Plenary Session—The Patient Journey: Cancer Survivor Care

Presented by Shannon M. Ansbaugh; Gary Deng, MD, PhD; Rev. George F. Handzo, MA, MDiv, APBCC; and Karen L. Syrjala, PhD; Moderated by Jessica R. Bauman, MD

ABSTRACT

Quality survivorship care is critical for individuals dealing with the physical, mental, and emotional impacts of cancer and its treatment. Patients may not grasp the full traumatic impact of a cancer diagnosis until years later, but the mental health impacts of cancer can be significant. At the NCCN 2022 Annual Conference, a diverse panel discussed the cancer journey through the eyes of survivorship care, with voices representing both the patient and provider perspectives. Featured during the discussion were updates to the NCCN Distress Thermometer Problem List (to represent current psycho-oncology best practices more accurately), NCCN recommendations for mental health screening, and the benefit of integrative medicine both to relieve symptoms and improve overall wellness. Empowering patients to become active participants in their own treatment and strong survivors afterward was the overriding theme throughout the panel discussion.

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Struggles of Survivorship: Patient Viewpoint

Shannon M. Ansbaugh was diagnosed with Hodgkin lymphoma at age 14: the first chapter in what would become a life-long battle for both her physical and mental health.

"I didn't know anyone who had cancer, and I thought everyone who got cancer died," she said. Ms. Ansbaugh detailed her cancer journey during a roundtable discussion, moderated by Jessica R. Bauman, MD, Chief, Division of Head and Neck Medical Oncology, Associate Professor, Department of Hematology/Oncology, and Director, Hematology/Oncology Fellowship Training Program, Fox Chase Cancer Center, at the NCCN 2022 Annual Conference. "My family and I went into extreme distress and shock, and that set into motion my lifetime of cancer survivorship struggles."

She told about how, as much as she tried to outrun her history of cancer, it eventually caught up with her and she began to experience chronic insomnia and a diagnosis of generalized anxiety disorder. She kept it a secret for years, because she didn't know anyone in her family or social circle who even talked about mental health issues, much less admitted to struggling with them.

"You really never know how strong you are until being strong is the only choice you have," she said. "But there is a price."

At age 32, her world was shattered again, she said, when she was diagnosed with breast cancer due to the mantle radiation. She also learned she would not be able to have children. At age 38, she experienced a sudden-onset heart attack. "That was it for me," she said. "I kind of lost it and decided I needed to redefine my entire life."

However, after 8 years of remarkable health and several unforgettable experiences, her second heart attack led to the loss of her job, denial of disability coverage after open-heart surgery, a slew of financial and marital issues, and an inability to accept her new reality. When she finally ended up in the ICU during the COVID pandemic because of her second pulmonary hemorrhage, she said she was "completely broke."

Ms. Ansbaugh is now a 2-time breast cancer survivor and a 2-time heart attack survivor. She has undergone 3-way coronary artery bypass grafting and a transcatheter aortic valve replacement.

"I've spent the past 2 years rebuilding my mental health and working through my post-traumatic stress disorder [PTSD]," she said. "I've learned there is a gap in mental health coverage, especially for those of us who have Medicare, and for most people, this is a significant barrier to affording the treatment they need and deserve."

Ms. Ansbaugh continues to navigate the effects of her medical journey on her mental health. She now serves as a patient advocate representative on the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines) for Survivorship Panel and is involved in several initiatives geared toward supporting cancer survivors, their families, and healthcare providers.

According to Ms. Ansbaugh, when it comes to survivorship, patients may not even recognize they need help or know how to ask for it. However, the cancer journey impacts the whole family, so a strong support network is vital, and adaptation is necessary to survival.

Patients may not grasp the full traumatic impact of a cancer diagnosis until years later, but it's critical they realize that avoidance in dealing with the mental health impacts of cancer only leads to increased anxiety, depression, and suffering over time. This highlightes the crucial need for quality cancer survivorship care for individuals dealing with these issues.

The NCCN Distress Thermometer Problem List Update

Rev. George F. Handzo, MA, MDiv, APBCC, member of the NCCN Distress Management Panel and Director of Health Services, Research and Quality, HealthCare Chaplaincy Network, presented recent updates to the NCCN Distress Thermometer Problem List. The Problem List was established in 1999 as part of the NCCN Distress Thermometer (available at NCCN.org), to identify sources of distress stemming from 5 categories: physical, practical, family, emotional, and spiritual/religious.

No major revisions were made to the Problem List for more than 20 years, but a major update was authorized by the NCCN Distress Panel in August 2020, based on several concerns, including:

- The original version was heavily physical (now, physical concerns are covered in routine clinic assessments).
- New emotional concerns had arisen (ie, loneliness).
- Family and practical concerns were out of step with current practice.
- Evidence for spiritual/religious concerns had grown significantly.

In response to these issues, general changes included changing the word "problems" (ie, "practical problems," "physical problems") to "concerns." This edit attempted to simplify language in line with the experience of current users and reduce ambiguity and redundancy of terms.

According to Rev. Handzo, the current Problem List is more reflective of whole-person care and can effectively screen for all major domains of distress. It also reflects current psycho-oncology best practice, including social determinants of health and current distress management guidelines.

Management of Anxiety, Depression, Trauma, and Distress in Cancer Survivors

Mental health is a long-term issue in cancer survivors, and adult cancer survivors have higher rates of depression, anxiety, trauma, and distress than adults without cancer, according to Karen L. Syrjala, PhD, Professor, University of Washington School of Medicine, and Professor Emerita, Fred Hutchinson Cancer Research Center/Seattle Cancer Care Alliance. Distress related to cancer, its treatment, and fear of recurrence is common even in survivors who are not clinically depressed or anxious.

However, the good news is that conducting routine mental health evaluations with patients can be done quickly and efficiently, and a full screening requires fewer than 10 questions, she said. As described in Figure 1, post-treatment survivors experience mental health issues at higher rates than those without cancer. Dr. Syrjala noted that some of these outcomes, such as symptoms of post-traumatic stress (different from a full diagnosis of PTSD) can persist for 10 to 15 years after diagnosis.

"We also see what's been defined as post-traumatic growth or more recently called 'resilience': the ability to define positive outcomes of the cancer experience," she explained. "The ability to do this has been associated with better mental health overall, so it is an important element to consider in the evaluation of patients."

The NCCN Guidelines for Survivorship feature 3 general principles in the management of anxiety, depression, and trauma in cancer survivors.[1] First, the fear of recurrence often increases when surveillance testing or follow-up appointments are scheduled, and anxiety increases when physical symptoms occur. Second, mental health should be routinely monitored, especially at times of new diagnoses, transitions in care, significant loss or other major life events, and at times of social isolation. Third, survivors may not appear to be distressed and should be encouraged to inform their healthcare provider when they are feeling increased distress, anxiety, worry, or depression.

A myriad of risk factors contribute to these poor mental health outcomes,[2,3] including medical risk factors (ie, advanced disease, poor prognosis, comorbidities), personal (prior psychiatric/trauma history, avoidance coping, younger age), and social risk factors (lack of social support, financial issues, social stigma). However, protective factors for mental health outcomes also exist, including higher socioeconomic status, older age, and feelings of self-efficacy (confidence that one can manage their own healthcare and other health needs).[4,5]

The NCCN Guidelines for Survivorship endorse mental health screening at least once a year (based on the Diagnostic and Statistical Manual of Mental Disorders, 5th Edition criteria for diagnosing mental disorders) or when a patient experiences major changes in health status or life events (Figure 2). If a patient answers "yes" to any of the screening questions, continued evaluation (or referral) should be conducted.

"Your decision on whether to continue evaluation or make a referral to a mental health expert is going to depend on your available institutional and community resources, as well as your experience with treating mental health needs," Dr. Syrjala said. "If depression or other

NCCN Survivorship Guidelines General Principles (SANXDE-1):

"Cancer survivors are at elevated risk for mental health issues such as fear of recurrence, distress, anxiety, and depression that may persist for many years after diagnosis."

Outcome	Survivors	General Population
Fear of recurrence (moderate-severe)	28%–67%	--
Cancer-related distress/adjustment disorder	16%–43%	--
Anxiety	17%–25%	12%
Depression	8%–24%	10%–13%
PTSD/PTS symptoms Persists at elevated rates even 13 years after diagnosis	5%–12% / 33%–37%	2.4% (PTSD)
Post-traumatic growth, benefit finding, resilience, 'positive outcome of cancer'	83%–95%	--

Figure 1. Mental health outcomes in post-treatment survivors. These were predominantly cross-sectional cohorts and point prevalence designs. Abbreviations: PTS, post-traumatic stress; PTSD, post-traumatic stress disorder.

severe mental health symptoms are endorsed, it's essential to conduct a safety and suicide review or have someone available and trained to do that."

She emphasized that patient-reported outcomes can be incredibly useful in the screening of mental health disorders (ie, GAD-7 for anxiety, PHQ-9 for depression). These patient-reported outcomes are widely tested, reliable, valid, sensitive, and specific; all have cut points for clinically meaningful symptoms, and all can be reliably administered online or on paper in the clinic, she added.

For all survivors, nonpharmacologic interventions in the NCCN Guidelines include addressing treatable contributing factors (ie, pain, fatigue, sleep disturbances) and providing reassurance that symptoms of stress or fear of recurrence are typical among cancer survivors and can be treated. Additional interventions include providing support, education, and resources and developing a plan for regular physical activity and healthy nutrition.

"I want to emphasize that normalizing these concerns is one of the most valuable things that we can offer patients," said Dr. Syrjala. "Over the course of survivorship, more than half of patients will have one or more of these needs."

For individuals with depression, anxiety, PTSD, and fear of recurrence, cognitive behavioral therapy is consistently the nonpharmacologic intervention with the largest effect size across multiple meta-analyses.[6–8] The research also supports psychoeducational and supportive psychotherapy methods, although effect sizes for these interventions are smaller overall.[9]

Pharmacologic management is appropriate for many survivors, and most are usually started on selective serotonin reuptake inhibitors or serotonin-norepinephrine reuptake inhibitors. According to the NCCN Guidelines, patients on these medications should be followed up using phone or in-person visits within 2–4 weeks of initiation.

Dr. Syrjala emphasized that both pharmacologic and nonpharmacologic interventions require follow-up. "Take it on only if you can provide the follow-up needed; otherwise, refer," she advised.

Integrative Medicine for Oncology: The Memorial Sloan Kettering Experience

Cancer survivors experience several unique health issues—not only physical but also emotional and spiritual. Although several comprehensive treatment and management plans can potentially address these issues, one arguably underutilized approach involves integrative medicine, according to Gary Deng, MD, PhD, Medical Director, Bendheim Integrative Medicine Center, Memorial Sloan Kettering Cancer Center, and Professor of Clinical Medicine, Weill Medical College of Cornell University.

"Integrative medicine is not just about giving people acupuncture and taking herbs; it's really a comprehensive approach to their health," he said.

Integrative oncology is defined as a patient-centered, evidence-informed field of cancer care that uses mind and body practices, natural products, and/or lifestyle modifications from different traditions along with conventional cancer treatments. Integrative oncology aims to optimize health, quality of life, and clinical outcomes across the cancer care continuum and to empower people to prevent cancer and become active participants before, during, and beyond cancer treatment.[10]

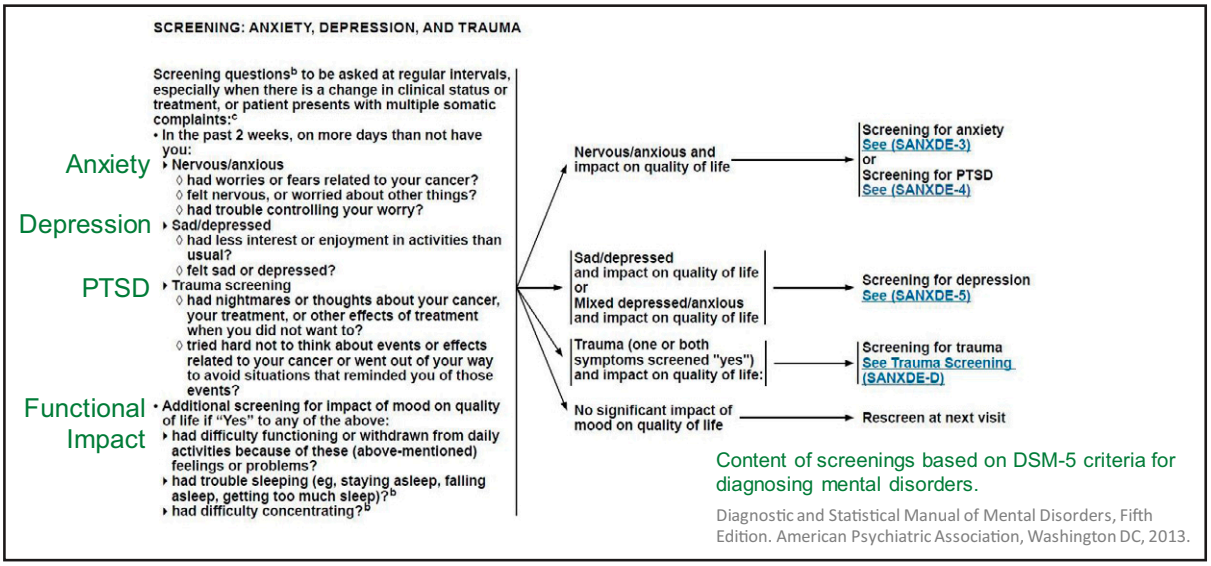

Figure 2. NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines) for Survivorship: anxiety, depression, trauma and distress [SANXDE-2]. Version 1.2022.

According to Dr. Deng, many patients prefer not to take conventional medications because of side effects and express interest in alternative methods of achieving symptom relief, preventing further health care problems and improving overall wellness. "Often, a diagnosis of cancer becomes a wake-up call for patients," he said. "They have a renewed interest in their health, especially in terms of overall wellness and improving their quality of life."

Established in 1999, Memorial Sloan Kettering Cancer Center was one of the first comprehensive cancer centers to build an integrative medicine program, Dr. Deng said, and it now sees close to 40,000 patients per year. Its goal is to incorporate nonpharmacologic interventions, many derived from non-Western traditions, to improve patient experience, outcomes, well-being, and survival. Before integrative medicine can be incorporated into standard cancer care, however, these therapies must demonstrate safety and efficacy.

"I think we have achieved this [at Memorial Sloan Kettering Cancer Center]. We're part of the whole cancer center, just like psychiatry, rehabilitation, and other supportive care services," he said. "The hope for the whole field is that we will eventually make integrative medicine part of standard cancer care, because patients really benefit from it."

Because it is still an emerging field, NCCN Guidelines on integrative medicine do not yet exist, but patients seeking integrative medicine therapies typically fall into 1 of 3 categories:

1. Newly diagnosed, wants to explore all treatment options and prepare for treatment;
2. In active treatment, wants to reduce side effects and improve outcomes; or
3. In remission, wants to improve wellness and reduce the risk of recurrence (ie, preventive medicine, dietary changes, lifestyle changes, mind/body therapy to reduce anxiety).

When patients are referred to the Integrative Medicine Center at Memorial Sloan Kettering Cancer Center, they first undergo a comprehensive physician consultation, and the NCCN Distress Thermometer is used to identify potential issues. "We look at a patient not as a collection of symptoms, but as a human being," he said.

According to Dr. Deng, the physician consultation serves to inspire and motivate them toward different techniques. Comprehensive plans tailored to each patient then empower and guide them toward specific lifestyle changes in areas such as diet, exercise, stress management, and sleep/circadian rhythm. The goal of these lifestyle changes is not only to solve acute issues, but also to contribute to a sense of meaning, he said.

Specific therapies are then prescribed to address certain symptoms. They include mind–body practices (eg, mindfulness meditation), body–mind practices (eg, yoga, Tai Chi, exercise training), acupuncture, massage therapy, music therapy, dietary advice, and natural health products. Dr. Deng noted that hundreds of these herbs

and supplements are on the market, and since some are helpful, some have no benefit, and others are downright harmful, patient counseling on their safe and effective use is also provided.

Education is another vital part of the mission at Memorial Sloan Kettering Cancer Center. In addition to offering fundamental training courses, the center has developed clinical practice guidelines for the American College of Chest Physicians and the Society for Integrative Oncology (which was later adapted by ASCO). The center also provides burnout prevention and wellness programs for their providers. Dr. Deng pointed out the benefits of integrative medicine for cancer care professionals, noting that improving wellness makes providers more effective at their jobs and actually enhances the overall quality of care they deliver.

According to Dr. Deng, the Memorial Sloan Kettering Cancer Center team has identified key factors to incorporating integrative medicine therapies into standard oncology care:

- Identify and bring together key stakeholders (patients/family members, oncology providers and administrators).
- Obtain leadership support.
- Secure financial backing.
- Build a professional team with people cross-trained in traditional and integrative medicines.
- Deliver superb clinical services.
- Achieve operational efficiency.
- Create sustainable referral streams.
- Generate public awareness.

"With integrative medicine, patients become ambassadors of a healthy lifestyle," added Dr. Deng. "When they change, their family and their friends will change. Rather than making disease contagious, they can make health contagious, and that's good for society."

Disclosures: Ms. Ansbaugh and Rev. Handzo have disclosed no relevant financial relationships. Dr. Deng has disclosed receiving royalty income from Phaidon Press. Dr. Syrjala has disclosed receiving royalty income from UpToDate. Dr. Bauman has disclosed receiving consulting fees from BeiGene Blueprint Medicines, Eli Lilly and Company, Janssen Pharmaceutica Products, LP, Mirati, and Turning Point; and serving as a scientific advisor for Merck & Co., Inc.

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