they are conservative cognitive schemas that resist change and disconfirmation². The questioning of the basic assumptions is what fractures the assumptive world and triggers the rebuilding of them to accommodate new realities². Sometimes this may lead to people developing post-traumatic stress disorder (PTSD), but it has also been shown that

people can positively re-evaluate aspects of their lives^{3–8}.

There is a growing body of literature supporting positive psychological change (PPC) following a range of traumas, including natural disasters, bereavement, and illness^{9,10}. However, to date there has been no single term used consistently in the literature. In 1991, Yalom and Lieberman used the term 'positive psychological

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changes', but this has also been referred to as 'perceived benefits', 'benefit finding', 'thriving', 'stress-related growth', 'adversarial growth', 'post-traumatic growth' (PTG), and 'existential growth'¹¹. Although varying underlying theories have been proposed and their authors have chosen specific terms, Tedeschi and Calhoun suggest that they are often direct synonyms, or include significant elements of, PPC¹². Scales developed to assess PPC from these different theoretical standpoints have been investigated and appear to measure an umbrella concept that can be labelled PPC. They may vary in the nature of the specific subscales that can also be reported¹³.

At the time of writing, the vast majority (68%) of quantitative research into PPC involving people with cancer has focused on breast cancer¹⁴. The pervasiveness of breast cancer research is likely due to the prevalence of the disease, the size of the population that it affects, and the availability of funding to investigate the impact of the disease and its treatment. However, the make-up of that population is different from those people diagnosed with head and neck cancer (HNC), with more than 99% of breast cancer patients being female. The equivalent figure is less than 45% in people with HNC. Higher levels of economic deprivation appear to have a greater role in HNC than in breast cancer¹⁵. To date, only six studies and one systematic review have been published that focus on PPC in HNC^{16–22}.

Four of the six HNC PPC articles identified used a cross-sectional study design^{17–20}, the other two used a prospective design with two time-points, the second time-point being only 6 months after baseline^{21,22}. The most common methodology of data collection in non-HNC PPC studies has been a single time-point or cross-sectional method^{23–25}. However, with cancer therapies becoming more effective, people are living longer following treatment. It is therefore important to understand the longitudinal pattern of PPC development, so that it may be understood in relation to coping and the future development of rehabilitation services.

Helgeson et al. undertook a meta-analytic review that included a mixture of trauma cohorts²⁶. These cohorts came from backgrounds that included natural disasters, bereavement, and illness. In studies in which the time since the traumatic event was more than 2 years, they found that PPC was related to lower levels of depression and a more positive effect, whereas PPC was related to higher levels

of global distress when time since the traumatic event was less than 2 years. Helgeson et al. also found that PPC was related to a reduction in anxiety when the time since the traumatic event was 2 years or less²⁶. This suggests that, as time elapses, PPC is more likely to reflect significant life changes and/or reprioritization of life values in response to the trauma rather than coping mechanisms.

All of the longitudinal studies that have investigated possible trajectories of PPC within a cancer cohort have so far focused on people who have previously been diagnosed as having breast cancer^{25,27–30}. Danhauer found that those who reported elevated levels of PPC at 4 months post diagnosis maintained these levels and could be described as having early-onset PPC²⁹. They also found that, in those people who reported early-onset PPC, higher levels of PPC were found in proportion to increasing time from diagnosis.

The aim of the current study was to investigate the pattern or trajectory of development of PPC within an HNC population and how this changes over time. A secondary area of investigation was to explore how biological, social, and psychological variables are associated with PPC.

Materials and methods

Design

This study used a 5-year, cross-sequential design with self-completion psychometric measures.

Procedure

Ethical review was sought and granted. Potential participants were identified through a regional health-informatics database. Questionnaire materials were sent to all potential participants annually each October. No follow-up letters were sent. Data collection was undertaken over a duration of 5 years. All potential participants (those matching the inclusion criteria, and not previously excluded) were approached through the Head and Neck Directorate of the regional hospital leading this study. As people with newly diagnosed HNC reached the inclusion criteria (being 3 months post-treatment), they were added to the list of people sent the questionnaire materials. A time frame of >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.

All questionnaires were sent out as hard copy via the Royal Mail, along with a stamped, return-addressed envelope. People who in previous years had indicated that they did not wish to answer the questionnaires were not included in subsequent years.

Participants

To be deemed eligible, a person had to be over the age of 18 years, with an understanding of English judged by clinical staff to be sufficient to complete a series of questionnaires in English. Tumours 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.

People were not approached, or were excluded from one or more rounds of data collection, if they were newly diagnosed with cancer (less than 3 months post-treatment) or had a tumour or recurrence in their HNC or in a location not included in this research.

A total of 416 completed or partially completed questionnaire materials were returned by 185 people over the 5 years of data collection. Table 1 shows the number of questionnaires sent and returned by year of recruitment. Demographic data collected included age at time of diagnosis, gender, Index of Multiple Deprivation (IMD)³¹, and family status (married, living with partner, living alone, living with relative/friends). Medical data collected included tumour stage, date of diagnosis, treatment regimen, and date of treatment completion. Treatment regimen was split into three categories: surgery, surgery and radiotherapy, and radiotherapy (with or without chemotherapy) but without surgery.

No significant differences in demographic and medical data were found between the responders and non-responders to the questionnaires (Mann–Whitney *U*-test). Table 2 provides demographic information on the respondents in relation to time since treatment completed.

Table 1. Number of questionnaire sets sent out and returned across the 5 years of data collection.

| | Sent | Returned (%) |
|--------|------|--------------|
| Year 1 | 151 | 67 (44) |
| Year 2 | 166 | 74 (45) |
| Year 3 | 194 | 95 (49) |
| Year 4 | 211 | 95 (45) |
| Year 5 | 239 | 85 (36) |

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