Title: Emotional distress and growth in survivors of head and neck cancers

Emily Pearson [a]

Supervised by Dr Peter Fisher [a] and Professor Joanne Patterson [ab]

[a] *Institute of Population Health, University of Liverpool*

[b] *Liverpool Head and Neck Centre*

Submitted on
19th June 2023

Submitted in partial fulfilment of the Doctorate in Clinical Psychology
University of Liverpool

Acknowledgments

I would like to take this opportunity to thank those who have supported me over the last three years of the course. Firstly, for my partner Josh, who has proof-read every piece of work, encouraged me, and always made me laugh during stressful times.

To family and friends who have checked in, offered support, comfort, and a listening ear. A shout out to the friends I have made on the course, whose support has made this process a lot easier.

I would like to thank my dog Walt for bringing such happiness, that wagging tail is always a welcome distraction!

A special thank you to the NHS services and charities who helped me spread the word about my research and for the participants who kindly offered their time to take part.

Lastly, thank you to my research supervisors Peter and Jo for your your guidance and expertise throughout the process!

CONTENTS

List of figures and tables

Chapter one: Systematic Review

Chapter two: Empirical Project

List of appendices

Total word count: 20,147

Introductory chapter: 1018

Systematic Review: 11080

Empirical Project: 8049

Introductory Chapter: Thesis Overview

Cancer survivorship

Cancer describes a group of diseases that feature abnormal cell growth which invade adjoining tissues and spread abnormal cells to other organs (Jaafar et al., 2021). Cancer is the second leading cause of death globally, accounting for nearly 10 million individuals in 2020 (World Health Organisation, 2022). The growing population of cancer survivors has prompted public health initiatives to understand the healthcare issues in survivors of cancer as it is poorly understood. The Department of Health (DoH) funded the Cancer Reform Strategy, in which the UK National Survivorship Initiative (NCSI), Macmillan Cancer Support and the National Health Service (NHS) Improvement are exploring ways of improving the post treatment experiences of survivors (Allberry, 2008). Traditionally survivors were described as individuals who had been disease-free for a minimum of five years (Rowland et al., 2013). However, the current definition of a survivor is "someone who is living with or beyond cancer" (Macmillan, 2008; Davies & Bateup, 2011).

Head and neck cancer (HNC) is an umbrella term for tumours originating in the oral cavity, salivary glands, pharynx, larynx, paranasal sinuses, and the nasal cavity (So et al., 2012). The global disease burden study estimated 890,000 new HNC cases worldwide (Global Burden of Disease Cancer Collaboration, 2019). HNC is the seventh most common cancer in the UK (Sung et al., 2021). Its incidence has increased by 34% across the four nations of the UK. Due to the aging population in the UK, this prevalence of survivors across cancer diagnoses is predicted to increase, which is expected to reach 4 million people by 2030 (Maddams et al., 2012). Although most people diagnosed with HNC are over the age of seventy, this increased rate is mainly due to the rise in Human Papillomavirus (HPV) associated oropharyngeal cancers (Cancer Research UK [CRUK], 2014; Marur et al., 2010). These tumours typically affect

younger people and are associated with good survival rates. However, this means survivors are often living longer with the side-effects of treatment (Marur, et al., 2010). Furthermore, the highest rates of HNC are observed in those living in the most socioeconomically deprived communities (Louie et al., 2015; Purkayastha et al., 2016). Tobacco smoking and tobacco in combination with alcohol consumption are risk factors for developing HNC, which have been linked to more deprived communities (Gormley et al., 2022).

Improvements in the early detection and treatment of cancer have led to an increase in the number of cancer survivors worldwide, including HNC (Funk et al., 2012). Survivorship has doubled over the last forty years in the UK, and it is reported that between 19-59% of people diagnosed with HNC in England survive for ten years or more (CRUK, 2014). 13% of HNC survivors are aged 65 or over (Maddams et al., 2009). Due to the aging population in the UK, this prevalence of survivors across cancer diagnoses is predicted to increase, which is expected to reach 4 million people by 2030 (Maddams et al., 2012).

Head and neck cancer survivorship and psychosocial outcomes

Medical treatments for HNC can include surgery, radiotherapy, chemotherapy, or a combination of modalities (So et al., 2012). Treatments can be complex, and aggressive, resulting in lifechanging long-term consequences (Sharp et al., 2018; So et al., 2012). These consequences can have detrimental effects on physical health, mental health, appearance, employment, social functioning, and family interactions, all of which greatly impact on a person's quality of life (Funk et al., 2012; El-Deiry et al., 2005; Buckwalter et al., 2007). Changes to breathing, difficulties speaking and eating following HNC are common, often chronic, and can increase in severity over time due to progressive treatment side effects (Patterson et al., 2018), substantially affecting social functioning (Patterson et al., 2022). Psychological distress is common in HNC. A large study (n = 2561) found that 23% of HNC survivors reported significant depression and decreased quality of life, due to difficulties with

social eating and less social contact (Patterson, et al., 2021). A cohort study found that 29.9% (*n* = 52,641) HNC survivors experienced mental health difficulties post treatments compared with 20.6% before a HNC diagnosis, suggesting that treatments can cause or increase the prevalence of mental health difficulties (Lee et al., 2019). Additionally, some research has found associations between depression symptoms and shorter survival and higher rates of chemoradiation interruption (Zimmaro et al., 2018).

Understanding the difficulties HNC survivors experience and what contributes to maintaining mental health difficulties is fundamental to inform evidence-based practice. At the same time, further understanding factors HNC survivors need to overcome adversity and experience positive change can also inform evidence-based psychological interventions. The terms Post-traumatic Growth (PTG) and Benefit-Finding (BF) are often used to describe such experiences (Tedeschi & Calhoun, 2004). Chapter one describes a systematic review of the research literature exploring predictors and correlates of PTG/BF in HNC. The review considered this relationship following treatments within the survivorship period. Twelve studies (across thirteen articles) met inclusion criteria and were included within the review. Extrapolation of the findings suggest that there are some factors which are associated with PTG and BF in HNC survivors. Clinical implication of the research and future directions were discussed. One recommendation is for research with more robust methods to explore these factors further, such as prospective and experimental designs. NHS services should provide more psychological support for HNC survivors, to help support the development of PTG/BF.

Chapter 2 is an empirical study which includes the results of an original research project that tested the metacognitive and self-compassion models and their associations with anxiety, depression and PTSS in HNC survivors. The findings indicate that metacognitive beliefs about the uncontrollability of worry and cognitive confidence were associated with anxiety, depression, and PTSS symptoms when controlling for demographic and clinical variables. Self-

compassion did not make a significant contribution for anxiety, depression or PTSS. Therefore, interventions addressing metacognitive beliefs and processes might be more effective compared with self-compassion-based approaches. Research employing prospective designs is necessary to investigate this further. This might help inform new psychological interventions for HNC survivors. The systematic review and empirical project are intended to be submitted to Frontiers and the Journal of Affective Disorders respectively.

References

Allberry J. (2008). Cancer Reform Strategy: Maintaining Momentum, Building for the Future – First Annual Report. Department of Health, December 2008.

Buckwalter, A. E., Karnell, L. H., Smith, R. B., Christensen, A. J., & Funk, G. F. (2007). Patient-reported factors associated with discontinuing employment following head and neck cancer treatment. *Archives of Otolaryngology--Head & Neck Surgery*, *133*(5), 464–470. https://doi.org/10.1001/archotol.133.5.464

Cancer Research UK (2014). England and Wales survival 2010-2011 summary. https://www.cancerresearchuk.org/sites/default/files/cs_dt_survival.xlsx

Davies, N.J. & Batehup, L. (2011). Towards a personalised approach to aftercare: a review of cancer follow up in the UK. *Journal of Cancer Survivorship*, 5, 142, 142-151. https://doi.org/10.1007/s11764-010-0165-3

El-Deiry, M., Funk, G. F., Nalwa, S., Karnell, L. H., Smith, R. B., Buatti, J. M., Hoffman, H. T., Clamon, G. H., Graham, S. M., Trask, D. K., Dornfeld, K. J., & Yao, M. (2005). Long-term quality of life for surgical and nonsurgical treatment of head and neck cancer. *Archives of Otolaryngology--Head & Neck Surgery*, *131*(10), 879–885. https://doi.org/10.1001/archotol.131.10.879

Funk, G. F., Karnell, L. H., & Christensen, A. J. (2012). Long-term health-related quality of life in survivors of head and neck cancer. *Archives of Otolaryngology--Head & Neck Surgery*, *138*(2), 123–133. https://doi.org/10.1001/archoto.2011.234

Global Burden of Disease Cancer Collaboration. (2019). Global, Regional, and National Cancer Incidence, Mortality, Years of Life Lost, Years Lived With Disability, and Disability-Adjusted Life-Years for 29 Cancer Groups, 1990 to 2017: A Systematic Analysis for the Global Burden of Disease Study. *JAMA Oncology*;5(12):1749–1768. https://doi:10.1001/jamaoncol.2019.2996

Gormley, M., Creaney, G., Schache, A. *et al.* (2022). Reviewing the epidemiology of head and neck cancer: definitions, trends and risk factors. *Br Dent J* **233**, 780–786 (2022). https://doi.org/10.1038/s41415-022-5166-x

Louie, K. S., Mehanna, H., & Sasieni, P. (2015). Trends in head and neck cancers in England from 1995 to 2011 and projections up to 2025. *Oral Oncology*, *51*(4), 341–348. https://doi.org/10.1016/j.oraloncology.2015.01.002

Maddams, J., Utley, M., & Møller, H. (2012). Projections of cancer prevalence in the United Kingdom, 2010-2040. *British Journal of Cancer*, *107*(7), 1195–1202. https://doi.org/10.1038/bjc.2012.366

Marur, S., D'Souza, G., Westra, W. H., & Forastiere, A. A. (2010). HPV-associated head and neck cancer: a virus-related cancer epidemic. *The Lancet. Oncology*, *11*(8), 781–789. https://doi.org/10.1016/S1470-2045(10)70017-6

Nik Jaafar, N. R., Abd Hamid, N., Hamdan, N. A., Rajandram, R. K., Mahadevan, R., Mohamad Yunus, M. R., & Leong Bin Abdullah, M. F. I. (2021). Posttraumatic Growth and Coping Strategies Among Patients with Head and Neck Cancer: Do

Approach Coping and Avoidant Coping Predict Posttraumatic Growth Over Time? *Frontiers in Psychology*, 4846. https://doi.org/10.3389/fpsyg.2021.716674

Patterson, J. M., Lu, L., Watson, L. J., Harding, S., Ness, A. R., Thomas, S., Waylen, A., Pring, M., Waterboer, T. & Sharp, L. (2022). Associations between markers of social functioning and depression and quality of life in survivors of head and neck cancer: Findings from the Head and Neck Cancer 5000 study. *Psycho-Oncology*, *31*(3), 478-485. https://doi.org/10.1002/pon.5830

Patterson, J. M., McColl, E., Carding, P. N., & Wilson, J. A. (2018). Swallowing beyond six years post (chemo)radiotherapy for head and neck cancer; a cohort study. *Oral Oncology*, *83*, 53–58. https://doi.org/10.1016/j.oraloncology.2018.06.003

Purkayastha, M., McMahon, A. D., Gibson, J., & Conway, D. I. (2016). Trends of oral cavity, oropharyngeal and laryngeal cancer incidence in Scotland (1975-2012) - A socioeconomic perspective. *Oral Oncology*, *61*, 70–75. https://doi.org/10.1016/j.oraloncology.2016.08.015

Rowland, J. H., Kent, E. E., Forsythe, L. P., Loge, J. H., Hjorth, L., Glaser, A., Mattioli, V., & Fosså, S. D. (2013). Cancer survivorship research in Europe and the United States: where have we been, where are we going, and what can we learn from each other?. *Cancer*, *119 Suppl 11*(0 11), 2094–2108. https://doi.org/10.1002/cncr.28060

So, W. K. W., Chan, R. J., Chan, D. N. S., Hughes, B. G. M., Chair, S. Y., Choi, K. C., & Chan, C. W. H. (2012). Quality-of-life among head and neck cancer survivors at one

year after treatment–a systematic review. *European Journal of Cancer*, *48*(15), 2391-2408. DOI: 10.1016/j.ejca.2012.04.005

World Health Organization (2021). Cancer. Available at: https://www.who.int/news-room/fact-sheets/detail/cancer (Accessed May 8, 2023).

Zimmaro, L. A., Sephton, S. E., Siwik, C. J., Phillips, K. M., Rebholz, W. N., Kraemer, H. C., & Cash, E. D. (2018). Depressive symptoms predict head and neck cancer survival: examining plausible behavioral and biological pathways. *Cancer*, *124*(5), 1053-1060. https://doi.org/10.1002/cncr.31109

Chapter 1: Systematic Review

Title: Factors Associated with Post-Traumatic Growth after a Head and Neck Cancer Diagnosis: A Systematic Review.

Word count: 11080 (including abstract and tables)

Prepared in accordance with guidelines for submission to Frontiers

Abstract

Purpose

Head and neck cancer (HNC) diagnoses and treatments can be traumatic, and survivors can develop post-traumatic stress symptoms. Although the literature has tended to focus on negative experiences of cancer, some survivors report positive experiences. Post-traumatic growth (PTG) and Benefit-Finding (BF) are constructs of positive change which can be experienced following trauma and adversity such as HNC cancer diagnoses and treatments.

Methods

Five electronic databases (AMED, CINAHL PLUS, MEDLINE, APA PsycINFO) were searched for articles. Published studies examining correlates and predictors of PTG or BF in adults with experience of a HNC diagnosis and treatments were included.

Results

The search strategy identified twelve studies across thirteen articles were eligible for data extraction and synthesis. Barriers to PTG or BF included demographic factors such as, being a younger survivor, being male, clinical factors, such as having a higher stage tumour, radiotherapy, and chemotherapy, either standalone or in conjunction with surgery, functional difficulties because of medical treatments, as well as higher levels of anxiety, depression, and fear of recurrence.

Conclusions

This review highlights that research examining PTG/BF in HNC survivors has focused on demographic and clinical factors. Factors which were found to be significantly associated were being male, having functional impairments from HNC treatments, receiving chemotherapy or radiotherapy, anxiety, fear of recurrence and depression. However, the review highlights mixed results from a small number of studies and therefore the results are inconclusive. Taken together, research with more robust methods and exploring psychological mechanisms are needed to explore these factors further.

Keywords: Head and neck cancer, cancer-related posttraumatic stress, post-traumatic growth, benefit finding.

Introduction

Cancer can be life-threatening; therefore, it is unsurprising that it can be marked by severe physical and psychological trauma which can impact quality of life (Connerty, 2013). Most research has focused on the negative consequences life-threatening events such as cancer can cause (Page & Alder, 2008). Most of the trauma literature has focused on survivors of breast cancer; however, it is apparent that survivors of different tumour types can have markedly different experiences and outcomes (Ringash et al., 2017). This necessitates research exploring other tumour types as standalone samples. Head and Neck Cancer (HNC) has among the most complex rehabilitation needs of all cancers due to the anatomical location of the tumour sites, coupled with the side effects of aggressive treatments (List & Bilir, 2004; Kar et al., 2020). HNC survivors are often left with substantial functional impairments, such as problems with speech, swallowing, eating, and breathing as well as disfigurement, all of which can impact on social functioning and psychological well-being (List & Bilir, 2004; Kar et al., 2020). HNC-specific stressors during survivorship have been reported as spanning a broad range of issues such as, interpersonal concerns, uncertainty, interference with daily activities, communication, fear of recurrence, stigma, concerns around distress, disease and treatments, existential stressors, financial issues, and concerns with appearance and body image (Ringash et al., 2018). Rates of depression and anxiety are higher in HNC populations when compared with other tumour types (breast, gynaecologic sites, prostate, urologic sites, gastrointestinal, lung, brain and other) (Singer et al., 2012). Cohort studies have reported 18.5% of people with HNC to meet clinical severity of depression (Rieke et al., 2017), whereas a systematic review reports the same threshold as 9% in breast cancer survivors (Pilevarzadeh, 2019). Within US samples rates of suicide were three times higher in HNC, compared with the general population (Kam et al., 2015). The same study found that suicide rates were higher in male HNC survivors who had later stage disease, and who were not married (Kam et al., 2015). Due to HNC treatments

being intrusive and often resulting in adverse changes, some individuals perceive these events as traumatic and are therefore at risk of developing cancer-related Post-traumatic Stress Symptoms (PTSS) and Post-traumatic Stress Disorder (PTSD) (Bjorklund et al., 2010). PTSD is a mental health difficulty with typical symptoms in cancer groups being reported as flashbacks, avoiding cancer-related experiences and increased anxiety (Andrykowski et al., 2000). PTSS refers to experiencing the symptoms of PTSD that do not meet clinical severity for a formal diagnosis (O'Connor et al., 2011). Limited studies have explored PTSD and PTSS in HNC populations. A prospective study reported 22% of HNC and lung cancer survivors met diagnostic criteria for PTSD, 6 months after diagnosis compared with 28% one month after diagnosis (Kangas et al., 2005). These findings suggest that PTSD symptoms may decrease over time. However, as the sample consisted of mixed tumour types, it is uncertain the specific trends for HNC survivors. Another study reported that 12% of HNC survivors met PTSD criteria between 4-and-16-weeks post-diagnosis (Posluszny et al., 2015). These findings are consistent with conceptual models of coping with life-threatening illnesses, such as Morse and Johnson's (1991) Illness constellation model, which postulates that there are four stages between psychological development and a life-threatening illness. The initial stage is described as consisting of uncertainty and distress, with the fourth and final stage when an individual has recovered and accepted any changes to their life. Although research has mainly focused on the negative effects of cancer, the importance of examining positive psychological well-being is equally as important to understand how to alleviate distress (Pat-Horenczyk et al., 2015). However, research understanding factors linked to positive change in HNC is limited.

Given the increasing population of HNC survivors (Funk et al., 2012) it is imperative to further understand the experiences within this period, both from negative and positive perspectives. Positive psychology seeks to expand the broader aspects of mental health and well-being with

core concepts such as personal recovery, resilience, optimism, and hope (Bejerhlm & Roe, 2019; Chiba et al., 2020). Positive psychological changes may be identified as an opportunity for survivors to learn something about themselves and to find benefits from a traumatic experience (Folkman, 2008).

Tedeschi & Calhoun, (1996) coined the term Post-traumatic Growth (PTG) which can be conceptualised as an outcome which encompasses a positive transformative experience, resulting from a cognitive shift that is undergone following adversity. Generally, PTG has been defined as 'the experience of positive change that occurs because of the struggle with highly challenging life crises' (Tedeschi & Calhoun, 2004). Other terms have been used to describe PTG including *stress-related growth* (Park et al., 1996) *thriving* (O'Leary et al., 1998), *positive psychological changes* (Yalom & Lieberman, 1991) or *adversarial growth* (Linely & Joseph, 2004). Another term that is widely used to describe positive experiences following adversity is Benefit finding (BF). Some literature defines BF as conceptually different to PTG, with BF being described as "the acquisition of benefit" whereas PTG is a reflective process which reconstructs or strengthens perceptions of self, others, and the meaning of events (Tedschi & Clhoun, 1996). However, these terms are often used interchangeably in the literature (Zoellner & Maercker, 2006). As a result, research exploring positive experiences is largely inconsistent. Life crises and adversity are described as anything that evokes distressing emotional responses. This includes a threat to an individual's physical well-being, such as cancer diagnoses and treatments (Collins et al. 1990; Cordova et al., 2001). However, experiencing a traumatic event does not mean an individual will experience positive change. For PTG to occur, individuals are psychologically required to reflect and seek meaning behind the events (Tedeschi & Calhoun, 2004). Additionally, PTSS and PTG are not mutually exclusive experiences and they have been shown to occur in conjunction in breast cancer survivors (Chen et al., 2019). Examples of PTG are an increased sense of personal strength, changed priorities and richer existential and

spiritual life (Calhoun et al., 2000). The PTG Inventory (PTGI [Tedeschi & Calhoun 1996]) reflects these domains and measures: 'personal strength', 'new possibilities', 'improved relationships', 'spiritual growth' and 'appreciation for life' (Tedeschi & Calhoun, 1996). Similarly, the Benefit Finding Scale (BFS [Antoni et al., 2001]) and the Silver Lining Questionnaire (SLQ [Sodergren et al., 2002]) measure growth across similar domains such as: 'improved relationships', 'greater appreciation for life', 'life priorities', 'inner strength', 'spirituality', 'changes in life philosophy' and 'acceptance of the circumstances.' Cancer survivors identify with positive changes across these domains; however, literature has mainly focused on breast cancer, or mixed cancer samples in which limited or no HNC survivors are included (Cordova et al., 2001; Tomich & Helgeson, 2004; Mols et al., 2009). For example, a systematic review found that the threat of advanced stage cancer was more strongly associated with PTG (Marzilliano et al., 2019). However, this sample did not include any HNC survivors. Given HNC's distinct characteristics and experiences, literature assessing PTG/BF in other cancer samples might not be generalisable to HNC.

Varying rates of PTG have been reported in a small number of HNC studies, with moderate-high PTG ranging from 10-60% (n = 74-583). (Holmaat et al., 2017; Sharp et al., 2018). Further research is needed to explore this disparity. These initial findings report lower PTG in HNC compared with other cancer populations, which range between 60-90% in breast cancers and up to 76% in testicular cancers (Cordova et al., 2001). Therefore, further understanding into BF and PTG within the HNC population is warranted to inform the development of interventions to support PTG. There has been a previous review exploring the psychological experiences of HNC survivorship which synthesises qualitative data (Lang et al., 2013). Another review examines questionnaire studies mostly using BF scales (80%) compared with PTG and only included HNC survivors after surgery, radiotherapy and/or chemotherapy (Harding et al., 2014). No systematic review has been conducted, exploring a wide range of

PTG concepts using validated measures with an HNC survivor sample at set time points in their cancer journey. The purpose of this review was to develop an understanding about the links between PTG and other variables in HNC by systematically reviewing, critically appraising, and synthesising the findings of studies investigating demographic, clinical and psychosocial correlates, or predictors of PTG in adult survivors of HNC. There are subtle differences between growth concepts such as PTG and BF and a wide search was used to include both these concepts (stress-related growth, thriving, positive psychological changes, or adversarial growth).

Materials and methods

Protocol and pre-registration

The protocol was registered to in the International Prospective Register of Systematic Reviews, in January 2023 (PROSPERO; registration number CRD42023364745, https://www.crd.york.ac.uk/PROSPERO . The form includes the search strategy and data synthesis plan (appendix B).

Search strategy

A search for relevant literature was conducted systematically within five databases on the 15th of February 2023. EbscoHost was used to search AMED, CINAHL PLUS, MEDLINE, APA PsycINFO. Scopus was searched individually, and hand searching was also conducted. Search terms and Medical Subject Headings (MESH) were devised in collaboration with an information specialist from the University of Liverpool. No restrictions were placed on publication date. Appendix C details the search syntax used for each database. Although, this article is focusing on PTG, other terms which have been used interchangeably within the literature (Zoellner & Maercker, 2006) were also included in the search strategy to provide

comprehensive results. Searches were repeated on the 1st of May 2023 to identify any new publications.

Study selection

Firstly, all identified articles were downloaded from the five databases and duplicates were removed using Endnote software (version 20). Once duplicates were removed, all articles were transferred to the Rayyan data management software (www.rayyan.ai) to be screened for eligibility. Abstracts and titles were screened for inclusion by the first author. Two trainee clinical psychologists and a Lead Reconstructive Scientist from Aintree HNC service screened 25% of titles and abstracts as well as 100% of the full text articles. Any discrepancies in study suitability were resolved through consensus with the research team (PF, JP).

Eligibility Criteria

Studies were included if they: 1) used a cross-sectional or prospective design; 2) conducted and reported findings of a quantitative analysis exploring the relationship between PTG or BF and demographic and/or psychosocial variables; 3) reported findings specifically for adults with experiences of HNC diagnoses and/or treatments; 4) assessed either PTG, or BF constructs using validated questionnaires (or subscales); and 5) were published in English in a peer-reviewed journal. Prospective studies were included if relevant analyses were conducted at baseline or if PTG or BF was measured at follow-up. Intervention studies were included if relevant quantitative analysis pre-intervention were conducted and reported (post-intervention data were excluded). Commentaries, conference abstracts, case-studies, editorials, and review articles were excluded.

Articles were excluded from the review if they presented qualitative or a mixed method design that did not report on predictors or covariates related to PTG or BF. Any participant samples which included child populations, up to age 17 years of age were excluded, including any

combination of child and adult sample groups if adult data were not reported separately. Any studies which included mixed cancer samples and failed to report findings separately for HNC survivors, were excluded as it was not possible to interpret results specifically for HNC. Studies that included thyroid cancers within the sample were excluded, due to the treatment pathway in the UK being different to other HNC tumour sites.

Data extraction and analysis

For each study, relevant demographic, methodological and summary data were extracted using a standardised data extraction form (Appendix D). This was checked for accuracy by the research team (PF, JP). Disagreements or uncertainties were discussed until a consensus was reached. The following information was extracted for the study characteristics: 1) author, year of publication, country data were collected, sample size, study design, 2) demographic data of the survivors (age, sex, ethnicity, relationship status, education, socioeconomic status, religion, smoking/alcohol status, 3) clinical and treatment variables (HNC type, stage of cancer, time since diagnosis/treatment, treatment type). The following information was extracted for the main findings and stored using an Excel spreadsheet: PTG / BF measure used, PTG / BF scores, analysis used and any correlates or predictors of PTG / BF.

Assessment of risk of bias

Methodological quality and risk of bias was assessed at the individual study level using a quality appraisal tool. This was adapted from the Agency for Healthcare Research and Quality (Appendix E) (Williams et al., 2010). This tool assesses risk of bias in observational studies on 10 methodological factors. It has been used previously in physical health (Williams et al., 2010) and cancer populations (O'Rourke et al., 2021). Risk of bias of the included studies was independently assessed by the first author and another trainee clinical psychologist. Any

discrepancy and uncertainty were resolved through wider discussions with the research team (PF, JP).

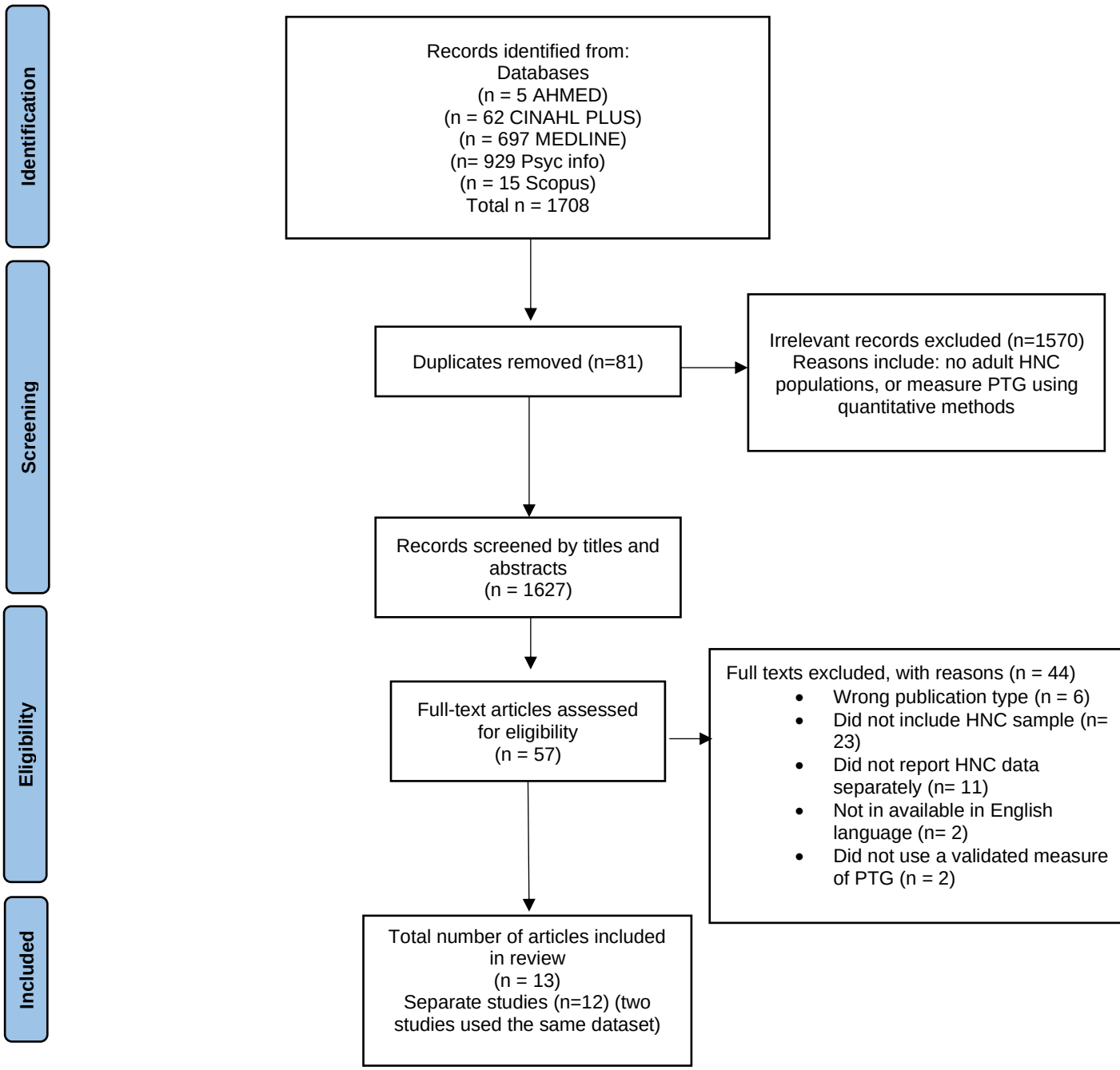
Results

Studies included in the review

The search strategy identified 1708 relevant articles. After removing duplicate articles and screening the titles and abstracts, 57 full text articles were reviewed. After reviewing 57 full text articles for eligibility, 12 articles and 11 studies were included in the final analysis. Two articles used the same dataset and therefore they were treated as the same study (Oginska-Bulik, 2017; 2018). Harding & Moss (2018) and Harding (2018) used different samples and therefore were treated as separate studies. Jaafar et al. (2021) and Jaafar et al. (2022) used different samples and were also treated as separate studies. When the searches were rerun again on the 1st of May 2023, 1 article was added, making a final sample of 13 articles and 12 studies, see Figure 1.

Figure 1.

PRISMA flowchart of the study selection process



Note. Searches were repeated on the 1st of May 2023 to identify any new publications and have been included in the flowchart.

Characteristics of included studies

Table 1a and 1b display the characteristics of the included studies. Four studies were conducted in the UK (Harding, 2018; Harding & Moss, 2018; Llewellyn et al., 2013; Sharp et al., 2018), five were in East Asian countries: Malaysia (Abdulla et al., 2015; Jaafar et al., 2021; 2022), Taiwan (Chang et al., 2022) and Hong Kong (Ho et al., 2011). Three studies (four articles) were conducted in Germany (Hoene et al., (2021), the Netherlands (Holtmaat et al., 2017) and Poland (Oginska-Bulik 2017; 2018). Studies used either convenience (Abdullah et al., 2015; Chang et al., 2022; Harding, 2018; Harding & Moss, 2018; Ho et al., 2011; Hoene et al., 2021; Oginska-Bulik, 2017;2018; Sharp et al., 2018) or consecutive (Jaafar et al., 2021; 2022; Llewellyn et al., 2013 sampling methods.

Seven studies were cross sectional (Chang et al., 2022; Harding, 2018; Harding & Moss, 2018; Holmaat et al., 2017; Jaafar et al., 2022; Oginska-Bulik 2017;2018; Sharp et al., 2018). Three studies were prospective (Abdullah et al., 2015; Llewellyn et al., 2013; Jaafar et al., 2021). One study used a retrospective cross-sectional design (Ho et al., 2011) and another used retrospective longitudinal data (Hoene et al., 2021). All twelve of the studies included HNC samples only, with varying subtypes, as outlined in Table 1b below. The shortest time since diagnosis was 0-3 months (n = 20, 40%) (Abdullah et al., 2015) and the longest was 10+ months (n = 92 16%) (Sharp et al., 2018). The shortest time since treatment was 3-6 months n = 37 (Harding, 2018) and the longest was 61 months n = 25 (Harding, 2018).

Table 1a

Study Characteristics part1

Author, (year), country	Design	N	Age (years) (SD)	Sex, *n* (%)	Ethnicity, *n* (%)	Relationship status, *n* (%)	Education, *n* (%)	Religion (%)
Abudullah et al. (2015), Malaysia	Prospective (Baseline; T2 = 6 months)	60	49.76 (11.56)	Male: 33 (66) Female: 17 (34)	Chinese: 27 (54) Malaysian: 19 (38) Indian: 3 (6) Other: 1 (2)	Married: 45 (90) Unmarried: 5 (10)	Primary school: 13 (26) Secondary school: 28 (56) Degree or higher: 9 (18)	NR
Chang et al. (2022), Taiwan	Cross-sectional	114	54.59 (1.06)	Male 105 (92.1) Female: 9 (7.9)	NR	Unmarried: 33 (28.9) Married: 81 (71.1)	No education: 1(0.9) Primary school: 24 (21.1) Middle school: 24 (21.1) Secondary school: 53 (46.5) Degree or higher: 12 (10.5)	None: 13 (11.4) Buddhism/Taoism: 98 (85.9) Christianity/Catholicism: 3 (2.6)
Harding (2018), UK	Cross-sectional	185	61.35 (11.33)	Male: 123 Female: 55	NR	Married/ cohabiting:117 Living alone: 33 Living with others: 7	NR	NR
Harding & Moss (2018), UK	Cross-sectional	52	64.54(10.34)	Male: 36 Female: 16	NR	Married/ cohabiting: n=35 Living alone: n=8 Living with others: n=1	NR	NR
Ho et al. (2011) Hong Kong	Retrospective cross-sectional	50	60 (13.06)	Male: 21(42) Female: 29(58)	NR	Single: 5(10) Married: 45(90)	No education: 8(16) Primary school: 14(28) Middle school: 6(12) Secondary school: 10(20) University: 9(18) Graduate: 3(6)	Yes: 21(42) No: 27(58)

Author, (year), country	Design	N	Age (years) (SD)	Sex, *n* (%)	Ethnicity, *n* (%)	Relationship status, *n* (%)	Education, *n* (%)	Religion (%)
Hoene et al. (2021) Germany	Retrospective Longitudinal T1= 1-month post operation T2=6 months post op T3=12 months post operation	15	Range: 48-94	Male: 10 Female: 5	NR	Married: n=7 Not married: n=6 Divorced: n=1	NR	Evangelic: 4 Catholic: 4 None: 5 Muslim: 1
Holtmaat et al. (2017) Netherlands	Cross-sectional	74	61.2(8.5 Range: 41-83	Female: 31 (41.9) Male: 43 (59.1)	NR	Living with partner: 52 (70.3)	Years of education: 11.5 (3.4)	NR
Jaafar et al. (2021) Malaysia	Longitudinal T1= baseline T2= 5-7 months afterwards	200	18-25: n=7(3.5) 26-45: n=48(24.0) 45-60: n=104 (52.0) >60: n=41(20.5)	Male: 109 (54.5) Female: 91(45.5)	NR	NR	NR	Islam: 149 (74.5) Buddhism: 32(16.0) Hinduism: 13(6.5) Christianity: 6(3.0)
Jaafar et al. (2022) Malaysia	Cross-sectional	190	18-40: n=8(4.2) 41–60: n=139 (73.2) >60: n=43 (22.6)	Male: 103 (54.2) Female: 87 (45.8)	NR	NR	NR	Islam: 145 (76.3) Buddhist: 28 (14.7) Hindu: 12 (6.3) Others: 5 (2.7)
Llewellyn et al. (2013) UK	Prospective T1= before treatment T2= 6 months post treatment	65	63 (13.9)	Male: 73(71) Female: 30(29)	White: 95(93) Other: 9(7)	Married/ cohabiting: 47(46) Divorced/ separated: 25(24) Single: 11(11) Widowed: 20(19)	Secondary School or less: 61(59) More than Secondary School: 43(41)	NR
Oginska-Bulik et al. (2017; 2018) Poland	Cross-sectional	60	50.40 (17.74)	NR	NR	NR	NR	NR

Sharp et al. (2018) UK	Cross-sectional	583	Range: 28-92	Male: 392 (67) Female: 191 (33)	NR	Married/ cohabiting: 413 (71) Other: 165 (29)	Primary School: 190 (36) Secondary School: 254 (47) Degree: 59 (11) Postgraduate: 32 (6)	NR

Note: NR = Not reported

Table 1b

Study Characteristics part 2

Author, (year), country	Design	N	HNC type, *n* (%)	Stage, *n* (%)	Time since diagnosis / treatment (months)	Treatment, n (%)
Abudullah et al. (2015), Malaysia	Prospective (Baseline; T2 = 6 months)	60	Nasopharyngeal: 20(4) Squamous cell: 27 (54) Spindle cell: 1(2) Mucoepidermal: 2(4)	I: 11 (22) II: 14 (28) III: 12 (24) IV: 13 (26)	Diagnosis New case: 20(40) <3: 9 (18) 3-6:	NT: 2 (4) S: 3 (6) C: 0 (0) RT: 3 (6) S + C: 1 (2) S + RT: 11 (22) C + RT: 17 (34) S + C + RT: 13 (26)
Chang et al. (2022), Taiwan	Cross-sectional	114	Oral Cavity: 96 (84.2) Other: 18 (15.8)	I: 5 (4.4) II: 13 (11.4) III: 13 (11.4) IV: 83 (72.8)	Diagnosis 16.22 weeks (SE=0.93)	Undergoing treatment: 52 (45.6) Completed treatment 62 (54.4)
Harding (2018), UK	Cross-sectional	185	Subtypes NR	I: 37 II: 30 III: 34 IV: 64	Treatment 3-6: n=37 7-12: n=33 13-18: n=22 19-24: n=11 25-36: n=20 37-60: n=23 >61: n=25.	S: 64 S+R: 71 R with or without C: 39
Harding & Moss (2018), UK	Cross-sectional	52	Subtypes NR	I: 10 II: 1 III: 13 IV: 26	Treatment m=6.52(2.80)	S: 16 S + R: 17 R + C: 18
Ho et al. (2011) Hong Kong	Retrospective cross-sectional	50	Oral Cavity	I + II: 41(89) III + IV: 5(11)	NR	S: 34(68) S + R: 16(32)
Hoene et al. (2021) Germany	Retrospective Longitudinal T1= 1-month post operation T2=6 months post op T3=12 months post operation	15	Oral cavity	NR	NR	NR

Author, (year), country	Design	N	HNC type, *n* (%)	Stage, *n* (%)	Time since diagnosis / treatment (months)	Treatment, n (%)
Holtmaat et al. (2017) Netherlands	Cross-sectional	74	Lip/oral/oropharynx: 42(56.8) Hypopharynx/larynx: 20(27) Other: 12(16.2)	I & II: 33(44.6) III & IV: 37(50) Unknown: 4(5.4)	Treatment m=22.4 (SD25.8)	S: 12 (16.2) R: 27 (36.5) C+R: 10(13.5) S + other: 25(33.8)
Jaafar et al. (2021) Malaysia	Longitudinal T1= baseline T2= 5-7 months afterwards	200	Subtypes NR	I: 43(21.5) II: 54(27.0) III: 65(32.5) IV: 38(19.0)	Diagnosis < 6: 113(56.5) 6-12: 87(43.5)	S: 7(3.5) C: 28(14.0) S+C: 23(11.5) S+R: 24(12.0) C+R: 73(36.5) C+R+S: 45(22.5)
Jaafar et al. (2022) Malaysia	Cross-sectional	190	Squamous cell: 128 (67.3) Adenocarcinoma: 25 (13.2) Mucoepidermal: 18 (9.5) Others: 19 (10.0)	I: 42 (22.2) II: 51 (26.8) III: 62 (32.6) IV: 35 (18.4)	Diagnosis < 6: 73 (38.4) 6-9: 67 (35.3) >9: 50(26.3)	S: 7(3.7) C: 25 (13.2) S+C: 24 (12.6) S+R: 24 (12.6) C+R: 69 (36.3) C+R+S: 41 (21.6)
Llewellyn et al. (2013) UK	Prospective T1= before treatment T2= 6 months post treatment	65	Oral cavity: 68(66) Pharynx 8(8) Larynx 19(18) Other 8(8)	I: 34(33) II:25(25) III: 23(22) IV: 17(17) Missing 4(4)	Currently receiving treatment	S: 36(35) R: 25(24) C: 3(2) S+R: 17(17) R+C: 13(13) S+R+C: 9(9)
Oginska-Bulik et al. (2017; 2018) Poland	Cross-sectional	60	subtypes NR	NR	NR	Completed directly after surgery
Sharp et al. (2018) UK	Cross-sectional	583	Oropharynx: 93 (16) Oral Cavity: 225 (39) Larynx: 178 (31) Other: 87 (15)	I: 169 (41) II: 108 (18) III: 77(11) IV: 137 (20) Unstaged: 92 (15)	Diagnosis (years) <5: 289 (50) 5-9: 199 (34) 10+: 92 (16)	R: 86 (17) C + R: 59 (11) S: 164 (33) S + C/R: 209 (39)

Note: S = Surgery, R = Radiotherapy, C = Chemotherapy, NR = Not reported NT= No treatment.

0

Results of assessment of risk bias

Table 2 outlines the results of the risk of bias assessment. All studies included an unbiased selection of samples, apart from two. Hoene et al. (2011) and Oginska-Bulik, (2017; 2018) were rated as unclear/partial as it was not reported how the samples were recruited. Limitations were highlighted across twelve studies regarding justification of sample sizes, with only one study including a power analysis (Jaafar et al., 2022). All but two of the studies adequately described the sample. Llewellyn et al. (2013) and Oginska-Bulk (2017; 2018) were scored as partial for this domain due to not including study characteristics tables, and only describing some of the demographic data collected within the text. All studies used validated methods and outcome measures for the correlates and predictor variables. All but one study was marked highly for using validated measures of PTG/BF. Abdullah et al. (2015) was scored as unclear, due to it being unclear if the Malaysian version of the PTGI has been validated in Malaysian samples by the time of writing. However, this study was still included in the final sample, given the wide use of the PTGI in cancer samples (Marzilliano et al., 2019). Only four studies reported data across two time points and all reported data within an adequate follow up period (Abdullah et al., 2015; Hoene et al., 2011; Jaafar et al., 2021; Llewellyn et al., 2013). Eight out of the twelve studies scored highly for having minimal missing data (Abdullah et al., 2015; Chang et al., 2022; Harding, 2018; Harding & Moss, 2018; Ho et al., 2011; Holtmaat et al., 2017; Jaafar et al., 2021; 2022; Llewellyn et al., 2013; Sharp et al., 2018). The remaining four studies were marked as partial/unclear due to not reporting on missing data and how this was managed. All studies used appropriate analysis for the study aims and most reported controlling for potential confounding factors. Hoene et al. (2011) and Oginska-Bulik, (2017;2018) did not report for this and therefore were marked as partial/unclear. Overall, the two studies by Jaafar et al. (2021; 2022) had the least risk of bias (scores of 8 and 9 respectively).

Table 2
Risk of bias assessment (Williams et al. 2010)

Authors	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Total score
Abdullah et al. (2015)	●	○	●	●	⊘	●	●	●	●	7.5
Chang et al. (2022)	●	○	●	●	●	N/a	●	●	●	7.0
Harding (2018)	●	○	●	●	●	N/a	⊘	●	●	6.5
Harding and Moss (2018)	●	○	●	●	●	N/a	⊘	●	●	6.5
Ho et al. (2011)	●	○	●	●	●	N/a	⊘	●	●	6.5
Hoene et al. (2011)	⊘	○	●	●	●	●	●	⊘	●	6.5
Holtmaat et al. (2017)	●	○	●	●	●	N/a	●	●	●	7.0
Jaafar et al. (2021)	●	○	●	●	●	●	●	●	●	8.0

Q1- Unbiased selection of cohort? Q2- Sample size calculation? Q3- Adequate description of cohort? Q4 – Validated method for predictor/outcome variables? Q5- Validated method for ascertaining PTG? Q6 – Adequate follow up period? Q7- Minimal missing data? Q8 – Confounders controlled for? Q9 – Appropriate Analyses?

KEY:
Yes ●
Unclear/partially ⊘

No ○

Authors	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Total score
Jaafar et al. (2022)	●	●	●	●	●	N/a	●	●	●	8.0
Llewellyn et al. (2013)	●	○	⊘	●	●	●	●	●	●	7.5
Oginska-Bulik (2017; 2018)	⊘	○	⊘	●	●	N/a	⊘	⊘	●	5.0
Sharp et al. (2018)	●	○	●	●	●	N/a	●	●	●	7.0

Q1- Unbiased selection of cohort? Q2- Sample size calculation? Q3- Adequate description of cohort? Q4 – Validated method for predictor/outcome variables? Q5- Validated method for ascertaining PTG? Q6 – Adequate follow up period? Q7- Minimal missing data? Q8 – Confounders controlled for? Q9 – Appropriate Analyses?

KEY:
Yes ●
Unclear/partially ⊘
No ○

Post-traumatic growth / Benefit-Finding measures

Table 4 outlines the demographic and psychosocial factors, including which validated questionnaires were used to assess PTG/BF. Six of the twelve studies used the PTGI (Chang et al., 2022; Ho et al., 2011; Hoene et al., 2021; Holtmaat et al., 2017; Oginska-Bulik, 2017; 2018; Sharp et al., 2018), and three used the short version of the PTGI (PTGI-SF) (Abdullah et al., 2015; Jaafar et al., 2021; 2022). Two studies used the Silver Linings Questionnaire (SLQ) (Harding, 2018; Harding & Moss, 2018) and one used the Benefit Finding Scale (BFS) (Llewellyn et al., 2013). Table 3 gives a brief overview of the questionnaires used.

Table 3

Overview of the questionnaires

Questionnaire	Description
Post-traumatic growth Inventory (PTGI) and short form (PTGI-SF) (Tedeschi & Calhoun, 1996)	Assesses positive outcomes reported by persons who have experienced traumatic events. The long version is a 21-item scale includes factors of New Possibilities, Relating to Others, Personal Strength, Spiritual Change, and Appreciation of Life (Tedeschi & Calhoun, 1996). The short form consists of 10 items across the same factors. Both versions have been validated in physical health populations and have shown to have good internal consistency (Cann et al. 2008; Weiss, 2002).
Silver Lining Questionnaire (SLQ-38) (Sodergren et al. 2002)	Assesses ten aspects of adversarial growth. It consists of 38 items which can be factored into five subscales: improved personal relationships, greater appreciation for life, positive influence on others, personal inner strength and changes in life philosophy and has been used with breast cancer populations (Bride et al. 2006).
Benefit finding Scale (BFS) (Antoni et al. 2001)	The 17-item BFS is a unitary scale focusing on potential benefits ranging from family and social relationships, life priorities, sense of spirituality and ability to accept the circumstances. The BFS has been reported to have good internal reliability and validity within breast cancer populations (Antoni et al. 2001).

Post-traumatic growth / Benefit-Finding scores

The PTG scores were examined across the studies. There are no standardised cut off scores for PTG using both versions of the PTGI (Steffens, & Andrykowski 2015), the BFS (Antoni et al., 2001) and the SLQ (Sodergren et al., 2002). Therefore, it is difficult to ascertain clinical levels

of PTG/BF and if they are comparable across studies. However, previous studies with cancer survivors have used mean item scores of 2.5 and less as having little to no PTG and including or more than 2.5 is classified as moderate-to-high PTG (e.g., Jansen et al., 2011).

Using this framework, five studies reported a moderate-high level of PTG using the PTGI *m* = 53.65 (*sd* = 2.40) (Chang et al., 2022), *m* = 51.76 (*sd* =11.18) (Ho et al., 2011) and *m* = 72.2 (*sd* = 35.7) (Hoene et al., 2021), *m* = 59.41(18.77) (Oginska-Bulik et al., 2017; 2018) *m* = 55.7 (Sharp et al., 2018) and for the BFS *m* = 58.13 (Llewellyn et al., 2015). Three studies reported low overall levels of PTG using the PTGI *m* = 30.0 (Abdullah et al., 2015), *m* = 30.8 (*sd* = 19.7) (Holtmaat et al., 2017), *m* = 39.5 (9.3) (Jaafar et al., 2021), *m* = 39.3 (*sd* = 9.5) (Jaafar et al., 2022). One study reported low levels of PTG using the SLQ *m* = 11.85 (*sd* = 9.46) (Harding & Moss, 2018). However, the other study which measured growth using the SLQ did not report a mean overall score, so this cannot be interpreted (Harding, 2018). The two prospective studies which used the PTGI had varying results. One study found that mean scores of PTG increased over time (Jaafar et al., 2021). Whereas another found that the PTG decreased over time (Abdullah et al., 2015).

Demographic factors

The twelve studies were examined across the demographic factors. Nine studies examined the associations (Abdullah et al., 2015; Harding & Moss, 2018; Ho et al., 2011; Holtmaat et al., 2017; Jaafar et al., 2021; 2022; Sharp et al., 2018) or mean differences (Hoene et al., 2021; Oginska-Bulik, 2017;2018) between age and PTG. Three studies collected data for age, but it was not used within the analyses (Chang et al., 2022; Harding, 2018; Llewellyn et al., 2013). Only, three studies reported significant findings. One study found that younger survivors reported significantly higher levels of PTG within multivariate models (Sharp et al., 2018). Hoene et al., (2021) also reported higher PTG for younger survivors using mean difference

scores. Within random-intercept models, another study reported that those aged 60 and above scored higher PTG scores, compared with those aged 18-40 (Jaafar et al., 2021).

All the studies collected information on sex. Six studies examined the correlation between sex and PTG (Hoene et al., 2021; Holtmaat et al., 2017; Jaafar et al., 2021; 2022; Oginska-Bulik, 2017;2018; Sharp et al., 2018). Five of these six studies reported that women scored significantly higher total PTG scores compared with men (Holtmaat et al., 2017; Jaafar et al., 2021; 2022; Oginska-Bulik, 2017;2018; Sharp et al., 2018). One study found that using univariate analyses women scored significantly higher for total PTG compared with men on the PTGI (Holtmaat et al., 2017). One study found no significant correlations between sex and PTG (Hoene et al., 2021). However, two studies that reported sex as correlating with PTG, reported it was no longer significant within multivariate analyses (Abdullah et al., 2015; Holtmaat et al., 2017). Three studies reported sex as a significant factor within multivariate analyses (Jaafar et al., 2021; 2022; Sharp et al., 2018). Sex was not significant within multiple regression analyses with baseline or follow-up PTG scores (Abdullah et al., 2015).

Six of the studies explored associations between marital status and PTG (Abdullah et al., 2015; Harding, 2018; Harding & Moss, 2018; Holtmaat et al., 2017; Hoene et al., 2021; Llewellyn et al., 2013). Four studies reported significant findings with marital status and PTG/BF scores across all three questionnaires: the SLQ (Harding & Moss, 2018), the BFS (Llewellyn et al., 2013) and the PTGI (Ho et al., 2011; Sharp et al., 2018). All four studies reported significantly higher levels of PTG/BF and being married or cohabiting compared with being unmarried or living alone (Harding & Moss, 2018; Llewellyn et al., 2013; Ho et al., 2011). Ho et al. (2011) only reported differences in mean PTG scores. Correlations were found between post-treatment BFS scores and marital status (r = 0.29) (Llewellyn et al., 2013). Marital status was not a significant factor with multiple regression analyses with baseline or follow up PTG scores (Abdullah et al., 2015).

Only five studies examined correlations between PTG/BF and educational attainment (Abdullah et al., 2015; Chang et al., 2022; Ho et al., 2011; Holtmaat et al., 2017; Llewellyn et al., 2013). One study collected this data but did not use it for any analysis (Hoene et al., 2021). Two studies found that higher educational attainment was significantly associated with higher PTG and BF levels (Chang et al., 2022; Llewellyn et al., 2013). These findings were significant for both the overall score on the PTGI-SF (adjusted $r^2 = 0.386$) and all the five subscales of the PTGI (Chang et al., 2022), as well as BF 6 months after treatment ($r = 0.32$) (Llewellyn et al., 2013). It was not a significant with multiple regression analyses with baseline or follow up PTG scores (Abdullah et al., 2015).

Ten studies reported data on socioeconomic status (Abdullah et al., 2015, Chang et al., 2022; Harding, 2018; Harding & Moss, 2018; Ho et al., 2011; Hoene et al., 2021; Holtmaat et al., 2017; Jaafar et al., 2022; Llewellyn et al., 2013; Sharp et al., 2018). One study collected the data but did not use this in the analysis (Chang et al., 2022). Seven of the studies examined the relationship between socioeconomic status and PTG/BF (Abdullah et al., 2015; Harding, 2018; Harding & Moss, 2018; Ho et al., 2011; Holtmaat et al., 2017; Jaafar et al., 2022; Llewellyn et al., 2013; Sharp et al., 2018). One study reported significantly higher socioeconomic status was associated with higher PTG (F (3.46) = 2.852 (Ho et al., 2011). One study reported significantly higher PTG in those with more difficult financial situation's both pre-diagnosis and for those with cancer related financial stress (Sharp et al., 2018). Therefore, findings were mixed, and studies examined socioeconomic status using different variables, such as monthly income (Ho et al., 2011) annual income (Chang et al., 2022), employment status (Holtmaat et al., 2017; Llewellyn et al., 2013) indices of multiple deprivation (Harding, 2018; Sharp et al., 2018) and cancer-related financial stress (Sharp et al., 2018).

Clinical factors

Time since diagnosis / treatment

Nine studies reported sample data for time since diagnosis or treatment (Abdullah et al., 2015; Chang et al., 2022; Harding, 2018; Harding & Moss, 2018; Hoene et al., 2011; Holtmaat et al., 2017; Jaafar et al., 2021; 2022; Sharp et al., 2018). Three studies did not report any data on time since diagnosis or treatment (Ho et al., 2011; Llewellyn et al., 2013; Oginska-Bulik, 2017;2018). Five studies included time since treatment or diagnosis within multivariate analyses (Harding, 2018; Harding & Moss, 2018; Holtmaat et al., 2017; Jaafar et al., 2022; Sharp et al., 2018). PTG and time since treatment or diagnosis were not associated in eight studies. One study (Hoene et al., 2021) reported significantly higher overall mean scores for PTG one-month post-surgery compared with 6- and 12-months post operation, these findings were significant across all PTGI subscales, with appreciation for life and relating to others decreasing the most (Hoene, et al., 2021).

Cancer Treatment Type

Ten studies reported on type of HNC treatment (Abdullah et al., 2015; Harding, 2018; Harding & Moss, 2018; Ho et al., 2011; Holtmaat et al., 2017; Jaafar et al., 2021; 2022; Oginska-Bulik et al. 2017; 2018; Sharp et al., 2018). One study did not analyse this data as all the sample recruited were post-surgical patients (Hoene et al., 2021). One study did not report any data on treatment type (Llewelyn et al., 2013). Three studies reported significant findings between treatment type and PTG. Surgery as a single modality treatment, indicated higher levels of PTG (measured using the SLQ), compared with survivors who had surgery and either adjuvant chemotherapy or radiotherapy (Harding & Moss, 2018; Harding 2018). Only two studies controlled for treatment type within regression modelling (Abdullah et al., 2015; Jaafar et al., 2021). Treatment type was not significant with multiple regression analyses for baseline or follow up PTG scores (Abdullah et al., 2015). Jaafar et al. (2021) found that survivors who had

received chemotherapy only, or chemotherapy and surgery, or chemotherapy and radiotherapy had significantly higher levels of PTG, compared with those who had surgery alone.

Stage of tumour

Four studies examined associations between tumour stage and PTG using multivariate analyses (Abdullah et al., 2015; Harding, 2018; Harding & Moss, 2018; Holtmaat et al., 2017). Harding (2018) reported that people with stage 1 disease, reported more positive change using SLQ compared with higher stage tumours (*F = 1.533*). There were inconsistent results when examining the association between PTG and tumour stage. Specifically, Ho et al. (2011) found that survivors with stages 3 and 4 disease reported higher levels of PTG, compared with stages 1 and 2 *t* (44) =2.403*. Within linear mixed effect models Harding & Moss (2018) found that survivors with stage 1 disease had higher PTG (SLQ), compared with survivors with stages 2 and 3. They found that PTG was lowest for people with stage 4 disease (Harding & Moss, 2018). Only four studies examined tumour stage within regression modelling (Abdullah et al., 2015; Holtmaat et al., 2017; Jaafar et al., 2021; 2022). Only one study reported stage as significant with PTG, specifically that survivors with stages 1 and 2 tumours had higher PTG scores compared with stages 3 and 4 Holtmaat et al. (2017)

Physical health

Only five studies collected data on physical health (Harding, 2018; Harding & Moss, 2018; Hoene et al., 2021; Holtmaat et al., 2021; Sharp et al., 2018). Four studies report significant associations between physical health and PTG. Improvements in physical functioning, as measured by the UW-QOL questionnaire, such as chewing, swallowing, saliva production, recreation was associated with higher levels of PTG, as measured by the SLQ (Harding, 2018). Physical domains in the HRQOL scale were significantly correlated with the PTG subscales 'new possibilities' and appreciation of life' subscales of the PTGI (Hoene et al., 2021). Higher

degree of unmet needs on physical and daily needs were predictive of lower PTG (Jaafar et al., 2022). There was a weak correlation between overall PTG and HRQoL. HRQoL was lower in those that had no or little PTG, than those in the moderate to high PTG group (Sharp et al., 2018).

Distress

Six studies examined symptoms of distress with PTG/BF (Abdullah et al., 2015; Chang et al., 2022; Holtmaat et al., 2017; Jaafar et al., 2022; Llewellyn et al., 2013; Oginska- Bulik, 2017;2018). Fear of recurrence was significantly positively associated with PTG in 2 studies (Chang et al., 2022; Jaafar et al., 2022). Higher overall PTG was significantly associated with greater fear of cancer recurrence, longer time since an oncologic emergency, less anxiety and having had a previous cancer recurrence and greater educational attainment, these factors explained 36.6% of the variance in PTG (β = 0.559) (Chang et al., 2022). Similarly, within multivariate analyses lower scores for depression and better social functioning were associated with higher PTGI scores (Holtmaat et al., 2017). Absence of anxiety and alcohol disorders were associated with higher scores on the PTGI (r^2 = 0.321) (Holtmaat, et al., 2017). Additionally, an improvement in mood was associated with higher PTG, measured using the SLQ (Harding, 2018). Lastly, at the same time the subscale of emotional growth within the BFS was found to be negatively related (r = -0.31) to the mental component subscale of the SF-12, indicating that higher levels of emotional growth are associated with lower levels of mental health related QoL (Llewellyn et al., 2013).

Psychological processes

Only four studies explored associations between PTG/BF and psychological mechanisms (Ho et al., 2011; Jaafar et al., 2021; Llewellyn et al., 2013; Oginska-Bulik, 2017; 2018). Two studies measured ways of coping with HNC using the Brief COPE questionnaire (Carver,

1997). One found significant associations with the subscales ‘planning’ and ‘coping acceptance’ skills, predicted higher PTG (Jaafar et al., 2021) and the other reported modest relationships (R>0.32 to 0.44) between BF and the following coping domains ‘use of emotional support’, ‘positive reframing’ and ‘self-blame’ (Llewellyn et al., 2013).

Two studies reported significant associations between PTG and Optimism (Ho et al., 2011) and BF and Optimism (Llewellyn et al., 2013). Hope (r = 0.49) and optimism (r = 0.31) were both positively correlated with higher PTG scores (Ho et al., 2011). Hope and optimism together contributed a 25% variance of PTG within the regression equation and were significant. However, only hope was a significant individual indicator of PTG, accounting for 16% unique variance, whereas optimism only accounted for 1% (Ho et al., 2011). Optimism was related to BF scores across the ‘sense of spirituality’ and ‘ability to accept the circumstances’ domains but were not related to the for ‘life purpose’ and ‘support’ domains (Llewellyn et al., 2013). 39% of the variance in the BFS was predicted by pre-treatment BF, active coping strategies, optimism, and marital status (r^2 = 0.43) (Llewellyn et al., 2013).

One study found associations between personality and rumination, with two components of the PTGI: namely appreciation of life and spiritual change (Oginska-Bulik, 2017;2018). In addition, appreciation of life was also found to be related to intrusive and deliberate rumination (Oginska-Bulik, 2017;2018). Both extraversion and openness to experiences were found to reduce the tendency to engage in intrusive ruminations but not deliberate ruminations (Oginska-Bulik, 2017;2018). Therefore, extraversion and openness to experiences may indirectly reduce appreciation of life. Additionally, neuroticism was found to positively predict intrusive rumination, which in turn increases the changes in the spiritual domain of the PTGI (Oginska-Bulik, 2017;2018). However, this study (across two articles) did not report a power calculation and therefore it is unclear if this study’s sample had enough power to make causal inferences.

Table 4

Main Study Findings

Author, (year)	Dependent variable(s)		Analysis	Independent variables			Significant findings
	Scale used	Scale score (SD)		Non-psychosocial (demographic)	Non-psychosocial (clinical)	Psychosocial	
Abudullah et al. (2015)	PTGI-SF (Malay version)	T1 = 37.5 T2 = 30.0	Correlations; multiple regression	Age; Sex, Race, Monthly Income; Education, Marital status	Cancer site, Duration of diagnosis, Cancer stage, Treatment type (no treatment, surgery, chemotherapy, radiotherapy, and combinations).	Anxiety and Depression (HADS)	<u>*Demographic:*</u> None Clinical: None <u>*Psychosocial:*</u> *T1: HADS (A) B=0.590***. HADS (D) -0.635***. R2 =0.363*.*
Chang et al. (2022)	PTGI	M =53.65 (SE=2.40)	Mean comparison; Multiple regression	Age; Sex; Employment after diagnosis, Marital status, educational level; Religion; Family income (NT$)	Cancer subsite, Cancer Stage, Body Mass Index, use of feeding tube, Fear of cancer recurrence (FoP-Q-SF); medical treatment; treatment status; time since cancer diagnosis; time since, number of and type of oncology emergencies.	Symptom distress, anxiety, FCR.	<u>*Demographic*</u> Education level (year) β =0.187*, PTGI subscales – a) relating to others β =0.182*, b) new possibilities β =0.187*, c) personal strength β = 0.155***, d) appreciation of life β =0.209** <u>*Clinical*</u> Time since oncologic emergencies β =0.273***, PTGI subscales a) new possibilities β= Anxiety β =-0.338*** Having a recurrence β =0.198*** (Adj r2=0.386) <u>*Psychosocial:*</u> FCR (Fop-Q-SF) β =0.559*** Anxiety β =-0.338***
Harding (2018)	SLQ	NR	Linear mixed effects models	Age at time of diagnosis; Sex; Index of multiple deprivation; Family status	Tumour stage; Date of diagnosis; Treatment regimen; Date of treatment completion.	HRQoL (UW-QoL;SF-12)	<u>*Demographic:*</u> None <u>*Clinical:*</u> III and IV tumours lower PPC F=1.533* Surgery alone more positive change th*an S+R/C t=2.317** <u>*Psychosocial:*</u> UW-QoL p=0.009

Author, (year)	Dependent variable(s)		Analysis	Independent Variables			Significant Findings
	Scale used	Scale score (SD)		Non-psychosocial (demographic)	Non-psychosocial (clinical)	Psychosocial	
Harding & Moss (2018)	SLQ	M=11.85(9.46)	Regression	Age at time of diagnosis; sex, Index of multiple deprivation; Family status	Tumour stage, Date of diagnosis; Treatment regime.	HRQoL (UW-QoL; SF-12).	*Demographic:* Married/cohabiting Estimate (SE)=-7.60(9.43)*, *Clinical:* cancer stage: 1: 11.90* (3.10), treatment regime: Surgery: 6.99* (3.10) *Psychosocial:* None
Ho et al. (2011)	PTGI (Chinese version)	M=51.76(11.18)	Correlations; Multiple regression	Age; Sex; Religion; Education level; Income	Time since diagnosis, Treatment type	Hope (HS); Optimism (LOT-R)	*Demographic:* Higher Income: (F(3.46)= 2.852* Being Married: t(48)=2.403* *Clinical:* None *Psychosocial:* Hope: r=0.49*** Optimism: r = 0.31* Hope: β = 0.44** Optimism: Beta = 0.34*
Hoene et al. 2021	PTGI	MV 72.2+35.7 (95% CI, 69.9-74.5)	Correlations	Age; Sex; Marital status, Employment	Tumour location, Surgery Type	HRQoL (UW-QoL)	*Demographic:* None *Clinical:* Physical functioning: Swallowing: MV=24.7+25.6*, Chewing: MV=31.926**, Speech: MV= 19.1+20.7** Socio-emotional: Shoulder function: MV = 15.`+23.0*** *Psychosocial:* PTG subscales**:** New possibilities: $r_{s=}$0.49*, Appreciation of life: r_s=-0.61** (physical function score), r_s=-0.46*

Author, (year)	Dependent variable(s)		Analysis	Independent Variables			Significant Findings
	Scale used	Scale Score (SD)		Non-psychosocial (demographic)	Non-psychosocial (clinical)	Psychosocial	
Holtmaat et al. (2017)	PTGI	M= 30.8 (19.7) Relating to others: 13.1(7.7) New possibilities: 5.8(5.2) Personal strength: 5.1(4.7) Spiritual Change: 1.4(2.2) Appreciation of Life: 5.5(4.1)	Univariate analyses; Backward elimination regression analysis	Age; Sex; Relationship status; Number of years of education; Employment status	Tumour location; Tumour stage; Type of treatment; Time since treatment.	Anxiety and depression (HADS), Cancer quality of life questionnaire-30; Nicotine and alcohol disorders (World Mental Health CIDI)	<u>*Demographic:*</u> Sex: *t*(48.4) =-2.057* <u>*Clinical:*</u> Tumour stage: *t*(51.0) = 2.490* Tumour stage: β =-0.0355** <u>*Psychosocial:*</u> Depression: r=-0.331** Social functioning: $r_{s=}$2.64* Anxiety disorder (CIDI): β =-0.309* Alcohol use disorder: β =-0.221* Social functioning: β =0.272**
Jaafar et al. (2021)	PTGI-SF	Baseline: 33.7 (11.5) T2: 39.5 (9.3)	Mean comparisons; Mixed effect and random intercept models	Sex; Age; Religion	Time since diagnosis; Stage of cancer; Cancer treatment received.	Coping strategies (Brief COPE).	<u>*Demographic:*</u> *Sex* β *=-2.975*** *>60years* β *=6.479** <u>*Clinical:*</u> *Chemotherapy* β *=6.015** *Surgery and Chemotherapy* β *=5.503** <u>*Psychosocial:*</u> *Brief COPE, Planning* β *=1.256***, *Acceptance B=1.162**, *Denial* β *=-1.078***
Jaafar et al. (2022)	PTGI-SF	M=39.3 (9.5)	Mean comparisons; General linear model	Age; Sex; Religion; Monthly household income (in Malaysian Ringgit).	Duration from diagnosis (months); Stage of cancer; Histopathological types of HaNC; Type of treatment.	Unmet supportive care needs (SCNS-34); Fear of Cancer Progression (FoP-Q-SF)	<u>*Demographic:*</u> Sex B=3.037* <u>*Clinical:*</u> None <u>*Psychosocial:*</u> Total FoPQ-SF β =-0.184** Unmet needs (physical and daily living) β = -0.430*

Author, (year)	Dependent variable(s)		Analysis	Independent Variables			Significant Findings
	Scale used	Scale score (SD)		Non-psychosocial (demographic)	Non-psychosocial (clinical)	Psychosocial	
Llewellyn et al. (2013).	BFS	Baseline: M=59.79 (7.59) T2: M=58.13 (8.22)	Multivariate linear regression	Age; Sex; Ethnicity, Education; Employment; Marital status.	Type of treatment; Site and stage of cancer	Anxiety and Depression (HADS), Optimism (LOT-R), Coping (Brief COPE), Quality of life (SF-12v2; QLQ-C30)	*Demographic:* Marital status R=0.29* Education = R=0.32* *Clinical:* None *Psychosocial:* BFS total score R2=0.39*** BF life purpose and support R2=0.41*** BF negatively worded R2=0.35*** BF emotional growth R2=0.49***
Oginska-Bulik et al. (2017;2018)	PTGI	M=59.41 (18.77)	Correlations; Mediation models	Age; Sex	None	Personality dimensions (NEO-FFI); Rumination (RRQ and ERRI); Sense of Discomfort (IES-R)	*Demographic:* None *Clinical:* None *Psychosocial:* *Neuroticism* β *=-0.28*, Conscientiousness,* β *=0.39**, Reflection* β *=0.26*, Intrusive rumination* β *=0.39**, Deliberate Rumination* β *=0.47**** *PTGI subscales – a) Appreciation of life: Deliberate rumination r=0.34**, Intrusive rumination r=0.31*. b) Spiritual changes: intrusive rumination r=0.39**.*
Sharp et al. (2018)	PTGI	55.7 (95%CI 51.2-58.3)	Mean comparison; Multiple regression	Age; Sex; Marital status; Highest level of education; Number of children; Deprivation category (based on 2002 census data).	Pre and post diagnosis cancer-related financial stress; Social support; Cancer site, Cancer stage, Cancer Recurrence; Time since diagnosis; Cancer directed	HRQoL (FACT-G and FACT-H&N).	*Demographic:* Sex F=10.53** Age F=5.47** Social support F=16.45** Pre-diagnosis financial situation F=4.66* Cancer-related financial stress F=13.56** *Clinical:* None

		treatment(s) within 8 months of diagnosis.	*Psychosocial:* HRQoL Spearman Rho= .12**

***p < 0.001; **p < 0.01; *p < 0.05, BFS = Benefit Finding Scale, FCR = Fear of cancer recurrence. Fop-Q-SF Fear of Progression Questionnaire, HADS (A) = Anxiety subscale of the Hospital Anxiety and Depression Scale, HADS (D) = Depression subscale of the Hospital Anxiety and Depression Scale, Hope (HS) = Hope is measured by the Hope Scale, HRQoL (FACT-G and FACT-H&N) = Health related quality of life was measured using Functional Assessment of Cancer Therapy General Questionnaire and the HNC component, HRQoL (UW-QoL) = Health related quality of life measured using the University of Washington Quality of Life Questionnaire version 4, NR = Not reported, NT$ = New Taiwan Dollars, Optimism (LOT-R) = Optimism is measured by the Life Orientation Test-Revised, PTGI-SF = Posttraumatic Growth Inventory – Short Form, RM = Malaysian Ringgit, SAS = State Anxiety Scale

Discussion

This review examined demographic, clinical and psychosocial factors with PTG/BF in survivors of HNC. Literature included cross-sectional and prospective research examining PTG and BF across three validated questionnaires. Twelve studies, consisting of thirteen articles were included and summarised. Six of the twelve studies used the PTGI (Chang et al., 2022; Ho et al., 2011; Hoene et al., 2021; Holtmaat et al., 2017; Oginska-Bulik, 2017; 2018; Sharp et al., 2018), and three used the short version of the PTGI (PTGI-SF) (Abdullah et al., 2015; Jaafar et al., 2021; 2022). Two studies used the Silver Linings Questionnaire (SLQ) (Harding, 2018; Harding & Moss, 2018) and one used the Benefit Finding Scale (BFS) (Llewellyn et al., 2013).

Demographic variables findings

Of the nine studies which explored age and PTG, only two reported significant findings and these results were mixed. One study reported that younger HNC survivors experience higher PTG (Sharp et al., 2018), whereas the other found that those over 60 years of age reported higher levels of PTG (Jaafar et al., 2021). One of these studies used prospective methods, and therefore might have more accurate findings (Jaafar et al. 2021). However, given that only two out of nine studies reported significant findings, it is unlikely that it is associated with PTG. Of the five studies which examined correlations between PTG/BF and educational attainment (Abdullah et al., 2015; Chang et al., 2022; Ho et al., 2011; Holtmaat et al., 2017; Llewellyn et al., 2013), only two studies found that higher educational attainment was significantly associated with higher PTG (Chang et al., 2022) and BF (Llewellyn et al., 2013). A previous review in HNC samples also reports that higher education is linked to higher PTG (Harding et al., 2014). However, given that less than half of the studies found significant associations

within this review, it is unlikely that educational attainment is a relevant factor with PTG or BF, although further research is needed to make more definite conclusions.

Of the seven studies which explored sex and PTG, five found significant differences between men and women, with women reporting higher PTG (Holtmaat et al., 2017; Jaafar et al., 2021; 2022; Oginska-Bulik, 2017;2018; Sharp et al., 2018). These studies all used versions of the PTGI. This finding has been supported within the wider PTG literature, including validating the PTGI (Tedeschi & Calhoun, 1996). Thus, women might be more likely to experience PTG compared to men with HNC, given the large proportion of studies within this review reporting significant associations. Additionally, four out of six studies found that being married or living with a partner was found to be positively associated with higher levels of PTG (Harding & Moss, 2018; Ho et al., 2021; Sharp et al., 2018) and BF (Llewellyn et al., 2013). Given the high proportion of significant findings, this factor is likely to be associated. Sventina et al. (2012) found that having family support systems accounted for more PTG compared with psychological coping strategies with breast cancer survivors. Taken together these findings are consistent with previous research reporting that suicide rates were higher in male HNC survivors who had later stage disease, and who were not married (Kam et al., 2015). Thus, it might be that men who are not married are more likely to use maladaptive coping strategies, rather than techniques which are supportive of PTG/BF.

Although, seven studies examined the relationship between PTG and socioeconomic status, only two reported significant findings (Ho et al., 2011; Sharp et al., 2018). Due to a small number of studies reporting significant findings, it is likely that SES does not impact PTG in HNC. There is some literature which reports strong associations between socioeconomic status and risk factors for developing HNC, however there is less literature on how this can influence PTG/BF.

Clinical variable findings

Of the five studies which included time since diagnosis / treatment and PTG within correlation or regression analyses, none found significant associations (Harding, 2018; Harding & Moss, 2018; Holtmaat et al., 2017; Jaafar et al., 2022; Sharp et al., 2018). One study with a longitudinal design reported a decrease in PTG over time 1-month post-surgery compared with 6-12 months post-surgery (Hoene et al., 2021). However, this study compared mean scores over time and therefore is not as robust as multivariate analyses. Thus, this review indicates that time since diagnosis or treatment might not impact PTG/BF. This finding is inconsistent with the Illness constellation model (Morse & Johnson, 1991), which postulates that cancer survivors will proceed through four stages of reflective processing over time before reaching PTG. However, this study monitored HNC survivors over a relatively short time within the survivorship period and therefore perhaps more time is needed to reach PTG. Research in breast cancer survivors has reported that those who experienced PTG within a year of diagnosis had better outcomes 8 years post-diagnosis (Carver & Antoni 2004). This suggests that there is continuous PTG and that it can take a long time for people to reach, however it is unclear how long HNC might take to reach this stage, or if as many will reach PTG compared with breast cancer survivors.

Although ten studies collected data on treatment type, only two studies included these variables within multivariate analyses. One of these studies which included in multivariate analyse one did not find any significant results (Abdullah et al., 2015). The other study found that survivors who had received surgical interventions only reported the lowest levels of PTG compared with radiotherapy and chemotherapy. Thus, these findings suggest that treatment type does not impact PTG with HNC samples.

Four studies controlled for cancer stage within regression modelling (Abdullah et al., 2015; Holtmaat et al., 2017; Jaafar et al., 2021; 2022). Only one study reported stage as significant with PTG, specifically that survivors with stages 1 and 2 tumours had higher PTG scores compared with stages 3 and 4 (Holtmaat et al., 2017). A systematic review including mixed cancer samples reports that the higher the stage of the cancers the more severe PTSD symptoms would be reported (Marziliano et al., 2019). This fits with the explanations provided by existential theory, which postulates that the more an event is perceived as threatening (as with higher cancer stages), the more likely survivors will engage in rumination and experience stress (Einspruch, 1994).

Only six studies examined symptoms of distress with PTG/BF (Abdullah et al., 2015; Chang et al., 2022; Holtmaat et al., 2017; Jaafar et al., 2022; Llewellyn et al., 2013; Oginska-Bulik, 2017;2018). Four studies reported significant findings, across all three questionnaires. However, there were inconsistencies across the studies, one reporting that higher fear of recurrence predicted lower PTG (Chang et al., 2022) and another reporting that higher fear of recurrence predicted higher levels of PTG (Jaafar et al., 2022). However, his review indicates that given the high proportion that found significant associations that distress might impact PTG/BF and this needs further exploration.

Only five studies collected data on physical health (Harding, 2018; Harding & Moss, 2018; Hoene et al., 2021; Holtmaat et al., 2021; Sharp et al., 2018). Four studies report significant associations between more physical health problems and lower levels of PTG. Given this large proportion of significant findings within the papers that examined these factors, the review highlights that physical health and functioning is a factor which needs further exploration in HNC. This finding is expected due to the literature reporting the multitude of physical health difficulties within HNC.

Four studies examined psychological processes and their associations with PTG and BF, with only one of these studies found hope and optimism to be significantly associated with PTG (Ho et al., 2021). Given that this finding represents such a small proportion, it is unlikely that hope and optimism are important factors within HNC. A previous systematic review in breast cancer survivors reported PTG to be negatively associated with depression and anxiety which were directly related to hope and optimism processes (Casellas-Grau et al., 2017). However, anxiety and depression were not explored within this article and therefore it is unclear if this is the same pattern for HNC survivors (Ho et al., 2021).

Specific psychological ways of coping such as 'planning' (devising strategies to cope with the difficulty) and 'coping acceptance skills' (accepting the reality of the situation) were reported to be associated with PTG (Jaafar et al., 2021). This finding was found to be consistent over two time points suggesting that these strategies continued to influence PTG over time. A previous study in HNC has reported the most frequent coping styles to be acceptance, and religion and active coping (Sherman et al., 2000). However, this study did not examine PTG and therefore the links between this are unclear. No significant differences were found between acceptance and planning coping styles across various treatment phases (pre-treatment, undergoing treatment, less than 6 months post treatment or more than 6 months post-treatment) (Sherman et al., 2000). However, this study did not explore PTG or BF, so it is unclear how these findings would relate.

There are cultural differences across PTG, for example Gall et al. (2011) identified that positive religious coping showed positive associations with PTG in breast cancer. The findings of this review suggest that this is not the case for survivors of HNC, however only four out of the twelve studies collected data on religion, so further exploration is needed.

Methodological limitations and implications for future research

There are several limitations to be noted about this review. Firstly, grey literature was excluded, and only published research was included, and it is possible that relevant studies were excluded. Research articles which were published not in the English language were excluded. Therefore, this could have resulted in a cultural bias of the included studies as research was linked to English speaking populations only. Only one study reported data on alcohol and smoking status. This is a limitation given the relationship between these and HNC.

Additionally, examining the associations with sociodemographic status was not possible across all the studies as there were differing ways of reporting this. Income was examined as this was the most prominent data reported across the studies. At the same time, sociodemographic status is also an important factor in HNC. Although nine studies examined the relationship between sociodemographic status and PTG, this was examined through a broad range of variables (employment status, deprivation indices, financial stress, and annual income), which means comparing across studies is challenging.

It is also important to note any methodological limitations of the reviewed studies. Firstly, only four studies were conducted within the UK and therefore findings might not be generalisable to UK HNC samples and NHS services. Seven of the studies used a cross-sectional design and therefore casual inferences cannot be made from these studies. Eight of the studies used convenience sampling and therefore internal bias might be present. Additionally, only one of the studies used a power analysis to determine a sample size. Therefore, for the studies which did not use a power analysis, the findings might not have enough power within the sample size to be generalisable to all HNC samples. Only four studies (five articles) included information on psychological processes and how they are associated with PTG (Ho et al., 2011; Jaafar et al., 2021; Llewellyn et al., 2013; Oginska-Bulik, 2017;2018). To improve psychological

interventions and support offered to people with HNC, future research should examine the psychological processes that underpin mental health difficulties and PTG.

Due to the explored questionnaires within this review not reporting clinical cut off scores, it is challenging to compare results across the included studies. Although all questionnaires measure positive change following HNC, there are subtle differences between the items within the questionnaires which could have impacted individual responses. Additionally, there are subtle differences between the underlying constructs that were included in the review, namely PTG and BF, which again could have influenced results. Most of the studies in this review used the PTGI which is the most widely used and validated measure of PTG. The questionnaires used have mostly been validated to be used within breast cancer populations, consisting of mostly female survivors. However, HNCs are more commonly experienced in men, who might present with their own distinct challenges and ways of reaching PTG which is not captured within these questionnaires.

Even though significant correlations were found, these were often only at weak to moderate levels (Dancey & Reidy 2007), for example with PTG health related quality of life (r = .12).

Clinical Implications

The findings from the review suggest that there are some associated factors with PTG/BF were namely being younger in age, a man, living alone, higher stages of tumours, physical health difficulties because of HNC treatments, fear of recurrence, anxiety, depression, as well as receiving chemotherapy or radiotherapy either alone or in conjunction with surgery. Clinicians working within HNC services should be aware of these factors and further screening processes should be offered to identify which survivors might need more support with their mental health.

Previous research has reported PTSD symptoms to be correlated with perceived threat of HNC (Posluszny et al., 2014), thus education within clinical appointments around prognosis and

treatment outcomes is important. These findings suggest that clinical psychologists should be within HNC multidisciplinary teams and could help to inform or train other health professionals about how to support survivors of HNC with anxiety depression and PTSD. Interventions for anxiety, depression and fear of recurrence are typically delivered by clinical psychologists, although they are not currently commissioned within HNC multi-disciplinary teams (Humphries, 2008). Therefore, this review demonstrates the need for psychologists and other mental health specialists to work within such physical health settings. Psychologists are best placed to deliver group and one-to-one interventions, for mental health difficulties. A possible intervention for fear of recurrence could be in the form of psychoeducation, normalising and validating worries and anxious responses during cancer diagnoses and treatments. This review highlighted that living alone and thus perceiving to have limited support systems, was associating with lower levels of PTG and BF. Therefore, another possibility for an intervention is for peer support groups to be developed and offered for HNC survivors who fit into this category. These could be set up and facilitated by a clinician, using evidence-based practices around group therapy within cancer populations, which has found to improve psychosocial outcomes in mixed cancer populations (Macvean et al., 2008). Other studies have highlighted the need for psychologists to be integrated within HNC multi-disciplinary teams (e.g., Humphries, 2008).

Psychologists also provide training and consultations to other healthcare professionals who typically work within HNC services, such as nurses, oncologists, occupational therapists, speech, and language therapists regarding such clinical issues with HNC. Such training might be around how to use mental health screening materials routinely within services, using self-help materials with survivors and other psychological services they could be referred to for support.

Through their training, psychologists are also well equipped to develop services in response to a clinical need of a population. Such developments could be trialling screening and interventions for mental health difficulties such as anxiety, depression, and fear of recurrence within HNC clinics, with the aim of promoting more PTG/BF.

Lastly, there are very few studies that have examined psychological interventions within clinical settings for HNC. Processes that are grounded in psychological therapies would be worthwhile to be explored, to help infer if psychological modalities would be beneficial in survivors with HNC. Additionally, no intervention studies met criteria of this review and therefore no specific psychological interventions were explored. More research exploring specific interventions is needed.

It is important for healthcare professionals to recognise that PTG/BF is possible following diagnoses and treatments for HNC. However, given the findings of this review PTG does not occur in all HNC and therefore it should not be an expectation.

Conclusion

The results of this review indicate that research examining PTG/BF within HNC is limited and studies tend to explore wide ranges of correlates and associates, and thus making definite conclusions from the review is not possible. Weak to moderate associations were found between some demographic and clinical factors which were significantly associated with PTG/BF. These factors can increase or decrease the development of positive experiences following treatments for HNC. Limited research examined psychological processes that impact PTG/BF. Therefore, more research is needed to explore what psychological processes may be able to support this within clinical practice. Additionally, psychologists are not commonly employed within HNC services in the UK and this review highlights the need for psychological

input within them to educate healthcare professionals and to inform service development based on evidence-based psychological practices.

References

Abdullah, M. F. I., Nik Jaafar, N. R., Zakaria, H., Rajandram, R. K., Mahadevan, R., Mohamad Yunus, M. R., & Shah, S. A. (2015). Posttraumatic growth, depression and anxiety in head and neck cancer patients: examining their patterns and correlations in a prospective study. *Psycho-Oncology*, *24*(8), 894-900. https://doi.org/10.1002/pon.3740

Andrykowski, M. A., Cordova, M. J., McGrath, P. C., Sloan, D. A., & Kenady, D. E. (2000). Stability and change in posttraumatic stress disorder symptoms following breast cancer treatment: a 1-year follow-up. *Psycho-Oncology*, *9*(1), 69–78. https://doi.org/10.1002/(sici)1099-1611(200001/02)9:1<69::aid-pon439>3.0.co;2-r

Antoni, M. H., Lehman, J. M., Kilbourn, K. M., Boyers, A. E., Culver, J. L., Alferi, S. M., Yount, S. E., McGregor, B. A., Arena, P. L., Harris, S. D., Price, A. A., & Carver, C. S. (2001). Cognitive-behavioral stress management intervention decreases the prevalence of depression and enhances benefit finding among women under treatment for early-stage breast cancer. *Health Psychology*, *20*(1), 20–32. https://doi.org/10.1037/0278-6133.20.1.20

Booth A, Fry-Smith A. 2004. Developing a research question. In: Petticrew M, Roberts H, eds. Systematic reviews in the social sciences. Oxford: Blackwell.

Cann, A., Calhoun, L. G., Tedeschi, R. G., Taku, K., Vishnevsky, T., Triplett, K. N., & Danhauer, S. C. (2010). A short form of the Posttraumatic Growth Inventory. *Anxiety, Stress, and Coping*, *23*(2), 127–137. https://doi.org/10.1080/10615800903094273

Carver, C. S. (1997). You want to measure coping but your protocol is too long: Consider the brief cope. *International Journal of Behavioral Medicine*, 4(1), 92-100. https://doi.org/10.1207/s15327558ijbm0401_6

Carver, C. S., & Antoni, M. H. (2004). Finding Benefit in Breast Cancer During the Year After Diagnosis Predicts Better Adjustment 5 to 8 Years After Diagnosis. *Health Psychology*, *23*(6), 595–598. https://doi.org/10.1037/0278-6133.23.6.595

Casellas-Grau, A., Ochoa, C., & Ruini, C. (2017). Psychological and clinical correlates of posttraumatic growth in cancer: A systematic and critical review. *Psycho-oncology*, *26*(12), 2007–2018. https://doi.org/10.1002/pon.4426

Chang, Y. L., Huang, P. W., Liao, C. T., Wang, H. M., Lin, C. Y., & Chen, S. C. (2022). Factors impacting posttraumatic growth in head-and-neck cancer patients with oncologic emergencies. *Supportive Care in Cancer*, *30*(5), 4515-4525. https://doi.org/10.1007/s00520-021-06772-y

Chen, H. M., Chen, V. C., Hsiao, H. P., Weng, Y. P., Hsu, Y. T., Weng, J. C., Su, J. A., & Chen, Y. L. (2019). Correlations And Correlates of Post-Traumatic Growth And Post-Traumatic Stress Symptoms In Patients With Breast Cancer. *Neuropsychiatric Disease and Treatment*, *15*, 3051–3060. https://doi.org/10.2147/NDT.S218450

Connerty, T.J. & Knott, V. (2013). Promoting positive change in the face of adversity: experiences of cancer and post-traumatic growth. European Journal of Cancer Care, 22, 334-344. https://doi.org/10.1111/ecc.12036

Cordova, M. J., Cunningham, L. L. C., Carlson, C. R., & Andrykowski, M. A. (2001). Posttraumatic growth following breast cancer: A controlled comparison study. *Health Psychology*, *20*(3), 176–185. https://doi.org/10.1037/0278-6133.20.3.176

Dancey, C. P., & Reidy, J. (2007). *Statistics without maths for psychology*. Pearson education.

Einspruch, B. C. (1994). Living Beyond Limits: New Hope and Help for Facing Life-Threatening Illness. *JAMA*, *271*(18), 1457-1457.

Folkman, S. (2008). The case for positive emotions in the stress process. *Anxiety, Stress, and Coping*, *21*(1), 3-14. https://doi.org/10.1080/10615800701740457

Gall, T. L., Charbonneau, C., & Florack, P. (2011). The relationship between religious/spiritual factors and perceived growth following a diagnosis of breast cancer. *Psychology & Health*, *26*(3), 287–305. https://doi.org/10.1080/08870440903411013

Harding, S. A. (2018). The trajectory of positive psychological change in a head and neck cancer population. *International Journal of Oral and Maxillofacial Surgery*, *47*(5), 578-584. https://doi.org/10.1016/j.ijom.2017.09.010

Harding, S., & Moss, T. P. (2018). The impact of treatment for head and neck cancer on positive psychological change within a year of completing treatment. *International Journal of Oral and Maxillofacial Surgery*, *47*(3), 302-308. https://doi.org/10.1016/j.ijom.2017.07.023

Harding, S., Sanipour, F., & Moss, T. (2014). Existence of benefit finding and posttraumatic growth in people treated for head and neck cancer: a systematic review. *PeerJ*, *2*, e256. https://doi.org/10.7717/peerj.256

Hoene, G., Gruber, R. M., Leonhard, J. J., Wiechens, B., Schminke, B., Kauffmann, P., & Brockmeyer, P. (2021). Combined quality of life and posttraumatic growth evaluation during follow-up care of patients suffering from oral squamous cell carcinoma. *Molecular and Clinical Oncology*, *15*(3), 1-7. https://doi.org/10.3892/mco.2021.2351

Ho, S., Rajandram, R. K., Chan, N., Samman, N., McGrath, C., & Zwahlen, R. A. (2011). The roles of hope and optimism on posttraumatic growth in oral cavity cancer patients. *Oral Oncology*, *47*(2), 121-124. https://doi.org/10.1016/j.oraloncology.2010.11.015

Holtmaat, K., van der Spek, N., Cuijpers, P., Leemans, C. R., & Verdonck-de Leeuw, I. M. (2017). Posttraumatic growth among head and neck cancer survivors with psychological distress. *Psycho-Oncology*, *26*(1), 96–101. DOI: 10.1002/pon.4106 https://doi.org/10.1002/pon.4106

Humphris, G. M. (2008). The missing member of the head and neck multidisciplinary team: the psychologist. Why we need them. *Current Opinion in Otolaryngology & Head and Neck Surgery*, *16*(2), 108-112. DOI: 10.1097/MOO.0b013e3282f470f9

Jaafar, N. R., Abd Hamid, N., Hamdan, N. A., Rajandram, R. K., Mahadevan, R., Mohamad Yunus, M. R., ... & Leong Bin Abdullah, M. F. I. (2021). Posttraumatic Growth and Coping Strategies Among Patients with Head and Neck Cancer: Do Approach Coping and Avoidant Coping Predict Posttraumatic Growth Over Time? *Frontiers in Psychology*, 4846. https://doi.org/10.3389/fpsyg.2021.716674

Jaafar, N. R., Hamdan, N. A., Abd Hamid, N., Rajandram, R. K., Mahadevan, R., Zakaria, H., & Leong Bin Abdullah, M. F. I. (2022). Posttraumatic growth and its association with unmet supportive care needs and fear of cancer progression among head and neck cancer patients. *Plos One*, *17*(3). https://doi.org/10.1371/journal.pone.0265502

Jansen, L., Hoffmeister, M., Chang-Claude, J., Brenner, H., & Arndt, V. (2011). Benefit finding and post-traumatic growth in long-term colorectal cancer survivors: prevalence, determinants, and associations with quality of life. *British Journal of Cancer*, *105*(8), 1158-1165. https://doi.org/10.1038/bjc.2011.335

Janoff-Bulman, R. (1992). *Shattered assumptions: Towards a new psychology of trauma.* Free Press.

Kam, D., Salib, A., Gorgy, G., Patel, T. D., Carniol, E. T., Eloy, J. A., & Park, R. C. W. (2015). Incidence of suicide in patients with head and neck cancer. *JAMA Otolaryngology–Head & Neck Surgery*, *141*(12), 1075-1081. doi:10.1001/jamaoto.2015.2480

Kangas, M., Henry, J. L., & Bryant, R. A. (2005). Predictors of posttraumatic stress disorder following cancer. *Health Psychology*, *24*(6), 579–585. https://doi.org/10.1037/0278-6133.24.6.579

Lang, H., France, E., Williams, B., Humphris, G., & Wells, M. (2013). The psychological experience of living with head and neck cancer: a systematic review and meta-synthesis. *Psycho-oncology*, *22*(12), 2648-2663. https://doi.org/10.1002/pon.3343

Lee, J. H., Ba, D., Liu, G., Leslie, D., Zacharia, B. E., & Goyal, N. (2019). Association of head and neck cancer with mental health disorders in a large insurance claims database. *JAMA Otolaryngology–Head & Neck Surgery*, *145*(4), 339-344. doi:10.1001/jamaoto.2018.4512

List, M. A., & Bilir, S. P. (2004). Functional outcomes in head and neck cancer. *Seminars in Radiation Oncology*, *14*(2), 178–189. https://doi.org/10.1053/j.semradonc.2003.12.008

Ogińska-Bulik, N. (2017). The negative and positive effects of trauma resulting from cancer–the role of personality and rumination. *Current Issues in Personality Psychology*, *5*(4), 232-243. DOI: https://doi.org/10.5114/cipp.2017.67016

Ogińska-Bulik, N. (2018). The role of ruminations in the relation between personality and positive posttraumatic changes resulting from struggling with cancer. *Health Psychology Report*, *6*(4), 296-306. DOI: https://doi.org/10.5114/hpr.2019.77176

O'Connor, M., Christensen, S., Jensen, A. B., Møller, S., & Zachariae, R. (2011). How traumatic is breast cancer? Post-traumatic stress symptoms (PTSS) and risk factors for severe PTSS at 3 and 15 months after surgery in a nationwide cohort of Danish women treated for primary breast cancer. *British Journal of Cancer*, *104*(3), 419–426. https://doi.org/10.1038/sj.bjc.6606073

O'Rourke, L., Fisher, P. L., Campbell, S., Wright, A., & Cherry, M. G. (2021). Factors associated with fear of cancer recurrence in family caregivers of cancer survivors: a systematic review. *Frontiers in Psychology*, 541. https://doi.org/10.3389/fpsyg.2021.625654

Macvean, M. L., White, V. M., & Sanson-Fisher, R. (2008). One-to-one volunteer support programs for people with cancer: a review of the literature. *Patient Education and Counseling*, *70*(1), 10-24. https://doi.org/10.1016/j.pec.2007.08.005

Marziliano, A., Tuman, M., & Moyer, A. (2019). The relationship between post-traumatic stress and post-traumatic growth in cancer patients and survivors: A systematic review and meta-analysis. *Psycho-Oncology*, *29*(4), 604-616. https://doi.org/10.1002/pon.5314

Morse, J.M, Johnson, J.L. (1991). *Towards a theory of illness: the illness constellation model. In: Morse JM, Johnson JL, eds.* The Illness Experience. London: Sage, 315–342.

Page, A. E., & Adler, N. E. (Eds.). (2008). *Cancer care for the whole patient: Meeting psychosocial health needs.*

Page, M. J., McKenzie, J. E., Bossuyt, P. M., Boutron, I., Hoffmann, T. C., Mulrow, C. D., Shamseer, L., Tetzlaff, J. M., Akl, E. A., Brennan, S. E., Chou, R., Glanville, J., Grimshaw, J. M., Hróbjartsson, A., Lalu, M. M., Li, T., Loder, E. W., Mayo-Wilson, E., McDonald, S., McGuinness, L. A., & Moher, D. (2021). The PRISMA 2020

statement: an updated guideline for reporting systematic reviews. *BMJ (Clinical research ed.)*, *372*, n71. https://doi.org/10.1136/bmj.n71

Pat-Horenczyk, R., Perry, S., Hamama-Raz, Y., Ziv, Y., Schramm-Yavin, S., & Stemmer, S. M. (2015). Posttraumatic Growth in Breast Cancer Survivors: Constructive and Illusory Aspects. *Journal of Traumatic Stress*, *28*(3), 214–222. https://doi.org/10.1002/jts.22014

Pilevarzadeh, M., Amirshahi, M., Afsargharehbagh, R., Rafiemanesh, H., Hashemi, S. M., & Balouchi, A. (2019). Global prevalence of depression among breast cancer patients: a systematic review and meta-analysis. *Breast Cancer Research and Treatment*, *176*(3), 519–533. https://doi.org/10.1007/s10549-019-05271-3

Posluszny, D. M., Dougall, A. L., Johnson, J. T., Argiris, A., Ferris, R. L., Baum, A., Bovbjerg, D. H., & Dew, M. A. (2015). Posttraumatic stress disorder symptoms in newly diagnosed patients with head and neck cancer and their partners. *Head & Neck*, *37*(9), 1282–1289. https://doi.org/10.1002/hed.23760

Sharp, L., Redfearn, D., Timmons, A., Balfe, M., & Patterson, J. (2018). Posttraumatic growth in head and neck cancer survivors: is it possible and what are the correlates? *Psycho-Oncology*, *27*(6), 1517-1523. https://doi.org/10.1002/pon.4682

Sherman, A. C., Simonton, S., Adams, D. C., Vural, E., & Hanna, E. (2000). Coping with head and neck cancer during different phases of treatment. *Head & Neck*, *22*(8), 787–793. https://doi.org/10.1002/1097-0347(200012)22:8<787::aid-hed7>3.0.co;2-r

Sodergren, S. C., Hyland, M. E., Singh, S. J., & Sewell, L. (2002). The effect of rehabilitation on positive interpretations of illness. *Psychology & Health, 17*(6), 753–760. https://doi.org/10.1080/0887044021000009674

Steffens, R.F., Andrykowski, M.A. (2015). Posttraumatic Growth Inventory: Overview. In: Martin, C., Preedy, V., Patel, V. (eds) Comprehensive Guide to Post-Traumatic Stress Disorder. Springer, Cham. https://doi.org/10.1007/978-3-319-08613-2_12-1

Sung, H., Ferlay, J., Siegel, R. L., Laversanne, M., Soerjomataram, I., Jemal, A., & Bray, F. (2021). Global Cancer Statistics 2020: GLOBOCAN Estimates of Incidence and Mortality Worldwide for 36 Cancers in 185 Countries. *CA: A Cancer Journal for Clinicians*, *71*(3), 209–249. https://doi.org/10.3322/caac.21660

Svetina, M., & Nastran, K. (2012). Family relationships and post-traumatic growth in breast cancer patients. *Psychiatria Danubina*, *24*(3), 298–306.

Tedeschi R.G. & Calhoun L.G. (2004) Posttraumatic growth: conceptual foundations and empirical evidence. *Psychological Inquiry* **15**, 1– 18. doi: 10.1207/s15327965pli1501_01.

Tedeschi, R. G., & Calhoun, L. G. (1996). The Posttraumatic Growth Inventory: measuring the positive legacy of trauma. *Journal of Traumatic Stress*, *9*(3), 455–471. https://doi.org/10.1007/BF02103658

Tomich, P. L., & Helgeson, V. S. (2004). Is Finding Something Good in the Bad Always Good? Benefit Finding Among Women with Breast Cancer. *Health Psychology*, *23*(1), 16–23. https://doi.org/10.1037/0278-6133.23.1.16

Rieke, K., Schmid, K. K., Lydiatt, W., Houfek, J., Boilesen, E., & Watanabe-Galloway, S. (2017). Depression and survival in head and neck cancer patients. *Oral Oncology*, *65*, 76–82. https://doi.org/10.1016/j.oraloncology.2016.12.014

Ringash, J., Bernstein, L. J., Devins, G., Dunphy, C., Giuliani, M., Martino, R., & McEwen, S. (2018). Head and Neck Cancer Survivorship: Learning the Needs, Meeting the Needs. *Seminars in Radiation Oncology*, *28*(1), 64–74. https://doi.org/10.1016/j.semradonc.2017.08.008

Singer S, Krauß O, Keszte J. (2012) Predictors of emotional distress in patients with head and neck cancer. *Head & Neck* 34:180–187. doi:10.1002/hed.21702

Stanton A. L. (2006). Psychosocial concerns and interventions for cancer survivors. *Journal of Clinical Oncology: Official Journal of the American Society of Clinical Oncology*, *24*(32), 5132–5137. https://doi.org/10.1200/JCO.2006.06.8775

Vishnevsky, T., Cann, A., Calhoun, L. G., Tedeschi, R. G., & Demakis, G. J. (2010). Gender differences in self-reported posttraumatic growth: A meta-analysis. *Psychology of Women Quarterly*, *34*(1), 110–120. https://doi.org/10.1111/j.1471-6402.2009.01546.x

Williams, J.W., Plassman, B.L., Burke, J., Holsinger, T., Benjamin, S. (2010). Preventing Alzheimer's disease and cognitive decline. *Evidence Report/Technology Assessment*, *193*(1), 1-727.

Zoellner, T., & Maercker, A. (2006). Posttraumatic growth in clinical psychology—A critical review and introduction of a two-component model. *Clinical psychology Review*, *26*(5), 626-653. https://doi.org/10.1016/j.cpr.2006.01.008

Chapter two: Empirical paper

Title: Exploring the Role of Metacognitive Beliefs and Self-compassion with Post-Traumatic Stress Disorder, Anxiety and Depression in Adults who have had Treatments for Head and Neck Cancer.

Word count: 8049 (including abstract, highlights and tables)

Prepared in accordance with guidelines for submission to Journal of Affective Disorders

Abstract

Background

Due to advancements in medical treatments, cancer survivorship is increasing. Head and neck cancer (HNC) treatments frequently have detrimental effects on mental health and quality of life. More research is needed to explore the distinct difficulties for HNC survivors and how best to support them.

Methods

One hundred and thirty-one HNC survivors were recruited from social media, and two NHS hospitals in the northwest of England. They completed self-reported questionnaires measuring anxiety, depression, cancer-related post-traumatic stress symptoms (PTSS), self-compassion, and metacognitive beliefs Hierarchal regression modelling tested if metacognitive beliefs and self-compassion were associated with anxiety, depression, and PTSS.

Results

Negative metacognitive beliefs about danger and uncontrollability of worry and lack of cognitive confidence made a significant contribution to all forms of distress controlling for clinical and demographic variables and self-compassion. Self-compassion was not associated with anxiety, depression or PTSS after controlling for clinical and demographic factors.

Limitations

The final sample included an equal split of men and women. Therefore, this could be biased as men are more likely to be diagnosed with head and neck cancers. This study adopted a cross sectional design and therefore it cannot determine causality. Research employing prospective designs is necessary to investigate whether metacognitive beliefs measured at baseline predict PTSS, anxiety, and depression over time.

Conclusions

This study found that negative metacognitive beliefs about the uncontrollability of worry and cognitive confidence were associated with anxiety, depression, and PTSS symptoms when controlling for demographic and clinical variables. Self-compassion did not make a significant contribution for anxiety, depression or PTSS. Therefore, interventions addressing metacognitive beliefs and processes might be more effective compared with self-compassion-based approaches. Research employing prospective designs is necessary to investigate this further. This might help inform new psychological interventions for HNC survivors.

Keywords: *head and neck cancer, mental health, psychology, self-compassion, metacognition, post-traumatic stress symptoms, cancer survivorship*

Highlights

- A significant proportion of HNC survivors expressed mental health difficulties.
- Metacognitive beliefs account for more variance of mental health compared with self-compassion.
- The metacognitive model should be further tested using more robust methods

Introduction

Head and neck cancer (HNC) is an umbrella term for tumours originating in the oral cavity, salivary glands, pharynx, larynx, paranasal sinuses, and the nasal cavity (So et al., 2012). Over the last twenty years, the incidence of HNC has increased from 8000 to approximately 12,000 new cases each year in the UK (Cancer Research UK [CRUK] 2015-2017). The Northwest records the highest incidence in the UK. In Merseyside, rates are 30% higher than the average for England (Northwest Cancer Charity, 2018). Prevalence rates differ between males and females, with 8500 new cases in males and 3800 new cases in females in the same year (CRUK, 2015-2017). As cancer treatments continue to advance, survival rates are also increasing. In HNC between 19-59% of survivors will live for ten years or more (CRUK, 2014). However, despite advancements in medical care, cancer remains a life-threatening diagnosis – where treatments can be invasive and life changing. Treatment regimens for HNC can impair physical and psychological wellbeing, caused by facial disfigurement or disability, for example impairments with basic functions such as speaking, breathing, or swallowing (Bhushan, 2019). These impairments are strongly associated with poor quality of life and have detrimental effects on psychosocial function, which can occur years post treatment (Duncan et al., 2017). HNC survivors may adopt maladaptive and avoidant coping strategies such as, avoiding medical follow up, and continuing addictions to tobacco and alcohol (Howren et al., 2013). Engaging in such strategies can increase the risk of malignancy recurrence, of which one third of deaths within HNC are attributable to (Aarstad et al., 2011). Interventions to support survivors of HNC with maladaptive coping such as using tobacco, drinking alcohol and depressive symptoms have shown little evidence of effectiveness (Duffy et al., 2006).

Survivors of HNC have been reported as having pre-diagnosis mental health difficulties at approximately 12%, which increases the vulnerability of chronic mental health difficulties after a HNC diagnosis (Department of Health, 2001; Huang et al., 2022). A large cohort study (*n*

=52,641) reported the prevalence of depression and anxiety in HNC survivors increased to 29.9% compared with 20.6% before the cancer diagnosis (Lee et al., 2019). Additionally, HNC survivors have higher suicidal attempts compared with other cancer survivors. An eight-year survey study concluded that two types of HNC (oral and pharynx) accounted for nearly 20% of the total suicide rates across a range of cancer diagnoses (Farberow et al., 1971). A more recent systematic review has confirmed this, with survivors of HNC survivors reporting one of the highest rates of suicide compared with other tumour sites (Anguiano et al., 2012; Bhushan, 2019). These rates have been reported as four times higher than the general population (Henson et al., 2019; Kam et al., 2015). Additionally, mental health difficulties around body image are particularly high within HNC survivors, with 75% reporting shame around one or more bodily changes during treatments (Fingeret et al., 2012).

Survivors of HNC also experience higher rates of mental health issues, such as depression, anxiety and PTSD compared with other cancer diagnoses (Singer et al., 2012). Cohort studies have reported 18.5% of people with HNC to meet clinical severity of depression (Rieke et al., 2017), whereas a systematic review reports the same threshold as 9% in breast cancer survivors (Pilevarzadeh, 2019). HNC survivors also experience detrimental psychosocial difficulties which impact quality of life (Singer et al., 2005; Kugaya et al., 2000). Mental health and psychosocial difficulties have been reported both when newly diagnosed and post-treatment (Singer et al., 2005; Kugaya et al., 2000). Examples of psychosocial difficulties have been reported as having detrimental effects on, physical and mental health, appearance, employment, social functioning, and family interactions, all of which greatly impact on a person's quality of life (Funk et al., 2012; El-Deiry et al., 2005; Buckwalter et al., 2007). HNC cohort research has found inequality to be observed with education level, education, annual household income and financial concerns following a cancer diagnosis (Ingarfield et al., 2021). Studies have highlighted that HNC survivors from disadvantaged socioeconomic backgrounds experience

worse outcomes, however this effect can be lost when factoring in smoking and alcohol consumption (Chu et al., 2016; Ingarfield et al., 2021).

Additionally, due to the life-threatening nature of cancer diagnoses and treatments, survivors of HNC are also at an increased risk of developing mental health difficulties post diagnosis (Connerty, 2013). Such difficulties include developing cancer related Post Traumatic Stress Symptoms (PTSS) or post-traumatic stress disorder (PTSD) and can occur anytime during or after treatment (National Cancer Institute [NCI], 2019). PTSD is a recognised mental health difficulty (American Psychiatric Association, 2022), symptoms in cancer populations typically include flashbacks, avoiding cancer-related experiences and increased anxiety (Andrykowski et al., 2000). Cancer related PTSS refers to a survivor experiencing PTSD symptoms which are distressing but would not meet criteria for a PTSD diagnosis (O'Connor et al., 2011). Longitudinal research reports that a year after diagnosis people with HNC were three times more likely to develop anxiety and depression compared to other tumour types (Singer et al., 2012). Depression, anxiety, and PTSS has been recorded at rates of 19-31%, 16% and 21% respectively in HNC (CRUK, 2015-2017). Other studies report depression rates in HNC to be as high as 57% (Bhushan, 2019).

Despite HNC survivors facing relatively well-recognised medical, psychological, and social challenges, there is a lack of screening for such difficulties with these survivors (Bhunshan, 2019). Therefore, cancer related mental health difficulties are often unrecognised, and psychological interventions are not offered. One reason for this is due to the lack of clinical psychologists within HNC multi-disciplinary teams (Humpris, 2008). There's a link between a survivors perceived unmet needs and increased rates of distress within HNC samples (Wells et al., 2015). PTSS contributes to medical treatment non-adherence, pain, desire to die and increased disability (NCI, 2019; Kangas, Henry, & Bryant, 2005).

It is imperative that healthcare professionals understand why mental health difficulties and maladaptive coping distinct differences in survivors with HNC have compared with some other tumour types. One way of understanding why such difficulties might persist is to further understand the underpinning psychological mechanisms which contribute to common mental health difficulties, such as PTSS, anxiety, and depression, as such information could help inform suitable psychosocial interventions. There are several systematic reviews and meta-analyses supporting the use of psychological interventions in improving psychological distress, and quality of life in cancer populations (Hart et al., 2012; Jacobsen & Jim, 2008; Williams & Dale, 2006). However, most meta-analyses have found heterogenous effects across trials.

CBT is recommended as the first-line psychological intervention for mental health difficulties within physical health populations (NICE, 2009). Whilst some research demonstrates CBT as an effective intervention with cancer samples (Xiao et al., 2017) others have not shown any improvement (Stanton, 2006), and others report small effect sizes (Temple et al., 2020). One hypothesis for this might be that CBT interventions involve reframing or challenging negative automatic thoughts (Beck, 2011); however, fear of cancer recurrence is the most reported problem in adult cancer survivors (Baker et al., 2005). Such thoughts are valid, rational and realistic and might not respond to traditional CBT interventions (Cherry et al., 2019).

Other models for alleviating distress within physical health populations have shown promise within the evidence base. Firstly, the metacognitive model conceptualises that emotional symptoms are part of normal recovery and focuses on modifying psychological factors (Wells & Matthews, 1994). The metacognitive model focuses on the Self-Regulatory Executive Function model (S-REF), namely how psychological information involved in mental health difficulties is processed. It hypothesises that abnormal and persistent psychological distress results from metacognitive beliefs which cause negative preservative styles of thinking, known as Cognitive Attentional Syndrome (CAS; Wells & Matthews, 1994). Wells & Matthews

(1994) propose that CAS consists of three elements: rumination or worry, threat monitoring and maladaptive coping strategies, which maintain psychological difficulties. As such, metacognitive therapy focuses on modifying the processes that maintain repetitive negative thinking rather than the content of an individual's thoughts, it theorises that in doing so aids an individual in becoming more flexible managing concerns (Capobianco et al., 2020). Research suggests that metacognitive beliefs are associated with anxiety and depression with other physical health conditions, such as multiple sclerosis (Heffer-Rahn & Fisher, 2018) epilepsy (Fisher & Noble, 2017) as well as breast and prostate cancers (Cook et al., 2015a). A systematic review found that the metacognitive model is applicable to anxiety and depression across a range of chronic physical health conditions. Specifically, negative metacognitive beliefs of uncontrollability and danger significantly and positively predicted anxiety and depression symptoms after controlling for age, gender, and disease factors (Capobianco et al., 2020). Intervention studies have shown preliminary evidence for brief metacognitive therapy to be effective in reducing anxiety depression and PTSS in mixed cancer populations (Fisher et al., 2019). Additionally, metacognitive therapy was found to be more parsimonious compared with CBT in cardiac rehabilitation survivors (McPhillips et al., 2019). Although the metacognitive model has some support for its effectiveness within physical health populations, no HNC survivors were included within the previous research samples and therefore before testing metacognitive therapy, effectiveness of the metacognitive model within HNC should first be examined.

The second theoretical model is Neff's (2003a) model of self-compassion which underpins Compassion Focused Therapy (Gilbert, 2009). The self-compassion model postulates that excessive self-criticism and self-blame cause mental health difficulties (Neff, 2003a). Self-compassion is defined as including three inter-related components: self-kindness, common humanity, and mindfulness. Self-kindness refers to offering accepting and understanding to

oneself instead of negative self-judgement in response to suffering (Neff, 2003a). Common humanity recognises that suffering is part of the human experience, in contrast to feeling isolated during difficult times (Neff, 2003a). Lastly, the mindfulness component refers to a balanced awareness of painful experiences, instead of over-identification with them (Neff, 2003a).

Research has suggested that individuals with chronic physical health conditions who engage with these self-compassionate elements have more robust coping strategies and, therefore experience less mental health difficulties (Sirois, Molnar & Hirsch, 2015). Significant correlations between lower self-compassion and higher anxiety and depression have been reported in diabetes, (Ferrari, Dal Cin & Steel, 2017), epilepsy (Baker, Caswell & Eccles, 2019) and breast cancer (Pinto-Gouveia et al., 2014) populations. Additionally, Przezdziecki et al., (2012) found that self-compassion played a protective role in the development of depression, across cancer diagnoses. A systematic review reports moderate to large associations between self-compassion scores and anxiety and depression in survivors of chronic physical illness, and thus they may have a role in alleviating distress (Hughes et al., 2021). Self-compassion has preventative qualities for the development of depression with cancer survivors (Pinto-Gouveia et al., 2014). Longitudinal research has found that self-compassion is beneficial for cancer patients and their future functioning, such as less symptoms of anxiety, depression and fatigue over time (Zhu et al., 2019).

More research exploring the distinct experiences of HNC is needed for multiple reasons. Exploring psychological adjustments to cancer diagnoses and treatments has been relatively unexplored in cancer populations, with even less research including HNC samples. More research of this kind is needed in order to be able to support positive mental health post diagnoses and treatments. The evidence base has tended to explore the metacognitive and self-compassion models for singular or mixed cancer samples, often with no inclusivity of HNC

samples. Given that some research suggests these models might be associated with distress in other physical health populations, further exploration is needed within HNC. Due to the increased risk of HNC survivors developing mental health difficulties and engaging in maladaptive coping strategies, it is important for more research to explore the contribution of psychological mechanisms which cause and maintain difficulties to be further examined within HNC survivors. This study aims to address these limitations.

Aims and objectives

To explore the relationship between metacognitive beliefs, self-compassion, with cancer-related PTSS, anxiety and depression whilst controlling for demographic and clinical variables.

It is hypothesised that:

a) Self-compassion will negatively correlate with anxiety, depression, and PTSS.
b) Metacognitive beliefs will positively correlate with anxiety, depression, and PTSS.
c) Self-compassion and metacognitive beliefs will be associated with anxiety, depression, and PTSS when demographic and clinical covariates are controlled.

Methods

Study Design

A cross-sectional design using self-report questionnaire measures was used. Data were collected between June 2022 to March 2023. All aspects of the study (e.g., study design, measures used, recruitment documents and dissemination methods) were decided in consultation with experts in the field including researchers, HNC clinicians, and service-users with personal experience of HNC. This was to ensure the research was relevant to the population being studied.

Participants

Adults over the age of eighteen with a new or reoccurring diagnosis of HNC were included in the study. Survivors with cancers of the thyroid were excluded from the study, due to this tumour type having a different HNC treatment pathway. Survivors were included regardless of the type of cancer treatment (e.g., surgery, chemotherapy, radiotherapy), including combinations of modalities. Survivors who had received acute medical treatments less than 3 months ago or more than 5 years were not approached in clinics to take part. This is in line with Rowland's (2013) definition of a survivor. If survivors who completed the survey via social media streams were outside of this range, they were excluded from the analysis.

Procedure

Sponsorship was obtained from the University of Liverpool and ethical approval from Camberwell St Giles Research and Ethics Committee (REC reference 22/LO/0185) (Appendix G).

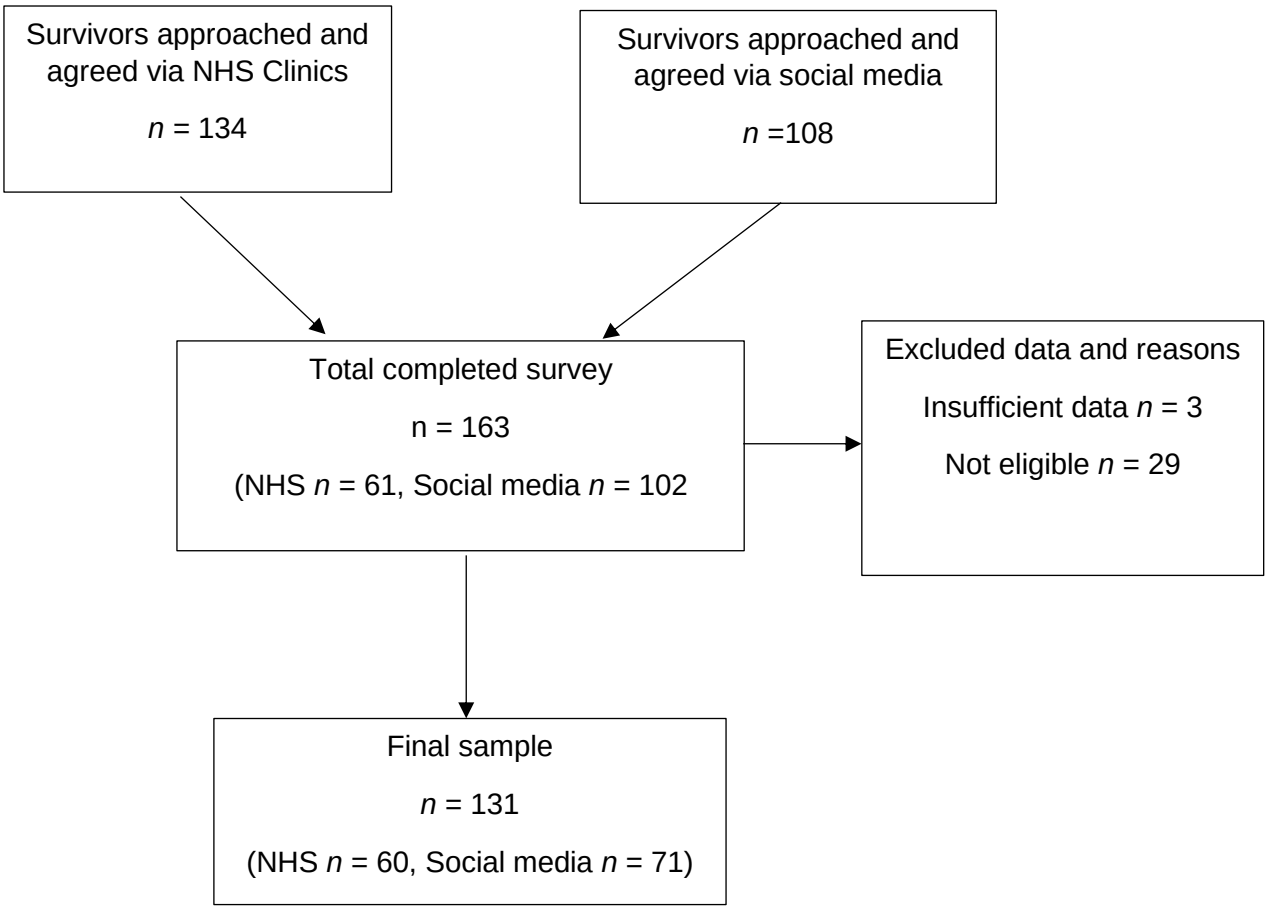
Survivors were recruited at HNC clinics in two NHS hospital sites in dedicated HNC clinics; Aintree University Hospital and St Helens and Knowsley Teaching Hospital. Clinicians pre-screened survivors, and eligible survivors were approached during their clinic visit. Survivors were given the option to complete the measures via pen and paper or online using the Qualtrics database (www.Qualtrics.com). An amendment was obtained from REC to recruit using social media sites (Appendix G). HNC charities were approached and asked to share study information with members, using Twitter, Facebook, and email distribution lists. A third recruitment stream was using the Prolific platform, (www.prolific.co) which contains a database of survivors who are signed up to participate in online research studies. As it would not be possible to access survivors' medical records who were recruited via social media, additional questions gathering the demographic and clinical variables was included. The recruitment flowchart (Figure 1) summarises recruitment across the three streams. In total *n*

=163 survivors completed the survey, *n* = 32 were excluded for not meeting eligibility criteria. Therefore, leaving *n* = 131 for the final analysis.

All survivors were provided with the information sheet outlining the study aims, procedures and details of how to contact the research team with any questions. Survivors were asked to complete a consent form prior to them completing the survey.

Figure 1.

Participant flowchart



Note: NHS = National Health Service HNC clinics, social media = Facebook, twitter and prolific platforms.

Demographic information

Demographic and clinical information were collected in two distinct ways. Firstly, for survivors recruited via NHS clinics, the first author extracted available demographic and

clinical variables from the electronic notes systems. Data collected included, age, sex, postcode (used for social deprivation status) relationship status, type, and stage of HNC, type of treatment(s), and time since treatment. Data for ethnicity, religion, alcohol, and smoking status were collected where recorded for survivors who were recruited via social media, they self-completed the demographic and clinical data on the Qualtrics platform. Data collected from social media survivors included, age, sex, ethnicity, religion, postcode (used for social deprivation status), relationship status, type, and stage of HNC, type of treatment(s), and time since treatment.

The English, Scottish, Welsh and Northern Irish Indexes of Multiple Deprivation data were used to calculate deprivation scores (English indices of deprivation, 2020, Scottish indices of deprivation, 2020, Welsh index of multiple deprivation, 2019, Northern Ireland multiple deprivation measures, 2017). These tools provide postcode look up files which were used for this study, each postcode is given a decile deprivation rank from the most deprived to the least deprived neighbourhoods. Deciles are calculated by ranking the neighbourhoods and dividing them into 10 equal groups. The index rank scores are not directly comparable Nationally. For this study, the percentage deprivation score was calculated by dividing the index score by the number of neighbourhoods in the index. All the postcodes were then ranked so they could be compared.

Dependent variables:

Anxiety and Depression

The Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983) was used to examine anxiety and depression. The HADS comprises 14 items (7 for anxiety and 7 for depression) assessing symptoms over the past week. It is scored on a 4-point scale, with options ranging from 0-3, with higher scores indicating more distress. It has a high sensitivity and

specificity for both initial diagnoses and to track progression of symptoms (Bjelland et al., 2002). It focuses on the non-physical symptoms, so it can be used to diagnose depression in physical health populations (Bjelland et al., 2002) and it has been validated for use with cancer populations (Vodermaier & Millman 2011). The HADS is the gold-standard self-report questionnaire for anxiety and depression in cancer populations (Luckett et al., 2010). Scores for the anxiety and depression subscales can be interpreted as: 0-7 are within the normal range, between 8-10 indicate a borderline range, and 11 or more indicates clinical severity (Aben et al., 2022). Internal consistency was excellent for the anxiety subscale (α= 0.91) and good for the depression subscale (α= 0.81) in this study.

Cancer related post-traumatic stress symptoms

The Impact of Events Scale-Revised (IES-R) (Weiss & Marmar, 1997) is a 22-item questionnaire measuring PTSS symptoms over the last seven days. The IES-R is scored on a 5-point scale (0 = not at all) to (4 = extremely). A score of 24 or more indicates that PTSS is a clinical concern, and scores of 33 and above represents the best cut off for a probable PTSD diagnosis. The scale has been found to accurately discriminate between traumatised and non-traumatised groups in the general population (Beck et al., 2008). The scale has also been used in multiple cancer populations (e.g., Fisher et al., 2019). Internal consistency was excellent for the IES-R scale (α= 0.95) for this study.

Independent Variables:

Self-compassion

The Self-compassion scale (SCS) (Neff, 2003b) is a 26-item questionnaire scored on a 5-point Likert scale (1= almost never, to 5 = almost always). Self-kindness and self-judgment subscales have scores ranging from 5 to 25. The remaining four subscales (common humanity, isolation, mindfulness, over-identification) range from 4-20. The total score ranges from 26-130, with

higher scores indicating greater levels of self-compassion. The SCS is a reliable and valid measure in adults (Neff, 2003) and has been used with cancer survivors (e.g., Przezdziecki et al., 2012). Within this study, subscales were used rather than the total self-compassion score. The self-judgment, isolation and over-identification subscales represent pathology rather than self-compassion. Whereas the self-kindness (e.g., 'when I'm going through a very hard time, I give myself the caring and tenderness I need'), common humanity (e.g., 'I try to see my failings as part of the human condition') and mindfulness (e.g., 'when something upsets me, I try to keep my emotions in balance' subscales measure self-compassion, therefore only these subscales were used in the analysis (Muris & Petrocchi, 2017). This is consistent with other research in the field (e.g., Brown et al., 2019). Subscale Cronbach alphas were good for self-kindness (α= 0.81), questionable for common humanity (α= 0.69) and good for mindfulness (α= 0.82) for this study.

Metacognitive beliefs

The Metacognitions Questionnaire ([MCQ-30] Wells & Cartwright-Hatton (2004). consists of 30-items which measure a range of metacognitive beliefs, judgements, and monitoring tendencies across five factors. It is measured on a 5 -point Likert scale (1 = do not agree to 4 = agree very much). The five factors are: lack of cognitive confidence, positive beliefs about worry, cognitive self-consciousness, negative beliefs about uncontrollability of thoughts and danger, and beliefs about the need to control the thoughts. The scores of the subscales range from 6 to 24 and total scores range from 30 to 120. Higher scores indicate higher levels of unhelpful metacognitions. The MCQ-30 has sound psychometric properties (Wells & Cartwright-Hatton, 2004) and with cancer populations (Cook et al, 2015a). Cronbach alpha scores for the subscales were: good for cognitive confidence (α= 0.90), good for positive beliefs (α= 0.88), acceptable for cognitive self-consciousness (α= 0.80), good for negative beliefs, (α= 0.89), and acceptable for need to control thoughts (α= 0.73).

Cognitive attentional syndrome

The Cognitive Attentional Syndrome Scale-1 Revised (CAS-1R) is a 10-item questionnaire that assesses maladaptive metacognitions (Wells, 2015). Six-items measure the use of maladaptive coping strategies and 4 measure positive and negative metacognitive beliefs that promote active use of CAS. Responses are on an 11-point scale (0= not at all to 100 = all of the time). The CAS-1R found to have good psychometric properties in physical health populations with co-morbid anxiety and/or depression (Faija et al., 2019). Items 7-10 are a duplication of the MCQ-30 and therefore only items 1-6 were used. These items had good internal consistency in this study ($\alpha = 0.87$)

Power calculation

A priori power calculation was performed using G*Power 3.1 software to determine the minimum number of survivors required to adequately power the study using hierarchical linear regression analysis with approximately 12 predictor variables. To adequately detect a medium effect size with 80% power and an alpha level of .05, the study needed to recruit a minimum of 127 survivors.

Statistical analysis

Data were inputted into Excel during study recruitment. When recruitment had closed, data were cleaned and analysed using the Statistical Package for Social Science (version 27). If Kurtosis values ranged between -2 to +2, variables were treated as normally distributed. All study variables met this assumption and therefore parametric tests were used for the analysis. Independent samples t-tests were used to examine the differences in anxiety, depression, and PTSS scores across demographic variables (site recruited, sex, marital status, religion) as well as a clinical variable (treatment type, time since treatment and cancer stage). Intercorrelations between predictor variables were tested with Pearson's correlations. The scores from the CAS-

1R were used to describe how frequent the sample were using maladaptive coping strategies such as worry and rumination.

Three hierarchal regression analyses were used to test if metacognitive beliefs or self-compassion explained additional variance in PTSS, anxiety, and depression, after controlling for demographic and clinical variables. The first step controlled for the demographic variables (age, sex, marital status, and deprivation status). The second step controlled for time since treatment, treatment type and stage of cancer. The third step controlled for the subscales of the SCS (self-kindness, common humanity, and mindfulness). The final step tested the prediction that metacognitive beliefs would contribute to PTSS, anxiety and/or depression after controlling for demographic, clinical and self-compassion variables.

Missing data

Survivors who had equal to or over half of the questionnaire data missing were also excluded from the final analysis. For any missing data within the measures that was below half, an average score was taken from the survivors' responses and was used. There were some survivors from Ireland and Scotland whose postcodes are not covered within any national deprivation indices and therefore this could not be included in the analysis.

Results

Sample characteristics

Table 1 outlines the study sample characteristics. The overall mean age was 58.18 years (*sd* = 14.13). Females made up 51.9% of the participant sample. This is higher than the incidence of HNC (CRUK, 2014). Seventy-eight (59.5%) of survivors were either married, in a civil partnership or living with a partner.

Table 1.
Characteristics of the study sample (n = 131)

Variable			
Demographic variables	*N (%) or Mean (SD)*	*Clinical variables*	*N (%) or Mean (SD)*
Age	58.18 (14.13)	Tumour Type	
		Oral	58 (44.6%)
		Oropharynx	31 (23.8%)
		Larynx	9 (6.9%)
		Unknown primary	2 (1.5%)
		Hypopharynx	1 (0.8%)
		Nasopharynx	1 (0.8%)
		Multiple sites	12 (9.2%)
		Other	15 (11.5%)
		Not reported/missing	1 (0.8%)
Sex		Tumour Stage	
Male	63 (48.1%)	1	27 (20.8%)
Female	68 (51.9%)	2	23 (17.7%)
		3	10 (7.7%)
		4	15 (11.5%)
		Not reported/missing	56 (42.7%)
Marital status		Type of treatment	
Married/civil partnership/cohabiting	78 (59.5%)	Surgery only	46 (35.4%)
Single/lives alone/divorced	34 (26%)	Surgery + chemo	5 (3.8%)
Not reported/missing	19 (14.5%)	Surgery +RT	27 (20.8%)
		Chemo only	2 (1.5%)
		Chemo + RT	23 (17.7%)
		RT only	15 (11.5%)
		Surgery + Chemo + RT	12 (9.2)
		Not reported/missing	56 (42.7%)
Religion		Time since treatment (months)	
Christian	63 (48.1%)	3-6	
Jewish	1 (0.8%)	7-12	18 (13.8%)
Atheist	42 (32.1%)	13-23	25 (19.2%)
Not reported/missing	25 (19.1%)	24-48	37 (28.5%)
		49-60	35 (26.9%)
			14 (10.8%)
Smoking		SCS	
Never smoked	43 (32.8%)	Self-kindness	13.95 (4.47)
Ex-smoker (NHS definition)	58 (44.3%)	Common humanity	12.08 (3.45)
Current smoker	6 (4.6%)	Mindfulness	13.28 (3.80)
Not reported	24 (18.3%)		
Alcohol		MCQ	
Never drank	8 (6.2%)	POS	10.22 (4.16)
Ex-drinker	28 (21.5%)	NEG	13.04 (5.44)
Currently drinks	60 (46.2%)	CSC	14.95 (4.29)
Not reported/missing	35 (26.7%)	NC	11.38 (3.99)
		CC	12.05 (4.99)
Deprivation status			
10% (most deprived)	18 (13.7%)	CAS-1R	235 (145.15)
10-20%	9 (6.9%)		
20-30%	9 (6.9%)		
30-40%	12 (9.2%)		
40-50%	13 (9.9%)		
50-60%	11 (8.5%)		
60-70%	13 (9.9%)		
70-80%	9 (6.9%)		
80-90%	12 (9.2%)		
90-100% (least deprived)	11 (8.4%)		
Not reported/data not available	14 (10.7%)		

Note. Tumour types: Oral. POS = Positive metacognitive beliefs; NEG = Negative metacognitive beliefs; CSC = Cognitive self-consciousness; NC= Need to control thoughts, CC=Cognitive confidence RT

Table 2 reports the clinical scores for PTSS, anxiety, and depression. The sample mean for depression was within the normal range and did not meet clinical cut-off scores (*m* = 6.04, *sd* = 5.17). However, 36% of the sample met criteria for depression symptoms being a clinical concern, most were within the borderline range 22.9% (*n* = 30) and the remaining were within the moderate to severe range. The sample mean for anxiety was (*m* = 8.50, *sd* = 5.17), which represents a borderline score. Over half of the sample met caseness criteria for anxiety (52.7%, *n* = 71), 19.85% were within the borderline range and 34.35% met criteria within the moderate to severe range. The sample reported an overall mean score for PTSS which met clinical severity (*m* = 28.44, *sd* = 19.44). Nearly half of the sample met criteria for a PTSD diagnosis (41.22%).

Table 2.
Clinical scores for PTSS, anxiety, and depression

Variable	*N (%) or Mean (SD)*
HADS	
Anxiety	8.50 (5.17)
Depression	6.04 (4.08)
Clinical concern for depression	47 (36%)
Borderline range	30 (22.9%)
Moderate – Severe range	17 (13.1%
Clinical concern for anxiety	71 (52.7%)
Borderline range	26 (19.85%)
Moderate – Severe range	45 (34.35)
IES-R	
Total score	28.44 (19.44)
Clinical concern for PTSS	19 (14.50%
Cut off for PTSD	54 (41.22%)

Note: HADS: A score of 8 or more on both subscales indicated clinical concern for depression and anxiety. Scores between 8-10 are within the borderline range, scores of over 11 indicate a moderate – severe range.
IES-R: A score of 24 or more indicates that PTSS is a clinical concern, a score of 33 or above indicates that score would meet criteria for PTSD.

Independent samples t-tests indicated that survivors who were recruited via social media reported significantly higher anxiety scores (m = 9.49, sd = 5.39) compared with those who were recruited via NHS clinics (m = 7.32, sd = 4.60; t (df = -2.46, p = 0.02, two tailed). There were no significant differences between PTSS or depression scores between site recruited.

Females scored significantly higher for PTSS symptoms (m = 31.81, sd = 19.98), compared to males (m = 24.81, sd = 18.31; t (df = -2.09, p = 0.04). There were no significant differences for anxiety or depression scores between men and women. There were no significant differences between marital status or religion for PTSS, anxiety, or depression scores.

Correlations

Correlations and descriptive statistics for the independent and dependent study variables are shown in correlation matrix in table 3. The age of survivors was negatively correlated with PTSS (r = - .218) anxiety (r = -.263) and negative metacognitive beliefs (r = -.199). Therefore, younger HNC survivors reported higher levels of PTSS and anxiety and had more negative metacognitive beliefs. PTSS symptoms had a weak positive correlation with the MCQ subscales: positive beliefs (r = .330), cognitive self-consciousness (r =.347), need to control thoughts (r = .395) and cognitive confidence (r = .382). PTSS symptoms had moderate positive correlation with the MCQ negative beliefs subscale (r = .616). PTSS symptoms had a weak negative correlation with the mindfulness self-compassion subscale (r = -.227).

Anxiety had a moderate positive correlation with MCQ negative beliefs (r = .696), cognitive self-consciousness (r = .414). Anxiety had a weak positive correlation with the MCQ subscales: positive beliefs, (r = .323), need to control thoughts (r =.383) and cognitive confidence (r = .382) and a weak negative correlation with the self-compassion subscales: self-kindness (r = -.225) and mindfulness (r = -.300).

Depression scores had a weak negative correlation with the self-compassion subscales: self-kindness (r =-.264) and mindfulness (r =-.276). Depression scores had a weak positive correlation with the MCQ subscales: positive beliefs (r = .173) and cognitive self-consciousness (r =.219). Depression scores had a moderate positive correlation with the MCQ subscales: negative beliefs (r =.505), need to control thoughts (r =.405) and cognitive confidence (r =.404).

Table 3.
Descriptive statistics and Pearson's correlations between the independent variables and PTSS, anxiety, and depression.

Variable	2	3	4	5	6	7	8	9	10	11	
1 Survivor age	-.218*	-.263**	-.145	.032	.088	.127	-.145	-.199*	-.151	-.074	
2 IES-R		.710**	621**	-.154	-.036	-.227**	-.330	.616**	.347**	.395**	.
3 HADS-A			.657**	-.225**	-.065	-.300**	-.323**	.696**	.414**	.383**	.
4 HADS-D				-.264**	-.166	-.276**	.173*	.505**	.219*	.405**	.
5 SCS: SK					.487**	.620**	-.052	-.153	.013	-.007	
6 SCS: CH						.628**	-.015	-.042	.110	.049	
7 SCS: M							-.096	-.301**	-.033	-.118	
8 MCQ: POS								.343**	.408**	.452**	
9 MCQ: NEG									.564**	.592**	.
10 MCQ: CSC										.490**	.
11 MCQ: NC										-	.
12 MCQ: CC										-	

Note. IES-R = PTSS; HADS-A= anxiety; HADS-D = depression; SCS:SK = self-kindness; SCS:CH = common humanity; POS = positive metacognitive beliefs; MCQ: NEG = negative metacognitive beliefs; MCQ: CSC = cognitive self-conscio control; MCQ:CC = cognitive confidence.
***Correlation is significant at the 0.01 level (2-tailed) *Correlation is significant at the 0.05 level (2-tailed)*

Regression models

The results for the hierarchal regression analyses are outlined in table 4. Within the PTSS model, the demographic variables were entered in step 1 were significant (F = 2.85, df = 4, 125, p =.027). Clinical variables were added at step 2 and were not significant (F = .413, df = 3, 122, p =.744). Self-compassion subscales were added in step 3 and were not significant (F = 2.27, df = 3, 119, p = .084) After controlling for both demographic and clinical variables, within the final model metacognitive beliefs accounted for an additional 31.9% of the variance in PTSS symptoms (F = 13.47, df = 5, 114, p = <.001). Negative beliefs about the uncontrollability and danger of worry (β =1.554, p = <.001) and cognitive confidence (β =.816, p =.018) both made independent contributions to the PTSS model.

Within the anxiety regression model, the demographic variables were added at step 1 and were significant (F = 3.415, df = 4, 125, p = 011). The clinical variables were added at step 2 and were not significant (F = .808, df = 3, 122, p = .492). At step 3, the self-compassion subscales were added and were significant (F = 4.606, df = 3, 119, p = 004) and accounted for 14.1% of the model when controlling for demographic and clinical factors. Within the fourth and final model, metacognitive beliefs significantly accounted for 37.4% of the variance of the model, when controlling for the other factors (F = 20.357, df = 5, 114, p = <.001).

The first step for the depression model was to examine the demographic variables. These were significant (F = 2.852, df = 4, 125, p = .027). The clinical variables were added at step 2, and were not significant (F = .941, df = 3, 122, p = .423). The self-compassion subscales were added at step 3 and were significant (F = 3.773, df = 3, 119, p = .013). For the final model, metacognitive beliefs accounted for 24.3% of the variance in the depression model, when controlling for the other factors (F = 9.661, df = 5, 114, p = <.001).

Table 4.
Regression model's summary, explained by self-compassion and metacognitive beliefs, when controlling for demographic and clinical variables

	PTSS model				Anxiety model				Depression model			
Variable	**ΔR^2**	**β**	***t***	**Sig**	**ΔR^2**	**β**	***t***	**Sig**	**ΔR^2**	**β**	***t***	**Sig**
Constant			-.188	.851			.884	.379			2.045	.043*
Demographics	.083*				.099**				.084*			
Age		-.121	-1.126	.262		-.041	-1.600	.112		-.020	-.865	.389
Sex		5.419	1.705	.091		1.063	1.426	.157		.592	.855	.394
Marital status		3.390	1.382	.170		.569	.989	.325		.596	1.114	.268
Social deprivation		-.278	-.621	.536		-.047	-.446	.656		-.174	-1.781	.078
Clinical	.009				.018				.021			
Time since treatment		-1.076	-.930	.354		-.418	-1.538	.127		-.420	-1.665	.099
Treatment type		-.008	-.011	.991		-.027	-.170	.865		.039	.266	.791
Stage of cancer		-1.362	-1.231	.221		-.443	-1.706	.091		-.373	-1.547	.125
Self-compassion	.049				.092*				.078**			
SCS: SK		-.395	-.976	.331		-.154	-1.623	.107		-.168	-1.908	.059
SCS: CH		.193	.360	.719		.093	.737	.462		-.120	-1.026	.307
SCS: M		-.073	-.133	.895		-.070	-.543	.588		.054	.449	.654
Metacognition	.319***				.374***				.243***			
MCQ: POS		.577	1.516	.132		.117	1.309	.193		-.033	-.396	.693
MCQ: NEG		1.554	3.787	<.001***		.522	5.423	<.001***		.264	2.953	.004*
MCQ: CSC		.008	.019	.985		.058	.597	.552		-.101	-1.114	.267
MCQ: NC		-.042	-.086	.932		-.123	-1.067	.288		.169	1.580	.117
MCQ: CC		.816	2.391	.018*		.194	2.414	.017*		.169	2.277	.025*
Model summary												
R^2	.461***				.582***				.426***			
Adjusted R^2	.390***				.527***				.350***			

Note. SCS:SK = self-kindness; SCS:CH = common humanity; SCS:M = mindfulness; MCQ: POS = positive metacognitive beliefs; MCQ: NEG = negative metacognitive beliefs; MCQ: CSC = cognitive self-consciousness; MCQ: NC = need to control; MCQ:CC = cognitive confidence.
**** p <.001; **p<.01; *p<.05*

Discussion

This is the first study to test the metacognitive model and self-compassion model and their contribution to PTSS, anxiety, and depression symptoms in a HNC population. Metacognitive

beliefs explained additional variance in PTSS, depression and anxiety when controlling for demographic, clinical variables, compared with self-compassion. This is supportive of the second hypothesis that survivors with greater conviction in metacognitive beliefs will have higher levels of PTSS, anxiety, and depression. It is also supportive of the S-REF model for understanding the maintenance of anxiety, depression and PTSS symptoms in HNC. Given the high proportion of survivors engaging in maladaptive metacognitive beliefs, it is unlikely that they would also be adopting self-compassionate ways of thinking.

Demographic and clinical characteristics

Descriptive data of the sample indicated that over one third of survivors met caseness criteria for depression, with approximately 13% being in the clinical severity range. Previous cohort studies in HNC report rates of around 18% (Rieke et al., 2017) and 23% (Patterson et al., 2021). Over half met caseness criteria for PTSS, with approximately 40% being within the probable diagnosis range, this is higher compared with previous prospective research, which reports rates of 22% in a mixed sample of HNC and lung cancer (Kangas et al., 2005).

Survivors who were recruited via social media reported higher levels of anxiety compared with those recruited via NHS clinics. As survivors within the NHS recruitment stream were recruited when they were attending an NHS appointment, it may be that the social media survivors are attending fewer clinical appointments and therefore have more uncertainty and fear around their cancer diagnosis. An interview study found that HNC survivors were reluctant to raise fear of recurrence with clinicians due to worries about appearing “ungrateful” or for damaging a relationship they value (Ozakinci et al., 2017). There were no differences between recruitment type and PTSS or depression, suggesting that still being under a clinical service does not impact these symptoms.

Female survivors reported higher PTSS symptoms compared with male survivors. This is consistent with the PTSS literature, with studies over the last 25 years exploring PTSS in the general population reporting that women are more likely to meet criteria for PTSS, even though they are less likely to experience traumatic events (Tolin & Foa, 2008). However, due to HNC being more commonly experienced by men, the sample within this study might not be representative of a general HNC sample.

Metacognitive beliefs and anxiety, depression and PTSS

Regression analyses reported that metacognitive beliefs accounted for a significant variance across models for PTSS, anxiety, and depression. Specifically, of the five MCQ-30 subscales, included within the analysis, two (negative beliefs about worry and cognitive confidence) independently predicted anxiety, depression and PTSS symptoms. Within all three models' negative beliefs about worry made the largest contribution. These findings are consistent with the metacognitive model which hypotheses that negative beliefs about uncontrollability and danger of worry (e.g., "my worrying is dangerous for me" or "worrying persists even when trying to make it stop") may contribute to negative interpretations of internal experiences, which then causes an escalation of depression, anxiety and PTSS symptoms (Cook et al., 2015a; Wells, 2002). This finding is consistent with previous research which reports the negative beliefs about worry subscale to contribute the largest variance to distress within other physical health populations such as Parkinson's disease (Allott et al., 2005), multiple sclerosis, (Fisher et al., 2020) diabetes (Purewal & Fisher, 2018) and mixed cancer populations (Cook et al., 2015a; Cook et al., 2015b). They are reported as a commonality across disease populations due to their association with health-related anxious thoughts (Bailey & Wells, 2013). This finding was replicated within this study, suggesting a commonality of experiencing negative metacognitive beliefs within physical health populations.

The regression analysis also indicated that a second set of metacognitive beliefs, a belief that your memory works well (lack of cognitive confidence, for example "I do not trust my memory") is relevant in contributing to levels of PTSS, anxiety, and depression in HNC survivors. Thus, having low levels of cognitive confidence is hypothesised as contributing to distress as it limits the survivor's choice of effective coping strategies (Wells, 2002). A prospective study exploring metacognitive beliefs within a mixed cancer sample reported similar findings whereby negative metacognitive beliefs contributed the most variance with cognitive confidence predicted the second highest across anxiety, depression and PTSS symptoms (Cook et al., 2015b). However, findings are mixed for this subscale as previous studies have reported that cognitive confidence predicted symptoms of depression but not anxiety (Spada et al., 2008).

Strengths and limitations

This study was cross-sectional in design and therefore it explored emotional distress across one time point. Therefore, it is not possible to determine causality and if maladaptive metacognitive beliefs are a consequence of anxiety, depression and PTSS after HNC treatments, or if these beliefs were present before participation in the study. At the same time, within the remit of this study, it was not possible to include information of survivor's previous mental health difficulties and if these were pre-existing prior to participating in this study. Studies adopting prospective designs and experimental designs are needed to make such inferences.

Information pertaining to HPV and non-HPV status, physical and mental health history and ethnicity was unavailable, and therefore the influence of these variables on the outcome is unknown. Data was not available for all participants for certain variables such as marital status, religion, smoking and alcohol intake. The study was strengthened by having multiple recruitment streams broadening the geographical area, including a high proportion from areas of high deprivation, with a range of survivors with different tumour sites and treatment. This

also increased the sample size and power of the study. However, the accuracy of some variables was difficult to check for example, self-reported tumour stages, tumour types or medical treatment modality and therefore these could not be confirmed by a medical professional.

As the sample had more female participants compared with male, these results may not be representative of a true HNC population, given that these HNC tumours are more commonly found in males.

Clinical implications and service development

This study is the first to explore the metacognitive and self-compassion models and their contribution to anxiety, depression and PTSS with HNC survivors. It provides preliminary indications into the psychological processes which underpin some common mental health difficulties in HNC populations. Firstly, the study suggests that a large proportion of HNC survivors experience anxiety, depression and PTSS, so support for such experiences would be helpful. Thus, as HNC NHS services do not routinely screen for symptoms of anxiety, depression and PTSS, this would be helpful to highlight which survivors are experiencing such difficulties and might require psychological support. Screening for symptoms would also help gather further information with regards to the frequency and severity of symptoms which could help inform how adaptations to services could be developed further. Clinicians within HNC services screen for symptoms by asking survivors about their experience of diagnosis and treatments, for example are they experiencing any flashbacks, nightmares, or hypervigilance in line with PTSS.

As clinical services are unable to change survivor's demographic or clinical details which can impact mental health, one way of addressing mental health difficulties is to explore psychological process. Metacognitive beliefs added to the variance explained in anxiety, depression and PTSS beyond the contribution of demographic, clinical and self-compassion

variables. This suggests that the way in which a person responds to distressing situations maintains these mental health difficulties and that modifying metacognitive beliefs might be helpful as a transdiagnostic intervention would be the most parsimonious and efficient approach, compared with self-compassion. Additionally, if survivors are experiencing mental health difficulties and engaging in metacognitive beliefs, it is unlikely that they would also be engaging in self-compassionate thoughts. Previous research outlines that when cancer survivors are still adjusting to their diagnoses and treatments, they are often very self-critical of themselves and thus are unlikely to be experiencing self-compassionate thoughts (Przezdziecki et al., 2013). One way to address this within HNC services could be for members of the multi-disciplinary team to routinely use the MCQ-30 to screen for such underlying beliefs. Psychoeducation and self-help materials could be developed and provided for survivors who are experiencing negative meta-cognitive beliefs and lack of cognitive confidence. A previous randomised controlled trial reported that such self-help materials about metacognitive beliefs have been found to reduce symptoms of anxiety and depression in cardiac rehabilitation survivors (Wells et al., 2023).

Training and education to staff members would be important when integrating new processes into routine clinical practice. Such training could provide information around common symptoms of anxiety depression and PTSS. Given the high proportion of HNC survivors reporting PTSS symptoms within this study and that trauma symptoms are less routinely screened for, this indicates that training on this might be given priority over anxiety or depression. Training could include how to recognise PTSS symptoms and how such symptoms might impact a survivor's communication and engagement within services and how to support this.

Additionally, providing staff with guidance on how to normalise and validate emotional states and worries of HNC survivors might help to mitigate anxiety, depression and PTSS symptoms.

NHS services are stretched and busy and therefore this might be challenging to implement. Using initiatives such as training for continuing professional development might support with this. Additionally, implementing roles such as mental health champions within the service might support with maintaining these ideas after training sessions.

Providing more space and time for discussions around mental health might be supportive in normalising and validating such experiences within the context of HNC. Another way to normalise mental health symptoms and worries could be by integrating peer support within services. Lastly, when implementing new processes within services, it is important to include HNC survivors within this so they can share their valuable knowledge. When support around mental health has been provided, self-compassion and metacognitive beliefs could be measured again to see if these have changed. Perhaps it would be expected for less mental health difficulties to be experienced, and therefore less metacognitive beliefs and more self-compassionate thoughts to be adopted.

Research implications

Due to the limitations within of this study, research employing prospective designs is necessary to investigate whether metacognitive beliefs measured at baseline predict PTSS, anxiety, and depression over time, whilst controlling for baseline levels of distress, demographic and clinical variables. Additionally, further research examining the metacognitive model further is needed, such as experimental designs exploring metacognitive therapy for alleviating distress within HNC is needed. Due to the results supporting the elements of the metacognitive model for understanding anxiety, depression, and PTSS in HNC, one helpful approach might be metacognitive therapy, but results need to be explored further through experimental designs and intervention-based research. Other research has reported that self-compassion mediates the relationship between maladaptive cognitions and depression (Palmer-Cooper et al., 2023). Future research could explore these relationships within HNC.

Conclusion

Negative metacognitive beliefs (negative metacognitive beliefs and cognitive confidence) were associated with anxiety, depression, and PTSS symptoms over and above self-compassion, when controlling for demographic and clinical variables. Therefore, the findings suggest that for survivors of HNC who are experiencing such mental health difficulties, interventions addressing metacognitive beliefs and processes might be more effective compared with self-compassion-based approaches. Research employing prospective designs is necessary to investigate whether metacognitive beliefs measured at baseline predict PTSS, anxiety, and depression over time, whilst controlling for baselines levels of distress, demographic and clinical variables. This might help inform new psychological interventions for HNC survivors.

References

Aarstad, A. K. H., Lode, K., Larsen, J. P., Bru, E., & Aarstad, H. J. (2011). Choice of psychological coping in laryngectomized, head and neck squamous cell carcinoma patients versus multiple sclerosis patients. *European Archives of Otorhinolaryngology*, 268, 907–915. doi:10.1007/ s00405-010-1417-6

Allott, R., Wells, A., Morrison, A. P., & Walker, R. (2005). Distress in Parkinson's disease: contributions of disease factors and metacognitive style. *The British Journal of Psychiatry*, *187*(2), 182-183. https://doi.org/10.1192/bjp.187.2.182

American Psychiatric Association. (2022). Diagnostic and Statistical Manual of Mental Disorders (5th ed., text rev.). https://doi.org/10.1176/appi.books.9780890425787

Andrykowski, M. A., Cordova, M. J., McGrath, P. C., Sloan, D. A., & Kenady, D. E. (2000). Stability and change in posttraumatic stress disorder symptoms following breast cancer treatment: a 1-year follow-up. *Psycho-Oncology*, *9*(1), 69–78. https://doi.org/10.1002/(sici)1099-1611(200001/02)9:1<69::aid-pon439>3.0.co;2-r

Anguiano, L., Mayer, D. K., Piven, M. L., & Rosenstein, D. (2012). A literature review of suicide in cancer patients. *Cancer Nursing*, *35*(4), E14-E26. DOI:10.1097/NCC.0b013e31822fc76c

Armes, J., Crowe, M., Colbourne, L., Morgan, H., Murrells, T., Oakley, C., Palmer, N., Ream, E., Young, A., & Richardson, A. (2009). Patients' supportive care needs beyond the end of cancer treatment: a prospective, longitudinal survey. *Journal of Clinical Oncology:*

Official Journal of the American Society of Clinical Oncology, *27*(36), 6172–6179. https://doi.org/10.1200/JCO.2009.22.5151

Bailey, R., & Wells, A. (2013). Does metacognition make a unique contribution to health anxiety when controlling for neuroticism, illness cognition, and somatosensory amplification? *Journal of Cognitive Psychotherapy*, *27*(4), 327-337. https://doi.org/10.1891/0889-8391.27.4.327

Baker, F., Denniston, M., Smith, T., & West, M. M. (2005). Adult cancer survivors: how are they faring? *Cancer*, *104*(11 Suppl), 2565–2576. https://doi.org/10.1002/cncr.21488

Baker, D. A., Caswell, H. L., & Eccles, F. J. R. (2019). Self-compassion and depression, anxiety, and resilience in adults with epilepsy. *Epilepsy & Behavior: E&B*, *90*, 154–161. https://doi.org/10.1016/j.yebeh.2018.11.025

Beck, J. G., Grant, D. M., Read, J. P., Clapp, J. D., Coffey, S. F., Miller, L. M., & Palyo, S. A. (2008). The impact of event scale-revised: psychometric properties in a sample of motor vehicle accident survivors. *Journal of Anxiety Disorders*, *22*(2), 187–198. https://doi.org/10.1016/j.janxdis.2007.02.007

Brown, S. L., Hughes, M., Campbell, S., & Cherry, M. G. (2020). Could worry and rumination mediate relationships between self-compassion and psychological distress in breast cancer survivors?. *Clinical Psychology & Psychotherapy*, *27*(1), 1-10. https://doi.org/10.1002/cpp.2399

Campbell, C. L., & Campbell, L. C. (2012). A systematic review of cognitive behavioral interventions in advanced cancer. *Patient Education and Counseling*, *89*(1), 15-24. https://doi.org/10.1016/j.pec.2012.06.019

Cancer Research UK (2021). Head and Neck Cancer: Head and neck cancer | Cancer Research UK

Cancer Research UK (2017). Head and Neck Cancer Statistics. https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/head-and-neck-cancers

Capobianco, L., Faija, C., Husain, Z., & Wells, A. (2020). Metacognitive beliefs and their relationship with anxiety and depression in physical illnesses: A systematic review. *PloS One*, *15*(9). https://doi.org/10.1371/journal.pone.0238457

Cherry, M. G., Salmon, P., Byrne, A., Ullmer, H., Abbey, G., & Fisher, P. L. (2019). Qualitative evaluation of cancer survivors' experiences of metacognitive therapy: a new perspective on psychotherapy in cancer care. *Frontiers in Psychology*, *10*, 949. https://doi.org/10.3389/fpsyg.2019.00949

Chu, K. P., Habbous, S., Kuang, Q., Boyd, K., Mirshams, M., Liu, F. F., & Liu, G. (2016). Socioeconomic status, human papillomavirus, and overall survival in head and neck squamous cell carcinomas in Toronto, Canada. *Cancer Epidemiology*, *40*, 102-112. https://doi.org/10.1016/j.canep.2015.11.010

Cloitre M, Shevlin M, Brewin CR, Bisson, J.I., Roberts, N.P., & Maercker, A. (2018). The International Trauma Questionnaire: development of a self-report measure of ICD-11 PTSD and complex PTSD. *Acta Psychiatrica Scandinavica*; 138 (*6*), 536–46. https://doi: 10.1111/acps.12956

Cook, S. A., Salmon, P., Dunn, G., Holcombe, C., Cornford, P., & Fisher, P. (2015a). The association of metacognitive beliefs with emotional distress after diagnosis of cancer. *Health Psychology*, *34*(3), 207. http://dx.doi.org/10.1037/hea0000096

Cook, S.A., Salmon, P., Dunn, G. Holcombe, C., & Cornford, P. (2015b). A Prospective Study of the Association of Metacognitive Beliefs and Processes with Persistent Emotional

Distress After Diagnosis of Cancer. *Cognitive Therapy and Research* **39**, 51–60. https://doi.org/10.1007/s10608-014-9640-x

Department of Health (2001) The NHS Cancer Plan. Available from: www.dh.gov.uk

Duncan, M., Moschopoulou, E., Herrington, E., Deane, J., Roylance, R., Jones, L., Bourke, L., Morgan, A., Trudie Chalder, T., Thaha, M.A., Taylor, S.C., Korszun, A., White, P.D., & Bhui, K. (2017). Review of Systematic reviews of non-pharmacological interventions to improve quality of life in cancer survivors. *BMJ Open, 7(11).* http://dx.doi.org/10.1136/bmjopen-2017-015860

English Indices of Deprivation (2019). *Ministry of Housing, Communities and Local Government*. English indices of deprivation 2019 - GOV.UK (www.gov.uk)

Faija, C. L., Reeves, D., Heal, C., Capobianco, L., Anderson, R., & Wells, A. (2019). Measuring the cognitive attentional syndrome in cardiac patients with anxiety and depression symptoms: Psychometric properties of the CAS-1R. *Frontiers in Psychology*, *10*, 2109. https://doi.org/10.3389/fpsyg.2019.02109

Farberow, N. L., Ganzler, S., Cutter, F., & Reynolds, D. (1971). An eight-year survey of hospital suicides. *Suicide and Life-Threatening Behavior*, *1*(3), 184.

Farrand, P., & Woodford, J. (2015). Effectiveness of Cognitive Behavioural Self-Help for the Treatment of Depression and Anxiety in People with Long-Term Physical Health Conditions: a Systematic Review and Meta-Analysis of Randomised Controlled Trials. *Annals of Behavioral Medicine: A Publication of the Society of Behavioral Medicine*, *49*(4), 579–593. https://doi.org/10.1007/s12160-015-9689-0

Ferrari, M., Dal Cin, M., & Steele, M. (2017). Self-compassion is associated with optimum self-care behaviour, medical outcomes, and psychological well-being in a cross-sectional sample of adults with diabetes. *Diabetic Medicine: A Journal of the British Diabetic Association*, *34*(11), 1546–1553. https://doi.org/10.1111/dme.13451

Fingeret, M. C., Yuan, Y., Urbauer, D., Weston, J., Nipomnick, S., & Weber, R. (2012). The nature and extent of body image concerns among surgically treated patients with head and neck cancer. *Psycho-Oncology*, *21*(8), 836-844. https://doi.org/10.1002/pon.1990

Fisher, P. L., McNicol, K., Young, B., Smith, E., & Salmon, P. (2015). Alleviating emotional distress in adolescent and young adult cancer survivors: an open trial of metacognitive therapy. *Journal of Adolescent and Young Adult Oncology*, *4*(2), 64-69.

Fisher, P. L., & Noble, A. J. (2017). Anxiety and depression in people with epilepsy: The contribution of metacognitive beliefs. *Seizure*, *50*, 153–159. https://doi.org/10.1016/j.seizure.2017.06.012

Fisher, P. L., Salmon, P., Heffer-Rahn, P., Huntley, C., Reilly, J., & Cherry, M. G. (2020). Predictors of emotional distress in people with multiple sclerosis: A systematic review of prospective studies. *Journal of Affective Disorders*, *276*, 752-764. https://doi.org/10.1016/j.jad.2020.07.073

Gillanders, D. T., Sinclair, A. K., MacLean, M., & Jardine, K. (2015). Illness cognitions, cognitive fusion, avoidance, and self-compassion as predictors of distress and quality of life in a heterogeneous sample of adults, after cancer. *Journal of Contextual Behavioral Science*, *4*(4), 300–311. https://doi.org/10.1016/j.jcbs.2015.07.003

Gilbert, P. (2009). *The Compassionate Mind*. Robinson.

Gilbert, P. (2017). A brief outline of the evolutionary approach for compassion focused therapy. *EC Psychology and Psychiatry*, 3(6): 218-227.

González-Fernández, S. & Concepción Fernández-Rodríguez, C. (2019) Acceptance and commitment therapy in cancer: Review of applications and findings. *Behavioral Medicine*, 45:3, 255-269, Doi:10.1080/08964289.2018.1452713

Hart, S. L., Hoyt, M. A., Diefenbach, M., Anderson, D. R., Kilbourn, K. M., Craft, L. L., ... & Stanton, A. L. (2012). Meta-analysis of efficacy of interventions for elevated depressive symptoms in adults diagnosed with cancer. *Journal of the National Cancer Institute*, *104*(13), 990-1004. DOI:10.1093/jnci/djs256

Heffer-Rahn, P., & Fisher, P. L. (2018). The clinical utility of metacognitive beliefs and processes in emotional distress in people with multiple sclerosis. *Journal of Psychosomatic Research*, *104*, 88–94. https://doi.org/10.1016/j.jpsychores.2017.11.014

Henson, K.E., Brock, R., Charnock, J., Wickramasinghe, B., Will, O., Pitman, A. (2019). Risk of suicide after Cancer Diagnosis in England. *JAMA Psychiatry,* 76(1):51-60. doi:10.1001/jamapsychiatry.2018.3181

Howren, M. B., Christensen, A. J., Karnell, L. H., & Funk, G. F. (2013). Psychological factors associated with head and neck cancer treatment and survivorship: Evidence and opportunities for behavioral medicine. *Journal of Consulting and Clinical Psychology, 81*(2), 299–317. https://doi.org/10.1037/a0029940

Huang, R. W., Chang, K. P., Marchi, F., Loh, C. Y. Y., Lin Jr, Y., Chang, C. J., & Kao, H. K. (2022). The impact of depression on survival of head and neck cancer patients: A

population-based cohort study. *Frontiers in Oncology*, *12*, 871915. https://doi.org/10.3389/fonc.2022.871915

Hughes, M., Brown, S.L., Campbell, S. *Dandy, S., Cherry,M.G. (2021).* Self-Compassion and Anxiety and Depression in Chronic Physical Illness Populations: A Systematic Review. *Mindfulness* **12**, 1597–1610. https://doi.org/10.1007/s12671-021-01602-y

Humphris G. M. (2008). The missing member of the head and neck multidisciplinary team: the psychologist. Why we need them. *Current Opinion in Otolaryngology & Head and Neck Surgery*, *16*(2), 108–112. https://doi.org/10.1097/MOO.0b013e3282f470f9

Ingarfield, K., McMahon, A. D., Hurley, K., Toms, S., Pring, M., Thomas, S. J., & Conway, D. I. (2021). Inequality in survival of people with head and neck cancer: Head and Neck 5000 cohort study. *Head & Neck*, *43*(4), 1252-1270. https://doi.org/10.1002/hed.26589

Jacobsen, P. B., & Jim, H. S. (2008). Psychosocial interventions for anxiety and depression in adult cancer patients: achievements and challenges. *CA: A Cancer Journal for Clinicians*, *58*(4), 214-230. https://doi.org/10.3322/CA.2008.0003

Kangas, M., Henry, J.L., & Bryant, R.A. (2005). Predictors of posttraumatic stress disorder following cancer. *Health Psychology*, 24(*6*), 579-585. https://doi.org/10.1037/0278-6133.24.6.579

Kugaya, A., Akechi, T., Okuyama, T., Nakano, T., Mikami, I., Okamura, H., & Uchitomi, Y. (2000). Prevalence, predictive factors, and screening for psychologic distress in patients with newly diagnosed head and neck cancer. *Cancer*, *88*(12), 2817–2823. https://doi.org/10.1002/1097-0142(20000615)88:12<2817::aid-cncr22>3.0.co;2-n

Lee, J. H., Ba, D., Liu, G., Leslie, D., Zacharia, B. E., & Goyal, N. (2019). Association of head and neck cancer with mental health disorders in a large insurance claims database. *JAMA*

Otolaryngology–Head & Neck Surgery, *145*(4), 339-344. doi:10.1001/jamaoto.2018.4512

McPhillips, R., Salmon, P., Wells, A., & Fisher, P. (2019). Qualitative analysis of emotional distress in cardiac patients from the perspectives of cognitive behavioral and metacognitive theories: why might cognitive behavioral therapy have limited benefit, and might metacognitive therapy be more effective?. *Frontiers in Psychology*, *9*, 2288.

Muris, P., & Petrocchi, N. (2017). Protection or vulnerability? A meta-analysis of the relations between the positive and negative components of self-compassion and psychopathology. *Clinical Psychology & Psychotherapy*, *24*(2), 373-383. https://doi.org/10.1002/cpp.2005

Murphy, D., Shevlin, M., Pearson, E., Greenberg, N., Wessely, S., Busuttil, W., & Karatzias, T. (2020). A validation study of the International Trauma Questionnaire to assess post-traumatic stress disorder in treatment-seeking veterans. *British Journal of Psychiatry*, 216, 132–137. https://doi: 10.1192/bjp.2020.9

National Cancer Institute (2019). https://www.cancer.gov/aboutcancer/coping/survivorship/new-normal/ptsd-pdq

National Institute for Health Care Excellence (2009). Depression in Adults with a Chronic Health Problem: Recognition and Management. Clinical Guideline [CG91]. https://www.nice.org.uk/guidance/cg91

National Institute for Health Care Excellence (2004). Improving Supportive and Palliative Care for Adults with Cancer: the manual. https://www.nice.org.uk/guidance/csg4/resources/improving-supportive-and-palliative-care-for-adults-with-cancer-pdf-773375005

National Statistics, English Indices of deprivation (2019). English indices of deprivation 2019 - GOV.UK (www.gov.uk)

Neff, K.D. (2003a) Self-Compassion: An Alternative Conceptualization of a Healthy Attitude Toward Oneself. *Self and Identity*, 2:2, 85-101, DOI:10.1080/15298860309032

Neff, K. D. (2003b). The development and validation of a scale to measure self-compassion. *Self and Identity*, *2*(3), 223-250. https://doi.org/10.1080/15298860309027

Northern Ireland Multiple Deprivation measures (2017). Northern Ireland Statistics and Research Agency. Home Page | NI Area Statistics | NISRA

North West Cancer Charity, annual report (2018-2019). https://nwcr.org/media/2152/nwcr-2018-19-annual-report.pdf

O'Cathain A, Croot L, Duncan E, Rousseau,N., Sworn, K., Turner, K.M., Yardley, L., & Hoddinott, P. (2019). Guidance on how to develop complex interventions to improve health and healthcare. *British Medical Journal Open*, 9. doi:10.1136/bmjopen-2019-029954

O'Connor, M., Christensen, S., Jensen, A. B., Møller, S., & Zachariae, R. (2011). How traumatic is breast cancer? Post-traumatic stress symptoms (PTSS) and risk factors for severe PTSS at 3 and 15 months after surgery in a nationwide cohort of Danish women treated for primary breast cancer. *British Journal of Cancer*, *104*(3), 419–426. https://doi.org/10.1038/sj.bjc.6606073

Oncology Times: (2018). Head & Neck Cancer Survivors at Increased Risk of Suicide - Volume 40(22), 43 doi:10.1097/01.COT.0000549792.20066.19

Ozakinci, G., Swash, B., Humphris, G., Rogers, S., & Hulbert-Williams, N. J. (2018). Fear of cancer recurrence in oral and oropharyngeal cancer patients: An investigation of the clinical encounter. *European Journal of Cancer Care*, *27*(1). https://doi.org/10.1111/ecc.12785

Palmer-Cooper, E. C., Woods, C., & Richardson, T. (2023). The relationship between dysfunctional attitudes, maladaptive perfectionism, metacognition and symptoms of mania and depression in bipolar disorder: The role of self-compassion as a mediating factor. *Journal of Affective Disorders*. https://doi.org/10.1016/j.jad.2023.08.117

Patterson, J. M., Lu, L., Watson, L. J., Harding, S., Ness, A. R., Thomas, S., ... & Sharp, L. (2022). Associations between markers of social functioning and depression and quality of life in survivors of head and neck cancer: Findings from the Head and Neck Cancer 5000 study. *Psycho-Oncology*, *31*(3), 478-485. https://doi.org/10.1002/pon.5830

Pinto-Gouveia, J., Duarte, C., Matos, M., & Fráguas, S. (2014). The protective role of self-compassion in relation to psychopathology symptoms and quality of life in chronic and in cancer patients. *Clinical Psychology & Psychotherapy*, *21*(4), 311–323. https://doi.org/10.1002/cpp.1838

Przezdziecki, A., Sherman, K.A., Baillie, A., Taylor, A., Foley, E., Staggis-Bilinski, K. (2012). My changed body: breast cancer, body image, distress, and self-compassion. *Psycho-Oncology*, 22(*8*), 1872-1879. https://doi.org/10.1002/pon.3230

Purewal, R., & Fisher, P. L. (2018). The contribution of illness perceptions and metacognitive beliefs to anxiety and depression in adults with diabetes. *Diabetes Research and Clinical Practice*, *136*, 16-22. https://doi.org/10.1016/j.diabres.2017.11.029

Rieke, K., Schmid, K. K., Lydiatt, W., Houfek, J., Boilesen, E., & Watanabe-Galloway, S. (2017). Depression and survival in head and neck cancer patients. *Oral Oncology*, *65*, 76–82. https://doi.org/10.1016/j.oraloncology.2016.12.014

Richardson, A. E., Broadbent, E., & Morton, R. P. (2019). A systematic review of psychological interventions for patients with head and neck cancer. *Supportive Care in Cancer*, *27*, 2007-2021. https://doi.org/10.1007/s00520-019-04768-3

Rowland, J. H., Kent, E. E., Forsythe, L. P., Loge, J. H., Hjorth, L., Glaser, A., Mattioli, V., & Fosså, S. D. (2013). Cancer survivorship research in Europe and the United States: where have we been, where are we going, and what can we learn from each other?. *Cancer, 119 Suppl 11*(0 11), 2094–2108. https://doi.org/10.1002/cncr.28060

Salmon, P., Clark, L., McGrath, E., & Peter Fisher (2015). Screening for psychological distress in cancer: renewing the research agenda. *Psycho-Oncology*, 24, 262-268. https://doi:10.1002/pon.3640

Semple, C., Parahoo, K., Norman, A., McCaughan, E., Humphris, G., & Mills, M. (2013). Psychosocial interventions for patients with head and neck cancer. *Cochrane Database of Systematic Reviews*, (7). https://doi.org/10.1002/14651858.CD009441.pub2

Scottish Index of Multiple Deprivation (2020). *Communities and third sector, equality and rights, Health and Social Care*. Scottish Index of Multiple Deprivation 2020v2 postcode lookup file - gov.scot (www.gov.scot)

Singer, S., Herrmann, E., Welzel, C., Klemm, E., Heim, M., & Schwarz, R. (2005). Comorbid mental disorders in laryngectomees. *Onkologie*, *28*(12), 631–636. https://doi.org/10.1159/000088978

Sirois, F. M., Molnar, D. S., & Hirsch, J. K. (2015). Self-compassion, stress, and coping in the context of chronic illness. *Self and Identity*, *14*(3), 334–347. https://doi.org/10.1080/15298868.2014.996249

So, W. K. W., Chan, R. J., Chan, D. N. S., Hughes, B. G. M., Chair, S. Y., Choi, K. C., & Chan, C. W. H. (2012). Quality-of-life among head and neck cancer survivors at one year after treatment–a systematic review. *European Journal of Cancer*, *48*(15), 2391-2408. https://doi.org/10.1016/j.ejca.2012.04.005

Spada, M. M., Mohiyeddini, C., & Wells, A. (2008). Measuring metacognitions associated with emotional distress: Factor structure and predictive validity of the metacognition's questionnaire 30. *Personality and Individual Differences*, *45*(3), 238-242. https://doi.org/10.1016/j.paid.2008.04.005

Spitzer, R. L., Kroenke, K., & Williams, J. B. (1999). Validation and utility of a self-report version of PRIME-MD: the PHQ primary care study. Primary Care Evaluation of Mental Disorders. Patient Health Questionnaire. *JAMA*, *282*(18), 1737–1744. https://doi.org/10.1001/jama.282.18.1737

Stanton, A. L. (2006). Psychosocial concerns and interventions for cancer survivors. *Journal of Clinical Oncology*, *24*(32), 5132-5137. DOI: 10.1200/JCO.2006.06.8775

Temple, J., Salmon, P., Smith, C. T., Huntley, C. D., Byrne, A., & Fisher, P. L. (2020). The questionable efficacy of manualized psychological treatments for distressed breast cancer patients: An individual patient data meta-analysis. *Clinical Psychology Review*, *80*, 101883. https://doi.org/10.1016/j.cpr.2020.101883

Tolin, D. F., & Foa, E. B. (2008). Sex differences in trauma and posttraumatic stress disorder: A quantitative review of 25 years of research. *Psychological Trauma: Theory, Research, Practice, and Policy*, *S*(1), 37–85. https://doi.org/10.1037/1942-9681.S.1.37

Van Helmondt, S.J., Van der Lee, M.L., Van Woezik, R.A.M., Lodder, P., & De Vries, J. (2019). No effect of CBT-based online self-help training to reduce fear of cancer recurrence: First results of the CAREST multicenter randomized controlled trial. *Psycho-Oncology*, 29(*1*), 86-97. https://doi.org/10.1002/pon.5233

Vodermaier, A., & Millman, R. D. (2011). Accuracy of the Hospital Anxiety and Depression Scale as a screening tool in cancer patients: A systematic review and meta-analysis. *Supportive Care in Cancer*, *19*,1899–1908. doi:10.1007/s00520-011-1251-4

Weiss, D. S., & Marmar, C. R. (1997). The Impact of Event Scale—Revised. In J. P. Wilson & T. M. Keane (Eds.), *Assessing Psychological Trauma and PTSD* (pp. 399–411). The Guilford Press.

Wells, A. (2002). *Emotional disorders and metacognition: Innovative cognitive therapy*. John Wiley & Sons.

Wells, A. (2015). *Cognitive Attentional Syndrome Scale 1 Revised* (CAS-1R). Manchester: University of Manchester.

Wells, A. (2009). *Metacognitive Therapy for Anxiety and Depression*. Guildford Press.

Wells, A., & Cartwright-Hatton, S. (2004). A short form of the metacognitions questionnaire: Properties of the MCQ-30. *Behaviour Research and Therapy*, *42*(4), 385–396. https://doi.org/10.1016/S0005-7967(03)00147-5

Wells, A., & Matthews, G. (1994). *Attention and Emotion: A clinical perspective*. Psychology Press.

Wells, M., Cunningham, M., Lang, H., Swartzman, S., Philp, J., Taylor, L., & Thomson, J. (2015). Distress, concerns, and unmet needs in survivors of head and neck cancer: a

cross-sectional survey. *European Journal of Cancer Care*, *24*(5), 748-760. https://doi.org/10.1111/ecc.12370

Wells, A., Reeves, D., Heal, C., Fisher, P., Doherty, P., Davies, L., & Capobianco, L. (2023). Metacognitive therapy home-based self-help for anxiety and depression in cardiovascular disease patients in the UK: A single-blind randomised controlled trial. *PLoS Medicine*, *20*(1), e1004161. https://doi.org/10.1371/journal.pmed.1004161

Welsh Index of Multiple Deprivation (2019). *Analysis Relating to Areas of Deep-rooted Deprivation*. Welsh Index of Multiple Deprivation | GOV.WALES

Williams, S., & Dale, J. (2006). The effectiveness of treatment for depression/depressive symptoms in adults with cancer: a systematic review. *British Journal of Cancer*, *94*(3), 372-390. doi:10.1038/sj.bjc.6602949

Xiao, F., Song, X., Chen, Q., Dai, Y., Xu, R., Qiu, C., & Guo, Q. (2017). Effectiveness of psychological interventions on depression in patients after breast cancer surgery: a meta-analysis of randomized controlled trials. *Clinical Breast Cancer*, *17*(3), 171-179. https://doi.org/10.1016/j.clbc.2016.11.003

Zigmond, A.S., & Snaith, R.P. (1983). The Hospital Anxiety and Depression Scale. *Acta Psychiatrica Scandinavica*; 67:361–370

Zhu, L., Yao, J., Wang, J., Wu, L., Gao, Y., Xie, J., Liu, A., Ranchor, A., & Schroevers, M. J. (2019). The predictive role of self-compassion in cancer patients' symptoms of depression, anxiety, and fatigue: A longitudinal study. *Psycho-Oncology*, *28*(9). https://doi.org/10.1002/pon.5174

Appendices

Chapter one Systematic review:

Appendix A: Author guidelines for submission to Frontiers Journal

3.10. Support and Ethical concerns

1. Summary Table

Please view the table below for a summary on currently accepted article types and general manuscript style guidelines. Article types may vary depending on journal.

	Abstract (max. length)	Running title (5 words)	Figures and/or tables (combined)	Manuscript (max. length)	Peer review	Author fees	Submitted to PubMed Central or other indexing databases
Original Research	350 words	✔	15	12'000 words	✔	✔	✔
Review	350 words	✔	15	12'000 words	✔	✔	✔
Book Review	✘	✘	1	1'000 words	✔	✘	✔
Brief Research Report	250 words	✔	4	4'000 words	✔	✔	✔
Case Report	350 words	✔	4	3'000 words	✔	✔	✔
Clinical Trial	350 words	✔	15	12'000 words	✔	✔	✔
Community Case Study	350 words	✔	5	5'000 words	✔	✔	✔
Conceptual Analysis	350 words	✔	10	8'000 words	✔	✔	✔
Curriculum, Instruction, and Pedagogy	350 words	✔	5	5'000 words	✔	✔	✔
Data Report	✘	✔	2	3'000 words	✔	✔	✔
Editorial	✘	✘	0	1'000 words*	✔	✘	✔
Field Grand Challenge	✘	✔	1	2'000 words	✔	✘	✔

Appendix B: Prospero form

PROSPERO
International prospective register of systematic reviews

NHS National Institute for Health Research

UNIVERSITY of York
Centre for Reviews and Dissemination

Systematic review

A list of fields that can be edited in an update can be found here

1. * Review title.

Give the title of the review in English

Assessing post-traumatic growth after treatments for head and neck cancers: a systematic review using validated patient-reported measures

2. Original language title.

For reviews in languages other than English, give the title in the original language. This will be displayed with the English language title.

3. * Anticipated or actual start date.

Give the date the systematic review started or is expected to start.

19/12/2022

4. * Anticipated completion date.

Give the date by which the review is expected to be completed.

05/06/2023

5. * Stage of review at time of this submission.

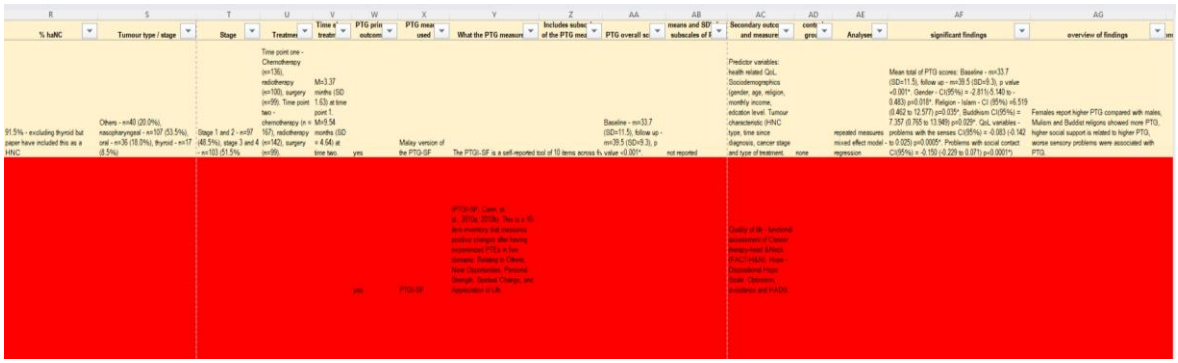
This field uses answers to initial screening questions. It cannot be edited until after registration.

Tick the boxes to show which review tasks have been started and which have been completed.

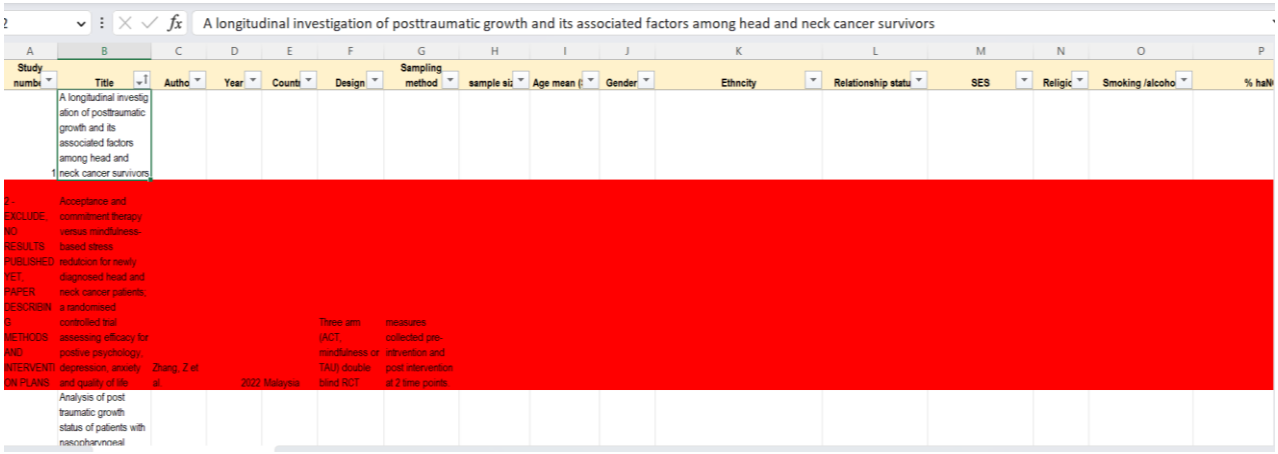
Appendix C: Search strategy terms

Table 1. Search terms used	
Term	Terms
HNC	head and neck neoplasm*, OR head and neck ca*ncer*, OR head and neck squamous cell ca*ncer*, OR head and neck squamous cell neoplasm* OR oral ca*ncer*, OR oral neoplasm* OR mouth neoplasm*, OR mouth ca*ncer* OR laryngeal neoplasm*, OR laryngeal ca*ncer* OR gingival neoplasm*, OR gingival ca*ncer* OR oral leukoplakia* OR lip neoplasm*, OR lip ca*ncer* OR palatal neoplasm* OR palatal ca*ncer* OR tongue neoplasm*, OR tongue ca*ncer* OR pharyngeal neoplasm* OR pharyngeal ca*ncer* OR oncology* OR nasopharyngeal cancer* OR salivary gland ca*ncer* OR salivary gland neoplasm* OR parotid ca*ncer* OR parotid neoplasm* OR hypopharyngeal cancer* OR oropharyngeal squamous cell carcinoma* OR occult primary OR unknown primary OR squamous cell carcinoma
PTG	“post-traumatic growth*” OR “posttraumatic growth*” OR “PTG*” OR “posttraumatic growth inventory*” OR “perceived benefit*” OR “stress-related growth*” OR “stress related growth*” “adversarial growth*” OR “existential growth*” OR “psychological growth*” OR “emotional growth*” OR “self-transform*ation” OR “transformational cop*ing” OR “positive psychological change*” OR “positive change*” OR thriv* OR “personal growth*” OR “positive psychological outcome*” OR “positive adjustment*” OR “positive adaptation*” OR “meaning-making*” OR “meaning making*” OR “sense making*”

Appendix D: Data Extraction form



R	S	T	U	V	W	X	Y	Z	AA	AB	AC	AD	AE	AF	AG
% haNC	Tumour type / stage	Stage	Treatmen	Time p treatm	PTG prin outcom	PTG mea used	What the PTG measure	Includes subsc of the PTG mea	PTG overall sc	means and SD subscales of t	Secondary outco and measure	conti gro	Analyses	significant findings	overview of findings
91.5% - excluding thyroid but paper have included this as a HNC	Others - n=40 (20.9%), nasopharyngeal - n=107 (53.5%), oral - n=36 (18.0%), thyroid - n=17 (8.5%)	Stage 1 and 2 - n=97 (48.5%), stage 3 and 4 - n=103 (51.5%	Time point one - Chemotherapy (n=136), radiotherapy (n=100), surgery (n=99). Time point two - chemotherapy (n = 167), radiotherapy (n=142), surgery (n=99).	M=3.37 months (SD 1.63) at time point 1; M=9.54 months (SD = 4.64) at time two.	yes	Malay version of the PTGI-SF	The PTGI-SF is a self-reported tool of 10 items across fi		Baseline - m=33.7 (SD=11.5), follow up - m=39.5 (SD=9.3), p value <0.001*	not reported	Predictor variables: health related QoL, Sociodemographics (gender, age, religion, monthly income, edcation level, Tumour characteristic (HNC type, time since diagnosis, cancer stage and type of treatment	none	repeated measures mixed effect model - linear regression	Mean total of PTG scores: Baseline - m=33.7 (SD=11.5), follow up - m=39.5 (SD=9.3), p value <0.001*. Gender - CI(95%) = -2.811(-5.140 to -0.483) p=0.018*. Religion - Islam - CI (95%) =5.519 (0.462 to 12.577) p=0.035*. Buddhism CI(55%) = 7.357 (0.765 to 13.949) p=0.029*. QoL variables - problems with the senses CI(95%) = -0.093 (-0.142 to -0.025) p=0.005*. Problems with social contact CI(95%) = -0.150 (-0.229 to 0.071) p=0.000(1*)	Females report higher PTG compared with males, Muliom and Buddist religions showed more PTG, higher social support is related to higher PTG, worse sensory problems were associated with PTG.



A longitudinal investigation of posttraumatic growth and its associated factors among head and neck cancer survivors

A	B	C	D	E	F	G	H	I	J	K	L	M	N	O	P
Study numbe	Title	Autho	Year	Counti	Design	Sampling method	sample siz	Age mean (	Gender	Ethncity	Relationship statu	SES	Religic	Smoking /alcoho	% haN
1	A longitudinal investigation of posttraumatic growth and its associated factors among head and neck cancer survivors														
2 - EXCLUDE_NO RESULTS PUBLISHED YET, PAPER DESCRIBING METHODS AND INTERVENTION PLANS	Acceptance and commitment therapy versus mindfulness-based stress reduction for newly diagnosed head and neck cancer patients: a randomised controlled trial assessing efficacy for postive psychology, depression, anxiety and quality of life	Zhang, Z et al.	2022	Malaysia	Three arm (ACT, mindfulness or TAU) double blind RCT	measures collected pre-intervention and post intervention at 2 time points									
3	Analysis of post traumatic growth status of patients with nasopharyngeal														

Appendix E: Risk of Bias Tool

William's Tool: Quality assessment of observational studies

- General instructions: Grade each criterion as "Yes," "No," "Partially," or "Can't tell."
- Factors to consider when making an assessment are listed under each criterion. Where appropriate (particularly when assigning a "No," "Partially," or "Can't tell" score), please provide a brief rationale for your decision (in parentheses) in the evidence table.

1) Unbiased selection of the cohort?

Factors that help reduce selection bias:

• Prospective study design and recruitment of subjects

• Inclusion/exclusion criteria

o Clearly described (especially re: age and cancer status)

o Assessed using valid and reliable measures

• *Recruitment strategy*

o Clearly described

o Relatively free from bias (selection bias might be introduced, e.g., by recruitment via advertisement)

2) Sample size calculated/5% difference?

Factors to consider:

• Did the authors report conducting a power analysis or describe some other basis for determining the adequacy of study group sizes for the primary outcome(s) of interest to us?

• Was the sample size sufficiently large to detect a clinically significant difference of 5% in event rates or an OR/RR increase of ≥ 1.5 or decrease of ≥ 0.67 between groups in at least one primary outcome measure of interest to us?

3) Adequate description of the cohort?

Consider whether the cohort is well-characterized in terms of baseline:

• Age

• Sex

E-2

• Race

• Educational level

• Cancer status

• For genetic association studies, were the diseased and non-diseased populations drawn from groups with the same ethnic/racial mix?

4) Validated method for predictor/outcome variables?

Factors to consider:

• Was the method used to ascertain exposure clearly described? (Details should be sufficient to permit replication in new studies.)

• Was a valid and reliable measure used to ascertain exposure? (Subjective measures based on self-report tend to have lower reliability and validity than objective measures such as clinical reports and lab findings.)

• For gene association studies, is the "call rate" of genotyping (the proportion of samples in which the genotyping provides an unambiguous reading) reported? Were quality checks implemented or rules established to determine when genotyping results would be considered valid?

To clarify your score, please make a note of the method/measure used to ascertain exposure.

5) Validated method for assessing PTG?

Factors to consider:

• Were primary outcomes (Post traumatic growth) assessed using valid and reliable measures? (See details below.)

• Were these measures implemented consistently across all study participants?

6) Adequate follow-up period?

Factors to consider:

• Follow-up period should be the same for all groups

o In cohort studies, length of follow-up should be the same across all groups.

o In nested case-control studies, period between the intervention/exposure and outcome should be the same for cases and controls.

o OK if differences in follow-up time were adjusted for using statistical techniques, e.g., survival analysis.

7) Minimal missing data?

Factors to consider:

• Did attrition from any group exceed 30%? (Attrition is measured in relation to the time between baseline/allocation and outcome measurement. Where different numbers of patients are followed up for different outcomes, use the number followed up for the primary outcome for this calculation.)

• Did attrition differ between groups by more than 10%?

8) Confounders controlled for?

Factors to consider:

• Did the analysis control for any baseline differences between groups?

• Does the study identify and control for important confounding variables and effect modifiers? (Confounding variables are risk factors that are correlated with the intervention/exposure and outcome and may therefore bias the estimation of the effect of intervention/exposure on outcome if unmeasured. Effect modifiers are not correlated with the intervention/exposure, but change the effect of the intervention/exposure on the outcome. Age, race/ethnicity, education, and measures of SES are examples of effect modifiers and confounding variables for the exposures and outcomes of interest in this study.)

9) Appropriate analyses?

Factors to consider:

• Was the kind of analysis done appropriate for the kind of outcome data?

o Dichotomous – logistic regression, survival

o Categorical – mixed model for categorical outcomes

o Continuous – ANCOVA, mixed model

• Was the analysis done on an intention-to-treat basis? (That is, was the impact of

loss to follow-up [or differential loss to followup] assessed, e.g., through sensitivity analysis or another intent-to-treat adjustment method?

• Was the number of variables used in the analysis appropriate for the sample size? (The statistical techniques used must be appropriate to the data and take into account issues such as controlling for small sample size, clustering, rare outcomes, multiple comparison, and number of covariates for a given sample size. The multiple comparisons issue may be a problem particularly when performance results on numerous PTG measures are being compared.
When assessing change on PTG measure over time, consider whether change score should be adjusted for baseline score, and consider distribution of baseline scores and change scores.)

• For gene association studies:

o Did the investigators conduct statistical tests to check whether the observed genotype frequencies are consistent with the Hardy-Weinberg Equilibrium?

o Did the investigators adjust for multiple comparisons?

Chapter two Empirical paper Appendices

Appendix F: Author guidelines for the Journal of Affective Disorders

Types of Papers

The Journal primarily publishes:

Full-Length Research Papers (up to 5000 words, excluding references and up to 6 tables/figures)

Preparation of Manuscripts

Articles should be in English. The title page should appear as a separate sheet bearing title (without article type), author names and affiliations, and a footnote with the corresponding author's full contact information, including address, telephone and fax numbers, and e-mail address (failure to include an e-mail address can delay processing of the manuscript).

Papers should be divided into sections headed by a caption (e.g., Introduction, Methods, Results, Discussion). A structured abstract of no more than 250 words should appear on a separate page with the following headings and order: Background, Methods, Results, Limitations, Conclusions (which should contain a statement about the clinical relevance of the research). A list of three to six key words should appear under the abstract.

Tables: Tables should be numbered consecutively with Arabic numerals and must be cited in the text in sequence. Each table, with an appropriate brief legend, comprehensible without reference to the text, should be typed on a separate page and uploaded online. Tables should be kept as simple as possible and wherever possible a graphical representation used instead. Table titles should be complete but brief. Information other than that defining the data should be presented as footnotes.

Highlights: Highlights are mandatory for this journal as they help increase the discoverability of your article via search engines. They consist of a short collection of bullet points that capture the novel results of your research as well as new methods that were used during the study (if any). Please have a look at the examples here: example Highlights.Please have a look at the examples here: example Highlights. Include 3 to 5 bullet points (maximum 85 characters, including spaces, per bullet point).

Full guidance can be found here: 506077 (elsevier.com)

Appendix G: Ethical Approval Letters

Ymchwil Iechyd a Gofal Cymru
Health and Care Research Wales

NHS
Health Research Authority

Dr Peter Fisher
Primary Care and Mental Health
Eleanor Rathbone Building
Liverpool
L69 3GB

Email: approvals@hra.nhs.uk
HCRW.approvals@wales.nhs.uk

19 May 2022

Dear Dr Fisher

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title:	**Exploring the role metacognitive beliefs, self-compassion with emotional distress in adults with Head and Neck Cancer.**
IRAS project ID:	**306454**
Protocol number:	**UoL001673**
REC reference:	**22/LO/0185**
Sponsor	**University of Liverpool**

I am pleased to confirm that **HRA and Health and Care Research Wales (HCRW) Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?
HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?
HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?

The standard conditions document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

Who should I contact for further information?
Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **306454**. Please quote this on all correspondence.

Yours sincerely,

Natalie Wilson
Approvals Manager

Email: camberwellstgiles.rec@hra.nhs.uk

Copy to: *Miss Karen Wilding, Sponsor contact*

NHS
Health Research Authority
London - Camberwell St Giles Research Ethics Committee
Ground Floor
Temple Quay House
2 The Square
Bristol
BS1 6PN

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

19 May 2022

Dr Peter Fisher
Primary Care and Mental Health
Eleanor Rathbone Building
Liverpool
L69 3GB

Dear Dr Fisher

Study title:	**Exploring the role metacognitive beliefs, self-compassion with emotional distress in adults with Head and Neck Cancer.**
REC reference:	**22/LO/0185**
Protocol number:	**UoL001673**
IRAS project ID:	**306454**

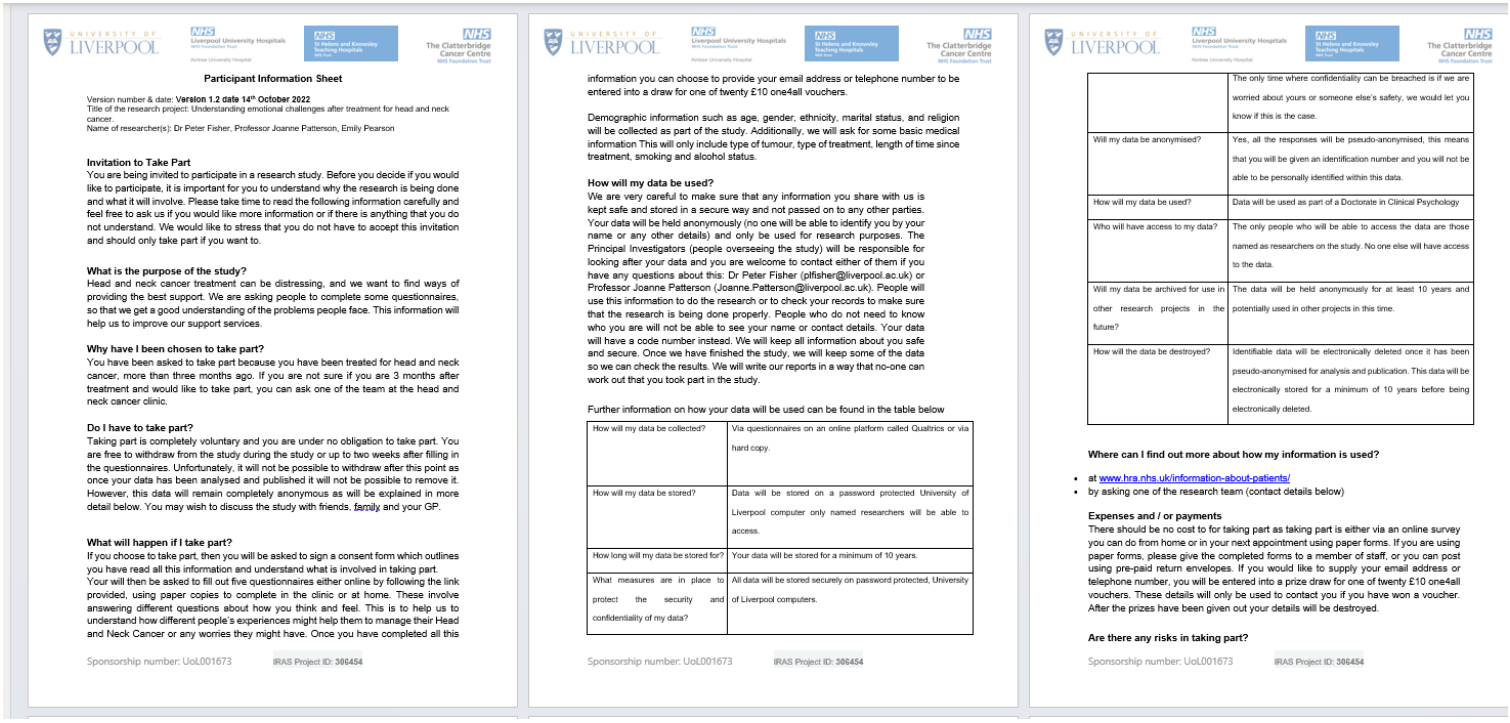
Thank you for your letter of 13th May 2022, responding to the Research Ethics Committee's (REC) request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair Mark Tanner, Hilary Lavender and Susan Harrison.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Appendix H: Participant Information Sheet



Participant Information Sheet

Version number & date: **Version 1.2 date 14th October 2022**
Title of the research project: Understanding emotional challenges after treatment for head and neck cancer.
Name of researcher(s): Dr Peter Fisher, Professor Joanne Patterson, Emily Pearson

Invitation to Take Part
You are being invited to participate in a research study. Before you decide if you would like to participate, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and feel free to ask us if you would like more information or if there is anything that you do not understand. We would like to stress that you do not have to accept this invitation and should only take part if you want to.

What is the purpose of the study?
Head and neck cancer treatment can be distressing, and we want to find ways of providing the best support. We are asking people to complete some questionnaires, so that we get a good understanding of the problems people face. This information will help us to improve our support services.

Why have I been chosen to take part?
You have been asked to take part because you have been treated for head and neck cancer, more than three months ago. If you are not sure if you are 3 months after treatment and would like to take part, you can ask one of the team at the head and neck cancer clinic.

Do I have to take part?
Taking part is completely voluntary and you are under no obligation to take part. You are free to withdraw from the study during the study or up to two weeks after filling in the questionnaires. Unfortunately, it will not be possible to withdraw after this point as once your data has been analysed and published it will not be possible to remove it. However, this data will remain completely anonymous as will be explained in more detail below. You may wish to discuss the study with friends, family and your GP.

What will happen if I take part?
If you choose to take part, then you will be asked to sign a consent form which outlines you have read all this information and understand what is involved in taking part.
Your will then be asked to fill out five questionnaires either online by following the link provided, using paper copies to complete in the clinic or at home. These involve answering different questions about how you think and feel. This is to help us to understand how different people's experiences might help them to manage their Head and Neck Cancer or any worries they might have. Once you have completed all this

Sponsorship number: UoL001673 IRAS Project ID: 306454

information you can choose to provide your email address or telephone number to be entered into a draw for one of twenty £10 one4all vouchers.

Demographic information such as age, gender, ethnicity, marital status, and religion will be collected as part of the study. Additionally, we will ask for some basic medical information This will only include type of tumour, type of treatment, length of time since treatment, smoking and alcohol status.

How will my data be used?
We are very careful to make sure that any information you share with us is kept safe and stored in a secure way and not passed on to any other parties. Your data will be held anonymously (no one will be able to identify you by your name or any other details) and only be used for research purposes. The Principal Investigators (people overseeing the study) will be responsible for looking after your data and you are welcome to contact either of them if you have any questions about this: Dr Peter Fisher (plfisher@liverpool.ac.uk) or Professor Joanne Patterson (Joanne.Patterson@liverpool.ac.uk). People will use this information to do the research or to check your records to make sure that the research is being done properly. People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead. We will keep all information about you safe and secure. Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

Further information on how your data will be used can be found in the table below

How will my data be collected?	Via questionnaires on an online platform called Qualtrics or via hard copy.
How will my data be stored?	Data will be stored on a password protected University of Liverpool computer only named researchers will be able to access.
How long will my data be stored for?	Your data will be stored for a minimum of 10 years.
What measures are in place to protect the security and confidentiality of my data?	All data will be stored securely on password protected, University of Liverpool computers.

Sponsorship number: UoL001673 IRAS Project ID: 306454

	The only time where confidentiality can be breached is if we are worried about yours or someone else's safety, we would let you know if this is the case.
Will my data be anonymised?	Yes, all the responses will be pseudo-anonymised, this means that you will be given an identification number and you will not be able to be personally identified within this data.
How will my data be used?	Data will be used as part of a Doctorate in Clinical Psychology
Who will have access to my data?	The only people who will be able to access the data are those named as researchers on the study. No one else will have access to the data.
Will my data be archived for use in other research projects in the future?	The data will be held anonymously for at least 10 years and potentially used in other projects in this time.
How will the data be destroyed?	Identifiable data will be electronically deleted once it has been pseudo-anonymised for analysis and publication. This data will be electronically stored for a minimum of 10 years before being electronically deleted.

Where can I find out more about how my information is used?

- at www.hra.nhs.uk/information-about-patients/
- by asking one of the research team (contact details below)

Expenses and / or payments
There should be no cost to for taking part as taking part is either via an online survey you can do from home or in your next appointment using paper forms. If you are using paper forms, please give the completed forms to a member of staff, or you can post using pre-paid return envelopes. If you would like to supply your email address or telephone number, you will be entered into a prize draw for one of twenty £10 one4all vouchers. These details will only be used to contact you if you have won a voucher. After the prizes have been given out your details will be destroyed.

Are there any risks in taking part?

Sponsorship number: UoL001673 IRAS Project ID: 306454

There are no known risks to taking part in this study. However, some of the questions will ask about your mood which some people might find upsetting. If you do experience any distress taking part, then we would recommend you contacting your GP. Other helpful charities and organisations to contact should you experience any distress include:

- Samaritans. To talk about anything that is upsetting you, you can contact Samaritans 24 hours a day, 365 days a year. You can call 116 123 (free from any phone), email jo@samaritans.org or visit some branches in person. You can also call the Samaritans Welsh Language Line on 0808 164 0123 (7pm–11pm every day).
- National Suicide Prevention Helpline UK. Offers a supportive listening service to anyone with thoughts of suicide. You can call the National Suicide Prevention Helpline UK on 0800 689 5652 (open 24/7).
- Campaign Against Living Miserably (CALM). You can call the CALM on 0800 58 58 58 (5pm–midnight every day) if you are struggling and need to talk. Or if you prefer not to speak on the phone, you could try the CALM webchat service.
- Papyrus HOPELINEUK. If you're under 35 and struggling with suicidal feelings, or concerned about a young person who might be struggling, you can call Papyrus HOPELINEUK on 0800 068 4141 (weekdays 10am-10pm, weekends 2pm-10pm and bank holidays 2pm–10pm), email pat@papyrus-uk.org or text 07786 209 697.
- Switchboard. If you identify as gay, lesbian, bisexual or transgender, you can call Switchboard on 0300 330 0630 (10am–10pm every day), email chris@switchboard.lgbt or use their webchat service. Phone operators all identify as LGBT+.
- C.A.L.L. If you live in Wales, you can call the Community Advice and Listening Line (C.A.L.L.) on 0800 132 737 (open 24/7) or you can text 'help' followed by a question to 81066.
- Helplines Partnership. For more options, visit the Helplines Partnership website for a directory of UK helplines. Mind's Infoline can also help you find services that can support you. If you're outside the UK, the Befrienders Worldwide website has a tool to search by country for emotional support helplines around the world.

Are there any benefits in taking part?
There are no known direct benefits to you in taking part in this study. However, we hope that by taking part in the research you will help to improve the support we can provide to other adults with Head and Neck cancer who experience low mood or anxiety.

What will happen to the results of the study?
The results of the study will be written up as part of a Doctorate in Clinical Psychology (qualification that allows someone to practice as a Clinical Psychologist) and will be published in a peer reviewed journal (where research is published and can be accessed). No one who has taken part will be identifiable to anyone reading the paper

Sponsorship number: UoL001673 IRAS Project ID: 306454

and your name will not appear in the paper. All who take part are welcome to hear about the results of the study and you will receive a copy of the paper and brief overview of the results. If you would not like to receive this please contact Emily Pearson (Emily.jayne.pearson@liverpool.ac.uk).

What will happen if I want to stop taking part?
If you decide that you would no longer like to take part while completing the questionnaires, you can stop your responses by closing the browser. However, all data already collected will be retained up until this point. If you complete the questionnaires and later decide you would like to withdraw your responses, you have up until two weeks after submitting to do so by emailing a member of the research team. As was explained above, once your data has been included in analysis and published it will not be possible to remove your data however it will all remain anonymous. If you wish to withdraw from the study or discuss this further, please get in contact with the research team who will be able to help you.

What if I am unhappy or if there is a problem?
If you are unhappy, or if there is a problem, please feel free to let us know by contacting Dr Peter Fisher (plfisher@liverpool.ac.uk, 01517944160) or Professor Joanne Patterson (Joanne.patterson@liverpool.ac.uk, 0151 795 1359) and we will try to help. If you remain unhappy or have a complaint which you feel you cannot come to us with then you should contact the Research Ethics and Integrity Office at ethics@liv.ac.uk. When contacting the Research Ethics and Integrity Office, please provide details of the name or description of the study (so that it can be identified), the researchers involved, and the details of the complaint you wish to make.

The University strives to maintain the highest standards of rigour in the processing of data and authorities responsible for the research may want to access the study to ensure appropriate measures have been taken. However, if you have any concerns about the way in which the University processes your personal data, it is important that you are aware of your right to file a complaint with the Information Commissioner's Office by calling 0303 123 1113.

Who can I contact if I have further questions?
If you have any further questions, please feel free to contact any of the research team:

Emily Pearson — Trainee Clinical Psychologist at the University of Liverpool, the project will be completed in partial completion of the Doctorate in Clinical Psychology. She is the main contact for the study.

Primary care and mental health, The Elanor Rathbone Building, Liverpool, L693GB.
Emily.jayne.pearson@liverpool.ac.uk
01517944160

Sponsorship number: UoL001673 IRAS Project ID: 306454

Dr Peter Fisher — Senior Lecturer in Clinical Psychology, University of Liverpool and an Honorary Consultant Clinical Psychologist at the Department of Clinical Health Psychology, Royal Liverpool, and Broadgreen NHS Trust.
Primary care and mental health, The Elanor Rathbone Building, Liverpool, L693GB.
plfisher@liverpool.ac.uk
01517944160

Professor Joanne Patterson — Professor of Speech and Language Therapy and Head and Neck Oncology, University of Liverpool and Liverpool Head & Neck Centre.

Thompson Yates Building, The Quadrangle, Brownlow Hill, Liverpool, L69 3GB
Joanne.patterson@liverpool.ac.uk
0151 795 1359

Reply slip

***Only complete this form if you are interested in taking part in the study and would like us to contact you** to answer any questions you may have about the study.*

Name: _____

Contact details:

Daytime: _____

Evening: _____

Email: _____

Please tick your preferred contact time(s)

Morning (9am –12 noon) ☐
Afternoon (12noon – 3pm) ☐
Late afternoon (3pm-6pm) ☐
Early evening (6pm – 8pm) ☐

Sponsorship number: UoL001673 IRAS Project ID: 306454

Appendix I: Consent Form

Participant consent form

Version 1.2 dated 14th October 2022

Title of project: Understanding emotional challenges after head and neck cancer treatments.

Centre Number: Study Number:

Participant Identification Number:

Please initial box

1. I confirm that I have read the information sheet dated 14th October 2022 (version 1.2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. ☐
3. I understand that the information collected about me may be used to support other research in the future and may be shared anonymously with other researchers. ☐
4. I understand that my records may be accessed to obtain information about cancer diagnoses and treatments received as well as some basic demographic information such as age, and gender. ☐
5. I am aware that all information will be kept strictly confidential except in the rare circumstances in which it is judged that I am or someone else is at risk of serious harm. ☐
6. I would like to receive the lay summary of the study results. ☐
7. I agree to take part in the above study. ☐

_____	_____	_____
Name of Participant	Date	Signature
_____	_____	_____
Name of Person taking consent	Date	Signature

One copy of this form is for participant, and one is for the researcher

Sponsorship number: UoL001673
IRAS Project ID: 306454

Appendix J: Debrief Sheet.

~~Participant~~ debrief sheet

Version 1.0 dated 16th February 2022

Title of project: Understanding emotional challenges after head and neck cancer treatments.

There are no known risks to taking part in this study. However, some of the questions will ask about your mood which some people might find upsetting. If you do experience any distress taking ~~part~~ then we would recommend you contacting your GP. Other helpful charities and organisations to contact should you experience any distress include:

- Samaritans. To talk about anything that is upsetting you, you can contact Samaritans 24 hours a day, 365 days a year. You can call 116 123 (free from any phone), email jo@samaritans.org or visit some branches in person. You can also call the Samaritans Welsh Language Line on 0808 164 0123 (7pm–11pm every day).

- National Suicide Prevention Helpline UK. Offers a supportive listening service to anyone with thoughts of suicide. You can call the National Suicide Prevention Helpline UK on 0800 689 5652 (open 24/7).

- Campaign Against Living Miserably (CALM). You can call the CALM on 0800 58 58 58 (5pm–midnight every day) if you are struggling and need to talk. Or if you prefer not to speak on the phone, you could try the CALM webchat service.

- Papyrus HOPELINEUK. If you're under 35 and struggling with suicidal feelings, or concerned about a young person who might be struggling, you can call Papyrus HOPELINEUK on 0800 068 4141 (weekdays 10am-10pm, weekends 2pm-10pm and bank holidays 2pm–10pm), email pat@papyrus-uk.org or text 07786 209 697.

- Switchboard. If you identify as gay, lesbian, bisexual or transgender, you can call Switchboard on 0300 330 0630 (10am–10pm every day), email chris@switchboard.lgbt or use their webchat service. Phone operators all identify as LGBT+.

- C.A.L.L. If you live in Wales, you can call the Community Advice and Listening Line (C.A.L.L.) on 0800 132 737 (open 24/7) or you can text 'help' followed by a question to 81066.

- Helplines Partnership. For more options, visit the Helplines Partnership website for a directory of UK helplines. Mind's Infoline can also help you find services that can support you. If you're outside the UK, the Befrienders Worldwide website has a tool to search by country for emotional support helplines around the world.

Appendix K: Hospital Anxiety and Depression Scale

Hospital Anxiety and Depression Scale (HADS)

Tick the box beside the reply that is closest to how you have been feeling in the past week.
Don't take too long over you replies: your immediate is best.

D	A		D	A	
		I feel tense or 'wound up':			**I feel as if I am slowed down:**
	3	Most of the time	3		Nearly all the time
	2	A lot of the time	2		Very often
	1	From time to time, occasionally	1		Sometimes
	0	Not at all	0		Not at all
		I still enjoy the things I used to enjoy:			**I get a sort of frightened feeling like 'butterflies' in the stomach:**
0		Definitely as much		0	Not at all
1		Not quite so much		1	Occasionally
2		Only a little		2	Quite Often
3		Hardly at all		3	Very Often
		I get a sort of frightened feeling as if something awful is about to happen:			**I have lost interest in my appearance:**
	3	Very definitely and quite badly	3		Definitely
	2	Yes, but not too badly	2		I don't take as much care as I should
	1	A little, but it doesn't worry me	1		I may not take quite as much care
	0	Not at all	0		I take just as much care as ever
		I can laugh and see the funny side of things:			**I feel restless as I have to be on the move:**
0		As much as I always could		3	Very much indeed
1		Not quite so much now		2	Quite a lot
2		Definitely not so much now		1	Not very much
3		Not at all		0	Not at all
		Worrying thoughts go through my mind:			**I look forward with enjoyment to things:**
	3	A great deal of the time	0		As much as I ever did
	2	A lot of the time	1		Rather less than I used to
	1	From time to time, but not too often	2		Definitely less than I used to
	0	Only occasionally	3		Hardly at all
		I feel cheerful:			**I get sudden feelings of panic:**
3		Not at all		3	Very often indeed
2		Not often		2	Quite often
1		Sometimes		1	Not very often
0		Most of the time		0	Not at all
		I can sit at ease and feel relaxed:			**I can enjoy a good book or radio or TV program:**
	0	Definitely	0		Often
	1	Usually	1		Sometimes
	2	Not Often	2		Not often
	3	Not at all	3		Very seldom

Please check you have answered all the questions

Scoring:
Total score: Depression (D) _____ Anxiety (A) _____
0-7 = Normal
8-10 = Borderline abnormal (borderline case)
11-21 = Abnormal (case)

Appendix L: Impact of Events Scale-Revised

IMPACT OF EVENTS SCALE-Revised (IES-R)

INSTRUCTIONS: Below is a list of difficulties people sometimes have after stressful life events. Please read each item, and then indicate how distressing each difficulty has been for you DURING THE PAST SEVEN DAYS with respect to _____ (event) that occurred on _____ (date). How much have you been distressed or bothered by these difficulties?

	Not at all	A little bit	Moderately	Quite a bit	Extremely
1. Any reminder brought back feelings about it	0	1	2	3	4
2. I had trouble staying asleep	0	1	2	3	4
3. Other things kept making me think about it.	0	1	2	3	4
4. I felt irritable and angry	0	1	2	3	4
5. I avoided letting myself get upset when I thought about it or was reminded of it	0	1	2	3	4
6. I thought about it when I didn't mean to	0	1	2	3	4
7. I felt as if it hadn't happened or wasn't real.	0	1	2	3	4
8. I stayed away from reminders of it.	0	1	2	3	4
9. Pictures about it popped into my mind.	0	1	2	3	4
10. I was jumpy and easily startled.	0	1	2	3	4
11. I tried not to think about it.	0	1	2	3	4
12. I was aware that I still had a lot of feelings about it, but I didn't deal with them.	0	1	2	3	4
13. My feelings about it were kind of numb.	0	1	2	3	4
14. I found myself acting or feeling like I was back at that time.	0	1	2	3	4
15. I had trouble falling asleep.	0	1	2	3	4
16. I had waves of strong feelings about it.	0	1	2	3	4
17. I tried to remove it from my memory.	0	1	2	3	4
18. I had trouble concentrating.	0	1	2	3	4
19. Reminders of it caused me to have physical reactions, such as sweating, trouble breathing, nausea, or a pounding heart.	0	1	2	3	4
20. I had dreams about it.	0	1	2	3	4
21. I felt watchful and on-guard.	0	1	2	3	4
22. I tried not to talk about it.	0	1	2	3	4

Total IES-R Score:_____

INT: 1, 2, 3, 6, 9, 14, 16, 20
AVD: 5, 7, 8, 11, 12, 13, 17, 22
HYP: 4, 10, 15, 18, 19, 21

Weiss, D.S. (2007). The Impact of Event Scale-Revised. In J.P. Wilson, & T.M. Keane (Eds.) *Assessing psychological trauma and PTSD: a practitioner's handbook* (2nd ed., pp. 168-189). New York: Guilford Press.

AETR2N 22 1/13/2012

Appendix M: Metacognition Questionnaire-30

BetterMind BetterWorld HEALTHCARE

Client Information

Client Name	Test Client
Date of birth (age)	23 March 1980 (37)

Assessment Information

Assessment	Metacognition Questionnaire-30 (MCQ-30)
Date administered	18 April 2017
Assessor	Mr. Demo Assessor
Time taken	0 minutes 25 seconds

Results

	Raw Score	Percentile
Total Score	99	100
(Lack of) Cognitive Confidence	18	98.2
Positive Beliefs About Worry	22	100
Cognitive Self-Consciousness	22	98.7
Negative Beliefs About Uncontrollability and Danger	18	98.5
Need To Control Thoughts	19	100

Scoring and Interpretation Information

Subscale scores range from 6 to 24, and total scores range from 30 to 120, with higher scores indicating higher levels of unhelpful metacognitions (for example, high scores on "cognitive confidence" indicates distrust of memory and other unhelpful beliefs about their cognition). Results are also presented as percentiles based on a normative community sample (Wells & Cartweight-Hatton, 2004).

Subscales are calculated by summing the following items:
- (Lack of) Cognitive Confidence: 8, 14, 17, 24, 26 and 29
- Positive Beliefs about Worry: 1, 7, 10, 19, 23 and 28
- Cognitive Self-Consciousness: 3, 5, 12, 16, 18 and 30
- Negative Beliefs about Uncontrollability and Danger: 2, 4, 9, 11, 15 and 21
- Need to Control Thoughts: 6, 13, 20, 22, 25 and 27

Client Responses

		Do not agree	Agree slightly	Agree moderately	Agree very much
1	Worrying helps me to avoid problems in the future	1	2	3	**4**
2	My worrying is dangerous for me	1	2	**3**	4

BetterMind BetterWorld HEALTHCARE

Client Name Test Client

Client Responses (cont.)

		Do not agree	Agree slightly	Agree moderately	Agree very much
3	I think a lot about my thoughts	1	2	3	**4**
4	I could make myself sick with worrying	1	2	**3**	4
5	I am aware of the way my mind works when I am thinking through a problem	1	2	3	**4**
6	If I did not control a worrying thought, and then it happened, it would be my fault	1	2	**3**	4
7	I need to worry in order to remain organised	1	2	3	**4**
8	I have little confidence in my memory for words and names	1	2	**3**	4
9	My worrying thoughts persist, no matter how I try to stop them	1	2	**3**	4
10	Worrying helps me to get things sorted out in my mind	1	2	3	**4**
11	I cannot ignore my worrying thoughts	1	2	**3**	4
12	I monitor my thoughts	1	2	3	**4**
13	I should be in control of my thoughts all of the time	1	2	**3**	4
14	My memory can mislead me at times	1	2	3	**4**
15	My worrying could make me go mad	1	2	**3**	4
16	I am constantly aware of my thinking	1	2	**3**	4
17	I have a poor memory	1	2	**3**	4
18	I pay close attention to the way my mind works	1	2	3	**4**
19	Worrying helps me cope	1	2	**3**	4
20	Not being able to control my thoughts is a sign of weakness	1	2	3	**4**
21	When I start worrying, I cannot stop	1	2	**3**	4

Client Name Test Client

Client Responses (cont.)

		Do not agree	Agree slightly	Agree moderately	Agree very much
22	I will be punished for not controlling certain thoughts	1	2	**3**	4
23	Worrying help me to solve problems	1	2	3	**4**
24	I have little confidence in my memory for places	1	2	**3**	4
25	It is bad to think certain thoughts	1	2	**3**	4
26	I do not trust my memory	1	**2**	3	4
27	If I could not control my thoughts, I would not be able to function	1	2	**3**	4
28	I need to worry, in order to work well	1	2	**3**	4
29	I have little confidence in my memory for actions	1	2	**3**	4
30	I constantly examine my thoughts	1	2	**3**	4

Appendix N: Self-Compassion Scale

Self-Compassion Scale (SCS)

HOW I TYPICALLY ACT TOWARDS MYSELF IN DIFFICULT TIMES

Please read each statement carefully before answering. For each item, indicate how often you behave in the stated manner, using the following 1-5 scale. Please answer according to what really reflects your experience rather than what you think your experience should be.

Almost never				Almost always
1	2	3	4	5

1. I'm disapproving and judgmental about my own flaws and inadequacies.
2. When I'm feeling down I tend to obsess and fixate on everything that's wrong.
3. When things are going badly for me, I see the difficulties as part of life that everyone goes through.
4. When I think about my inadequacies, it tends to make me feel more separate and cut off from the rest of the world.
5. I try to be loving towards myself when I'm feeling emotional pain.
6. When I fail at something important to me I become consumed by feelings of inadequacy.
7. When I'm down, I remind myself that there are lots of other people in the world feeling like I am.
8. When times are really difficult, I tend to be tough on myself.
9. When something upsets me I try to keep my emotions in balance.
10. When I feel inadequate in some way, I try to remind myself that feelings of inadequacy are shared by most people.
11. I'm intolerant and impatient towards those aspects of my personality I don't like.
12. When I'm going through a very hard time, I give myself the caring and tenderness I need.
13. When I'm feeling down, I tend to feel like most other people are probably happier than I am.
14. When something painful happens I try to take a balanced view of the situation.
15. I try to see my failings as part of the human condition
16. When I see aspects of myself that I don't like, I get down on myself.
17. When I fail at something important to me I try to keep things in perspective.
18. When I'm really struggling, I tend to feel like other people must be having an easier time of it.
19. I'm kind to myself when I'm experiencing suffering.
20. When something upsets me I get carried away with my feelings.
21. I can be a bit cold-hearted towards myself when I'm experiencing suffering.
22. When I'm feeling down I try to approach my feelings with curiosity and openness.
23. I'm tolerant of my own flaws and inadequacies.
24. When something painful happens I tend to blow the incident out of proportion.
25. When I fail at something that's important to me, I tend to feel alone in my failure.
26. I try to be understanding and patient towards those aspects of my personality I don't like.

Reference

Neff, K. D. (2003). Development and validation of a scale to measure self-compassion. *Self and Identity*, 2, 223-250.