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# Pain and Psychological Well-Being among People with Dementia in Long-Term Care

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## Abstract

**Objective**—To examine the relationship between self-reported pain and psychological well-being of people with dementia (PWD) living in residential long-term care as indicated by displays of observed emotional expression over the daytime period.

**Design**—Secondary analysis using repeated measures of self-report and observational data.

**Setting and subjects**—A total of 177 PWD were included from 17 nursing homes and six assisted living facilities in Michigan and Pennsylvania.

**Methods**—Negative emotional expression was used as an indicator of reduced psychological well-being. Pain was assessed through PWD's response to a question about presence of pain obtained at each observation. Cognitive impairment was assessed using the Mini-Mental Status Examination (MMSE). Linear mixed models were used that accounted for correlation of negative emotional expression measurements over time for each participant and between participants within the same facility.

**Results**—Among 171 participants who were able to express their pain, 44% of PWD reported pain once or more during the daytime period. Severity of cognitive impairment was related to expression of negative emotion. PWD with pain displayed more negative emotional expression than PWD without pain.

**Conclusions**—Routine pain assessment is feasible among PWD with moderate to severe dementia and positive report of pain is associated with greater observed negative emotional expression, an indicator of reduced psychological well-being. Improving pain management holds potential for enhancing psychological well-being among PWD living in residential long-term care.

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## Keywords

pain; psychological well-being; dementia

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## Introduction

Major neurocognitive disorders such as Alzheimer's disease and related dementias have a devastating impact on quality of life (QoL), in part due to progressive and profound losses in functional ability, autonomy, and ability to express needs. Under-recognized or under-treated pain represent important potential threats to QoL among people with dementia (PWD) who live in nursing homes, as pain is associated with a variety of behavioral and psychological symptoms of dementia (1, 2). Contemporary conceptual models of QoL in dementia underscore the importance of focusing on psychological well-being, noting that although the progression of most dementias is not modifiable, related factors such as control of co-morbid conditions and subjective appraisal of personal and environmental factors may be potentially modifiable influences on QoL (3). Developing an empirical base for understanding relationships among variables affecting psychological well-being is urgently needed in order to improve QoL among PWD, particularly those in more advanced stages of illness.

Although an estimated 5.2 million Americans age 65 and older have Alzheimer's disease, and 68% of nursing home residents suffer from some cognitive impairment (4), psychological well-being of PWD in long-term care has received little attention. Nursing home staff tend to ignore or discount PWD's feelings because they believe that dementia interferes with the ability to reliably express emotions (5, 6). However, a growing body of literature indicates that PWD retain the ability to express emotion even in the later stages of their disease (6-9). Specifically, these studies demonstrate that observable indicators of positive and negative emotional expression can be measured reliably among nursing home residents with moderate to severe dementia, and vary over the course of the day, both within and between individuals. Importantly, intra-individual variability in negative emotions is greater than variability in positive emotional expression, and therefore may represent a response to unmet need states that can be addressed through changes in the PWD care or environment (7). Unrelieved pain is an important example of such an unmet need state that could contribute to negative emotional expression because pain prevalence is high among PWD in long-term care (10) and it is often under-treated (11).

Unmet needs of PWD resulting from an inability of caregivers to comprehend needs and the inability of PWD to make needs known (12), have been associated with psychological problems such as anxiety and depression (13) and behavioral disturbances (14, 15). Although PWD may have difficulty expressing their needs due to language deficits associated with dementia (13), some clinicians routinely attempt to elicit subjective information from PWD in the course of providing care for them since PWD, even at advanced stages of illness, can respond reliably about their "here and now" experiences (16). Understanding the relationship between subjective experience of unmet need and emotional

expression would improve clinicians' ability to recognize unmet needs and take action to enhance psychological well-being.

Jonker's model of QoL in dementia suggests that psychological well-being results from more than the objectively defined characteristics of disease (both dementia-related and nondementia related) and the environment; rather, the person with dementia's subjective experience is also an important determinant of psychological well-being (3). Demonstrating that a person with dementia's subjective evaluation of basic need states relates to negative emotional expression could lead to greater understanding of how to improve psychological well-being, and consequently QoL. Thus, the purpose of this study was to examine the relationship between frequency of pain report and psychological well-being of PWD using observed displays of emotional expression during daytime hours. Two specific questions were addressed:

1. How frequently do PWD report pain during daytime hours?
2. How do observed displays of emotional expression of PWD change with the subjective report of pain during daytime hours after controlling for objective indicators of disease, specifically severity of cognitive impairment, and severity of comorbid illness?

## Methods

### Design

A secondary analysis was conducted using data with repeated measures obtained from a subset of participants enrolled in a multi-site descriptive study of factors influencing wandering behavior in PWD who lived in residential long-term care. The design of the parent study was descriptive with repeated measures nested within subjects and has been described in detail elsewhere (17).

### Participants and setting

In the parent study, participants (n=185) were PWD recruited from 17 nursing homes and six assisted living facilities in Michigan and Pennsylvania. Each facility was selected by a random cluster sampling approach; long term care facilities (serving as clusters) within a 60 mile radius of the research institution were eligible. Inclusion criteria for the parent study were as follows: age 65 years or older, English-speaking, Mini-Mental Status Examination (MMSE) score < 24/30, DSM-IV criteria for dementia met, and not wheelchair-bound. The present study included those participants who completed more than three emotional expression observations (n=177). For the second research question, 171 PWD who responded to pain question at least one time among 12 observations were included.

### Measures

Psychological well-being, as indicated by observed displays of emotional expression, was measured by the Observable Displays of Affect Scale (ODAS). The ODAS was specifically developed for coding videotaped emotional expressions in cognitively impaired patients; it measures 34 behaviors including six subscales (i.e., facial displays, vocalizations, and body

movement/posture categorized by positive and negative quality) (18). Specifically, positive emotional expression consists of 4 positive facial displays (e.g., “Has relaxed facial expression”; “makes eye contact with object/ activity”; and “smiles”, etc.), 7 types of positive verbal expressions (e.g., “Verbalizes needs, wants, or feelings about self”; “calls caregiver by name or ‘Honey’ “sweetheart’,” etc.; and “initiates conversation”), and 6 positive body movements/postures (e.g., “Has open posture”; “initiates positive physical contact”; and “aligns head and/or body toward person/object”). Negative emotional expression consists of 4 negative facial displays (e.g., “Has hardened, sad, or worried expression”; “grimaces”; and “keeps eyes closed”), 8 negative verbal contents (e.g., “Curses or swears”; “repeated words or phrases”; and “makes no vocal response to question or statements”) and 6 negative body movements/postures (e.g., “Makes repetitive body movements”; “attempts to leave”; and “has closed posture”). The description for each behavior was provided to coders. For example, one behavior of the negative facial displays is “grimaces”. The specific observation description for grimaces is “making a face, i.e., contorting mouth and/or face”. Higher number of ODAS scores indicates more emotional expression. Studies showed that inter-rater reliability for the ODAS was ranged from .68 to 1.00 and test-retest reliability for the ODAS ranges from .97 to 1.00 (18, 19). In this study, only negative emotional expression was used as an indicator of psychological well-being because negative emotional expression is more likely to accompany pain experience than positive emotional expression. More frequent negative emotional expression was interpreted as reduced psychological well-being.

Pain was assessed through a single direct question “Are you in pain?” asked by trained data collectors. Data collectors coded any verbalization or non-verbal cue (e.g., head nodding) indicating a positive response as a “yes,” those indicating a negative response as a “no,” those that could not be understood clearly as either yes or no as “unintelligible,” and no verbalization or non-verbal cue as “did not answer.”

As covariates, cognitive impairment, severity of comorbid illness, and time of day were included. Cognitive impairment was assessed using the Mini-Mental State Examination (MMSE) (20). The MMSE combines questions and simple tasks to assess a range of cognitive domains, including memory, orientation, calculations, naming, ability to follow single-step and multi-step commands, and constructional praxis; it has a maximum score of 30 points, and a score of 23 or less is widely accepted as indicating the presence of cognitive impairment. Participants who were too impaired to complete testing were assigned a score of -1 as had been done in the parent study. The number of comorbidities was assessed using the Cumulative Illness Rating Scale-Geriatric (CIRS-G). The CIRS-G estimates comorbidity based on physician or nurse practitioner ratings of presence and severity of chronic medical condition for 14 organ systems, with 0 indicating no problem and 4 indicating severe level of problem. A mean score across 14 systems was calculated, higher scores indicating severe chronic medical condition. Good reliability and validity have been established among elderly people (21). Time of day corresponded to the time when an observation was made, recorded using a 24-hour clock.

## Procedure

Participants who met inclusion criteria were observed for 20 minutes on 12 occasions on two-nonconsecutive days. All observation periods were videotaped and occurred between 8AM and 8PM. The order in which participants were observed was determined through random assignment to specific hourly intervals, thus ensuring that participants were observed at each hour of the 12-hour daytime period. Written consent was obtained from legal proxies and assent was also obtained from participants prior to every observation. The pain question was asked at the conclusion of each observation period, during which participants' emotional expression had been videotape-recorded in accord with parent study protocols. Institutional review board approval was obtained from the university and from each participating institution.

Video tapes of participants' emotional expressions were coded using Noldus Observer® 5.0 software. Trained research assistants coded the presence/absence of each scale from a 20 minute videotape using the Noldus Observer® 5.0 software. In the parent study, an inter- and intra-rater agreement among coders was established at greater than 95% using training videotapes before coding for the ODAS measures began. Reliability was assessed throughout the study by sampling 10% of the videotapes and retraining coders if needed. A full description of the procedures used in the parent study has been published elsewhere (17).

## Statistical Analyses

Descriptive statistics were examined to address the first research question. For the presence/absence of pain, we only included observations that participants responded a pain question either 'yes' or 'no' (n=1464).

For the second research question, linear mixed models were used to account for correlation of psychological well-being measurements (i.e., negative emotional expression) over time for each participant and between participants within the same facility. Log transformation was performed to adjust for skewness of the dependent variable (i.e., negative emotional expression). A random intercept was used to account for correlation for responses from residents of the same facility. The covariance structure for responses over time for the same resident was determined by minimizing the Akaike Information Criterion (AIC) with fixed effects to pain, time of the day, and the pain by time of day interaction. AIC is a well-established criterion for model selection (22). It is the best known of what are called penalized likelihood criteria. The likelihood, which in our case is the multivariate normal density, gets better as more terms are added to the model. The likelihood is adjusted by a penalty factor, the number of model parameters for AIC, to obtain the penalized likelihood, which is usually transformed so that smaller scores indicate better models. As more parameters are added to the model, the likelihood gets better while the penalty factor gets worse so that the improvement in the likelihood has to be strong enough to offset the larger penalty. Model selection in this way is more objective than using p-values for tests of zero model parameters. This fixed effects model was then reduced, also using AIC scores, to identify a parsimonious alternative model. The MMSE score and the CIRS-G score were

added to control for covariates. SAS 9.3 (SAS institute, Cary, NC) was utilized to estimate these statistical models.

## Results

### Sample Characteristics

As seen Table 1, a majority of participants were female (76%) and Caucasian (79%) with a high school education or greater (74%). Mean age was 83.6 years ( $SD \pm 6.4$ ) and mean MMSE score was 7.4 with range of -1 to 23. With respect to severity of cognitive impairment, 13% were classified as having mild dementia (MMSE = 17-23); 21% were classified as having moderate dementia (MMSE = 11-16); 39% were classified as having severe dementia (MMSE = 0-10); and 27% were untestable (MMSE = -1). Approximately 62 % of participants resided in a nursing home.

### Summary of Pain Experience

Among 177 participants, 97% of PWD ( $n=171$ ) were able to report their pain at least one time among 12 observations and 41% of PWD ( $n=72$ ) were able to report for all observations; only 3% of PWD ( $n=6$ ) were never able to respond to the pain question. PWD were able to respond to the pain question in 79 % of observations ( $n=1464$ ). We then conducted analyses of data for the subgroup of participants who were able to express their pain. Among 171 participants, 44% of PWD ( $n=74$ ) endorsed having pain once or more during the daytime period. Among 1464 observations, PWD did not endorse having pain in 88% of observations ( $n=1289$ ) while PWD endorsed having pain in 12% of observations ( $n=175$ ). As seen Table 2, the presence of pain was not different by time of day. PWD with pain had a higher comorbidity score than PWD without pain ( $t=-3.03$ ,  $p=.003$ ) but the presence of pain was not significantly different by the MMSE score ( $t=-1.07$ ,  $p=.287$ ; result not shown).

### Relation between Presence of Pain and Negative Emotional Expression

Table 3 contains results from the linear mixed model for the relationship between the presence of expressed pain and negative emotional expression. Among five covariance structures (i.e., compound symmetry, compound symmetry heterogeneous (CSH), autoregressive of order 1, autoregressive of order 1 with heterogeneous variances, and unstructured), CSH was the preferable covariance model for the negative emotional expression data. The interaction between pain and time of day was removed from the model because AIC score improved without it, indicating that the effect of pain on mean negative emotional expression did not change with time of day. PWD endorsing pain expressed more negative emotional expression than PWD without pain ( $p=.002$ ). The MMSE score was significantly related to negative emotional expression after controlling for the presence of pain and hour ( $p=.001$ ). Specifically, PWD who had better cognitive function tend to display less negative emotional expression. There was a significant within-facility correlation between negative emotional expression for participants in the same facility ( $p=.038$ ). This finding suggests that there is an unmeasured facility-level effect on the relationship between pain endorsement and negative emotional expression.



## Discussion

This study generated three important findings that could inform approaches to improving QoL among PWD living in residential long-term care. First, although over 87% of participants had moderate to severe cognitive impairment, the vast majority of PWD (97%) were able to respond to a single-item pain question at least one observation among 12 observations and 41% of PWD responded to the pain question at each observation; likewise, during the majority of observations (79%) PWD were able to respond to a pain question. The frequency of pain reported was lower in this study than in other studies (23), however, in this secondary data analysis, we only had a single-item indicator of pain. Prior studies have shown the importance of asking follow-up questions to ensure that pain is not missed (11), and therefore this study likely under-estimates the frequency of pain in this population. However, the result that even those with severe dementia could report pain is consistent with previous studies summarized in a systematic review, which show that PWD retain the ability to report their pain when asked in a simplified manner (24-26).

Second, severity of cognitive impairment was significantly associated with more negative emotional expression. Better MMSE scores are related to less negative emotional expression. This finding is consistent with prior studies showing that better cognitive function is related to better QoL (27). This finding is also consistent with Jonker's model of QoL in dementia, which proposes that objective indicators of dementia related problems, such as severity of cognitive impairment, are related to QoL, although not the sole influence.

Third, after controlling for cognitive impairment, the presence of pain reported by PWD was significantly related to greater negative emotional expression. Although several studies have previously reported that scores on a self-reported pain assessment scale are correlated with pain behaviors such as negative facial expressions (26, 28), a unique feature of this study was that it showed the relationship between observable negative emotional expressions and self-reported pain indicated by a simple yes or no response. Although this is a very crude measure of pain presence, the use of very simple indicators of pain is important to promote pain recognition in PWD with very severe disease who may not be able to respond to more complex questions.

A positive report of pain was associated with greater observed negative emotional expression. This means that self-reported pain is congruent with their emotional expressions, which suggests that self-reported pain among PWD could be used to identify situations in which the PWD's psychological well-being and QoL are diminished. Although this simple yes/no indicator is insufficient as a pain assessment, it is an example of the type of question that could readily be incorporated into resident care rounds to screen for conditions or factors that could be modified to enhance a PWD's well-being. Two prior studies have shown that greater self-rated QoL in people with mild dementia was correlated with fewer behavioral observations of pain (29, 30). Our findings were consistent with their work, even though the measurement approaches differed.

Several study limitations relate to the use of secondary analysis to examine relationships between pain and psychological well-being. The MMSE was the only measurement of

cognition available. Although the MMSE is a useful instrument to measure the level of impairment in dementia, it is not a comprehensive measure of the many cognitive domains that may affect the PWD's ability to report or cope with pain. Prospective studies of these relationships should include a more comprehensive measure of cognition that would include more information about language skills and executive function. Likewise, we were unable to control for depression due to the lack of a depression measure in the parent study. However, sampling criteria for the parent study included only residents whose medication regimen was stable during the 30 days prior to observation and were free of acute illness and psychiatric illnesses. In addition, the single-item question regarding pain may have resulted in an underestimate of pain in this sample. Prior studies have shown that asking "Are you in Pain?" would result in decreased identification of pain and use of other words such as aching, hurting, discomfort might be needed as follow-up to assure pain is not present. Since this was a secondary analysis, it was not possible to ask these follow-up questions. Other studies have found a much higher rate of pain (26, 31), and therefore our finding that 88% of observations reported no pain is likely related to the question used. We also recognize that negative emotional expression captures only one aspect of psychological well-being; psychological well-being is more complex than the absence of negative emotional expression; however, attending to and treating sources of negative emotions would be expected to positively influence psychological well-being generally. Observations were obtained over just a few days, and therefore are essentially cross-sectional data. Cross-sectional studies can efficiently identify associations among variables, but cannot demonstrate causal relationships. Longitudinal or intervention studies are needed to justify inferences regarding a causal relationship between pain and psychological well-being among PWD. Such studies would need to include multiple measures of pain report such as behavioral observations to strengthen confidence in our findings (32).

This study provides preliminary support for Jonker's model of quality of life in dementia, among long-term care residents with moderate to severe disease. Specifically, both objective personal factors (cognitive function), and the individual subjective evaluation of circumstance (pain report), each influences indicators of psychological well-being (negative emotional expression). These findings warrant further examination in prospective study designs that would include more robust measures of both pain and cognition. These findings also have important clinical implications. To more effectively identify opportunities to improve psychological well-being among PWD in residential long-term care, nursing home staff should routinely ask PWD whether or not they have pain using a simple yes/no question format; equivocal or negative responses should be followed up with questions about aching, hurting, or discomfort. Positive responses should be followed up with a more comprehensive pain assessment. Based on pain assessment, improved pain control, considering both non-pharmacologic approaches, such as repositioning and distraction, as well as considering adjustments to pharmacologic management of painful conditions could improve PWD's psychological well-being and ultimately their QoL.

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**Table 1**

Participants' characteristics (N=177)

Variable	Label	N (%)	Mean (SD)
Observation-level			
Negative emotional expression *	(range: 0.00-86.00)		8.70 (10.72)
Person-level			
Age			83.64 (6.39)
Gender	Male	42 (23.7)	
	Female	135 (76.3)	
Education	Less than high school	40 (26.1)	
	High school	65 (42.5)	
	College or higher	48 (31.4)	
Ethnicity	Caucasian	139 (79.0)	
	African American	37 (21.0)	
Facility Type	Nursing home	110 (62.1)	
	Assisted living	67(37.9)	
Comorbidity †	(range: 0.00-1.36)		0.69 (0.22)
MMSE	Mild (17-23)	22 (13.4)	
	Moderate (11-16)	34 (20.7)	
	Severe or (0-10)	64 (39.0)	
	Untestable (-1)	44 (26.8)	

Note.

\* Higher scores indicates more frequent negative emotional expression

† Higher scores indicates severe chronic medical condition

**Table 2**

## Pain report by time of day

Time of day	Pain	
	No n (%)	Yes n (%)
8am	100 (85.5)	17 (14.5)
9am	102 (84.3)	19 (15.7)
10am	93 (88.6)	12 (11.4)
11am	108 (87.1)	16 (12.9)
12pm	115 (93.5)	8 (6.5)
1pm	108 (89.3)	13 (10.7)
2pm	114 (87.7)	16 (12.3)
3pm	108 (87.8)	15 (12.2)
4pm	114 (91.9)	10 (8.1)
5pm	108 (84.4)	20 (15.6)
6pm	113 (89.7)	13 (10.3)
7pm	105 (86.8)	16 (13.2)

Note.  $\chi^2 = 10.07$ ,  $p = .52$

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**Table 3**

Relation between Presence of Pain and Log of Negative Emotional Expression (N=171)

<b>Fixed effects</b>	<b>Estimate</b>	<b>SE</b>	<b>df</b>	<b>t</b>	<b>p</b>
Intercept	2.80	0.19	151	14.97	<.001
Presence of pain (yes)	0.39	0.12	1006	3.18	0.002
hour	0.01	0.01	1006	0.81	0.418
MMSE	-0.02	0.01	151	-3.27	0.001
CIRS-G	-0.05	0.22	151	-0.24	0.808

  

<b>Covariate parameter estimates</b>	<b>Subject</b>	<b>Estimate</b>	<b>SE</b>	<b>Z</b>	<b>p</b>
Intercept	Facility	0.09	0.05	1.77	0.038
CSH temporal correlation	participant	0.05	0.03	1.73	0.084

Note. SE: standard error; df: degree of freedom; CSH: compound symmetry heterogeneous; MMSE: Mini-Mental State Examination; CIRS-G: Cumulative Illness Rating Scale-Geriatric (CIRS-G)

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