Decision Factors Nurses use to Assess Pain in Nursing Home Residents with Dementia

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INTRODUCTION

Poorly treated pain in people with dementia is a major quality of care and quality of life issue. The population of older adults aged 65 – 84 is expected to increase from 40 million in 2010 to 80 million in 2030 (Administration on Aging, 2010), and the number of individuals with dementia will increase accordingly. By 2050, those with Alzheimer's disease, the most common form of dementia, will grow from 4 million to between 16 and 17 million in the United States (Alzheimer's Association, 2009; Hebert, Scherr, Bienias, Bennett, & Evans, 2003). With increasing age comes an increasing number of illnesses and conditions associated with pain, such as cancers, inflammatory diseases, and neurologic diseases. Furthermore, pain prevalence in nursing homes ranges up to 70% among residents (A. B. Krueger & Stone, 2008; Sengupta, Bercovitz, & Harris-Kojetin, 2010; Takai, Yamamoto-Mitani, Okamoto, Koyama, & Honda, 2010). Thus, many nursing home residents with dementia have pain.

People with worsening dementia present specific assessment and management challenges with many individuals unable to reliably self-report pain (Ferrell, Ferrell, & Rivera, 1995; A. Horgas & Miller, 2008; Tsai et al., 2008). Indeed, when compared to nursing home residents without dementia, residents with mild to moderate dementia reported their pain less frequently to nurses (Monroe, Misra, et al., 2013). Self-report becomes unfeasible as dementia progresses because severe dementia blunts speech and individuals eventually lose the ability to verbally report pain (Herr, Bjoro, & Decker, 2006). Behavioral markers, such as facial grimacing, may be impacted as well. While some have shown that persons with

dementia exhibit pain behavior when caregivers move the residents' limbs or body, others have reported that chronic pain behaviors are often blunted with disease progression (Husebo, Strand, Moe-Nilssen, Husebo, & Ljunggren, 2009; Monroe, Carter, Feldt, Tolley, & Cowan, 2012; Stevenson, Brown, Dahl, Ward, & Brown, 2006). Despite blunted verbal and behavioral cues, people with severe dementia appear to experience similar pain intensity as those with only mild dementia (Husebo et al., 2008). Many with severe dementia will live their lives in nursing homes. Determining appropriate pain management strategies in these settings is critical to providing quality care. Poorly treated pain in nursing homes has been extensively documented. Early studies found that between 16% and 40% of nursing home residents received inadequate pain medication (Feldt, Ryden, & Miles, 1998; A. L. Horgas & Tsai, 1998; Lichtenberg & McGrogan, 1987), and among nursing home residents with dementia and terminal cancer, 40% did not receive any opioid analgesic during the final weeks of life (Monroe, Carter, Feldt, Dietrich, & Cowan, 2013). Reasons for these findings may include providers' feeling they are not adequately trained to provide strong analgesic medications, residents' and families' concerns about initiating opioid therapy, and provider concerns about administering high doses of opioids (Gardiner et al., 2012; Gilmore-Bykovskyi & Bowers, 2013).

Pain is correlated with higher behavioral signs of dementia (BSDs). Findings from a recent randomized controlled trial found that people with dementia who expressed verbal agitation (e.g., cursing, complaining, negativism) and displayed restlessness and pacing responded positively to pain treatment concluding that pain behaviors may mimic BSDs (Husebo, Ballard, Cohen- Mansfield, Seifert, & Aarsland, 2013). Furthermore, overall agitation in people with dementia can be one outward display of underlying pain. Using a stepwise protocol (e.g., acetaminophen, morphine, buprenorphine, and pregabalin) to treat pain in nursing home residents with dementia led to decreased agitation and improved overall severity of neuropsychiatric symptoms. The authors concluded that accurately assessing and treating pain in nursing home residents may reduce the need for and use of psychotropic agents (Husebo, Ballard, Sandvik, Nilsen, & Aarsland, 2011). Reduction of potentially unnecessary psychotropic agents, and particularly antipsychotics, in the treatment of nursing home residents is a priority for the Centers for Medicare Services (http://cms.hhs.gov/Regulations-and-Guidance/Guidance/Manuals/downloads/som107ap_pp_guidelines_ltcf.pdf), and adequate pain management may be a component of that effort.

Although best practice recommendations for the assessment and treatment of pain in residents with dementia are available (American Geriatrics Society, 1998; American Geriatrics Society Panel on Persistent Pain in Older Persons, 2002; Herr, Coyne, et al., 2006; Herr, Coyne, McCaffery, Manworren, & Merkel, 2011; Herr & Decker, 2004), clinicians in the nursing home setting may not routinely follow -- or even be aware -- of these guidelines. Nursing home nurses are the frontline leaders in pain assessment. Since many people with dementia are at risk for poor pain management, determining current methods in which nurses assess and manage pain in nursing home residents will aid in recognizing potential barriers to using current pain management guidelines and guide strategies to enhance nurses' assessment and management of pain in this vulnerable population. Improved assessment and treatment of pain has the potential to reduce the use of psychotropic agents in this

population. Thus, the aim of this exploratory study was to assess nursing home nursing personnel's cues and practices to identify and alleviate pain in nursing home residents with dementia.

METHODS

Sample and setting

An exploratory study using focus group methodology was conducted at two long term care facilities in the greater Nashville, Tennessee area. Facility A had 250 beds and was located in an urban area; Facility B had 160 beds and was located in a suburban setting. Criteria for participation were: registered (RN) or licensed practical (LPN) nurses with direct care responsibilities. Nurses were excluded if their responsibilities did not include the assessment and management of pain.

Procedure

The study was approved by the Vanderbilt University Institutional Review Board. A waiver of documented informed consent was granted to allow for anonymity. No identifying data were collected (e.g., location, gender, age) to facilitate participants' overall comfort in voicing opinions. Participants were recruited using posters, email, and word of mouth. Interested participants directly contacted the investigators for participation. Two focus groups were conducted at each site ranging in size from 4 to 11 participants for a total sample size of 29. All focus groups were conducted onsite in a private conference room over a meal time and a boxed meal was provided to participants. Focus groups lasted approximately one hour. Administrative staff at each site agreed to provide coverage to allow the staff to participate.

The focus group methodology for this study was an in person dual moderator design following Krueger's guidelines (A. B. Krueger & Stone, 2008). The same procedure was used with each group. Each focus group was led by one investigator as the moderator with a second investigator as an assistant moderator to run the digital recorder, take notes, and note and record body language or other subtle relevant cues. The two investigators welcomed the participants, provided them with the meals, explained the study and obtained consent. The ground rules were explained (e.g., not to speak simultaneously, maintaining confidentiality of statements) and introductions were completed. The moderator led the discussion using semi-structured, open-ended questions. These questions were developed by using the conceptual framework developed by Monroe, Gore, Chen, Mion, and Cowan (2012), pertaining to pain sensation in individuals with dementia. Nurse participants were asked to identify the prevalence and presentation of pain in residents with dementia, how they determined the presence of pain, and what management strategies they typically use. We specifically probed for challenges in each of these areas. In addition, we encouraged peer-to-peer interactions to better simulate real-world dynamics (R. A. Krueger & Casey, 2009). Each session was audio recorded. Participants received a $30.00 gift card as compensation for participating.

Qualitative data analysis

Recordings of the sessions were transcribed verbatim by an independent third party service. The three investigators conducted the analyses; all are doctoral-prepared nurses specializing in geriatrics with prior experience in the conduct of focus groups and analysis of focus group data. We used the scissor-and-sort technique (A. B. Krueger & Stone, 2008), which is a well-known technique for approaching focus-group transcript analyses. Initially, the three investigators independently examined and coded the field notes and transcripts for recurring themes. Our approach consisted of: a) a first time read through of all transcripts, b) color-coding similar themes, and c) cut and paste similar colors together. We then met as a group and, using a collaborative and iterative process, identified larger themes that connected the codes (Miles & Huberman, 1994). Trustworthiness was addressed by using multiple coders and audit trails. Last, supporting quotes were pulled to reflect each of the themes.

RESULTS

An overarching theme was identified that recurred and underpinned the nurses' reflections about pain management in people with dementia, "Putting together a complex jigsaw puzzle." Five additional subthemes were noted throughout the transcripts of the nurses' responses: uncertainty about the pain experience of residents with dementia; 'being a detective' to determine pain extent and site; clarifying factors; conflict resolution; and the role of the nurse.

Overarching theme: Putting together a complex jigsaw puzzle to optimize resident comfort

In contrast to the simple questions posed to cognitively intact patients for pain assessment, nurses working with residents with advanced dementia described a complex process of pulling in a large amount of information from the patient, family, environment, medical record, and healthcare team in order to assess and treat pain. This process takes time as the nurse comes to know the resident. Last, nurses focused on comfort as the overarching concern.

> "So the first thing you should do [when you admit a resident] is just to make sure that they're comfortable…So, you make sure all of those things are in place. And then, you start piece by piece looking at other aspects. You can't know [everything about their pain] that day. It's gonna take you at least a couple of weeks to get to know that resident through the diagnosis, through their history, through anything you could get from family members. And you begin putting that together with everything you do."

Subtheme 1: Uncertainty about the pain experience of residents with dementia

Nurses noted that despite their best efforts to understand the pain experience of their residents with severe dementia, nurses remained uncertain regarding the residents' pain experience. The inability of residents to express themselves is a major challenge.

> "We don't really know for sure all the time."

"Especially with the demented patients, unless we physically see them do something that would cause pain, [or we know] they have a UTI [urinary tract infection] or… something [else] we're currently treating, something like that, but normally we don't [know]."

"I don't think they have any less [pain], I mean, I don't think sensory-wise. It's just harder for us as clinicians to determine how much pain they're in."

Subtheme 2: 'Being a detective'

Nurses describe a complex assessment process as they attempt to gauge a resident's comfort that involves the assessment and integration of various types of information. Nurses examine verbal and behavioral cues, utilize pain scales, and conduct reviews of the medical record. They evaluate the resident's environment, such as weather changes, noise levels, temperature. Last, nurses attempt to distinguish emotional from physical discomfort.

"So, you know, there's a lot of indicators and a lot of things that you would have to look at to determine whether this resident is in pain, because [they] have advanced dementia, and they're not able to let me know that they're in pain. I just know if they're in pain because of the way that they're acting. And then, I look back at their chart and they have arthritis, and then, I go by the weather because last couple days, I had more crying and more whining because it was so cold at night. And I said, 'Well, this patient has arthritis. So, they're probably in pain.'"

"It's all together. Yeah, lots of times you'll see increase in blood pressure. But then, other times, you'll just see the facial grimacing, or the guarding of the body, or there could be a combination. You just have to use your best nursing judgment."

"Sometimes I think too we're seeing different pain. A lot of emotional pain going on. That's where the pain medicines don't helpthat's where we have to bring in psychotropics…and look at other means of pain control because it's a different pain, but it's just as real."

Subtheme 3: Clarifying factors

Several factors were identified that may assist in clarifying if resident with dementia is experiencing pain. These included the nurse's clinical expertise, family communication, interdisciplinary communication, and knowing the resident over an extended period of time.

"Especially with a demented patient because Nurse A may work just one day a week, but if I've been here six years and I know this lady's baseline, I'm going to see and look at her differently than a nurse coming in from the pool, from a private duty or a staffing agency. They may not see what the normal nurse does, because you've watched all stages of dementia through."

"Normally our families are children that've been there the entire lives of the patient. So, momma may've had a fall at, you know, 35 and broke her hip, or knee, or something, and it's of course not going to be on our records because she did it 50 years ago."

"I think most of the time [the certified nursing assistants] are the first line of defense with diagnosing someone that may have pain, an increase in pain."

"I have a lot of new nurses that have extreme difficulty in giving [morphine sulfate] to somebody who is not verbalizing pain or appearing to be in pain. And it's difficult to get them to understand that our goal is to keep them pain free and not have them get in pain. It's an experience thing."

Subtheme 4: Conflict resolution

Nurses noted that conflict often arises during the assessment and treatment of pain. Specifically, they described the challenges of balancing the family's wishes with the resident's needs. Examples included potential ethical issues and nurse/family hesitancy regarding the administration of narcotic medications -- particularly at the end of life.

"It's a catch 22."

"And [the family] is asking for all these things. It's just interesting because it's like, on one side it seems that they're pulling back, and then the other side, they're saying, 'Do something.'"

"[The family] wanted them to be awake but not hurting, but you couldn't have both."

Subtheme 5: Role of the nurse

Nurses reflected on their role in pain assessment and management in residents with severe dementia. They identified a number of responsibilities: the need for constant vigilance, nursing the entire family, willingness to do trial and error, and prioritizing resident comfort and quality of life. Throughout the study, the nurses demonstrated enthusiasm and, at times, strong emotions that further supported this subtheme.

"We're nurses. We've got to fix it."

"So it's a lot of little things I believe that go into just making their life as comfortable as we can possibly make it."

DISCUSSION

The focus group forum provided a picture of the long term care nurses' roles and necessary skills in determining and treating pain among residents with dementia. Indeed, there is a wide spectrum of issues that nurses must juggle in addressing this issue. We found that nurses use the constructs of 'comfort' and 'quality of life' as key components in their overall pain assessment strategy in people with dementia. Indeed, the extensive process they use involving frequent reassessment and application of interventions is geared towards "appearance of comfort."

Nurses reported difficulty in ascertaining whether a person with dementia was in pain and further difficulty determining the magnitude or intensity associated with their pain. Consistent with Gilmore -Bykovskyi and colleagues' findings (2013), guidelines and assessment scales were frequently described as inadequate to help the nurse in his/her

decision making; this may explain why practice guidelines are not consistently followed. Given the complexity and nuance in determining the existence of pain, it is not surprising that there is substantial documentation of poor pain management for people with dementia (Monroe, 2010; Morrison & Siu, 2000). We found that nurses judge a change of behavior as an important manifestation of pain and that a return to baseline seems to indicate pain relief. Additionally, we found that nurses used a complex set of strategies to assess and determine presence of pain. Importantly, nurses admitted that at times they just do not know when someone with dementia is having pain. Uncertainty can be a major determinant in the nurses' decision making and whether to initiate analgesia versus other interventions (Gilmore-Bykovskyi & Bowers, 2013).

The role of the family bears mention. Family members were discussed frequently as partners and facilitators in determining the residents' comfort levels and person-centered strategies to promote comfort. On the other hand, family members can also present challenges to the nurses, especially when opioid analgesia is necessary for end-of-life care. It was not unusual for nurses to discuss the importance of conflict resolution among family members, as well as allowing for open expression of family's concerns. Nurses had to focus not only on the resident's comfort, but also the families' comfort.

There are several limitations of the study. A focus group versus one-on-one methodology was used. One-on-one interviews provide more in depth information and potentially allows participants a greater sense of freedom in voicing opinions. However, focus group methodology is better suited for overview, discovery and exploration; simulating real-world responses; and understanding commonalities within segments (R. A. Krueger & Casey, 2009). Our study was also limited by the small sample size and restricted number of facilities. Thus, generalizability is limited. Further, nurses' practices were reported, not observed. Nevertheless, the study uncovered a number of challenges that long term care nurses face when determining presence of pain in those with dementia.

In summary, our findings provide critical insights into understanding the attitudes of the long term care nurses in pain assessment in dementia by promoting measures to increase comfort and improve quality of life. Long term care nurses in the current study prided themselves in taking a leadership and coordinating role in the interdisciplinary effort to ensure comfort. Moreover, they focused on the family as well as the resident in their quest to assure comfort and quality of life. Thus, future work will focus on comfort care qualities as well as nurse attitudes and strategies that would allow facilitation of nurses' identification and management of pain in this vulnerable population. This study focused on nurses' identification and treatment of pain, but nurses in our study did acknowledge the overlap between pain and behavioral symptoms of dementia, and further research is indicated to better understand the relationship between nurses' decisions to use pain medications vs. psychotropic agents. Findings support further use and development of discomfort behavior tools such as *The Discomfort Behavior Scale* (Stevenson et al., 2006) in treating overall pain. Our findings also support using comfort theories (e.g., (Kolcaba, 1994) in developing pain management and assessment tools for people with limited ability communicate.

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