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Behavioral Characteristics of Agitated Nursing Home Residents With Dementia at the End of Life

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Abstract

Purpose—The purpose of this study was to examine group differences in verbal agitation, verbal interaction, bed restraint, pain, analgesic and neuroleptic medication use, and medical comorbidity among agitated nursing home residents who died during a 6-month clinical trial compared with residents of the same gender and similar initial cognitive status who did not die during the trial.

Design and Methods—We conducted a two-group secondary data analysis of prospective observational data from 10 nursing homes in Birmingham, Alabama. By means of chart review, resident assessments, surveys of certified nursing assistants, and direct observation of residents' daily behaviors and environment, 32 residents (87.34 ± 7.29 years) with a Mini-Mental State Examination (MMSE) score = 4.31 (±5.54) who died were compared with 32 residents (84 ± 6.96 years) with a mean MMSE score = 4.28 (±5.49) who did not die during the clinical trial.

Results—Residents who died displayed more verbal agitation, less time in verbal interaction with staff, and almost twice as much time restrained in bed during observation time in comparison with residents who did not die during the clinical trial. However, groups did not differ significantly in severity of comorbid illness, functional status, number of painful diagnoses, certified nursing assistants' reports of residents' pain, or opioid or nonopioid analgesic prescription or dosage. Surviving residents were more likely to receive neuroleptic medication than residents who died.

Implications—Results suggest that agitated nursing home residents may exhibit a heightened level of verbal agitation, decreased verbal interaction with staff, and increased bed restraint up to 3 months prior to death. Prospective observational studies are needed to identify markers for imminent mortality among nursing home residents.

Keywords

End of life; Agitation; Pain; Nursing homes

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Recent studies demonstrate the need for improved provision of end-of-life care for nursing home residents, 66% of whom die in place (Hanson, Henderson, & Rodgeman, 1999; Kayser-Jones, 2002; Kayser-Jones et al., 2003; National Consensus Project for Quality Palliative Care, 2004; Teno et al., 2004; Zimmerman, Sloane, Hanson, Mitchell, & Shy, 2003). One strategy for improving end-of-life care is to identify medical status change events that might signal the need for family decisions regarding life-prolonging intervention or the initiation of palliative care among nursing home residents (Cohen-Mansfield & Lipson, 2003). Data suggest certain factors arc of particular relevance in the identification of risk for 1-year mortality, including precipitous weight loss, respiratory symptoms, functional decline, cognitive impairment, pain, and verbal agitation (Cohen-Mansfield, Marx, Lipson, & Werner, 1999; Covinsky, Eng, Lui, Sands, & Yaffe, 2003; Schonwetter et al., 2003).

In this study, we examined the duration of specific behaviors and potential outcomes of these behaviors (i.e., verbal agitation, verbal engagement with staff, and bed restraint) among nursing home residents, selected to display a clinically significant level of agitation, who died during the course of a 6-month psychosocial clinical trial; we compared their behaviors with those of a group of similar residents that did not die. We hypothesized that residents who died would demonstrate significantly greater verbal agitation (Cohen-Mansfield et al., 1999) and less verbal engagement with staff through direct observation in the phase of data collection prior to their deaths in comparison with similar residents who did not die during that phase. We also hypothesized that individuals who died would be reported to experience greater pain by their certified nursing assistants (CNAs) and would demonstrate greater prescription and analgesic medication use. Furthermore, as a result of a recent Federal Drug Administration (FDA) Public Health Advisory warning, we explored the possibility of increased mortality among residents secondary to neuroleptic drug exposure (FDA, 2005). In contrast to prior studies, our data (a) consisted of real-time, second-by-second computer-assisted behavioral observation rather than staff report, and (b) covered only a 6-month time period. In our analyses we examined additional correlates of medical status change, including medical comorbidity, functional status, cognitive status, and restraint in bed.

Methods

Settings

We conducted this study in 10 nursing homes in Birmingham, Alabama with an average census of 135 residents in each facility. On average, 8% of the beds were Medicare, 44% were Medicaid, and the remainder were private pay. Residents had an average length of stay of 4 years. Average resident-to-CNA ratios were 8:1 during the day shift and 12:1 during the evening shift. Yearly rates of staff turnover averaged 32% among registered nurses, 39% among licensed practical nurses, and 44% among CNAs.

Participants

Participants were enrolled in a clinical trial investigating the efficacy of a psychosocial intervention for agitation ($N = 112$ at 6-month follow-up; see Burgio, 1997). More specifically, units within a nursing home were randomly assigned to control or intervention groups, with residents on each type of unit assigned to that group. Intervention group residents received an audiotape intervention by means of continuous-play audiocassette recorders and tapes of either a relaxing voice or soothing environmental sounds. Residents were included in the clinical trial if they were at least 55 years of age, passed an audiological assessment conducted by an audiologist, engaged in a clinically significant amount of verbal agitation, were receptive to the intervention (i.e., did not resist wearing earphones), and had a life expectancy greater than 6 months. Thirty-two residents died during the 6-month clinical trial. As a comparison group, 32 residents of the same gender and similar cognitive status who did not die (i.e., survivors)

during the clinical trial were chosen randomly. Female gender and impaired cognitive status have been shown to be related to the display of verbal agitation among nursing home residents (Burgio et al., 2000; Vance et al., 2003), and it was reasoned that randomly selecting a comparison sample with similar characteristics would result in two comparable groups. Six men and 26 women were included in each group. The groups did not differ in assignment to the control or intervention conditions, $\chi^2(1, N = 64) = 0.66$, $p = .72$. At the baseline assessment, individuals who died had a mean Mini-Mental State Examination.(MMSE; Folstein, Folstein, & McHugh, 1975) score of 4.31 + 5.54 (range 0–15). The surviving comparison residents had a mean MMSE score of 4.28 + 5.49 (range 0–15) at baseline.

Measures

Mini-Mental State Examination—The MMSE consists of items measuring orientation, recall, working memory, language, and visual construction (possible score range = 0–30). The test–retest and interevaluator reliabilities are .89 and .83, respectively.

Charlson Comorbidity Index—The Charlson Comorbidity Index (Charlson, Pompei, Ales, & Mackenzie, 1987) is a scale containing 19 weighted categories of comorbidity; it was designed for use in obtaining medical diagnostic information from medical records (completed once only; possible score range = 0–37). The overall comorbidity score reflects the cumulative increased likelihood of 1-year mortality, with higher scores indicating greater comorbidity. Scale scores correlate with additional outcomes such as length of hospital stay and discharge to nursing homes (Deyo, Cherkin, & Ciol, 1992).

Physical Self-Maintenance Scale—Six activities of daily living domains were represented by the Physical Self-Maintenance Scale (PSMS; see Lawton & Brody, 1969), a 5-point Likert scale with a total score ranging from 6 to 30. This measure has satisfactory interrater reliability based on the independent ratings of nurses (Pearson's $r = .87$) and trained research assistants (Pearson's $r = .91$), as well as adequate construct validity based on association with other measures of functional competence.

Proxy Pain Questionnaire—The Proxy Pain Questionnaire (Fisher et al., 2002) consists of three items that assess presence, frequency, and intensity of pain. A fourth item assesses CNA beliefs about the relationship between resident agitation and pain. Test–retest reliability of this measure is good, ranging from $r = .84$ ($p = .0007$) for presence and intensity of pain to $r = .87$ ($p = .0003$) for frequency of pain.

Medication Tracking Form—All medications prescribed for the residents were catalogued on a detailed tracking form used by our research group from the nursing medication administration record. We assigned medications a therapeutic classification code (Aloisi, 1999). We considered only nonopioid and opioid analgesics and neuroleptic medications in this study. We classified residents whose analgesic regimen consisted of only one regular or baby aspirin per day as not receiving analgesics, because aspirin prescribed at low doses may be used for its anticoagulation effects rather than pain management.

We coded analgesic medication dosages as described in our prior research (Allen et al., 2003). We converted nonopioid analgesic dosages to acetaminophen-equivalent dosages and opioid analgesic dosages to morphine-equivalent dosages. For mixed opioid–nonopioid analgesics, we converted each component part to its respective equivalency dosage. In this way, each resident had a total amount of opioid and nonopioid dosages to show the total amount of analgesia received in the data-collection period.

Computer-Assisted Behavioral Observation System—We generated real-time computer-assisted behavioral observation system (CABOS) data by using the software programs previously used by our research group (Burgio et al., 1994; Repp, Karsh, van Acker, Felce, & Harman, 1989) and adapted for this study (Burgio, 1997). Resident behaviors were sampled during 0.5-hr periods between the hours of 8 a.m. and 8 p.m., with oversampling between the hours of 8 a.m. and 10 a.m., noon and 2 p.m., 3 p.m. and 5 p.m., and 6 p.m. and 8 p.m. for an average total of eight hours (range 2.00–8.51 hours per resident). These periods were oversampled because prior research indicated that residents were more likely to display verbal agitation during these times (Burgio et al., 2000). We observed and recorded *verbal agitation* (i.e., unintelligible speech or babbling, self-talk, repeated words, screaming or yelling, moaning, cursing, and singing outside an organized activity), *resident activity* (i.e., no activity, daily care, or engagement with materials), *verbal interaction* (i.e., nursing home staff speaking to residents), *physical restraint*, and the *presence of others*. We coded all targeted behaviors with the observed resident as the point of reference. We calculated interobserver agreement through a second-by-second comparison of the observational files, using Cohen's kappa (Cohen, 1968). Average kappa reliability across all categories was K = .89 (range .62–96).

Procedure

Observational and paper-and-pencil data collection for the clinical trial consisted of a 10- to 14-day baseline phase followed by 10- to 14-day assessments at Week 3, Week 6, 3 months, and 6 months. Data for all measures used in the analysis were from (a) the last phase for which data were available for residents who died during the clinical trial and (b) the corresponding phase for survivors compared with the deceased. For example, if a resident died during Week 6, the last available data were used for that resident and the survivor's data from Week 6 were used for comparison.

Statistical Analysis

Because we could not do a priori matching of residents who died to survivors, we used the more conservative independent-samples *t* test rather than related-samples *t* tests to compare residents on all variables of interest. In case-control studies, the effective sample size is determined by the number of "cases," which in this research is the number of residents who died during the 6-month clinical trial. Power is a function of effective sample size and, thus, of the number of cases or residents who died ($n = 32$). Generally, case-control studies match 1:1 (one case to one control) because power rapidly asymptotes (i.e., reaches a point where adding additional controls makes no difference). All hypothesis tests were two-tailed tests for more conservative comparisons, and we used all available data in the analyses. When the test statistics compared highly skewed variables (e.g., analgesic medication data), we used nonparametric tests (e.g., Wilcoxon two-sample tests).

Results

Sample Characteristics

The average age of the 32 residents who died during the 6-month clinical trial was 87.34 ± 7.29 years (range 70–101); 78% were White and 22% were African American. Their average PSMS score at baseline was 23.48 ± 4.96 (range 9–30), where higher numbers indicate greater impairment. Chart review indicated that residents' average score on the Charlson Comorbidity Index was 1.38 ± 0.87 (range 0–3), indicating a relatively low degree of comorbid illness. Sixteen percent ($n = 5$) of these residents had cancer diagnoses.

The average age of the 32 survivors was 84.00 ± 6.96 years (range 67–94); 91% were White and 9% were African American. Their average baseline PSMS score was 23.26 ± 4.49 (range

11–28). Chart review indicated that residents' average score on the Charlson Comorbidity Index was 1.53 ± 1.11 (range 0–5), again indicating a low degree of comorbid illness. Six percent (n = 2) of these residents had cancer diagnoses. Residents did not differ significantly by group in age, gender, race, cognitive status, severity of comorbid illness, cancer diagnoses, or functional impairment.

Of the 32 residents who died, 15 had observational data within 2 weeks of their deaths. The last observational sample for the other 17 residents who died was obtained between 2 weeks and 3 months prior to their deaths, as determined by the data-collection schedule of the clinical trial.

Verbal Agitation, Verbal Interaction With Staff, and Bed Restraint

Direct observation during the last observational phase showed that residents who died were more verbally agitated (approximately 70 min ± 65 min) in comparison with survivors at the same phase (approximately 43 min ± 36 min), $t(62) = 2.03$, $p = .0465$, Cohen's $d = 0.51$. However, these groups were not observed to differ in agitation at baseline, $t\ (62) = 0.94$, $p = .35$. Furthermore, residents who died spent significantly less time in verbal interaction with nursing home staff before their deaths (M = 101.14 min ± 47.95 min) than did surviving residents at an equivalent study phase (M = 151.97 min ± 99.41 min), $t\ (62) = 2.60$, $p = .0115$, Cohen's $d = 0.65$. Finally, residents who died spent almost twice as much observation time restrained in bed prior to their deaths (M = 312.29 min ± 143.09 min) than did survivors (M = 161.90 min ± 151.25 min), $t\ (62) = 4.09$, $p = .0001$, Cohen's $d = 1.02$.

Cognitive Status

In an attempt to assess whether cognitive status deteriorated more among residents who died than survivors, we compared MMSE scores of both groups at the last assessment occasion. We hypothesized that residents who died may have suffered from delirium that would preclude cognitive assessment or differentially impair their performance. However, our data did not support differential cognitive impairment at the last assessment occasion, $t(62) = 0.51$, $p = .61$. Residents who died had a mean MMSE score of 4.00 ± 5.61 (range 0–21) in comparison with survivors (MMSE, M = 4.75 ± 6.08, range 0–22).

Pain Diagnoses and Proxy Pain Reports

Sixty-two percent of residents who died had at least one diagnosis listed in their medical charts associated with chronic pain (Horgas & Tsai, 1998), compared with 66% of survivors. Residents were compared on CNA-reported presence of pain in the past week, pain frequency, pain intensity, and the extent to which pain seemed to be related to the residents' agitation. Although 52% (n = 16) of the residents who died were reported by CNAs to have experienced pain in the past week, in contrast to 34% of surviving residents (n = 10), this difference was not statistically significant, $\chi^2\ (1, N = 60) = 1.79$, $p = .18$. There were no statistically significant differences between groups on any item, although residents who died were consistently reported to be in more frequent, more intense pain that was related to a greater extent to agitation in the opinion of the CNAs.

Analgesic and Neuroleptic Medication Use

There were no statistically significant differences between the two groups in the overall number of medications prescribed, the number of analgesic medications prescribed, the number of neuroleptic medications prescribed, or the number of opioid and nonopioid analgesics prescribed. Fifty-nine percent (n = 19) of residents who died were prescribed analgesic medication, in comparison with 52% (n = 17) of survivors. Fifty-five percent (n = 18) of residents who subsequently died and 48% of survivors (n = 15) received opioid analgesic

medication during the last phase of data collection. There were no differences between groups in nonopioid analgesic medication dosage or opioid analgesic medication dosage received. Neuroleptic medication usage by the two groups was in the opposite direction of prediction based on the recent FDA warning. Twelve percent ($n = 4$) of residents who subsequently died were prescribed and received neuroleptic medication, in comparison with 37% of survivors ($n = 12$), χ^2 (l, $N = 64$) = 5.45, $p = .039$.

Discussion

These data lend support to the hypotheses that agitated nursing home residents may exhibit behaviors indicative of medical status change up to 3 months prior to their deaths. In this study, residents who died displayed more verbal agitation and less verbal interaction with nursing home staff, and they were almost twice as likely to be physically restrained in bed. In earlier studies, researchers have investigated these notions in nursing homes by using primarily qualitative data (Brajtman, 2003; Kayser-Jones, 2002; Kayser-Jones et al., 2003), staff-reported data over a much longer time span (Cohen-Mansfield et al., 1999), or observational data targeting resident behavior in the nursing home environment without reference to resident mortality (Werner, Cohen-Mansfield, Braun, & Marx, 1989). In contrast to prior research, our study utilized clear operational definitions of resident behaviors such as verbal agitation and verbal interaction with staff, using second-by-second real-time computer-assisted behavioral observation. Our data, although based on a small sample, appear to support the need for prospective observational studies to examine whether behavioral markers or environmental cues of impending mortality can be identified.

Our hypothesis regarding CNA report of resident pain was not supported. However, group differences were in the expected direction in that residents who subsequently died were reported to be in more frequent, more intense pain than survivors. Although it is tempting to attribute this nonsignificant finding to a lack of statistical power, our relatively small sample size did not preclude our ability to find statistically significant differences between groups when we tested hypotheses about observable behaviors of residents and nursing home staff. A small sample size increases the probability of Type II error but cannot increase the probability of getting spuriously significant results (i.e., Type I error; see Zuckerman, Hodgins, Zuckerman, & Rosenthal, 1993). The absence of group difference in prescription or receipt of analgesic medication may reflect pain assessment and analgesic treatment strategies that are not adequately sensitive or responsive to changes in resident expression of pain. In an ongoing nursing home intervention study, our research group is training CNAs to recognize observational indicators of pain (Snow et al., 2003) among nursing home residents and to communicate these observations to licensed practical nurses (Burgio & Fisher, 2003). Future research should use similarly sensitive measures of resident pain (i.e., direct observation of pain cues) to explore the potential usefulness of these behaviors as markers of mortality risk.

Interestingly, our finding regarding use of neuroleptic medication was in the opposite direction of that predicted by the recent FDA warning regarding atypical and, potentially, older antipsychotics. Specifically, a greater percentage of surviving residents were found to use antipsychotic drugs in comparison with residents who died. Clearly, future prospective studies are needed to explore mortality risk secondary to neuroleptic use among frail nursing home residents, particularly because neuroleptic medications arc the best studied and most common pharmacologic intervention for agitation in dementia.

We acknowledge the limitations of this study: a secondary data analysis from a project originally designed to test the efficacy of an intervention for agitation among nursing home residents (Burgio, 1997). Because our data are based on correlations, agitation and decreased verbal interaction with staff might be markers of increased risk of mortality or contributors to

increased mortality in this population. These behaviors might contribute to mortality indirectly by interfering with life-sustaining care (e.g., administration of antibiotics or medications for congestive heart failure, respiratory therapy, or assistance with feeding or eating). Although all residents were reported by staff to display a significant level of agitation and met other entry criteria for the larger study (including life expectancy of at least 6 months), we were unable to diagnose delirium or other medical conditions among our residents because availability of medical data were limited. The degree to which resident groups might have differed in respect to the presence or absence of hepatic failure, fluid or electrolyte imbalance, renal insufficiency, hypoxia, infection, or abnormalities of calcium metabolism at the time of observational data collection is unknown. In addition, the extremely low baseline MMSE scores in this study left little capacity for this instrument to detect further cognitive deterioration caused by delirium, and thus the lack of difference between the groups may have been due to floor effects on this measure.

It is noteworthy that the only group differences observed in this study were behavioral: Greater resident verbal agitation, less verbal interaction with staff, and more frequent physical restraint in bed were observed among residents who subsequently died in comparison with surviving residents. Previous studies, such as that by Werner and colleagues (1989), have demonstrated a link between agitation and restraint use, showing the same amount or more resident agitation in the presence of physical restraints. However, the study by Werner and colleagues did not investigate the relationships among agitation, restraint, pain, and resident mortality. Our current data suggest, at the least, less staff attention (as measured by verbal interaction between staff and residents) allocated to residents who may benefit from palliative care, and, potentially, active avoidance of residents who may be drawing near to death. It is our belief that identification of residents in need of referral to palliative care or hospice would improve the quality of life among these residents in nursing homes, yet none of the residents included in this sample received hospice care. Medical status variables and observable resident and staff behaviors must be measured prospectively in order to identify potential markers of impending mortality. Potential constructs of interest in such studies include weight loss, respiratory symptoms, functional decline, verbal agitation and interaction, pain, and cognitive impairment including delirium (Cohen-Mansfield et al., 1999; Covinsky et al., 2003; Schonwetter et al., 2003).

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