Published in final edited form as:

J Am Geriatr Soc. 2015 June ; 63(6): 1084–1090. doi:10.1111/jgs.13435.

Healthcare Proxy Awareness of Suspected Infections Among Nursing Home Residents with Advanced Dementia

Jane L. Givens, MD, MSCE^{1,2}, Sara Spinella, BA³, Claire K. Ankuda, MD, MPH⁴, Erika D'Agata, MD, MPH², Michele L. Shaffer, PhD⁵, Daniel Habtemariam, BA¹, and Susan L. Mitchell, MD, MPH^{1,2}

¹Hebrew SeniorLife Institute for Aging Research, Boston, MA

²Department of Medicine, Beth Israel Deaconess Medical Center, Harvard Medical School, Boston, MA

³University of Rochester School of Medicine

⁴Department of Family Medicine, University of Washington, Seattle, WA

⁵Department of Pediatrics, University of Washington and Children's Core for Biomedical Statistics, Seattle Children's Research Institute, Seattle, WA

Abstract

Background—Infections are common in advanced dementia. Little is known about healthcare proxy involvement in decision making regarding infections.

Design—Prospective cohort study

Setting/Participants—362 nursing home (NH) residents with advanced dementia and their proxies in 35 Boston-area facilities.

Measurements—Charts were abstracted monthly (up to 12 months) for documentation of suspected infections and provider/proxy discussions for each episode. Proxies were interviewed within 8 weeks of the infection to determine their awareness and decision-making involvement. Factors associated with proxy awareness and discussion documentation were identified.

Corresponding author: Jane L. Givens, MD, MSCE, Hebrew SeniorLife Institute for Aging Research, 1200 Centre Street, Boston, MA, 02131, Tel: 617 971-5316, Fax: 617 971-5329. JaneGivens@hsl.harvard.edu.

Paper Presentation: Results from this study were presented in abstract form at the Annual Meeting of the American Geriatrics Society, 2012, Seattle, WA.

Conflict of Interest: The editor in chief has reviewed the conflict of interest checklist provided by the authors and has determined that the authors have no financial or any other kind of personal conflicts with this paper. Dr. Erika D'Agata is a Member of Data Safety Monitoring Board of Cubist Pharmaceuticals.

Author Contributions:

Study concept and design: Jane L. Givens, Sara Spinella, Claire K. Ankuda, Susan L. Mitchell

Acquisition of subjects and/or data: Jane L. Givens, Sara Spinella, Claire K. Ankuda, Erika D'Agata, Michele L. Shaffer, Daniel Habtemariam, Susan L. Mitchell

Analysis and interpretation of data: Jane L. Givens, Sara Spinella, Claire K. Ankuda, Erika D'Agata, Michele L. Shaffer, Daniel Habtemariam, Susan L. Mitchell

Preparation of manuscript: Jane L. Givens, Sara Spinella, Claire K. Ankuda, Erika D'Agata, Michele L. Shaffer, Daniel Habtemariam, Susan L. Mitchell

Sponsor's Role: None

Results—There were 496 suspected infections; proxies were reached for interview for 395 (80%). Proxy/provider discussions were documented for 207/395 episodes (52%), yet proxies were aware of only 156/395 (39%). Proxies participated in decision-making for 89/156 (57%) episodes of which they were aware. Proxy awareness was associated with antimicrobial use (adjusted odds ratio (AOR) 3.43, 95% confidence interval (CI) 1.94–6.05), hospital transfer (AOR 3.00, 95% CI 1.19–7.53), infection occurrence within 30 days of death (AOR 3.32, 95% CI 1.54–7.18) and fewer days between infection and study interview (AOR 2.71, 95% CI 1.63–4.51). Discussion documentation was associated with the resident residing in a dementia special care unit (AOR 1.71, 95% CI 1.04–2.80), not on hospice (AOR 3.25, 95% CI 1.31–8.02), more provider visits (AOR 1.71, 95% CI 1.07–2.75), proxy visits > 7 hours/week (AOR 1.93, 95% CI 1.02–3.67), and episode within 30 days of death (AOR 3.99, 95% CI 1.98–8.02).

Conclusion—Proxies are unaware of and do not participate in decision-making for most suspected infections experienced by NH residents with advanced dementia. Proxy awareness of episodes and documentation of provider/proxy discussions are not congruent.

Keywords

Dementia; Nursing home; Surrogate decision-making

INTRODUCTION

Alzheimer's disease was the sixth leading cause of death in the United States in 2012¹ and is increasingly recognized as a terminal illness.² Nursing homes (NHs) are a major site of care for persons with dementia; ninety percent of those with advanced dementia will be cared for in a NH,³ and 70% of Americans with dementia will die in a NH.⁴

Surrogate medical decision making for patients with advanced dementia is common,^{5,6} although health care proxies often feel unprepared and unsupported in this role, especially in the NH setting.^{7–10} There is a high prevalence of both infections and antimicrobial among NH residents with advanced dementia,^{2, 11} with infections accounting for over 20% of proxy medical decisions and approximately 60% of the hospital or emergency room transfers.^{6, 12} Although the overwhelming majority of proxies for NH patients with advanced dementia believe comfort to be the goal of care,² most patients do not have specific instructions regarding the treatment of suspected infections.¹³ Thus, some discussion between proxies and health care providers is needed if proxies are to participate in determining the treatment course most consistent with the patient's goals of care.

Currently, there is little understanding of the frequency with which proxies of NH residents with advanced dementia are informed by NH providers about suspected infections, or the degree to which they are involved in treatment decisions. Moreover, proxy and provider perceptions of such communication may differ. The objective of this report is to utilize data from a prospective cohort study of NH residents with advanced dementia and their proxies to assess proxy awareness of suspected infections as compared to chart documentation of proxy/provider discussions, and identify resident, proxy, and infectious episode characteristics associated with proxy awareness and discussion documentation.

METHODS

Study Population

Study participants were from the Study of Pathogen Resistance and Antimicrobial Use in Dementia (SPREAD), a five year prospective cohort study of nursing home residents with advanced dementia and their health care proxies, defined as either the formal or informally designated surrogate decision-maker for the patient.¹⁴ This study was approved by the institutional review board of the Hebrew SeniorLife Institute for Aging Research.

Between September 2009 and November 2012, residents with advanced dementia and their health care proxies were recruited from 35 Boston-area NHs. Resident eligibility criteria included: age > 65, dementia (any type), an available English-speaking proxy, and Global Deterioration Scale (GDS) score of 7 (range 1–7, higher scores indicate worse dementia).¹⁵ A GDS score of 7 is characterized by profound memory deficits, verbal ability <5 words, incontinence, and non-ambulatory status. Proxies provided informed consent for the residents and for themselves.

Resident Variables

Resident data were collected for up to 12 months from full chart review assessments (baseline, quarterly, and within 14 days of death), and monthly infection screens. Resident data abstracted from the chart at baseline included age, gender, race, NH length of stay and whether the resident resided in a dementia special care unit. At baseline and quarterly assessments, nurses evaluated functional status using the Bedford Alzheimer's Nursing Severity-Subscale (BANS-S) (range 7–28; higher scores indicate greater disability).¹⁶ Other data collected from the chart at each full assessment included the presence of advance directives including do-not-hospitalize (DNH) orders, directives to withhold antimicrobials, and information regarding hospice enrollment and the number of physician or nurse practitioner visits since the last assessment.

Infection screens were conducted at baseline, monthly, and death. Charts were reviewed to determine if a possible infection occurred during the intervals between screens (or 30 days prior to baseline), defined by any of the following: 1. documentation by a physician, physician assistant, nurse practitioner or nurse of a suspected infection; 2. antimicrobial use (other than for prophylaxis); or 3. temperature > 37.9 °C. Details about each episode were ascertained, including: i. suspected source (fever only, respiratory, urinary or skin); ii. antimicrobial use; iii. hospital or emergency room transfer; and iv. documented discussion between a provider (physician, physician assistant, nurse practitioner or nurse) and proxy regarding the infection. The suspected source was determined through chart review based on provider documentation and localizing symptoms. Infections with the same suspected source (respiratory, urinary tract, skin, or fever) separated by at least seven days were counted as separate episodes. Infections with different suspected sources were counted as separate episodes regardless of when they occurred in relation to each other.

Proxy Variables—Two types of proxy telephone interviews were conducted: full interviews and infection interviews. Full interviews were conducted at baseline, quarterly,

and 2 months after resident death (questions referred to the month before death). Baseline proxy information included age, gender, relationship to resident (child vs. other), and whether there was an advance care planning discussion of at least 15 minutes duration at the time of NH admission. At each full interview, proxies were asked how many hours they spent visiting the resident each week, the primary goal of care (i.e., comfort versus life prolongation), whether they felt infections were common in advanced dementia and whether they felt the resident had less than 6 months to live.

If the monthly resident infection screens detected documentation of a suspected infection, an attempt was made to contact the proxies by telephone. If contacted, the proxies were asked whether to the best of their knowledge, the resident experienced a suspected infection over the last 8 weeks. We attempted to interview the proxy between one month and 8 weeks of the suspected infection, but allowed for interviews beyond this time period in order to maximize proxy response rate. To assess recall bias, the number of days between the date of the suspected infection as documented in the residents chart and proxy interview date was determined. If the proxy was not aware of an infection, no further questions were asked. If the proxy was aware of a suspected infection, they were asked about the date of the infection, the suspected source, and whether they participated in any treatment decisions. If the proxies said they did not participate in decision-making, they were asked if they would have wanted to be involved in that process.

Analysis

Descriptive statistics of all variables were calculated using frequencies for categorical variables and medians and ranges to describe continuous variables.

Logistic regression was used to examine the unadjusted and adjusted associations between resident, proxy, and episode characteristics with two outcomes: i. proxy awareness of the documented suspected infection, and ii. chart documentation of discussion between the proxy and provider for each episode. Only episodes for which the proxy could be contacted for the infection interview were included. Analyses were conducted at the episode level. Independent variables included resident, proxy, and episodes characteristics. Static independent variables (i.e. demographic information) were brought forward from the baseline assessment. Dynamic variables (BANS-S score, advance directives, hospice enrollment, number of physician/nurse practitioner visits, proxy visits > 7 hours/week, goals of care is comfort, understanding of infections as common in advanced dementia, understanding of the resident's prognosis), were drawn from the quarterly assessment or interviews that immediately preceded the infectious episode. Continuous independent variables (age, BANS-S score, days between infection and interview, NH length of stay) were dichotomized at the median for ease of analysis and interpretation. Variables associated with outcomes at a p-value < 0.1 in unadjusted analyses were included in the adjusted logistic regression model. Odds ratios (OR) and 95% confidence intervals (CIs) were generated from logistic regression models. All models were adjusted for clustering at the resident/proxy dyad level using robust standard errors. Analyses were performed using STATA version 12.1 (STATA Corporation, College Station, TX).

RESULTS

Characteristics of Residents, Proxies and Infectious Episodes

Based on chart documentation, a total of 496 suspected infections were experienced by the cohort of 362 residents over 12 months, with 240 residents (66.1%) experiencing at least one infection (range 0–9). The research staff were able to contact proxies for telephone interviews for 395 of the 496 documented suspected infections (79.6%). The source of infection and basic demographic characteristics of proxies and residents did not differ between those episodes excluded in the analysis (i.e., for which proxy could be not contacted) and those included in the analyses with the exception that contacted proxies were significantly older than those not contacted (median age 61.1 vs. 57.3 years), $p < 0.001$.

Among the 395 episodes, the suspected sources were as follows: urinary tract, $N=155$ (39.2%); respiratory tract, $N=119$ (30.1%); fever with unknown source, $N=63$ (16.0%); and skin, $N=58$, (14.7%) (Table 1). A total of 71.7% of documented episodes were treated with antimicrobials, 7.9% resulted in a hospital or emergency room transfer and 12.2% occurred within 30 days of death. The median number of days between infection and proxy interview was 41. Although the study staff attempted to contact the HCP within 8 weeks of the infection, the range of time between infection and interview was 8–167 days with the majority (75%) falling within the 8 week time frame.

Resident, proxy and infectious episode characteristics for the 395 suspected infections included in the analyses are reported in Table 1. The median resident age was 87 years. Close to 93% of infections occurred in white residents, 17.5% in male residents, and 46.6% in residents who lived in special care units. The residents' median BANS-S score was 22 and median length of stay was 3.2 years. Residents had DNH directives and orders to withhold antimicrobials for 36.6% and 10.1% of infectious episodes, respectively. The vast majority of residents (94.4%) were not enrolled in hospice, and the median number of provider visits in the past 30 days was 3. The proxies' median age was 60 years, 62.3% were female, 62.8% were children of the resident, and 14.3% visited the resident more than seven hours per week. The vast majority (92.9%) of the proxies stated comfort was the primary goal of care, 51.4% perceived infections to be common in advanced dementia, 9.1% believed that the resident had less than 6 months to live and 50.7% had discussed advance care planning for more than 15 minutes at the time of admission to the NH.

Proxy Involvement in Infectious Episodes

Figure 1 describes proxy involvement in decision making for infectious episodes. Among the episodes for which proxies were successfully contacted ($N=395$), they reported being aware of only 156 (39.5%) of suspected infections. Proxies stated they participated in treatment decisions for 89 of these 156 recalled episodes (57.1%). Therefore, from the proxies' perspective, overall participation in decision-making occurred in 89/395 (22.5%) of suspected infections documented in the chart. Among the recalled episodes for which proxies did not participate in decision-making, 85% ($N=56/66$) of proxies said they did not want to participate in that process (denominator is 66 not 67 due to missing data for one episode).

A discussion between the proxy and provider was documented in the chart for 207/395 (52.4%) of suspected infections. Of these, physicians were involved in 27(13.0%), nurse practitioners in 70 (33.8%), and nurses in 116 (56.0%) (six episodes had involvement of more than one discipline). Figure 2 presents the concordance between proxy awareness and chart documentation of a discussion. There was concurrent proxy awareness and documentation for 105/395 (26.6%) of suspected infections. There was chart documentation of a discussion without proxy awareness for 102/395 (25.8%) of episodes, and proxy awareness without documentation for 51/395 (12.9%). For 137/395 (34.7%) of suspected infections, there was neither proxy awareness nor documentation.

Factors Associated with Proxy Awareness and Chart Documentation of a Discussion

Table 1 presents resident, proxy and infectious episode characteristics associated with proxy awareness and chart documentation of proxy discussion. In adjusted analysis, proxy awareness was associated with treatment with antimicrobials (adjusted OR (AOR) 3.43, 95% CI 1.94–6.05), hospital transfer (AOR 3.00, 95% CI 1.19–7.53), occurrence within 30 days of death (AOR 3.32, 95% CI 1.54–7.18) and fewer days between the documented date of the infectious episode and the study interview (AOR 2.71, 95% CI 1.63–4.51).

Documentation of a proxy/provider discussion was associated with the resident being cared for in a dementia special care unit (AOR 1.71, 95% CI 1.04–2.80), not being on hospice (AOR 3.25, 95% CI 1.31–8.02), a greater number of physician or nurse practitioner visits in the prior 30 days (AOR 1.71, 95% CI 1.07–2.75), proxy visits > 7 hours/week (AOR 1.93, 95% CI 1.02–3.67), and infection occurrence within 30 days of death (AOR 3.99, 95% CI 1.98–8.02).

DISCUSSION

In this cohort of 362 NH residents with advanced dementia, we describe the occurrence of proxy involvement in 395 suspected infections. In interviews, proxies stated they were aware of only 40% of episodes, while the medical chart documented proxy/provider discussions for 52% of episodes. For 35% of episodes, there was neither proxy awareness nor chart documentation of communication. Among the 395 infections for which study staff were able to contact the proxy, awareness was associated with characteristics of the infection, whereas documentation of proxy/provider discussion was mostly associated with characteristics of the medical care given the resident.

We found that proxies were unaware of 60% of all suspected infections. To our knowledge, there is no prior work documenting this lack of communication or recollection of communication regarding infections among NH residents with dementia. There are multiple reasons to encourage greater proxy involvement in shared decision-making. In general, families of NH residents report that they want more communication with staff about the resident's status,¹⁰ and often feel inadequately informed about their loved one's situation near death.¹⁷ Moreover, treatment decisions for advanced dementia should ideally reflect the primary goal of care, which the majority of proxies for these residents state is comfort. It is not clear whether antimicrobial use promotes comfort since such treatments may involve burdensome interventions such as parenteral therapy or hospital transfer,¹² therefore a

discussion with the proxy would enhance the chances that a decision would align with the goals of care. Even among residents for whom life prolongation is the goal of care, antimicrobials may not improve survival as infections are commonly a terminal event.² Finally, families may wish to participate in decision making given the fact that antimicrobials are commonly prescribed in the NH without adequate evidence that a bacterial infection is present, and that this practice likely contributes to the emergence multidrug-resistant organisms in the NH setting.¹⁸

Proxies reported not being involved in decision making in 43% of infections of which they were aware. We were not able to discern the reasons for this lack of involvement; however, it is possible that NH providers made treatment decisions prior to informing proxies of the infection, or that proxies did not recall being involved even when they did participate. Prior work has shown that inadequate communication with NH staff is a major contributor to proxy dissatisfaction with decision-making in similar cohorts.^{6, 10} On the other hand, we found that among infections where proxies did not participate in decision-making, only 15% stated they wished they done so. This may reflect the fact that for some proxies, participation in decision-making can be burdensome.¹⁰ Documentation of whether proxies wish to be involved in decision making and greater use of advance directives may aid in aligning proxy and patient wishes with clinical practice. Use of Physician Orders for Life Sustaining Treatment (POLST) or Medical Orders for Life Sustaining Treatment (MOLST) forms at the time of NH admission may increase documentation of preferences regarding the treatment of infections, as these forms have a designated section for preferences for antibiotic use.

We found a considerable lack of concordance between proxy report of awareness of infections and NH documentation of proxy discussions regarding these infections. Our finding that proxies were more likely to be aware of infections when interviewed closer to the time of the infection suggest that recall bias may play a role. In terms of informing research methodology related to provider communication, our study suggests that reliance on information solely from either proxies or the medical chart is likely to yield biased results, and thus acquisition of data from both sources is optimal. Future work might include correlation of proxy and chart information with a gold standard from direct observation of provider/proxy discussions.

We found that proxy awareness was associated with characteristics of the infection which may indicate worse severity of illness, including the use of antimicrobials, hospital transfer, and the episode occurring just prior to death. This result makes sense in the context of NH staff wanting to communicate about a more acutely ill patient or use of more aggressive treatment. However, this also implies that infections not treated aggressively may not have adequate proxy/provider communication. In contrast, chart documentation of proxy discussion regarding the infection was mostly associated with characteristics of the medical care given the resident, including residing in a dementia special care unit, not being in hospice, and a greater number of physician or nurse practitioner visits. In addition, documentation of discussions was associated with greater proxy visitation, as well as the infection occurring just prior to resident death. It is difficult to know whether these results indicate a true difference in practice (i.e. greater proxy communication) or simply represent

better chart documentation. However, in the case of special care units, there is prior work documenting an association with some markers of better quality of care in this patient population.¹⁹

This study has certain limitations. First, the majority of participants were white and female, and all came from Boston area NHs. This has the potential to limit the generalizability of the findings. Secondly, poor proxy recall may reduce measurable proxy awareness of suspected infections, although we have accounted for time between infection and interview in our adjusted analyses. While NHs must address advance directives with all residents, there are no regulations or standardized approaches to document care planning discussions in the NH record. Thus, it is possible that informal discussions about infection management occurred that were not documented. Finally, we were unable to adjust for clustering on the facility level in our analysis, due to lack of convergence of those models, although it is possible that facility-level characteristics influence proxy awareness or chart documentation.

As the population ages, dementia will become an ever-growing issue for patients, families, and health care providers. Given the high prevalence of infections in this population, it is critical that providers and proxies work together to make the best treatment decisions. We have documented in this cohort that proxy awareness of infections is relatively low, even when the NHs documents an attempt to contact the proxy. Our study highlights the need for improved quality of communication between providers and proxies around infections in advanced dementia.

Acknowledgments

FUNDING: Supported by funding from the grants R01AG032982, K24AG033640 (Susan L. Mitchell), T35AG038027-01 MSTAR (Sara Spinella), 5T32 AG 23480-7 (Claire K. Ankuda) and K23AG034967 (Jane L. Givens) from the National Institute on Aging

References

1. National Center for Health Statistics. National Vital Statistics Reports. 2012; 61(6) http://www.cdc.gov/nchs/data/nvsr/nvsr61/nvsr61_06.pdf.
2. Mitchell SL, Teno JM, Kiely DK, et al. The clinical course of advanced dementia. *N Engl J Med*. 2009; 361:1529–1538. [PubMed: 19828530]
3. Smith GE, Kokmen E, O'Brien PC. Risk factors for nursing home placement in a population-based dementia cohort. *J Am Geriatr Soc*. 2000; 48:519–525. [PubMed: 10811545]
4. Mitchell SL, Teno JM, Miller SC, et al. A national study of the location of death for older persons with dementia. *J Am Geriatr Soc*. 2005; 53:299–305. [PubMed: 15673356]
5. Maust DT, Blass DM, Black BS, et al. Treatment decisions regarding hospitalization and surgery for nursing home residents with advanced dementia: The CareAD Study. *Int Psychogeriatr*. 2008; 20:406–418. [PubMed: 17825116]
6. Givens JL, Kiely DK, Carey K, et al. Healthcare proxies of nursing home residents with advanced dementia: Decisions they confront and their satisfaction with decision-making. *J Am Geriatr Soc*. Jul.2009 57:1149–1155. [PubMed: 19486200]
7. Gessert CE, Forbes S, Bern-Klug M. Planning end-of-life care for patients with dementia: Roles of families and health professionals. *Omega (Westport)*. 2000; 42:273–291. [PubMed: 12569923]
8. Mitchell SL, Berkowitz RE, Lawson FM, et al. A cross-national survey of tube-feeding decisions in cognitively impaired older persons. *J Am Geriatr Soc*. 2000; 48:391–397. [PubMed: 10798465]

9. Forbes S, Bern-Klug M, Gessert C. End-of-life decision making for nursing home residents with dementia. *J Nurs Scholarsh*. 2000; 32:251–258. [PubMed: 12462819]
10. Givens JL, Lopez RP, Mazor KM, et al. Sources of stress for family members of nursing home residents with advanced dementia. *Alzheimer Dis Assoc Disord*. 2012; 26:254–259. [PubMed: 22037596]
11. D'Agata E, Mitchell SL. Patterns of antimicrobial use among nursing home residents with advanced dementia. *Arch Intern Med*. 2008; 168:357–362. [PubMed: 18299489]
12. Givens JL, Selby K, Goldfeld KS, et al. Hospital transfers of nursing home residents with advanced dementia. *J Am Geriatr Soc*. 2012; 60:905–909. [PubMed: 22428661]
13. Chen JH, Lamberg JL, Chen YC, et al. Occurrence and treatment of suspected pneumonia in long-term care residents dying with advanced dementia. *J Am Geriatr Soc*. 2006; 54:290–295. [PubMed: 16460381]
14. Mitchell SL, Shaffer ML, Kiely DK, et al. The study of pathogen resistance and antimicrobial use in dementia: Study design and methodology. *Arch Gerontol Geriatr*. 2013; 56:16–22. [PubMed: 22925431]
15. Reisberg B, Ferris SH, de Leon MJ, et al. The Global Deterioration Scale for assessment of primary degenerative dementia. *Am J Psychiatry*. 1982; 139:1136–1139. [PubMed: 7114305]
16. Volicer L, Hurley AC, Lathi DC, et al. Measurement of severity in advanced Alzheimer's disease. *J Gerontol*. 1994; 49:M223–226. [PubMed: 8056941]
17. Biola H, Sloane PD, Williams CS, et al. Physician communication with family caregivers of long-term care residents at the end of life. *J Am Geriatr Soc*. 2007; 55:846–856. [PubMed: 17537084]
18. Pop-Vicas A, Mitchell SL, Kandel R, et al. Multidrug-resistant gram-negative bacteria in a long-term care facility: Prevalence and risk factors. *J Am Geriatr Soc*. 2008; 56:1276–1280. [PubMed: 18557965]
19. Cadigan RO, Grabowski DC, Givens JL, et al. The quality of advanced dementia care in the nursing home: The role of special care units. *Med Care*. Oct.2012 50:856–862. [PubMed: 22982735]

Figure 1.
Proxy Awareness of Suspected Infections and Involvement in Decision Making for a Cohort of Nursing Home Residents with Advanced Dementia (N=362 residents)

Figure 2.

Proxy awareness and nursing home (NH) documentation of discussion with proxy regarding suspected infections among residents with advanced dementia (N=395). Diagram represents infections with NH documentation only (A) (N=102), both NH documentation and proxy awareness, (B) (N=105), proxy awareness only (C) (N=51), and neither (D) (N=137).

Table 1

Resident, Proxy and Infectious Episode Characteristics according to Proxy Awareness of Infection among Nursing Home Residents with Advanced Dementia (N = 395 episodes)

	All episodes N (%)	Proxy aware of infection N (%)		Unadjusted odds ratio, 95% CI	Adjusted odds ratio, 95% CI
		With characteristic	Without characteristic		
RESIDENT					
Age > 87 (median)	213/395 (53.9)	80/213 (37.6)	76/182 (41.8)	0.84 (0.54–1.29)	
White	366/395 (92.7)	141/366 (38.5)	15/29 (51.7)	0.58 (0.23–1.48)	
Male	69/395 (17.5)	27/69 (39.1)	129/326 (39.6)	0.98 (0.56–1.72)	
Special care unit for dementia	184/395 (46.6)	76/184 (41.3)	80/211 (37.9)	1.15 (0.75–1.77)	
BANS-S* score > 22 (median)	152/395 (38.5)	58/152 (38.2)	98/243 (40.3)	0.91 (0.60–1.40)	
NH length of stay > 3.2 years (median)	199/395 (50.4)	81/199 (40.7)	75/196 (38.3)	1.11 (0.72–1.70)	
Do-Not-Hospitalize	138/395 (36.6)	60/138 (43.5)	90/239 (37.7)	1.27 (0.80–2.02)	
Order for no antimicrobials	40/395 (10.1)	21/40 (52.5)	135/355 (38.0)	1.80 (0.94–3.46)	1.45 (0.71–2.99)
Not on hospice	373/395 (94.4)	148/373 (39.7)	8/22 (36.4)	0.87 (0.37–2.02)	
No. provider visits in past 30 days > 3 (median)	189/395 (47.9)	80/189 (42.3)	76/206 (36.9)	1.26 (0.82–1.93)	
PROXY					
Age > 60 (median)	235/395 (59.5)	88/235 (37.5)	68/160 (40.5)	0.81 (0.52–1.26)	
Female	246/395 (62.3)	109/246 (44.3)	47/149 (31.5)	1.73 (1.09–2.75)	1.59 (0.97–2.59)
Child of the resident	248/395 (62.8)	104/248 (41.9)	52/147 (35.4)	1.32 (0.85–2.06)	
Visits more than 7h/wk	50/395 (14.3)	20/50 (40.0)	117/301 (85.8)	1.05 (0.53–2.06)	
Comfort is goal of care	367/395 (92.9)	143/367 (39.0)	13/28 (46.4)	0.74 (0.41–1.32)	
Perceives infections are common in advanced dementia	203/395 (51.4)	80/203 (39.4)	76/192 (39.6)	0.99 (0.65–1.50)	
Perceives resident has < 6 months to live	36/395 (9.1)	16/36 (44.4)	140/359 (39.0)	1.25 (0.62–2.53)	
15 min spent discussing advance directives at time of admission	176/395 (50.7)	70/176 (39.8)	64/171 (37.4)	1.10 (0.70–1.75)	
SUSPECTED INFECTION					
Source					
Urinary tract	155/395 (39.2)	58/155 (37.4)	98/240 (40.8)	0.91 (0.60–1.38)	
Respiratory tract	119/395 (30.1)	56/119 (47.1)	100/276 (36.2)	1.60 (1.04–2.48)	1.60 (0.93–2.75)

	All episodes N (%)	Proxy aware of infection N (%)		Unadjusted odds ratio, 95% CI	Adjusted odds ratio, 95% CI
		With characteristic	Without characteristic		
Fever only	63/395 (16.0)	19/63 (30.2)	137/332 (41.3)	0.57 (0.32–1.01)	0.82 (0.39–1.70)
Skin	58/395 (14.7)	23/58 (39.7)	133/337 (39.5)	0.86 (0.49–1.50)	
Treated with antimicrobials	283/395 (71.7)	131/283 (46.3)	25/112 (22.3)	3.00 (1.80–5.00)	3.43 (1.94–6.05)
Hospital transfer	31/395 (7.9)	20/31 (64.5)	134/361 (37.1)	3.08 (1.40–6.79)	3.00 (1.19–7.53)
Within 30 days of death	48/395 (12.2)	25/48 (52.1)	131/347 (37.8)	1.79 (0.97–3.32)	3.32 (1.54–7.18)
Days between documented date of infection and interview < 41 (median)	193/395 (48.9)	91/193 (47.2)	65/202 (32.2)	1.88 (1.24–2.85)	2.71 (1.63–4.51)

* Bedford Alzheimer's Nursing Severity-Subscale (range 7–28; higher scores indicate greater disability)

All unadjusted and adjusted analyses account for clustering at level of resident/proxy dyad

Table 2

Resident, Proxy and Infectious Episode Characteristics according to Charted Documentation of Discussion Regarding Infection among Nursing Home Residents with Advanced Dementia (N = 395 episodes).

	Nursing home chart documentation of a provider/proxy discussion (%)		Unadjusted odds ratio, 95% CI	Adjusted odds ratio, 95% CI
	With characteristic	Without characteristic		
RESIDENT				
Age > 87 (median)	108/212 (50.9)	99/182 (54.4)	0.87 (0.54–1.41)	
White	195/365 (53.4)	12/29 (41.4)	1.62 (0.62–4.23)	
Male	37/69 (53.6)	170/325 (52.3)	1.05 (0.52–2.14)	
Special care unit for dementia	113/184 (61.4)	94/210 (44.8)	1.96 (1.22–3.16)	1.71 (1.04–2.80)
BANS-S* score > 22 (median)	84/152 (55.3)	123/242 (50.8)	1.20 (0.75–1.89)	
NH length of stay > 3.2 years (median)	104/198 (52.5)	103/196 (52.6)	1.00 (0.62–1.62)	
Do-Not-Hospitalize	77/138 (55.8)	116/238 (48.7)	1.33 (0.82–2.14)	
Order for no antimicrobials	29/40 (72.5)	178/354 (50.3)	2.61 (1.17–5.80)	1.73 (0.75–4.00)
Not on hospice	200/372 (53.8)	7/22 (31.8)	2.49 (1.10–5.63)	3.25 (1.31–8.02)
No. provider visits in past 30 days > 3 (median)	113/189 (59.8)	94/205 (45.9)	1.76 (1.11–2.78)	1.71 (1.07–2.75)
PROXY				
Age > 60 (median)	124/234 (53.0)	83/160 (51.9)	1.05 (0.64–1.70)	
Female	134/246 (54.5)	73/148 (49.3)	1.23 (0.75–2.01)	
Child of the resident	133/247 (53.9)	74/147 (50.3)	1.15 (0.70–1.90)	
Visits more than 7h/wk	32/50 (64.0)	148/300 (49.3)	1.83 (0.96–3.49)	1.93 (1.02–3.67)
Comfort is goal of care	194/366 (53.0)	13/28 (46.4)	1.30 (0.51–3.33)	
Perceives infections are common in advanced dementia	111/203 (54.7)	96/191 (50.3)	1.19 (0.77–1.86)	
Perceives resident has <6 months to live	22/36 (61.1)	185/358 (51.7)	1.47 (0.70–3.10)	
15 min spent discussing advance directives at time of admission	84/175 (48.0)	94/171 (55.0)	0.76 (0.46–1.25)	
SUSPECTED INFECTION				
Source				
Urinary tract	69/154 (44.8)	138/240 (57.5)	0.71 (0.47–1.08)	
Respiratory tract	71/119 (59.7)	136/276 (49.3)	1.62 (1.02–2.57)	1.38 (0.86–2.21)

	Nursing home chart documentation of a provider/proxy discussion (%)		Unadjusted odds ratio, 95% CI	Adjusted odds ratio, 95% CI
	With characteristic	Without characteristic		
Fever only	36/63 (57.1)	171/332 (51.1)	1.10 (0.63–1.91)	
Skin	31/58 (53.5)	176/337 (52.2)	0.99 (0.59–1.68)	
Treated with antimicrobials	156/282 (55.3)	51/112 (45.5)	1.48 (0.96–2.28)	1.60 (0.97–2.65)
Hospital transfer	18/30 (60.0)	187/361 (51.8)	1.40 (0.69–2.83)	
Within 30 days of death	37/48 (77.1)	170/346 (49.1)	3.48 (1.74–6.96)	3.99 (1.98–8.02)
Days between documented date of infection and interview < 41 (median)	95/192 (49.5)	112/202 (55.5)	1.27 (0.86–1.87)	

* Bedford Alzheimer's Nursing Severity-Subscale (range 7–28; higher scores indicate greater disability)

All unadjusted and adjusted analyses account for clustering at level of resident/proxy dyad