Nursing Advocacy in North Carolina

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This article has been chosen as particularly suitable for reading and discussion in a Journal Club format. The following questions are posed to stimulate thoughtful critique and exchange of opinions, possibly leading to changes on your unit. Formulate your answers as you read the article. Photocopying of this article for group discussion purposes is permitted.

1. What are some examples from our own experience or setting that match or expand on the article's definition of advocacy?
2. Identify at least three situations in our unit's experience that indicate successful advocacy or highlight cases when advocacy activities would have been useful.
3. Are the resources identified in the article available to our unit? Do we have additional resources that were not mentioned?
4. Are any of us members of ONStat or grassroots representatives?
5. How many of us have written to our senators or representatives about a healthcare issue? What mechanisms did we use?
6. What are our personal barriers to increasing our advocacy efforts? Can we identify any institutional barriers?

At the end of the session, take time to recap the discussion and make plans to follow through with suggested strategies.

Purpose/Objectives: To identify the ways oncology nurses in one state advocate for patients, as well as the resources they use to do so.

Design: Descriptive, cross-sectional survey.

Setting: North Carolina.

Sample: 141 RNs in North Carolina who were members of the Oncology Nursing Society (ONS).

Methods: Subjects completed a two-page, self-administered questionnaire comprised of fixed-choice and open-ended questions.

Main Research Variables: Demographics, frequency of advocating for patient services, and awareness of ONS resources.

Findings: Nurses in North Carolina advocate for patients in a variety of ways. A need exists to develop ongoing methods to keep nurses up to date on advocacy issues, as well as to establish mentoring opportunities for them. Nurses believe that they are most challenged in addressing patients' financial and insurance concerns.

Conclusions: Oncology nurses frequently advocate for patients' needs. The findings provide direction for future initiatives to educate nurses about their role in patient advocacy and available resources.

Implications for Nursing: Ongoing education and research are needed to enhance the role of oncology nurses as patient advocates.

Key Points . . .

- ➤ Nurses advocate for individual patients and the oncology population in general.
- ➤ Resources for patients vary depending on practice setting.
- ➤ Oncology nurses are not aware of all available resources.

In North Carolina, approximately 38,210 new cases of cancer are diagnosed each year (Jemal et al., 2007). Patients facing diagnosis of cancer in North Carolina may receive treatment at comprehensive cancer centers, community-based cancer programs, or freestanding centers. Changes in healthcare reimbursement have led to blending of healthcare providers' roles and of resources available to patients in all practice settings. Oncology nurses, who once may have had the support of social workers, case managers, and others, now find that they are serving in those capacities to meet the complex needs of patients and their families. Understanding how nurses advocate for patients and how they use available resources can facilitate the development of strategies to improve patient care. The specific objectives of the current study were to identify the ways in which oncology nurses advocate for patients, as well as the resources they use to do so.

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Literature Review

Advocacy is one of many roles of healthcare providers. This is especially true in nursing practice. According to the American Nurses Association (2001), a nurse "promotes, advocates for, and strives to protect the health, safety, and rights of the patient." The role of nurses as primary advocates for patients is as old as the profession itself (Morra, 2000). Historically, nurses are thought of as providers of care. But behind the scenes, they orchestrate patient care and ensure that physical, emotional, and financial needs are met. Nurses typically advocate for patient needs, but the concept becomes broader when issues have social and political implications.

Nurses can accomplish advocacy by encouraging and supporting patients' autonomy and ability to make their own healthcare decisions and creating an atmosphere and relationships that are open to the individual decision-making process (Mallik, 1997a). Advocacy also is accomplished when nurses take appropriate and responsible actions on behalf of patients when they are unable to do so (Schroeter, 2002). Nurses, unlike other healthcare providers, are able to take such actions because they are consistently close and accessible to patients and their families. Also, nurses are in a position to communicate with other members of the healthcare team when patients and families may be unable to do so. Nurses help to ensure optimum decision making as it relates to treatment, quality of life, and the end of life. They make certain that patients are well informed and supported during decision making and treatment by providing educational resources.

As advocates for oncology populations, nurses are defenders and promoters of patients' rights and interests (Willard, 1996). Advocates also are teachers, advisors, informers, and counselors (Mallik, 1997b). Nurses may find themselves playing those roles for their patients on multiple occasions on any given day. Nurses also may assume the role of advocate for the oncology population in general. The role of an advocate includes protecting, promoting, and supporting a cause. For nurses, this seems a natural part of what they do each day, but contacting legislators and becoming individually involved in health policy at the local and national levels are not common. Nurses typically partner with professional organizations, healthcare organizations, and patient-centered organizations to promote causes.

In the literature, the concept of advocacy in nursing is a common theme, but evidence of it is lacking in the clinical specialty of oncology nursing. Research has been conducted in many specialties, including hospice and palliative care and preoperative nursing. Briggs and Colvin (2002) found a significant gap in research, specifically in end-of-life nursing care and the advocacy role. Understanding how oncology nurses advocate for patients and how they use available resources can facilitate the development of strategies to improve patient care.

Methods

Procedure

The investigators developed a semistructured questionnaire to elicit information about how oncology nurses in North Carolina advocate for patient care needs and the resources they use. Advocacy was defined as how nurses support patients directly and indirectly as part of the work they do. The two-page, self-administered questionnaire contained 20 fixed-choice and 3 open-ended questions regarding respondents' demographic and professional characteristics, practice settings, and advocacy resources available, as well as resources used. A panel of experts and the Oncology Nursing Society (ONS) Research Team reviewed the questionnaire for content validity.

A cover letter, the questionnaire, and a self-addressed, stamped envelope for anonymous return of the questionnaire were mailed to 344 oncology nurses in North Carolina who were members of ONS. A total of 142 (41%) surveys were returned. One questionnaire was determined to be ineligible because the respondent was a non-nurse associate member of ONS, leaving 141 eligible for evaluation. The surveys were not coded, so respondents could not be identified; participation was completely voluntary.

Data Analysis

All data were entered into a database and examined using Toro Analysis Command. Descriptive statistics were calculated and response distributions were used to represent individual responses to the questionnaire items.

Results

Sample

The target population for the study consisted of oncology nurses who worked in diverse practice settings, lived in North Carolina, and were members of ONS. Table 1 shows the demographic characteristics of the sample. Many respondents were 40–49 years of age (47%); most were Caucasian (96%). The predominant level of education was bachelor's degree (36%), followed by master's degree (35%). Sixty-one percent were OCN® or AOCN® certified nurses, whereas 13% held other types of certification.

Many respondents had been nurses for 21–25 years (25%), and sixty-one (43%) reported being in oncology nursing for 16 years or more. Of the respondents, 38% indicated that they were in direct patient care roles, whereas 18% held supervisory or leadership roles such as nurse manager, supervisor, or director. Fifty-seven percent reported that their primary specialty was hematology/oncology.

Advocacy at the Local Level

The most common types of support staff available to the RNs in their practice settings were social workers (75%), counselors (40%), and patient and visitor relations staff (36%). Many respondents had access to patient support programs (68%) and patient resource libraries (65%) available to support patients' and families' educational needs. Types of nursing support staff included nurse clinicians and oncology clinical nurse specialists. Program coordinator roles were found in palliative care, screening and detection, research, oncology support, and transplantation. Other members of the interdisciplinary team were nutritionists, clinical pharmacists, psychologists, psychiatrists, and those who provided pastoral care. Child-life programs, art therapy, interpreters, and volunteers also were reported.

Forty-three percent of the nurses indicated that they frequently advocated for individual patients' needs (see Table 2), whereas only 32% of respondents indicated that they referred individuals to patient advocacy groups (see Table 3). Fifty-nine percent of the nurses indicated that they often or frequently advocate for pharmaceuticals and medicine. The need for financial assistance related to pharmaceuticals most likely will grow as the uninsured and underinsured population grows and copayments increase.

Table 1. Sample Demographics

Variable	n	%
Age (years) (N = 141)		
25–29	2	1
30–34	17	12
35–39	16	11
40–44	25	18
45–49	41	29
50–54	19	14
55–59	13	9
60–65	7	5
Older than 65	1	1
Ethnic group (N = 141)		
African American	2	1
Asian	1	1
Hispanic	1	1
Caucasian	135	96
Other	1	1
No response	1	1
Educational level (N = 141)		
Diploma	14	10
Associate degree	22	16
Bachelor's degree	51	36
Master's degree	49	35
Doctorate	5	4
Specialty certification (N = 141)		
OCN®	77	55
AOCN®	9	6
Other	18	13
No certification	37	26
General nursing experience (years) (N = 141)		
1–5	4	3
6–10	20	14
11–15	19	14
16–20	25	18
21–25	35	25
26–30	23	16
31–35	11	8
More than 35	4	3
Oncology nursing experience (years) (N = 136)		
1–5	10	7
6–10	30	21
11–15	35	25
16–20	33	23
21–25	20	14
26–30	7	5
31–35	1	1
More than 35	–	–

Variable	n	%
Primary position (N = 139)		
Direct patient pare	53	38
Nurse manager	9	6
Educator	8	6
Researcher	8	6
Clinical nurse specialist	13	9
Nurse practitioner	12	9
Case manager	3	2
Consultant	1	1
Supervisor and coordinator	8	6
Director or assistant director	8	6
Pharmaceuticals	4	3
Other	12	3
Specialty (N = 141)		
Chemotherapy and biotherapy	25	18
Pain management	8	6
Gynecologic oncology	6	4
Radiation oncology	11	8
Bone marrow transplantation	13	9
Prevention and detection	2	1
Surgical oncology	8	6
Hematology/oncology	81	57
Head and neck cancer	2	1
Palliative care	12	9
Genetic counseling	–	–
Breast oncology	10	7
Other	19	14
Number of specialties (N = 141)		
1	107	76
2	22	16
3	5	4
4	5	4
5	1	1
6	1	1
Type of staff available (N = 141)		
Social worker	106	75
Case manager	50	36
Discharge planner	44	31
Counselor	57	40
Patient resource manager	28	20
Patient resource library	92	65
Cancer patient support program	96	68
Patient and visitor relations	51	36
Other	18	13

Note. Because of rounding, percentages may not total 100.

Need for financial assistance also may affect patients with out-of-pocket costs for items that were covered at one time.

Respondents believed that they should advocate on behalf of patients and families by teaching self-care strategies, assisting with symptom diaries, developing question lists, providing resources, and communicating and coordinating care with other members of the healthcare team. They said that they had the skills to advocate but that they needed ongoing education in the area. Many believed that they were not familiar enough with insurance, reimbursement, and financial issues to assist patients properly. One consistent theme was that nurses did not have enough time to do so. One person wrote, "For inpatient nurses this is an 'extra' above routine care—they have little to no time to either learn the skill or use it." Ninety-seven percent of respondents indicated that nurses should advocate for patients, but only 81% believed that nurses had the appropriate to skills to do so. A discrepancy existed between wanting to advocate for patients and having the necessary resources.

When asked about their knowledge of specific resources for advocacy, only 48% were aware of the ONS Web site (www

Table 2. Frequency of Advocating for Individual Patient Needs

Type of Advocacy	Never (%)	Occasionally (%)	Often (%)	Frequently (%)
Advocate for patients	1	19	34	43
Advocate for pharmaceuticals and medicine	11	28	30	29
Advocate for transportation and housing	32	45	11	9
Teach patients how to advocate for themselves	6	33	37	21

N = 141

.ons.org) and only 21% had referred patients to the Cancer Survival Toolbox (Walsh-Burke & Marcusen, 1999). The toolbox, updated by ONS, the Association of Oncology Social Work, and the National Coalition for Cancer Survivorship, contains 10 audio modules: six related to helping patients meet the challenges of their illnesses and four focusing on survivorship issues. The toolbox can be ordered from the National Coalition for Cancer Survivorship (visit www.cancersurvivaltoolbox.org/default.aspx). One respondent noted that she uses the toolbox with her students in clinical settings, and another noted that the recordings have been very helpful to patients and families who have used them.

Advocacy at the National Level

Twenty-three percent of respondents had written one or two letters to Congress (see Table 4). Topics written about most frequently had to do with finances, including reimbursement and Medicare and Medicaid. Only a few letters were written regarding managed care and ambulatory payment classifications. Pertinent clinical topics (e.g., pain management, access to care) were addressed less frequently. One respondent stated, "Nurses do not have enough interest or political will."

When asked how they thought nurses could be better educated to advocate for patients, respondents shared many similar thoughts. The central theme was education: workshops, educational materials (videos and print pieces), and advocacy information incorporated into educational curricula. Many respondents felt a need to know what resources are available in their communities as well as have a mentor. One respondent stated, "We need to develop a curriculum/program for NC nurses in oncology re: advocacy and address topics at chapter meetings, in the workplace, and also have community consumers and patient advocacy groups work with us." The need to stay abreast of current resources and issues also was mentioned.

Table 3. Nursing Advocacy and Resources

Variable	n	%
Advocacy groups		
Ever referred a patient to a patient advocacy group	45	32
Awareness of resources		
ONS Web site	68	48
Cancer Survival Toolbox	82	58
Provided patient or caregiver with the toolbox	30	21
Advocacy skills (self-assessment)		
Believe nurses advocate on behalf of patients	136	97
Believe nurses have the skills to advocate for patients	114	81

N = 141

Discussion

This survey is the first detailed description of how oncology nurses advocate for patients. Advocacy is a key component of nursing practice, whether in patient care, education, or research. Nurses are advocating for patients but at times do not believe that they have the resources, background, education, and time to do so. Nurses must understand the influence they have on patient outcomes and the legislative process.

The results demonstrate that oncology nurses currently are advocating and linking patients to appropriate resources yet still need ongoing education. Many resources are available to ONS members to help them learn about ways to become involved. Advocacy sessions frequently are held at ONS conferences. They focus on mechanisms for nurses to get involved and highlight nurses' success stories.

One such mechanism is ONS's ONStat program. Members of the grassroots response network are contacted when their elected officials are critical to legislative issues that ONS wants to influence in some way. ONStat members receive background materials on the issues, sample language for correspondence, talking points for calls, and legislators' contact information. To learn more about ONS health policy activities, visit the ONS Legislative Action Center at www.ons.org/lac.

ONS also is working to establish grassroots positions in its chapters. Many chapters have used the positions to coordinate dinner meetings with elected officials. Such meetings may serve as an overview of current healthcare issues (e.g., genetic testing, reimbursement, the Healthcare Insurance Portability and Accountability Act) as well as time for members to have question-and-answer sessions with officials.

Clear from the survey is that nurses believe that they should advocate, even though only 48 letters reportedly were sent by survey respondents to elected officials. The low number likely can be attributed to time constraints. Although nurses felt ill equipped to manage issues related to insurance, reimbursement, and financial matters, the reimbursement category represented the most letters written to Congress. Time concerns also affect newer nurses, who may not have opportunities to work with seasoned nurses who demonstrate advocacy beliefs and skills, thus leaving new nurses unaware of this important aspect of nursing.

The ONS Web site (www.ons.org) also serves as a resource for its members. On the site, nurses can access the Legislative Action Center, where they can learn who their elected officials are and how to contact them. The site also allows members to send e-mail messages to selected officials, requiring minimal time from nurses. Although the survey sample consisted exclusively of ONS members, only 48% of the respondents knew that they could access their legislators and write them letters via e-mail from the ONS Web site.

Because of ongoing financial pressures, many institutions struggle with increased costs and decreased reimbursements while

Table 4. Frequency of Letters and Topics

Variable	n	%
Number of letters written by respondents to Congress		
1	17	12
2	15	11
3	5	4
4	5	4
5	1	1
10	3	2
12	1	1
20	1	1
No response	93	66
Number of letters sent to Congress based on topic		
Reimbursement	14	–
Medicare and Medicaid	9	–
Pain management	9	–
Access to care	5	–
Nursing issues	4	–
Ambulatory payment classifications legislation	2	–
Funding	2	–
Medication costs	2	–
Tobacco	2	–
Bill of rights	1	–
Disability	1	–
Managed care	1	–
Marijuana use	1	–
Stark amendment	1	–
Stem cell research	1	–
Women's health care	1	–

N = 141

Note. Because of rounding, percentages may not total 100.

trying to provide high-quality patient care. A small survey of ambulatory nurses conducted by ONS found that 83% of the responders believed that reimbursement for the cost of drugs was inadequate (Halpern & Culhane, 2004). Other factors that will continue to complicate matters include the growing number of uninsured and underinsured people and the immigration of migrant workers. Nurses in North Carolina face the latter challenge daily because the state has one of the highest influxes of migrant workers in the country. With the aging U.S. population and an increase in chronic diseases, people must understand out-of-pocket costs prior to initiating treatment. Typically, such costs include insurance copayments, deductibles, and expenses incurred as a direct result of disease, such as transportation, food, lodging, child and elder care, housekeeping assistance, wigs, ostomy supplies, prostheses, and assistive devices (Wagner & Lacey, 2004).

Oncology nurses are in a unique position to affect practice, education, and research by advocating for patient needs across the healthcare continuum and to influence policy at the local and national levels. Nurses should realize the power and skill they have as a collective group. Nurses spend more time with patients than any other type of healthcare provider and know patients' unique needs better than anyone else; they also must understand what resources are available to patients and their families. They should follow local and national policy changes and recognize the impact such changes may have on care delivery.

Study Limitations

Study respondents were primarily female, and data could not be correlated with specific practice settings. The study could not determine whether different types of settings (e.g., comprehensive cancer centers versus freestanding cancer clinics) have different resources available for staff or whether nurses believed that they needed to advocate more or less based on practice setting. Results obtained from a single state cannot be generalized to all oncology nurses nationally. In addition, the data collection instrument did not have established reliability. Respondents were not asked whether they attended advocacy training. Despite its limitations, the descriptive study is one of the first attempts using a fairly large sample to capture information regarding how nurses advocate for patients with cancer.

Conclusion

Results of the study provide a snapshot of oncology nurses in a single state and the role they play in advocating for patients, as well as the use of the resources available to them. The findings may be useful in promoting current educational programs and materials for nurses, as well as establishing mechanisms to keep nurses up to date about what resources exist. The results provide insight into some of the obstacles nurses face in advocating for patients. As the field of oncology nursing continues to grow and patient needs become more complex, the role of oncology nurses will expand. Efforts are needed at the local and national levels to educate nurses about advocacy and the important role they play in facilitating optimal care for patients with cancer.

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