When Nurses Lead

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ABSTRACT

In Fall 2011, the Centers for Medicare and Medicaid Services (CMS) began a major initiative to improve dementia care in nursing homes. The initial goal was to reduce the prevalence of antipsychotic medication use in long-stay nursing home residents with dementia by 15%. Through a new, public-private collaboration, the National Partnership to Improve Dementia Care established coalitions in every state. After 18 months, a 15.1% reduction was achieved nationally. Throughout the initiative, many nurses played key roles in leading the process for change. This article describes the roles of nurse leaders in this national policy work. [Journal of Gerontological Nursing, 40(6), 17-21.]

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Some of the nursing home staff described 84-year-old Howard Blackstone (names changed to maintain confidentiality) as “cantankerous.” He regularly refused his whirlpool baths and other treatments related to his diabetic foot care. His chart reflected that this “resistance to care” and “behaviors related to dementia” led the nurses to request an antipsychotic medication from the physician. Mr. Blackstone was more sedated on the medication and listed as more “cooperative” with his whirlpool treatments; however, his appetite worsened and his oral intake declined. He spent more time in his room and required a wheelchair for mealtimes instead of walking to the dining room.

A new nurse manager, Joyce Hopkins, was hired by the facility. Mr. Blackstone’s daughter (his health care agent) expressed concern to Ms. Hopkins and the interdisciplinary team during a care plan meeting. Ms. Hopkins asked the nurses, activities director, and certified nursing assistants (CNAs) on the unit what they knew about Mr. Blackstone regarding his preferences and previous routines. One of the CNAs said that she used to take walks with Mr. Blackstone, and he seemed to enjoy being outside. The family confirmed that he always took an evening walk around 7:00 p.m. when he was home. Ms. Hopkins asked the staff if they thought they might try reducing Mr. Blackstone’s medication, working with therapy to improve his mobility, and scheduling an evening walk.
walk with one of the CNAs or activities aides prior to his whirlpool treatment. If Mr. Blackstone knew that he could take a walk in the evening, the family thought he might be more likely to accept the whirlpool treatment afterward. The staff also explained the risks and benefits of allowing Mr. Blackstone to refuse some whirlpool treatments and encouraged the family to continue to ask questions and engage in the decision making, reminding them that they could change their mind and make a different decision on the resident’s behalf at any time.

Over the next several months, the medication was gradually reduced and discontinued. Mr. Blackstone’s mobility and appetite improved, and he was able to walk outside with evening staff most nights. He was generally in a good mood after these walks, and usually (although not always) accepted his whirlpool treatments.

Based on the success of this case, the nurse manager led the team in instituting a performance improvement project (PIP) for all residents with dementia on the unit receiving antipsychotic medication. The team reviewed each case individually and came up with ideas for nonpharmacological interventions to try as part of a gradual dose reduction (GDR) for each resident. Along with the advanced practice RN (APRN) and behavioral health team, unit staff prioritized which residents would have their antipsychotic medication dose reduced first. Over several months, the team used data from the Minimum Data Set and pharmacy reports to track progress on the unit. At the end of 3 months, antipsychotic medication use had been reduced by 26%. The majority of residents who had been tapered off of their antipsychotic medications were able to be maintained off of the medication using other strategies to address their behaviors.

Nurse leadership played a critical role in ensuring quality of life and person-centered care for this nursing home resident with behavioral symptoms of dementia. The nurse manager recognized the importance of engaging the entire team, including the direct care staff (e.g., CNAs, activities aides, nurses) and family in the care planning process. She arranged for a PIP, encouraging innovation and monitoring of interventions to assess the benefits over time. She shared data with staff and families and applied learnings systematically throughout the unit and facility.

This is one of many examples of nursing leadership from around the country passed on to the Centers for Medicare and Medicaid Services (CMS) over the past 2 years. These stories demonstrate how nursing home nurses leading interdisciplinary teams are changing culture and improving comprehensive dementia care. This article describes several ways in which nursing leaders have played a pivotal role in the CMS National Partnership to Improve Dementia Care: in clinical care at the bedside; through activities by professional organizations; in policy development with government agencies; and as patient advocates.

**IMPETUS FOR THE CMS INITIATIVE**

Within CMS, there are many different divisions and departments. Some divisions address payment issues, such as insurance coverage for Medicare beneficiaries or types of services that must be covered. Other groups are regulatory in nature, overseeing inspections of health care facilities and ensuring compliance with the conditions of participation (e.g., the Survey and Certification Group). Finally, some groups, such as the Quality Improvement Group, address issues related to health care quality improvement and measures.

In fall 2011, a group of nursing home advocates met with CMS Administrator Dr. Donald Berwick and expressed concern over the high rate of antipsychotic medication use in nursing homes, particularly in older adults with dementia. One quarter to one third of all nursing home residents receive antipsychotic medication (Huybrechts et al., 2012). An Office of the Inspector General report on atypical antipsychotic medications in 2011 reported that in 83% of cases in which an antipsychotic agent was prescribed, the drug was used for off-label indications (Levinson, 2011). In other research, antipsychotic medications were prescribed for too long, or at too high a dose; in many cases, there was no appropriate clinical indication for use (Briesacher et al., 2005; Tjia, Gurwitz, & Briesacher, 2012).

**WHY IS THIS IMPORTANT?**

Antipsychotic medications can be effective, even life-saving, drugs when used appropriately for people with serious mental illness under the care of skilled clinicians. However, the U.S. Food and Drug Administration (FDA) issued a black box warning on atypical antipsychotic agents in 2005 and another warning in 2008 for conventional antipsychotic agents. There is an increased risk of death with the use of these drugs in frail older adults, including those with dementia (U.S. FDA, 2005). Federal nursing home guidelines (http://www.cms.gov/Medicare/Provider- Enrollment-and-Certification/SurveyCertificationGenInfo/Downloads/Survey-and-Cert-Letter-13-35.pdf) do not support the use of these medications as first-line treatment for behavioral or psychological symptoms of dementia (BPSD).

Over the past several decades, antipsychotic medications have traditionally been used in nursing homes to treat BPSD; in some cases, this has led to clinically improved outcomes for certain residents (Maher et al., 2011). However, government studies report that in many cases, there is poor documentation...
of the reasons for use, lack of target behaviors, lack of monitoring, failure to attempt nonpharmacological or other potentially safer interventions first, lack of involvement of the resident or family in the decision making, and lack of evidence of the decision-making process in the care plan (Center for Medicare Advocacy, Inc., 2013; Levinson, 2013). Furthermore, numerous nursing home residents take more than one antipsychotic or psychopharmacological agent, receive doses that exceed the maximum daily recommended dose, and are continued for too long before any re-evaluation (e.g., GDR) is attempted (Briesacher et al., 2005; Tjia et al., 2012).

CMS NATIONAL PARTNERSHIP TO IMPROVE DEMENTIA CARE

In discussions with both advocates and nursing home professional associations, it became clear that the issue of over-medication for BPSD was not just about a particular class of drugs. The dialogue revealed a significant gap in the way nursing homes across the country approach comprehensive dementia care. A questionnaire and interviews with frontline surveyors also reflected potential weaknesses in the nursing home enforcement system (Center for Medicare Advocacy, Inc., 2013). There was a compelling need to better articulate the minimum standards for dementia care, building on the current federal regulations in the nursing home reform law, the Omnibus Budget and Reconciliation Act of 1987. Setting clear expectations for the use of nonpharmacological approaches in people with dementia, requirements for provider staff training, and enhanced surveyor training were key components of the initiative. Clearly, no one organization or agency would be able to do this alone. CMS reached out to multiple stakeholders to join forces in a public-private partnership to address this issue.

State Coalitions

CMS established dementia care coalitions in every state; members included (but were not limited to) nursing home residents and family members, advocates, professional organizations, trade associations, ombudsmen, quality improvement organizations, clinicians (e.g., nurses, physicians, pharmacists, social workers, activities professionals, therapists, psychologists, behavioral specialists), researchers, educators, survey agencies, and other government entities. The goals of these initiatives were to bring together resources at the state level; raise awareness about the issue of overuse of antipsychotic medications in nursing homes; educate providers, residents, families, and communities; and lower unnecessary antipsychotic drug use in nursing home residents with dementia in each state.

CMS also began public reporting of the prevalence of antipsychotic medication use in long-stay nursing home residents on Nursing Home Compare (http://www.nursinghomecompare.gov) in July 2012. This enabled each state and facility to track progress over time and benchmark their rates with others in their region and nationally.

Additional components of the initiative that supported this work were:

- A technical expert panel of international dementia practitioners, clinicians, researchers, advocates, and family members who established goals and strategies for the National Partnership (April 2012).
- Regular (monthly, quarterly) conference calls with states, regions, and national calls with state coalitions that established communities of practice. In addition to calls with state coalitions, in 2013, CMS and its partners increased direct outreach to nursing facilities, hospitals, advocates, professionals, and professional associations.
- E-mails or letters sent by several partner organizations such as state survey agencies, regional offices, and professional organizations to nursing homes with high rates of antipsychotic drug use.
- A series of three mandatory training programs for all state surveyors (2012–2013). These training videos are also available to the public and may be accessed at http://surveyortraining.cms.hhs.gov/pubs/AntiPsychoticMedHome.aspx.

THE IMPACT OF NURSING LEADERSHIP

In many nursing homes, when residents exhibited certain behaviors, the response by a nurse has historically been to try to make the resident and others safe by calling the physician or nurse practitioner to obtain an order for an antipsychotic medication. Although this is not always the case, it has been a common practice over the years, in part because nurses have not had leadership that promoted nonpharmacological interventions. The practice of trying to deter-
mine the underlying cause of the behavior—working with families to identify previous life preferences and routines—was not consistently implemented.

Directors of Nursing Step Up

In a number of nursing home organizations, directors of nursing (DONs) made the decision to personally review 100% of antipsychotic medication prescriptions at or before admission, and to discuss the case with the interdisciplinary team and/or the prescribing or attending physician or nurse practitioner before the order goes to the pharmacy. This included decisions made on admission and during urgent situations, such as a change in condition or new behavior that might occur at 2:00 a.m. By providing support and guidance to frontline nurses 24 hours per day, 7 days per week (in the form of a nurse manager or DON willing to speak with direct care staff or family members at any time), nurses were able to learn and implement alternatives and were resourced to be able to utilize nonpharmacological approaches. In most cases, these changes did not require a significant increase in staff or cost (and in some cases, lowered overall costs).

Another priority described by several DONs was obtaining a list of every resident with dementia in the facility who received antipsychotic medication and reviewing that list with the interdisciplinary team, medical director, and family members at any time. DONs on national CMS calls expressed that, “It’s a leadership decision to use nonpharmacological approaches first, and to explain to physicians and families that other than in very rare cases, we don’t use drugs for behaviors related to dementia in this facility” (February 26, 2014). These innovations were shared with other facilities on monthly state, regional, and national conference calls; more and more facilities began adopting these practices. In addition, several of the largest nursing home chains revised their policies and procedures to include similar strategies led by nurses, in many cases working closely with their medical directors, pharmacy consultants, and behavioral health teams.

Leadership from Nurse Researchers and Clinicians

Hand-in-Hand is a comprehensive toolkit for CNA education on dementia and abuse developed by CMS under the Affordable Care Act and distributed to all nursing homes in the United States in 2013 (http://www.cms-handinhandtoolkit.info/HandinHand13.aspx). It became clear that there was a need for a similar resource for long-term care nurses—a clearinghouse for tools, resources, educational materials, and guidance on program implementation. A group of senior nurse researchers and psychologists secured a grant from The Commonwealth Fund to develop and test a toolkit. The website is available at http://www.nursinghome-toolkit.com and can also be accessed via the Advancing Excellence website https://www.nhqualitycampaign.org (see Resnick, Kolanowski, and Van Haitsma [2014] for more information). Additional resources related to the National Partnership are available on the Advancing Excellence website as well, including tools for entering data on facility medication management that can generate reports useful for benchmarking and individual facility quality improvement efforts.

Nurse Leadership Within Survey and Certification

State and federal surveyors received new State Operations Manual guidance from CMS via Certification Memo 13-35-NH, dated May 24, 2013, on how to evaluate nursing homes for compliance with dementia care practices and practices related to the use of unnecessary medications (http://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/SurveyCertificationGenInfo/Downloads/Survey-and-Certification/Enrollment-and-Certification/SurveyEnrollment-and-Certification/NurseLeadershipWithinSurveyandCertificationLetter-13-35.pdf). This included more detailed guidance on §483.25 Quality of Care, Care and Services of a Resident with Dementia, F Tag 309; and revisions/clarifications to §483.25(l) Unnecessary Medications, F329. The purpose of these revisions was to improve surveyors’ ability to detect deficient practices related to dementia care and unnecessary antipsychotic medication use, and to ensure that residents with dementia who are taking antipsychotic medication are included on all standard surveys.

Nurse leaders who work as state or federal surveyors from around the country, as well as their colleagues with backgrounds in social work, physical therapy, behavioral health, psychology, and activities, worked closely with CMS to develop the new guidance and to design surveyor training programs that are available to anyone (non-surveyors may view these without a login) on the national surveyor training website: http://surveyortraining.cms.hhs.gov/pubs/AntiPsychoticMedHome.aspx.
Nurse surveyors shared experiences from their interviews and observations with nurses and direct care staff, and those experiences helped inform the new guidance, including ways that surveyors can accurately evaluate for the presence of positive dementia care practices as well as enforce regulations when residents may be at risk. Finally, survey leaders in several regions made this initiative a priority for state and federal agencies and continue to shine a light on this vital quality and safety issue by discussing it at staff meetings and debriefing with staff after they return from surveys.

MOVING FORWARD WITH PERSON-CENTERED DEMENTIA CARE: NEXT STEPS

Although a 15.1% reduction in unnecessary antipsychotic medication use is a first step toward better dementia care, much more remains to be done. The CMS National Partnership demonstrates how a public-private partnership with a broad array of stakeholders, including many nurse leaders, can make an impact in promoting this initiative.

Nursing organizations such as the National Association of Directors of Nursing Administration, Gerontological Advanced Practice Nurses Association, National Gerontological Nurses Association, Coalition of Geriatric Nursing Organizations, and nursing assistant organizations such as the National Association of Health Care Assistants continue to play a major role in promoting peer-to-peer networking. Nurse leaders recognize that the CNA who is caring for residents 8 or 10 hours per day is likely to have valuable insights into residents’ behaviors, their needs, and preferences. Thus, effective teamwork between DONs, nurse managers, charge nurses, and CNAs is critical to ensuring comprehensive dementia care. Nursing teams that focus on direct care workers, as well as residents and families, and engage them in team decisions are likely to have more success than those who do not.

Nursing and other professional organizations influence policy development in areas such as nursing home staffing and training requirements that affect resident outcomes and staff stability as well. Professional associations of medical directors, geriatricians, psychiatrists, other physicians, psychologists, pharmacists, activities professionals, social workers, and nursing home administrators have provided input and helped shape national and state policy. However, it is only through the active engagement of nurses at the facility, state, and national level that further improvement in resident outcomes for people with dementia will be achieved.

REFERENCES


