
CANCER SURVIVORSHIP ADVOCACY

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OBJECTIVES: *To review the advocacy initiatives of major cancer-related organizations and coalitions that are working to effect funding, planning, and implementation of care and services for cancer survivors.*

DATA SOURCES: *Web sites of cancer-related member organizations, advocacy associations' policy staff representatives, and published peer-reviewed health policy literature.*

CONCLUSION: *Health care reform creates near endless opportunities for nurses to participate in and contribute to the development of public policy to support meeting the needs of cancer survivors.*

IMPLICATIONS FOR NURSING PRACTICE: *Emerging public policy initiatives, including legislation and regulation created with professional nursing's contributions are most likely to reflect the needs of cancer survivors.*

KEY WORDS: *Survivorship advocacy, survivorship legislation, survivorship regulation*

PUBLIC policy is a system of regulatory decisions, legislative actions, funding priorities, and other courses of action.¹ Everyone who is diagnosed with cancer, and health care professionals who provide care and services for people diagnosed with cancer, is impacted by public policy.¹ This impact can include funding for all measures associated with cancer control: best practices and guidelines for prevention and early detection, research for new, effective, and less toxic therapies, public and pri-

vate payer coverage for treatment, and financial and practical issues related to care.¹ There is strong emphasis on public policy to improve survivors' access to care, explore and implement evidence-based efforts to identify, prevent, or minimize short and long-term effects of the disease and its treatment, to eliminate disparities in cancer-related outcomes, and to improve coordination of care for survivors of cancer. Initiatives arising from advocacy, research, education and practice sectors underlie the most recent meaningful outcomes to occur in the history of cancer survivorship. Throughout the three decades of the survivorship movement, policy change has been and continues to be essential to ensure that cancer survivors have access to high-quality, evidence-based cancer care.¹⁻³

Advocacy among oncology nurses can be defined very simply as a voice for the vulnerable.⁴ Oncology nurses view advocacy efforts as existing on a continuum, ranging from one-on-one negotiations to arrive at effective symptom management strategies

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for individual patients, institution and delivery-system level efforts to advance evidence-based practices, to local, state, and national levels to effect change that promotes quality cancer care.⁴ The first organization in the world to focus solely on issues of cancer survivorship, the National Coalition for Cancer Survivorship (NCCS) was a catalyst for survivor advocacy, that also exists on a continuum, perhaps beginning at personal levels with self-advocacy, but broadening along the survivorship journey to include group, organization, and public advocacy efforts.³

In its Position Statement on Access to Quality Cancer Care, the Oncology Nursing Society (ONS) affirms its philosophy that “access to quality cancer care is the right of all people.”⁵ This ONS statement identifies basic characteristics of quality cancer care as “safety, efficacy, timeliness, a patient-centered approach coordinated by a multidisciplinary team, and integration of evidence-based practice to continuously improve care.”⁵ The statement notes that without essential services (prevention, early detection, risk reduction, clinical trials, treatment, psychosocial care and survivorship) patients may experience diminished quality of life and/or sub-optimal outcomes.⁵ What the ONS calls the “substantive role of oncology nurses” in quality

cancer care is affirmed and consistent with the Institute of Medicine’s *Future of Nursing: Leading Change, Advancing Health*.^{5,6} Major elements of the ONS Access to Quality Cancer Care position are identified in Table 1.

The NCCS recognizes quality cancer care as cancer patients having access to comprehensive and coordinated care that adheres to practice guidelines and evidence-based standards.¹ Essential components of care include¹:

- Written care plan detailing patient-centered goals and intentions of therapy, all elements of care
- Access to appropriate clinical trials
- Assessment and attention to psychosocial needs
- Treatment summary
- Services to monitor health status, early recognition of complications, and surveillance for recurrent and second cancers
- Coordinated care

PUBLIC POLICY PRIORITIES AND INITIATIVES

The Affordable Care Act (ACA) implementation processes present nearly endless opportunities for nurses’ participation and contributions—development of regulatory language and legislation to further define health care delivery consistent with the intent of the ACA and nursing ethics.

Coalitions

Cancer-related organizations and associations share a number of public policy priorities. In recognition of power in numbers, coalitions are formed that allow organizations to avoid duplication of efforts and combine resources to reach a shared goal. One such example is One Voice Against Cancer (OVAC), a coalition of 40 associations.⁷ Recognizing implications of the 14 million Americans living today with a history of cancer, the nearly 70% survival rate of the 1.6 million Americans diagnosed with cancer annually, and the lack of optimal treatment for many forms of cancer and limited options for management of long-term and late effects, OVAC was formed to advocate for increases in cancer-related funding.⁷ The American Society for Clinical Oncology, the American College of Surgeons Commission on Cancer, the American Society for Radiation Oncology, the Intercultural Cancer Council Caucus, and the ONS, are among coalition

TABLE 1.
Elements of the ONS Position Statement: Access to Quality Cancer Care⁵

<p>Provision of comprehensive health care coverage for cancer prevention, early detection, risk assessment and reduction services, appropriate use of genetic predisposition testing and counseling.</p> <p>The provision of health care coverage that is accessible and affordable and includes consumer choice and control.</p> <p>Access to evidence-based conventional and integrative therapies, including regimens incorporating off-label therapies approved by the U.S. Food and Drug Administration, symptom management and palliative care, psychosocial care, long-term survivorship, and rehabilitation services.</p> <p>Access to affordable full range of proven-effective tobacco cessation strategies and therapies.</p> <p>Services provided by professional oncology nurses, including advanced practice nurses who are competent in the essentials of oncology nursing and the administration of oncologic therapies, are accessible and eligible for reimbursement.</p> <p>Health disparities and access to care and treatment challenges are addressed for at-risk and underserved populations and appropriate referrals are made to community resources.</p>
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