A Conceptual Model of Pain Assessment for Noncommunicative Persons With Dementia

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Purpose. Our objectives are to present a conceptual model of the pain assessment process in persons with dementia and discuss methods for validating our model within this population. Design and Methods. This conceptual work is based on an integrative review and current pain theory, pain assessment research in demented and nondemented populations, and research on the science of self-report. Results. We present a multidimensional model of pain assessment that emphasizes the role of the external rater. Our model posits that a nociceptive stimulus leads to pain sensation, followed by pain perception, followed by the exhibition of external signs of pain by the patient, followed by an external rater’s observation and interpretation of those external signs. Further, the model specifies the effects of nociceptive stimulus factors on pain sensation; patient-specific factors on pain perception; method-specific factors on external sign observation; and rater-specific factors on external sign interpretation. Implications. Pain assessment in persons with dementia must go beyond a unidimensional model of pain assessment. This multidimensional model also directly addresses the challenges of using external ratings to assess pain in persons with dementia. Finally, we present clinical recommendations for applying the model to pain assessment endeavors and research recommendations for evaluating models of pain in this population.

Key Words: Dementia, Pain, Assessment

Appropriate pain assessment is the foundation of effective pain management. However, pain assessment in persons with dementia has proven to be a difficult endeavor for health providers. For example, in the nursing home setting, where the majority of patients suffer from dementia (67.4%; Rovner et al., 1990), researchers have reported that 62% of the residents reported pain during an interview, yet only 37% had pain documented in their charts (Ferrell, Ferrell, & Rivera, 1995). Difficulties in assessment inevitably lead to difficulties in pain management. Several studies report that one quarter or less of demented nursing home residents identified as in pain were receiving analgesics (Scherder, Bouma, Borkent, & Rahman, 1999; Won et al., 1999). These pain assessment and subsequent pain management difficulties are reflected in and maintained by the paucity of pain research in persons with dementia. Studies of pain in the elderly population have often excluded persons with dementia, and even studies focusing on pain in persons with dementia have typically excluded those who are too severely impaired to communicate (e.g., Feldt, Warne, & Ryden, 1998; Won et al., 1999).

At the root of these assessment and research difficulties is the decreased or absent self-report...
capacity of individuals with dementia due to the language, memory, and abstract thinking deficits inherent in the disease (White & Cummings, 1997). Theoretical explanations of the pain experience have evolved toward increasingly intricate multidimensional models, yet these advances have failed to directly address the unique challenge of pain assessment in persons with dementia (Harkins & Price, 1992). Without an adequate conceptual model, research and clinical advancement in pain assessment in persons with dementia has been restricted. Although enormous strides in measurement have been made (e.g., Feldt, 2000; Hurley, Volicer, Hanrahan, Houde, & Volicer, 1992), current instruments tend to focus on a limited part of the pain experience (presence or absence of pain, and pain intensity), and there is little understanding of how these restricted results are tied into a multidimensional understanding of pain.

In this article, we present a multidimensional conceptual model of pain assessment for persons with dementia, which is based on the concepts of current pain theory. We then explain how our model serves as a guide for the development of a pain assessment strategy for these persons. Finally, we provide methodological recommendations for designing evaluations of pain assessment approaches for persons with dementia.

An Overview of Pain Theory

Over the past 30 years, there has been a revolution in the conceptualization of pain. Before then, the leading view was a unidimensional model, in which pain was posited to be directly and proportionally due to the amount of nociceptive stimulation received to pain-specific nerve fibers when tissue damage occurred (Novy, Nelson, Francis, & Turk, 1995a). By 1959, two-dimensional models of pain had been developed, based on Beecher’s description of the experience as divided into “pain” and “no pain” components. In 1965, Melzack and Wall introduced their landmark multidimensional model of pain, the gate-control theory, which postulated that nociceptive information is modulated by a “gate” in the spinal cord dorsal horn. Three neural processing systems (sensory–discriminative, motivational–affec-
tive, and cognitive–evaluative) affect this gate. Thus, pain was conceptualized as the product of complex interactions between physiological, emotional, cognitive, and eventually behavioral components. Other multidimensional perspectives have been introduced since then, including the nonrestrictive operant model (Fordyce, 1976), the cognitive–behavioral model (Turk, Meichenbaum, & Genest, 1983), and the biobehavioral model (Turk & Flor, 1999).

In a review of major pain models, Novy and colleagues (1995a) noted that all current multidimensional theories agree regarding the following: (a) simple nociception does not equal pain; (b) pain is a multidimensional construct; and (c) pain is best conceptualized as having sensory, behavioral, emotional, and cognitive components. Although these theoretical advances have affected pain assessment in children (McGrath & Brigham, 1992) and adults (Turk & Melzack, 1992), they have not directly addressed the unique challenges posed by pain assessment in persons with dementia (Harkins & Price, 1992). In the next section, we examine the applicability of these models to persons with dementia.

Application of the Existing Models to Persons With Dementia

The first question that must be addressed is whether or not persons with dementia experience pain similarly to cognitively intact individuals. Evidence from experimental pain studies and the neuropsychological and neuropsychological literatures strongly suggests the pain experience is altered in dementia. Pain thresholds (minimum level at which a painful stimulus is recognized) are not altered in mildly demented patients, but pain tolerance (maximum level at which a pain stimulus is voluntarily tolerated) is significantly increased (Benedetti et al., 1999; Porter et al., 1996). Thus, it appears that mild dementia does not affect the sensory pain system (implicated in threshold paradigms) but does affect emotional and cognitive pain systems (implicated in tolerance paradigms). In sum, persons with mild dementia experience nociceptive sensations in the same way as nondemented persons, but in some situations they fail to interpret such sensations as painful, or as painful as they would if they were not impaired. Given that nociceptive capacity develops very early (even preterm neonates display pain perception signs; see Craig, Whitfield, Grunau, Linton, & Hadjistavropoulos, 1993), and that deterioration of brain function in dementia generally follows a reverse developmental course, it is highly unlikely that persons with dementia ever become so impaired as to lose all pain perception. Perhaps these findings help explain why studies have consistently reported that increased cognitive impairment is associated with decreased pain self-report. For example, in adult day care participants, self-reported pain prevalence was 48–71% in those without cognitive deficits, versus 30–57% in those with mild to moderate deficits (Werner, Cohen-Mansfield, Watson, & Pasis, 1998). Although it is possible that these findings reflect an actual decrease in experienced pain, they more likely reflect difficulties in pain self-report and interpretation of noxious sensations. Indeed, self-report assessment can be problematic because of the language and higher order processing deficits that accompany even mild dementia. To accurately self-report, one must be able to understand
the pain rating request, recall pain events in the given time frame, label noxious sensations as painful, and have the language and higher order processing abilities to report these experiences. This conclusion is supported by research evidence that, when pain is induced by medical procedures or physically demanding activities, persons with dementia exhibit pain behaviors at rates comparable with those for persons without dementia (Hadjistavropoulos et al., 1998; Hadjistavropoulos, LaChapelle, MacLeod, Snider, & Craig, 2000).

In sum, the literature suggests that multidimensional pain models are applicable to individuals with dementia, but with the caveat that such individuals may be unable to correctly label painful sensations. The assessment of pain in those with dementia thus requires extrapolation of the meaning of observed behaviors by external raters, despite the uncertainty that may bring. Further, because most models of pain were developed with communicative individuals, we must be vigilant in identifying components of such models that are inapplicable to nonverbal individuals. In the next section we present a pain assessment model based on those concepts held similar by the current multidimensional pain models. Further, this model is testable and accounts for the unique features of pain assessment in persons with dementia.

A Testable Model of Pain Assessment in Persons With Dementia

Basic Model of Pain

Our basic model of pain contains those elements that were consistent across current multidimensional models (illustrated in the “pain perception” box in Figure 1). We frame our model as a structural equation model (SEM), which is particularly appropriate for pain because it allows the researcher to (a) specify a variable as latent (one whose existence is not directly observable but inferred on the basis of putative indicators), which is a designation prominent pain theorists apply to pain (Cleeland, 1986; Melzack, 1993; Turk, 1989); (b) account a priori for measurement errors that are due to imperfect assessment tools through the measurement model specification (Byrne, 1994); and (c) account for contemporaneous and predictive relationships between latent and manifest (directly observable) variables through structural model specification (Rudy, 1989). A challenge to pain assessment in patients with dementia is our lack of understanding about how pain indicators are related to each other (Turk, 1989). The SEM approach allows us to begin to address this challenge by modeling different relationships between pain components.

The basic model specifies pain as a second-order latent variable (an overarching construct that consists of distinct components but is more than the simple sum of these components), subsuming four first-order latent variables (sensory, behavioral, emotional, and cognitive; Melzack, 1993). Novy and colleagues (1995b) noted that this structure is explicitly designated in the gate-control theory and can be interpreted as consistent with the nonrestrictive operant and cognitive–behavioral approaches. Clear definitions of the pain components do not appear in the literature, but after extensive review to clarify the intents of Melzack and the other prominent theorists, we offer the following definitions.

The sensory component refers to sensations experienced in response to a nociceptive stimulus. Researchers usually measure it by asking about pain intensity, quality (burning, throbbing, etc.), temporality (continuous, intermittent, etc.), location, or duration (Melzack & Wall, 1965). The emotional component refers to emotions that accompany pain and occur as a result of the pain. This includes emotional valences attached to the pain (e.g., is the pain horrible, awful, frightening; see Melzack, 1975), and emotional reactions to the pain (e.g., depression). Some instruments assess emotions generally (e.g., “Rate your overall mood during the past week”), whereas others are more specific (e.g., “During the past week, [has] pain interfered with your mood”; see Cleeland & Ryan, 1994; Kerns, Turk, & Rudy, 1985). The behavioral component refers to pain’s effect on patient function or activity (Cleeland & Ryan, 1994; Jamison, Rudy, Penzien, & Mosley, 1994). This definition specifies deliberate or functional behaviors (e.g., dressing), as opposed to automatic or nonfunctional behaviors (e.g., grimacing), because we posit that automatic pain behaviors in persons with dementia are regarded as pain intensity indicators (part of the sensation component). For example, most observational pain measures recommend summing behavior counts or intensities, and treat this total as a global pain measure; the correlation of this total with another pain intensity measure is often cited as concurrent validity evidence (Abbey et al., 2004; Lefebvre-Chapiro, 2001; Warden, Hurley, & Volicer, 2003).

A challenge in defining the emotional and behavior components is determining the extent to which pain must be established as the cause. Finally, the cognitive component refers to thoughts that accompany pain and occur as a result of the pain. Most instruments focus on cognitions that make it harder or easier to tolerate pain, such as coping, self-esteem, and self-efficacy (Turk, 1992).

Incorporating Factors Affecting Pain Assessment in Persons With Dementia

We next expand this basic model to clarify the specific factors that affect the pain assessment outcome in persons with dementia (see Figure 1). In our expanded model, we specify that a nociceptive...
stimulus gives rise to painful sensations (influenced by stimulus-specific factors), which influence pain perception (influenced by patient-specific factors). Pain perception is described by our basic model of pain. The internal pain experience is communicated through external signs. An external rater observes these signs (influenced by the method through which signs are observed) and interprets them (influenced by rater-specific factors). The result is the external rater’s pain assessment. To emphasize the process leading to the pain assessment, all arrows point that direction, although in actuality, many of the relationships are bidirectional. The proposed model is compatible with the pain communications model, which posits that an internal pain experience is encoded in expressive behavior, which is then decoded by an observer (Hadjistavropoulos & Craig, 2002); we refer the reader to this model for a thorough discussion of pain communication from an ontogenetic, adaptation perspective. We next explore each of the categories that influence the pain assessment process.

**Sensation.**—Determined by pain etiology and by how the body reacts to nociceptive nervous signals (Melzack & Wall, 1965), the pain experience is affected by the nature of both the nociceptive stimulus and the nociceptive sensations (Melzack & Wall, 1965): location (e.g., stomach or head),
intensity, pattern (intermittent or continuous), duration (acute or chronic), frequency, and quality (e.g., crushing or stabbing; see the AGS Panel on Chronic Pain in Older Adults, 1998).

**Perception.**—Experimental psychology defines sensation as “immediate and basic experiences generated by isolated, simple stimuli,” and perception as “the interpretation of those sensations, giving them meaning and organization” (Matlin & Foley, 1992). The proposed model posits the internal pain experience to be affected by not only the nociceptive stimulus but also by the perception of that stimulus, which may be affected by several patient-specific factors. Gender, emotional states, cognitive content, and behaviors are associated with markedly different pain intensity reports in response to the exact same physical stimulus (Turk & Flor, 1999; Vallerand & Polomano, 2000). Pain history is also associated with such differences, particularly for individuals with chronic pain, because of the effect of learning in one’s interpretation of the stimulus (Turk & Flor, 1999) and because the nociceptive nervous system itself can be altered by prolonged exposure to noxious stimuli (Perl & Kruger, 1996). Physical status is another important factor for similar reasons (Hunter, 2001). Finally, as discussed previously, cognitive impairment can also affect one’s interpretations of painful signals.

**External Signs.**—The patient’s internal experience of pain can be displayed in several ways: verbal signs (complaining of pain or other negative emotional or physical states or making sounds such as moans or groans) nonverbal signs (e.g., grimacing or exhibiting unusual motor behavior; Bachino, Snow, Kunik, Cody, & Wristers, 2001), or physiological signs (elevated heart rate or blood pressure; Williams, 1996).

Unlike the sensory, behavioral, and emotional pain components, there are no external indications of cognitive content. The cognitive component is shaded in the proposed model because it is a “black box.” This does not mean that persons with dementia do not cognitively evaluate pain, but that in the presence of self-report impairment, it is not possible to predict the effects of such evaluations. Perhaps it is possible for researchers to assess the cognitive component by using informant reports, but the black box indicates uncertainty about the validity of such reports.

**Observation of External Signs.**—The fundamental difference between pain assessment in intact and severely demented persons is an almost exclusive reliance on external signs. Even in people with milder dementia, deciding how to weight self-report versus observation is a substantial challenge because self-report impairment is gradual and varies even within the same dementia stage. Using external rater reports necessitates several important considerations, because discrepancies consistently exist between self-reports and external reports. For example, studies comparing pain self-ratings to the ratings of others report low to moderate agreement and significant patient–rater discrepancies across a variety of raters (family, nurses, aides, physicians) and settings (postoperative recovery, palliative care, geriatric inpatient and cancer outpatient settings, intensive care units, nursing homes) (Krulwich et al., 2000; Nekolaichuk et al., 1999; Teske, Daut, & Cleeland, 1983; Weiner, Peterson, Ladd, McConnell, & Keefe, 1999; Zalon, 1993). External raters tend to rate pain lower than the patient. Further, the magnitude and bias (overreporting or underreporting relative to the patient) of these discrepancies are affected by characteristics of the assessment method used. We next examine these method factors: construct characteristics, rater type, data-collection method, and assessment instrument characteristics (Magaziner, 1997; Neumann, Araki, & Gutterman, 2000).

**Construct Characteristics.**—Researchers can rate some aspects of pain by using more objective procedures such as frequency counts (e.g., “How often was the patient able to make the bed last week?”). Other aspects require more subjective judgments based on the rater’s experience (e.g., “Rate the intensity of the patient’s pain, from no pain at all to worst possible pain.”). The more subjective the construct, the larger the discrepancy. For example, studies report higher agreement between patient and informant for levels of functioning and less private physical conditions, and lower agreement for more private physical conditions, depressive symptoms, psychological well-being, and pain (Neumann et al., 2000). Thus, conclusions may vary if they are based on more objective as opposed to more subjective data types.

**Rater Type.**—Discrepancy magnitude varies by rater type. There is evidence of greater discrepancies between physicians and patients than between nurses and patients (Nekolaichuk et al., 1999), and between licensed practical nurses and patients than between aides and patients (Engle, Graney, & Chan, 2001). Differences may be due in part to varying experiences with the patient. For example, the nursing home physician must base ratings on information derived from short, infrequent visits in which the physician is focused on examining the patient to identify problems. In contrast, the nursing assistant has frequent patient contact each day, but in this contact the assistant is focused on care tasks. Raters also bring different attitudes toward and knowledge about the construct. Finally, the patient may behave differently with different raters. Perhaps rater discrepancies do not reflect variations in accuracy but rather that truth is best estimated by assembling multiple perspectives from different raters.
Data-Collection Method.—External raters can collect pain assessment data through patient subjective verbal report, informant subjective verbal report, or objective behavioral observations. These methods may evaluate different aspects of the same construct. Studies comparing self-ratings to behavioral observations, and informant ratings to behavioral observations, have demonstrated that different methods yield moderately different results (Gotay, 1996; Turk & Flor, 1987; Zanetti, Geroldi, Frisoni, Bianchetti, & Trabucchi, 1999). Self-ratings and informant ratings are more subject to rater bias than performance-based ratings, yet they allow for assessment of situations that are unlikely to be observed by a standardized rater (e.g., toileting, aggression). The breadth of a complicated construct such as pain is probably more likely to be represented by combining self-reports, informant reports, and behavioral observations.

Assessment Instrument Characteristics.—Finally, even within the same data-collection method, discrepancies often exist between assessment instruments. One cause could be the scope of assessment. For example, the Brief Pain Inventory includes items measuring pain interference, whereas the McGill Pain Inventory does not (Cleeland, 1989; Melzack, 1987). Alternatively, discrepancies could reflect the superior psychometric qualities of an instrument for certain populations. For example, the 21-point box scale of pain intensity has superior psychometric qualities in persons with dementia compared with a 5-point verbal rating scale (Chibnall & Tait, 2001).

Interpretation of External Signs.—Many of the same factors that affect a patient’s perception of his or her pain also affect an external rater’s interpretation of the patient’s pain. These can include the demographic characteristics and pain history factors discussed earlier. The rater’s knowledge of and beliefs about pain and dementia are also powerful. If the rater believes that pain is an inevitable part of aging, or that persons with dementia can no longer feel pain, the rater may be insensitive to subtle distress signs. Similarly, the rater’s relationship with the patient can affect interpretation. Amount of time spent with the patient has been shown to affect informant–patient discrepancies (Magaziner, 1997). Finally, secondary gain can affect a rater’s interpretations, unconsciously or consciously. For example, the caregiver reporting a hospice patient as in intractable pain may benefit from the emotional support provided by nurse home visits.

Applying the Model

Assessment Instrument Recommendations

The clinical application of the proposed model to persons with dementia relies on the existence of appropriate pain assessment tools. In the paragraphs that follow, we review verbal and nonverbal pain assessment instruments in regard to applicability to the model.

Verbal Pain Assessment.—The majority of the pain assessment literature has focused on self-report (Melzack & Katz, 1999; Weiner, 1999). Results of studies of verbal pain assessment tools in persons with dementia have been variously touted as evidence that persons with dementia can, or cannot, validly use such tools, depending on whether one’s perspective is the glass half-empty or half-full. For example, one study reported that, of five simple pain intensity scales administered to a group of cognitively impaired nursing home residents, 83% of the residents could complete at least one of the instruments; however, only 17% could complete all five instruments (Ferrell et al., 1995). The ability to respond to a verbal pain assessment is generally associated with level of cognitive impairment (e.g., Chibnall & Tait, 2001; Cohen-Mansfield, 2002; Wynn, Ling, & Remsburg, 2000). Completion rates are negatively correlated with degree of cognitive impairment (Scherder & Bouma, 2000). Two limitations of this literature are that (a) only unidimensional scales, almost exclusively pain intensity scales, have been examined, and (b) accuracy of pain self-reports in people who can complete the scales has yet to be examined. In sum, it is probably best to include verbal pain assessment for individuals with dementia, but it is not sufficient to rely solely on it, particularly in moderately and severely demented persons. Further, the assessment techniques from this literature do not meet the needs described by the proposed model (or any current comprehensive pain model) because these instruments do not assess all four pain components.

Nonverbal Pain Assessment.—There are currently at least seven published behavioral observational scales with adequate to good reliability and validity evidence for persons with dementia. All require the rater (typically a nurse, although one scale has been validated with aides) to observe the patient and rate the presence or absence, intensity, or frequency of behaviors. The majority of these scales focus only on the sensation component (Feldt, 2000; Snow et al., 2004b) or on the sensory and emotional components (Abbey et al., 2004; Hurley et al., 1992; Warden et al., 2003). Only two scales include sensory, affective, and behavioral components (Lefebvre-Chapiro, 2001; Villanueva, Smith, Erickson, Lee, & Singer, 2003).

In addition, even those tools that appear to be multidimensional may be limited in their scope of the emotional and behavioral components. Emotional component evaluations are limited to using affective language to describe some rated facial expressions (e.g., frightened, anxious, or sad facial expression).
Behavioral component evaluations are limited to rating independence during the past few meals and the extent to which washing, dressing, and mobility are affected. Thus, in striving for a clinical application of the proposed model, we find it important to consider alternative assessment approaches in addition to these scales.

Adapting Scales Developed for Demented Persons.—As we discuss in an upcoming section (Testing the Model), it is important for researchers to be able to use the same set of measures in both demented and nondemented persons. This allows them to accomplish one kind of validation work by comparing the self-reports of nondemented persons (the gold standard) against external ratings. Therefore, it is important to consider differences that might occur when behavioral observation scales are used with nondemented persons.

One important concern is that behavior will be unduly influenced by an observer. Indeed, Hurley and Volicer (2001) found it impossible to use the Discomfort Scale with nondemented persons because of the observer’s impact on the patient’s behavior. However, observational instruments have been shown to be feasible, reliable, and valid in nondemented patients with chronic pain (Keefe & Block, 1982; Richards, Nepomuceno, Riles, & Suer, 1982). Keefe and Richards required the patient to engage in a series of activities, thus distracting the patient from the observation. In contrast, in Hurley’s method the patient is at rest and thus free to focus all attention on the observer. Thus, observational measures that engage the patient in a competing activity during the period of observation may be better suited if nondemented persons are to be assessed (e.g., Feldt, 2000; Snow et al., 2004b).

Adapting Scales Developed for Nondemented Persons.—One might assume that comprehensive pain assessment in persons with dementia could be achieved by adapting existing multidimensional tools. For example, several multidimensional assessment instruments exist for nondemented adults, such as the McGill Pain Questionnaire (Melzack, 1975), the Multidimensional Pain Inventory (Kerns et al., 1985), and the Geriatric Pain Measure (Ferrell, Stein, & Beck, 2000). However, all of these instruments rely almost exclusively on the patients’ pain reports. Few elicit reports from significant others, and the content is often inappropriate for persons with dementia (e.g., “Does your significant other’s pain interfere with his or her ability to mow the lawn?”; see Kerns et al., 1985). Assessment instruments also exist for nonverbal neonates and infants, such as the CRIES (Krechel & Bildner, 1995). However, in addition to having not been validated in persons with dementia, these instruments are not truly multidimensional because they focus only on the sensory component. In sum, no single instrument is available that adequately assesses sensory, behavioral, emotional, and cognitive pain components in persons with dementia—existing nonverbal tools are not multidimensional, and existing multidimensional tools are not appropriate for nonverbal populations.

Given these limitations, we recommend the following strategies for comprehensive pain assessment. First, bring together multiple measures (e.g., use one of the pain scales for persons with dementia to assess parts of the emotional, behavioral and sensory components and other measures to assess other aspects of the emotional and behavioral components). Second, adapt existing pain measures for cognitively intact persons to make them appropriate for use with persons with verbal impairments (e.g., change the wording of the Multidimensional Pain Inventory to third person so an informant can rate the person with dementia); this strategy has produced valid results in the assessment of other psychosocial constructs, including depression (Teri & Wagner, 1991), deficit awareness (Snow et al., 2004a), and functional status (Kiyak, Teri, & Borson, 1994). Third, adapt existing measures for persons with dementia to assess other pain components; for example, measure the emotional pain component by using the Affect Rating Scale (a behavioral observation scale that assesses negative affect; see Lawton, Van Haitsma, & Klapper, 1996) during a known painful episode.

These strategies are recommended because, given the current available instrumentation, the only alternative to these strategies is to not attempt comprehensive pain assessment in persons with dementia. However, the clinician should be aware that such adaptations alter the psychometric properties of instruments, and thus the reliability and validity of the adapted instrument will be unknown. Clinical hypotheses based on such assessments should therefore be considered tentative, and the clinician should look for independent corroborating evidence of these hypotheses. The researcher is encouraged to undertake psychometric studies of such adapted instruments so that adequate validated instrumentation for comprehensive pain assessment in persons with dementia will soon be available.

Assessment Strategy Recommendations

The proposed model emphasizes the effects of nociceptive stimulus and patient, method, and rater factors on the external rater’s pain assessment. The rater might note such factors when performing a comprehensive pain assessment, and possible effects of such factors on the assessment outcome. In particular, a thorough history of the patient’s psychosocial well-being and pain will provide helpful information. Given the effects rater and method factors can have on pain assessment, another strategy
suggested by the model is the importance of using multiple methods and multiple raters when feasible.

**Testing the Model**

**Validation Recommendations**

An inherent research difficulty is the challenge of validating pain assessments in a population for which no gold standard exists. Self-report is the typical gold standard in pain studies, but self-report is suspect, even in persons with mild dementia. We have developed two SEM approaches to provide evidence for the basic pain model.

We call the first validation paradigm the Self-Report Comparison Model (see Figure 2). This approach compares the pain latent variable from the basic pain model to pain self-reports in persons without dementia. The pain latent variable would be modeled by use of pain assessment instruments that rely on external ratings rather than self-ratings to assess each of the four pain components. Agreement between the pain latent variable and pain self-report (the typical gold standard) would serve as evidence of validity of the pain latent variable. The pain latent variable could then be modeled in patients with mild to moderate dementia. The individuals without dementia would then be compared with those with mild to moderate dementia to see if there were similar patterns of relationships between the pain assessment instruments included in the pain latent variable model. If the patterns were similar in the
two groups, a comparison could then be conducted between individuals with mild to moderate dementia and those with severe dementia. Thus, there would be evidence for validity of the pain latent variable in persons with severe dementia if the patterns of relationships between other-rated pain assessments were similar in these last two groups, even though it would not be possible to obtain the typical gold standard, self-report data, in this population.

We call the second validation paradigm the Known Correlates Validity Model (see Figure 3). In this approach, empirically supported correlates of pain in patients with dementia would be used as evidence of concurrent validity. This model specifies that the pain latent variable is associated with these correlates. We include in Figure 3 only those constructs for which we have found strong evidence of such an association: pain history (Zeichner, Widner, Loftin, Panopoulos, & Allen, 1999), presence of pain-related condition (Hunter, 2001), functional disability (Deyo, 1988), agitation (Feldt et al., 1998), negative affect (Lawton et al., 1996), and depression (Cohen-Mansfield & Taylor, 1998).

**Research Design Recommendations**

The proposed model (Figure 3) has important implications for assessment research design. Because varying rater type and method type are known to affect assessment results, we propose the following research design strategies, based on multiple methods and raters, to control for these effects. First, studies of pain in persons with dementia should include a control group of cognitively intact persons with similar medical comorbidities. For each construct assessed, (a) self-ratings should be collected from all participants who can provide them, and (b) external ratings should be collected for all participants—both those with dementia and those from the control group. This strategy allows one to explore the effects of dementia on rater variance by comparing self-ratings versus external ratings across demented and nondemented participants. Second, multiple raters should complete each assessment instrument. Whenever possible, the same instrument should be used for self-ratings and external ratings. This allows one to make rater comparisons while controlling for method variance. Third, in addition to verbal reports, behavioral assessment should be used as much as practical, given the extensive time and rater effort required to collect behavioral information. This will allow one to explore method variance. Fourth, the multiple assessments of each construct (provided by multiple raters and in some cases multiple methods) should be integrated, guided by the basic model of pain. The use of SEM would be an excellent way to achieve this integration. Building on the multitrait, multimethod matrix of Campbell and Fiske (1959), this approach will allow for a direct test of the conceptual model. In addition, this assembling of multiple perspectives will allow for the best possible estimate of pain as a latent variable.

**Conclusions**

We have developed a conceptualization of the pain assessment process for persons with dementia, based on the current theoretical literature and the assessment challenges unique to persons with dementia (particularly the challenges of using external raters). We have provided recommendations for integrating this information into a comprehensive clinical assessment strategy. We have also given research recommendations for evaluating our model or other pain models for persons with dementia. Important questions, such as “Should pain assessment strategies vary by dementia severity?,” and “Which combination of pain assessment information sources generates the most accurate yet parsimonious data for nursing home residents?,” can only be answered if pain research in persons with dementia moves beyond a unidimensional model of pain assessment.

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