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 oncology 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 funding.
federal funding to advance research in prevention, early detection, treatment, and quality of life. If ONS had taken the resources used for advocacy and instead invested them directly in research, it would amount to only a few thousand dollars. Yet by leveraging its resources at the federal level, ONS reaped a much greater return by delivering millions of new dollars for essential federal cancer research and application efforts. Specifically, ONS health policy advocacy activities include educating policymakers at the local, state, and national levels; advancing proactive legislation; and working to defeat proposals that would have adverse effects on oncology nursing patients with cancer.

Health policy advocacy activities offer many oncology nurses a way to let their voices be heard. Figure 1 provides a sample of effective advocacy activities.

Turning Outrage into Action

Every day, people have experiences that are frustrating, unbelievable, or so outrageous that they think, “How can this be? There ought to be a law.” From conducting health policy training sessions throughout the country for ONS, I have learned that oncology nurses often experience this frustration and want to know how to be proactive to effect change. Health policy advocacy means channeling this sense of outrage about poorly conceived laws, policies, and regulations or about the absence of a law when the need for one is clear. Advocates let policymakers know what they as citizens and constituents believe elected officials should do.

In fact, Americans have the constitutional right to tell federal legislators what concerns them. Policymakers work for the citizens. Taxpayers fund their salaries, health insurance, and retirement benefits. Therefore, they have every right to hold them accountable and give feedback on the job they are doing. Policymakers expect to hear from their constituents. Systems, processes, and staff are devoted solely to being responsive to input and requests from the public. Although thousands of useful and important bills are introduced every year in the U.S. Congress, senators and representatives often say that they will not lend their support until they hear from home about the need to cosponsor particular measures. Therefore, letters, e-mails, phone calls, or faxes from people in their districts or states asking them to lend support can spur them to take action on issues of priority to oncology nurses.

Challenges to Health Policy Advocacy

Despite a long-standing history of and commitment to traditional patient advocacy (i.e., advocacy within the clinical setting), many nurses have steered clear of public policy and political advocacy. I believe that the two greatest challenges to oncology nurses engaged in health policy advocacy are the misconceptions that (a) advocacy takes a lot of time, is difficult, and requires a new set of skills and (b) calling, writing, faxing, e-mailing, or meeting with policymakers will not make a difference.

Fact: Advocacy Can Be Fast, Easy, and Effective

We all lead busy lives and have many competing responsibilities and priorities, and oncology nurses give so much of themselves to their jobs. Understandably, little time and energy are left for political involvement. When short on time, not engaging in activities that could be futile or will require specialized knowledge and understanding is a rational decision.

Nurses are professional advocates. They regularly represent and work on behalf of their patients, as well as their family members, physicians, and sometimes health insurers. Health policy advocacy does not require oncology nurses to develop a new skill set. Rather, it involves taking existing skills and applying them in a different arena. To that end, ONS makes engaging in advocacy easy, effective, and efficient by providing everything oncology nurses need on the ONS Legislative Action Center (LAC) on ONS Online (www.ons.org) and through the ONSStat electronic grass roots response network. By using LAC tools and responding to ONSStat alerts, weighing in on a priority issue can take less than five minutes.

Fact: One Letter Can Result in One Law

One of the most common questions that oncology nurses ask me is whether advocacy really makes a difference. As someone who has lived and worked in health policy advocacy in Washington for more than nine years, including a stint as an aide to U.S. Senator Dianne Feinstein, I have seen firsthand how opinions voiced to policymakers can make a difference in the outcome of deliberations. For example, individuals who wrote to members of Congress with horror stories about health maintenance organizations stimulated the development and consideration of the Patients’ Bill of Rights. Women undergoing mastectomy who were discharged from the hospital the same day of surgery wrote and called policymakers; now numerous states have enacted laws banning “drive-through mastectomies.”

Other examples exist of individuals affecting public policy. The creator of Mothers Against Drunk Driving lost a child to a drunk driver. She developed and led a grass roots movement that changed how the United States addresses drinking and driving. Megan’s Law, which requires sex offenders to register and notify communities where they live, is another example of how one family turned anger into action. The family members’ efforts after they lost their daughter resulted in changes in both state and federal policies on public notification of potential risk. Recently, ONS provided input on the bipartisan National Cancer Act of 2002 as it was being developed and helped secure a number of cosponsors for the Access to Cancer Therapies Act of 2001. These are just a few examples of how people who took a few minutes to communicate with policymakers made a difference for years to come.

Fact: Advocacy Counts More Than Once

With regards to health policy advocacy, I ascribe to the “cockroach theory.” The concept is based on the idea that when you see one cockroach crawling across a kitchen counter, it represents 100–1,000 cockroaches crawling in the walls of the kitchen. Although this is an unappealing analogy, the theory applies to communications with policymakers. One letter, e-mail, phone call, or fax represents many people who support its contents. Each policymaker’s office has its own procedures for handling communication and its own formula for the relative weight of a communication. For example, in some offices, just 5–10 letters about an issue constitutes a critical mass or major trend and warrants attention and response. Your letter, e-mail, phone call, or fax represents more than just your opinion to your elected officials. Your correspondence is counted, and a policymaker is informed that
constituents are communicating and requesting action about an issue.

**Communicating With Policymakers**

Many ways to communicate with policymakers exist: letters, postcards, e-mail, phone calls, faxes, telegrams, and face-to-face meetings. Often, I am asked to rate which method is most effective and whether all are counted equally. Each congressional office has its own calculus for different communications. Generally, each policymaker gets a regular report from staff regarding how many letters, postcards, e-mails, phone calls, and faxes have been received recently on various issues and what positions constituents are advocating.

Personal notes (i.e., handwritten letters either mailed or faxed) are very effective because they illustrate that the authors took the time to send in personal missives on particular issues. When an issue is time sensitive, phone calls are most effective because they allow citizens to weigh in immediately. In addition, in the postanthrax environment of new precautions, the effectiveness of mailing letters via the U.S. Postal Service is tenuous because prompt delivery cannot be guaranteed. Therefore, e-mails and faxes ensure timely delivery.

When communicating with policymakers, do not worry about party affiliation. Unlike other healthcare issues, cancer is nonpartisan. It is personal and pervasive and crosses cultures, geographies, and party affiliations. If ideologically opposite senators Ted Kennedy and Jesse Helms can join forces in sponsoring the Eliminate Colorectal Cancer Act, then cancer clearly spans the range of political views. When contacting or meeting with policymakers and their staff, identify yourself as a voter, constituent, and oncology nurse; these are suitable qualifications for you to be treated with respect.

**Public Policy and the Basic Legislative Process**

The details and nuances of the federal policy-making process are difficult to follow, but advocates do not need to know them all or remember fourth-grade civics lessons. ONS’s LAC Action Alerts tell nurses what they need to know about each bill’s status and context. Template letters include all of the relevant details. Health policy advocates only need to know a few basics. Each state has two senators who represent the entire state; states are divided into congressional districts based on population, and each district has one representative in the House of Representatives. In both the House and Senate, members are assigned to committees, which have jurisdiction over different issues and consider pending legislation before measures go before the entire chamber for final votes. The key committees that have jurisdiction over ONS priority issues are the House Energy and Commerce Committee and its Health Subcommittee; the House Ways and Means Committee and its Health Subcommittee; the Senate Health, Education, Labor, and Pensions Committee; the Senate Finance Committee; and the House and Senate Appropriations Committees and their Labor-Health and Human Services Subcommittees. If your representative or one of your senators sits on one of these key committees, your participation in advocacy is even more important because these members play a key role in crafting, advancing, or defeating legislative proposals of concern to ONS. To find out which committees your members of Congress serve, visit ONS’s LAC.

**Conclusion**

Advocacy and health policy are integral parts of the ONS mission and affect what oncology nurses do every day. Unless oncology nurses communicate with policymakers about key issues of concern, legislative and regulatory proposals will be crafted and enacted without the benefit of oncology nurses’ expertise and perspective. Oncology nurses are a powerful and respected constituency, and their active involvement in health policy advocacy will help U.S. policymakers take action on key issues, including the nursing shortage, funding for cancer research and application, and Medicare reimbursement for expenses such as chemotherapy administration. Policymakers and their staff expect, welcome, and appreciate input from constituents, especially those with understanding and experience.

ONS recognizes that engaging oncology nurses in health policy advocacy is essential to ensuring that their views and priorities are received and addressed by policymakers. Oncology nurses can and should become involved in health policy advocacy. Using ONS’s LAC resources, members have the tools necessary to be effective health advocates at the national, state, and local levels.

**Bibliography**


