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HOSPICE & Palliative Care

Assessing pain at end of life is often a challenge for the home health clinician, especially in different age groups or in the presence of severe cognitive impairment, language barriers, or communication difficulties. The task of assessing and monitoring the severity of pain and measuring the effectiveness of treatment measures is essential for effective pain management. This article provides home health clinicians with some practical skills and essential tools to assess and record pain intensity as the first step for effective pain management.

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7 Tools to Assist Hospice and Home Care Clinicians in Pain Management at End of Life

Choosing and Using Pain Rating Scales

Shirley Ruder, RN, MS, MSN, EdD

The Caregiver's Story

Mrs. M is an 84-year-old woman with late-stage Alzheimer's disease. The family has reported that over the past week she has had worsening agitation, labored breathing, facial grimacing, and has been pushing away and striking out at family members. Mrs. M is dependent in all of her activities of daily living and is not cognitively oriented. Her vital signs are normal. The health clinician believes the patient is in pain, but is unsure how to assess for pain since Mrs. M does not answer when asked about pain.

Pain: An Overview

To assess, manage, and treat pain is often a challenge to health clinicians. Pain is "defined by the International Association for the Study of Pain as an unpleasant sensory and emotional experience arising from actual or potential tissue damage. Approximately one half of the persons who seek medical help do so because of pain" (*Taber's Cyclopedic Medical Dictionary,* 2009, p. 1680). Because pain can be physical, social, emotional, or spiritual, it is a subjective experience. Because clinicians cannot know about a patient's pain, clinicians must rely on what a patient tells them. Only the patient can determine how much pain he or she is experiencing. As professionals, it is our obligation to assess and manage pain (McCaffery & Pasero, 1999). Standards for accreditation include the right to receive appropriate assessment and management

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of pain (The Joint Commission, 2007). This assessment of pain starts with the clinician asking the patient about pain. Defining pain as what the person says it is (McCaffery & Pasero) is a good standard for patients who can accurately report their pain. It is an incorrect assumption to assume that no report of pain means that the patient is not having any pain. In fact, failure to ask about pain is the most common cause of unrelieved pain and unnecessary suffering (McCaffery & Pasero).

Some healthcare clinicians assess a patient's pain intuitively by recognizing certain behaviors associated with pain and discomfort. Unfortunately, this is a very subjective method and may not be accurate. It also does not measure severity, quality, or other unique characteristics of pain. To more effectively assess pain, there should be some form of standardized self-report. This requires that a patient can communicate the existence of pain either verbally or through non- verbal communication and is able to rate the pain intensity. There are many pain assessment scales and monitoring tools that can be used to guide pain assessment and pain control. Available instruments usually help to identify the intensity of pain or pain behaviors within a specific population. It is important to note that there is no single pain assessment tool that can objectively rate every behavior associated with pain. In addition to using a scale to assess pain intensity, the clinician must also perform a thorough clinical assessment of the pain to determine the quality of the pain and how it is affecting functioning. This assessment includes asking about the presence of pain and observing for signs of pain, taking a history of the pain, describing the characteristics of the pain such as location, nature of the pain, intensity of the pain, patterns, aggravating and relieving factors, the emotional response to the pain, the impact on quality of life or activities of daily living, and assessing the response to medications (Royal College of Physicians, British Geriatrics Society, & British Pain Society, 2007). One of the most important parts of a pain assessment is to look at and examine where a patient has pain to try and identify the cause of the pain. Pain can exist even if a physical examination is normal.

The Use of Standardized Pain Scales

When measuring pain it is important to use a standardized scale that is easy to use and document, and has high validity and reliability ratings (Royal College of Physicians, British Geriatrics Society, & British Pain Society, 2007). Pain scales should be used consistently with

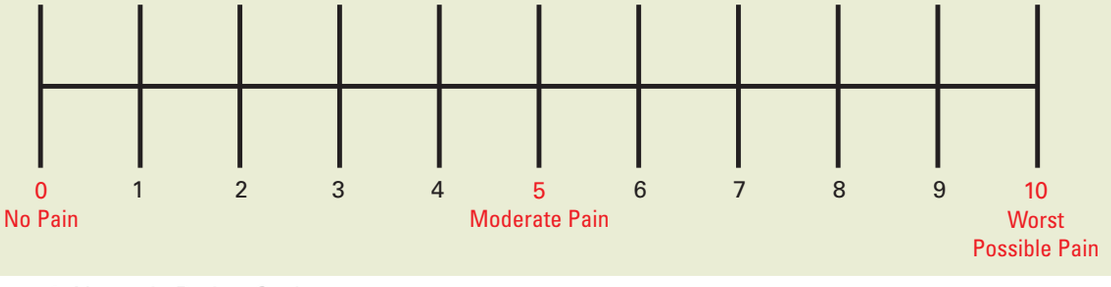

Figure 1. Numeric Rating Scale.
Adapted with permission from McCaffery, M., and Pasero, C. (1999). *Pain: Clinical manual.* (2nd ed.). St. Louis: Mosby, Inc.

all caregivers and healthcare providers. No one pain scale is clearly superior. One of the most commonly used is the 1 to 10 numeric rating scale (NRS). This scale allows a patient to rate pain on a scale of 0 meaning "no pain" to a 10 meaning "severe pain" (Figure 1). The middle of the scale describes "moderate pain," whereas a score of 2 to 3 would indicate "mild pain." This scale is easy to use in patients who can communicate effectively and has been found to have high validity and reliability in older adults as well as in older adults with mild-to-moderate cognitive impairment (Chibnall & Tait, 2001; Herr et al., 2004). The American Geriatrics Society (AGS) recommends using the verbally administered NRS as the first choice for older patients (Ferrell et al., 2002). A verbal descriptor scale (VDS), which uses words such as *mild, moderate*, and *severe* to describe pain, has also been found to be helpful in adults and for patients who have mild-to-moderate cognitive impairment. According to National Guidelines developed by the Royal College of Physicians, better success has been reported in an NRS that is vertically oriented as opposed to horizontal as it may help avoid misinterpretation in the presence of visuospatial neglect. This can be often found in patients who have had a stroke (Royal College of Physicians, British Geriatrics Society, & British Pain Society, 2007).

In a study by Gagliese et al. (2005), researchers compared the NRS, VDS, the McGill Pain Questionnaire (a multidimensional pain scale), and some different configurations of scales in younger and older patients with acute surgical pain. The patients were all receiving patient-controlled analgesia to manage pain. In both age groups, the NRS was the pain scale selected as easiest to use, with the lowest error rate and highest validity scores. The VDS received the second-best ratings. An important finding was the lack of age differentiation in scoring. The

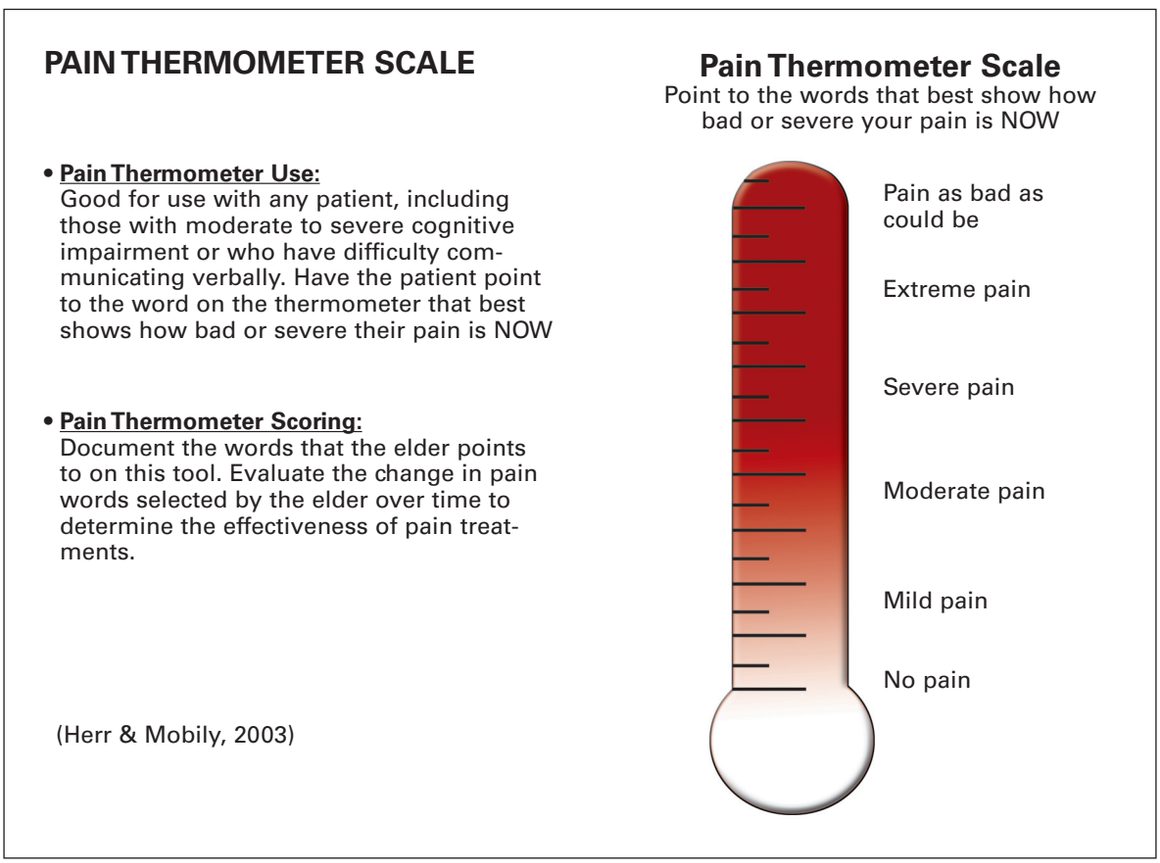

Figure 2. Vertically oriented pain thermometer.
Used with permission from Keela Herr, PhD, RN, AGSF, FAAN, the University of Iowa College of Nursing.

Figure 3. Wong-Baker FACES pain rating scale.
From Hockenberry, M. J., Wilson, D., and Winkelstein, M. L. (2005). *Wong's essentials of pediatric nursing* (7th ed., p. 1259). St. Louis, MO: Mosby. Copyright Mosby; used with permission.

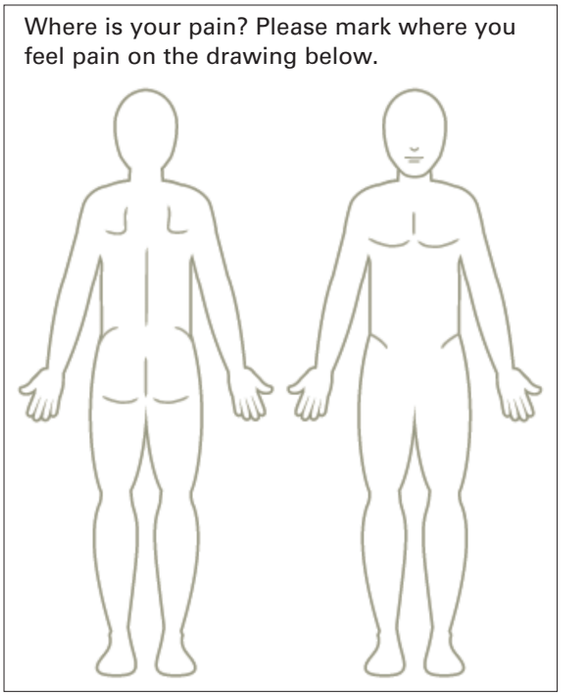

Figure 4. Pain map.
Reprinted with permission from Royal College of Physicians, British Geriatrics Society, and British Pain Society. (2007). *The assessment of pain in older people: National guidelines.* Concise guidance to good practice series, No 8. London: Royal College of Physicians.

older adults liked it as well as the younger patients and found it easy to use.

The Vertically Oriented Pain Thermometer is a pain intensity scale that combines the VDS and NRS (Figure 2). This tool is easy to use and has been found to be helpful in older people with moderate-to-severe cognitive and/or communication impairment; however, its validity has not been fully evaluated (Royal College of Physicians, British Geriatrics Society, & British Pain Society, 2007).

Another scale that is widely used is the Wong-Baker FACES Scale (Hockenberry et al., 2005). This scale is universal and may be easier to use, especially in children age 3 and older as well as with confused patients. Each face shows a different amount of pain. The face on the left is smiling because it does not have pain, whereas the face on the right is crying because it feels the worst pain even though you do not have to be crying to be experiencing the worst pain. The patient identifies which face represents his or her pain level (Figure 3). It is important that the clinician considers cultural differences and/or bias when using the various scales as it may influence how patients answer.

Defining pain as what a person says it is might work well with most patients, but this standard does not work with some groups. This includes infants and children, persons with communication difficulties or cultural or language barriers, persons with decreased level of consciousness, persons at end of life, and persons with severe cognitive impairment such as in Alzheimer's disease or in some forms of stroke or Parkinson's disease. In these groups, the assessment of pain can be very challenging. The clinician must observe for behaviors, signs, or other symptoms of pain. Some persons who lack visual skills or who have communication impairment such as after a stroke may be able to respond to pictures, pain flash cards, or write down a pain response (U.S. Department of Health and Human Services, 1992). In patients who have difficulty identifying the location of their pain, a pain map may be helpful. A pain map is an example of a picture that can be used by having patients point to the area of the body where their pain is located (Figure 4).

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Observing behaviors has always been a part of a pain assessment, but in someone whose verbal communication is limited or has poor verbal communication, it may be the only way to collect information. Patients who cannot communicate well must be observed directly for pain behaviors. Behavioral issues in someone could be due to pain but are often difficult to measure in a person who cannot tell you where the pain is and how much pain he or she is having. Because of this, the clinician must carefully observe for changes in mood, sleep, eating, breathing, behavior, physical movements, mental status changes, verbalizations and vocalizations, and/or changes in interpersonal interactions. When a self-report is not possible, ask family members and caregivers for information about the patient's usual behaviors and any changes that might be occurring. It is important that a protocol for consistent documentation and plan of care be developed and used by both the healthcare clinicians and the family caregivers.

The AGS (2002) identified the following behaviors to indicate pain:

- Verbalizations: moaning, calling out, asking for help and groaning
- Facial expressions: grimacing, frowning, wrinkled forehead, distorted expression
- Body movements: rigid, tense body posture, guarding, rocking, fidgeting, pacing, massaging the painful area
- Changes in interactions: aggression, combative behavior, resisting care, disruptive, withdrawn
- Changes in activity patterns or routines: refusing food, appetite changes, increases in rest or sleep, increased wandering
- Mental status changes: crying, tears, increased confusion, irritability, or distress.

There are several observational pain scales that have been developed. A review of these scales can be found at http://prc.coh.org/pain_assessment.asp. Many of these scales are being used in clinical practice, but reliability and validity may not have been fully evaluated.

One behavioral scale that is easy use in older patients with cognitive impairment is the Pain Assessment in Advanced Dementia (PAINAD) scale (Warden et al., 2003). This scale is a five-item observational tool that includes breathing, negative vocalization, facial expression, body language, and consolability (Table 1). Each item is scored, and then a total score is obtained (based on a scale of 0 to 2 for five items). The higher the score, the greater the pain. This scale relies on the caregiver's or healthcare provider's opinion, and is a good option to ensure consistent, standardized pain assessment and to monitor and document trends and outcomes.

Another pain scale that is used in older patients with severe cognitive/communication impairment is the Abbey Pain Scale (Abbey et al., 2004). This scale used six behaviors to indicate pain and is short and easy to apply. Scores can range from 0 to 18 (Figure 5). This scale does not differentiate between distress and pain, so the effectiveness of any pain-relieving interventions is essential. With this scale, it is recommended that a second

An assessment of pain should lead to an appropriate treatment. Whether it is an intervention (such as turning or repositioning) or an alternative treatment (such as acupuncture and/or a medication) depends on the assessment findings. At end of life, the goal of treatment is comfort.

evaluation be conducted 1 hour after any pain-relieving interventions were taken in response to the first assessment score. It is important that all interventions related to pain management be assessed for effectiveness. It is important to remember that even when using a validated behavioral scale, the clinician should always first ask the patient for a self-report of pain.

Update on Mrs. M

As discussed in the beginning of this article, Mrs. M demonstrated an example of pain in an Alzheimer's patient. Although there were no other abnormal symptoms except the changes in behavior, this patient was found to have a urinary tract infection. By using the PAINAD scale, the healthcare provider was able to document a pain score of 8 and provide appropriate pain relief interventions.

Assessment of Spiritual Pain

The impact of spirituality as a component of quality of life and well-being is gaining recognition by healthcare professionals (Baider et al., 1999; McClain et al., 2003). A number of studies have examined the relationship between religiousness and mortality. In a study of 60 adults enrolled in hospice care, Kruse et al. (2007) found highly significant positive correlations among spiritual

Table 1. Pain Assessment in Advanced Dementia Scale

Item	0	1	2	Score
Breathing independent of vocalization	Normal	Occasional labored breathing. Short period of hyperventilation	Noisy labored breathing. Long period of hyperventilation. Cheyne-Stokes respirations	
Negative vocalization	None	Occasional moan or groan. Low-level speech with a negative or disapproving quality	Repeated troubled calling out. Loud moaning or groaning. Crying	
Facial expression	Smiling or inexpressive	Sad, frightened, frowning	Facial grimacing	
Body language	Relaxed	Tense, distressed pacing, fidgeting	Rigid, fists clinched, knees pulled up, pulling or pushing away, striking out	
Consolability	No need to console	Distracted or reassured by voice or touch	Unable to console, distract, or reassure	
Total:				

Note. Reprinted with permission from Warden, V., Hurley, A. C., & Volicer, L. (2003). Development and psychometric evaluation of the Pain Assessment in Advanced Dementia (PAINAD) scale. *Journal of American Medical Directors Association, 4,* 9-15.

Abbey Pain Scale

For measurement of pain in people with dementia who cannot verbalise.

How to use scale: While observing the resident, score questions 1 to 6

Name of Resident: _____

Name and designation of person completing the scale: _____

Date: _____ Time: _____

Latest pain relief given was _____ at _____ hrs.

Q1. Vocalisation
eg. whimpering, groaning, crying
Absent 0 *Mild 1* *Moderate 2* *Severe 3* **Q1** ☐

Q2. Facial expression
eg. looking tense, frowning grimacing, looking frightened
Absent 0 *Mild 1* *Moderate 2* *Severe 3* **Q2** ☐

Q3. Change in body language
eg. fidgeting, rocking, guarding part of body, withdrawn
Absent 0 *Mild 1* *Moderate 2* *Severe 3* **Q3** ☐

Q4. Behavioural Change
eg. increased confusion, refusing to eat, alteration in usual patterns
Absent 0 *Mild 1* *Moderate 2* *Severe 3* **Q4** ☐

Q5. Physiological change
eg. temperature, pulse or blood pressure outside normal limits, perspiring, flushing or pallor
Absent 0 *Mild 1* *Moderate 2* *Severe 3* **Q5** ☐

Q6. Physical changes
eg. skin tears, pressure areas, arthritis, contractures, previous injuries.
Absent 0 *Mild 1* *Moderate 2* *Severe 3* **Q6** ☐

Add scores for 1 – 6 and record here → **Total Pain Score** ☐

Now tick the box that matches the Total Pain Score →

0–2 No pain	3–7 Mild	8–13 Moderate	14+ Severe

Finally, tick the box which matches the type of pain →

Chronic	Acute	Acute on Chronic

Dementia Care Australia Pty Ltd
Website: www.dementiacareaustralia.com

Abbey. J: De Bellis, A: Piller, N: Easterman, A: Giles, L: Parker, D and Lowcay, B.
Funded by the JH & JD Gunn Medical Research Foundation 1998 – 2002
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Figure 5. Abbey pain scale.
Reprinted with permission from Abbey, J., Piller, N., De Bellis, A., Esterman, A., Parker, D., Giles, L., et al. (2004). The Abbey pain scale: A 1-minute numerical indicator for people with end-stage dementia. *International Journal of Palliative Nursing, 10*(1), 6-13.

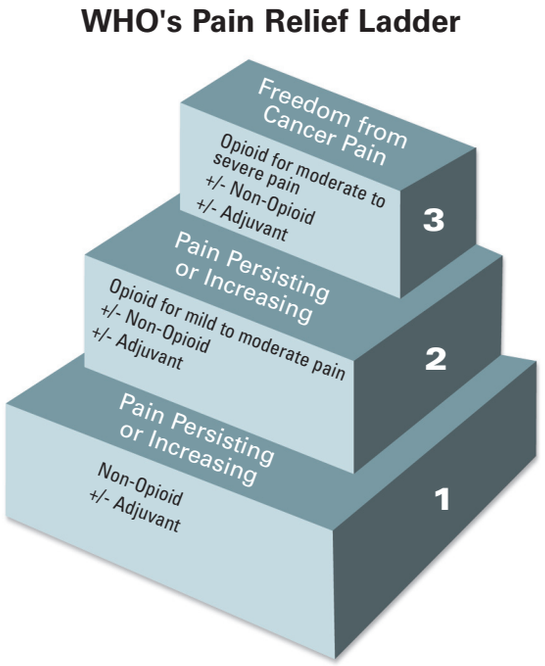

Figure 6. Step 1—Mild pain, pain intensity level 1 to 3 on NRS: acetaminophen, NSAIDs; step 2—mild-to-moderate pain, pain intensity level 4 to 6: combination medication containing acetaminophen and oxycodone or hydrocodone; step 3—moderate-to-severe pain, pain intensity level 7 to 10; opioid medications such as morphine, fentanyl, hydromorphone, methadone.
Reprinted with permission from World Health Organization. (n.d.). WHO's Pain Relief Ladder. Retrieved November 25, 2009 from http://www.who.int/cancer/palliative/painladder/en/.

well-being, peacefulness, comfort, and serenity at end of life. Pargament et al. (2001) found that elderly ill men and women, who experienced religious struggles with their illness, appeared to be at increased risk for death. In nursing, there are accepted nursing diagnoses of spiritual distress or at risk for spiritual distress (Ralph & Taylor, 2008). Conducting a spiritual assessment to assess for spiritual pain is as important as assessing for physical pain. Various tools are available for the clinicians use in conducting a spiritual assessment including FICA: A Spiritual Assessment Tool and the Functional Assessment of Chronic Illness Therapy (FACIT) Spiritual Well-Being Scale (Ruder, 2008).

Treatment and Interventions Related to Pain and Its Management

In any patient, an assessment of pain should lead to an appropriate treatment. Effective pain management at end of life typically requires a combination of treatments or interventions. Whether it is an intervention, such as turning or repositioning, an alternative treatment such as acupuncture and/or a medication depends on the assessment findings. At end of life, the goal of treatment is comfort. It is important to examine the patient to try to determine the cause of the pain. For example, if the pain is spiritual, then spiritual interventions may be indicated. If the cause is not identifiable, then the symptoms need to be assessed and treated. In all causes, the healthcare provider should work closely with the family caregivers to interpret the meaning of behaviors and provide individualized care.

Medication Management

Pharmacotherapy is the most common method to control pain at end of life and in the older patient. When managing pain, it is important to determine what evidence supports current practice related to the use of medications to treat pain. The goal of pain management at end of life, whether the pain is caused by cancer or by other causes, is comfort. Medications need to be evaluated as to the risks and benefits, and side effects need to be anticipated and managed. Medication options for treating pain can be listed according to the World Health Organization's (WHO) Pain Analgesic Ladder. This ladder can be used as a framework to match the patient's pain intensity to an appropriate medication and/or other interventions. This ladder provides a step approach to possible medication options arranged by steps based on pain intensity. When planning care, always evaluate all medications that the patient is currently taking, and starting with a low dose is the best approach. This is the basis for the well-known saying "start low and go slow" (Figure 6).

For mild-to-moderate pain, acetaminophen and nonsteroidal anti-inflammatory agents are the drugs of choice. Acetaminophen is usually tolerated by older adults (D'Arcy, 2008); however, patients need to be assessed for hepatic, renal, cardiovascular, gastrointestinal, and hematologic functioning. Because acetaminophen is one reason for hepatic failure, the AGS (2002) recommends that liver failure, hepatic insufficiency, and/or alcohol use or abuse be an absolute contraindication for acetaminophen use. Because of risks associated with the use of NSAIDs, the Food and Drug Administration states that NSAIDs

should not be used for patients with increased cardiovascular risks (Sclaerth, 2007; Smeltzer et al., 2008). Gastrointestinal tract bleeding and ulceration is also a risk (Food and Drug Administration, n.d.).

In the treatment of moderate-to-severe cancer pain or noncancer pain, opioids are the treatment of choice. Safe and effective use of opioid therapy requires clinical skills and knowledge regarding principles of prescribing, and on the assessment and ongoing management of risks. The healthcare provider should refer to clinical guidelines for the use of opioid therapy (American Pain Society, 2005; Chou et al., 2009).

Medication Management in the Older Adult

According to the Royal College of Physicians, British Geriatrics Society, and British Pain Society (2007), pain is often not recognized or is undertreated in older adults. When working with the older patient, there are some things to consider. Many older patients have a different attitude about pain. They are often reluctant to complain and think that pain is a normal part of aging. Some are worried about becoming addicted. Many are already taking many medications, and it is important to know about their medication regimen including the side effects and interactions. The older patient may also have a variety of factors that affect the way the medications are absorbed, utilized, and excreted such as renal impairment and poor nutrition.

Nonpharmacologic Therapies

Nonpharmacologic therapies can also be incorporated. These can include exercise, stretching, repositioning, massage, and the use of heat/cold. Many nonpharmacologic therapies have been found to reduce pain, boost energy levels, reduce side effects from medications, and promote an overall improvement in quality of life (Breastcancer.org, 2009). Some other nonpharmacologic therapies that can be used either without medication use or in conjunction with medications can include acupuncture, visualization, meditation, music therapy, hypnosis, Reiki therapy, relaxation, and biofeedback.

Conclusion

Assessing pain can be a challenge at end of life. This is especially true in the patient who has difficulty with communication. Choosing the appropriate pain scale and using it consistently can assist the healthcare provider with documenting pain assessment and choosing appropriate pain relief interventions. By providing pain relief measures, the health clinician will help meet standards of accreditation and provide comfort for their patients.

See Table 2 for Web sites that can provide helpful information about pain and its management. ■

Table 2. Resources for Information About Pain and Its Management

- American Academy of Pain Medicine: **http://www.painmed.org**
- American Pain Society: **http://www.ampainsoc.org**
- American Pain Foundation: **http://www.painfoundation.org**
- American Chronic Pain Association: **http://www.theacpa.org**
- City of Hope Pain Resource Center: **http://prc.coh.org**
- Medline Plus- Service U.S. National Library of Medicine and National Institute of Health: **http://www. nlm.nih.gov**
- National Center for Complimentary and Alternative Medicine: **http://www.nccam.nih.gov**
- National Pain Foundation: **http://www.nationalpainfoundation.org**
- Pain Resource Center: **http://www.prc.coh.org**
- WebMD Pain Management Center: **http://www.webmd.com/pain-management/default.htm**
- WHOs Pain Relief Ladder: **http://www.who.int/cancer/palliative/painladder/en**

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The author has no significant ties, financial or otherwise, to any company that might have an interest in the publication of this educational activity.

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DOI: 10.1097/NHH.0b013e3181ed7504

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