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### Permalink

<https://escholarship.org/uc/item/26q9c56w>

### Journal

Otolaryngologic Clinics of North America, 50(4)

### ISSN

0030-6665

### Author

Williams, Charlene

### Publication Date

2017-08-01

### DOI

10.1016/j.otc.2017.04.002

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Peer reviewed

# Psychosocial Distress and Distress Screening in Multidisciplinary Head and Neck Cancer Treatment



Charlene Williams, PhD

## KEYWORDS

- Psychosocial distress screening • Depression • Anxiety • Head and neck cancer
- Multidisciplinary • Quality of life (QOL) • Cognitive behavioral therapy (CBT)
- Behavioral medicine • Patient-centered

## KEY POINTS

- Psychosocial distress is an important indicator of suffering, and a risk factor for negative psychological, quality-of-life, and medical outcomes.
- Patients with head and neck cancer (HNC) evidence high rates of psychosocial distress, yet distress is often not recognized in oncology treatment settings.
- Although untreated distress is associated with negative psychological and medical outcomes, distress is highly responsive to treatment, with resultant improvements in psychosocial and medical outcomes.
- Screening and referral for psychosocial distress is rapidly becoming the standard of care, and is now required of cancer centers to retain accreditation with the American College of Surgeons. Distress screening guidelines are available to help HNC centers implement effective psychosocial distress screening programs.
- Multidisciplinary HNC treatment can provide a solid foundation from which to implement psychosocial distress screening clinical intervention and research. Integrative cognitive behavioral (CBT)-behavioral medicine intervention may be of particular benefit in this population.

## INTRODUCTION

Multidisciplinary cancer care involves assessment, diagnosis, and treatment of the significant variables impacting patients' health and well-being. Traditionally, the field of medicine and head and neck cancer (HNC) treatment has focused on diagnosis and treatment of physical symptoms and disorders to the exclusion of psychological

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Disclosure Statement: The author has nothing to disclose.

UCLA Department of Head and Neck Surgery, Head and Neck Cancer Program, 200 UCLA Medical Plaza, Suite 550, Los Angeles, CA 90095-6959, USA

*E-mail address:* [cwilliams@mednet.ucla.edu](mailto:cwilliams@mednet.ucla.edu)

Otolaryngol Clin N Am 50 (2017) 807–823

<http://dx.doi.org/10.1016/j.otc.2017.04.002>

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variables. This paradigm led to cancer treatment that may be described as reductionist (or mechanistic), treating patients as physical “cases,” rather than whole persons who experience physical and psychological responses to cancer and cancer treatment.

As cancer and HNC treatment has evolved, the field has progressed toward what is referred to as “whole-patient” or “patient-centered” care. Fundamental to this shift is the increasing recognition of psychosocial factors and psychological well-being as inherently important aspects of patients’ health, in addition to their impact on quality-of-life (QOL) and medical outcomes. Accordingly, HNC research has increasingly included a focus on QOL outcomes, concurrent with the development of surgical procedures designed to maximize organ and functional preservation and improve cosmesis, as well as de-intensification of radiation treatment protocols. However, routine inclusion of psychosocial assessment and intervention into HNC treatment has lagged behind, largely due to the mismatch between busy HNC settings and obstacles to implementation (perceived time burden, incomplete understanding of negative impacts of psychosocial variables, medical/HNC subculture norms).

Psychosocial distress screening (DS) originated as an effort to legitimize and facilitate the recognition, measurement, and treatment of psychosocial aspects of cancer care. This early work led to the creation of a concise DS instrument, the Distress Thermometer (DT), that could be rapidly administered, and would therefore be likely to be used in busy oncology settings.<sup>1,2</sup>

Patients with HNC experience significantly elevated rates of psychosocial distress, with 20% to 60% reporting distress at various points throughout the treatment trajectory.<sup>3–5</sup> Despite the high frequency of clinically significant distress in oncology patients, medical professionals frequently fail to recognize distress in their patients.<sup>6</sup> This is particularly concerning in that although distress is very responsive to treatment, untreated distress is associated with significantly worse psychosocial and medical outcomes.<sup>3,7</sup>

To address these concerns, routine DS and appropriate referral of all patients with cancer is now considered the standard of care by the American College of Surgeons (ACoS) Commission on Cancer,<sup>8</sup> the National Comprehensive Cancer Network<sup>9</sup> (NCCN), and the Institute of Medicine.<sup>10</sup> In accord with this position, DS and referral have been required of cancer centers since 2015 to maintain accreditation with the ACoS. To facilitate the adoption of DS programs, the ACoS, NCCN, American Psychosocial Oncology Society, and other major psycho-oncology professional associations have published standards and guidelines for implementation.<sup>3,8,11–13</sup>

In this article, the characteristics and impacts of psychosocial distress in patients with HNC are examined and guidelines for HNC DS programs are presented. Successful implementation requires understanding the essential components of DS, common challenges, and effective strategies needed to initiate and sustain DS programs. Multidisciplinary HNC treatment that includes a psychosocial component can provide an ideal foundation for the implementation of DS, and facilitate integrative HNC treatment and research that serves the whole patient.

## PSYCHOSOCIAL DISTRESS

Psychosocial distress is defined by the NCCN as an “unpleasant emotional experience of a psychological (cognitive, behavioral, emotional), social, and/or spiritual nature that may interfere with the ability to cope with cancer, its physical symptoms and its treatment.”<sup>14(p6)</sup> Although distress shares significant overlap with depression, anxiety, and other psychosocial symptomatology, the term was designed to be broadly

inclusive rather than diagnostic, readily understandable to patients and medical staff, and relatively free of the stigma associated with psychiatric labels or diagnoses.

Early workers in DS strove to create a measure that would be familiar to patients and medical professionals, and brief enough to be routinely implemented into busy oncology practices.<sup>2</sup> This effort resulted in the Distress Thermometer (DT),<sup>1</sup> a combined visual analogue/numerical rating scale modeled after the well-known pain scale (with pain rated 0–10).<sup>15</sup> The DT reflects the conceptualization of psychosocial distress as an indicator of suffering, with distress referred to as “the sixth vital sign” (in addition to pulse, respiration, blood pressure, temperature, and pain).<sup>2,16</sup>

The DT continues to be one of the most widely used self-report measures of psychosocial distress, although distress is also frequently assessed by other self-report questionnaires measuring anxiety and depressive symptoms that yield, or are viewed as, proximal measures of distress (Hospital Anxiety and Depression Scale [HADS]<sup>17</sup>; Brief Symptom Inventory-18 [BSI-18]<sup>18</sup>).<sup>3,12,13,19</sup>

## CHARACTERISTICS OF PSYCHOSOCIAL DISTRESS IN PATIENTS WITH HEAD AND NECK CANCER

### *Distress Rates in Patients with Head and Neck Cancer*

Patients with HNC demonstrate significantly heightened rates of psychological distress, ranging from 20% to 60%,<sup>4,20–23</sup> with elevations noted when patients undergo treatments with significant side effects (surgery, radiation, chemoradiation), and associated with functional losses, particularly impairments in swallowing or speaking,<sup>24–27</sup> as well as disfigurement, fatigue, and pain.<sup>28–31</sup> Additional risk factors for distress in patients with HNC include pretreatment mental status (depression, distress),<sup>20,32,33</sup> lack of perceived social support,<sup>34–36</sup> smoking and alcohol use disorders,<sup>37–39</sup> and avoidant coping.<sup>40–44</sup>

In addition to distress, patients with HNC also evidence among the highest rates of depression compared with other cancer populations, as well as significantly elevated rates of anxiety.<sup>21,45–47</sup> Although levels of distress, depression, and anxiety diminish for most patients after conclusion of treatment, a substantial proportion of patients with HNC continue to demonstrate heightened rates of psychosocial distress and depression even long after treatment has ended.<sup>29,48</sup> Of significant concern, patients with HNC are at markedly elevated risk of suicide, with a suicide rate 4 times that of the general population, and one of the highest suicide rates of all cancer populations.<sup>49–52</sup>

### *Head and Neck Cancer Distress Rates: Functional Losses and Tumor Site*

Among patients with HNC, certain subgroups are at significantly greater risk of psychological impacts, including severe distress, clinical depression, and suicide.<sup>45,49–52</sup> These subpopulations can be identified by functional losses and/or by tumor site. It is well known that distress and related negative psychological impacts are significantly greater in HNC patients in whom the function of swallowing is impaired.<sup>24,25,53</sup> Patients who are likely to experience these functional losses typically have head and neck cancers of the upper aerodigestive tract (eg, oropharyngeal, hypopharyngeal). In addition, speech impairment or loss is strongly predictive of distress and negative psychological outcomes in patients with HNC.<sup>26,27</sup>

Recent research has found that HNC patients with upper aerodigestive tract cancer have a significantly elevated risk of suicide compared with other HNC patients, and patients with cancer overall. Specifically, Kam and colleagues<sup>49</sup> found that patients with hypopharyngeal, laryngeal, oropharyngeal and oral cavity, and nasopharyngeal cancers are at markedly greater risk of suicide. Disturbingly, incidence of suicide

was increased 12-fold in patients with hypopharyngeal cancer and 5-fold in patients with laryngeal cancer.<sup>49</sup>

### ***Distress Through the Treatment Trajectory***

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The nature of distress throughout the treatment trajectory can vary dependent on a number of factors, including treatment modality and morbidity. HNC treatment is often multimodal, with patients frequently undergoing sequential and/or combined treatment modalities (surgery, radiation, chemotherapy, and immunotherapy). Some combined treatment regimens, such as chemoradiation, can result in significantly greater side effects and aftereffects (eg, swallowing and eating difficulties, nutritional deficits, distress, and depression).

The components of distress (anxiety and depression) tend to vary throughout the arc of treatment. Typically, higher rates of anxiety are observed at or near the beginning of treatment, or when shifting to a new treatment mode. The incidence of anxiety typically decreases as patients progress through treatment and immediately after completing treatment.<sup>54,55</sup> However, some reports indicate the incidence of anxiety may increase long after treatment has ended.<sup>56</sup>

In contrast, the incidence of depressive symptoms appears to increase as patients move into and through the active phase of HNC treatment, as they experience increasing side effects and morbidity due to treatment and/or the cancer itself.<sup>4,45</sup> Although the incidence of depression is found to typically decrease after treatment has been completed, a significant proportion of patients with HNC evidence heightened levels of depressive symptoms long after treatment has ended, particularly when patients must contend with enduring deficits in swallowing, speech, disfigurement, and related social withdrawal and isolation.<sup>26,27,29,48,53,57</sup>

## **PSYCHOLOGICAL AND MEDICAL OUTCOMES OF DISTRESS IN PATIENTS WITH HEAD AND NECK CANCER**

Psychosocial distress has been found to be associated with significantly worse psychological and medical outcomes. When studied prospectively, psychosocial distress at baseline, or at the beginning of HNC treatment, is predictive of heightened distress at later time points.<sup>4,32,56,58</sup> In addition, psychosocial distress has been found to be both associated with, and a predictor of, depression, anxiety, and lower QOL in patients with HNC throughout the treatment trajectory.<sup>27,56,58,59</sup>

In addition to impacting psychological variables, psychosocial distress has been found to predict multiple negative medical outcomes, including negative health-related behaviors, delays in seeking treatment, poor treatment adherence, and survival.<sup>37,44,60,61</sup> Further, in a recent study of patients with HNC, Aarstad and colleagues<sup>7</sup> found that psychosocial distress was an independent predictor of survival, even after statistically controlling for multiple factors (eg, physical morbidities, smoking and alcohol use).

## **PSYCHOSOCIAL DISTRESS SCREENING: GUIDELINES AND CHALLENGES**

Given the high rate of psychosocial distress in patients with HNC, the multiple, often severe negative outcomes of untreated distress, and the fact that distress is highly responsive to treatment, it is increasingly evident that the inclusion of DS in HNC treatment comprises an essential component of best practice. Successful implementation of an effective DS program is a challenging task for any HNC center, and is greatly facilitated by using the criteria and guidelines established by key medical and oncology organizations.<sup>8,9,11–13</sup> Crucial guidance regarding challenges faced by

1. Establish multidisciplinary cancer committee	<ul style="list-style-type: none"> <li>• Should include all disciplines, including head and neck cancer physician</li> <li>• Must include psychosocial representation</li> </ul>
2. Screening	<ul style="list-style-type: none"> <li>• Validated distress measure assessing <math>\geq 2</math> areas of distress               <ul style="list-style-type: none"> <li>◦ Recommended: include depression measure</li> </ul> </li> <li>• Sensitivity and specificity of distress measure must be adequate</li> <li>• Administered at <math>\geq 1</math> pivotal visit</li> </ul>
3. Follow-up assessment/evaluation	<ul style="list-style-type: none"> <li>• Establish algorithm for distress screening follow-up               <ul style="list-style-type: none"> <li>◦ Use established distress cutoff scores</li> <li>◦ Follow-up with validated depression and anxiety measures, clinical interview</li> </ul> </li> </ul>
4. Referral/treatment and follow-up	<ul style="list-style-type: none"> <li>• Referral for psychosocial intervention</li> <li>• Follow-up with patient, oncology team, and family caregivers (as appropriate)</li> </ul>
5. Documentation	<ul style="list-style-type: none"> <li>• Documentation of distress screening results, further assessment, referrals/treatment, and follow-up</li> <li>• Can be used for quality assurance and research</li> </ul>

oncology centers in implementing DS may be found in excellent “lessons learned” articles that describe common obstacles and effective strategies to facilitate DS.<sup>3,62</sup> Core components of DS implementation for HNC centers are outlined in the next section and in [Table 1](#).

### **IMPLEMENTING BEST PRACTICE HEAD AND NECK CANCER PSYCHOSOCIAL DISTRESS SCREENING: PROACTIVELY MEETING CHALLENGES AND AVOIDING PITFALLS**

#### ***Establish Multidisciplinary Head and Neck Cancer Distress Screening Committee***

The first step in initiating HNC DS programs is to establish a multidisciplinary HNC committee with representation from all stakeholders (surgery, radiation, and medical oncology physicians, mental health professionals, HNC specialist providers such as swallowing/speech therapists and maxillofacial prosthodontics, nurses, and key administrative personnel). Inclusion of psychosocial representation is mandatory. Consistent with a patient-centered approach, an important point made in the literature is the recommendation to systematically include patient feedback as DS is implemented, so as to more completely include input from all stakeholders.<sup>11,12,62</sup>

Using a multidisciplinary approach in formulating, refining, and further development of HNC distress screening facilitates implementation of an effective DS program tailored to the needs and concerns of all stakeholders. Further, this increases buy-in and avoids the potential pitfalls of staff overload, resentment, and burnout. Communication with, and inclusion of, higher-level administrators of the medical/HNC center in the development and implementation of the DS program is essential to its success, and serves to proactively develop support for the resources needed, and results obtained.

Guidelines for implementation of DS increasingly emphasize the necessity of prioritizing development of the referral/treatment component.<sup>11,12,62</sup> Only when screening for distress is combined with appropriate referral and treatment are patients’ psychological and medical outcomes improved.<sup>3,11,63</sup> It is strongly recommended that the committee develop and have referrals and/or treatment well in place before beginning actual screening, as significant resources are required to develop and manage this essential component.

## Screening

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### Timing of screening

DS should be initiated at one or more “pivotal medical visits”<sup>9</sup> to be in compliance with best care practice and ACoS requirements. Pivotal medical visits refer to those medical visits or encounters at which patients may be expected to be at higher risk of (or more vulnerable to) experiencing distress. Examples include the initial or second visit, time of diagnosis, beginning or ending treatment, changes in treatment modality, changes in HNC disease status (recurrence, progression), and when transitioning to palliative care.<sup>9,12</sup>

Of note, there is some disagreement in the literature as to whether the initial screening should be administered at the first versus the second visit. Although the NCCN has recommended screening on the first visit, other experts raise the issue that often patients do not yet know crucial information, such as whether they in fact have a diagnosis of cancer, let alone potential treatment recommendations.<sup>9,12</sup> Consequently, distress scores at the first visit for initial patients with HNC may reflect the distress related to not yet knowing their disease status, rather than distress due to cancer diagnosis and treatment recommendations. Thus, it may be important to consider screening initial patients with HNC at the second visit, when distress scores are more likely to reflect patients’ increased knowledge and reactions to diagnostic and treatment information.

Timing and frequency of DS should be tailored to the relative risk of distress in the HNC patient population throughout the treatment trajectory. Initial DS at the first or second visit should be augmented by screening at pivotal medical visits, and when HNC patients may be at higher risk for distress related to adverse HNC treatment effects and morbidities, such as swallowing or speech deficits, disfigurement, pain, fatigue, and nutritional deficits.

In addition, psychosocial factors associated with higher risk for distress, poor QOL, and negative medical outcomes in patients with HNC may affect timing and frequency of screening in this population, such as low perceived social support,<sup>35,64</sup> pretreatment mental status (depression, distress),<sup>27,48</sup> and avoidant coping style.<sup>40,44,58,65</sup> For example, patients with HNC with a predominantly avoidant coping style may appear less distressed at initial visits, but be particularly susceptible to distress and negative psychological and medical outcomes as they progress further into treatment, when their avoidance coping is more likely to falter in the face of adverse treatment effects or HNC progression.<sup>58</sup> Thus, it is important that the timing of DS be tailored to the unique vulnerabilities and multiple risk points for patients with HNC throughout the treatment trajectory (**Table 2**).

### Screening tools

Excellent reviews offer guidance in selecting DS measures, information concerning validity, reliability, sensitivity and specificity, and recommended cutoff scores.<sup>3,12,19,66,67</sup> One of the most commonly used DS questionnaires is the NCCN DT,<sup>1</sup> usually administered with its modifiable Problem Checklist. Other well-regarded DS measures also have been frequently used with patients with cancer, including the HADS<sup>17</sup> and the BSI-18.<sup>18</sup> Three of the most commonly used DS instruments with patients with HNC are listed in **Table 3**. Alternatively, distress may be assessed by clinical interview, although validity and reliability are not ensured unless a validated structured or semi-structured interview format is used.<sup>12,19</sup>

In selecting DS measures, careful consideration must be given to balancing time demands (patients’ “response burden” and staff time) with the quality and quantity of the information obtained. Selection of DS measures should be guided by not only the

**Table 2**  
Distress screening for patients with head and neck cancer: time periods and risk factors associated with increased distress

Time Period/Risk Factor	Factors Contributing to Distress Risk
Initial or second visit	Symptoms, diagnosis, treatment planning
Changes in treatment modality	Surgery, radiation, chemotherapy, chemoradiation, immunotherapy
Change in head and neck cancer status	Cancer stage (progression, recurrence)
Shift to palliative care	Increased morbidity Fear of dying/death
Functional losses	Swallowing Speech Disfigurement
Biopsychosocial factors	Pain Fatigue Nutritional deficits/malnutrition Low perceived social support, social isolation Avoidant coping style Smoking/alcohol use disorders Pretreatment history of depression

brevity/rapidity, but also the validity and sensitivity of the measure. Validity has multiple components, but here we are primarily referring to (1) construct validity: does the scale measure what it claims to measure, and (2) predictive validity: do scores accurately predict important outcomes. Sensitivity, in the case of DS, refers to the likelihood that the measure will correctly identify distressed patients as, in fact, distressed (true-positive). Screening measures must have a high sensitivity to achieve their primary goal of being able to correctly identify distress when it is present, as well as moderate to good specificity to correctly identify nondistressed patients as not distressed (true-negative).

The NCCN DT measure meets criteria for brevity, as a 1-item DT measure (usually given in tandem with a Problem Checklist modifiable to the population being assessed). The DT has been found to have acceptable validity and sensitivity, and compares favorably with longer distress measures, including the HADS (considered a “criterion measure” of distress) and the BSI-18.<sup>66</sup> It is strongly recommended that the DT be administered

**Table 3**  
Validated distress screening measures frequently used with patients with head and neck cancer

Distress Screening Measure	Description of Distress Screening Measure
<ul style="list-style-type: none"> <li>Distress Thermometer (DT) (usually administered with Problem Checklist)</li> </ul>	<ul style="list-style-type: none"> <li>1-item DT, and modifiable Problem Checklist</li> <li>Recommended: administer in combination with validated depression measure (eg, Patient Health Questionnaire-4)</li> </ul>
<ul style="list-style-type: none"> <li>Hospital Anxiety and Depression Scale (HADS)</li> </ul>	<ul style="list-style-type: none"> <li>HADS-Total = 14 items</li> <li>HADS-Depression = 7 items</li> <li>HADS-Anxiety = 7 items</li> </ul>
<ul style="list-style-type: none"> <li>Brief Symptom Inventory-18</li> </ul>	<ul style="list-style-type: none"> <li>18-items; Global Severity Index</li> <li>Subscales: Depression, Anxiety, Somatization</li> </ul>



in combination with a validated depression screening measure, given the high incidence of depression in patients with cancer overall,<sup>68</sup> a concern even more pronounced in patients with HNC due to markedly elevated rates of depression and suicide in the HNC patient population.<sup>5,21,46,47,49</sup> Both the Patient Health Questionnaire-4 (PHQ-4)<sup>69</sup> and the Patient Health Questionnaire-2 (PHQ-2)<sup>70</sup> are excellent brief depression measures frequently used for this purpose.<sup>68</sup>

It is important that HNC centers using DS measures choose cutoff scores based on previous empirical research, rather than due to a felt need to limit the volume of patients identified and referred for distress.<sup>12,66</sup> With regard to the DT, much of the research suggests a cutoff score of 4 offers optimal sensitivity/specificity (true-positive/true-negative) for accurately identifying distressed cancer patients.<sup>66</sup> However, other literature cautions that a cutoff score of 4 may be too high, causing too many distressed patients to be missed.<sup>11,71</sup> This may be particularly pertinent for the HNC population, given the heightened risk of depression and suicide. Distress cutoff scores for the HADS and the BSI-18 are also available in the literature.<sup>12,13</sup>

Screening may be administered via either paper-and-pencil questionnaires or electronic/online self-report measures. Several electronic versions of DS are available.<sup>22,68,72</sup> Many cancer centers also create paper or electronic versions of DS measures tailored to their patient population, although the format and wording of empirically validated measures must be replicated precisely to ensure validity.

### ***Follow-up Assessment/Evaluation***

As part of the DS algorithm, when patients exceed the preestablished cutoff scores for distress, further evaluation should be rapidly implemented. Review of the initial DS measure may provide information as to the severity and causes of distress (depressed or anxious mood, social, spiritual, or other areas of distress). Follow-up evaluation may include self-report measures such as the HADS, Patient Health Questionnaire-9 (PHQ-9),<sup>73</sup> Generalized Anxiety Disorder-7 (GAD-7),<sup>74</sup> and/or clinical interview with a mental health professional, or clinical staff member sufficiently trained in the initial evaluation of DS results (**Table 4**).

Evaluation of patients who score above the established distress cutoff criteria should include follow-up assessment concerning depression, anxiety, other biopsychosocial problems, and potential suicidal ideation (if depression or suicidal ideation are indicated). If suicidal ideation is present, immediate follow-up evaluation by a mental health professional is mandatory (or a physician or nurse appropriately well-trained in suicide risk assessment), with treatment and/or referral appropriate to the level of risk.

### ***Referral/Treatment***

Referral and treatment are increasingly recognized as a critical component of DS, although one of the more challenging, planning-intensive aspects.<sup>62</sup> It is essential that HNC DS programs develop an integrated referral network of mental health specialists, social work, multidisciplinary health providers (eg, swallowing/speech therapists, maxillofacial prosthodontics, nutritionists) and administrative personnel, all of whom have expertise in helping distressed patients with HNC with a range of biopsychosocial concerns (**Box 1**).

Although the literature evaluating psychosocial interventions for patients with HNC is not yet well developed, preliminary evidence suggests there may be significant potential benefit for patients with HNC.<sup>36,38,75–82</sup> In addition, there is considerable evidence for the effectiveness of several psychosocial interventions with patients with cancer that may well be applicable to the HNC population.<sup>83–89</sup>

<b>Table 4</b>		
<b>Follow-up assessment/evaluation: psychosocial measures</b>		
<b>Measurement Tool</b>	<b>Domains Assessed</b>	<b>Special Considerations</b>
Patient Health Questionnaire-9 (PHQ-9)	Depression (9 items total) Suicidal ideation (1 item)	<ul style="list-style-type: none"> <li>When suicidal ideation present, immediate clinical response is mandatory</li> </ul>
Hospital Anxiety and Depression Scale (HADS)	HADS-T = Distress HADS-D = Depression HADS-A = Anxiety	<ul style="list-style-type: none"> <li>HADS-T score increasingly used as measure of distress, although not intended by original authors of scale</li> <li>HADS-D considered more reliable than HADS-A</li> </ul>
Generalized Anxiety Disorder-7 (GAD-7)	Anxiety	<ul style="list-style-type: none"> <li>Considered more reliable than HADS-A</li> </ul>
Clinical interview	Distress, depression, anxiety, other psychosocial distress, suicidal ideation/intent (if indicated)	<ul style="list-style-type: none"> <li>Should be conducted by mental health professional, or well-trained clinical staff</li> <li>Suicidal ideation/intent must be evaluated by mental health professional</li> </ul>

Management of psychosocial distress includes referrals to mental health professionals, and can involve nurses and allied clinical staff trained in psychoeducational interventions. Some investigators recommend a flexible “stepped care” algorithm based on matching distress severity and characteristics to level and type of intervention.<sup>76</sup>

<b>Box 1</b>
<b>Common biopsychosocial problems in patients with head and neck cancer (HNC)</b>
<ul style="list-style-type: none"> <li>Distress</li> <li>Mood disorders (depression, anxiety)</li> <li>Swallowing impairment</li> <li>Nutritional deficits/malnutrition</li> <li>Speech impairment</li> <li>Disfigurement</li> <li>Pain</li> <li>Fatigue</li> <li>Low perceived social support, social isolation</li> <li>Avoidant coping, maladaptive coping</li> <li>Smoking and/or alcohol use disorders</li> <li>Fear of recurrence</li> <li>Death and dying (fear, depression, coping)</li> <li>Spiritual/religious concerns</li> <li>Financial difficulties, insurance difficulties</li> <li>Work-related problems (secondary to effects of HNC and treatment)</li> </ul>

More intensive treatment of psychosocial distress should include in-house and outside referrals to mental health professionals with experience in treating cancer and patients with HNC, and optimally with behavioral medicine and/or medical hypnosis expertise.

A burgeoning body of research offers substantial evidence for the efficacy of integrative cognitive behavioral therapy (CBT)–behavioral medicine, medical hypnosis, and mindfulness-based treatments for many cancer populations in reducing many of the aftereffects of cancer and cancer treatments (surgery, radiation, chemotherapy, immunotherapy)<sup>84–86,88,89</sup> that are relevant to HNC patients' experience, as listed in **Box 2**.

Empirical investigations of integrative CBT-behavioral medicine, medical hypnosis, and mindfulness, or mindfulness-based stress reduction (MBSR), treatments with patients with HNC are in the initial stages, with preliminary evidence suggesting that HNC patients may derive significant benefit from such interventions.<sup>36,79–81,90</sup> Psychosocial and behavioral medicine interventions that have demonstrated efficacy with cancer/HNC patients, or promising initial evidence with patients with HNC are listed in **Box 3**.

In devising treatment tailored to the HNC population, it is important to note that some reports indicate that many patients with HNC appear to prefer individualized treatment, as opposed to group treatment, and are more likely to accept and adhere to individualized treatment tailored to their specific needs, particularly when treatment is focused on reducing and/or coping with side effects or aftereffects of HNC treatment (pain, fatigue, nausea), coping with presurgical anxiety, or related HNC challenges.<sup>91</sup>

### **Documentation**

Documentation is an essential component of DS, and should include screening measures used, patient distress score, clinical interpretation of distress score, further evaluation, suicidal ideation (if present, and intervention for same), referrals for treatment, and plan for follow-up, if needed. If patients refuse treatment referrals, this should also be documented. Note that when suicidal ideation is present, if results of immediate evaluation indicate significant risk, patients may not have the right to refuse care due to safety concerns.

Effective documentation provides multiple benefits, including improving patient care, quality assurance, and developing a baseline of initial data on patients' psychosocial distress that serve as a foundation for clinical intervention and research

#### **Box 2**

#### **Therapeutic targets of integrative cognitive behavioral therapy (CBT)–behavioral medicine for patients with HNC**

- Pain
- Fatigue (secondary to radiation, or other HNC treatment)
- Nausea (secondary to chemotherapy, postsurgical)
- Malnutrition/difficulties with eating
- Smoking cessation
- Distress
- Anxiety
- Depression

**Box 3****Psychosocial treatments for patients with HNC and other cancers**

- CBT treatment<sup>77,78,83,92</sup>
- Integrative CBT-behavioral medicine<sup>36,86</sup>
- Behavioral medicine (may include hypnosis, relaxation training, mindfulness and/or mindfulness-based stress reduction techniques, pain management)<sup>36,79–81,84,87,90</sup>
- Smoking cessation, alcohol cessation/reduction<sup>38</sup>
- Psychoeducational interventions<sup>77,93</sup>
- Coping and social skills interventions<sup>82,94</sup>

(distress, QOL, psychological and medical outcomes). Using this information will allow HNC centers to evaluate the effectiveness of their DS programs, which can facilitate provision of support from hospital administration, and aid in the development of whole-patient HNC care.

### SUMMARY AND FUTURE DIRECTIONS

The provision of DS and referral routinely for patients with HNC is appropriately and rapidly becoming the standard of care. DS is of particular importance for patients with HNC, given their heightened incidence of distress, depression, and suicide, and the impact of psychosocial distress on QOL and medical outcomes. In the absence of formalized DS, psychosocial distress is frequently missed in HNC settings. However, once identified, distress is highly responsive to treatment.

Multidisciplinary HNC teams are uniquely positioned to implement effective psychosocial DS programs preventively to identify and treat distress that, left untreated, frequently leads to worsening psychological status, lower QOL, and negative medical outcomes. Further, multidisciplinary HNC teams can combine their expertise to tailor DS to the unique medical and psychological vulnerabilities of patients with HNC, using their shared understanding of the factors associated with increased risk for distress in this population.

Although research on psychosocial distress in cancer is burgeoning, more information is critically needed regarding distress in patients with HNC, the impact of distress on QOL and medical outcomes, and effective clinical interventions. To meet this need, it is essential that HNC centers implement DS routinely, using validated instruments, and follow through with referrals for treatment. Documentation of results is crucial, and can serve to inform clinical intervention and research.

Clinical interventions targeting common causes of distress in the HNC population are critically needed. Behavioral medicine (including medical hypnosis and mindfulness) is a promising area of specialization in mental health provision that has demonstrated efficacy with patients with cancer in reducing negative aftereffects of treatment and biopsychosocial problems similar to those faced by patients with HNC. Integrative CBT-behavioral medicine approaches have been found to be particularly effective. Tailoring treatment to the HNC population will be essential.

As the field of HNC moves beyond a reductionist medical model, narrowly focused on survival, and increasingly recognizes the importance of patients' psychological well-being and QOL, DS will provide an essential methodology and algorithm to aid the evolution toward whole-patient care. HNC centers can use DS to establish baseline data regarding patients' risk for distress, related negative impacts on QOL,

psychological and medical outcomes, and use this information to improve clinical intervention and research. Multidisciplinary HNC teams offer a foundation from which to fulfill the original purpose of DS, to provide whole-patient care that targets and effectively meets the real needs of HNC patients to relieve suffering and improve well-being as they traverse the treatment trajectory.

## ACKNOWLEDGMENTS

The author thanks Elizabeth Ercolano, DNSc for her very helpful comments on this article.

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