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From Diagnosis to Recovery: Emotional Wellbeing in Head and Neck Cancer

by

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Abstract

Receiving a diagnosis of head and neck cancer (HNC) can lead to shock and fear. Treatments such as radiotherapy and surgery are invasive and lead to significant side effects such as lack of saliva, poor nutrition and difficulties with eating and drinking. Research has shown that wellbeing and quality of life, both before and after treatment, impact recovery times and survival rates. This thesis explores patient experience from prehabilitation (the time between receiving a diagnosis and starting treatment) to the rehabilitation period and recovery posttreatment. This thesis aims to explore patients experiences of receiving diagnosis and treatment for HNC; considering the impact on mental wellbeing and the support patients need.

Chapter one provides a bridging chapter to introduce the two projects of this thesis. It considers aspects important to the research such as the patient journey, prehabilitation and personalised care – exploring the wider literature and barriers to implementing change. Ontological and epistemological positions are discussed alongside reflexivity.

Chapter two reports on the systematic review that explores the factors that help or harm quality of life in adults who have received treatment for HNC. This chapter uses a synthesis without meta-analysis, with an accompanying narrative synthesis to explore and summarise the data. The findings suggest that a range of factors influence quality of life, but that further research is required to better understand these relationships.

Chapter three explores the experiences of individuals diagnosed with HNC, specifically within the prehabilitation time period. The researcher also investigated what, if any, psychological support patients would have liked to have received during this time period. Four themes are presented: 1) cancer challenges, alters and expands self-view and identity; 2) coping strategies utilised to increase control – context is important; 3) dual states before treatment: normalcy vs living in limbo; 4) balancing act: getting the right support at the right time. The findings highlight the need for individualised care and summarises the findings within the context of the Common-Sense Model.

Keywords: oncology, cancer, head and neck, quality of life, prehabilitation

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Research Thesis: Declaration of Authorship

Print name: Holly Stokes

Title of thesis: From Diagnosis to Recovery: Emotional Support and Wellbeing in Head and Neck Cancer

I declare that this thesis and the work presented in it are my own and has been generated by me as the result of my own original research.

I confirm that:

1. This work was done wholly or mainly while in candidature for a research degree at this University;
2. Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
3. Where I have consulted the published work of others, this is always clearly attributed;
4. Where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
5. I have acknowledged all main sources of help;
6. Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
7. None of this work has been published before submission.

Signature: Date: 18/09/2025

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Definitions and Abbreviations

CASP	Critical Appraisal Skills Programme; provider of checklists for use in systematic reviews.
CNS	Clinical Nurse Specialist
CSM	Common Sense Model of illness self-regulation; a model to explain how people understand and react to illness.
ERGO	Ethics and Research Governance Online; system used by the University of Southampton to assess research and provide ethical approval.
HNC	Head and Neck Cancer; cancer that develops across the head and neck region.
HRQoL	Health-Related Quality of Life; an individual's subjective enjoyment, satisfaction and wellbeing as influenced by their health.
IRAS	Integrated Research Application System; system used by the NHS to assess research and provide ethical approval.
MDT	Multidisciplinary Team; a group of professionals with different training backgrounds who work together to provide care for patients in healthcare settings.
NHS	National Health Service; healthcare system for individuals living within the United Kingdom.
NICE	National Institute for Health and Care Excellence; a public body that creates recommendations and guidance for use within healthcare systems.
PICOSS	Population, Intervention, Comparator, Outcome, Study design and Setting; a framework designed to aid good research design.
PPI	Patient and Public Involvement; active involvement and collaboration with patients and/or members of the public throughout the research process.
PPT	Participant.
Prehabilitation	An extension of rehabilitation being used across healthcare settings which offers patients physical and mental health support prior to treatment with the aim to improve aspects of recovery.

PRISMA	Preferred Reporting Items for Systematic reviews and Meta-Analyses; guidelines to assist consistent reporting of systematic reviews.
PROSPERO	International prospective register of systematic reviews protocols.
QoL	Quality of Life; an individual's subjective enjoyment, satisfaction and wellbeing.
REC	Research Ethics Committee; a group who review and assess research proposals of research within the NHS to ensure they are ethically sound.
RTA	Reflexive Thematic Analysis.
SACT	Systemic Anti-Cancer Therapy; an overarching term used to encompass drug treatments (e.g., chemotherapy, hormone therapies) used to target cancer cells.
SWiM	Synthesis Without Meta-analysis; guideline to assist clear reporting in systematic reviews not using meta-analysis methods.
WHO	World Health Organisation.

From Diagnosis to Recovery: Emotional Wellbeing in Head and Neck Cancer

Chapter 1: Linking concepts and context; Processing and coping with head and neck cancer.

Head and neck cancer (HNC) is a general term that encompasses cancers that develop in the upper aerodigestive tract including the mouth, tongue and pharynx(1). The most common risk factors for developing HNC are smoking (including second-hand smoke), alcohol use and additionally the human papilloma virus (HPV) is linked to the development of oropharyngeal cancers(1-3). Over 12,000 people are diagnosed in the UK each year, among men it is the fourth most common type of cancer after prostate, lung and bowel cancer and it is less common in women than men(4, 5). In spite of this, it is under researched when compared to other forms of cancer due to challenges such as a lack of funding, the diverse and aggressive nature of tumours and a small number of large-scale randomised controlled trials(6-8).

The Impact of Cancer Diagnosis and Treatment

Receiving a diagnosis of cancer can be challenging and bring a range of emotions such as shock, anger and sadness(9, 10). Not only is cancer diagnosis associated with affect change but also social and economic impacts (for example financial strain as a result of being unable to work)(11). For those with HNC, anxiety, depression and general distress have been found to be highest at diagnosis(12-14), with depression appearing to persist throughout and beyond treatment(12). Additionally, depression has been found to be more prevalent in HNC patients when compared to those with other cancer diagnoses(15).

Suicidality has been found to be higher in cancer patients than the general population, and patients diagnosed with cancers that have a poor prognosis (such as HNC) are at increased risk of dying by suicide(16). The likelihood of suicide is greatest within six months of HNC diagnosis and those with hypopharyngeal cancers are associated with higher rates of suicide mortality(17). Qualitative research has found that after receiving their diagnosis, HNC patients can feel isolated, let down by others and have fears of the future or dying (18) which may contribute to the high levels of anxiety and depression found.

Treatments for HNC include surgery, radiotherapy, systemic anti-cancer therapies (e.g., chemotherapy or targeted drug therapies) or a combination of treatments(19, 20). These treatments can be complex, consist of high doses and can lead to significant side effects(21). Physical side effects can include dry mouth, difficulty swallowing or changes to taste, sticky saliva, loss of voice and physical disfigurement which can last from a few weeks to years posttreatment(22-24). Some patients also report that treatment impacts their cognitive abilities with symptoms such as attention deficits, memory loss and difficulties completing cognitive tasks (e.g., reasoning, organisation and planning)(24). These can occur as a result of structural changes to the brain from exposure to radiation(25).

Treatment for HNC and its significant side effects are associated with depression, anxiety, psychological distress and poor quality of life (QoL)(26, 27). Posttreatment, patients experience increased stigma (both internal and external) which has been linked to increased anxiety and a poor QoL(28, 29). Additionally, patients report feelings of loneliness and isolation which negatively impacts QoL(30). Isolation and stigma have been associated with withdrawal from socialising and embarrassment of the changes caused by treatment, for example increased risk of choking leading to not want to eat with others(31).

The trend of QoL shows that it is worst for patients during the first month of treatment and will return to pre-treatment levels after one year(32). Research into pre-treatment QoL suggests that in HNC patients it is lower than that of the general population(33), suggesting that although QoL improves posttreatment it may still be poor when compared to peers who have not experienced cancer. Depression and poor QoL have been associated with worse survival outcomes for patients(34-36). Alternatively, one study found that depression posttreatment was found to improve survival and that receiving psychological support was a protective factor(37).

Psychological Prehabilitation in Cancer Care

Prehabilitation is a term that encompasses the period between an individual receiving a physical health diagnosis and starting their treatment. The aim of prehabilitation in cancer services is to prepare patients for their treatment by providing support across three areas: exercise, nutrition and psychological support(38). The outcomes of these intend to strengthen the effectiveness of treatments, improve survival outcomes while increasing a patients sense of control and purpose(38, 39). Cancer prehabilitation can be delivered universally or through targeted, specialist support. Universal psychological support consists of general advice, signposting and self-help resources alongside compassionate and empathic communication, while targeted psychological support includes specialist interventions (e.g., solution-focused therapy or CBT) and is likely to be needed by those who have complexities or may be at risk of significant late side effects(38, 40).

There is a growing interest in prehabilitation over recent years(41), however it appears that within HNC research nutrition and exercise interventions are studied more frequently than psychological support(42). This section will therefore speak to psychological prehabilitation across cancer diagnoses due to the lack of literature within HNC.

Current literature on psychological prehabilitation in cancer suggests that while it does not appear have an impact on medical outcomes (such as survival) it does improve anxiety, pain and QoL(43, 44). This fits with findings exploring psychological prehabilitation prior to surgery for non-cancer diagnoses (such as bariatric surgery) which suggests that it is associated with reduced length of stay in hospital and postoperative pain(45). Additionally, psychological prehabilitation has been associated with increased immune function, reduced fatigue and improved mood(46). One narrative review concluded that when physical activity, nutrition and anxiety interventions are offered together in the prehabilitation period that this aids recovery and helps restore the ability to complete activities of daily living to baseline levels(47). Qualitative findings highlight patients report that psychological prehabilitation interventions increase a sense of control and confidence in their ability to cope while also allowing them to talk to people who understand their experience(48).

Many reviews of the literature report that current research into prehabilitation have high levels of bias or methodological flaw(46) and it is difficult to compare results due to high levels of heterogeneity and a lack of standardisation of the interventions or outcome measures used(41). In addition, there may be barriers to implementing prehabilitation interventions within cancer settings in the UK. Firstly, it may be important to consider who will benefit from psychological prehabilitation and if it is needed for all patients. Macmillan discuss different levels of intervention (universal and targeted/specialist)(38) however it is questioned if this could lead to increased patient burden. For example if universal support offers patients extra information and advice this may be adding to the already substantial levels of information patients receive and increase overwhelm(39). Secondly, the NHS is currently experiencing cuts to funding and staffing(49) and prehabilitation requires the input of a highly trained multi-disciplinary team (MDT) and a wide range of professionals(38, 39). Therefore, recommendations from research need to consider not only clinical implications but also take into account financial or staffing issues(41). Personalised approaches to research and outcomes of prehabilitation may help to overcome these barriers and may help to direct funding where it is needed, rather than apply broad interventions with high variability in their usefulness.

The Role and Challenges of Personalised Approaches

The findings across the literature base in cancer care suggest that a holistic approach should be taken - understanding all aspects of a person's experience (e.g., care needs, ability, spirituality etc.) and not just focussing on their illness or medical treatment plans(50). For example, when medical professionals can acknowledge psychological factors effecting the patient as a result of their cancer diagnosis (e.g., worry or uncertainty) wellbeing improves(51). These findings highlight the importance of acknowledging psychological and social aspects of patient experience, alongside their physical health needs.

Another example of why personalised care is important can be seen in research exploring gender. HNC is more prevalent in males, and it is unclear from the literature as to why this might be. One hypothesis is that men are more likely to smoke tobacco and drink alcohol(52), however another study found that men were more vulnerable to HNC regardless of tobacco or alcohol intake(53). Research on coping with cancer appears to be mixed with many citing that although there are some gender differences (e.g., males appear more likely to accept their diagnosis, where females may continue to socialise) there also appears to be overlap and similarities in coping strategies utilised (for example, in connection to spirituality)(54, 55). This suggests that it may not be helpful to view coping through a demographic, such as gender, alone.

There are barriers to personalised care when it comes to transferring the research into clinical practice. There can be clinical barriers including burnout in medical professionals which has been associated with increased unprofessionalism(56) and reduced empathy(57). Practical barriers within the current climate of the NHS can be seen in the recent cuts to staffing and prioritisation of financial savings(49) which are likely to impact both practical and clinical aspects of care and have the potential to negatively influence the application of personalised care.

In relation to holistic care, specifically psychosocial input, the researcher was able to use their current experience of working within a physical health hospital setting to reflect on the difficulties of psychological staff being integrated into medical multidisciplinary teams (MDT). This is reflected in NICE guidelines for HNC(58) which recommend that psychological services are extended members of the MDT who should be available when the medical team require psychological expertise or opinion. This means they may not be central to the MDT or be utilised consistently. Medical professionals report busy workloads, lack of training in psychosocial care alongside a lack of clarity in assessment and referral of psychosocial difficulties as barriers to psychological input for patients(59). These suggest that a lack of integration and understanding of psychosocial support could negatively impact the support that patients receive.

Epistemology and Ontology

The overall ontological approach for this thesis is pragmatism. A pragmatic ontological perspective allows researchers to hold multiple perceptions of one reality by seeking to find the truth through the researcher's observation(60). Pragmatism acknowledged that human behaviour is complex and encourages researchers to be curious, open and flexible(61). Traditionally, physical health holds a realist perspective which suggests that one knowable reality exists within the world that can be investigated and understood – recognising this truth can be influenced by personal beliefs or values(62). However, psychological research that is exploring human experience tends to sit within relativist perspectives. Relativism proposes that reality is a result of human interaction and that one objective truth is not possible as reality can vary across culture and experience(63). It was felt that pragmatism was a helpful approach for this thesis project which was straddling the worlds of both physical and mental health and also using both quantitative and qualitative research methods.

The systematic review used a post-positivist epistemology, combining a quantitative synthesis methodology with an additional narrative synthesis. The addition of the narrative element was felt to compliment and help to understand the quantitative findings. Post-positivism suggests that an objective reality exists and researchers should strive to find it. However, reality cannot be known perfectly and is dependent on context and bias(63). Therefore, the post-positivist approach allowed for an objective exploration of the factors that are related to long-term quality of life for HNC patients, while the narrative synthesis allowed for a contextual interpretation, acknowledging complexity.

A social constructionist approach was used for the empirical chapter. Constructionism believes that there is no knowable truth, but that reality is constructed through subjective experiences shaped by factors such as culture or language(64). Constructionist researchers have been described like artists – creating art with tools they have; this may be constrained by existing meaning and knowledge but aims to create a reality from language(63). For the empirical project, interviews were conducted where the interactions between researcher and participant constructed knowledge and a reality of the participants experiences.

Reflexivity

Researchers are encouraged to take ownership of their views and position when undertaking qualitative methodology(65). The motivation for this thesis came from my experience of being a Trainee Clinical Psychologist on placement in a hospice setting and working with male patients who were recovering from treatment for HNC. From working with these men I saw firsthand the impact that treatments like radiotherapy can have on someone's identity and quality of life. One example of this can be seen in men whose social and emotional outlets could be having a pint of beer with a friend, walking or eating nice meals. However, posttreatment, patients experienced physical pain, a lack of saliva or facial disfigurement meaning they were no longer able to drink alcohol, eat the same foods or in some cases developed speech impediments or changes to speech. These physical ailments led to patients becoming more isolated, experiencing fear of judgement from others and perceiving their lives as being more limited. I felt a great sense of accomplishment when my therapeutic input allowed patients to open their perspectives and increase their quality of life. It also raised questions around wanting to understand the wider context of healthcare systems for individuals with HNC and how patients are offered support throughout their cancer trajectory.

In the empirical project I recognised some challenges – particularly in relation to the overlap of being a therapist vs being an interviewer. I have worked in a variety of areas of mental health, am a qualified Cognitive Behavioural Therapist and am now completing a doctorate in Clinical Psychology. My idea for this project stemmed from my experiences and a desire to help people based on that previous experience. It was important throughout conducting the interviews to hold in mind that the participants were not asking for therapy but were contributing their views and experiences. While conducting the interviews, I therefore recognised the importance of using the reflexive log and meetings with the supervisory team to reflect on my personal beliefs or values (e.g., helping others) that might have led to deviations from the project aims or interview topic guide.

In addition, I acknowledged that I am a young female exploring a cancer that typically affects older males. The supervisory team were utilised particularly when setting up the empirical project to reflect on this and consider ways to prepare for this visible difference. One example of this is how the interview topic guide was prepared. It was recognised that the original draft was written from the context of a female working in mental health, using words such as stress and anxiety. This was then adapted to encourage participants to not get caught in any preconceptions or beliefs around specific words and create an open environment, leading to questions such as "how would you have dealt with difficult things that happen in life".

References

1. Gormley M, Creaney G, Schache A, Ingarfield K, Conway DI. Reviewing the epidemiology of head and neck cancer: definitions, trends and risk factors. Br Dent J [Internet]. 2022 PMC9652141]; 233(9):[780-6 pp.]. Available from: https://doi.org/10.1038/s41415-022-5166-x.
2. Dhull AK, Atri R, Dhankhar R, Chauhan AK, Kaushal V. Major Risk Factors in Head and Neck Cancer: A Retrospective Analysis of 12-Year Experiences. World J Oncol [Internet]. 2018; 9(3):[80-4 pp.]. Available from: https://doi.org/10.14740/wjon1104w.
3. Mariano LC, Warnakulasuriya S, Straif K, Monteiro L. Secondhand smoke exposure and oral cancer risk: A systematic review and meta-analysis. Tobacco Control [Internet]. 2022; 31:[597-607 pp.]. Available from: https://doi.org/10.1136/tobaccocontrol-2020-056393.
4. Macmillan. Head and neck cancer. n.d. [Available from: https://www.macmillan.org.uk/cancer-information-and-support/head-and-neck-cancer#:~:text=as%20rarer...-,Types%20of%20head%20and%20neck%20cancer,Tongue%20cancer.
5. Cancer Research UK. Cancer incidence for common cancers n.d. [Available from: https://www.cancerresearchuk.org/health-professional/cancer-statistics/incidence/common-cancers-compared#heading-One.
6. Sun GH, Houlton JJ, Moloci NM, MacEachern MP, Bradford CR, Prince ME, Jagsi R. Prospective head and neck cancer research: a four-decade bibliometric perspective. Oncologist [Internet]. 2013; 18(5):[584-91 pp.]. Available from: https://doi.org/10.1634/theoncologist.2012-0415.
7. Shuman AG, Entezami P, Chernin AS, Wallace NE, Taylor JM, Hogikyan ND. Demographics and efficacy of head and neck cancer screening. Otolaryngol Head Neck Surg [Internet]. 2010; 143(3):[353-60 pp.]. Available from: https://doi.org/10.1016/j.otohns.2010.05.029.
8. Bhat GR, Hyole RG, Li J. Head and neck cancer: Current challenges and future perspectives. Adv Cancer Res [Internet]. 2021; 152:[67-102 pp.]. Available from: https://doi.org/10.1016/bs.acr.2021.05.002.
9. Krieger T, Salm S, Dresen A, Cecon N. Cancer patients' experiences and preferences when receiving bad news: a qualitative study. J Cancer Res Clin Oncol [Internet]. 2023; 149:[3859-70 pp.]. Available from: https://doi.org/10.1007/s00432-022-04311-8.
10. Fortin J, Leblanc M, Elgbeili G, Cordova MJ, Marin MF, Brunet A. The mental health impacts of receiving a breast cancer diagnosis: A meta-analysis. Br J Cancer [Internet]. 2021; 125(11):[1582-92 pp.]. Available from: https://doi.org/10.1038/s41416-021-01542-3.
11. Alzehr A, Hulme C, Spencer A, Morgan-Trimmer S. The economic impact of cancer diagnosis to individuals and their families: a systematic review. Support Care Cancer [Internet]. 2022; 30(8):[6385-404 pp.]. Available from: https://doi.org/10.1007/s00520-022-06913-x.
12. Haisfield-Wolfe ME, McGuire DB, Soeken K, Geiger-Brown J, De Forge BR. Prevalence and correlates of depression among patients with head and neck cancer: A systematic review of implications for research. Oncol Nurs Forum [Internet]. 2009; 36(3):[E107-E25 pp.]. Available from: https://doi.org/10.1188/09.onf.e107-e125.
13. Jimenez-Labaig P, Aymerich C, Brana I, Rullan A, Cacicedo J, Gonzalez-Torres MA, et al. A comprehensive examination of mental health in patients with head and neck cancer: systematic review and meta-analysis. JNCI Cancer Spectrum [Internet]. 2024; 8(3):[pkae031 p.]. Available from: https://doi.org/10.1093/jncics/pkae031.

14. Wu YS, Lin PY, Chien CY, Fang FM, Chiu NM, Hung CF, et al. Anxiety and depression in patients with head and neck cancer: 6-month follow-up study. Neuropsychiatr Dis Treat [Internet]. 2016; 12:[1029-36 pp.]. Available from: https://doi.org/10.2147/NDT.S103203.

15. Martinez MC, Finegersh A, Baik FM, Holsinger FC, Starmer HM, Orloff LA, et al. Comorbid depression in patients with head and neck cancer compared with other cancers. JAMA Otolaryngol Head Neck Surg [Internet]. 2024; 150(12):[1097–104 pp.]. Available from: https://doi.org/10.1001/jamaoto.2024.3233.

16. Heinrich M, Hofmann L, Baurecht H, Kreuzer PM, Knuttel H, Leitzmann MF, Seliger C. Suicide risk and mortality among patients with cancer. Nat Med [Internet]. 2022; 28(4):[852-9 pp.]. Available from: https://doi.org/10.1038/s41591-022-01745-y.

17. Hanna JR, McCloy K, Anderson J, McKeever A, Semple CJ. Suicide and Head and Neck Cancer: A Systematic Review With Meta-Analysis and Narrative Synthesis. Psychooncology [Internet]. 2025; 34(7):[e70233 p.]. Available from: https://doi.org/10.1002/pon.70233.

18. Saghafi E, Andas CA, Bernson J, Kjeller G. Patients' experiences of adverse symptoms, emotions, and coping strategies in connection to treatment of head and neck cancer - an interview study. BMC Oral Health [Internet]. 2023; 23:[641 p.]. Available from: https://doi.org/10.1186/s12903-023-03366-4.

19. Kitamura N, Sento S, Yoshizawa Y, Sasabe E, Kudo Y, Yamamoto T. Current Trends and Future Prospects of Molecular Targeted Therapy in Head and Neck Squamous Cell Carcinoma. Int J Mol Sci [Internet]. 2020; 22(1). Available from: https://doi.org/10.3390/ijms22010240.

20. Mody MD, Rocco JW, Yom SS, Haddad RI, Saba NF. Head and neck cancer. Lancet [Internet]. 2021; 398(10318):[2289-99 pp.]. Available from: https://doi.org/10.1016/S0140-6736(21)01550-6.

21. Anderson G, Ebadi M, Vo K, Novak J, Govindarajan A, Amini A. An Updated Review on Head and Neck Cancer Treatment with Radiation Therapy. Cancers (Basel) [Internet]. 2021; 13(19). Available from: https://doi.org/10.3390/cancers13194912.

22. List MA, Bilir SP. Functional outcomes in head and neck cancer. Semin Radiat Oncol [Internet]. 2004; 14(2):[178-89 pp.]. Available from: https://doi.org/10.1053/j.semradonc.2003.12.008.

23. Brook I. Early side effects of radiation treatment for head and neck cancer. Cancer Radiother [Internet]. 2021; 25(5):[507-13 pp.]. Available from: https://doi.org/10.1016/j.canrad.2021.02.001.

24. Brook I. Late side effects of radiation treatment for head and neck cancer. Radiat Oncol J [Internet]. 2020 PMC7533405]; 38(2):[84-92 pp.]. Available from: https://doi.org/10.3857/roj.2020.00213.

25. Voon NS, Abdul Manan H, Yahya N. Cognitive Decline following Radiotherapy of Head and Neck Cancer: Systematic Review and Meta-Analysis of MRI Correlates. Cancers (Basel) [Internet]. 2021; 13(24). Available from: https://doi.org/10.3390/cancers13246191.

26. Hammermuller C, Hinz A, Dietz A, Wichmann G, Pirlich M, Berger T, et al. Depression, anxiety, fatigue, and quality of life in a large sample of patients suffering from head and neck cancer in comparison with the general population. BMC Cancer [Internet]. 2021; 21(1):[94 p.]. Available from: https://doi.org/10.1186/s12885-020-07773-6.

27. Lenze NR, Bensen JT, Yarbrough WG, Shuman AG. Characteristics and outcomes associated with anxiety and depression in a head and neck cancer survivorship cohort. Am J Otolaryngol [Internet]. 2022; 43(3):[1-6 pp.]. Available from: https://doi.org/10.1016/j.amjoto.2022.103442.

28. Zhang Y, Cui C, Wang Y, Wang L. Effects of stigma, hope and social support on quality of life among Chinese patients diagnosed with oral cancer: a cross-sectional study. Health Qual Life Outcomes [Internet]. 2020; 18(1):[112 p.]. Available from: https://doi.org/10.1186/s12955-020-01353-9.

29. Reyes IM, Arenilla MJ, Alarcon D, Jaenes JC, Trujillo M. Psychological impact after treatment in patients with head and neck cancer. Med Oral Patol Oral Cir Bucal [Internet]. 2023; 28(5):[e467-e73 pp.]. Available from: https://doi.org/10.4317/medoral.25878.

30. Dahill A, Al-Nakishbandi H, Cunningham KB, Humphris GM, Lowe D, Rogers SN. Loneliness and quality of life after head and neck cancer. Br J Oral Maxillofac Surg [Internet]. 2020 10; 58(8):[959-65 pp.]. Available from: https://dx.doi.org/10.1016/j.bjoms.2020.04.041.

31. Fitchett RC, Aldus EJ, Fitchett LR, Cross J. The lived experience of head and neck cancer patients receiving curative radiotherapy: A systematic review and meta-ethnography. Psychooncology [Internet]. 2018; 27(9):[2077-86 pp.]. Available from: https://doi.org/10.1002/pon.4790.

32. Hammerlid E, Silander E, Hörnestam L, Sullivan M. Health-related quality of life three years after diagnosis of head and neck cancer: A longitudinal study. Head and Neck [Internet]. 2001; 23(2):[113-25 pp.]. Available from: https://doi.org/10.1002/1097-0347(200102)23:2<113::Aid-hed1006>3.0.Co;2-w.

33. Borggreven PA, Verdonck-de Leeuw IM, Muller MJ, Heiligers ML, de Bree R, Aaronson NK, Leemans CR. Quality of life and functional status in patients with cancer of the oral cavity and oropharynx: pretreatment values of a prospective study. Eur Arch Otorhinolaryngol [Internet]. 2007; 264(6):[651-7 pp.]. Available from: https://doi.org/10.1007/s00405-007-0249-5.

34. Van der Elst S, Bardash Y, Wotman M, Kraus D, Tham T. The prognostic impact of depression or depressive symptoms on patients with head and neck cancer: A systematic review and meta-analysis. Head Neck [Internet]. 2021; 43(11):[3608-17 pp.]. Available from: https://doi.org/10.1002/hed.26868.

35. van Nieuwenhuizen AJ, Buffart LM, Langendijk JA, Vergeer MR, Voortman J, Leemans CR, Verdonck-de Leeuw IM. Health-related quality of life and overall survival: a prospective study in patients with head and neck cancer treated with radiotherapy. Qual Life Res [Internet]. 2021; 30(4):[1145-53 pp.]. Available from: https://doi.org/10.1007/s11136-020-02716-x.

36. Rieke K, Schmid KK, Lydiatt W, Houfek J, Boilesen E, Watanabe-Galloway S. Depression and survival in head and neck cancer patients. Oral Oncol [Internet]. 2017; 65:[76-82 pp.]. Available from: http://dx.doi.org/10.1016/j.oraloncology.2016.12.014.

37. Huang RW, Chang KP, Marchi F, Loh CYY, Lin YJ, Chang CJ, Kao HK. The impact of depression on survival of head and neck cancer patients: A population-based cohort study. Front Oncol [Internet]. 2022; 12:[1-8 pp.]. Available from: https://doi.org/10.3389/fonc.2022.871915.

38. Macmillan Cancer Support. Principles and guidance for prehabilitation within the management and support of people with cancer.; 2020.

39. Giles C, Cummins S. Prehabilitation before cancer treatment. BMJ [Internet]. 2019; 366:[1-2 pp.]. Available from: https://doi.org/10.1136/bmj.l5120.

40. Cancer Research UK. What is prehabilitation? 2024 [Available from: https://www.cancerresearchuk.org/about-cancer/treatment/prehabilitation/what-is-prehabilitation.

41. Coderre D, Brahmbhatt P, Hunter TL, Baima J. Cancer Prehabilitation in Practice: the Current Evidence. Curr Oncol Rep [Internet]. 2022; 24(11):[1569-77 pp.]. Available from: https://doi.org/10.1007/s11912-022-01304-1.

42. Seth I, Bulloch G, Qin KR, Xie Y, Sebastian B, Liew H, et al. Pre-rehabilitation interventions for patients with head and neck cancers: A systematic review and meta-analysis. Head Neck [Internet]. 2024; 46(1):[86-117 pp.]. Available from: https://doi.org/10.1002/hed.27561.

43. Tsimopoulou I, Pasquali S, Howard R, Desai A, Gourevitch D, Tolosa I, Vohra R. Psychological Prehabilitation Before Cancer Surgery: A Systematic Review. Ann Surg Oncol [Internet]. 2015; 22(13):[4117-23 pp.]. Available from: https://doi.org/10.1245/s10434-015-4550-z.

44. Scriney A, Russell A, Loughney L, Gallagher P, Boran L. The impact of prehabilitation interventions on affective and functional outcomes for young to midlife adult cancer patients: A systematic review. Psychooncology [Internet]. 2022; 31(12):[2050-62 pp.]. Available from: https://doi.org/10.1002/pon.6029.

45. Hall AE, Nguyen NH, Cascavita CT, Shariati K, Patel AK, Chen W, et al. The Impact of Psychological Prehabilitation on Surgical Outcomes: A Meta-analysis and Meta-regression. Ann Surg [Internet]. 2025; 281(6):[928-41 pp.]. Available from: https://doi.org/10.1097/SLA.0000000000006677.

46. Treanor C, Kyaw T, Donnelly M. An international review and meta-analysis of prehabilitation compared to usual care for cancer patients. J Cancer Surviv [Internet]. 2018; 12(1):[64-73 pp.]. Available from: https://doi.org/10.1007/s11764-017-0645-9.

47. Carli F, Gillis C, Scheede-Bergdahl C. Promoting a culture of prehabilitation for the surgical cancer patient. Acta Oncol [Internet]. 2017; 56(2):[128-33 pp.]. Available from: http://dx.doi.org/10.1080/0284186X.2016.1266081.

48. Powell R, Davies A, Rowlinson-Groves K, French DP, Moore J, Merchant Z. Impact of a prehabilitation and recovery programme on emotional well-being in individuals undergoing cancer surgery: a multi-perspective qualitative study. BMC Cancer [Internet]. 2023; 23(1):[1232 p.]. Available from: https://doi.org/10.1186/s12885-023-11717-1.

49. Triggle N. NHS plans 'unthinkable' cuts to balance books 2025 [Available from: https://www.bbc.co.uk/news/articles/cgle2xkg3wpo.

50. Sedhom R, Bates-Pappas GE, Feldman J, Elk R, Gupta A, Fisch MJ, Soto-Perez-de-Celis E. Tumor Is Not the Only Target: Ensuring Equitable Person-Centered Supportive Care in the Era of Precision Medicine. Am Soc Clin Oncol Educ Book [Internet]. 2024; 44(3):[e434026 p.]. Available from: https://doi.org/10.1200/EDBK_434026.

51. Street RL, Jr., Treiman K, Wu Q, Kranzler EC, Moultrie R, Mack N, Garcia R. Managing uncertainty and responding to difficult emotions: Cancer patients' perspectives on clinician response during the COVID-19 pandemic. Patient Educ Couns [Internet]. 2022; 105(7):[2137-44 pp.]. Available from: https://doi.org/10.1016/j.pec.2022.03.029.

52. Amercian Cancer Society. Risk Factors for Oral Cavity and Oropharyngeal Cancers 2021 [Available from: https://www.cancer.org/cancer/types/oral-cavity-and-oropharyngeal-cancer/causes-risks-prevention/risk-factors.html#:~:text=Oral%20cavity%20and%20oropharyngeal%20cancers%20are%20twice%20as%20common%20in,seen%20more%20often%20in%20men.

53. Park JO, Nam IC, Kim CS, Park SJ, Lee DH, Kim HB, et al. Sex Differences in the Prevalence of Head and Neck Cancers: A 10-Year Follow-Up Study of 10 Million Healthy People. Cancers (Basel) [Internet]. 2022; 14:[2521 p.]. Available from: https://doi.org/10.3390/cancers14102521.

54. Zhou J, Wang Z, Chen X, Li Q. Gender Differences in Psychosocial Outcomes and Coping Strategies of Patients with Colorectal Cancer: A Systematic Review. Healthcare (Basel) [Internet]. 2023; 11:[2591 p.]. Available from: https://doi.org/10.3390/healthcare11182591.

55. McCaughan E, Prue G, Parahoo K, McIlfatrick S, McKenna H. Exploring and comparing the experience and coping behaviour of men and women with colorectal cancer at diagnosis and during surgery. J Adv Nurs [Internet]. 2011; 67(7):[1591-600 pp.]. Available from: https://doi.org/10.1111/j.1365-2648.2010.05594.x.

56. Dyrbye LN, Massie FS, Eacher A, Harper W, Power D, Durning SJ, et al. Relationship between burnout and professional conduct and attitudes among US medical students. JAMA [Internet]. 2010; 304(11):[1173-80 pp.]. Available from: https://doi.org/10.1001/jama.2010.1318.

57. Thomas MR, Dyrbye LN, Huntington JL, Lawson KL, Novotny PJ, Sloan JA, Shanafelt TD. How do distress and well-being relate to medical student empathy? A multicenter study. J Gen Intern Med [Internet]. 2007; 22(2):[177-83 pp.]. Available from: https://doi.org/10.1007/s11606-006-0039-6.

58. National Institute for Clinical Excellence (NICE). Improving outcomes in head and neck cancers: The manual. 2004 [Available from: https://www.nice.org.uk/guidance/csg6/resources/improving-outcomes-in-head-and-neck-cancers-update-pdf-773377597.

59. Dilworth S, Higgins I, Parker V, Kelly B, Turner J. Patient and health professional's perceived barriers to the delivery of psychosocial care to adults with cancer: a systematic review. Psychooncology [Internet]. 2014; 23(6):[601-12 pp.]. Available from: https://doi.org/10.1002/pon.3474.

60. Maarouf H. Pragmatism as a Supportive Paradigm for the Mixed Research Approach: Conceptualizing the Ontological, Epistemological, and Axiological Stances of Pragmatism. International Business Research [Internet]. 2019; 12(9):[1-12 pp.]. Available from: https://doi.org/10.5539/ibr.v12n9p1.

61. Yvonne Feilzer M. Doing Mixed Methods Research Pragmatically: Implications for the Rediscovery of Pragmatism as a Research Paradigm. Journal of Mixed Methods Research [Internet]. 2009; 4(1):[6-16 pp.]. Available from: https://doi.org/10.1177/1558689809349691.

62. Tebes JK. Community science, philosophy of science, and the practice of research. Am J Community Psychol [Internet]. 2005; 35(3/4):[213-30 pp.]. Available from: https://doi.org/10.1007/s10464-005-3399-x.

63. Braun V, Clarke V. Thematic analysis: A practical guide. London, England: SAGE Publications Ltd; 2022.

64. Burr V. What is Social Constructionism? 2024. In: Social Constructionism [Internet]. London: Routledge; [1-30]. Available from: https://doi.org/10.4324/9781003335016.

65. Braun V, Clarke V. One size fits all? What counts as quality practice in (reflexive) thematic analysis? Qualitative Research in Psychology [Internet]. 2020; 18(3):[328-52 pp.]. Available from: https://doi.org/10.1080/14780887.2020.1769238.

Chapter 2: What helps or harms quality of life following treatment for head and neck cancer: A synthesis without meta-analysis (SWiM).

Abstract

Background: Head and Neck cancer (HNC) is the eighth most common cancer in the UK. Rates of survival are increasing due to early diagnosis and treatment improvements. Quality of life (QoL) explores physical, social and psychological domains of wellbeing in relation to an individual's health or diagnosis. Factors such as age, distress and side effects of treatment, have been found to impact QoL across cancer research.

Aims: This systematic review aimed to explore what helps or harms QoL, in adults over time, following treatment for HNC.

Method: A systematic search was conducted across Ovid MEDLINE, APA PsycINFO and Web of Science, following PRISMA and SWiM guidelines. Analysis was conducted via an effect direction plot, sign tests and a follow-up narrative synthesis to aid interpretation of the results. Quality was assessed using the CASP checklist for cohort studies.

Results: Eighteen studies were included in this review. 37 different factors were identified as being associated with QoL. These were categorised across six domains: psychological factors, cancer related factors, treatment type, demographics, smoking/alcohol use and side effects. Only the categories of cancer type and side effects significantly showed a negative direction of effect on QoL.

Conclusion: These findings highlight that a range of factors are found to influence QoL over time for HNC patients but that there is also large variability within data collection and results. Further research is needed to better understand the relationship between treatment, demographic and psychological factors on long-term QoL.

Background

Head and neck cancer (HNC) is the eighth most common cancer in the UK(1), with more than 12,000 people diagnosed each year(2). Rates have been rising over time, particularly in the diagnosis of oropharyngeal cancer(3). HNC develops within the upper aerodigestive tract, including the mouth, throat and nose(4). The majority of HNC start in the squamous cells (cells within the outermost surface of skin in the head and neck region)(2). Common causes of head and neck cancer include smoking, alcohol intake and human papillomavirus (HPV) infection(5). Survival rates for cancer patients are increasing, with early diagnosis and improvements in cancer treatments being cited as potential reasons(6, 7). It is predicated that by 2040, 25% of over 65-year-olds in the UK will be cancer survivors(6); this is compared to 2008 where survival rates were predicted at 13%(8).

Treatment for HNC includes a combination of surgery, radiotherapy and systemic anti-cancer treatments (SACT), such as chemotherapy and immunotherapy(9). Side effects of treatment can have significant impact on an individual's life, and in the short-term can lead to symptoms such as difficulties swallowing, hair loss, poor nutrition and pain(10, 11). Some side effects can be chronic and continue beyond the end of treatment. There can be physical symptoms such as permanent saliva loss, tooth decay and fibrosis, in addition to psychological or cognitive changes such as difficulties concentrating, poor memory or mood instability(12). These can lead to significant changes in appearance, challenges with communicating and difficulties completing activities of daily life (such as working, eating or drinking)(12). Psychologically, this can impact mood with patients experiencing fear of recurrence, increased sense of vulnerability or low mood(13).

Mental wellbeing and quality of life have many different definitions. The World Health Organization (WHO) defines mental health and wellbeing as having an ability to cope with life stresses, capability to engage with life and activities, and to hold positive relationships(14). People with mental health diagnoses are more likely to experience reduced mental wellbeing(14). Quality of life (QoL) is a broad term that explores an individual's subjective view of their enjoyment of life in the context of their environment, culture and values(15). Within oncology research, the term health-related QoL (HRQoL) is used interchangeably with QoL. It is a multidimensional construct that explores someone's wellbeing across physical, social and psychological domains in relation to a health or diagnosis(16).

Research into QoL has been growing with patient-reported outcomes being recognised as a beneficial measure in medical and health settings. Questionnaires have been developed to use with patients across health conditions and have been validated in cancer populations (including HNC) to explore QoL across physical, social and psychological domains (e.g., University of Washington Quality of Life Questionnaire (UW-QOL) and the European Organisation for Research and Treatment Centre (EORTC) questionnaire(17)). Using patient-reported outcomes (such as the EORTC) can improve care quality, track progress over time and by involving patients can improve the relationship between patient and professional(18). QoL has been deemed to be an important clinical and research outcome and has been found to inform treatment choice over outcomes such as survival and recovery; however professionals appear to underestimate levels of patient QoL(19).

QoL for HNC patients has been found to be at its lowest during treatment, with negative effects being found most predominantly during the first month(20, 21). Most QoL domains improve over time and it has been found that, for most patients, scores will return to pre-treatment levels after a year(20). However, HNC patients' pre-treatment scores may not be reflective of the general population, suggesting that their overall scores of QoL may be lower than those without cancer(22). In addition, greater QoL both pre- and posttreatment has been associated with better survival outcomes, whereas QoL deterioration within the first year, is linked with worse survival outcomes(23).

Across cancer diagnoses, factors such as age, fatigue and income have been found to influence patient wellbeing and QoL posttreatment(24, 25). Social and emotional support from family has been found to reduce distress and predict positive QoL, more so than support from health professionals(26). Demographic factors, such as older age and female gender, have been associated with a lower QoL(27, 28). Whereas cancer and treatment-related factors, such as having surgery only, or an early-stage tumour are associated with improved QoL(29). Two recent narrative reviews highlight that an increased stage of cancer with additional negative side effects are associated with a worse QoL(30, 31). Psychological factors such as resilience and optimism are associated with higher QoL(32, 33). In addition, those who view their illness negatively have been found to score their QOL lower than those with a neutral or positive appraisal(34). Smoking has been associated with a reduced QoL(24, 35, 36) while moderate alcohol intake has been found to increase wellbeing(37, 38). It is hypothesised that moderate alcohol intake offers stress relief, enhances social interaction and a sense of normality after cancer treatment(38, 39). Awareness of these factors could help medical professionals identify patients who may be at risk of reduced QoL posttreatment.

As deaths from HNC are reducing over time, the result is that more patients are surviving(40). With the significant and complicated side effects following treatment for patients who survive HNC, it is important to consider what factors improve or reduce an individual's QoL over time. This may provide direction on how healthcare professionals can support patients to cope with their symptoms and have continued meaning in life.

While prior reviews have explored QoL in cancer they have not considered it from a longitudinal perspective and appear to look across cancer diagnoses, leaving HNC underexplored. Additionally, this review uses a synthesis without meta-analysis (SWiM) methodology. This provides a structured approach when meta-analysis cannot be undertaken as a result of heterogeneity and/or missing data. Previous studies have relied on narrative synthesis to understand the current literature, whereas the use of the SWiM in this review uses predefined rules and structured reporting to reduce bias and improve transparency and reproducibility.

This systematic review aims to explore what helps or harms QoL following treatment for HNC. Long-term QoL in HNC patients has been explored and discussed within current research but there does not appear to be any systematic review at present exploring the current aims. Specifically, this review aimed to explore what biological, psychological or social factors are associated with QoL, measured longitudinally (pre-treatment and posttreatment) using at least one QoL measure. The objective of this review is to provide a SWiM of the quantitative literature.

Methods

A SWiM design(41) was used due to incomplete data reporting and low quality of the study designs(42). In addition, it is advised that reviews exploring longitudinal data do not complete meta-analysis due to risk of bias in the outcomes(43). A follow-up narrative synthesis was conducted. The study was registered with PROSPERO (international prospective register of systematic reviews) - assigned protocol ID: CRD42024588655. This systematic review followed PRISMA(44) and SWiM(41) recommended guidelines.

Eligibility Criteria

The eligibility criteria (Table S1) used the PICOSS framework (population, intervention, comparator, outcome, study design and setting)(45). Only studies written in English were considered (this included papers where English translation was available). Only peer-reviewed literature published since the year 2000 were included. Research that investigated cancers of the oesophagus, skin and thyroid were excluded as these are often not included in the overarching title of HNC in epidemiological and research studies(3).

Table S1

Inclusion and Exclusion Criteria

	Inclusion Criteria	Exclusion Criteria
Population	Head and neck cancer diagnosis. Adult (18y +). Human.	Diagnosis of cancer other than head and neck or of the oesophagus, skin and/or thyroid. No cancer diagnosis. Children. Animals.
Intervention	Treatment as usual.	Psychological intervention (e.g., groups/therapy) aimed at improving quality of life.
Comparator	Pre- and post-measures.	Single time point.

Outcome	Outcomes related to patients' post-cancer treatment psychological condition and quality of life. Valid quality-of-life measure used.	Survival. Non-valid or no quality-of-life measure used.
Study Design	Published studies. Quantitative research including RCTs, non-RCT and observational studies.	Qualitative research. Book chapters. Protocols. Conference proceedings. Unpublished studies. Case reports.
Setting	Hospital. Hospice. Community.	

Search Strategy

Initial database searches were completed in November 2024. Searches were performed across three databases: Ovid MEDLINE, APA PsycINFO and Web of Science using Boolean search techniques. Following consultation with a research librarian, the search terms used were well-being OR "quality of life" OR "mental health" AND ((Cancer or neoplasm*), (head OR neck OR throat OR oral OR oropharyngeal OR pharyn* OR tongue OR mouth OR laryn* OR paranasal OR nasal OR "squamous cell" OR salivary)) AND (predictor* OR determinant* OR antecedent* OR indicator*). Search terms were used at both title and abstract level.

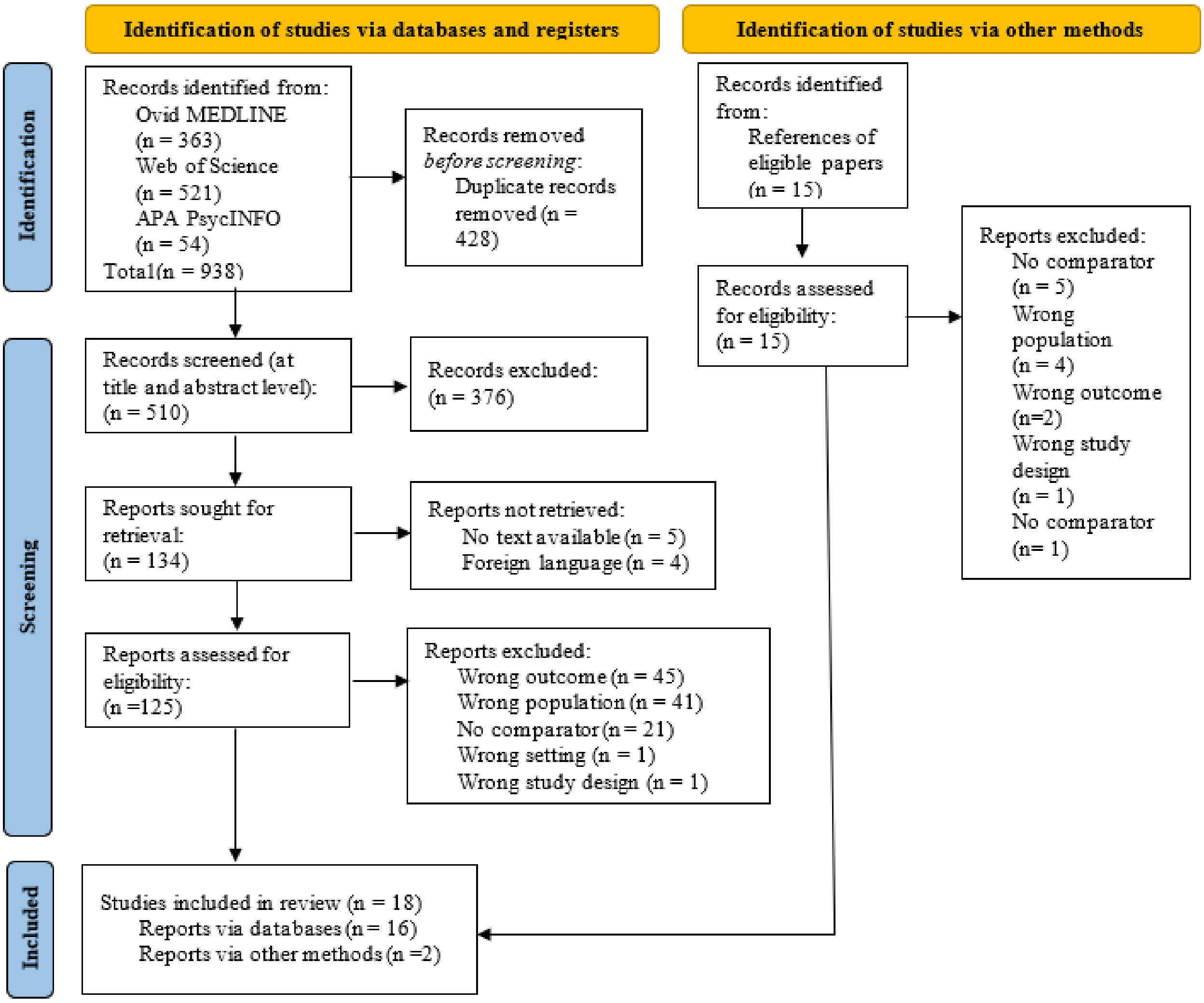
Selection Process

To aid screening and selection the web-based tool, Rayyan, was used(46). The primary researcher conducted a title and abstract search. The identified studies were then screened against the inclusion and exclusion criteria at full text level. Stoll et al.(47) recommends that a second, independent, reviewer is used. For this process, the second reviewer (a doctoral student) screened a random selection of 10% of papers, blind to the primary researcher's decisions, at both the title/abstract and full text levels. Any discrepancies were discussed between the reviewers, considering the eligibility criteria, until an agreement was reached. The second reviewer screened a total of 64 papers (51 initially and 13 subsequently). Agreement was high, with 82.9% of papers (53 out of 64) requiring no discussion. The 11 papers that needed resolution (eight initially and three subsequently) mostly related to the cancer site (e.g., thyroid or oesophagus needing to be excluded) and QoL (e.g., the paper focussed on specific QoL such as voice, rather than global QoL).

Figure S1 shows the number of studies selected, screened and included or excluded from this review. Initial database searches identified 938 records, of these 428 were removed as duplicates. 510 papers were screened at title/abstract level where 376 were excluded due to not meeting inclusion criteria. 134 papers were sought for full text retrieval; five could not be sourced and four were not in the English language. Of the 125 papers assessed for eligibility, 109 were excluded for not meeting inclusion criteria (see supplementary materials S1 for further details). Of these 16 eligible papers, the reference lists were searched at title level. This identified 15 papers, for which the full texts were assessed for eligibility, with 2 meeting the inclusion criteria. This resulted in18 papers being included in the final review.

Figure S1

PRISMA 2020 flow diagram



Quality Assessment

The quality of each included study was assessed using the Critical Appraisal Skills Programme (CASP) checklist for cohort studies(48). Each study was rated by the primary researcher on 12 questions, across three categories (validity, results and generalisability). Every question is marked as 'yes', 'no', or 'can't tell'. A summary table (see supplementary materials S2) was created to summarise the overall quality of each paper but does not provide an overall 'score'. CASP do not provide specific guidance for rating papers. However, they do suggest that studies can be categorised as high, moderate or low quality based on the researcher's assessment(49). The researcher categorised papers as low quality if four or more questions were rated as 'no' or 'can't tell', moderate quality if two to three questions were rated as 'no' or 'can't tell' and as high quality if zero to one were rated as 'no' or 'can't tell'. All studies were included following the quality assessment, however, four papers had four or more 'no' ratings, suggesting higher levels of bias or methodological flaw (see supplementary materials S2). For transparency the four papers have also been clearly identified in analysis tables.

Data Extraction

Data was extracted from eligible studies by the primary researcher. Initial data extraction was collected based on the PICOSS and consisted of 1) author and study design; 2) patient characteristics (including age, gender, cancer type, treatment received and any other demographic information reported); 3) time points of data collection; 4) questionnaires used; 5) variables found to be associated with global QoL; 6) any other relevant information (including location of research and limitations). See a summary of extracted data in Table S2.

Synthesis Methods

SWiM guidelines were followed for this systematic review(41). Heterogeneity was assessed informally by tabulating study and patient characteristics (see Table S2) Considerable heterogeneity was found among the included studies, particularly in the reporting of patient characteristics such as cancer stage or education level, length of follow-up and variation in the findings. Additionally, effect sizes were inconsistently reported across the included studies(42) and therefore a meta-analysis was not possible.

Instead, the alternative synthesis method of vote counting, based on direction of effect, was used. Based on guidance by Boon and Thomson(50) an effect direction plot was created. Firstly, the researcher reviewed the outcomes of each study, identified common themes and grouped these into overarching categories: 1) psychological factors (which encompassed pessimism, anxiety, depression and low hope); 2) cancer related factors (increased comorbidity, higher stage, bigger size of tumour and cancer site); 3) treatment type; 4) demographics (older age, single, lower education and lower income); 5) smoking or alcohol use and 6) side effects (poor physical functioning or low performance score). Once these had been categorised, the direction of effect on QoL was counted within each study and sign tests were completed. A sign test is a nonparametric test that looks at the direction of change (positive or negative effect). The sign tests were used in this review to explore if there was adequate evidence to reject the null hypothesis - that the positive or negative effect on QoL is likely due to chance, rather than the specific domain. Two-tailed *p*-values for each overarching domain were calculated using GraphPad (https://www.graphpad.com/quickcalcs/binomial1/). If the direction of effect was not reported in the study, it was excluded from the calculation as it could not be confirmed if the direction of effect was positive or negative – specific studies are referred to in the results section. Two papers were not included in the analysis as they found no factors to be predictive of global QoL(51, 52).

A follow-up narrative synthesis of the factors associated with QoL was completed to allow for a more meaningful summary of the included studies. For consistency, the groupings for the SWiM analysis were used in the narrative synthesis.

Results

A summary of the results and study characteristics are provided in Table S2. The results are reported within the six categories used for analysis (psychological factors, cancer related factors, treatment, demographics, smoking/alcohol use and side effects), incorporating both the SWiM and narrative syntheses. Table S3 shows the effect direction plot and the narrative data extraction tables can be found in supplementary materials S3-S8.

Study Characteristics

Eighteen studies were included in this systematic review. They reported 2448 participants – studies reported demographic information at different data collection points with seven reporting at time one (baseline) and 11 reporting at the final time point. At each study's final time point of data collection, sample size ranged from 36 to 316. Of the 2448 participants, 1890 (77%) were male. Only 15 of the studies reported the mean age of participants (M=58.5 years, range= 46.7-64). Two studies did not provide specific data on cancer site; the 16 studies that did reported that patients HNC affected the pharynx (n=655), tongue (n=472), oral cavity (n=452), larynx (n=306), tonsils (n=146), other (n=78), and soft palate (n=34). Studies reported a variety of treatments, with most reporting that patients were treated by surgery alone (n=14), followed by radiotherapy + surgery (n=11), radiotherapy alone (n=7), surgery + radio-chemotherapy (n=6), radiotherapy + chemotherapy (n=3), chemotherapy alone (n=1), radiotherapy, cetuximab + surgery (n=1) and surgery + chemotherapy (n=1).

The studies were conducted across 10 countries: The Netherlands (n=4), France (n=3), Germany (n=2), China (n=2), Canada (n=1), Turkey (n=1), Sweden (n=1), Spain (n=1), UK (n=1), USA (n=1) and Taiwan (n=1). The majority of studies used the European Organization for Research and Treatment of Cancer Questionnaire (EORTC QLQ-C30; n=12) alongside the EORTC HNC QoL module (EORTC QLQ-H&N35; n=11). The remaining studies used the University of Washington Quality of Life Questionnaire (UW-QOL; n=3), Functional Assessment of Cancer Therapy – Head and Neck Scale (FACT-HN; n=2) and the 36-Item Short Form Survey (SF-36; n=1). Of the 18 studies included, eight used an additional psychological measure: Hospital Anxiety and Depression Scale (HADS; n=3), Centre for Epidemiologic Studies – Depression (CES-D, n=2), Life Orientation Test (measuring levels of optimism; LOT, n=1), Geriatric Depression Scale (GDS-5, n=1), and the Herth Hope Index (HHI, n=1). Length of follow-up varied across the studies with most final time points being 12 months post-treatment (n=7), followed by six-months (n=4), three-months (n=3), three years (n=2), 10-months (n=1), and two and half months (n=1).

The most commonly studied variables were age (n=18), cancer site (n=18) and gender (n=17). Across the 18 studies, 37 different variables were found to be significantly associated with global QoL. Two studies found that no variables were significantly associated with a change in QoL over time(51, 52). The factors most reported to influence QoL were treatment (n=7), cancer stage (n=5), age (n=5), and tobacco/alcohol use (n=5).

Table S2

Summary of the results and study characteristics

Author (date)	**Country (area)**	**Study design**	**Measurement time points**	**Total sample at last time point**	**HNC site (n)**	**QoL measure**	**Other psychological measures used**	**Variables associated with QoL**
Allison et al. (2000)	France	Observational	T1 = prior to treatment. T2 = 3 months posttreatment T3 = 12 months posttreatment	88	Oral (23) Pharyngeal (27) Laryngeal (38)	EORTC QLQ-C30	LOT	High optimism (+) High pessimism (-) Comorbidity (-) Treatment modality Cancer site
Alvarez-Camacho et al. (2016)	Canada (Northern Alberta)	Longitudinal	T1 = prior to treatment. T2 = end of treatment T3 = 2.5 months posttreatment	85	Pharynx (88) Larynx (36) Oral cavity (18) Other (salivary glands, nasal cavity & paranasal sinuses) (18)	UW-QoL v3	None	High chemosensory complaint score (-) Advanced tumour stage (-) Pharynx (-) Never-smoker (+) Older age (+)
Borggreven et al. (2007)	The Netherlands (Amsterdam)	Prospective longitudinal	T1 = pretreatment T2 = 6-month follow-up T3 = 12-month follow-up	45	Oral cavity (38) Oropharynx (42)	EORTC QLQ-C30 EORTC QLQ-H&N35	None	Not having a partner (-) Older age (-)

Table S2 Continued

Author (date)	Country (area)	Study design	Measurement time points	Total sample at last time point	HNC site (n)	QoL measure	Other psychological measures used	Variables associated with QoL
Bozec et al. (2019)	France	Prospective multicentric	T1 = pretreatment T2 = 6-months posttreatment	129	Oral cavity (83) Oropharynx (41) Hypopharynx (20) Larynx (56)	EORTC QLQ-C30 EORTC QLQ-H&N35	None	No predictive factors of global QOL.
Bozec et al. (2018)	France	Prospective multicentric	T1= pretreatment T2 = at least 1 year posttreatment	58	Base of tongue (26) Lateral pharyngeal wall (40) Posterior pharyngeal wall (5) Soft palate (34)	EORTC QLQ-C30 EORTC QLQ-H&N35	HADS	Alcohol/tobacco consumption before or after treatment (-) HADS score (higher psychological distress) (-)
Citak & Tulek. (2013)	Turkey (Istanbul)	Prospective	T1 = start of treatment T2 = end of treatment T3 = 1 month posttreatment T4 = 3 months posttreatment	54	Larynx (36) Oral cavity (10) Pharynx (8)	EORTC QLQ-C30 EORTC QLQ-H&N35	None	>60yo (+) Lower education level (+) Lower income (+) Radiotherapy (+) Malnourished (-)

Table S2 Continued

Author (date)	Country (area)	Study design	Measurement time points	Total sample at last time point	HNC site (n)	QoL measure	Other psychological measures used	Variables associated with QoL
De Graeff et al. (2000)a	The Netherlands	Prospective longitudinal	T1 = before treatment T2 = 6 months posttreatment T3 = 12 months posttreatment T4 = 24 months posttreatment T5 = 36 months posttreatment	107	Oral cavity (49) Oropharynx (7) Hypopharynx (3) Larynx (46) Double tumour (2)	EORTC QLQ-C30 EORTC QLQ-H&N35	CES-D	Female (-) Higher stage (-) Combination treatments (-)
De Graeff et al. (2000)b	The Netherlands	Prospective	T1 = before treatment T2 = 6 months posttreatment T3 = 12 months	153	Larynx treated with radiotherapy (67) Oral cavity or oropharynx treated with surgery (35) Oral cavity or oropharynx treated with surgery or radiotherapy (40) Hypopharynx or larynx treated with surgery and radiotherapy (11)	EORTC QLQ-C30 EORTC QLQ-H&N35	CES-D	Depressive symptoms (-) Older age (-) Low performance score (-) Combination treatment (-)

Table S2 Continued

Author (date)	Country (area)	Study design	Measurement time points	Total sample at last time point	HNC site (n)	QoL measure	Other psychological measures used	Variables associated with QoL
Hammerlid et al. (2001)	Sweden (Göteborg)	Longitudinal	T1 = weekly tumour conference T2-6 = 5 times during the first year. T7 = 3 years after diagnosis	133	Larynx (43) Oral cavity (74) Pharyngeal (64) Other – sinus and nose, unknown primary, salivary gland (51)	EORTC QLQ-C30 EORTC QLQ-H&N35	HADS	< 65yo (+) Pharyngeal (-) Small tumour (+) Poor physical functioning (-) Depression at diagnosis (-)
Oskam et al. (2010)	The Netherlands (Amsterdam)	Prospective	T1 = before treatment T2 = 6 months posttreatment	55	Oral cavity (38) Oropharynx (42)	EORTC QLQ-C30 EORTC QLQ-H&N35	None	Emotional functioning. Physical functioning. Pain. Fatigue. Nausea and vomiting. Dyspnoea. Insomnia. Diarrhoea. Trouble with social contacts.

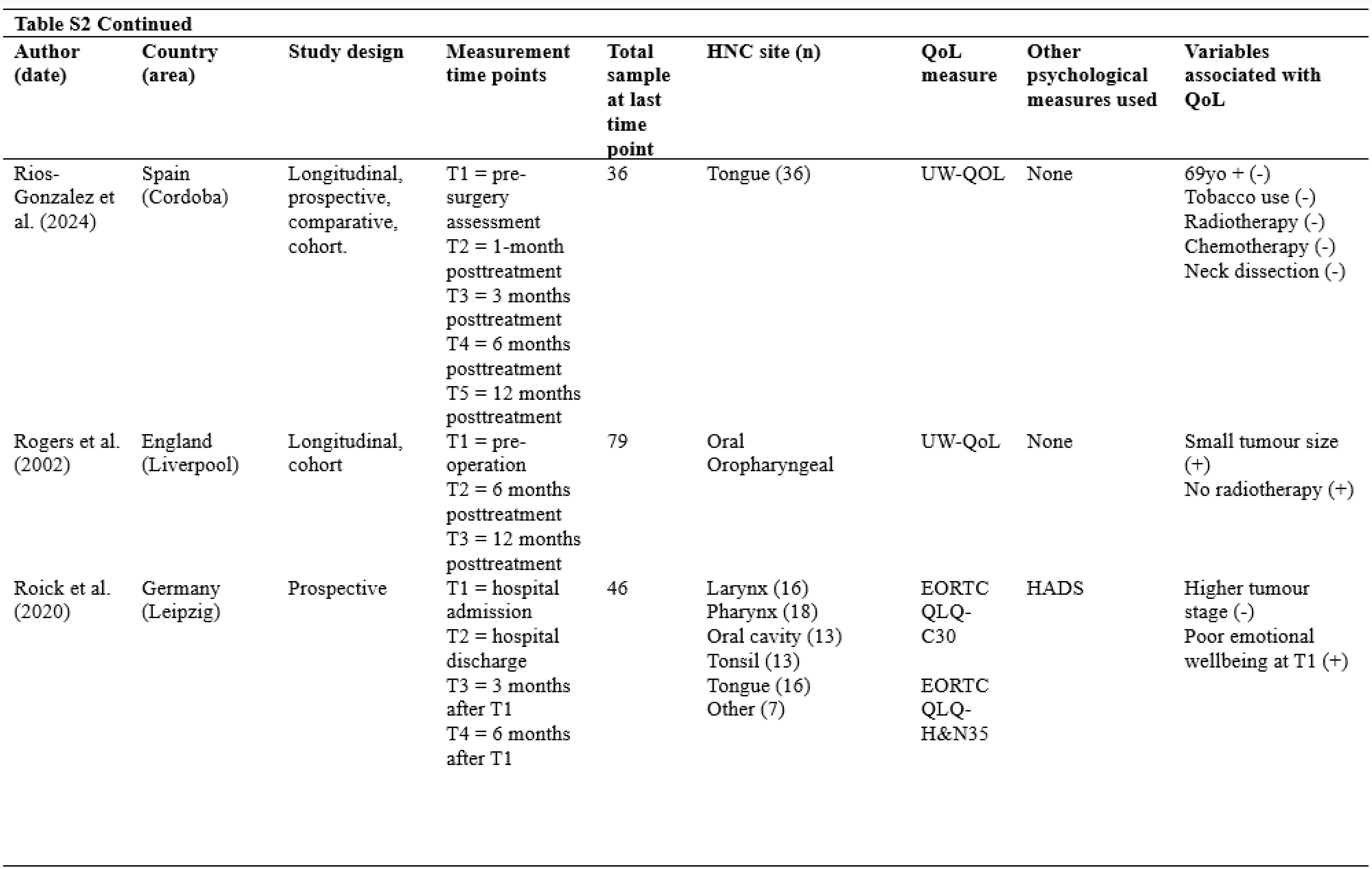


Table S2 Continued

Author (date)	Country (area)	Study design	Measurement time points	Total sample at last time point	HNC site (n)	QoL measure	Other psychological measures used	Variables associated with QoL
Rios-Gonzalez et al. (2024)	Spain (Cordoba)	Longitudinal, prospective, comparative, cohort.	T1 = pre-surgery assessment T2 = 1-month posttreatment T3 = 3 months posttreatment T4 = 6 months posttreatment T5 = 12 months posttreatment	36	Tongue (36)	UW-QOL	None	69yo + (-) Tobacco use (-) Radiotherapy (-) Chemotherapy (-) Neck dissection (-)
Rogers et al. (2002)	England (Liverpool)	Longitudinal, cohort	T1 = pre-operation T2 = 6 months posttreatment T3 = 12 months posttreatment	79	Oral Oropharyngeal	UW-QoL	None	Small tumour size (+) No radiotherapy (+)
Roick et al. (2020)	Germany (Leipzig)	Prospective	T1 = hospital admission T2 = hospital discharge T3 = 3 months after T1 T4 = 6 months after T1	46	Larynx (16) Pharynx (18) Oral cavity (13) Tonsil (13) Tongue (16) Other (7)	EORTC QLQ-C30 EORTC QLQ-H&N35	HADS	Higher tumour stage (-) Poor emotional wellbeing at T1 (+)

Table S2 Continued.

Author (date)	**Country (area)**	**Study design**	**Measurement time points**	**Total sample at last time point**	**HNC site (n)**	**QoL measure**	**Other psychological measures used**	**Variables associated with QoL**
Ronis et al. (2008)	United States of America (Michigan)	Longitudinal, cohort	T1 = before treatment T2 = 1 year later.	316	Oral cavity (68) Pharynx, oropharynx, hypopharynx, nasopharynx or unknown primary site (169)	SF-36 HNQoL	GDS-5	Depression (-) Smoking Feeding tube at T2 (-)
Tamer et al. (2020)	China (Changsha City, Hunan Province)	Prospective, comparative	T1 = before surgery T2 = 1 month after surgery T3 = 3 months after surgery	265	First part of tongue (214) Second part of tongue (51)	FACT-H&N	None	Diet (+)
Tsan et al. (2021)	Taiwan	Prospective, correlational	T1 = after diagnosis, before treatment T2 = during 3rd-4th week of treatment T3 = last week of treatment T4 = 1 month posttreatment T5 = 3 months posttreatment	54	Hypopharyngeal (7) Oropharyngeal (9) Oral (38)	FACT-H&N	HHI (traditional Chinese version).	Increased symptom severity (-) Increased hope (+) Time (3-months posttreatment) (+)

Table S2 Continued

Author (date)	**Country (area)**	**Study design**	**Measurement time points**	**Total sample at last time point**	**HNC site (n)**	**QoL measure**	**Other psychological measures used**	**Variables associated with QoL**
Veldhuis et al. (2016)	Germany	Prospective	T1 = prior to treatment T2 = 10 months posttreatment	67	Oropharynx (32) Larynx (35)	EORTC QLQ-C30 EORTC QLQ-H&N35	None	None
Yin et al. (2020)	China (Hebei)	Cohort	T1 = pretreatment T2 = 3-6 months posttreatment	294	Base of tongue (129) Tonsil (133) Glossopharyngeal sulcus (32)	EORTC QLQ-C30 EORTC QLQ-H&N35	None	Married (+) Drinking alcohol (-) Smoking (-) Earlier stage (T1) (+) Surgery (-) Combination treatment (-)

Note. CES-D: Center for Epidemiologic Studies Depression Scale; EORTC QLQ-30: core quality of life European Organization for Research and Treatment of Cancer Questionnaire; EORTC QLQ-H&N35: head and neck cancer specific quality of life questionnaire from European Organisation for Research and Treatment of Cancer; FACT-H&N: Functional Assessment of Cancer Therapy – head and neck; GDS-5: Geriatric Depression Scale-5; HADS: Hospital Anxiety and Depression Scale; HHI: Herth Hope Index; HNQoL: Head and Neck Quality of Life Instrument; LOT: Life Orientation Test; SF-36: 36-Item Short Form Health Survey; UW-QoL v3: University of Washington Quality of Life Questionnaire.

Psychological Factors

For psychological factors, the SWiM analysis found that eight of the included studies reported at least one psychological factor was correlated with an improved or reduced QoL. One(53) of seven studies(20, 54-58) showed that individuals presenting with psychological distress were associated with an improved QoL and one(59) did not report the direction of effect. The two-tailed p-value for the sign test is $p = .125$.

In the narrative synthesis, four studies highlighted that depression was associated with a poorer quality of life(20, 55-57), with one specifying that QoL is impacted posttreatment when depression is evident pre-treatment(20). Alternatively, one study(53) reported that poor emotional wellbeing at time-point one positively affected QoL after treatment. Other studies found that higher levels of optimism(54) and hope(58) were associated with better QoL posttreatment. The Hospital Anxiety and Depression Scale (HADS) was the most used measure of psychological distress with three(20, 53, 55) out of the eight studies using it. There is large variety across the studies in relation to patient reported variables, treatment and study quality meaning that tentative conclusions should be made.

Cancer Related Factors

Six studies in the SWiM analysis reported that a factor associated with cancer (e.g., site or stage) was correlated with a poor QoL(20, 53, 60-63) ($p = .031$). One study(54) did not report any direction of effect.

Two studies in this narrative synthesis reported a correlation between cancer of the pharynx and reduced QoL(20, 60). Four studies reported that cancer diagnosed at a higher stage was associated with lower QoL(53, 60, 61, 63). Two studies reported that smaller sized tumours are associated with improved QoL(20, 62). All but one study(60) used the EORTC QLQ-30 to measure QoL. There was large variety in the sample sizes and in the follow-up duration.

Treatment Type

In the treatment domain, the SWiM analysis found that one(64) out of seven studies(56, 57, 61-63, 65) reported that a type of treatment was associated with a positive QoL (*p* = .125). One study(54) did not report a direction of effect.

The narrative synthesis found that one study reported treatment modality influenced QoL but did not specify which treatments were associated or the direction of effect(54). Radiotherapy, chemotherapy, surgery, neck dissection and combinations of treatments were found to be correlated with a lower QoL (56, 61, 63, 65). Alternatively, one study found that radiotherapy was associated with a better QoL(64). One study reported that individuals with a feeding tube a year after treatment were associated with a decreased QoL(57). All but one(63) study's sample was exploring cancers of the oral cavity, pharynx and larynx. The majority of studies used the EORTC-QLQ-30 to measure QoL. There is some variety in sample size (range 36-316) and follow- up period; the shortest being three months and the longest being 36 months posttreatment.

Demographics

For the demographics domain, the SWiM analysis found that three(20, 60, 64) out of eight studies(56, 61, 63, 65, 66) showed that a patient's demographic information was associated with a positive QoL (*p* = .727).

In the narrative synthesis, a range of demographic factors were identified across eight of the included studies as impacting QoL negatively, such as older age(20, 56, 65, 66), not having a partner(63, 66), and female gender(61). Alternatively, two studies found that older age was associated with a better QoL(60, 64). Patients with a lower education level and income were also found to have an improved QoL(64). There was variety in the patient variables reported, for example not all studies collected information on marital status, income or education and again there was large range in the sample sizes (range 36-294) and follow-up length (range two and a half months to three years). Therefore, tentative conclusions should be made.

Smoking or Alcohol Use

Five studies(55, 57, 60, 63, 65) associated smoking and/or alcohol use with a reduced QoL (*p* = .063) in the SWiM analysis.

The narrative synthesis found that four studies reported alcohol intake and smoking as being associated with a worse QoL(55, 57, 63, 65) and one found that individuals who had ‘never smoked’ were associated with a better QoL(60). Again, there was large variability across the included studies within the sample size (range 36-316), length of follow-up (range two and a half months to one year) and QoL measure used (two used the EORTC QLQ-30(55, 63), two used the UW-QoL(60, 65) and one used the SF-36(57)). Due to this variability, it may be difficult to make meaningful conclusions.

Side Effects

Finally, six studies(20, 56, 58, 60, 64, 67) reported that a negative side-effect of treatment was associated with a reduced QoL (*p* = .031) in the SWiM analysis. One study did not report the direction of effect(59).

A range of side effects were found to influence quality of life both positively and negatively across seven of the included studies from the narrative synthesis. Two studies found that poor physical functioning was associated with a reduced QoL(20, 56). A further two studies found that patients with increased symptom severity and who experienced large changes to taste and smell were also associated with a worse QoL(58, 60). Nutrition appeared in two studies, with one stating that diet (ability to eat solid food) was associated with a more positive QoL(67) and another found that patients who were malnourished were likely to have a worse QoL(64). One paper found that physical functioning, pain, fatigue, nausea and vomiting, dyspnoea, insomnia, & diarrhoea were associated with QoL but did not comment on direction of effect(59). Again, there is large variability across the studies in relation to sample size (range 54-265), length of follow-up (range two and half months to three years), and treatment – for example one study investigated patients receiving surgery only(58) and one did not specify the treatment patients received(59).

Table S3

Effect direction plot summarising the direction of effect of the six defined categories on QoL for the included studies.

Study	Study Design	Psychological Factors	Cancer Related Factors	Treatment	Demographics	Smoking /Alcohol Use	Side effects
🟧 Allison et al (2000)	Observational	▼	◀▶$_2$	◀▶			
🟧 Alvarez-Camacho et al. (2016)	Longitudinal		▼$_2$		▲	▼	▼
🟧 Borggreven et al. (2007)	Prospective longitudinal				▼		
🟧 Bozec et al. (2019)	Prospective multicentric						
🟩 Bozec et al. (2018)	Prospective multicentric	▼				▼	
🟩 Citak & Tulek (2013)	Prospective			▲	▲$_3$		▼
🟥 De Graeff et al. (2000)a	Prospective longitudinal		▼	▼	▼		
🟩 De Graeff et al. (2000)b	Prospective	▼		▼	▼		▼
🟩 Hammerlid et al. (2001)	Longitudinal	▼	▼$_2$		▲		▼
🟧 Oskam et al. (2010)	Prospective	◀▶					◀▶$_8$
🟧 Rios-Gonzalez et al. (2024)	Prospective longitudinal			▼$_3$	▼	▼	
🟧 Rogers et al. (2002)	Longitudinal cohort		▼	▼			
🟥 Roick et al. (2020)	Prospective	▲	▼				
🟩 Ronis et al. (2008)	Longitudinal cohort	▼		▼		▼	
🟩 Tamer et al. (2020)	Prospective comparative						▼
🟥 Tsan et al. (2021)	Prospective correlational	▼					▼
🟥 Veldhuis et al. (2016)	Prospective						
🟧 Yin et al. (2020)	Cohort		▼	▼$_2$	▼	▼	

Note. Effect direction: upward arrow ▲= positive impact on QoL, downward arrow ▼= negative impact on QoL, sideways arrow ◀▶= conflicting findings/direction not reported. Sample size: Final sample size. Large arrow ▲ >300; medium arrow ▲ 50-300; small arrow ▲ <50. Subscript numbers: Number of outcomes within each category synthesis is 1 unless indicated in the subscript beside effect direction. Study quality: denoted by row colour: green = high quality; amber = moderate quality (2-4 areas not meeting threshold); red = low quality (4+ areas not meeting threshold)

Discussion

This systematic review aimed to explore what biological, social or psychological factors are associated with QoL over time. Eighteen studies were included in this review and reported a range of factors associated with QoL posttreatment. For analysis, these factors were synthesised into six categories: psychological factors, cancer related factors, treatment type, demographics, smoking/alcohol use, and side effects. There was large variability across the studies, for example within sample size (range 36-316), length of follow-up (two and a half months to three-years), QoL measures used, and patient variables reported. Therefore, interpretations are made tentatively.

Two studies found that no biological, psychological or social factors are associated with QoL. The results of the effect direction plot and sign tests suggest that findings across psychological factors, treatment, demographics and smoking/alcohol use are not strong enough to conclude a significant impact on QoL. The sign tests indicated that cancer related factors and negative side effects are significantly associated with a worse QoL.

In relation to psychological factors, one study included in this review(53) reported that poor emotional wellbeing at hospital admission was associated with better QoL posttreatment. They hypothesised that patients who are distressed pre-treatment are able to adjust or recognise adverse side-effects earlier than those with lower levels of distress. This finding is not in line with the wider literature which suggests that low mood can lead to worse QoL in HNC patients posttreatment, when compared to those who are not depressed(68, 69). The increased distress may change how someone understands their diagnosis or functioning, with this negative view point leading to worse QoL(69). Systematic reviews across cancer diagnoses more broadly, have found that individuals who display dispositional optimism or have higher levels of hope show an increased satisfaction with life and improved QoL(32, 70).

Research into treatment-related factors appear to be inconsistent across the literature base, which fit with the findings of this review. For example, it has been reported that surgery can negatively impact QoL in HNC(29) while others recommend surgery due to associations with improved QoL(71). In relation to smoking, QoL has been found to be reduced in smokers within lung(35), colon(36) and breast(24) cancers. In contrast to the findings of this review, results from the literature suggest that individuals who drink alcohol appear to have improved QoL, alongside improved functioning and reduced mood disorders(37, 38). Across cancer diagnoses, a range of demographic factors have been found to be negatively associated with QoL including being single, poor education and finances, unemployment and younger age(72-75).

When considering cancer related factors and side effects, research suggests that these overlap. Recent narrative reviews(30, 31) exploring a range of cancer diagnoses summarise that an advanced stage alongside negative side effects such as pain, anxiety, and fatigue are associated with poorer QoL. Early diagnosis and treatment for patients is recommended in order to better support patient QoL(30). In breast cancer research, it has been found that individuals with poorer physical functioning had worse QoL(76). In addition, they found if patients viewed themselves as unable to function posttreatment they had a reduced QoL suggesting that perception, rather than the actual level of ability, impacts QoL. Within HNC specifically, side effects of treatment have been found to impact patients' lives through discomfort, emotional distress or challenges with eating and sleeping(12).

Limitations

Across the literature, differing definitions of QoL and HRQoL are used and the two terms are used interchangeably or inconsistently(77). As a result, it has been found that the terminology, and in turn some measures, may not capture all information that is important to an individual's wellbeing, for example factors like social contact or cultural attributes(78, 79). Additionally, the majority of the included studies did not collect information on race, ethnicity or culture. Research suggests that race, culture and discrimination can lead to different QoL experiences in cancer patients(80, 81) and therefore this is not accounted for within this review.

Due to the nature of the papers in this review, a meta-analysis could not be undertaken, and so a SWiM (through vote counting based on effect direction) and a narrative synthesis were conducted. Although these can usefully synthesize data and allow conclusions to be found in a systematic way(42), the SWiM method only provides information on the direction of effect and not the degree of change(82). This analysis method also has reduced power, as it does not take account of the sample sizes of each study(83).

Finally, the papers included in this review had small sample sizes, used a range of QoL measures, and did not use control groups. Therefore, comparisons to similar participants without cancer is not possible and conclusions cannot be generalised.

Implications (Clinical and Research)

The findings of this review suggest that a wide breadth of factors across biological, psychological and social areas can impact QoL, both positively and negatively. For example, within the side effects category alone aspects such poor physical functioning, pain and malnutrition were associated with a worse QoL. This may suggest that a person-centred approach to assessment of QoL within cancer care is beneficial in order to gain a full picture of factors that might be impacting an individual's QoL (e.g., assessing the individuals side effects as well as how they view these symptoms). This will allow patients to feel heard and ensure support can be targeted to each individual dependant on their current and perceived QoL.

This study found that cancer related factors and side effects were significantly associated with QoL, and recent reviews highlight there may be a relationship between the two categories. Future research may benefit from exploring reasons for the overlap between cancer related factors and negative side effects on QoL.

It may be beneficial for future research to standardise its approach to QoL in relation to measures and content. For example, collecting all data that is known to impact QoL such as smoking, ethnicity and treatment type. It may also be helpful to explore patients' subjective views of their functioning and to consider if this is impacting patient QoL, rather than the symptom itself. This study specifically excluded qualitative literature, it may be helpful for future reviews to incorporate this type of research.

Conclusion

This review highlights that there are many biological, social and psychological factors found to be associated with QoL across six themes (psychological factors, cancer related factors, treatment type, demographics, smoking or alcohol use and side effects). However, results should be interpreted cautiously due to the heterogeneity within the included studies. Only cancer related factors and side effects were found to have a significant association with a worse QoL in HNC patients over time. Further research is needed to better understand how patient factors impact long-term quality of life.

References

1. Jones K MZ, Watt S. Atlas of health variation in head and neck cancer in England. In: Office for Health Improvement & Dispatities, editor. 2024.
2. Macmillan. Head and neck cancer. n.d. [Available from: https://www.macmillan.org.uk/cancer-information-and-support/head-and-neck-cancer#:~:text=as%20rarer...-,Types%20of%20head%20and%20neck%20cancer,Tongue%20cancer.
3. Gormley M, Creaney G, Schache A, Ingarfield K, Conway DI. Reviewing the epidemiology of head and neck cancer: definitions, trends and risk factors. Br Dent J [Internet]. 2022 PMC9652141]; 233(9):[780-6 pp.]. Available from: https://doi.org/10.1038/s41415-022-5166-x.
4. NHS. Head and neck cancer 2021 [Available from: https://www.nhs.uk/conditions/head-and-neck-cancer/#:~:text=Head%20and%20neck%20cancer%20is,the%20nose%20and%20mouth%20(nasopharynx).
5. National Cancer Instiitute. Head and neck cancers. 2021. [Available from: https://www.cancer.gov/types/head-and-neck/head-neck-fact-sheet.
6. Maddams J, Utley M, Moller H. Projections of cancer prevalence in the United Kingdom, 2010-2040. Br J Cancer [Internet]. 2012; 107(7):[1195-202 pp.]. Available from: https://doi.org/10.1038/bjc.2012.366.
7. NHS England. The NHS long term plan.2019:[1-136 pp.]. Available from: https://www.longtermplan.nhs.uk/publication/nhs-long-term-plan/.
8. Maddams J, Brewster D, Gavin A, Steward J, Elliott J, Utley M, Moller H. Cancer prevalence in the United Kingdom: estimates for 2008. Br J Cancer [Internet]. 2009; 101(3):[541-7 pp.]. Available from: https://doi.org/10.1038/sj.bjc.6605148.
9. Mody MD, Rocco JW, Yom SS, Haddad RI, Saba NF. Head and neck cancer. Lancet [Internet]. 2021; 398(10318):[2289-99 pp.]. Available from: https://doi.org/10.1016/S0140-6736(21)01550-6.
10. List MA, Bilir SP. Functional outcomes in head and neck cancer. Semin Radiat Oncol [Internet]. 2004; 14(2):[178-89 pp.]. Available from: https://doi.org/10.1053/j.semradonc.2003.12.008.
11. Brook I. Early side effects of radiation treatment for head and neck cancer. Cancer Radiother [Internet]. 2021; 25(5):[507-13 pp.]. Available from: https://doi.org/10.1016/j.canrad.2021.02.001.
12. Brook I. Late side effects of radiation treatment for head and neck cancer. Radiat Oncol J [Internet]. 2020 PMC7533405]; 38(2):[84-92 pp.]. Available from: https://doi.org/10.3857/roj.2020.00213.
13. Penner JL. Psychosocial care of patients with head and neck cancer. Semin Oncol Nurs [Internet]. 2009; 25(3):[231-41 pp.]. Available from: https://doi.org/10.1016/j.soncn.2009.05.008.
14. World Health Organisation. Mental Health. 2022. [Available from: https://www.who.int/news-room/fact-sheets/detail/mental-health-strengthening-our-response#:~:text=Mental%20health%20is%20a%20state%20of%20mental,work%20well%2C%20and%20contribute%20to%20their%20community.&text=They%20include%20our%20individual%20social%20and%20emotional,safe%20neighbourhoods%20and%20community%20cohesion%2C%20among%20others.

15. World Health Organisation. Programme on mental health: WHOQOL user manual.2012. Available from: https://iris.who.int/bitstream/handle/10665/77932/WHO_HIS_HSI_Rev.2012.03_eng.pdf?sequence=1.

16. Revicki DA, Kleinman L, Cella D. A history of health-related quality of life outcomes in psychiatry. Dialogues Clin Neurosci [Internet]. 2014; 16(2):[127-35 pp.]. Available from: https://doi.org/10.31887/DCNS.2014.16.2/drevicki.

17. Ojo B, Genden EM, Teng MS, Milbury K, Misiukiewicz KJ, Badr H. A systematic review of head and neck cancer quality of life assessment instruments. Oral Oncol [Internet]. 2012; 48(10):[923-37 pp.]. Available from: https://doi.org/10.1016/j.oraloncology.2012.03.025.

18. Campbell R, Ju A, King MT, Rutherford C. Perceived benefits and limitations of using patient-reported outcome measures in clinical practice with individual patients: a systematic review of qualitative studies. Qual Life Res [Internet]. 2022; 31(6):[1597-620 pp.]. Available from: https://doi.org/10.1007/s11136-021-03003-z.

19. Demez PH, Moreau PR. Perception of head and neck cancer quality of life within the medical world: a multicultural study. Head Neck [Internet]. 2009; 31(8):[1056-67 pp.]. Available from: https://doi.org/10.1002/hed.21069.

20. Hammerlid E, Silander E, Hörnestam L, Sullivan M. Health-related quality of life three years after diagnosis of head and neck cancer: A longitudinal study. Head and Neck [Internet]. 2001; 23(2):[113-25 pp.]. Available from: https://doi.org/10.1002/1097-0347(200102)23:2<113::Aid-hed1006>3.0.Co;2-w.

21. do Nascimento Santos Lima E, Ferreira IB, Lajolo PP, Paiva CE, de Paiva Maia YC, das Gracas Pena G. Health-related quality of life became worse in short-term during treatment in head and neck cancer patients: a prospective study. Health Qual Life Outcomes [Internet]. 2020; 18(1):[307 p.]. Available from: https://doi.org/10.1186/s12955-020-01543-5.

22. Borggreven PA, Verdonck-de Leeuw IM, Muller MJ, Heiligers ML, de Bree R, Aaronson NK, Leemans CR. Quality of life and functional status in patients with cancer of the oral cavity and oropharynx: pretreatment values of a prospective study. Eur Arch Otorhinolaryngol [Internet]. 2007; 264(6):[651-7 pp.]. Available from: https://doi.org/10.1007/s00405-007-0249-5.

23. van Nieuwenhuizen AJ, Buffart LM, Langendijk JA, Vergeer MR, Voortman J, Leemans CR, Verdonck-de Leeuw IM. Health-related quality of life and overall survival: a prospective study in patients with head and neck cancer treated with radiotherapy. Qual Life Res [Internet]. 2021; 30(4):[1145-53 pp.]. Available from: https://doi.org/10.1007/s11136-020-02716-x.

24. Di Meglio A, Havas J, Gbenou AS, Martin E, El-Mouhebb M, Pistilli B, et al. Dynamics of Long-Term Patient-Reported Quality of Life and Health Behaviors After Adjuvant Breast Cancer Chemotherapy. J Clin Oncol [Internet]. 2022; 40(27):[3190-204 pp.]. Available from: https://doi.org/10.1200/JCO.21.00277.

25. Wilding S, Downing A, Wright P, Selby P, Watson E, Wagland R, et al. Cancer-related symptoms, mental well-being, and psychological distress in men diagnosed with prostate cancer treated with androgen deprivation therapy. Qual Life Res [Internet]. 2019; 28(10):[2741-51 pp.]. Available from: https://doi.org/10.1007/s11136-019-02212-x.

26. Ruiz-Rodriguez I, Hombrados-Mendieta I, Melguizo-Garin A, Martos-Mendez MJ. The Association of Sources of Support, Types of Support and Satisfaction with Support Received on Perceived Stress and Quality of Life of Cancer Patients. Integr Cancer Ther [Internet]. 2021; 20:[1-10 pp.]. Available from: https://doi.org/10.1177/1534735421994905.

27. Silveira APG, J. Sequeira, T. Ribeiro, C. Lopes, C. Monteiro, E. Pimentel, F.L. Geriatric oncology: Comparing health related quality of life in head and neck cancer.2011; 3(3):[1-8 pp.]. Available from: https://doi.org/10.1186/1758-3284-3-3.

28. Morimata J, Otomaru T, Murase M, Haraguchi M, Sumita Y, Taniguchi H. Investigation of factor affecting health-related quality of life in head and neck cancer patients. Gerodontology [Internet]. 2013; 30(3):[194-200 pp.]. Available from: https://doi.org/10.1111/j.1741-2358.2012.00662.x.

29. Chaukar DA, Walvekar RR, Das AK, Deshpande MS, Pai PS, Chaturvedi P, et al. Quality of life in head and neck cancer survivors: a cross-sectional survey. Am J Otolaryngol [Internet]. 2009; 30(3):[176-80 pp.]. Available from: https://doi.org/10.1016/j.amjoto.2008.05.001.

30. Chung KC, Muthutantri A, Goldsmith GG, Watts MR, Brown AE, Patrick DL. Symptom impact and health-related quality of life (HRQoL) assessment by cancer stage: A narrative literature review. BMC Cancer [Internet]. 2024; 24(884):[1-23 pp.]. Available from: https://doi.org/10.1186/s12885-024-12612-z.

31. Valsecchi AA, Di Maio M. Association Between Health-Related Quality of Life Measures and Survival Endpoints in Oncology Clinical Trials and in Clinical Decision Making: A Narrative Review. Pharmaceut Med [Internet]. 2025; 39(3):[171-82 pp.]. Available from: https://doi.org/10.1007/s40290-025-00568-9.

32. Marton G, Monzani D, Vergani L, Pizzoli SFM, Pravettoni G. "Optimism is a strategy for making a better future": A systematic review on the associations of dispositional optimism with health-related quality of life in cancer patients. European Psychologist [Internet]. 2020; 27(1):[41-61 pp.]. Available from: https://doi.org/10.1027/1016-9040/a000422.

33. Oliva A, Garcia-Cebrian JM, Calatayud EF, Serrano-Garcia I, Herraiz MA, Coronado PJ. A comparison of quality of life and resilience in menopausal women with and without a history of gynaecological cancer. Maturitas [Internet]. 2019; 120:[35-9 pp.]. Available from: https://doi.org/10.1016/j.maturitas.2018.11.012.

34. Osmialowska E, Stas J, Chabowski M, Jankowska-Polanska B. Illness Perception and Quality of Life in Patients with Breast Cancer. Cancers (Basel) [Internet]. 2022; 14(5). Available from: https://doi.org/10.3390/cancers14051214.

35. Halms T, Strasser M, Hasan A, Ruther T, Trepel M, Raab S, Gertzen M. Smoking and quality of life in lung cancer patients: Systematic review. BMJ Support Palliat Care [Internet]. 2023; 13:[e686-e94 pp.]. Available from: https://doi.org/10.1186/s12885-024-12612-z.

36. Tiselius C, Rosenblad A, Strand E, Smedh K. Risk factors for poor health-related quality of life in patients with colon cancer include stoma and smoking habits. Health Qual Life Outcomes [Internet]. 2021; 19(216):[1-11 pp.]. Available from: https://doi.org/10.1186/s12955-021-01850-5.

37. Allison PJ. Alcohol consumption is associated with improved health-related quality of life in head and neck cancer patients. Oral Oncol [Internet]. 2002; 38(1):[81-6 pp.]. Available from: https://doi.org/10.1016/S1368-8375(01)00031-8.

38. Revesz D, Bours MJL, Wegdam JA, Keulen ETP, Breukink SO, Slooter GD, et al. Associations between alcohol consumption and anxiety, depression, and health-related quality of life in colorectal cancer survivors. J Cancer Surviv [Internet]. 2022; 16:[988-97 pp.]. Available from: https://doi.org/10.1007/s11764-021-01090-y.

39. Sayette MA. The effects of alcohol on emotion in social drinkers. Behav Res Ther [Internet]. 2017; 88:[76-89 pp.]. Available from: https://doi.org/10.1016/j.brat.2016.06.005.

40. Cancer Research UK. Head and neck cancers mortality statistics. 2022. [Available from: https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/head-and-neck-cancers/mortality#ref-2.

41. Campbell M, McKenzie JE, Sowden A, Katikireddi SV, Brennan SE, Ellis S, et al. Synthesis without meta-analysis (SWiM) in systematic reviews: reporting guideline. BMJ [Internet]. 2020; 368:[1-6 pp.]. Available from: https://doi.org/10.1136/bmj.l6890.

42. McKenzie JE, Brennan SE. Chapter 12: Synthesizing and presenting findings using other methods. 2024. In: Higgins JPT, Thomas J, Chandler J, Cumpston M, Li T, Page MJ, Welch VA, editors Cochrane Handbook for Systematic Reviews of Interventions version 65 (updated August 2024) [Internet]. Available from: https://training.cochrane.org/handbook/current/chapter-12#section-12-2.

43. Cuijpers P, Weitz E, Cristea IA, Twisk J. Pre-post effect sizes should be avoided in meta-analyses. Epidemiol Psychiatr Sci [Internet]. 2017; 26(4):[364-8 pp.]. Available from: https://doi.org/10.1017/S2045796016000809.

44. Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ [Internet]. 2021; 372:[n71 p.]. Available from: https://doi.org/10.1136/bmj.n71.

45. Dundar Y FN. Applying inclusion and exclusion criteria. In: Cherry MG BA, Dickson R, editor. Doing a systematic review: A student's guide. 3rd ed. London: Sage; 2024. p. 43-58.

46. Ouzzani M, Hammady H, Fedorowicz Z, Elmagarmid A. Rayyan-a web and mobile app for systematic reviews. Syst Rev [Internet]. 2016; 5(1):[210 p.]. Available from: https://doi.org/10.1186/s13643-016-0384-4.

47. Stoll CRT, Izadi S, Fowler S, Green P, Suls J, Colditz GA. The value of a second reviewer for study selection in systematic reviews. Res Synth Methods [Internet]. 2019 PMC6989049]; 10(4):[539-45 pp.]. Available from: https://doi.org/10.1002/jrsm.1369.

48. Critical Appraisal Skills Programme. CASP Checklist: For Cohort Studies.2024. Available from: https://casp-uk.net/casp-tools-checklists/cohort-study-checklist/.

49. Critical Appraisal Skills Programme. FAQs 2025 [Available from: https://casp-uk.net/faqs/#:~:text=As%20these%20tools%20were%20designed,domains%20where%20there%20are%20biases.

50. Boon MH, Thomson H. The effect direction plot revisited: Application of the 2019 Cochrane Handbook guidance on alternative synthesis methods. Res Synth Methods [Internet]. 2021; 12(1):[29-33 pp.]. Available from: https://doi.org/10.1002/jrsm.1458.

51. Bozec A, Schultz P, Gal J, Chamorey E, Chateau Y, Dassonville O, et al. Evolution and predictive factors of quality of life in patients undergoing oncologic surgery for head and neck cancer: A prospective multicentric study. Surg Oncol [Internet]. 2019; 28:[236-42 pp.]. Available from: https://dx.doi.org/10.1016/j.suronc.2019.01.012.

52. Veldhuis D, Probst G, Marek A, Noack V, Ural A, Adamietz I, et al. Tumor site and disease stage as predictors of quality of life in head and neck cancer: a prospective study on patients treated with surgery or combined therapy with surgery and radiotherapy or radiochemotherapy. Eur Arch Otorhinolaryngol [Internet]. 2016; 273(1):[215-24 pp.]. Available from: https://doi.org/10.1007/s00405-015-3496-x.

53. Roick J, Danker H, Dietz A, Papsdorf K, Singer S. Predictors of changes in quality of life in head and neck cancer patients: a prospective study over a 6-month period. Eur Arch Otorhinolaryngol [Internet]. 2020; 277(2):[559-67 pp.]. Available from: https://dx.doi.org/10.1007/s00405-019-05695-z.

54. Allison PJ, Guichard C, Gilain L. A prospective investigation of dispositional optimism as a predictor of health-related quality of life in head and neck cancer patients. Quality of Life Research: An International Journal of Quality of Life Aspects of Treatment, Care & Rehabilitation [Internet]. 2000; 9(8):[951-60 pp.]. Available from: https://doi.org/10.1023/A:1008931906253.

55. Bozec A, Demez P, Gal J, Chamorey E, Louis M-Y, Blanchard D, et al. Long-term quality of life and psycho-social outcomes after oropharyngeal cancer surgery and radial forearm free-flap reconstruction: A GETTEC prospective multicentric study. Surg Oncol [Internet]. 2018; 27(1):[23-30 pp.]. Available from: https://doi/org/10.1016/j.suronc.2017.11.005.

56. de Graeff A, de Leeuw JR, Ros WJ, Hordijk GJ, Blijham GH, Winnubst JA. Pretreatment factors predicting quality of life after treatment for head and neck cancer. Head Neck [Internet]. 2000; 22(4):[398-407 pp.]. Available from: https://dx.doi.org/10.1002/1097-0347(200007)22:4<398::aid-hed14>3.0.co;2-v.

57. Ronis DL, Duffy SA, Fowler KE, Khan MJ, Terrell JE. Changes in quality of life over 1 year in patients with head and neck cancer. Archives of Otolaryngology-Head & Neck Surgery [Internet]. 2008; 134(3):[241-8 pp.]. Available from: https://doi.org/10.1001/archoto.2007.43.

58. Tsan YH, Wung SH, Lin MW, Lo WL, Wang YJ. Predictors of Quality of Life Change in Head-and-Neck Cancer Survivors during Concurrent Chemoradiotherapy: A Prospective Study. Asia-Pac [Internet]. 2021; 8(3):[237-45 pp.]. Available from: https://dx.doi.org/10.4103/2347-5625.311132.

59. Oskam IM, Verdonck-de Leeuw IM, Aaronson NK, Kuik DJ, de Bree R, Doornaert P, et al. Quality of life as predictor of survival: A prospective study on patients treated with combined surgery and radiotherapy for advanced oral and oropharyngeal cancer. Radiotherapy and Oncology [Internet]. 2010; 97(2):[258-62 pp.]. Available from: https://doi.org/10.1016/j.radonc.2010.02.005.

60. Alvarez-Camacho M, Gonella S, Ghosh S, Kubrak C, Scrimger RA, Chu KP, Wismer WV. The impact of taste and smell alterations on quality of life in head and neck cancer patients. Qual Life Res [Internet]. 2016; 25(6):[1495-504 pp.]. Available from: https://dx.doi.org/10.1007/s11136-015-1185-2.

61. de Graeff A, de Leeuw JR, Ros WJ, Hordijk GJ, Blijham GH, Winnubst JA. Long-term quality of life of patients with head and neck cancer. Laryngoscope [Internet]. 2000; 110(1):[98-106 pp.]. Available from: https://doi.org/10.1097/00005537-200001000-00018.

62. Rogers SN, Lowe D, Fisher SE, Brown JS, Vaughan ED. Health-related quality of life and clinical function after primary surgery for oral cancer. Br J Oral Maxillofac Surg [Internet]. 2002; 40(1):[11-8 pp.]. Available from: https://doi.org/10.1054/bjom.2001.0706.

63. Yin X, Shan C, Wang J, Zhang H. Factors associated with the quality of life for hospitalized patients with HPV-associated oropharyngeal squamous cell carcinoma. Oral Oncol [Internet]. 2020; 103:[1-6 pp.]. Available from: https://doi.org/10.1016/j.oraloncology.2020.104590.

64. Citak E, Tulek Z. Longitudinal quality of life in Turkish patients with head and neck cancer undergoing radiotherapy. Support Care Cancer [Internet]. 2013; 21(8):[2171-83 pp.]. Available from: https://dx.doi.org/10.1007/s00520-013-1774-y.

65. Rios-Gonzalez S, Heredero-Jung S, Ruiz-Masera JJ, Martinez-Sahuquillo-Marquez A. Quality of life and functional outcomes in tongue cancer patients: a long-term, prospective, comparative study. Medicina Oral Patologia Oral Y Cirugia Bucal [Internet]. 2024; 29(2):[e232-e40 pp.]. Available from: https://doi.org/10.4317/medoral.26228.

66. Borggreven PA, Aaronson NK, Verdonck-de Leeuw IM, Muller MJ, Heiligers ML, Bree R, et al. Quality of life after surgical treatment for oral and oropharyngeal cancer: A prospective longitudinal assessment of patients reconstructed by a microvascular flap. Oral Oncol [Internet]. 2007.; 43(10):[1034-42 pp.]. Available from: https://doi.org/10.1016/j.oraloncology.2006.11.017.

67. Tamer R, Chen Y, Xu X, Xie C, Swai J. Short-Term Quality of Life, Functional Status, and Their Predictors in Tongue Cancer Patients After Anterolateral Thigh Free Flap

Reconstruction: A Single-Center, Prospective, Comparative Study. Cancer Manag Res [Internet]. 2020; 12:[11663-73 pp.]. Available from: https://doi.org/10.2147/CMAR.S268912.

68. Lenze NR, Bensen JT, Yarbrough WG, Shuman AG. Characteristics and outcomes associated with anxiety and depression in a head and neck cancer survivorship cohort. Am J Otolaryngol [Internet]. 2022; 43(3):[1-6 pp.]. Available from: https://doi.org/10.1016/j.amjoto.2022.103442.

69. Heyda A, Ksiezniak-Baran D, Wygoda A, Skladowski K. Low Post-Treatment Quality of Life and the High Incidence of Pain Are Common and Significantly Exacerbated in Depressed Head and Neck Patients Treated with Definitive Accelerated Radiotherapy. Cancers (Basel) [Internet]. 2024; 16:[1-13 pp.]. Available from: https://doi.org/10.3390/cancers16010079.

70. Guliyeva G, Forte AJ, McLeod H, Salinas M, Avila FR, Perlman AI. Increased hope levels correlate with life satisfaction in cancer patients: A systematic review. Advances in Integrative Medicine [Internet]. 2022; 9(3):[145-50 pp.]. Available from: https://doi.org/10.1016/j.aimed.2022.06.002.

71. Xu MJ, Plonowska KA, Gurman ZR, Humphrey AK, Ha PK, Wang SJ, et al. Treatment modality impact on quality of life for human papillomavirus-associated oropharynx cancer. Laryngoscope [Internet]. 2020; 130:[E48-E56 pp.]. Available from: https://doi.org/10.1002/lary.27937.

72. Potosky AL, Ahn J, Xia Y, Lin L, Chen RC, Graves KD, et al. Demographic and clinical factors associated with health-related quality-of-life profiles among prostate cancer survivors. American Society of Clinical Oncology Practice [Internet]. 2024; 20(7):[921-31 pp.]. Available from: https://doi.org/10.1200/OP.24.00076.

73. Konieczny M, Cipora E, Sygit K, Fal A. Quality of Life of Women with Breast Cancer and Socio-Demographic Factors. Asian Pac J Cancer Prev [Internet]. 2020; 21(1):[185-93 pp.]. Available from: https://doi.org/10.31557/APJCP.2020.21.1.185.

74. Ramasubbu SK, Pasricha RK, Nath UK, Rawat VS, Das B. Quality of life and factors affecting it in adult cancer patients undergoing cancer chemotherapy in a tertiary care hospital. Cancer Rep (Hoboken) [Internet]. 2021; 4(e1312):[1-11 pp.]. Available from: https://doi/org/10.1002/cnr2.1312.

75. Bonzanini LIL, Soldera EB, Ortigara GB, Schulz RE, Antoniazzi RP, Ardenghi TM, Ferrazzo KL. Clinical and sociodemographic factors that affect the quality of life of survivors of head and neck cancer. Support Care Cancer [Internet]. 2020; 28:[1941-50 pp.]. Available from: https://doi.org/10.1007/s00520-019-05008-4.

76. Crouch A, Champion VL, Von Ah D. Comorbidity, cognitive dysfunction, physical functioning, and quality of life in older breast cancer survivors. Support Care Cancer [Internet]. 2022; 30:[359-66 pp.]. Available from: https://doi.org/10.1007/s00520-021-06427-y.

77. Karimi M, Brazier J. Health, Health-Related Quality of Life, and Quality of Life: What is the Difference? Pharmacoeconomics [Internet]. 2016; 34(7):[645-9 pp.]. Available from: https://doi.org/10.1007/s40273-016-0389-9.

78. McCabe C, Cronin P. Issues for researchers to consider when using health-related quality of life outcomes in cancer research. Eur J Cancer Care (Engl) [Internet]. 2011; 20:[563-9 pp.]. Available from: https://doi.org/10.1111/j.1365-2354.2010.01229.x.

79. Kaplan RM, Hays RD. Health-Related Quality of Life Measurement in Public Health. Annual Review of Public Health [Internet]. 2022; 43:[355-73 pp.]. Available from: https://doi.org/10.1146/annurev-publhealth-052120-012811.

80. Reeve BB, Graves KD, Lin L, Potosky AL, Ahn J, Henke DM, et al. Health-related quality of life by race, ethnicity, and country of origin among cancer survivors. J Natl Cancer Inst [Internet]. 2023; 115(3):[258-67 pp.]. Available from: https://doi.org/10.1093/jnci/djac230.

81. Shariff-Marco S, Sangaramoorthy M, Ellis L, Thomsen C, Roh JM, Kroenke C, et al. Impact of Racial/Ethnic Discrimination on Quality of Life Among Breast Cancer Survivors. Am J Epidemiol [Internet]. 2023; 192(3):[367-76 pp.]. Available from: https://doi.org/10.1093/aje/kwac208.

82. Field A. Discovering statistics using IBM SPSS statistics. 5th ed: Sage Edge; 2018.

83. Borenstein M, Hedges LV, Higgins JPT, Rothstein HR. Meta-Analysis methods based on direction and p-values. Introduction to Meta-Analysis. Chichester (UK): John Wiley & Sons, Ltd;; 2009. p. 325–30.

Chapter 3: *"It's a shock, out of nowhere. And it does take a few minutes to deal with it"*: Experiences of the prehabilitation period and emotional support for head and neck cancer patients.

Abstract

Prehabilitation is defined as the time between receiving a diagnosis of cancer and starting treatment. Receiving a cancer diagnosis can be shocking and patients may use a range of strategies to try and process and cope with their distress. However, research on the prehabilitation period for head and neck cancer (HNC) mainly focuses on nutritional and physical wellbeing rather than psychological. Physical and psychological prehabilitation interventions have been found to be beneficial for patients, but it is unclear what emotional support is needed during this time. The current study aimed to explore HNC patients experiences of the prehabilitation period and investigate what, if any, psychological support might be helpful during this time. Semi-structured interviews were carried out with ten participants who had experienced diagnosis and treatment for HNC. Interviews were analysed using inductive reflexive thematic analysis. Four themes were generated: 1) cancer challenges, alters, and expands self-view and identity; 2) coping strategies utilised to increase control – context is important; 3) dual states before treatment: normalcy vs living in limbo; 4) balancing act: getting the right support at the right time. These findings highlight that context plays a vital role in how participants cope with a diagnosis of HNC and that support needs during the prehabilitation phase are specific to the individual. Participants communicated differing experiences across themes such as change to identity, use of coping strategies and level of information wanted from the medical team. This study emphasizes the need for personalised care and early signposting to psychological support. Further research is needed to explore how psychological prehabilitation can be best utilised for HNC patients.

Background

There is growing interest in supporting patient recovery from cancer treatments by offering interventions in the time between receiving a diagnosis and treatment starting. This time period is also known as prehabilitation and is viewed as an extension of rehabilitation. The aim of prehabilitation is to prepare patients mentally and physically for treatment, enhance recovery and improve independence(1).

Receiving a diagnosis of cancer can generate feelings of shock, anxiety or helplessness(2-4). Patients have been found to cope with these feelings through a range of strategies. One qualitative study, exploring how emotional coping influences symptoms posttreatment found that patients held a determined mindset, sought out social support and had trust in medical professionals(5). Cancer patients have been found to oscillate coping strategies between focussing on their cancer and the impact of it to adapting their life or focusing on future goals(6). Oncological research has also found that patients may discover a new sense of purpose or form new identities following cancer diagnosis, in line with Acceptance and Commitment Therapeutic theories(7) and posttraumatic growth(3, 8, 9).

Prehabilitation is offered across three areas of life: physical activity, nutrition and mental health(10). Psychological prehabilitation can range from universal interventions such as advice and self-management to more targeted specialist support, such as individual or group treatment programmes(1, 10). Research into psychological prehabilitation is limited but growing. Systematic reviews have shown that while psychological prehabilitation in cancer care does not appear to affect medical outcomes (e.g., survival) it has a positive impact on anxiety and patient reported outcomes (such as quality of life and bodily symptoms)(11, 12). Psychological prehabilitation prior to surgery for other medical issues (such as heart bypass or bariatric surgery) has been found to reduce length of stay and postoperative pain(13). It is advised that services screen patients appropriately and use a stepped-care approach to guide if and what interventions are useful for patients(14). Patients have described prehabilitation programmes as highly valuable - reporting a better sense of control, increased confidence to cope and found it supported interactions with people who understood (professionals or peers)(15).

Current literature within prehabilitation for head and neck cancers (HNC) primarily focuses on nutrition and exercise. Patients may be physically and/or nutritionally compromised prior to treatment and therefore prehabilitation aims to provide advice and support to increase strength for treatment and improve outcomes(1). Physical prehabilitation for HNC appears beneficial for patients, with studies showing improvements in quality of life and seeing reductions in mortality post-treatment(16, 17). However, there appears to be a lack of psychological input into prehabilitation literature, in a recent meta-analysis only one of the 46 papers included provided psychological support(17).

Research suggests a lack of consistency in the definition of prehabilitation being used and in the application of it across the literature (e.g., differences in treatment duration or exercises used)(18). Within psychological prehabilitation, there appears to be variety in interventions and outcome measures used making it difficult to compare and generalise findings(19). Given the limited literature on how people with HNC make sense of their diagnosis and prepare for treatment, it is important to understand more about what patients need during this time to guide formulation and intervention(20).

This study aims to explore the prehabilitation needs of patients diagnosed with HNC. Receiving a diagnosis of HNC is life changing and treatments can be highly invasive. The literature suggests that supporting individuals after they receive their diagnosis can be beneficial, however research into psychological prehabilitation is limited. Macmillan emphasise that prehabilitation should be personalised and flexible to patient needs(1) and therefore patient voice is key to the development of any prehabilitation programme. There is currently no existing research exploring HNC patients experiences of the prehabilitation period. Therefore, a qualitative approach was taken to answer the following research questions:

1. What are patients' experiences of the cancer journey, between diagnosis and treatment, for individuals who have experienced treatment for HNC?
2. What psychological support, if any, would HNC patients have found helpful in their prehabilitation period?

Methods

Participants and Recruitment

A total of ten participants took part in the study. Participants were included if they were 18 years or older, if this was their first cancer diagnosis, if HNC was their primary diagnosis and if they had received treatment for HNC. Exclusion criteria included having a prognosis of less than six months and currently being in active treatment. Table E1 shows participant characteristics. All participants had completed treatment and were either having ongoing reviews or were five-years post-treatment and deemed cancer free. Time between receiving a diagnosis to treatment starting ranged from three weeks to four months and time between treatment ending and attending the interview ranged from two months to 11 years. None of the participants in this study had received formal psychological support during their prehabilitation period.

Participants were recruited from The Swallows (a UK nationwide charity), who advertised the study through their online monthly meeting and newsletter and also via Clinical Nurse Specialists (CNS) at University Hospitals Dorset NHS Foundation. If people were interested in taking part they were asked to email the researcher who provided further information, and if eligible an interview was arranged.

Table E1

Participant Characteristics

Participant Characteristic	N (%)
Age at interview	
40-49	1 (10)
50-59	1 (10)
60-69	2 (20)
70-79	5 (50)
80-89	1 (10)
Gender	
Male	7 (70)
Female	3 (30)
Age at diagnosis	
40-49	1 (10)
50-59	1 (10)
60-69	3 (30)
70-79	4 (40)
80-89	1 (10)
Ethnicity	
White English	7 (70)
White Irish	1 (10)
Ulster Scot	1 (10)
Mixed Ethnic Background	1 (10)
Primary HNC Diagnosis	
Throat	2 (20)
Oropharynx	2 (20)
Tongue	4 (40)
Tonsil	1 (10)
Jaw	1 (10)
Treatment(s) Received	
Dental extraction pre-treatment	2 (20)
Radiotherapy and chemotherapy concurrent	3 (30)
Operation followed by radiotherapy	3 (30)
Operation only	2 (20)
Radiotherapy only	2 (20)
Time Between Diagnosis and Treatment (weeks)	
1-4	4 (40)
5-10	4 (40)
11+	2 (20)
Time Between Treatment Ending and Interview (months)	
1-10	4 (40)
11-20	1 (10)
21-30	2 (20)
31-40	1 (10)
40+	2 (20)
Recruitment Route	
Charity	8 (80)
NHS	2 (20)

Design and Procedure

Qualitative methods were chosen to gain insight into the experiences of HNC patients and to allow their voices to be heard. This research was conducted from a social constructionist epistemological perspective to explore participants subjective experiences that are likely to have been influenced by their language, culture and historical, political and social contexts(21). Ethical approval was gained from the University of Southampton Ethics Committee (ERGO reference: 90671), the South East Scotland Research Ethics Committee 01 (REC reference: 25/SS/0002; IRAS ID: 339405) and University Hospitals Dorset NHS Foundation Research and Development Department.

Before taking part in the interview, participants were given the study poster (Appendix A), and information sheet (Appendix B) explaining the purpose, risk and benefits of taking part. Informed consent (Appendix C) was gathered from all participants. After the interview, a debrief form was given (Appendix D) explaining the purpose of the study and signposting for support was provided.

The demographic questionnaire, interview topic guide and poster were developed with Patient and Public Involvement (PPI) – comprising three individuals who had received cancer diagnosis and treatment. PPI reviewed materials and gave feedback to the researcher directly, feedback suggested increasing font size and using pale backgrounds where there was written text. Feedback suggested that while questions were probing, they were appropriate and encouraged conversations. The topic guide was developed to explore experiences within and around the prehabilitation period such as “what was your initial reaction to receiving your diagnosis?” and “how well did you feel your emotional or psychological needs were supported in between your diagnosis and treatment starting?” The interviews utilised semi-structured and open-ended questions, in line with Willig(22) who encourages interviews to be flexible, allow participants to provide in-depth answers and be open to unanticipated answers that might come. To aid exploration, the interview guide incorporated prompts to ask about changes to intimacy, relationships and activity/hobbies in addition to questions such as “what did you find helpful?” or “what was missing?”

The semi-structured interviews were mostly conducted via Microsoft Teams, with one being conducted via telephone due to participant preference. Interviews lasted between 60-90 minutes and were then transcribed verbatim with all identifiable information such as names, hospitals or places being removed or anonymised. Notes and reflections were kept by the interviewer in a reflexive log (Appendix E) during each stage: interview, transcription and familiarisation and coding.

Analysis

An inductive Reflexive Thematic Analysis (RTA) was used, following the six-phase approach outlined by Braun and Clarke(23). For phase one, transcription, it included listening back to recordings, reading the transcripts and reflecting on thoughts, beliefs and perspectives in a reflexive log which allowed for familiarisation to the data. Within phase two, initial codes were generated to identify content of interest by reading through transcripts. This inductive coding process was completed twice to help refine codes. Codes were created at both a semantic and latent level. Multiple codes were assigned to one section of text, where appropriate. Similarities among codes were organised into themes for phase three. Phase four involved reviewing the transcripts to ensure themes were refined and distinct. This then allowed for a thematic map to be created and identification of overarching themes and emerging sub-themes. Final themes were then determined by refining, defining and naming them in phase five. Transcripts were reviewed to ensure themes were in line with the essence of interviews and were consistent with participant experience. Finally, for phase six, four themes were identified to report in detail and the research questions, codes and wider psychological literature was referred to.

Reflexivity

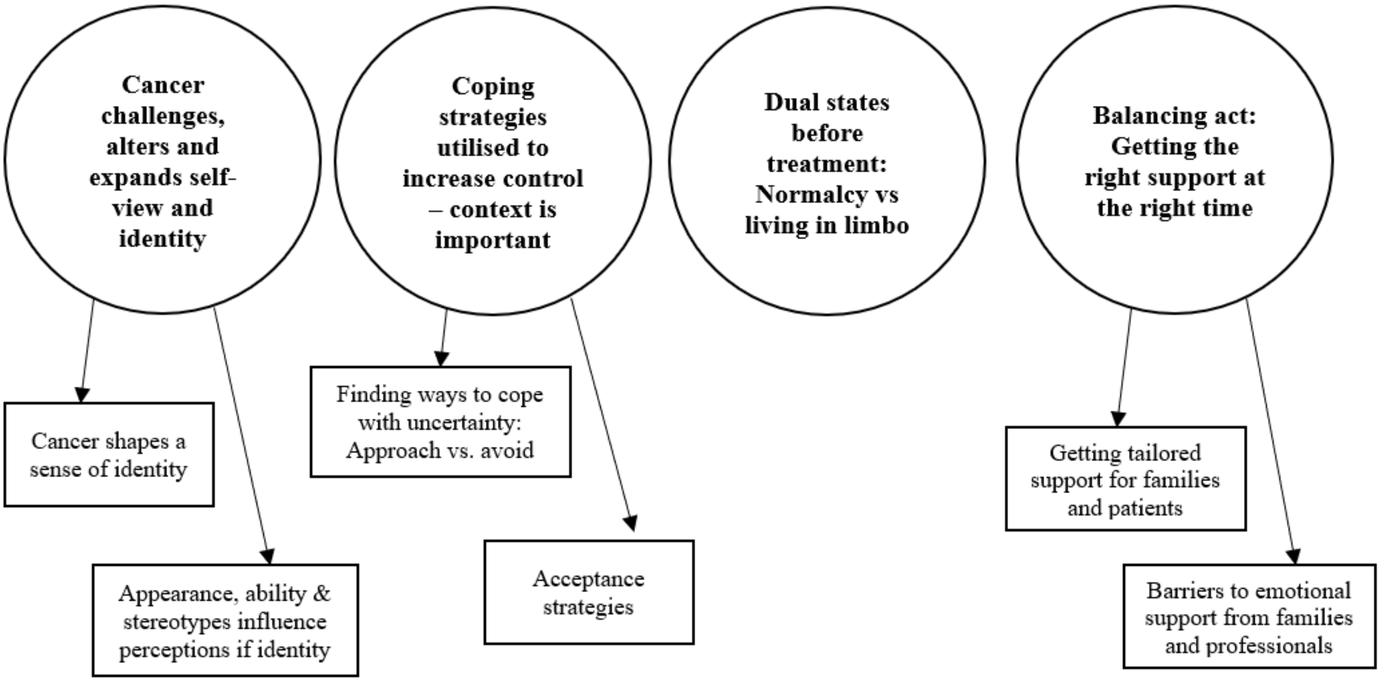
It is important to examine the researchers’ own assumptions, judgements and influences throughout the whole process, from conception to reporting(24). The researcher has no direct link to HNC in their personal life however this project was borne out of experiences as a Trainee Clinical Psychologist on placement in a hospice setting. The researcher witnessed first-hand the long-lasting side effects that treatment for HNC has and the impact this has on ability, enjoyment and identity of patients. The researcher utilised PPI, the reflexive log, and regular meetings with the research team to question responses, explore engagement with data and increase self-awareness(23).

Results

The RTA produced four themes (see figure E1) that reflect HNC patients experiences of the prehabilitation period and the support they did or did not receive. Two subthemes were generated within three of the superordinate themes, see Table E3 for a summary of the themes and subthemes.

Figure E1

Thematic map highlighting themes and subthemes



Note. Text in circles shows themes and in boxes denotes subthemes.

Table E2

Summary of themes and subthemes.

Theme	Subtheme(s)
One: Cancer challenges, alters and expands self-view and identity	1a. Cancer shapes a sense of identity 1b. Appearance, ability & stereotypes influence perceptions of identity
Two: Coping strategies utilised to increase control - context is important.	2a. Finding ways to cope with uncertainty: approach vs. avoid 2b. Acceptance strategies
Three: Dual states before treatment: normalcy vs. living in limbo	
Four: Balancing act: getting the right support at the right time	4a. Getting tailored support for families and patients 4b. Barriers to emotional support from families and professionals

Theme one: Cancer challenges, alters and expands self-view and identity

This theme reflects how participants identities interacted with their cancer diagnosis. This occurred in multiple ways, for example the identity they brought from life experiences or how diagnosis and subsequent treatment challenged participants self-view or, in some cases, brought in new identities. Both positive and negative experiences were shared, with positive experiences suggesting that cancer allowed them to be someone who helps others and negative experiences highlighting the discomfort with the identity of being a patient. In addition, participants discussed the impact of stigma (both internal and external) and the impact this has on how they live their life, post-cancer diagnosis.

1a. Cancer shapes a sense of identity

Participants held strong views on their identity prior to receiving their diagnosis describing themselves as “resilient”, “independent” and “problem solvers” sometimes attributing this to job roles or gender. Many reported bringing these traits through their cancer journey in their coping styles or their approach to appointments with professionals. Some recognised that their cancer diagnosis changed their self-view, which had a negative impact.

> “I feel much more exposed and vulnerable than I’ve ever felt” (PPT9)

Many participants spoke about the identity of being a patient, one describing herself as a “full-time patient” (PPT3) after receiving her cancer diagnosis. Some found this comforting, as it offered support and safety by providing a space that allowed them to receive care and be able to share experiences. However, others described a need to reject the ‘patient’ identity and hold on to their pre-cancer self. Some reported feeling unable to get away from this identity which became overwhelming, and others reported feeling defined and restricted by their diagnosis, for example wanting to be recognised for good things they had done, not just their cancer. Some participants found the transition from ‘normal’ life to being a patient more challenging, particularly the aspects of being a patient that clashed with their already established identities, such as being independent.

> “I don’t rely on other people” (PPT9)

Five of the ten participants spoke about how their experience of being a patient led to them want to give back in some way and did so through a variety of routes such as starting charities, providing feedback, or volunteering. This led to participants developing new identities as a result of their cancer.

> “He [Consultant] refers to us as patient presidents” (PPT10)

1b. Appearance, ability & stereotypes influence perceptions of identity

When reflecting on their experiences, participants expressed feeling that how others saw them impacted how they were approached. For some it was felt that if they appeared as ‘strong’ and ‘able’ they were deemed as coping with the diagnosis and therefore not offered psychological support. Others recognised that, in hindsight, they were treated differently based on staff bias or perception. For example, feeling that professionals did not take the time to get to know their identity or what is important to them due to older age, and an assumption that they live a quiet or slow lifestyle.

> “So, I wonder if I was seen a bit as another old lady with cancer that we’re dealing with. As opposed to an incredibly active, very articulate manager” (PPT7)

This feeling extended beyond just medical appointments and to wider society. Other participants spoke about the impact of being viewed as ‘old’ and the negative stereotypes that come with this, particularly when linked with side effects of treatment, such as dribbling or slurred speech. Older aged participants recognised a feeling of embarrassment or shame when socialising with friends or family and how this might look to others.

> “So that’s one thing I think is being in public, you have to accept there are certain norms that um er you would not want to see um. Elderly man dribbling onto his chin you know” (PPT6)

Two participants had a free-flap operation for cancer of the tongue. Both reflected the negative impact of this operation on their physical appearance and ability which took away elements that were “integral to personality”. This led to both internal and external self-judgements; worrying not only what others would think of them but also seeing themselves as less articulate or capable.

> “But don’t forget, you know, I’ve been talking for my living, you know for the last 30 odd years sort of thing, you know, doing presentations and all the rest of it. And. And it sounds very different. And sometimes, you know I begin to dribble a little bit, you know. And it gets very self-conscious” (PPT8)

Theme two: Coping strategies utilised to increase control – context is important

When sharing their experiences, participants reported utilising different coping strategies to help them process and cope with their diagnosis and treatment. All participants described using a range of strategies, some swinging between approaching and avoiding their emotions while others struggled to face their emotions and some felt more able to accept their situation. Participants recognised having differing needs and contexts that influenced coping styles. Not all participants reported acceptance of their emotions and diagnosis, and it appeared that the more participants relied on avoidance the less able they were to adapt or rely on others.

2a. Finding ways to cope with uncertainty: approaching vs. avoiding

Upon reflection during interviews, many participants recognised that their natural coping strategy was to problem solve and spoke about wanting to "move on" from problems. This meant that many participants felt a need to "keep busy" while waiting for treatment, often either through distraction or completing tasks (such as preparing things they would need posttreatment). For some, this was helpful, it appeared to allow them to hold some autonomy and control during the uncertainty of waiting for treatment to start.

> "Because they said you're going to be really tired afterwards. Err I was like, well I'll just pre-empt that. I'll just download all this stuff that I want to see" (PPT1)

For others, this appeared to be a technique to distract and reduce focus on their diagnosis and emotions, which could at times have a negative impact on their wellbeing. For one participant they reported that keeping busy was a distraction coming from "survival mode", rather than doing things they enjoyed. Others described how keeping busy meant acting as they did pre-diagnosis (e.g., supporting others) which led to feelings of overwhelm, isolation and low mood.

> "I managed because I was resilient and I still found times that I could have literally and I said to someone I could have gone upstairs and hid in the corner and that was it, you know" (PPT3)

Some participants recognised that it was helpful to be able to swing between talking to others about their feelings, being open and approaching their diagnosis and treatment head on, while also allowing time for distraction and being busy. There appeared to be a fine balance between the two which was not always easy to achieve. For example, most participants spoke about googling their diagnosis or treatments at some point, which appeared to be both helpful and unhelpful. Some felt that researching allowed them to go into treatments with an increased knowledge and confidence, while others felt it could become obsessive and increase worry.

> "I can remember waking up. Sort of three o'clock in the morning and realise that she's sat in bed next to me on her iPad, diving down to all the sort of google rabbit holes. Yeah, and and so I I said to myself, I am not going to do that. I'm not going to that at all" (PPT10)

2b. Acceptance strategies

This subtheme represents how some participants were able to hold a more accepting position towards life and their diagnosis. Acceptance can be defined as being open to difficult experiences rather than resisting or fighting them(25). Some participants described holding this accepting mindset by acknowledging they have received a cancer diagnosis and facing it head on, recognising there will be challenging times ahead. They spoke about having to manage what they have "been dealt" and make difficult choices about treatments or telling family members. Some participants reflected that it helped to take each day as it came and one thing at a time, rather than trying to solve all problems or plan for how they might feel at the end of treatment.

> "Because I was just dealing with everything day-to-day, I didn't. I didn't even think how I'd feel at the end" (PPT2)

Others spoke about how their cancer diagnosis and treatment gave a new appreciation for life. They described a sense of being on borrowed time or feeling grateful to be alive which led them to want to be more open to life and experiences. Additionally, participants reported that holding this accepting and appreciative mindset allowed them to adapt routines or cope with treatment and side effects.

> "Because I know time is, anyway, time is short, whether it's cancer or age. I know that my my time ahead is a lot shorter than what's behind, and so I I try to appreciate every day" (PPT9)

Ability or willingness to accept the cancer diagnosis appeared to be associated with the perceived level of trust in the medical team. Participants who reported trusting their medical team would use phrases such as "go with it", "this is my hand" and "it is the situation". The perceived confidence in the medical professional's ability and skill seemed to allow participants the space to focus on their needs and take each day as it came, knowing the medical team would support them:

> "Just breathe in and out and just let the time go by. I can't do anything about it. It's in the hands of other people I know they're doing the right thing and just let them get on with it" (PPT8)

Theme three: Dual states before treatment: Normalcy vs. living in limbo

When discussing the time period between diagnosis and treatment of HNC, participants reported there being two clear states. The first reflects the normalcy of life – that the day after your diagnosis feels the same as the day before. The other state was a sense of living in limbo and that although life felt typical, there was the impending treatment, ongoing medical appointments and friends and family acting differently (e.g., offering more support or concern). Many participants felt that having a connection to 'normal life' (e.g., continuing to work or doing hobbies) was helpful as it gave distraction from the cancer diagnosis and kept a link to life pre-cancer.

> "I tend to absorb myself in work more than anything, so like during the days if I was off, I would go into my office um. Maybe I didn't do very much when I was there, but at the going in and seeing people and driving up and back, it is all positive stuff" (PPT5)

During this time period, participants spoke about high levels of uncertainty and having a lack of control, for example some participants who had longer prehabilitation periods spoke about having to undergo lots of tests and then wait for results before treatment plans could be discussed. This led to reports of anxiety and stress during this time – so while life continued as normal there was a background of apprehension, which for some led to them reporting that while life was continuing as normal, they were not engaged with it or were just "going through the motions"

> "It felt like a ticking time bomb because I'd already found the lump in August battled to get an appointment. So to me I'd sat on this secondary from August. I had to have my teeth out. I had a few complications after that and I kept saying please don't delay the mask fitting. Please don't delay the treatment" (PPT3)

Theme four: Balancing act: Getting the right support at the right time

When reflecting on their experiences, participants spoke about how support that was direct and clear, but also personal and compassionate, was helpful to them. They identified a range of barriers to receiving emotional, as well as clinical, support such as a mismatch between family and patient needs, too much vs. not enough information, and psychology not being introduced as part of the MDT before treatment. It was recognised that the support wanted by patients is highly dependent on the individual, for example some participants wanted lots of information about their diagnosis and treatment, while others wanted to know as little as possible.

4a. Getting tailored support for families and patients

This subtheme highlights two key findings in how participants spoke about receiving support. Firstly, participants discussed that how their families and friends coped with their diagnosis impacted their ability to process and cope. Secondly, participants reflected on interactions with their medical professionals and appeared to hold a preference for direct and clear communication that was personalised to their needs.

Participants reflected that family and friends struggled to process the cancer diagnosis and experienced their own emotional responses. Family and friends appeared to have a wide range of reactions, some of which were received negatively by participants, for example being ignored by others or family showing concern that becomes overwhelming. In some cases, participants felt they needed to care for their family or friends which added extra demands and led to them feeling unable to show when they were struggling. Some participants reflected how family members can feel that they have little control over the situation and are often unsure how to best offer support.

> "They are there to support me, but I'm there as well to support them … After that, the endoscopy on that day, it's a bit of like a role reversal because whereas like my wife had been supporting me, I had to support her because she was really like upset" (PPT2)

Some participants described the process of receiving their diagnosis alone. Reasons for attending their initial appointments alone appeared to be through choice, not having someone to take and being told not to bring someone. It was reported that if attending alone participants were questioned on this but there was no offer of additional support or alternatives if they had no one to join them. Participants identified that bringing a family member to appointments was generally a positive experience as it allowed for them to feel supported and took pressure off having to hold all the information or remember all the questions they wanted to ask.

> "They were quite surprised that I was on my own, but they did at least ask if I wanted somebody with me, if I had someone to come with me. But when I said no, that they there wasn't anything, there wasn't anyone, you know" (PPT3)

Finally, the way information was relayed to the patient appeared to be important, impacting aspects such as trust, confidence and hope. It was reflected that a lot of interactions with the medical team focussed on physical aspects of care, rather than emotional. However, many participants reflected that it felt most helpful when the consultant giving the diagnosis and information about treatment was direct, clear and efficient. In addition, participants discussed that when care was personalised this was important and appreciated. Equally when care was not adapted to the participant this had a detrimental impact. Personalised care was described by participants as getting to know them in regard to their lifestyle, interests and values alongside feeling listened to and being treated like an individual rather than another patient. Participants reflected that when professionals took a personalised approach to their care it improved mood and trust in the medical team.

> "To know that there's a team, of specialists who are prepared, to treat you as a as an individual um and not just another case whizzing in was was very, very um meant a lot to me" (PPT6)

4b. Barriers to emotional support from families and professionals

This final subtheme explores the barriers to emotional support for patients with HNC. Three key barriers were identified from interviews: a mismatch between family and patient need, receiving too much vs. not enough information and psychology not being a part of the MDT in the prehabilitation phase.

When reflecting on their experiences, participants recognised times when others made assumptions about how they were feeling or made judgements as to how they must be coping. Often support appeared to come from what the family member needed, rather than finding out what the participant actually wanted. For example, family and friends saying 'you should feel so angry' or 'it will all be okay' when the participant was feeling lucky the cancer had been found early or felt very uncertain about what treatment might bring. It was also seen as important that support from family and friends was received at the right time and by the right people. Participants described "safe support" which was not always the person who was the closest to the participant (e.g., a spouse). "Safe supports" appeared to know the right care to give and felt reliable. For some, their safe support was unavailable due to bereavement or not having someone close to lean on which appeared to have a detrimental effect and led to feelings of isolation.

> "My two best friends used to come and sit either side of me and we did jigsaws er. And they sat either of me and they talked… and that that was that was very, very supportive. I mean it kept me going really. Jigsaw club continues to this day." (PPT7)

The second barrier was the level of information patients received. Some participants recognised that too much information was given and that this became overwhelming. On the other hand, some participants found it helpful to know as much as possible about their diagnosis, treatment and side effects. It appeared that for these people increased knowledge led to decreased uncertainty and worry. There was a link between the level of information given and the time it was received. For example, some participants spoke about being given lots of information with their diagnosis but then when treatment started, they were not given information they wanted. It was recognised that it may be helpful to provide patients with simplified, practical information. Some participants appeared to want to know less about the specific side effects. In some cases, participants expressed that they wanted to know more about their 'journey' or to be given simple, practical advice (e.g., what to expect from radiotherapy or what happens when you wake from surgery), rather than receive lots of information.

> "Just a simple, not a word, not a carrier bag for the info, just a one little sheet you're having chemo wear easy fitting clothes, bring snack with you. Oh, someone can come with you" (PPT3)

Finally, participants reported that psychology was not actively promoted within the prehabilitation period and often was not introduced as part of the MDT. Many participants sought emotional support themselves following their treatment but recognised that this was through their own research or time, rather than being given access to it. It was felt across participants that it might have been helpful to have opportunities to gain emotional support during the prehabilitation period. However, it was not felt that this always needed to be through individual psychological therapy but could have been achieved through opportunities to speak to people who had been through treatment for HNC, charities or groups.

> "No there wasn't anything and it would have been, I think it would have been nice if someone at that stage had said when you come round, I'll be there to have a chat with you, you know" (PPT7)

Discussion

This study aimed to explore HNC patient experiences of the cancer journey in the prehabilitation period (between receiving diagnosis and starting treatment). In addition, it hoped to understand what psychological support, if any, HNC patients would have found helpful during this time. Four themes were generated; 1) cancer challenges, alters, and expands self-view and identity; 2) coping strategies utilised to increase control – context is important; 3) dual states before treatment: normalcy vs. living in limbo; 4) balancing act: getting the right support at the right time. These themes highlighted the importance of patient specific context and needs; this was consistent across the themes in both how patients cope in the prehabilitation period and in the support they desire.

Across the superordinate themes, it appeared that patient experiences varied, for example in the level of change to identity, coping strategies utilised, and the amount of information patients wished to receive. These findings suggest that context is important and that not all patients will need the same support. The literature suggests that cancer care should encompass the patient as an individual person, including those providing support, and not solely focus on the physical aspects of their illness(26). However, this is not a new finding, and research has been exploring holistic models of cancer care for many years. It appears that although this is seen to be important, the research does not translate into practice due to barriers such as a lack of funding, poor understanding, and geographical inequality(27); suggesting a systemic flaw between research and organisations such as the NHS.

The results suggested that some participants were able to find a sense of acceptance following their diagnosis. Participants found that this was a helpful coping strategy during a time of increased uncertainty and decreased control. This is consistent with previous literature which reports that acceptance can support people to find a new sense of purpose or develop aspects of life whilst experiencing and acknowledging their pain(7). In addition to acceptance and finding positives after cancer diagnosis, some participants were able to build new identities which fits with research into posttraumatic growth(28). Research in gynaecological cancer found that women were able to gain more meaning in life and find a new sense of purpose(8). The current findings compliment recent qualitative research on posttraumatic growth in HNC which found that patient experience altered identity and roles in life(29). It is important to note that research exploring posttraumatic growth after cancer has largely focused on female experience and therefore may have limited representation of the male experience(9). The current study's sample was predominantly male, and many reported a desire to use their experiences in a positive way. For example, participants spoke about raising money for charity, setting up support groups and volunteering to develop prehabilitation pathways and found this provided new possibilities and positive affect. Therefore, we may tentatively intimate that posttraumatic growth is applicable to the male experience, but this could be explored in further research.

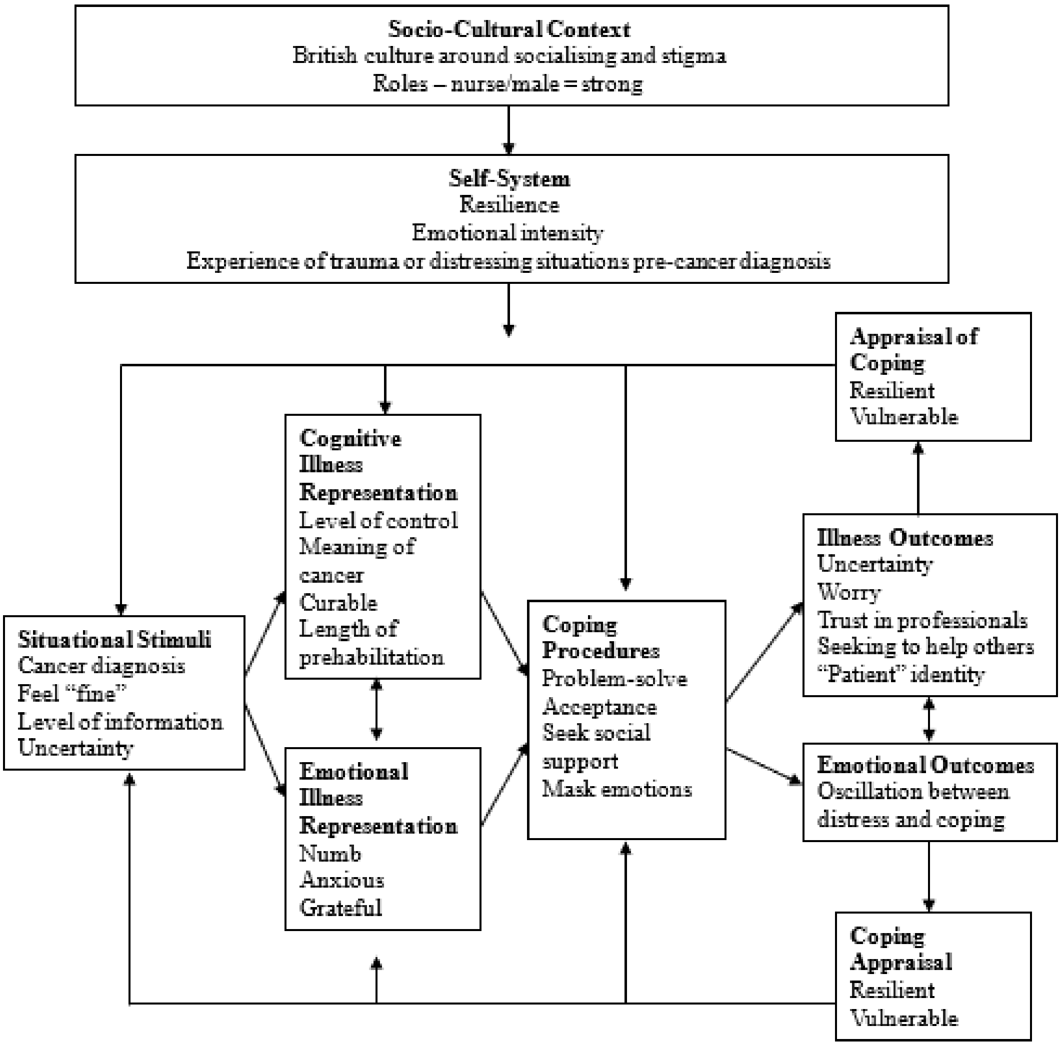
Communication and information were discussed through all interviews. Participants spoke about wanting direct, clear communication that also recognised them as an individual, rather than simply another patient. Additionally, some participants reflected they would have preferred more simple, practical information. Previous research has found that information needs can vary widely across cancer patients and suggests that healthcare professionals assess individual needs so that information can be tailored to the patient(30). Furthermore, communication focusing on the uncertainty and difficult emotions that cancer brings is important to patients and is correlated with improved mental wellbeing(31). Most participants in the current study reported not being aware of psychological support available to them. This is supported by the literature, which additionally reports that patients with higher self-reported anxiety and depression or more comorbid health diagnoses were more likely to describe their information needs as unmet(32, 33).

The overall results from this study could be contextualised and brought together through the Common-Sense Model (CSM) of Illness Self-regulation(34). A visual representation, based on Leventhal et al.(35), can be seen in Figure E1. The key findings illustrated in Figure E1 suggest that participants reported a combination of cognitive and emotional illness representations of their cancer diagnosis which led to a variety of coping procedures. This was connected to their emotional and illness outcomes and their appraisals of coping. For example, participants described beliefs about their cancer being curable or feeling lucky for a short prehabilitation period. They discussed emotionally feeling numb or grateful that the cancer was caught early. This led to coping strategies such as problem-solving or masking emotions and perceptions of being resilient or vulnerable, all within the context of identity and stigma. Understanding how patients view and interpret their diagnosis, and upcoming treatments can help medical professionals to create a space where interventions can be tailored to the patient's needs.

The CSM model has helped to better understand attendance of cancer screening programmes(36) and to identify patterns between illness representations and how an individual might cope with their diagnosis(37). Additionally, social support, level of physical symptoms and satisfaction with information have been found to influence illness representations (38). A longitudinal study exploring HNC patients found that beliefs related to length of illness and coping strategies (e.g., self-blame and acceptance) predicted emotional outcomes such as depression and quality of life(39). This suggests that the CSM could be useful for professionals when assessing patients in the prehabilitation period.

Figure E2

The Common-Sense Model applied to the experiences of the prehabilitation period.



Strengths and Limitations

This study utilised an opportunistic sampling method which may limit generalisability due to volunteer bias. It may be helpful for future research to open recruitment for a longer period to allow for probability-based sampling methods to be used. Additionally, some participants had an invested interest in the prehabilitation period – either wanting to make positive change or currently working to do so which may have influenced the responses they gave. Furthermore, eight of the ten participants were recruited via The Swallows charity which could have introduced selection bias. Participants may have had higher engagement with support services, or their views may not be reflective of individuals who used other care pathways or did not access charity resources post-treatment. In spite of participants volunteering to take part, interviews revealed rich data that showed a range of experiences of the prehabilitation period, both positive and negative. Though there may be limitations in the sampling method, the demographics of the sample appear to be reflective of the population of HNC patients(40). This is particularly evident in that 70% of participants were male and the majority of patients were aged 60-79 years old (n=7).

The use of PPI in developing the interview topic guide and study poster allowed the study to feel relevant and applicable to cancer patients. However, the interviewer for this research was a female who has not experienced receiving a cancer diagnosis. Although an independent coder is not needed for reliability (as subjectivity is a key tool in RTA)(41, 42), it may have been beneficial to include PPI within the analysis process as their experiences could have deepened the interpretations and findings. For example, people who have received cancer diagnosis and treatment may have contributed a different perspective, found different themes more salient and might have facilitated further reflexivity in the researcher and depth to the analysis.

Finally, interviews were conducted with individuals who were not currently in the prehabilitation period. Additionally, for some the prehabilitation time was very short (the shortest being three weeks) or for others was not recent (the longest time since treatment was 11 years). Interview questions asked participants to look back, retrospectively, and therefore their answers may have been influenced by memory and bias from experiences of treatment or what their cancer diagnosis led to (e.g., volunteering for the NHS or surviving). The decision was made to conduct interviews retrospectively due to the risk of causing additional distress to participants if asking difficult questions in an already difficult time period.

Implications (Clinical and Research)

The results of this study highlight the need for universal levels of psychological support, including professionals communicating with patients in a clear but also personal manner and early signposting to local supports and charities. Specifically, it would be beneficial for consultants to be clear that patients can discuss emotional struggles with the CNS or members of the wider MDT who can signpost to relevant supports. It may also be helpful for patients to be asked their preference on the amount of information they wish to receive and to recognise that this preference may change throughout the course of an individual's cancer treatment.

Within NICE guidance for HNC(43), psychological services are deemed as extended members of the multi-disciplinary team (MDT). Although they are stated as playing an important role, it is not recommended that they be at all MDT meetings. Our results would indicate that it may be helpful for psychological services to be introduced within the prehabilitation period and to be a more integral part of the MDT. This will help patients to be more aware of psychological support closer to cancer diagnosis; benefits of this may include that patients' emotional reactions can be validated, they are made aware of who they can talk to and those who may need extra support can be identified sooner.

The current literature within the prehabilitation period exploring psychological aspects is limited. Future research might benefit from exploring further the links between HNC and the CSM during the prehabilitation period as a way to understand how individuals make sense of and cope with their diagnosis prior to treatment.

References

1. Macmillan Cancer Support. Principles and guidance for prehabilitation within the management and support of people with cancer.; 2020.
2. Jensen CB, Pitt SC. Patient perception of receiving a thyroid cancer diagnosis. Curr Opin Endocrinol Diabetes Obes [Internet]. 2021; 28(5):[533-9 pp.]. Available from: https://doi.org/10.1097/MED.0000000000000655.
3. Leao D, Pereira ER, Silva R, Rocha R, Cruz-Quintana F, Garcia-Caro MP. Spiritual and Emotional Experience With a Diagnosis of Breast Cancer: A Scoping Review. Cancer Nurs [Internet]. 2022; 45(3):[224-35 pp.]. Available from: https://doi.org/10.1097/NCC.0000000000000936.
4. Krieger T, Salm S, Dresen A, Cecon N. Cancer patients' experiences and preferences when receiving bad news: a qualitative study. J Cancer Res Clin Oncol [Internet]. 2023; 149:[3859-70 pp.]. Available from: https://doi.org/10.1007/s00432-022-04311-8.
5. Saghafi E, Andas CA, Bernson J, Kjeller G. Patients' experiences of adverse symptoms, emotions, and coping strategies in connection to treatment of head and neck cancer - an interview study. BMC Oral Health [Internet]. 2023; 23:[641 p.]. Available from: https://doi.org/10.1186/s12903-023-03366-4.
6. Ferrie O. What psychological mechanisms are used to understand how people make sense of a diagnosis of metastatic breast cancer? [Doctorate Thesis]: University of Southampton; 2023.
7. Harris R. The reality slap: How to survive and thrive when life hits hard. London, UK: Robinson; 2021.
8. Berktaş Y, Kabukcuoğlu K. Transforming Pain into a Purpose: Post-Traumatic Growth and Life Meaning in Gynaecological Cancer. CURARE Journal of Nursing [Internet]. 2024; 6:[30-7 pp.]. Available from: https://doi.org/10.26650/curare.2024.1573108.
9. Menger F, Mohammed Halim NA, Rimmer B, Sharp L. Post-traumatic growth after cancer: a scoping review of qualitative research. Support Care Cancer [Internet]. 2021; 29(11):[7013-27 pp.]. Available from: https://doi.org/10.1007/s00520-021-06253-2.
10. Cancer Research UK. What is prehabilitation? 2024 [Available from: https://www.cancerresearchuk.org/about-cancer/treatment/prehabilitation/what-is-prehabilitation.
11. Tsimopoulou I, Pasquali S, Howard R, Desai A, Gourevitch D, Tolosa I, Vohra R. Psychological Prehabilitation Before Cancer Surgery: A Systematic Review. Ann Surg Oncol [Internet]. 2015; 22(13):[4117-23 pp.]. Available from: https://doi.org/10.1245/s10434-015-4550-z.
12. Scriney A, Russell A, Loughney L, Gallagher P, Boran L. The impact of prehabilitation interventions on affective and functional outcomes for young to midlife adult cancer patients: A systematic review. Psychooncology [Internet]. 2022; 31(12):[2050-62 pp.]. Available from: https://doi.org/10.1002/pon.6029.
13. Hall AE, Nguyen NH, Cascavita CT, Shariati K, Patel AK, Chen W, et al. The Impact of Psychological Prehabilitation on Surgical Outcomes: A Meta-analysis and Meta-regression. Ann Surg [Internet]. 2025; 281(6):[928-41 pp.]. Available from: https://doi.org/10.1097/SLA.0000000000006677.
14. Sanjida S, McPhail SM, Shaw J, Couper J, Kissane D, Price MA, Janda M. Are psychological interventions effective on anxiety in cancer patients? A systematic review and meta-analyses. Psychooncology [Internet]. 2018; 27(9):[2063-76 pp.]. Available from: https://doi.org/10.1002/pon.4794.

15. Powell R, Davies A, Rowlinson-Groves K, French DP, Moore J, Merchant Z. Impact of a prehabilitation and recovery programme on emotional well-being in individuals undergoing cancer surgery: a multi-perspective qualitative study. BMC Cancer [Internet]. 2023; 23(1):[1232 p.]. Available from: https://doi.org/10.1186/s12885-023-11717-1.

16. De Pasquale G, Mancin S, Matteucci S, Cattani D, Pastore M, Franzese C, et al. Nutritional prehabilitation in head and neck cancer: A systematic review of literature. Clin Nutr ESPEN [Internet]. 2023; 58:[326-34 pp.]. Available from: https://doi.org/10.1016/j.clnesp.2023.10.033.

17. Seth I, Bulloch G, Qin KR, Xie Y, Sebastian B, Liew H, et al. Pre-rehabilitation interventions for patients with head and neck cancers: A systematic review and meta-analysis. Head Neck [Internet]. 2024; 46(1):[86-117 pp.]. Available from: https://doi.org/10.1002/hed.27561.

18. Loewen I, Jeffery CC, Rieger J, Constantinescu G. Prehabilitation in head and neck cancer patients: a literature review. J Otolaryngol Head Neck Surg [Internet]. 2021; 50(2):[1-11 pp.]. Available from: https://doi.org/10.1186/s40463-020-00486-7.

19. Grimmett C, Heneka N, Chambers S. Psychological Interventions Prior to Cancer Surgery: a Review of Reviews. Curr Anesthesiol Rep [Internet]. 2022; 12(1):[78-87 pp.]. Available from: https://doi.org/10.1007/s40140-021-00505-x.

20. Johnstone L, Dallos R. Introduction to formulation. Formulation in psychology and psychotherapy: Making sense of people's problems. 2nd ed. East Sussex, UK: Routledge; 2014.

21. Burr V. What is Social Constructionism? 2024. In: Social Constructionism [Internet]. London: Routledge; [1-30]. Available from: https://doi.org/10.4324/9781003335016.

22. Willig C. Introducing qualitative research in psychology. Berkshire, England.: Open University Press.; 2013.

23. Braun V, Clarke V. Thematic analysis: A practical guide. London, England: SAGE Publications Ltd; 2022.

24. Lazard L, McAvoy J. Doing reflexivity in psychological research: What’s the point? What’s the practice? Qualitative Research in Psychology [Internet]. 2017; 17(2):[159-77 pp.]. Available from: https://doi.org/10.1080/14780887.2017.1400144.

25. Harris R. ACT made simple. 2nd ed. Oakland, CA: New Harbinger Publications; 2009.

26. Sedhom R, Bates-Pappas GE, Feldman J, Elk R, Gupta A, Fisch MJ, Soto-Perez-de-Celis E. Tumor Is Not the Only Target: Ensuring Equitable Person-Centered Supportive Care in the Era of Precision Medicine. Am Soc Clin Oncol Educ Book [Internet]. 2024; 44(3):[e434026 p.]. Available from: https://doi.org/10.1200/EDBK_434026.

27. Tsao PA, Fann JR, Nevedal AL, Bloor LE, Krein SL, Caram MEV. A Positive Distress Screen...Now What? An Updated Call for Integrated Psychosocial Care. J Clin Oncol [Internet]. 2023; 41(31):[4837-41 pp.]. Available from: https://doi.org/10.1200/JCO.22.02719.

28. Tedeschi RG, Shakespeare-Finch J, Taku K. Posttraumatic growth: Theory, research, and applications. New York: Routledge; 2018. Available from: https://doi.org/10.4324/9781315527451.

29. Menger F, Deane J, Patterson JM, Fisher P, O'Hara J, Sharp L. “After the horrible cancer…” Post-traumatic growth through the lens of head and neck cancer survivors. Journal of Psychosocial Oncology Research and Practice [Internet]. 2025; 7(1):[1-8 pp.]. Available from: https://doi.org/10.1097/or9.0000000000000158.

30. Squiers L, Finney Rutten LJ, Treiman K, Bright MA, Hesse B. Cancer patients' information needs across the cancer care continuum: evidence from the cancer information service. J

Health Commun [Internet]. 2005; 10(S1):[15-34 pp.]. Available from: https://doi.org/10.1080/10810730500263620.

31. Street RL, Jr., Treiman K, Wu Q, Kranzler EC, Moultrie R, Mack N, Garcia R. Managing uncertainty and responding to difficult emotions: Cancer patients' perspectives on clinician response during the COVID-19 pandemic. Patient Educ Couns [Internet]. 2022; 105(7):[2137-44 pp.]. Available from: https://doi.org/10.1016/j.pec.2022.03.029.

32. Faller H, Koch U, Brahler E, Harter M, Keller M, Schulz H, et al. Satisfaction with information and unmet information needs in men and women with cancer. J Cancer Surviv [Internet]. 2016; 10(1):[62-70 pp.]. Available from: https://doi.org/10.1007/s11764-015-0451-1.

33. Beckjord EB, Arora NK, McLaughlin W, Oakley-Girvan I, Hamilton AS, Hesse BW. Health-related information needs in a large and diverse sample of adult cancer survivors: implications for cancer care. J Cancer Surviv [Internet]. 2008; 2(3):[179-89 pp.]. Available from: https://doi.org/10.1007/s11764-008-0055-0.

34. Leventhal H, Phillips LA, Burns E. The Common-Sense Model of Self-Regulation (CSM): a dynamic framework for understanding illness self-management. J Behav Med [Internet]. 2016; 39(6):[935-46 pp.]. Available from: https://doi.org/10.1007/s10865-016-9782-2.

35. Leventhal H, Diefenbach M, Leventhal EA. Illness cognition: Using common sense to understand treatment adherence and affect cognition interactions. Cognitive Therapy and Research [Internet]. 1992; 16(2):[143-63 pp.]. Available from: https://doi.org/10.1007/BF01173486.

36. Anagnostopoulos F, Dimitrakaki C, Fitzsimmons D, Potamianos G, Niakas D, Tountas Y. Health beliefs and illness perceptions as related to mammography uptake in randomly selected women in Greece. J Clin Psychol Med Settings [Internet]. 2012; 19:[147-64 pp.]. Available from: https://doi.org/10.1007/s10880-011-9272-1.

37. Orbell S, O'Sullivan I, Parker R, Steele B, Campbell C, Weller D. Illness representations and coping following an abnormal colorectal cancer screening result. Soc Sci Med [Internet]. 2008; 67(9):[1465-74 pp.]. Available from: https://doi.org/10.1016/j.socscimed.2008.06.039.

38. Lee JY, Jang Y, Hyung W. Mediating Effect of Illness Perception on Psychological Distress in Patients With Newly Diagnosed Gastric Cancer: Based on the Common-Sense Model of Self-regulation. Cancer Nurs [Internet]. 2023; 46(3):[E138-E45 pp.]. Available from: https://doi.org/10.1097/NCC.0000000000001103.

39. Llewellyn CD, McGurk M, Weinman J. Illness and treatment beliefs in head and neck cancer: is Leventhal's common sense model a useful framework for determining changes in outcomes over time? J Psychosom Res [Internet]. 2007; 63(1):[17-26 pp.]. Available from: https://doi.org/10.1016/j.jpsychores.2007.01.013.

40. Cancer Research UK. Head and neck cancers incidence statistics 2024 [Available from: https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/head-and-neck-cancers/incidence#heading-One.

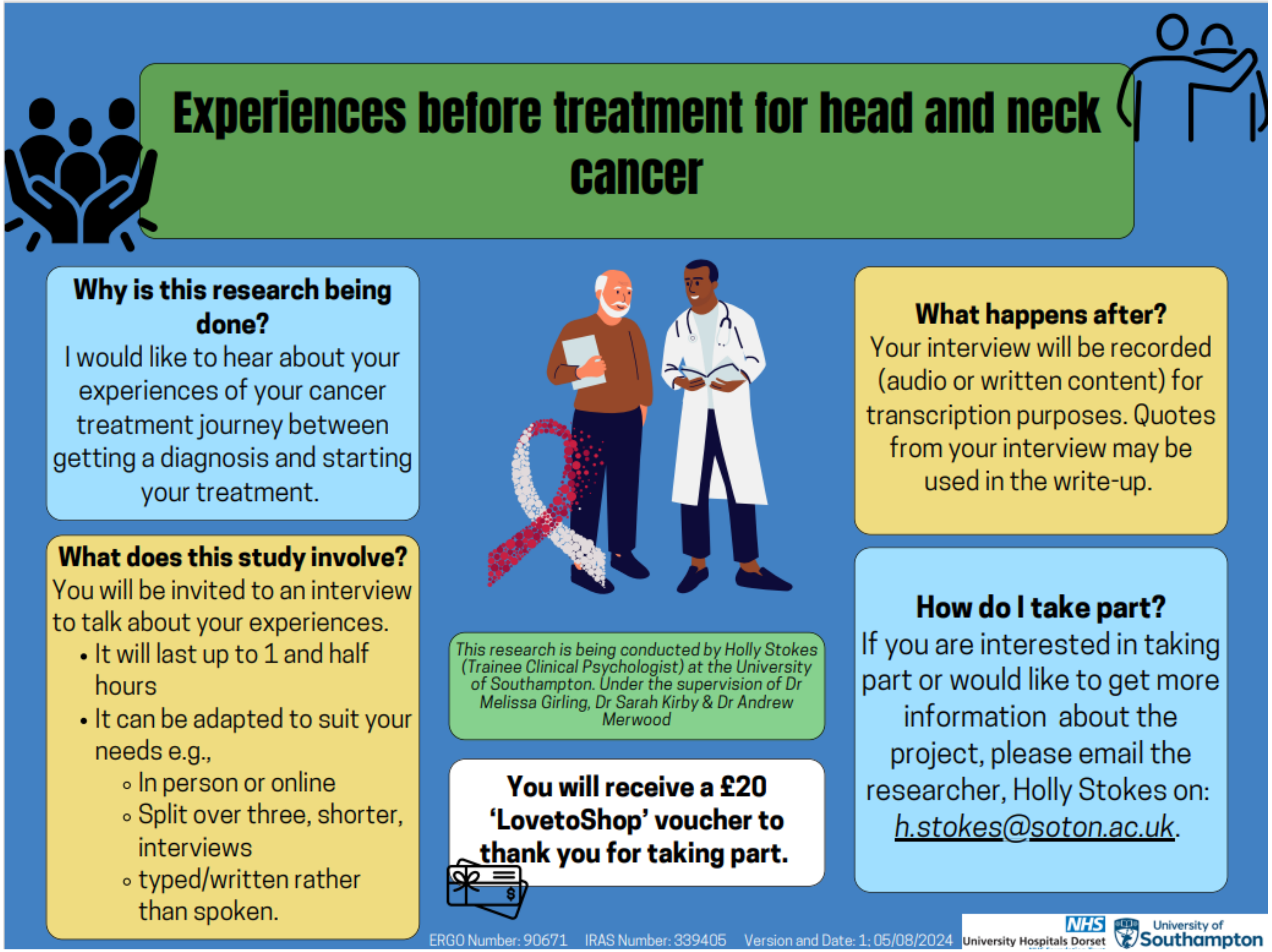
41. Braun V, Clarke V. Conceptual and design thinking for thematic analysis. Qualitative Psychology [Internet]. 2022; 9(1):[3-26 pp.]. Available from: https://doi.org/10.1037/qup0000196.

42. Braun V, Clarke V. Toward good practice in thematic analysis: Avoiding common problems and be(com)ing a knowing researcher. Int J Transgend Health [Internet]. 2023; 24(1):[1-6 pp.]. Available from: https://doi.org/10.1080/26895269.2022.2129597.

43. National Institute for Clinical Excellence (NICE). Improving outcomes in head and neck cancers: The manual. 2004 [Available from:

https://www.nice.org.uk/guidance/csg6/resources/improving-outcomes-in-head-and-neck-cancers-update-pdf-773377597.

Appendix A: Study Poster



Experiences before treatment for head and neck cancer

Why is this research being done?

I would like to hear about your experiences of your cancer treatment journey between getting a diagnosis and starting your treatment.

What does this study involve?

You will be invited to an interview to talk about your experiences.

- It will last up to 1 and half hours
- It can be adapted to suit your needs e.g.,
  - In person or online
  - Split over three, shorter, interviews
  - typed/written rather than spoken.

This research is being conducted by Holly Stokes (Trainee Clinical Psychologist) at the University of Southampton. Under the supervision of Dr Melissa Girling, Dr Sarah Kirby & Dr Andrew Merwood

You will receive a £20 'LovetoShop' voucher to thank you for taking part.

What happens after?

Your interview will be recorded (audio or written content) for transcription purposes. Quotes from your interview may be used in the write-up.

How do I take part?

If you are interested in taking part or would like to get more information about the project, please email the researcher, Holly Stokes on: h.stokes@soton.ac.uk.

ERGO Number: 90671 IRAS Number: 339405 Version and Date: 1; 05/08/2024

Appendix B: Participant Information Sheet

University of Southampton

Participant Information Sheet

Study Title: Experiences of the start of the treatment journey for head and neck cancer.

Researcher: Holly Stokes
ERGO number: 90671
IRAS number: 339405

You are being invited to take part in the above research study. To help you decide whether you would like to take part or not, it is important that you understand why the research is being done and what it will involve. Please read the information below carefully and ask questions if anything is not clear or you would like more information before you decide to take part in this research. You may like to discuss it with others, but it is up to you to decide whether or not to take part. If you are happy to participate you will be asked to sign a consent form.

What is the research about?

My name is Holly Stokes, and I am a trainee Clinical Psychologist on the Doctorate in Clinical Psychology at the University of Southampton. This study is being conducted as part of my postgraduate thesis. This study aims to explore the support people receive (if any), in the time before diagnosis of head and neck cancer until starting treatment (this is known as 'prehabilitation'). The hope is that the outcomes from this study can inform future treatment provided by cancer services. The research project will be sponsored by the University of Southampton.

Why have I been asked to participate?

You have been invited to take part in this study as you are 18 years or older, have received a primary diagnosis of head and neck cancer, this is your first cancer diagnosis and you have had treatment for this (this can be surgery, chemotherapy, radiotherapy, or a combination). I am aiming to recruit up to 20 participants for this project.

What will happen to me if I take part?

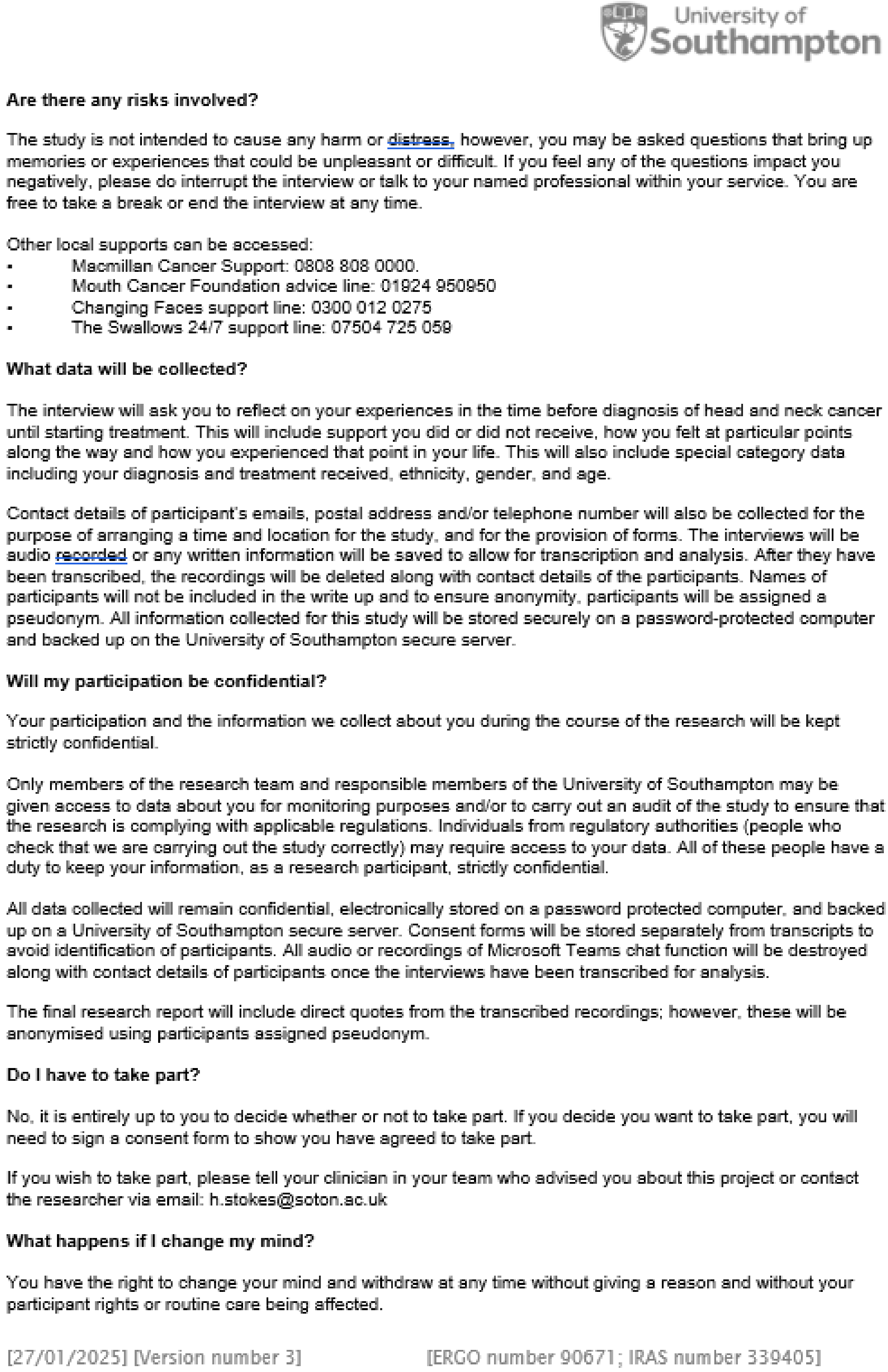
If you decide to take part, you will be required to read this participant information sheet and then give your consent to participate by completing a consent form and returning it to the researcher. The consent form may be given to you in person at the start of the interview or can be sent via email or post. An appropriate time and place for the interview will then be arranged with you. The interview can either take place in person or remotely, via Microsoft Teams (using video and/or chat functions). In person interviews can be verbal conversation, use writing boards or a combination. Before the interview, the researcher will confirm that you are still willing to participate. The questions will ask you to reflect on your experiences in the time before diagnosis of head and neck cancer up until your treatment started. You will be asked if you are comfortable and are encouraged to bring anything that will increase your comfort (e.g., thickened drinks). The interview will be recorded using an audio recorder or through Microsoft Teams so that the interview can be transcribed and analysed. It is expected to take anywhere between 1 hour and 1 hour 30 minutes. The interview can be split into smaller (e.g., 30 minute) chunks if this is preferably. After the interview, you will be given a debriefing form, and your involvement in the study will end.

Your involvement in this study will not impact any care you are currently receiving.

Are there any benefits in my taking part?

There are no direct benefits to yourself for taking part in this interview, however, the aim of this project is to inform support provided to those who receive a similar diagnosis in the future. It is hoped that this project will improve our current understanding of prehabilitation within Oncology.

For your involvement in this project, all participants will receive a £20 LovetoShop voucher to say thank you for taking part.



Are there any risks involved?

The study is not intended to cause any harm or distress, however, you may be asked questions that bring up memories or experiences that could be unpleasant or difficult. If you feel any of the questions impact you negatively, please do interrupt the interview or talk to your named professional within your service. You are free to take a break or end the interview at any time.

Other local supports can be accessed:

- Macmillan Cancer Support: 0808 808 0000.
- Mouth Cancer Foundation advice line: 01924 950950
- Changing Faces support line: 0300 012 0275
- The Swallows 24/7 support line: 07504 725 059

What data will be collected?

The interview will ask you to reflect on your experiences in the time before diagnosis of head and neck cancer until starting treatment. This will include support you did or did not receive, how you felt at particular points along the way and how you experienced that point in your life. This will also include special category data including your diagnosis and treatment received, ethnicity, gender, and age.

Contact details of participant's emails, postal address and/or telephone number will also be collected for the purpose of arranging a time and location for the study, and for the provision of forms. The interviews will be audio recorded or any written information will be saved to allow for transcription and analysis. After they have been transcribed, the recordings will be deleted along with contact details of the participants. Names of participants will not be included in the write up and to ensure anonymity, participants will be assigned a pseudonym. All information collected for this study will be stored securely on a password-protected computer and backed up on the University of Southampton secure server.

Will my participation be confidential?

Your participation and the information we collect about you during the course of the research will be kept strictly confidential.

Only members of the research team and responsible members of the University of Southampton may be given access to data about you for monitoring purposes and/or to carry out an audit of the study to ensure that the research is complying with applicable regulations. Individuals from regulatory authorities (people who check that we are carrying out the study correctly) may require access to your data. All of these people have a duty to keep your information, as a research participant, strictly confidential.

All data collected will remain confidential, electronically stored on a password protected computer, and backed up on a University of Southampton secure server. Consent forms will be stored separately from transcripts to avoid identification of participants. All audio or recordings of Microsoft Teams chat function will be destroyed along with contact details of participants once the interviews have been transcribed for analysis.

The final research report will include direct quotes from the transcribed recordings; however, these will be anonymised using participants assigned pseudonym.

Do I have to take part?

No, it is entirely up to you to decide whether or not to take part. If you decide you want to take part, you will need to sign a consent form to show you have agreed to take part.

If you wish to take part, please tell your clinician in your team who advised you about this project or contact the researcher via email: h.stokes@soton.ac.uk

What happens if I change my mind?

You have the right to change your mind and withdraw at any time without giving a reason and without your participant rights or routine care being affected.

If you wish to withdraw during the interview, please stop the interview and tell the researcher that you do not wish to continue. If you want to withdraw after the interview, you will have 7 days to do so. This is because once the interview is transcribed, it will no longer be identifiable and so it will not be possible to know which interview belongs to who. In this instance, please contact the researcher via email: h.stokes@soton.ac.uk (within 7 days) and state that you no longer wish your interview to be part of the project.

What will happen to the results of the research?

Your personal details will remain strictly confidential. Research findings made available in any reports or publications will not include information that can directly identify you without your specific consent.

All data collected will remain confidential, electronically stored on a password protected computer, and backed up on a University of Southampton secure server. It will be kept by the researcher and used for the purpose of this study. All participants will be assigned a pseudonym. All data will be pooled and complied into a report and will be written up as part of the researcher's postgraduate thesis. The report of this research project will be seen by University of Southampton staff who mark and moderate; it may also be seen by external examiners. The results will be presented at a conference. The researcher hopes that the project will be published in a psychological journal.

Where can I get more information?

For more information about this research project please contact the researcher: Holly Stokes at h.stokes@soton.ac.uk.

What happens if there is a problem?

If you have a concern about any aspect of this study, you should speak to the researchers who will do their best to answer your questions.

If you remain unhappy or have a complaint about any aspect of this study, please contact the University of Southampton Head Research Ethics and Governance (023 8059 5058, rgoinfo@soton.ac.uk). If you were recruited through an NHS service you can also contact the NHS Complaints Procedure, PALS (Patient Advice and Liaison Service) in your area:

- If based in Poole: 0800 5874997
- If based in Dorset: 0800 5874997

Data Protection Privacy Notice

How will we use information about you?

For the purposes of data protection law, the University of Southampton is the 'Data Controller' for this study, we will need to use information from you for this research project.

This information will include your:

- Name
- Contact details

People will use this information to do the research or to check your records to make sure that the research is being done properly. Only members of the research team and responsible members of the University of Southampton may be given access to data about you for monitoring purposes and/or to carry out an audit of the study to ensure that the research is complying with applicable regulations. Individuals from regulatory authorities (people who check that we are carrying out the study correctly) may require access to your data. All of these people have a duty to keep your information, as a research participant, strictly confidential.

We will keep all information about you safe and secure. All data collected will remain confidential, electronically stored on a password protected computer, and backed up on a University of Southampton secure server. Consent forms will be stored separately from transcripts to avoid identification of participants. All audio or recordings of Microsoft Teams chat function will be destroyed along with contact details of participants once the interviews have been transcribed for analysis.

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.

What are your choices about how your information is used?

- You can stop being part of the study at any time, without giving a reason, but we will keep all anonymous information about you that we already have.
- We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

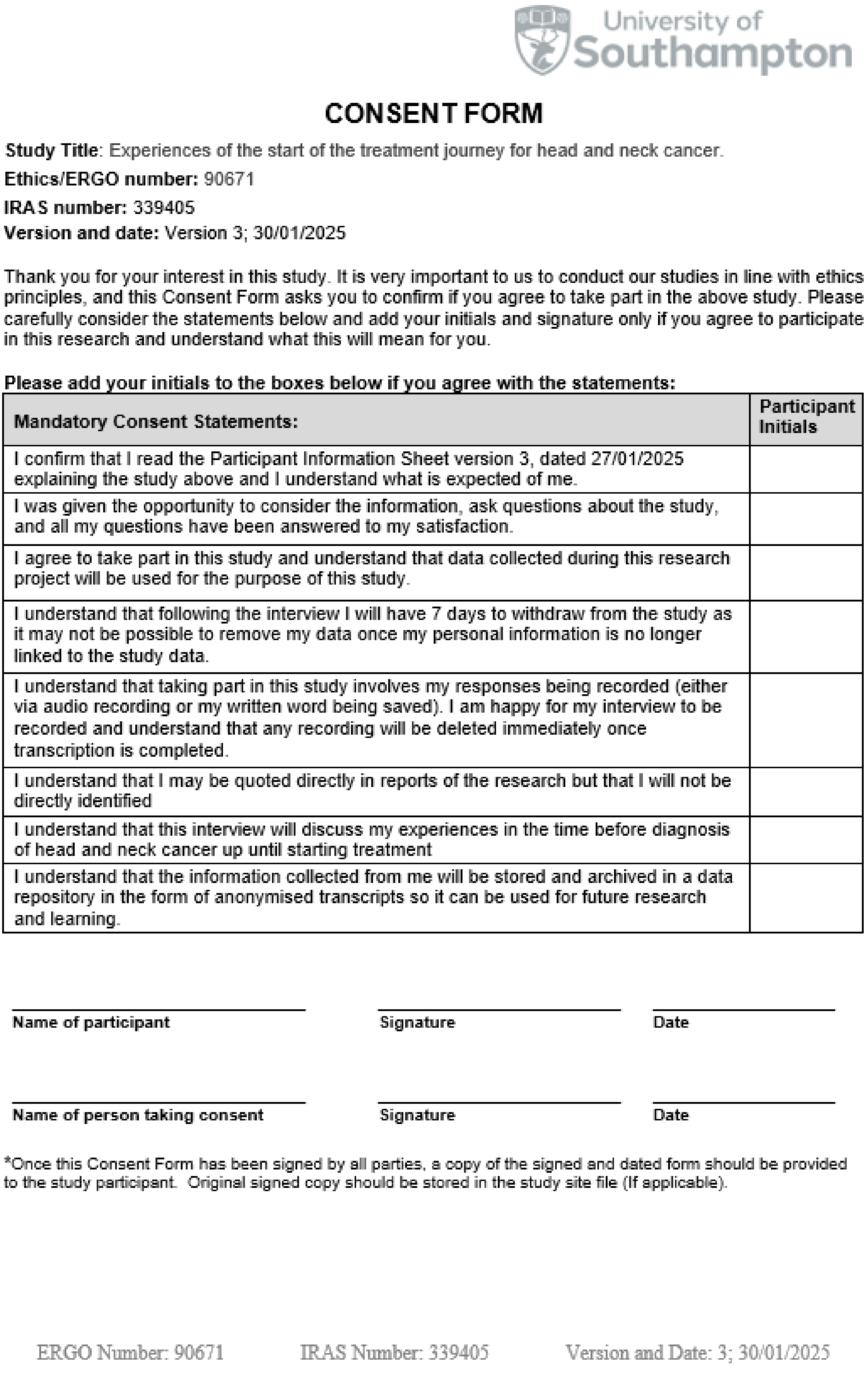
Where can you find out more about how your information is used?

You can find out more about how we use your information:

- By sending an email to University's Data Protection Officer (data.protection@soton.ac.uk).
- By asking one of the research team or from our general privacy policy.
- By sending an email to h.stokes@soton.ac.uk

Thank you for taking the time to read the information sheet and considering taking part in this research study.

Appendix C: Participant Consent Form



University of Southampton

CONSENT FORM

Study Title: Experiences of the start of the treatment journey for head and neck cancer.

Ethics/ERGO number: 90671

IRAS number: 339405

Version and date: Version 3; 30/01/2025

Thank you for your interest in this study. It is very important to us to conduct our studies in line with ethics principles, and this Consent Form asks you to confirm if you agree to take part in the above study. Please carefully consider the statements below and add your initials and signature only if you agree to participate in this research and understand what this will mean for you.

Please add your initials to the boxes below if you agree with the statements:

Mandatory Consent Statements:	Participant Initials
I confirm that I read the Participant Information Sheet version 3, dated 27/01/2025 explaining the study above and I understand what is expected of me.	
I was given the opportunity to consider the information, ask questions about the study, and all my questions have been answered to my satisfaction.	
I agree to take part in this study and understand that data collected during this research project will be used for the purpose of this study.	
I understand that following the interview I will have 7 days to withdraw from the study as it may not be possible to remove my data once my personal information is no longer linked to the study data.	
I understand that taking part in this study involves my responses being recorded (either via audio recording or my written word being saved). I am happy for my interview to be recorded and understand that any recording will be deleted immediately once transcription is completed.	
I understand that I may be quoted directly in reports of the research but that I will not be directly identified	
I understand that this interview will discuss my experiences in the time before diagnosis of head and neck cancer up until starting treatment	
I understand that the information collected from me will be stored and archived in a data repository in the form of anonymised transcripts so it can be used for future research and learning.	

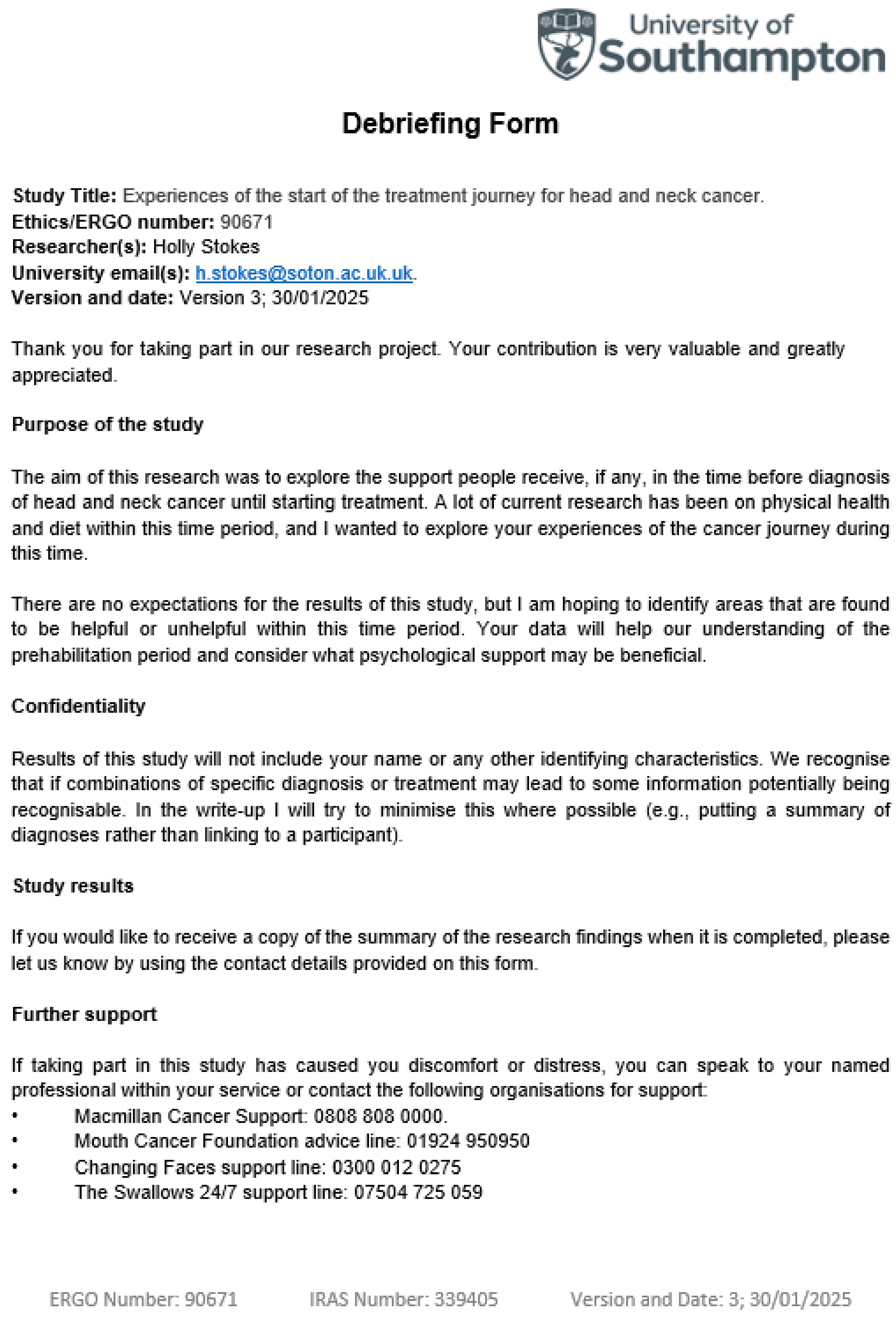
Name of participant **Signature** **Date**

Name of person taking consent **Signature** **Date**

*Once this Consent Form has been signed by all parties, a copy of the signed and dated form should be provided to the study participant. Original signed copy should be stored in the study site file (If applicable).

ERGO Number: 90671 IRAS Number: 339405 Version and Date: 3; 30/01/2025

Appendix D: Participant Debrief



Debriefing Form

Study Title: Experiences of the start of the treatment journey for head and neck cancer.
Ethics/ERGO number: 90671
Researcher(s): Holly Stokes
University email(s): h.stokes@soton.ac.uk.uk.
Version and date: Version 3; 30/01/2025

Thank you for taking part in our research project. Your contribution is very valuable and greatly appreciated.

Purpose of the study

The aim of this research was to explore the support people receive, if any, in the time before diagnosis of head and neck cancer until starting treatment. A lot of current research has been on physical health and diet within this time period, and I wanted to explore your experiences of the cancer journey during this time.

There are no expectations for the results of this study, but I am hoping to identify areas that are found to be helpful or unhelpful within this time period. Your data will help our understanding of the prehabilitation period and consider what psychological support may be beneficial.

Confidentiality

Results of this study will not include your name or any other identifying characteristics. We recognise that if combinations of specific diagnosis or treatment may lead to some information potentially being recognisable. In the write-up I will try to minimise this where possible (e.g., putting a summary of diagnoses rather than linking to a participant).

Study results

If you would like to receive a copy of the summary of the research findings when it is completed, please let us know by using the contact details provided on this form.

Further support

If taking part in this study has caused you discomfort or distress, you can speak to your named professional within your service or contact the following organisations for support:

- Macmillan Cancer Support: 0808 808 0000.
- Mouth Cancer Foundation advice line: 01924 950950
- Changing Faces support line: 0300 012 0275
- The Swallows 24/7 support line: 07504 725 059

ERGO Number: 90671 IRAS Number: 339405 Version and Date: 3; 30/01/2025

Further information

If you have any concerns or questions about this study, please contact Holly Stokes at h.stokes@soton.ac.uk who will do their best to help.

If you remain unhappy or would like to make a formal complaint, please contact the Head of Research Integrity and Governance, University of Southampton, by emailing: rgoinfo@soton.ac.uk, or calling: + 44 2380 595058. Please quote the Ethics/ERGO number which can be found at the top of this form. Please note that if you participated in an anonymous survey, by making a complaint, you might be no longer anonymous.

Thank you again for your participation in this research.

Appendix E: Excerpts from Reflexive Log

Interview 2:

Initial reflections:

- He appeared calm at the start.
- Private room – at home.
- I've had a busy day on placement. Feeling slightly less relaxed than the first interview. Tired.

Overall notes during the interview:

- Shock – couldn't find the tumour – upset family
- Annoyance
- Why me? Sorry for self.
- Week bad – zen, accepting
- Talk. Hold on to things. Write things.
- Hanging over me – low after
- Q3 – break down more?
- Try to do everything

Reflections post-interview:

- Did I become leading to psychological stuff? Consider this when transcribing and listening back.
- He gave less than previous interviews and needed more prompting/follow-up questions. Stark contrast between first two interviews and how much they shared. I felt some discomfort at times – felt like I was talking more than I should?? This ppt was more thoughtful and succinct in his answers.
- At times I noted whether validating his responses might have appeared as suggesting that an answer was 'right' or 'better'. Note this for future interviews.
- Felt interview went well overall.
- Think I need to be mindful of my responses or how I move between questions so as to not be unintentionally leading – especially when interviews are late or at the end of a busy day when I might be more likely to fall into natural therapy type patterns.
- I recognised a desire for this research to be meaningful and to have an impact – taken so long to get here, feel like every word needs to count. Be aware of this – challenge thought, looking at experiences so every word will be important as it is their experience, I don't need to force anything.

Interview 7:

Initial reflections:

- At home.
- Lots of pictures behind – protest type posters. Assumption: charity/giving personality??
- Quirky style

Overall notes during the interview:

- Prehab period was short.
- Numb
- Word Macmillan – 'hit', powerful. Different for husband – importance of language and how people interpret/what is important.

- Matter of fact.
- Type of person who wants to fix things now.
- 'No one got to know me'. Impact of speech on personality. Stigma from staff / no time to get to know her / how much of herself was she able to share???

Reflections post-interview:

- Creative and supportive family/friends – this was lovely to listen to – particularly her friends sitting by her and including her even though she could not speak.
- The impact that treatment/losing her voice had on her identity surprised me – made sense afterwards but had not anticipated this aspect of people's experience.
- This lady appeared kind and quirky – engaged with the interview.
- She reported that it felt therapeutic – said she had not spoken to anyone outside of her close circle about her cancer experiences before – brave – curious to what made her volunteer for this and what was different for her now. I also thought about the impact of these questions – she has avoided this and asking quite deep questions and asking her to reflect, what impact might this have on her moving forward?

Notes Across Interviews During Transcription, Familiarisation and Coding:

- Power – medical professionals hold a lot of power over patients – for some there are thoughts of life vs. death and the impact that the medical team in administering lifesaving treatments. Where do I fit into this? People talking to me are well and wanting to share their experiences. I hold power in being able to share their voice. This feels like it comes with a sense of responsibility.
- Family and friends – really mixed reports – some find support helpful while others don't. Some seem to suggest a mismatch between what they feel they need and what family and friends can provide – seems like a thin line and dependant on lots of context (communication styles, avoidance, how they process the cancer themselves etc.).
- Strong words about ending treatment – dropped, cliff edge, abandoned.
- I recognise that for all the preparation I did and experiences I had prior to this research project I was still not full prepared for how intrusive cancer treatments are (e.g., free flap operations and radiotherapy) and the impact they have on people's lives and identities. It was emotional at times, particularly listening back from a different perspective than when interviews. It makes me think about my position as a young female who has not experienced cancer and how this means I am interpreting the interviews and the perspective I will bring.

Appendix F: Journal Choice and Guidelines

Chapter One: Psycho-Oncology

This journal was chosen due to its relevant aims to the systematic review I completed. The scope of this journal is oriented to research exploring the biopsychosocial aspects of cancer care, particularly research that promotes holistic and individualised care.

The journal requests Vancouver style referencing, a structured abstract (250 words maximum) and reviews have a 5000-word maximum word count (not including title, abstract, references or appendices). Systematic reviews are encouraged to follow PRISMA guidelines and should be written using the headings: Abstract, Background, Methods, Results, Discussion, Implications (clinical and research), Limitations, Conclusions.

Please see further information about author guidelines here: https://onlinelibrary.wiley.com/page/journal/10991611/homepage/forauthors.html#manuscript

Chapter Two: Psychology Health & Medicine

This is a multidisciplinary journal exploring the overlap of health and psychology in relation to illness, treatment, intervention and adjustment. The journal is aimed at professionals working across health contexts (including psychologists, doctors and managers).

The journal does not provide strict requirements for referencing or formatting and so Vancouver styles was used to allow cohesion across chapters. The journal asks for an unstructured abstract (300 words) and research articles have a 7000-word maximum word count.

Please see further information about author guidelines here: https://www.tandfonline.com/action/authorSubmission?show=instructions&journalCode=cphm20#article-types

Supplementary Materials

Supplementary Materials S1: Studies screened at full text level and excluded, and reason for exclusion.

Reference	Main reason for exclusion
Abouzeid WM, Mokhtar SA, Mahdy NH, El Kwsky FS. Quality of life of patients with oral and pharyngeal malignancies. J Egypt Public Health Assoc. 2009;84(3-4):299-329.	Single time point for data collection.
Abendstein H, Nordgren M, Boysen M, Jannert M, Silander E, Ahlner-Elmqvist M, Hammerlid E, Bjordal K. Quality of life and neck cancer: A 5 year prospective study. Laryngoscope. 2005;115:2183-2192. **https://doi.org/10.1097/01.MLG.0000181507.69620.14**	Wrong outcome – exploring trends rather than predictors.
Allison PJ, Locker D, Wood-Dauphinee S, Black M, Feine JS. Correlates of health-related quality of life in upper aerodigestive tract cancer patients. Qual Life Res. 1998;7:713-722. **https://doi.org/10.1023/A:1008880816543**	Single time point for data collection.
Al-Mamgani A, Tans L, van Rooij P, Levendag PC. A single-institutional experience of 15 years of treating T3 laryngeal cancer with primary radiotherapy, with or without chemotherapy. Int J Radiation Oncol Biol Phys. 2012;83(3):1000-1006. **http://dx.doi.org/10.1016/j.ijrobp.2011.07.045**	Single time point of data collection. Wrong outcome – exploring trends and survival.
Amar A, Rapoport A, Franzi SA, Bisordi C, Lehn CN. Quality of life and prognosis of squamous cell carcinoma of the head and neck. Rev Bras Otottinolaringol. 2002;68(3):400-4003.	Not available in English.
Aminnudin AN, Doss JG, Ismail SM, Chai MB, Abidin MZ, Basri CSJM, Kipli NP, Wei LC. Can post-treatment oral cancer patients' concerns reflect their cancer characteristics, HRQoL, psychological distress level and satisfaction with consultation? Ecancer. 2020;14:1-18. **https://doi.org/10.3332/ecancer.2020.1118**	Single time point for data collection.
Andersen LP, Dietrich MS, Murphy BA, Deng J. Factors associated with quality of life among patients with a newly diagnosed oral cavity and oropharyngeal cancer. Eur J Oncol Nurs. 2023;66:102384. **https://doi.org/10.1016/j.ejon.2023.102384**	Wrong outcome – looking at pre-treatment QoL.
Artopoulou II, Sarafanou A, Perisanidis C, Polyzois G. Effectiveness of prosthetic rehabilitation and quality of life of older edentulous head and neck cancer survivors following resection of the maxilla: a cross-sectional study. Support Care cancer. 2022;30:4111-4120. **https://doi.org/10.1007/s00520-022-06850-9**	Wrong outcome - looking at effectiveness of denture and denture specifics on QoL.
Artopoulou II, Karademas EC, Perisanidis C, Polyzois G. Quality of life in patients with soft palate resection: The	Single time point for data collection.

relationship between reported functional prosthetic outcomes and the patient's psychological adjustment. J Prosthet Dent. 2022;128(6):1387-1397. **https://doi.org/10.1016/j.prosdent.2021.04.009**	
Badr H, Lipnick D, Gupta V, Miles B. Survivorship challenges and information needs after radiotherapy for oral cancer. J Canc Educ. 2017;32:799-807. **https://doi.org/10.1007/s13187-016-1048-8**	No QoL measure used. Single time point for data collection.
Bajwa HK, Singareddy R, Alluri KR. High-dose-rate interstitial brachytherapy in oral cancer: Its impact on quality of life. Bracytherapy. 2016;16:381-386. **http://dx.doi.org/10.1016/j.brachy.2016.02.002**	No lower limit age reported.
Barber B, Dergousof J, Nesbitt M, Mitchell N, Harris J, O'Connell D, Cote D, Biron V, Seikaly H. Depression as a predictor of postoperative functional performance status (PFPS) and treatment adherence in head and neck cancer patients: a prospective study. J Otolaryngol Head Neck Surg. 2015;44:1-8. **http://dx.doi.org/10.1186/s40463-015-0092-4**	Wrong outcome – exploring correlation between depression and performance status/treatment adherence rather than QoL.
Berg M, Silander E, Bove M, Johansson L, Nyman J, Hammerlid E. Fatigue in long-term head and neck cancer survivors: From diagnosis until five years after treatment. The Laryngoscope. 2023;133:2211-2221. **http://dx.doi.org/10.1002/lary.30534**	Wrong outcome – fatigue.
Binnal A, Rajesh G, Saxena PUP, Banjeree S, Denny C, Tadakamadla SK. Health-related quality of life among oral and oropharyngeal cancer patients: An exploratory study. Oral Dis. . 2022;28:585–599. **http://dx.doi.org/10.1111/odi.13772**	Single time point for data collection.
Bower WF, Vlantis AC, Chung TML, Van Hasselt CA. Mode of treatment affects quality of life in head and neck cancer survivors: Implications for holistic care. Acta Oto-Laryngologica. 2010;130(10);1185-1192. **https://doi.org/10.3109/00016481003667366**	Single time point for data collection. No lower age limit reported.
Bozec A, Shultz P, Gal J, Chamorey E, Chaeau Y, Dassonville O, Poissonnet G, Santini J, Peyrade F, Saada E, Guiday J, Benezery K, Leysalle A, Santini L, Giovannie A, Messaoudi L, Fakhry N. Evaluation of the information given to patients undergoing head and neck cancer surgery using the EORTC QLQ-INFO25 questionnaire: A prospective multicentric study. Eur J Cancer. 2016;67:73-82. **http://dx.doi.org/10.1016/j.ejca.2016.08.005**	Wrong outcome – exploring perceptions of information received by patients.
Bozec A, Shultz P, Gal J, Chamorey E, Chaeau Y, Dassonville O, Poissonnet G, Peyrade F, Saada E, Guigay J, Benezery K, Leysalle A, Santini L, Giovanni L, Messaoudi L, Fakhry N. Evaluation of the information given to patients undergoing total	No lower age limit reported.

pharyngolaryngectomy and quality of life: a prospective multicentric study. Eur Arch Otorhinolaryngol. 2019;276:2531-2539. **https://doi.org/10.1007/s00405-019-05513-6**	
Bozec A, Boscagli M, Serris M, Chamorey E, Dassonville O, Poissonnet G, Culie D, Scheller B, Benezery K, Gal J. Long-term functional and quality of life outcomes in laryngectomized patients after successful voice restoration using tracheoesophageal prostheses. Surgical Oncology. 2021;38:1-8. **https://doi.org/10.1016/j.suronc.2021.101580**	Single time point for data collection. No lower age limit reported.
Čanković M, Tesic M, Jevtic M, Stevanovic D, Jovanovic MB, Kostic D, Antic J, Trivic SK. Predictors of health-related quality of life in Serbian patients with head and neck cancer. Med Oral Patol Oral Cir Bucal. 2022;27(4): e340-350. **https://doi.org/10.4317/medoral.25274**	Single time point for data collection.
Chan KKW, Willan AR, Gupta M, Pullenayegum E. Underestimation of uncertainties in health utilities derived from mapping algorithms involving health-related quality-of-life measures: Statistical explanations and potential remedies. Med Decis Making. 2014;34:863-872 **https://doi.org/10.1177/0272989X13517750**	Wrong outcome – provides an algorithm for health utility predictions.
Chen SC, Huang BS, Hung TM, Chang YL, Lin CY, Chung CY, Wu SC. Swallowing ability and its impact on dysphagia-specific health-related QOL in oral cavity cancer patients post-treatment. EJON. 2018;36;89-94. **https://doi.org/10.1016/j.ejon.2018.07.002**	Wrong outcome - dysphagia-specific health-related QOL.
Clasen D, Keszte J, Dietz A, Oeken J, Meister EF, Guntinas-Lichius O, Pabst F, Buntzel J, Jenzewski EM, Singer S, Meyer A. Quality of life during the first year after partial laryngectomy: Longitudinal study. Head & Neck. 2018;40:1185–1195. **https://doi.org/10.1002/hed.25095**	Wrong outcome – exploring QoL over time, not predictors of QoL.
Cruz MSP, Reis TG, Oliveira AC, Macedo MM, de Bessa J, Oliveira MC. Nighttime salivary cortisol as a biomarker of stress and an indicator of worsening quality of life in patients with head and neck cancer: A cross-sectional study. Health Sci Rep. 2022;5:1-6. **https://doi.org/10.1002/hsr2.783**	Single time point for data collection. Wrong outcome – impact of cortisol on QOL.
D'Antonio LL, Long SA, Zimmerman GJ, Peterman AH, Petti GH, Chonkich GD. Relationship between quality of life and depression in patients with head and neck cancer. Laryngoscope. 1998;108(6):806-811. **https://doi.org/10.1097/00005537-199806000-00006**	Single time point for data collection. Pre-2000.
Dahill A, Al-Nakishbandi H, Cunningham KB, Humphris GM, Lowe D, Rogers SN. Loneliness and quality of life after head and neck cancer. Br J Oral Maxillofac Surg. 2020;58:959-965. **https://doi.org/10.1016/j.bjoms.2020.04.041**	Wrong outcome – loneliness.

De Carvalho A, Grubits H, Vera JA, Durazo F. QoL and coping in patients after head and neck surgery. Psicologia, Saúde & Doenças. 2021;22(1):240-251. **http://dx.doi.org/10.15309/21psd220121**	Not available in English.
De Graeff A, de Leeuw JR, Ros WJ, Hordijk GJ, Blijham GH, Winnubst JA. Prediction of quality of life and depression after treatment for head and neck cancer. Gedrag en Gezondheid. 2002;30(3):178-91.	No full text available.
De Melo NB, de Macedo Bernardino I, de Melo DP, Gomes DQC, Bento PM. Head and neck cancer, quality of life, and determinant factors: a novel approach using decision tree analysis. Oral Sug Oral Med Oral Pathol Oral Radiol. 2018;126(6):486-493. **https://doi.org/10.1016/j.oooo.2018.07.055**	Single time point for data collection.
De Melo NB, de Sousa VM, de Macedo Bernardino I, de Melo DP, Gomes DQC, Bento PM. Oral health related quality of life and determinant factors in patients with head and neck cancer. Med Oral Patol Oral Cir Bucal. 2019;24(3):e281-289. **http://dx.doi.org/doi:10.4317/medoral.22670**	Single time point for data collection.
Demez PH, Moreau PR. Perception of head and neck cancer quality of life within the medical workd: A multicultural study. Head Neck. 2009;31:1056-1067. **https://doi.org/10.1002/hed**	Sample was Otolaryngologists (professionals, rather than patients).
De Vries J, Bras L, Sidorenkov G, Festen S, Steenbakkers RJHM, Langendijk JA, Witjes MJH, ver der Laan BFAM, de Bock GH, Halmos GB. Frailty is associated with decline in health-related quality of life of patients treated for head and neck cancer. Oral Oncol. 2020;111:1-8. **https://doi.org/10.1016/j.oraloncology.2020.105020**	Skin cancer patients included.
De Vries J, Vermue DJ, Sidorenkov G, Festen S, Langendijk JA, de Bock GH, Halmos GB. Head and neck cancer patients with geriatric deficits are more often non-responders and lost from follow-up in quality of life studies. Eur Arch Otorhinolaryngol. 2024;281:2619-2626. **https://doi.org/10.1007/s00405-024-08528-w**	Wrong outcome – looking at factors influencing drop outs and non-responders in QoL research.
Doss JG, Thomson WM, Drummond BK, Ghani WMN. Impact of treatment modalities on oral cancer patients' health-related quality of life over a time trajectory. Front Oral Maxillofac Med. 2022;4:1-14. **https://dx.doi.org/10.21037/fomm-21-90**	Wrong outcome – exploring only treatment modality, not general predictors.
Dzebo S, Mahmutovic J, Erkocevic H. Quality of Life of Patients with Oral Cavity Cancer. Mater Sociomed. 2017;29(1):30-34. **https://dx.doi.org/10.5455/msm.2017.29.30-34**	Wrong outcome – looking at trend of QoL rather than predictors.
Eadie TL, Bowker CB. Coping and quality of life after total laryngectomy. OTO Journal. 2012;146(6):959-965. **https://doi.org/10.1177/0194599812437315**	Single time point for data collection.
Efunkoya AA, Adebola RA, Omeje KU, Amole IO, Akhiwu BI, Osunde DO. Quality of life following surgical	Under 18's included.

treatment of oral cancers. J Korean Assoc Oral Maxillofac Surg. 2015;41:19-25. **http://dx.doi.org/10.5125/jkaoms.2015.41.1.19**	
El-Deiry MW, Futran ND, McDowell JA, Weymuller EA, Yueh B. Influences and predictors of long-term quality of life in head and neck cancer survivors. Arch Otolaryngol Head neck Surg. 2009;135(4):380-384. **https://doi.org/10.1001/archoto.2009.18**	No lower age limit reported.
Funk GF, Karnell LH, Christensen AJ. Long-term health-related quality of life in survivors of head and neck cancer. Arch Otolaryngol Head Neck Surg. 2012;138(2):123-133. **https://doi.org/10.1001/archoto.2011.234**	No QoL measure used.
Gamba A, Romano M, Grosso LM, Tamburini M, Cantu G, Molinari R, Ventafridda V. Psycholsocial adjustment of patients surgically treated for head and neck cancer. Head Neck. 1992;14(3):218-223. **https://doi.org/10.1002/hed.2880140309**	Single time point for data collection. Pre-2000.
Gane EM, McPhail SM, Hatton AL, Panizza BJ, O'Leary SP. Predictors of health-related quality of life in patients treated with neck dissection for head and neck cancer. Eur Arch Otorhinolaryngol. 2017;274:4183–4193. **https://doi.org/10.1007/s00405-017-4754-x**	Single time point for data collection. Thyroid cancer patients included.
Giuliani M, Papadakos J, Broadhurst M, Jones J, McQuestion M, Le LW, Beck L, Waldron J, Ringash J. The prevalence and determinants of return to work in head and neck cancer survivors. Support Care Cancer. 2019; 27:539–546. **https://doi.org/10.1007/s00520-018-4343-6**	Wrong outcome – exploring barriers to returning to work rather than QoL.
Goyal AK, Bakshi J, Panda NK, Kapoor R, Vir D, Kumar K, Aneja P. Shame and stigma over long-term survival in postoperative cases of head and neck cancer. J. Maxillofac. Oral Surg. 2024;3:1057–1062. **https://doi.org/10.1007/s12663-023-01931-6**	Single time point for data collection. No QoL measure.
Granstrom B, Ehrsson YT, Holmberg E, Hammerlid E, Beran M, Tano K, Laurell G. Return to work after oropharyngeal cancer treatment: Highlighting a growing working-age population. Head & Neck. 2020;42:1893–1901 **https://doi.org/10.1002/hed.26123**	Wrong outcome – exploring returning to work rather than QoL.
Griemel ER, Padilla GV, Grant MM. Gender differences in outcomes among patients with cancer. Psycho-oncology. 1998;7:197-206. **https://doi.org/10.1002/(SICI)1099-1611(199805/06)7:3%3C197::AID-PON303%3E3.0.CO;2-Q**	Pre-2000. Sample across cancer diagnoses, not just HNC.
Gritz ER, Carmack CL, de Moor C, Coscarelli A, Schacherer CW, Meyers EG, Abemayor E. First year after head and neck cancer: Quality of life. J Clin Oncol. 1999;17(1):352-360. **https://doi.org/10.1200/JCO.1999.17.1.352**	Paper published pre-2000.

Guerriero, MK, Redman MW, Baker KK, Martins RG, Eaton K, Chow LQ, Santana-Davila R, Baik C, Goulart BH, Lee S, Rodriguez CP. Racial disparity in oncologic and quality-of-life outcomes in patients with locally advanced head and neck squamous cell carcinomas enrolled in a randomized phase 2 trial. Cancer. 2018;124:2841-2849. **https://doi.org/10.1002/cncr.31407**	Wrong outcome – exploring racial disparities in QoL measurement.
Gurney TA, Eisele DW, Orloff LA, Wang SJ. Predictors of quality of life after treatment for oral cavity and oropharyngeal carcinoma. OTO Journal. 2008;139:262-267. **http://dx.doi.org/10.1016/j.otohns.2008.05.024**	Single time point for data collection.
Hammerlid E, Ahlner-Elmqvist M, Biörklund K, Evensen J, Boysen J, Jannert M, Kaasa S, Sullivan M, Weston T. A prospective multicentre study in Sweden and Norway of mental distress and psychiatric morbidity in head and neck cancer patients. Br J Cancer. 1999;80(5/6):766-774. **https://doi.org/10.1038/sj.bjc.6690420**	No QoL measure. Pre-2000.
Henry M, Sargi E, Frenkiel S, Hier M, Zeitouni A, Kost K, Mlynarek A, Black M, MacDonald C, Richardson K, Chartier G, Sadeghi N, Rosberger, Z. Longitudinal study indicating antecedent psychosocial vulnerability as predictor of anxiety disorders post-treatment in people with head and neck cancer. Psycho-Oncology. 2021;30:1910–1919. **https://doi.org/10.1002/pon.5760**	Skin cancer patients included.
Holloway RL, Hellewell JL, Marbella AM, Layde PM, Myers KB, Campbell BH. Psychosocial effects in long-term head and neck cancer survivors. Head & Neck. 2005;27(4):281-288. **https://doi.org/10.1002/hed.20147**	Single time point for data collection. No lower age limit reported.
Howren MB, Seaman A, Super GL, Christensen AJ, Pagedar NA. Examination of predictors of pain as 12 months postdiagnosis in head and neck cancer survivors. OTO Journal. 2023;169(6):1506-1512. **https://doi.org/10.1002/ohn.416**	Wrong outcome – exploring predictors of pain.
Huang K, Przeslawski C, Ramirez CA. What risk factors are associated with poorer quality of life in patients with head and neck cancer? J Oral Maxillofac Surg. 2023;81(5):648-653. **https://doi.org/10.1016/j.joms.2022.11.016**	Single time point of data collection.
Humphris GM, Ozakinci G. Psychological responses and support needs of patients following head and neck cancer. Int J Surg. 2006;4(1):37-44. **https://doi.org/10.1016/j.ijsu.2005.12.004**	Review/summary of literature.
Hung CY, Hsu MH, Lee SH, Hsueh SW, Lu CH, Yeh KY, Wang HM, Chang JTC, Hung YS, Chou WC. Impact of pretreatment quality of life on tolerance and survival outcome in head and neck cancer patients undergoing	Data collected pre-treatment. Single time point for data collection. Wrong outcome – exploring how QoL can predict survival.

definitive CCRT. J Formos Med Assoc or J Formos Med Assoc. 2024;123:1010-1017. **https://doi.org/10.1016/j.jfma.2024.01.022**	
Ichikura K, Yamashita A, Sugimoto T, Kishimoto S, Matsushima E. Persistence of psychological distress and correlated factors among patients with head and neck cancer. Palliat Support care. 2016;14:42-51. **https://doi.org/10.1017/S1478951515000711**	No lower age limit reported.
Kanatas A, Lowe D, Rogers SN. Health-related quality of life at 3 months following head and neck cancer treatment is a key predictor of longer-term outcome and of benefit from using the patient concerns inventory. Cancer Medicine. 2022;11:1879–1890. **https://doi.org/10.1002/cam4.4558**	No age limit in inclusion criteria and no age range/lower age limit reported
Khan K, Pelletier G. Identity processing styles and quality of life in head and neck cancer. Can J Behav Sci. 2021;53(3):243-253. **http://dx.doi.org/10.1037/cbs0000241**	Single time point for data collection.
Khan L, Tjong M, Raziee H, Lee J, Erler D, Chin L, Poon I. Role of stereotactic body radiotherapy for symptom control in head and neck cancer patients. Support Care Cancer. 2015;23:1099–1103. **https://doi.org/10.1007/s00520-014-2421-y**	Skin cancer patients included.
Kiafi P, Kouri MA, Patatoukas G, Kougioumtzopoulou A, Chalkia M, Nicolatou-Galitis O, Kouloulias V, Kyrodimos E, Platoni K. Unravelling quality of life for head and neck cancer patients after VMAT radiation therapy: Insights from toxicity, dosimetry and symptoms correlation. Clin. Pract. 2024;14:1085–1099. **https://doi.org/10.3390/clinpract14030086**	Wrong outcome – exploring benefits of QoL measures.
Kim SA, Roh JL, Lee SA, Lee SW, Kim SB, Choi SH, Nam SY, Kim SY. Pretreatment depression as a prognostic indicator of survival and nutritional status in patients with head and neck cancer. Cancer. 2016;122:131-140. **https://doi.org/10.1002/cncr.29693**	Wrong outcome – exploring the impact of depression on survival and nutritional status.
Kobayashi W, Kukobota K, Ito R, Sakaki H, Nakagawa H, The BG. Can superselective intra-arterial chemoradiotherapy replace surgery followed by radiation for advanced cancer of the tongue and floor of the mouth? J Oral Maxillofac Surg. 2016;74:1248-1254. **http://dx.doi.org/10.1016/j.joms.2016.01.007**	Wrong outcome – exploring treatments on survival.
Lebel S, Payne AYM, Mah K, Irish J, Rodin G, Devins GM. Do stigma and its psychosocial impact differ between Asian-born Chinese immigrants and western-born Caucasians with head and neck cancer? Psychol Health Med. 2016;21(5):583-592 **https://doi.org/10.1080/13548506.2016.1139138**	Thyroid cancer patients.
Lenze NR, Bensen JT, Farnan L, Sheth S, Zevallos JP, Yarbrough WG, Zanation AM. Evaluation of patient-	Wrong outcome – exploring barriers to care.

reported delays and affordability-related barriers to care in head and neck cancer. OTO Open. 2021;5(4):1-9. **https://doi.org/10.1177/2473974X211065358**	
Lenze NR, Bensen JT, Yarbrough WG, Shuman AG. Characteristics and outcomes associated with anxiety and depression in a head and neck cancer survivorship cohort. Am J Otolaryngol Head Neck Surg. 2022;42:1-6. **https://doi.org/10.1016/j.amjoto.2022.103442**	Wrong outcome – exploring predictors of mental health disorders.
Lin A, Kim HM, Terrell JE, Dawson LA, Shit JA, Eisbruch A. Quality of life after partoid-sparing IMRT for head-and-neck cancer: A prospective longitudinal study. Int J Rad Oncol Bio Phys. 2003;57(1): 61–70. **https://doi.org/10.1016/S0360-3016(03)00361-4**	Wrong outcome – exploring xerostomia-specific QoL.
Lin CR, Hung TM, Shen EYL, Cheng AJ, Chang PH, Huang SF, Kang CJ, Fang TJ, Lee LA, Chang CH, Chang JTC. Impacts of employment status, partnership, cancer type, and surgical treatment on health-related quality of life in irradiated head and neck cancer survivors. Cancers. 2024;16:1-12. **https://doi.org/10.3390/cancers16193366**	Single time point for data collection.
List MA, Ritter-Sterr CA, Baker TM, Colangelo LA, Matz G, Pauloski BR, Logemann JA. Longitudinal assessment of quality of life in laryngeal cancer patients. Head & Neck. 1996;18:1-10. **https://doi.org/10.1002/(SICI)1097-0347(199601/02)18:1%3C1::AID-HED1%3E3.0.CO;2-7**	Single time point for data collection.
Llewellyn CD, Homey DJ, McGurk M, Weinman J, Herold K, Altman K, Smith HE. Assessing the psychological predictors of benefit finding in patients with head and neck cancer. Psycho-Oncology. 2013;22:97-105. **https://doi.org/10.1002/pon.2065**	Wrong outcome – exploring benefit finding in HNC patients.
Long SA, D'Antonio LL, Robinson EB, Zimmerman G, Petti G, Chonkich G. Factors related to quality of life and functional status in 50 patients with head and neck cancer. Laryngoscope. 1996;106(9):1084-1088. **https://doi.org/10.1097/00005537-199609000-00008**	Single time point of data collection.
Lorenz FJ, King TS, Engle L, Beauchamp-Perez F, Goyal N. Predictors of quality of life for head and neck cancer patients at an academic institution. OTO Open. 2023;7(4):1-8. **https://doi.org/10.1002/oto2.82**	Single time point for data collection. No lower age limit or age range reported.
Lovell SJ, Wong HB, Loh KS, Ngo RYS, Wilson JA. Impact of dysphagia on quality-of-life in nasopharyngeal carcinoma. Head & Neck. 2005;27:864-872. **https://doi.org/10.1002/hed.20250**	Single time point for data collection. Wrong outcome – exploring only impact of dysphagia on QoL.
Lu CH, Hung CY, Hsueh SW, Yeh KY, Hug YS, Chou WC. Frailty is an independent factor for health-related quality of life in patients with head and neck cancer receiving definitive concurrent Chemoradiotherapy. Support Care Cancer. 2024;32:1-9.	Single time point for data collection. Wrong outcome – exploring only impact of frailty on QoL.

https://doi.org/10.1007/s00520-024-08313-9	
Malmström M, Klefsgard R, Ivarsson B, Roman M, Johansson J. Quality of life measurements as an indicator for timing of support after oesophagectomy for cancer: A prospective study. BMC Health Serv Res. 2015;15:1-7. **https://doi.org/10.1186/s12913-015-0747-x**	Sample made up of oesophagus cancer patients.
Markovic MM, Petrovic M, Latas M, Djordjevic I, Milovanovic S, Jovanovic S. Quality of life of patients with oral squamous cell carcinoma. Iran J Public Health. 2024;53(2):414-424. **https://doi.org/10.18502/ijph.v53i2.14926**	Single time point for data collection.
McDowell L, So N, Keshavarzi S, Xu W, Rock K, Chan B, Waldron J, Bernstein LJ, Huang SH, Giuliani M, Hope A, O'Sullivan B, Bratman SV, Cho J, Kim J, Jang R, Bayley A, Ringash J. Sexual satisfaction in nasopharyngeal carcinoma survivors: Rates and determinants. Oral Oncology. 2020;109:104865. **https://doi.org/10.1016/j.oraloncology.2020.104865**	Wrong outcome – exploring sexual satisfaction in HNC patients.
Mehanna HM, Morton RP. Deterioration in quality-of-life of late (10-year) survivors of head and neck cancer. Clin Otolaryngol. 2006;31:204-211. **https://doi.org/10.1111/j.1749-4486.2006.01188.x**	No lower age limit or age range reported.
Meier JK, Schuderer JG, Zeman F, Klingelhoffer C, Hullmann M, Spanier G, Reichert TE, Ettl T. Health-related quality of life: A retrospective study on local vs. microvascular reconstruction in patients with oral cancer. 2019;62:1-8. **https://doi.org/10.1186/s12903-019-0760-2**	Single time point for data collection. No lower age limit or age range reported.
Moubayed SP, Sampalis JS, Ayad T, Guertin L, Bissada E, Gologan OE, Soulieres D, Lambert L, Filion E, Nguyen-Tan PF, Christopoulos A. Predicting depression and quality of life among long-term head and neck cancer survivors. Otolaryngol Head Neck Surg. 2015;152(1):91-97. **https://doi.org/10.1177/0194599814557772**	Wrong outcome – results only report predictors of depressive symptoms.
Neralla M, Gouthaman SS, Satheesh SPT, Singarapu R. Quality of life: Determinant of success of head and neck cancer therapy in the battle of survival vs. rehabilitation. Minerva Dent Oral Sc. 2023;72:271-279. **https://doi.org/10.23736/S2724-6329.23.04722-8**	Single time point for data collection. No lower age limit or age range reported.
Nilsen ML, Mady LJ, Hodges J, Wasserman-Wincko T, Johnson JT. Burden of treatment: Reported outcomes in a head and neck cancer survivorship clinic. Laryngoscope. 2019;129:E437–E444. **https://doi.org/10.1002/lary.27801**	Single time point for data collection.
Nilsen ML, Moskovitz J, Lyu L, Harrison C, Randazza E, Peddada SD, Johnson JT. Health literacy: Impact on quality of life in head and neck cancer survivors. Laryngoscope. 2020;130:2354–2359. **https://doi.org/10.1002/lary.28360**	Wrong outcome – exploring specifically health literacy on QoL rather than general predictors.

O'Neill M, Heron DE, Flickinger JC, Smith R, Ferris RL, Gibson M. Posttreatment quality-of-life assessment in patients with head and neck cancer treated with intensity-modulated radiation therapy. Am J Clin Oncol. 2011;34:478–482. **https://doi.org/10.1097/COC.0b013e3181f4759c**	Wrong outcome – looking specifically at a treatment regime and effect on QoL.
Pandey M, Devi N, Ramdas K, Krishnan R, Kumar V. Higher distress relates to poor quality of life in patients with head and neck cancer. Int J Oral Maxillofac Surg. 2009;38:955-959. **http://dx.doi.org/10.1016/j.ijom.2009.04.004**	Age not reported.
Parkar S, Sharma A, Shah M. A prospective study to evaluate the impact of cancer directed treatment on quality of life in head and neck cancer patients. Gulf J Oncolog. 2022;1(38):61-71.	Single time point for data collection.
Patil V, Joshi A, Noronha V, Bhattacharjee A, Dhumal S, Chandrakanth DMV, Karpe A, Talreja V, Chandrasekharan A, Turkar S, Pande N, Ramaswamy A, Prabhash K. Quality of life and quality-adjusted time without toxicity in palliatively treated head-and-neck cancer patients. South Asian J Cancer 2018;7:249-53. **https://doi.org/10.4103/sajc.sajc_233_17**	Wrong outcome – exploring the impact specifically of palliative chemotherapy on QoL, not general predictors.
Penedo FJ, Traeger L, Benedict C, Thomas G, Dahn JR, Krause MH, Goodwin WJ. Perceived social support as a predictor of disease-specfic quality of life in head-and-neck cancer patients. J Support Oncol. 2012;10:119 –123. **https://doi.org/10.1016/j.suponc.2011.09.002**	Wrong outcome – exploring specifically the availability of social support on QoL.
Pierre CS, Dassonville O, Chamorey E, Poissonnet G, Ettaiche M, Santini J, Peyrade F, Benezery K, Sudaka A, Bozec A. Long-term quality of life and its predictive factors after oncologic surgery and microvascular reconstruction in patients with oral or oropharyngeal cancer. Eur Arch Otorhinolaryngol. 2014;271:801–807. **https://doi.org/10.1007/s00405-013-2592-z**	No lower age limit or age range reported.
Psoter WJ, Aguilar ML, Levy A, Baek LS, Morse DE. A preliminary study on the relationships between global health/quality of life and specific head and neck cancer quality of life domains in Puerto Rico. J Prosthodont. 2012;21:460-471. **https://doi.org/10.1111/j.1532-849X.2012.00848.x**	Single time point for data collection.
Rajeev-Kumar G, Moreno J, Kelley A, Sharma S, Gupta V, Bakst R. Emotional quality of life after radiation therapy for oropharyngeal carcinoma. Adv Radiat Oncol. 2019;4:674-682. **https://doi.org/10.1016/j.adro.2019.05.001**	No lower age limit or age range reported. Wrong outcome – exploring mood rather than general QoL.
Ramaekers BLT, Joore MA, Grutters JPC, van den Ende P, de Jong J, Houben R, Lambin P, Christianen M, Beetz I, Pijls-Johannesma M, Langendijk JA. The impact of late treatment-toxicity on generic health-related quality of life	Wrong outcome – exploring specifically xerostomia and dysphagia.

in head and neck cancer patients after radiotherapy. Oral Oncology. 2011;47:768-774. **http://dx.doi.org/10.1016/j.oraloncology.2011.05.012**	
Ramirez MJF, Ferriol EE, Domenech FG, Llatas MC, Suarez-Varela MM, Martinez RL. Psychsocial adjustment in patients surgically treated for laryngeal cancer. Otolaryngol Head Neck Surg. 2003;129:92-97. **https://doi.org/10.1016/S0194-5998(03)00478-9**	Wrong outcome – exploring adjustment and confidence.
Rapoport Y, Kreitler S, Chaitchik S, Algor R, Weissler K. Psychosocial problems in head-and-neck cancer patients and their change with time since diagnosis. Ann Oncol. 1993; 4:59-73. **https://doi.org/10.1093/oxfordjournals.annonc.a058365**	Single time point of data collection.
Richardson AE, Morton RP, Broadbent E. Coping strategies predict post-traumatic stress in patients with head and neck cancer. Eur Arch Otorhinolaryngol. 2016;273:3385–3391 . **https://doi.org/10.1007/s00405-016-3960-2**	Skin cancer patients included.
Ringash J, Bezjak A, O'Sullivan B, Redelmeier DA. Interpreting differences in quality of life: The FACT-H&N in laryngeal cancer patients. Qual Life Res. 2004;13:725-733. **https://doi.org/10.1023/B:QURE.0000021703.47079.46**	Wrong outcome – exploring the minimal important difference for the FACT measure in HNC patients.
Ringash J, Lockwood G, O'Sullivan B, Warde P, Bayley A, Cummings B, Kim J, Sellmann S, Waldron J. Hyperfractionated, accelerated radiotherapy for locally advanced head and neck cancer: Quality of life in a prospective phase I/II trial. Radiother Oncol. 2008;87:181-187. **https://doi.org/10.1016/j.radonc.2007.12.028**	Wrong outcome – only exploring links between QoL and a specific treatment.
Ringash J, Fisher R, Peters L, Trotti A, O'Sullivan B, Corry J, Kenny L, van den Bogaert W, Wratten C, Rischin D. Effect of p16 status on the quality-of-life experience during chemoradiation for locally advanced oropharyngeal cancer: A substudy of randomized trial trans-tasman radiation oncology group (TROG) 02.02 (HeadSTART). Int J Radiation Oncol Biol Phys. 2017;97(4):678e686. **http://dx.doi.org/10.1016/j.ijrobp.2016.03.017**	Wrong outcome – exploring p16 status on QoL and exploring trends rather than predictors.
Rogers SN, Lowe D, Brown JS, Vaughan ED. The university of Washington head and neck cancer measure as a predictor of outcome following primary surgery for oral cancer. Head Neck. 1999;21:394–401. **https://doi.org/10.1002/(SICI)1097-0347(199908)21:5%3C394::AID-HED3%3E3.0.CO;2-Q**	No lower age limit or age range reported. Pre-2000.
Rogers SN, Lowe D, Brown JS, Vaughan ED. The relationship between length of stay and health-related quality of life in patients treated by primary surgery for oral and oropharyngeal cancer. Int J Oral Maxillofac Surg. 2001;30:209–215.	Wrong outcome – exploring length of stay in hospital specifically.

https://doi.org/10.1054/ijom.2001.0040	
Rogers SN, Lowe S. Health-related quality of life after oral cancer treatment: 10-year outcomes. Oral Surg Oral Med Oral Pathol Oral Radiol. 2020;130(2):1-6. **https://doi.org/10.1016/j.oooo.2020.02.018**	Single time point for data collection.
Sapir E, Tao Y, Feng F, Samuels S, El Naqa I, Murdoch-Kinch CA, Feng M, Schipper M, Eisbruch A. Predictors of dysgeusia in patients with oropharyngeal cancer treated with chemotherapy and intensity modulated radiation therapy. Int J Radiation Oncol Biol Phys. 2016;96(2):354e361. **http://dx.doi.org/10.1016/j.ijrobp.2016.05.011**	Wrong outcome – exploring predictors of dysgeusia not QoL.
Sauder C, Kapsner-Smith M, Baylor C, Yorkston K, Futran N, Eadie T. Communicative participation and quality of life in pretreatment oral and oropharyngeal head and neck cancer. Otolaryngol Head Neck Surg. 2021;164(3):616-623. **https://doi.org/10.1177/0194599820950718**	Single time point for data collection. Pre-treatment only.
Scharpf, J, Karnell LH, Christensen AJ, Funk GF. The role of pain in head and nek cancer recurrence and survivorship. Arch Otolaryngol Head Neck Surg. 2009;135(8):789-794. **https://doi.org/10.1001/archoto.2009.107**	Wrong outcome – exploring pain and survival.
Scott B, Butterworth C, Lowe D, Rogers SN. Factors associated with restricted mouth opening and its relationship to health-related quality of life in patients attending a Maxillofacial Oncology clinic. Oral Oncology. 2008;44:430-438. **https://doi.org/10.1016/j.oraloncology.2007.06.015**	Wrong outcome – exploring impact of mouth opening on QoL specifically.
Seignemartin, CP, Miranda ME, Gualberto J, Tiexeira RG. Understandability of speech predicts quality of life among maxillectomy patients restored with obturator prosthesis. J Oral Maxillofac Surg. 2015;73:2040-2048. **http://dx.doi.org/10.1016/j.joms.2015.04.031**	Single time point of data collection.
Siddiqui F, Pajak TF, Watkins-Bruner D, Konski A, Coyne JC, Gwede CK, Garden AS, Spencer SA, Jones C, Movsas B. Pretreatment quality of life predictors for locoregional control in head and neck cancer patients: A radiation therapy oncology group analysis. Int. J. Radiation Oncology Biol Phys. 2008;70(2):353–360. **https://doi.org/10.1016/j.ijrobp.2007.06.024**	Single time point of data collection – pre-treatment only.
Singer S, et al. Measuring quality of life in patients with head and neck cancer: Update of the EORTC QLQ-H&N Module, Phase III. Head Neck. 2014;37(9):1358-1367. **https://doi.org/10.1002/hed.23762**	Wrong outcome – piloting a new QOL measure version.
Silva MS, de Castro EK, Chem C. Quality of life and self-image in patients with head and neck cancer. Univ Psychol. 2012;11(1):13-23	Text not available in English.
Silveira AP, Goncalves J, Sequeira T, Ribeiro C, Lopes C, Monteiro E, Pimentel FL. Geriatric oncology: Comparing	Single time point for data collection.

health related quality of life in head and neck cancer patients. Head Neck Oncol. 2011;3(3):1-8. **https://doi.org/10.1186/1758-3284-3-3**	
Suzuki M. Quality of life, uncertainty, and perceived involvement in decision making in patients with head and neck cancer. Oncol Nurs Forum. 2012;39(6):541-548. **https://doi.org/10.1188/12.ONF.541-548**	Thyroid cancer patients. Single time point for data collection.
Tan S, Dinh TAD, Westofen M. Evaluation of gender-specific aspects in quality-of-life in patients with larynx carcinoma. Acta Otolaryngol. 2016;136(12):1201-1205. **https://doi.org/10.1080/00016489.2016.1211319**	Wrong outcome – exploring age only.
Tang A, Li J, Scheff N, Johnson JT, Contrera KJ, Milsen ML. Quality of life outcomes for parotid malignancies. Laryngoscope. 2024;13:4549–4556. **https://doi.org/10.1002/lary.31554**	No lower age limit or age range reported.
Terrell JE, Fisher SG, Wolf GT. Long-term quality of life after treatment of laryngeal cancer. Arch Otolaryngol Head Neck Surg. 1998;124(9):964–971. **https://doi.org/10.1001/archotol.124.9.964**	Single time point of data collection – only talk about baseline results.
Terrell JE, Nanavati K, Esclamado RM, Bradford CR, Wolf GT. Health impact of head and neck cancer. Otolaryngol Head Neck Surg. 1999;120(6):852-859. **https://doi.org/10.1016/S0194-5998(99)70326-8**	Skin cancer patients included. Pre-2000.
Terrell JE, Ronis DL, Fowler KE, Bradford CR, Chepeha DB, Prince ME, Teknos TN, Wolf GT, Duffy SA. Clinical predictors of quality of life in patients with head and neck cancer. Arch Otolaryngol Head Neck Surg. 2004;130:401-408. **https://doi.org/10.1001/archotol.130.4.401**	Single time point for data collection.
Thomas CM, Sklar MD, Su J, Xu W, de Almeida JR, Alibhai SMH, Goldstein DP. Longitudinal assessment of frailty and quality of life in patients undergoing head and neck surgery. Laryngoscope. 2021;131:E2232–E2242. **https://doi.org/10.1002/lary.29375**	Thyroid cancer patients included.
Truong MT, et al. Quality of life and performance status from a sub-study conducted within a prospective phase III randomized trial of concurrent accelerated radiation plus cisplatin with or without cetuximab for locally advanced head and neck carcinoma: NRG Oncology RTOG 0522. Int J Radiat Oncol Biol Phys. 2017;97(4): 687–699. **https://doi.org/10.1016/j.ijrobp.2016.08.003**	Wrong outcome – exploring differences between two treatment groups and trends rather than predictors.
Venchiarutti RL, Dunn M, Charters E, Cheng K, Froggatt C, Mukherjee P, Wallace C, Howes D, Leinkram D, Singh J, Nguyen K, Low THH, Ch'ng S, Wykes J, Wu R, Clark JR. Effect of radiotherapy on functional and health-related quality of life outcomes after jaw reconstruction. Cancers. 2022;14:1-13. **https://doi.org/10.3390/cancers14194557**	Not only looking at cancers, but other diagnoses also included.
Vigano A, et al. Quality of life changes over time and predictors in a large head and neck patients' cohort:	No QoL measure used.

secondary analysis from an Italian multi-center longitudinal, prospective, observational study: A study of the Italian Association of Radiotherapy and Clinical Oncology (AIRO) head and neck working group. Support Care Cancer. 2023;31:220. **https://doi.org/10.1007/s00520-023-07661-2**	
Wang AY, Palme CE, Wang JT, Morgan GJ, Gebski V, Gilchrist J, Veness MJ. Quality of life assessment in patients treated for metastatic cutaneous squamous cell carcinoma of the head and neck. J Laryngol Otol. 2013;127:S39-S47. **https://doi.org/10.1017/S0022215113000303**	Skin cancer patients included.
Wells M, Swartzman S, Lang H, Cunningham M, Taylor L, Thomson J, Philp J, McCowan C. Predictors of quality of life in head and neck cancer survivors up to 5 years after end of treatment: A cross-sectional survey. Support Care Cancer. 2016;24:2463-2472. **https://doi.org/10.1007/s00520-015-3045-6**	Single time point for data collection.
Woodard TD, Oplatek A, Petruzzeli GJ. Life after total laryngectomy: A measure of long-term survival, function, and quality of life. Arch Otolaryngol Head Neck Surg. 2007;133:526-532. **https://doi.org/10.1001/archotol.133.6.526**	QoL only measured at one time point.
Woolley E, Magennis P, Shokar P, Lowe D, Edwards D, Rogers SN. The correlation between indices of deprivation and health-related quality of life in patients with oral and oropharyngeal squamous cell carcinoma. Br J Oral Maxillofac Surg. 2006;44:177-186. **https://doi.org/10.1016/j.bjoms.2005.06.024**	No lower age limit or age range reported.
Xiang L, Wan H, Zhu Y, Wang S, Zheng M. Latent profiles of resilience and associations with quality of life in head and neck cancer patients undergoing proton and heavy ion therapy. Front Oncol. 2024;13:1-10. **https://doi.org/10.3389/fonc.2023.1270870**	Wrong outcome – exploring resilience and creating resilience profiles.
Xiao C, et al. Quality of life and performance status from a substudy conducted within a prospective phase 3 randomized trial of concurrent standard radiation versus accelerated radiation plus cisplatin for locally advanced head and neck carcinoma: NRG oncology RTOG 0129. Int J Radiat Oncol Biol Phys. 2017;97(4):667–677. **https://doi.org/10.1016/j.ijrobp.2016.07.020**	Wrong outcome – exploring association between QoL and survival.
Yan R, Chen X, Gong X, Wang J, Yu J. The association of tooth loss, toothbrushing, and quality of life among cancer survivors. Cancer Medicine. 2018;7:6374–6384. **https://doi.org/10.1002/cam4.1835**	Single time point of data collection. Participants across cancer diagnoses, not just HNC.
Yuan L, Pan B, Wang W, Wang L, Zhang X, Gao Y. Prevalence and predictors of anxiety and depressive symptoms among patients diagnosed with oral cancer in China: A cross-sectional study. BMC Psych. 2020;20:394. **https://doi.org/10.1186/s12888-020-02796-6**	Single time point of data collection. Wrong outcome – exploring predictors of mood not QoL.

Supplementary Materials S2: Summary of quality assessment of each paper as rated on the CASP checklist for cohort studies.

	Allison et al (2000)	Alvarez-Camacho et al (2016)	Borggreven et al (2007)	Bozec et al (2018)	Bozec et al (2019)	Citak & Tulek (2013)	De Graeff et al (2000)a	De Graeff et al (2000)b
1. Clear, focussed issue.	Y	Y	Y	Y	Y	Y	Y	Y
2. Acceptable recruitment.	Y	Y	Y	Y	Y	Y	Y	Y
3. Exposure accurately measured.	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
4. Outcome accurately measured.	Y	Y	Y	Y	Y	Y	Y	Y
5a. All confounding factors identified.	N	N	N	N	N	N	N	N
5b. Confounding variables accounted for in design and/or analysis.	N	Y	Y	Y	Y	Y	N	Y
6a. Follow-up complete enough.	Y	Y	N	Y	N	Y	N	Y
6b. Follow-up long enough.	Y	N	Y	Y	Y	Y	Y	Y
7. What are the results?	Y	Y	Y	Y	Y	Y	Y	Y
8. Are results precise?	Y	Y	Y	Y	Y	Y	N	Y
9. Results believable.	Y	Y	Y	Y	Y	Y	N	Y
10. Results applicable to local population.	Y	Y	Y	Y	Y	Y	N	Y
11. Results fit with other, available evidence.	Y	Y	Y	Y	Y	Y	Y	Y
12. Implications for practice.	Y	Y	Y	Y	Y	Y	Y	Y
Overall quality rating	Moderate	Moderate	Moderate	Moderate	High	High	Low	High

Supplementary Material 2 cont.:

Summary of quality assessment of each paper as rated on the CASP checklist for cohort studies.

	Hammerlid et al (2000)	Oskam et al (2010)	Rios-Gonzalez et al (2024)	Rogers et al (2002)	Roick et al (2020)	Ronis et al (2008)	Tamer et al (2020)	Tsan et al (2021)
1. Clear, focussed issue.	Y	Y	Y	Y	Y	Y	Y	Y
2. Acceptable recruitment.	Y	Y	Y	Y	Y	Y	Y	Y
3. Exposure accurately measured.	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
4. Outcome accurately measured.	Y	Y	Y	Y	Y	Y	Y	Y
5a. All confounding factors identified.	Y	N	N	N	N	Y	Y	N
5b. Confounding variables accounted for in design and/or analysis.	Y	Y	Y	N	Y	Y	Y	N
6a. Follow-up complete enough.	Y	N	Y	N	N	Y	Y	N
6b. Follow-up long enough.	Y	N	Y	Y	N	Y	N	N
7. What are the results?	Y	Y	Y	Y	Y	Y	Y	Y
8. Are results precise?	Y	Y	Y	Y	N	Y	Y	Y
9. Results believable.	Y	Y	Y	Y	Y	Y	Y	Y
10. Results applicable to local population.	Y	Y	Y	Y	Y	Y	Y	Y
11. Results fit with other, available evidence.	Y	Y	Y	Y	Y	Y	Y	Y
12. Implications for practice.	Y	Y	?	Y	Y	Y	Y	Y
Overall quality rating	High	Moderate	Moderate	Moderate	Low	High	High	Low

Supplementary Material 2 cont.:

Summary of quality assessment of each paper as rated on the CASP checklist for cohort studies.

	Veldhuis et al (2016)	Yin et al (2020)
1. Clear, focussed issue.	Y	Y
2. Acceptable recruitment.	Y	Y
3. Exposure accurately measured.	N/A	N/A
4. Outcome accurately measured.	Y	Y
5a. All confounding factors identified.	N	N
5b. Confounding variables accounted for in design and/or analysis.	N	Y
6a. Follow-up complete enough.	N	Y
6b. Follow-up long enough.	N	N
7. What are the results?	Y	Y
8. Are results precise?	N	Y
9. Results believable.	?	Y
10. Results applicable to local population.	Y	Y
11. Results fit with other, available evidence.	Y	Y
12. Implications for practice.	Y	?
Overall quality rating	Low	Moderate

Note. Scoring: 'Y' suggests that the author felt the study met the criteria for that section; 'N' suggests that the author felt the study did not meet the criteria for that section; '?' suggests that it was unclear if the study met the criteria, either due to missing information or unclear description.

Supplementary Materials S3: Narrative synthesis table for studies reporting psychological factors associated with QoL.

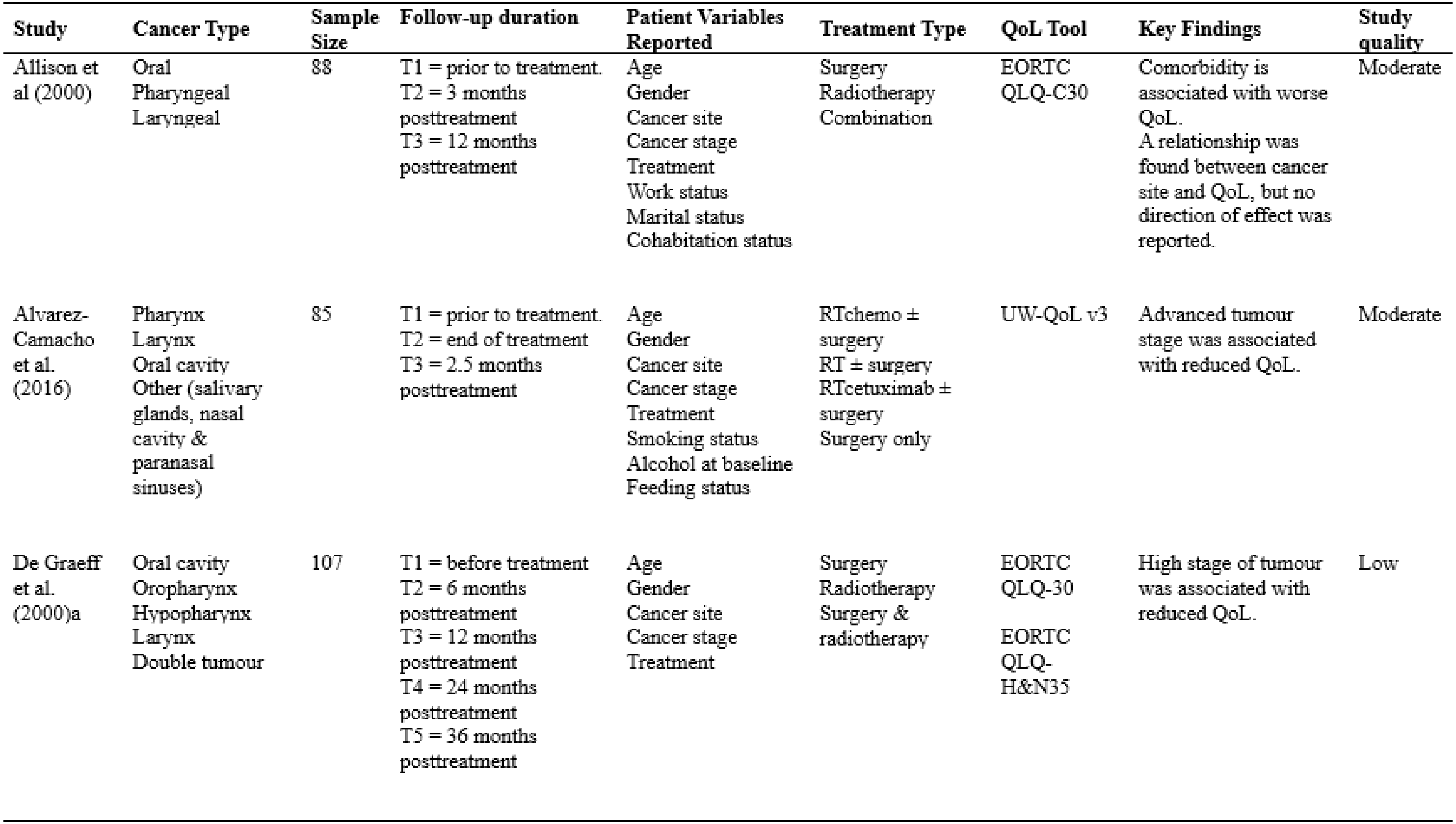
Study	Cancer Type	Sample Size	Follow-up duration	Patient Variables Reported	Treatment Type	Measure(s) Used	Key Findings	Study Quality
Allison et al (2000)	Oral Pharyngeal Laryngeal	88	T1 = prior to treatment. T2 = 3 months posttreatment T3 = 12 months posttreatment	Age Gender Cancer site Cancer stage Treatment Work status Marital status Cohabitation status	Surgery Radiotherapy Combination	EORTC QLQ-C30 LOT	High optimism is associated with increased QoL. High pessimism is associated with decreased quality of life	Moderate
Bozec et al. (2018)	Base of tongue Lateral pharyngeal wall Posterior pharyngeal wall Soft palate	58	T1= pretreatment T2 = at least 1 year posttreatment	Age Gender Cancer site T-stage N-stage Treatment Adjuvant treatment Education level Professional activity Alcohol intake	Surgery Radiotherapy Radiotherapy & chemotherapy	EORTC QLQ-C30 EORTC QLQ-H&N35 HADS	Higher HADS score (authors use term psychological distress) is associated with reduced QoL.	Moderate
De Graeff et al. (2000)b	Larynx Oral cavity Oropharynx Hypopharynx	153	T1 = before treatment T2 = 6 months posttreatment T3 = 12 months	Age Gender Cancer stage N stage	Radiotherapy Surgery Radiotherapy & surgery	EORTC QLQ-C30 EORTC QLQ-H&N35 CES-D	Depressive symptoms are associated with reduced QoL.	High

Study	Cancer Type	Sample Size	Follow-up duration	Patient Variables Reported	Treatment Type	Measure(s) Used	Key Findings	Study Quality
Hammerlid et al. (2001)	Larynx Oral cavity Pharyngeal Other – sinus and nose, unknown primary, salivary gland	133	T1 = weekly tumour conference T2-6 = 5 times during the first year. T7 = 3 years after diagnosis	Age Gender Cancer site Cancer stage Treatment Survival time Employment Cohabitation status Education level Smoking status	Radiotherapy Surgery Radiotherapy & surgery Radiotherapy, chemotherapy & surgery Radiotherapy & chemotherapy	EORTC QLQ-C30 EORTC QLQ-H&N35 HADS	Depression at diagnosis is associated with reduced QoL.	High
Oskam et al. (2010)	Oral cavity Oropharynx	55	T1 = before treatment T2 = 6 months posttreatment	Age Gender Cancer site Cancer stage	Unclear	EORTC QLQ-C30 EORTC QLQ-H&N35	Emotional functioning is associated with QoL but no comment on direction of effect.	Moderate
Roick et al. (2020)	Larynx Pharynx Oral cavity Tonsil Tongue Other	46	T1 = hospital admission T2 = hospital discharge T3 = 3 months after T1 T4 = 6 months after T1	Age Gender Cancer site Cancer type Cancer stage Treatment Education level	Radiotherapy Chemotherapy	EORTC QLQ-C30 EORTC QLQ-H&N35 HADS	Poor emotional wellbeing at hospital admission is associated with positive QoL	Low

Ronis et al. (2008)	Oral cavity Pharynx, oropharynx, hypopharynx, nasopharynx or unknown primary site	316	T1 = before treatment T2 = 1 year later.	Age Gender Cancer site Cancer stage Treatment Race/ethnicity Marital status Marital status Education status Smoker status Alcohol intake	Radiotherapy Chemotherapy Surgery	SF-36 HNQoL GDS-5	Depression is associated with reduced QoL.	High
Tsan et al. (2021)	Hypopharyngeal Oropharyngeal Oral	54	T1 = after diagnosis, before treatment T2 = during 3rd-4th week of treatment T3 = last week of treatment T4 = 1 month posttreatment T5 = 3 months posttreatment	Age Gender Cancer site Cancer stage Surgery Living status Marital status Education level Religion Occupation Smoking history	Surgery	FACT-H&N HHI	Increased hope is associated with positive QoL.	Low

Note. CES-D: Center for Epidemiologic Studies Depression Scale; EORTC QLQ-30: core quality of life European Organization for Research and Treatment of Cancer Questionnaire; EORTC QLQ-H&N35: head and neck cancer specific quality of life questionnaire from European Organisation for Research and Treatment of Cancer; FACT-H&N: Functional Assessment of Cancer Therapy – head and neck; GDS-5: Geriatric Depression Scale-5; HADS: Hospital Anxiety and Depression Scale; HHI: Herth Hope Index; HNQoL: Head and Neck Quality of Life Instrument; LOT: Life Orientation Test; SF-36: 36-Item Short Form Health Survey; UW-QoL v3: University of Washington Quality of Life Questionnaire.

Supplementary Materials S4: Narrative synthesis table for studies reporting cancer-related factors associated with QoL



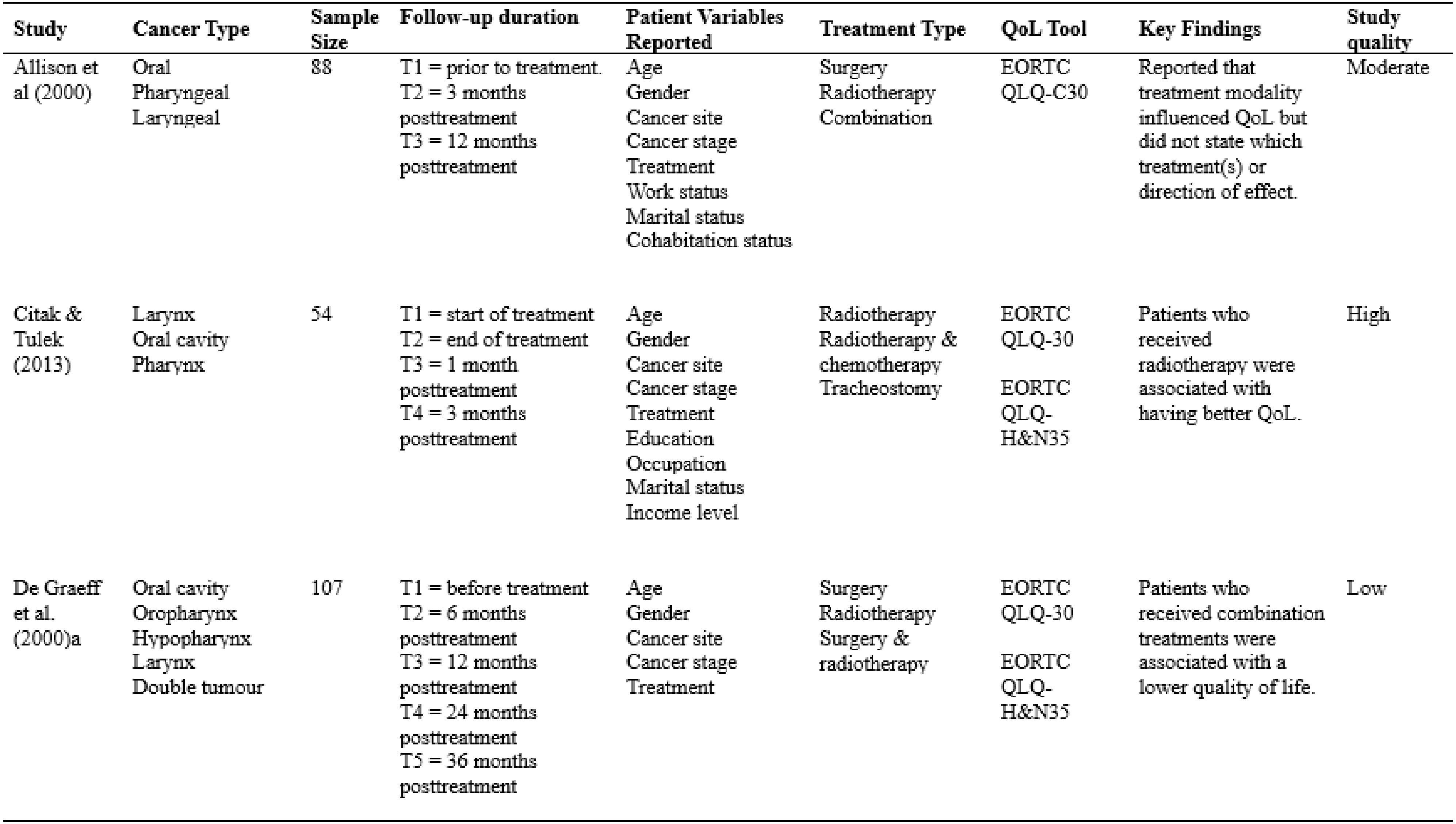
Study	Cancer Type	Sample Size	Follow-up duration	Patient Variables Reported	Treatment Type	QoL Tool	Key Findings	Study quality
Allison et al (2000)	Oral Pharyngeal Laryngeal	88	T1 = prior to treatment. T2 = 3 months posttreatment T3 = 12 months posttreatment	Age Gender Cancer site Cancer stage Treatment Work status Marital status Cohabitation status	Surgery Radiotherapy Combination	EORTC QLQ-C30	Comorbidity is associated with worse QoL. A relationship was found between cancer site and QoL, but no direction of effect was reported.	Moderate
Alvarez-Camacho et al. (2016)	Pharynx Larynx Oral cavity Other (salivary glands, nasal cavity & paranasal sinuses)	85	T1 = prior to treatment. T2 = end of treatment T3 = 2.5 months posttreatment	Age Gender Cancer site Cancer stage Treatment Smoking status Alcohol at baseline Feeding status	RTchemo ± surgery RT ± surgery RTcetuximab ± surgery Surgery only	UW-QoL v3	Advanced tumour stage was associated with reduced QoL.	Moderate
De Graeff et al. (2000)a	Oral cavity Oropharynx Hypopharynx Larynx Double tumour	107	T1 = before treatment T2 = 6 months posttreatment T3 = 12 months posttreatment T4 = 24 months posttreatment T5 = 36 months posttreatment	Age Gender Cancer site Cancer stage Treatment	Surgery Radiotherapy Surgery & radiotherapy	EORTC QLQ-30 EORTC QLQ-H&N35	High stage of tumour was associated with reduced QoL.	Low

Study	Cancer Type	Sample Size	Follow-up duration	Patient Variables Reported	Treatment Type	QoL Tool	Key Findings	Study quality
Hammerlid et al. (2001)	Larynx Oral cavity Pharyngeal Other – sinus and nose, unknown primary, salivary gland	133	T1 = weekly tumour conference T2-6 = 5 times during the first year. T7 = 3 years after diagnosis	Age Gender Cancer site Cancer stage Treatment Survival time Employment Cohabitation status Education level Smoking status	Radiotherapy Surgery Radiotherapy & surgery Radiotherapy, chemotherapy & surgery Radiotherapy & chemotherapy	EORTC QLQ-C30 EORTC QLQ-H&N35	Small tumour size was associated is associated with better QoL.	High
Rogers et al. (2002)	Oral Oropharyngeal	79	T1 = pre-operation T2 = 6 months posttreatment T3 = 12 months posttreatment	Age Gender Cancer site Cancer type Cancer stage Treatment Education level	Radiotherapy Chemotherapy	EORTC QLQ-30 EORTC QLQ-H&N35	Small tumour size is associated with better QoL.	Moderate
Roick et al. (2020)	Larynx Pharynx Oral cavity Tonsil Tongue Other	46	T1 = hospital admission T2 = hospital discharge T3 = 3 months after T1 T4 = 6 months after T1	Age Gender Cancer site Cancer type Cancer stage Treatment Education level	Radiotherapy Chemotherapy	EORTC QLQ-C30 EORTC QLQ-H&N35	Higher tumour stage was associated with reduced QoL.	Low

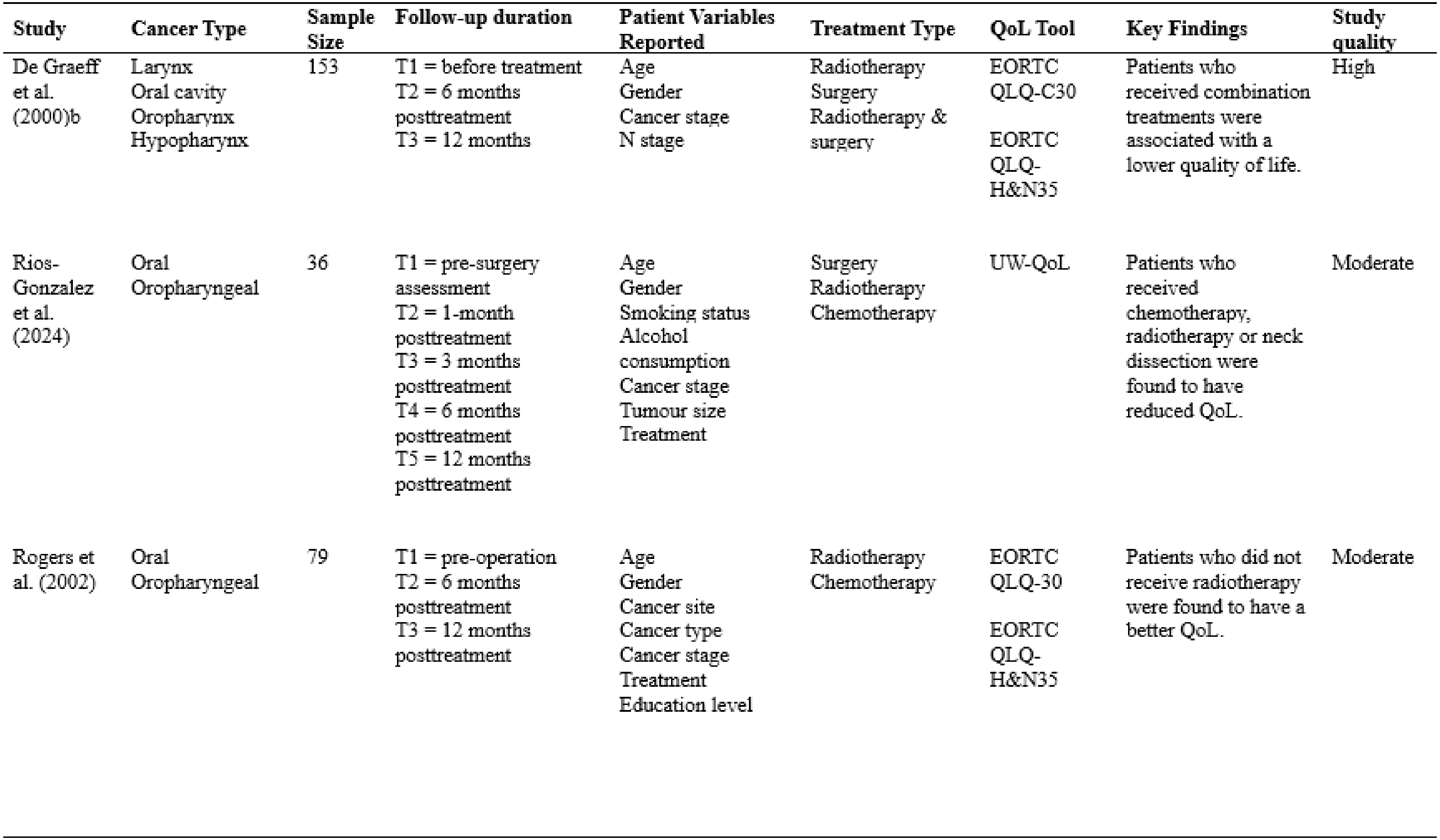
Yin et al. (2020)	Base of tongue Tonsil Glossopharyngeal sulcus	294	T1 = pretreatment T2 = 3-6 months posttreatment	Age Gender Cancer site T-stage N-stage Treatment Marital status Education level Race Employment status Smoking history Alcohol history	Surgery Radiotherapy Combination	EORTC QLQ-30 EORTC QLQ-H&N35	Patients with a T1 stage cancer were found to have better QoL.	Moderate

Note. EORTC QLQ-30: core quality of life European Organization for Research and Treatment of Cancer Questionnaire; EORTC QLQ-H&N35: head and neck cancer specific quality of life questionnaire from European Organisation for Research and Treatment of Cancer; FACT-H&N: Functional Assessment of Cancer Therapy – head and neck; HNQoL: Head and Neck Quality of Life Instrument; SF-36: 36-Item Short Form Health Survey; UW-QoL v3: University of Washington Quality of Life Questionnaire.

Supplementary Materials S5: Narrative synthesis table for studies reporting treatment-related factors associated with QoL



Study	Cancer Type	Sample Size	Follow-up duration	Patient Variables Reported	Treatment Type	QoL Tool	Key Findings	Study quality
Allison et al (2000)	Oral Pharyngeal Laryngeal	88	T1 = prior to treatment. T2 = 3 months posttreatment T3 = 12 months posttreatment	Age Gender Cancer site Cancer stage Treatment Work status Marital status Cohabitation status	Surgery Radiotherapy Combination	EORTC QLQ-C30	Reported that treatment modality influenced QoL but did not state which treatment(s) or direction of effect.	Moderate
Citak & Tulek (2013)	Larynx Oral cavity Pharynx	54	T1 = start of treatment T2 = end of treatment T3 = 1 month posttreatment T4 = 3 months posttreatment	Age Gender Cancer site Cancer stage Treatment Education Occupation Marital status Income level	Radiotherapy Radiotherapy & chemotherapy Tracheostomy	EORTC QLQ-30 EORTC QLQ-H&N35	Patients who received radiotherapy were associated with having better QoL.	High
De Graeff et al. (2000)a	Oral cavity Oropharynx Hypopharynx Larynx Double tumour	107	T1 = before treatment T2 = 6 months posttreatment T3 = 12 months posttreatment T4 = 24 months posttreatment T5 = 36 months posttreatment	Age Gender Cancer site Cancer stage Treatment	Surgery Radiotherapy Surgery & radiotherapy	EORTC QLQ-30 EORTC QLQ-H&N35	Patients who received combination treatments were associated with a lower quality of life.	Low

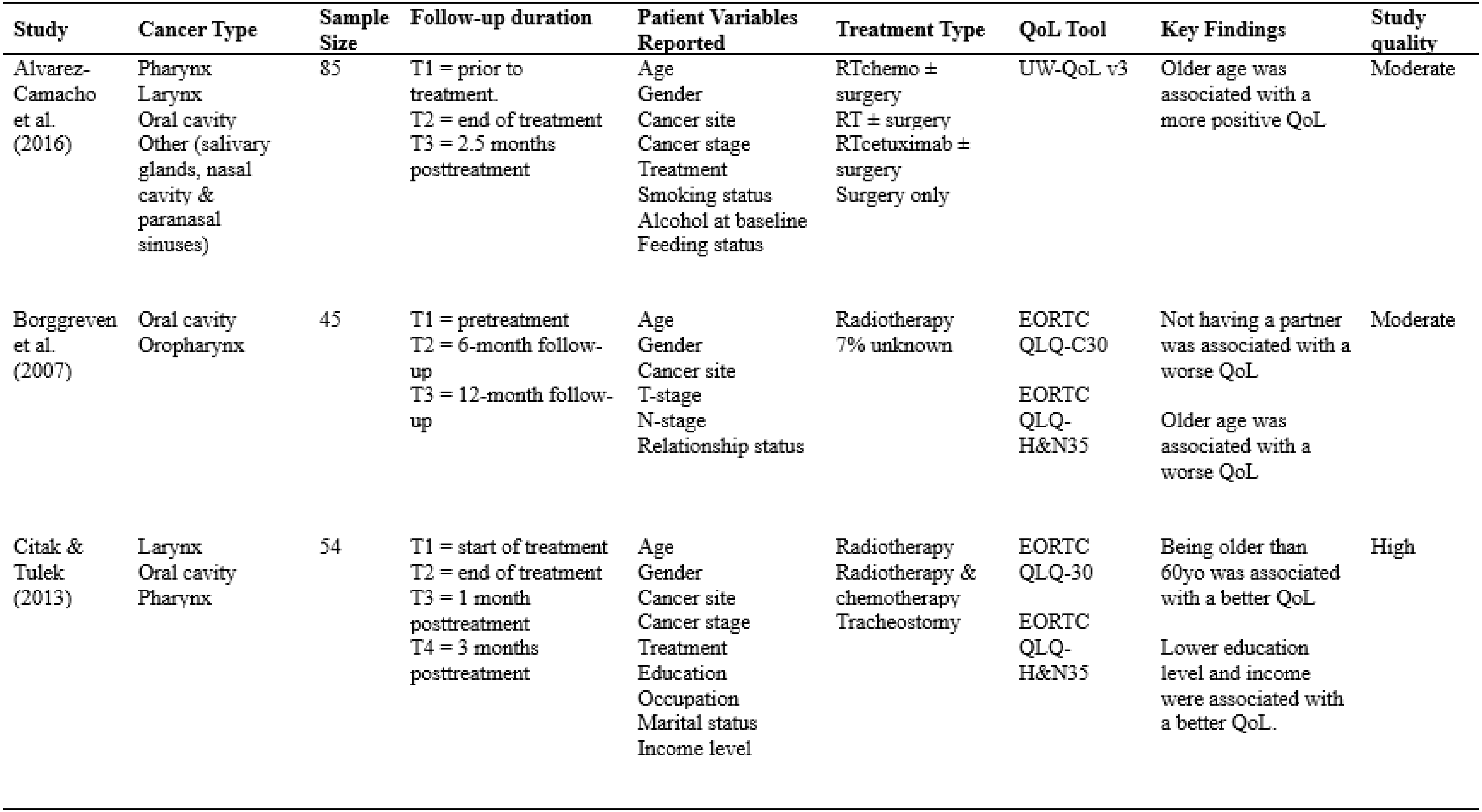


Study	Cancer Type	Sample Size	Follow-up duration	Patient Variables Reported	Treatment Type	QoL Tool	Key Findings	Study quality
De Graeff et al. (2000)b	Larynx Oral cavity Oropharynx Hypopharynx	153	T1 = before treatment T2 = 6 months posttreatment T3 = 12 months	Age Gender Cancer stage N stage	Radiotherapy Surgery Radiotherapy & surgery	EORTC QLQ-C30 EORTC QLQ-H&N35	Patients who received combination treatments were associated with a lower quality of life.	High
Rios-Gonzalez et al. (2024)	Oral Oropharyngeal	36	T1 = pre-surgery assessment T2 = 1-month posttreatment T3 = 3 months posttreatment T4 = 6 months posttreatment T5 = 12 months posttreatment	Age Gender Smoking status Alcohol consumption Cancer stage Tumour size Treatment	Surgery Radiotherapy Chemotherapy	UW-QoL	Patients who received chemotherapy, radiotherapy or neck dissection were found to have reduced QoL.	Moderate
Rogers et al. (2002)	Oral Oropharyngeal	79	T1 = pre-operation T2 = 6 months posttreatment T3 = 12 months posttreatment	Age Gender Cancer site Cancer type Cancer stage Treatment Education level	Radiotherapy Chemotherapy	EORTC QLQ-30 EORTC QLQ-H&N35	Patients who did not receive radiotherapy were found to have a better QoL.	Moderate

Ronis et al. (2008)	Oral cavity Pharynx, oropharynx, hypopharynx, nasopharynx or unknown primary site	316	T1 = before treatment T2 = 1 year later.	Age Gender Cancer site Cancer stage Treatment Race/ethnicity Marital status Marital status Education status Smoker status Alcohol intake	Radiotherapy Chemotherapy Surgery	SF-36 HNQoL	Patients who had a feeding tube at time point 2 were associated with a worse QoL.	High
Yin et al. (2020)	Base of tongue Tonsil Glossopharyngeal sulcus	294	T1 = pretreatment T2 = 3-6 months posttreatment	Age Gender Cancer site T-stage N-stage Treatment Marital status Education level Race Employment status Smoking history Alcohol history	Surgery Radiotherapy Combination	EORTC QLQ-30 EORTC QLQ-H&N35	Patients who have surgery or a combination of treatments were found to have lower QoL	Moderate

Note. EORTC QLQ-30: core quality of life European Organization for Research and Treatment of Cancer Questionnaire; EORTC QLQ-H&N35: head and neck cancer specific quality of life questionnaire from European Organisation for Research and Treatment of Cancer; FACT-H&N: Functional Assessment of Cancer Therapy – head and neck; HNQoL: Head and Neck Quality of Life Instrument; SF-36: 36-Item Short Form Health Survey; UW-QoL v3: University of Washington Quality of Life Questionnaire.

Supplementary Materials S6: Narrative synthesis table for studies reporting demographic factors associated with QoL



Study	Cancer Type	Sample Size	Follow-up duration	Patient Variables Reported	Treatment Type	QoL Tool	Key Findings	Study quality
Alvarez-Camacho et al. (2016)	Pharynx Larynx Oral cavity Other (salivary glands, nasal cavity & paranasal sinuses)	85	T1 = prior to treatment. T2 = end of treatment T3 = 2.5 months posttreatment	Age Gender Cancer site Cancer stage Treatment Smoking status Alcohol at baseline Feeding status	RTchemo ± surgery RT ± surgery RTcetuximab ± surgery Surgery only	UW-QoL v3	Older age was associated with a more positive QoL	Moderate
Borggreven et al. (2007)	Oral cavity Oropharynx	45	T1 = pretreatment T2 = 6-month follow-up T3 = 12-month follow-up	Age Gender Cancer site T-stage N-stage Relationship status	Radiotherapy 7% unknown	EORTC QLQ-C30 EORTC QLQ-H&N35	Not having a partner was associated with a worse QoL Older age was associated with a worse QoL	Moderate
Citak & Tulek (2013)	Larynx Oral cavity Pharynx	54	T1 = start of treatment T2 = end of treatment T3 = 1 month posttreatment T4 = 3 months posttreatment	Age Gender Cancer site Cancer stage Treatment Education Occupation Marital status Income level	Radiotherapy Radiotherapy & chemotherapy Tracheostomy	EORTC QLQ-30 EORTC QLQ-H&N35	Being older than 60yo was associated with a better QoL Lower education level and income were associated with a better QoL.	High

Study	Cancer Type	Sample Size	Follow-up duration	Patient Variables Reported	Treatment Type	QoL Tool	Key Findings	Study quality
De Graeff et al. (2000)a	Oral cavity Oropharynx Hypopharynx Larynx Double tumour	107	T1 = before treatment T2 = 6 months posttreatment T3 = 12 months posttreatment T4 = 24 months posttreatment T5 = 36 months posttreatment	Age Gender Cancer site Cancer stage Treatment	Surgery Radiotherapy Surgery & radiotherapy	EORTC QLQ-30 EORTC QLQ-H&N35	Female gender was associated with a worse QoL	Low
De Graeff et al. (2000)b	Larynx Oral cavity Oropharynx Hypopharynx	153	T1 = before treatment T2 = 6 months posttreatment T3 = 12 months	Age Gender Cancer stage N stage	Radiotherapy Surgery Radiotherapy & surgery	EORTC QLQ-C30 EORTC QLQ-H&N35	Older age was associated with a worse QoL	High
Hammerlid et al. (2001)	Larynx Oral cavity Pharyngeal Other – sinus and nose, unknown primary, salivary gland	133	T1 = weekly tumour conference T2-6 = 5 times during the first year. T7 = 3 years after diagnosis	Age Gender Cancer site Cancer stage Treatment Survival time Employment Cohabitation status Education level Smoking status	Radiotherapy Surgery Radiotherapy & surgery Radiotherapy, chemotherapy & surgery Radiotherapy & chemotherapy	EORTC QLQ-C30 EORTC QLQ-H&N35	Being younger than 65yo was associated with a better QoL	High

Study	Cancer Type	Sample Size	Follow-up duration	Patient Variables Reported	Treatment Type	QoL Tool	Key Findings	Study quality
Rios-Gonzalez et al. (2024)	Oral Oropharyngeal	36	T1 = pre-surgery assessment T2 = 1-month posttreatment T3 = 3 months posttreatment T4 = 6 months posttreatment T5 = 12 months posttreatment	Age Gender Smoking status Alcohol consumption Cancer stage Tumour size Treatment	Surgery Radiotherapy Chemotherapy	UW-QoL	Age older than 69yo was associated with worse QoL.	Moderate
Yin et al. (2020)	Base of tongue Tonsil Glossopharyngeal sulcus	294	T1 = pretreatment T2 = 3-6 months posttreatment	Age Gender Cancer site T-stage N-stage Treatment Marital status Education level Race Employment status Smoking history Alcohol history	Surgery Radiotherapy Combination	EORTC QLQ-30 EORTC QLQ-H&N35	Being married was associated with a better QoL.	Moderate

Note. EORTC QLQ-30: core quality of life European Organization for Research and Treatment of Cancer Questionnaire; EORTC QLQ-H&N35: head and neck cancer specific quality of life questionnaire from European Organisation for Research and Treatment of Cancer; FACT-H&N: Functional Assessment of Cancer Therapy – head and neck; HNQoL: Head and Neck Quality of Life Instrument; SF-36: 36-Item Short Form Health Survey; UW-QoL v3: University of Washington Quality of Life Questionnaire.

Supplementary Materials S7: Narrative synthesis table for studies reporting smoking and alcohol use associated with QoL

Study	Cancer Type	Sample Size	Follow-up duration	Patient Variables Reported	Treatment Type	QoL Tool	Key Findings	Study quality
Alvarez-Camacho et al. (2016)	Pharynx Larynx Oral cavity Other (salivary glands, nasal cavity & paranasal sinuses)	85	T1 = prior to treatment. T2 = end of treatment T3 = 2.5 months posttreatment	Age Gender Cancer site Cancer stage Treatment Smoking status Alcohol at baseline Feeding status	RTchemo ± surgery RT ± surgery RTcetuximab ± surgery Surgery only	UW-QoL v3	A patient who has never smoked was found to have a better QoL	Moderate
Bozec et al. (2018)	Base of tongue Lateral pharyngeal wall Posterior pharyngeal wall Soft palate	58	T1= pretreatment T2 = at least 1 year posttreatment	Age Gender Cancer site T-stage N-stage Treatment Adjuvant treatment Education level Professional activity Alcohol intake	Surgery Radiotherapy Radiotherapy & chemotherapy	EORTC QLQ-C30 EORTC QLQ-H&N35	Alcohol/tobacco consumption before or after treatment was associated with a worse QoL	Moderate

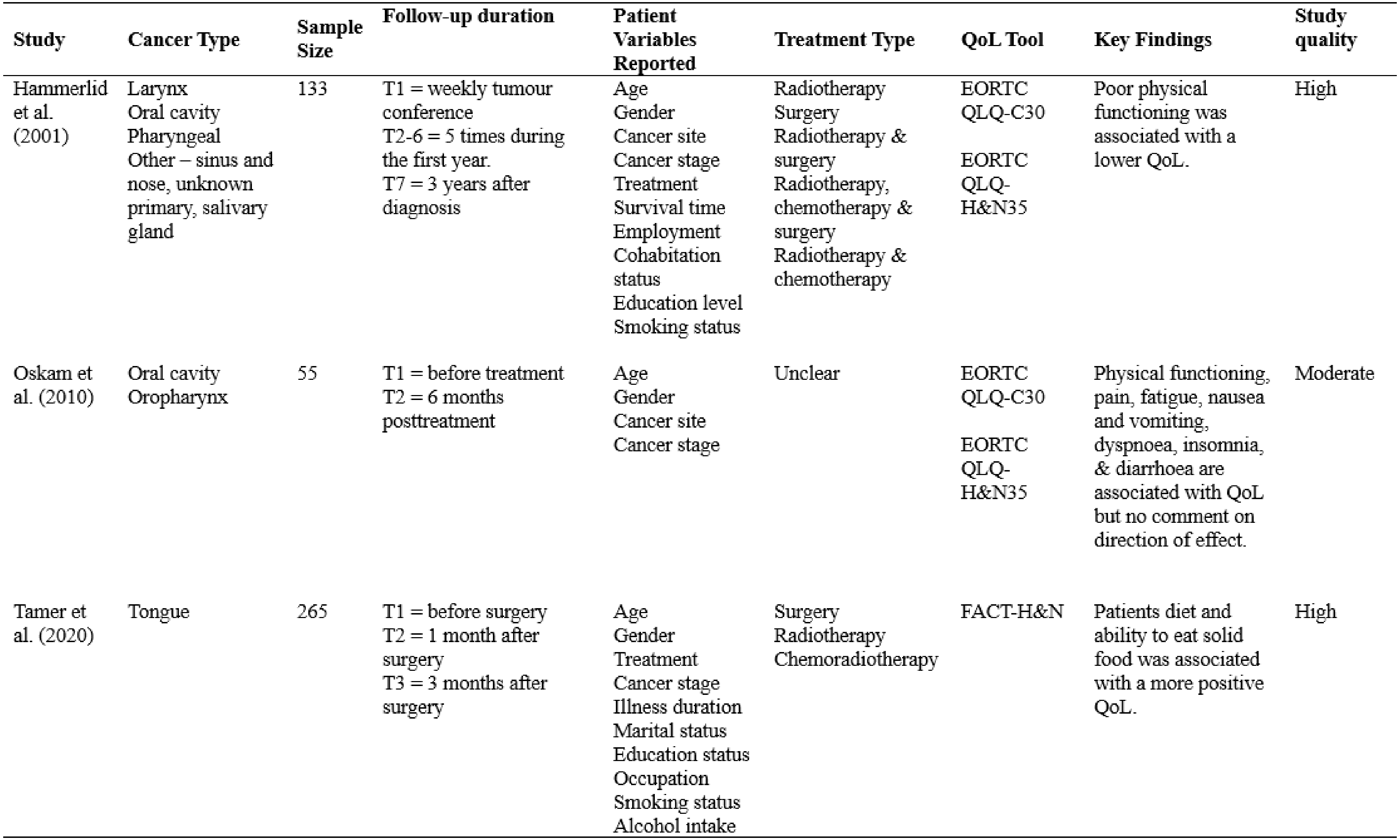
Study	**Cancer Type**	**Sample Size**	**Follow-up duration**	**Patient Variables Reported**	**Treatment Type**	**QoL Tool**	**Key Findings**	**Study quality**
Rios-Gonzalez et al. (2024)	Oral Oropharyngeal	36	T1 = pre-surgery assessment T2 = 1-month posttreatment T3 = 3 months posttreatment T4 = 6 months posttreatment T5 = 12 months posttreatment	Age Gender Smoking status Alcohol consumption Cancer stage Tumour size Treatment	Surgery Radiotherapy Chemotherapy	UW-QoL	Tobacco use was associated with a worse QoL	Moderate
Ronis et al. (2008)	Oral cavity Pharynx, oropharynx, hypopharynx, nasopharynx or unknown primary site	316	T1 = before treatment T2 = 1 year later.	Age Gender Cancer site Cancer stage Treatment Race/ethnicity Marital status Marital status Education status Smoker status Alcohol intake	Radiotherapy Chemotherapy Surgery	SF-36 HNQoL	Smoking was found to be associated with QoL, but direction of effect was not reported.	High

Study	Cancer Type	Sample Size	Follow-up duration	Patient Variables Reported	Treatment Type	QoL Tool	Key Findings	Study quality
Yin et al. (2020)	Base of tongue Tonsil Glossopharyngeal sulcus	294	T1 = pretreatment T2 = 3-6 months posttreatment	Age Gender Cancer site T-stage N-stage Treatment Marital status Education level Race Employment status Smoking history Alcohol history	Surgery Radiotherapy Combination	EORTC QLQ-30 EORTC QLQ-H&N35	Drinking alcohol and smoking were associated with worse QoL.	Moderate

Note. EORTC QLQ-30: core quality of life European Organization for Research and Treatment of Cancer Questionnaire; EORTC QLQ-H&N35: head and neck cancer specific quality of life questionnaire from European Organisation for Research and Treatment of Cancer; FACT-H&N: Functional Assessment of Cancer Therapy – head and neck; HNQoL: Head and Neck Quality of Life Instrument; SF-36: 36-Item Short Form Health Survey; UW-QoL v3: University of Washington Quality of Life Questionnaire.

Supplementary Materials S8: Narrative synthesis table for studies reporting side effects associated with QoL

Study	Cancer Type	Sample Size	Follow-up duration	Patient Variables Reported	Treatment Type	QoL Tool	Key Findings	Study quality
Alvarez-Camacho et al. (2016)	Pharynx Larynx Oral cavity Other (salivary glands, nasal cavity & paranasal sinuses)	85	T1 = prior to treatment. T2 = end of treatment T3 = 2.5 months posttreatment	Age Gender Cancer site Cancer stage Treatment Smoking status Alcohol at baseline Feeding status	RTchemo ± surgery RT ± surgery RTcetuximab ± surgery Surgery only	UW-QoL v3	High chemosensory complaint score (large changes to taste and smell) was associated with worse QoL	Moderate
Citak & Tulek (2013)	Larynx Oral cavity Pharynx	54	T1 = start of treatment T2 = end of treatment T3 = 1 month posttreatment T4 = 3 months posttreatment	Age Gender Cancer site Cancer stage Treatment Education Occupation Marital status Income level	Radiotherapy Radiotherapy & chemotherapy Tracheostomy	EORTC QLQ-30 EORTC QLQ-H&N35	Patients who were malnourished were found to have worse QoL	High
De Graeff et al. (2000)b	Larynx Oral cavity Oropharynx Hypopharynx	153	T1 = before treatment T2 = 6 months posttreatment T3 = 12 months	Age Gender Cancer stage N stage	Radiotherapy Surgery Radiotherapy & surgery	EORTC QLQ-C30 EORTC QLQ-H&N35	Significant functional impairment was associated with a lower QoL.	High

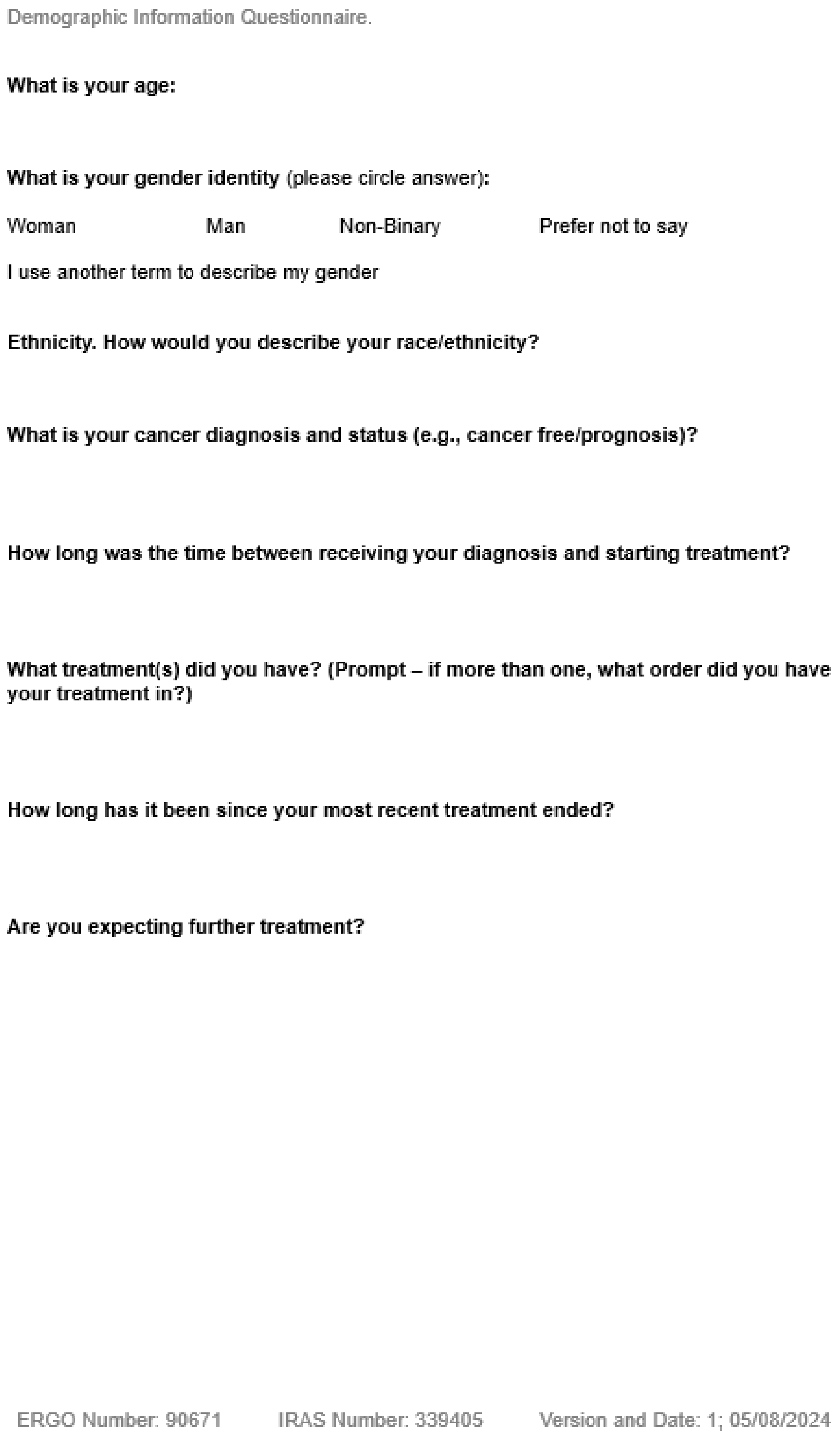


Study	**Cancer Type**	**Sample Size**	**Follow-up duration**	**Patient Variables Reported**	**Treatment Type**	**QoL Tool**	**Key Findings**	**Study quality**
Hammerlid et al. (2001)	Larynx Oral cavity Pharyngeal Other – sinus and nose, unknown primary, salivary gland	133	T1 = weekly tumour conference T2-6 = 5 times during the first year. T7 = 3 years after diagnosis	Age Gender Cancer site Cancer stage Treatment Survival time Employment Cohabitation status Education level Smoking status	Radiotherapy Surgery Radiotherapy & surgery Radiotherapy, chemotherapy & surgery Radiotherapy & chemotherapy	EORTC QLQ-C30 EORTC QLQ-H&N35	Poor physical functioning was associated with a lower QoL.	High
Oskam et al. (2010)	Oral cavity Oropharynx	55	T1 = before treatment T2 = 6 months posttreatment	Age Gender Cancer site Cancer stage	Unclear	EORTC QLQ-C30 EORTC QLQ-H&N35	Physical functioning, pain, fatigue, nausea and vomiting, dyspnoea, insomnia, & diarrhoea are associated with QoL but no comment on direction of effect.	Moderate
Tamer et al. (2020)	Tongue	265	T1 = before surgery T2 = 1 month after surgery T3 = 3 months after surgery	Age Gender Treatment Cancer stage Illness duration Marital status Education status Occupation Smoking status Alcohol intake	Surgery Radiotherapy Chemoradiotherapy	FACT-H&N	Patients diet and ability to eat solid food was associated with a more positive QoL.	High

Study	Cancer Type	Sample Size	Follow-up duration	Patient Variables Reported	Treatment Type	QoL Tool	Key Findings	Study quality
Tsan et al. (2021)	Hypopharyngeal Oropharyngeal Oral	54	T1 = after diagnosis, before treatment T2 = during 3rd-4th week of treatment T3 = last week of treatment T4 = 1 month posttreatment T5 = 3 months posttreatment	Age Gender Cancer site Cancer stage Surgery Living status Marital status Education level Religion Occupation Smoking history	Surgery	FACT-H&N	Increased symptom severity was associated with a reduced QoL.	Low

Note. EORTC QLQ-30: core quality of life European Organization for Research and Treatment of Cancer Questionnaire; EORTC QLQ-H&N35: head and neck cancer specific quality of life questionnaire from European Organisation for Research and Treatment of Cancer; FACT-H&N: Functional Assessment of Cancer Therapy – head and neck; HNQoL: Head and Neck Quality of Life Instrument; SF-36: 36-Item Short Form Health Survey; UW-QoL v3: University of Washington Quality of Life Questionnaire.

Supplementary Information E1: Demographic Questionnaire



Demographic Information Questionnaire.

What is your age:

What is your gender identity (please circle answer)**:**

Woman Man Non-Binary Prefer not to say

I use another term to describe my gender

Ethnicity. How would you describe your race/ethnicity?

What is your cancer diagnosis and status (e.g., cancer free/prognosis)?

How long was the time between receiving your diagnosis and starting treatment?

What treatment(s) did you have? (Prompt – if more than one, what order did you have your treatment in?)

How long has it been since your most recent treatment ended?

Are you expecting further treatment?

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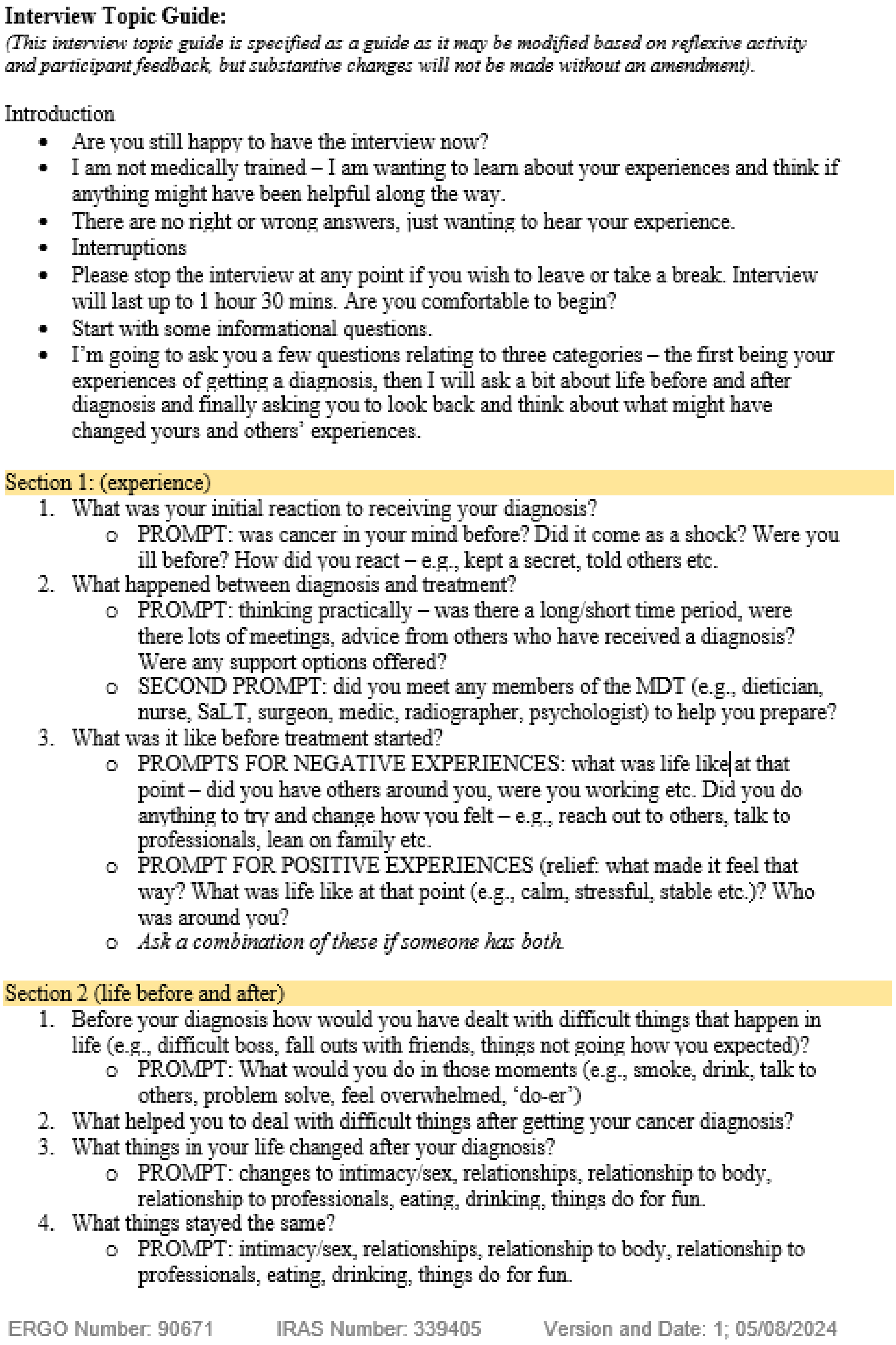
Supplementary Information E2: Interview Topic Guide



Interview Topic Guide:

(This interview topic guide is specified as a guide as it may be modified based on reflexive activity and participant feedback, but substantive changes will not be made without an amendment).

Introduction

- Are you still happy to have the interview now?
- I am not medically trained – I am wanting to learn about your experiences and think if anything might have been helpful along the way.
- There are no right or wrong answers, just wanting to hear your experience.
- Interruptions
- Please stop the interview at any point if you wish to leave or take a break. Interview will last up to 1 hour 30 mins. Are you comfortable to begin?
- Start with some informational questions.
- I'm going to ask you a few questions relating to three categories – the first being your experiences of getting a diagnosis, then I will ask a bit about life before and after diagnosis and finally asking you to look back and think about what might have changed yours and others' experiences.

Section 1: (experience)

1. What was your initial reaction to receiving your diagnosis?
    - PROMPT: was cancer in your mind before? Did it come as a shock? Were you ill before? How did you react – e.g., kept a secret, told others etc.
2. What happened between diagnosis and treatment?
    - PROMPT: thinking practically – was there a long/short time period, were there lots of meetings, advice from others who have received a diagnosis? Were any support options offered?
    - SECOND PROMPT: did you meet any members of the MDT (e.g., dietician, nurse, SaLT, surgeon, medic, radiographer, psychologist) to help you prepare?
3. What was it like before treatment started?
    - PROMPTS FOR NEGATIVE EXPERIENCES: what was life like at that point – did you have others around you, were you working etc. Did you do anything to try and change how you felt – e.g., reach out to others, talk to professionals, lean on family etc.
    - PROMPT FOR POSITIVE EXPERIENCES (relief: what made it feel that way? What was life like at that point (e.g., calm, stressful, stable etc.)? Who was around you?
    - *Ask a combination of these if someone has both.*

Section 2 (life before and after)

1. Before your diagnosis how would you have dealt with difficult things that happen in life (e.g., difficult boss, fall outs with friends, things not going how you expected)?
    - PROMPT: What would you do in those moments (e.g., smoke, drink, talk to others, problem solve, feel overwhelmed, 'do-er')
2. What helped you to deal with difficult things after getting your cancer diagnosis?
3. What things in your life changed after your diagnosis?
    - PROMPT: changes to intimacy/sex, relationships, relationship to body, relationship to professionals, eating, drinking, things do for fun.
4. What things stayed the same?
    - PROMPT: intimacy/sex, relationships, relationship to body, relationship to professionals, eating, drinking, things do for fun.

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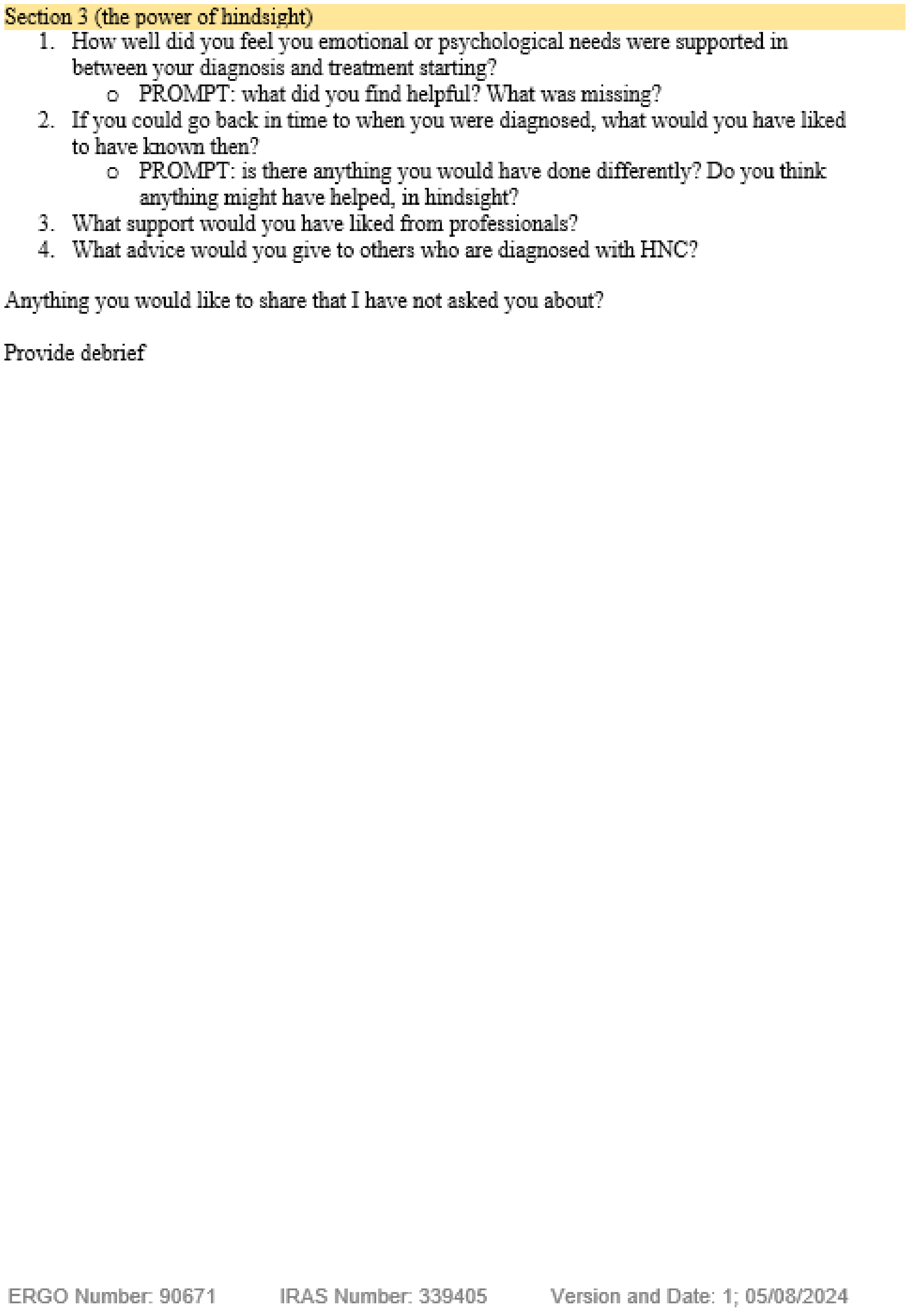

Section 3 (the power of hindsight)

1. How well did you feel you emotional or psychological needs were supported in between your diagnosis and treatment starting?
    - PROMPT: what did you find helpful? What was missing?
2. If you could go back in time to when you were diagnosed, what would you have liked to have known then?
    - PROMPT: is there anything you would have done differently? Do you think anything might have helped, in hindsight?
3. What support would you have liked from professionals?
4. What advice would you give to others who are diagnosed with HNC?

Anything you would like to share that I have not asked you about?

Provide debrief

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