



Oncology Nursing Society

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Oncology Nursing Society Medicare Payment for Cancer Patient Treatment Education Issue Brief

The Oncology Nursing Society (ONS), the largest professional oncology group in the United States – composed of more than 37,000 nurses and other health professionals – exists to promote excellence in oncology nursing and the provision of quality care to those individuals affected by cancer. As part of its mission, the Society honors and maintains nursing's historical and essential commitment to advocacy for the public good. The Society stands ready to work with policymakers at the local, state, and federal levels to advance policies and programs that will reduce and prevent suffering from cancer, including the provision and payment of treatment education for cancer patients and their caregivers.

What is Cancer Patient Treatment Education?

Generally, cancer treatment education is an educational session delivered orally in person by a registered nurse to a patient and his/her caregiver. The goal of such a session is to: educate the patient and the patient's caregiver about all aspects of the care to be provided to the individual; inform the patient regarding any potential symptoms, side-effects, or adverse events; explain ways in which side effects and adverse events can be minimized and health and well-being maximized; and offer clear guidance regarding when the patient and/or caregiver should contact the health care provider with respect to a particular side effect or symptom and when to seek urgent or emergency care.

Patient treatment education also should include the provision, in written form, of information about the course of treatment, any responsibilities of the patient with respect to self-dosing, and ways to address symptoms and side-effects. The information provided – both orally and in written form – should take into account cultural and linguistic needs of the individual, in order to make the information comprehensible to the patient and the patient's caregiver. Ideally, patient treatment education should be provided on a day different both from the day of diagnosis and the first day of treatment, as well as, anytime when the plan of care and/or the course of therapy is modified.

The Importance of Patient Treatment Education and Symptom Management

Many people with cancer experience side effects, symptoms, and late side effects associated with their disease and their treatment, and such effects can have a serious adverse impact on the effectiveness of their treatment, their health, well-being, and quality of life. Every day, oncology nurses witness the suffering which patients experience, caused by the side effects of cancer treatment and the symptoms of cancers themselves.

To support oncology nurses and patients, ONS offers the premier Website devoted to patient education and symptom management – www.CancerSymptoms.org – which offers up-to-date information about the most common symptoms that patients receiving treatment for cancer experience: pain, nausea, anorexia, cognitive dysfunction, depression, fatigue, hormonal disturbances, sexual dysfunction, dyspnea (difficulty breathing), mucositis (the most common is oral mucositis – irritation of the mouth and esophagus), neutropenia (low white blood count, which leaves people more susceptible to infection), and peripheral neuropathy (loss of feeling in hands and feet).

Nurse education of patients and their caregivers about what symptoms to expect or watch for, when and how to contact their physicians and nurses, and how to manage their conditions and symptoms can help ensure that the side effects of cancer and its treatment are moderated, alleviated, and/or prevented. Such education empowers patients and their caregivers; helps to optimize treatment outcomes; decreases adverse events, office visits, and hospitalizations; and substantially reduces costs in an already burdened health system. Evidence from medical

and nursing literature shows the value of patient education and the value of nursing interventions. For example:

- Teaching effective self-care behaviors enhances patients' independence, comfort, control, and quality of life.¹
- An educational intervention provided by nurses before the start of chemotherapy may assist women with breast cancer to increase their knowledge of chemotherapy treatment, enhance their ability to manage side effects, and improve their coping strategies.²
- In patients with head and neck cancer, provision of an educational tool explaining self-care behaviors enhanced outcomes by promoting patient safety, patient quality of life (specifically pain control), and patient self-advocacy.³

The Impact of Cancer Patient Education: Case Examples

The following case examples, provided by ONS members, illustrate the power and importance of treatment education among people with cancer.

- A woman with advanced kidney cancer was treated with a new drug that frequently causes a rash. Prior to the commencement of her treatment, she received from her oncology nurse detailed information about the likelihood of a rash, what the rash would look like, and ways to manage it. She also was instructed that the rash was *not* a sign of an allergy and that under no circumstances should she stop taking her medication, available as a home-administered oral tablet, without consulting her health care provider. She did develop a mild rash that she managed with skin moisturizers, as instructed. She immediately contacted her oncology practice to inform her physician and nurse of the rash, accepted advice to maintain her regimen, and experienced a good response to her course of therapy. In this case, patient education ensured that the patient continued to take her medication and taught her ways to manage her symptoms without an interruption in her course of treatment.
- A man with acute myelogenous leukemia was treated with aggressive chemotherapy in his physician's office that caused his blood counts to decline dramatically. When he went home, he experienced a severe headache. Although his wife encouraged him to call the oncology practice, he resisted. He did "not want to bother the doctor or nurse" on a Saturday. The headache was still present on Monday when he went to the clinic. His platelet count was extremely low, and he was admitted to the hospital where he suffered a brain bleed, because of his low platelet count, and he died. Unfortunately, he had never received clear instructions and education from the practice about when to contact his healthcare provider with respect to side effects and symptoms. Had he and his caregiver been educated about the potentially serious implications of various side effects and what to do upon experiencing a particular symptom, his life could have been saved.
- As part of patient and caregiver education, a registered nurse practicing in oncology taught a young man to care for his mother's peripherally inserted central catheter (PICC) that was used to administer chemotherapy in the oncologist's office. It required daily flushing with heparin at home between chemotherapy cycles to prevent infection and clotting. The oncology nurse taught the caregiver how to apply a mask, use his covered mouth to remove the heparin syringe cap, place the syringe on a table to eject the air, and flush the PICC line. The instruction from the nurse enabled him to care for his mother for several months at home, a much less costly option than daily visits to the physician's office or

¹ Williams, S.A., & Schreier, A.M. (2004). The effect of education in managing side effects in women receiving chemotherapy for treatment of breast cancer. *Oncology Nursing Forum*, 31, Online Exclusive, E16-E23.

² Keller, J.S. (2006). Implementation of a prechemotherapy educational intervention for women newly diagnosed with breast cancer. *Clinical Journal of Oncology Nursing*, 10, 57-60.

³ Smink, K.A., Gosselin-Acomb, TK. (2004). Evaluation of an educational tool to enhance outcomes for patients with head and neck cancer. *Clinical Journal of Oncology Nursing*, 8, 490-494.

homecare visits from the nurse. During that time, the nurse checked in periodically by phone to reinforce the instructions for the daily procedure, so it would be done correctly, and to ask specific questions to assess the patient's condition.

The Need for Medicare Coverage of Cancer Patient Treatment Education

ONS has long advocated that patients and their caregivers should have in-person instruction about their plan of care, therapies/medications, and potential symptoms, as well as have access to services and management associated with the alleviation of those symptoms. ONS has found that individuals with cancer often do not receive adequate education in advance of the onset of their treatment about their course of care and the possible side effects and symptoms they may experience. According to ONS members, often direct patient treatment education is far less than optimal because Medicare and other payers do not cover the provision of this important service. As such, too many patients and their caregivers do not receive the comprehensive symptom management education they so urgently need and deserve to maximize treatment effectiveness and well-being and minimize symptoms and adverse events.

With more than half of all cancer diagnoses occurring in patients 65 years and older, it is essential that the Medicare program provide payment for patient treatment education services to help enhance quality of life, improve treatment outcomes, and reduce adverse events and the associated economic and social costs for beneficiaries being treated for cancer. **To that end, the *Assuring and Improving Cancer Treatment Education and Cancer Symptom Management Act* takes an important step forward in ensuring that people with cancer have their symptoms and side effects managed and minimized by:**

- (1) Amending Medicare to provide for coverage of comprehensive cancer patient treatment education services;**
- (2) expanding federal research on cancer symptom management and its improvement; and**
- (3) providing for an Institute of Medicine report on cancer symptom management.**

ONS urges all Members of Congress to support people with cancer by cosponsoring this important bipartisan legislation.