CE Ethics Series
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When Advocacy Extends Life

Age and Diagnosis Discrimination in Patients With Serious Illness

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Despite education and professional preparation, age and diagnosis discrimination persists in health care. A case scenario describes discrimination that could have resulted in untimely death without advocacy and intervention by 1 informed professional. Nurses must identify their own attitudes and behaviors associated with age, diagnosis, and their role within the interprofessional team to identify when discrimination may be occurring and claim their responsibility as advocate to ethically intervene on behalf of patients and families when appropriate.

KEY WORDS
advocacy, ageism, cancer, discrimination, ethics

The realities of our society reveal that, despite our education and professional exposure, discrimination persists. Preconceived ideas about the elderly, or those with serious illness, may affect patient care decision making and can have dramatic consequences for patients. As advocacy is a central tenet of the professional nurse's role, it is critical that nurses are aware of, can recognize, and can respond to situations where age or diagnosis discrimination may be negatively affecting patient outcomes.

> A.H., a 79-year-old woman with a history of non–small cell lung cancer (NSCLC), presented to the emergency department with acute nausea, vomiting, and confusion. Diagnosed as having NSCLC 18 months prior, she underwent a right middle lobectomy and radiation therapy and 11 months of erlotinib, which she electively discontinued 1 month prior to presentation.
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> A.H. maintained a Karnofsky Performance Status of 80 to 90 since completion of radiation and throughout the course of erlotinib, despite experiencing the adverse effects of diarrhea and anorexia, both requiring pharmacologic intervention. A.H. maintained active participation in her church, her family, and community and enjoyed reading, knitting, visiting with her grandchildren, and caring for her dog. She complained of escalatory headaches and sinus pressure in the 4 weeks prior to presentation, which she self-medicated with cetirizine and acetaminophen.
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> A.H. was disoriented to person, time, place, and situation; she was somnolent and aphasic and had intractable nausea and vomiting. Visual fields appeared normal, although she was unable to follow verbal directions. The family reported a 12-hour onset of escalating and violent vomiting, decreased verbalization, and their perception that she was “seeing things.” The chief of neurosurgery evaluated A.H. in the emergency department, reviewed her history, and, following examination, admitted her to the neurologic intensive care unit with the diagnoses of “idiopathic intracranial hypertension versus normal pressure hydrocephalus; dementia; NSCLC.” The surgeon's note stated that the patient was a “terminal lung cancer patient” and “no treatment is recommended” except that of referral to hospice care. A lumbar puncture revealed elevated opening pressure; cerebral spinal fluid specimens were sent for culture/sensitivity and cytology. A.H.'s vomiting and aphasia were immediately and dramatically relieved as a result of the procedure.
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> Following stabilization, A.H. was transferred to the neurology/stroke unit. Within 6 hours, her hallucinations, vomiting, and slurred speech returned. The family sought attention repeatedly; eventually, a hospitalist informed the family that the patient was experiencing dementia, referencing the chief of neurology's note characterizing the patient as “elderly and terminal.” Although the family insisted that the symptoms were acute, the inpatient team encouraged the family to accept the “inevitable course” of the patient's disease. Vomiting, aphasia, and hallucinations escalated as the family sought assistance. Several nurses expressed sympathy to the family but did not elevate their concerns to anyone in a leadership position.

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AGEISM AND CANCER DIAGNOSES

Concepts associated with ageism came into the social zeitgeist in 1969, associating advanced age with infirmity, disease, weakness, cognitive loss, and a lack of respect or a revulsion toward age and with death.[1] Negative contact with older persons can affect perceptions of the "humanness" of older adults, with subsequent potential for directing dehumanizing behavior or thinking toward the elderly.[2] Therapeutic nihilism, or the concept that some treatments may do more harm than good, have questionable benefit or worth, or are not necessary for specific people or populations has been identified as it relates to the elderly.[3,4]

Although cancer is a common diagnosis in the aged, the elderly often are excluded from clinical trials or undertreated as compared with younger adults.[1] With recognition that comorbidities and pharmacokinetic changes must be taken into account, advanced age should not be a contraindication for treatment or care that improves or enhances quality of life. Although it is more common to die in old age than earlier in life, it must not be assumed that treatment decisions, whether limited in benefit or potentially life lengthening, should not be considered based simply on a patient's advanced age or assumptions about their life preferences.[5] Nevertheless, ageism persists and can affect treatment decision making.

DIAGNOSIS DISCRIMINATION

In addition to age discrimination realities, social stigma associated with a diagnosis of lung cancer and the perception of it as a self-inflicted disease whether "felt" or "enacted" and whether the patient was a smoker or a nonsmoker has been well documented.[6-9] Stigmas reinforce negative stereotypes and prejudices; providers are not immune to the effect of stigmata; therefore, these beliefs can and are present in clinical encounters.[10] A study by Wysham et al[11] surveying 303 clinicians in the intensive care unit setting (nurses, intensivists, and advanced practice providers) found that 67% of clinicians preferred an automatic electronic health record–based trigger system for identification of patients in need of palliative support, rather than identification of this need as part of their own patient assessment; however, no clear dominant set of trigger characteristics emerged. Themes that did emerge as commonly agreed-upon triggers included family needs and conflict. The findings suggest that identification of need for palliative consultation may be highly individualistic or not on the "daily radar" of factors to assess when evaluating patients.

Nihilistic attitudes of clinicians about treatment for a lung cancer diagnosis also have been well documented.[7,8,12-14] Patients, as well as providers who do not routinely care for patients with lung cancer, may possess knowledge gaps that inform belief structures that treatment for lung cancer or associated symptoms is pointless.

NURSE BEHAVIORS AND BARRIERS

Even if nurses do not identify or participate in age or diagnosis discrimination, they may face challenges in advocating for their patients. Although nurses report feeling intensely their responsibility to the care of the patient and family, they often report a sense of powerlessness or lack of authority in patient care decision making, which can contribute to moral distress.[15] Furthermore, hierarchical relationships often present in health care settings may result in nurse hesitancy to challenge assumptions of those perceived as "in charge." This sense of powerlessness in affecting the course of patient care events may result from poor interprofessional team relationships, lack of nursing resources, limited leadership or peer support, a fear of retribution or legal recourse, or cultural influences of the organization.[15-17] Wittenberg and colleagues[18] report that goals-of-care conversations are often ineffective or lacking altogether and that team communication barriers and role tension between nurses and others in the team when sharing information or discussion of care options persist. Nurses have reported infringement on patient autonomy, inadequate communication, and issues associated with decision making as ethical dilemmas encountered in everyday practice but may not utilize mechanisms such as ethics committees to address them.[19]

In addition, professional compassion fatigue can affect nurses' willingness to intervene in situations where a moral wrong has been identified. Repeated exposure to suffering can result in apathy and desensitization toward patients.[20] Physical and psychological exhaustion may prevent nurses from "getting involved," even when a need for advocacy is recognized.

NURSING IMPLICATIONS

Nurses are educated to view advocacy as a holistic understanding of the patient and family as a unit, where their goals, needs, and values are appreciated when making care decisions. Successful advocacy entails a willingness to invest in the patient and the issue at hand, as well as knowledge about the issue for which the nurse should advocate. Importantly, advocacy requires that the nurse feels the support to express emotional energy and the autonomy to perform the act of advocacy.[21] Self-awareness, confidence in personal knowledge, and personal and professional investment in embracing this nursing skill must be present for effective advocacy to occur.[15,21,22] Because each individual brings his/her own values to every patient encounter, successful advocacy requires the learned ability to separate one's own values from that of the patient and family. This ability allows for true patient-centered care, where patient and family goals, such as comfort, despite diagnosis or prognosis, can emerge as priority issues.[23] Furthermore, Montgomery and colleagues[22] found that committed nurse advocacy exists in a framework that includes knowledge, core values of caring, and an understanding of palliative care as an evolving concept about which colleagues and others in the interprofessional team are advancing their own knowledge and acceptance.

In addition, training in essential palliative care activities for oncology nurses who are not palliative care specialists, but who care for patients who may not otherwise have access to palliative care services, is needed.[24] The inconsistent awareness, availability, training, and execution of palliative care contribute to care disparities for oncology patients and certainly affect their quality of life and care outcomes. O'Shea[25] found that although staff nurses can play crucial roles in the trajectory of treatment and illness for older hospitalized patients, they are often confused about the difference between palliative and hospice care. This may play a role in how assertively palliative care interventions are advocated for by the nurse. Although palliative relief of intracranial pressure clearly improved the quality of life for A.H., nurses did not advocate for intervention to maintain the improved status; several nurses repeated the chief's assertion that “nothing could be done.”

It is critical for nurses to be aware of the knowledge and attitudes of others, as well as their own self-awareness, related to age, diagnosis, and advanced disease palliative care management, so that they may appropriately facilitate the autonomy and maintain the dignity of their patients. Although there is general agreement that palliative care optimizes quality of life, is patient and family centered, and is an essential component of all care, regardless of care setting,[11] attitudes toward age, diagnosis, and prognosis, as well as personal and cultural influences, may affect patients' access to that care.

After persistent insistence by the family, 1 nurse facilitated a late-night discussion with the on-call hospitalist. This discussion initiated eventual placement of a catheter into the lumbar subarachnoid space to allow for temporary cerebrospinal fluid draining and pressure monitoring and for relief of intractable vomiting. Later that day, the pathologic diagnosis of leptomeningeal carcinomatosis secondary to NSCLC was confirmed; a palliative ventriculoperitoneal shunt was then offered and inserted later that day. The nurse later told the family that her own father had recently died, and she was distressed by the family's anguish. She commented that she knew that inattention to the escalating intracranial pressure would lead to a premature death, and this knowledge compelled her to act.

WHEN ADVOCACY CAN EXTEND LIFE

At what points would nurse advocacy have offered assistance to this patient and family?

Early Suspicion and Evaluation. Symptoms suggested that more than dementia was evolving. Family reports of visual hallucinations were not taken seriously, and the patient's aphasia was considered a consequence of dementia, rather than associated with an alternative pathology. Nurses at the bedside have an opportunity to analyze symptoms in the context of the comprehensive patient and family history that they collect and can advocate for more extensive investigation. Although leptomeningeal carcinomatosis in NSCLC is atypical,[26] it is not unprecedented and could have been suspected earlier had all symptoms been considered concurrently, rather than as occurring uniquely.

Caregiver Support. The family was in distress but had difficulty being heard in the context of an urgent, acute change in status rather than as a terminal course of illness. References to the underlying history of NSCLC and the patient's age were frequently made, suggesting the symptomatology to be a normal course of metastatic disease and age, despite clear communication that the patient had been alert, oriented, and functioning independently only days before presentation. Ethical standards of communication for nurses include respect for patients and families and an active role as advocate. Active listening, careful history taking, and recognition of the nursing responsibility to investigate what the family was reporting are an expected component of professional nursing practice.[23,27]

Support for Further Evaluation. The strength of the chief of neurosurgery's note was compelling and was often referenced in discussions with the family as an accurate baseline assessment of the patient, when, in reality, it did not reflect the true acute nature of the rapidly increasing intracranial pressure secondary to leptomeningeal disease. Nurses who recognize inconsistencies between the reports from patient or family and potential erroneous conclusions drawn must advocate for investigation of these possible errors, as outlined in the American Nurses Association's *Nursing Code of Ethics*.[27] As an integral member of the interprofessional team, nurses must claim their role in the shared decision-making process for effective patient care.[28]

Assessment of Patient and Family Goals Needs, and Values. Patient and family priorities must be recognized and validated.[28] Skilled communication about these issues is a learned behavior for which nurses should be adequately educated,[18] and nurses should include treatment, functional, and symptom control preferences in these discussions.[29]

Following shunt placement, the patient was discharged to the home with hospice care in place. A.H. lived an additional 7 weeks at home. Although hallucinations persisted, and her speech increasingly deteriorated, she was free of nausea and vomiting and was able to spend time with family and friends, care for her dog, and say her goodbyes.

Nurses must never underestimate how their own knowledge, attitudes, and behaviors can impact another's life. The impact of 1 nurse, who listened to the family's account of A.H.'s preadmission functionality and the acuity of her deficits and who validated the goals and values of the patient and family, allowed A.H. to gain comfortable weeks at home and to die with dignity.

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