

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

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The purpose of this document is to provide guidance for clinicians caring for populations in which pain assessment is difficult. Recommendations provided are based on the best evidence available at the time of preparation.

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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 under recognition and under- or over-treatment. 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 non-maleficence (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 1.
Hierarchy of Pain Assessment Techniques (Pasero & McCaffery, 2011) and Specific Considerations by Subpopulation

Hierarchy	Infants/Preverbal Toddlers	Critically Ill/ Unconscious	Dementia	Intellectual Disability (ID)	End of Life
1. Obtain self-report	Infants, toddlers, & developmentally preverbal children lack cognitive skills necessary to report & describe pain.	Self-report should be attempted; however, may be hampered by delirium, cognitive & communication limitations, level of consciousness, presence of endotracheal tube, sedatives, & neuromuscular blocking agents.	Self-report of pain often possible in mild to moderate cognitive impairment, but ability to self-report decreases as dementia progresses.	Majority of individuals with ID are verbal & can self-report pain using appropriate self-report pain assessment tool.	Cognitive abilities often fail as disease progresses. Pain assessment must include assuming that pain is present if pain was previously a complaint.
2. Search for potential causes of pain	Infections, injuries, diagnostic tests, surgical procedures, & disease progression possible causes.	Sources of pain include existing medical condition, traumatic injuries, surgical/ medical procedures, invasive instrumentation, drawing blood, & other routine care: suctioning, turning, positioning, drain & catheter removal, & wound care.	Consider common chronic pain etiologies. Musculoskeletal, & neurologic disorders most common causes of pain in older adults.	Prevalence & burden of pain higher than in healthy children, & prevalence of pain in adults with ID higher than in adults without ID.	Causes of pain in this population typically very complex; numerous sites & etiologies of pain not uncommon.
3. Observe patient behavior	Primary behavioral categories used to help identify pain in infants include facial expression, body activity/motor movement, & crying/ verbalization. As cognitive abilities increase, toddlers & children demonstrate fewer overt pain behaviors. Evaluate response to painful stimuli and use of effective consoling techniques	Facial tension & expressions, such as grimacing, frowning, & wincing, often seen in critically ill patients experiencing pain.	Observe facial expressions, verbalizations/ vocalizations, body movements, changes in interactions, changes in activity patterns or routines, & mental status. Behavioral observation should occur during activity whenever possible	Behavioral pain tools should be used for initial & ongoing assessments.	Use indicators shown to be relevant to specific patient. Intensive assessment required.

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.
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.	Initiate analgesic trial if pain is suspected.	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.

in behavior that may be indicators of pain presence. Discrepancies exist between self-report of pain and external observer judgments of pain intensity that occur across varied raters (e.g., physician, nurse, family, aides) and settings (e.g., inpatient, outpatient, acute care, long-term care), with family members overestimating and providers underestimating the intensity of pain experienced (Kappesser, Williams, & Prkachin, 2006). Therefore, judgments by caregivers and clinicians are considered to be proxy assessments of pain intensity and should be combined with other evidence when possible. A multifaceted approach is recommended that combines direct observation, family/caregiver input, consideration of known pain-producing conditions, and evaluation of response to treatment.

Attempt an Analgesic Trial. An empiric analgesic trial should be initiated if there are pathologic conditions or procedures likely to cause pain or if pain behaviors continue after attention to basic needs and comfort measures. Provide an analgesic trial and titration appropriate to the estimated intensity of pain based on the patient's pathology and analgesic history. In general, if mild to moderate pain is suspected, non-pharmacologic approaches and nonopioid analgesics may be given initially (e.g., adult dose: 500 to 1,000 mg acetaminophen every 6 hours for 24 hours). If behaviors improve, assume pain was the cause, continue the analgesic, and add appropriate nonpharmacologic interventions. Consider giving a single low-dose short-acting opioid (e.g., hydrocodone, oxycodone, morphine) and observe the effect if behaviors that suggest pain continue. If there is no change in behavior, rule out other potential sources of pain or discomfort. Doses may then be carefully adjusted until a therapeutic effect is seen, bothersome or worrisome side effects occur, or lack of benefit is determined. In the case of neuropathic pain, it is not uncommon for analgesic trials to fail and therefore health care providers to assume there is no pain. It is important to consider medications to treat neuropathic pain if there is a history of conditions that might suggest a neuropathic etiology. It may be appropriate to start the analgesic trial with an opioid for conditions in which moderate to severe pain is expected. Reassess for other potential causes if behaviors continue after a reasonable analgesic trial.

The analgesic titration recommendation above is conservative and, although strategies for safe titration should be followed, more aggressive approaches may be needed (Gordon, Dahl, Phillips, Franderson, Crowley, Foster, et al., 2004). Titration doses should consider the patient's underlying comorbidities, because certain populations (e.g., obstructive sleep

apena, 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, Hodsmann, McLintock, Gillies, 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 & Gelinias, 2010; Foster, Yucha, Zuk, & Vojir, 2003; Gelinias & Johnston, 2007; Gelinias & 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, Mylius, 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/vocalizations, 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, Schepelmann, & 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, Borgehusebo, 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

TABLE 2.
Persons with Advanced Dementia: Behavioral Pain Assessment Tools

Tool	References	Tested In: Sample	Tested in: Setting
CNPI: Checklist of Nonverbal Pain Indicators	Feldt, Ryden, & Miles, 1998; Feldt, 2000; Jones et al., 2005; Nygaard & Jarland, 2006	Acute/chronic pain	Acute care, long-term care
CPAT: Certified Nursing Assistant Pain Assessment Tool	Cervo et al., 2007; Cervo et al., 2009	Dementia	Long-term care
NOPAIN: Nursing Assistant-Administered Instrument to Assess Pain in Demented Individuals	Horgas, Nichols, Schapson, & Vietes, 2007; Snow et al., 2004; Zwakhalen, Hamers, Abu-Saad, & Berger, 2006	Acute and chronic pain	Long-term care
Mahoney Pain Scale	Mahoney & Peters, 2008	Advanced dementia	Long-term care
PACSLAC: Pain Assessment Scale for Seniors with Severe Dementia	Fuchs-Lacelle & Hadjistavropoulos, 2004; Fuchs-Lacelle, Hadjistavropoulos, & Lix, 2008; van Nispen tot Pannerden et al., 2009; Zwakhalen et al., 2006; Zwakhalen, Hamers, & Berger, 2007; Zwakhalen, Koopmans, Geels, Berger, & Hamers, 2009	Chronic pain	Long-term care
PAINAD: Pain Assessment in Advanced Dementia Scale	Costardi et al., 2007; DeWaters et al., 2008; Lane et al., 2003; Leong, Chong, & Gibson, 2006; Liu, Briggs, & Closs, 2010; Schuler et al., 2007; Warden, Hurley, & Volicer, 2003; Zwakhalen et al., 2006	Chronic pain	Long-term care, acute care
PAINE: Pain Assessment in Noncommunicative Elderly Persons	Cohen-Mansfield, 2006; Cohen-Mansfield & Lipson, 2008		Long-term care

(AGS, 2009). Low-dose opioids have been effective in validating agitation as a pain indicator (Kovach et al., 2006; Manfredi, Breuer, Wallenstein, Stegmann, Bottomley, & Libow, 2003). Advancing to opioid use 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 psychotropic 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 trial (Kovach et al., 2006).

INFANTS AND PREVERBAL TODDLERS: GUIDING PRINCIPLES FOR ASSESSMENT OF PAIN

Recommendations for pain assessment in infants/non-verbal 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 (Fanurik, 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

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, Anand, Roofthoof, van Lingen, & Tibboel, 2003; Stanik-Hutt, Soeken, Belcher, Fontaine, & Gift, 2001). Verbal adult patients experiencing painful conditions such as

TABLE 3.
Infants and Preverbal Toddlers: Behavioral Pain Assessment Tools

Tool	References	Tested in: Sample	Tested in: Setting
CHEOPS: Children's Hospital of Eastern Ontario Pain Scale	McGrath et al., 1985; Suraseranivongse et al., 2001	Children 4 mo to 17 y; procedural pain & brief postsurgical pain, short-term postsurgical pain	Postanesthesia care unit
CHIPPS: Children's and Infants' Postoperative Pain Scale	Bringuier et al., 2009; Buttner & Finke, 2000	Children birth to 5 y; surgical pain	Acute care
COMFORT Behavior Scale	de Jong et al., 2010; van Dijk et al., 2000; van Dijk, Peters, van Deventer, & Tibboel, 2005	Neonate to 3 y; surgical pain	Intensive care
CRIES	Ahn & Jun, 2007; Krechel & Bildner, 1995	Neonates; procedural & surgical pain	Neonatal & pediatric intensive care
FLACC: Faces, Legs, Activity, Cry, and Consolability Observational Tool	Ahn & Jun, 2007; Manworren & Hynan, 2003; Merkel, Voepel-Lewis, Shayevitz, & Malviya, 1997; Voepel-Lewis et al., 2002; Voepel-Lewis, Zanotti, Dammeyer, & Merkel, 2010; Willis, Merkel, Voepel-Lewis, & Malviya, 2003	Children 0 mo to 18 y; postoperative hospital & procedural pain, surgical pain, & acute pain	Postanesthesia care, intensive care, acute care
N-PASS: Neonatal Pain, Agitation, and Sedation Scale	Hummel, Puchalski, Creech, & Weiss, 2008; Hummel, Lawlor-Klean, & Weiss, 2010	Premature neonates 23-40 wk gestation; procedural & postoperative pain during mechanical ventilation	Neonatal intensive care unit
PIPP: Premature Infant Pain Profile	Ahn & Jun, 2007; Stevens et al., 1996; Stevens, Johnston, Taddio, Gibbins, & Yamada, 2010	Premature and term neonates; procedural pain	Neonatal intensive care unit
Toddler-Preschooler Postoperative Pain Measure	Suraseranivongse et al., 2001; Tarbell, Cohen, & Marsh, 1992	Children 1-5 y; short-term postsurgical pain	Postanesthesia care, acute care

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. Nonsedating 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.

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
DSVNI: 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

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 comorbid 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 5.
Adults—Critically Ill/Unconscious: Behavioral Pain Assessment Tools

Tool	References	Tested in: Sample	Tested in: Setting
BPS: Behavioral Pain Scale	Ahlers et al., 2008; Ahlers, van der Veen, van Dijk, Tibboel, & Knibbe, 2010; Aissaoui et al., 2005; Chanques et al., 2009; Payen et al., 2001; Young, Siffleet, Nikoletti, & Shaw, 2006	Nonverbal & verbal adults; procedural pain	Intensive care
CPOT: Critical-Care Pain Observation Tool	Gelinas, Fillion, Puntillo, Viens, & Fortier, 2006; Gelinas & Johnston, 2007; Gelinas & Arbour, 2009; Gelinas, Fillion, & Puntillo, 2009; Gelinas, 2010; Marmo & Fowler, 2010	Nonverbal & verbal adults; procedural pain	Intensive care
FLACC: Face, Legs, Activity, Cry, and Consolability Behavioral Scale	Voepel-Lewis et al., 2010	Nonverbal adults; procedural pain	Intensive care
PBAT: Pain Behavioral Assessment Tool	Li, Miaskowski, Burkhardt, & Puntillo, 2009; Puntillo et al., 2004	Verbal adults & children; procedural pain	Intensive care
NPAT: Nonverbal Pain Assessment Tool	Klein, Dumpe, Katz, & Bena, 2010	Nonverbal & verbal adults	Intensive care
NVPS: Nonverbal Pain Scale	Kabes, Graves, & Norris, 2009; Marmo & Fowler, 2010; Odhner, Wegman, Freeland, Steinmetz, & Ingersoll, 2003; Topolovec-Vranic et al., 2010	Nonverbal adults	Cardiac postanesthesia care, intensive care

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 undertreated. 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.

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 Hunt et al., 2004	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

TABLE 7.
Persons at End of Life: Behavioral Pain Assessment Tools

Tool	References	Tested in: Sample	Tested in: Setting
MOPAT: Multidimensional Objective Pain Assessment Tool	McGuire et al., 2011	Adults	Hospice
PAINAD: Pain Assessment in Advanced Dementia Tool	van Iersel, Timmerman, & Mullie, 2006	Older adults	Long-term care

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, Reifsnnyder, Soeken, 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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REFERENCES

- Agar, M., & Lawlor, P. (2008). Delirium in cancer patients: A focus on treatment-induced psychopathology. *Current Opinion in Oncology*, 20(4), 360-366.
- American Geriatric Society Panel on Persistent Pain in Older Persons (2002). The management of persistent pain in older persons. *Journal of the American Geriatrics Society*, 50(6 Suppl), S205-S224.
- Ahlers, S. J., van der Veen, A. M., van Dijk, M., Tibboel, D., & Knibbe, C. A. (2010). The use of the behavioral pain scale to assess pain in conscious sedated patients. *Anesthesia and Analgesia*, 110(1), 127-133.
- Ahlers, S. J., van Gulik, L., van der Veen, A. M., van Dongen, H. P., Bruins, P., Belitser, S. V., de Boer, A., Tibboel, D., & Knibbe, C. A. (2008). Comparison of different pain scoring systems in critically ill patients in a general ICU. *Critical Care (London, England)*, 12(1), R15.
- Ahn, Y., & Jun, Y. (2007). Measurement of pain-like response to various NICU stimulants for high-risk infants. *Early Human Development*, 83(4), 255-262.
- Aissaoui, Y., Zeggwagh, A. A., Zekraoui, A., Abidi, K., & Abouqal, R. (2005). Validation of a behavioral pain scale in critically ill, sedated, and mechanically ventilated patients. *Anesthesia and Analgesia*, 101(5), 1470-1476.
- Ambuel, B., Hamlett, K. W., Marx, C. M., & Blumer, J. L. (1992). Assessing distress in pediatric intensive care environments: The COMFORT scale. *Journal of Pediatric Psychology*, 17(1), 95-109.
- American Academy of Pediatrics Committee on Fetus and Newborn, American Academy of Pediatrics Section on Surgery, & Canadian Paediatric Society Fetus and Newborn Committee (2006). Prevention and management of pain in the neonate: An update. *Pediatrics*, 118(5), 2231-2241.
- American Geriatrics Society Panel on Pharmacological Management of Persistent Pain in Older Persons (2009). Pharmacological management of persistent pain in older persons. *Journal of the American Geriatrics Society*, 57(8), 1331-1346.
- American Nurses Association (2001). *Code of ethics for nurses with interpretive statements*. Silver Springs, MD: American Nurses Publishing.
- American Pain Society (2008). *Guideline for the use of chronic opioid therapy in chronic noncancer pain*, (1st ed.) Glenview, IL: American Pain Society.
- American Pain Society (2009). *Principles of analgesic use in the treatment of acute pain and cancer pain*, (6th ed.) Glenview, IL: American Pain Society.
- American Psychiatric Association (1994). *Diagnostic & statistical manual of mental disorders DSM-IV*. Washington, DC: American Psychiatric Association.
- Anand, K. J. (2007). Pain assessment in preterm neonates. *Pediatrics*, 119(3), 605-607.
- Arbour, C., & Gelinas, C. (2010). Are vital signs valid indicators for the assessment of pain in postoperative cardiac surgery ICU adults? *Intensive & Critical Care Nursing*, 26(2), 83-90.
- Bosch, J. J. (2002). Use of directed history and behavioral indicators in the assessment of the child with a developmental disability. *Journal of Pediatric Health Care*, 16(4), 170-179.
- Bottos, S., & Chambers, C. T. (2006). The epidemiology of pain in developmental disabilities. In T. F. Oberlander, & F. J. Symons (Eds.), *Pain in children and adults with developmental disabilities*. Baltimore, MD: Brookes.
- Breau, L. M. (2003). Non-communicating children's pain checklist: Better pain assessment for severely disabled children. *Expert Review of Pharmacoeconomics & Outcomes Research*, 3(3), 327-339.
- Breau, L. M., & Camfield, C. S. (2011). The relation between children's pain behaviour and developmental characteristics: A cross-sectional study. *Developmental Medicine and Child Neurology*, 53(2), e1-e7.
- Breau, L. M., Camfield, C., McGrath, P. J., Rosmus, C., & Finley, G. A. (2001). Measuring pain accurately in children with cognitive impairments: Refinement of a caregiver scale. *The Journal of Pediatrics*, 138(5), 721-727.
- Breau, L. M., Camfield, C. S., McGrath, P. J., & Finley, G. A. (2004). Risk factors for pain in children with severe cognitive impairments. *Developmental Medicine and Child Neurology*, 46(6), 364-371.
- Breau, L. M., McGrath, P. J., Camfield, C. S., & Finley, G. A. (2002). Psychometric properties of the noncommunicating children's pain checklist-revised. *Pain*, 99(1-2), 349-357.
- Breau, L. M., McGrath, P. J., Camfield, C., Rosmus, C., & Finley, G. A. (2000). Preliminary validation of an observational pain checklist for persons with cognitive impairments and inability to communicate verbally. *Developmental Medicine and Child Neurology*, 42(9), 609-616.
- Bringuier, S., Picot, M. C., Dadure, C., Rochette, A., Raux, O., Boulhais, M., & Capdevila, X. (2009). A prospective comparison of post-surgical behavioral pain scales in pre-schoolers highlighting the risk of false evaluations. *Pain*, 145(1-2), 60-68.
- Brown, K. A., Laferriere, A., & Moss, I. R. (2004). Recurrent hypoxemia in young children with obstructive sleep apnea is associated with reduced opioid requirement for analgesia. *Anesthesiology*, 100(4), 806-810.
- Burkitt, C. C., Breau, L. M., & Zabalia, M. (2011). Parental assessment of pain coping in individuals with intellectual and developmental disabilities. *Research in Developmental Disabilities*.
- Burns, J. W., Hodsman, N. B., McLintock, T. T., Gillies, G. W., Kenny, G. N., & McArdle, C. S. (1989). The influence of patient characteristics on the requirements for

postoperative analgesia. A reassessment using patient-controlled analgesia. *Anaesthesia*, 44(1), 2-6.

Busoni, P. (2007). Difficulties in controlling pain in children. *Regional Anesthesia and Pain Medicine*, 32(6), 505-506-509.

Buttner, W., & Finke, W. (2000). Analysis of behavioural and physiological parameters for the assessment of postoperative analgesic demand in newborns, infants and young children: A comprehensive report on seven consecutive studies. *Paediatric Anaesthesia*, 10(3), 303-318.

Carlino, E., Benedetti, F., Rainero, I., Asteggiano, G., Cappa, G., Tarenzi, L., Vighetti, S., & Pollo, A. (2010). Pain perception and tolerance in patients with frontotemporal dementia. *Pain*, 151(3), 783-789.

Carnevale, F. A., & Razack, S. (2002). An item analysis of the COMFORT scale in a pediatric intensive care unit. *Pediatric Critical Care Medicine*, 3(2), 177-180.

Carr, E. G., & Owen-Deschryver, J. S. (2007). Physical illness, pain, and problem behavior in minimally verbal people with developmental disabilities. *Journal of Autism and Developmental Disorders*, 37(3), 413-424.

Cervo, F. A., Bruckenthal, P., Chen, J. J., Bright-Long, L. E., Fields, S., Zhang, G., & Strongwater, I. (2009). Pain assessment in nursing home residents with dementia: Psychometric properties and clinical utility of the CNA pain assessment tool (CPAT). *Journal of the American Medical Directors Association*, 10(7), 505-510.

Cervo, F. A., Raggi, R. P., Bright-Long, L. E., Wright, W. K., Rows, G., Torres, A. E., Levy, R. B., & Komaroff, E. (2007). Use of the certified nursing assistant pain assessment tool (CPAT) in nursing home residents with dementia. *American Journal of Alzheimer's Disease and Other Dementias*, 22(2), 112-119.

Chanques, G., Payen, J. F., Mercier, G., de Lattre, S., Viel, E., Jung, B., Cisse, M., Lefrant, J. Y., & Jaber, S. (2009). Assessing pain in nonintubated critically ill patients unable to self-report: An adaptation of the behavioral pain scale. *Intensive Care Medicine*, 35(12), 2060-2067.

Chapman, C. R. (2008). Progress in pain assessment: The cognitively compromised patient. *Current Opinion in Anaesthesiology*, 21(5), 610-615.

Cohen-Mansfield, J. (2006). Pain Assessment in Noncommunicative Elderly Persons—PAINe. *The Clinical Journal of Pain*, 22(6), 569-575.

Cohen-Mansfield, J., & Lipson, S. (2008). The utility of pain assessment for analgesic use in persons with dementia. *Pain*, 134(1-2), 16-23.

Costardi, D., Rozzini, L., Costanzi, C., Ghianda, D., Franzoni, S., Padovani, A., & Trabucchi, M. (2007). The Italian version of the Pain Assessment in Advanced Dementia (PAINAD) scale. *Archives of Gerontology and Geriatrics*, 44(2), 175-180.

Crellin, D., Sullivan, T. P., Babl, F. E., O'Sullivan, R., & Hutchinson, A. (2007). Analysis of the validation of existing behavioral pain and distress scales for use in the procedural setting. *Paediatric Anaesthesia*, 17(8), 720-733.

Davies, R. B. (2010). Pain in children with Down syndrome: Assessment and intervention by parents. *Pain Management Nursing*, 11(4), 259-267.

de Jong, A., Baartmans, M., Bremer, M., van Komen, R., Middelkoop, E., Tuinebreijervan, W., & von Loey, N. (2010). Reliability, validity and clinical utility of three types of pain behavioural observation scales for young children with burns aged 0-5 years. *Pain*, 150(3), 561-567.

del Fabbro, E., Dalal, S., & Bruera, E. (2006). Symptom control in palliative care—part III: Dyspnea and delirium. *Journal of Palliative Medicine*, 9(2), 422-436.

DeWaters, T., Faut-Callahan, M., McCann, J. J., Paice, J. A., Fogg, L., Hollinger-Smith, L., Sikorski, K., & Stanaitis, H. (2008). Comparison of self-reported pain and the PAINAD scale in hospitalized cognitively impaired and intact older adults after hip fracture surgery. *Orthopaedic Nursing/National Association of Orthopaedic Nurses*, 27(1), 21-28.

Dubois, A., Capdevila, X., Bringuier, S., & Pry, R. (2010). Pain expression in children with an intellectual disability. *European Journal of Pain (London, England)*, 14(6), 654-660.

Eccleston, C., Bruce, E., & Carter, B. (2006). Chronic pain in children and adolescents. *Paediatric Nursing*, 18(10), 30-33.

Eritz, H., & Hadjistavropoulos, T. (2011). Do informal caregivers consider nonverbal behavior when they assess pain in people with severe dementia? *The Journal of Pain*, 12(3), 331-339.

Fanurik, D., Koh, J. L., Harrison, R. D., Conrad, T. M., & Tomerlin, C. (1998). Pain assessment in children with cognitive impairment an exploration of self-report skills. *Clinical Nursing Research*, 7(2), 103-119, discussion 120-4.

Feldt, K. S. (2000). The checklist of nonverbal pain indicators (CNPI). *Pain Management Nursing*, 1(1), 13-21.

Feldt, K. S., Ryden, M. B., & Miles, S. (1998). Treatment of pain in cognitively impaired compared with cognitively intact older patients with hip-fracture. *Journal of the American Geriatrics Society*, 46(9), 1079-1085.

Fink, R. M., & Gates, R. A. (2010). Pain assessment. In B. R. Ferrell, & N. Coyle (Eds.), *Oxford textbook of palliative care*, (3rd ed.) (pp. 137-160) New York: Oxford University Press.

Foster, R. L., Yucha, C. B., Zuk, J., & Vojir, C. P. (2003). Physiologic correlates of comfort in healthy children. *Pain Management Nursing*, 4(1), 23-30.

Fuchs-Lacelle, S., & Hadjistavropoulos, T. (2004). Development and preliminary validation of the Pain Assessment Checklist for Seniors with Limited Ability to Communicate (PACSLAC). *Pain Management Nursing*, 5(1), 37-49.

Fuchs-Lacelle, S., Hadjistavropoulos, T., & Lix, L. (2008). Pain assessment as intervention: A study of older adults with severe dementia. *The Clinical Journal of Pain*, 24(8), 697-707.

Fuller, B. F. (2001). Infant behaviors as indicators of established acute pain. *Journal of the Society of Pediatric Nurses*, 6(3), 109-115.

Fuller, B. F., & Conner, D. A. (1995). The effect of pain on infant behaviors. *Clinical Nursing Research*, 4(3), 253-273.

Gauvain-Piquard, A., Rodary, C., Rezvani, A., & Serbouti, S. (1999). The development of the DEGR(R): A scale to assess pain in young children with cancer. *European Journal of Pain (London, England)*, 3(2), 165-176.

Gelinas, C. (2010). Nurses' evaluations of the feasibility and the clinical utility of the critical-care pain observation tool. *Pain Management Nursing*, 11(2), 115-125.

Gelinas, C., & Arbour, C. (2009). Behavioral and physiologic indicators during a nociceptive procedure in conscious and unconscious mechanically ventilated adults: Similar or different? *Journal of Critical Care*, 24(4), 628.e7-628.e17.

Gelinas, C., Fillion, L., & Puntillo, K. A. (2009). Item selection and content validity of the critical-care pain

observation tool for nonverbal adults. *Journal of Advanced Nursing*, 65(1), 203–216.

Gelinas, C., Fillion, L., Puntillo, K. A., Viens, C., & Fortier, M. (2006). Validation of the critical-care pain observation tool in adult patients. *American Journal of Critical Care*, 15(4), 420–427.

Gelinas, C., & Johnston, C. (2007). Pain assessment in the critically ill ventilated adult: Validation of the critical-care pain observation tool and physiologic indicators. *The Clinical Journal of Pain*, 23(6), 497–505.

Goodenough, B., Thomas, W., Champion, G. D., Perrott, D., Taplin, J. E., von Baeyer, C. L., & Ziegler, J. B. (1999). Unravelling age effects and sex differences in needle pain: Ratings of sensory intensity and unpleasantness of venipuncture pain by children and their parents. *Pain*, 80(1-2), 179–190.

Gordon, D. B., Dahl, J. L., Miaskowski, C., McCarberg, B., Todd, K. H., Paice, J. A., Lipman, A. G., Bookbinder, M., Sanders, S. H., Turk, D. C., & Carr, D. B. (2005). American Pain Society Recommendations for Improving the Quality of Acute and Cancer Pain Management: American Pain Society Quality of Care Task Force. *Archives of Internal Medicine*, 165(14), 1574–1580.

Gordon, D. B., Dahl, J., Phillips, P., Frandsen, J., Cowley, C., Foster, R. L., Fine, P. G., Miaskowski, C., Fishman, S., Finley, R. S., & American Society for Pain Management Nursing, & American Pain Society (2004). The use of “as-needed” range orders for opioid analgesics in the management of acute pain: A consensus statement of the American society for pain management nursing and the American pain society. *Pain Management Nursing*, 5(2), 53–58.

Grunau, R. V. E., & Craig, K. D. (1990). Facial activity as a measure of neonatal pain expression. In D. C. Tyler, & E. J. Krane (Eds.), *Advances in pain research and therapy: Pediatric pain* (pp. 147–156). New York: Raven.

Hadjistavropoulos, T., Herr, K., Turk, D. C., Fine, P. G., Dworkin, R. H., Helme, R., Jackson, K., Parmelee, P. A., Rudy, T. E., Lynn Beattie, B., Chibnall, J. T., Craig, K. D., Ferrell, B., Ferrell, B., Fillingim, R. B., Gagliese, L., Gallagher, R., Gibson, S. J., Harrison, E. L., Katz, B., Keefe, F. J., Lieber, S. J., Lussier, D., Schmader, K. E., Tait, R. C., Weiner, D. K., & Williams, J. (2007). An interdisciplinary expert consensus statement on assessment of pain in older persons. *The Clinical Journal of Pain*, 23(1 Suppl), S1–S43.

Hamill-Ruth, R. J., & Marohn, M. L. (1999). Evaluation of pain in the critically ill patient. *Critical Care Clinics*, 15(1), 35–54, v-vi.

Hatfield, L. A., Gusic, M. E., Dyer, A. M., & Polomano, R. C. (2008). Analgesic properties of oral sucrose during routine immunizations at 2 and 4 months of age. *Pediatrics*, 121(2), e327–e334.

Herr, K., Bursch, H., Ersek, M., Miller, L. L., & Swafford, K. (2010). Use of pain-behavioral assessment tools in the nursing home: Expert consensus recommendations for practice. *Journal of Gerontological Nursing*, 36(3), 18–29.

Horgas, A. L., Nichols, A. L., Schapson, C. A., & Vietes, K. (2007). Assessing pain in persons with dementia: Relationships among the noncommunicative patient’s pain assessment instrument, self-report, and behavioral observations. *Pain Management Nursing*, 8(2), 77–85.

Hospice and Palliative Nurses Association (2008). *HPNA position statement: Pain management*. Retrieved March 4, 2011, from <http://www.hpna.org/DisplayPage.aspx?Title=PositionStatements>.

Hummel, P., Lawlor-Klean, P., & Weiss, M. G. (2010). Validity and reliability of the N-PASS assessment tool with acute pain. *Journal of Perinatology*, 30(7), 474–478.

Hummel, P., Puchalski, M., Creech, S. D., & Weiss, M. G. (2008). Clinical reliability and validity of the N-PASS: Neonatal pain, agitation and sedation scale with prolonged pain. *Journal of Perinatology*, 28(1), 55–60.

Hunt, A., Goldman, A., Seers, K., Crichton, N., Mastroyannopoulou, K., Moffat, V., Oulton, K., & Brady, M. (2004). Clinical validation of the paediatric pain profile. *Developmental Medicine and Child Neurology*, 46(1), 9–18.

Husebo, B. S., Strand, L. I., Moe-Nilssen, R., Borgehusebo, S., Aarsland, D., & Ljunggren, A. E. (2008). Who suffers most? Dementia and pain in nursing home patients: A cross-sectional study. *Journal of the American Medical Directors Association*, 9(6), 427–433.

International Association for the Study of Pain. IASP Declaration of Montreal. Statement of access to pain management as a fundamental human right Retrieved February 6, 2011, from http://www.iasp-pain.org/AM/Template.cfm?Section=Declaration_of_MontrandNum233_al.

Johansson, M., & Kokinsky, E. (2009). The COMFORT behavioural scale and the modified FLACC scale in paediatric intensive care. *Nursing in Critical Care*, 14(3), 122–130.

Johnston, C. C., Fernandes, A. M., & Campbell-Yeo, M. (2011). Pain in neonates is different. *Pain*, 152(3 Suppl), S65–S73.

Jones, K. R., Fink, R., Hutt, E., Vojir, C., Pepper, G. A., Scott-Cawiezell, J., & Mellis, B. K. (2005). Measuring pain intensity in nursing home residents. *Journal of Pain and Symptom Management*, 30(6), 519–527.

Kabes, A. M., Graves, J. K., & Norris, J. (2009). Further validation of the nonverbal pain scale in intensive care patients. *Critical Care Nurse*, 29(1), 59–66.

Kappesser, J., Williams, A. C., & Prkachin, K. M. (2006). Testing two accounts of pain underestimation. *Pain*, 124(1-2), 109–116.

Karp, J. F., Shega, J. W., Morone, N. E., & Weiner, D. K. (2008). Advances in understanding the mechanisms and management of persistent pain in older adults. *British Journal of Anaesthesia*, 101(1), 111–120.

Kelley, A. S., Siegler, E. L., & Reid, M. C. (2008). Pitfalls and recommendations regarding the management of acute pain among hospitalized patients with dementia. *Pain Medicine (Malden, Mass.)*, 9(5), 581–586.

Klein, D. G., Dumpe, M., Katz, E., & Bena, J. (2010). Pain assessment in the intensive care unit: Development and psychometric testing of the nonverbal pain assessment tool. *Heart & Lung: The Journal of Critical Care*, 39(6), 521–528.

Kovach, C. R., Noonan, P. E., Schlidt, A. M., Reynolds, S., & Wells, T. (2006). The Serial Trial Intervention: An innovative approach to meeting needs of individuals with dementia. *Journal of Gerontological Nursing*, 32(4), 18–25.

Krechel, S. W., & Bildner, J. (1995). CRIES: A new neonatal postoperative pain measurement score. initial testing of validity and reliability. *Paediatric Anaesthesia*, 5(1), 53–61.

Kunz, M., Mylius, V., Scharmann, S., Schepelman, K., & Lautenbacher, S. (2009). Influence of dementia on multiple components of pain. *European Journal of Pain (London, England)*, 13(3), 317–325.

Kunz, M., Scharmann, S., Hemmeter, U., Schepelman, K., & Lautenbacher, S. (2007). The facial expression of pain in patients with dementia. *Pain*, 133(1-3), 221–228.

- Lane, P., Kuntupis, M., MacDonald, S., McCarthy, P., Panke, J. A., Warden, V., & Volicer, L. (2003). A pain assessment tool for people with advanced Alzheimer's and other progressive dementias. *Home Healthcare Nurse, 21*(1), 32-37.
- Leong, I. Y., Chong, M. S., & Gibson, S. J. (2006). The use of a self-reported pain measure, a nurse-reported pain measure and the PAINAD in nursing home residents with moderate and severe dementia: A validation study. *Age and Ageing, 35*(3), 252-256.
- Lester, P. E., Daroowalla, F., Harisingani, R., Sykora, A., Lolis, J., Patrick, P. A., Feuerman, M., & Berger, J. T. (2011). Evaluation of housestaff knowledge and perception of competence in palliative symptom management. *Journal of Palliative Medicine, 14*(2), 139-145.
- Li, D., Miaskowski, C., Burkhardt, D., & Puntillo, K. (2009). Evaluations of physiologic reactivity and reflexive behaviors during noxious procedures in sedated critically ill patients. *Journal of Critical Care, 24*(3), 472.e9-472.e13.
- Liu, J. Y., Briggs, M., & Closs, S. J. (2010). The psychometric qualities of four observational pain tools (OPTs) for the assessment of pain in elderly people with osteoarthritic pain. *Journal of Pain and Symptom Management, 40*(4), 582-598.
- Lotan, M., Ljunggren, E. A., Johnsen, T. B., Defrin, R., Pick, C. G., & Strand, L. I. (2009). A modified version of the noncommunicating children pain checklist-revised, adapted to adults with intellectual and developmental disabilities: Sensitivity to pain and internal consistency. *The Journal of Pain, 10*(4), 398-407.
- Macintyre, P. E., & Jarvis, D. A. (1996). Age is the best predictor of postoperative morphine requirements. *Pain, 64*(2), 357-364.
- Mahoney, A. E., & Peters, L. (2008). The Mahoney pain scale: Examining pain and agitation in advanced dementia. *American Journal of Alzheimer's Disease and Other Dementias, 23*(3), 250-261.
- Malviya, S., Voepel-Lewis, T., Burke, C., Merkel, S., & Tait, A. R. (2006). The revised FLACC observational pain tool: Improved reliability and validity for pain assessment in children with cognitive impairment. *Paediatric Anaesthesia, 16*(3), 258-265.
- Manfredi, P. L., Breuer, B., Wallenstein, S., Stegmann, M., Bottomley, G., & Libow, L. (2003). Opioid treatment for agitation in patients with advanced dementia. *International Journal of Geriatric Psychiatry, 18*(8), 700-705.
- Manworren, R. C., & Hynan, L. S. (2003). Clinical validation of FLACC: Preverbal patient pain scale. *Pediatric Nursing, 29*(2), 140-146.
- Marmo, L., & Fowler, S. (2010). Pain assessment tool in the critically ill post-open heart surgery patient population. *Pain Management Nursing, 11*(3), 134-140.
- McCaffery, M. (1968). *Nursing practice theories related to cognition, bodily pain, and man-environment interactions*. Los Angeles, CA: University of California at Los Angeles Students' Store.
- McGrath, P. J., Johnson, G. I., Goodman, J. T., Schillinger, J., Dunn, J., & Chapman, J. (1985). CHEOPS: A behavioral scale for rating postoperative pain in children. In H. L. Fields (Ed.), *Advances in pain research* (pp. 395-402). New York: Raven.
- McGrath, P. J., Walco, G. A., Turk, D. C., Dworkin, R. H., Brown, M. T., Davidson, K., Eccleston, C., Finley, G. A., Goldschneider, K., Haverkos, L., Hertz, S. H., Ljungman, G., Palermo, T., Rappaport, B. A., Rhodes, T., Schechter, N., Scott, J., Sethna, N., Svensson, O. K., Stinson, J., von Baeyer, C. L., Walker, L., Weisman, S., White, R. E., Zajicek, A., Zeltzer, L., & PedIMMPACT (2008). Core outcome domains and measures for pediatric acute and chronic/recurrent pain clinical trials: PedIMMPACT recommendations. *The Journal of Pain, 9*(9), 771-783.
- McGuire, D. B., Reifsnnyder, J., Soeken, K., Kaiser, K. S., & Yeager, K. A. (2011). Assessing pain in nonresponsive hospice patients: Development and preliminary testing of the Multidimensional Objective Pain Assessment Tool (MOPAT). *Journal of Palliative Medicine, 14*(3), 287-292.
- Merkel, S. (2002). Pain assessment in infants and young children: The finger span scale. *The American Journal of Nursing, 102*(11), 55-56.
- Merkel, S. I., Voepel-Lewis, T., Shayevitz, J. R., & Malviya, S. (1997). The FLACC: A behavioral scale for scoring postoperative pain in young children. *Pediatric Nursing, 23*(3), 293-297.
- Miaskowski, C., Cleary, J., Burney, R., Coyne, P., Finley, R., Foster, R., Grossman, S., Janjan, N., Ray, J., Syrjala, K., Weisman, S., & Zahrbock, C. (2005). *Guideline for the management of cancer pain in adults and children (Clinical practice guidelines series, no. 3)*. Glenville, IL: American Pain Society.
- Nygaard, H. A., & Jarland, M. (2006). The Checklist of Non-verbal Pain Indicators (CNPI): Testing of reliability and validity in Norwegian nursing homes. *Age and Ageing, 35*(1), 79-81.
- Odhner, M., Wegman, D., Freeland, N., Steinmetz, A., & Ingersoll, G. L. (2003). Assessing pain control in nonverbal critically ill adults. *Dimensions of Critical Care Nursing: DCCN, 22*(6), 260-267.
- Overdyk, F. J., Carter, R., Maddox, R. R., Callura, J., Herrin, A. E., & Henriquez, C. (2007). Continuous oximetry/capnometry monitoring reveals frequent desaturation and bradypnea during patient-controlled analgesia. *Anesthesia and Analgesia, 105*(2), 412-418.
- Paice, J. A. (2010). Pain at the end of life. In B. R. Ferrell, & N. Coyle (Eds.), *Oxford textbook of palliative care*, (3rd ed.) (pp. 161-185) New York: Oxford University Press.
- Pasero, C., & McCaffery, M. (2005). No self-report means no pain-intensity rating. *The American Journal of Nursing, 105*(10), 50-53.
- Pasero, C., & McCaffery, M. (2011). *Pain assessment and pharmacologic management*. St. Louis: Mosby.
- Pautex, S., Herrmann, F. R., Michon, A., Giannakopoulos, P., & Gold, G. (2007). Psychometric properties of the doloplus-2 observational pain assessment scale and comparison to self-assessment in hospitalized elderly. *The Clinical Journal of Pain, 23*(9), 774-779.
- Payen, J. F., Bru, O., Bosson, J. L., Lagrasta, A., Novel, E., Deschaux, I., Lavagne, P., & Jacquot, C. (2001). Assessing pain in critically ill sedated patients by using a behavioral pain scale. *Critical Care Medicine, 29*(12), 2258-2263.
- Pesonen, A., Kauppila, T., Tarkkila, P., Sutela, A., Niinisto, L., & Rosenberg, P. H. (2009). Evaluation of easily applicable pain measurement tools for the assessment of pain in demented patients. *Acta Anaesthesiologica Scandinavica, 53*(5), 657-664.
- Puntillo, K. A., Morris, A. B., Thompson, C. L., Stanik-Hutt, J., White, C. A., & Wild, L. R. (2004). Pain behaviors observed during six common procedures: Results from Thunder Project II. *Critical Care Medicine, 32*(2), 421-427.
- Puntillo, K. A., White, C., Morris, A. B., Perdue, S. T., Stanik-Hutt, J., Thompson, C. L., & Wild, L. R. (2001). Patients' perceptions and responses to procedural pain:

Results from Thunder Project II. *American Journal of Critical Care*, 10(4), 238-251.

Reuben, D., Herr, K., Pacala, J., Pollack, B., Potter, J., & Semla, T. (2010). *Geriatrics at your fingertips*, (12th ed.) New York: American Geriatrics Society.

Reynolds, K. S., Hanson, L. C., DeVellis, R. F., Henderson, M., & Steinhauer, K. E. (2008). Disparities in pain management between cognitively intact and cognitively impaired nursing home residents. *Journal of Pain and Symptom Management*, 35(4), 388-396.

Saliba, D., & Buchanan, J. (2008). Rand Corporation Health: Development & validation of a revised nursing home assessment tool: MDS 3.0. Retrieved April 4, 2011, from http://www.cms.gov/NursingHomeQualityInits/25_NHQIMDS30.asp

Scherder, E., Herr, K., Pickering, G., Gibson, S., Benedetti, F., & Lautenbacher, S. (2009). Pain in dementia. *Pain*, 145(3), 276-278.

Schuler, M. S., Becker, S., Kaspar, R., Nikolaus, T., Kruse, A., & Basler, H. D. (2007). Psychometric properties of the German "Pain Assessment in Advanced Dementia Scale" (PAINAD-G) in nursing home residents. *Journal of the American Medical Directors Association*, 8(6), 388-395.

Shega, J. W., Hougham, G. W., Stocking, C. B., Cox-Hayley, D., & Sachs, G. A. (2004). Pain in community-dwelling persons with dementia: Frequency, intensity, and congruence between patient and caregiver report. *Journal of Pain and Symptom Management*, 28(6), 585-592.

Shega, J. W., Rudy, T., Keefe, F. J., Perri, L. C., Mengin, O. T., & Weiner, D. K. (2008). Validity of pain behaviors in persons with mild to moderate cognitive impairment. *Journal of the American Geriatrics Society*, 56(9), 1631-1637.

Simons, S. H., van Dijk, M., Anand, K. S., Roofthoof, D., van Lingen, R. A., & Tibboel, D. (2003). Do we still hurt newborn babies? A prospective study of procedural pain and analgesia in neonates. *Archives of Pediatrics & Adolescent Medicine*, 157(11), 1058-1064.

Snow, A. L., Weber, J. B., O'Malley, K. J., Cody, M., Beck, C., Bruera, E., Ashton, C., & Kunik, M. E. (2004). NOPPAIN: A nursing assistant-administered pain assessment instrument for use in dementia. *Dementia and Geriatric Cognitive Disorders*, 17(3), 240-246.

Solodiuk, J., & Curley, M. A. (2003). Pain assessment in nonverbal children with severe cognitive impairments: The Individualized Numeric Rating Scale (INRS). *Journal of Pediatric Nursing*, 18(4), 295-299.

Solodiuk, J. C., Scott-Sutherland, J., Meyers, M., Myette, B., Shusterman, C., Karian, V. E., Harris, S. K., & Curley, M. A. (2010). Validation of the Individualized Numeric Rating Scale (INRS): A pain assessment tool for nonverbal children with intellectual disability. *Pain*, 150(2), 231-236.

Spagrud, L. J., Piira, T., & Von Baeyer, C. L. (2003). Children's self-report of pain intensity. *The American Journal of Nursing*, 103(12), 62-64.

Sparshott, M. (1996). The development of a clinical distress scale for ventilated newborn infants: Identification of pain and distress based on validated scores. *Journal of Neonatal Nursing*, 2(2), 5-11.

Stanford, E. A., Chambers, C. T., & Craig, K. D. (2006). The role of developmental factors in predicting young children's use of a self-report scale for pain. *Pain*, 120(1-2), 16-23.

Stanik-Hutt, J. A., Soeken, K. L., Belcher, A. E., Fontaine, D. K., & Gift, A. G. (2001). Pain experiences of

traumatically injured patients in a critical care setting. *American Journal of Critical Care*, 10(4), 252-259.

Stevens, B., Johnston, C., Petryshen, P., & Taddio, A. (1996). Premature infant pain profile: Development and initial validation. *The Clinical Journal of Pain*, 12(1), 13-22.

Stevens, B., Johnston, C., Taddio, A., Gibbins, S., & Yamada, J. (2010). The premature infant pain profile: Evaluation 13 years after development. *The Clinical Journal of Pain*, 26(9), 813-830.

Stevens, B., McGrath, P., Gibbins, S., Beyene, J., Breau, L., Camfield, C., Finley, A., Franck, L., Howlett, A., McKeever, P., O'Brien, K., Ohlsson, A., & Yamada, J. (2003). Procedural pain in newborns at risk for neurologic impairment. *Pain*, 105(1-2), 27-35.

Suraseranivongse, S., Santawat, U., Kraiprasit, K., Petcharatana, S., Prakkamodom, S., & Muntraporn, N. (2001). Cross-validation of a composite pain scale for pre-school children within 24 hours of surgery. *British Journal of Anaesthesia*, 87(3), 400-405.

Symons, F. J., Shinde, S. K., & Gilles, E. (2008). Perspectives on pain and intellectual disability. *Journal of Intellectual Disability Research: JIDR*, 52(Pt 4), 275-286.

Tarbell, S. E., Cohen, I. T., & Marsh, J. L. (1992). The Toddler-Preschooler Postoperative Pain Scale: An observational scale for measuring postoperative pain in children aged 1-5. Preliminary report. *Pain*, 50(3), 273-280.

Topolovec-Vranic, J., Canzian, S., Innis, J., Pollmann-Mudryj, M. A., McFarlan, A. W., & Baker, A. J. (2010). Patient satisfaction and documentation of pain assessments and management after implementing the adult nonverbal pain scale. *American Journal of Critical Care*, 19(4), 345-354.

van Dijk, M., de Boer, J. B., Koot, H. M., Tibboel, D., Passchier, J., & Duivenvoorden, H. J. (2000). The reliability and validity of the COMFORT scale as a postoperative pain instrument in 0 to 3-year-old infants. *Pain*, 84(2-3), 367-377.

van Dijk, M., Peters, J. W., van Deventer, P., & Tibboel, D. (2005). The COMFORT behavior scale: A tool for assessing pain and sedation in infants. *The American Journal of Nursing*, 105(1), 33-36.

van Iersel, T., Timmerman, D., & Mullie, A. (2006). Introduction of a pain scale for palliative care patients with cognitive impairment. *International Journal of Palliative Nursing*, 12(2), 54-59.

van Nispen tot Pannerden, S. C., Candel, M. J., Zwakhalen, S. M., Hamers, J. P., Curfs, L. M., & Berger, M. P. (2009). An item response theory-based assessment of the pain assessment checklist for seniors with limited ability to communicate (PACSLAC). *The Journal of Pain*, 10(8), 844-853.

Voepel-Lewis, T., Malviya, S., Merkel, S., & Tait, A. R. (2003). Behavioral pain assessment and the Face, Legs, Activity, Cry and Consolability instrument. *Expert Review of Pharmacoeconomics & Outcomes Research*, 3(3), 317-325.

Voepel-Lewis, T., Malviya, S., & Tait, A. R. (2005). Validity of parent ratings as proxy measures of pain in children with cognitive impairment. *Pain Management Nursing*, 6(4), 168-174.

Voepel-Lewis, T., Marinkovic, A., Kostrzewa, A., Tait, A. R., & Malviya, S. (2008). The prevalence of and risk factors for adverse events in children receiving patient-controlled analgesia by proxy or patient-controlled analgesia after surgery. *Anesthesia and Analgesia*, 107(1), 70-75.

Voepel-Lewis, T., Merkel, S., Tait, A. R., Trzcinka, A., & Malviya, S. (2002). The reliability and validity of the Face, Legs, Activity, Cry, Consolability observational tool as a measure of pain in children with cognitive impairment. *Anesthesia and Analgesia*, *95*(5), 1224-1229.

Voepel-Lewis, T., Zanotti, J., Dammeyer, J. A., & Merkel, S. (2010). Reliability and validity of the Face, Legs, Activity, Cry, Consolability behavioral tool in assessing acute pain in critically ill patients. *American Journal of Critical Care*, *19*(1), 55-61.

von Baeyer, C. L., Forsyth, S. J., Stanford, E. A., Watson, M., & Chambers, C. T. (2009). Response biases in preschool children's ratings of pain in hypothetical situations. *European Journal of Pain (London, England)*, *13*(2), 209-213.

von Baeyer, C. L., & Spagrud, L. J. (2007). Systematic review of observational (behavioral) measures of pain for children and adolescents aged 3 to 18 years. *Pain*, *127*(1-2), 140-150.

Walco, G. A., Conte, P. M., Labay, L. E., Engel, R., & Zeltzer, L. K. (2005). Procedural distress in children with cancer: Self-report, behavioral observations, and physiological parameters. *The Clinical Journal of Pain*, *21*(6), 484-490.

Warden, V., Hurley, A. C., & Volicer, L. (2003). Development and psychometric evaluation of the Pain Assessment in

Advanced Dementia (PAINAD) scale. *Journal of the American Medical Directors Association*, *4*(1), 9-15.

Wennstrom, B., & Bergh, I. (2008). Bodily and verbal expressions of postoperative symptoms in 3- to 6-year-old boys. *Journal of Pediatric Nursing*, *23*(1), 65-76.

Willis, M. H., Merkel, S. I., Voepel-Lewis, T., & Malviya, S. (2003). FLACC behavioral pain assessment scale: A comparison with the child's self-report. *Pediatric Nursing*, *29*(3), 195-198.

Young, J., Siffleet, J., Nikolett, S., & Shaw, T. (2006). Use of a behavioural pain scale to assess pain in ventilated, unconscious and/or sedated patients. *Intensive & Critical Care Nursing*, *22*(1), 32-39.

Zwakhaleh, S. M., Hamers, J. P., Abu-Saad, H. H., & Berger, M. P. (2006). Pain in elderly people with severe dementia: A systematic review of behavioural pain assessment tools. *BMC Geriatrics*, *6*, 3.

Zwakhaleh, S. M., Hamers, J. P., & Berger, M. P. (2007). Improving the clinical usefulness of a behavioural pain scale for older people with dementia. *Journal of Advanced Nursing*, *58*(5), 493-502.

Zwakhaleh, S. M., Koopmans, R. T., Geels, P. J., Berger, M. P., & Hamers, J. P. (2009). The prevalence of pain in nursing home residents with dementia measured using an observational pain scale. *European Journal of Pain (London, England)*, *13*(1), 89-93.

OTHER POSITION PAPERS/STATEMENTS/GUIDELINES

American Academy of Pediatrics Committee on Fetus and Newborn, American Academy of Pediatrics Section on Surgery, & Canadian Paediatric Society Fetus and Newborn Committee (2006). Prevention and management of pain in the neonate: An update. *Pediatrics*, *118*(5), 2231-2241.

American Medical Directors Association (2009). *Pain management in the long-term care setting*. Columbia, MD: Author.

American Pain Society (2008). *Principles of analgesic use in the treatment of acute pain and cancer pain*, (6th ed.) Glenview, IL: Author.

American Pain Society & American Academy of Pediatrics (2001). *The assessment and management of acute pain in infants, children, and adolescents*. [Position statement]. Retrieved from <http://aappolicy.aappublications.org/cgi/reprint/pediatrics;108/3/793.pdf>

National Association of Neonatal Nurses Board of Directors (2010). Palliative care for newborns and infants. Position statement no. 3051. Retrieved April 4, 2011, from http://www.nann.org/uploads/files/Palliative_Care-final2-in_new_template_01-07-11.pdf