



DEREK FALK, PhD, MSW

Derek Falk, PhD, MSW, is an Assistant Professor in the Department of Population and Quantitative Health Sciences at the Case Western Reserve University School of Medicine.

Dr. Falk's research focuses on advancing health equity across the cancer continuum leveraging supportive care services, such as patient navigation, in community settings. He has trained at various institutions across the country, including the Brown School at Washington University in St. Louis (MSW), the Population Research Center and Steve Hicks School of Social Work at the University of Texas at Austin (PhD), and most recently the Wake Forest University School of Medicine (postdoctoral in cancer control and prevention). His work has been supported by the American Cancer Society (dissertation award) and the National Cancer Institute (T32).

His work highlights the role of supportive care in improving cancer screening and survivorship outcomes for medically underserved populations.

doi: 10.6004/jnccn.2022.7043

The ideas and viewpoints expressed in this commentary are those of the author and do not necessarily represent any policy, position, or program of NCCN.

Advancing Health Equity in Cancer-Related Distress: Lessons Learned From the COVID-19 Pandemic on Leveraging Digital Tools and Future Directions

Derek Falk, PhD, MSW, and Bradley J. Zebrack, PhD, MSW, MPH

The COVID-19 pandemic has amplified the need for healthcare systems to integrate digital tools, including patient portals, telehealth, and electronic health records, to optimize whole-person cancer care. Pandemic protocols have limited and, in many cases, prohibited the presence of loved ones at the bedside of hospitalized patients, thus increasing levels of distress for patients and families. Meanwhile, the cancer care workforce faced reductions due to downtime from their own COVID-related exposures and illness.¹ Burnout further contributed to workforce reductions and challenged providers in their efforts to manage patients' distress in addition to their own.¹ The pandemic conditions are current and ongoing, albeit varied by region and health system, yet they foreshadow fast-approaching challenges on the horizon that estimate larger patient populations, fewer healthcare workers, and increased reliance on digital tools to address gaps in cancer care. A study elsewhere in this issue investigated screening for cancer-related distress through online patient portals and the factors contributing to its use and efficiency.²

Disparities in Screening

The COVID-19 pandemic has also unveiled critical and persistent disparities in distress and cancer outcomes for persons who are marginalized based on their skin color, sexual orientation, and/or gender identity (ie, racism and sexism); by monolingual healthcare systems; and/or due to poverty and inequality. Cancer care leadership, including NCCN, NCI, the American Cancer Society, and others, have tasked clinicians and researchers with improving access to high-quality, patient-centered cancer care while advancing health equity in population subgroups experiencing disparities. Technology once again promises to improve engagement with members of underserved communities by expanding access to distress screening tools and resources to manage physical and mental health with increased monitoring and direct patient-provider communication. Evidence supporting the achievement of this promise, however, remains to be seen.

As illustrated by the findings of Sutton et al,² who investigated disparities in distress screening using online patient portals, these disparities relating to distress and cancer outcomes permeate digital distress screening uptake. They found that older age, certain races or ethnicities (eg, Black, Hispanic, Hawaiian/Pacific Islander), and types of insurance (eg, Medicare, Veterans' Affairs/military) or no insurance coverage were independently associated with lower odds of being offered distress screening. These findings point to systemic omission and underwhelming success in the conduct of distress screening for under-represented populations. The lack of consistent, equitable screening leads to providers underestimating the needs of cancer survivors. Indeed, the Institute of Medicine's 2008 report, *Cancer Care for the Whole Patient*, still rings true today: that patients who could benefit the most from distress



See page 765 for related article.

screening and subsequent psychosocial intervention are the least likely to engage with (be exposed to) and benefit from supportive care services, thus further widening distress disparities.³ Sutton et al's study serves as a blueprint for healthcare systems to determine gaps in portal distress screening for patient populations and to develop tailored solutions that diverse patient populations find relevant to their own needs and circumstances.

Distress Management and the Role of Social Determinants of Health

Screening, digital or otherwise, is the first step of a comprehensive clinical approach to distress management that includes subsequent assessment, triage, intervention, and outcome monitoring. A key element of distress management within a healthcare system is a systematic approach to identifying symptoms in the population of patients with cancer coupled with the implementation of evidence-informed interventions with demonstrated efficacy.⁴ The benefits of effective psychosocial interventions include increased therapy adherence, improved quality of life, greater symptom management, and lengthened survival. Digital tools such as patient portals may facilitate these interventions; however, their existence does not assure patient use and benefit. Barriers to use and benefit are multidimensional and complex, and can arise from stressors related to cancer diagnosis and treatment as well as family, community, and social contexts. Multilevel solutions are needed.

Screening must be comprehensive in the evaluation of known social determinants of health such as housing, food, and transportation, which are rarely addressed in current standardized distress screening measures. The National Academies of Sciences, Engineering, and Medicine recently recognized the importance of these factors in the delivery of healthcare as well as the role of supportive care services, including social work and patient navigation, in addressing barriers to care.⁵ However, moving beyond assessment to intervention has proven challenging given the limited and uneven investment in resources and services.⁶ Screening for these needs also risks exposing patients to trauma by asking them to report these concerns if healthcare systems are unable to address these barriers despite assessing them.

The extreme costs of cancer care, varying levels of insurance coverage, and lack of a comprehensive policy strategy has positioned financial hardship as one of the key barriers to high-quality, whole-person cancer care.⁷ The impact of financial hardship is an evolving area of research that includes material, psychological, and behavioral components. Again, persons of color, sexual and gender minorities, and patients who lack economic resources, including adequate health insurance, bear an unequal burden of hardship.

As with other social determinants of health, no standardized system of assessing and addressing hardship has been adopted. Although 40 years of social and behavioral science have yielded evidence of the effectiveness of various psychosocial and supportive care interventions, state and national policy-level interventions are still needed to support their implementation. Interventions are also needed to deal with the impact of financial hardship that often extends many years past initial treatment.

Advancing Equity With Social Work and Patient Navigation

Social work has more than 100 years of history assessing the social environment's impact on patient health and mitigating the impact of social factors on patient experience, behavior, and outcomes.⁸ Conversely, the role of patient navigation in addressing barriers has a much shorter history, beginning in the 1990s with varying definitions and scope of responsibilities, yet patient navigators also contribute to care by evaluating and addressing barriers to timely treatment.⁹ Quality cancer care depends on an entire team of healthcare providers who work collaboratively



BRADLEY J. ZEBRACK, PhD, MSW, MPH

Bradley J. Zebrack, PhD, MSW, MPH, is a Professor at the University of Michigan School of Social Work and member of the University of Michigan Rogel Cancer Center, Division of Cancer Control and Population Sciences. He is a fellow to the Society for Social Work and Research (SSWR), the American Psychosocial Oncology Society (APOS), and the Association for Oncology Social Work (AOSW).

Dr. Zebrack has clinical social work experience in both pediatric and adult oncology, and also has been involved in the development and evaluation of peer support programs for adolescent and young adult cancer survivors.

His research on quality of life and cancer survivorship over the past 20 years has been supported by the National Cancer Institute (K07, R03, R01), the Patient-Centered Outcomes Research Institute (PCORI), and HopeLab Inc. His work demonstrates the unique and essential role for social work in medical care settings and addressing inequities in service delivery.

to address the varied conditions that influence patient outcomes. Social workers and patient navigators have also played an essential role in advancing health equity by prioritizing the needs of populations experiencing disparities as a function of systemic racism and other forms of marginalization. They can provide culturally and linguistically congruent representation for individuals and communities who may view healthcare organizations negatively due to historical injustices and perceived bias.¹⁰ Social work has also advocated for increased support at both local and national levels to recognize and address social determinants of health and the needs of underserved individuals in healthcare that require policy-level interventions beyond the scope of any individual healthcare organization.

Conclusions

The COVID-19 pandemic highlights the need to leverage patient portals, telehealth, and novel uses of electronic health records to address current and future challenges in cancer care. However, cancer-related distress is multifaceted and requires multilevel interventions to mitigate its impact on survivors. Distress management must expand to include redress

of the social determinants of health, especially financial hardship, with supportive policies requiring assessment and mitigation plans for underserved populations. Achieving equity in cancer care requires dedicated effort from providers at all levels to implement systematic assessment for all patients and incorporate this knowledge into treatment plans. Commitment toward this goal also challenges healthcare systems to value the role of supportive care services, including social work and patient navigation, in using evidence-informed interventions to manage distress in patients with cancer. Finally, policies recognizing health equity as a priority and providing material support to achieve these goals are essential to overcoming the unequal landscape of cancer care and outcomes in the United States.

Disclosures: The authors have disclosed that they have no financial interests, arrangements, affiliations, or commercial interests with the manufacturers of any products discussed in this article or their competitors.

Correspondence: Derek Falk, PhD, MSW, Department of Population and Quantitative Health Sciences, Case Western Reserve University School of Medicine, 10900 Euclid Avenue, Cleveland, OH 44106-7288.
Email: derek.falk@case.edu

References

- Hlubocky FJ, Shanafelt TD, Back AL, et al. Creating a blueprint of well-being in oncology: an approach for addressing burnout from ASCO's Clinician Well-Being Taskforce. *Am Soc Clin Oncol Educ Book* 2021;41:e339–353.
- Sutton T, Kropowski M, Gold J, et al. Disparities in electronic screening for cancer-related psychosocial distress may promote systemic barriers to quality oncologic care. *J Natl Compr Canc Netw* 2022;20:765–773.
- Institute of Medicine Committee on Psychosocial Services to Cancer Patients/Families in a Community Setting. Cancer care for the whole patient: meeting psychosocial health needs. In: Adler NE, Page AEK, eds. *The National Academies Collection: Reports Funded by National Institutes of Health*. Washington, DC: The National Academies Press; 2008.
- Deshields TL, Wells-Di Gregorio S, Flowers SR, et al. Addressing distress management challenges: recommendations from the consensus panel of the American Psychosocial Oncology Society and the Association of Oncology Social Work. *CA Cancer J Clin* 2021;71:407–436.
- National Academies of Sciences Engineering and Medicine. Integrating Social Care into the Delivery of Health Care: Moving Upstream to Improve the Nation's Health. Washington, DC: The National Academies Press; 2019.
- Zebrack B, Kayser K, Padgett L, et al. Institutional capacity to provide psychosocial oncology support services: a report from the Association of Oncology Social Work. *Cancer* 2016;122:1937–1945.
- Yabroff KR, Bradley C, Shih YT. Understanding financial hardship among cancer survivors in the United States: strategies for prevention and mitigation. *J Clin Oncol* 2020;38:292–301.
- Gehlert S, Hudson D, Sacks T. A critical theoretical approach to cancer disparities: breast cancer and the social determinants of health. *Front Public Health* 2021;9:674736.
- Bernardo BM, Zhang X, Beverly Hery CM, et al. The efficacy and cost-effectiveness of patient navigation programs across the cancer continuum: a systematic review. *Cancer* 2019;125:2747–2761.
- Winkfield KM, Regnante JM, Miller-Sonet E, et al. Development of an actionable framework to address cancer care disparities in medically underserved populations in the United States: expert roundtable recommendations. *JCO Oncol Pract* 2021;17:e278–293.