

# Positive Yet Unequal Trends

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*Community engagement strategies are beneficial for understanding barriers to healthcare utilization.*

The American Cancer Society recently reported a second consecutive year of very positive data regarding cancer survival (Siegel et al., 2021). Although the latest data may have been affected by pandemic-associated delays, the trend in the data indicates that the overall death rate from cancer in the United States continues to decline. The death rate from cancer has fallen 31% from 1991 to 2018, with an estimated 2.9 million fewer cancer deaths during that interval than would have occurred if death rates had remained at their peak level (based on five-year age-specific, sex-specific, and population-based data) (Siegel et al., 2021). Multiple factors have contributed to this improvement in cancer survival. For example, notable improvements in treatments for childhood cancers have resulted in overall survival increasing from 30% in the 1960s to greater than 80% in most high-income countries in 2020 (Erdmann et al., 2020). In addition, vaccines against human papillomavirus are reducing cervical cancer risk, enhancement in breast cancer diagnosis and treatment have led to marked survival gains, and targeted therapies (e.g., immune checkpoint inhibitors) for malignant melanoma have increased long-term survival by 50% in some cases (Michielin et al., 2020). However, other cancer types, such as pancreatic and brain, have seen lower levels of improvement.

Although therapeutic advances have contributed to improved cancer survival for many, lifestyle changes and focused screening has had a prominent role in some of the survival gains. A decline in smoking in the United States, for example, accounted for

about 40% of the decrease in overall male cancer-related deaths and has prevented at least 146,000 lung cancer deaths in men from 1991 to 2003 (Thun & Jemal, 2006). In addition to the success from smoking cessation efforts, in 2013, the U.S. Preventive Services Task Force (USPSTF, 2021) began recommending lung cancer screening for high-risk smokers and former smokers, aged 55 to 80 years, using low-dose computed tomography (LDCT) to help with early identification of lung masses. Earlier screening is now recommended for colorectal cancer as well, with the American Cancer Society modifying age guidelines for screening to begin at age 45 years instead of 50 (Wolf et al., 2018). This change was made because of increasing evidence for early-onset colorectal cancer. The new guidelines also support noninvasive screening in addition to a colonoscopy, such as the use of the fecal immunochemical test and genomic assays, which provide another method for individuals who prefer noninvasive screening options (Wolf et al., 2018).

What are the messages for oncology nurse scientists as they plan future research to enhance cancer survivorship? First, there is an ongoing need to consider the data, both big data from a quantitative perspective and the narrative, and deeper understanding provided by qualitative inquiry. From a big data perspective, smoking cessation and improved screening using LDCT have led to a lower incidence of lung cancer in the United States. However, the improved incidence numbers may mask the fact that African Americans may be less likely to “qualify” for LDCT because of different patterns of smoking and, therefore, remain disproportionately affected by lung cancer risk and mortality compared to White Americans. Current guidelines for LDCT lung cancer screening may not adequately capture African Americans at risk, particularly younger African Americans and those

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who are light smokers or intermittent smokers (Li et al., 2019). The global trends in cancer also reveal disparate outcomes (Watson et al., 2020). Despite a lower incidence of cancer in low- and middle-income countries (LMICs) compared to high-income countries, total cancer-related mortality is significantly higher in LMICs, particularly in people younger than age 65 years (Shah et al., 2019). Age may also be a risk factor for focus of cancer clinical trials; however, by 2050, an estimated 6.9 million new cancers will be diagnosed in adults aged 80 years or older worldwide (20.5% of all cancer cases) (Pilleron et al., 2021). A recent study found that age disparities between trial participants and the incident disease population are pervasive across industry-supported trials and appear to be increasing (Ludmir et al., 2019).

From a qualitative perspective, gaining a better understanding of modifiable risk behaviors and uptake of screening recommendations requires understanding the perspectives of patients and family members. Community engagement strategies, such as the SHARED Project (focusing on lung cancer screening in African American male smokers), are beneficial for understanding barriers to healthcare utilization and may provide answers hidden in big data, including individual, family, community, and global perspectives. In addition, improving the understanding of the barriers to trial enrollment among various underrepresented groups is important, as is recognizing patient, practice, community, and trial-specific factors as an essential part of clinical trial development and design and not a disclaimer after completion. A better understanding of increasing the enrollment of underrepresented groups in clinical trials is imperative. The Cancer Disparities Research Network, for example, undertook an evaluation of biobanks among 10 representative facilities. They found that only 10% of samples came from non-White patients, and only a handful of centers targeted underrepresented populations (Brady & Weeraratna, 2020). Future big data will be derived from these biobanks, and limitations in diversity of participants could lead to spurious conclusions if the sample composition does not represent the population.

Finally, a continued problem—and not just in cancer research but in all biomedical research—is the vast underrepresentation of minority groups in biohealthcare career paths. This education and research training of the next generation of oncology nurse scientists will drive forward biomedical research while also attending to the human factors that promote well-being for individuals, families, and communities affected by cancer.



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