


Editorial

Addressing health-related quality of life inequities in cancer: where do we go from here?

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In 2019, the National Cancer Institute hosted a cancer survivorship workshop with the goal of identifying specific evidence gaps in cancer survivorship (1). Prioritized among these gaps was improving the understanding of and addressing patient-reported physical, psychosocial, and financial needs of cancer survivors from diverse racial and ethnic backgrounds as well as countries of origin. Optimizing health-related quality of life (HRQOL), defined as “a multidomain concept that represents the patient’s general perception of the effect of illness and treatment on physical, psychological, and social aspects of life,” (2) is foundational to providing high-quality, holistic care for individuals living with a cancer diagnosis.

In response to the National Cancer Institute’s call to action, Reeve et al. (3) conducted a population-based, cross-sectional study to characterize HRQOL in a diverse group of 5366 adult cancer survivors. Latent profile analysis, a sophisticated statistical methodology, was employed to robustly evaluate Patient-Reported Outcomes Measurement Information System measures of fatigue, pain interference, anxiety, depression, sleep disturbance, physical function, ability to participate in social roles, and cognitive function, with 4 clinically relevant “profiles” or clusters of cancer survivors emerging. The racial and ethnic diversity of the study sample (17% Asian, 21% Hispanic, 18% non-Hispanic Black, and 41% non-Hispanic White) is a notable strength, because racial and ethnic minority groups are often underrepresented in cancer research studies. Furthermore, 60% of participants were younger than 65 years, which sets this work apart from SEER-Medicare-linked studies that report findings for Medicare-eligible cancer survivors.

Perhaps most unique, this study examined the contribution of country of origin on membership in HRQOL clusters. Often, individuals from different countries with distinct cultures, traditions, and beliefs are grouped together into an overarching racial or ethnic group (ie, “Asian patients” or “Hispanic or Latino patients”), which masks important, group-specific differences. The large sample in this study allowed the research team to examine HRQOL domains across multiple groups (with >100 individuals per group): Caribbean, Chinese, Filipino, Mexican, non-Hispanic Black, non-Hispanic White, other Asian, other Hispanic, other non-Asian, and other non-Hispanic. This level of granularity is an innovative contribution of this study, which may inform oncology providers of specific groups of patients who may be especially susceptible to HRQOL decrements during and after cancer

treatment. For example, Reeve et al. (4) found that Cuban, Dominican, and Puerto Rican cancer survivors were more likely to be in the “very low HRQOL” cluster, which was 15 points lower than US general population norms (mean of 50 and SD of 10). Cancer centers and practices that serve immigrant patients from these 3 countries may benefit from the knowledge of these findings and potentially offer culturally tailored resources to better support patient needs.

It should be noted that the HRQOL assessment at a single time point (6–13 months after cancer diagnosis) may not fully capture the experience of patients across the cancer care continuum. Prior studies have shown that different racial and ethnic groups have distinct HRQOL patterns over time (5–7) and that minority patients are more likely to experience HRQOL decrements as they progress into survivorship (8). Building on the findings of Reeve et al. (3), future studies should be designed to longitudinally collect HRQOL data, allowing for the identification of distinct trajectories of HRQOL over time. A similar methodology, latent transition analysis (9), could be useful in identifying risk factors for poor or worsening trajectories of HRQOL, beginning at diagnosis, through treatment, and into long-term survivorship. Given the growing number of cancer survivors (10), including those from diverse racial and ethnic backgrounds and different countries of origin, approaches to identifying individuals at greatest risk for poor HRQOL outcomes can help target resources to patients who need them most.

As next steps in this line of research are considered, Reeve et al (3) suggest that routine HRQOL assessments be integrated in clinical practice to develop HRQOL risk prediction tools that will identify patients with cancer who are at increased risk for declining HRQOL. Leveraging patient-reported information to directly inform HRQOL risk assessment and subsequent management has tremendous potential, yet the practical challenges and barriers to implementation in a “real world” setting should first be acknowledged. Many unanswered questions remain, including “can (and should) HRQOL assessments be deployed in the primary care setting or limited to oncology practices and how frequently should these assessments occur across the care continuum?” “How do we develop and implement follow-up protocols and processes to respond to information collected from assessments?” For example, if a patient self-reports debilitating pain, fatigue, or sleep disturbance, pathways for how the clinical

care team is alerted and responds should be delineated. Finally, feasibility of implementation of HRQOL assessments into routine clinical care across a wide variety of cancer care centers, including community hospitals, is a critical step to reaching underrepresented groups of patients who may not have access to academic cancer centers for care.

Reeve et al. (3) underscore the potential impact of ongoing (11) pragmatic studies that are rigorously evaluating the implementation and effectiveness of patient-reported symptom monitoring intervention in diverse practice settings to positively affect outcomes. HRQOL experiences of patients from diverse racial and ethnic backgrounds and countries of origin should be captured to support high-quality cancer care. Future pragmatic studies may inform best approaches to implementation of these interventions following the completion of active treatment, helping to support all cancer survivors through and beyond their diagnosis.

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