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CONSENSUS STATEMENT

Guidelines needed for the management of fear of cancer recurrence in adult survivors of cancer in the United States: A consensus statement

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INTRODUCTION

The recent American Society of Clinical Oncology (ASCO) guideline update[1] advances our understanding of the management of anxiety and depression in adult cancer survivors. Grounded in a systematic and comprehensive review of the evidence by a multidisciplinary expert panel, the recommendations for screening, treatment, and delivery pathways from Andersen et al.[1] will promote access and engagement of cancer survivors in evidence-based psychological treatment.

This guideline update also affords a timely opportunity to spotlight a common experience that has become increasingly recognized as a salient and distressing concern among cancer survivors—fear of cancer recurrence (FCR). FCR, defined as fear, worry, or concern about cancer returning or progressing, is common, causing near-daily distress or impairment among as many as 59% of cancer survivors.[2–5] FCR has well defined triggers (e.g., somatic symptoms, survivorship events) and can be associated with unhealthy behaviors that negatively affect survivors' psychological, financial, and clinical outcomes. Increased alcohol use, reduced physical activity, and either unscheduled, nonguideline-concordant health care utilization, or avoidance of recommended surveillance can result from FCR.[2–4] There have been significant advances in FCR definitions, theory, and measurement in the past 10 years. In 2016, a Delphi consensus panel established a definition of FCR and the features of clinical impairment,[2] leading to the development and validation of psychological measures that have demonstrated the validity of FCR as an independent construct that has moderate correlations with generalized anxiety and other anxiety disorders but, unlike distress, does not generally decrease over time.[6–8] In the United States, FCR-related research recently has been funded by the National Institutes of Health and the American Cancer Society, in recognition of its salience and the need for effective, available treatments.

To ensure optimal psychosocial care, guidelines are needed within the United States for the clinical management of FCR, including recommendations for screening, referral, and treatment pathways. To date, there are no recommendations from US cancer

bodies regarding the management of FCR. The 2022 *ASCO Educational Book* highlighted the need for early and effective FCR intervention and detailed how, if left unmanaged, FCR can persist for years posttreatment and increase risks for anxiety and depression.[4] However, FCR management was not discussed in the 2023 ASCO update[1] and remains unaddressed in US guidelines.

Recently, the European Society for Medical Oncology published clinical practice guidelines for managing anxiety and depression in adult patients with cancer, including considerations for assessing FCR in the setting of a positive *anxiety* screen.[9] In Australia and Canada, guidelines are currently in preparation for managing FCR that will highlight these advances in FCR screening, treatment, and delivery pathways. To incorporate knowledge into clinical practice, we suggest parallel efforts from US-based cancer bodies and/or endorsement of guidelines being developed internationally.

Guidelines in the United States should highlight advances in FCR screening and referral pathways. Measures of FCR have been rigorously tested for convergent and divergent validity, leading to the validation of screening instruments for use in clinical trials and, recently, in routine clinical settings.[10] FCR can be easily and quickly identified with brief, single-item screening instruments[10]; however, there is a need to validate these instruments in diverse groups (e.g., non-English language preference survivors and those with advanced disease). Further testing is also needed of the incremental validity, following single-item FCR screeners with a severity measure in a two-step process to guide treatment recommendation in routine practice. Similar to measures of anxiety and depression, although longer FCR screening measures may offer superior psychometric properties, feasibility of implementation may point to single-item screening. In the context of a clinical assessment, clinicians should be aware that younger survivors often experience higher levels of FCR. Furthermore, because *scanxiety* is common before, during, and after cancer surveillance,[2,4] screening efforts may need to happen at several points along the cancer trajectory. Counterintuitively, FCR is largely independent of cancer site, stage, and time since diagnosis and treatment, so clinicians should not assume that objective risk for recurrence is correlated with a survivor's subjective experience of fear. Thus routine screening of all cancer survivors for FCR, irrespective of recurrence risk, is imperative.

Once FCR is identified, clinicians can normalize and validate FCR as common (e.g., *even years after diagnosis*, *even with low-risk cancers*) and let the survivor know that more intensive support is available if needed. FCR normalization and validation may be conducted in conjunction with screening; however, guidelines are needed to clarify whether there should be any interval between initial screening and further assessment/referral to intervention (i.e., stepped care) and whether care should be matched to the severity of FCR (i.e., nonelevated, elevated, clinically elevated). For example, survivors with elevated or nonelevated FCR may benefit from referral for asynchronous content, deliverable through remote technologies (e.g., website[11]), whereas survivors with clinically elevated FCR may require a referral for a higher level of care, including treatments that are delivered by a clinician. Clinically elevated FCR occurs in approximately 19% of survivors (i.e., Fear of Cancer Recurrence Inventory-Short Form scores from 22 to 36), and an additional 40% of cancer survivors experience FCR at elevated levels (i.e., Fear of Cancer Recurrence Inventory-Short Form scores from 13 to 21).[5] Thus nearly four in five survivors may not require the highest intensity FCR-specific treatments, although they may find benefit from less intensive treatments that have demonstrated efficacy in reducing elevated levels of FCR.

If clinically elevated FCR persists (i.e., ≥3 months), a psychiatric diagnosis may be considered as part of either *stepping up* or *matching* a survivor to more intensive care.[2,4] In the United States, a psychiatric diagnosis is of particular importance because it is required for billing reimbursements from insurers. For many cancer survivors, an adjustment disorder may be the most accurate diagnosis because this diagnosis reflects the understandable nature of fear after a major stressor: specifically, the diagnosis of a life-threatening illness, including cancer. FCR can also occur in the absence of anxiety and/or depressive disorders, in which case a diagnosis of adjustment disorder with anxiety or with mixed anxiety and depressed mood should be considered. For cancer survivors with clinically elevated FCR, comorbidities can include generalized anxiety disorder and major depressive disorder as well as other psychiatric illnesses, including posttraumatic stress disorder and illness anxiety disorder, and thus should also be assessed and co-treated.[4] Clinicians working within health care systems that use electronic health records may have the option to view details about a survivor's history of mental illness, which can be discussed with the patient when determining a current diagnosis. In many clinical settings, it may not be feasible to collect multiple measures; however, when possible, it allows providers to differentiate FCR from related concerns (e.g., general worry, fear of death, decisional regret).

Guidelines should highlight advances in FCR treatment. Meta-analyses of psychotherapy and mind-body interventions for FCR have demonstrated the effectiveness of targeted treatments.[12–14] FCR may require a more nuanced intervention approach than *standard* CBT treatment, which typically focuses on reframing irrational fears, exposure therapy, or behavioral activation. Although these coping strategies are evidence-based for certain anxiety and mood disorders, such as generalized anxiety disorder and major depressive disorder, they have the potential to be ineffective and invalidating for survivors faced with ongoing uncertainty. Without guidelines for FCR management, a cancer survivor with FCR might be offered *traditional* CBT for anxiety, which includes challenging beliefs in probabilities of catastrophic outcomes or exposure therapy (revisiting cancer stimuli, imaginal or in vivo). These therapy techniques can be unpleasant for survivors and, to date, have not been shown to improve FCR. Similarly, a cancer survivor might be referred for *traditional* CBT for depression, which includes behavioral activation (i.e., engaging in mood-uplifting activities) and mood ratings. These techniques may improve anhedonia and pleasure but have limited support for treating FCR. Both treatment pathways, although well intentioned, are not empirically supported compared with FCR-targeted treatments.[12,13] For example, a recent trial testing the effect of behavioral activation

on FCR found small effects,[15] whereas pooled effect sizes from FCR interventions are generally more robust (pooled Hedges g values of −0.36, −0.33, and −0.61, respectively[12–14]).

To date, the majority of randomized clinical trials have examined psychological interventions (i.e., CBT, acceptance and commitment therapy, and positive psychology skills training like gratitude journaling) and mind-body interventions that teach skills for enhancing the mind's ability to affect bodily function and symptoms (i.e., mindfulness meditation, relaxation training, guided imagery),[12,13] with larger effects coming from programs that are delivered to groups and/or that include mindfulness training.[12,13] These systematic reviews and meta-analyses have indicated that the skills that work best for FCR are highly focused and include: (1) reframing uncertainty about one's health, (2) scheduling worry time/cognitive diffusion techniques, (3) eliciting the relaxation response and mindful awareness of physiological sensations, and (4) managing health behaviors associated with risk for recurrence (e.g., cancer testing, sleep, physical activity, nutrition, smoking). Notably, these skills directly target FCR processes[3] as opposed to general distress. Certain positive psychology strategies, such as noting appreciations, creative expression, and using humor, may be useful for managing FCR, although empirical support for these techniques is less robust.[12] As clinicians and clinical supervisors working in cancer centers, we caution against attempting to reframe recurrence estimates, expose patients to feared outcomes, or increase their general level of activation, which have a limited evidence base for FCR but are evidence-based for treating anxiety disorders and depression. Educating survivors on their risk of recurrence and late effects of treatment is an essential component of quality survivorship care. We note that, even when a survivor's recurrence risk is very low, this education may not be sufficient to ameliorate FCR.

Finally, guidelines should be complemented by focused efforts to develop and sustain access to resources and training to support evidence-based FCR screening and treatment (e.g., by integration into psychosocial screening, conference workshops, continuing education courses) as well as asynchronous resources for clinicians to enhance delivery (e.g., manuals, handouts). In addition to training clinicians, it will be critical to engage survivors at highest risk for clinically elevated FCR (i.e., younger survivors, women).[5] Implementation of digital delivery can be helpful for targeting subpopulations at highest risk and may be noninferior to in-person–delivered FCR treatment.[14] For transparency, one of the authors (Allan "Ben" Smith) has developed an e-health FCR intervention that is being commercialized. In addition to addressing logistical challenges of in-person attendance and overcoming health-related social needs that may impede access to care, implementation of digital delivery may be optimal for cancer survivors who may feel that accessing FCR treatment in a setting that reminds them of cancer diagnosis or treatment (i.e., a hospital) is emotionally challenging. In the United States, randomized controlled trials have recently demonstrated the promise of digitally delivered FCR interventions at community sites (e.g., see Wagner et al.[11]). Still, some cancer survivors prefer to receive treatment in-person and may gain intangible benefits from connecting with a facilitator or other patients in-person, so referrals should be patient-centered and, when possible, should include both digital and in-person options. Ultimately, cancer survivors should be educated about empirically supported FCR treatments and encouraged to choose based on their preferences.

Guidelines must also acknowledge critical knowledge gaps in optimizing FCR management for underserved populations, including racial and ethnic minorities and survivors living with advanced cancer or undergoing treatment.[16] Like most cancer survivorship research to date, FCR research has been predominantly conducted with patients who are White, non-Hispanic, and have been treated with curative intent for nonmetastatic cancer (*curvivors*). Consequently, less is understood about benefits for survivors who are racially diverse as well as survivors who are living with metastatic cancer (*metavivors*) or undergoing active treatment (*in treatment*) who may be experiencing fear of progression. Current efforts in Australia and Canada are engaging stakeholders from community and home-care settings. Parallel efforts in the United States could engage stakeholders from underrepresented groups through existing clinical research infrastructures (e.g., the National Cancer Institute Community Oncology Research Program).[11]

Our stance is that survivorship is enhanced by addressing salient concerns, in agreement with the ASCO guidelines and guidelines from international organizations. To this extent, FCR interventions have been developed, tested, and deemed effective for reducing FCR but have yet to be integrated into existing guidelines for managing distress, increasing the odds that survivors will be suffering in silence, naive that evidence-based treatments exist for managing FCR. We are ready to improve the quality of life of cancer survivors who are tasked with the challenge of managing FCR largely on their own.

AUTHOR CONTRIBUTIONS

All authors contributed to conceptualizing, writing, and reviewing the final article.

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CONFLICT OF INTEREST STATEMENT

Daniel L. Hall reports personal/consulting fees from Goodpath, Inc., outside the submitted work. Lynne I. Wagner reports personal/consulting fees from Celgene Corporation outside the submitted work. Allan "Ben" Smith holds a copyright licensed to Blue Note Therapeutics, Inc., for the ConquerFear and iConquerFear fear of cancer recurrence interventions. The remaining authors disclosed no conflicts of interest.

DATA AVAILABILITY STATEMENT

Data sharing is not applicable to this article as no new data were created or analyzed in this study.

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