Dissemination and Implementation of Guidelines for Cancer-Related Fatigue

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Evidence-based recommendations for cancer-related fatigue (CRF) have been disseminated recently by all major cancer organizations (NCCN, Oncology Nursing Society [ONS], Canadian Partnership Against Cancer/Canadian Association of Psychosocial Oncology [CPAC/CAPO], and ASCO). Panel members have invested considerable time and energy to reach consensus on these recommendations, and dissemination is an active and systematic approach of spreading evidence-based interventions to target audiences via formal and informal channels of communication. NCCN releases annual updates to the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines) for CRF, which are available online. But what good are guidelines if they are not used?

The next phase is implementation, defined as the process of putting to use or integrating evidence-based interventions within a care delivery setting. Challenges at the patient, clinician, and system levels hinder consistent implementation of what is known into practice. Our work to reduce CRF severity and impact on functioning and quality of life (QOL) is not finished! We propose that collaborations and partnerships among administrators and leaders, clinicians, and researchers are needed to translate the science to practice and to reach patients and families.

At the patient level, current barriers include attitudes and beliefs that CRF is an expected result of cancer and its treatment, and that CRF will resolve when treatment ends. Patients also express fears of dose delays or discontinuance if they report severe symptoms. All patients and families deserve, but do not consistently receive, the “Education, Counseling, and General Strategies for Management of Fatigue” (algorithm page FT-5 in the NCCN Guidelines for CRF, available at NCCN.org). When adult patients rate their CRF at 4 or higher (moderate or severe) on a scale of 0 to 10 over the past 7 days, many do not receive a primary evaluation as recommended in the NCCN Guidelines (algorithm page FT-4, available at NCCN.org). Patients need to be encouraged to not only rate CRF severity but also communicate its impact on their life and their expectation that their symptoms be addressed. We shouldn’t expect CRF to improve unless severity scores are linked to effective interventions.

Historically, the lack of evidence-based interventions has posed a clinician-level challenge. The premier cancer organizations now agree that several interventions are likely to be beneficial for relieving CRF. Clinicians may not realize that the green light is on to disseminate and implement these CRF interventions in oncology practice and policy. Clinicians must examine their assumptions about CRF and ask whether they have clinical inertia about CRF and other symptoms for which no pharmacologic agent is recommended. Recommended nonpharmacologic interventions include addressing treatable contributors for CRF, managing concurrent symptoms, physical activity and exercise, yoga, rehabilitation, psychoeducation, meditation, mindfulness-based stress reduction, cognitive behavioral stress management, and cognitive behavioral therapy for CRF, depression, pain, and sleep disturbances. Clinicians may lack the ability to provide these evidence-based interventions in their settings and communities.

Healthcare system challenges include a lack of access to and reimbursement for integrated supportive care services. Clinics specifically focused on symptom control and with CRF management programs have the potential for the greatest impact but are not widely available for patients at all stages of the cancer trajectory. This may be because CRF is complicated, and we lack specific etiology or mechanisms, biomarkers, and a taxonomy to classify it. Multicomponent interventions are complex and difficult to deliver with fidelity in routine clinical care. We need to overcome the
unknown critical elements of an intervention’s effectiveness. Interventions using protocols ready to be adapted for local use and with diverse populations in a variety of settings will promote evaluation of outcomes in the real world.

Implementation strategies refer to the systematic processes, activities, and resources that are used to integrate interventions into usual settings. The NIH Annual Conference on the Science of Dissemination & Implementation in Health (D&I) has focused on measuring D&I processes and outcomes, measuring stakeholder perspectives on processes and outcomes, measuring the impact of successful D&I to public health outcomes, and capturing the costs of implementation. However, research progress in D&I is currently hampered by underdeveloped concepts and measurement tools. The Agency for Healthcare Research and Quality has distinguished 5 process categories: provider, information systems, financial, organizational, and patient education and reminder. Literature reflects at least 8 conceptually distinct implementation outcomes: acceptability, adoption, appropriateness, feasibility, fidelity, implantation cost, penetration, and sustainability. Considerable efforts are needed to develop and test D&I processes and outcomes for CRF.

A system-level solution has been the decade of NCI grant funding to support researcher-clinician partnerships for implementation research in cancer prevention and control. Studies along the translational continuum have addressed the various implementation outcomes listed previously. Despite this progress, implementation research on CRF has been lacking. Examples of service delivery models to support implementation of physical activity interventions for CRF in practice include physical activity and exercise programs for cancer survivors, fatigue clinics, and physical rehabilitation programs for women with breast cancer. Other recommended interventions can be tailored to the individual and the phase of cancer treatment (active, post, end of life; see pages FT-5–7 in the NCCN Guidelines, available at NCCN.org). More exemplars of successful implementation research focused on CRF are needed, especially in the most common cancer sites.

An administrative clinician-level solution occurs when oncology leaders overcome the challenges in implementing CRF guidelines into practice. We believe the value that oncology leaders place on CRF and supportive care services influences progress in this area. We recognize that oncology leaders face challenges in prioritizing the resources that are needed to screen, evaluate, and manage CRF. Placing a priority on CRF management must compete with demands for accountability in other quality of care issues, such as distress screening, survivorship care planning, palliative care referrals, and adherence to oral chemotherapy. Issues linked to accreditations receive highest priority. Care delivery systems may need to be restructured to allow for routine symptom monitoring that triggers interventions to improve outcomes. We cannot expect clinicians to do a better job without additional time and reimbursement. Advanced practice nurse–led models hold high potential because nurse practitioners have expertise in symptom management and can bill using an ICD-10 code for CRF. The NCCN Guidelines format is not designed for clinicians who see a patient with several poorly controlled symptoms. We urge NCCN to prompt development of a clinician-friendly decision support system that complements the guidelines so they are useable and actionable.

When CRF is selected as a priority symptom for implementation, administrators and clinicians need to identify strategies to improve the capacity to screen, evaluate, and deliver evidenced-based interventions to reduce severity in patients. Strategies for building routine symptom screening into clinician workflow include use of electronic patient-reported outcome measures. An example of this is PROMIS computer adaptive testing, which is both efficient and precise, embedded into the eletronic health records (EHRs) or in waiting room kiosks. A system-wide process that incorporates this kind of testing into the EHR should include built-in triggers of alerts for actionable levels of CRF and other symptoms and provide decision support to help clinicians evaluate and manage patients with moderate to severe CRF. Interventions need to be delivered and followed up in a prompt manner to reduce CRF and other symptoms.
and to improve functioning and QOL. The effective components of a intervention for CRF need to be included in manuals and standardized for delivery. Support needs to be provided at a distance and facilitated by access to an EHR, accessible team members, available technology, and ease of documentation. These resources need to be available within cancer care delivery systems, via community agencies, or on the Web. Major organizations that have published recommendations for clinicians are urged to improve access to services by disseminating evidence-based interventions in patient-focused online versions. We see a great need to test telehealth approaches to making effective interventions widely available.

Translation of CRF recommendations for patients can benefit from recent advancements in other areas, such as psychosocial care and distress. One widely used technique to measure and provide feedback on implementation of recommendations is through audit and feedback. The American College of Surgeons Commission on Cancer’s release of cancer program standards, titled “Ensuring Patient-Centered Care,” includes a standard for screening of psychosocial distress but not for CRF. Integrating the distress thermometer as a standard for psychosocial distress screening has led to database development to demonstrate quality metrics such as “proportion screened for distress at baseline and follow-up.” Databases have the highest potential when they are integrated into clinician workflow and the EHR. Such data resources also provide opportunities for benchmarking and for examining trends among several symptoms and in various settings. A standard for CRF is needed now.

Areas ripe for policy work include reimbursement for CRF interventions and payment mechanisms to assure sustained adoption. We know that what gets paid for becomes priority, and evidence-based treatment of moderate to severe CRF should be reimbursed. Although improved processes and policies will facilitate dissemination of CRF guidelines, individual clinicians remain the access point for guideline implementation in patient care. Until clinicians and policymakers see more evidence generated in circumstances like their own, they will remain skeptical of the applicability, relevance, and fit.

Clinicians may ask on a patient-level, “How do I help this patient select a recommended intervention for CRF?” Or, they may consider on a systems level what it will take to implement CRF guidelines in their practice. We call for integrated and multicomponent approaches to the screening, evaluation, and management of CRF and other symptoms in clinical settings. When patients report moderate to severe CRF, clinicians can conduct the “NCCN Primary Evaluation” and use shared decision-making with patients to select an evidence-based intervention, set goals, and refer to appropriate programs. Ongoing reassessment can assist in documenting both short- and long-term impact of the intervention on CRF, functioning, and QOL. Our work won’t be complete until patients are receiving routine periodic screening and referral to programming, with outcomes of reduced CRF severity and improved functioning and QOL.

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References