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

S. Harding Department of Health and Social Sciences, University of the West of England, Bristol, UK
T.P. Moss Centre for Appearance Research, University of the West of England, Bristol, UK

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

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)1. 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 measures2. 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), 'thriving', 'stress-related growth', '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 overlap3. 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 not4. 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 trauma5. 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 HNC6, 7, 8, 9, 10, 11. 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 associations6. 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 PPC7. However, Leong et al. failed to find an association between tumour stage and the development of PPC10. 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 PPC6, 7, 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 PPC12, 13. Two studies following the treatment for HNC reported a beneficial effect of marriage or stable cohabiting over single status in the reporting of PPC7, 9.

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 depression6. Once again Llewellyn et al.9 supported the findings of Harrington et al.6 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 correlated7. However, only hope was a significant individual indicator of PPC7.

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)14, 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.

Table 1. Psychosocial characteristics of participants.

	Number	Mean	SD
Index of Multiple Deprivation	46	18.88	10.74
Gender			
Male	36		
Female	16		
Age at diagnosis, years	51	64.54	10.34
Family status			
Married/living with partner	35		
Living alone	8		
Living with relatives/friends	1		
Cancer stage			
I	10		
II	1		
III	13		
IV	26		
Treatment regimen			

	Number	Mean	SD
Surgery	16		
Surgery + radiotherapy	17		
Radiotherapy ± chemotherapy (no surgery)	18		
Months since treatment	52	6.52	2.80
SF-12 domains			
Mental component scale	26	41.68	10.00
Physical component scale	26	38.99	8.42
SLQ	52	11.85	9.46
UW-QOL – total	49	885.00	191.96
UW-QOL – physical function sub-scale	52	71.54	18.92
UW-QOL – social function sub-scale	52	75.40	16.78
UW-QOL domains			
Pain	52	75.96	23.35
Appearance	52	77.46	20.98
Activity	52	70.33	23.33
Recreation	52	74.31	23.71
Swallowing	52	76.98	23.74
Chewing	52	68.41	32.04
Speech	51	85.82	19.10
Shoulder	50	84.25	27.29
Taste	51	61.66	33.77
Saliva	50	61.84	35.72
Mood	51	75.00	23.49
Anxiety	51	72.39	24.78

SD, standard deviation; SF-12, Short Form 12; SLQ, Silver Lining Questionnaire; UW-QOL, University of Washington Quality of Life Questionnaire.

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 ill15, 16. The SLQ has not been used to investigate PPC in people specifically with or following HNC, other than in unpublished literature by the present authors. The SLQ has been used with mixed cancer cohorts (breast, colorectal, gynaecological, and lung)17. 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 undertaken15.

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 function18. The UW-QOL has been validated by comparison to the Karnofsky scale and Sickness Impact Profile, demonstrating an average criterion validity of 0.8518.

The medical outcomes Short-Form 12 (SF-12) is a generic health-related quality of life questionnaire with 12 items19. Results for each patient are expressed in terms of two meta-scores: the physical component summary (PCS) and the mental component summary (MCS). The SF-12 was selected over other longer versions or questionnaires in order to keep the total number of questions the respondents were asked to answer to a minimum.

Analysis

Baseline models of PPC were assessed. Linear mixed-effect models were used to assess effects of demographic, medical, and psychosocial variables on SLQ scores at baseline, and random coefficient models were used to assess effects of these variables on PPC scores. Separate models were run for total PPC score and each domain score. Time was calculated as months since diagnosis and was included in the model using both linear and quadratic terms. The intercept and time slope were included as random effects in the models.

Predictor variables included in the model were socio-demographic (age, marital status) and medical (cancer stage) characteristics. Beta coefficients and standard errors were estimated using models containing all covariates listed earlier, and least squares mean estimates for SLQ total score were calculated from the models with covariates set to their mean levels. IBM SPSS Statistics version 19.0 (IBM Corp., Armonk, NY, USA) was used for all analyses.

Results

The mean age of the participants at the time of diagnosis was 64.69 years (standard deviation 10.28), with an average age at time of completing the questionnaires of 65.63 years (standard deviation 10.31). Table 1 summarizes the descriptive data for all bio-psychosocial variables of participants completing the measures at between 3 and 12 months. The table provides data on the sample size of each variable, including sub-categories of variables such as the four categories of cancer stage.

Table 2 shows the results of the linear mixed-effects model with SLQ as the dependent variable. This modelling was split into four sections to allow for the number of responses per variable to not exceed the rule of thumb of 10 responses per variable of Kleinbaum et al.20. The first included modelling with IMD, gender, age at diagnosis, and family status. The sentence should therefore read: The second included modelling cancer stage, with stage II and III amalgamated, treatment regime and time since treatment (Table 2). The third section included modelling the SF-12 with the mental and physical component scales, but not the other sub-scales due to the small number of respondents. The fourth section included modelling with the total UW-QOL without the sub-scales for the same reason as not including the SF-12 sub-scales.

Table 2. Association of demographic, medical, and psychosocial characteristics with SLQ scores.

Covariate	Baseline model	
	Estimate (SE)	P-value
Index of Multiple Deprivation	8.706 (16.941)	0.114
Gender	0.128 (6.108)	0.321
Age at diagnosis	8.637 (18.590)	0.257
Family status		0.050
Married/living with partner	−7.600 (9.428)	
Living alone	−18.125 (9.860)	
Living with relatives/friends	–a	
Cancer stage		0.006
I	11.900 (3.104)	
II and III combined	50.090 (9.437)	
IV	−0.804 (3.209)	
Treatment regimen		0.044
Surgery	6.989 (3.104)	
Surgery + radiotherapy	22.764 (3.056)	
Radiotherapy ± chemotherapy (no surgery)	–a	
Time since treatment	14.549 (25.252)	0.806
SF-12 domains		
Mental component scale	91.333 (74.573)	0.634
Physical component scale	91.333 (74.573)	0.634
UW-QOL – total	57.000 (30.468)	0.231
UW-QOL – physical function sub-scale	10945.6 (2544.8)	0.198
UW-QOL – social function sub-scale	12710.7 (2709.9)	0.488

SE, standard error; SF-12, Short Form 12; SLQ, Silver Lining Questionnaire; UW-QOL, University of Washington Quality of Life Questionnaire.

a

Covariance parameter is redundant.

The results show that at between 3 and 12 months after the completion of treatment, family status, stage of the tumour, and the treatment regimen all had a relationship with PPC as defined with the SLQ (P = 0.050, P = 0.006, and P = 0.044, respectively). Figure 1 shows that between 3 and 12 months post-treatment, participants with low stage tumours (stage I) had a higher reported level of PPC than those with stage II and III tumours and noticeably higher PPC than those with stage IV tumours. In the same time frame, participants who had undergone surgery alone reported more positive changes than those who had undergone surgery with radiotherapy, and than those who were not treated surgically but who had radiotherapy with or without chemotherapy.

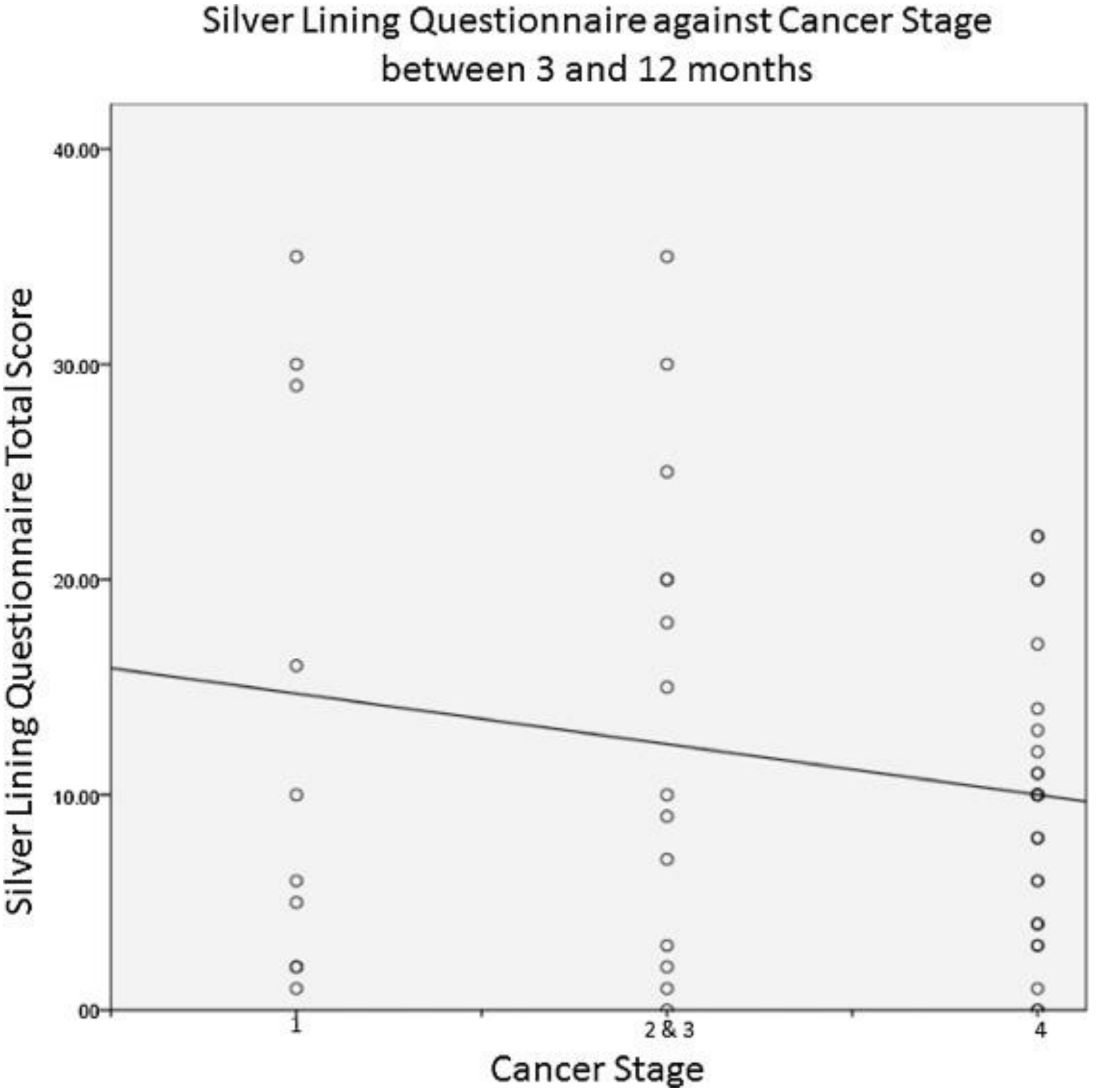

Fig. 1. Relationship between the Silver Lining Questionnaire (SLQ) score and cancer stage.

‘Time since completion’ was entered into the model as raw interval data (unlike data used in the longitudinal model where time was categorized into groups) and did not show any relationship with change.

Figure 2 shows how family status was associated with PPC (SLQ total). For the period covered by this analysis, it was found that being married or living with a partner rather than living alone was associated with a greater level of PPC (Table 2).

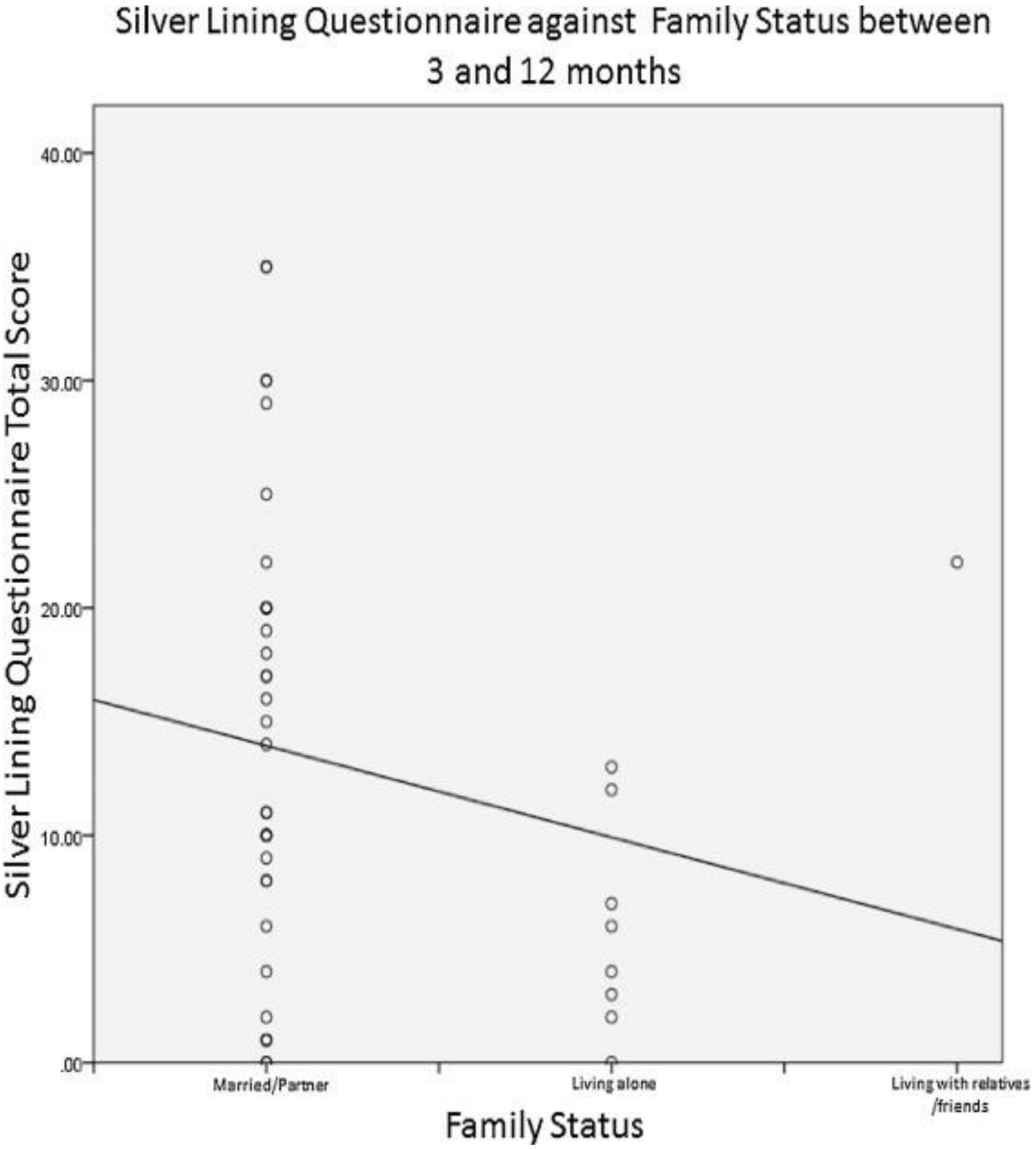

Fig. 2. Relationship between the Silver Lining Questionnaire (SLQ) score and family status.

Discussion

The aim of this study was to investigate patient reports of PPC in relation to HRQoL at 3 to 12 months following the completion of treatment for HNC. A postal survey of patients with HNC had a good response rate (63%), which is comparable to other studies21, 22.

Linear mixed-effects models suggested that both the clinical stage of the tumour and the treatment regimen undergone by the person had a relationship with PPC as defined with the SLQ. People with stage I tumours had a higher reported level of PPC than those with stage II and III tumours, and patients with stage I–III tumours had higher PPC than those with stage IV tumours. This may be because people diagnosed with a low stage (I or tumour in-situ) did not interpret this as a significant life-changing event. People diagnosed with stage IV tumours may have experienced such significant distress, or negative treatment side effects, that they were not able to find any positive change, at least up to 1 year post treatment. This may change in the long term, but has yet to be investigated in an HNC population.

Respondents who had surgery alone reported more PPC than those who had surgery with just radiotherapy and those who had radiotherapy with or without chemotherapy (no surgery). There is an interrelationship between tumour staging and treatment regimen that may also impact PPC. Lower stage tumours, i.e. smaller, locally defined (no invasion into other tissues, or metastasis), will receive less aggressive curative treatments. People who are treated with surgery alone, while still receiving the diagnosis of cancer and undergoing the same diagnostic investigations as those people who have radio- and chemotherapy, are likely to have surgery as a one-off event with a minimal hospital stay time. Many surgical interventions do not require multiple hospital visits to receive treatment. On completion of the surgery, people with low stage tumours may receive a clear report from the surgeon that they could remove the entire tumour (if the surgery does not fully clear the tumour, these people usually go on to receive radiotherapy). This acute experience of a cancer diagnosis and treatment along with reassurance from the surgeon may mean that a person does not perceive the experience as traumatic enough to change their perceptions of self and how they relate to others.

Using the IMD to measure socio-economic status showed that, in the short term (3–12 months), there was no relationship with PPC. This differs from research undertaken in people with breast cancer, where those who were more deprived had more PPC23. It is unclear why these differences may exist, but it may be that the IMD is not sensitive enough to show a change or that the sample was not large enough. It may also be that people with a higher socio-economic status are more likely to return the measures and may be less worried about financial matters in the short term and subsequently are able to develop PPC.

A social factor that was found to be related to higher levels of PPC in this short time frame (3–12 months) was being married when compared to living alone, and this in turn was more beneficial than living with a partner or relative(s). This supports the work of Ho et al., who found that oral cancer patients who were married reported higher levels of PPC than those who were unmarried7. Having close social relationships with family and friends is a key trait of PPC24.

No psychological variables (collected using the SF-12 and UW-QOL) showed an association with PPC. This differs from the results reported in breast cancer studies. Danhauer et al. suggested that PPC is mediated in people with a ‘high’ quality of life and or mental health25. These HRQoL factors may be affected by the passage of time and overcoming or adaptation to the side effects of treatment. However, the time since completion of therapy in the short term (between 3 and 12 months) did not show any relationship with PPC. These findings suggest that PPC within an HNC population might be affected by certain demographic, medical, and psychological factors in the short term (3 to 12 months).

In treatment and research on long-term cancer survivorship, a follow-up of at least 5 years after diagnosis is typical. The patients in the current study were assessed at between 3 and 12 months post treatment. Consideration should be given to the changes and experiences that people may encounter in the extended timeframe, including other stressful events and concurrent diseases. Additionally, there is evidence that positive changes may sometimes represent biased, self-enhancing, and self-protecting illusions rather than actual improvements26, 27. Some reports of growth are likely to reflect actual change that can be linked to behaviour, whereas other reports of growth may represent cognitive distortions that individuals make in their efforts to cope with distress26.

No one would disagree that on first consideration a diagnosis of cancer is traumatic; however cancer is not a discrete, singular stressful experience. Rather it entails a cascade of potential stressors, from diagnosis, treatment, and treatment side effects to ongoing concerns of recurrence28. This raises the question as to what is the trauma. Are there multiple traumas experienced by people diagnosed with cancer? Unlike an acute trauma, where the likelihood of re-experiencing the same event is low, Humphries et al. found that patients with HNC may think continuously about what might happen, with the fear of recurrence, “waiting for the other shoe to drop”29. So what an individual identifies as the trauma is a challenge to the investigation of PPC.

Further investigation of PPC may benefit from the identification of a single traumatic time point in the cancer journey, or the participant identifying compounding events on their trauma journey, the summation of which represents a traumatic event. Clinical experience has shown that patients attending clinics may fear or suspect a diagnosis of cancer and the confirmation of a cancer diagnosis is in some part a relief. Furthermore, with the long-term side effects of treatment such as radionecrosis, xerostomia, or trismus, they may not feel that they have reached the end of their cancer journey. In these ways, cancer patients are never really ‘post trauma’, and further longitudinal investigations into the development of PPC in general and specifically in people who have experienced HNC would be beneficial.

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Competing interests

The authors have no competing interests.

Ethical approval

Ethical approval was obtained and issued from NRES Committee East Midlands — Northampton (reference number 167514 - 15/EM/0052).

Patient consent

Not required.

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