Advancing a Quality-of-Life Agenda in Cancer Advocacy
Beyond the War Metaphor

Cancer advocacy has reached a pivotal point. When President Nixon declared “War on Cancer” by signing the National Cancer Act in 1971, advocates advanced a narrative that suffering and death from cancer should not be accepted; cancer should be fought and eradicated. Since then, nonprofit and academic institutions have focused their research and marketing strategies on prolonging survival, via cure and prevention. This strategy has been successful. Whereas only 3 million survivors lived in the United States in 1970, nearly 14 million Americans with a history of cancer were living in 2012. They will number 18 million by 2022. As survival for many types of cancer has improved, however, goals must evolve as well. Cancer survivors desire both more days and better days. In response to the improved survival rates, cancer advocates have begun to place equal emphasis on prolonging survival and improving quality of life. They assert—and we agree—that it is time to move beyond the “war” metaphor to embrace a dual message of surviving and thriving. We propose 3 priority areas—in clinical practice, in messaging, and in research—in which a successful quality-of-life agenda can be implemented.

Advances in early detection and treatment, coupled with advocacy campaigns organized around “conquering” or “eradicating” cancer, have driven the substantial gains in life expectancy among certain cancer types. Breast cancer is a stark example: 5-year survival for breast cancer alone has increased from 63% in the early 1960s to more than 90% today, due largely to improvements in early detection and treatment. Alongside research investment, cancer advocacy efforts have helped improve detection and survival and, for some cancers, even offer a cure.

There are limitations of a narrow focus on cure and prevention, however. The risks of overdiagnosis and overtreatment from large-scale cancer screening programs and associated treatment are now well known. Previous advocacy efforts have also fallen short in addressing family caregiver support needs, the high costs of cancer treatment, and symptoms and late effects that cause substantial preventable suffering. Long-term health consequences of cancer treatment are increasingly evident. Among adult survivors of childhood cancer, more than 98% experience a chronic health condition by age 45 years, including cardiomyopathy and pulmonary disease, that are in many cases attributable to treatment received early in life. Furthermore, total inflation-adjusted medical costs of cancer have nearly doubled between 1987 and 2005. The exorbitant costs of some novel chemotherapies and screening tools add another wrinkle to the complicated history of the metaphorical “war on cancer.”

Health care professionals, activists, and patients need a new narrative—and a new metaphor—that responds to the changing demographic characteristics of the cancer population. Fortunately, the success of research and advocacy efforts in prolonging survival has paved the path for modernizing the high-quality care paradigm to reflect patients’ and families’ expanded priorities of survival and quality of life. Greater life expectancy for adults and children with cancer has inspired researchers, practitioners, and patient advocates to address pain, symptoms, distress, and other quality-of-life concerns alongside disease-directed treatment as an integral part of high-quality care.

Clinically, tending to quality-of-life concerns and patient values in oncology treatment is now universally recommended by professional oncology organizations and accrediting entities. Integrating palliative care with standard therapy is one evidence-based strategy proven to improve quality of life and care while reducing costs—particularly among our nation’s sickest adults and children. Concurrent oncologic and palliative care is supported not only by a majority of patients in public opinion research but also by clinicians via evidence-based recommendations from the American Society for Clinical Oncology and American College of Surgeons. Recommendations in recent Institute of Medicine consensus reports have also underscored the importance of prioritizing clinical communication skills training in all oncology programs. To maintain physical and emotional functioning and support quality of life at any age and any stage across the care continuum, psychosocial and rehabilitation services must be integrated into palliative care (see Figure). Yet, despite known benefits, palliative care referral practices vary widely across the United States, and palliative care services remain rare outside the hospital setting. Advocacy organizations should seek to make palliative care services more widely available, promote communication training, and integrate psychosocial and rehabilitation services in clinical settings.

Consistent and clear messaging through coordinated advocacy is also essential. As an initial step, more than 20 groups have partnered in building a “Patient Quality of Life Coalition” (www.patientqualityoflife.org) that provides the organizational and strategic framework for multiple disciplines to join forces in advancing this national quality-of-life movement. The coalition’s agenda involves legislation; informational campaigns using print and social media; and Internet resources for patients, families, and health care profes-

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Finally, advocacy groups must emphasize balanced support of quality-of-life-focused research across the National Institutes of Health grants portfolio, which currently lags substantially behind research dedicated to disease-directed treatment. The American Cancer Society and the National Palliative Care Research Center have partnered to support dedicated palliative care research grants and mentorship for building a community of researchers and collaborative projects. To meet increasing burdens as the population of individuals living with cancer or living after cancer continues to grow, however, government and nongovernment organizations together must prioritize research investigating best practices to support medical and psychosocial needs during treatment and survivorship.

Advocates should never abandon the fight to prevent and cure cancer. But changing demographic characteristics of the cancer population require updated strategies and messaging. Cancer advocates should engage in clinical, legislative, and research efforts that help reduce the medical, economic, and emotional consequences of cancer. It is time to break down the silos across diseases and disciplines to advance the fundamental care tenet of curing when we can and comforting always. Saving lives with high quality of life demands it, and a quality-of-life agenda is the best place to take this first next step.