2.1: Management of Pain and Physical Symptoms

The greatest evil is physical pain. -Saint Augustine

Learning Objectives

- Identify various types of pain and the pharmacological and non-pharmacological interventions used for management.
- Describe components of a comprehensive pain assessment.
- Explain barriers associated with effective pain management.
- Identify the most common non-pain symptoms associated with patients nearing the end of life.
- Describe the interventions used to relieve refractory dyspnea and terminal restlessness in patients nearing the end of life.

Perhaps one of the greatest concerns of patients who are nearing the end of life is pain and discomfort. Most terminal illnesses are associated with one or more physical manifestations of discomfort. For instance, patients with cancer usually have some type of pain, and patients with chronic pulmonary disease suffer from breathlessness. The International Association for the Study of Pain defines pain as “an unpleasant sensory or emotional experience associated with tissue damage” (IASP, 2014). Clinically, pain has been defined as what the patient subjectively says that it is. In a report by the National Center for Health Statistics, approximately 90% of patients being admitted to hospice care had their pain assessed at the initial visit; however, one-third of those patients continued to report pain near the time of their death (Caffrey, Sengupta, Moss, Harris-Kojetin, & Valverde, 2011). Pain is a symptom that requires continual assessment and evaluation of the current interventions used for its management. As those who work with patients in pain know, the longer pain is left unmanaged, the more difficult it may be to treat. In addition to pain, patients nearing the end of life often have other types of negative symptoms including: dyspnea, cough, nausea and vomiting, constipation, anorexia and cachexia, dysphagia, fatigue, seizures, lymphedema, depression, anxiety and terminal restlessness or delirium. The aim of this chapter is to examine the current assessment and treatment options for pain...
and other symptoms that can occur in patients as they near the end of life. Additionally, we will discuss some common barriers associated with the pharmacological management of pain.

Pain at the End of Life

Types of Pain

Pain is usually classified in terms of its physiological mechanism (somatic, visceral, or neuropathic) and its temporal pattern (acute or chronic) (Coyle & Layman-Goldstein, 2001). It is important for the clinician to understand what type of pain is involved in order to be able to tailor their assessment and interventions for that patient. Somatic pain, also known as nociceptive pain, is often well-localized to one area, usually within deep musculoskeletal tissues. Bone pain is an example of somatic pain. Visceral pain is described as deep squeezing or pressure and is not as well localized to one area. It is often associated with the compression or stretching of thoracic or abdominal viscera. Pancreatic or liver cancer often causes this type of pain (Coyle & Layman-Goldstein, 2001). Lastly, neuropathic pain is associated with illness or injury to the peripheral or central nervous system, such as a tumor pressing on a specific nerve in a patient with cancer. Neuropathic pain is described as a sharp, shooting, or burning pain, often like an electrical shock that penetrates one’s body. The management of pain is often dependent on the origin of the pain and which type of pain is involved.

Pain can also be classified in terms of temporal pattern. Patients can have both acute and chronic pain with more than one type or location of affliction. Acute pain is best defined by its onset. For the most part, the source of the pain can be identified and is often accompanied by other physiological signs and symptoms, such as trauma to the afflicted area. Acute pain often comes on suddenly from a well-identified cause. It is typically also short-lived, meaning that once the underlying problem is resolved and/or analgesia is initiated, the pain usually resolves. Sub-acute pain is a type of acute pain characterized by a slower onset, often over a few days, in which pain slowly escalates from mild to more severe. Another type of acute pain is called intermittent or episodic pain. Intermittent or episodic pain occurs only once in a while, often during a regular time period, such as cramping pain associated with the monthly menstrual cycle; or it may also occur irregularly, such as with a migraine headache.

Chronic pain often worsens over time, lasts for an extended period of time and is accompanied by having a negative effect on the patients overall functioning or quality of life (Fink & Gates, 2010). Chronic pain can further be categorized as chronic malignant or chronic non-malignant pain. Chronic malignant pain is related to pain derived from a primary cancer or metastasis from cancer. It can also be a result from cancer related treatment, such as radiation. Chronic non-malignant pain refers to all other non-cancer chronic pain, such as chronic back pain, fibromyalgia or arthritis.

Assessment of Pain

A thorough and comprehensive assessment of pain is by far one of the most important skills that nurses who care for patients nearing the end of life should possess. As mentioned before, pain is one of the most feared symptoms but also one that can be managed well following a thorough assessment and pain management plan. While there are a plethora of formal pain assessment tools that are used in practice, we will describe the necessary components of any good pain assessment plan.
Terminology

First, as clinicians it is important to remember that patients may not always use the term “pain” to identify their pain or discomfort. Sometimes this is due to cultural reasons and other times, it can be the patient’s way of denying the real pain they are feeling. It may be helpful for the clinician to re-word the question using another term for pain, such as discomfort or aching. For example, a nurse asks their patient a general question such as, “Mr. Smith, are you having any pain today?” He replies “no;” but when based on the objective signs the nurse is observing, they assess that he is having some type of discomfort. The nurse could then re-phrase the question as, “Mr. Smith, I understand you are not having any pain, but I notice you are holding onto your left arm and wincing when you move. Are you having any discomfort or soreness in that area?” A more direct question that incorporates your observations, as well as using a different term for pain, may be more effective in getting you an accurate answer.

Current and usual pain experience

Next, the nurse needs to gather all the necessary information about the pain. They will need to understand both the patient’s current pain level and their usual pain experience. This may differ and is especially important for those living with some type of chronic pain. What is their pain like today, and how is that pain in relation to what they usually experience? If the nurse is regularly assigned to this particular patient, they will become familiar with their usual pain experience; however, if the nurse is new to the patient, they will have to elicit that information. In end-of-life care, knowing the patient’s usual pain levels will help guide the interventions and next steps related to the patient’s individual pain management plan.

Location

Next, the nurse needs to assess the site where the patient is experiencing pain. This could be multiple locations, depending on the patient. The nurse will need to evaluate each site as a separate location, if applicable, for the remaining assessment questions.

Intensity

The intensity or severity of pain is often obtained in a numeric format such as on a scale from 0 to 10. Zero is considered to be having no pain and 10 is considered to be the worst pain possible. Be sure to tell the patient the scaling information each time you are rating the intensity of their pain. This is because they might not have ever been informed about this scale before, they may have forgotten what the values represent, or they may have recent cognitive changes that have affected their ability to remember pain scale values. If the patient is deemed to have severe cognitive impairment, then another alternative form of pain intensity rating will have to be used. Always re-state the numerical rating back to the patient once they give it to you for clarification. A follow-up to this rating would be to evaluate whether this value is higher or lower than their usual pain intensity at that pain site.

Quality

The quality of pain refers to a description about what the patient’s pain feels like. What kind of pain is it? Is it sharp or dull? Is it aching or squeezing? Does the pain stay in that one location or does it seem to spread out or radiate to nearby areas? This rating can be very helpful in understanding the type of pain involved (somatic, visceral, or neuropathic) and initiating the most effective pharmacological intervention for that specific type of pain.
**Duration**

It is important to understand how long the patient has experienced this pain and whether it is a new pain. Is this pain always present or is it intermittent? The nurse needs to evaluate how long the patient has been dealing with this pain in terms of hours, days, weeks, months or years.

**Aggravating factors**

Part of a thorough pain assessment always involves understanding any factors that bring about the pain or make the pain worse? Is there something that the patient does that precipitates the pain?

**Alleviating factors**

In addition to understanding what brings on the pain, it is also as important to understand what helps to alleviate the pain. This could include medications, positioning, or even a lack of movement. Of those alleviating factors, if any, how long do they last before the pain returns?

**Current pain regimen**

In the clinical setting, asking about the patient’s current pain regimen is often forgotten. Nurses and clinicians are very good at asking about the intensity and duration of pain but often never evaluate exactly what the patient is using to manage the pain. Although the patient’s medical record and medication record may be available to the nurse, it is very important to actually ask the patient (or family) what the patient is actually taking for pain and how often. They may have several medications listed for pain in their medical record that are ordered on an as needed basis. In the inpatient setting, the nurse will have the good fortune of having documentation as to when the last dose was administered and how often they have been getting each medication. In the home or clinic setting, this may not be the case. Just because a medication is ordered every 2 hours as needed, it does not mean the patient is actually taking it every 2 hours. Also, the opposite holds true in that a medication may be ordered for every 8 hours but the patient has been taking it every 6 hours. This is invaluable information that is often overlooked and could be the crucial key in providing adequate pain management for the patient. It could show the nurse if the patient is under or over medicated and if a change in dosing or schedule may be warranted. Refer to Table 6.1 for examples of questions the nurse could ask for each component of the pain assessment.

**Table 6.1 Components of a Comprehensive Pain Assessment**

<table>
<thead>
<tr>
<th>Components of Pain Assessment</th>
<th>Sample Question</th>
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<tbody>
<tr>
<td>Current Presence of Pain</td>
<td>Do you have any pain or discomfort anywhere right now?</td>
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<tr>
<td>Usual Pain Experience</td>
<td>What is your usual level of pain like?</td>
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<td>Could you tell me what your usual pain is like on a typical day?</td>
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<td>Components of Pain Assessment</td>
<td>Sample Question</td>
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<td><strong>Location of Pain</strong></td>
<td>How do you normally deal with the pain you experience?</td>
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<td>Tell me all the places in your body that you have any pain, discomfort or soreness right now.</td>
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<td>Have you had pain in that location before or is this a new pain?</td>
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<td>If it is a new pain, how does it compare with your previous pain?</td>
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<tr>
<td><strong>Intensity/Severity of Pain</strong></td>
<td>On a scale of 0 to 10, with 0 being no pain at all and 10 being the worst possible pain, what number is your current pain level? (You will need to have patient rate their pain at each location, if multiple areas identified.)</td>
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<td></td>
<td>Is this number higher or lower than your usual pain experience at that location?</td>
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<td></td>
<td>Have you ever had this level of pain before or is this the worst it's ever been?</td>
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<td>What words would you use to describe the kind of pain you are feeling?</td>
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<tr>
<td><strong>Quality of Pain</strong></td>
<td>Is your pain sharp, dull, throbbing, aching, cramping, burning, shooting, squeezing?</td>
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<td>Does the pain stay in that one spot (site or sites patient identified) or does it seem to spread or radiate to other areas too?</td>
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<tr>
<td><strong>Duration of Pain</strong></td>
<td>When did this pain begin? (Ask for each location of pain.)</td>
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<td></td>
<td>If you have had this kind of pain before, how long does it usually last?</td>
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<td>Is your pain always there or does it ever completely go away?</td>
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<td>If it goes away, for how long?</td>
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<td></td>
<td>How long have you been living with this pain? (Days, weeks, months or years)</td>
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<td></td>
<td>Does this pain seem to come and go?</td>
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<tr>
<td><strong>Aggravating Factors</strong></td>
<td>Is there anything that you do that seems to start your pain?</td>
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<td></td>
<td>What kinds of things make your pain worse?</td>
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<tr>
<td><strong>Alleviating Factors</strong></td>
<td>Is there anything that you do that seems to make your pain go away?</td>
</tr>
<tr>
<td></td>
<td>What kinds of things make your pain get better?</td>
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<tr>
<td><strong>Current Pain</strong></td>
<td>What are you using to help your pain recently?</td>
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</tbody>
</table>
Components of Pain Assessment

**Regimen/Last Dose**
- Are you taking medications for pain? (Ask about prescription and over the counter medications.)
- Are you doing other things to help relieve your pain? (Heat, ice, positioning, etc.)

**Patients Concerns about Pain**
- Is there anything else you’d like to tell me about your pain that we haven’t talked about yet?

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Pharmacological Interventions for Pain

As you may be aware from any courses you have already taken that focused on pharmacology, there could be an entire book devoted to discussing the latest pharmacological interventions for pain management. While there are many books already written about this topic, we will focus specifically on a general overview of the most widely used medications for pain management. There are many algorithms that our physician colleagues use to calculate proper medication dosage, and since prescribing medications is not within the scope of practice for the registered nurse, we will focus on gaining an understanding about the most commonly used classes of medications for the various types and severity of pain and our specific role in the continual evaluation of the patient’s response to these pharmacological interventions.

In 1990, the World Health Organization (WHO) first developed a three-step ladder for cancer pain in adults. This approach has been widely cited and used to help clinicians determine analgesic selection for patients with cancer. It includes the administration of certain classes of analgesics in a specific order based on the patient’s pain level. The first step of the ladder includes non-opioid medications, plus an adjuvant medication if appropriate. Acetaminophen or NSAIDS are examples that would be used during this first step of the ladder. The next step on the ladder for increasing mild to moderate pain are mild opioid medications, plus a non-opioid and/or adjuvant medication if applicable. An example of this is use of codeine, plus a non-opioid and/or adjuvant medication if applicable. Lastly, the third and final step on the WHO ladder is the use of strong opioid medications, such as morphine, also with or without the non-opioid and/or adjuvant medication if applicable. Often, patients who are living with pain related to a terminal illness have more than one pain medication. Breakthrough pain is pain that occurs in between a patient’s usual dosing schedule. The use of a second pain medication on an as needed (PRN) basis for this type of pain can help provide additional relief of pain for patients who have breakthrough pain. Next, we will discuss some key points associated with the various classes of medications commonly used for pain management at the end of life.

**Non-steroidal anti-inflammatory drugs (NSAIDS)**

NSAIDS are widely used because they affect the inflammatory process. They are commonly used for mild type pain and used as an adjuvant medication, along with an opioid, to manage bone pain in cancer patients. The most common adverse effect from this class of medications are prolonging bleeding times and gastrointestinal problems such as ulcerations in the lining of the stomach. The elderly and those with previous renal problems are more prone to devastating effects from NSAIDS. NSAIDS do have a ceiling effect, which means that there is a maximum dosage that...
should not be exceeded, as no added analgesia will occur beyond those recommended levels.

**Opioids**

Opioid medications are typically used to manage pain in patients nearing the end of life. Opioids provide comfort and relief for not only pain, but other symptoms such as dyspnea or breathlessness. Opioids bind to receptors in the brain to help prevent the release of pain transmission to neuroreceptors (Coyle & Layman-Goldstein, 2001). Further classified, opioids can be divided into sub-categories based on the specific receptor they bind to. These include: pure agonists, agonist-antagonists, and pure antagonists (Paice, 2010). Morphine is among the most well known opioid medications and can be quite effective in managing moderate to severe pain. It is commonly used for symptom management for patients nearing the end of life to provide relief from pain and breathlessness. Morphine is cost-effective, as it has been on the market for a long time. On Table 6.2 you will find a list of some commonly used opioid medications.

<table>
<thead>
<tr>
<th>Commonly Used Opioid Medications</th>
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<tbody>
<tr>
<td>Codeine</td>
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<tr>
<td>Fentanyl</td>
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<tr>
<td>Hydrocodone</td>
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<tr>
<td>Hydromorphone</td>
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<tr>
<td>Levorphanol</td>
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<tr>
<td>Methadone</td>
</tr>
<tr>
<td>Morphine</td>
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<tr>
<td>Oxycodone</td>
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<td>Tramadol</td>
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**Side effects of opioids**

There are several side effects that can be anticipated with the use of an opioid medication. These include sedation, constipation, nausea and vomiting, pruritus, myoclonus, and respiratory depression. Nursing interventions include teaching the patient and family about the effects and side effects of these medications. Sedation commonly occurs with the initiation of an opioid medication but usually subsides after forty eight hours. If sedation persists, the opioid dose may have to be adjusted and/or a stimulant medication ordered to counter the effects. Constipation is by far the most common side effect related to opioid use in patients and can cause a great deal of distress if not proactively managed from the initiation of the opioid. Nurses should instruct patients to incorporate a bowel regimen into their plan of care using prophylactic laxatives and stool softeners. Patients should also be encouraged to increase their fluid intake. Nausea and vomiting is another common side effect that can be managed with incorporation of an anti-emetic medication. Pruritus, or itching, is most commonly found with morphine specifically (Paice, 2010), but can occur with any of the opioids. Antihistamines can help manage this side effect. Myoclonus, or uncontrolled muscle twitching or jerking,
occurs most often in patients using higher doses of opioid medications and opioid rotation may be recommended to counter this effect. In cases where opioid rotation is contraindicated, the use of Clonazepam may help to alleviate symptoms. Lastly, respiratory depression is a well known and feared side effect of opioid medications, particularly with morphine; however, it has been found to be less of an issue in patients who are opioid tolerant (Paice, 2010). Often respiratory depression in these patients results from the underlying advanced disease. Naloxone is the medication used to reverse the effects of opioids when respiratory depression is suspected.

**Additional information about opioids**

Opioid rotation occurs when the currently prescribed opioid is not effective or is causing too many adverse effects. Opioid rotation is when the patient is prescribed a different type of opioid medication. Often patients will have to switch opioids from time to time and the principle of equivalent dosing (or equianalgesia) is the process of calculating the correct dose as a patient transfers from one opioid medication to another. The numeric doses of opioid medications vary and 10 mg of morphine is not necessarily the same as 10 mg of fentanyl, so careful calculation of an equivalent dose in the new medication is done to ensure that the patient is neither under nor overmedicated with the new opioid. Lastly, an effective pain regimen usually includes more than one medication used for pain. This is particularly true in patients with cancer who suffer from both constant and breakthrough pain. Patients will usually receive a long-acting medication that they take twice daily, along with a short-acting opioid used for breakthrough pain and prescribed more frequently, such as every 2-4 hours. As a nurse caring for these patients, it is especially important to assess their response to their medication regimen. If the patient is taking their breakthrough medication at each available time interval and they are still reporting pain, then the patient’s long-acting medication may need to be adjusted.

**Adjuvant Medications**

Adjuvant medications are medications that are used alongside analgesics to provide additional comfort. Although most of these medications are not considered analgesics, they can help to reduce pain caused by other conditions (Paice, 2010).

**Corticosteroids**

Corticosteroids are commonly used to reduce tumor size and edema, particularly in patients with cancer. In addition to providing additional pain reduction, steroidal medications such as Dexamethasone have been found to improve both mood and appetite in patients. Nurses should instruct patients to try to avoid taking late doses of this medication, as it may cause insomnia and affect the patient’s normal sleep pattern (ELNEC, 2010).

**Antidepressants**

Tricyclic antidepressants such as Nortriptyline have also been effective in helping to reduce pain through the inhibition of norepinephrine and serotonin (ELNEC, 2010). They can be very useful, particularly for patients who suffer from neuropathic pain conditions. Nurses should educate patients to anticipate the side effects of sedation, constipation, and dry mouth with these medications.

**Anticonvulsants**

Newer anticonvulsants, such as gabapentin and pregabalin, have been successfully used to help reduce neuropathic
Non-Pharmacological Interventions for Pain

There are several non-pharmacological interventions that can be used to manage pain. Most often than not, patients will use a combination of both pharmacological and non-pharmacological interventions to maximize comfort. Some common non-pharmacological therapies include: cognitive behavioral techniques, physical measures, and complementary therapies (ELNEC, 2010). Cognitive behavioral interventions can include guided imagery, relaxation, hypnosis and distraction. Physical measures include the use of heat or cold, massage, acupuncture, and aromatherapy. Therapies that influence the energy fields of the body, such as Reiki or therapeutic touch, have also been used. Music and art therapy have also emerged as beneficial ways to help reduce the pain experience in some patients, and can be instituted and reimbursed for patients who are receiving the hospice benefit.

Barriers to Adequate Pain Management

There has been much written in the literature about the various barriers associated with adequate pain management. Barriers can be multi-faceted and include patient-related, provider-related and system-related factors. The concerns and fears surrounding addiction and adverse effects, particularly with opioid medications, are patient-related barriers which present some of the greatest challenges. As a hospice nurse, this topic has by far been the most questioned by patients and families alike. Patients fear becoming addicted to their pain medication, and families who administer opioid medications fear that it could potentially cause respiratory depression. We will discuss some of the ethical dilemmas surrounding hastening death and giving that “final dose” in Chapter 8 on ethics. The best advice for student and novice nurses on this topic is to provide the patient and family with the most recent evidence-based information. The nurse can educate them on the differences between dependence, tolerance, and addiction. Addiction (or psychological dependence) has been found to rarely occur in patients who are using opioids as pain management for cancer or other advanced illnesses. While it is true that physical tolerance can occur, this is a common effect of using any medication, not just opioids. It is most commonly experienced after abrupt withdrawal of the opioid, and can be accompanied by real physiological symptoms such as sweating, nausea, and dizziness. If no longer warranted, careful and slow withdrawal of the medication helps to counteract these symptoms.

Provider-related barriers can also negatively affect adequate pain management as well. Care providers may be afraid of contributing to side effects, tolerance, and even death in patients. Providers are especially cautious in prescribing opioids for the elderly, children, or in patients with a history of substance abuse. This has contributed to poor pain management within these populations. Improvements in pain education have been helpful in the recent decade, but more work is needed to help improve this barrier. Improvements in pain assessment skills, regulation of controlled substances, and pain management strategies are warranted (ELNEC, 2010).

Lastly, health care system barriers include a variety of issues from geography to reimbursement. Patients living in rural areas often do not have access to pain specialists or do not have local pharmacies which carry a wide range of pain medications. Often pain management is not a top priority within healthcare institutions, and reimbursement mechanisms for pain specialists and pain clinics, as well as palliative care services, are often lacking.
Symptoms at the End of Life

While pain has been the most widely recognized and researched symptom experienced by those nearing the end of life, it is not the only adverse symptom that patients can experience. A terminal illness can impact any part of the patient’s body and the disease can wreak havoc on any of the available body systems. While certain diseases seem to affect certain parts of the body, there are some general symptoms which are commonly experienced by most patients who are nearing the end of life. In this next section we will identify and describe several of the most commonly experienced symptoms patients can have as they near the end of life and the most widely used interventions used to manage them. Additionally, we will more closely examine two symptoms that can cause a great deal of distress: refractory dyspnea and terminal restlessness.

Dyspnea/Refractory Dyspnea

Dyspnea, also referred to as shortness of breath or breathlessness, can be a disabling symptom in patients nearing the end of life and can cause more distress and suffering than other types of pain. Patients with dyspnea have said that they would much prefer to have pain than the constant feeling that they cannot get enough air. When some illnesses become advanced or end-stage, dyspnea becomes refractory, meaning that the underlying cause cannot be reversed and the focus of care must shift to interventions aimed at palliating the symptom (Abernathy et al., 2003). Since the causes of dyspnea can be multidimensional, effective management of this symptom can pose challenges for clinicians. In addition to the physical sensation of not being able to get enough air, dyspnea can contribute to anxiety, depression, fear and panic. Dyspnea has been found in patients diagnosed with some cancers, including lung and esophageal, heart failure and COPD.

In order to best manage this symptom, nurses have to complete a thorough assessment of the respiratory system and patients’ self-reported dyspnea intensity score. Using a scale similar to the common pain intensity 0 through 10 scale, patients should be asked about their reported rating of dyspnea. Additionally, nurses should use the “assess, document, re-assess, and advocate” strategy described by Lowey and colleagues (2013). As with pain, it is important to conduct a thorough assessment, document your findings, re-assess whether your interventions are effective, and continue to advocate for the patient as needed in order to facilitate pharmacological interventions on the part of the physician.

Management for refractory dyspnea includes treating the underlying cause, if possible, and then opting for palliative measures. Opioid medications are considered to be the gold standard pharmacological treatment for the palliation of dyspnea in patients with advanced illnesses (Lanken et al, 2008). In a recent narrative review examining the effectiveness of opioids for palliation of dyspnea, significant reductions in dyspnea intensity scores were reported in 80% of the studies included in the analysis (Lowey, Xue, & Powers, 2013). Clinically significant reductions in patients’ reported dyspnea scores occurred even in studies that failed to achieve statistical significance. This is known as the minimal clinically important difference (MCID) which has been found to differ between patients with chronic versus acute breathlessness (Oxberry, Bland, Clark, Cleland & Johnson, 2003).

There has also been some research conducted that suggested the use of benzodiazepines to be effective in reducing dyspnea intensity (Navigante, Castro & Cerchietti, 2010). The addition of oxygen to manage refractory dyspnea is inconclusive. If the oxygen saturation levels are within normal range, then oxygen administration should have minimal effects on dyspnea intensity scores. However, some patients report the additional air helps them to catch their breath.
Use of a cool fan, pursed lip breathing, and sitting upright slightly hunched over have also been used as nursing interventions that can help reduce dyspnea intensity in patients, but no large scale research has been conducted to evaluate their effectiveness.

**Cough**

Cough can be a troubling symptom for patients diagnosed with illnesses such as COPD and lung cancer, heart failure, pulmonary fibrosis and cystic fibrosis. Additionally, in patients with cancer, a cough can result from cancer related treatments, such as radiation therapy (Dudgeon, 2010). Sometimes, hemoptysis (blood in the sputum) can occur from frequent and poorly managed coughing episodes. Antitussive and opioid medications, particularly codeine, have been found to be effective interventions for this symptom.

**Nausea & Vomiting**

Multiple receptors in the brain are responsible for the development of nausea in patients with advanced illnesses. Therefore, antiemetic medications target to block these receptors. This symptom occurs in over 50% of patients with advanced cancer, often from the cancer itself and sometimes secondary to cancer treatment (King & Tarcatu, 2010). The causes can be multi-factorial stemming from both the central nervous and/or gastrointestinal systems. The management plan for this symptom should include: assessment, identification of the causes, selecting an anti-emetic and the route of administration, changing protocol if not effective, considering the addition of steroids or antacids, decreasing or rotating opioid medication, and considering the role of anxiety in contributing to nausea (King & Tarcatu, 2010).

There are various classes of antiemetics, but the most common medications used are: Prochlorperazine, Metoclopramide, Haloperidol, Dronabinol, and Diphenhydramine. Depending on the patient’s vomiting status, medications may need to be ordered rectally or transdermally, if available. Nursing interventions for the patient with nausea and vomiting include education about various self-care activities and nutrition/hydration. Patients should be advised to eat small, bland meals that are either cold or at room temperature. Care should be given to avoid odors in the patient’s surroundings, including those usually thought to be pleasant. A cool breeze using a fan or open window may also help with nausea.

**Constipation**

As mentioned previously with pain management, constipation can be a common and distressing symptom associated with patients nearing the end of life. Although the use of opioid medications is the largest contributor to this problem, changes in a patient’s nutritional, hydration, or activity levels can also precipitate constipation. Patients may experience pain or cramping with this symptom and also intermittent periods of loose stools. Laxatives and stool softeners are typically part of the patient’s bowel regimen with this symptom. Additionally, sometimes enemas need to be incorporated as well. There are also some herbal teas and drinks that can help keep patients regular, but be cautious with advising these unless approved by the physician. Educate the patient on their individual bowel regimen both verbally and in writing.
**Anorexia & Cachexia**

A patient’s lack of desire to eat and reduced or non-existent appetite often accompany advanced illness. Anorexia is defined as a loss of appetite with reduced caloric intake. Cachexia is often the outcome of anorexia and is defined as wasting away from lack of adequate nutrition (ELNEC, 2010). Weight loss is present in both anorexia and cachexia and is rarely reversible if it is the result of advanced illness in patients nearing the end of life. Families who have loved ones suffering from anorexia or cachexia often inquire about the use of more aggressive nutritional interventions, such as artificial nutrition or hydration. Depending on the individual patient’s diagnosis and prognosis, these options can be explored. More often than not, artificial nutrition and hydration may be contraindicated as it could result in nausea, vomiting, increased edema or dyspnea.

Nursing interventions are to support patient and family and provide education on the benefits and burdens associated with each individual patient. Family members feel badly about seeing their loved ones fade away and not eat and nurses should help provide emotional support and help families understand the symbolism associated with mealtimes. Patients should be encouraged to eat their favorite foods and family members should be encouraged to serve the patient smaller sized portions, so they do not become overwhelmed by the volume of food on their plate. Appetite stimulants, such as Megestrol, may also be used to help boost patients’ appetite.

**Fatigue**

Fatigue is commonly associated with several advanced illnesses including cancer, heart disease, and advanced renal disease (ELNEC, 2010). It is defined as a subjective and multidimensional experience of exhaustion (Anderson, Dean & Piech, 2010). Fatigue can negatively affect quality of life, but can also be difficult to manage. Often there are several factors contributing to fatigue including both physiological and psychological. A thorough assessment will include questions about the onset, duration and impact of fatigue on the patient’s life, as well as evaluating vital signs, including oxygenation level, thyroid function and hemoglobin levels (ELNEC, 2010). Nursing interventions can include educating the patient about non-pharmacological measures such as energy conservation techniques, physical or occupational therapies, and assistance with the activities of daily living.

**Dysphagia**

Dysphagia is defined as “difficulty swallowing food or liquids” (Dahlin, Kurash-Cohen & Goldsmith, 2010) and is found to accompany several illnesses including cancers of the head, neck, esophagus and brain, amyotrophic lateral sclerosis, Parkinson’s disease, multiple sclerosis, and dementia. Dysphagia in patients with dementia is very prevalent and has been found to be a causative factor in development of aspiration pneumonia among this population (Dahlin, Kurash-Cohen & Goldsmith, 2010). General debility, medications, and inflammatory disorders have been found to be the most common causes of dysphagia.

Dysphagia is also present in patients who are nearing the end of life, and difficulty swallowing or inability to swallow is found in the majority of patients where death is imminent. Nursing interventions for these patients and their family include education on providing good oral care to keep mucous membranes moist and to provide comfort. Additionally, nurses will need to evaluate the patient’s medications, and changes in route of administration may be necessary if the patient is no longer able to swallow.
Seizures

Patients with primary brain cancers or with metastasis to the brain are at risk for developing seizures as they near the end of life. Seizure management is focused on treatment of the underlying cause if possible, prevention with medications, and implementation of seizure safety precautions. In patients where death is imminent, seizures can be very distressing to the family, and alternative routes for administration of the patient’s anticonvulsant medications may be warranted.

Lymphadema

Lymphadema is chronic swelling as a result of abnormal accumulation of lymphatic fluid. Unmanaged lymphadema can lead to more serious complications including cellulitis, infections, septicemia, and elephantiasis (ELNEC, 2010). It is most commonly seen in patients who have undergone some lymph node dissection during surgical removal of a malignant tumor, or as a result of radiation treatment for cancer. Nursing interventions include educating the patient on monitoring skin integrity, refraining from using affected area (if limb) from auscultation of blood pressure or blood draws, and use of compression garments (ELNEC, 2010).

Depression & Anxiety

Anxiety and depression are two symptoms that can be found in patients with serious illnesses. Often, the nature of all the factors that coincide with their terminal diagnosis can result in psycho-social issues and emotional turmoil. The stresses associated with the diagnosis and treatment for serious illnesses can lead some patients to develop anxiety and depression. Sometimes the medical illness itself can contribute or exacerbate anxiety or depression. The losses associated with their illness, such as functional abilities or social status (not being able to work any longer) impact their sense of identity. Many times, these patients feel as if their entire world has been turned upside down and things will never be the same.

Patients who have been informed of poor prognosis or limited life expectancy can be at more risk for development of anxiety and depression. As discussed in Chapter 3, patients may go through periods of depression and grief as they work through the stages of death. Sometimes, patients will need to have extra supports in place, whether they are pharmacological or non-pharmacological, during this time. The patient’s previous coping mechanisms, social support networks, and symptoms associated with their terminal condition can all contribute to how they handle these stressors (Pasacreta, Minarik, Nield-Anderson, 2010).

It is important for nurses to assess patients who may be at risk for, or who are exhibiting signs and symptoms of, anxiety or depression. Just because a patient is dying does not mean that they are at less risk for suicide, and nurses should continue to assess for suicide risk in these patients. Nursing interventions for patients suffering from anxiety or depression can include the use of both pharmacological and non-pharmacological measures. Common medications used for anxiety include the benzodiazepines and some anti-depressants. Selective serotonin reuptake inhibitors and serotonin/norepinephrine reuptake inhibitors have been found to be effective to help manage depression. Psychotherapy can be an effective non-pharmacological intervention that can be used in conjunction with medication management (Pasacreta, Minarik, Nield-Anderson, 2010).
Terminal Restlessness/Delirium

Delirium is a common disorder which is frequently under-diagnosed and poorly managed (Heidrich & English, 2010). There has been much in the literature regarding this disorder in the elderly and its differentiation with dementia. One possible reason that delirium is under-diagnosed may be because it is commonly mistaken for dementia in the elderly. The hallmark difference between delirium and dementia is that delirium has a very abrupt onset with changes in consciousness, cognition, and fluctuation throughout the day (Heidrich & English, 2010). In patients nearing death, delirium has been found to occur in nearly 90% of patients and has been termed “terminal delirium” or “terminal restlessness” (ELNEC, 2010). Medications have been found to be the most common reversible causes of delirium, and thorough evaluation of the patient’s medication regimen should be the initial step in determining delirium etiology. Often, in patients nearing the end of life, metabolic or endocrine disturbances are the cause and may not be reversible in patients with advanced disease. In some patients, unfinished business or spiritual distress can also contribute to terminal restlessness or delirium.

Nursing interventions for patients with terminal delirium or restlessness include supportive care and support for the family. This symptom can be especially troubling for family members to witness in their loved one. Caring for a patient who has terminal restlessness can be difficult and time consuming, especially if there is a risk to the patients safety, such as falling out of bed. Nurses should assist getting the patient and family any additional services they qualify for, such as home health aide service, which can help the family with some of the care. Educating the family about providing a quiet and peaceful environment may be helpful to help ease symptoms in the patient. Aromatherapy using lavender or sandalwood has provided a calming effect in some patients (Heidrich & English, 2010). Pharmacological management includes the use of Haloperidol as the primary medication used to treat this symptom. Benzodiazepines such as Lorazepam may also be used, but often seem to have a worsening effect, particularly in elderly patients. Risperidone may also be given, but often is contraindicated in patients with hypotension.

Sometimes, patients nearing the end of life will have “nearing death awareness.” This was identified by Callanan & Kelley (1992) in their book about hospice patients entitled Final Gifts. Sometimes mistakenly confused with components of delirium or hallucinations, many patients nearing the end of life will describe having seen their deceased loved ones in their room or talking about a place they have visited in their dreams. Some patients are very concrete in that they tell you that their death is near while others persist that they have to go or travel somewhere. Most of the time, patients describe these occurrences as peaceful and happy.

What You Should Know

- Fears surrounding the inadequate management of pain and other symptoms at the end of life are among the top concerns of patients who are dying.
- A comprehensive pain assessment includes evaluating the location, duration, quality of pain, usual pain experience, and alleviating/aggravating factors.
- Refractory dyspnea and terminal restlessness are distressing symptoms in patients nearing the end of life and require a proactive approach to their management.
References


- End of Life Nursing Education Consortium (2010). *ELNEC – core curriculum training program*. City of Hope and American Association of Colleges of Nursing. Materials can be found at http://www.aacn.nche.edu/ELNEC


