# Palliative Wound Care at the End of Life

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*Wound care, a form of palliative care, supports the health care needs of dying patients by focusing on alleviating symptoms. Although wound care can be both healing and palliative, it can impair the quality of the end of life for the dying if it is done without proper consideration of the patient's wishes and best interests. Wound care may be optional for dying patients. This article will discuss the ethical responsibilities and challenges of providing wound care for surgical wounds, pressure ulcers, and wounds associated with cancer as well as wound care in home health compared to end of life.*

The majority of people die from chronic degenerative diseases (Lynn, 1996). As the population ages and the incidence and prevalence of chronic conditions are widespread, patients' needs are increasing in their complexity. Patients referred to palliative and hospice care are quickly becoming debilitated by the nature of their serious or life-threatening illness. Owing to advanced chronic conditions (e.g., neurological, cardiac, or respiratory diseases) or malignancies, wound care can complicate care, increase the cost of care, and threaten the quality of life for patients. In considering problems targeted by nurses in caring for dying patients, wound care is rarely discussed (Stromgren et al., 2001). Because dying patients may have surgical wounds, complicating wounds (e.g., pressure ulcers), and malignant wounds, home health care nurses need to understand the critical issues facing patients nearing the end of their lives.

## PLANNING CARE: PALLIATIVE CARE VERSUS WOUND HEALING

After patients' diseases are no longer responsive to curative treatment, patients can benefit from palliative or end-of-life care. The goal of palliative care is to promote the quality of life, being supportive by focusing on managing and controlling patients' symptoms to achieve the best possible quality of life for patients and their families, neither hastening nor postponing death (World Health Organization, 1989). Pain is the most common symptom that is often undertreated (Cleeland et al., 1994; SUPPORT Principal Investigators, 1995) and the one that dying patients fear the most. Although certain aspects of palliative care, specifically comfort care, can be of benefit earlier in the course of illness, end-of-life palliative care enables patients to spend their last days with dignity by having elected care, not care that is forced upon them. Palliative care has a more holistic approach by focusing on the physical (including pain, nausea and vomiting, or dyspnea), psychosocial, and spiritual problems of the dying.

Providing wound care, although it is often curative, is also palliative. It may seem contradictory, but patients nearing the end of their lives may benefit from the curative aspects of wound care. Wound care may lead to wound healing, even among the dying. Physiologically, prior to a patient's death, body systems begin to shut down usually over a period of 10 to 14 days or within 24 hours (Weissman, 2000) and blood circulation slows down. In some instances, the wound will heal in the weeks or days preceding death. Although

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wound healing may be thwarted by the physiology of the terminally ill, poor wound care and management of symptoms can be responsible for patient discomfort and can have a devastating effect on patients' quality of dying (Mallett et al., 1999).

When patients enter the last months, weeks, and days of their lives, the quality of their lives needs to be understood from the patient's subjective perspective in the context of the broader elements of their physical, functional, emotional, and social situations (Cella, 1994). Dying patients are generally weak and dependent on the care from others, often finding their ability to perform everyday functions impaired. Patients can often feel split between who they are and their illness. When possible, promoting self-care rather than having others perform all dressing changes or having others perform all essential activities of daily living can improve a patient's sense of dignity and wholeness (Dirkson, 1995; Grey, 1994) and quality of life while dying.

## ETHICAL OBLIGATIONS AND PATIENTS' RIGHTS

According to the principles of autonomy (or self-determination), providers and patients have an interdependent, shared decision-making relationship that is conducive to enabling patients' self-determination. Providers share their clinical knowledge and expertise, treatment recommendations, and values, and patients use their experience, perceptions, and values. Legally, patients are considered competent to make decisions when they are informed and able to understand the facts, are able to make rational treatment decisions and understand their implications, and can communicate their choices. Clinicians must respect and not unduly pressure patients when they request withholding or withdrawal of treatment, even refusing some or all treatments. Yet when the patient is not competent, the best interest of the patient must then be considered by clinicians and the patient's loved ones; they are challenged to balance potential benefits with previously expressed wishes, if known (Beauchamp & Childress, 1994).

Since the passage of the Patient Self-Determination Act, patients have legal rights to make health care decisions. Some patients have made advanced autonomous choices about their care at the end of life. These advanced directives or living wills, including do-not-resuscitate orders, are intended to reduce aggressive interventions. However, research has found that when patients have advanced directives, they are more likely to have more invasive and expensive care than patients without an advanced directive (Teno et al., 1997) thus illustrating that their a priori wishes are ignored, primarily after the patient becomes incompetent.

Care for dying patients with wounds consists of (a) care that should be provided, (b) care that should not be provided, and (c) care that can be considered optional. Health care providers together with patients (and their families) should make decisions on the merits of a particular intervention or treatment. Determining whether a specific aspect of wound care is to be provided hinges on balancing benefits with burdens (including harms and risks). In all cases, patients' choices must be respected. However, if the patient is not competent and there are no advanced directives, then the intervention would be considered obligatory and should be provided. For example, treatment measures to relieve distressing symptoms, such as pain associated with a wound, should be provided. Conversely, treatment should not be provided if (a) the competent patient refuses the treatment; (b) the treatment is considered futile or clinically inappropriate, for example, if the treatment will not fulfill its purpose when the patient is imminently dying; or (c) the burden of treatment outweighs potential benefits. If a clinician makes the decision to not treat on the basis of their knowledge and experience and considers the burdens to outweigh the benefits, then they may be justified in not offering the treatment.

In most instances, the balance of benefits to burdens is not clear in either direction, meaning that such interventions are considered optional. Part of the challenge in providing care is that predictions of life expectancies of the terminally ill are imprecise (Rhymes, 1990). As a result palliative care for the dying may never be given, and patients may receive care that offers no benefit. Interventions such as antibiotics and wound irrigation would then be considered optional. Making the decision for or against optional interventions according to the merits of a particular intervention need to be made jointly by health care providers and their patients (and their families). Although clinicians may feel obligated to continue life-sustaining treatments or reluctant to withdraw these interventions, nurses are obligated to represent and advocate for the best interests of the patient.

Nurses need to be effective advocates for dying patients to achieve what the Institute of Medicine

(IOM, 1997) defines as a "decent and good death—one that is free from avoidable distress and suffering for patients, families, and caregivers; in general accord with patients' and families' wishes; and reasonably consistent with clinical, cultural, and ethical standards" (p. 4). As a patient's illness progresses and death nears, the goals of care, including wound care, may change (von Gunten, Ferris, & Emanuel, 2000) by shifting from cure to comfort and from life extension to preserving dignity (Chochinov, 2002). Although there is no legal distinction between withdrawing or withholding treatment, not providing treatment to aid wound healing or ending wound treatment may be not only what the patient wants, but what can or should be done for the patient to be free from pain and other distressing symptoms before they die.

## TRANSITIONING FROM HOME HEALTH CARE TO HOSPICE AND END-OF-LIFE CARE

Home health care nurses are challenged to care for patients that will be transitioning to hospice care or whose needs should have necessitated referral to hospice. Hospice and end-of-life care generally include palliative care at home, except for those who live alone or do not have a family member who can provide support and assistance. The philosophy behind hospice care is to assist patients and their families in achieving the best quality of life and to die peacefully and comfortably with dignity. One of the goals of hospice care is enhancing the quality of life through comfort care, not curative treatment. This includes management of pain and physical symptoms.

Efforts to improve end-of-life care through the timely referral to and use of hospice and palliative care (Wilkinson, Harrold, Kopits, & Ayers, 1998) are sometimes challenged by physicians' understanding what hospice care is (Bradley et al., 2000) and attitudes toward care of the dying (Berry, Boughton, & McNamee, 1994; Hanson, Danis, Garret, & Mutran, 1996). One of the most common reasons patients do not benefit from hospice care is that they die before they can make that transition (MacDonald, 1989). Even though decisions regarding when to transition to hospice may come only a few days before the patient dies, the patient's needs must be accurately assessed and conveyed.

Transitions from home health care to hospice are the time when patient safety issues are of more concern than when the person is in one setting or the other. It is the time when medication errors and patient treatment protocol errors are most likely to occur. Transferring patients requires expert communication between the nurses from each agency (or within an agency if the agency has both traditional home care and hospice care). For example, because many older adults take multiple medications (an average of five) they are at a higher risk for medication errors. If they *slip*(in patient safety language) and do not tell the hospice nurse about the medications or if the home health nurse slips and does not tell the hospice nurse about the medications that the patient is taking it is a medical error. Although the nurse intended to do the correct thing, the slip may have occurred because of system errors that have the nurse doing too many things at the same time. In addition, communication between the hospice nurse and physician offers the potential for other communication errors. Careful consideration should be given to the mode of communication. Although the physician will eventually provide a written order form for hospice care, the transfer occurs between the nurses based on verbal communication with the physician. To decrease the chance of error from communication slips, communication should be written and verified by repeating back all verbal orders.

The goals of care in home care compared to hospice differ. Clinicians need to effectively communicate with the patient, family, and other caregivers as the transition to hospice and different care goals are made. In home health care nurses focus on wound treatment and healing, and the use of medication therapies. In hospice care, nurses focus on the primary goal of symptom management, especially the relief from pain and less on what becomes the secondary caring needs of wound treatment and healing (Storey 1990). Pain management can be complicated by concerns of over sedation and untoward effects of medication, which can result in the under treatment of pain. Since the goals of care change, hospice nurses should discuss the patient's care needs, including wound care, with physicians and specify how they differ from the former home health care needs.

## WOUND CARE TREATMENT IN HOME CARE COMPARED TO HOSPICE (ISSUE OF COMFORT VERSES HEALING)

Dying patients with existing wounds are at risk of the wounds not healing, beginning, and/or becoming larger. The skin of dying patients can be fragile and sensitive and is subsequently at risk of being compro-

mised from wound exudates, body fluids, pressure, and friction. Given the underlying life-threatening condition, wounds and the nature of pain associated with the wound should also be fully assessed and described. Patients should have an individualized, systematic approach to assessment, planning, treatment, and evaluation of their wounds in the context of their life-threatening illness.

Nurses are critical to assessing each patient's physiologic, psychosocial, and environmental factors with particular emphasis on impairments of the skin's integrity and potential for infection. A detailed assessment would include physical characteristics (e.g., size, location, and condition of surrounding tissue; Collier, 1997; Naylor, 2001), risk factors (e.g., immobility, malnutrition, incontinence), and the effects of the wound on the patient's quality of life and on their family. The nurses' goals are to preserve and maintain the skin's integrity and prevent further deterioration of existing wounds and to provide care that the patient would want to have. Some patients may not choose these goals.

Terminally ill patients often have compromised mobility, malnutrition and dehydration, functional incontinence, and, in some instances, advanced age thereby making them particularly susceptible to developing pressure ulcers (Bale, Finlay, & Harding, 1995; DeConno, Ventafridda, & Saita, 1991; Emanuel, Fairclough, Slutsman, & Emanuel, 2000). The prevention and management of pressure ulcers for terminally ill patients is not only a clinical issue but an emotional and ethical issue as well. Pressure ulcers are painful, causing suffering and complicating the care and quality of life for the dying (Colburn, 1987). Contrary to the prevailing belief that pressure ulcers should be preventable even at the end of life, some research suggests that skin, the largest organ in the human body, begins to fail along with the other organ systems, and such prevention is not possible.

Evidence suggests that even in the presence of aggressive preventive measures, critically ill individuals will have alterations in tissue perfusion, immune functioning, and coagulation, which compromise muscle cells and the overall healing response (Hadley & Hinds, 2002; Peerless, Davies, Klein, & Yu, 1999; Williams & Harding, 2003). In fact, pressure ulcer formation may be a visual biomarker that the critical illness has totally overwhelmed the body and that skin breakdown is neither preventable nor treatable (Brown, 2003; Eisenberger & Zeleznik, 2003).

As the current controversy regarding the contributing factors to pressure ulcer formation continues, wound care standards will depend on whether interventions should be focused on prevention, treatment, or palliation. Skin barriers, not adhesives, should be used for vulnerable skin (Naylor, 2001) to provide a protective film on or barrier for the nonaffected skin (Hampton, 1998). Yet, the exact treatment protocols and methods for treating wounds of the dying are not necessarily standardized. Part of the reason for the debate surrounding a recognized standard of wound care for dying patients is that there is little research on the factors that contribute to skin breakdown in this population.

Emotional concerns for family members of terminally ill patients surface because they can view pressure ulcer formation as a failure on the part of the health care staff caring for the patient or even as their own failing if they are responsible for providing care. Hospice staff may feel that turning a patient frequently may contribute to an increase in pain, so standard preventive measures such as turning a patient every 2 hours may be suspended. Eisenberger and Zeleznik (2003) reported that when patients experienced a single position of comfort—that is, when patients are more comfortable in a particular position due to advanced illness—overall comfort becomes of greater importance. In fact, some staff felt that prevention and treatment could potentially compromise the overall hospice philosophy of providing comfort care.

Often, clinicians have to strike a balance between the patient's quality of life and administering opioids. Although they relieve pain, which often increases functional ability, they can decrease the patient's mental status thereby leading to a decrease in activity level, which contributes to pressure ulcer formation. Additionally, when pressure ulcers are considered to be inevitable or have a small chance of healing, the goals of care can shift from prevention and treatment toward palliation and managing pressure ulcer pain and odor (Eisenberger & Zeleznik, 2003).

## WOUND AND SKIN CARE IN THE TERMINALLY ILL CANCER PATIENT

Terminally ill cancer patients are at risk for a number of dermatologic and mucous membrane alterations. The specific skin problems include ulcerating or fungating cutaneous metastasis, pressure ulcers, stomas and fistulas, peripheral edema, lymphedema,

and pruritis. Among these problems, peripheral edema and lymphedema account for the largest proportion of skin problems in this population (Waller & Caroline, 2000). Oral complications include xerotomia, oral mucositis, taste abnormalities, and halitosis. Sweeney and Bragg (1995) estimated that 70% of hospice patients, which include patients dying from diseases other than cancer, suffer from xerostomia. For both skin and oral mucosal problems, pain is the major symptom afflicting terminally ill cancer patients. If not adequately managed, patients can develop severe emotional distress coupled with feelings of isolation and helplessness. In addition, patients are at risk for systemic infections, malnutrition, dehydration, and bleeding. Adequate support and teaching of family members to provide much of this care is critical to ensuring high-quality care at the end of life.

The management of pressure ulcers in the terminally ill cancer patient is no different from for other terminally ill patients and has been discussed elsewhere in this article. A two-pronged approach, including pharmacotherapy and physical therapy, are keys to managing peripheral edema and lymphedema (Rockson et al., 1998). Pharmacologic approaches include diuretics, such as furosemide and spironalactone, and corticosteroids. A comprehensive nursing therapy program includes meticulous skin care, protecting the limb from trauma, use of compression bandages, lymphatic massage, and range-of-motion exercises. The nurse can teach these activities to family members.

Management of oral mucosa complications poses a number of challenges to family members and health care providers. With the onset of pain and xerostomia, patients often become anorexic and ultimately cachectic. Both topical and systemic analgesic treatment approaches are needed for adequate pain relief. Topical approaches include single agents, such as lidocaine, benzydamine, and sucralfate, and combinations of agents, such as milk of magnesia and diphenhydramine (Epstein & Schubert, 2004). Traditional general measures for the prevention and treatment of oral mucositis that have been employed for a number of decades remain the hallmark of care. These include serving bland, moist food at room temperature; performing regular mouth care; and using a soft toothbrush and mild solutions every 4 hours around the clock.

Managing skin alterations, both externally and orally, are important to relieving the pain and suffering that terminally ill cancer patients often experience. Evidenced-based guidelines are very limited for these two problems, and more research is needed to discover the underlying mechanisms and novel therapies to alleviate the associated symptoms.

## NEXT STEPS

There is little research on the quality of life and quality of care for dying patients with wounds. The National Institute of Nursing Research issued a program announcement, *Long-Term Care Recipients: Quality of Life and Quality of Care Research* (2002), which could be used to identify and test strategies to maintain and improve skin integrity of hospice patients in long-term care facilities. A goal of this program announcement is to stimulate clinical research to advance knowledge about long-term care populations such as those at the end of life and to encourage the testing of interventions to improve the quality of life of those residing in long-term care institutions and other extended care facilities. This initiative can be found at http://grants.nih.gov/grants/guide/pa-files/PA-02-162.html.

Currently, evidence-based guidelines for managing skin alterations and oral mucosal complications are very limited in scope. In recognition of the paucity of research, the National Cancer Institute (NCI) is participating in both National Institutes of Health initiatives as well as supporting a clinical trials program in cancer control and symptom management. As a cosponsor of the program announcement, *Pathogenesis and Treatment of Lymphedema and Lymphatic Diseases* (National Institutes of Health, 2004), the NCI is interested in seeing projects that will identify the developmental, molecular, and cellular defects that contribute to lymphedema as well as the development of effective therapeutic interventions to treat both primary and secondary lymphedemas. Through the Community Clinical Oncology Program (CCOP), a cooperative agreement that has been in existence for more than 20 years, the NCI supports several clinical trials aimed at testing new interventions for oral mucositis (CCOP, 2004). These include:

- a randomized, double-blind, placebo-controlled clinical trial to assess the efficacy of Traumeel S for the prevention and treatment of mucositis in children undergoing hematopoietic stem cell transplantation;
- a phase III randomized study of zinc sulfate for the prevention of altered taste in patients with head and neck cancer undergoing radiotherapy; and

- a double-blind trial to study the efficacy and safety of L-glutamine upon radiation therapy-induced oral mucositis in head and neck cancer patients.

Although these trials are primarily focused on patients undergoing tumor-directed therapies who may or may not be terminally ill, findings from these trials could very well be applicable to the terminally ill cancer population and may affect the scope of practice for home health care nurses.

Wound care is an essential component of palliative care for dying patients with existing or developing wounds. Home health care nurses can provide invaluable insight for those providing wound care for dying patients. More research is necessary in the area of wound care at the end of life to improve the quality of life for dying patients and their families.

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