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Implementing a tailored psychosocial distress screening protocol in a head and neck cancer program

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Abstract

Objective—Psychosocial distress is common among patients with head and neck cancer and is associated with poorer quality of life and clinical outcomes. Despite these risks, distress screening is not widely implemented in head and neck cancer care. In this study, we investigated the prevalence of psychosocial distress and its related factors in routine care of patients with head and neck cancer.

Methods—Data from medical records between September 2017 to March 2020 were analyzed. Psychosocial distress was measured by the National Comprehensive Cancer Network’s Distress Thermometer (DT), and a modified, head and neck cancer-specific Problem List; depression and anxiety were assessed using the Patient Health Questionnaire-4. Descriptive statistics and logistic regression were conducted to report prevalence of distress, depression and anxiety, and factors associated with clinical distress. Implementation outcomes, including rates of referrals and follow-up for distressed patients, are also reported.

Results—287 HNC patients completed the questionnaire (age 64.3 ± 14.9 years), with a mean distress score of 4.51 ± 3.35 . Of those, 57% ($n = 163$) reported clinical distress (DT ≥ 4). Pain

(OR=3.31, 95% CI=1.75, 6.26), fatigue (OR=2.43, 95% CI=1.17, 5.05), anxiety (OR=1.63, 95% CI=1.30, 2.05) and depression (OR=1.51, 95% CI=1.04, 2.18) were significantly associated with clinical distress ($p<.05$). Of patients identified as distressed, 79% received same-day psychosocial evaluation.

Conclusions—Clinical distress was identified in 57% of patients who completed the questionnaire, suggesting that an ultra-brief psychosocial screening protocol can be implemented in routine ambulatory oncology care, and identifies patients whose distress might otherwise go unrecognized.

Level of Evidence: 4

Keywords

distress screening; depression; head and neck cancer

INTRODUCTION

Psychosocial distress is defined as an unpleasant emotional experience of a psychosocial (cognitive, behavioral, emotional), social, and/or spiritual nature that may interfere with the ability to cope with cancer, its physical symptoms, and its treatment.¹ Distress screening is now mandated by the American College of Surgeons (ACoS) Commission on Cancer (CoC),² and strongly recommended by the National Comprehensive Cancer Network (NCCN),¹ Institute of Medicine (now known as the National Academy of Medicine),³ and American Psychosocial Oncology Society (APOS),⁴ as an essential component of high quality cancer care.

Head and neck cancers (HNCs) are associated with higher levels of psychosocial distress; prevalence levels have been observed at approximately 60% among patients with HNCs, as compared to 40% among cancer patients more generally.⁵⁻⁹ The elevated rates observed in HNC patients have been attributed to significant treatment side effects, functional impairment and loss (eg, speech and swallowing),¹⁰⁻¹² disfigurement,¹³ and persistent pain and fatigue.^{14,15} Prior studies in patients with HNCs have identified distress as an important predictor of a range of negative medical outcomes,^{16,17} such as delays in seeking treatment,^{17,18} poor adherence to treatment,¹⁹ increased costs,²⁰ increased health care utilization,²¹ longer hospital stays, poorer quality of life,²² and decreased survival.^{23,24} Despite the high prevalence of distress in HNC patients and its negative impact on clinical outcomes, the implementation of distress screening and management in routine care is not widespread. Consequently, distress is often unrecognized and untreated in clinical practice.¹

Given the clinical implications of psychosocial distress in patients with HNCs, a tailored screening protocol that targets the unique concerns of this group is warranted. Very few studies have applied this approach for patients with HNCs, and more research is needed to determine whether it will improve clinical outcomes.²⁵⁻²⁷ The Head and Neck Cancer Program (HNCP) at University of California, Los Angeles (UCLA) Health developed and implemented a HNC-specific questionnaire-based protocol for psychosocial distress screening as part of routine care. The standardized protocol, in accordance with NCCN

and CoC guidance,^{1,2} aims to identify distress in patients efficiently, as well as the psychological, social, financial, and behavioral issues that may interfere with a patient's treatment plan or contribute to adverse clinical outcomes. In this study, we report the prevalence of distress and associated factors in a sample of patients at the outpatient HNCP clinic of UCLA. In addition, we discuss early implementation experiences with a brief psychosocial screening protocol in the clinical workflow of a busy multidisciplinary clinic.

MATERIALS AND METHODS

Participants and Setting

The UCLA HNCP comprises a team of clinicians from oncologic subspecialties and provides multidisciplinary evaluation, treatment, and care coordination for patients with both new cancer diagnoses and recurrent disease across all HNC tumor sites. Program activities include a weekly multidisciplinary case conference, followed by a clinic, wherein patients are seen by all necessary subspecialists in one day and one location. In September 2017, the HNCP implemented a new standard of care for psychosocial distress screening as part of an existing intake process. At the initial HNCP appointment, patients were asked to complete the HNCP Distress (HNCP-DS) questionnaire in the clinic waiting room using paper and pen. Questionnaire responses were reviewed immediately by clinical staff and documented in the medical record. A distress score threshold (DT = 4) was used to trigger referrals for same-day evaluation by the HNCP Mind-Body Team (MBT), which includes HNCP-affiliated psychologists, social workers from the cancer center, and a dedicated patient navigator. The questionnaire-based screening program was implemented alongside the existing method for MBT referral in which HNCP staff refer directly based on clinical judgment of patients' psychosocial needs. Patients who were identified as distressed using either method were referred to the MBT for same-day further evaluation in the same clinic. Data from all new HNCP patients who were seen in clinic were included in the analysis; return patients (n=11) were omitted from analysis due to different clinical circumstances.

Screening Instrument

Developed by the HNCP clinical team, the HNCP-DS questionnaire is a 1-page instrument combining 3 brief screening tools: (1) the NCCN Distress Thermometer (DT), (2) a modified version of the DT Problem List (PL), and (3) the Patient Health Questionnaire-4 (PHQ-4). The entire questionnaire is shown in Figure 1.

Distress Thermometer—The NCCN DT is a validated, 1-item visual analogue scale in which patients are asked to rate their level of distress on a scale of 0 to 10, ranging from “No Distress” to “Extreme Distress.”^{1,28} As one of the simplest and widely used distress screening tools, the DT has been tested in diverse cancer populations and settings with acceptable validity and reliability.²⁹ While it can be completed in approximately less than 1 minute, the DT is strongly correlated with more comprehensive measures of depressive and anxious symptoms.³⁰ A standard threshold in distress screening (DT = 4), with acceptable sensitivity ($\alpha = 0.70$) and specificity ($\alpha = 0.70$) in ambulatory cancer patients, was defined as clinically significant distress and served as the trigger for MBT referrals.³¹⁻³⁴

Modified HNC-Specific Problem List—To identify the nature of the problems contributing to distress, the DT was implemented with an accompanying Problem List. As recommended by the NCCN guidelines,¹ the HNCP clinicians modified the standard DT Problem List to focus on the unique concerns and experiences of patients with HNC. The HNC-specific Problem List contains 28 items across 4 categories: “Practical,” “Family,” “Physical,” and “Spiritual/Religious.” When compared to the standard NCCN version, the “Food” item was excluded from the “Practical” category; two items, “Isolation/Loneliness” and “Lack of support,” were added to the “Family” category; and the “Physical” category was abridged by removing the “Bathing/Dressing,” “Changes in Urination,” “Feeling Swollen,” “Fever,” “Indigestion,” “Nose Dry/Congested,” “Skin Dry/itchy,” and “Tingling in hands and feet” items and by collapsing “Constipation” and “Diarrhea” into a single item. As with the standard Problem List, patients were asked to check “Yes” or “No” to indicate the presence or absence of a problem in the past week. During follow-up evaluations with the MBT, endorsed Problem List items were used to focus the assessment and identify potentially useful resources.

Patient Health Questionnaire-4 (PHQ-4)—To provide a comprehensive psychosocial assessment, the HNCP-DS questionnaire included the Patient Health Questionnaire-4 (PHQ-4), a validated, ultra-brief tool comprised of the PHQ-2 and the Generalized Anxiety Disorder-2 (GAD-2) tools to screen for depression and anxiety, respectively.³⁵ The PHQ-4 replaced the “Emotional” category of the standard Problem List to reduce patient burden. Both the PHQ-2 and GAD-2 ask patients 2 questions about the frequency of problems in the previous 2 weeks. Responses range from 0 (“not at all”) to 3 (“nearly every day”) on each item and a score of ≥ 3 on either tool indicates a positive screening result.³⁵⁻³⁷

Implementation Measures

Initial implementation of the standardized protocol was evaluated by reviewing the 2 methods of identifying patients with distress, analyzing the extent of overlap between methods, and tracking the rates of documented same-day follow-ups with the MBT for patients identified as distressed.

Data Analysis

Data from completed questionnaires were consolidated with abstracted sociodemographic and clinical information. Descriptive statistical analyses were used to characterize the sample in terms of demographic and clinical variables as well as distress screening results, including both raw scores and a dichotomous distress outcome indicating the presence of clinically significant distress. Differences between distressed and non-distressed patients were analyzed using t-tests and chi-square tests. Items endorsed on the Problem List were analyzed in overall totals, categorical totals, and, individually, for comparisons between distressed and non-distressed groups. A multivariable logistic regression model was used to identify variables associated with clinically significant distress (DT ≥ 4). Outcomes of the implementation were evaluated by comparing the 2 methods of identification and analyzing the rates of same-day follow-up. All analyses were performed using R Studio (version 1.3).

Ethical Considerations

The institutional review board at UCLA reviewed and approved this study.

RESULTS

Patient Characteristics

From September 2017 to March 2020, a total of 328 patients attended the HNCP clinic for in-person appointments, and of these, 298 (90.9%) completed psychosocial screening questionnaires. Reasons for incomplete questionnaires included patient refusal (n=10) or failure of clinic staff to provide the questionnaire to patients (n = 20). Eleven questionnaires (3.7%) were identified as return patients and excluded from analysis due complex clinical circumstances, leaving 287 evaluable questionnaires. The sample was predominantly male (64.8%), and ranged in age from 17 to 99 years, with 55.4% of patients aged 65 or older. Table 1 presents the sociodemographic and clinical characteristics of the sample, mean distress scores, and proportion of patients classified as clinically distressed.

The average DT score of the total sample was 4.51 ± 3.35 . Of the 287 total patients, 163 (57%) reported a DT score ≥ 4 . In the distressed group, the average DT score was 7.07 ± 1.85 , whereas the average DT for non-distressed patients was 1.14 ± 1.16 . Distress levels varied significantly across sociodemographic characteristics. For example, age was inversely related to distress ($r = -0.14$, $p < 0.05$), with younger patients reporting higher DT scores. Female patients reported a higher average DT score than males (5.5 ± 3.15 vs. 3.96 ± 3.34 , $p < 0.01$), with more than two-thirds of females (69.3%) reporting clinically significant distress compared to only half of male patients. Differences in distress were also observed across marital status, with divorced patients reporting higher DT scores than single patients (6.36 ± 2.73 vs. 4.41 ± 3.25 , $p < 0.05$) and partnered patients (6.36 ± 2.73 vs. 4.44 ± 3.25 , $p < 0.05$). Patients with a professional degree reported significantly lower DT scores than patients with a high school degree (3.66 ± 3.51 vs. 4.94 ± 3.43 , $p < 0.05$) and patients with a trade or associate's degree (3.66 ± 3.51 vs. 5.14 ± 3.52 , $p < 0.05$). No significant differences in DT scores were found with respect to employment status, alcohol use, and tobacco use.

Problems Endorsed by Distressed and Non-Distressed Patients on HNC-Specific Problem List

Among the total sample, patients reported an average of 4.0 ± 3.7 problems on the modified HNC-specific Problem List, and 232 (81%) patients endorsed at least one problem from any category. In the "Physical" category, 214 (75%) patients reported at least one problem, with *pain*, *fatigue*, and *sleep* cited most frequently. In the "Practical," "Family," and "Spiritual/Religious" categories, 111 (38%), 56 (20%), and 3 (1%) patients reported at least one problem, respectively. To identify differences between distressed or non-distressed patients, we compared the number of problems and the frequencies of specific problems reported by the two groups. As shown in Table 2, distressed patients reported a significantly higher number of problems in total and in each category compared to non-distressed patients. In the distressed group, pain was the most frequent problem, endorsed by 62% patients, followed by fatigue (50.3%), sleep (44.8%), and eating (39.3%).

Anxiety and Depression Screening Results in Distressed and Non-distressed Patients

In addition to the DT and the modified Problem List, patients were asked to complete the PHQ-4 to screen for anxiety and depression. Among the total sample, 81 (28.2%) had positive screening results for anxiety, while 39 (13.6%) patients were positive for depression. Table 2 shows comparisons in PHQ-4 screening results of distressed versus non-distressed patients. Distressed patients reported significantly higher scores than non-distressed patients on both the GAD-2 (3.08 ± 2.14 vs. 0.78 ± 0.33 , $p < 0.01$) and the PHQ-2 (2.04 ± 1.97 vs. 0.33 ± 0.86 , $p < 0.01$). Furthermore, distressed patients were significantly more likely to screen positive for anxiety, $\chi^2 (1, N=287)=49.2$, $p < 0.001$, and depression, $\chi^2 (1, N=287)=24.9$, $p < 0.001$.

Variables Associated with Clinically Significant Distress

Multivariable logistic regressions were performed to identify variables associated with clinically significant distress (DT = 4) using a hierarchical process to select contributing sociodemographic (age, gender), psychological (PHQ-2 and GAD-2 scores), and Problem List variables. In the final model, presented in Table 3, pain and fatigue significantly increased the likelihood of clinically significant distress by 3.31 (95 % CI 1.75–6.26, $p < 0.01$) and 2.43 (95 % CI 1.17– 5.05, $p < 0.05$), respectively. Additionally, higher scores on the PHQ-2 and the GAD-2 also increased the odds of clinically significant distress by 1.51 (95% CI 1.04–2.18, $p < 0.05$) and 1.63 (95 % CI 1.30–2.05, $p < 0.01$). Significant associations between age or gender and distress were not observed.

Evaluation of distress screening implementation

Two parallel strategies were used to refer patients for psychosocial MBT evaluation: DT score on the patient questionnaire and clinician judgment during patient encounter. Using at least one of the two methods, 210 patients (73%) were identified as distressed. Clinician judgment resulted in 150 MBT referrals, while positive DT screening results triggered 163 referrals. Figure 2 depicts the extent of overlap between these methods, with 103 (36%) patients identified by both methods, 47 patients by clinician judgment only, and 60 patients using the DT score alone. Chi-square tests showed a weak association between the two methods (Cramer's V: 0.25, $p < 0.01$), suggesting that the two referral methods identify many distinct patients as distressed. We also reviewed adherence to psychological follow-up with the MBT as indicated by the protocol, and found 166/210 (79%) patients received a same-day psychosocial evaluation, as documented in the medical record.

DISCUSSION

Assessment and management of the psychosocial needs of patients with cancer is now considered a fundamental aspect of cancer care, and distress has been referred to as the sixth vital sign.^{21,38,39} Prior studies exploring the feasibility and acceptability of distress screening in oncology care have emphasized the importance of ultra-brief, validated measures for successful implementation.^{40,41} Distress screening is particularly critical for patients with HNC, who suffer disproportionately higher rates of distress and increased risks for adverse physical, psychological, and social outcomes compared to other oncology

populations.^{26,42-46} A tailored protocol for distress screening and management may facilitate early identification, intervention, and ongoing support for patients with complex needs.

In the current study, a HNC-specific psychosocial screening protocol was developed and implemented in an outpatient setting. Our findings demonstrate a high prevalence (57%) of clinically significant distress in this sample that was slightly higher than other studies reporting distress in approximately half of HNC patients using the DT.^{5,47,48} This study also highlights the importance of both the quantity and quality of contributing factors when evaluating distress, and supports the utility of a HNC-specific Problem List in efficiently capturing multidimensional factors. Findings from this study indicate that pain, fatigue, anxiety, and depression are associated with distress at intake. Therefore, efforts by the multidisciplinary care team to address physical and psychological problems early in the cancer care trajectory may contribute to better outcomes.

This standardized questionnaire-based screening protocol was created to complement, rather than replace, the existing method of clinician judgment to refer patients for psychosocial support. The clinicians were highly engaged in both developing the questionnaire and incorporating this new distress screening protocol into the existing clinic workflow. Several factors may account for the modest proportion of distressed patients identified by both methods: the questionnaire explores patient or caretaker self-identified physical, social and emotional factors, whereas clinician referrals were generally based on perceived circumstances such as serious mental illness, socioeconomic hardship, or patient or caretaker behaviors indicating distress. Such behaviors included barriers to treatment adherence, low retention of treatment details, negative interactions with HNCP staff, or mismatched goals of care between the patients and caregivers. Although beyond the scope of this project, it may be valuable to explore improvements to the screening protocol to capture a higher proportion of such patients systematically.

These findings demonstrate high rates of positive screening results, which can pose challenges to follow-up in clinical practice. In a systematic review of randomized controlled trials, only 1 in 3 patients who screened positive for distress received appropriate follow-up care.⁴⁹ In contrast, this study suggests that providing same-day psychosocial evaluation to a substantial proportion of patients is achievable, as evidenced by a 79% same day MBT evaluation rate. Reasons for missed MBT follow-ups were not systemically tracked, but included occasional staff limitations, conflicting appointments in other locations (e.g., CT simulation scan), as well as patient inability or unwillingness to stay for additional evaluation. Specific aspects of the HNCP protocol likely enhance the clinic's capacity to follow through on psychosocial referrals. In particular, the embedding of psychosocial staff within the clinic reduces many common barriers to accessing psychosocial services, such as requiring an additional appointment or a separate clinic, or being seen by a clinician who is not well integrated with the oncology team. Some MBT members participate in multiple services while others work exclusively with this population. The MBT communicates weekly to plan for patient volume and staffing needs, with generally three members present and available to assess patients during clinic. To this end, substantive incorporation of psychosocial clinicians will be a key factor as health systems move toward providing care in the context of Integrated Practice Units. In settings without an embedded

psychosocial provider, alternative approaches to screening follow-up could incorporate telehealth psychosocial consultations, structured counseling by the primary team or tailored referrals to appropriate supportive services based on specific problems endorsed by the patient.

Initial implementation of the distress protocol targeted patients' first HNCP appointment pre-treatment. With the focus on this initial stage of care, it is unsurprising that treatment decisions and anxiety were commonly endorsed issues. Future plans include incorporating the screening protocol at other clinically meaningful time points to understand the longitudinal patterns of distress and associated problems through treatment and transition to survivorship care. Further research is needed to evaluate the impact of distress screening on both clinical and health services outcomes.

Limitations

This study presents a unique, disease-specific approach of distress screening. However, the generalizability of results is limited, as the study was performed in a single institution and did not include all eligible patients, which may contribute to sampling bias. For example, patients who did not have a clinic appointment when their case was discussed at the HNCP conference were not screened (n = 440). However, the rapid uptake of telehealth in response to the COVID-19 pandemic has facilitated the expansion of distress screening for this patient population recently. The protocol was also implemented in an established multidisciplinary program; institutions without these resources will likely require adjustments. Although the questionnaire could be adopted, developing appropriate follow-up approaches, compatible with available institutional resources, would be necessary. Our findings suggest that not all patients with DT 4 received psychosocial follow-up as indicated by the protocol and understanding barriers in these cases is beyond the scope of this analysis. Future work will focus on increasing rates of psychosocial consultation when indicated and developing processes for longitudinal distress screening, beyond the initial appointment. This work will help address psychosocial needs effectively over time, and expand access to supportive care services for patients during and after primary treatment.

CONCLUSION

Patients with HNC report high levels of psychosocial distress and physical, emotional and practical problems at the time of diagnosis and treatment planning consultation. Findings from early implementation suggest that an ultra-brief psychosocial screening process with an embedded mental health team may facilitate identification and same-day evaluation of patients whose distress might otherwise go unrecognized. Longitudinal assessment of distress represents the next step to determine patterns of distress and problems specific to HNC patients at key points along the cancer care trajectory.

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REFERENCES

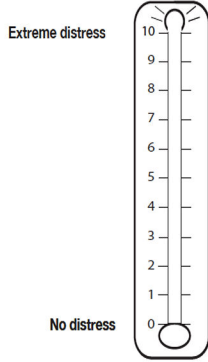
1. National Comprehensive Cancer Network. NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines[®]) Distress Management (Version 1.2021). Accessed June 11, 2020. https://www.nccn.org/professionals/physician_gls/default.aspx#distress
2. American College of Surgeons Commission on Cancer. Optimal Resources for Cancer Care 2020 Standards. Published 2019. Accessed June 11, 2020. <https://www.facs.org/quality-programs/cancer/coc/standards/2020>
3. Adler NE, Page AEK, eds. Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs. National Academies Press; 2008. doi:10.17226/11993
4. American Psychosocial Oncology Society. Clinical Guidelines. Accessed June 11, 2020. <https://apos-society.org/professionals/clinical-guidelines/>
5. Mehnert A, Hartung TJ, Friedrich M, et al. One in two cancer patients is significantly distressed: Prevalence and indicators of distress. *Psychooncology*. 2018;27(1):75–82. doi:10.1002/pon.4464 [PubMed: 28568377]
6. Funk R, Cisneros C, Williams RC, Kendall J, Hamann HA. What happens after distress screening? Patterns of supportive care service utilization among oncology patients identified through a systematic screening protocol. *Support Care Cancer*. 2016;24(7):2861–2868. doi:10.1007/s00520-016-3099-0 [PubMed: 26838023]
7. Yang A, Sokolof J, Gulati A. The effect of preoperative exercise on upper extremity recovery following breast cancer surgery. *Int J Rehabil Res*. 2018;41(3):189–196. doi:10.1097/MRR.0000000000000288 [PubMed: 29683834]
8. Howren MB, Christensen AJ, Karnell LH, Funk GF. Psychological factors associated with head and neck cancer treatment and survivorship: evidence and opportunities for behavioral medicine. *J Consult Clin Psychol*. 2013;81(2):299–317. doi:10.1037/a0029940 [PubMed: 22963591]
9. Riba MB, Donovan KA, Andersen B, et al. Distress management, version 3.2019. *JNCCN J Natl Compr Cancer Netw*. 2019;17(10):1229–1249. doi:10.6004/jnccn.2019.0048
10. Silveira MH, Dedivitis RA, Queija DS, Nascimento PC. Quality of life in swallowing disorders after nonsurgical treatment for head and neck cancer. *Int Arch Otorhinolaryngol*. 2015;19(1):46–54. doi:10.1055/s-0034-1395790 [PubMed: 25992151]
11. Perry A, Casey E, Cotton S. Quality of life after total laryngectomy: Functioning, psychological well-being and self-efficacy. *Int J Lang Commun Disord*. 2015;50(4):467–475. doi:10.1111/1460-6984.12148 [PubMed: 25703153]
12. Lin BM, Starmer HM, Gourin CG. The relationship between depressive symptoms, quality of life, and swallowing function in head and neck cancer patients 1 year after definitive therapy. *Laryngoscope*. 2012;122(7):1518–1525. doi:10.1002/lary.23312 [PubMed: 22467530]
13. Gilony D, Gilboa D, Blumstein T, et al. Effects of tracheostomy on well-being and body-image perceptions. *Otolaryngol - Head Neck Surg*. 2005;133(3):366–371. doi:10.1016/j.otohns.2005.04.025 [PubMed: 16143183]
14. Gill SS, Frew J, Fry A, et al. Priorities for the head and neck cancer patient, their companion and members of the multidisciplinary team and decision regret. *Clin Oncol*. 2011;23(8):518–524. doi:10.1016/j.clon.2011.03.014
15. List MA, Rutherford JL, Stracks J, et al. Prioritizing treatment outcomes: Head and neck cancer patients versus nonpatients. *Head Neck*. 2004;26(2):163–170. doi:10.1002/hed.10367 [PubMed: 14762885]
16. Williams C Psychosocial Distress and Distress Screening in Multidisciplinary Head and Neck Cancer Treatment. *Otolaryngol Clin North Am*. 2017;50(4):807–823. doi:10.1016/j.otc.2017.04.002 [PubMed: 28755706]
17. Tromp DM, Brouha XDR, De Leeuw JRJ, Hordijk GJ, Winnubst JAM. Psychological factors and patient delay in patients with head and neck cancer. *Eur J Cancer*. 2004;40(10):1509–1516. doi:10.1016/j.ejca.2004.03.009 [PubMed: 15196534]
18. Tromp DM, Brouha XDR, Hordijk GJ, et al. Medical care-seeking and health-risk behavior in patients with head and neck cancer: The role of health value, control beliefs and psychological distress. *Health Educ Res*. 2005;20(6):665–675. doi:10.1093/her/cyh031 [PubMed: 15863624]

19. Berry DL, Blonquist TM, Hong F, Halpenny B, Partridge AH. Self-reported adherence to oral cancer therapy: Relationships with symptom distress, depression, and personal characteristics. *Patient Prefer Adherence*. 2015;9:1587–1592. doi:10.2147/PPA.S91534 [PubMed: 26604712]
20. Rapkin D, Williams CL, Lazaro S, et al. Developing Supportive Care Services Within a Multidisciplinary Head and Neck Cancer Program. Vol 100.; 2018. doi:10.1016/j.ijrobp.2017.12.233
21. Bultz BD, Carlson LE. Emotional distress: The sixth vital sign in cancer care [4]. *J Clin Oncol*. 2005;23(26):6440–6441. doi:10.1200/JCO.2005.02.3259 [PubMed: 16155033]
22. Verdonck-de Leeuw IM, de Bree R, Keizer AL, et al. Computerized prospective screening for high levels of emotional distress in head and neck cancer patients and referral rate to psychosocial care. *Oral Oncol*. 2009;45(10):e129–e133. doi:10.1016/j.oraloncology.2009.01.012 [PubMed: 19362038]
23. Ehlers SL, Davis K, Bluethmann SM, et al. Screening for psychosocial distress among patients with cancer: Implications for clinical practice, healthcare policy, and dissemination to enhance cancer survivorship. *Transl Behav Med*. 2019;9(2):282–291. doi:10.1093/tbm/iby123 [PubMed: 30566662]
24. Pirl WF, Fann JR, Greer JA, et al. Recommendations for the implementation of distress screening programs in cancer centers: Report from the American Psychosocial Oncology Society (APOS), Association of Oncology Social Work (AOSW), and Oncology Nursing Society (ONS) joint task force. *Cancer*. 2014;120(19):2946–2954. doi:10.1002/cncr.28750 [PubMed: 24798107]
25. Aarstad HJ, Osthus AA, Olofsson J, Aarstad AKH. Level of distress predicts subsequent survival in successfully treated head and neck cancer patients: A prospective cohort study. *Acta Otolaryngol*. 2014;134(2):211–219. doi:10.3109/00016489.2013.841989 [PubMed: 24256042]
26. Buchmann L, Conlee J, Hunt J, Agarwal J, White S. Psychosocial distress is prevalent in head and neck cancer patients. *Laryngoscope*. 2013;123(6):1424–1429. doi:10.1002/lary.23886 [PubMed: 23553220]
27. Chen AM, Jennelle RLS, Grady V, et al. Prospective Study of Psychosocial Distress Among Patients Undergoing Radiotherapy for Head and Neck Cancer. *Int J Radiat Oncol Biol Phys*. 2009;73(1):187–193. doi:10.1016/j.ijrobp.2008.04.010 [PubMed: 18513884]
28. Roth AJ, Kornblith AB, Batel-Copel L, Peabody E, Scher HI, Holland JC. Rapid screening for psychological distress in men with prostate carcinoma: A pilot study. *Cancer*. 1998;82(10):1904–1908. doi:10.1002/(SICI)1097-0142(19980515)82:10<1904::AID-CNCR13>3.0.CO;2-X [PubMed: 9587123]
29. Akizuki N, Akechi T, Nakanishi T, et al. Development of a brief screening interview for adjustment disorders and major depression in patients with cancer. *Cancer*. 2003;97(10):2605–2613. doi:10.1002/cncr.11358 [PubMed: 12733160]
30. Mitchell AJ. Pooled results from 38 analyses of the accuracy of distress thermometer and other ultra-short methods of detecting cancer-related mood disorders. *J Clin Oncol*. 2007;25(29):4670–4681. doi:10.1200/JCO.2006.10.0438 [PubMed: 17846453]
31. Jacobsen PB, Donovan KA, Trask PC, et al. Screening for psychologic distress in ambulatory cancer patients: A multicenter evaluation of the distress thermometer. *Cancer*. 2005;103(7):1494–1502. doi:10.1002/cncr.20940 [PubMed: 15726544]
32. Hawkes AL, Hughes KL, Hutchison SD, Chambers SK. Feasibility of brief psychological distress screening by a community-based telephone helpline for cancer patients and carers. *BMC Cancer*. 2010;10(14):1–10. doi:10.1186/1471-2407-10-14 [PubMed: 20047689]
33. Jacobsen PB, Shibata D, Siegel EM, et al. Measuring quality of care in the treatment of colorectal cancer: The moffitt quality practice initiative. *J Oncol Pract*. 2007;3(2):60–65. doi:10.1200/JOP.0722002 [PubMed: 20859375]
34. Ma X, Zhang J, Zhong W, et al. The diagnostic role of a short screening tool - The distress thermometer: A meta-analysis. *Support Care Cancer*. 2014;22(7):1741–1755. doi:10.1007/s00520-014-2143-1 [PubMed: 24510195]
35. Kroenke K, Spitzer RL, Williams JBW, Löwe B. An ultra-brief screening scale for anxiety and depression: The PHQ-4. *Psychosomatics*. 2009;50(6):613–621. doi:10.1176/appi.psy.50.6.613 [PubMed: 19996233]

36. Kroenke K, Spitzer RL, Williams JBW. The patient health questionnaire-2: Validity of a two-item depression screener. *Med Care*. 2003;41(11):1284–1292. doi:10.1097/01.MLR.0000093487.78664.3C [PubMed: 14583691]
37. Kroenke K, Spitzer RL, Williams JBW, Monahan PO, Löwe B. Anxiety disorders in primary care: Prevalence, impairment, comorbidity, and detection. *Ann Intern Med*. 2007;146(5):317–325. doi:10.7326/0003-4819-146-5-200703060-00004 [PubMed: 17339617]
38. Howell D, Olsen K. Distress-the 6th vital sign. *Curr Oncol*. 2011;18(5):208–210. doi:10.3747/co.v18i5.790 [PubMed: 21980246]
39. Carlson LE, Waller A, Groff SL, Zhong L, Bultz BD. Online screening for distress, the 6th vital sign, in newly diagnosed oncology outpatients: Randomised controlled trial of computerised vs personalised triage. *Br J Cancer*. 2012;107(4):617–625. doi:10.1038/bjc.2012.309 [PubMed: 22828610]
40. Ehlers SL, Davis K, Bluethmann SM, et al. Screening for psychosocial distress among patients with cancer: Implications for clinical practice, healthcare policy, and dissemination to enhance cancer survivorship. *Transl Behav Med*. 2019;9(2):282–291. doi:10.1093/tbm/iby123 [PubMed: 30566662]
41. Pirl WF, Fann JR, Greer JA, et al. Recommendations for the implementation of distress screening programs in cancer centers: Report from the American Psychosocial Oncology Society (APOS), Association of Oncology Social Work (AOSW), and Oncology Nursing Society (ONS) joint task force. *Cancer*. 2014;120(19):2946–2954. doi:10.1002/cncr.28750 [PubMed: 24798107]
42. 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(9):955–959. doi:10.1016/j.ijom.2009.04.004 [PubMed: 19446438]
43. Kugaya A, Akechi T, Okuyama T, et al. Prevalence, predictive factors, and screening for psychologic distress in patients with newly diagnosed head and neck cancer. *Cancer*. 2000;88(12):2817–2823. doi:10.1002/1097-0142(20000615)88:12<2817::AID-CNCR22>3.0.CO;2-N [PubMed: 10870066]
44. Osazuwa-Peters N, Simpson MC, Zhao L, et al. Screening for psychosocial distress among patients with cancer: Implications for clinical practice, healthcare policy, and dissemination to enhance cancer survivorship. *Psychooncology*. 2015;141(3):772–778. doi:10.1093/tbm/iby123
45. Badr H, Gupta V, Sikora A, Posner M. Psychological distress in patients and caregivers over the course of radiotherapy for head and neck Cancer. *Oral Oncol*. 2014;50(10):1005–1011. doi:10.1016/j.oraloncology.2014.07.003 [PubMed: 25091150]
46. Linden W, Vodermaier A, MacKenzie R, Greig D. Anxiety and depression after cancer diagnosis: Prevalence rates by cancer type, gender, and age. In: *Journal of Affective Disorders*. Vol 141. J Affect Disord; 2012:343–351. doi:10.1016/j.jad.2012.03.025 [PubMed: 22727334]
47. Buchmann L, Conlee J, Hunt J, Agarwal J, White S. Psychosocial distress is prevalent in head and neck cancer patients. *Laryngoscope*. 2013;123(6):1424–1429. doi:10.1002/lary.23886 [PubMed: 23553220]
48. Patil V, Noronha V, Joshi A, et al. Distress Management in Patients with HHead and Neck Cancer Before Start of Palliative Chemotherapy: A Practical Approach. *J Glob Oncol*. 2018;4(4):1–10. doi:10.1200/JGO.17.00044
49. Mitchell AJ. Screening for cancer-related distress: When is implementation successful and when is it unsuccessful? *Acta Oncol (Madr)*. 2013;52(2):216–224. doi:10.3109/0284186X.2012.745949

UCLA Health
HNCP DISTRESS SCREENER FOR PATIENTS

Instructions: First please circle the number (0-10) that best describes how much distress you have been experiencing in the **PAST WEEK** including today.



Second, please indicate if any of the following has been a problem for you in the **PAST WEEK** including today. Be sure to check YES or NO for each.

Yes	No	Practical Problems	Yes	No	Physical Problems
<input type="checkbox"/>	<input type="checkbox"/>	Child Care	<input type="checkbox"/>	<input type="checkbox"/>	Appearance
<input type="checkbox"/>	<input type="checkbox"/>	Housing	<input type="checkbox"/>	<input type="checkbox"/>	Breathing
<input type="checkbox"/>	<input type="checkbox"/>	Insurance/Financial	<input type="checkbox"/>	<input type="checkbox"/>	Eating
<input type="checkbox"/>	<input type="checkbox"/>	Transportation	<input type="checkbox"/>	<input type="checkbox"/>	Changes in Swallowing
<input type="checkbox"/>	<input type="checkbox"/>	Work/School	<input type="checkbox"/>	<input type="checkbox"/>	Changes in Speech
<input type="checkbox"/>	<input type="checkbox"/>	Treatment Decisions	<input type="checkbox"/>	<input type="checkbox"/>	Constipation/Diarrhea
		Family Problems	<input type="checkbox"/>	<input type="checkbox"/>	Fatigue
<input type="checkbox"/>	<input type="checkbox"/>	Dealing with Children	<input type="checkbox"/>	<input type="checkbox"/>	Getting Around
<input type="checkbox"/>	<input type="checkbox"/>	Dealing with Partner	<input type="checkbox"/>	<input type="checkbox"/>	Memory/Concentration
<input type="checkbox"/>	<input type="checkbox"/>	Ability to Have Children	<input type="checkbox"/>	<input type="checkbox"/>	Nausea
<input type="checkbox"/>	<input type="checkbox"/>	Family Health Issues	<input type="checkbox"/>	<input type="checkbox"/>	Pain
<input type="checkbox"/>	<input type="checkbox"/>	Isolation/Loneliness	<input type="checkbox"/>	<input type="checkbox"/>	Mouth Sores
<input type="checkbox"/>	<input type="checkbox"/>	Lack of Support	<input type="checkbox"/>	<input type="checkbox"/>	Sexual
		Spiritual/Religious Concerns	<input type="checkbox"/>	<input type="checkbox"/>	Sleep
			<input type="checkbox"/>	<input type="checkbox"/>	Substance Abuse

Other: _____

Over the LAST TWO WEEKS how often have you been bothered by the following problems? (Use ✓ to indicate your answer)	Not At All	Several Days	More Than Half the Days	Nearly Every Day
1. Feeling nervous, anxious or on edge.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
2. Not being able to stop or control worrying.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
3. Little interest or pleasure in doing things.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
4. Feeling down, depressed, or hopeless.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3

Patient or Representative Signature: _____ Date _____ Time _____ Interpreter Signature: _____ ID # _____

If signed by someone other than the patient, please specify relationship to the Patient: _____ Date _____ Time _____

Figure 1. UCLA HNCP Distress Screener (HNCP-DS) Questionnaire.

The questionnaire is comprised of three brief screening tools: (1) the NCCN Distress Thermometer (DT) (left), (2) a modified version of the DT Problem List (PL) (upper right), and (3) the Patient Health Questionnaire-4 (PHQ-4) (lower right). A DT score of >4 indicated clinically significant distress and triggered same day evaluation by the Mind-Body Team.

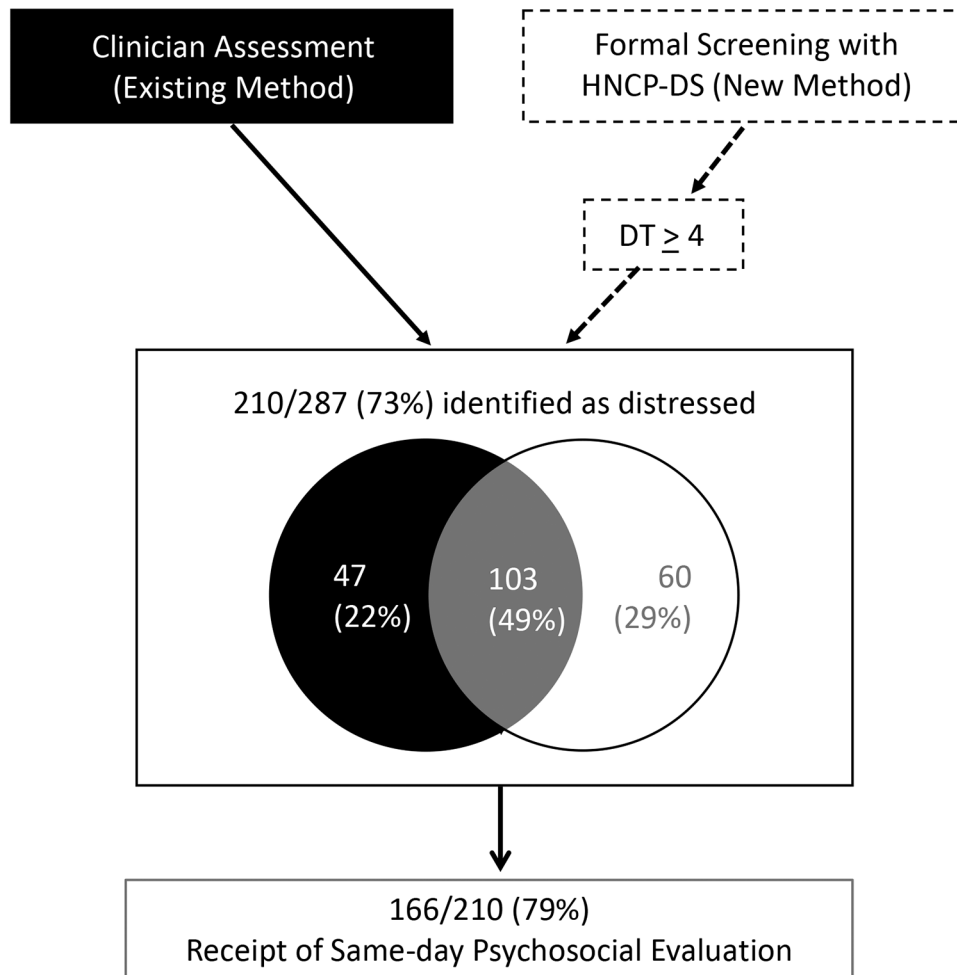


Figure 2. Identification and referral outcomes of distressed patients.

Two pathways were utilized to identify distressed patients: (1) Clinician assessment and referral for psychosocial evaluation and (2) formal screening using the UCLA HNCP-DS. Distress was defined as DT of 4 on the HNCP-DS. Patients identified as distressed by clinician judgment (black), screening questionnaire (white), and both (grey) are shown, as are the proportion of patients who received same-day evaluation by the Mind-Body Team.

Table 1.

Distress Status by the Sociodemographic and Clinical Characteristics of Patients.

Characteristic		Count	DT Score		Distressed (DT ≥ 4)	
		N=287	Mean	SD	Count	%
Gender	Female	101	5.48	3.13	70	69.3%
	Male	186	3.99	3.35	93	50.0%
Age	< 50	48	4.92	2.85	32	66.7%
	50-65	80	4.86	3.37	48	60.0%
	65	159	4.22	3.46	83	52.2%
Marital Status	Single	43	4.41	3.25	25	58.1%
	Married / Partnered	196	4.44	3.25	109	55.6%
	Divorced	18	6.36	2.73	15	83.3%
	Widowed	19	5.24	4.34	12	63.2%
	Unknown	11	2.05	2.97	2	18.2%
Educational Achievement	Some high school	16	5.69	3.24	11	68.8%
	High school graduate	46	4.93	3.43	28	60.9%
	Associate degree	48	5.14	3.52	30	62.5%
	Bachelor degree	85	4.25	3.07	47	55.3%
	Professional degree	71	3.68	3.51	32	45.1%
	Unknown	21	5.17	2.91	15	71.4%
Employment Status	Yes	124	4.47	3.23	71	57.3%
	No	26	5.27	3.48	17	65.4%
	Retired	137	4.41	3.43	75	54.7%
Tobacco Use	Current	13	5.81	3.86	9	69.2%
	Former	111	4.67	3.52	66	59.5%
	Never	160	4.37	3.16	88	55.0%
Alcohol Use	Yes	163	4.43	3.26	95	58.3%
	No	124	4.63	3.46	68	54.8%
Tumor Location	Face / Scalp	65	3.45	3.27	28	43.1%
	Larynx	19	3.89	3.35	7	36.8%
	Nasal / Paranasal sinus	22	6.09	3.26	17	77.3%
	Nasopharynx	7	5.64	1.75	6	85.7%
	Neck	6	4.33	3.44	3	50.0%
	Oral cavity	56	5.54	3.20	39	69.6%
	Oropharynx	56	4.31	3.41	32	57.1%
	Salivary gland	22	4.50	3.44	12	54.5%
	Thyroid / Parathyroid	15	5.13	3.12	10	66.7%
Other	18	3.67	3.46	8	44.4%	
Stage of Disease	Stage 0	9	4.33	3.74	5	55.6%
	Early stage	103	4.31	3.27	60	58.3%
	Locally advanced	63	5.21	3.33	41	65.1%

Characteristic	Count	DT Score		Distressed (DT 4)	
	N=287	Mean	SD	Count	%
Metastatic	28	3.70	3.58	12	42.9%
Multiple Primary	3	2.33	1.53	1	33.3%
Recurrence	11	5.36	3.85	7	63.6%
Not formally staged	15	4.50	3.65	7	46.7%
Unable to Stage	18	4.69	3.43	10	55.6%
Unknown	5	6.00	2.35	5	100.0%

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Table 2.

Problem List and PHQ-4 Screening Outcomes in Distressed and Non-Distressed Patients.

Problem List Domains	Distressed (n=163)	Non-Distressed (n=124)		
	Number of Problems (Mean \pm SD)	Percentage (%)	Number of Problems (Mean \pm SD)	Percentage (%)
Total Problems	5.42 \pm 3.93		2.16 \pm 2.59	**
Practical Problems	0.79 \pm 1.11		0.33 \pm 0.63	**
Child Care		1.8	0	
Housing		5.5	0.8	
Insurance / Financial		12.3	6.5	
Transportation		10.4	5.6	
Work / School		12.3	4	*
Treatment Decisions		37.4	16.1	**
Family Problems	0.45 \pm 0.86		0.14 \pm 0.48	**
Dealing with Children		4.9	0	*
Dealing with Partner		8	1.6	*
Ability to Have Children		0.6	0	
Family Health Issues		11.7	8.1	
Isolation / Loneliness		13.5	2.4	**
Lack of Support		6.1	1.6	
Physical Problems	4.17 \pm 2.96		1.73 \pm 2.17	**
Appearance		20.2	10.5	
Breathing		23.3	11.3	*
Eating		39.3	17.7	**
Changes in Swallowing		34.4	16.9	*
Changes in Speech		32.5	20.2	
Constipation / Diarrhea		25.2	12.1	*
Fatigue		50.3	16.1	**
Getting Around		20.9	4.8	**
Memory / Concentration		28.8	10.5	**
Nausea		11.7	1.6	**
Pain		62	25	**
Mouth Sores		18.4	5.6	**
Sexual		5.5	2.4	
Sleep		44.8	17.7	**
Substance Abuse		0.6	0	
Spiritual/Religious Problems	0.02 \pm 0.13		0	
PHQ-4 Domains	Score (Mean \pm SD)	Percentage	Score (Mean \pm SD)	Percentage
Depression	2.04 \pm 1.97		0.33 \pm 0.86	**

	Distressed (n=163)	Non-Distressed (n=124)		
+ PHQ-2		22.7	1.6	**
- PHQ-2		77.3	98.4	
Anxiety	3.08 ± 2.14		0.78 ± 0.33	**
+ GAD-2		44.8	6.5	**
- GAD-2		55.2	93.5	

**
p < 0.01

*
p < 0.05

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Table 3.

Variables Associated with Clinically Significant Distress (DT 4) in HNC Patients.

Variable	95% CI for Odds Ratio			p-value
	Odds Ratio	Lower	Upper	
Intercept	-	0.11	0.31	0.26
PHQ-2 Score	1.51	1.04	2.18	0.03
GAD-2 Score	1.63	1.30	2.05	<0.01
Fatigue	2.43	1.17	5.05	0.02
Pain	3.31	1.75	6.26	<0.01

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