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CONQUERING THE CANCER CARE CONTINUUM™

Access to Care

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This second issue of *Conquering the Cancer Care Continuum*™ focuses on the serious nature of the problems associated with access to care. Whether it be access to cancer screening, diagnosis, treatment, or follow-up care, it is an issue that remains unresolved. Some models aimed at early detection, such as the Centers for Disease Control and Prevention's National Breast and Cervical Cancer Early Detection Program, have been successful in reaching some individuals. Difficulty still remains, however, in screening certain populations and arranging for them to receive treatment.

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This publication contains articles written from the perspectives of a clinical oncology pharmacist and an oncology nurse practitioner. Both of these healthcare professionals provide their insight into the underlying causes of disparities in access to care, as well as the additional challenges associated with ensuring that a patient is receiving quality care.

We know that healthcare disparities in the United States continue to exist. Historically, these gaps were associated with low socioeconomic status and/or low educational levels. The lack of health insurance has been an issue as well, resulting in delayed diagnoses and higher mortality rates once an individual is diagnosed with cancer. Today, the circumstances that impact access to care have broadened. Although lack of insurance was identified by the Agency for Healthcare Research and Quality as the most significant contributing factor to gaps in access to care, we also must consider the escalating costs in cancer care. With medications and drug development being more expensive now than in the past, insurance companies are being forced to pass along more healthcare expenses to the patient, which are, in turn, associated with high copayments, higher deductibles, and even capitation for some episodes of cancer care. This means that having health insurance no longer completely solves the problem of access to care.

So, how do we wrap our arms around the rising costs of cancer care? One way is to utilize oncology nurses in a more expansive way. As the shortage of oncology specialists grows, along with a prexisting shortage of primary care physicians, we need to turn to nurses to fill in some of the gaps, as well as serve as bridges for continuity of care. Oncology pharmacists are serving in advocacy roles, thus helping patients obtain free or discounted drugs directly from the pharmaceutical companies. This service is needed not only by the indigent, but by working

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families as well. Although the development of new drugs is exciting, the costs associated with these agents are higher than we have ever witnessed before. Patients and their families do not and will not have the financial means to absorb the costs of cancer care that now rest on their shoulders.

Some patients may feel that treatment is simply not possible for financial reasons, and will seek care that lacks evidence-based research and deviates greatly from standards of care.

Add to this equation the fact that the American Society of Clinical Oncologists is encouraging oncologists to expand their discussion with cancer patients about treatment options by not limiting the conversation to the risks and benefits of each potential therapeutic option, but providing patients with information on treatment costs as well. And when it comes to offering treatment to patients with advanced metastatic cancer, a priority among such individuals is not to leave their families with any financial debt associated with their cancer care after they are gone.

And what will happen to the patient who gets screened and, as a result, is diagnosed with cancer? We can no longer assume that this individual will proceed with the treatment of his or her disease. Some patients may feel that treatment is simply not possible for financial reasons, and will seek care that lacks evidence-based research and deviates greatly from standards of care. Patients may also feel that they cannot afford to take time off from work to get the treatment that they need.

To date, there is no one solution to this dilemma. We must work as a team to develop practical strategies to improve access to care, whether it be screening, prevention, early detection, diagnosis, treatment, or follow-up care. We need to become creative…to become truly innovative. We must also remember that treatment for treatment's sake is not necessarily good quality of care. The healthcare system has rewarded physicians and hospitals for providing more and more treatment. Now is the time to step back and remember the Hippocratic Oath—"First, do no harm." To create accessible quality cancer care in different environments, such as the workplace. To shift treatment hours to when patients are available to receive their therapy, which is often not in the middle of their workday. To promote healthier lifestyles so we can decrease cancer risk. There is a lot to be done. We need to work together to develop solutions sooner, rather than later. ■

Access to Quality Care: A Nurse's Perspective

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The state of healthcare in 2014 necessitates that patients play an active role in the management of their health. But who, among Americans, has access to healthcare? This access occurs when an individual is fortunate enough to have available the timely use of services, so he or she can achieve the best health possible. These services include such primary preventive services as blood pressure checks, cancer and cardiovascular screenings, or what is known as "well visits." Americans older than 65 years of age have access to healthcare through a government-sponsored Medicare benefit. Individuals with very low incomes and those with chronic conditions, such as cancer, often have access to care through Medicaid. Many other individuals without healthcare coverage, however, do not fall within these categories. Healthcare disparities, including low socioeconomic status, ethnic inequalities, and a lower level of education, exist and are all factors that prevent access to care.[1] Limited access to care because of geographic location, lack of insurance, or ethnic inequalities may lead to delays in time to diagnosis of cancer, lengthier recovery, or other negative sequelae.[2,3]

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Access to healthcare services is one issue, but access to *quality* care is an equally important matter to address. The National Healthcare Quality Report, sponsored by the Agency for Healthcare Research and Quality, suggests that lack of health insurance is the most significant contributing factor limiting access to quality healthcare for the prevention and treatment of a variety of conditions, such as cancer.[4] Individuals who are uninsured or underinsured are less likely to engage in preventive healthcare, routine dental screenings, and healthy diet and exercise behaviors.

The concept of uninsured and underinsured individuals has been described more often in the past few decades. A person who is uninsured simply lacks medical insurance coverage. Years ago, it used to be true that you either had insurance or you did not. However, as drug development and medications have become more expensive, each has individually led to escalating healthcare costs. Just because an individual has health insurance does not mean that the insurance will cover his or her medical needs, which leads to high copays.[5] When a person is underinsured, he or she has medical expenses that are greater than 10% of his or her annual income, or has health plan deductibles that are equal to or greater than 5% of his or her annual income.[6] As such, health maintenance organization (HMO) insurers have protected themselves by creating tiers for service and a capitated benefits system.

Capitation is a type of healthcare reimbursement that affects both insured and underinsured patients with cancer. Capitation occurs when an HMO determines a fixed-rate payment for services rendered regardless of the volume of services rendered.[7] The HMO will pay a set amount to hospitals and providers regardless of level of complications that may develop, for example, during a hospital stay. Treatment (such as expensive, "newer" chemotherapy) may be postponed until the patient is discharged from the hospital if such therapy is not deemed to be critical to the well-being of the individual or not related directly to the individual's hospital admission.

Individuals who are uninsured or underinsured are less likely to engage in preventive healthcare, routine dental screenings, and healthy diet and exercise behaviors.

Patients with cancer who are not admitted to the hospital may also have their benefits "capped." Once the dollar amount has been met, the patient will no longer receive coverage through that plan. This capitated system will become more common in the future of healthcare in the United States and is an issue that will be addressed in an upcoming *Conquering the Cancer Care Continuum* article.

The significance of escalating healthcare costs has been highlighted in recent years because of the economic downturn that the United States has experienced within the last decade. Individuals lost their jobs and lost insurance benefits as a result. Further, a dearth of qualified providers were left to deliver healthcare, as hospitals were negatively affected as well. Nurses cannot be entirely responsible for repairing all of the broken issues with regard to access to care. But given these issues, I can think of 3 ways in which nurses can improve patient access to quality care: (1) maximization of nursing scope, (2) policy change, and (3) community involvement.

Nurses should learn about the barriers in their nursing practice that may negatively impact patient access and should determine ways in which to address these barriers.

In 2011, the Institute of Medicine (IOM) called on nurses to bridge the gap in which patients do not have access to healthcare, and to practice to the full extent of their education and training.[8] Licensed practical nurses (LPNs), registered nurses (RNs), and advanced practice nurses (APNs) are viewed as an effective, cost-effective, well-trained group of professionals who provide quality care at a variety of levels. Each nurse has the ability to contribute to the healthcare team and to enhance the delivery of quality care. Yet, there are very different scopes of practice, in particular where APNs are concerned. APN practice is often restricted by individual states or hospitals. This is true despite research showing that states with fewer restrictions on APN practice have lower hospitalization rates and improved health outcomes in their communities.[9]

I have seen a change in my state of Ohio in the 2 years since the IOM report. I am pleased to report that while my organization has always supported nurses and the role played by APNs, there has been an increase in statewide policy changes that have allowed patient access to quality healthcare in a timely manner. APNs in many therapeutic areas and with specialty training can conduct consultations independently, admit patients to the hospital when appropriate, and practice medicine independently. My APN colleagues across the country have also reported an increase in their independence, along with the ability to continue a collaborative practice with other members of the healthcare team.

However, allowing nurses to practice medicine and provide treatment to patients will not solve all of the problems associated with access to care. So, in what other ways can nurses improve access to quality healthcare? At 3 million members strong, they can use their voice to enact policy changes within their institutions, at a community or at a national level. Influencing different practice patterns among states that restrict LPN, RN, and APN practice can allow all nurses to maximize their scope of practice to expedite patient care. Nurses should learn about the barriers in their nursing practice that may negatively impact patient access and should determine ways in which to address these barriers.

Finally, community health and cancer screening workshops are routinely held and sponsored by academic institutions and religious groups. Community workshops offer free blood pressure, cancer, and other preventive health screenings. Raising awareness of these programs among groups and at-risk individuals, and even volunteering at these workshops, can all help to engage patients.

Although access to quality care will often exist, we as nurses should be aware of the disparities in access to care and do whatever is in our power to improve services for our patients. ■

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Access to Care: A Pharmacist's Perspective

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When I joined the faculty of the McWhorter School of Pharmacy (MSOP) at Samford University in Birmingham, Alabama, in July of 2008, I was excited to discover a corporate spirit and passion for involvement with underserved populations that were similar to that of my own. In Alabama, one does not have to travel far from a major city to find people in need; nowhere is this more true than in the university's original home in Perry County, which ranks as one of the poorest counties in the United States.[1] With Perry County located about an hour's drive from Birmingham, MSOP students and faculty routinely conduct health screenings, and operate full-time diabetes and hypertension clinics through the local department of health, thus promoting the health and wellness of this at-risk population and supplementing the severely stressed healthcare resources available there. Not surprisingly, with a shortage of primary care physicians, access to care in this region is significantly below both Alabama and United States medians, whereas cancer incidence and deaths from lung, colon, and prostate cancer are far above the national norms.[2] In this regard, Alabama is not unique. Underserved populations are found in every town, city, county, and state in this country, yet solutions for improving access to quality healthcare for all patients are difficult to implement.

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Recognizing that poor access to high-quality medical care is associated with a relative lack of cancer screening and early diagnosis, thus leading to the cancer trends observed in Perry County, the Institute of Medicine (IOM) and the Oncology Nursing Society (ONS) have authored recommendations and white papers to assist those of us "in the field" in making advances in our own backyards. The ONS advocates for "comprehensive healthcare coverage with respect to cancer prevention, early detection, risk assessment, risk reduction services, genetic counseling, and genetic predisposition testing," to ensure that cancer incidence is reduced and survivorship is maximized.[3] This is, unfortunately, much easier said than done, although some existing programs have had a significant effect on these underserved populations. One needs to look no farther than the success of the Centers for Disease Control and Prevention's National Breast and Cervical Cancer Early Detection Program for evidence of the impact on this population. This program assists low-income, uninsured, or underinsured women's access to breast and cervical cancer screening programs.[4] Early data published in 1998 suggested that among women who had received a prior mammogram, the rates of breast cancer detection declined and the size of invasive tumors was smaller than among those who had never previously been screened.[5] More recent data demonstrate that as a result of this program, 5904 breast cancers (of 340,038 women screened) and 261 cervical cancers (of 251,637 women screened) were detected in 2012 alone.[4] Although programs such as this certainly do not reach all women or all patients in need, they are a step in the right direction of meeting the goals of the ONS and the IOM.

Underserved populations are found in every town, city, county, and state in this country, yet solutions for improving access to quality healthcare for all patients are difficult to implement.

What about the role played by pharmacy and by oncology pharmacy, in particular? Screening and early detection programs are making huge strides in improving access to care, and in reducing morbidity and mortality from cancer, but the financial burdens faced by a patient and his or her family increase exponentially once a cancer diagnosis has been made. In 2010, the National Cancer Institute estimated that the average cost of managing a single patient with newly diagnosed lung cancer was ~$60,000 for the initial therapy and $7000 to $8000 for continuing treatment.[6] Far too often, the greatest finan-

cial burden is the cost of the drug therapy that is indicated by best practices and clinical practice guidelines. Certainly, county and state safety net hospitals and their indigent care programs, Medicaid and Medicare programs, and access to insurance via provisions of the Affordable Care Act ensure that many patients receive, at a minimum, standard of care therapy. However, these same programs may balk at the costs associated with the latest cutting-edge medications that could offer some patients improved outcomes.

Even with the best intentions, financial coverage gaps often leave families with massive debt or even worse, having to consider not pursuing additional treatments due to cost-related factors.

As an oncology pharmacist, I am often called upon to leverage contacts within the pharmaceutical industry in order to (1) provide samples of oral medications (which virtually never occurs with high-cost oral oncolytics, but is occasionally successful with other supportive care medications or even several hormonal therapies); (2) offer access and counseling for patients with respect to financial assistance programs available from drug manufacturers or cancer organizations; or (3) find clinical trials in which the costs associated with access to a drug may be provided by the sponsor (which is often rare in the case of oncology trials, where the expectation is that standard of care medications are still billed to insurance companies). Even with the best intentions, financial coverage gaps often leave families with massive debt or, even worse, having to consider not pursuing additional treatments due to cost-related factors.

These barriers to quality cancer care are unfortunately not limited to the indigent. Recently, a retired patient with lung cancer who had exhausted all standard of care options underwent foundation medical screening, where a driver mutation in the *BRAF* gene was identified. It was determined that she was ineligible for a clinical trial with an investigational BRAF inhibitor, and her insurance company refused payment for commercially available BRAF inhibitors solely because they were not approved by the US Food and Drug Administration for her particular disease state. As a practitioner, I lament the inability to successfully persuade an insurance provider that this type of therapy may be better than conventional cytotoxic chemotherapy for a patient such as this. Ultimately, the cost of several thousand dollars per month of these newer generation drugs prevented the patient from receiving a potentially active and beneficial treatment.

In our healthcare system, we must follow the lead established by the ONS and the IOM, and evaluate methods for improving access to quality healthcare, so that patients such as those in Perry County and those with insurance who have exorbitant copays or out-of-pocket expenses are permitted access to therapies that may prolong survivorship and quality of life. Although the boundaries for costs absorbed by insurance plans or taxpayers are far too often a politicized issue rather than one borne of empathy and compassion for our fellow man, we clearly still have a long way to go to ensure that all patients are provided with access to high-quality healthcare. The answer likely lies not with the newest, most expensive treatment option or the oldest, least expensive standard of care option, but with improved access to screening and early detection. Keeping our population engaged and informed, while promoting and incentivizing provider involvement in underserved populations, may be the best method for reducing healthcare disparities in cancer care. ■

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