Policy and advocacy: fundamental for advancing the oncology nursing specialty

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The International Council of Nurses (ICN) Code of Ethics for Nurses 2021 outlines the ethical values, responsibilities, and professional accountabilities of nurses and serves as a guide for nurses globally to meet the professional standards set by regulatory organizations (1). Advocacy crosses the four pillars described in the document: nurses and patients or other people requiring care or services, nurses and practice, nurses and the profession, and nurses and global health. As the largest health care professional group in the world, nurses have a critical role in shaping policy and advocating for their patients and the profession. According to the World Health Organization (WHO), there are approximately twenty-seven million nurses and midwives, representing almost half of the global health care workforce (2). WHO projects an additional nine million nurses and midwives will be needed by 2030. That number may be higher given the impact of the coronavirus disease 2019 (COVID-19) pandemic on the workforce.

In the United States, cancer is the second leading cause of death behind heart disease (3) and with the aging and large Baby Boomer generation, the demand for oncology nurses will continue to increase. Globally, cancer causes approximately ten million deaths and is an increasing health concern in low- and middle-income countries (LMICs) (4). A significant portion of cancers are attributed to lifestyle choices such as tobacco use and alcohol consumption, modifiable behaviors. Both cancer incidence and deaths could be reduced with interventions to avoid factors, such as these, linked to cancer.

Nurses are an important voice in advocating for the health of individuals, communities and public health standards and can bring evidence-based strategies for risk reduction.

Nursing and advocacy

Many identify Florence Nightingale as the first nurse activist, advocating for both patient care and standards for nursing education (5). Although the importance of advocacy is reinforced in many articles, books, and reports, barriers to nurses using their voice to influence policy is also discussed (6-8). Issues such as gender and lack of status of the profession may prevent nurses from speaking up or others from hearing them. Salvage and Stilwell (in 2018) in their editorial posit that nursing is not a fully accepted profession and nurses continue in subordinate roles and hesitate to speak up (9).

Silence is multifactorial and yet advocating for patients is a central tenant of nursing. They suggest that the root causes of nursing's silence must be addressed for sustained change. In their study, Hall *et al.* (in 2018) found that key to nurses speaking up in their institutions were their perceptions of leadership, quality, safety, process improvement, and the organization's culture (10). Nurses need to believe their nurse leader is listening to them and values their perspectives. A culture of trust and respect increases the likelihood that nurses will speak up.

In many countries, the importance of nursing was highlighted during the COVID-19 pandemic. Media coverage showed that nurses were the health care

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professionals with the most continuous contact with patients, innovating solutions to patient isolation and supply chain deficiencies. Many were given the opportunity to be interviewed, which is often reserved for physicians and administrators. They described their roles and the care and caring they brought to their jobs. In speaking up, they advocated improvements in the health care system and in some cases, were successful in creating change. For oncology nurses, COVID-19 brought both challenges and opportunities (11). Nursing has a role to help the public understand information being communicated whether about cancer, COVID-19, or the health care system. It is too early to assess the long-term impact this might have on the profession's influence on local and national policies.

In the United States, the Gallup organization has conducted an annual rating of the honesty and ethics of various professions. For twenty years, nursing has been the highest ranked profession. In fact, only once since 1999 has nursing not been the top ranked rank profession and that was in 2001 when firefighters received the top score (12). The trust of the public positions nursing well to have an influential voice with elected officials and other leaders. Combining this trust with the numbers of nurses and the availability of advocacy resources by professional organizations has created a strong platform for nursing.

In a review of the literature on nursing's political activism in the United States, Cohen *et al.* developed a framework identifying four stages of political development (13). As noted by the authors, political advocacy is most often facilitated by a professional organization. That may be the country's major nursing organization or one of many specialty nursing organizations that have developed. In the first stage of their framework, the focus is promoting political awareness. The second stage is called the self-interest stage in which profession is reactive to policies and issues that affect the profession. Stage 3 occurs when more diverse and sophisticated strategies develop and engagement with policy makers increases who recognize the expertise nurses can bring to health policy decisions. In the fourth stage, nursing takes a greater leadership role in both health and social policy issues, such as the discussions about climate change and its impact on the population. This framework can be useful for oncology nurses and professional organizations to develop the pathway to for developing advocacy skills.

Oncology nursing

As a specialty, oncology nursing became formalized in the 1970s and 1980s with the development of several oncology nursing organizations and continues to develop in more countries (*Table 1*). As the earliest oncology nursing organization to develop, the Oncology Nursing Society (ONS) has a history of advancing the science of oncology nursing, setting standards for clinical practice, and advocating for patients and the practice of oncology nursing. As the specialty has grown, educating and supporting nurses to be advocates in their communities and nationally on cancer policy has had an increasing focus. As the specialty continues to grow globally, oncology nurses will need to develop their voice in influencing policies that affect their patients and themselves as professionals, including health system policies and government laws and regulations.

Prior to the formalization of the specialty, there were nurses leading the development of caring for cancer patients, educating nurses in oncology clinical practice, and conducting research. In the book *It Took Courage*, *Compassion*, *and Curiosity*, twelve leaders in the development of cancer nursing from the late 1800s to 1970 were featured (14). A thread that connected them regardless of their focus was advocacy for patients and education for nurses. One, Virginia Barkley, was a cancer nursing consultant in the American Cancer Society and travelled throughout the United States and to many other countries promoting oncology nurse education and skill development. She and Renilda Hilkemeyer, also featured in the book, planned the first National Conference on Cancer Nursing in 1973 attended by 2,500 nurses. This meeting was the catalyst for forming the Oncology Nursing Society. At the invitation of WHO, Barkley and Hilkemeyer planned an international oncology nursing meeting and repeated the success of the US based meeting These two nurse leaders and the other ten presented in the book used their voice and influence in many ways within institutions, in public forums, and internationally advocating for patients and the specialty of oncology nursing.

Policy and oncology nursing

Oncology nurses have often been the implementers of policy but less commonly influence the substance of or create polity. However, as the specialty has developed in the United States and other countries, oncology nursing's voice is increasingly stronger on policies that affect patients or the profession. The political development framework described earlier can illustrate how policy and advocacy have been

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Table 1 Establishment of oncology cancer nursing organizations

Organization	Year established
Oncology Nursing Society (USA)	1975
Association of Pediatric Hematology & Oncology Nurses (USA)	1976
Japanese Society of Cancer Nursing	1978; 2013 transitioned to a general incorporated association
International Society of Nurses in Cancer Care	1984
European Oncology Nursing Society	1984
Canadian Association of Nurses in Oncology/Association Canadienne des Infirmières en Oncologie	1985
Taiwan Oncology Nursing Society	1992
Philippine Oncology Nurses Association	1993
Cancer Nurses Society of Australia	1998 Nurses Group of the Clinical Oncological Society of Australia; 2017 transitioned to an independent organization
United Kingdom Oncology Nursing Society	2005
Asian Oncology Nursing Society	2013
Emirates Oncology Nursing Society	2017
Ethiopian Oncology Nursing Society	2019

integral to the development of the oncology specialty. The experiences of ONS are given as examples in each of the stages.

Phase 1: promoting political awareness

This stage was identified as representative of the 1970s and 1980s. Some of the first books discussing nursing, power, and politics were published in these decades. In their study, Hayes and Fritsch (in 1988) found that the variable of education and professional organization membership were associated with political participation (15). They suggested that nursing students be socialized to professional engagement and that professional organizations develop methods for keeping members informed of pending legislation to promote political awareness.

As a young specialty, ONS benefited from collaborations with other established nursing organizations as it developed its activism. From its earliest newsletters though today's print and electronic communication methods, ONS informs members on national policy issues. This is fundamental work that a professional organization can do for its members. It can be as simple as informing members of a specific health care policy being discussed and giving directions on how to reach out to government leaders. Identifying oneself as an oncology nurse gives credibility to the information one sends. By also referencing membership in a professional organization, the oncology nurse educates elected officials to the size of the specialty. In promoting awareness, some of the tools that organizations use include development of position statements, issue briefs, and white papers. Although some organizations may support specific political candidates, ONS does not endorse candidates and seeks relationship with officials in both parties. ONS does encourage and promote that members use their voice by voting in elections.

Phase 2: responding to policies and actions specific to the specialty

Keeping informed, personally or through a professional organization, is an individual's responsibility. For oncology nurses, advocacy and political action may relate to the general profession of nursing, specific to a role such as advanced practice nurse, or to access to care for patients. A variety of strategies may be employed. One that was often used by ONS was to have post cards on an issue on the seats at the national meeting. Attendees would sign and personalize them. ONS then collected and hand delivered the cards to the appropriate offices in Washington, DC. As ONS and the oncology nursing specialty matured, dedicated training in grass roots advocacy became a standard.

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Creation of a health policy agenda, approved by the Board, guides responses to emerging policy issues and requests to collaborate with other cancer or nursing organizations on an issue. For example, ONS has been a leading organization on tobacco control through individual and collaborative efforts for several decades. There are also issues that may not be oncology specific but prompt the organization to action. When the Equal Rights Amendment, for the protection against sexual discrimination of women, was being ratified by the individual states, ONS made the decision not to hold conference in states that had not passed the amendment. Given a membership of more than 90% women, the outcome of this resolution was important by the members. This also led to the launch in 1980, of the Legislation and Resolution Committee, which remained a standing committee until the governance structure was modified (16).

Phase 3: recognition by policy makers

This phase is one of more sophisticated political engagement. Understanding what individual legislators and elected representatives prioritize informs nurses on what issue to promote with which official. In person visits and carefully crafted leave behind materials have a stronger effect that the post cards mentioned earlier. Through these visits, ONS members have learned that their experiences and knowledge are valued. By combining their unique stories of delivering cancer care, they humanize the statistics of cancer which is meaningful to policy makers. An outcome of the building strong relationships with many elected officials was development of proposed legislation on education benefits for patients undergoing cancer treatment. Finding sponsors from both parties was essential and it was introduced in more than one session of Congress. Although it never reached a vote, the act of proposing and promoting this legislation elevated ONS as a resource with policy makers. Subsequently, ONS has received requests to review legislation in development. When the White House launched the 2016 Cancer Moonshot, ONS was a resource to the administration to identify nurses for the listening sessions held around the country. ONS also successfully recommended nurses for the Moonshot Blue Ribbon Panel and working groups.

Phase 4: leadership in health and social policy

In this phase, nursing has more leadership in setting the agenda for health policy beyond relevance only to nursing. Issues that nursing engages in extend beyond health care. Today, issues such as violence and gun legislation, LGBTQ+ (Lesbian, Gay, Bisexual, Transgender, Queer+) concerns, housing, children's education, and climate change intersect with health care. For many of these and others, oncology nurses can contribute knowledge of concepts of caring, health promotion, self-care, alternative care delivery models, and more, which are often not presented in the decision-making process. Additionally, nurses have achieved elected and appointed leadership roles in local, state, and federal institutions.

Oncology issues of importance

There are cancer policy issues that have global connections and others that are specific to the country. Being aware of the issues and understanding local impact is important when responding to a call for action or suggesting solutions. For some issues, a unified voice across oncology professions and countries is best as global health has gained more emphasis. The pandemic reinforced that causes of disease do not recognize country borders. Whether cancer related policies are local, national, or international, oncology nurse need to make an assessment of the environment and ensure that policies include their professional values. The policy and regulatory environment are quite complex and choosing an issue about which one is passionate is a good place to begin (17). Globalization adds to the complexity, but also offers opportunity for oncology nurses. Collaboration can strengthen the voice of oncology nurses to influence policy decisions and ensure that all people have access to cancer care (18,19).

The *nursing workforce* is one policy issue that affects oncology nurses everywhere. It has been experienced differently, however, in high income versus low- and middle- income countries. In these countries, most nurses have not had training in oncology nursing and care for children and adults with many diagnoses (20). In some, nurses may be the only health care professional in the community. The oncology nursing specialty is more developed in high income countries and includes masters and doctoral programs with an oncology focus. Advanced clinical practice and nurse scientist roles are more prevalent in these countries.

Prior to the pandemic, many high resource countries were experiencing aging workforces and predicting increased shortages in the next 5–10 years. The pandemic

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amplified both current and predicted shortages (21,22). The intensity of caring for patients caused stress and burnout, leading to resignations and retirements from the profession as well as prolonged illness and death from COVID-19.

Nurse migration, especially from low- and middle income to high-income countries is a staffing solution that has been used for years and continued throughout the pandemic as institutions sought resources for patient care (23,24). Recruiting from outside own's country is not without ethical considerations, such as reducing nurses in countries with existing severe shortages, and legal considerations, such as immigration processes.

Many reports and papers that address reducing the cancer burden and access to care identify the importance of funding training for oncology nursing and palliative care (25-29). In 2021, a consortium of oncology nursing groups developed a position statement that was concurrently published in each organization's journal and outlined a Call to Action (30). This statement is agnostic to country and can be used by oncology nurses they advocate for specialty training support with government and non-governmental agencies.

Access to care and increasing diverse clinical trials enrollment are related to the oncology workforce. Access may be limited because of a lack of nursing and medical professionals but also lack of availability of standard treatments. The pandemic revealed the disparities in supplies of personal protective equipment, not only from country to country but within countries as well. During this period, oncology nurses reached out to colleagues to share clinical practice solutions.

Another universal issue that nurses have the expertise and ability to influence is tobacco control. Oncology nurses can use their expert power to educate an individual about risks associated with tobacco use or persuade government officials to support needed tobacco legislation. Both are situations in which a nurse uses advocacy and education skills.

The unequal burden of cancer, survivorship needs, and palliative care services are concerns that may engage oncology nurses in political action and advocacy. For professional organizations, identifying which concern(s) they have the best potential to influence is the first step. Preparing fact sheets and talking points for members to write government officials facilitates action.

Conclusions

Advocacy is a pillar of nursing practice throughout the world. Clearly, nurses advocate for their patients, communities, and profession. As nursing and its specialties have developed and matured, advocacy has expanded into the public policy realm and nurses' expertise has been welcomed by policy makers. The trust that the public has of nurses gives support to their voice. Although there continue to be barriers globally for nurses to be heard, nurses have and continue to learn the skills of advocacy and how to provide policy feedback and advice. Oncology nursing organizations can and must educate and develop oncology nurses as confident advocates for policies and practices that result in quality cancer care and continued growth of the specialty.

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