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Integration of Infection Management and Palliative Care in Nursing Homes:

An Understudied Issue

Patricia W. Stone, PhD, RN, FAAN

Centennial Professor in Health Policy, Director of the Center for Health Policy, School of Nursing, Columbia University, New York, New York

There are approximately 1.4 million residents in the 15,700 nursing homes (NHs) across the nation; on average, 85% of residents are at least age 65 (Harris-Kojetin, Sengupta, Park-Lee, & Valverde, 2013). Furthermore, an increased demand for NH services is expected in the coming years, in large part due to a growing older adult population (U.S. Census Bureau, 2014). Approximately 38% of NH residents have *advanced illness*, which is defined as when one or more conditions becomes serious enough that general health and functioning decline, and treatments begin to lose their impact (The Coalition to Transform Advanced Care, 2015). Race and ethnicity of the NH population is also changing; national trends between 1999 and 2008 showed the proportion of minority NH residents increased substantially due to fewer end-of-life (EOL) options for this population (Feng, Fennell, Tyler, Clark, & Mor, 2011). We need to understand how best to care for this growing population of high-risk, vulnerable older adults.

Older adult NH residents are particularly susceptible to infections due to compromised physiological barriers (e.g., skin breakdown, use of devices such as catheters), immunosuppression, malnutrition, dehydration, comorbidities, and/or functional impairments (e.g., incontinence and/or immobility); infections are common terminal events (Institute of Medicine [IOM], 2015). The estimated prevalence of infections in NH residents ranges from 1.4 to 5.2 per 1,000 resident care days, which translates to 765,000 to 2.8 million infections annually (Dwyer et al., 2013; Koch, Eriksen, Elstrøm, Aavitsland, & Harthug, 2009; Strausbaugh & Joseph, 2000; Tsan et al., 2008). Many of these infections are caused by multidrug-resistant organisms (MDROs). In a systematic review of the literature, it was found that as much as 59% of NH residents were infected with a multidrug-resistant gram negative bacteria organism (Aliyu, Smaldone, & Larson, 2017) and, in 35 NHs in Boston, researchers found 67% of residents with advanced dementia were colonized with a MDRO (Mitchell et al., 2014). Furthermore, methicillin-resistant *Staphylococcus aureus* (MRSA) colonization or infection prevalence in some NHs has been estimated to be 82% (van Buul et al., 2012). Despite the heterogeneity of estimates, infections are a frequent occurrence in NH residents and often caused by MDROs.

Effectively managing infections in NHs is difficult for multiple reasons. First, the NH is home for most residents and thus the environment is social—residents and families move throughout the facility and congregate in shared dining and recreational spaces (Cohen, Pogorzelska-Maziarz, et al., 2015; Mody, Bradley, & Huang, 2013; Richards, 2007; Stone et al., 2015). Second, older adult residents may not exhibit the same symptomology as younger adults and communication of symptoms may be difficult for those with cognitive decline (Strausbaugh & Joseph, 1996). Third, NHs do not have the same level of onsite technological and personnel resources as hospitals to support infection management efforts (e.g., many NHs do not have radiology capabilities to diagnosis pneumonia). NH infection control and management programs are inadequately staffed, with as much as four-fold fewer personnel than hospitals, and staff turnover is high (Roup, Roche, & Pass, 2006). In addition, physicians, nurse practitioners, or other advanced practice clinicians may not be available at all times to help with infection management decisions. Lastly, the decision of whether to prescribe antibiotic medications can be challenging to address in NH residents, especially in advanced illness and as death nears, and family members may perceive these drugs as relatively benign.

With these difficulties, it is not surprising that infection management is suboptimal. Approximately 40% of Centers for Medicare & Medicaid Services (CMS)-certified NHs receive deficiency citations for inadequate infection control every year (Cohen, Engberg, Herzig, Dick, & Stone, 2015; Herzig et al., 2016; Ye, Mukamel, Huang, Li, & Temkin-Greener, 2015). Furthermore, antibiotic medications are overused in NHs and account for approximately 40% of all medications administered (Nicolle, Bentley, Garibaldi, Neuhaus, & Smith, 2000). Between 47% and 79% of NH residents receive antibiotic medications at least once per year, and approximately one third of hospice patients receive these drugs in the last week of life (and most without a documented bacterial infection) (Albrecht, McGregor, Fromme, Bearden, & Furuno, 2013). Older adults are particularly susceptible to the adverse side effects of antibiotic medications due to altered pharmacokinetics, polypharmacy, dosing errors, and an increased risk of *Clostridium difficile* (*C. difficile*) infections (Faulkner, Cox, & Williamson, 2005; Kyne et al., 1999). Inappropriate use and/or overuse of antibiotic medications leads to increased incidence of MDROs, such as MRSA and extended-spectrum beta lactamase producing Enterobacteriaceae, as well as *C. difficile* infections (i.e., contagious diarrheal infection). Therefore, overuse of antibiotic medications not only increases the risk of adverse outcomes for those receiving the medications, but also increases the risk of transmission of MDROs and *C. difficile* to others.

Antibiotic medication use in those with advanced illness may delay entry to hospice, prolong the dying process, and cause patients to incur unnecessary costs with little or no benefit (Ford, Fraser, Davis, & Kodish, 2005). A systematic review of antibiotic therapy among patients receiving hospice and palliative care included eight studies in which investigators measured symptoms following antibiotic medication initiation (Rosenberg et al., 2013). None of these observational studies had comparison groups, and the methodological heterogeneity and contrasting findings limited conclusions about whether antibiotic medications provide symptom relief for residents at EOL. In the only subsequent prospective study, it was reported that NH residents with advanced dementia who were not treated with antibiotic medications had greater comfort, albeit shorter survival, compared with those who

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were treated (Givens, Jones, Shaffer, Kiely, & Mitchell, 2010). Another notable finding was that the survival benefit associated with antibiotic use (versus no treatment) was similar regardless of the route of administration, whereas the most aggressive treatment approaches (intravenous therapy or hospitalization) were associated with the greatest discomfort (Givens et al., 2010). For older adult NH residents, infection management should be integrated with palliative care goals by: (a) discussing decision making about infection management as part of advance care planning with treatment preferences about antibiotic drug use and hospitalization due to infection documented in advance directives; and (b) improving antibiotic stewardship algorithms by integrating resident treatment preferences (Ersek & Stevenson, 2013; Juthani-Mehta, Malani, & Mitchell, 2015). To date, no studies have examined the integration of infection management with palliative care at a national level.

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To help NHs prevent and manage infections, two major professional associations in the field of epidemiology jointly published guidelines (Smith et al., 2008). These guidelines are mainly based on evidence from acute care settings (Boyce & Pittet, 2002; Gould, Umscheid, Agarwal, Kuntz, & Pegues, 2010; “Immunization of health-care workers...,” 1997; Rutala & Weber, 2008; Sehulster & Chinn, 2003; Siegel, Rhinehart, Jackson, & Chiarello, 2007). Other guidelines, mainly based on expert opinion, have been developed specific to NHs (American Medical Directors Association, 2011; Centers for Disease Control and Prevention [CDC], 2017; High et al., 2009; Loeb et al., 2001). Although antibiotic stewardship is recommended, the guidelines do not directly discuss the integration of infection management and palliative care.

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Palliative care, an important aspect of NH care, is an approach that improves quality of life (QOL) through the prevention and relief of suffering by means of early identification, impeccable assessment, and treatment aimed at improving comfort (World Health Organization, n.d.). Approximately 20 years ago, the IOM’s (1997) seminal report, “Approaching Death: Improving Care at the End of Life,” was published. Since then, there have been two important reviews on the state of the science in EOL and palliative care. First, the National Institute of Nursing Research (NINR; 2013) published a summary of research trends from 1997–2010. The summary noted that a growing body of evidence demonstrating palliative care not only improves QOL and increases satisfaction, but can also help prolong survival (Meier, 2011). The summary also identified gaps in the science and called for research that incorporates variations in geographic locations as well as health care sectors, including NHs.

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In 2015, the IOM (now National Academy of Medicine) published *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*, in which they recommended that all NHs provide EOL care consistent with palliative care goals. Despite these recommendations, palliative care in NHs is suboptimal; in 2011, the Office of the Inspector General reported that NHs transferred one quarter of all Medicare NH residents to hospitals and three of the top four reasons for transfer were infections (Golladay, Collins, & Dorrill, 2013). Older adult NH residents transferred to hospitals have increased exposure to MDROs, a high risk for morbidity, iatrogenic illness, disruption of care plans, disorientation, stress, and decreased QOL (Ahmed et al., 2010; Boockvar et al., 2005; Kruse, Petroski, Mehr, Banaszak-Holl, & Intrator, 2013; Saliba et al., 2000; Smith et al., 2008). These

hospitalizations have been characterized as burdensome transitions and result in residents experiencing interventions that cause discomfort and produce little, if any, gain, which is not consistent with palliative care goals (IOM, 2015; Mitchell et al., 2009; Teno, Gozalo, Mitchell, Tyler, & Mor, 2013). Better understanding is needed of NH residents' total burden during transfers to hospitals due to infections, as well as the modifiable factors associated with these transfers.

Improving infection control and management, as well as palliative care, in NHs is a national priority, and several agencies are implementing initiatives. In 2016, CMS' final rule required that NHs develop an infection control program that includes an antibiotic stewardship program and infection preventionist whose main responsibility is the infection control program and to provide all staff with infection control training and education (CMS, 2016). Funded by CMS and with enrollment starting in April 2016, the *C. difficile* Infection Reporting and Reduction Project involves 14 regional NH learning collaboratives led by Quality Innovation Network-Quality Improvement Organizations (QIN-QIOs) (CDC, 2015). The QIN-QIOs support NHs in enrolling in the CDC National Healthcare Safety Network (NHSN), which is a web-based national health care-associated infection tracking system. Although similarities are likely to exist across the different regions in implementation activities, variations are also likely. Understanding how best to support NHs in enrolling and reporting to NHSN is not known.

State departments of health are also implementing initiatives. Since 2007, Pennsylvania has mandated NHs to publicly report infections and other states are following suit. In 2015, Nevada became the first state to mandate NHs to use the CDC's NHSN for reporting infections. The CDC does not specifically integrate palliative care concepts or resident and family preferences in their recommendations for infection control and management for NHs. Given the various regional and state infection control initiatives underway, there is a potential dilemma of holding NH personnel to standards that can be more suitable to life prolongation than palliation (e.g., aggressive culturing and/or antibiotic medication use); however, others may promote resident-centered care that integrates infection management and palliative care (Albrecht et al., 2013; Dwyer et al., 2013; Juthani-Mehta et al., 2015; "National action plan...", 2013). In surveys conducted in the United Kingdom and Germany, wide variation in infection control and management practices were found in hospice and palliative care units, with responding clinicians perceiving interventions as adversely impacting resident QOL (Bükki et al., 2013; Dand, Fyvie, Yee, & Sykes, 2005). No similar surveys have been conducted in the United States. The national Physician Orders for Life-Sustaining Treatment (POLST) paradigm is an initiative to improve EOL care planning by documenting residents' and their families' preferences for care (Jennings et al., 2016). Three states (i.e., California, Oregon, and West Virginia) have mature POLST programs (i.e., 50% of hospitals and NHs use the POLST method of advance care planning for those with advanced illness or frailty) and 25 states have developing programs. In some states, POLST physician order sets have integrated infection management with palliative care by including specific items about preferences related to antibiotic medication use and transfers to hospitals due to infection ("POLST Paradigm," 2017). No data are available on how many state POLST programs have this integration. These data are needed to understand how best to integrate infection management in EOL care.

In 2017, the NINR funded the Study of Infection Management and Palliative Care at End-of-Life (SIMP-EL; R01 NR R013687). The general aim of this study is to improve the understanding of how best to integrate infection management and palliative care, which is consistent with the care goals of most older adult residents and their families. Thus, the innovative study has the potential to make clinical and policy-relevant contributions by promoting resident-centered EOL care for millions of Americans and reducing antibiotic use and hospital transfers due to infections. Consistent with NINR's (2011) strategic plan, researchers are encouraged to develop other studies that will fill the important gaps identified.

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