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# Addressing Distress Management Challenges: Recommendations from the Consensus Panel of the American Psychosocial Oncology Society and the Association of Oncology Social Work

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**Abstract:** Distress management (DM) (screening and response) is an essential component of cancer care across the treatment trajectory. Effective DM has many benefits, including improving patients' quality of life; reducing distress, anxiety, and depression; contributing to medical cost offsets; and reducing emergency department visits and hospitalizations. Unfortunately, many distressed patients do not receive needed services. There are several multilevel barriers that represent key challenges to DM and affect its implementation. The Consolidated Framework for Implementation Research was used as an organizational structure to outline the barriers and facilitators to implementation of DM, including: 1) individual characteristics (individual patient characteristics with a focus on groups who may face unique barriers to distress screening and linkage to services), 2) intervention (unique aspects of DM intervention, including specific challenges in screening and psychosocial intervention, with recommendations for resolving these challenges), 3) processes for implementation of DM (modality and timing of screening, the challenge of triage for urgent needs, and incorporation of patient-reported outcomes and quality measures), 4) organization—inner setting (the context of the clinic, hospital, or health care system); and 5) organization—outer setting (including reimbursement strategies and health-care policy). Specific recommendations for evidence-based strategies and interventions for each of the domains of the Consolidated Framework for Implementation Research are also included to address barriers and challenges. *CA Cancer J Clin* 2021;71:407-436. © 2021 The Authors. *CA: A Cancer Journal for Clinicians* published by Wiley Periodicals LLC on behalf of American Cancer Society. This is an open access article under the terms of the Creative Commons Attribution-NonCommercial-NoDerivs License, which permits use and distribution in any medium, provided the original work is properly cited, the use is non-commercial and no modifications or adaptations are made.

**Keywords:** distress management, health policy, psychological/behavioral oncology, supportive care, survivorship

## Introduction

Managing distress in patients with cancer is well documented as an important component of evidence-based approaches to optimizing cancer outcomes and is a key component of whole-person cancer care. Distress management (DM) refers to the comprehensive system that includes screening, assessment, triage, intervention, and outcome monitoring related to patient distress (Fig. 1). The practice of DM involves proactive use of patient-reported outcomes to identify and triage distressed patients with specific care needs to appropriate supportive care services for relevant evidence-based intervention. Over 20 years ago, the National Comprehensive Cancer Network



**FIGURE 1.** Distress Management Components and Process.

(NCCN) proposed DM as a way to facilitate the delivery of evidence-based psychosocial support services to patients across the continuum of cancer care: diagnosis, treatment, posttreatment survivorship, advanced disease, and/or end of life.<sup>1</sup> In recent years, multidisciplinary cancer care teams have developed specific distress screening tools to effectively and systematically measure distress experienced by patients with cancer. In addition, clinical researchers have developed and tested novel and effective interventions to promote adherence to therapy, enhance shared decision-making, and improve patients' symptom management, quality of life, and long-term survival.<sup>2</sup> Despite these advances, many patients do not receive needed services, which may reflect lack of access or ineffective screening, such that those with the greatest need are not identified.<sup>3</sup> Moreover, those most likely to benefit from psychosocial support services often are the least likely to use them.<sup>4</sup> The incorporation of DM protocols can aid cancer centers to bridge the gap from screening to provision of evidence-based psychosocial oncology care.

The objective of systematic DM is not only to identify patients experiencing distress but also to address identified symptoms and needs by implementing evidence-based interventions with demonstrated efficacy.<sup>5</sup> Adherence to DM protocols in cancer care can improve patients' quality of life, reduce distress, reduce anxiety and depression, achieve medical cost offsets, reduce emergency department visits and hospitalizations, and is associated with improved survival through biobehavioral mechanisms.<sup>2,6,7,8,9,10,11,12</sup> However, many patients who could benefit from referral to psychosocial care after a positive distress screen do not receive appropriate referral or follow-up.<sup>4,13</sup> This gap in care is likely associated with variability in the extent to which DM procedures are implemented across and within cancer programs and specialty departments. In addition, professional/institutional responses to positive screens have lacked systematization and utilization of evidence-based interventions.

The goals of this review are to: 1) identify populations in need of more targeted screening and equitable access to interventions, 2) make specific recommendations for evidence-based interventions in response to positive screens, and 3) delineate operational challenges in DM and recommend process and policy changes to address these challenges. Therefore, we will identify and address specific population barriers encountered in the DM process as well as challenges and recommendations for screening,

assessment, triage, intervention, and outcome monitoring. We also provide recommendations to address gaps in research on DM.

## Background

The NCCN convened the first Distress Management Panel in 1997, producing the first DM Guidelines.<sup>14</sup> The current NCCN DM Guidelines define distress broadly as "a multifactorial unpleasant experience of a psychological, social, spiritual, and/or physical nature that may interfere with the ability to cope effectively with cancer, its physical symptoms, and its treatment."<sup>15</sup> The NCCN standard for DM management includes: 1) recognizing, monitoring, documenting, and treating distress promptly at all stages of disease; 2) identifying the level and nature of distress; 3) screening for distress at every medical visit or regular intervals; and 4) assessing and managing distress according to clinical practice guidelines.

In the ensuing years, more organizations have called attention to the importance of monitoring the psychosocial well-being of individuals with cancer. In 2007, the National Academies of Science, Engineering, and Medicine (formerly the Institute of Medicine) advocated routine assessment of the psychosocial needs of patients with cancer as a standard of care.<sup>16</sup> In 2009, the American Society of Clinical Oncology (ASCO) incorporated the assessment of patients' emotional well-being into the Quality Oncology Practice Initiative standards.<sup>17</sup> In 2012, the American College of Surgeons Commission on Cancer (CoC) identified distress screening as an essential part of quality cancer care.<sup>18</sup> In 2015, psychosocial distress screening became an accreditation standard for the CoC, providing the first critical step toward universal adoption of DM practices.<sup>19</sup> The CoC accreditation standard includes general requirements regarding timing, methods, and tools for screening, follow-up assessment and referral for positive screens, as well as documentation of screening results.

The American Psychosocial Oncology Society (APOS), the Association of Oncology Social Workers, and the Oncology Nursing Society issued a joint statement of recommendations for distress screening in 2014.<sup>20</sup> These recommendations included:

- Adoption of the NCCN definition of distress,
- Selection and use of validated screening instruments following published threshold values and ranges,

- Use of screening instruments that are focused broadly on components of distress (vs one particular symptom),
- Screening at multiple time points,
- Screening results to be communicated to and reviewed by the patient's treatment team in a timely manner,
- Follow-up of positive screens by a trained clinician who can differentiate causes of distress and ensure appropriate referral, and
- Inclusion of referrals for the assessment and management of distress as part of a patient's routine medical care.

In recent years, some have also advocated for the inclusion of caregivers as targets for distress screening,<sup>21</sup> especially for pediatric patients and their families.<sup>22</sup> In 2015, a special issue of *Pediatric Blood Cancer* identified 15 standards of care for essential services for patients with pediatric cancers and their families.<sup>23</sup> One of the standards, *Psychosocial Assessment*, outlines the provision of systematic early and ongoing assessment of patient and family psychosocial health care needs, including distress.<sup>24</sup>

### Distress Management Challenges

Existing guidelines, recommendations, and accreditation standards for DM are neither detailed implementation guides nor are they consistent.<sup>15,25,26</sup> For example, the CoC accreditation standards for patient-centered care generally do not state when, how, or how often to screen and respond to patients' psychosocial needs.<sup>25</sup> As a result, cancer treatment centers across the United States have implemented DM protocols that vary widely in screening characteristics, including instrumentation, periodicity of assessments, and procedures for responding to positive screens.<sup>11,27</sup> This lack of consistency within the United States (and across the world) contributes to variations observed in clinical practice outcomes related to the implementation of DM protocols and complicates the interpretation of research results across studies that are geared toward understanding and better managing this issue.<sup>27,28</sup> Thus further research is needed to determine which aspects of the DM process are essential to achieve optimal patient outcomes across a variety of cancer care delivery settings.

Multilevel barriers represent key challenges to DM and impact its implementation (see Table 1). In discussing these challenges, we have used the Consolidated Framework for Implementation Research (CIFR) as an organizational structure to outline the barriers and facilitators to the implementation of DM and to develop a roadmap to inform future research on and clinical guidelines for successful implementation of DM (see Fig. 2).<sup>29</sup> Specifically, we make recommendations for each of the 5 domains of CIFR: 1) individual characteristics (considering individual patient

characteristics with a focus on groups who may face unique barriers to distress screening and linkage to services), 2) intervention (examining the unique aspects of DM intervention, including the specific challenges in screening and psychosocial intervention and recommendations for resolving these challenges), 3) processes used to implement DM (modality and timing of screening, the challenge of triage for urgent needs, and incorporation of quality measures and outcomes assessment), 4) organization—inner setting (the internal context of the clinic, hospital, or health care system), and 5) organization—outer setting (including external factors, such as reimbursement strategies and health care policy).

### Individual Characteristics

Distress management may miss certain patient populations who experience inequities in cancer care or unique sociocultural barriers to engaging in psychosocial evaluation or treatment, or who are less adept at self-advocacy. Self-advocacy has been defined as the ability of a cancer survivor to get their needs met when facing a challenge and includes the skills of making informed decisions and communicating effectively with the oncology care team.<sup>30</sup> Given unique psychosocial needs, multilevel barriers to cancer treatment and supportive care, and disparities in cancer outcomes, targeted approaches are needed to increase the reach of distress screening and promote equity of access to appropriate services in response to positive screens. We have focused here on several vulnerable patient groups but recognize that intersectionality entails simultaneous consideration of social categorizations such as race, class, and sex to help understand potential underlying influences on persistent disparities in cancer treatment.<sup>31</sup>

### Patients Who Are Physically or Cognitively Unable to Complete Screening

Functional limitations (eg, severe fatigue, motor impairments secondary to cancer treatment, tumor-associated spinal cord or brain injuries) and cognitive impairment (eg, dementia, developmental delay, brain tumors, "chemo-brain," or delirium) can impact patients' ability to complete distress screening tools.

### Recommendations

We recommend using screening tools validated with proxy-report, being aware of potential discrepancies when proxies report symptoms, and noting when discrepancies occur between the patient's and proxy's report. Although the patient may need a caregiver or proxy to complete the screening instrument, if possible, the patient should also be asked about their mood, symptoms, and function according to the Americans with Disabilities Act guidelines.<sup>32</sup> For some patients, oral administration of screening or large-print

**TABLE 1. Consolidated Framework for Implementation Research (CFIR) Domains: Multilevel Barriers and Challenges to Distress Management and Recommendations**

CFIR DOMAIN	BARRIER/CHALLENGE	RECOMMENDATION(S)
Individual characteristics	<p>Patients who are physically or cognitively unable to complete screening</p> <p>Socioeconomically or geographically disadvantaged patients</p> <p>Language barriers, including health illiteracy</p> <p>Patients with preexisting mental health and substance use disorders</p> <p>Sexual and gender minority patients (LGBTQ)</p> <p>Older adult patients</p> <p>Pediatric and AYA patients</p>	<p>When possible, use screening tools validated with proxy-report, noting potential discrepancies when proxies report symptoms.</p> <p>Use large print for screening instruments.</p> <p>Ask screening questions orally.</p> <p>Follow ADA guidelines in ensuring access to care.</p> <p>Ensure screening does not incur additional financial burdens for patients.</p> <p>Screen for social determinants of health and material hardship.</p> <p>Consider referral to targeted resources to address financial toxicity and access issues, particularly for rural and other disadvantaged communities.</p> <p>Use formal translation/interpretation options.</p> <p>Choose measures that have been translated into local languages and made accessible.</p> <p>Include navigators from underrepresented groups.</p> <p>Provide materials in multiple formats (visual, auditory, written).</p> <p>Use teach-back and shared decision-making approaches to ensure patient understanding.</p> <p>Proactively identify and intervene with patients who have mental health and substance use disorders.</p> <p>Screen for suicidal ideation.</p> <p>Develop targeted triage strategy for patients with preexisting mental illness who do not screen positive.</p> <p>Use collaborative care models to enhance triage and access to specialty care.</p> <p>Train all oncology and mental health clinicians working in oncology settings on the use of universal precautions and screening, monitoring, and co-management to address the comorbidity of pain and addiction.</p> <p>Incorporate sexual orientation, gender identity (SOGI) questions and use inclusive language.</p> <p>Establish linkages to LGBTQ organizations in the community.</p> <p>Use targeted approaches to identify and support patients at higher risk for distress.</p> <p>Improve cultural competence through training of oncology clinicians on care of LGBTQ patients and family members.</p> <p>Use geriatric-specific assessment tools targeted to older adults, including comprehensive geriatric assessment.</p> <p>Attend to unique physical, functional, psychosocial, and support needs of geriatric patients/families with cancer.</p> <p>Use developmentally appropriate screening tools (DT, DT-P, PAT, PedsQL, PROMIS).</p> <p>Consider distress screening of parents/caregivers and siblings.</p> <p>Respect privacy when screening and planning care.</p> <p>Use follow-up assessment tools that address specific needs (ie, development, cognitive, academic, social, behavioral, emotional, family functioning).</p>

**TABLE 1. (Continued)**

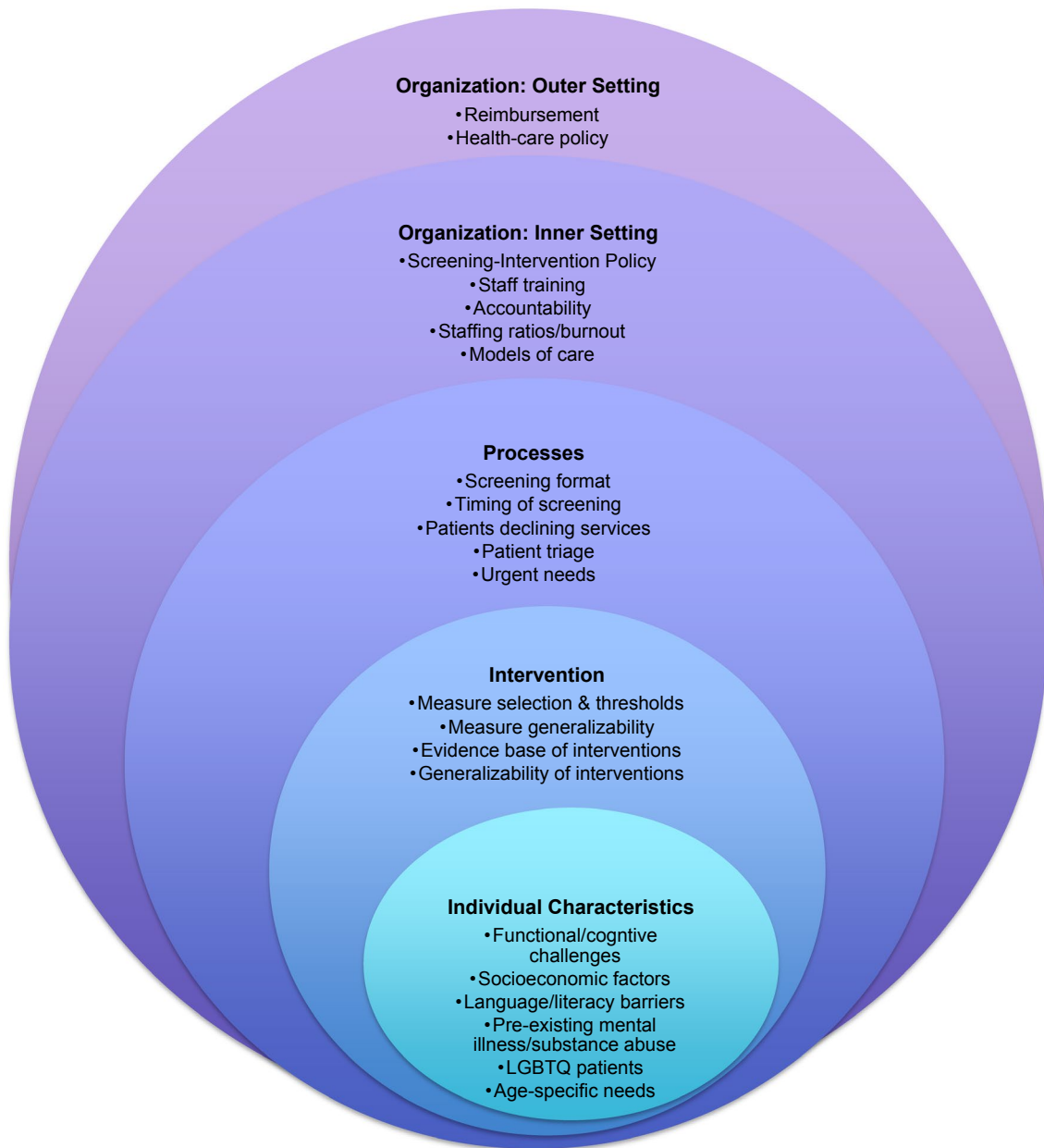
CFIR DOMAIN	BARRIER/CHALLENGE	RECOMMENDATION(S)
Intervention characteristics: Screening and intervention	Measure selection	<p>Determine locally relevant common and distressing unmet needs.</p> <p>Design screening to capture unmet needs and available resources.</p> <p>Involve members of the psychosocial treatment team in DM protocol development.</p> <p>Use a validated multidimensional tool that assesses broadly for distress.</p> <p>Use validated cutoff scores.</p> <p>Tie cutoffs to known clinical conditions amenable to treatment.</p> <p>Understand that diverse populations may not be adequately served by standard screening tools/methods warranting further validation with these populations.</p> <p>Use targeted, evidence-based interventions (per randomized trials, systematic reviews, and meta-analyses with graded evidence) and national and international guidelines for psychosocial care and symptom management when available.</p> <p>Consider culturally tailored interventions.</p> <p>Enhance workforce diversity.</p> <p>Vet community resources to meet specific cultural needs.</p> <p>Use national guidelines in recruitment and retention of diverse populations in the evaluation of intervention outcomes.</p> <p>Broaden clinical team to include peer advocates and/or navigators to increase patient access to culturally informed care.</p> <p>Use evidence-based treatments specific to disease phase when available.</p> <p>Utilize NCCN guidelines for clinical assessment, referral, and treatment.</p> <p>Consult the APOS Roadmap to help prioritize research on patients' most common and distressing needs.</p> <p>Use existing clinic processes and electronic methods to facilitate screening.</p> <p>Incorporate a back-up option to electronic screening.</p> <p>Train interdisciplinary staff and clinicians involved in the screening process.</p> <p>Optimally screen at every clinic visit; if not possible, screen within first 3 visits then at key points in the cancer care trajectory.</p> <p>Develop educational materials describing support services.</p> <p>Present supportive care services as a component of comprehensive cancer care.</p> <p>Educate clinicians about effective referral to support services and evidence of impact associated with psychosocial care.</p> <p>Improve access through collaborative care and telehealth interventions.</p> <p>Link psychosocial care with oncology visits.</p> <p>Refer patients to requested services for further screening and assessment.</p> <p>Consider use of self-management protocols and community resources to reduce referral volumes.</p> <p>Identify staff to triage positive screens.</p> <p>Establish referral resources internally and externally; resources should be vetted and up to date.</p>
Failure to use validated thresholds on selected measures	Failure to use evidence-based interventions	
Lack of generalizability of evidence-based interventions for underserved populations	Lack of evidence-based interventions for key psychosocial outcomes	
Process	Screening format	
	Timing of screening	
	Patients declining services	
	Patients requesting support, but not meeting screening criteria	
	Triage to relevant services	

TABLE 1. (Continued)

CFIR DOMAIN	BARRIER/CHALLENGE	RECOMMENDATION(S)
Organizational: Inner setting	<p>Urgent referrals (eg, end of life, crises, suicidal ideation)</p> <p>Lack of clearly defined policy and procedures for distress management</p> <p>Training for staff in procedures for distress management</p> <p>Procedural accountability</p> <p>Staff availability to meet demands</p> <p>Stepped or collaborative care models infrequently used</p> <p>Clinician burnout</p>	<p>Adjust schedules and/or systems for clinicians to accommodate urgent referrals.</p> <p>Establish risk-management and crisis procedures for addressing urgent patient needs.</p> <p>Use care in distributing urgent cases to reduce potential for clinician burnout.</p> <p>Seek to increase collaboration between psychiatric and oncologic programs in the inpatient and outpatient settings.</p> <p>Develop a clearly documented policy for distress screening, assessment, triage, intervention, and monitoring.</p> <p>Develop concise, user-friendly algorithms for assessment, triage, and intervention, including staff providing these interventions.</p> <p>Include processes for monitoring referral outcomes and adjusting course.</p> <p>Allocate time for training.</p> <p>Review policy and procedures at departmental and treatment team meetings.</p> <p>Hire psychosocial oncology staff with training and experience in cancer care.</p> <p>Establish procedures to review administration of screening protocols.</p> <p>Use quality-review processes to identify and address problems.</p> <p>Assign psychosocial services coordinator to oversee implementation and accountability for DM protocols.</p> <p>Set provider schedules to cover demand for services with a goal of time to first appointment of &lt;2 months; address staffing (patient:clinician) ratios if this is not possible.</p> <p>Monitor time to initial visit and time to first follow-up as quality indicators.</p> <p>Use stepped or collaborative care models for the most efficient use of resources.</p> <p>Monitor outcomes of interventions over time, and adjust the level of care based on patient response.</p> <p>Enhance organizational interventions to improve the efficiency of work processes, particularly electronic health record documentation, clinic flow, and adequate time for recovery between clinical shifts.</p> <p>Adhere to staffing guidelines promoted by APOS and other oncology-specific professional organizations.</p> <p>Support provider-based interventions, such as education about burnout and resilience, communication skills training, and cognitive behavioral interventions.</p> <p>Collaborate with professional organizations to set appropriate RVU targets and improve reimbursement rates.</p> <p>Support education in psychosocial oncology for providers to promote effective screening and treatment.</p> <p>Enhance access to psychosocial oncology care through parity of physical and mental health insurance coverage, telehealth and virtual care options, and expanded models of care (collaborative care, stepped care).</p>
Organization: Outer setting	<p>Reimbursement for psychosocial services</p> <p>Health care policy</p>	<p>Collaborate with professional organizations to set appropriate RVU targets and improve reimbursement rates.</p> <p>Support education in psychosocial oncology for providers to promote effective screening and treatment.</p> <p>Enhance access to psychosocial oncology care through parity of physical and mental health insurance coverage, telehealth and virtual care options, and expanded models of care (collaborative care, stepped care).</p>

Abbreviations: ADA, Americans With Disabilities Act; APOS, American Psychosocial Oncology Society; AYA, adolescents and young adults; DM, distress management; DT, Distress Thermometer; DT-P, Distress Thermometer-Parent; LGBTQ, lesbian, gay, bisexual, transgender/transsexual, and queer/questioning; NCCN, National Comprehensive Cancer Network; PAT, Psychosocial Assessment Tool 2.0; PedsQL, Pediatric Quality-of-Life Inventory; PROMIS, Patient-Reported Outcomes Measurement Information System; RVU, relative value units.





**FIGURE 2.** Consolidated Framework for Implementation Research (CFIR) Domains and Constructs for Distress Management.

screening tools may work better. If distress screening instruments or psychosocial interventions are completed or delivered orally, accommodations may be required for individuals with speech or hearing impairment.

### Socioeconomically or Geographically Disadvantaged Patients

Multiple studies have demonstrated that patients with low income are at risk for experiencing *financial toxicity* (financial distress related to cancer), which can contribute to the decision to forgo aspects of cancer care (or supportive services) to defray costs.<sup>33-35</sup> There are additional barriers for this patient group, including lack of insurance (or

inadequate insurance) and transportation issues. In general, lower socioeconomic status and rural residence have been associated with higher overall distress.<sup>36,37</sup> Living in a rural setting has also been associated with disparities in cancer diagnosis, incidence, and treatment as well as with poorer survival.<sup>38,39</sup>

### Recommendations

These groups may benefit from focused screening to identify sources of financial distress and to identify those at risk for experiencing financial toxicity. Screening for social determinants of health and material hardship could help identify patients at particularly high risk for distress and inequities.<sup>40,41</sup>

Referral to social workers, case managers, patient navigators, and/or financial counseling services may prove helpful if patients report financial distress or come from rural or disadvantaged communities.<sup>42,43</sup> Providing DM services through telehealth (including the option of phone) can reduce financial and other barriers (transportation, childcare, etc) to access to needed resources. It is also important to consider access to technology and preferences for which technology to use.

### Language Barriers, Including Poor Health Literacy, Among Patients and Insufficient Language Skills Among Providers

Non-English-speaking patients may not be screened because of minimal institutional or governmental investment in resources, including supportive care services adapted for different language groups, or because non-English-speaking patients may not feel comfortable with or understand the purpose of DM. Communication difficulties also result from a dearth of clinicians who speak multiple languages, thus precluding comprehensive screening and assessment. The inability of providers to speak the languages of their patient population or understand their culture may complicate discussions of distress and receptivity to support services. Furthermore, screening tools may not be validated in different languages.

The US Department of Education reports that approximately 36% of adults aged 18 to 64 years have poor health literacy.<sup>44</sup> Moreover, 59% of adults aged >65 years have poor health literacy related to declining cognitive function, longer time since formal education, and decreased sensory abilities (hearing and vision). Additional characteristics associated with poor health literacy include English as a second language, not graduating from high school, poverty, minority status, and poor health.<sup>44</sup>

#### Recommendations

Translation by family members should be avoided because of the difficult position this creates for the family member and the patient; instead, trained interpreters or translation services (including virtual resources) should be available and used. Ideally, measures and processes are adapted to cultural contexts in partnership with the community served. We recommend using screening instruments that have been validated in the most common languages for the local setting. The inclusion of navigators from underrepresented populations on treatment teams serving those populations can help to bridge cultural and language barriers.<sup>45</sup>

When possible, we recommend the development and dissemination of resources and products tailored for patient subgroups using multiple modes of communication (visual, pictograms, auditory, written) and originating from a trusted source of information. We recommend use of the

*teach-back* method—an effective tool for verifying that patients understand the information provided or recommendations made. A wide variety of patients benefit from the teach-back method, including those with low socioeconomic status, education, and health literacy as well as minority patients, geriatric patients, those with cognitive impairment, and those with limited English proficiency.<sup>46</sup> A recent systematic review demonstrated strong evidence for the use of teach-back, with 95% of included studies reporting positive findings for primary outcomes of knowledge, skills, and attitudes (disease knowledge, comprehension and retention, patient satisfaction), behavior change (self-care practices, medication adherence), and objective health-related outcomes (hospital readmissions, quality of life).<sup>47</sup>

Shared decision making should also be used as a tool to improve health literacy because it promotes patient comprehension of decisions to be made and ensures that patients understand their options as well as potential benefits and harms. This process also leads to improved patient-provider communication and empowers individuals to be involved in their own health care.<sup>48</sup> In addition, shared decision making, although perhaps more difficult in this context, is important to use with patients who have low health literacy to engage them in decisions relevant to their care, thereby increasing participation and reducing marginalization.<sup>49</sup>

### Patients With Preexisting Mental Illness and Substance Use Disorders

Patients with preexisting mental illness and addiction are at high risk for not receiving equitable cancer treatment. Individuals with preexisting psychiatric diagnoses are less likely to receive timely, guideline-concordant cancer care, and they have worse cancer-specific prognosis and survival and higher rates of acute care use and health care costs.<sup>50,51</sup> In part, the cause for this may be that individuals who have any mental illness (including anxiety disorder, post-traumatic stress disorder, major depressive disorder) are screened for cancer less frequently compared with the general population.<sup>52</sup> Adults with schizophrenia have increased mortality from breast, colorectal, and lung cancer and are at increased risk of not receiving guideline-concordant cancer care.<sup>51</sup> Oncologists may not document mental illness systematically, and mental health care is frequently delivered in separate health systems.<sup>53</sup> In addition, individuals with substance use disorders have greater comorbid medical and psychiatric disorders as well as a greater risk of homelessness.<sup>54</sup> These patients are also at risk of being undertreated for pain, although this could be mitigated by the use of universal precautions for opioid management.<sup>55</sup>

#### Recommendations

Proactive identification of mental illness and substance use disorders (using diagnostic codes, medical history in

the electronic health record (EHR), and substance screening approaches), and linkage to relevant treatment for these disorders may protect against delays and disruptions in comprehensive cancer care.<sup>53</sup> An ASCO guideline for assessment and treatment of anxiety and depression recommended the use of the Patient Health Questionnaire (PHQ-9)<sup>56</sup> for assessment of depression and the Generalized Anxiety Disorder (GAD-7) measure<sup>57</sup> for assessment of anxiety.<sup>58</sup> The guideline also includes pathways for management of depression and anxiety. Other practices include: 1) asking directly about mental health treatment, 2) establishing communication with community-based mental health clinicians and pharmacists, and 3) involving caregivers, including family members and community-based staff, in screening and treatment efforts. Given the increased risk of suicide among patients with cancer,<sup>59</sup> it is particularly important to screen for suicidal ideation and establish pathways to triage, refer, and link to mental health services. Evidence-based care delivery models, such as collaborative care (discussed below in more detail), have been adapted to proactively address the mental health needs of patients with cancer and extend the reach of psycho-oncology services.<sup>60,61</sup>

Symptom management (pain control) and treatment adherence for patients with substance use disorders can be enhanced by: screening for a history of substance use (particularly alcohol and opiate use disorders), the use of universal precautions for opioid management, regular monitoring of aberrant drug-related behaviors (eg, urine drug testing, prescription monitoring programs, *red flag* behaviors),<sup>62</sup> training of oncology clinicians, co-management of substance misuse, and the use of evidence-based treatments, including medication-assisted treatments.<sup>55,63</sup> As noted above, the most affordable and feasible approach for addressing these problems in the population of patients with cancer is to train oncology and psycho-oncology clinicians to co-manage pain and addiction in their patients, with referral to specialty clinics for addiction management when needed.

### Sexual and Gender Minority Patients

Currently, the lesbian, gay, bisexual, transgender/transsexual, and queer/questioning (LGBTQ) population experiences greater risk of poor cancer outcomes and heightened chronic stress because of experiences of discrimination and distrust associated with sexual and gender minority status<sup>64</sup> in addition to multiple barriers to accessing support services.<sup>65</sup>

#### Recommendations

Leading organizations, including the American Cancer Society and the National Academy of Medicine, have called for targeted approaches to working sensitively with the LGBTQ population.<sup>66,67</sup> Recommendations include incorporating standardized sexual orientation/gender identity (SOGI) information into the EHR using gender-affirming,

person-centered language. It is also recommended to use an affirming SOGI approach to clinical care, which entails developing targeted support services for LGBTQ patients with cancer and their caregivers, fostering relationships with community-based advocacy groups, and training clinicians in strategies for caring for this population (eg, National LGBT Cancer Network Cultural Competency Training).<sup>66,67</sup>

### Older Adult Patients' Needs

Cancer disproportionately affects older adults; however, the geriatric oncology population frequently faces significant barriers to accessing and receiving comprehensive cancer care. Older patients often have lower rates of reporting depression and anxiety on standard screening instruments, particularly ethnically diverse older adults.<sup>68,69</sup> This group is also more likely to experience deficits in multiple functional domains, including visual or hearing impairments, mobility, cognition, and social support, and is at higher risk for experiencing polypharmacy and treatment toxicity.<sup>70,71</sup> These barriers may impair the ability of these patients to actively participate in their cancer care, complete distress screening, and/or participate in psychosocial interventions.

#### Recommendations

Assessment of older adults should be sensitive to geriatric-specific issues (such as physical function, quality of life, and social support needs). We concur with ASCO in recommending the use of geriatric-specific assessment tools, such as the Geriatric Depression Scale.<sup>72</sup> When screening identifies problems, a comprehensive geriatric assessment can be useful for these patients to help address the multifactorial nature of their needs.<sup>73,74</sup>

### Pediatric and Adolescent and Young Adult Patients

When a child is diagnosed with cancer, patients and family members experience significant emotional upheaval and sudden changes to their lives, roles, and routines. Caregivers are expected to absorb a vast amount of information to make quick decisions about and consent to often complicated treatment plans. Importantly, family distress and anxiety are significantly elevated at the time of diagnosis.<sup>75</sup> Parents typically report more distress than pediatric patients with cancer, although adolescents and young adults (AYAs), patients with brain tumors, and siblings of patients who have cancer report still higher levels of distress.<sup>76-78</sup> Screening pediatric patients requires a developmental approach because sources of distress and their expression may vary across age and developmental stage.<sup>79,80</sup> Late effects of pediatric cancer may include neurocognitive sequelae<sup>81</sup> (ie, learning, attention, concentration, memory, executive functioning, etc) and/or long-term psychosocial challenges<sup>82</sup> (ie, anxiety, depression, posttraumatic stress, compromised social functioning, etc), which negatively correlate with patients' quality of life, warranting ongoing DM across the treatment trajectory.<sup>23</sup>

AYA patients experience unique psychosocial needs; they are different from pediatric and adult populations in the most common types of cancer diagnosed, the biology of the disease, and response to treatment.<sup>83,84</sup> AYAs also face unique stressors related to limited access to health insurance, delayed diagnosis, lack of AYA-specific treatment protocols (most are pediatric or adult protocols), fewer clinical trial protocols, lower clinical trial participation, poorer adherence, and lack of patient follow through.<sup>85,86</sup> In addition, this developmental phase includes multiple changes in cognitive, social, emotional, and physical development.<sup>23</sup> It is a time of increased autonomy, independence and separation from family of origin, and attainment of social, romantic, academic, and occupational milestones. A diagnosis of cancer can disrupt the normative developmental trajectory (because of having to move back home, reduced independence, loss of privacy) and important milestones (ie, playing on school team, attending prom, graduating, going away to college).

### Recommendations

We recommend using developmentally appropriate screening tools: the NCCN Distress Thermometer (DT),<sup>87</sup> the DT-Parent,<sup>88</sup> the Psychosocial Assessment Tool 2.0,<sup>89</sup> the Pediatric Quality-of-Life Inventory,<sup>90</sup> the Children's Depression Inventory,<sup>91</sup> or the Patient-Reported Outcomes Measurement Information System (PROMIS).<sup>92</sup> Distress screening of patients' parents or caregivers and siblings should also be considered. When follow-up assessment is indicated after initial general screening, we advise using assessment tools that address specific needs (ie, development, cognitive, academic, social, behavioral, emotional, and family functioning). We recommend that pediatric and AYA patients receive regular, ongoing psychosocial screening and that AYA patients are given the opportunity for care planning away from caregivers to promote privacy. Screening and assessment should include areas specific to the unique stressors of the AYA population, such as the following domains: emotional, physical, spiritual, social (peers, family, romantic), practical (education, career development, employment), and informational (fertility and healthy lifestyle behaviors—safe sex and tobacco, alcohol, and substance abuse).<sup>93</sup>

### Intervention Characteristics

Distress management outcomes are greatly determined by the selection of screening methods as well as the degree to which providers adhere to evidence-based interventions to address distress. In this section we explore the challenges associated with screening measure selection, use of validated thresholds on measures, selection of evidence-based interventions and the challenges specific to DM with underserved populations.

### Measure Selection

Institutions make decisions about screening tools based on various stakeholders and values (ie, dedicated resources, use of data, operational impact, administration/physician buy-in, time demands, etc). The CoC standard recommends the use of validated measure(s) of distress and validated cutoff score(s).<sup>25</sup> Current approaches to distress screening tend to rely on unidimensional distress screening instruments (eg, The PHQ-9 for depression<sup>56</sup>), which help with efficiency but fail to assess dimensions of distress that may contribute equally or additively to distress. Although the CoC does not advocate for specific measures, measurement domains are specified and include physical functioning and symptoms as well as emotional, cognitive, social, sexual, and spiritual needs.<sup>25,94,95</sup> Furthermore, clinicians and researchers have recognized the need to screen for social determinants of health given the association of financial toxicity with poor quality of life, reduced treatment adherence, and worse treatment outcomes.<sup>41</sup>

### Recommendations

According to NCCN DM guidelines, screening tools should be selected based on the most common and distressing needs of patients with cancer as well as available resources in the cancer center and local community.<sup>15</sup> Ideally, a backward design approach<sup>96</sup> should be used, in which DM oversight committees would begin with the end (available resources and desired outcomes) in mind. A screening system should be designed on the premise that a program will have available resources to meet screening target demand using institutional or community resources. According to NCCN guidelines, individuals who will screen and provide targeted interventions should be involved in developing the DM protocol, including selecting screening tool(s), planning triage procedures, and establishing intervention protocols to increase uptake.<sup>15</sup> This recommendation is addressed further in the Organization—Inner Setting section (see below).

We concur with the NCCN and the CoC recommendations for a broad, multidimensional conceptualization of distress and thus recommend the use of a multidimensional screening measure or combination of measures.<sup>15,25</sup> This aligns with other recommendations for more comprehensive screening of multiple symptoms and functional impairment.<sup>94,95,97,98</sup> Ideally, the measure(s) would include measurement of each domain (eg, physical, psychological, spiritual) on the same rating scale for ease of comparison and resource allocation. Recommended measures include: the DT and Problem List,<sup>87</sup> James Supportive Care Screening,<sup>99,100</sup> the Edmonton Symptom Assessment Scale,<sup>101</sup> the Functional Assessment of Cancer Therapy-General,<sup>102</sup> and PROMIS measures.<sup>92</sup> General multidimensional screening can be followed-up with measures tailored

to patient-centered needs (eg, depression, physical symptoms). Examples of specific follow-up measures include the PHQ-9 for depression,<sup>56</sup> the GAD-7 for anxiety,<sup>57</sup> and the Brief Pain Inventory.<sup>103</sup>

### Use of Validated Thresholds on Selected Measures

The use of validated instruments typically includes the use of empirically validated thresholds or cutoff scores for determination of positive screens.<sup>104</sup> Standardized thresholds ensure that patients above the cutoff score for specific symptoms receive appropriate referral for treatment, whereas those below the cutoff receive education and/or monitoring, when needed. Of note, high cutoff scores can result in false negative results and may miss patients who need services (ceiling effects), whereas low cutoff scores can result in false positive results and lead to an inefficient use of program resources (floor effects).<sup>105</sup> Some institutions may subjectively choose cutoff scores based on system and resource capacity, which can be problematic.

### Recommendations

Cutoff scores for screening should incorporate established, validated ratings or scores to identify patients with a targeted condition or problem who may benefit from intervention. Cutoff scores ideally should be tied to known clinical conditions amenable to treatment. For instance, cutoff scores for depression or anxiety should be validated in clinical studies and should be associated with clinical diagnoses of depression and anxiety that are amenable to treatment (vs those associated with other self-report measures of depression).<sup>106</sup> Cutoff scores can vary by age, sex, race/ethnicity, or other identifying variables, which warrants further evaluation of screening instruments for diverse populations.<sup>107,108</sup>

### Addressing Physical and Psychological Symptoms With Evidence-Based Care

Several authors point to the failure to triage distressed patients to evidence-based interventions as a primary reason DM protocols have failed to improve distress outcomes.<sup>109,110</sup> Screening alone, without targeted referrals or access to evidence-based intervention, is inadequate to address distress.

More generally, several problems persist in reviews and meta-analyses of psychosocial interventions for patients with cancer. In particular, there is broad variability in what is considered a psychosocial intervention. Several meta-analyses include nonevidence-based and basic, information-only psychosocial interventions in their reviews, diluting the potential effect size. Another notable research gap is the inclusion of patients who are not clinically distressed in psychosocial intervention studies, which also mutes the effect of targeted interventions.<sup>111</sup> Most studies to date have focused on interventions for patients with breast cancer, and further

work to determine the generalizability of these interventions is essential.<sup>112-114</sup>

### Recommendations

We recommend referral of patients to evidence-based interventions as determined by prior randomized trials, systematic reviews, meta-analyses, and national and international guidelines. This may involve establishing a referral network within and outside the local institution with the requisite skills to effectively address patient symptoms and problems. To address a potential knowledge gap, Table 2 provides an overview of the 12 most common cancer-related symptoms/problems and recommendations for evidence-based, targeted interventions to address each.<sup>40,42,111,115-203</sup>

In Table 2, we include evidence-based, targeted interventions with moderate-to-strong effects, as determined by meta-analyses, rigorous randomized controlled trials (RCTs), or oncology guidelines for each of these 12 cancer-related symptoms/problems. Although there are additional evidence-based biobehavioral interventions for patients with cancer,<sup>148,204</sup> for the current review, we have focused on targeted interventions to address specific problems contributing to patient distress. For most of these problems, psychosocial interventions are the recommended first-line intervention. For example, cognitive therapy is superior or equivalent to medications for moderate or severe depression.<sup>205</sup> To our knowledge, no current published research has reported comparative medication-therapy trials among patients with cancer—a significant gap given the association between depression and cancer mortality.<sup>206</sup> Given the substantial differences in biochemistry, immunity, and physical symptoms for patients with cancer, it is important not to assume that interventions (psychological, medical) that work in the general population will definitely work with the oncology population. RCTs are the standard to guide intervention selection. Additional RCTs are necessary to continue to translate intervention research from the general population to more diverse oncology samples.

### Interventions for Underserved Populations

Continued gaps remain in the psychosocial intervention literature with regard to demographic, disease, and treatment characteristics that may impact treatment effectiveness.<sup>144</sup> Current intervention studies frequently have limited diversity and often do not include patients with metastatic or advanced disease. In a 2006 review of 60 studies of psychosocial treatment and 12 studies of pharmacologic treatment for anxiety or depression in patients who had cancer, only 9% of studies focused on patients with stage IV or metastatic disease.<sup>207</sup> Furthermore, it is projected that, by 2044, approximately 50% of the US population will belong to a minority group,<sup>208</sup> suggesting that a key goal of future psychotherapy research in the cancer setting must involve a combination

**TABLE 2. Evidence-Based Psychosocial Interventions**

DISTRESS DOMAIN AND SYMPTOM/PROBLEM	INTERVENTIONS AND GUIDELINES	REFERENCE(S)
Physical symptoms	First-line interventions:	Hilfiker 2018, <sup>115</sup> Mustian 2017, <sup>116</sup> Heckler 2016, <sup>117</sup> Zhou & Recklitis 2020 <sup>118</sup>
Fatigue	<ul style="list-style-type: none"> <li>• CBT, including CBT-Insomnia</li> <li>• Exercise interventions, especially multimodal interventions (yoga, aerobic exercise, resistance training, stretching, Tai Chi)</li> <li>• Rehabilitation, including physical medicine, physical therapy, and occupational therapy</li> </ul>	Hilfiker 2018, <sup>115</sup> Meneses-Echavez 2015 <sup>119</sup>
	Second-line interventions:	NCCN 2020, <sup>120,121</sup> Bower 2014 <sup>122</sup>
	<ul style="list-style-type: none"> <li>• eHealth self-management programs</li> <li>• Erythropoietin and methylphenidate, with close attention to contraindications</li> </ul>	Xu 2019 <sup>123</sup> Tomlinson 2018, <sup>124</sup> Oberoi 2018, <sup>125</sup> Qu 2016 <sup>126</sup>
Pain (including neuropathy)	<ul style="list-style-type: none"> <li>• Systematic light therapy</li> </ul>	Wu 2018 <sup>127</sup>
	First-line interventions:	Swarm 2019 <sup>128</sup>
	<ul style="list-style-type: none"> <li>• NSAIDs or acetaminophen</li> <li>• Adjuvant opioid analgesics (antidepressants, anticonvulsants, topical agents, corticosteroids)</li> <li>• Psychosocial interventions (CBT, ACT, MBSR)</li> </ul>	Carmichael 2016 <sup>129</sup> Carmichael 2016 <sup>129</sup>
	<ul style="list-style-type: none"> <li>• Anticonvulsants and antidepressants alone or in combination with pain medications for neuropathic pain</li> <li>• Celiac plexus block for pancreatic cancer pain</li> <li>• Self-management interventions</li> </ul>	Gorin 2012 <sup>130</sup> Guan 2016, <sup>131</sup> Jongen 2013 <sup>132</sup> Zhong 2014 <sup>133</sup> Koller 2012, <sup>134</sup> Bennett 2009 <sup>135</sup>
	Second-line interventions:	Oliva 2017 <sup>136</sup>
	<ul style="list-style-type: none"> <li>• Opioid analgesics (first line intervention in pain crisis, oncologic emergency, or severe pain) always accompanied by bowel regimen and risk mitigation strategies</li> <li>• Massage therapy</li> <li>• Music interventions, especially patient selected music</li> </ul>	da Silva 2019, <sup>137</sup> Boyd 2016, <sup>138</sup> Lee 2015 <sup>139</sup> Yangoz & Ozer 2019, <sup>140</sup> Tsai 2014 <sup>141</sup> Lyons 2019, <sup>142</sup> NCCN 2020 <sup>143</sup>
Functional decline, weakness, participation in meaningful activities	Refer to physical medicine and rehabilitation services, including speech, physical therapy, and occupational therapy	Sanjida 2018, <sup>144</sup> Jacobsen & Jim 2008, <sup>144</sup> Lubbert 2001, <sup>145</sup> Devine & Westlake 1995 <sup>146</sup>
Psychological symptoms	Relaxation techniques	Devine & Westlake 1995, <sup>146</sup> McQuellon 1998 <sup>147</sup>
Anxiety-worry	Psychoeducation Stress management and skills training	Antoni 2006, <sup>148</sup> Jacobsen 2002 <sup>149</sup>

TABLE 2. (Continued)

DISTRESS DOMAIN AND SYMPTOM/PROBLEM	INTERVENTIONS AND GUIDELINES	REFERENCE(S)
Depression	CBT	Osborn 2006, <sup>150</sup> Traeger 2012 <sup>151</sup>
	Mindfulness-based interventions	Zhang 2015, <sup>152</sup> Piet 2012 <sup>153</sup>
	Hypnosis for procedural anxiety (pediatric)	Nunns 2018 <sup>154</sup>
	Exercise interventions	Loh 2018, <sup>155</sup> Chen 2015, <sup>156</sup> Jensen 2014, <sup>157</sup> Mehner 2011 <sup>158</sup>
	Mobile applications for patients with advanced cancer	Greer 2019 <sup>159</sup>
	Music interventions	Yangoz 2019, <sup>140</sup> Tsai 2014 <sup>160</sup>
	Behavioral activation and problem-solving therapy	Hopko 2011, <sup>161</sup> Neuz 2003 <sup>162</sup>
	CBT, including CBT-insomnia	Picceathly 2009, <sup>163</sup> Antoni 2001, <sup>164</sup> Tarrow & Montgomery 2006, <sup>165</sup> Sadler 2018 <sup>166</sup>
	Cognitive therapy for advanced cancer	Savard 2006 <sup>167</sup>
	Supportive-expressive therapy for advanced cancer	Goodwin 2001, <sup>168</sup> Kissane 2007 <sup>169</sup>
Fear of cancer recurrence	Collaborative care management	Eli 2008 <sup>170</sup>
	Group CBT	Simpson 2001 <sup>171</sup>
	Antidepressant medication	Rodin 2007, <sup>172</sup> Ng 2011 <sup>173</sup>
	Psychoeducation intervention	Dieng 2016 <sup>174</sup>
	CBT	Van de Wai 2017 <sup>175</sup>
	Meta-cognitive therapy and mindfulness	Cheli 2019 <sup>176</sup>
	Meaning-centered group therapy	Breitbart 2015, <sup>177</sup> 2019 <sup>178</sup>
	Managing Cancer and Living Meaningfully (CALM)	Lo 2014 <sup>179</sup>
	Existential interventions	Grossman 2018 <sup>180</sup>
	Supportive affective group therapy	Miller 2005 <sup>181</sup>
Feeling like a burden/loss of independence	Family and couples interventions	Regan 2012, <sup>182</sup> Applebaum & Breitbart 2013 <sup>183</sup>
	Psychoeducational interventions	Applebaum & Breitbart 2013, <sup>183</sup> Northouse 2010 <sup>184</sup>
	Problem solving and coping skills interventions, including caregiver goal adjustment	Northouse 2010, <sup>184</sup> McMillan 2006, <sup>185</sup> Majestic & Eddington 2019 <sup>186</sup>
	CBT and psychotherapy	Applebaum & Breitbart 2013, <sup>183</sup> Northouse 2010 <sup>184</sup>
	CHES, an eHealth intervention	DuBenske 2014 <sup>187</sup>
	Physical medicine and rehabilitation evaluation to address loss of function	Sanft 2019, <sup>188</sup> VanderWalde 2016 <sup>189</sup>
	First-line interventions:	
	<ul style="list-style-type: none"> <li>• Standardized screening for sleep disorders in oncology setting</li> </ul>	Zhou 2017 <sup>190</sup>
	<ul style="list-style-type: none"> <li>• CBT-insomnia</li> </ul>	Woodward 2011, <sup>191</sup> Johnson 2016 <sup>192</sup>
	<ul style="list-style-type: none"> <li>• Video and mobile app CBT-insomnia interventions</li> </ul>	Savard 2021, <sup>193</sup> Ritterband 2012 <sup>194</sup>
Insomnia	CBT and psychotherapy	Northouse 2010, <sup>184</sup> McMillan 2006, <sup>185</sup> Majestic & Eddington 2019 <sup>186</sup>
	CHES, an eHealth intervention	DuBenske 2014 <sup>187</sup>
	Physical medicine and rehabilitation evaluation to address loss of function	Sanft 2019, <sup>188</sup> VanderWalde 2016 <sup>189</sup>
	First-line interventions:	
	<ul style="list-style-type: none"> <li>• Standardized screening for sleep disorders in oncology setting</li> </ul>	Zhou 2017 <sup>190</sup>
	<ul style="list-style-type: none"> <li>• CBT-insomnia</li> </ul>	Woodward 2011, <sup>191</sup> Johnson 2016 <sup>192</sup>
	<ul style="list-style-type: none"> <li>• Video and mobile app CBT-insomnia interventions</li> </ul>	Savard 2021, <sup>193</sup> Ritterband 2012 <sup>194</sup>

TABLE 2. (Continued)

DISTRESS DOMAIN AND SYMPTOM/PROBLEM	INTERVENTIONS AND GUIDELINES	REFERENCE(S)
<p>Social-practical problems</p> <p>Financial "toxicity"</p>	<p>Second-line interventions:</p> <ul style="list-style-type: none"> <li>• For comorbid anxiety and insomnia, benzodiazepine, such as lorazepam, with attention to potential adverse effects (daytime drowsiness, dizziness, memory impairment)</li> <li>• Trazodone, mirtazapine, gabapentin, depending on comorbid symptoms</li> </ul> <p>Assessment of financial toxicity as part of comprehensive cancer care</p> <p>Patient and health professional education on financial toxicity</p> <p>Foundation grants through oncology specialty pharmacy teams</p> <p>Return-to-work interventions</p> <p>Equity interventions for clinical trial participation</p> <p>Patient-assistance programs</p>	<p>Holbrook 2000<sup>195</sup></p> <p>Kwak 2020<sup>196</sup></p> <p>Carrera 2018,<sup>40</sup> Ver Hoeve 2021<sup>197</sup></p> <p>Carrera 2018<sup>40</sup></p> <p>Farano &amp; Kandah 2019<sup>198</sup></p> <p>Pearce 2019<sup>199</sup></p> <p>Nipp 2019<sup>200</sup></p> <p>Yezefski 2018<sup>42</sup></p> <p>Padgett 2020,<sup>201</sup> Asher 2017<sup>202</sup></p>
<p>Problems obtaining medications</p>	<p>First-line interventions:</p> <ul style="list-style-type: none"> <li>• Referral for assessment recommendations</li> <li>• Neuropsychology</li> </ul> <p>Cognitive rehabilitation services:</p> <ul style="list-style-type: none"> <li>• Neuropsychology, occupational therapy, or speech therapy</li> <li>• Patient education on coping with cancer-related cognitive changes</li> </ul>	<p>Asher 2017<sup>202</sup></p> <p>Wilders 2014<sup>203</sup></p>
<p>Cancer-related cognitive impairment</p>	<p>Second-line interventions:</p> <ul style="list-style-type: none"> <li>• Medication trial if appropriate (methylphenidate, modafinil, donepezil)</li> </ul> <p>For older adults:</p> <ul style="list-style-type: none"> <li>• Geriatric cognitive screening or assessment (geriatrician, occupational therapy, neuropsychology)</li> <li>• Effective management of geriatric depression</li> </ul>	

Abbreviations: ACT, acceptance and commitment therapy; CBT, cognitive behavioral therapy; MBSR, mindfulness-based stress reduction; NCCN, National Comprehensive Cancer Network; NSAIDs, nonsteroidal anti-inflammatory drugs.



of discovery-oriented and standard hypothesis-testing paradigms to define and evaluate evidence-based treatments in diverse populations.<sup>209</sup>

### Recommendations

We recommend developing targeted approaches to identifying diverse and underserved patient populations proactively to help enable efficient clinician assessment and more nuanced triage to services.<sup>60</sup> Adaptation of DM efforts to different cultures/backgrounds is facilitated by cultural competency training and workforce diversity.<sup>210,211</sup> Enhancing workforce diversity in the context of limited finances may be accomplished by including chaplains, lay health workers, and peer navigators. These peer advocates and navigators can increase illness understanding across cultures, address *cultural-clinical mishaps*,<sup>210</sup> and facilitate referral of patients to programs and services to meet specific needs. It can be very helpful to include diverse voices on the Patient-Family Advisory Council in settings that use this structure.<sup>212</sup> Someone on the care team should be tasked with identifying and vetting community resources that fill in the gaps of resources for patients with cancer; this role often falls to social work.

Complementary qualitative, ethnographic, and quantitative approaches should respect and incorporate ethnic and cultural values into treatment research.<sup>41</sup> In addition, clinicians must develop proficiency in discussing race and ethnicity (as well as other aspects of sociodemographic diversity) and discerning when culturally tailored interventions are indicated as a standard component of assessment and intervention.<sup>213-215</sup>

### Interventions for Key Psychosocial Outcomes for Patients and Caregivers

Several psychosocial needs have not yet been addressed by evidence-based intervention research or have a fairly limited evidence base. Patients who are diagnosed with cancer use medication to treat depression or anxiety at twice the rate of the general population<sup>216</sup>; however, the reasons for this are not well understood. Furthermore, there are limited RCTs of psychosocial interventions for hot flashes, complicated grief, demoralization, fears of recurrence, self-perceived burden, financial toxicity, and coping with cognitive and functional changes by disease type—all issues of known importance to patients with cancer and caregivers.

Although caregiver intervention research has shown tremendous growth in recent years,<sup>217,218</sup> studies focused on screening and triage processes for caregivers have lagged far behind. This is particularly relevant for parents of children with cancer, caregivers of patients with brain tumors, and other vulnerable caregiver populations.<sup>219</sup>

### Recommendations

The current NCCN guidelines provide decision trees and clinical assessment and referral for each component of

distress.<sup>15</sup> These guidelines can serve as a map for clinical pathways that are consensus-based when evidence is not available. The APOS Roadmap is a useful resource outlining several key areas in need of research and clinical development.<sup>220</sup> National organizations should prioritize interventions and models of care that incorporate the patient (and caregiver) perspective with attention to the inclusion of vulnerable and diverse populations. Comparison trials featuring standardized pharmacologic and psychological interventions, including cost-effectiveness data, are also warranted.

### Processes

For DM programs to result in effective and efficient outcomes, careful planning is needed for the implementation of DM protocols. This includes the selection of screening format and timing, policies and training on triage processes, improvement in patient access to services to best meet their needs, and close attention to urgent situations such as patient and family crises, suicidality, and end-of-life needs.

### Screening Format

Programs must decide whether to implement paper versus electronic methods of screening. The use of paper-based screening requires additional work, such as entry of screening information into the electronic medical record and filing of forms in Health Insurance Portability and Accountability Act (HIPAA)-protected systems. Conversely, development of web-based entry systems can be time-consuming, expensive, and require the availability of technology support. Some systems are available for purchase<sup>221</sup> but can be costly in terms of both initial purchase and ongoing technology support. Other systems, such as PROMIS-CAT (computer-adaptive testing), have demonstrated low rates of completion (50%), particularly if sent using online systems,<sup>222,223</sup> necessitating back-up paper tools.

### Recommendations

We recommend implementation of procedures that are supportive of routine, regular screening, including selection of a tool that can be completed quickly (to not disrupt clinic flow) by patients using an electronic format. Useful strategies may include the incorporation of screening into existing procedures by registration staff or clinic check-in procedures (particularly if there is an electronic aspect to this). To the degree possible, the overall assessment process should be taken into account to reduce repetition of questions across the course of a patient visit, particularly coordinating distress screening with other nursing assessments.

We recommend electronic screening for its timeliness in getting screening data to relevant clinicians while the patient is on-site. Tablet-based screening can be very helpful,<sup>224</sup> particularly with a system that automatically sends results to

relevant staff members who can follow-up with the patient in meaningful and timely clinical encounters. This is particularly important for distress screening tools assessing suicidality because protocols for timely follow-up are crucial for risk mitigation and safety monitoring. Electronic methods can also be helpful for tracking of screening results. Ideally, information technology personnel would work collaboratively with supportive care staff to design, implement, and evaluate a user-friendly system for screening, triage, referral, and outcomes assessment. When DM becomes more systemic, time must also be allocated by administration for staff training in electronic implementation procedures. It can also be helpful to have templated language and *smart phrases* available to staff for documenting screening results or managing relevant triage to increase efficiency. For completeness, we recommend a back-up option for screening in the clinic setting (for patients who are unable or unwilling to use electronic means).

For programs that can only use paper-based screening, we recommend integration of the screening process into clinic procedures (eg, when completing other paperwork at check-in). Effective response to distress screening also requires timely distribution of the screening results to relevant clinicians who will see the patient. This can be accomplished by routing the paper results to the clinical staff seeing the patient or quickly entering the screening results into the EHR.

### Timing of Screening

The timing of administration can be another challenge faced by programs. Of note, if patients complete screening at their initial oncology visit, high levels of distress can be anticipated.<sup>225</sup> For instance, in the comprehensive cancer center pilot reported by Ehlers and colleagues, all new patients received DT and PROMIS screening at their first clinic visit.<sup>226</sup> The most commonly reported problems included fatigue, difficulty coping, feeling anxious or fearful, pain, and sleep disturbance. Although patients commonly report these symptoms, understanding how symptoms evolve across the disease trajectory and considering DM in this context will be important. Existing evidence suggests that psychological adjustment is likely to improve over time from diagnosis to completion of treatment for patients with early stage breast cancer.<sup>225</sup> However, patients diagnosed with advanced disease and those with severe physical symptoms or limited life expectancy are particularly vulnerable to distress,<sup>227</sup> with an often rapidly changing symptom picture, suggesting the need for more frequent screening.

The frequency of distress screening represents another point of variability in screening practice. The NCCN guidelines have specified the aspirational goal of screening every patient/every visit as a component of patient-centered care, but many institutions struggle with the logistics and resources associated with screening at every visit.<sup>15</sup> CoC

guidelines specify that patients should be screened once during their first course of treatment.<sup>25</sup> The latest Quality Oncology Practice Initiative Certification Program Standards (Standard 1.4) require screening and intervention with each cycle of chemotherapy.<sup>26</sup>

### Recommendations

On the basis of NCCN DM guidelines, we recommend screening at every medical visit, “as a hallmark of patient-centered care.”<sup>15</sup> Minimally, patients should be screened close to their initial visit, at regular intervals based on initial disease status, and as clinically indicated at certain times (ie, initiation/completion of treatment, disease recurrence/progression, and end of life). We recommend screening more frequently for patients with advanced disease because of the high prevalence and severity of symptoms and distress.<sup>227</sup>

### Patients Declining Services

Recent research suggests that some patients who report high levels of distress exhibit low uptake of services. In a review of EHRs, 30% of patients reported elevated distress.<sup>228</sup> Of those patients, approximately 17% declined further assessment; and, of the remaining patients who screened positive and completed the initial assessment, only 19% attended a follow-up appointment. This *leaky pipeline* presents a challenge in effectively addressing distress.

Multilevel factors can impact access to recommended follow-up, and tailored approaches are needed. Patients may not be aware of psychosocial or rehabilitation services or how these services can help them. Patients may be concerned about stigma associated with mental health care<sup>229</sup> or may also have had previous negative experiences with access to and utilization of mental health care. In addition, patients may lack insurance coverage for mental health services. Finally, depression symptoms can affect motivation for treatment and make it harder to follow through on referrals.

### Recommendations

Because of the multilevel factors that can negatively impact uptake of psychosocial services, tailored approaches to triage are needed. First, patient education materials should be available that explain each service to patients, the evidence base for interventions, logistics to access care, as well as costs of services. To address issues related to mental health stigma, physicians and nursing staff can normalize these services as part of state-of-the-art comprehensive cancer care. Occasional check-ins with patients reporting high distress and the provision of informational resources and written materials (ie, handouts outlining the importance of psychological, behavioral, and lifestyle factors in cancer treatment, recovery, survivorship/quality of life, and outcomes), even if the patient declines services, may prove beneficial over time and promote receptivity to services.

Oncology clinicians may benefit from education about the evidence for supportive care services so that they can answer patients' questions on these topics. This may also help to address negative biases about supportive care and facilitate oncologist buy-in,<sup>230</sup> which is key to patient uptake. In addition, it is recommended that psychosocial clinicians partner with oncology teams to provide regular educational presentations, inclusive of language that promotes interdisciplinary partnership and decreases stigma (eg, normalizing mental health care as akin to physical health care). Evidence suggests that training for clinicians that includes direct contact with individuals who have mental illness can change attitudes about mental illness.<sup>231</sup>

Given the low baseline of uptake, psychosocial oncology clinicians should explore ways of addressing barriers to access for psychosocial services. Collaborative care models that are integrated into cancer care increase access to psycho-oncology care.<sup>232</sup> Telehealth interventions, including phone and video conferencing, now widely available after the coronavirus disease 2019 (COVID-19) pandemic, can increase access to palliative and psycho-oncology care for patients and caregivers.<sup>233,234</sup> In addition, linking psychosocial visits with oncology visits on the same day or conducting joint visits can be effective ways to build trust and decrease patient burden.

### Patients Requesting Support but Not Meeting Screening Criteria

Patients who do not screen positive may request access to support resources. This may be attributable to the use of high thresholds for a positive screen, the use of a narrowly focused tool for screening, patient discomfort with the screening process or with self-disclosure, or high patient receptivity to support services. For example, one study of women with gynecologic cancer found that uptake of support services was higher among patients with a greater number of noncancer-related stressors as well as those with lower levels of support and an expressed interest in self-management options.<sup>235</sup> Although distress screening can assist in identifying patients with self-reported distress, staff may become aware of patients' desire for support through other means—patients with a negative screen who may nevertheless identify several problems on a problem list or patients who may share personal concerns with staff outside of the screening process.

### Recommendations

A negative screen should not preclude access to services. All oncology and support staff should feel comfortable reporting patient concerns to appropriate personnel and making referrals to psychosocial oncology staff and providers, with or without a positive distress screen. Brief assessments, education, or provision of information and resources can be offered and may be sufficient. As an alternative, when resources are limited, these patients can be directed to online, self-management, or community resources.

### Triage to Relevant Services

Diffusion of responsibility may play a role in failure to identify and help patients who are experiencing distress. In using a patient-centered approach for designing services, screening would be based on the most common and distressing problems/concerns experienced by patients with cancer.<sup>99</sup> On the basis of previous studies, the most common and distressing problems include pain, fatigue, worry, and uncertainty; feeling down or depressed; coping with functional challenges; concentration/memory issues; financial toxicity; and sleep difficulties.<sup>15,236</sup> The COVID-19 pandemic may be a new source of distress, including financial distress, the risk of being immunocompromised, and increased social isolation.<sup>237</sup> Most patients who screen positive for distress cite physical (49%), followed by emotional (42%) and then practical (28%) concerns.<sup>238</sup> Family problems and nutritional concerns are also prevalent.

Institutions vary on who/which discipline is responsible to triage positive screens. Many institutions have psychosocial-oncology clinicians respond to all positive distress screens. However, if more broad-based tools are used, other disciplines may need to assist with the identification and response to problems highlighted by screening. Importantly, proactive identification and linking of patients to appropriate treatment is associated with higher rates of completing cancer care.<sup>239</sup>

### Recommendations

Development of an institutional protocol identifying who is most appropriate to triage distress is helpful and should include both medical and psychosocial clinicians. Before initiation of screening, institutions will need to assure they have appropriate referral resources and trained clinicians in place. In some clinical settings, clinicians may feel overwhelmed by the sheer level of need. It is important to establish both triage models and extensive referral networks, using resources inside and outside the clinical setting, and to implement care delivery models that can expand reach, including collaborative care and telehealth. For example, for unmet general support needs, there may be community agencies, faith communities, or local champions that could be added to a referral network. A trained navigator can establish community partnerships, maintain connections between the cancer setting and community resources, and serve as the bridge to access for patients.<sup>45</sup> Having a broad array of available resources provides patients with multiple avenues for receiving needed support and perhaps greater opportunity to find an intervention that best fits their needs.

### Urgent Referrals

Some patient groups may require more urgent triage to certain services, including patients with advanced or terminal disease, patients in crisis, those recently hospitalized

for psychiatric reasons, and patients at high risk for suicide. Although this likely represents a minority of patients among those needing support services, usual triage procedures may not be able to accommodate the increased urgency. If these patients are unable to receive the support they need, not only could their participation in treatment or follow-up care be jeopardized, but their safety may be at risk.

### **Recommendations**

Systems should be put into place to ease access to services for patients with urgent needs for psychological/psychiatric care. This might include a few blocked hours in providers' schedules to accommodate urgent referrals, a psychosocial clinician on call during business hours, a crisis clinic with clinicians trained to address cancer-specific problems, and/or providers trained to meet the specific needs of patients approaching the end of life (eg, advance care planning, symptom management, spiritual issues, family communication needs). Care should also be taken to distribute urgent cases evenly among outpatient clinicians as well to prevent burnout, recognizing that patients with urgent needs often require greater time and coordination.

We also recommend program development and coordination between general inpatient psychiatric and inpatient or outpatient oncology programs. Patients requiring urgent psychiatric admissions related to cancer may have distinct needs that are not typically addressed by inpatient and intensive outpatient mental health programs that lack ease and expertise in caring for patients with cancer. Depending on the urgency of cancer care, psychiatric care may need to be integrated into a medical hospitalization to prevent delays in receiving needed chemotherapy or radiation. As examples, steroids given to decrease nausea and prevent allergic reaction to chemotherapy may contribute to symptoms of mania in a patient with bipolar disorder; or edema related to a frontotemporal brain tumor may cause disinhibition, aggression, or mood lability. Flexibility and person-centered approaches are needed given limited facilities with joint expertise in medical and psychiatric needs.

## **Organization—Inner Setting**

Institutional (hospital, clinic, and health care system) factors contribute to breakdowns in DM. These include the size and type of cancer programs, leadership engagement in psychosocial care and evaluation, organizational culture, and the system incentives and rewards for providers engaging in a comprehensive screening and psychosocial care model. These characteristics can vary across types of cancer center organizations (eg, large academic safety-net hospital vs small community cancer center) and within a single cancer center (eg, breast vs head/neck cancer clinic). In addition, surveys of clinical staff that address the barriers to adopting distress screening have found that time, staff uncertainties,

competing demands, and ambiguous accountability are some of the biggest barriers.<sup>151,152</sup> To incorporate DM into a comprehensive approach to evidence-based delivery of cancer care, the following potential inner organizational barriers should be addressed.

### **Lack of Clearly Defined Policy and Procedures for Distress Management**

According to the CoC 2020 accreditation standards, cancer centers are required to have a psychosocial service policy and a process that address the broad spectrum of distress, including “physical, psychological, social, spiritual, and financial needs” as well as procedures for the provision and monitoring of distress screening and referral.<sup>25</sup> Many cancer centers fail to establish procedures for addressing positive screens and making the relevant referral, leading to protocols that are difficult to maintain and do not adequately address the intervention and monitoring aspects of DM.

### **Recommendations**

A clearly documented policy for comprehensive DM should be readily available. Concise, user-friendly algorithms for the appropriate screening and triage of identified needs are necessary. These algorithms should include referral mechanisms to address patient's comprehensive supportive care needs, including the domains cited by the CoC standard.<sup>25</sup> As noted above, individuals who will screen and provide targeted interventions should be involved in developing the local DM protocol to increase uptake.<sup>15</sup> In addition, a process should be specified for monitoring outcomes over time and adjusting course when indicated.

### **Lack of Training for Relevant Staff in Procedures for Distress Management**

Mental health clinicians may lack training in psycho-oncology given the limited number of psycho-oncology training programs. Therefore, providers may not be aware of effective, evidence-based treatments for common areas of psychosocial distress, limiting interventions to supportive counseling and patient-led groups with more limited evidence of effect. Mental health clinicians who lack training in psycho-oncology may experience anxiety about treating patients with cancer, particularly at the end of life, leading to additional barriers to care in the community. In addition, oncology medical training and mental health training are fragmented, with the result that oncology physicians often receive limited education in strategies to address depression, anxiety, and the risk of suicide.

### **Recommendations**

Administrators must allocate time for training relevant staff on the policies for screening and the methods for assessing, triaging, and referring patients to supportive care services, as well as monitoring outcomes. Ideally, this is incorporated in

on-boarding procedures for new oncologists, advanced practice clinicians, nurses, and psychosocial and rehabilitation staff and is reviewed annually with all clinical staff. Policy and procedures should be reviewed at departmental and treatment team meetings, with regular reminders for use of the DM protocol in institutional publications. We strongly recommend that clinicians hired to work in psychosocial oncology have specific training in psychosocial assessment and evidence-based treatment of patients who have cancer. For those who are postdegree, educational opportunities are available at professional conferences (APOS, Association of Oncology Social Workers, Oncology Nursing Society), through continuing education programs, or through the professional literature. In addition, APOS has developed a core curriculum and is currently translating this into an on-line training program to expand the psychosocial oncology workforce.

### Lack of Procedural Accountability

Zebrack and colleagues<sup>240</sup> evaluated fidelity to DM protocols across 2 comprehensive cancer centers and found that clinicians deviated from the protocol 25% to 50% of the time. In subsequent research, adherence to a locally established DM protocol was associated with lower emergency room utilization and reduced rate of hospitalization.<sup>10</sup> Factors precluding adherence to DM protocols were identified and included inadequate numbers of psychosocial care personnel, lack of funding, inadequate amount of time, lack of systematic procedures, and inadequate training for oncology providers.<sup>241</sup> These findings highlight the potential importance of organizational and provider commitment to screening and adherence to the locally established protocol, recognizing the importance of provider acceptance or *buy-in* as a key contributor to adherence.<sup>230</sup> Attention to screening efficiency is an essential strategy to enhance oncology team *buy-in*.

### Recommendations

Programs must establish review procedures to ensure that screening tools are consistently administered across clinics. The CoC accreditation standard requires a psychosocial services coordinator as a member of the cancer committee and imbues this person with responsibility for overseeing the DM process.<sup>25</sup> This individual can lead a broadly multidisciplinary committee to develop and review DM protocols and outcomes. When specific clinics are not meeting screening targets, a quality-review process should be used to identify and address relevant issues. Ideally, these processes are integrated into quality incentives, and the psychosocial services coordinator has accountability for the success of the DM process. Even in settings not accredited by the CoC, it is useful to have one person identified as responsible and accountable for DM processes and procedures.

### Inadequate Staff to Meet Demands

On-site support services can reduce barriers to access for many patients. In practice, many psychosocial services are institutionally funded<sup>155</sup> and not financially self-supporting, thus many cancer settings have limited psychosocial staff in house. Even when on-site psychosocial staff are available, competing demands or urgent patient needs may preclude timely access to support services.

### Recommendations

Similar to palliative medicine clinician/patient metrics,<sup>242,243</sup> staffing ratios should be balanced to meet patients' needs based on standardized benchmarks for each specialty area (ie, psychology, psychiatry, social work, nursing, chaplaincy) and should take into account the complex case management and other nonclinical responsibilities of psychosocial providers, particularly in academic medical centers. APOS is currently completing benchmarking with psychosocial oncology programs nationwide to provide guidance on setting reasonable staffing ratios and other metrics. For an oncology social worker, a recommended staff-to-patient ratio is 1:400.<sup>244</sup> Preliminary results of an APOS survey of 104 members indicate that, for a full-time outpatient psychosocial oncology therapist/counselor, 20 to 25 direct patient hours is the average caseload for most institutions, resulting in a caseload of not more than 50 to 60 patients to accommodate twice-monthly follow-up visits.<sup>245</sup> If patients are unable to access initial appointments within 2 months, additional psychosocial hires are recommended.

### Lack of Utilization of Efficient Psychosocial Models of Care

Given the shortage of mental health care professionals in most cancer institutions,<sup>28</sup> it is essential that patients are triaged based on need. When screening measures lack high sensitivity or specificity, referred patients may have subthreshold symptoms, resulting in inefficient use of limited specialist resources. Clinicians may also be poorly used by not being asked to function at the peak of their licensed abilities.

### Recommendations

Stepped or collaborative care models incorporate screening and triage based on the patient's level of distress. These models also re-assess patients over time to ensure treatment effect. Butow and colleagues provide a useful review of a stepped care model, including a description of evidence-based interventions for each level of care.<sup>246</sup> Pirl and colleagues provide a similar endorsement of collaborative care, taking into account the variability of institutional mental health resources.<sup>61</sup> Collaborative care models are evidence-based, team-based approaches that increase access to mental health care and improve depression symptoms for patients in oncology settings while also being relatively more cost-effective.<sup>232,247,248</sup> These models can also be extended to

serious mental illness and cancer.<sup>60</sup> Stepped care and collaborative care models are consistent with ASCO guidelines<sup>26</sup> which recommend regular monitoring of clinical progress, side effects, and satisfaction with care using frequent psychosocial interventions, depending on the severity of the condition. These models allow for the right patient to be matched with the right treatment at the right time.

Organizations should familiarize themselves with stepped or collaborative care models and align their processes and providers accordingly, such that those patients who have subthreshold scores receive universal guidance or psychoeducation; those with mild-to-moderate symptoms receive supportive care, counseling, or coping skills training; and those with moderate-to-severe symptoms receive specialist care provided by a psychologist or psychiatrist. Patients referred for specialist care ideally would have moderate-to-severe distress, clinically significant levels of depression and/or anxiety, or preexisting mental illness. Community providers and resources can be used to address distress that is not related to cancer or distress that is subthreshold.

### Clinician Burnout

Compassion fatigue and burnout are well documented challenges in the oncology workforce among oncologists, nurses, and psychosocial providers.<sup>249,250</sup> Clinician burnout can interfere with and serve as a barrier to effective DM. Providers who are experiencing emotional exhaustion or depersonalization may have less energy, compassion, and empathy, and they may be less likely to recognize, initiate, or follow through with DM for their patients. When the workforce is affected by burnout, there are adverse costs to health care at various levels: institution (eg, staff turnover), clinician (eg, decreased job satisfaction), and patient (eg, increased risk of errors).<sup>251</sup> There is increased recognition of the problem in health care in general, particularly because of the COVID-19 pandemic, and many wellness efforts are underway.

### Recommendations

Contributing factors to burnout are numerous and complex and a result of both organizational and individual clinician factors,<sup>252</sup> with a disproportionate amount of burnout (80%) attributed to workplace environments.<sup>253</sup> Therefore, we recommend institutional efforts to build an organizational culture to support provider well-being, support workplace efficiency, and offer programs that support individual resilience. Examples of this may include acknowledgment and discussion of the problem, targeted interventions, development of peer support, and promotion of work-life balance.<sup>254,255</sup> Work environments that fully embody and implement a wellness culture will benefit all providers. In addition, we recommend addressing individual factors by including education about burnout, enhancing resilience,

and offering communication skills training, and cognitive-behavioral and mindfulness interventions.<sup>256,257</sup>

## Organization: Outer Setting

### Reimbursement for Psychosocial Services

The American Medical Association Common Procedural Terminology (CPT) Editorial Panel defines who can use specific CPT codes, and the American Medical Association Relative Value Scale Update Committee recommends reimbursement rates to the Centers for Medicare and Medicaid Services each year in the Physician Fee Schedule. These rates often influence how private insurers reimburse mental health clinicians. When patients are no longer able to work because of cancer or cancer treatment, they are often faced with large COBRA (Consolidated Omnibus Budget Reconciliation Act) payments for health insurance followed by a transition to Social Security Disability with Medicare and/or the Medicaid program, depending on their financial well-being before cancer. Medicaid reimbursement rates for Level 2 through 5 providers (ie, psychologists, social workers, clinical nurse specialists, mental health trainees), who provide the majority of psychosocial care,<sup>258</sup> are substantially lower than the rates for physicians. In effect, psychologists and social workers who work in communities with the highest proportion of Medicaid patients have difficulty meeting the productivity demands of their jobs when productivity is determined by revenue generation. Relative value units (RVUs) may be a poor measure of the complexity of care and coordination required of psychosocial clinicians.

### Recommendations

The American Psychological Association, the American Psychiatric Association, and the National Association of Social Workers have been working diligently to increase RVU and reimbursement rates for generalist clinicians. We recommend that the APOS partner with the American Cancer Society, ASCO, and the Association of Community Cancer Centers to seek RVU and reimbursement rates more representative of the specialized training and expertise of psychosocial oncologists, particularly noting the need for urgent care, for example, with the incidence of suicide for patients who have cancer being nearly twice the incidence of suicide in the general population.<sup>59</sup>

### Health Care Policy

In 2019, there were an estimated 1,762,450 new cancer cases diagnosed and 606,880 cancer-related deaths in the United States.<sup>259</sup> Approximately 20% to 52% of patients who have cancer are distressed<sup>260</sup>; however, in the United States, <19% of patients with newly diagnosed cancer<sup>228</sup> and 28% of those with advanced cancer access mental health services.<sup>261</sup> The most common barriers include lack of awareness regarding the benefit of psychosocial

interventions among patients and physicians, transportation issues, stigma, time pressure in the cancer clinic, and undervaluing of psychosocial care in the culture of the practice setting.<sup>262</sup>

### Recommendations

Individuals can work with professional organizations, such as the American Psychosocial Oncology Society and the Association of Oncology Social Workers, to advocate for necessary policy changes. US health care policy changes should focus on enhancing access to psychosocial oncology care, particularly in underserved geographic locations. All psychosocial oncology clinicians should have training in evidence-based interventions and work to ensure that patients and oncology teams are aware of the benefits and logistics of access for these services. Training of this sort ideally should come from established professional training programs, but continuing education is available through the professional societies listed above as well as through other organizations like ASCO or the Association of Community Cancer Centers. The NCCN DM guidelines include information and references for evidence-based interventions.<sup>15</sup>

Policy decisions should continue to ensure parity of physical and mental health care and access for our most vulnerable populations (see Individual Characteristics, above), striving for universal coverage, telehealth/virtual models of care, and educational strategies to reduce the stigma and increase patient and clinician understanding of evidence-based interventions. Policies would ideally prioritize reimbursement strategies that value complex emotional and interpersonal therapeutic skills commensurate with the value of physical procedures and tests.

## Implementation Science and Distress Management

Unless implemented successfully, evidence-based interventions have reduced chances for eliciting desired outcomes. Therefore, program evaluations are needed that assess explicitly defined implementation outcomes as well as factors that promote and/or prohibit successful implementation. For example, Proctor and colleagues describe a set of measurable implementation outcomes that are distinguishable from service and clinical outcomes, including: the perceived acceptability or appropriateness of an intervention (from either the patient or provider perspective); its feasibility, penetration and adoption across a system; its potential for sustainability over time; and its overall cost.<sup>263</sup> Emergent hybrid study designs evaluate both implementation and effectiveness and may be useful in this regard.

Implementation of DM protocols can be viewed as a multilevel intervention involving behavior and system changes across various levels (see Fig. 2). Qualitative and quantitative studies (including those reviewed by Ehlers

et al<sup>226</sup>) have identified specific factors influencing the uptake of implementation efforts, including characteristics of individuals (eg, language barriers, preexisting mental health/substance use conditions), characteristics of the intervention (eg, choice of instrument, threshold score for referral to services), aspects of the process (eg, methodology for screening, urgent referrals), and both internal and external organizational setting influences (eg, institutional and national policies, training, and availability of staff).<sup>98,264,265</sup>

These studies, however, are limited by the absence of standardized measures and/or the lack of a theoretical framework to assure validity of the results. Nor do they all elicit suggestions from direct practice providers of psychosocial care regarding strategies and institutional changes that may increase the likelihood of successful implementation of DM protocols and subsequent improvements in patient outcomes. The current knowledge base lacks empirical evidence regarding the contextual elements and interactions across these elements that, if addressed, would most likely enhance DM implementation and subsequent achievement of desired patient outcomes. In addition, research is needed on how to improve DM programs for and reduce disparities among subgroups of patients with cancer who are typically underserved in both medical and psychological care.

On the practice side, we encourage organizations to screen broadly for distress, followed by further assessment in the identified problem areas to delineate the patients' areas of need. Furthermore, we encourage organizations to identify online, community, and self-help resources to extend the array of options for referral for individuals who have a positive screen. We also suggest integration of screening results into clinic procedures to decrease burden and to facilitate response to a positive screen by allowing the clinician to review the details of a positive distress screen before seeing the patient and to address associated problems, when appropriate, or to make timely referral to relevant services or resources to address identified problems.

These recommendations are grounded in empirical evidence, but their success will depend upon the identification and implementation of evidence-based strategies that overcome organizational and system-level barriers that preempt successful DM protocol implementation and subsequent benefit for patients. A recent systematic review of screening and referral for psychosocial distress among patients with cancer identified 5 studies of interventions aimed at improving the uptake and implementation of routine DM and concluded that these studies were *methodologically weak*.<sup>98</sup> Jacobsen and Norton suggested that DM implementation interventions may lack clinical utility in routine care because of their complexity, the amount of resources required to deliver them, and the limited range of distress-related problems they address.<sup>98</sup>

The development and testing of interventions aimed at overcoming barriers to implementing an evidence-based DM protocol requires knowing which contextual elements, if changed or reinforced, have the greatest likelihood of achieving successful penetration and sustainability of DM protocols as well as improved patient outcomes. Patient ability to access and benefit from DM protocols and referrals to psychosocial and supportive care services may be a function of institutional structures and processes that comprise domains of the CIFR.<sup>29</sup> Further investigations are needed to identify organizational and system-level change strategies that overcome the structural and procedural barriers to DM protocol implementation.

## Summary and Next Steps

As cancer treatment has become increasingly tailored, psychosocial care and other supportive services must also become more tailored. We recommend patient-centered approaches

to screening and intervention, reducing patient burden, and increasing access to needed services. While recognizing that this approach is more complicated than a one-size-fits-all approach, it is consistent with comprehensive cancer care.

Ultimately, the primary indicator of success as it relates to DM and symptom management protocols must be patient utilization of and benefit from exposure to the protocol. A next logical step for research in DM may be to develop and test interventions that target high-priority contextual conditions/domains that evidence suggests are significant, changeable, and statistically associated with penetration or sustainability of DM protocols. Research is also needed to further examine the impact of combining patient-reported outcomes and EHR data on identification of the target population and linking distressed patients to appropriate treatment, such as multisymptom interventions<sup>266</sup> (vs solitary symptom and problem interventions) to enhance the efficiency of treatment delivery. ■

## References

- Holland JC. NCCN practice guidelines for the management of psychosocial distress. National Comprehensive Cancer Network. *Oncology (Williston Park)*. 1999;13(5A):113-147.
- Faller H, Schuler M, Richard M, Heckl U, Weis J, Kuffner R. Effects of psychosocial interventions on emotional distress and quality of life in adult patients with cancer: systematic review and meta-analysis. *J Clin Oncol*. 2013;31:782-793.
- Ernstmann N, Neumann M, Ommen O, et al. Determinants and implications of cancer patients' psychosocial needs. *Support Care Cancer*. 2009;17:1417-1423.
- Clover KA, Mitchell AJ, Britton B, Carter G. Why do oncology outpatients who report emotional distress decline help? *Psychooncology*. 2015;24:812-818.
- Jacobsen PB. Promoting evidence-based psychosocial care for cancer patients. *Psychooncology*. 2009;18:6-13.
- Schneider S, Moyer A, Knapp-Oliver S, Sohl S, Cannella D, Targhetta V. Pre-intervention distress moderates the efficacy of psychosocial treatment for cancer patients: a meta-analysis. *J Behav Med*. 2010;33:1-14.
- Carlson LE, Groff SL, Maciejewski O, Bultz BD. Screening for distress in lung and breast cancer outpatients: a randomized controlled trial. *J Clin Oncol*. 2010;28:4884-4891.
- Duarte A, Walker J, Walker S, et al. Cost-effectiveness of integrated collaborative care for comorbid major depression in patients with cancer. *J Psychosom Res*. 2015;79:465-470.
- Carlson LE, Bultz BD. Benefits of psychosocial oncology care: improved quality of life and medical cost offset. *Health Qual Life Outcomes*. 2003;1:8.
- Zebrack B, Kayser K, Bybee D, et al. Psychosocial distress screening and medical service utilization: a report from the Association of Oncology Social Work Project to Assure Quality Cancer Care (APAQCC). *J Natl Compr Canc Netw*. 2017;15:903-912.
- Mirosevic S, Jo B, Kraemer HC, Ershadi M, Neri E, Spiegel D. "Not just another meta-analysis": sources of heterogeneity in psychosocial treatment effect on cancer survival. *Cancer Med*. 2019;8:353-373. doi:10.1002/cam4.1895
- Lutgendorf SK, Andersen BL. Biobehavioral approaches to cancer progression and survival: mechanisms and interventions. *Am Psychol*. 2015;70:186-197.
- Shimizu K, Ishibashi Y, Umezawa S, et al. Feasibility and usefulness of the 'Distress Screening Program in Ambulatory Care' in clinical oncology practice. *Psychooncology*. 2010;19:718-725.
- Holland JC. Preliminary guidelines for the treatment of distress. *Oncology*. 1997;11(11A):109-114.
- National Comprehensive Cancer Network (NCCN). NCCN Clinical Practice Guidelines in Oncology: Distress Management. Version 1.2020. NCCN; 2020. Accessed September 4, 2020. nccn.org/professionals/physician\_gls/pdf/distress.pdf
- Institute of Medicine (US) Committee on Psychosocial Services to Cancer Patients/Families in a Community Setting; Adler NE, Page AEK, eds. *Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs*. National Academies Press; 2008.
- Neuss MN, Desch CE, McNiff KK, et al. A process for measuring the quality of cancer care: the Quality Oncology Practice Initiative. *J Clin Oncol*. 2005;3:6233-6239.
- Commission on Cancer. *Cancer Program Standards 2012: Ensuring Patient-Centered Care*. Version 1.0. Commission on Cancer, American College of Surgeons; 2012.
- Commission on Cancer. *Cancer Program Standards 2015: Ensuring Patient-Centered Care*. Commission on Cancer, American College of Surgeons; 2015.
- 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, Association of Oncology Social Work, and Oncology Nursing Society Joint Task Force. *Cancer*. 2014;120:2946-2954.
- Kent EE, Rowland JH, Northouse L, et al. Caring for caregivers and patients: research and clinical priorities for informal cancer caregiving. *Cancer*. 2016;122:1987-1995. doi:10.1002/cncr.29939
- Rodriguez EM, Dunn MJ, Zuckerman T, Vannatta K, Gerhardt CA, Compas BE. Cancer-related sources of stress for



- children with cancer and their parents. *J Psychol*. 2012;37:185-197.
23. Wiener L, Viola A, Koretski J, Perper ED, Patenaude AF. Pediatric psycho-oncology care: standards, guidelines, and consensus reports. *Psychooncology*. 2015;24:204-211.
  24. Kazak AE, Abrams AN, Banks J, et al. Psychosocial assessment as a standard of care in pediatric cancer. *Pediatr Blood Cancer*. 2015;62(suppl 5):S426-S459.
  25. Commission on Cancer. Optimal Resources for Cancer Care: Ensuring Patient-Centered Care. Commission on Cancer, American College of Surgeons; 2020. Accessed October 8, 2020. [facs.org/quality-programs/cancer/coc/standards/2020](https://www.facs.org/quality-programs/cancer/coc/standards/2020)
  26. American Society of Clinical Oncology (ASCO). Quality Oncology Practice Initiative (QOPI®). ASCO Institute for Quality; 2020. Accessed October 8, 2021. [practice.asco.org/quality-improvement/quality-programs/quality-oncology-practice-initiative](https://www.practice.asco.org/quality-improvement/quality-programs/quality-oncology-practice-initiative)
  27. Zebrack B, Kayser K, Oktay J, Sundstrom L, Sachs AM. The Association of Oncology Social Work's Project to Assure Quality Cancer Care (APAQCC). *J Psychosoc Oncol*. 2018;36:19-30.
  28. Zebrack B, Kayser K, Padgett LS, et al. Institutional capacity to provide psychosocial oncology support services: a report from the Association of Oncology Social Work. *Cancer*. 2016;122:1937-1945.
  29. Damschroder LJ, Aron DC, Keith RE, Kirsh SR, Alexander JA, Lowery JC. Fostering implementation of health services research findings into practice: a consolidated framework for advancing implementation science. *Implement Sci*. 2009;4:50. doi:10.1186/1748-5908-4-50
  30. Hagan TH, Rosenzweig M, Zorn K, van Londen J, Donovan H. Perspectives on self-advocacy: comparing perceived uses, benefits, and drawbacks among survivors and providers. *Oncol Nurs Forum*. 2017;44:52-59. doi:10.1188/17.ONF.52-59
  31. Bauer GR. Incorporating intersectionality theory into population health research methodology: challenges and the potential to advance health equity. *Soc Sci Med*. 2014;110:10-17.
  32. US Department of Justice, Civil Rights Division. Americans With Disabilities Act. Accessed October 8, 2020. [ada.gov/](https://www.ada.gov/)
  33. Nipp RD, Zullig LL, Samsa G, et al. Identifying cancer patients who alter care or lifestyle due to treatment-related financial distress. *Psychooncology*. 2016;25:719-725.
  34. Tucker-Seeley RD, Yabroff KR. Minimizing the "financial toxicity" associated with cancer care: advancing the research agenda. *J Natl Cancer Inst*. 2016;108:djv410. doi:10.1093/jnci/djv410
  35. Zafar SY. Financial toxicity of cancer care: it's time to intervene. *J Natl Cancer Inst*. 2016;108:djv370.
  36. Meeker CR, Geynisman DM, Egleston BL, et al. Relationships among financial distress, emotional distress, and overall distress in insured patients with cancer. *J Oncol Pract*. 2016;12:e755-e764.
  37. Burris JL, Andrykowski M. Disparities in mental health between rural and nonrural cancer survivors: a preliminary study. *Psychooncology*. 2010;19:637-645.
  38. Atkins GT, Kim T, Munson J. Residence in rural areas of the United States and lung cancer mortality. Disease incidence, treatment disparities, and stage-specific survival. *Ann Am Thorac Soc*. 2017;14:403-411.
  39. Paskett ED, Pennell ML, Ruffin MT, et al. A multi-level model to understand cervical cancer disparities in Appalachia. *Cancer Prev Res*. 2020;13:223-228.
  40. Carrera PM, Kantarjian HM, Blinder VS. The financial burden and distress of patients with cancer: understanding and stepping-up action on the financial toxicity of cancer treatment. *CA Cancer J Clin*. 2018;68:153-165.
  41. Alcaraz KI, Wiedt TL, Daniels ED, Yabroff KR, Guerra CE, Wender RC. Understanding and addressing social determinants to advance cancer health equity in the United States: a blueprint for practice, research, and policy. *CA Cancer J Clin*. 2020;70:31-46.
  42. Yezefski T, Schwemm A, Lentz M, Hone K, Shankaran V. Patient assistance programs: a valuable, yet imperfect, way to ease the financial toxicity of cancer care. *Semin Hematol*. 2018;55:185-188.
  43. McMullen L. Patient assistance programs: easing the burden of financial toxicity during cancer treatment. *Clin J Oncol Nurs*. 2019;23:36-40.
  44. Kutner M, Greenberg E, Jin Y, Paulsen C. The Health Literacy of America's Adults: Results From the 2003 National Assessment of Adult Literacy. National Center for Education Statistics (NCES 2006-483). US Department of Education; 2006. Accessed October 4, 2020. [nces.ed.gov/naal/health.asp](https://nces.ed.gov/naal/health.asp)
  45. Paskett ED, Harrop JP, Wells KJ. Patient navigation: an update on the state of the science. *CA Cancer J Clin*. 2011;61:237-249. doi:10.3322/caac.20111
  46. Shersher V, Haines TP, Sturgiss L, Weller C, Williams C. Definitions and use of the teach-back method in healthcare consultations with patients: a systematic review and thematic synthesis. *Patient Educ Counsel*. 2021;104:118-129. doi:10.1016/j.pec.2020.07.026
  47. Talevski J, Wong Shee A, Rasmussen B, Kemp G, Beauchamp A. Teach-back: a systematic review of implementation and impacts. *PLoS One*. 2020;15:e0231350. doi:10.1371/journal.pone.0231350
  48. Stiggelbout AM, Van der Weijden T, De Wit MP, et al. Shared decision making: really putting patients at the centre of healthcare. *BMJ*. 2012;344:e256. doi:10.1136/bmj.e256
  49. Grabinski VF, Myckatyn TM, Lee CN, Philpott-Streff SE, Politi MC. Importance of shared decision-making for vulnerable populations: examples from post-mastectomy breast reconstruction. *Health Equity*. 2018;2:234-238.
  50. Paredes AZ, Hyer JM, Tsilimigras DI, et al. Association of pre-existing mental illness with all-cause and cancer-specific mortality among Medicare beneficiaries with pancreatic cancer. *HPB (Oxford)*. 2021;23:451-458. doi:10.1016/j.hpb.2020.08.002
  51. Kisely S, Crowe E, Lawrence D. Cancer-related mortality in people with mental illness. *JAMA Psychiatry*. 2013;70:209-217.
  52. Solmi M, Firth J, Miola A, et al. Disparities in cancer screening in people with mental illness across the world versus the general population: prevalence and comparative meta-analysis including 4,717,839 people. *Lancet Psychiatry*. 2020;7:52-63. doi:10.1016/S2215-0366(19)30414-6
  53. Irwin KE, Park ER, Shin JA, et al. Predictors of disruptions in breast cancer care for individuals with schizophrenia. *Oncologist*. 2017;22:1374-1382.
  54. Ho P, Rosenheck R. Substance use disorder among current cancer patients: rates and correlates nationally in the Department of Veterans Affairs. *Psychosomatics*. 2018;59:267-276.
  55. Paice JA. Cancer pain management and the opioid crisis in America: how to preserve hard-earned gains in improving the quality of cancer pain management. *Cancer*. 2018;124:2491-2497.
  56. Kroenke K, Spitzer RL, Williams JB. The PHQ-9: validity of a brief depression severity measure. *J Gen Intern Med*. 2001;16:606-613. doi:10.1046/j.1525-1497.2001.016009606.x

57. Spitzer RL, Kroenke K, Williams JB, Lowe B. A brief measure for assessing generalized anxiety disorder: the GAD-7. *Arch Intern Med*. 2006;166:1092-1097. doi:10.1001/archinte.166.10.1092
58. Andersen BL, DeRubeis RJ, Berman BS, et al. Screening, assessment, and care of anxiety and depressive symptoms in adults with cancer: an American Society of Clinical Oncology guideline adaptation. *J Clin Oncol*. 2014;32:1605-1619. doi:10.1200/JCO.2013.52.4611
59. Misono S, Weiss NS, Fann JR, Redman M, Yueh B. Incidence of suicide in persons with cancer. *J Clin Oncol*. 2008;26:4731-4738.
60. Irwin KE, Park ER, Fields LE, et al. Bridge: person-centered collaborative care for patients with serious mental illness and cancer. *Oncologist*. 2019;24:901-910.
61. Pirl WF, Greer JA, Wells-Di Gregorio S, et al. Framework for planning the delivery of psychosocial oncology services: an American Psychosocial Oncology Society task force report. *Psychooncology*. 2020;29:1982-1987. doi:10.1002/pon.5409
62. Anghelescu DL, Ehrentraut JH, Faughnan LG. Opioid misuse and abuse: risk assessment and management in patients with cancer pain. *J Natl Compr Canc Netw*. 2013;11:1023-1031.
63. Webster LR, Dove B. *Avoiding Opioid Abuse While Managing Pain: A Guide for Practitioners*. Sunrise River Press; 2007.
64. Quinn GP, Sanchez JA, Sutton SK, et al. Cancer and lesbian, gay, bisexual, transgender/transsexual, and queer/questioning (LGBTQ) populations. *CA Cancer J Clin*. 2015;65:384-400.
65. Boehmer U, Elk R, eds. *Cancer and the LGBT Community: Unique Perspectives From Risk to Survivorship*. Springer; 2015.
66. Institute of Medicine (IOM). *The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding*. The National Academies Press; 2011.
67. Wender R, Sharp KB, Westmaas JL, Patel AV. The American Cancer Society's approach to addressing the cancer burden in the LGBT community. *LGBT Health*. 2016;3:15-18.
68. Nelson CJ, Cho C, Berk AR, Holland J, Roth AJ. Are gold standard depression measures appropriate for use in geriatric cancer patients? A systematic evaluation of self-report depression instruments used with geriatric, cancer, and geriatric cancer samples. *J Clin Oncol*. 2010;28:348-356.
69. Chun A, Reinhardt JP, Ramirez M, et al. Depression recognition and capacity for self-report among ethnically diverse nursing homes residents: evidence of disparities in screening. *J Clin Nurs*. 2017;26:4915-4926.
70. Magnuson A, Sattar S, Nightingale G, Saracino R, Skonecki E, Trevino KM. A practical guide to geriatric syndromes in older adults with cancer: a focus on falls, cognition, polypharmacy, and depression. *Am Soc Clin Oncol Educ Book*. 2019;39:e96-e109.
71. Decoster L, Van Puyvelde K, Mohile S, et al. Screening tools for multidimensional health problems warranting a geriatric assessment in older cancer patients: an update on SIOG recommendations. *Ann Oncol*. 2015;26:288-300.
72. Mohile SG, Dale W, Somerfield MR, et al. Practical assessment and management of vulnerabilities in older patients receiving chemotherapy: ASCO guideline for geriatric oncology. *J Clin Oncol*. 2018;36:2326-2347.
73. Hurria A. Management of elderly patients with cancer. *J Natl Compr Canc Netw*. 2013;11(5 suppl):698-701.
74. Mohile SG, Velarde C, Hurria A, et al. Geriatric assessment-guided care processes for older adults: a Delphi consensus of geriatric oncology experts. *J Natl Compr Canc Netw*. 2015;13:1120-1130.
75. Pai ALH, Greenley RN, Lewandowski A, Drotar D, Youngstrom E, Peterson CC. A meta-analytic review of the influence of pediatric cancer on parent and family functioning. *J Fam Psychol*. 2007;21:407-415.
76. McCarthy MC, McNeil R, Drew S, et al. Psychological distress and post-traumatic stress symptoms in adolescents and young adults with cancer and their parents. *J Adolesc Young Adult Oncol*. 2016;5:322-329.
77. Steele AC, Mullins LL, Mullins AJ, Muriel AC. Psychosocial interventions and therapeutic support as a standard of care in pediatric oncology. *Pediatr Blood Cancer*. 2015;62(suppl 5):S585-S618.
78. Gerhardt CA, Lehmann V, Long KA, Alderfer MA. Supporting siblings as a standard of care in pediatric oncology. *Pediatr Blood Cancer*. 2015;62(suppl 5):S750-S804.
79. Hedstom M, Liungman G, von Essen L. Perceptions of distress among adolescents recently diagnosed with cancer. *J Pediatr Hematol Oncol*. 2005;27:15-22.
80. Kupst MJ, Patenaude AF. Coping and adaptation in pediatric cancer: current perspectives. In: Wiener L, Muriel AC, Abrams AC, eds. *Pediatric Psychosocial Oncology: Textbook for Multidisciplinary Care*. Springer; 2016:67-79.
81. Krull KR, Hardy KK, Kahalley LS, Schuitema I, Kesler SR. Neurocognitive outcomes and interventions in long-term survivors of childhood cancer. *J Clin Oncol*. 2018;36:2181-2189.
82. Bitsko MJ, Cohen D, Dillon R, Harvey J, Krull K, Klosky JL. Psychosocial late effects in pediatric cancer survivors: a report from the Children's Oncology Group. *Pediatr Blood Cancer*. 2016;63:337-343.
83. Sender L, Zabokrtsky KB. Adolescent and young adult patients with cancer: a milieu of unique features. *Nat Rev Clin Oncol*. 2015;12:465-480. doi:10.1038/nrclinonc.2015.92
84. Bleyer A, Barr R, Hayes-Lattin B, Thomas D, Ellis C, Anderson B. The distinctive biology of cancer in adolescents and young adults. *Nat Rev Clin Oncol*. 2008;8:288-298. doi:10.1038/nrc2349
85. Burke ME, Albritton K, Marina N. Challenges in the recruitment of adolescents and young adults to cancer clinical trials. *Cancer*. 2007;110:2385-2393.
86. Coccia PF, Pappo AS, Beaupin L, et al. *Adolescent and Young Adult Oncology, Version 2.2018: NCCN Clinical Practice Guidelines in Oncology*. *J Natl Compr Canc Netw*. 2018;16:66-97.
87. 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;103:1494-1502.
88. Haverman L, van Oers HA, Limperg PF, et al. Development and validation of the Distress Thermometer for parents of a chronically ill child. *J Pediatr*. 2013;163:1140-1146.e2. doi:10.1016/j.jpeds.2013.06.011
89. Pai AL, Patino-Fernandez AM, McSherry M, et al. The Psychosocial Assessment Tool (PAT2.0): psychometric properties of a screener for psychosocial distress in families of children newly diagnosed with cancer. *J Pediatr Psychol*. 2008;33:50-62. doi:10.1093/jpepsy/jsm053
90. Varni JW, Seid M, Kurtin PS. PedsQL™ 4.0: reliability and validity of the Pediatric Quality of Life Inventory™ version 4.0 generic core scales in healthy and patient populations. *Med Care*. 2001;39:800-812. doi:10.1097/00005650-200108000-00006

91. Saylor CF, Finch AJ, Spirito A, Bennett B. The Children's Depression Inventory: a systematic evaluation of psychometric properties. *J Consult Clin Psychol*. 1984;52:955-967.
92. Wagner LI, Schink J, Bass M, et al. Bringing PROMIS to practice: brief and precise symptom screening in ambulatory cancer care. *Cancer*. 2015;121:927-934.
93. Smrke A, Leung B, Srikanthan A, McDonald M, Bates A, Ho C. Distinct features of psychosocial distress of adolescents and young adults with cancer compared to adults at diagnosis: patient-reported domains of concern. *J Adolesc Young Adult Oncol*. 2020;9:540-545. doi:10.1089/jyao.2019.0157
94. Reeve BB, Mitchell SA, Dueck AC, et al. Recommended patient-reported core set of symptoms to measure in adult cancer treatment trials. *J Natl Cancer Inst*. 2014;106:dju129. doi:10.1093/jnci/dju129
95. Kluetz PG, Slagle A, Papadopoulos EJ, et al. Focusing on core patient-reported outcomes in cancer clinical trials: symptomatic adverse events, physical function, and disease-related symptoms. *Clin Cancer Res*. 2016;22:1553-1558.
96. Wiggins G, McTighe J. What is backward design? In: Wiggins G, McTighe J, eds. *Understanding by Design*. Association for Supervision and Curriculum Development; 2005:13-34.
97. Marshall TF, Alfano CM, Sleight AG, et al. Consensus-building efforts to identify best tools for screening and assessment for supportive services in oncology. *Disabil Rehabil*. 2020;42:2178-2185.
98. Jacobsen PB, Norton WE. The role of implementation science in improving distress assessment and management in oncology: a commentary on "Screening for psychosocial distress among patients with cancer: implications for clinical practice, healthcare policy, and dissemination to enhance cancer survivorship." *Transl Behav Med*. 2019;9:292-295.
99. Wells-Di Gregorio S, Porensky EK, Minotti M, et al. The James Supportive Care Screening: integrating science and practice to meet the NCCN guidelines for distress management at a comprehensive cancer center. *Psychooncology*. 2013;22:2001-2008.
100. Wells-Di Gregorio S, Zaleta A, Porensky E, Graham L, McDowell K, Snapp J. Reducing patient suffering and preventing readmissions via supportive care screening: the James Cancer Hospital supportive-care screening model [abstract]. *J Clin Oncol*. 2014;32(31 suppl):S33.
101. Bruera E, Kuehn N, Miller MJ, Selmsler P, Macmillan K. The Edmonton Symptom Assessment System (ESAS): a simple method for the assessment of palliative care patients. *J Palliat Care*. 1991;7:6-9.
102. Cella DF, Tulsy DS, Gray G, et al. The Functional Assessment of Cancer Therapy scale: development and validation of the general measure. *J Clin Oncol*. 1993;11:570-579.
103. Cleeland CS, Ryan KM. Pain assessment: global use of the Brief Pain Inventory. *Ann Acad Med Singap*. 1994;23:129-138.
104. Glaros AG, Kline RB. Understanding the accuracy of tests with cutting scores: the sensitivity, specificity, and predictive value model. *J Clin Psychol*. 1988;44:1013-1023.
105. Trevethan R. Sensitivity, specificity, and predictive values: foundations, pliability, and pitfalls in research and practice. *Front Public Health*. 2017;5:307. doi:10.3389/fpubh.2017.00307
106. Manea L, Gilbody S, McMillan D. Optimal cut-off score for diagnosing depression with the Patient Health Questionnaire (PHQ-9): a meta-analysis. *CMAJ*. 2012;184:E191-E196.
107. Donovan KA, Grassi L, McGinty HL, Jacobsen PB. Validation of the Distress Thermometer worldwide: state of the science. *Psychooncology*. 2014;23:241-250.
108. Ashing-Giwa K, Rosales M. A cross-cultural validation of patient-reported outcomes measures: a study of breast cancers survivors. *Qual Life Res*. 2013;22:295-308.
109. Gilbody SM, House AO, Sheldon TA. Routinely administered questionnaires for depression and anxiety: systematic review. *BMJ*. 2001;322:406-409.
110. Meijer A, Roseman M, Delisle VC, et al. Effects of screening for psychological distress on patient outcomes in cancer: a systematic review. *J Psychosom Res*. 2013;75:1-17.
111. Sanjida S, McPhail SM, Shaw J, et al. Are psychological interventions effective on anxiety in cancer patients? A systematic review and meta-analyses. *Psychooncology*. 2018;27:2063-2076.
112. Agboola SO, Ju W, Elfiky A, Kvedar JC, Jethwani K. The effect of technology-based interventions on pain, depression, and quality of life in patients with cancer: a systematic review of randomized controlled trials. *J Med Internet Res*. 2015;17:e65.
113. Qan'ir Y, Song L. Systematic review of technology-based interventions to improve anxiety, depression, and health-related quality of life among patients with prostate cancer. *Psychooncology*. 2019;28:1601-1613.
114. Gabriel I, Creedy D, Coyne E. A systematic review of psychosocial interventions to improve quality of life of people with cancer and their family caregivers. *Nurs Open*. 2020;7:1299-1312.
115. Hilfiker R, Meichtry A, Eicher M, et al. Exercise and other non-pharmaceutical interventions for cancer-related fatigue in patients during or after cancer treatment: a systematic review incorporating an indirect-comparisons meta-analysis. *Br J Sports Med*. 2018;52:651-658.
116. Mustian KM, Alfano CM, Heckler C, et al. Comparison of pharmaceutical, psychological, and exercise treatments for cancer-related fatigue: a meta-analysis. *JAMA Oncol*. 2017;3:961-968.
117. Heckler CE, Garland SN, Peoples AR, et al. Cognitive behavioral therapy for insomnia, but not armodafinil, improves fatigue in cancer survivors with insomnia: a randomized placebo-controlled trial. *Support Care Cancer*. 2016;24:2059-2066.
118. Zhou ES, Recklitis CJ. Internet-delivered insomnia intervention improves sleep and quality of life for adolescent and young adult cancer survivors. *Pediatr Blood Cancer*. 2020;67:e28506.
119. Meneses-Echavez JF, Gonzalez-Jimenez E, Ramirez-Velez R. Effects of supervised exercise on cancer-related fatigue in breast cancer survivors: a systematic review and meta-analysis. *BMC Cancer*. 2015;15:77.
120. National Comprehensive Cancer Network (NCCN). NCCN Clinical Practice Guidelines in Oncology: Cancer-Related Fatigue. Version 4.2020. NCCN; 2020. Accessed October 4, 2020. [nccn.org/professionals/physician\\_gls/pdf/fatigue.pdf](http://nccn.org/professionals/physician_gls/pdf/fatigue.pdf)
121. National Comprehensive Cancer Network (NCCN). NCCN Clinical Practice Guidelines in Oncology: Survivorship. Version 2.2020. NCCN; 2020. Accessed October 4, 2020. [nccn.org/professionals/physician\\_gls/pdf/survivorship.pdf](http://nccn.org/professionals/physician_gls/pdf/survivorship.pdf)
122. Bower JE, Bak K, Berger A, et al. Screening, assessment, and management of fatigue in adult survivors of cancer: an American Society of Clinical Oncology clinical practice guideline adaptation. *J Clin Oncol*. 2014;32:1840-1850.
123. Xu A, Wang Y, Wu X. Effectiveness of e-health based self-management to

- improve cancer-related fatigue, self-efficacy and quality of life in cancer patients: systematic review and meta-analysis. *J Adv Nurs*. 2019;75:3434-3447.
124. Tomlinson D, Robinson PD, Oberoi S, et al. Pharmacologic interventions for fatigue in cancer and transplantation: a meta-analysis. *Curr Oncol*. 2018;25:e152-e167.
  125. Oberoi S, Robinson PD, Cataudella D, et al. Physical activity reduces fatigue in patients with cancer and hematopoietic stem cell transplant recipients: a systematic review and meta-analysis of randomized trials. *Crit Rev Oncol Hematol*. 2018;122:52-59.
  126. Qu D, Zhang Z, Yu X, Zhao J, Qiu F, Huang J. Psychotropic drugs for the management of cancer-related fatigue: a systematic review and meta-analysis. *Eur J Cancer Care*. 2016;25:970-979.
  127. Wu LM, Amidi A, Valdimarsdottir H, et al. The effect of systematic light exposure on sleep in a mixed group of fatigued cancer survivors. *J Clin Sleep Med*. 2018;14:31-39. doi:10.5664/jcsm.6874
  128. Swarm RA, Paice JA, Anghelescu DL, et al. Adult Cancer Pain. Version 3.2019. NCCN Clinical Practice Guidelines in Oncology. *J Natl Compr Canc Netw*. 2019;17:977-1007.
  129. Carmichael AN, Morgan L, Del Fabbro E. Identifying and assessing the risk of opioid abuse in patients with cancer: an integrative review. *Subst Abuse Rehabil*. 2016;7:71-79.
  130. Gorin SS, Krebs P, Badr H, et al. Meta-analysis of psychosocial interventions to reduce pain in patients with cancer. *J Clin Oncol*. 2012;30:539-547.
  131. Guan J, Tanaka S, Kawakami K. Anticonvulsants or antidepressants in combination pharmacotherapy for treatment of neuropathic pain in cancer patients: a systematic review and meta-analysis. *Clin J Pain*. 2016;32:719-725.
  132. Jongen JL, Huijsman ML, Jessurun J, et al. The evidence for pharmacologic treatment of neuropathic cancer pain: beneficial and adverse effects. *J Pain Symptom Manage*. 2013;46:581-590.
  133. Zhong W, Yu Z, Zeng JX, et al. Celiac plexus block for treatment of pain associated with pancreatic cancer: a meta-analysis. *Pain Pract*. 2014;14:43-51.
  134. Koller A, Miaskowski C, De Geest S, Opitz O, Spichiger E. A systematic evaluation of content, structure, and efficacy of interventions to improve patients' self-management of cancer pain. *J Pain Symptom Manage*. 2012;44:264-284.
  135. Bennett MI, Bagnall AM, Closs SJ. How effective are patient-based educational interventions in the management of cancer pain? Systematic review and meta-analysis. *Pain*. 2009;143:192-199.
  136. Oliva EM, Bowe T, Tavakoli S, et al. Development and applications of the Veterans Health Administration's Stratification Tool for Opioid Risk Mitigation (STORM) to improve opioid safety and prevent overdose and suicide. *Psychol Serv*. 2017;14:34-49.
  137. da Silva FP, Moreira GM, Zomkowski K, de Noronha MA, Sperandio FF. Manual therapy as treatment for chronic musculoskeletal pain in female breast cancer survivors: a systematic review and meta-analysis. *J Manipulative Physiol Ther*. 2019;42:503-513.
  138. Boyd C, Crawford C, Paat CF, et al. The impact of massage therapy on function in pain populations—a systematic review and meta-analysis of randomized controlled trials: part II, cancer pain populations. *Pain Med*. 2016;17:1553-1568.
  139. Lee SH, Kim JY, Yeo S, Kim SH, Lim S. Meta-analysis of massage therapy on cancer pain. *Integr Cancer Ther*. 2015;14:297-304.
  140. Yangoz ST, Ozer Z. The effect of music intervention on patients with cancer-related pain: a systematic review and meta-analysis of randomized controlled trials. *J Adv Nurs*. 2019;75:3362-3373.
  141. Tsai HF, Chen YR, Chung MH, et al. Effectiveness of music intervention in ameliorating cancer patients' anxiety, depression, pain, and fatigue: a meta-analysis. *Cancer Nurs*. 2014;37:E35-E50.
  142. Lyons KD, Padgett LS, Marshall TF, et al. Follow the trail: using insights from the growth of palliative care to propose a roadmap for cancer rehabilitation. *CA Cancer J Clin*. 2019;69:113-126. doi:10.3322/caac.21549
  143. National Comprehensive Oncology Network (NCCN). NCCN Clinical Practice Guidelines in Oncology: Older Adult Oncology. Version 1.2020. NCCN; 2020. Accessed October 4, 2020. nccn.org/professionals/physician\_gls/pdf/senior.pdf
  144. Jacobsen PB, Jim HS. Psychosocial interventions for anxiety and depression in adult cancer patients: achievements and challenges. *CA Cancer J Clin*. 2008;58:214-230.
  145. Luebbert K, Dahme B, Hasenbring M. The effectiveness of relaxation training in reducing treatment-related symptoms and improving emotional adjustment in acute non-surgical cancer treatment: a meta-analytical review. *Psychooncology*. 2001;10:490-502.
  146. Devine EC, Westlake SK. The effects of psychoeducational care provided to adults with cancer: meta-analysis of 116 studies. *Oncol Nurs Forum*. 1995;22:1369-1381.
  147. McQuellon RP, Wells M, Hoffman S, et al. Reducing distress in cancer patients with an orientation program. *Psychooncology*. 1998;7:207-217.
  148. Antoni MH, Wimberly SR, Lechner SC, et al. Reduction of cancer-specific thought intrusions and anxiety symptoms with a stress management intervention among women undergoing treatment for breast cancer. *Am J Psychiatry*. 2006;163:1791-1797.
  149. Jacobsen PB, Meade CD, Stein KD, Chirikos TN, Small BJ, Ruckdeschel JC. Efficacy and costs of two forms of stress management training for cancer patients undergoing chemotherapy. *J Clin Oncol*. 2002;20:2851-2862.
  150. Osborn RL, Demoncada AC, Feuerstein M. Psychosocial interventions for depression, anxiety, and quality of life in cancer survivors: meta-analyses. *Int J Psychiatry Med*. 2006;36:13-34.
  151. Traeger L, Greer JA, Fernandez-Robles C, Temel JS, Pirl WF. Evidence-based treatment of anxiety in patients with cancer. *J Clin Oncol*. 2012;30:1197-1205.
  152. Zhang MF, Wen YS, Liu WY, Peng LF, Wu XD, Liu QW. Effectiveness of mindfulness-based therapy for reducing anxiety and depression in patients with cancer: a meta-analysis. *Medicine (Baltimore)*. 2015;94:e0897. doi:10.1097/MD.0000000000000897
  153. Piet J, Wurtzen H, Zachariae R. The effect of mindfulness-based therapy on symptoms of anxiety and depression in adult cancer patients and survivors: a systematic review and meta-analysis. *J Consult Clin Psychol*. 2012;80:1007.
  154. Nunns M, Mayhew D, Ford T, et al. Effectiveness of non-pharmacological interventions to reduce procedural anxiety in children and adolescents undergoing treatment for cancer: a systematic review and meta-analysis. *Psychooncology*. 2018;27:1889-1899.
  155. Loh KP, Kleckner IR, Lin PJ, et al. Effects of a home-based exercise program on anxiety and mood disturbances in older adults with cancer receiving chemotherapy. *J Am Geriatr Soc*. 2019;67:1005-1011.
  156. Chen HM, Tsai CM, Wu YC, Lin KC, Lin CC. Randomised controlled trial on the effectiveness of home-based walking exercise on anxiety, depression

- and cancer-related symptoms in patients with lung cancer. *Br J Cancer*. 2015;112:438-445.
157. Jensen W, Oechsle K, Baumann HJ, et al. Effects of exercise training programs on physical performance and quality of life in patients with metastatic lung cancer undergoing palliative chemotherapy—a study protocol. *Contemp Clin Trials*. 2014;37:120-128.
  158. Mehner A, Veers S, Howaldt D, Braumann KM, Koch U, Schulz KH. Effects of a physical exercise rehabilitation group program on anxiety, depression, body image, and health-related quality of life among breast cancer patients. *Oncol Res Treat*. 2011;34:248-253.
  159. Greer JA, Jacobs J, Pensak N. Randomized trial of a tailored cognitive-behavioral therapy mobile application for anxiety in patients with incurable cancer. *Oncologist*. 2019;24:1111-1120. doi:10.1634/theoncologist.2018-0536
  160. Tsai HF, Chen YR, Chung MH, et al. Effectiveness of music intervention in ameliorating cancer patients' anxiety, depression, pain, and fatigue: a meta-analysis. *Cancer Nurs*. 2014;37:E35-E50.
  161. Hopko DR, Armento ME, Robertson S, et al. Brief behavioral activation and problem-solving therapy for depressed breast cancer patients: randomized trial. *J Consult Clin Psychol*. 2011;79:834-849.
  162. Nezu AM, Nezu CM, Felgoise SH, McClure KS, Houts PS. Project Genesis: assessing the efficacy of problem-solving therapy for distressed adult cancer patients. *J Consult Clin Psychol*. 2003;71:1036-1048.
  163. Pitceathly C, Maguire P, Fletcher I, Parle M, Tomenson B, Creed F. Can a brief psychological intervention prevent anxiety or depressive disorders in cancer patients? A randomised controlled trial. *Ann Oncol*. 2009;20:928-934.
  164. Antoni MH, Lehman JM, Kilbourn KM, et al. Cognitive-behavioral stress management intervention decreases the prevalence of depression and enhances benefit finding among women under treatment for early-stage breast cancer. *Health Psychol*. 2001;20:20-32.
  165. Tatrow K, Montgomery GH. Cognitive behavioral therapy techniques for distress and pain in breast cancer patients: a meta-analysis. *J Behav Med*. 2006;29:17-27.
  166. Sadler P, McLaren S, Klein B, Jenkins M. Advancing cognitive behaviour therapy for older adults with comorbid insomnia and depression. *Cogn Behav Ther*. 2018;47:139-154. doi:10.1080/16506073.2017.1359206
  167. Savard J, Simard S, Giguere I, et al. Randomized clinical trial on cognitive therapy for depression in women with metastatic breast cancer: psychological and immunological effects. *Palliat Support Care*. 2006;4:219-237.
  168. Goodwin PJ, Leszcz M, Ennis M, et al. The effect of group psychosocial support on survival in metastatic breast cancer. *N Engl J Med*. 2001;345:1719-1726.
  169. Kissane DW, Grabsch B, Clarke DM, et al. Supportive-expressive group therapy for women with metastatic breast cancer: survival and psychosocial outcome from a randomized controlled trial. *Psychooncology*. 2007;16:277-286.
  170. Ell K, Xie B, Quon B, Quinn DI, Dwight-Johnson M, Lee PJ. Randomized controlled trial of collaborative care management of depression among low-income patients with cancer. *J Clin Oncol*. 2008;26:4488-4496.
  171. Simpson JSA, Carlson LE, Trew ME. Effect of group therapy for breast cancer on healthcare utilization. *Cancer Pract*. 2001;9:19-26.
  172. Rodin G, Lloyd N, Katz M, et al. The treatment of depression in cancer patients: a systematic review. *Support Care Cancer*. 2007;15:123-136.
  173. Ng CG, Boks MP, Zainal NZ, de Wit NJ. The prevalence and pharmacotherapy of depression in cancer patients. *J Affect Disord*. 2011;131(1-3):1-7.
  174. Dieng M, Butow PN, Costa DS, et al. Psychoeducational intervention to reduce fear of cancer recurrence in people at high risk of developing another primary melanoma: results of a randomized controlled trial. *J Clin Oncol*. 2016;34:4405-4414. doi:10.1200/JCO.2016.68.2278
  175. Van de Wal M, Tewes B, Gielissen M, et al. Efficacy of a blended cognitive behaviour therapy for high fear of recurrence in breast, prostate and colorectal cancer survivors: the SWORD study, a randomized controlled trial. *J Clin Oncol*. 2017;35:2173-2183.
  176. Cheli S, Caligiani L, Martella F, De Bartolo P, Mancini F, Fioretto L. Mindfulness and metacognition in facing with fear of recurrence: a proof-of-concept study with breast-cancer women. *Psychooncology*. 2019;28:600-606. doi:10.1002/pon.4984
  177. Breitbart W, Rosenfeld B, Pessin H, Applebaum A, Kulikowski J, Lichenthal WG. Meaning-centered group psychotherapy: an effective intervention for improving psychological well-being in patients with advanced cancer. *J Clin Oncol*. 2015;33:749-754.
  178. Breitbart W, Pessin H, Rosenfeld B, et al. Individual meaning-centered psychotherapy for the treatment of psychological and existential distress: a randomized controlled trial in patients with advanced cancer. *Cancer*. 2018;124:3231-3239.
  179. Lo C, Hales S, Jung J, et al. Managing Cancer and Living Meaningfully (CALM): phase 2 trial of a brief individual psychotherapy for patients with advanced cancer. *Palliat Med*. 2014;28:234-242.
  180. Grossman CH, Brooker J, Michael N, Kissane D. Death anxiety interventions in patients with advanced cancer: a systematic review. *Palliat Med*. 2018;32:172-184.
  181. Miller DK, Chibnall JT, Videen SD, Duckro PN. Supportive-affective group experience for persons with life-threatening illness: reducing spiritual, psychological, and death-related distress in dying patients. *J Palliat Med*. 2005;8:333-343.
  182. Regan TW, Lambert SD, Girgis A, Kelly B, Kayser K, Turner J. Do couple-based interventions make a difference for couples affected by cancer? A systematic review. *BMC Cancer*. 2012;12:279.
  183. Applebaum AJ, Breitbart W. Care for the cancer caregiver: a systematic review. *Palliat Support Care*. 2013;11:231-252.
  184. Northouse LL, Katapodi MC, Song L, Zhang L, Mood DW. Interventions with family caregivers of cancer patients: meta-analysis of randomized trials. *CA Cancer J Clin*. 2010;60:317-339.
  185. McMillan SC, Small BJ, Weitzner M, et al. Impact of coping skills intervention with family caregivers of hospice patients with cancer: a randomized clinical trial. *Cancer*. 2006;106:214-222.
  186. Majestic C, Eddington KM. The impact of goal adjustment and caregiver burden on psychological distress among caregivers of cancer patients. *Psychooncology*. 2019;28:1293-1300.
  187. DuBenske LL, Gustafson DH, Namkoong K, et al. CHES improves cancer caregivers' burden and mood: results of an eHealth RCT. *Health Psychol*. 2014;33:1261-1272.
  188. Sanft T, Denlinger CS, Armenian S, et al. NCCN Guidelines Insights: Survivorship, version 2.2019: featured updates to the NCCN guidelines. *J Natl Compr Canc Netw*. 2019;17:784-794.
  189. VanderWalde N, Jagsi R, Dotan E, et al. NCCN Guidelines Insights: Older Adult Oncology, version 2.2016. *J Natl Compr Canc Netw*. 2016;14:1357-1370.

190. Zhou ES, Partridge AH, Syrjala KL, Michaud AL, Recklitis CJ. Evaluation and treatment of insomnia in adult cancer survivorship programs. *J Cancer Surviv.* 2017;11:74-79.
191. Woodward SC. Cognitive-behavioral therapy for insomnia in patients with cancer. *Clin J Oncol Nurs.* 2011;15:E42-E52. doi:10.1188/11.CJON.E42-E52
192. Johnson JA, Rash JA, Campbell TS, et al. A systematic review and meta-analysis of randomized controlled trials of cognitive behavior therapy for insomnia (CBT-I) in cancer survivors. *Sleep Med Rev.* 2016;27:20-28.
193. Savard J, Ivers H, Morin CM, Lacroix G. Video cognitive-behavioral therapy for insomnia in cancer patients: a cost-effective alternative. *Psychooncology.* 2021;30:44-51. doi:10.1002/pon.5532
194. Ritterband LM, Bailey ET, Thorndike FP, Lord HR, Farrell-Carnahan L, Baum LD. Initial evaluation of an internet intervention to improve the sleep of cancer survivors with insomnia. *Psychooncology.* 2012;21:695-705.
195. Holbrook AM, Crowther R, Lotter A, Cheng C, King D. Meta-analysis of benzodiazepine use in the treatment of insomnia. *CMAJ.* 2000;162:225-233.
196. Kwak A, Jacobs J, Haggert D, Jimenez R, Peppercorn J. Evaluation and management of insomnia in women with breast cancer. *Breast Cancer Res Treat.* 2020;181:269-277.
197. Ver Hoeve ES, Ali-Akbarian L, Price SN, Lothfi NM, Hamann HA. Patient-reported financial toxicity, quality of life, and health behaviors in insured US cancer survivors. *Support Care Cancer.* 2021;29:349-358. doi:10.1007/s00520-020-05468-z
198. Farano JL, Kandah HM. Targeting financial toxicity in oncology specialty pharmacy at a large tertiary academic medical center. *J Manag Care Spec Pharm.* 2019;25:765-769.
199. Pearce A, Tomalin B, Kaambwa B, et al. Financial toxicity is more than costs of care: the relationship between employment and financial toxicity in long-term cancer survivors. *J Cancer Surviv.* 2019;13:10-20.
200. Nipp RD, Lee H, Gorton E, et al. Addressing the financial burden of cancer clinical trial participation: longitudinal effects of an equity intervention. *Oncologist.* 2019;24:1048-1055.
201. Padgett LS, Van Dyk K, Kelly NC, Newman R, Hite S, Asher A. Addressing cancer-related cognitive impairment in cancer survivorship. *Oncology Issues.* 2020;35:52-57.
202. Asher A, Van Dyk K, Patel SK, et al. Cancer-related cognitive changes. *Arch Phys Med Rehabil.* 2017;98:2595-2596.
203. Wildiers H, Heeren P, Puts M, et al. International Society of Geriatric Oncology consensus on geriatric assessment in older patients with cancer. *J Clin Oncol.* 2014;32:2595-2603. doi:10.1200/JCO.2013.54.8347
204. Andersen BL, Yang HC, Farrar WB, et al. Psychologic intervention improves survival for breast cancer patients: a randomized clinical trial. *Cancer.* 2008;113:3450-3458.
205. DeRubeis RJ, Hollon SD, Amsterdam JD, et al. Cognitive therapy versus medications in the treatment of moderate to severe depression. *Arch Gen Psychiatry.* 2005;62:409-416.
206. Pinquart M, Duberstein PR. Depression and cancer mortality: a meta-analysis. *Psychol Med.* 2010;40:1797-1810.
207. Jacobsen PB, Donovan KA, Swaine ZN, et al. Management of anxiety and depression in adult cancer patients: toward an evidence-based approach. In: Chang AE, Ganz PA, Hayes DF, et al, eds. *Oncology: An Evidence-Based Approach.* Springer-Verlag; 2006:1552-1579.
208. Colby SL, Ortman JM. Projections of the Size and Composition of the U.S. Population: 2014 to 2060. Current Population Reports, P25-1143. U.S. Census Bureau; 2014.
209. Bernal G, Scharro-del-Rio MR. Are empirically supported treatments valid for ethnic minorities? Toward an alternative approach for treatment research. *Cultur Divers Ethnic Minor Psychol.* 2001;7:328-342.
210. Tam Ashing K, Loscalzo M, Burhansstipanov L, Hwei-Yu Wang J, Napoles A. Attending to distress as part of quality, comprehensive cancer care: gaps and diversity considerations. *Expert Rev Qual Life Cancer Care.* 2016;1:257-259. doi:10.1080/23809000.2016.1195689
211. Kagawa-Singer M, Dadia AV, Yu MC, et al. Cancer, culture, and health disparities: time to chart a new course? *CA Cancer J Clin.* 2010;60:12-39.
212. Jiang S, Wan B, Lam M, Agarwal A, Chow E. A qualitative review of patient and family advisory councils in cancer care. *J Pain Manage.* 2017;10:59-66.
213. Sue S. In search of cultural competence in psychotherapy and counseling. *Am Psychol.* 1998;53:440-448.
214. Cardemil EV, Battle CL. Guess who's coming to therapy? Getting comfortable with conversations about race and ethnicity in psychotherapy. *Prof Psychol Res Pract.* 2003;34:278-286.
215. Huey SJ, Tilley JL, Jones EO, Smith CA. The contribution of cultural competence to evidence-based care for ethnically diverse populations. *Annu Rev Clin Psychol.* 2014;10:305-338.
216. Hawkins NA, Soman A, Buchanan Lunsford N, Leadbetter S, Rodriguez JL. Use of medications for treating anxiety and depression in cancer survivors in the United States. *J Clin Oncol.* 2017;35:78-85. doi:10.1200/JCO.2016.67.7690
217. Northouse L, Williams AL, Given B, McCorkle R. Psychosocial care for family caregivers of patients with cancer. *J Clin Oncol.* 2012;30:1227-1234.
218. Ugalde A, Gaskin CJ, Rankin NM, et al. A systematic review of cancer caregiver interventions: appraising the potential for implementation of evidence into practice. *Psychooncology.* 2019;28:687-701.
219. Pierce L, Hocking MC, Schwartz LA, Alderfer MA, Kazak AE, Barakat LP. Caregiver distress and patient health-related quality of life: psychosocial screening during pediatric cancer treatment. *Psychooncology.* 2017;26:1555-1561.
220. American Psychosocial Oncology Society. Research, Practice, and Policy Imperatives for Psychosocial Care: A Roadmap in a New Era of Value-Based Cancer Care. American Psychosocial Oncology Society; 2021. Accessed March 15, 2021. [apos-society.org/wp-content/uploads/2021/02/APOS-Roadmap\\_FINAL-Print-2.23.21.pdf](https://www.apos-society.org/wp-content/uploads/2021/02/APOS-Roadmap_FINAL-Print-2.23.21.pdf)
221. Clark K, Strowbridge R, Rinehart R, Dillehunt J, Smith D, Loscalzo M. Support screen—automated screening for identifying and triaging problem-related distress in cancer settings. 7th Annual Conference of the American Psychosocial Society, New Orleans. *Psychooncology.* 2010;19:S35.
222. Aerny-Perreten N, Dominguez-Berion MF, Esteban-Vasallo MD, Garcia-Riolobos C. Participation and factors associated with late or non-response to an online survey in primary care. *J Eval Clin Pract.* 2015;21:688-693.
223. Fox RS, Moreno PI, Yanez B, et al. Integrating PROMIS® computerized adaptive tests into a web-based intervention for prostate cancer. *Health Psychol.* 2019;38:403-409.
224. Clark K, Bardwell WA, Arsenault T, DeTeresa R, Loscalzo M. Implementing

- touch-screen technology to enhance recognition of distress. *Psychooncology*. 2009;18:822-830.
225. Andersen BL, Goyal NG, Westbrook TD, Bishop B, Carson WE. Trajectories of stress, depressive symptoms, and immunity in cancer survivors: diagnosis to 5 years. *Clin Cancer Res*. 2017;23:52-61.
226. 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;9:282-291.
227. Kirkova J, Walsh D, Rybicki L, et al. Symptom severity and distress in advanced cancer. *Palliat Med*. 2010;24:330-339.
228. 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;24:2861-2868.
229. Holland JC, Kelly BJ, Weinberger MI. Why psychosocial care is difficult to integrate into routine cancer care: stigma is the elephant in the room. *J Natl Compr Cancer Netw*. 2010;8:362-366.
230. Carlson LE, Waller A, Mitchell AJ. Screening for distress and unmet needs in patients with cancer: review and recommendations. *J Clin Oncol*. 2012;30:1160-1177.
231. Corrigan PW, Rafacz JD, Hautamaki J, et al. Changing stigmatizing perceptions and recollections about mental illness: the effects of NAMI's In Our Own Voice. *Community Mental Health J*. 2010;46:517-522.
232. Li M, Kennedy EB, Byrne N, et al. Systematic review and meta-analysis of collaborative care interventions for depression in patients with cancer. *Psychooncology*. 2017;26:573-587. doi:10.1002/pon.4286
233. Jhaveri K, Cohen JA, Barulich M, et al. "Soup cans, brooms, and Zoom": rapid conversion of a cancer survivorship program to telehealth during COVID-19. *Psychooncology*. 2020;29:1424-1426.
234. Guzman D, Ann-Yi S, Bruera E, et al. Enhancing palliative care patient access to psychological counseling through outreach telehealth services. *Psychooncology*. 2020;29:132-138.
235. Lambert SD, Kelly B, Boyes A, et al. Insights into preferences for psychooncology services among women with gynecologic cancer following distress screening. *J Natl Compr Cancer Netw*. 2014;12:899-906.
236. Kendall J, Glaze K, Oakland S, Hansen J, Parry C. What do 1281 distress screeners tell us about cancer patients in a community cancer center? *Psychooncology*. 2011;20:594-600.
237. Baddour K, Kudrick LD, Neopaney A, et al. Potential impact of the COVID-19 pandemic on financial toxicity in cancer survivors. *Head Neck*. 2020;42:1332-1338.
238. Deshields TL, Howrey HL, Vanderlan JR. Distress in oncology: not just a psychosocial phenomenon. *J Oncol Pract*. 2018;14:699-700.
239. Yee MK, Sereika SM, Bender CM, Brufsky AM, Connolly MC, Rosenzweig MQ. Symptom incidence, distress, cancer-related distress, and adherence to chemotherapy among African American women with breast cancer. *Cancer*. 2017;123:2061-2069.
240. Zebrack B, Kayser K, Sundstrom L, et al. Psychosocial distress screening implementation in cancer care: an analysis of adherence, responsiveness, and acceptability. *J Clin Oncol*. 2015;33:1165-1170.
241. Kayser K, Brydon D, Moon H, Zebrack B. Institutional capacity to provide psychosocial care in cancer programs: addressing barriers to delivering quality cancer care. *Psychooncology*. 2020;29:1995-2002. doi:10.1002/pon.5488
242. Henderson JD, Boyle A, Herx L, et al. Staffing a specialist palliative care service, a team-based approach: expert consensus white paper. *J Palliat Med*. 2019;22:1318-1323.
243. Weissman DE, Meier DE, Spragens LH. Center to Advance Palliative Care palliative care consultation service metrics: consensus recommendations. *J Palliat Med*. 2008;11:1294-1298.
244. Zebrack B, Burg MA, Vaitones V. Distress screening: an opportunity for enhancing quality cancer care and promoting the oncology social work profession. *J Psychosoc Oncol*. 2012;30:615-624. doi:10.1080/07347332.2012.721485
245. Wells-Di Gregorio SM. RVUs, provider assets, and burnout prevention: development of a value-added psychosocial oncology service model. Virtual presentation at: 17th Annual American Psychosocial Oncology Society Conference; March 11-13, 2020; Portland, Oregon.
246. Butow P, Price MA, Shaw JM, et al. Clinical pathway for the screening, assessment and management of anxiety and depression in adult cancer patients: Australian guidelines. *Psychooncology*. 2015;24:987-1001. doi:10.1002/pon.3920
247. Sharpe M, Walker J, Holm Hansen C, et al. Integrated collaborative care for comorbid major depression in patients with cancer (SMaRT Oncology-2): a multicentre randomised controlled effectiveness trial. *Lancet*. 2014;384:1099-1108. doi:10.1016/S0140-6736(14)61231-9
248. Fann JR, Ell K, Sharpe M. Integrating psychosocial care into cancer services. *J Clin Oncol*. 2012;30:1178-1186. doi:10.1200/JCO.2011.39.7398
249. Medisauskaite A, Kamau C. Prevalence of oncologists in distress: systematic review and meta-analysis. *Psychooncology*. 2017;26:1732-1740. doi:10.1002/pon.4382
250. Turnell A, Rasmussen V, Butow P, et al. An exploration of the prevalence and predictors of work-related well-being among psychosocial oncology professionals: an application of the job demands-resources model. *Palliat Support Care*. 2016;14:33-41. doi:10.1017/S1478951515000693
251. Neumann JL, Mau LW, Virani S, et al. Burnout, moral distress, work-life balance, and career satisfaction among hematopoietic cell transplantation professionals. *Biol Blood Marrow Transplant*. 2018;24:849-860. doi:10.1016/j.bbmt.2017.11.015
252. Potter P, Deshields T, Rodriguez S. Developing a systemic program for compassion fatigue. *Nurs Adm Q*. 2013;37:326-332. doi:10.1097/NAQ.0b013e3182a2f9dd
253. Flowers SR, Hershberger PJ. Commentary: individual and organizational strategies for physician well-being. *Curr Probl Pediatr Adolesc Health Care*. 2019;49:100687.
254. Rothenberger DA. Physician burnout and well-being: a systematic review and framework for action. *Dis Colon Rectum*. 2017;60:567-576.
255. Olson K, Marchalik D, Farley H, et al. Organizational strategies to reduce physician burnout and improve professional fulfillment. *Curr Probl Pediatr Adolesc Health Care*. 2019;49:100664.
256. Shanafelt TD, Noseworthy JH. Executive leadership and physician well-being: nine organizational strategies to promote engagement and reduce burnout. *Mayo Clin Proc*. 2017;92:129-146. doi:10.1016/j.mayocp.2016.10.004
257. Back AL, Deignan PF, Potter PA. Compassion, compassion fatigue, and burnout: key insights for oncology professionals. *Am Soc Clin Oncol Educ*

- Book. 2014;34:e454-e459. doi:10.14694/EdBook\_AM.2014.34.e454
258. Deshields T, Zebrack B, Kennedy V. The state of psychosocial services in cancer care in the United States. *Psychooncology*. 2013;22:699-703.
259. American Cancer Society. Cancer Facts & Figures 2019. American Cancer Society; 2019.
260. Mehnert A, Hartung TJ, Friedrich M, et al. One in two cancer patients is significantly distressed: prevalence and indicators of distress. *Psychooncology*. 2018;27:75-82. doi:10.1002/pon.4464
261. Kadan-Lottick NS, Vanderwerker LC, Block SD, Zhang B, Prigerson HG. Psychiatric disorders and mental health service use in patients with advanced cancer: a report from the Coping with Cancer study. *Cancer*. 2005;104:2872-2881.
262. Dilworth S, Higgins I, Parker V, Kelly B, Turner J. Patient and health professional's perceived barriers to the delivery of psychosocial care to adults with cancer: a systematic review. *Psychooncology*. 2014;23:601-612.
263. Proctor E, Silmere H, Raghavan R, et al. Outcomes for implementation research: conceptual distinction, measurement challenges, and research agenda. *Adm Policy Ment Health*. 2011;38:65-76. doi:10.1007/s10488-010-0319-7
264. Pirl WF, Muriel A, Kwang V, et al. Screening for psychosocial distress: a national survey of oncologists. *J Support Oncol*. 2007;5:499-504.
265. BrintzenhofeSzoc K, Davis C, Kayser K, et al. Screening for psychosocial distress: a national survey of oncology social workers. *J Psychosoc Oncol*. 2015;33:34-47.
266. Wells-Di Gregorio SM, Marks DR, DeCola J, et al. Pilot randomized controlled trial of a symptom cluster intervention in advanced cancer. *Psychooncology*. 2019;28:76-84.



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