Symptom management for patients with cancer is complex. One set of symptoms that varies considerably among patients and is especially difficult to manage is oral complications from cancer therapy. Oral complications have major effects on treatment, quality of life, and overall survival (Borbasi et al., 2002; Miller & Kearney, 2001; Shih, Miaskowski, Dodd, Stotts, & MacPhail, 2002). Oral complications include mucositis, infections (viral, bacterial, and fungal), severe pain, xerostomia, and difficulties eating, swallowing, and speaking. These complications can affect course of treatment, treatment dose, location of head and neck radiation therapy, and ability to continue treatment (National Institutes of Health Consensus Development Panel, 1990). If a treatment course or dose is halted temporarily or stopped completely, the risk of tumor recurrence increases and can affect morbidity and overall survival (Borbasi et al.).

This article presents the innovative way that I combined expertise from my professional preparation as a registered dental hygienist (RDH) and an RN to meet the oral needs of patients with cancer. I use a metaphor of travel to illustrate how I began my journey as an RDH, became an oncology nurse, and finally synthesized the strengths of each practice to care for my patients.

Comparing Professions

RDHs and RNs have similar educational preparation and requirements for licensure to practice and must continue education to maintain competency. Both have almost identical prerequisite courses before admission to their respective programs (e.g., biology, chemistry, English, psychology, anatomy and physiology, mathematics, humanities). Both participate in classroom, laboratory, and clinical experiences that prepare them to care for a diverse patient population in a variety of healthcare settings. Both must understand different disease processes and how they affect individual patients. Both study pharmacology and are expected to apply concepts to patient care. Although the clinical experiences of each are different, both are taught to provide the best care for their patients, offer direct patient care and one-on-one patient education, and focus part of their practice on health promotion and disease prevention.

After graduation, RDHs and RNs take comprehensive licensure examinations to practice their professions. Both are able to continue education in their fields at baccalaureate and master’s levels. They also are able to develop expertise in their professions through continuing education and pursuit of advanced degrees. In most states, RDHs must complete 10–12 hours of specialized continuing education each year to maintain a license to practice. For RNs, this varies from state to state, but most RNs attend continuing education to maintain competency and learn new skills.

RDH training gives students the skills and knowledge to provide oral care to a wide variety of patients. The training prepares new practitioners to assess, identify, plan care for, treat, and evaluate oral health needs. However, RDHs lack the specialized knowledge to assess and manage the complex needs of patients with cancer.

Oncology nurses have the knowledge and expertise to care for the special population of patients with cancer. They know the goals of cancer treatment and the biophysiological effects of chemotherapy and radiation therapies. Even with this experience and knowledge, many nurses believe that they face barriers as they try to solve patients’ oral care problems (McGuire, 2003). Oral symptom management remains one of the most demanding and challenging responsibilities of oncology nursing. Significant knowledge and experience are necessary to correctly assess and provide for patients’ oral care needs. Yet oncology nurses sometimes may feel less prepared in this area of patient care (McGuire; Nieweg, van Tinteren, Poelhuis, & Abraham-Inpijn, 1992; Sadler, Oberle-Edwards, Farooqi, & Hryniuk, 2000).

The two professional paths have more similarities than differences, and I knew that combining both would bring me closer to realizing the vision of my future practice.

The Journey

My journey began in 1975 when I received a bachelor of science degree in dental hygiene from the University of Missouri-Kansas City (UMKC). During the next 15 years, I had the opportunity to care for a wide variety of patients. Many were healthy, but others had many types of diseases, including cancer. I was able to see how good oral health contributes to good overall health and stable disease. I was limited, however, in my ability to practice comprehensive dental hygiene care. Unlike nursing, dental hygiene is not self-regulated. Dental hygiene practice, education, and licensure are controlled by state administrative boards of dentistry and the Commission on Dental Accreditation, a nationally recognized accreditation agency run by organized dentistry. Recently, in a few states, legislatures have created dental hygiene committees. The committees advise the Board of Dentistry on matters related to dental hygiene licensure, education, and practice. Because of the practice restrictions, I decided to return to school and study nursing so that...
I could develop the knowledge base and skills to provide comprehensive care to all patients. I graduated in 1991 with a bachelor of science degree in nursing and received a master’s degree in oncology nursing in 1998. After a car accident that resulted in a neck injury that was not serious but did restrict my practice, I began to think about how to combine my two professional identities. I started reading and talking to advisors and friends to determine what avenue was best for me. When my beloved grandmother was diagnosed with a malignant brain tumor, I researched the effects of radiation therapy to the head and neck area and the resulting oral complications that can arise as a result of that therapy. During her course of radiation therapy, I became her “dental hygienist/nurse” to manage her mouth care. During that time, I fully realized how devastating oral complications can be to patients. I also realized how compatible my two backgrounds were. I decided that I would be able to provide more oral care to patients as a nurse and that I wanted to focus my practice on oral symptom management for patients with cancer.

After a comprehensive literature review in the area of oral complications of cancer therapy, I believed that I had a thorough understanding of the problems and the resources needed. I evaluated the community to determine what organized resources were available (e.g., specialized dental practices, hospital-based programs, practitioners who specialize) and found limited resources. Most oncology nurses to whom I spoke were glad that I had a “passion for mouths.” They, too, were struggling to find measures to effectively and efficiently alleviate oral symptoms that their patients were experiencing. None of those with whom I spoke understood how having a healthy mouth at the start of treatment could help prevent or reduce the severity of oral complications (Sadler et al., 2000). I began to share with my peers and patients what I knew about oral health and what I had learned about managing oral complications.

A lack of resources, knowledge deficits, and my passion for good oral health led me to set up a program that would address oral complications of cancer therapy within my husband’s periodontal practice, which was based at a local hospital. I had a wonderful and gifted mentor, Gerry Barker, RDH, MA, coordinator of the Oncology Dental Support Clinic at the UMKC School of Dentistry, who helped me set up my program.

A Stop Along the Way

The program, Oncology Dental Support Services© (ODSS©), was created to provide symptom management for oral complications experienced by patients during cancer therapy. It served as the instrumental link among patients, oncologists, dentists, and dental hygienists before, during, and after cancer therapy. Establishing ODSS© in a periodontal practice in a hospital was advantageous from the standpoint of available office space and staff to run the program. My husband and I consulted with the Missouri Dental Board to make sure that we were operating within the confines of the dental and dental hygiene practice acts. I also checked the Missouri State Nursing Practice Act. After confirming that we were operating legally, we began a systematic process of contacting other practitioners and patients in the area. I sent an announcement introducing the program to all oncologists, dentists, and dental hygienists. I also sent an announcement to members of the local chapter of the Oncology Nursing Society (ONS). My husband and I presented the program to the oncology group at the hospital where our practice was located.

Patients were referred to the program in a variety of ways. Some already were longtime patients of the periodontal practice. Oncologists and dentists in the larger community referred others. In many cases, the practice was contacted after symptoms already had occurred. We conducted phone consultations with dental care providers when patients presented to their practices with problematic oral symptoms. Some patients stayed in the periodontal practice after their cancer treatment concluded. Others returned to their original dental providers.

We used the existing employees in the periodontal practice to staff the program and, therefore, were able to care for patients regardless of their ability to pay and without the benefit of special funding. The program operated using resources generated from the periodontal practice; similar programs elsewhere in the country must rely on sponsorship and grants to operate.

To replicate the ODSS© program, staff requirements include a dentist with a background in dental oncology, an RDH with training in the oral care needs of patients with cancer, a dental assistant, and an oncology nurse with training in oral complications of cancer therapies (or an individual with training in both oncology and dental hygiene). Resources to consider include a funding source, dental equipment, institution support, staff training in oral assessment and oral symptom management, a convenient location for patients, and an ongoing mechanism to evaluate the program and make modifications as needed.

Oral examinations, pretreatment radiographs, treatment planning, patient education, and dental care coordination for patients before the start of cancer therapy all were performed at ODSS©. ODSS© provided preventive and surgical care, but restorative dental care was referred to patients’ dentists of record or the program’s dental referral sources. ODSS© made, fitted, and checked fluoride trays for patients undergoing head and neck radiation therapy. Patients were followed throughout the course of treatment, mostly on a weekly basis. Patients then were seen at a follow-up visit, usually one month after completion of treatment, to ensure that all of their oral symptoms had resolved. Communication among patients, oncologists, and dentists was ongoing during treatment. A follow-up letter was sent to each party after the last appointment with ODSS©. If a patient did not have a dentist to return to or wished to continue to be seen by the periodontal practice, he or she was placed on a periodontal maintenance schedule, typically with visits every three or four months.

As the nurse coordinator and oral care specialist, I took complete patient medical and dental histories; gathered records and other pertinent treatment information from patients’ oncologists; performed oral assessment and charting; assessed the need for dental radiographs; assessed patients’ oral hygiene and oral care habits; provided preventive oral hygiene care; educated patients, families, and caregivers regarding oral hygiene and oral complications from cancer therapy; and provided oral symptom management for patients undergoing cancer therapy. I also provided consultations, information, resources, and support for healthcare professionals who contacted me. I consulted with other healthcare professionals who were interested in this patient care challenge. I served as the contact for the ONS Oral Care Focus Group from 1992-1999. I continued to search the literature, attend professional meetings, and evaluate research reports for scientifically based ways to prevent or reduce the severity of oral complications.

Barriers

I encountered some barriers along the way, including resistance from oncologists, lack of support from hospitals and dentists in private practice, providers who were unwilling to change, and my husband’s retirement. I met resistance from oncologists who agreed that having a healthy mouth first was important but insisted on starting cancer treatment immediately and dealing with oral problems after they developed. I found that establishing a dialogue with these oncologists was important. My husband was one of the dentists on the staff of a local hospital and was well respected by the physicians. His professional stature facilitated the dialogue. When the physicians understood our mission and how we wanted to assist them in caring for their patients, they began to work with us when problems developed. Although we would have preferred to see patients before cancer treatment, we were happy to contribute to their programs of oral symptom management at any point.

I also met with resistance from hospitals that were slow to investigate and implement standardized oral care protocols for their patients with cancer. These hospitals also were unwilling to invest money in dental care services. Although few hospitals have on-site dental services, standardized oral care protocols for
patients have become a standard of care at some. I have been privileged to work with wonderfully innovative oncology nurses who were willing to assert their ideas and stand up for their beliefs despite reticent administrators. They endeavored to create multidisciplinary committees and develop and implement an oral care protocol for their patients. I was happy to serve as an oral care consultant and sounding board for them.

I met with resistance from dentists in private practice who were not sure how to manage the care of these patients. They were concerned that the care would be perceived as unnecessary or as special services and, therefore, not be covered by insurance. This concern was fueled by a knowledge deficit that was corrected easily with education and experience. Most dentists now have patients in their practices undergoing cancer treatment. Professional dental journals have published articles and guidelines on how to care for such patients. Numerous continuing education courses (some of which I have provided) have addressed the needs of this patient population. Dentists have become much more comfortable providing care for patients with cancer. Compensation issues seem to be no different for patients with cancer than for those with other conditions.

Another barrier was unwillingness among providers to change their ways of practice. I believe that this reluctance was a result of a lack of information or misinformation about oral care and oral health (McGuire, 2003; Sadler et al., 2000). So, I began volunteering to talk to any group or individual who would listen: nursing students, dental hygiene students, practicing nurses, dental hygienists, dentists, and oncologists. I was asked to present continuing education programs on the topic of oral complications of cancer therapy at professional meetings throughout the country. As word spread about my background and expertise in this area, I received patient referrals and conducted phone consultations with professionals from all over the United States. I met some innovative professionals who also had a “passion for mouths,” and they shared their research, experiences, and expertise.

The most significant challenge I encountered occurred two years ago. After 41 years of practice, my husband decided to retire and give up our location at the hospital. I no longer was able to see patients within the context of his practice. During the first year of his retirement, I temporarily relocated ODSS© to the office of one of the referring general dentists. Although this allowed me to continue to see patients, the location was inconvenient and not ideal for the program. I accepted a position as a clinical nurse in the cancer information center at another local hospital and began the task of finding a more permanent home for ODSS© with a new dentist. The search has not been easy. Although people are interested, I still am searching for a new dentist collaborator.

A New Road

ODSS© currently does not have a physical location (i.e., office or clinic site), but the program remains. I continue to provide educational programs on managing the oral complications of cancer therapy. I still consult with nurses, dental hygienists, and other professional and community groups about oral symptom-management dilemmas. I have started a dialogue with the radiation oncologists, radiation oncology nurse, head and neck surgeons, inpatient oncology clinical nurse specialist, and onsite dentist at my hospital about the need to prevent or reduce the severity of oral complications of cancer therapy. I hope this will lead to the formation of a multidisciplinary committee to address the lack of standardized oral assessments for inpatients and outpatients, as well as the lack of standardized oral care protocols (e.g., for patients receiving chemotherapy and those undergoing radiation for head and neck cancer). Recently, the on-site dentist has expressed an interest in incorporating ODSS© into his practice setting. He also is director of the general practice dental residency program and is looking into ways to use the residents as part of the program.

Looking Ahead

Oral complications from cancer therapy continue to be a major challenge for oncology nurses, as well as for their colleagues in dentistry and dental hygiene. A multidisciplinary approach, using the backgrounds of oncology nursing and dental hygiene, provides one way to meet these complex needs.

References


