Palliative Nursing Care for the Patient Experiencing End-Stage Renal Failure

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What happens to patients with chronic illnesses who frequently fall "through the cracks" when seeking traditional medical interventions, yet who would clearly benefit from palliative care? Who carries out such conversations with these patients and their families? When do palliative care and quality of life issues surpass the curative medical model?

The following discussion of advanced directives and palliative care, and common interventions used for the patient with end-stage renal disease (ESRD), will be highlighted. Because patients often have more than one chronic disease (for example, chronic obstructive pulmonary disease [COPD], heart failure, and cancer), various end-of-life symptoms and related management beyond what may be experienced by patients with ESRD are also discussed.

Advanced Directives

“We plan for births, for new jobs, for weddings, for many events in life, but one of the things we don’t plan for is our own death. One of the biggest tragedies in the hospital setting is not giving people that opportunity” Erica Perry, MSW (Shears, 1990).

While advanced planning is important to everyone it is particularly important for the kidney failure patient. Advanced medical technology, such as dialysis, is often used to prolong the dying process and, unfortunately, patients and their families are often not informed that they have the option of either not starting, or deciding to stop treatment (Dombrouski, Joy, Perry, & Smith-Wheelock, 2000). Many people with kidney failure are grateful for the information necessary to make such decisions, allowing them the opportunity to plan for the future and be more fully in control of their lives after completing their advanced directives for medical care (Swartz & Perry, 1993).

Most patients who undergo dialysis have many other health problems, such as COPD, heart failure, or pulmonary edema, in addition to their kidney failure. These co-morbid conditions also contribute to the patient’s poor quality of life and may question the benefit gained by the use of dialysis (United States Renal Data System, 1999).

Unfortunately many health care professionals, for a variety of reasons (lack of time, lack of comfort, and/or concern for the patient’s feelings), do not conduct the important discussions that surround advanced directives (Perry et al., 1995). The literature points out that patients want to discuss advance plan-
Palliative Care

The World Health Organization (1990, p. 1) has defined palliative care as: “the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms and of psychological, social and spiritual problems, is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families.” Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with traditional therapeutics.

“Palliative care affirms life and regards dying as a normal process, it neither hastens nor postpones death. Palliative care provides relief from pain and other distressing symptoms. It integrates the psychological and the spiritual aspects of care and offers a support system to help patients live as actively as possible until death. Palliative care offers a support system to help the family cope during the patient’s illness and in their own bereavement” (Doyle, Hanks, & MacDonald, 1998, p. 3).

Dialysis is considered a life-sustaining intervention. Many kidney failure patients and their families often desire to proceed with every available medical intervention; yet this patient population should also be able to choose palliative interventions to help improve their quality of life while receiving hemodialysis and/or should they choose to terminate treatment.

Curative Versus Palliative

At what point do the patient and family wish to say that enough is enough, and after trying all reasonable and tolerable medical care have decided to discontinue life-sustaining interventions? Death represents failure from technical medical interventions, yet when does one’s quality of life become a priority over medical advancements? Who has these discussions with the patient and his/her family? One physician states that for him “discussing death as an expected outcome throughout the [patient] relationship can ease grief when death actually comes.” A death that is medically expected, discussed, and worked through ahead of time is what [he] describes as successful medical care (Shears, 1990). This same physician highlights the difference between treatment and therapy. He defines treatment as doing procedures to people because they are available and may be medically and technically indicated. He describes therapy as doing things for people because they would actually improve their quality of life. This physician points out that the distinction between treatment and therapy is especially important for dialysis patients who live for years with chronic illness, alive yet nearing the limits of medical science’s power to heal (Shears, 1990).

Ongoing and open communication with dialysis patients and their families can help people realize the reality of their illness, its complications, and what medical interventions can and cannot be done. The balance between science and reality must always be measured and evaluated for the patient with ESRD. Deciding to end dialysis is not an easy subject and an even more difficult choice for patients and families to make. Experts in the field have identified this as a “process” and not an “event.” It takes time and communication for patients and their families to arrive at an emotional and intellectual state when they are ready to accept the futility of treatment and face impending death (Shears, 1990).

Common Symptoms at the End of Life

“To cure sometimes, to relieve often, to comfort always.” Anonymous

Pain

Pain is a common symptom for the patient experiencing ESRD and is often the result of other concomitant diseases such as diabetes, cardiovascular insufficiency, and metabolite accumulation. The patient described in the accompanying case study did have intermittent complaints of pain resulting from the suprapubic catheter and bladder spasms. Managing pain in this patient population requires a skilled knowledge of the pharmacokinetics of individual analgesics. Morphine, for example, is commonly used at the end of life but is not a good choice for patients with renal failure. Patients with renal failure receiving morphine will often develop side effects that interfere with their quality of life such as sedation, drowsiness, and myoclonus. The metabolites of morphine (morphine-6-glucuronide, morphine-3-glucuronide) are not easily cleared through the kidney and promote negative side effects. Better analgesic choices include fentanyl, methadone, and hydromorphone due to their metabolite clearance (Chater, 2000).

Pain is a multidimensional phenomenon. An individual’s pain experience is not only a physical response to an underlying pathology or a disease state; pain also has emotional, intellectual, behavioral, sensory, and...
cultural dimensions (Foley, 1996).

Pain is not like blood pressure that is easily measured in millimeters of mercury; health care providers must rely on the patient’s subjective (self-rated) experience. Only the experiencing person can tell us when pain is present, the character of the pain, and the effects the pain has on that person (McGuire, 1998).

Under certain circumstances, patients do exhibit observable pain behaviors that serve as indicators of pain. However, the absence of pain behaviors does not indicate the absence of pain, merely an adaptation to the pain. These pain behaviors may include frowning, grimacing, crying, moaning, guarding, holding or rubbing the painful area, complaining of pain, and actively seeking pain medications.

Subjective or self-rated pain assessment. The most common cause of inadequate pain management is the lack of proper pain assessment. Health care providers must ask patients about pain, accept their self-report of pain, and act accordingly from their report of pain (Agency for Health Care Policy and Research [AHCPR], 1994; McGuire, 1998).

As noted earlier, pain is a subjective experience; only the experiencing person can know the intensity and character of his/her pain. In addition, only the experiencing person can tell us the effectiveness of pain interventions.

Nurses are in the best position to initiate conversations with patients about their pain experience. Important questions to ask include:

- What does your pain feel like?
- Can you show me where your pain is?
- Do you get any relief after taking your medication?
- Does your pain interfere with your mood, your appetite, and your overall sense of well-being?

Many patients will not report their pain unless asked. They may not want to complain for fear of being labeled a “complainer” or “bad patient.” They may also believe that they will continuously have pain. These persons will welcome questions about their pain and they will welcome the information and reassurance that pain should be reported and can be managed.

Most clinical settings utilize a Subjective (Self-Rated) Pain Assessment Tool to determine clients’ self-rating of pain intensity. Numerical pain scales are the most frequently used and can be incorporated into daily pain assessment. For example, “On a scale of 0 to 10, with 0 meaning ‘no pain’ and 10 meaning ‘the worst pain possible’, how would you rate your pain?” Some settings use a scale of 0 to 5, and others may use verbal descriptor scales such as: no pain, mild pain, moderate pain, severe pain.

The advantage of having several pain rating scales from which to choose is that health care providers can find a tool that is meaningful to the patient. Assessment scales must make sense to the patient or they will not provide reliable information. The potential disadvantage of using several rating scales is that it can cause confusion when one provider who prefers a specific type of scale is caring for a patient who is familiar with another type of pain rating scale used by another provider.

Subjective pain assessment tools must be used on an ongoing basis to determine the presence of pain, intensity of pain and effectiveness of pain interventions. Using an agreed-upon assessment tool allows for everyone involved in the patient’s care to have a mutual understanding of the person’s pain.

Objective or observational assessment. When a patient is unable to report pain, nurses must rely upon objective, observational data and background information regarding the patient’s previously reported pain. Although there are some pain assessment tools for nonverbal infants and children, there are very few pain assessment tools for nurses to use to assess pain in adult patients who are nonresponsive or cognitively impaired. Current studies are underway to develop assessment tools for this patient population (Kuebler & Ogle, 1998). As the care provider at the bedside, there are certain observable behavioral and physiological indicators of pain for which nurses intuitively can assess (Mateo & Krenzischek, 1993). One indicator of pain in the nonresponsive patient is restlessness which may be demonstrated by agitation, frequent moving, inability to get comfortable, or picking at things. Vocalizations such as moaning, groaning, or crying out are another indicator. Tense muscles, clenched teeth, tightened fists, guarded movements, facial grimacing or frowning are additional indicators of pain in the nonresponsive patient. Some physiological indicators include tachycardia, frequent and labored breathing, and diaphoresis (Kuebler & Heidrich, 2001).

It is not true that nonresponsive patients do not experience pain. Pain does not change if the patient suddenly becomes cognitively impaired; what changes is the patient’s ability to report his/her pain experience. Observation of behavioral indicators of pain will help the bedside clinician assess patient comfort and determine appropriate interventions (Foley, 1996).

Pharmacologic Interventions for Pain

Opioid medications. Opioids are the mainstay for effectively treating moderate to severe pain. These medications work by binding with opiate receptors within the central nervous system (and
possibly the peripheral nervous system) to block the transmission of the pain impulse to the higher brain centers (AHCPR, 1994). Thus, the perception of pain is diminished or blocked. The word narcotic should not be used when discussing essential medications. Narcotics are illegal drugs and are often sought for recreational purposes. Opioids are therapeutic and without them the patient can experience excruciating pain.

There are three types of opioid receptors: mu, delta, and kappa. Most of the clinically useful opioid medications bind to the mu receptor and are called mu agonists. Morphine, hydromorphone, fentanyl, and oxycodone are examples of mu agonist opioids frequently used in treating pain. There is no ceiling to the analgesic effect of mu agonist opioids. However, because metabolism of medications is altered in the patient with end-stage renal failure, medication dosages should be monitored closely. Dosages are usually lower for ESRD patients than dosages used for patients with normal renal function.

In addition to modulating the transmission and perception of the pain impulse, opioids may bind with receptors in other tissues leading to the potential for side effects. There are opioid receptors in the gastrointestinal tract. When opioids bind with these receptors, intestinal motility is decreased and gastric emptying is delayed, leading to constipation. Prophylactic treatment of constipation with both a stool softener and a stimulant is essential and should be initiated along with the first opioid dose. The clinician should not wait for the patient to complain of constipation before beginning treatment. Constipation is the only side effect of opioids to which a person will not develop tolerance. Patients will need to continue on a bowel protocol for the entire duration of treatment with opioids. The fluid restrictions required in patients with ESRD also increase the risk of constipation.

Other potential side effects of opioids include respiratory depression, nausea and vomiting, and sedation. Clinically significant respiratory depression is rare when treating pain if the opioid dose is titrated slowly and decreased if sedation is noted. Sedation and respiratory depression should be monitored closely because of the decreased excretion of many medications in the patient with ESRD. Usually, persons develop tolerance to the respiratory depressive side effects of opioids after the first several days of treatment. The person who has been maintained on the same dose of an opioid for several weeks is generally not at risk for a clinically significant opioid-induced respiratory depression.

While not a problem for all patients, many will experience nausea and vomiting as a side effect of opioids. This occurs when the chemoreceptor trigger zone of the brain is stimulated by these medications. A patient is less likely to develop nausea when opioids are administered via the oral route versus the parenteral route. Similar to respiratory depression, patients develop a tolerance to this side effect. Patients who experience nausea should be treated with anti-emetics for the first 2 to 3 days after the opioid is initiated until tolerance develops.

A patient who has been in pain and receives an initial dose of an opioid will experience some degree of sedation. This is due, in part, to the direct effect of opioids on the brain. In addition to the sedative side effect of the opioid, the patient is likely to be exhausted from not sleeping well while in pain. It is important to teach the patient that some sleepiness is expected and that it may be completely a result of the new medication. Like the other side effects of opioids, a person will develop tolerance after the first 2 to 3 days. However, if the patient is difficult to arouse or if the sedation lasts more than 2 to 3 days, it may be a sign the opioid dose is too high for the patient’s pain intensity or that the medication has accumulated due to impaired metabolism and excretion that may occur with renal failure.

Medication dosing. Most analgesic medication doses must be titrated to effectiveness, both at the beginning of therapy and during the course of treatment. Although many times clinicians think of titration as increasing the dose of a medication, circumstances may also make it very appropriate to titrate down to a lower dose of medication. The goal is to use the smallest dose that relieves the pain with the fewest side effects.

Patients with persistent or chronic pain need to maintain therapeutic levels of analgesics at all times in order to manage their pain. Therefore, an around-the-clock (ATC) schedule is most appropriate. The frequency of doses to maintain therapeutic levels will be determined by the route of administration and the duration of action of the medication. Immediate-release oral morphine will require dosing every 4 hours, oral hydromorphone (Dilaudid®) may need to be on an every 3-hour schedule. Sustained-release medications offer the benefit of more convenient (every 8, 12, or 24-hour) dosing schedules.

Rescue dosing. The goal of ATC dosing is to keep the level of the analgesic in a range high enough to manage the pain but under the point where a patient experiences avoidable or unmanageable side effects. Unfortunately, pain does not stay at the same intensity 24 hours a day. Many patients experience pain above their normal baseline pain. This pain is often labeled “breakthrough pain.” The pain may
Case Study

Initial assessment of Mr. S by a palliative care nurse practitioner revealed a 57-year-old retired plumber who had recently been discharged from an acute care setting. Mr. S has been a heavy smoker with a long history of exposure to asbestos and suffers from chronic obstructive pulmonary disease. His surgical history includes a coronary artery bypass graft surgery prior to his diagnosis of congestive heart failure. He also has a history of carcinoma in-situ of the bladder, which was treated with multiple intravesical BCG bladder instillations. These resulted in a remission of the bladder cancer. During his treatment with intravesical chemotherapy, Mr. S experienced ongoing problems with urinary retention, which lead to intermittent bladder and kidney infections. A Foley catheter was used to manage the urinary retention; over time this was switched to a suprapubic catheter. His condition caused a dramatic decrease in his glomerular filtration rate, which then required a renal shunt and the initiation of hemodialysis.

During a recent hospital admission, Mr. S was newly diagnosed with end-stage renal failure. He was not considered a candidate for peritoneal dialysis because of his long-standing history of COPD and congestive heart failure. Mr. S underwent fistula placement while hospitalized and in the interim developed a systemic infection from his central venous line. After aggressive antibiotic therapy he was able to return home. During his hospitalization he had a significant weight loss of just over ten pounds. While home he complained of being severely weak, confused, short of breath, agitated, and had difficulty sleeping at night. Despite these many symptoms that affected his quality of life, he and his family were committed to his every other day hemodialysis.

Mr. S resides in a rural community that required him and his wife to drive an hour (one-way) for his hemodialysis. The demands that accompanied travel were also intensified by his ongoing symptoms (insomnia, confusion, agitation, lethargy, diet and fluid restrictions) all of which were very difficult for his family to understand and manage. The palliative care nurse practitioner investigated supportive home services for this patient and his family and quickly found that hospice services would not be appropriate as Mr. S still wanted to seek life-prolonging interventions (hemodialysis). The interdisciplinary support that comes with hospice services would certainly be useful for this patient and his family. Mr. S didn’t have any specific or immediate medical needs that could qualify him for skilled home services. He remained under management by his urologist for the suprapubic catheter and ongoing bladder evaluations. A nephrologist was also involved in Mr. S’s care, managing both his primary care along with his hemodialysis. The nephrologist was not comfortable with the palliative interventions suggested by the palliative care nurse practitioner to improve his ongoing symptoms.

Treatment Plan

After discussion with the palliative care nurse practitioner and the nephrologist, Mr. S was placed on methadone 10 mg bid with the dosage eventually titrated to 20 mg tid for his pain. His anxiety and agitation were controlled with haloperidol 5 mg tid and prn. He was placed on prednisone 20 mg every day for his shortness of breath, poor appetite, and generalized malaise. Shortly after initiating these medications and additional discussions related to quality of life with the palliative care nurse practitioner and his family, he eventually decided to discontinue hemodialysis. Following discontinuation of hemodialysis, he was managed palliatively for symptoms at home. The nurse provided education and support and prepared Mr. S and his family for what to expect during the dying process. His family provided most of the supportive care. Mr. S was without symptoms until his death. His family was by his side.

spike above the therapeutic blood level of analgesia and additional medications are required to manage these episodes of breakthrough pain. A short-acting (or immediate release) dose of an opioid should be administered to “cover” the spike in the patient’s level of pain.

For patients taking oral opioids, the recommended rescue dose is in the range of 10% to 15% of the total daily ATC dose of opioid (AHCPR, 1994). The rescue dose should be made available every 1 to 2 hours, as most immediate-release opioids reach peak effectiveness in 60 to 90 minutes. After that point, the level of the opioid in the system begins to decrease. A patient who experiences pain 2 hours after a rescue dose should not be made to wait for additional medication, as the level of analgesia will continue to decrease and the patient will become more and more uncomfortable. As a general rule, a patient requiring more than two rescue doses during a 12-hour period should be re-evaluated. An increase in the ATC dose is often appropriate under these circumstances.
Dyspnea

Dyspnea is one of the most prevalent symptoms experienced by the person diagnosed with an advanced disease, occurring in as many as 50% to 70% of persons at the end of life (Cowcher & Hanks, 1990; De Stoutz & Stiefel, 1997; Dudgeon, 1997; Dudgeon & Rosenthal, 1996). Dyspnea is a subjective experience described as being a difficult or “uncomfortable awareness” of breathing (Bruera, MacEachern, Ripamonti, & Hanson, 1993; Dudgeon, 1997). Additional patient descriptors include labored breathing, shortness of breath, and feelings of suffocation. Renal failure patients often experience dyspnea secondary to pulmonary edema that develops when the kidneys no longer excrete urine and fluids. Anemia that is the result of decreased production of erythropoietin to stimulate red blood cell synthesis also contributes to the development of dyspnea.

Dyspnea, not unlike other symptoms, is multidimensional and often accounts for a high proportion of the patient’s inability to carry out activities of daily living and gravely affects their perceived quality of life (Bruera, Macmillan, Pither, & MacDonald, 1990; Cohen, Johnson-Anderson, Krasnow, & Wadleigh, 1992). The continuous exhaustion that accompanies breathlessness has been described as being one of the most devastating symptoms for both the patient and the observing family members (De Stoutz & Stiefel, 1997; Dudgeon & Rosenthal, 1996).

Etiology. Dyspnea generally results from an increased awareness of changes from normal breathing, having an increased workload of breathing, or abnormalities in the ventilatory system. In their 1999 consensus statement, the American Thoracic Society emphasized that there may be many factors contributing to the symptom of breathlessness, including pathophysiologic changes as well as individuals’ emotional and spiritual evaluation of the changes in their functional status and quality of living (Kuebler, Dahlin, Heidrich, & Zeri, 1996).

Disease processes commonly associated with dyspnea include acute and chronic pulmonary disorders, pulmonary edema, heart failure, and neuromuscular disorders. In the end-stage renal failure population and other terminally ill patients, anemia and generalized weakness are also seen quite frequently and contribute to dyspnea. Emotions also play a big role in dyspnea. The fear associated with the inability to “catch one’s breath” can lead to panic and worsen the sensation of dyspnea (Gift & Pugh, 1993).

Assessment. Assessment of clients with dyspnea includes subjective and observational data. Much like pain, clients should be asked to rate dyspnea on a rating scale. The scale must make sense to the patient and to anyone caring for the patient who is using the same scale. This information will assist in determining the severity of the symptom as well as provide a baseline to evaluate the effectiveness of interventions. The patient’s evaluation of his/her own functional status and the impact of dyspnea on his/her activities of daily living provide helpful information on both the physical and emotional responses to dyspnea.

An objective assessment of the patient provides additional information about the symptom of dyspnea. The clinician must observe for an increase in the respiratory rate, use of accessory muscles, gasping or labored breathing, adventitious lung sounds, restlessness, and diaphoresis. Observation of these symptoms is essential to identify dyspnea in the nonresponsive patient.

Interventions for Dyspnea

The underlying cause of dyspnea should be treated as is appropriate for where the patient is on the dying trajectory. For example, pneumonia in a patient who is alert and oriented and has a good quality of life should be treated. However, it may be very appropriate to not treat pneumonia in a patient who is clearly near the end of the disease trajectory and if treating the pneumonia will not improve the quality of life. All reasonable treatment options should be reviewed with the patient and family, including the option of “no” treatment.

While it may not be possible or practical to treat the underlying cause of dyspnea at the end of life, there are many effective interventions to manage the distress and uncomfortable sensations associated with dyspnea. Interdisciplinary team support is essential in managing dyspnea. The psychosocial and existential issues contributing to the symptom of dyspnea will require the support of professionals trained in these areas. The following content will predominately focus on the pharmacologic management of dyspnea.

Opioids. Morphine is widely used for the relief of dyspnea (Bruera et al., 1990; Brueuer et al., 1993). Data from several clinical studies reveal that 80% to 95% of terminal cancer patients found significant relief from morphine (Bruera et al., 1990; Brueuer et al., 1993). Other opioids may be used for managing dyspnea in ESRD (remember that morphine is usually not the drug of choice for patients with ESRD as described earlier). While it is not known exactly why opioids alleviate dyspnea, it is believed that they blunt the perceptual response to dyspnea or reduce the respiratory drive (Cohen et al., 1992; Cowcher & Hanks, 1990).

There is no standard optimal dose of opioids for treating dysp-
stage renal disease patients should be monitored closely if corticosteroids are used to manage dyspnea because these patients retain fluid and are at risk for pulmonary edema. The benefits of the treatment must outweigh the side effects of treatment.

Bronchodilators. Bronchodilators help to decrease the effort of breathing. The significant decrease in dyspnea from theophylline is believed to result from an improvement in the length-tension relationship of the diaphragm (Kuebler et al., 1996).

Oxygen therapy. The palliative care literature does not support the use of oxygen therapy for the relief of dyspnea in and of itself (Ahmedzai, 1998; Twycross, 1997). Oxygen therapy should be used primarily for patients who are hypoxic or who have a tendency to develop pulmonary hypertension. If O₂ saturation is below 90% on room air the clinician may want to consider O₂ by nasal cannula at 1 to 3 liter/min, rechecking client’s O₂ saturation in 20 to 30 minutes and titrating up to 6 liters/min if necessary by nasal cannula. For patients with anemia secondary to renal failure, oxygen may be used to maximize the oxygen-carrying capacity of the hemoglobin that is present.

Nonpharmacologic Interventions for Dyspnea

In addition to medications, there are many other interventions that contribute to comfort in patients experiencing dyspnea. These nonpharmacologic interventions are important additions to the care plan. Nurses are frequently the care providers to introduce these interventions to patients and families and assure that these interventions are being used to maximal effectiveness through education and support. The interventions include:

- Positioned (semi-Fowler’s)
- Fan
- Coping techniques
- Calming presence
- Relaxation therapy
- Hypnosis
- Complementary therapies: massage, visualization, acupuncture
- Hypnosis

Delirium

Delirium affects 77% to 85% of terminally ill cancer patients (Fainsinger, Tapper, & Bruera, 1993; Lipowski, 1989) and 57% of terminally ill AIDS patients (Brietbart & Jacobson, 1996). In renal failure patients, the delirium may be related to the build up of waste products in the blood or electrolyte imbalances. Some clinicians consider delirium the “hallmark” of dying. Studies have indicated that 25% to 35% of episodes are reversible (Bruera, Miller, & McCallion, 1992; Twycross, 1997). In the palliative care setting, early detection and assessment are likely to improve outcomes.

A variety of terms have been used to describe delirium, such as acute brain failure, acute confusional state, acute secondary psychosis, exogenous psychosis, sundown syndrome, and organic brain syndrome (Massie, Holland, & McCallion, 1993). According to the American Psychiatric Association (APA) DSM-IV (1994) criteria, delirium is defined as “an etiologically non-specific, global, cerebral dysfunction characterized by concurrent disturbances of level of consciousness, attention, thinking, perception, memory, psychomotor behavior, emotion, and the sleep-wake cycle” (Brietbart & Jacobson, 1996; De Stoutz & Stiefel, 1997). It is often identified as a sudden and significant decline in a previous level of functioning and is conceptualized as a reversible process. Delirium can also affect sleep, psychomotor activity, and emotions (Caraceni, 1995; Ingham &
Caraceni, 1998; Lipowski, 1989). Following are APA’s DMS-IV (1994) criteria for delirium:
- Disturbance of consciousness with reduced ability to focus, sustain, or shift attention.
- A change in cognition (such as memory deficit, disorientation, language disturbance) or the development of a perceptual disturbance that is not better accounted for by pre-existing, established, or evolving dementia.
- The disturbance develops over a short period of time (usually hours to days) and tends to fluctuate over the course of the day.

Diagnosing delirium. The diagnosis of delirium is primarily clinical, based on careful observation and awareness of its key features (Ingham & Caraceni, 1998). Because the signs and symptoms are nonspecific, the clinician must look for a constellation of findings (signs of a disturbance in consciousness and a change in cognition), identify the rapidity of onset, and assess for associated medical and environmental risks that lead to a definitive diagnosis. It is frequently unrecognized by clinicians and misdiagnosed (Bruera et al., 1992; Inouye, 1994). The fact that demented, depressed, and anxious patients may develop delirium makes the diagnosis difficult (Inouye, 1994).

Assessment. The most commonly used assessment instrument to identify cognitive changes is the Mini Mental State Examination (MMSE). The MMSE provides a systematic scored method for evaluating cognitive function. This exam can indicate early changes in cognition as it relates to the cortical function of the brain. Orientation, attention, recall, and language are evaluated. Scores below 24 out of a maximum of 30 are indicative of cognitive changes. However, one of the ambiguities of this assessment instrument is that it is unable to provide the clinician with a definitive diagnosis for delirium. Nor does it help determine the differences between dementia, anxiety, and depression. The MMSE relies heavily on patient cooperation and does not account for the abrupt changes that may often occur in the patient’s cognitive status (Brietbart, Chochinov, & Passik, 1998).

Interventions for Delirium

The prognosis for the patient experiencing delirium is often poor; yet this should not deter the clinician from looking for the underlying cause since a significant number of cases are reversible (Inouye, 1994; Ingham & Caraceni, 1998). Bruera and colleagues (1992) were able to determine cognitive failure in 80% to 90% of clients prior to death and were able to identify a reversible cause of delirium in 44% of clients studied (29 out of 66 patients). Frequently cited reversible causes of delirium include (a) medications (for example, opioids, sedatives, anticholinergics, and steroids), (b) hypoxia, (c) dehydration, (d) metabolic causes (for example, hypercalcemia), and (e) sepsis. Over-medication with opioids and sedatives in the renal failure patient as well as metabolic and electrolyte imbalances must be corrected and often relieve the delirium. One must always evaluate the potential benefits and burdens of each intervention, remembering that in palliative care reversing the cause may not always contribute to a better quality of living.

Depression

Studies indicate the prevalence of depression in chronically ill and terminally ill patients ranges anywhere from 10% to 25% (Rhodes & McDaniel, 1999; Story, 1998). The prevalence appears to increase in the presence of functional losses, advancing illness, and unmanaged symptoms. It is believed many cases of depression go unrecognized by clinicians due to the fact that many of its signs and symptoms, such as fatigue, anorexia/weight loss, and insomnia, can be attributed to the disease processes associated with a chronic or terminal illness. Key indicators of clinical depression in chronically and terminally ill patients are alterations in mood; feelings of hopelessness, worthlessness, or excessive guilt; and, recurrent death wishes, including suicidal ideation (Pereira & Bruera, 1997).

A terminal diagnosis potentiates both anxiety and depression. Persons with a family or personal history of depressive episodes are at even higher risk of depression than the general population. It is not clear if psychological or physiological factors are involved with this increased risk (Pollack, 1999).

It is thought that depression is a direct result of abnormal serotonin (5-hydroxytryptamine, or 5-HT) neurotransmission in the central nervous system. This abnormal secretion may be genetic or induced by some unknown mechanism. Other neurotransmitters, such as γ-aminobutyric acid (GABA) and norepinephrine, have also been closely linked in unconditioned anxiety and may be associated with depression (Pollack, 1999).

Assessment. Nurses play a pivotal role in identifying persons with depression. Important questions the nurse can ask include: “Are you depressed?” or, “How has your mood been lately?” Although feeling sad and anxious at times is a normal response to a terminal diagnosis or chronic illness, it is important not to ignore these symptoms. There are several tools that can be used to assess depression...
such as the Geriatric Depression Scale, Beck Inventory, and Zung Self-Report Inventory. Persons with signs of a clinical depression should be referred to skilled health care professionals for further evaluation and treatment.

Interventions for Depression

Optimal therapy is achieved by combining supportive psychotherapy, cognitive-behavioral techniques, and pharmacologic management. This requires the coordination of the interdisciplinary team. Antidepressant medications can be very effective in treating depression. There are several classes of antidepressants. The newer selective serotonin reuptake inhibitors (SSRIs) have fewer side effects and are at least as effective as the tricyclic antidepressants (Pollack, 1999). A trial of antidepressant therapy is warranted in the terminally ill as these medications can greatly enhance the patient's quality of life.

Other Symptoms

Thirst. If the patient is taking anticholinergic medications along with opiate therapy the nurse may consider discontinuing those medications that continually dry out the mucosa. Renal failure patients are on severe fluid restrictions and often complain of dry mucosa. Employ good oral care and provide the patient with ice chips and sips of fluid.

Pruritus. Pruritus is another common symptom in the uremic patient requiring palliative interventions. Common medications used to control this symptom include diphenhydramine, hydroxyzine, and/or ondansetron (Chater, 2000). Nursing interventions include bathing the patient without soap, using moisturizing oils in bath water or lotions, and avoiding products that contain alcohol or perfumes that may promote dryness and increase pruritus.

Psychological Interventions

Patients who have a chronic, terminal, or end-stage illness may elect to stop curative or life-saving interventions. Nurses and specially trained palliative care nurses are often the members of the health care team who first notice that a patient may be tired of life-saving measures such as hemodialysis for renal failure. It is up to the nurse to talk with the patient and family about their feelings and wishes, answer questions, and in some cases give the patient and family permission to stop curative treatments and employ palliative measures. Nurses are often the advocates for these patients and may need to inform physicians of the change in patients' wishes. A group meeting of the patient, family, and all health care providers should occur to discuss all options for the patient (Kuebler & Heidrich, 2001).

If the decision is made to move to palliative interventions and cease all other interventions, the nurse will be a major provider of support. Communication and support of the grieving patient and family are essential to end-of-life care. The dying process can be a time of emotional crisis for many families. The nurse must be comfortable with personal feelings about death and be able to communicate with patients and families. Patients and families facing the last days of life should be given the opportunity to express any or all of their concerns about issues that matter the most to them. The nurse acts as a listener, friend, and advocate for the patient and family. Involvement of the patient and family in the decisions and through the final act of living are essential. They should know what to expect in the final days before death. Through ongoing assessment, communication, and skilled physical care, the nurse can communicate reassurance, confidence, and support for the patient and family through the journey of dying and make the journey one of peace and comfort (Kuebler & Heidrich, 2001).

Conclusion

The goal of palliative care is to provide comfort and support for the patient and family at the end of life. For the end-stage renal patient the challenge lies in having the communication and discussion that lead up to delivering palliative care interventions and possibly withdrawing from life-sustaining dialysis. The literature provides the nurse with evidenced-based practice interventions to help promote quality of life up until the patient's death. Knowledge and recognition about the manner in which medications are used and their pharmacokinetic properties ensure a symptom-free dying experience for both the patient and their loved ones.

References


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