Pain Assessment in the Patient Unable to Self-Report: Position Statement with Clinical Practice Recommendations

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POSITION STATEMENT

Pain is a subjective experience, and no objective tests exist to measure it (American Pain Society, 2009). Whenever possible, the existence and intensity of pain are measured by the patient’s self-report, abiding by the clinical definition of pain which states, “Pain is whatever the experiencing person says it is, existing whenever he/she says it does” (McCaffery, 1968). Unfortunately, some patients cannot provide a self-report of pain verbally, in writing, or by other means, such as finger span (Merkel, 2002) or blinking their eyes to answer yes or no questions (Pasero & McCaffery, 2011).

This position statement addresses five populations of patients who may be unable to self-report: older adults with advanced dementia, infants and preverbal toddlers, critically ill/unconscious patients, persons with intellectual disabilities, and patients at the end of life. Each of these populations may be unable to self-report pain owing to cognitive, developmental, or physiologic issues, including medically induced conditions, creating a major barrier for adequate pain assessment and achieving optimal pain control. Inability to provide a reliable report about pain leaves the patient vulnerable to underrecognition and undertreatment. Nurses are integral to ensuring assessment and treatment of these vulnerable populations.

ETHICAL TENETS

The ethical principles of beneficence (the duty to benefit another) and nonmaleficence (the duty to do no harm) oblige health care professionals to provide pain management and comfort to all patients, including those vulnerable individuals who are unable to speak for themselves. Providing quality and comparable care to individuals who cannot report their pain is directed by the principle of justice (the equal or comparative treatment of individuals). Respect for
human dignity, the first principle in the ‘Code of Ethics for Nurses’ (American Nurses Association, 2001), directs nurses to provide and advocate for humane and appropriate care. Based on the principle of justice, this care is given with compassion and unrestricted by consideration of personal attributes, economic status, or the nature of the health problem. In alignment with these ethical tenets, the International Association for the Study of Pain (IASP) initiated the Declaration of Montreal at the International Pain Summit, a statement acknowledging access to pain management as a fundamental human right endorsed by 64 IASP Chapters and many other organizations and individuals (International Association for the Study of Pain, 2011).

The American Society for Pain Management Nursing positions that all persons with pain deserve prompt recognition and treatment. Pain should be routinely assessed, reassessed, and documented to facilitate treatment and communication among health care clinicians (Gordon, Dahl, Miaskowski, McCarberg, Todd, Paice, et al., 2005). In patients who are unable to self-report pain, other strategies must be used to infer pain and evaluate interventions. No single objective assessment strategy, such as interpretation of behaviors, pathology or estimates of pain by others, is sufficient by itself.

GENERAL RECOMMENDATIONS FOR CLINICAL PRACTICE

A Hierarchy of Pain Assessment Techniques (Pasero & McCaffery, 2011; Hadjistavropoulos, Herr, Turk, Fine, Dworkin, Helme, et al., 2007) has been recommended as a framework to guide assessment approaches and is relevant for patients unable to self-report. Table 1 provides a summary of the key tenets as they relate to specific subpopulations. General recommendations for assessing pain in those unable to self-report follow.

Use the Hierarchy of Pain Assessment Techniques

Self-Report. Attempts should be made to obtain self-report of pain from all patients. A self-report of pain from a patient with limited verbal and cognitive skills may be a simple yes/no or other vocalizations or gestures, such as hand grasp or eye blink. When self-report is absent or limited, explain why self-report cannot be used and further investigation and observation are needed.

Search for Potential Causes of Pain. Pathologic conditions (e.g., surgery, trauma, osteoarthritis, wounds, history of persistent pain) and common procedures known to cause iatrogenic pain (e.g., wound care, rehabilitation activities, positioning/turning, blood draws, heel sticks), should trigger an intervention, even in the absence of behavioral indicators. Iatrogenic pain associated with procedures should be treated before initiation of the procedure. A change in behavior requires careful evaluation of pain or other sources of distress, including physiologic compromise (e.g., respiratory distress, cardiac failure, hypotension). Generally, one may assume that pain is present, and if there is reason to suspect pain, an analgesic trial can be diagnostic as well as therapeutic (American Pain Society, 2008). Other problems that may be causing discomfort should be ruled out (e.g., infection, constipation) or treated.

Observe Patient Behaviors. In the absence of self-report, observation of behavior is a valid approach to pain assessment. Common behaviors that may indicate pain, as well as evidence-based valid and reliable behavioral pain tools for the selected populations, have been identified for each subpopulation. Although weak to moderate correlations have been found between behavioral pain scores and the self-report of pain intensity, these two means of pain assessment measure different components of pain (sensory and behavioral) and should be considered to provide complementary information about the pain experience. Therefore, a behavioral pain score should not be considered to be equivalent to a self-report of pain intensity (e.g., a behavioral pain score of 4/10 does not equal a self-report of pain intensity of 4/10).

Moreover, pain behaviors are not specific reflections of pain intensity, and in some cases indicate another source of distress, such as physiologic or emotional distress (Pasero & McCaffery, 2005). It is difficult to discriminate pain intensity from pain unpleasantness and emotions such as fear. Potential causes and the context of the behavior must be considered when making treatment decisions. Remember that sleep and sedation do not equate with the absence of pain or with pain relief. Awareness of individual baseline behaviors and changes that occur during procedures known to be painful or other potential sources of pain are useful in differentiating pain from other causes.

Proxy Reporting (family members, parents, unlicensed caregivers, professional caregivers) of Pain and Behavior/Activity Changes. Credible information can be obtained from a family member or another person who knows the patient well (e.g., spouse, parent, child, caregiver). Parents and consistent caregivers should be encouraged to actively participate in the assessment of pain. Familiarity with the patient and knowledge of usual and past behaviors can assist in identifying subtle less obvious changes
<table>
<thead>
<tr>
<th>Hierarchy</th>
<th>Infants/Preverbal Toddlers</th>
<th>Critically Ill/ Unconscious</th>
<th>Dementia</th>
<th>Intellectual Disability (ID)</th>
<th>End of Life</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Obtain self-report</td>
<td>Infants, toddlers, &amp; developmentally preverbal children lack cognitive skills necessary to report &amp; describe pain.</td>
<td>Self-report should be attempted; however, may be hampered by delirium, cognitive &amp; communication limitations, level of consciousness, presence of endotracheal tube, sedatives, &amp; neuromuscular blocking agents.</td>
<td>Self-report of pain often possible in mild to moderate cognitive impairment, but ability to self-report decreases as dementia progresses.</td>
<td>Majority of individuals with ID are verbal &amp; can self-report pain using appropriate self-report pain assessment tool.</td>
<td>Cognitive abilities often fail as disease progresses. Pain assessment must include assuming that pain is present if pain was previously a complaint.</td>
</tr>
<tr>
<td>2. Search for potential causes of pain</td>
<td>Infections, injuries, diagnostic tests, surgical procedures, &amp; disease progression possible causes.</td>
<td>Sources of pain include existing medical condition, traumatic injuries, surgical/ medical procedures, invasive instrumentation, drawing blood, &amp; other routine care: suctioning, turning, positioning, drain &amp; catheter removal, &amp; wound care.</td>
<td>Consider common chronic pain etiologies. Musculoskeletal, &amp; neurologic disorders most common causes of pain in older adults.</td>
<td>Prevalence &amp; burden of pain higher than in healthy children, &amp; prevalence of pain in adults with ID higher than in adults without ID.</td>
<td>Causes of pain in this population typically very complex; numerous sites &amp; etiologies of pain not uncommon.</td>
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<tr>
<td>3. Observe patient behavior</td>
<td>Primary behavioral categories used to help identify pain in infants include facial expression, body activity/motor movement, &amp; crying/ verbalization. As cognitive abilities increase, toddlers &amp; children demonstrate fewer overt pain behaviors. Evaluate response to painful stimuli and use of effective consoling techniques</td>
<td>Facial tension &amp; expressions, such as grimacing, frowning, &amp; wincing, often seen in critically ill patients experiencing pain.</td>
<td>Observe facial expressions, verbalizations/ vocalizations, body movements, changes in interactions, changes in activity patterns or routines, &amp; mental status. Behavioral observation should occur during activity whenever possible</td>
<td>Behavioral pain tools should be used for initial &amp; ongoing assessments.</td>
<td>Use indicators shown to be relevant to specific patient. Intensive assessment required.</td>
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</table>
4. **Proxy reporting**
Parents usually know their child’s typical behavioral response to pain and can identify behaviors unique to the child to include in the assessment of pain.

Parents, caregivers, & family members can help identify specific pain indicators for critically ill/ unconscious individuals.

In long-term care setting, the certified nursing assistant is a key health care provider shown to be effective in recognizing presence of pain.

Family helpful if visit regularly.

Parents & caregivers may know individual’s typical behavioral response to pain & can identify unique pain behaviors. However, caregivers of children with ID frequently underestimate pain intensity.

Family and/or caregivers play an essential role in recognizing pain and evaluating comfort as the person transitions toward death.

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**5. Attempt an analgesic trial**
Base initial opioid dose on weight and titrate as appropriate.

Initiate analgesic trial if pain is suspected to verify presence of pain.

Estimate the intensity of pain based on information obtained from prior assessment steps & select appropriate analgesic. Opioid dosing in older adults warrants initial dose reduction to 25%-50% of adult dose.

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apnea, neurologic impairment, older adults) are at risk for opioid adverse effects (Brown, Laferriere, & Moss, 2004; Overdyk, Carter, Maddox, Callura, Herrin, & Henriquez, 2007; Voepel-Lewis, Marinkovic, Kostrzewa, Tait, & Malviya, 2008). No research confirms that weight (except in children) should be used to determine starting dose (Burns, Hodsman, McIntock, Gille, Kenny, & McArdle, 1989; Macintyre & Jarvis, 1996).

**Establish a Procedure for Pain Assessment**

A procedure for evaluating pain presence and response to treatment should be instituted in each health care setting. The hierarchy of assessment techniques discussed above is recommended, and the following can be used as a template for the initial assessment and treatment procedure (Pasero & McCaffery, 2011).

a. Attempt first to elicit a self-report from patient and, if unable, document why self-report cannot be used.
b. Identify pathologic conditions or procedures that may cause pain.
c. List patient behaviors that may indicate pain. A behavioral assessment tool may be used.
d. Identify behaviors that caregivers and others knowledgeable about the patient think may indicate pain.
e. Attempt an analgesic trial.

**Use Behavioral Pain Assessment Tools as Appropriate**

Use of a behavioral pain assessment tool may assist in recognition of pain in these vulnerable populations. It is incumbent on health care providers to consider the strength of psychometric evaluation data (e.g., reliability and validity of the tool in a specific patient population and a given context) and the clinical feasibility of instruments (e.g., training required, time to complete). Clinicians should select a tool that has been evaluated in the population and setting of interest. Tools with repeated supporting research by multiple authors are considered to be stronger. Use of a reliable and valid tool helps to ensure that clinicians are using appropriate criteria in their pain assessments. Standardized tools promote consistency among care providers and care settings and facilitate communication and evaluation of pain management treatment decisions. However, the appropriateness of a tool must be assessed patient by patient, and no one tool should be an institutional mandate for all patients (Pasero & McCaffery, 2005). For example, a behavior pain tool developed for persons with dementia may not be appropriate for patients in the intensive care unit who are unable to communicate, and tools for children are not generalizable to adults.

For some behavioral tools that are scored, the intensity of the pain may be assumed to be reflected in the sum of the score. However, a behavioral pain score is not the same as a self-reported pain intensity rating, nor can the scores be compared with standard pain intensity ratings or categories of pain intensity. Behavioral assessment tools can be helpful to identify the presence of pain and to evaluate treatment effects (Pasero & McCaffery, 2011). When selecting a behavioral pain assessment tool, if the score and determination of pain depend on a response in each category of behavior, it is important that the patient is able to respond in all categories. For example, a tool that includes bracing/rubbing or restlessness would not be appropriate for a patient who is intentionally sedated.

**Keys to the use of behavioral pain tools are to focus on the individual's behavioral presentation (at both rest and on movement or during procedures known to be painful) and to observe for changes in those behaviors with effective treatment.** Increases or decreases in the number or intensity of behaviors suggest increasing or decreasing pain.

**Minimize Emphasis on Physiologic Indicators**

Physiologic indicators (e.g., changes in heart rate, blood pressure, respiratory rate), though important for assessing for potential side effects, are not sensitive for discriminating pain from other sources of distress. Although physiologic indicators are often used to document pain presence, the correlation of vital sign changes with behaviors and self-reports of pain has been weak or absent (Aissaoui, Zeggwagh, Zekraoui, Abidi, & Abouqal, 2005; Arbour & Gelinas, 2010; Foster, Yucha, Zuk, & Vojir, 2003; Gelinas & Johnston, 2007; Gelinas & Arbour, 2009; Walco, Conte, Labay, Engel, & Zeltzer, 2005). Absence of a change in vital signs does not indicate absence of pain.

**Reassess and Document**

After intervention and regularly over time, the patient should be reassessed with methods of pain assessment and specific behavioral indicators that have been identified as significant and appropriate for the individual patient. Assessment approaches and pain indicators should be documented in a readily visible and consistent manner that is accessible to all health care providers involved in the assessment and management of pain (Gordon et al., 2005; Miaskowski, Cleary, Burney, Coyne, Finley, et al., 2005). In the case of temporary inability to self-report, patient capacity to self-report should be reevaluated periodically.
**PERSONS WITH ADVANCED DEMENTIA: GUIDING PRINCIPLES FOR ASSESSMENT OF PAIN**

An approach to recognizing pain in dementia that has been demonstrated to be effective in nursing homes (NHs) is the Serial Trial Intervention (STI) that incorporates most of the hierarchy components discussed above (Kovach, Noonan, Schlidt, Reynolds, & Wells, 2006). Recommendations for pain assessment in older adults with advanced dementia unable to self-report that are unique from the general recommendations include the following.

**Self-Report**

The pathologic changes in dementia seriously affect the ability of those with advanced stages of disease to communicate pain. Damage to the central nervous system affects memory, language, and higher-order cognitive processing necessary to communicate the experience. Yet, despite changes in central nervous system functioning, persons with dementia still experience pain sensation to a degree similar to the cognitively intact older adult (Karp, Shega, Morone, & Weiner, 2008; Kunz, Myllis, Scharmann, Schepelman, & Lautenbacher, 2009; Scherder, Herr, Pickering, Gibson, Benedetti, & Lautenbacher, 2009). However, pathologic changes associated with dementia affect the interpretation of the pain stimulus and the affective response to that sensation (Reynolds, Hanson, DeVellis, Henderson, & Steinhauser, 2008; Scherder et al., 2009) and differences in pain processing have been noted in distinct types of dementia (Carlino, Benedetti, Rainero, Asteggiano, Cappa, Tarenzi, et al., 2010). Although self-report of pain is often possible in those with mild to moderate cognitive impairment, as dementia progresses the ability to self-report decreases and eventually is no longer possible (Kelley, Siegler, & Reid, 2008; Pesonen, Kauppila, Tarkkila, Sutela, Niinisto, & Rosenberg, 2009).

**Search for Potential Causes of Pain**

Consider chronic pain etiologies common in older persons (e.g., history of arthritis, low back pain, neuropathies). Musculoskeletal (e.g., osteoporosis, degenerative disk disease, osteoarthritis) and neurologic disorders (e.g., postherpetic neuralgia, trigeminal neuralgia, diabetic neuropathy, fibromyalgia) are the most common causes of pain and should be given priority in the assessment process. Pain resulting from cancer, trauma, or other sources should also be explored. A recent fall or other acute pain-related problem (e.g., urinary tract infection, pneumonia, skin tear) could also be the cause of pain.

**Observation of Patient Behaviors**

Observe for behaviors recognized as indicators of pain in this population. Facial expressions, verbalizations, body movements, changes in interpersonal interactions, changes in activity patterns or routines, and mental status changes have been identified as categories of potential pain indicators in older persons with dementia (American Geriatric Society Panel on Persistent Pain in Older Persons, 2002; Hadjistavropoulos et al., 2007). A list of indicators included in these categories and an algorithm for evaluating pain in persons unable to self-report is available (Reuben, Herr, Pacala, Pollack, Potter, & Semla, 2010). Some behaviors are common and typically considered to be pain related (e.g., facial grimacing, moaning, groaning, rubbing a body part), but others are less obvious (e.g., agitation, restlessness, irritability, confusion, combativeness [particularly with care activities or treatments], changes in appetite or usual activities) and require follow-up evaluation. Typical pain behaviors may not be present and more subtle indicators may be the only indicator of unrecognized pain. It is not clear which behaviors are most often associated with pain in persons with dementia, although research is building evidence in this area (Chapman, 2008; Kunz, Scharmann, Hemmeter, Schepelman, Lautenbacher, 2007; Shega, Rudy, Keefe, Perri, Mengin, & Weiner, 2008). Use the American Geriatric Society’s indicators of pain (AGS, 2002), the Minimum Data Set 3.0 pain behaviors (Saliba & Buchanan, 2008), or a nonverbal pain assessment tool that is appropriate, valid, and reliable for use with this population. Behavioral observation should occur during activity whenever possible, because pain may be minimal or absent at rest (Hadjistavropoulos et al., 2007; Husebo, Strand, Moe-Nilssen, Borghusebo, Aarsland, & Ljunggren, 2008; Liu, Briggs, & Closs, 2010). Vital sign changes are not an accurate reflection of pain in persons with dementia (Kunz et al., 2009).

**Use of Behavioral Pain Assessment Tools**

Existing nonverbal pain assessment tools for use in persons with dementia have varying levels of established reliability, validity, and clinical usefulness (including ease of use, time to complete, training needed). Ongoing studies are contributing new information and refinement of existing tools, as well as evaluating approaches to recognizing pain in this population. Behavioral tools with few indicators may be more clinically feasible but may not detect pain in patients who present with less obvious behaviors. Longer and more comprehensive checklists may be more sensitive but also identify patients for whom behaviors...
represent another unmet need rather than pain. Given the current state of frequent underrecognition of pain in this population, increased sensitivity may be preferable but requires further evaluation to validate pain as the cause of the suspect behaviors.

A comprehensive review of currently published tools for assessing pain in nonverbal persons with dementia is available at http://prc.coh.org/PAIN-NOA.htm, and recommendations for older adults in the nursing home have been recently reported (Herr, Bursch, Ersek, Miller, & Swafford, 2010). Other sound tools have been developed internationally but are not yet validated in English-speaking populations. Tools tested in English-speaking populations with the strongest conceptual and psychometric support as well as clinical usefulness are presented in Table 2, although users should consult the literature regularly for updates. Clinicians are encouraged to review selected tools for appropriateness to the older adult’s care setting and obtain data to support their use through Quality Improvement projects.

**Proxy Reporting of Pain**

In the long-term care setting, the certified nursing assistant is a key health care provider shown to be effective in recognizing the presence of pain (Nygaard & Jarland, 2006; Pautex, Herrmann, Michon, Giannakopoulos, & Gold, 2007). Education on screening for pain should be a component of all certified nursing assistant training. Family members are likely to be the caregiver with the most familiarity with typical pain behaviors or changes in usual activities that might suggest pain presence in the acute care setting and in other settings in which the health care providers do not have a history with the patient (Nygaard & Jarland, 2006; Shega, Hougham, Stocking, Cox-Hayley, & Sachs, 2004); although frequent contact with the resident is necessary (Eritz & Hadjistavropoulos, 2011).

**Attempt an Analgesic Trial**

Estimate the intensity of pain based on information obtained from prior assessment steps and select an appropriate analgesic, starting low and titrating to effect (American Geriatrics Society Panel on Pharmacological Management of Persistent Pain in Older Persons, 2009). For example, when mild to moderate pain is suspected, 325-500 mg acetaminophen every 4 hours or 500 to 1,000 mg acetaminophen every 6 hours may be appropriate initially, with titration to stronger analgesics if there is no change in behaviors and pain continues to be suspected. The maximum daily dose should be reduced to 50%-75% in patients with hepatic insufficiency or history of alcohol abuse.

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**Table 2. Persons with Advanced Dementia: Behavioral Pain Assessment Tools**

<table>
<thead>
<tr>
<th>Tool</th>
<th>Tests in: Sample</th>
<th>Setting</th>
</tr>
</thead>
<tbody>
<tr>
<td>CNPI: Checklist of Nonverbal Pain Indicators</td>
<td>Acute/chronic pain, Dementia</td>
<td>Long-term care</td>
</tr>
<tr>
<td>CPAT: Certified Nursing Assistant Pain Assessment Tool</td>
<td>Acute and chronic pain, Dementia</td>
<td>Long-term care</td>
</tr>
<tr>
<td>NOPPAIN: Nursing Assistant–Administered Instrument to Assess Pain in Demented Individuals</td>
<td>Acute and chronic pain, Dementia</td>
<td>Long-term care</td>
</tr>
<tr>
<td>Mahoney Pain Scale</td>
<td>Advanced dementia</td>
<td>Chronic pain</td>
</tr>
<tr>
<td>PACSLAC: Pain Assessment Scale for Seniors with Severe Dementia</td>
<td>Chronic pain</td>
<td>Long-term care, acute care</td>
</tr>
<tr>
<td>PAINAD: Pain Assessment in Advanced Dementia Scale</td>
<td>Chronic pain</td>
<td>Long-term care, acute care</td>
</tr>
<tr>
<td>PAINE: Pain Assessment in Noncommunicative Elderly Persons</td>
<td>Chronic pain</td>
<td>Long-term care, acute care</td>
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</table>
Improving pain management in older adults may be met with resistance from providers and family, although it may be necessary to establish pain presence. Opioid dosing in older adults (those older than 70 years) warrants an initial dose reduction of 25%-50% of the recommended starting dose for adults (AGS, 2009; American Pain Society, 2008). Using an analgesic trial to validate presence of pain before increasing or adding psychotropic medications has several advantages. Compared with psychotrophic intervention, response will be seen more quickly with an analgesic intervention, the adverse reactions to analgesics are usually less serious, and pain will not be obscured by the sedative properties of psychotherapeutic agents. With this approach, pain is more likely to be detected and treated. Consider psychiatric approaches, such as adding or changing doses of new psychiatric pharmacologic approaches (e.g., antipsychotics, sedatives), if behaviors do not improve with an analgesic intervention (Kovach et al., 2006).

INFANTS AND PREVERBAL TODDLERS: GUIDING PRINCIPLES FOR ASSESSMENT OF PAIN

Recommendations for pain assessment in infants/nonverbal children unable to self-report that are unique from the general recommendations include the following.

Self-Report

Infants, toddlers, and developmentally preverbal children lack the cognitive skills necessary to report and describe pain. As children develop verbal and cognitive skills they are able to report the experience and intensity of pain. The ability to express the presence of pain emerges at about 2 years of age. Developmentally appropriate children as young as 3 years of age may be able to quantify pain using simple validated pain tools (Fanjurik, Koh, Harrison, Conrad, & Tomerlin, 1998; McGrath, Walco, Turk, Dworkin, Brown, et al., 2008; Spagrud, Piira, & von Baeyer, 2003); however, report bias is very common in children aged 3-5 years, complicating the interpretation of their pain scores (Stanford, Chambers, & Craig, 2006; von Baeyer, Forsyth, Stanford, Watson, & Chambers, 2009). Young children have difficulty discriminating between the sensory experience of pain and the distress or fear of pain, as well as distressing symptoms such as nausea (Goodenough, Thomas, Champion, Perrott, Taplin, et al., 1999; Wennstrom & Bergh, 2008). The majority of developmentally appropriate children >8 years of age are able to reliably use a self-report numeric rating tool.

Search for Potential Causes of Pain

Infections, injuries, diagnostic tests, surgical procedures, and disease progression are possible causes for pain in infants and young children and should be treated with the presumption that pain is present. Developmentally nonverbal children often have a higher burden of pain from frequent medical/surgical procedures and illness, and suspicion of pain should be high, warranting careful assessment (McGrath et al., 2008; Stevens, McGrath, Gibbins, Beyene, Breau, et al., 2003).

Observation of Patient Behaviors

Infants and children react to pain by exhibiting specific behaviors. The primary behavioral categories used to help identify pain in this population include facial expression, body activity/motor movement, and crying/verbalization (McGrath et al., 2008). Body posture, changes in muscle tone, and response to the environment are also indicators of pain. Facial expressions of an infant experiencing acute pain include eyebrows lowered and drawn together to form a vertical furrow, a bulge between the brows with the eyes tightly closed, cheeks raised with a furrow between the nose and upper lip, and the mouth open and stretched in the shape of square (Grunau & Craig, 1990). In addition, high pitched, tense, and harsh cries have been indicated as a behavioral measure of infant pain (Fuller & Conner, 1995). However, infant behaviors such as motor movement and facial expressions that accompany crying are not independent indicators of acute pain (Fuller, 2001).

The primary behavioral signs of pain are often more apparent and consistent for procedural pain and postoperative pain than for chronic pain. Neonates who are experiencing prolonged or persistent pain may not exhibit the usual behavioral signs of pain seen in neonates who are experiencing acute pain, instead exhibiting signs and symptoms of energy conservation (American Academy of Pediatrics Committee on Fetus and Newborn, American Academy of Pediatrics Section on Surgery, & Canadian Paediatric Society Fetus and Newborn Committee, 2006; Anand, 2007).

Observed behavioral responses to pain change as a child gains control over body movement. Sleeping and withdrawn behavior may be the child’s attempts to control pain by limiting activity and interactions. There may be a dampening of the primary pain behaviors in children who experience prolonged pain or chronic pain. Behaviors seen in children with chronic pain may not be obscured by the sedative properties of psychotherapeutic agents. With this approach, pain is more likely to be detected and treated. Consider psychiatric approaches, such as adding or changing doses of new psychiatric pharmacologic approaches (e.g., antipsychotics, sedatives), if behaviors do not improve with an analgesic intervention (Kovach et al., 2006).
cancer pain include posturing, wariness of being moved, and psychomotor inertia, which has been described as withdrawal, lack of expression, and lack of interest in surroundings (Gauvain-Piquard, Rodary, Rezvani, & Serbouti, 1999). Distress behaviors, such as irritability, agitation, and restlessness, may or may not be related to pain and in many cases may indicate physiologic distress, such as respiratory compromise or drug reactions. Therefore, consider the context of the behaviors, medical history, and caregiver opinions when using behavioral pain assessment tools and making treatment decisions. Children who suffer from chronic pain may not demonstrate behavioral changes that are noticeable to the nurse. The subtle signs of pain in these children might include a difference in their willingness or ability to play (Busoni, 2007; Eccleston, Bruce, & Carter, 2006).

Physiologic indicators, such as heart rate, respiratory rate, and oxygen saturation, have been reported to provide information about the neonatal response to noxious stimuli and are associated with acute pain (Stevens, Johnston, Petryshen, & Taddio, 1996). Physiologic indicators, however, are also affected by disease, medications, and changes in physiologic status and are therefore not specific to the presence or absence of pain in children (Foster et al., 2003).

Use of Behavioral Pain Assessment Tools
Although no single behavioral tool has been shown to be superior to others, several have been recommended for use in clinical settings (Crellin, Sullivan, Babl, O’Sullivan, & Hutchinson, 2007; von Baeyer & Spagrud, 2007), and clinicians should select a tool that is appropriate to the patient and types of pain on which it has been tested. Behavioral pain tools should be used for initial and ongoing assessments. See Table 3 for tools to be considered.

Proxy Reporting of Pain
Include evaluation of the response of the infant, toddler, or developmentally nonverbal child to parents and the environment in the assessment of pain. Explain behavioral tools to parents and encourage them to actively participate in identifying pain and evaluating their child’s response to interventions. Responsiveness to interventions by a trusted caregiver to console the child, such as rocking, touch, and verbal reassurance, should be considered when observing distressed behaviors. Parents usually know their child’s typical behavioral response to pain and can identify behaviors unique to the child that can be included in the assessment of pain. However, the nursing staff may be most familiar with the infant or young child’s pain behavior if the child has not been home since birth or for infants and children’s first experience with surgical or procedural pain.

Analgesic Trial
Initiate an analgesic trial with a nonopioid or low-dose opioid if pain is suspected and comfort measures, such as parental presence, security items, sucking, and distraction, are not effective in easing behaviors that may suggest pain. Base initial opioid dose on weight in children up to 50 kg, at which weight adult dosing may be appropriate, and titrate as appropriate. Very young infants and those with comorbidities demand careful titration of opioids, because these children are more sensitive to respiratory depressant effects. Oral sucrose can be an effective analgesic for infants 3 months old and younger who are undergoing minor pain procedures and could be used in an analgesic trial (Hatfield, Gusic, Dyer, & Polomano, 2008; Johnston, Fernandes, & Campbell-Yeo, 2011). Explore other potential causes of distress if behaviors continue after a reasonable analgesic trial.

CRITICALLY ILL/UNCONSCIOUS PERSONS: GUIDING PRINCIPLES FOR ASSESSMENT OF PAIN

Recommendations for pain assessment in critically ill and/or unconscious persons unable to self-report that are unique from the general recommendations include the following.

Self-Report
Self-report of pain should be attempted; however, obtaining a report of pain from a critically ill patient may be hampered by delirium, cognitive and communication limitations, altered level of consciousness, presence of an endotracheal tube, sedatives, and neuromuscular blocking agents. Owing to delirium that can wax and wane and affect ability to self-report, serial assessment for the ability to self-report should be conducted.

Potential Causes of Pain
Sources of pain in critically ill patients include the existing medical condition, traumatic injuries, surgical/medical procedures, invasive instrumentation, drawing blood, and other routine care, such as turning, positioning, suctioning, drain and catheter removal, and wound care (Puntillo, White, Morris, Perdue, Stanik-Hutt, et al., 2001; Puntillo, Morris, Thompson, Stanik-Hutt, White, & Wild, 2004; Simons, van Dijk, Soeken, Belcher, Fontaine, & Gift, 2001). Verbal adult patients experiencing painful conditions such as
<table>
<thead>
<tr>
<th>Tool</th>
<th>References</th>
<th>Tested in: Sample</th>
<th>Tested in: Setting</th>
</tr>
</thead>
<tbody>
<tr>
<td>CHEOPS: Children's Hospital of Eastern Ontario Pain Scale</td>
<td>McGrath et al., 1985; Suraseranivongse et al., 2001</td>
<td>Children 4 mo to 17 y; procedural pain &amp; brief postsurgical pain, short-term postsurgical pain</td>
<td>Postanesthesia care unit</td>
</tr>
<tr>
<td>CHIPPS: Children's and Infants’ Postoperative Pain Scale</td>
<td>Bringuier et al., 2009; Buttner &amp; Finke, 2000</td>
<td>Children birth to 5 y; surgical pain</td>
<td>Acute care</td>
</tr>
<tr>
<td>COMFORT Behavior Scale</td>
<td>de Jong et al., 2010; van Dijk et al., 2000; van Dijk, Peters, van Deventer, &amp; Tibboel, 2005</td>
<td>Neonate to 3 y; surgical pain</td>
<td>Intensive care</td>
</tr>
<tr>
<td>FLACC: Faces, Legs, Activity, Cry, and Consolability Observational Tool</td>
<td>Ahn &amp; Jun, 2007; Manworren &amp; Hyman, 2003; Merkel, Voepel-Lewis, Shayevitz, &amp; Malviya, 1997; Voepel-Lewis et al., 2002; Voepel-Lewis, Zanotti, Dammeyer, &amp; Merkel, 2010; Willis, Merkel, Voepel-Lewis, &amp; Malviya, 2003</td>
<td>Children 0 mo to 18 y; postoperative hospital &amp; procedural pain, surgical pain, &amp; acute pain</td>
<td>Postanesthesia care, intensive care, acute care</td>
</tr>
<tr>
<td>PIPP: Premature Infant Pain Profile</td>
<td>Ahn &amp; Jun, 2007; Stevens et al., 1996; Stevens, Johnston, Taddio, Gibbins, &amp; Yamada, 2010</td>
<td>Premature and term neonates; procedural pain</td>
<td>Neonatal intensive care unit</td>
</tr>
<tr>
<td>Toddler-Preschooler Postoperative Pain Measure</td>
<td>Suraseranivongse et al., 2001; Tarbell, Cohen, &amp; Marsh, 1992</td>
<td>Children 1-5 y; short-term postsurgical pain</td>
<td>Postanesthesia care, acute care</td>
</tr>
</tbody>
</table>
those noted earlier, describe a constant baseline aching pain with intermittent procedure-related pain descriptors such as sharp, stinging, stabbing, shooting, and awful pain; therefore it should be assumed that those unable to report pain also experience these sensations (Puntillo et al., 2001). In addition, immobility, hidden infection, and early pressure ulcers can cause pain and discomfort.

Observation of Patient Behavior
Facial expressions such as grimacing, frowning, and wincing are often seen in critically ill patients experiencing pain (Puntillo et al., 2004). Physical movement, immobility, and increased muscle tone may indicate the presence of pain. Tearing and diaphoresis in the sedated, paralyzed, and ventilated patient represent autonomic responses to discomfort (Hamill-Ruth & Marohn, 1999). Behavioral pain tools are not appropriate for pharmacologically paralyzed infants, children, adults, or those who are flaccid and cannot respond behaviorally to pain. In addition, behavioral pain tools may not be appropriate for brain-injured patients. Indeed, it was found that brain-injured patients’ exhibit different pain behaviors, such as no frowning, brow lowering, or closed eyes, compared with other critically ill patients (Gelinas & Arbour, 2009). Therefore, behaviors included in existing pain tools may not apply to those with a brain injury.

Assume that pain is present, and administer analgesics appropriately to patients who are given muscle relaxants and/or deep sedation and experience conditions and procedures thought to be painful. Patients may exhibit distress behaviors as a result of the fear and anxiety associated with being in the intensive care unit.

Relying on changes in vital signs as a primary indicator of pain can be misleading, because these may also be attributed to underlying physiologic conditions, homeostatic changes, and medications. Evidence that supports the use of vital signs as a single indicator of pain is limited; however, both physiologic and behavioral responses often increase temporarily with a sudden onset of pain (Gelinas & Arbour, 2009). Changes in physiologic measures should be considered to be a cue to begin further assessment for pain or other stressors.

Use of Behavioral Pain Assessment Tools
Although no single behavioral tool has been shown to be superior for use with this population, tools tested in other settings may be useful if found to be valid in the patient population and pain problem. Tools should be tested to ensure that they are reliable and valid if used with a population in which they have not been studied. See Table 4 for pediatric/critically ill/unconscious tools and Table 5 for tools specific to adults who are critically ill/unconscious.

Proxy Reporting of Pain
Parents of children, caregivers, family members, and surrogates can help to identify specific pain indicators for critically ill individuals. A family member’s report of their impression of a patient’s pain and response to an intervention should be included as one aspect of a pain assessment in the critically ill patient.

Analgesic Trial
An analgesic trial may be helpful in distinguishing distress behaviors from pain behaviors. Initiate an analgesic trial if pain is suspected. Ongoing treatment should consider the unique characteristics and needs of this population and should be carefully based on initial responses. The ongoing use of analgesics, sedatives, and comfort measures can provide pain relief and reduce the effect of the stress response. Paralyzing agents and sedatives are not substitutes for analgesics. This population often requires weaning from opioid and sedative agents to facilitate extubation. Non-sedating agents and approaches (such as nonsteroidal antiinflammatory drugs, lower doses of patient-controlled analgesics, and nonopioid epidural agents) should be considered to treat pain during these periods. In patients with head injury, the judicious use of opioids, in consideration of their risk of sedation, may be appropriate. Short-acting opioids, such as fentanyl, may facilitate appropriate titration and analgesic reversal if needed.

PERSONS WITH INTELLECTUAL DISABILITY: GUIDING PRINCIPLES FOR ASSESSMENT OF PAIN

Persons with intellectual disability (ID) have been cognitively impaired since birth or very early childhood, and the ID continues throughout life; in contrast, cognitive impairment can be acquired at any age. ID may or may not be accompanied by physical disability (Bottos & Chambers, 2006). ID patients are usually defined by intelligence quotient (IQ) scores. An IQ score of 50 to 70 indicates mild cognitive impairment and represents 85% of those with IDs. These persons are verbal and usually acquire a sixth-grade academic skills level; IQ scores <50 indicate moderate, severe, or profound impairment (American Psychiatric Association, 1994; Bottos & Chambers, 2006). The Faces Pain Tool–Revised is a self-report method for those with suspected mental age >5 years (Goodenough et al., 1999). IQ scores that indicate moderate ID or more severe ID pose the greatest challenge to pain assessment.
Because the purpose of the present clinical practice recommendations is to address pain assessment in patients unable to self-report, it is these individuals with ID that will be the focus of this section. Recommendations for pain assessment in individuals with ID unable to self-report that are unique from the general recommendations include the following.

**Self-Report**

The majority of individuals with ID are verbal and can self-report pain using a developmentally appropriate self-report pain assessment tool. Therefore, seeking self-report and establishing reliability of self-report should be a first step.

**Search for Potential Causes of Pain**

Children and adults with ID experience a higher burden of pain compared to healthy individuals, which may be related to challenges in recognizing and communicating presence of pain (Bottos & Chambers, 2006). Patients with ID have also been observed carrying out normal activities even when seriously injured. Children and adults with IDs often have multiple co-morbid conditions that are associated with pain or require repeated or frequent procedures associated with pain. It is therefore imperative that providers carefully assess for the presence, location, and severity of pain, particularly when a potential source of pain is present. Furthermore, treating these potential sources on the assumption that pain is present may be appropriate.

**Observation of Patient Behaviors**

The individual behavioral response to painful stimuli varies from increases in behaviors to decreases in or dampening of behaviors. Some data have demonstrated differences in responses to pain (e.g., response time and sensitivity) in patients with ID due to differing diagnoses; however, the majority of children appear to have intact sensory function (Symons, Shinde, & Gilles, 2008). Researchers have also noted that self-injurious behaviors may be indicative of pain in some individuals with ID (Bosch, 2002; Carr & Owen-Deschryver, 2007). This variability in pain expression may be related to neurologic perception, or motor or communication abilities of the individual and poses unique challenges for effective recognition and treatment by clinicians and parents or caregivers. These individual differences in response to pain may contribute to under- or overestimation of pain. The importance of knowing the patient’s individual behaviors and recognizing behavioral and emotional patterns and changes requires collaboration with a parent or caregiver to effectively assess pain (Davies, 2010; Dubois, Capdevila, Bringuier, & Pry, 2010; Hunt, Goldman, Seers, Crichton, Mastroyannopoulou, et al., 2004).

**Use of Behavioral Pain Assessment Tools**

Although considerable research has focused on creating assessment tools for children with ID, few studies have included adults with ID. Clinicians should select a tool that is appropriate to the patient and types of pain on which it has been tested, weighing

| Table 4. Pediatrics—Critically Ill/Unconscious: Behavioral Pain Assessment Tools |
|---------------------------------|---------------------------------|---------------------------------|---------------------------------|
| Tool                            | References                      | Tested in: Sample               | Tested in: Setting              |
| COMFORT Behavior Scale          | Johansson & Kokinsky, 2009      | Children aged 0-10 y; surgical pain | Intensive care                  |
| Revised COMFORT Scale (measures other constructs than pain) | Ambuel, Hamlett, Marx, & Blumer, 1992; Carnevale & Razack, 2002 | Children newborn to 17 y of age; mechanically ventilated | Intensive care                  |
| DSVNl: Distress Scale for Ventilated Newborn Infant | Sparshott, 1996 | Ventilated newborns; procedural pain | Intensive care                  |
| FLACC: Faces, Legs, Activity, Cry, and Consolability Observational Tool | Ahn & Jun, 2007; Voepel-Lewis et al., 2002; Voepel-Lewis et al., 2010 | Children 0 months to 18 years of age; surgical pain & acute pain, post-operative hospital and procedural pain | Postanesthesia care, intensive care, & acute care |
| N-PASS: Neonatal Pain, Agitation, and Sedation Scale | Hummel et al., 2010 | Premature neonates 23-40 wk gestation; procedural & postoperative pain during mechanical ventilation | Neonatal intensive care unit |
psychometrics with tools having repeated supporting research by multiple authors being the strongest. The tools included in Table 6 have been evaluated in settings with individuals with ID.

### Proxy Reporting of Pain

Caregivers are often consulted regarding the interpretation of a person’s behavior and the relationship to pain. After reviewing several studies of children with ID, Symons et al. (2008) found that caregivers of children with ID were relatively sensitive pain detectors but frequently underestimated pain intensity compared with their children’s estimates (in those who could communicate) and that pain may be under-treated. Parents’ estimations of their children’s pain improved when they were provided information and a structured observational tool (Solodiuk et al., 2010). Most of the research on pain in patients with ID has been conducted in infants and children; however, many of the issues raised in these studies may be relevant to the care of adults with ID (Symons et al., 2008).

The Individualized Numeric Rating Scale (INRS) is based on proxy ratings by parents. Parents use knowledge of their child’s previous behaviors in response to painful conditions and procedures to complete the INRS. The Revised Face, Legs, Activity, Crying, and Consolability (rFLACC) scale provides descriptors unique to this population and suggests that clinicians seek input about the person’s baseline and pain behaviors. The Pediatric Pain Profile includes a section for caregivers to complete about the child’s pain history. These three tools allow for the identification of behaviors that are unique to the individual patient’s response to pain.

### Analgesic Trial

Initiate an analgesic trial if pain is suspected. The trial should be tailored to the age of the patient or weight in those <50 kg.

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**Table 6.** Adults—Critically Ill/Unconscious: Behavioral Pain Assessment Tools

<table>
<thead>
<tr>
<th>Tool</th>
<th>References</th>
<th>Tested in: Sample</th>
<th>Tested in: Setting</th>
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<tr>
<td>BPS: Behavioral Pain Scale</td>
<td>Ahlers et al., 2008; Ahlers, van der Veen, van Dijk, Tibboel, &amp; Knibbe, 2010; Aissaoui et al., 2005; Chanques et al., 2009; Payen et al., 2001; Young, Siffleet, Nikoletti, &amp; Shaw, 2006</td>
<td>Nonverbal &amp; verbal adults; procedural pain</td>
<td>Intensive care</td>
</tr>
<tr>
<td>FLACC: Face, Legs, Activity, Cry, and Consolability Behavioral Scale</td>
<td>Voepel-Lewis et al., 2010</td>
<td>Nonverbal adults; procedural pain</td>
<td>Intensive care</td>
</tr>
<tr>
<td>PBAT: Pain Behavioral Assessment Tool</td>
<td>Li, Miaskowski, Burkhardt, &amp; Puntillo, 2009; Puntillo et al., 2004</td>
<td>Verbal adults &amp; children; procedural pain</td>
<td>Intensive care</td>
</tr>
<tr>
<td>NPAT: Nonverbal Pain Assessment Tool</td>
<td>Klein, Dumpe, Katz, &amp; Bena, 2010</td>
<td>Nonverbal &amp; verbal adults</td>
<td>Intensive care</td>
</tr>
<tr>
<td>NVPS: Nonverbal Pain Scale</td>
<td>Kubes, Graves, &amp; Norris, 2009; Marmo &amp; Fowler, 2010; Odhner, Wegman, Freeland, Steinmetz, &amp; Ingersoll, 2003; Topolovec-Vranic et al., 2010</td>
<td>Nonverbal adults</td>
<td>Cardiac postanesthesia care, intensive care</td>
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PAIN AT END OF LIFE: GUIDING PRINCIPLES FOR ASSESSMENT OF PAIN

Pain is a common symptom in most illnesses that are life-threatening and/or progressive in nature. In fact, untreated pain may actually accelerate death by limiting mobility, increasing physiologic stress, and affecting factors such as pneumonia and thromboembolism (Hospice and Palliative Nurses Association, 2008; Paice, 2010). Recommendations for pain assessment in those at the end of life rely heavily on general principles that apply to most populations. As nurses advocate for effective pain management in this population, a major emphasis is appropriate pain assessment.

Self-Report
Cognitive abilities to verbalize pain often fail as disease progresses. Additionally, the frequency of delirium for patients with cancer at end of life is reported to be between 85% and 90% in the final days before death (Agar & Lawlor, 2008; del Fabbro, Dalal, & Bruera, 2006). The absence of reported pain does not necessarily mean that the patient is not experiencing pain or that pain has resolved. Pain assessment must include assuming that pain is present if pain was previously a complaint when the patient was cognitively intact.

Search for Potential Causes of Pain
Pain assessment is always a challenging process, but in end-of-life care a skilled pain assessment, as well as physical assessment, is critical (Fink & Gates, 2010; Lester, Daroowalla, Harisingani, Sykora, Lolis, et al., 2011). The causes of pain in this population of patients are typically very complex; numerous sites and causes of pain are not uncommon. A patient may be experiencing disease progression, altered metabolism, changes in medication metabolites, and

| Table 6. Persons with Intellectual Disability (ID): Behavioral Pain Assessment Tools |
|---------------------------------|-----------------|-----------------|-----------------|
| Tool                            | References      | Tested in: Sample | Tested in: Setting |
| rFLACC: Revised Faces, Legs, Activity, Cry, and Consolability Observational Tool | Malviya, Voepel-Lewis, Burke, Merkel, & Tait, 2006; Voepel-Lewis et al., 2002; Voepel-Lewis, Malviya, Merkel, & Tait, 2003; Voepel-Lewis, Malviya, & Tait, 2005 | Children 4-19 y, mild to severe impairment; postoperative pain | Acute care |
| NCCPC: Noncommunicating Children’s Pain Checklist | Breau, McGrath, Camfield, Rosmus, & Finley, 2000; Breau, Camfield, McGrath, Rosmus, & Finley, 2001; Breau, McGrath, Camfield, & Finley, 2002; Breau, 2003; Breau, Camfield, McGrath, & Finley, 2004; Breau & Camfield, 2011; Burkitt, Breau, & Zabalia, 2011; Lotan et al., 2009 | Children with ID; chronic pain | Postoperative, rehabilitation hospital; Revised NCCPC tested in children and adults in home/residential settings |
| Individualized Numeric Rating Scale (INRS) Paediatric Pain Profile | Solodiuk & Curley, 2003; Solodiuk et al., 2010 | Children 6-18 y, severe intellectual disability Children 1-18 yrs of age, severe neurologic disability & unable to communicate through speech or augmentative communication; chronic and postoperative pain | Acute care Home, hospice, acute care |
| NCAPC: Noncommunicating Adult Pain Checklist | Lotan et al., 2009 | Adult population, all levels of intellectual and developmental disabilities | Residential or community setting |
the need for frequent changes in routes of medications, including analgesics (Paice, 2010). The appearance of myoclonus, often related to use of opioids, may exacerbate pain. Pain etiology may also be from spiritual distress and existential suffering. Cognitive, affective, behavioral, and cultural factors may affect the assessment of pain in this population (Fink & Gates, 2010).

**Observation of Patient Behaviors**

Delirium and agitation frequently occurs as death approaches and may be due to intractable pain, but many other etiologies exist, such as disease progression, withdrawal, urinary retention, and electrolyte imbalances, necessitating intensive assessment. This population requires a proactive approach in the last months of life, because changes may occur quickly.

**Use of Behavioral Pain Assessment Tools**

To date there are limited tools developed and validated specifically for use with persons at the end of life. A recently developed tool to assess acute pain in patients who are unable to self-report in hospice and palliative care settings is the Multidimensional Objective Pain Assessment Tool (MOPAT). This tool has preliminary evidence of reliability, validity, and clinical usefulness for use by hospice staff nurses trained in use of the tool (McGuire, Reifsnyder, Socken, Kaiser, & Yeager, 2011). With limited validated tools for patients at the end of life, clinicians should consider tools intended for specific populations that may be relevant as the person moves toward death, such as those studied in long-term care settings. See other special population behavior tool sections. Tools that have been evaluated in a palliative care setting are listed in Table 7. Research is needed to guide practice with end-of-life patients in various settings of care.

**Proxy Reporting of Pain**

Family and/or caregivers play an essential role in recognizing pain and evaluating comfort as the person transitions toward death (Fink & Gates, 2010). Decisions in advanced care planning regarding patient goals for pain management and sedation must be considered and incorporated into the plan of care. Family education and support is important in supporting this vulnerable population in pain management, as many fears and barriers exist.

**Attempt an Analgesic Trial**

Determining presence of pain based on response to analgesia is very challenging in this population, because intentional sedation may obscure behaviors often used to detect pain. Because of this, it may be prudent to assume that pain is present and to continue analgesic treatment in the sedated patient. Assuring adequate analgesia while monitoring for presence of pain requires diligence and consideration of pathology, conditions known to be pain-related, and estimates of pain by others (Paice, 2010).

**SUMMARY**

Individuals who are unable to communicate their pain are at greater risk for under recognition and undertreatment of pain. This position paper describes the magnitude of this issue, defines populations at risk and offers clinical practice recommendations for appropriate pain assessment using a hierarchical framework for assessing pain in those unable to self-report. Nurses have a moral, ethical, and professional obligation to advocate for all individuals in their care, particularly those who are vulnerable and unable to speak for themselves. Just like all other patients, these special populations require consistent, ongoing assessment, appropriate treatment, and evaluation of interventions to insure the best possible pain relief. Because of continued advances and new developments in strategies and tools for assessing pain in these populations, clinicians are encouraged to stay current through regular review of new research and practice recommendations.

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**OTHER POSITION PAPERS/STATEMENTS/GUIDELINES**


