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# Pain Assessment in the Patient Unable to Self-Report: Clinical Practice Recommendations in Support of the ASPMN 2019 Position Statement

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ABSTRACT

Pain is a subjective experience, unfortunately, some patients cannot provide a self-report of pain verbally, in writing, or by other means. In patients who are unable to self-report pain, other strategies must be used to infer pain and evaluate interventions. In support of the ASPMN position statement “Pain Assessment in the Patient Unable to Self-Report”, this paper provides clinical practice recommendations for five populations in which difficulty communicating pain often exists: neonates, toddlers and young children, persons with intellectual disabilities, critically ill/unconscious patients, older adults with advanced dementia, and patients at the end of life. Nurses are integral to ensuring assessment and treatment of these vulnerable populations.

Pain is a distressing experience associated with actual or potential tissue damage, with sensory, emotional, cognitive, and social components (Williams & Craig, 2016). Although researchers continue to seek physiological measures to evaluate pain, no valid and reliable objective test currently exists to measure pain. Pain is a subjective experience, consistent with the clinical definition of pain, which states that “Pain is whatever the experiencing person says it is, existing whenever he/she says it does” (McCaffery, 1968, p.). Unfortunately, some patients cannot provide a self-report of pain verbally, in writing, or by other means (such as head nod or blinking to answer yes-or-no questions).

The clinical practice recommendations provided address five populations of patients who may be unable to self-report pain: neonates, infants, toddlers and young children, persons with intellectual disabilities (ID), critically ill or unconscious patients, older adults with advanced dementia, and patients at the end of life. Each of these populations may be unable to self-report pain due to cognitive, developmental, or physiologic issues, including medically induced conditions. Inability to self-report pain creates a major barrier for adequate pain assessment and leaves the patient vulnerable to underrecognition and under- or overtreatment of pain. Nurses are integral to ensuring assessment and treatment of these vulnerable populations.

This document provides clinical practice recommendations in support of the revised ASPMN 2019 Position Statement on Pain Assessment in the Patient Unable to Self-Report published in this volume (Herr et al., 2019). Two major changes in clinical practice recommendations were made from the previous 2011 position statement (Herr, Coyne, McCaffery, Manworren, & Merkel, 2011). First, the hierarchy of pain assessment techniques has changed. The first technique is now *be aware of potential causes of pain*. The most common painful experiences in health care settings are iatrogenic. Preventing iatrogenic pain from needle procedures, wound care, diagnostic tests, and even repositioning, require clinician awareness and interventions before these painful events. Therefore, it is important to be proactive in anticipating pain in known painful conditions and experiences before soliciting a patient's self-report of pain or identifying behavioral responses to the pain. Second,

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neonates and young children were added to better define the five populations of patients who may be unable to self-report. This addition defines vulnerable pediatric patients based on cognitive development rather than age. New cognitive development data relative to pain intensity self-report and emerging knowledge of brain-based evidence of pain are referenced to support this change. In addition, current evidence and references have been updated throughout this document.

## ETHICAL TENETS

The ethical principles of beneficence (the duty to benefit another) and nonmaleficence (the duty to do no harm) oblige health care professionals to provide pain management and comfort to all patients, including those vulnerable individuals who are unable to speak for themselves (Paice & Coyne, 2017). Providing comparable and high-quality care to individuals who cannot report their pain is required 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, 2015), directs nurses to provide and advocate for humane and appropriate care. Based on the principle of justice, this care is given with compassion, 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, the World Health Organization and many other organizations and individuals (International Association for the Study of Pain, 2010). The declaration acknowledges that the inability to communicate verbally does not negate the possibility that an individual is experiencing pain and is in need of appropriate pain-relieving treatment (International Association for the Study of Pain, 2017). Concerns about the opioid crisis in North America create tension affecting treatment decisions, despite the status of pain assessment as foundational to effective and evidence-based treatment. In 2018, the American Nurses Association, affirmed the ethical responsibility to provide clinically excellent care to address patients' pain, with assessment and reassessment being key to informing treatment decisions (ANA, 2018).

Pain should be routinely assessed, reassessed, and documented to facilitate treatment and communication among health care clinicians. The requirement to provide effective and appropriate pain and symptom management is paramount. In patients who are unable to self-report pain, other strategies must be used to infer pain and evaluate interventions.

## GENERAL RECOMMENDATIONS FOR CLINICAL PRACTICE

A hierarchy of pain assessment techniques, recommended as a framework to guide assessment approaches, remains relevant for patients unable to self-report (Hadjistavropoulos et al., 2007; Pasero & McCaffery, 2011), although we have revised the hierarchy to address the importance of proactive consideration of painful conditions and procedures. A combination of hierarchy elements is often needed to determine presence of pain in vulnerable populations unable to self-report.

Table 1 provides a summary of the adapted hierarchy of pain assessment techniques as they relate to each of the five identified subpopulations. Tables 2–6 identify pain assessment tools with the strongest conceptual and psychometric support in English-speaking countries, as well as clinical usefulness when best matched to the patient's condition. Due to space limitations, table references are limited to original development and validation papers and selected key recent studies. General recommendations for assessing pain in those unable to self-report follow.

1. Use the Hierarchy of Pain Assessment Techniques

a. *Be Aware of Potential Causes of Pain*

Pathological conditions (e.g., surgery, trauma, osteoarthritis, wounds, a history of persistent pain), and common procedures known to cause iatrogenic pain (e.g., wound care, rehabilitation activities, positioning/turning, tube or drain removal, needle insertion) should trigger a preemptive intervention (emphasizing nonpharmacologic and nonopioid analgesics as a first choice). Iatrogenic pain associated with procedures should be treated prior to 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). However, commonly painful conditions associated with the patient's comorbid conditions are frequently the cause of the behavioral change: for example, urinary tract and implanted hardware infections, constipation, or sub-therapeutic medication levels (Quinn, Solodiuk, Morrill, & Mauskar, 2018). Diagnostic tests are typically indicated to rule out life-threatening causes of pain in persons unable to provide self-report (Quinn et al., 2018). Generally, one may assume pain is present if problems or conditions known to be painful (e.g., infection, constipation) are identified, and appropriate treatment to resolve the problem should be initiated (e.g., antibiotics, laxatives).

b. *Attempt 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, head nod, or eye blink. When self-report is absent or limited, document inability to reliably obtain self-report and selected method of pain assessment (e.g. select a behavioral pain assessment tool).

c. *Observe Patient Behaviors*

In the absence of ability to self-report, observation of behavior is a valid alternative approach for pain assessment. Across populations, many behavioral pain assessment tools can be found in the literature with varying levels of psychometric strength. Common behaviors that may indicate pain, and reliable evidence-based behavioral pain-assessment tools for the selected populations, have been identified for each subpopulation. Mild to moderate correlation has been found between behavioral pain assessment tool scores and the self-report of pain intensity. Although these two scores are correlated, these two methods of assessing pain measure different pain components (sensory, behavioral response) and provide complementary information about the pain experience. Thus a behavioral pain score is not equivalent to a self-report of pain intensity (i.e., a behavioral pain score of four out of ten does not equal a self-report of pain intensity of four out of ten).

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 (Jordan, Regnard, O'Brien, & Hughes, 2012). 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 to the absence of pain or 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. Pain behavior assessment tools have been developed to support behavioral observation, and are discussed below.

d. Solicit *Proxy Reporting of Pain and Behavior/Activity Changes*

Proxy reporters are varied and can include family members, parents, unlicensed caregivers, and professional caregivers. Credible information can be obtained from a family member or another person who knows the patient well (e.g., spouse, parent, child, or caregiver). For example, proxy assessments of pain intensity by family members in critically ill patients are in moderate agreement with the patients' self-reports of pain (Puntillo et al., 2012). When appropriate, family can be involved in their loved one's pain assessment process (Devlin et al., 2018). Familiarity with the patient and knowledge of usual and past behaviors can assist in identifying subtle, less obvious changes in behavior, or unique behaviors that may be indicators of pain presence (Quinn et al., 2018). 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) (Ngu et al., 2015). Proxy ratings often underestimate pain experiences (Quinn et al., 2018). Thus judgments by caregivers and clinicians are considered proxy assessments of pain intensity, and should be combined with other evidence when possible. A multifaceted approach is recommended that combines consideration of known pain-producing conditions, direct observation, family or caregiver input, and evaluation of response to treatment.

e. *Attempt Analgesic Trial*

An empiric analgesic trial should be initiated if behavioral scores indicate the presence of pain, or if pain behaviors continue after attention to basic needs and comfort measures in those unable to self-report pain. An analgesic trial can be diagnostic as well as therapeutic (American Pain Society, 2016). Selection of the appropriate analgesic for the trial is dependent on the individual, population, and potential underlying cause of pain. It may be appropriate to start the analgesic trial with a nonpharmacologic strategy or nonopioid (acetaminophen or nonsteroidal anti-inflammatory drugs). If no behavioral response or decrease in behavioral pain scores results, consider giving a short-acting opioid and observing effects. Doses may then be carefully adjusted until a clinically significant decrease in behavioral pain score is seen, bothersome or worrisome side effects occur, or no benefit is determined. In the case of neuropathic pain, it is not uncommon for analgesic trials to fail and health care providers assume there is no pain. It is important to take a multimodal approach and consider medications to treat neuropathic pain if there is a history of conditions that might suggest a neuropathic etiology (Devlin et al., 2018). The analgesic titration recommendation above is conservative, and although strategies for safe titration should be followed, more aggressive approaches may be needed. Titration doses should consider the patient's underlying comorbidities, as certain populations (premature babies and neonates, frail older adults, those with obstructive sleep apnea or neurologic impairment) are at risk for opioid adverse effects.

The goal of an analgesic trial as part of the assessment process is to establish whether or not pain is the cause of behaviors. If behaviors improve or behavioral pain scores decrease, assume pain was the cause. Next, establish an appropriate multimodal pain treatment plan based on identified or suspected pain etiology, individual characteristics (e.g., comorbidities, polypharmacy, cognitive status, caregiver support), and individual plan of care. If there is no change in behavior or in behavioral pain score after a reasonable analgesic trial, reassess for other potential causes of the observed behaviors.

2. Utilize Behavioral Pain Assessment Tools, as Appropriate

Behavioral pain assessment tools assist in recognition of pain in these vulnerable populations. It is incumbent on health care providers to consider the strength of psychometric evidence (e.g., reliability and validity of the tool for specific patient populations, considering developmental level, comorbid conditions like spasticity or paralysis, and context), and the clinical feasibility of instruments (e.g., training required, time to complete). Each health care organization should incorporate behavioral pain assessment tools appropriate for specific populations and settings of interest into policies and procedures related to pain assessment (Mamhidir et al., 2017). Tools with repeated supporting research by multiple authors are considered strongest. Use of reliable and valid tools helps ensure that clinicians are using appropriate criteria in their pain assessments. Standardized tools promote consistency among care providers and settings, and facilitate communication and evaluation of pain management treatment decisions. Despite their validity, more than 90% of behavioral pain scale scores documented by nurses for nonverbal children admitted for pain are zero, suggesting no pain despite hospital admission for family concerns of uncontrolled pain (Quinn et al., 2018). Further study of behavioral pain assessment tool use is thus imperative.

As previously mentioned, a behavioral pain score is not equivalent to a self-reported pain intensity rating on a numeric rating scale. Behavioral pain assessment tools can be helpful to identify the presence of pain, to monitor for changes, and to evaluate the effectiveness of pain treatments (Crellin, Babl, Santamaria, & Harrison, 2018). When selecting a behavioral pain assessment tool, make sure that the behavior indicators are suitable for the population (e.g. vocalization in a patient who is mechanically ventilated would not be appropriate). Key to the use of behavioral pain assessment tools is to focus on the individual's behavior during movement (or comparing between rest and movement, depending on the tool; Ersek et al., 2019b), or during procedures known to be painful, and observe for changes in those behaviors with effective treatment. Increases or decreases in the number or strength of behaviors suggest changes in pain expression.

3. Minimize Emphasis on Vital Signs

While vital signs (e.g., changes in heart rate, blood pressure, respiratory rate) may be important for identifying adverse effects of severe pain (De Jong et al., 2013), vital signs are not valid for discriminating pain from other sources of distress (Gélinas, 2016). Correlation of vital sign changes with behaviors and self-reports of pain has been weak or absent (Gélinas, 2016; Relland, Gehred, & Maitre, 2019). Changes in vital signs do not necessarily indicate pain, and the absence of changes in vital signs does not indicate the absence of pain. Vital signs should be used only as cues to initiate further assessment using appropriate and validated methods such as the patient's self-report of pain (whenever possible) or a behavioral pain assessment tool (Devlin et al., 2018).

4. Assess Regularly, Reassess Post-intervention and Document

Each patient should be evaluated regularly using methods of pain assessment that have been identified as significant and appropriate for the population to which they belong. Pain reassessment should also be done post-intervention (i.e., pharmacologic or nonpharmacologic) to determine the effectiveness of analgesia. A systematic approach to pain assessment should be instituted, and pain scores should be documented in a readily

**Table 1**
Adapted Hierarchy of Pain Assessment Techniques (Pasero & McCaffery, 2011) With Subpopulation Considerations

| Hierarchy | Neonates, Infants, Toddlers & Young Children | Intellectual Disability (ID) | Critically Ill/Unconscious | Dementia | End of Life |
|---|---|---|---|---|---|
| 1. Be aware of potential causes of pain | Most common source of pain is preventable procedural pain from needle sticks. | Prevalence & burden of pain higher than in individuals without ID. | Sources of pain include routine critical care: turning, positioning, drain and catheter insertion & removal suctioning, and wound care. | Musculoskeletal & neurologic disorders most common causes of chronic pain in older adults. | Causes of pain in this population typically very complex, numerous sites & etiologies of pain not uncommon. |
| 2. Attempt self- report | By 2 yr of age, children can self-report pain; but young children's ability to rate pain intensity varies greatly. | Majority can verbally self-report pain using developmentally-appropriate pain assessment tools.<br>Teach individuals with ID how to use tools & ensure understanding. | Self-report of pain may be hampered by cognitive & communication limitations, level of consciousness, presence of endotracheal tube, delirium, 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. | Cognitive abilities often fail as disease progresses. Assume pain is present if pain was previously reported. |
| 3. Observe patient behaviors | Facial expression is primary behavioral category used to help identify pain.<br>As cognitive abilities increase, young children demonstrate fewer overt pain behaviors.<br>Evaluate response to consoling techniques | Seek input from knowledgeable caregivers about common pain behaviors to enhance existing tools.<br>Behavioral observation should occur during activity whenever possible | Facial expressions, such as grimacing, brow lowering, & wincing, are often seen in critically ill patients experiencing pain. | Facial expressions, verbalizations/vocalizations, and body movements are key categories for behavior observation.<br>Behavioral observation should occur during activity whenever possible | Use indicators shown relevant to specific patient. Intensive assessment required. |
| 4. Solicit Proxy reporting | Parents usually know their child's typical behavioral response to common pain experiences, like needle procedures; but nurses are more familiar with children's responses to unique pains, like surgery. | Parents and caregivers may know individual's typical behavioral response to pain & can identify unique pain behaviors. However, caregivers of children with ID frequently underestimated pain intensity. | Family members and, caregivers can help identify recurring pain indicators for critically ill/unconscious individuals. | In LTC setting, the CNA is a key health care provider shown to be effective in recognizing presence of pain.<br>Helpful, if family visits regularly. | Family and caregivers play an essential role in recognizing pain and evaluating comfort as the person transitions toward death. |
| 5. Attempt analgesic trial | Base initial analgesic dose on weight for patients <50 kg.<br>Titrate opioids as appropriate. | Analgesic trial based on patient's condition | Analgesic trial based on patient's condition | Select appropriate analgesic considering comorbidities and suspected pain problem. | Requires diligence and consideration of pathology, conditions known to be pain-related, and estimates of pain by others. |

LTC = long-term care; CNA = certified nursing assistant.

visible and consistent manner that is accessible to all health care providers involved in the management of pain (Mamhidir et al., 2017). In the case of temporary inability to self-report, patient capacity to self-report should be re-evaluated periodically.

## NEONATES, INFANTS, TODDLERS, AND YOUNG CHILDREN: GUIDING PRINCIPLES FOR ASSESSMENT OF PAIN

Pain alters neurodevelopment and may have long-term effects (Maitre et al., 2017; Young, D'Agata, Vittner & Baumbauer, 2017). Recommendations for pain assessment in young (from birth) children unable to self-report that are unique from the general recommendations include the following:

### 1. *Be Aware of Potential Causes of Pain*

Infections, injuries, diagnostic tests, surgical procedures, and disease progression are possible causes for pain in 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 or surgical procedures and illness (Quinn et al., 2018). Suspicion of pain should therefore be high, warranting careful assessment.

### 2. *Attempt Self-Report*

Neonates and infants lack the verbal and cognitive skills necessary to report and describe pain. However, self-report of pain is not used as often as it should be with toddlers and young children. 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 typically emerges before two years of age (Chan & von Baeyer, 2016). By three years of age most children have a basic pain vocabulary; although their words for pain vary (e.g., ow, ouch, ache). Young children 3-6 years of age may have difficulty discriminating between the sensory experience of pain and the distress or fear of pain, as well as other distressing symptoms such as nausea (Wennström & Bergh, 2008). Developmentally normal children as young as three years of age may be able to quantify pain using simple validated pain tools (Birnie, Hundert, Lalloo, Nguyen, & Stinson, 2019; Hicks, von Baeyer, Spafford, van Korlaar, & Goodenough, 2001; Beyer, Denyes, & Villarruel, 1992; Wong & Baker, 1988). However, evidence is weak for children younger than 5 years of age, and report bias is common in children 3-6 years of age, further complicating the interpretation of their pain scores (von Baeyer, Chambers, Forsyth, Eisen, & Parker, 2013; von Baeyer et al., 2017). Report bias can be reduced by limiting the number of potential responses from six to three choices. By 4 years of age, most children can reliably use the terms “less” and “more” (Chan & von Baeyer, 2016). These relational terms can aid children's reporting of pain intensity changes. By 8 years of age, most developmentally normal children are able to reliably use a self-report numeric rating tool. However, the desire of health care professionals to standardize pain reports to a 0-10 metric fails to recognize the varied cognitive abilities of children.

### 3. *Observe Patient Behaviors*

Over 60 observational pain scales have been developed to assess pain in children from birth to young adulthood (Andersen, Langius-Eklöf, Nakstad, Bernklev, & Jylli, 2017). The primary behavioral categories used to help identify pain with these scales are facial expression, body activity/motor movement, and crying/verbalization. Yet reflexive withdrawal from a painful stimulus is most strongly associated with brain-based evidence of pain (Relland et al., 2019). This behavior may not be included in pain assessment scales, since reflexive withdrawal is almost exclusively observed with acute procedural pain that should be treated in health care settings to prevent this reflexive response. Of the behavioral categories included in observational pain scales, only facial expression is weakly associated with brain-based evidence of pain (Relland et al., 2019). Correlation improves with increasing gestational age and prior experiences 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). Similar facial actions correlate with pain in children and adults (Arif-Rahu, Fisher, & Matsuda, 2012). Despite the sensitivity and specificity of facial expressions as an indicator for pain, the criteria itemized in observational scales vary substantially from empirically described facial actions (Chang, Versloot, Fashler, McCrystal, & Craig, 2015).

Observed behavioral responses to pain change as a child gains control over body movement. The primary behavioral signs of pain are often more apparent and consistent for procedural pain and acute pain. While the psychometrics for acute pain assessment tools are more robust, the clinical utility of these scales and their value for guiding pain treatment decisions are questionable (Crellin et al., 2018). 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. Sleeping and withdrawn behavior may be the child's attempts to control pain by limiting activity and interactions. Young children who are experiencing prolonged, persistent, or chronic pain may not exhibit the usual behavioral signs of pain seen in those responding to acute pain. Instead, these children may exhibit signs of energy conservation and functional limitations. Therefore, consider the context of the behaviors, medical history, and caregiver opinions when using behavioral pain assessment tools and making treatment decisions.

Physiologic measures, such as heart rate, respiratory rate, and oxygen saturation are included in multidimensional observational pain assessment tools. In studies of acute procedural pain, heart rate and oxygen saturation do not correlate with brain-based evidence of pain (Relland et al., 2019). Vital signs are not specific or sensitive to the presence or absence of pain.

#### 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 (Andersen et al., 2017), and clinicians should select a tool that is appropriate to the types of patient and pain on which it has been tested. See Table 2 for tools to be considered for neonates, infants, toddlers, and young children who are unable to provide self-report of pain. Tools that are appropriate for use with critically-ill children are also designated.

### 4. Solicit *Proxy Reporting of Pain*

Encourage parents to actively participate in identifying pain and evaluating their child's response to interventions. Parents 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 more familiar with young children's pain behaviors for more unique pain experiences, like surgery, or for infants who have not been home since birth. Responsiveness to consoling interventions by a trusted caregiver, such as rocking, touch, music, and verbal reassurance, should be considered when assessing children's pain. These interventions are a component of some observational pain assessment tools and may be effective nonpharmacologic comfort measures or treatments for young children's pain.

5. *Attempt 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 suggest pain (Hatfield, Murphy, Karp, & Polomano, 2019; Davidson, Snow, Hayden, & Chorney, 2016). Oral sucrose and breastfeeding can be effective analgesics for neonates and infants who are undergoing minor pain procedures, and could be used in an analgesic trial (Hatfield et al., 2019; Benoit, Martin-Misener, Latimer, & Campbell-Yeo, 2017; Davidson et al., 2016). Base initial analgesic dose on weight in children up to 50 kilograms, at which time adult dosing may be appropriate. Titrate as appropriate (American Pain Society, 2016). Very young infants and those with comorbidities should start at one fourth to one third of initial recommended opioid dose recommendations for children, and demand careful opioid titration, because these children are more sensitive to respiratory depressant effects. Explore other potential causes of distress if behaviors continue after a reasonable analgesic trial.

## PERSONS WITH ID: GUIDING PRINCIPLES FOR ASSESSMENT OF PAIN

Persons with ID have cognitive impairments related to injury or disease processes. ID can be congenital or acquired. ID present at birth continues throughout life, and may or may not be accompanied by physical disability (Meir, Strand, & Alice, 2012). ID is usually defined by Intelligence Quotient (IQ) scores. An IQ score of 50-70 indicates mild ID; people scoring in this range comprise 85% of those with ID. Individuals with mild ID are verbal and usually have skills equivalent to a sixth-grade academic level. IQ scores below 50 indicate moderate, severe, or profound ID (Bottos & Chambers, 2006; Shogren & Turnbull, 2010). Since the purpose of these clinical practice recommendations is to address pain assessment in patients unable to self-report, it is these individuals with moderate to profound ID who 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:

1. *Be Aware of 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 (Genik, McMurtry, & Breau, 2017; McDowell, Duffy, & Lundy, 2017). Patients with ID have also been observed carrying out normal activities even when seriously injured. Children and adults with ID 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.

2. *Attempt Self-Report*

The majority of individuals with ID are verbal and can self-report pain using a developmentally appropriate self-report pain assessment tool. Ensuring the individual understands the tool and can use it effectively should thus be a first step (de Knegt, Evenhuis, Lobbezoo, Schuengel, & Scherder, 2013a; Quinn, Seibold, & Hayman, 2015).

3. *Observe Patient Behaviors*

Individual behavioral responses to pain vary from increases in behaviors to decreases or dampened behaviors. Responses to pain may vary by diagnosis associated with ID (e.g. response time and

**Table 2**
Neonates, Infants, Toddlers and Young Children: Behavioral Pain Assessment Tools

| Tool | References* | Sample | Setting |
|---|---|---|---|
| CHEOPS: Children's Hospital of Eastern Ontario Pain Scale | (McGrath et al., 1985; Chang et al., 2015; Andersen et al., 2017) | Children 4 mo to 17 yr of age; Procedural pain and brief post-surgical pain, short-term post-surgical pain | Post Anesthesia Care Unit |
| CHIPPS: Children's and Infants' Postoperative Pain Scale | (Buttner & Finke, 2000; Chang et al., 2015) | Children birth to 5 yr of age; Surgical pain | Acute care |
| COMFORT and revised COMFORT Behavior Scale | (Ambuel, Hamlett, Marx, & Blumer, 1992; van Dijk et al., 2000; Maaskant et al., 2016) | Neonate to 3 yr of age; Surgical pain<br>Children newborn to 17 yr 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, Consolability Observational Tool | (Merkel, Voepel-Lewis, Shayevitz, & Malviya, 1997; Willis, Merkel, Voepel-Lewis, & Malviya, 2003; Voepel-Lewis, Zanotti, Dammeyer, & Merkel, 2010), (Chang et al., 2015; Crellin, Harrison, Santamaria, & Babl, 2015; Ge,Tao, Wang, Pan, & Wang, 2015) | Children 0 mo to 18 yr of age; Post-operative and procedural pain, and acute pain | Post anesthesia care, intensive care, acute care |
| N-PASS: Neonatal Pain, Agitation, and Sedation Scale | (Hummel, Puchalski, Creech, & Weiss, 2008; Hummel, Lawlor-Klean, & Weiss, 2010; Hummel, 2017; Desai, Nanavati, Jasani, & Kabra, 2017; Desai, Aucott, Frank, & Silbert-Flagg, 2018) | Premature neonates 23-40 wk gestation to 3 mo of age; procedural and post-operative pain during mechanical ventilation | Neonatal Intensive Care Unit, Pediatric Intensive Care Unit |
| NIPS: Neonatal Infant Pain Scale | (Lawrence et al., 1993; Ge et al., 2015; Desai et al., 2018) | Premature and full-term neonates, procedural and postoperative pain | Neonatal Intensive Care Unit |
| PIPP: Premature Infant Pain Profile and PIPP-revised | (Stevens, Johnston, Petryshen, & Taddio, 1996; Stevens, Johnston, Taddio, Gibbins, & Yamada, 2010; Stevens et al., 2014; Desai et al., 2017) | Premature and term neonates; acute, procedural pain and prolonged pain | Neonatal Intensive Care Unit |
| Toddler-Preschooler Postoperative Pain Measure | (Tarbell, Cohen, & Marsh, 1992; Chang et al., 2015) | Children 1-5 yr of age; short-term post-surgical pain | Post anesthesia care, acute care |

* Includes development and validation references and selected recent evaluation studies.

sensitivity); however, the majority of individuals with ID appear to have intact sensory function (Symons, Shinde, & Gilles, 2008). In addition, self-injurious behaviors may be indicative of pain in some individuals with ID (Carr & Owen-DeSchryver, 2007; de Knegt et al., 2013b). This variability in pain expression may be related to neurological perception or motor or communication abilities of the individual, and poses unique challenges for effective recognition and treatment by clinicians, parents, and caregivers. Individual differences in response to pain may contribute to under- or over-estimation of pain. Individuals' behavior associated with pain therefore requires collaboration with family and caregivers in order to effectively assess pain (Davies, 2010; Dubois, Capdevila, Bringuier, & Pry, 2010; Hunt et al., 2004).

### Use of Behavioral Pain Assessment Tools

Considerable research has focused on creating assessment tools for children with ID, but few studies have included adults with ID. Evidence exists that adults with severe ID display different behavioral indicators of pain than children, supporting the use of the Non-Communicating Children's Pain Checklist in those adults (Meir et al., 2012). The tools included in Table 3 have been evaluated in settings with individuals with ID.

### 4. Solicit *Proxy Reporting of Pain*

Caregivers are often consulted regarding the interpretation of behaviors of individuals with ID and their relationship to pain. Caregivers of children with ID are relatively sensitive pain detectors, but frequently underestimate and undertreat pain intensity when able to compare to their child's actual pain report (in those who can communicate; Symons et al., 2008). Parents' and caregivers' estimations of pain improve when they are provided information and a structured observational tool (Chen-Lim et al., 2012; 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 (de Knegt et al., 2013a; Symons et al., 2008).

Three tools use the family member or caregiver's input to identify relevant pain behaviors and are unique to children with ID. The Individualized Numeric Rating Scale 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 Individualized Numeric Rating Scale. The Revised Faces, Legs, Activity, Cry, Consolability scale provides descriptors unique to this population, and suggests that the clinicians seek input about the person's baseline and pain behaviors from parents or caregivers (Chen-Lim et al., 2012). The Paediatric Pain Profile includes a section for caregivers to complete about the child's pain history.

### 5. *Attempt Analgesic Trial*

Initiate an analgesic trial if pain is suspected. The trial should be tailored to the patient's age, weight (in those under 50 kilograms), and comorbidities.

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

The assessment of pain is challenging in critically-ill patients due to their clinical condition (which may affect multiple systems), the use of invasive devices (e.g. mechanical ventilation), and the use of medications (e.g. sedatives) that may alter their capacity to communicate or alter their level of consciousness (Devlin et al., 2018). Recommendations for pain assessment in critically ill or unconscious persons unable to self-report that are distinct from the general recommendations include the following:

### 1. *Be Aware of Potential Causes of Pain*

Critically-ill patients experience pain at rest (Chanques et al., 2007), and pain is significantly increased during standard intensive care unit (ICU) procedures, such as tube/drain removal, endotracheal/tracheal suctioning, turning, and wound care (Al Sutari, Abdalrahim, Hamdan-Mansour, & Ayasrah, 2014; Puntillo et al., 2014; LaFond et al., 2019). Surgical and trauma diagnoses are also associated with higher pain (Al Sutari et al., 2014; Puntillo et al., 2004). In addition, immobility, hidden infection, and early skin pressure injury can cause pain and discomfort.

**Table 3**
Persons With Intellectual Disabilities (ID): Behavioral Pain Assessment Tools

| Tool | References* | Sample | Setting |
|---|---|---|---|
| rFLACC: Revised Faces, Legs, Activity, Cry, Consolability Observational Tool | (Malviya, Voepel-Lewis, Burke, Merkel, & Tait, 2006; Voepel-Lewis, Merkel, Tait, Trzcinka, & Malviya, 2002; Voepel-Lewis, Malviya, & Tait, 2005) | Children 4-19 yr of age, 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; Lotan et al., 2009; Burkitt, Breau, & Zabalia, 2011) | Children with ID; chronic and acute pain | Postoperative, rehabilitation hospital, home/residential |
| INRS: Individualized Numeric Rating Scale | (Solodiuk & Curley, 2003; Solodiuk et al., 2010) | Children 6-18 yr of age, severe intellectual disability | Acute care |
| Paediatric Pain Profile | (Hunt et al., 2004; McDowell et al., 2017) | Children 1-18 yr of age, severe neurological disability & unable to communicate through speech or augmentative communication; chronic and postoperative pain<br>Children 4-27 yr of age, severe cerebral palsy; acute pain | Home, hospice, acute care |
| NCAPC: The Non-Communicating Adult Pain Checklist | (Lotan et al., 2009; Meir et al., 2012) | Adult population, all levels of Intellectual and Developmental Disabilities (IDD); procedural pain | Residential or community setting; acute care |

[*] Includes development and validation references and selected recent evaluation studies.

### 2. *Attempt Self-Report*

Self-report of pain should be attempted in all patients. A Numeric Rating Scale (NRS) administered either verbally or visually is a valid and feasible pain assessment tool to use in critically ill patients (Devlin et al., 2018). However, obtaining a self-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, or neuromuscular blocking agents (Gélinas, 2016). Since delirium can wax and wane and impact ability to provide a reliable self-report, delirium should be assessed on a regular basis (LaFond et al., 2019).

### 3. *Observe Patient Behavior*

Facial expressions such as grimacing, frowning/brow lowering, and wincing are often seen in critically ill patients experiencing pain (Gélinas, Puntillo, Levin, & Azoulay, 2017). Body movement and muscle rigidity may also indicate the presence of pain. Behavioral pain assessment tools are not appropriate for pharmacologically paralyzed patients, or those who cannot respond behaviorally to pain (e.g. with a score of three on the Glasgow Coma Scale or five on the Richmond Agitation Sedation Scale). They are also of limited use in heavily sedated patients (i.e., Richmond Agitation Sedation Scale score of −4). In addition, behavioral pain assessment tools may not be appropriate for brain-injured patients with altered levels of consciousness. Indeed, it was found that critically ill patients with a brain injury exhibit specific pain behaviors, such as tearing and face flushing, and low frequency of grimace and muscle rigidity (Arbour et al., 2014; Gélinas et al., 2019; Roulin & Ramelet, 2014). Therefore, behavioral pain assessment tools may need to be adapted for brain-injured ICU patients.

Patients may also exhibit distress behaviors as a result of the fear and anxiety associated with being in the intensive care unit. Assume pain is present and administer analgesics appropriately to patients who are given neuromuscular blocking agents and experience conditions and procedures known to be painful. When high doses of opioids are used as a sedative with or without other sedatives, muscle relaxants, and neuromuscular blocking agents, pain behaviors may be blunted or absent; pain may therefore be underdetected and undertreated.

Changes in vital signs may be considered a cue to begin further assessment for pain or other stressors (Devlin et al., 2018). Evidence does not support the use of vital signs as a sensitive or specific measure of pain (Gélinas, 2016). Relying on changes in vital signs as a measure of pain or pain relief therefore fails to acknowledge critically ill patients' homeostatic instability and underlying physiologic pathology.

#### Use of Behavioral Pain Assessment Tools

A number of behavioral pain assessment tools are available for assessing critically ill patients who are unable to self-report pain. Among these, the Behavioral Pain Scale in intubated and non-intubated patients and the Critical-Care Pain Observation Tool have demonstrated the strongest cumulative validity for assessing pain in this population (Devlin et al., 2018) and are available in multiple languages (Azevedo-Santos & DeSantana, 2018; Klein et al., 2018). The Behavior Pain Assessment Tool, which consists of a brief checklist of eight behaviors inspired by previous work (Puntillo et al., 2004), is also available in 12 different languages and was validated in critically ill patients from 28 countries (Gélinas et al., 2017). See Table 4 for tools for critically ill adults.

### 4. *Solicit Reporting of Pain*

Family members can help identify specific pain indicators for critically ill individuals (Mohand-Said et al., 2019; Richard-Lalonde et al., 2018; Vanderbyl & Gelinas, 2017). A family member's report of their impression of a patient's pain and response to an intervention may be included as one aspect of a pain assessment in the critically ill patient (Gélinas & Puntillo, 2018). Family members are more familiar with behavioral responses to common pains related to a patient's health condition or procedures. Family members may assist the nurses in identifying specific pain behaviors in their loved one based on their intimate knowledge of the patient, but are less familiar with the technology used in the critical care context, such as mechanical ventilation, which may influence their loved one's behaviors.

### 5. *Attempt Analgesic Trial*

Initiate an analgesic trial if pain is suspected (Gélinas, 2016). A multimodal pain management treatment plan should consider the patient's individual characteristics, needs, and response to the initial analgesic trial (Devlin et al., 2018). Paralyzing agents and sedatives are not substitutes for analgesics. The use of assessment-driven standardized pain and sedation management protocols is strongly suggested, although individualization is essential, the "Clinical Practice Guidelines for the Prevention and Management of Pain, Agitation/Sedation, Delirium, Immobility, and Sleep Disruption in Adult Patients in the ICU" provide best practice guidance (Devlin et al., 2018).

This population often requires weaning from sedating doses of opioids in order to facilitate extubation despite continued pain. Consider the addition of nonopioid agents to treat pain while facilitating extubation. In patients with brain injury, the judicious use of opioids, taking into account their risk of sedation, may be appropriate.

**Table 4**
Adults-Critically Ill/Unconscious: Behavioral Pain Assessment Tools

| Tool | References* | Sample | Setting |
|---|---|---|---|
| BPS: Behavioral Pain Scale<br>BPS-NI: Behavioral Pain Scale – Non-Intubated | BPS (Payen et al., 2001), BPS-NI (Chanques et al., 2009; Chanques et al., 2014; Severgnini et al., 2016) | Nonverbal and verbal adults; procedural pain | Intensive care |
| Behavior Assessment Tool | (Puntillo et al., 2004) | Verbal adults and children; procedural pain | Intensive care |
| BPAT: Behavior Pain Assessment Tool | (Gélinas et al., 2017) | Nonverbal and verbal adults; procedural pain | Intensive care |
| CPOT: Critical-Care Pain Observation Tool | (Gélinas, Fillion, Puntillo, Viens, & Fortier, 2006; Gélinas, Fillion, & Puntillo, 2009; Joffe, McNulty, Boitor, Marsh, & Gelinas, 2016; Kanji et al., 2016; Dale, Prendergast, Gelinas, & Rose, 2018) | Nonverbal and verbal adults; procedural pain | Intensive care |
| NPAT: Nonverbal Pain Assessment Tool | (Klein, Dumpe, Katz, & Bena, 2010) | Nonverbal and verbal adults | Intensive care |
| NVPS: Nonverbal Pain Scale, and its revised version | NVPS (Odhner, Wegman, Freeland, Steinmetz, & Ingersoll, 2003), revised NVPS (Kabes, Graves, & Norris, 2009; Rahu et al., 2013; Topolovec-Vranic et al., 2013) | Nonverbal adults | Cardiac post anesthesia care, intensive care |

* Includes development and validation references and selected recent evaluation studies.

## PERSONS WITH ADVANCED DEMENTIA: GUIDING PRINCIPLES FOR ASSESSMENT OF PAIN

The approach described in this position statement has been applied in older persons with advanced dementia. An algorithm to guide this pain assessment process is available (Reuben et al., 2019). Recommendations for pain assessment in older adults with advanced dementia unable to self-report that are distinct from the general recommendations include the following:

### 1. *Be Aware of Potential Causes of Pain*

A careful review of the medical history and a thorough physical examination are important when looking for potential causes of pain in this population. 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 (Reuben et al., 2019). Pain resulting from cancer, trauma, procedures 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.

### 2. *Attempt Self-Report*

The pathologic changes in dementia seriously impact 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 pathological changes in central nervous system functioning, persons with dementia still experience pain sensation, although the experience and processing of pain sensation varies between subtypes of dementia (Herr, Gibson, & Hadjistavropoulos, 2018). Although self-report of pain is often possible in older adults with mild to moderate cognitive impairment, as dementia progresses the ability to self-report decreases and eventually disappears (Lukas, Barber, Johnson, & Gibson, 2013).

### 3. *Observe Patient Behaviors*

Observe for behaviors recognized as indicators of pain in this population. A large number of behavioral indicators have been identified and captured in over 20 pain behavior observational tools for those with dementia. Most behaviors fall into one of the following categories: Facial expressions, verbalizations/vocalizations, body movements, changes in interpersonal interactions, changes in activity patterns or routines, and mental status changes. Some behaviors are common and typically considered 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. Researchers have begun examining which behaviors are most often associated with and predictive of pain in persons with dementia. A recent review of body movements as pain indicators in older people with cognitive impairment identified five with strong evidence of validity, including restlessness (agitation), rubbing, guarding, rigidity, and physical aggression. These indicators responded to pain-provoking activities, painful procedures, or pain medication. Facial expression of pain is a strong behavioral indicator and should be part of any assessment process (Lautenbacher & Kunz, 2017). Other behaviors most useful in detecting pain have been identified and captured in new pain behavior assessment tools (Corbett et al., 2014; Ersek et al., 2019a; Ersek et al., 2019b), although additional evaluation is needed. Behavioral observation should occur during activity whenever possible because pain indicators are often minimal or absent at rest (Herr et al., 2018). Vital sign changes are blunted in dementia and, as noted earlier, are not appropriate indicators of pain (Plooij, Swaab, & Scherder, 2011).

#### Use of Behavioral Pain Assessment Tools

Behavioral pain assessment tools are intended to be used to supplement other assessment processes and data, such as identification of diagnoses or procedures known to be painful and obtaining proxy reports regarding potential pain. 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). Although no one tool is best for all settings, a number of these tools have undergone repeated psychometric evaluation and can be used to systematically evaluate behaviors as one piece of evidence of potential pain (Lichtner et al., 2014). Studies suggest that use of behavioral pain assessment tools can improve detection of pain and improve treatment in cognitively impaired older adults (Apinis, Tousignant, Arcand, & Tousignant-Laflamme, 2014; Hadjistavropoulos et al., 2018; Liu & Lai, 2017; Ngu et al., 2015). These studies contribute new information to refine existing tools and evaluate pain assessment approaches in this population.

Current reviews of existing pain behavior observation tools indicate growing evidence of psychometric properties, and reinforce the importance of careful selection of the best tool for the target population and setting (Chow et al., 2016; Husebo, Achterberg, & Flo, 2016). Brief summaries of published tools for assessing pain in nonverbal persons with dementia, along with copies of tools and permissions to use, are available at https://geriatricpain.org/. Tools tested in English-speaking populations with the strongest conceptual and psychometric support as well as clinical usefulness are included in Table 5, although users should consult the literature regularly for updates.

### 4. *Solicit Proxy Reporting of Pain*

In the long-term care setting, the certified nursing assistant is a key health care provider who is often the first to recognize changes in patients' behavior suggestive of pain (Jansen et al., 2017). Education on screening for pain should be a component of all certified nursing assistant training. Family members are likely to be the caregivers most familiar 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 (Ammaturo, Hadjistavropoulos, & Williams, 2017). Health care providers underestimate pain in this population (Apinis et al., 2014); thus other sources of information (e.g., behavioral pain scales, caregiver reports) are needed to increase recognition of pain.

### 5. *Attempt Analgesic Trial*

Use of an analgesic trial has been evaluated in randomized control trials as a means to establish the existence of pain in the presence of behavior disturbance, such as agitation. Studies have found that the majority of persons with dementia respond with behavior improvements after a trial of acetaminophen (Sandvik et al., 2014), although some require advancement to stronger analgesics. A recent randomized control trial found buprenorphine to be poorly tolerated with increased adverse events in advanced dementia, particularly if the older adult with dementia is co-prescribed antidepressants; thus caution is warranted in selecting analgesics in this population (Erdal et al., 2018). Clinical guidance for an analgesic trial based on clinical trial evidence (Husebo et al., 2016) and drug mechanisms and pharmacokinetics that can be adjusted based on individual comorbidities, risk factors, and contraindications (Reuben et al., 2019):

Try acetaminophen first (if no hepatic dysfunction) every 4-6 hours around the clock, not PRN, trialing other analgesics if there is no change in behaviors and pain continues to be suspected. If there is no response to acetaminophen after 24-48 hours and localized inflammatory pain is suspected, try topical nonsteroidal anti-inflammatory drugs or lidocaine. If no response occurs within 24-48 hours, try a low-dose short-acting oral opioid. If no response to acetaminophen and neuropathic pain occurs, try topical lidocaine or gabapentin for 2-3 weeks. Careful monitoring for response to the analgesic is essential to verify that pain is the cause of the behavior identified. If behavior improves with treatment, establish and implement a pain treatment plan, considering both pharmacologic and non-pharmacologic options and risk and benefits of treatment options for the individual patient.

## PAIN AT END OF LIFE: GUIDING PRINCIPLES FOR ASSESSMENT OF PAIN

Pain at the end of life continues to be of great concern, as it may go unrecognized or untreated (Noreika, Bobb, & Coyne, 2015). Although nurses have an ethical obligation to reduce suffering, barriers remain regarding adequate pain management at the end of life (Coyne, Mulvenon, & Paice, 2018). 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, which should be integrated as part of the medical record (McGuire, Kaiser, Haisfield-Wolfe, & Iyamu, 2016). Recommendations for pain assessment in those unable to self-report at the end of life that are distinct from the general recommendations include the following:

### 1. *Be Aware of Potential Causes of Pain*

The causes of pain in this population of patients are typically very complex; numerous sites and etiologies of pain are not uncommon. A patient may be experiencing disease progression, altered metabolism, and changes in medication metabolites, as well as the need for frequent changes in routes of medications including analgesics (Paice, 2015). Myoclonus, related to disease or use of opioids, may exacerbate pain. Pain experience may be accentuated or exacerbated by spiritual distress and existential suffering. At the end of life, cognitive, affective, behavioral, and cultural factors may contribute to pain and need to be considered as potential causes (Fink, Gates, & Montgomery, 2015).

### 2. *Attempt Self-Report*

Cognitive abilities to verbalize pain often fail as disease progresses. A systematic review suggested that 13%-42% of patients admitted to palliative care inpatient units have delirium impacting ability to self-report (Hosie, Davidson, Agar, Sanderson, & Phillips, 2013). The absence of reported pain does not necessarily mean the patient is not experiencing pain or that pain has resolved. Pain assessment must include assuming pain is present if pain was previously a complaint when the patient was cognitively intact.

### 3. *Observe Patient Behaviors*

Delirium and agitation frequently occur as death approaches and may be due to intractable pain or other etiologies such as disease progression, medication withdrawal, urinary retention, or electrolyte imbalances necessitating intensive assessment. This population requires a proactive approach in the last months of life as ability to self-report, causes of pain, and behavioral indicators of pain may appear or change quickly.

#### ***Use of Behavioral Pain Assessment Tools***

To date, limited tools have been 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 (Wiegand et al., 2018). It is the only tool with evidence of reliability, validity, and clinical usefulness in

**Table 5**
Persons With Advanced Dementia: Behavioral Pain Assessment Tools

| Tool | References* | Sample | Setting |
|---|---|---|---|
| Abbey | (Abbey et al., 2004; Lukas et al., 2013; Neville & Ostini, 2014) | Older adults with dementia<br>Acute/chronic pain | Long-term care |
| CNPI: Checklist of Nonverbal Pain Indicators | (Feldt, Ryden, & Miles, 1998; Feldt, 2000; Ersek, Herr, Neradilek, Buck, & Black, 2010; Ersek, Polissar, & Neradilek, 2011) | Older adults with dementia<br>Acute/chronic pain | Acute care; long-term care |
| Doloplus-2 | (Lefebvre-Chapiro, 2001; Holen et al., 2007; Pickering et al., 2010; Neville & Ostini, 2014) | Older adults with dementia<br>Chronic pain | Acute care; long-term care; palliative care |
| MOBID & MOBID 2: Mobility-Observation-Behavior-intensity-Dementia Pain Scale | (Chan, Hadjistavropoulos, Williams, & Lints-Martindale, 2014; Husebo, Strand, Moe-Nilssen, Husebo, & Ljunggren, 2010; Herr, Sefcik et al., 2019; Husebo, Ostelo, & Strand, 2014) | Older adults with dementia<br>Chronic pain | Long-term care |
| PACSLAC: The Pain Assessment Scale for Seniors with Severe Dementia & PACLSLAC-II | (Fuchs-Lacelle & Hadjistavropoulos, 2004; Fuchs-Lacelle & Hadjistavropoulos, 2005; Chan et al., 2014; Hadjistavropoulos et al., 2018) | Older adults with dementia<br>Chronic pain | Long-term care |
| PAINAD: The Pain Assessment in Advanced Dementia Scale | (Warden, Hurley, & Volicer, 2003; Lints-Martindale, Hadjistavropoulos, Lix, & Thorpe, 2012; Ruest et al., 2017; Zwakhalen, van der Steen, & Najim, 2012) | Older adults with dementia<br>Chronic pain | Long-term care; acute care; palliative care |

[*] Includes development and validation references and selected recent evaluation studies.

**Table 6**
Persons at End of Life: Behavioral Pain Assessment Tools

| Tool | References* | Sample | Setting |
|---|---|---|---|
| MOPAT: Multidimensional Objective Pain Assessment Tool | (McGuire, Reifsnyder, Soeken, Kaiser, & Yeager, 2011; Wiegand et al., 2018) | Adults | Hospice; Intensive Care Unit |
| PAINAD: The Pain Assessment in Advanced Dementia Tool | (van Iersel, Timmerman, & Mullie, 2006) | Older adults | Long-term care |

* Includes development and validation references and selected recent evaluation studies.

palliative care patients as well as other settings. However, this tool is not readily accessible for clinical use and is undergoing final evaluation and publication (contact dbmcguire@vcu.edu for further information). With limited validated tools for patients at end of life, clinicians should consider tools intended for specific populations, which may be relevant as the person moves toward death, such as those studied in long-term care settings. See other special population behavior tools in Table 6. Research is needed to guide clinical practice in various settings of care with patients at the end of life (Gagliese, Rodin, Chan, Stevens, & Zimmermann, 2016).

### 4. Solicit *Proxy Reporting of Pain*

Family and caregivers play an essential role in recognizing pain and evaluating comfort as persons transition toward death (Fink et al., 2015). 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 since many fears and barriers to effective pain management exist.

### 5. *Attempt Analgesic Trial*

Determining presence of pain based on response to analgesia is very challenging in this population, as intentional sedation may obscure behaviors often used to detect pain. Therefore, it may be prudent to assume pain is present and 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, 2015).

## SUMMARY

Individuals who are unable to communicate their pain are at greater risk for underrecognition and undertreatment of pain. This position paper provides updates for five populations at risk and offers clinical practice recommendations for appropriate pain assessment using an adapted 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 ensure optimal pain management. Because of continued advances and new developments in strategies and tools for assessing pain in these vulnerable populations, clinicians are encouraged to stay current through regular review of new research and practice recommendations.

## OTHER POSITION PAPERS/STATEMENTS/GUIDELINES

American Academy of Pediatrics, 2016; American Nurses Association, 2018; American Pain Society, 2012; Herr, Coyne, et al., 2019; National Association of Neonatal Nurses, 2015; Schofield, 2018.

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