

## Moving to new settings: Pilot study of families' perceptions of professional caregivers' pain management in persons with dementia

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**Abstract**—Persons with advanced dementia often have pain that is underrecognized and undertreated primarily because they cannot clearly communicate their needs. Consequently, they receive fewer analgesics than cognitively intact persons with the same conditions. Several assessment methods have been developed in the past decade, yet pain assessment and management problems persist in all care settings. These problems are likely to persist when patients move between levels of care. In this study, we determined from family caregivers whether pain was problematic when their family members with dementia moved to different care settings (e.g., admission or transfer). A total of 34 family caregivers responded to an anonymous survey; 50% reported that pain was not discussed at admission or after entry into a new care setting, and 67% were not confident that staff could detect pain. Respondents' recommendations for improving pain management included regular observation and assessment, timely and consistent pain medication administration, communication with family caregivers, and staff education.

**Key words:** Alzheimer's disease, analgesia, caregivers, dementia, nursing homes, outcome and process assessment (healthcare), pain, pain measurement, patient admission, rehabilitation.

### INTRODUCTION

Persons with advanced or severe dementia often have pain that is underrecognized and undertreated [1–2]. While these patients' pain management issues are multifaceted and complex, one major problem is that these

patients cannot clearly communicate their needs and, consequently, they receive fewer analgesics than cognitively intact persons with the same conditions [3–4]. Several assessment methods have been developed in the past decade, yet pain assessment and management problems persist in all care settings [5–6]. With the establishment of pain as the fifth vital sign, Department of Veterans Affairs (VA) providers have attempted to incorporate measures for evaluating pain in patients who cannot communicate [7–8]. Despite tool development and VA National Pain Strategy concept articles, no standard or consistent measurement exists across facilities within or outside the VA.

Pain assessment in this vulnerable population is further complicated when patients are admitted to, moved from, or transferred between levels of care, such as from the home or nursing home to the hospital. Qualitative data suggest that the family caregivers who are most familiar with the patient with dementia are in a position to inform healthcare providers about the patient's history, idiosyncratic expressions, and specific needs [9]. To date, the use of informal caregivers as resources for pain management information when patients move between care settings

**Abbreviations:** VA = Department of Veterans Affairs, VAMC = VA medical center.

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has not been explored. Hence, the purpose of the current study was to learn family caregivers' perspectives on pain management after their family members with dementia were admitted to unfamiliar healthcare environments.

## BACKGROUND

Pain management includes assessment; development, implementation, and evaluation of a treatment plan; and ongoing reassessment of pain. Pain in patients with advanced dementia is defined as manifestations of discomfort that may be expressed in displays of behavior, verbal and nonverbal expressions, motor movements, and changes in the individual's usual behavior. While discomfort can be caused by other states, such as thirst, hunger, frustration, loneliness, boredom, constipation, infection, or other conditions and situations, it may be considered pain when a known painful condition exists or a known painful procedure has been performed. That is, what causes pain in cognitively intact persons is likely to cause pain in cognitively impaired persons; hence, the pain could be acute or chronic or both. Information exchange among staff about pain in patients with dementia is often overshadowed by more evident or visible problems. When patients move to new care settings, communicating about pain management poses additional challenges to the continuity of care.

Past research has focused on pain assessment and treatment issues in different types of dementia (and is mentioned in a review article in this issue [10]). Prior studies have noted differences in pain ratings between patients and their family caregivers. Krulewitch and colleagues noted that of 104 patient-caregiver dyads, one-third gave pain ratings that did not correlate [11]. Specifically, 16 patients reported moderate pain but their caregivers rated them as having minimal or no pain and 18 patients reported minimal or no pain but their caregivers rated them as having severe pain. Another one-third of patients were unable to rate their pain because of severe cognitive impairments. These investigators highlight the need for training of family caregivers in standardized pain assessment with observational measures [11].

Other authors have discussed the need to teach both formal (healthcare) and informal (family or nontrained) caregivers about pain assessment in their patients with cognitive and communication impairments. Snow and colleagues described distinct strategies that care providers

can use to elicit pain assessment information from all important persons (e.g., nursing staff, family caregivers). Their method includes the saying "No BODIES in Pain!," where B asks for pain-related behaviors, O asks for how often the behaviors occur, D asks for duration of pain as indicated by the behaviors, I asks for intensity of pain as indicated by the behaviors, E asks for effectiveness of pain treatment, and S asks what stops the behaviors [6].

Literature specifically for informal caregivers discusses pain management in persons with dementia and emphasizes the importance of sharing information with healthcare professionals. For example, one newsletter provides descriptors from a pain assessment tool to help caregivers learn to identify and describe possible pain [12]. These descriptors are from Feldt's Checklist of Nonverbal Pain Indicators [13] and include vocal complaints that express pain, such as moaning, groaning, grunting, crying, gasping; facial grimacing or wincing; bracing and holding onto nearby equipment; restlessness; rubbing; and verbal remarks such as "ouch" or "stop, that hurts." Another publication for informal caregivers, *The Family Caregiver Alliance* newsletter, documents one family caregiver's experience interacting with professionals. This particular caregiver describes insisting on pain management after recognizing and describing signs of pain in the family member with dementia [14].

Communicating information about pain management between family caregivers and professional staff at receiving facilities is a major research gap. No studies to date have examined the role that family caregivers play when patients with dementia move to new and unfamiliar healthcare settings. Only anecdotal evidence documents family experiences with patients' poor pain management upon admission to other levels of care. For example, one legal case involved an elderly patient undertreated in a hospital and then transferred to extended care with little or no pain management. Although the family demanded better pain control, the patient's treatment did not change and the patient died in pain. The physician was deemed legally responsible and required to provide financial and educational remediation [15].

Assumptions driving the current study are that (1) pain is underrecognized in patients with advanced dementia; (2) preexisting pain persists when patients move between settings; (3) unrecognized pain continues to be unrecognized after patients move to another setting; (4) without anyone to advocate for patients who cannot speak for themselves (i.e., patients with severe or

advanced dementia), the patients' needs, including pain, may go unnoticed; and (5) family caregivers are included in interactions at admission, after entry, or during a stay in a different care setting. Hence, we sought to answer the following research questions:

1. What are family caregivers' perspectives on their communication with professional caregivers about pain management when their family members with dementia enter unfamiliar healthcare settings?
2. What are family caregivers' perspectives about pain management once their family members with dementia have entered these new settings?

## METHODS

### Design

This pilot exploratory study used survey methodology with a convenience sample of informal family caregivers of persons with dementia. Dementia is considered severe and advanced when cognitive impairment is extensive and includes memory loss, incoherent speech, inability to care for oneself, and inability to speak for oneself.

### Sample and Setting

The survey was conducted at a regional Alzheimer's Association conference (North Bay Chapter, California) that was held in November 2003 and discussed updated diagnostic methods, issues in care, and dementia treatments. This annual conference targets all persons actively caring for patients with dementia, including formal service providers and informal caregivers and family members. The 1-day conference includes didactic lectures and breakout sessions. One of the investigators (MDB) was invited to speak to this audience about pain and dementia. We selected this setting for the pilot study in order to learn from family caregivers' whether pain communication and pain management are indeed issues when patients with dementia are moved to different care settings (e.g., admitted from home to hospital or nursing home or from nursing home to hospital).

Persons were invited to participate if they cared for a family member with dementia who had been admitted to a setting for a worsening medical condition (i.e., hospital, nursing home, assisted living facility). Persons were excluded from participation if they were not caring for a family member with dementia. The diagnosis and sever-

ity of the patients' dementia were based on respondent (family caregiver) evaluation.

## PROCEDURE

The study was approved by the Alzheimer's Association North Bay Chapter and our institutional review board at the University of California and the VA Medical Center (VAMC) in San Francisco, California. An Alzheimer's Association staff member distributed the survey during conference registration. This staff member informed registrants that the investigator wanted to learn about communication between family and professional caregivers regarding pain management in persons with dementia. During the investigator's presentation about pain and dementia, she explained the survey and specifically invited participation from family caregivers of persons with advanced dementia. Audience members were told that the survey results would help healthcare professionals understand families' needs when patients unable to self-advocate enter different settings. Participants were asked not to identify themselves on the survey, and participation in the survey was interpreted as consent. Surveys were returned to a receptacle in the registration area.

The investigator-created survey was a self-administered set of six items designed to explore generally the family perspective on pain management. The survey and its questions are depicted in the **Figure**. The first two questions forced the respondent to skip to later questions because some patients might not have entered new settings or might not have had pain. Five items were dichotomous, with three soliciting further explanation. A sixth item was qualitative and required a write-in response.

Three healthcare professionals who were also family caregivers and two Alzheimer's Association lay members established face validity. The survey was anonymous so that participants could comfortably express honest opinions and experiences without fear of identifying either themselves or an undesirable setting (e.g., hospital, nursing home, assisted living) where a family member might still have been receiving care.

## DATA ANALYSIS

Frequencies were calculated for each dichotomous item. The write-in questions were coded for themes. We

### Survey about Pain in Persons with Dementia

The purpose of this survey is to determine family members' perceptions about pain management in persons with dementia after admission to a setting for a worsening medical condition (such as a hospital, nursing home, or assisted living). Please do not put your name on this survey. This survey is voluntary and you do not have to respond to any question you are not comfortable answering. Findings from this survey will be used to develop research to improve communication about pain management when persons with dementia move between settings and can no longer speak for themselves.

1. Has your family member been admitted to assisted living, nursing home, or other facility for worsening condition? Yes No

If **no**, answer only questions 2 and 6.

2. Has your family member had pain related to a chronic condition prior to their dementia? (for example, arthritis) Yes No

If **no**, skip to question 6.

If **yes**, how has your family member treated the pain?

For example, has your family member regularly taken pain medication or practiced specific strategies (heat, ice, exercise, a Tylenol before bedtime, etc.) before developing severe dementia?

3. When your family member went to the nursing home (or other setting), did staff discuss with you management of your relative's pain or discomfort? Yes No

If **yes**, was pain management initiated? Yes No

4. Are you confident (or were you at the time) that the staff can detect your relative's discomfort? Yes No

Please explain: \_\_\_\_\_

5. Has the pain or discomfort been well-managed since your relative was admitted to the new care setting? Yes No

Please explain: \_\_\_\_\_

Are you informed of changes? Yes No

6. What, in your opinion, would be an ideal way to manage pain when people develop dementia and need nursing home care (or care by other persons in another setting)?

Comments: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Thank you for participating in this survey!

Please return your completed survey to the Registration Desk at the end of the conference.

#### Figure.

Survey distributed to family caregivers at regional Alzheimer's Association conference.

used Wilson's techniques for content analysis [16]: (1) the caregiver response was the unit of analysis, (2) the set of categories was developed from the topics in the responses, and (3) two authors individually coded the content and then discussed the categorization. Themes were established based on the two authors' consensus. When any disagreement occurred, the authors discussed the rationale for the theme of each response until they reached consensus. The frequencies of responses in these categories were calculated.

## RESULTS

The conference comprised 196 attendees. Of these, 65 percent ( $n = 128$ ) were healthcare professionals and 35 percent ( $n = 68$ ) were family caregivers. The number of persons who were both healthcare professionals and family caregivers could not be determined from either the conference attendance demographics or the returned surveys. Attendees included professional representatives

from acute care hospitals; long-term care settings; assisted living, board, and care homes; hospices; adult day health centers; pharmaceutical companies; and agency resources (e.g., ombuds officers, public guardians). Participants represented multiple disciplines and included nurses, physicians, hospital chaplains, psychologists, physical therapists, occupational therapists, social workers, and counselors. Sample size was decreased because nonfamily caregivers were excluded and most of the conference attendees were professionals who were not likely to have been family caregivers as well.

Of the 68 family caregivers, 34 (50%) responded to the survey. Responses are depicted in **Table 1**. Of these 34 respondents, 17 reported admissions to a new setting and 14 reported pain for their family member with dementia. Thus, 14 respondents met our inclusion criteria. Out of these 14, 12 responded; specifically, 6 reported that they did and 6 reported that they did not have discussions about pain with professional staff and 4 were confident that staff could detect pain. Of 9 respondents, 6 reported that pain was well-managed and 5 had been told of changes to the patient's

**Table 1.**

Responses to survey distributed to family caregivers at regional Alzheimer's Association conference (see **Figure**).

Question	<i>n</i>	Response: No. (%) and/or Written Comments
1. Admission to new setting?	34	Yes: 17 (50)* No: 17 (50)
2. Pain prior to dementia?	34 (1 no response)	Yes: 14 (42) No: 19 (58)
How was pain treated?	14 (multiple answers)	<b>Description of pain treatment:</b> Anti-inflammatory agents ( $n = 2$ ); acetaminophen ( $n = 5$ ); aspirin ( $n = 1$ ); other medication, nonspecified ( $n = 4$ ); ice, heat, or rubbing ( $n = 3$ ); exercise ( $n = 2$ ); rest ( $n = 1$ ).
3. Staff discussion about pain?	12	Yes: 6 (50) No: 6 (50)
If yes, was pain management initiated?	6	Yes: 6 (100)
4. Confident that staff can detect pain?	12	Yes: 4 (33) No: 8 (67) <b>Positive comments:</b> Praise for professional care ( $n = 1$ ), praise for staff skills with family communication & patient assessment ( $n = 1$ ). <b>Negative comments:</b> Problematic understaffing ( $n = 1$ ), lack of communication with family ( $n = 1$ ).
5. Pain well managed?	9 (3 died)	Yes: 6 (67) No: 3 (33)
Informed of changes?	9	Yes: 5 (56) No: 4 (44)

\*Included admissions to hospital ( $n = 2$ ), nursing home ( $n = 2$ ), board and care ( $n = 2$ ), and unknown ( $n = 11$ ).

pain management. A total of 9 persons answered all survey questions. No data are available for the nonrespondents to the survey in general or to the specific questions.

The sixth survey question solicited caregivers' suggestions for optimal pain management: "What, in your opinion, would be an ideal way to manage pain when people develop dementia and need nursing home care (or care by another person)?" A total of 29 (85%) of the 34 participants responded, some giving more than one response. Responses were categorized according to the frequency of the following themes: (1) regular observation and assessment, (2) timely and consistent pain medication administration, (3) communication and/or information exchange with family caregivers, (4) staff education, (5) alternative methods, and (6) psychosocial support. The number of respondents and examples from each theme are presented in **Table 2** in order of frequency.

## ADDITIONAL COMMENTS

Respondents wrote other comments that were not solicited. Examples of these additional comments, in the respondents' words, included, "Mild discomfort was assumed, so no one pays attention to her complaints," and "The staff is very kind and cares for her but don't seem to think of pain as a cause of her restlessness." One anecdote described a patient's functional deterioration in acute care because pain was ignored; when the family caregiver advocated giving the prescribed analgesic and the staff followed the suggestion, the patient markedly improved. Specifically, the patient's affect brightened and she became interested in eating and willing to participate in physical therapy.

## DISCUSSION

This study provides preliminary evidence that family caregivers are concerned about pain management when their family members with dementia enter unfamiliar care settings. From the caregivers' perspectives, pain information is not communicated between family caregivers and staff at new care settings. A total of 17 persons were eligible to complete the survey based on the study inclusion criterion, but this number decreased to 14 based on the study criterion for pain and then to 12 based on

actual respondents. Though the numbers are small, 8 of the 12 respondents (67%) felt that staff could not detect their family members' pain; however, 6 of 9 respondents (67%) thought that pain was managed well. This discrepancy could not be resolved, but family caregivers may have differentiated physician care from nursing staff or may have felt that changes were made after they gave input. (Additionally, no information is available about reasons for nonresponses to either the survey or individual questions.) Generally, the findings suggest that pain detection and treatment problems exist at both entry into and during a stay in a new healthcare environment. The findings also demonstrate that family caregivers had recommendations for improving pain management and for fostering better communication about pain.

The respondents' written comments about recommendations for ideal practice in healthcare settings reflect the need for staff members' increased knowledge, attention to patients, and communication with other staff and family. Our findings are similar to those of other researchers. Martin and colleagues interviewed seniors, nursing staff members, and family caregivers to qualitatively study their views about pain management in patients with dementia. The investigators reported that the reasons for undertreatment of pain in persons with dementia included (1) inadequate communication among nursing staff about assessment and treatment and (2) staff shortages [17]. Even if staff members have increased knowledge, understaffing can easily result in less consistent treatment and inadequate communication among staff and family. Patients with dementia who cannot ask for pain medication are unlikely to receive it, much less in a timely and consistent manner.

Staff education about pain management should result in better assessment, treatment, and interaction with family, particularly when enough staff members are available to do so for every patient. In a long-term care pilot study, Alexander and colleagues provided education and training to nursing and medical staff about pain assessment and management. They specifically addressed strategies to improve communication between medical providers and nursing staff and optimize pain management in patients with dementia [18]. Outcomes included improved assessments of pain, increased number and frequency of pain medications, and decreased problematic pain-related behaviors among residents [18].

Our study was the first in an exploratory effort to determine family caregivers' perspectives about pain

**Table 2.**

Survey Question 6: Family caregivers' suggestions for improving pain management.

Category ( <i>n</i> )	Example
Regular Observation and Assessment ( <i>n</i> = 12)	<p>“Watch body language. Be sensitive and ask frequently. It was very interesting and a challenging experience to see different nurses and doctors and family members’ attitudes and understanding of pain issues.”</p> <p>“By being observant and being patient about finding the source of discomfort, staff could improve.”</p> <p>“Taking time to assess with nonverbal cues and repeating assessments over time would be an improvement.”</p> <p>“More emphasis should be placed on pain screening as part of the person’s ongoing care plan. Also, staff has to become familiar with the person—the ‘whole’ person from previous caregivers before placement and the person they are caring for now, with an eye toward the person they may become.”</p>
Timely and Consistent Pain Medication Administration ( <i>n</i> = 6)	<p>“Maintenance doses of safe medications and evaluation for physical pain should be done.”</p>
Communication/Information Exchange with Family Caregivers ( <i>n</i> = 5)	<p>“Communicate with caregiver(s) in the presence of the patient in case there is any response from the patient. Gather as much information and previous medications and administration of same. Observe the patient and rely on information from caregivers if dementia is total.”</p> <p>“One person should be the communication point person in the facility and talk to the family after visits to get input.”</p> <p>“I recommend family history told by caregiver, the patient themselves, and observations made by physicians and all persons involved. Caregivers probably have more information than anyone else involved.”</p> <p>“Short weekly written reports to family. Good way for family advocate to see if they’re (staff) catching things that are a problem for the patient who has problem verbalizing.”</p> <p>“Listen to family’s concern about pain management. Your talk brought tears to my eyes when I think of my aunt who is in a fetal position and stays alive because she can still swallow thickened liquid. She has all the indicators of nonverbal pain on your checklist. I’m going to check with Hospice.”</p>
Staff Education ( <i>n</i> = 5)	<p>“Need better trained nursing assistants and more staff. I wish I had known some about pain management or even its existence. My mother also had a bed sore—I advocated but do not recall pain medicines being administered.”</p> <p>“Training caregivers in the use of an appropriate scale for persons with dementia and how to use it. Ongoing in-service or refresher courses for both caregiver and family.”</p>
Alternative Methods ( <i>n</i> = 3)	<p>“Visiting with spiritual professionals would help. Healing touch and massage should be tried.”</p>
Psychosocial Support ( <i>n</i> = 1)	<p>“Hand holding and providing reassurance would be helpful.”</p> <p>“Psychosocial professionals could help.”</p>

management when their family members with dementia move to unfamiliar healthcare settings. However, findings must be interpreted cautiously. The survey was conducted with a small convenience sample of interested persons from one geographic region. Only limited information is known about the conference attendees, and no information is available on the nonresponders. Also, the anonymity of the surveys precluded validation with patient records. Respondents recalled incidents that could have occurred recently or in the past. Their responses were subject to recall bias. Respondents answered in relation to actual admission and stay in the facility. Only family caregivers attending this particular meeting had an opportunity to respond and their experiences were limited to institutions in their immediate region. The surveys provide no information about the number, type, or identity of problematic institutions. Respondents sometimes mentioned multiple types of settings—nursing home, intensive care, rehabilitation, and board and care.

Furthermore, without the caregivers' demographic information, we cannot determine the similarities or differences between participants (e.g., perceptions of male and female caregivers, differing relationships with the patient, professional and lay family member caregivers) or their family members with dementia (e.g., severity or type of dementia). Also, the age, economic resources, and health of these caregivers are unknown and depression, physical illness, or insufficient social support could all affect caregivers' responses. As has been mentioned previously, they may not think of pain as a priority. Also possible is that survey nonresponders may not have recognized that their family members with dementia had pain.

## **CONCLUSIONS AND IMPLICATIONS FOR PRACTICE AND RESEARCH**

Despite the study limitations, our findings have implications for practice and research. Several caregivers said that pain management knowledge among staff could be improved. Continuous staff education about best practices for pain management is generally needed at most healthcare institutions. Likely, education on the assessment and management of pain in patients with dementia is also needed at all care, staff, and discipline levels. Knowledgeable staff members should share their information with family caregivers and teach them how to

assess pain. Staff members need to ask family caregivers about the patients' history, patterns and responses to pain, and treatment methods both prior to dementia and during the course of dementia. The onus is on staff to question family caregivers and to welcome dialogue about discomfort or pain. Certainly, multidisciplinary team planning that includes the family caregiver is optimal.

We reported caregivers' recommendations for improvement in order of frequency of occurrence and not necessarily in order of importance. The study limitations of small sample size and heterogeneous institutional representation prevent generalizations about which categories are most important. However, the frequency of occurrence can help guide quality improvement efforts to provide optimal care when patients enter new settings.

While our survey was not specific to any institution, a single facility could also use a survey or another method (e.g., focus groups, interviews) to determine the extent to which staff members discuss pain issues with caregivers, whether caregivers feel listened to, and whether caregivers feel that their family members with dementia are responding adequately to pain management interventions. One major finding from the study is that caregivers want to convey their stories, even if it means writing them. This desire to share was also evidenced by caregivers approaching the investigator after the conference presentation and tearfully describing incidents.

Based on the findings from this pilot work, further research is warranted. While some VA facilities may have been included in the caregivers' responses, we do not know this information for certain. Therefore, we need to determine whether VAMCs are similar to other care settings found in the community. Since many VAMCs have attached nursing homes, communication processes when patients move between levels of care could be studied within one or more VAMCs. A major research gap is how to help family caregivers and professionals stay attuned to patient pain and discomfort in the face of competing priorities. The effect of family caregiver education, currently done through newsletters or lectures, has not been systematically investigated. Research is needed to determine the best methods and times for involving caregivers in communicating with healthcare professionals about patient needs that include pain.

Much work is needed in the assessment, treatment, and evaluation of pain in patients with dementia. Family caregivers are an untapped and valuable resource for

information that can greatly improve the quality of life for patients who are unable to advocate for themselves.

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