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The purpose of this article is to describe current evidence-based strategies to manage severe pain in patients living with terminal illnesses. A comprehensive pain assessment is a critical step in the initial development of a pain management plan and for ongoing evaluation of patients' pain. Although we have many effective clinical tools available for pain assessment, they are not always used consistently, which can negatively affect the pain management plan. Home care and hospice nurses need to be consistent in using the tools and documenting the patient's pain level and response to the pain management plan. Patients and caregivers have concerns and fears surrounding medication use, particularly with narcotic analgesics. It is vital that nurses provide thorough patient-centered teaching about medications to help address these concerns. Research has found that nurses who also provided validation to patients and families regarding their concerns, followed by education, were the most effective.

Management of SEVERE PAIN in Terminally Ill Patients at Home

An Evidence-Based Strategy

RICHARD MARSHALL/KRT/Newscom

Susan E. Lowey, PhD, RN, CHPN, CNE, FPCN


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Experiencing severe pain is one of the greatest fears among patients who have been diagnosed with a terminal or life-limiting illness. The International Association for the Study of Pain (2014) defines pain as "an unpleasant sensory or emotional experience associated with tissue damage." Pain can accompany any terminal illness; however, it is most prevalent in patients with cancer and end stages of chronic and progressive diseases. In a systematic review, pain was identified as the second most prevalent distressing symptom during the last 2 weeks of life behind terminal dyspnea (Kehl & Kowalkowski, 2013). A longitudinal cohort study, spanning from 1998 to 2010, found the presence of pain at the end of life to have increased among decedents from 54.3% to 60.8% (Singer et al., 2015). In another study that examined the most important aspects for a "good death" among terminally ill patients, being pain-free was identified by 81% of respondents (Meier et al., 2016). Unmanaged pain can significantly and negatively impact quality of life and cause substantial distress in not only the patient, but also the family caregivers.

In 2016, approximately 4.5 million patients received care from one of the 12,200 home healthcare agencies in the United States (Centers for Disease Control and Prevention [CDC], 2016a) with 1.4 million terminally ill patients who received home hospice care (CDC, 2016b). Home has been identified by patients with terminal illnesses as their preferred care setting and preferred place to die (Higginson et al., 2010; Holdsworth & Fisher, 2010). The preference to die at home among patients with serious illnesses was found in 75% of the 130 studies analyzed in a large systematic review (Gomes et al., 2013). In the United States, a majority of days of care (55.6%) received by patients on hospice occurred in the home setting (National Hospice & Palliative Care Organization, 2018). Nurses provide much of the medical care for patients with terminal illnesses and their primary focus is on symptom management and improving overall quality of life.

Patients with terminal illnesses can experience physical, emotional, and/or spiritual pain; however, this article focuses on evidence-based strategies for the management of severe physiological pain in patients nearing the end of life. Although there are many nonpharmacological and complementary therapies widely used for pain management, this article will focus on pharmacological interventions for pain. Additionally, the most common issues and challenges of pain management in home healthcare for this population will be discussed.

Patients suffering from severe pain resulting from a terminal illness should ideally have two types of pain medications: a sustained-release and an immediate-release medication.

Assessing Pain in Patients at the End of Life

The first step in managing severe pain in patients with terminal illnesses is through a comprehensive pain assessment. Pain must be continually reassessed as the patient's condition can progress rapidly. Pain that has not been treated early often takes longer to subside in patients who suffer from terminal illnesses; therefore, it is vital to treat pain as soon as possible for best outcomes (Pasero & McCaffery, 2010). Once the patient has been placed on an individualized pain regimen, continue to assess pain, monitor the effects and side effects of the interventions, document these findings, and report any changes in status to the attending physician.

Current and Usual Pain

Assessing pain in patients nearing the end of life involves a comprehensive approach. This includes establishing a good understanding of the patient's current and usual pain experience. It is important to understand the patient's typical presentation of pain and pain-related symptoms. Some of the more commonly and easily used tools include the *Numeric Rating Scale* and *Faces Scale*, which can provide information about the intensity of the pain, and the *Pain Map*, which can provide details about the location and radiation (if any) of the pain (Ruder, 2010). This information will help the home healthcare/hospice team evaluate further disease progression and develop an individualized pain management plan. Home care nurses have the advantage of getting to know their patients well because they are able to observe them in their natural home environment. This is an important facet of the assessment, as the nurse can obtain a firsthand look at how the patient is functioning with pain in their daily life.

Terminal illnesses may progress to a point when the patient is no longer able to communicate or describe the pain. This can result from unresponsiveness due to organ system failure, cognitive impairments due to decreased cerebral perfusion or underlying dementia, delirium caused by terminal agitation or restlessness, and/or physical impairments as seen with progressive musculoskeletal disease (Morita et al., 2003). The communication capacity of patients is greatly decreased during the last week of life with only 43% (5 days before death), 28% (3 days before death), and 13% (1 day before death) of patients able to communicate (Morita et al.). Among patients who did not take a narcotic medication, the ability to communicate was only slightly higher (Morita et al.).

Pain Assessment in Unresponsive Patients

Assess and document the location, intensity, quality, and duration of pain at every visit and evaluate the effectiveness of the pain management regimen. There are many clinical tools available for assessing pain intensity. Some of these include the *Behavioral Pain Scale, Critical Care Pain Observation Tool, Multidimensional Observation Pain Assessment Tool*, and *Checklist of Non-Verbal Pain Indicators* (McGuire et al., 2016). Most of these tools rely on evaluating common pain-related behaviors such as vocalizations, restlessness, and facial expressions and can be utilized in any care setting. You can also ask the family caregiver to describe the patient's usual pain behaviors and whether they believe the patient has pain. This can be particularly useful when the patient has limited responsiveness or ability to self-report their pain upon admission to home care. Although the family caregiver's report can be helpful, research suggests this is not the most ideal way to evaluate pain in an unresponsive patient as family assessment often underestimates pain, resulting in undertreatment (Masman et al., 2018).

Home healthcare agencies have an obligation to provide comprehensive pain management for this special population so patients can fulfill their goals of care.

When assessing an unresponsive patient, observe common nonverbal signs that could be signs of discomfort. These include facial grimacing, vocalizations that may indicate discomfort such as moaning or crying, excessive perspiration, shaking or trembling, and guarding of specific areas of the body (End of Life Nursing Education Consortium [ELNEC], 2010). Observe these signs during patient care and/or turning and positioning the patient, as some pain may become aggravated or worsen with movement. When a patient with an end-stage terminal illness becomes unresponsive, it indicates that the illness has progressed and the patient is nearing the final stages toward end of life. This can take a great toll on family caregivers and it is imperative to ensure proper pain assessment and management throughout the remainder of the actively dying, transitioning and imminent phases of the end-of-life processes.

Pharmacological Interventions

The World Health Organization (n.d.) developed a three-step ladder approach for pain management. Although this approach was initially developed to aid clinicians in selection of analgesics for patients with cancer, it has been widely used in end-of-life care to manage pain in patients with other types of terminal illnesses. An important feature of this approach is around-the-clock dosing (Pasero & McCaffery, 2010). Patients suffering from severe pain resulting from a terminal illness should ideally have two types of pain medications: a sustained-release and an immediate-release medication. It is vital to keep a consistent level of pain medication in the patient's body and this is best achieved with use of a sustained-release medication that is given around the clock. Patients should also be prescribed an immediate-release medication that can be used as needed to manage breakthrough or periodic pain. This method has been found to be the most effective in managing severe pain in patients with advanced illnesses (Chou et al., 2009). Analgesics can be classified as nonopioids, opioids, and adjuvant medications (ELNEC, 2010).

Opioid Medications

Opioid medications are the most common class of medications used to treat moderate-to-severe pain in patients with terminal illnesses (Chou et al., 2009). Opioids work by binding to specific receptors in the brain that contributes to the classification system used to identify various types of opioids. This includes agonists, agonist–antagonists, and pure antagonists (ELNEC, 2010). Morphine is the most widely used opioid medication used to treat severe pain among hospice patients. It is cost-effective and available in many routes of administration. Hydromorphone, hydrocodone, oxycodone, and fentanyl are all commonly used to manage severe pain. Methadone use has emerged as a viable pharmacological medication used to treat severe pain at the end of life due to its long half-life and cost-effectiveness (ELNEC). Medications such as codeine, meperidine, propoxyphene, and buprenorphine are opioids that are not recommended for long-term usage in end-of-life care. Nausea, sedation, urinary retention, and pruritus are common side effects of opioids that are often short lived and resolve on their own with tolerance.

Adjuvant Medications

Adjuvants are not considered analgesics but help to provide pain relief when used with opioid and nonopioid medications for further enhancement of comfort. Nonsteroidal anti-inflammatory drugs are widely utilized adjuvant medication because they affect the inflammatory process. The most common adverse effects from this class of medications are prolonged bleeding times and gastrointestinal problems such as ulcerations in the lining of the stomach (ELNEC, 2010). Corticosteroids are the most commonly used adjuvant medication in patients with severe pain nearing the end of life. They have been shown to have benefits when used with opioids, particularly in patients with cancer. Used to reduce tumor size, they have the added benefit of improvement in mood and appetite (ELNEC). Tricyclic antidepressants such as amitriptyline and nortriptyline have been found to provide both analgesia and increase mood (ELNEC). Gabapentin is a commonly used adjuvant medication used to manage neuropathic pain.

Medication Administration in Patients Nearing the End of Life

A recent study identified oral, subcutaneous, and transdermal as the three most common routes of administration at the end of life (Masman et al., 2015). Although oral medication administration remains the preferential route in patients with terminal illnesses, when patients lose the ability to swallow, an alternative route of administration is needed. Subcutaneous medication delivery is highly effective and has been found to be associated with lower rates of infection compared with the intravenous route (Bartz et al., 2014). Transdermal medications such as fentanyl can also be utilized, however be aware there is a delay in peak onset following application of the initial transdermal patch with an average of 17 hours before full effectiveness ensues (ELNEC, 2010). Additional considerations with the use of a transdermal medication are the effects of body fat, body temperature, and circulation on drug distribution. Sublingual medications are also quite popular, inexpensive, and easy to administer by caregivers. Often when patients are admitted to hospice care, a sublingual morphine or other opioid will be ordered or provided in a hospice kit. Rectal route of administration is also commonly used to deliver pain control at the end of life. This method may be ideal in patients with gastrointestinal conditions who suffer from nausea and vomiting (Kestenbaum et al., 2014). Lastly, transdermal gels and compounds have also emerged as a viable route of administration in home hospice care. The biggest issue with this route is lack of availability depending on the geographic location as not all home healthcare and hospice agencies have access to pharmacies that can provide these compounds.

Common Issues and Challenges With Pain Management in Home Healthcare

There are many factors that impact the successful management of severe pain in patients with terminal illnesses. Patients and family members may be hesitant to use narcotic medications amid the recent opioid epidemic. Tolerance is the diminished effect of a medication requiring increased doses to maintain the same effect. Physical dependence commonly occurs, particularly with opioid medications, after several weeks of use. Patients and family caregivers should be cautioned that abrupt cessation of the medication will result in withdrawal symptoms. Patients with terminal illnesses are often on opioid medications for prolonged periods of time and, as the disease progresses, may require higher doses. Research has shown that although tolerance and dependence do commonly occur in these patients, addiction occurs infrequently in patients who do not have a previous history of substance abuse (Ferrell et al., 2015). Family members may incorrectly assume that too much morphine use will cause their loved one's death. Advise the caregivers that the progression of the terminal illness will be what causes death, not the proper administration of morphine (Ferrell et al.). Table 1 outlines some common concerns and misconceptions about pain management along with factual responses that can be used to alleviate concerns.

Healthcare providers may also be cautious in prescribing opioid medications for similar reasons, including dependence, respiratory depression, and fear of hastening death. Respiratory depression can best be prevented by starting opioid naïve patients on small doses and titrating as needed (Ferrell et al., 2015). The fear of hastening death has been the discussion of many ethical papers on medication administration at the end of life. The principle of double effect is when an action (i.e., administering pain medication) could lead to both a desirable effect (pain reduction) and an undesirable effect (hastening death) (Ferrell et al.). Remember the reason why the medication is being given to the patient and follow the ethical principles, remembering the intent of administering the medication is to act toward providing the desirable effect, not the undesirable effect of causing harm or death.

TABLE 1. Addressing Common Concerns and Myths About Pain Medication in Home Healthcare

Concern or Myth	Nurses in the Home Response(s)
Concern 1: Fear of becoming addicted to morphine	• Please tell me more about what concerns you have about becoming addicted to morphine? • Addiction to morphine is rare in people with serious illnesses who use it to manage their symptoms. People will build up a tolerance to a medication that is used regularly, but addiction and tolerance are not the same thing.
Concern 2: Fear of causing death or overdosing from morphine	• There is no evidence that using appropriate doses of morphine causes death in patients who need it for symptom management. • There is evidence that suggests using appropriate doses of morphine can lengthen patient survival because it reduces physical and psychological distress associated with pain.
Myth 1: The fact that morphine is being prescribed means that death is imminent	• The choice of pain medication is related to the severity of pain rather than life expectancy. When a patient of any age has severe pain, opioid medications such as morphine will likely be prescribed in order to control pain.
Myth 2: Morphine makes patients comatose	• Morphine can cause some sedation initially, but this effect decreases within a few days. Due to its effects to decrease pain, it often enables patients to catch up on sleep that has been lost due to pain. Thus, patients will likely sleep more in the first few days of morphine initiation.

Research on Pain Management in Home Care

Patient and Family Barriers to Pain Management

Several issues related to the ability of family caregivers to manage and treat the patient's pain have been identified, including physical and mental exhaustion and feelings of burden (Chi et al., 2018). Studies have identified the perceptions and fears surrounding the effects of opioid medications, including the fear of overdose (Chi et al.; Mayahara et al., 2015). Male caregivers have been found to be more likely to have concerns about causing the patient's death than their female counterparts (Mayahara et al.).

Family members' lack of knowledge about pain medication administration was a theme identified in recent research. Family members felt inadequately prepared to administer medications despite receiving training. They reported not feeling confident in knowing important details about the medications and many felt embarrassed to keep calling the nurse for help (Chi et al., 2018). One study found higher rates of pain and depression among patients whose caregiver had higher scores related to fear of causing death by giving too much pain medication (Mayahara et al., 2015). Family caregivers also felt that they lacked the skills to adequately tell if their loved one was in pain, especially in patients who were unresponsive (Chi et al.). Patients also were more hesitant to use and adhere to their analgesic medication regimen if their family expressed hesitancy toward it (Lee et al., 2015).

Caregiver Distress Associated With Pain Management

In a study by Mehta et al. (2014), family members identified four themes that contributed to distress related to pain management at home. The first was an overwhelming feeling of distress related to the immense responsibility of their loved one's pain control, equating it to feeling trapped in a prison providing around-the-clock medications. Family members felt unprepared and lacked knowledge about pain management. This was identified as having an impact on their ability to feel confident in the role and ultimately contributed to feelings of frustration and inadequacy. The feeling of being trapped in the house and not fully understanding the medications made them rely heavily on the home care nurse. Although many nurses were helpful, participants felt others seemed to be bothered by the phone calls and questions seeking help. Caregivers felt the healthcare team was hesitant to provide information about what could happen, and this impacted them because they were not fully prepared to handle challenging issues that may arise. Lastly, caregivers can have long-lasting scars associated with witnessing their family member in pain. Despite administering the medications as directed, some patients were still be in a great deal of pain, and caregivers felt helpless. This contributed to several caregivers having mixed emotions and even guilt over quietly wishing that their loved ones would pass away just so that they could be out of pain (Mehta et al., 2014).

Factors Associated With Nursing Care and the Healthcare System in Pain Management

Han et al. (2018) examined audio recordings of hospice nurses' home visits. They found four responses by nurses: (1) provided validation, (2) provided information, (3) did not address the concern, and (4) provided a combination of the previous three responses. Providing validation was the most frequent action when addressing patient/family concerns about pain management. Nurses would validate the identified concerns by agreeing with the concern that was raised in an effort to show the patient/family that their concern has been heard and is valid. Providing information often occurred alongside validation, with specific information given about medication schedules, effects, dosing, and refills. The study found the home hospice nurses most often gave short direct pieces of information about components of pain management and tended not to focus on negative aspects, such as side effects. The least effective response by nurses was to not address the concern at all. Lack of effective communication and poorly developed nurse–patient relationships were identified as central to this response.

In a large secondary data analysis using the National Home Health and Hospice Care Survey, the use of reliable and valid pain rating scales to assess patients' pain was found to be low (Cea et al., 2016). Patients' ethnicity was found to play a role in both assessments and interventions. Compared with White patients, African Americans had fewer pain assessments and Hispanic patients were less likely to be given opioid medications or have a pain-free status at discharge (Cea et al.). This demonstrates a need to address continued inequities and disparities that plague our healthcare system.

Innovative Interventions to Improve Pain Management in Home Healthcare

The "Power Over Pain" project (Vallerand et al., 2010) involved separate educational interventions for nurses and patients/caregivers. The interventions for both groups included information about various aspects of pain management, including information about analgesics, addressing misconceptions and concerns, and management of side effects. Results were positive for both groups. Nurses had higher levels of knowledge and reductions in reported barriers. Among the patient/caregiver group, knowledge levels also increased while pain and symptom distress decreased (Vallerand et al.).

Effective Management of Pain: Overcoming Worries to Enable Relief (EMPOWER) is an intervention used to address barriers to pain management (Cagle et al., 2015). The intervention consists of four components: training of staff, completing the screening tool for EMPOWER at admission, educating hospice staff using the EMPOWER brochure, and following-up. The study showed promising results with improvements in three out of the five areas under study (knowledge in the caregiver, barriers, and patient pain). Patients' pain severity was significantly lowered at the 2-week point and those who received the intervention had fewer barrier-related concerns than those in the control group (Cagle et al.).

Conclusion

Many patients diagnosed with a life-limiting condition have identified a preference to remain at home for the duration of their terminal illness (Gomes et al., 2013). Home healthcare agencies have an obligation to provide comprehensive pain management for this special population so patients can fulfill their goals of care. This care setting affords home care nurses the opportunity to establish good relationships with patients and assess them in their natural environment. A comprehensive pain assessment is a critical step in the initial development and ongoing evaluation of patients' pain. Although we have many effective clinical tools available to assess pain, they are not often used in a consistent and systematic way, which can negatively affect the overall pain management plan. Home care teams should ideally identify a few select pain scales/methods they will adopt and use for pain assessment. Nurses in the home need to be consistent in using the tools and documenting the patients' pain levels and response to the pain management plan in the medical record.

There are many effective pharmacological therapies to manage severe pain in patients with life-limiting illnesses. Opioid medications and around-the-clock dosing schedules have shown to provide the most effective relief in patients with severe illnesses (Pasero & McCaffery, 2010). Patients and caregivers have identified many concerns and fears surrounding medication use, particularly with narcotic analgesics. It is vital that nurses provide thorough patient-centered teaching about medications to help address these concerns. Research has found that nurses who also provided validation to patients and families regarding their concerns, followed by education, were the most effective. Nurses should never minimize patient and family concerns about use of medications for pain or change the subject without addressing the topic.

In home/hospice care, family members provide around-the-clock care for their loved ones with severe pain and have identified many negative aspects of taking on the caregiver role. Bearing witness to their loved one in pain despite having a pain management plan had the most profound effect on their mental health and well-being. It is important to provide teaching and support to patients and families in order to fully assess and respond to the caregiver's ability to effectively function in that role. If the patient continues to report pain when the pain management plan is being adhered to, the plan needs to be reevaluated. The nurse should report assessment findings to the medical provider so that changes can be made.

Innovative interventions to reduce barriers and to improve delivery of home-based pain management have shown promise. Replication of these interventions in larger sample and in multiple settings can help provide more support and generalizability for their adoption and integration. The healthcare system is changing from predominately acute to community-based in order to accommodate the care of a diverse population who are living longer with chronic and terminal illnesses (Lowey, 2017). Further research that develops and tests the most effective strategies to ensure pain management for patients with terminal illnesses in the home healthcare setting is warranted. Nurses in the home are an instrumental part of this process and have a leading role in implementing and evaluating pain management delivery for their patients. They are on the front lines of patient care and should be part of the continuous quality improvement within home healthcare. ☗

Susan E. Lowey, PhD, RN, CHPN, CNE, FPCN, *is an Associate Professor & Advisement Coordinator, Department of Nursing, State University of New York College at Brockport, Brockport, New York.*

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Address for correspondence: Susan E. Lowey, PhD, RN, CHPN, CNE, FPCN, Department of Nursing, Lathrop Hall 113, 350 New Campus Drive, Brockport, NY 14420 (slowey@brockport.edu).

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