UNIVERSITY OF LEEDS

This is a repository copy of *Risk stratification for poor health-related quality of life following head and neck cancer through the aid of a one-page item prompt list*.

White Rose Research Online URL for this paper:
https://eprints.whiterose.ac.uk/178941/

Version: Accepted Version

Article:
Twigg, J, Kanatas, A orcid.org/0000-0003-2025-748X, Humphris, GM et al. (2 more authors) (2022) Risk stratification for poor health-related quality of life following head and neck cancer through the aid of a one-page item prompt list. International Journal of Oral and Maxillofacial Surgery, 51 (8). pp. 1000-1006. ISSN 0901-5027

https://doi.org/10.1016/j.ijom.2021.08.028

© 2021 International Association of Oral and Maxillofacial Surgeons. Published by Elsevier Inc. All rights reserved. This manuscript version is made available under the CC-BY-NC-ND 4.0 license http://creativecommons.org/licenses/by-nc-nd/4.0/.

Reuse
This article is distributed under the terms of the Creative Commons Attribution-NonCommercial-NoDerivs (CC BY-NC-ND) licence. This licence only allows you to download this work and share it with others as long as you credit the authors, but you can't change the article in any way or use it commercially. More information and the full terms of the licence here: https://creativecommons.org/licenses/

Takedown
If you consider content in White Rose Research Online to be in breach of UK law, please notify us by emailing eprints@whiterose.ac.uk including the URL of the record and the reason for the withdrawal request.

White Rose university consortium
Universities of Leeds, Sheffield & York

eprints@whiterose.ac.uk
https://eprints.whiterose.ac.uk/

Risk stratification for poor health-related quality of life following head and neck cancer through the aid of a one-page item prompt list

Joshua Twigg, Anastasios Kanatas, Gerald M Humphris, Derek Lowe and Simon N Rogers

Dr Joshua Twigg, Leeds Teaching Hospitals and St James Institute of Oncology, Leeds Dental Institute and Leeds General Infirmary, Leeds, UK joshua.twigg@nhs.net

Professor Anastasios Kanatas, Leeds Teaching Hospitals and St James Institute of Oncology, Leeds Dental Institute and Leeds General Infirmary, Leeds, UK anastasios.kanatas@nhs.net

Professor Gerald M Humphris School of Medicine, Medical & Biological Sciences, North Haugh, St Andrews, UK gmh4@st-andrews.ac.uk

Mr Derek Lowe Medical Statistician, Director, Astraglobe Ltd, Congleton, Cheshire. astraglobeltd@btconnect.com

Professor Simon N Rogers Faculty of Health and Social Care, Edge Hill University, Ormskirk, L39 4QP and Liverpool Head and Neck Centre, Liverpool University Hospital Aintree, Liverpool, UK
simonn.rogers@aintree.nhs.uk ORCID: 0000-0002-5989-6142

Corresponding author
Anastasios Kanatas, FRCS (OMFS), MD, SFHEA. Consultant Surgeon / Professor, Leeds Teaching Hospitals and St James Institute of Oncology, Leeds Dental Institute and Leeds General Infirmary, LS1 3EX.

Tel: 00447769946105 e-mail: anastasios.kanatas@nhs.net

Abstract

Introduction

The aim of this work is to evaluate the usability of a single page, patient completed, condition specific prompt list, the Patient Concerns Inventory (PCI-HN), to risk stratify for poor quality of life.

Methods

Data was collected between 2008 and 2017. The main dataset comprised 310 patients first completing the PCI-HN and University of Washington Quality of Life questionnaire (UW-QOLv4) between 2012 and 2017. Another 201 patients (second dataset) first completing the PCI-HN between 2008 and 2011 provided a second dataset for independent validation. Subsequent completions of the PCI-HN from both groups and the Distress thermometer (DT) were also used as further validation datasets. Associations between PCI-HN items selected by patients and a range of UWQOLv4 outcomes were explored using conventional logistic regression and Chi-Squared automated interaction detection (CHAID) analyses.

Results

One quarter of patients reported less than good QOL, range 26-29% across the 4 datasets. Several individual items from within the PCI-HN were predictive of adverse outcomes. The total number of items selected was also predictive.

Conclusions

The single sheet prompt list enables clinicians to identify patients at high risk of poor QOL. This simple approach has the potential to be integrated into routine clinical practice.

Keywords: Quality of life; Screening; Patient Concerns Inventory; Stratified follow-up; Head and neck cancer

Introduction

Survival rates following head and neck cancer (HNC) are improving and more patients are living with the consequence of their cancer and its treatment. In survivorship there can be high morbidity and significant detrimental impact on health-related quality of life (HRQOL) for patients[1]. Most patients cope to a greater or lesser degree with the long-term consequences, however there is a small but significant number who manage very badly, even to a point of suicide risk[2] . Recommendations regarding outpatient follow-up for patients receiving curative treatment for HNC exist but are largely empirical[3]. Stratified follow-up frequency based on risk is advocated. This is in part related to the risk of recurrence and significant dysfunction but also could be stratified by HRQOL outcomes. Irrespective of treatment failure, patients reporting a lot of concerns or poor QOL might benefit from additional follow-up interventions, whilst those with few concerns and good QOL outcomes could be reviewed less frequently.

The PCI-HN is 56 items condition specific prompt list designed for use in HNC patient consultations[4,5]. It is a modification of the question prompt list (QPL) approach[6] and has been favoured compared to 13 other tools in systematic review and content comparison of unmet needs[7]. The PCI-HN is comprised of five domains; physical and functional well-being; treatment related issues; social care and social well-being; psychological, emotional and spiritual well-being. Its use in the form of a single sheet has been reported in a multi-centre international study[8]. Together, these items are intended to encapsulate holistic, personalised care, by allowing patients to highlight and prioritise areas of need, acting as an aide-memoir for medical professionals and patients, providing a mutually transparent structure to the consultation, and facilitating discussion of various topics which otherwise can be hard to raise such as anxiety, fear of recurrence, intimacy[9,10,11]. The routine use of the PCI-HN in clinic has been found to be acceptable among clinicians and patients[12,13] and its use adds on average just one minute to the out-patient consultation[14]. There has been two recent randomised trials reporting on the PCI-HN[15,16]. One found that its use was associated with a small but clinically meaningful benefit in HRQOL outcomes[15] and the other concluded the type and number of patients' concerns reflect HRQoL and psychological distress[16]. Taking into account an increased and complex patient workload there is a need for simplified cancer surveillance protocols. These may provide safe care and a better patient experience[17]. As a short, single sheet assessment it can be conveniently completed during the otherwise unproductive waiting time prior to consultations and can be a way of helping stratify patients' needs during follow-up. Hence, the aim of this paper is to report the use of the PCI-HN as an aid to risk stratification,

following head and neck cancer treatment. The associations between PCI-HN items selected by patients and a range of QoL outcomes identified by the UW-QOL questionnaire are explored.

Methods

The data are derived from PCI-HN inventories completed by patients of one consultant in Aintree University Hospital, immediately before attending routine follow-up clinics from 2 April 2008 to 25 January 2017, and were collected as part of service audit, meeting local Clinical Governance department criteria for service evaluation (Aintree University Hospital Clinical Audit Department approved this study). Patients were disease-free and under routine follow-up at least 6 weeks following completion of treatment. Patients excluded were pre-treatment, palliative, attending clinic for other post-operative wound management or if part of another outcomes study. When approached virtually all patients participated. The PCI-HN, The UW-QOLv4 and the DT were used in this study. The UW-QOLv4 consists of 12 domains, scaled from 0 (worst) to 100 (best) according to response hierarchy[18] . The UWQOL physical function subscale score is the simple average of the swallowing, chewing, speech, saliva, taste and appearance domain scores whilst the social-emotional function subscale score is the simple average of the activity, recreation, pain, mood, anxiety and shoulder domain scores[19]. Criteria derived from earlier work can indicate the domains in which patients have a significant problem or dysfunction[20]. There is also an 'overall' QOL question with response options of 'outstanding', 'very good', 'good', 'fair', 'poor', 'very poor', for which patients were asked to consider not only physical & mental health, but also other factors, such as family, friends, spirituality or personal leisure activities important to their enjoyment of life. The Distress thermometer (DT) is a rapid screening instrument for cancer-related distress[21] and a DT cut-off score ≥4 was effective in identifying those with significant distress[22]. All study data were collected electronically while patients waited for their consultations and the consultant was able to retrieve the data during the consultation. DT data were only collected from September 2014.

The UWQOL was analysed as a binary outcome in a number of ways. First, whether overall QOL was less than good; second, whether the subscale scores were under 60, which approximated to the worst quartile of scores; third, for each domain whether there was a 'significant problem/dysfunction'. Furthermore, the Distress Thermometer was analysed as a cut-off score ≥4. Predictor variables came only from the PCI-HN, comprising each PCI-HN

item (Yes/No) and the total number of PCI items selected (0-4, 5-9, 10-14, ≥15 items). The PCI-HN used from 12 March 2012 has 56 items. Patients using the PCI for the first time from then until 25 January 2017 comprised the sample for the main analysis (n=310). A separate cohort of patients (n=201) using the PCI-HN for the first time from 4 June 2008 to 26 October 2011 comprised the main validation sample. A large subset of patients from both the main analysis cohort (n=186) and the validation cohort (n=150) used the PCI-HN more than once (mean times used 2.5 and 3.6, respectively) and their subsequent records enabled two other validation samples. From 2008 to 2011 the PCI-HN had 54 items, before 'dry mouth' and 'sore mouth' were added in 2012.

Chi-square automated interaction detection (CHAID) was used with STATA version 13. This method searched for an optimal decision tree structure based on associations between outcome and PCI-HN predictor variables. Bonferroni adjustments were made to prevent Type one 'false-positive' inferential errors when forming branches of the decision tree, with the default overall threshold for statistical significance set to $p<0.05$. To avoid small numbers in final branch endpoints, the minimum subgroup size allowed was set at 15 patients (5% of sample) and the minimum number to allow further branching during the analysis was set at 25. To minimise over-fitting CHAID optimally merges together adjacent levels of ordered predictor variables, which was relevant to the number of PCI-HN items selected. CHAID was first run using only the number of items, then with just the 56 items (Yes/No) as a set, and finally was run with both. As Bonferroni adjustments might give overly conservative results, logistic regression analyses were also undertaken using SPSS version 25, first for each PCI-HN item in turn and then in stepwise mode ($p<0.001$ for entry) considering just those PCI-HN items individually significant at $p<0.001$ that were also the more commonly selected items (≥5% of PCI records).

Audit approval was given by Liverpool University Hospital Foundation NHS trust (CAMS number 9939).

Results

511 patients used the PCI-HN on 1506 occasions, at a median (IQR) of 2 (1-4) clinics, range 1-17. The median (IQR) age when first completing the PCI-HN was 63 (56-71) years and 64% (328) were men. Sixty-eight percent of patients (297/437) had oral cavity tumours, 24% (103/437) oropharynx and 8% (37/437) located elsewhere. Overall clinical stage was advanced

(stages 3-4) for 39% (154/393), and 93% (362/391) were diagnosed with squamous cell carcinoma.

From 12/3/2012 to 25/1/2017, 310 patients first used the 56 item PCI-HN. Overall QOL was less than good for 27% (83) of patients. Median (IQR) UWQOL physical function and social emotional scores were 72 (56-89) and 78 (63-88), while 41% (60/145) of patients had a DT score of ≥4. The PCI-HN was used another 457 times by 186 of these 310 patients. Overall QOL was less than good for 26% (118), median function scores were 70 and 78 respectively, and 45% of patients (119/264) had DT scores ≥4. From 04/06/2008 to 26/10/2011, a separate cohort of 201 patients first used the 54 item PCI-HN and their results were analysed as a validation dataset. Overall QOL was less than good for 29% (57/199). Median (IQR) UWQOL physical function and social-emotional scores were 72 (54-91) and 75 (58-91). The PCI-HN was used another 538 times by 150 of these 201 patients. Overall QOL was less than good for 28% (148/535), the median function scores were 73 and 78 respectively and 43% (24/56) had DT scores ≥4. Results from the CHAID and logistic regressions are displayed in Table 1 for the 310 patients first using the PCI-HN from 2012. There was some variation between the results produced using the two approaches, though overall there was considerable overlap. There was agreement on the importance of the total number of PCI-HN items selected as a predictor of all binary outcomes, with the exception of dysfunction in appearance, taste and shoulder issues. For some outcomes, notably overall QOL, social emotional function scores and social-emotional domain dysfunction, logistic regression produced many univariate predictors at $p<0.001$. The considerable amount of association amongst PCI-HN items (not shown) meant that when imputing these items in a stepwise fashion only a small number (usually one or two, as highlighted in Table 1) emerged as independent predictors. The CHAID method, incorporating Bonferoni adjustments produced a single predictor only for each outcome. Even when the number of items was considered alongside the 56 individual items only a single predictor emerged, with the exception of social-emotional function, for which the total number of items selected emerged entwined with specific selection of depression.

The variables identified across Table 1 as predictors of the HRQOL outcomes were further evaluated, as summarised in Tables 2, 3 and 4 (see supplementary tables). Here, the results for the main patient cohort (n=310) were compared to the three other validation groups, one of which was the group of 201 different patients who first used the PCI-HN in an earlier time period. Patients in both groups used the PCI-HN on subsequent occasions and results for these two sets of records formed the remaining two validation datasets. Most variables previously

identified as significant were confirmed as predictors, both in the first instance of use of the PCI-HN and in subsequent use over time. However, although there was consistently increased risk for detrimental outcomes there was notable variation in the absolute risks. A simple checklist was assembled (Table 5) to aid clinicians using the PCI-HN to estimate the likelihood of patients having adverse levels of HRQOL based on what items were selected and the total number of items selected. Two levels of absolute risk were identified. Firstly, a higher level of risk indicating that at least 2 out of every 3 patients was likely to have serious HRQOL issues. Secondly, a medium level indicating at least 1 in every 3 patients were at risk. Since some of the adverse outcomes were more common than others in the patient population as a whole, a further requirement for inclusion in Table 5 was that the absolute risk for the predictor should be at least double the background risk among the total patient population. The exception to this was when the absolute risk appeared to be at least 50%. Due to the challenges inherent in balancing out the results in Tables 2-4 over the validation groups, where risks were borderline they were included. Perhaps most notably, Table 5 showed that patients selecting 'depression' had a strong chance of being distressed, having less than good overall QOL and compromised mood and social-emotional functioning. Selection of 15 or more items by patients conferred a strong likelihood of being distressed, have less than good overall QOL and reduced social-emotional and physical functioning.

Discussion

During follow-up of HNC patients it can be difficult to identify patients who are coping poorly and could benefit from additional support and increased frequency of multi-professional review. Patients are individual and not defined by their cancer site, stage or treatment, hence a simple and feasible way to help provide a fuller holistic understanding of their concerns and how this might relate to their QOL, is potentially valuable. In addition. QOL outcomes are related to symptoms and these can be elicited with a single page prompt list[23].

When interpreting the results from this study, there are a number of specific limitations which need to be accounted for. This work was conducted within a single centre (mainly including oral cancer patients). QOL data, for some patients, started at 6 weeks post-treatment. Although this may have been too early for some patients, this analysis includes data reflecting the pragmatic management of head and neck cancer patients in a tertiary-care centre. At its initial stages 2008-2011, the PCI-HN was an evolving prompt list with 54 items, whilst from 2012 to

date has 56 items. When evaluating the results, one needs to remember that the PCI-HN is an effective communication tool that can identify unmet needs in a busy clinic, rather than a pure screening tool for poor HRQOL. Also, the Distress thermometer (DT) was only recorded from September 2014, meaning data was only recorded from 145/310 cases in the analysis dataset and was not recorded in the main validation set. On the other hand, this study includes a large number of patients with prospective and electronically collected data that ensured completeness. Overfitting in decision trees is a common problem (addressed by adopting the Bonferroni correction in the CHAID analyses), particularly when there are a high number of decision nodes such as in the data presented here[24]. To address the possibility of over-correction, the combined use of an independent validation dataset and a complementary logistic regression approach have been included. The two approaches provided broadly similar results when a multivariate approach was adopted (CHAID & stepwise regression). The univariate regression analyses illustrated the multiple predictors competing for inclusion in the final parsimonious models presented. The many univariate predictors for the overall QOL and the composite scores in particular helps explain the cumulative impact of such variables – i.e. the importance of the total number of items. With few exceptions, test and validation datasets showed similar performance (Tables 2-4), suggesting that the PCI-HN items selected to indicate risks of less-than-good QOL or specific issues such as mood dysfunction, distress or swallow dysfunction are applicable to the broader HNC patient population.

Implementation of the prompt list (Table 5) into consultations could allow clinicians to screen and identify patients at risk of specific adverse outcomes within the appointment and without the need for additional resources, staff or time. For instance, at least 2 out of every three patients who select 15 or more PCI-HN items was likely to have significant emotional distress (characterised as a Distress Thermometer score ≥ 4) and had less-than-good QOL according to the UW-QOL tool. Similarly, at least 2 out of every 3 individuals selecting depression on the PCI were likely to have significant emotional distress. The number of items selected on the PCI-HN was particularly predictive of emotional distress and of specific dysfunction across the physical and social-emotional domains of the UWQOL. The QOL risk stratification in table 5, could be augmented by clinical factors that are known to be associated with poor HRQOL outcomes such as site, stage, treatment, and inform the decision regarding individualised stratified follow-up frequency. The evaluation of quality of life issues in patients with head and neck cancer is no easy task, as there are several instruments with specific limitations and benefits[25]. In an attempt to provide an exceptional standard of care clinicians

may need to incorporate a prompt list, the DT and a validated HRQOL instrument in their routine consultations. This will identify those patients in need of further support. However, a pragmatic approach for a busy service will be the regular use of the PCI-HN as a communication as well as a HRQOL identification tool. The ability to simply classify a patient to high or medium risk of worse QOL outcome -without significant resources and additional personnel contact-in real time during the clinical consultation, may be of benefit during the current COVID-19 pandemic.

The data presented in this study supports an additional role for the PCI-HN, that of a screening tool to identify patients at risk of worse QOL outcomes. This information can be used immediately at the time consultation to help address unmet needs, can be a trigger for additional multidisciplinary assessment, and also to plan the focus and timing of the next appointment. Further research is need to evaluate how best to incorporate this approach into current guidelines for HNC survivorship care.

Conflict of interest: The authors have no conflict of interest to declare

References

[1]. Giuliani M, McQuestion M, Jones J, Papadakos J, Le LW, Alkazaz N, Cheng T, Waldron J, Catton P, Ringash J. Prevalence and nature of survivorship needs in patients with head and neck cancer. Head Neck, 2016;38(7):1097-103.

[2]. Twigg JA, Anderson JM, Humphris G, Nixon I, Rogers SN, Kanatas A. Best practice in reducing the suicide risk in head and neck cancer patients: a structured review. Br J Oral Maxillofac Surg, 2020 Jul 15:S0266-4356(20)30314-4.

[3]. Kanatas A, Bala N, Lowe D, Rogers SN. Outpatient follow-up appointments for patients having curative treatment for cancer of the head and neck: are the current arrangements in need of change? Br J Oral Maxillofac Surg, 2014 Oct;52(8):681-7.

[4]. Rogers, S.N., El-Sheikha, J. and Lowe, D., 2009. The development of a Patients Concerns Inventory (PCI) to help reveal patients concerns in the head and neck clinic. Oral oncology, 45(7), pp.555-561.

[5]. Ghazali, N., Kanatas, A., Bekiroglu, F., Scott, B., Lowe, D. and Rogers, S.N.The Patient Concerns Inventory: a tool to uncover unmet needs in a cancer outpatient clinic. The Bulletin of the Royal College of Surgeons of England, 2013;95(3):1-6.

[6]. Miller N, Rogers SN. A review of question prompt lists used in the oncology setting with comparison to the Patient Concerns Inventory. Eur J Cancer Care (Engl), 2016 Mar 14. doi: 10.1111/ecc.12489.

[7]. Shunmugasundaram C, Rutherford C, Butow PN, Sundaresan P, Dhillon HM. Content comparison of unmet needs self-report measures used in patients with head and neck cancer: A systematic review. Psychooncology, 2019;28:2295-2306.

[8]. Rogers SN, AnesiA, Valerini S, Babin E, Batstone M, Nhongo S, Brockmeyer P, Schliephake H, Chien C-Y, Lin YT, Chirila M, Tiple C, Ransy P, Dholam KP, Gurav SV, Doss JG, Kadir K, Ghani WMN, Tiblom Ehrsson Y, Finizia C, Tuomi L, Kolator M, Zatonski T, Peker K, Ozdemir-Karatas M, Balik A, Pesic Z, Santos IC, Lima RMA, Souza FGR, Shah K, Thankappan K, Sunil G, Vasquez P, Lowe D. Variations in concerns reported on the Patient Concerns Inventory (PCI) in head and neck cancer patients from different health settings across the world. Head Neck, 2020 Mar;42(3):498-512.

[9]. Ghazali, N., Roe, B., Lowe, D., Tandon, S., Jones, T., Shaw, R., Risk, J. and Rogers, S.N., 2017. Using the patients concerns inventory for distress screening in post-treatment head and neck cancer survivors. Journal of Cranio-Maxillofacial Surgery, 45(10), pp.1743-1748.

[10]. Ghazali, N., Kanatas, A., Langley, D.J., Scott, B., Lowe, D. and Rogers, S.N., 2011. Treatment referral before and after the introduction of the Liverpool Patients Concerns Inventory (PCI) into routine head and neck oncology outpatient clinics. Supportive Care in Cancer, 19(11), pp.1879-1886.

[11]. Ghazali, N., Cadwallader, E., Lowe, D., Humphris, G., Ozakinci, G. and Rogers, S.N., 2013. Fear of recurrence among head and neck cancer survivors: longitudinal trends. Psycho-oncology, 22(4), pp.807-813.

[12]. Rogers SN, Ahiaku S, Lowe D. Is routine holistic assessment with a prompt list feasible during consultations after treatment for oral cancer? Br J Oral Maxillofac Surg, 2018 Jan;56(1):24-28.

[13]. Rogers SN, Thomson F, Lowe D. The Patient Concerns Inventory integrated as part of routine head and neck cancer follow-up consultations: frequency, case-mix, and items initiated by the patient. Ann R Coll Surg Engl, 2018;100:209-215.

[14]. Rogers SN, Semple C, Humphris GM, Lowe D, Kanatas A. Using a patient prompt list to raise concerns in oncology clinics does not necessarily lead to longer consultations. Br J Oral Maxillofac Surg, 2020 Nov;58(9):1164-1171.

[15]. Rogers SN, Allmark C, Bekiroglu F, Edwards RT, Fabbroni G, Flavel R, Highet V, Ho MWS, Humphris GM, Jones TM, Khattak O, Lancaster J, Loh C, Lowe D, Lowies C, Macareavy D, Moor J, Ong TK, Prasai A, Roland N, Semple C, Spencer LH, Tandon S, Thomas SJ, Schache A, Shaw RJ, Kanatas A. Improving quality of life through the routine use of the patient concerns inventory for head and neck cancer patients: Main results of a cluster preference randomised controlled trial. Eur Arch Otorhinolaryngol (In press) doi: 10.1007/s00405-020-06533-3.

[16]. 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? Ecancermedicalscience, 2020 Oct 8;14:1118. doi: 10.3332/ecancer.2020.1118.

[17]. Peña HDL. Stratified follow-up pathways for cancer patients. Clin Med (Lond), 2019 Jun;19(Suppl 3):80–1. doi: 10.7861/clinmedicine.19-3s-s80.

[18]. Rogers SN, Gwane S, Lowe D, Humphris G, Yueh B, Weymuller EA .The addition of mood and anxiety domains to the University of Washington Quality of Life Scale. Head Neck, 2002;24:521-529.

[19]. Rogers SN, Lowe D, Yueh B, Weymuller EA (2010) The Physical function and Social-Emotional function subscales of the University of Washington Quality of Life questionnaire (UW-QOL). Arch Otolaryngol Head Neck Surg, 136(4):352-7

[20]. Rogers SN, Lowe D. Screening for dysfunction to promote multidisciplinary intervention by using the University of Washington Quality of Life Questionnaire. Arch Otolaryngol Head Neck Surg, 2009;135:369-75. doi: 10.1001/archoto.2009.7.

[21]. Cutillo A, O'Hea E, Person S, Lessard D, Harralson T, Boudreaux E. The Distress Thermometer: Cutoff Points and Clinical Use. Oncol Nurs Forum, 2017;44(3):329-336.

[22]. Ghazali N, Roe B, Lowe D, Tandon S, Jones T, Brown J, Shaw R, Risk J, Rogers SN. Screening for distress using the distress thermometer and the University of Washington Quality of Life in post-treatment head and neck cancer survivors. Eur Arch Otorhinolaryngol, 2017 May;274(5):2253-2260.

[23]. Astrup GL, Hofsø K, Bjordal K, Guren MG, Vistad I, Cooper B, Miaskowski C, Rustøen T. Patient factors and quality of life outcomes differ among four subgroups of oncology patients based on symptom occurrence. Acta Oncol, 2017;56(3):462-470.

[24]. Bramer, M., 2007. Avoiding overfitting of decision trees. Principles of data mining, pp.119-134.

[25]. Vartanian JG, Rogers SN, Kowalski LP. How to evaluate and assess quality of life issues in head and neck cancer patients. Curr Opin Oncol, 2017 Mar 9. doi: 10.1097/CCO.0000000000000369. Online ahead of print.

Table 1. PCI predictor variables of adverse HRQOL outcomes, for 310 patients using the PCI for the first time from 12/3/2012 to 25/1/2017

OUTCOMES	Analyses using CHAID			Analyses using logistic regression*	
	Univariate approach	Multivariate approach		Number of univariate predictors at p<0.001	All 56 PCI items (Yes/No) considered, each in turn. Commonly selected items (≥5% oF records) that were also significant at p<0.001 were considered for stepwise regression (entry p<0.001). Emerging variables are underlined.
	Only total number of PCI items (0-4, 5-9, 10-14, ≥15) considered	ALL 56 PCI items (Yes/No)	ALL 56 PCI items and total number		
	Variables selected by CHAID				
UWQOL Overall QOL (less than good)	Total (0-4, 5-9, 10-14, ≥15)	Depression	Total (0-4, 5-9, 10-14, ≥15)	26	Depression (46), self-esteem (37), mood (37), appetite (37), anxiety (34), weight (26), fatigue (25), sleeping (19), pain elsewhere (18), appearance (17), mobility (16), bowel habit (15), mouth opening (15), chewing/eating (14), energy levels (14), financial benefits (14), pain HN (13), swelling (13),
UWQOL Physical function score (<60)	Total (0-4, 5-14, ≥15)	Speech	Total (0-4, 5-14, ≥15)	10	Speech (28), dry mouth (26), swallowing (26), taste (19), self-esteem (17), sore mouth (16), mucus (16), chewing/eating (13),
UWQOL Social-emotional function score (<60)	Total (0-4, 5-9, ≥10)	Depression	Total (0-4, 5-9, ≥10 without depression, ≥10 with depression)	20	Depression (49), mobility (30), sleeping (27), anxiety (24), shoulder (24), self-esteem (23), fatigue (23), memory (22), pain elsewhere (22), appearance (19), energy levels (18), mood (18), hearing (17), appetite (13),
UWQOL Physical function domains dysfunction):					
Appearance	-	Appearance	Appearance	5	Appearance (48), self-esteem (12)
Swallowing	Total (0-9, ≥10)	Peg tube	Peg tube	5	Speech (17), hearing (17), sore mouth (15), swallowing (13)
Chewing	Total (0-9, ≥10)	Sore mouth	Total (0-9, ≥10)	7	Sore mouth (20), speech (19), chewing/eating (17), salivation (13), appetite (13)
Speech	Total (0-14, ≥15)	Speech	Speech	11	Speech (46), mood (23), hearing (22), swallowing (20), self-esteem (15), depression (13), pain elsewhere (13)
Taste	-	Taste	Taste	2	Taste (26), swallowing (12)
Saliva	Total (0-4, ≥5)	Dry Mouth	Dry Mouth	3	Dry mouth (62), salivation (15)
UWQOL Social emotional domains (dysfunction):					
Pain	Total (0-9, 10-14, ≥15)	Sore Mouth	Total (0-9, 10-14, ≥15)	15	Sore mouth (36), head/neck pain (22), mouth opening (21), swallowing (19), anxiety (14), swelling (14), chewing/eating (13), appearance (13), depression (13), wound (12), self-esteem (11)
Activity	Total (0-9, ≥10)	Coping	Coping	14	Mobility (29), breathing (23), mood (21), fatigue (17), self-esteem (16), energy levels (14), sleeping (13), bowel habit (13)
Recreation	Total (0-9, ≥10)	Mobility	Mobility	11	Mobility (29), sleeping (17), fatigue (17), weight(17), hearing (13), mood (11), pain elsewhere (11)

Shoulder	-	Shoulder	Shoulder	3	Shoulder (94), fatigue (14)
Mood	Total (0-14, ≥15)	Depression	Depression	16	Depression (64), mood (40), anxiety (22), memory (22), self-esteem (19), energy levels (13), pain elsewhere (12), taste (11)
Anxiety	Total (0-9, ≥10)	Anxiety	Anxiety	16	Depression (50), anxiety (50), mood (31), self-esteem (30), sleeping (22), bowel habit (19), fear of recurrence (17), memory (17), energy levels(15)
Distress thermometer score (n=145)					
DT ≥4	Total (0-14, ≥15)	Depression	Depression	4	Pain elsewhere (16), depression (16), self-esteem (15)

*The number in brackets after each item is the univariate Chi-squared value. Note that values ≥11 are $p<0.001$ and values ≥20 are $p<0.00001$

Table 2. Adverse HRQOL results by PCI predictors across 4 groups

		Analysis data		Validation data					
		First PCI record (310 patients) 12/3/12 to 25/1/17		First PCI record (201 patients) 4/8/08 to 16/10/11		Subsequent PCI records (186 of 310 patients) 12/3/12 to 25/1/17		Subsequent PCI records (150 of 201 patients) 4/8/08 to 25/1/17	
		%	Patients	%	Patients	%	Records	%	Records
UWQOL OVERALL QOL : % Less than good									
	ALL	27	83/310	29	57/199	26	118/457	28	148/535
PCI	0-4	11	15/141	15	17/111	13	35/273	15	53/357
items	5-9	23	21/92	33	18/54	38	39/104	40	48/119
total	10-14	50	23/46	52	11/21	41	20/49	71	25/35
	≥15	77	24/31	85	11/13	77	24/31	92	22/24
Depression		73	27/37	59	13/22	71	37/52	79	46/58
Self-esteem		86	18/21	75	6/8	71	15/21	76	25/33
Mood		72	23/32	64	16/25	68	30/44	77	41/53
Appetite		68	25/37	53	10/19	59	22/37	60	18/30
Anxiety		60	31/52	60	15/25	50	28/56	67	49/73
Weight		56	28/50	54	15/28	53	27/51	44	18/41
Fatigue		47	40/85	52	23/44	51	54/105	52	48/92
Sleeping		50	28/56	68	19/28	55	41/75	60	50/84
Pain elsewhere		55	21/38	45	9/20	44	18/41	72	36/50
Appearance		58	18/31	43	9/21	47	14/30	58	21/36
Mobility		67	12/18	67	10/15	69	24/35	63	24/38
Bowel habit		57	17/30	60	9/15	44	11/25	47	15/32
Mouth opening		47	28/60	37	10/27	38	26/69	39	26/67
Chewing/eating		41	38/92	35	19/54	32	34/105	42	35/84
Energy levels		51	21/41	56	14/25	60	24/40	42	21/50
Financial benefits		62	13/21	70	7/10	61	14/23	61	11/18
Pain HN		44	28/63	55	23/42	42	30/71	54	57/106
Swelling		50	21/42	38	9/24	36	14/39	45	15/33
UWQOL PHYSICAL FUNCTION: <60									
	ALL	28	87/310	31	62/201	33	151/457	24	129/538
PCI	0-4	17	24/141	19	21/111	20	54/273	16	57/359
items	5-9	25	23/92	43	23/54	43	45/104	30	36/119
total	10-14	37	17/46	36	8/22	55	27/49	57	20/35
	≥15	74	23/31	71	10/14	81	25/31	64	16/25
Speech		55	35/64	43	13/30	66	40/61	67	26/39
Dry mouth*		45	53/119	Not recorded		49	74/152	40	19/47
Swallowing		53	35/66	67	30/45	65	54/83	53	48/91
Taste		53	28/53	48	13/27	67	42/63	55	24/44
Self-esteem		67	14/21	78	7/9	67	14/21	41	14/34

Sore mouth*		45	37/82	Not recorded		40	39/97	41	13/32
Mucus		53	23/43	50	13/26	55	27/49	33	22/66
Chewing/eating		42	39/92	54	30/56	57	60/105	40	34/85
UWQOL SOCIAL-EMOTIONAL FUNCTION: <60									
	ALL	21	65/310	26	53/201	19	88/457	22	118/538
PCI	0-4	9	12/141	9	10/111	8	23/273	10	37/359
items	5-9	17	16/92	37	20/54	20	21/104	32	38/119
total	10-14	39	18/46	45	10/22	49	24/49	60	21/35
	≥15	61	19/31	93	13/14	65	20/31	88	22/25
Depression		65	24/37	70	16/23	65	34/52	68	40/59
Mobility		72	13/18	56	9/16	57	20/35	72	28/39
Sleeping		46	26/56	54	15/28	43	32/75	48	40/84
Anxiety		46	24/52	67	18/27	43	24/56	61	45/74
Shoulder		45	25/55	47	18/38	36	22/61	57	46/81
Self-esteem		62	13/21	78	7/9	52	11/21	76	26/34
Fatigue		39	33/85	49	22/45	43	45/105	47	44/93
Memory		63	12/19	58	7/12	44	14/32	55	18/33
Pain elsewhere		50	19/38	50	10/20	41	17/41	55	28/51
Appearance		52	16/31	50	11/22	43	13/30	65	24/37
Energy levels		46	19/41	52	14/27	50	20/40	37	19/51
Mood		50	16/32	65	17/26	55	24/44	72	39/54
Hearing		45	19/42	47	7/15	38	18/48	28	11/40
Appetite		43	16/37	60	12/20	43	16/37	55	17/31
DISTRESS THERMOMETER: ≥4**									
	ALL	41	60/145	Not recorded		45	119/264	43	24/56
PCI	0-4	34	24/70	Not recorded		34	57/168	23	8/35
items	5-9	32	13/41			49	30/61	69	9/13
total	10-14	50	9/18			83	15/18	100	3/3
	≥15	88	14/16			100	17/17	80	4/5
Depression		88	14/16	Not recorded		89	25/28	100	7/7
Pain Elsewhere		88	15/17	Not recorded		65	13/20	78	7/9
Self-esteem		92	12/13	Not recorded		82	9/11	100	6/6

*recorded from 12/3/12
**recorded from 3/9/14

Table 3. UWQOL physical function dysfunction by PCI predictors across 4 groups

		Analysis data		Validation data					
		First PCI record (310 patients) 12/3/12 to 25/1/17		First PCI record (201 patients) 4/8/08 to 16/10/11		Subsequent PCI records (186 of 310 patients) 12/3/12 to 25/1/17		Subsequent PCI records (150 of 201 patients) 4/8/08 to 25/1/17	
		%	Patients	%	Patients	%	Records	%	Records
UWQOL APPEARANCE DYSFUNCTION									
	ALL	9	27/310	13	26/201	6	27/457	9	48/538
Appearance		42	13/31	68	15/22	43	13/30	43	16/37
Self-esteem		29	6/21	56	5/9	5	1/21	36	12/34
UWQOL SWALLOWING DYSFUNCTION									
	ALL	15	46/310	20	41/201	19	85/457	16	85/538
PCI	0-4	8	11/141	17	19/111	11	30/273	12	44/359
items	5-9	12	11/92	19	10/54	25	26/104	14	17/119
total	10-14	30	14/46	23	5/22	24	12/49	26	9/35
	≥15	32	10/31	50	7/14	55	17/31	60	15/25
Peg tube		69	9/13	50	7/14	69	11/16	69	11/16
Speech		31	20/64	27	8/30	41	25/61	51	20/39
Hearing		36	15/42	20	3/15	31	15/48	25	10/40
Sore mouth*		28	23/82	Not recorded		25	24/97	25	8/32
Swallowing		29	19/66	40	18/45	43	36/83	43	39/91
UWQOL CHEWING DYSFUNCTION									
	ALL	15	47/310	15	31/201	15	69/457	13	68/538
PCI	0-4	7	10/141	14	16/111	10	27/273	10	36/359
items	5-9	13	12/92	17	9/54	16	17/104	13	15/119
total	10-14	26	12/46	9	2/22	24	12/49	23	8/35
	≥15	42	13/31	29	4/14	42	13/31	36	9/25
Sore mouth*		30	25/82	Not recorded		19	18/97	25	8/32
Speech		33	21/64	7	2/30	38	23/61	33	13/39
Chewing/eating		28	26/92	27	15/56	23	24/105	20	17/85
Salivation		27	23/85	16	5/31	31	30/97	20	19/96
Appetite		35	13/37	20	4/20	27	10/37	32	10/31
UWQOL SPEECH DYSFUNCTION									
	ALL	12	36/310	9	19/201	11	48/457	8	44/538
PCI	0-4	6	9/141	7	8/111	5	13/273	4	15/359
items	5-9	9	8/92	6	3/54	12	12/104	8	10/119
total	10-14	13	6/46	14	3/22	22	11/49	17	6/35
	≥15	42	13/31	36	5/14	39	12/31	52	13/25
Speech		36	23/64	23	7/30	33	20/61	44	17/39
Mood		38	12/32	19	5/26	30	13/44	24	13/54
Hearing		33	14/42	27	4/15	25	12/48	8	3/40
Swallowing		27	18/66	18	8/45	23	19/83	20	18/91

Self-esteem		38	8/21	22	2/9	33	7/21	35	12/34
Depression		30	11/37	30	7/23	29	15/52	20	12/59
Pain elsewhere		29	11/38	10	2/20	24	10/41	24	12/51
		UWQOL TASTE DYSFUNCTION							
	ALL	16	50/310	13	26/201	18	82/457	10	53/538
Taste		40	21/53	33	9/27	65	41/63	34	15/44
Swallowing		30	20/66	24	11/45	33	27/83	19	17/91
		UWQOL SALIVA DYSFUNCTION							
	ALL	23	70/310	21	42/201	28	129/457	22	119/538
PCI	0-4	14	20/141	13	14/111	22	60/273	17	62/359
items	5-9	33	30/92	33	18/54	39	41/104	27	32/119
total	10-14	30	14/46	27	6/22	39	19/49	43	15/35
	≥15	19	6/31	29	4/14	29	9/31	40	10/25
Dry mouth*		46	55/119	Not recorded		55	83/152	62	29/47
Salivation		38	32/85	52	16/31	51	49/97	49	47/96

*recorded from 12/3/12

Table 4. UWQOL social-emotional dysfunction by PCI predictors across 4 groups

		Analysis data		Validation data					
		First PCI record (310 patients) 12/3/12 to 25/1/17		First PCI record (201 patients) 4/8/08 to 16/10/11		Subsequent PCI records (186 of 310 patients) 12/3/12 to 25/1/17		Subsequent PCI records (150 of 201 patients) 4/8/08 to 25/1/17	
		%	Patients	%	Patients	%	Records	%	Records
		UWQOL PAIN DYSFUNCTION							
	ALL	23	70/310	24	48/201	17	78/457	18	97/538
PCI	0-4	11	16/141	13	14/111	10	28/273	11	40/359
items	5-9	20	18/92	28	15/54	18	19/104	26	31/119
total	10-14	37	17/46	41	9/22	33	16/49	34	12/35
	≥15	61	19/31	71	10/14	48	15/31	56	14/25
Sore mouth		46	38/82	Not recorded		36	35/97	38	12/32
Pain HN		44	28/63	56	24/43	42	30/71	38	41/108
Mouth opening		45	27/60	37	10/27	33	23/69	26	18/68
Swallowing		42	28/66	36	16/45	27	22/83	24	22/91
Anxiety		42	22/52	48	13/27	27	15/56	35	26/74
Swelling		45	19/42	54	13/24	31	12/39	32	11/34
Chewing/eating		36	33/92	34	19/56	19	20/105	22	19/85
Appearance		48	15/31	59	13/22	37	11/30	51	19/37
Depression		46	17/37	57	13/23	48	25/52	42	25/59
Wound		43	19/44	42	8/19	34	11/32	35	7/20
Self-esteem		52	11/21	56	5/9	38	8/21	56	19/34
		UWQOL ACTIVITY DYSFUNCTION							
PCI	ALL	9	28/310	11	23/201	9	39/457	9	46/538
Items	0-4	4	5/141	6	7/111	4	12/273	5	17/359
total	5-9	7	6/92	15	8/54	15	16/104	9	11/119
	10-14	22	10/46	23	5/22	12	6/49	34	12/35
	≥15	23	7/31	21	3/14	16	5/31	24	6/25
Coping		47	8/17	20	3/15	22	4/18	30	6/20
Mobility		44	8/18	25	4/16	31	11/35	26	10/39
Breathing		38	8/21	31	5/16	22	6/27	25	11/44
Mood		31	10/32	27	7/26	25	11/44	22	12/54
Fatigue		20	17/85	27	12/45	20	21/105	23	21/93
Self-esteem		33	7/21	11	1/9	10	2/21	21	7/34
Energy levels		24	10/41	26	7/27	25	10/40	33	17/51
Sleeping		21	12/56	25	7/28	23	17/75	20	17/84
Bowel habit		27	8/30	25	4/16	16	4/25	9	3/32
		UWQOL RECREATION DYSFUNCTION							
	ALL	9	28/310	10	21/201	10	46/457	7	37/538
	0-4	4	6/141	4	4/111	7	19/273	3	10/359
	5-9	8	7/92	15	8/54	9	9/104	6	7/119

PCI	10-14								
items		17	8/46	14	3/22	18	9/49	37	13/35
total									
	≥15	23	7/31	43	6/14	29	9/31	28	7/25
Mobility		44	8/18	31	5/16	40	14/35	28	11/39
Sleeping		23	13/56	21	6/28	21	16/75	18	15/84
Fatigue		20	17/85	24	11/45	21	22/105	14	13/93
Weight		24	12/50	18	5/28	20	10/51	20	8/41
Hearing		24	10/42	20	3/15	21	10/48	15	6/40
Mood		25	8/32	31	8/26	25	11/44	19	10/54
Pain elsewhere		24	9/38	15	3/20	22	9/41	20	10/51
		UWQOL SHOULDER DYSFUNCTION							
	ALL	11	33/310	10	21/201	7	31/457	11	59/539
Shoulder		47	26/55	37	14/38	26	16/61	47	38/81
Fatigue		21	18/85	16	7/45	15	16/105	17	16/93
		UWQOL MOOD DYSFUNCTION							
	ALL	15	47/310	20	40/201	16	71/457	15	80/538
PCI	0-4	8	11/141	4	4/111	6	17/273	6	22/359
items	5-9	12	11/92	30	16/54	16	17/104	22	26/119
total	10-14	20	9/46	27	6/22	33	16/49	40	14/35
	≥15	52	16/31	100	14/14	68	21/31	72	18/25
Depression		59	22/37	74	17/23	73	38/52	61	36/59
Mood		53	17/32	73	19/26	64	28/44	57	31/54
Anxiety		37	19/52	70	19/27	43	24/56	50	37/74
Memory		53	10/19	50	6/12	38	12/32	39	13/33
Self-esteem		48	10/21	78	7/9	67	14/21	56	19/34
Energy levels		34	14/41	44	12/27	50	20/40	27	14/51
Pain elsewhere		34	13/38	45	9/20	34	14/41	35	18/51
Taste		30	16/53	44	12/27	21	13/63	18	8/44
		UWQOL ANXIETY DYSFUNCTION							
	ALL	18	55/310	19	39/201	16	75/457	18	95/538
PCI	0-4	9	13/141	8	9/111	9	25/273	11	38/359
items	5-9	13	12/92	19	10/54	17	18/104	20	24/119
	10-14	30	14/46	36	8/22	33	16/49	43	15/35
	≥15	52	16/31	86	12/14	52	16/31	72	18/25
Anxiety		52	27/52	63	17/27	45	25/56	57	42/74
Depression		59	22/37	61	14/23	52	27/52	56	33/59
Mood		53	17/32	62	16/26	45	20/44	50	27/54
Self-esteem		62	13/21	78	7/9	48	10/21	50	17/34
Sleeping		39	22/56	43	12/28	29	22/75	29	24/84
Bowel habit		47	14/30	38	6/16	20	5/25	34	11/32
Fear of recurrence		28	38/137	31	23/75	28	37/133	41	54/131
Memory		53	10/19	50	6/12	28	9/32	33	11/33
Energy levels		39	16/41	41	11/27	35	14/40	25	13/51

Table 5. Checklist: PCI item selection and risk of adverse HRQOL outcome

PCI items selected	Adverse HRQOL outcome*
High risk (likely in 2 or more of every 3 patients seen)	
Total number of PCI items ≥15	Overall QOL, Physical and Social-emotional function, Distress thermometer
Depression	Overall QOL, Social-emotional function, Distress thermometer, Mood
Mood	Overall QOL
Pain elsewhere	Distress thermometer
Self-esteem	Overall QOL, Distress thermometer
Medium risk (likely in 1 or more of every 3 patients seen)	
Total number of PCI items ≥15	Anxiety, Chewing, Mood, Pain, Swallowing, Speech
Total number of PCI items 10-14	Overall QOL, Physical and Social-emotional function, Distress thermometer
Anxiety	Overall QOL, Social-emotional function, Mood, Anxiety
Appearance	Overall QOL, Social-emotional function, Appearance, Pain
Appetite	Overall QOL, Social-emotional function
Bowel habit	Overall QOL,
Chewing /eating	Physical function
Depression	Pain, Anxiety
Dry mouth	Saliva
Energy levels	Overall QOL, Social-emotional function, Mood, Anxiety
Fatigue	Overall QOL, Social-emotional function
Financial benefits	Overall QOL
Memory	Social-emotional function, Mood, Anxiety
Mobility	Overall QOL, Social-emotional function, Recreation
Mood	Social-emotional function, Mood, Anxiety
Mucus	Physical function
Pain in head/neck	Overall QOL, Pain

Pain elsewhere	Overall QOL, Social-emotional function, Mood
Peg tube	Swallowing
Salivation	Saliva
Self-esteem	Physical and Social-emotional function, Mood, Anxiety
Shoulder	Social-emotional function, Shoulder
Sleeping	Overall QOL, Social-emotional function
Sore mouth	Pain
Speech	Physical function, Speech, Swallowing
Swallowing	Physical function, swallowing
Swelling	Pain
Taste	Physical function, Taste
Weight	Overall QOL

*UWQOL Overall QOL 'Less than good', UWQOL Physical function score <60, UWQOL Social-emotional functioning score < 60, Distress thermometer score ≥4. UWQOL domain dysfunction is indicated simply by the name of the domain, such as Anxiety, Chewing, Pain and Mood.