

Reflections of a Health Policy Advocate: The Natural Extension of Nursing Activities

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The words lobbying and lobbyist often bring to mind negative images for most people who live outside the beltway of Washington, DC. Based on images in Hollywood movies, unfavorable news reports, and regular examples of how money drives policy making, many people perceive lobbyists as highly paid, morally bankrupt individuals who advocate on behalf of greedy and evil corporations, such as Big Tobacco. Instead of lobbying and lobbyist, I prefer the terms advocacy and advocate. As the Oncology Nursing Society's (ONS's) health policy associate in Washington, DC, I have the honor and responsibility of representing ONS's interests and those of people with cancer to U.S. policymakers, as well as working with ONS and its members to enhance and expand the capacity of oncology nurses to engage in effective health policy advocacy.

The purpose of this article is to describe what constitutes health policy advocacy, present some challenges associated with it, and provide an overview and resources about how oncology nurses can engage in health policy advocacy. The term policymaker is used throughout this article; although many of the points refer to senators and representatives in the U.S. Congress, they also apply to local and state officials.

Health Policy Advocacy Is Essential to Advancing Oncology Nursing

During the past 20 years, health and consumer-based organizations have incorporated advocacy into their missions and principal activities. They have seen the gains that can be attained through such initiatives. For example, the HIV and AIDS activism of the 1980s and the breast cancer movement of the 1990s are well-known, tangible examples of what organizations and communities can achieve if they choose to allocate human and financial resources to affect public policies. Both causes have benefited from increases in research and programmatic funding for efforts to reduce and prevent the diseases' incidence, morbidity, and mortality. In addition, media coverage, public awareness, patient understanding, and healthcare-provider education have increased along with the public policy focus. For oncol-

ogy nursing and broader cancer issues to begin to receive the kind of attention, public policy response, and funding they deserve, oncology nurses must engage in proactive and aggressive advocacy efforts to help drive the national agenda toward ONS's concerns.

Increasingly, much of what oncology nurses do and experience daily while caring for patients is affected directly by laws, regulations, and other policies. Priority issues of concern to oncology nurses include adequate Medicare reimbursement for community-based cancer care, the nursing shortage, access to clinical trials, privacy of health information, genetic discrimination, and federal funding for cancer research and application. Federal policymakers take action and can positively and negatively influence each of these issues. Lawmakers regularly make decisions that affect physicians, nurses, health insurers, hospital administrators, and researchers, and they might do so with limited substantive knowledge and understanding of the people and systems they are affecting.

Without hearing directly from oncology nurses about priority problems and recommended solutions, policymakers either will fail to address such concerns or use information and expertise provided to them by others. Some of their sources may not share the views of the oncology nursing community. However, nurses are perceived to be on the side of patients, not profits. Their opinions are well respected and welcomed by policymakers. In fact, many policymakers seek input and expertise from healthcare professionals in their communities when they need information or additional viewpoints about pending legislative or regulatory matters. Policymakers must have input so they are aware of the needs in their communities and the ramifications of changes in policy.

What Is Health Policy Advocacy?

Advocacy is defined as the support and defense of a cause and the act of pleading on behalf of another person. Despite its simple definition, advocacy is multifaceted, and the types of advocacy activities in which ONS leaders engage are many and diverse. Health policy

advocacy is a principal concern of ONS and its membership. Through health policy advocacy efforts, ONS seeks to influence the outcomes of local, state, and national policies, laws, and regulations to ensure access to quality care for people with cancer, advance cancer prevention and early detection, reduce suffering from cancer, and bolster and expand the nursing workforce.

Although many issues of concern to ONS can be addressed adequately through nonprofit and private sector efforts, only government action will achieve the desired changes regarding other issues. For example, the Health Insurance Portability and Accountability Act (HIPAA) created national policy and standards relating to how health insurance companies provide coverage to individuals with pre-existing conditions. Under HIPAA, regardless of where people live, they are ensured the same protections in terms of guaranteed issuance of insurance even if they have pre-existing health conditions. If such an issue had been left up to individual states, the United States likely would have had a patchwork of policies with a wide variance in coverage and safeguards.

In other cases, ONS recognizes that, because of economies of scale and infrastructure or capacity issues, the government can be more efficient at certain endeavors than individual organizations. For example, although ONS can and does fund important research, it has limited resources. However, by using some of its resources to encourage increases in federal funding for the National Institutes of Health, the National Cancer Institute, and the Centers for Disease Control and Prevention, ONS and others in the cancer advocacy community have secured millions of dollars in

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Digital Object Identifier: 10.1188/02.ONF.1261-1263