

SUPPORTING FAMILY CAREGIVERS NO LONGER HOME ALONE

By Theresa A. Harvath, PhD, RN, FAAN,
Allison Lindauer, PhD, RN, FNP, and
Kathryn Sexson, PhD, RN, APRN, FNP-BC



Managing Complex Medication Regimens

Nurses can enhance a family caregiver's knowledge, skill, and confidence.

This article is the first in a series, *Supporting Family Caregivers: No Longer Home Alone*, published in collaboration with the AARP Public Policy Institute. Results of focus groups conducted as part of the AARP Public Policy Institute's No Longer Home Alone video project supported evidence that family caregivers aren't being given the information they need to manage the complex care regimens of their family members. This series of articles and accompanying videos aims to help nurses provide caregivers with the tools they need to manage their family member's medications. Each article explains the principles nurses should consider and reinforce with caregivers and is accompanied by a video for the caregiver to watch. The first video can be accessed at http://links.lww.com/AJN/A74.

A lthough caring for an older family member with a chronic or disabling condition can be a rewarding and meaningful experience, it can also be challenging and stressful. In a recent study of family caregiving in the United States, it was estimated that approximately 34.2 million caregivers provide unpaid care to an adult older than age 50.1 As the baby boomers continue to age, this number is expected to grow dramatically.

Increasingly, family caregivers are performing tasks that nurses typically perform. Referred to as "medical or nursing tasks," these include the management of medications and incontinence, dressing changes, and the handling of equipment such as oxygen tanks. Sometimes the need to provide care begins abruptly—for example, immediately following a hospital stay. The stress of this transition is further compounded by the need to learn new tasks quickly.

It's important to recognize that most family caregivers have had little or no formal training in caregiving and may find tasks that nurses complete with relative ease daunting. Therefore, open communication among family caregivers, the care recipient, other family members, and members of the health care team (nurses, pharmacists, and other providers) is necessary.

RNs are in a unique position to provide guidance to family caregivers regarding the performance of medical and nursing tasks. Only about a third (32%) of family caregivers report being asked by a nurse, physician, or other health care provider what they need to care for their family member. Although 57% of caregivers report that they perform medical and nursing tasks, only 14% said they had received any preparation or training to do so. 1

One especially challenging task for family caregivers involves the management of an older person's medications. In a nationally representative study of family care, 78% of family caregivers reported managing the care recipient's medication regimen, including administering IV fluids and injections.² Almost half (46%) reported managing five to nine medications each day. Family caregivers reported that medication administration was stressful because of fears about making mistakes, the time-consuming nature of the task, and episodes in which the care recipient refused to take the medications.²

Nurses can provide medication management education during discharge planning, during home visits, over the phone, or during clinic visits. For hospitalized older adults, it's important to identify the family caregivers who will be responsible for medication management and coordinate time for teaching and return demonstration prior to discharge. (Note that the person taking on this task may not be the most frequent family visitor during the hospitalization.) After the patient is at home, nurses should be prepared to assist family caregivers in troubleshooting any problems that arise during the course of care.

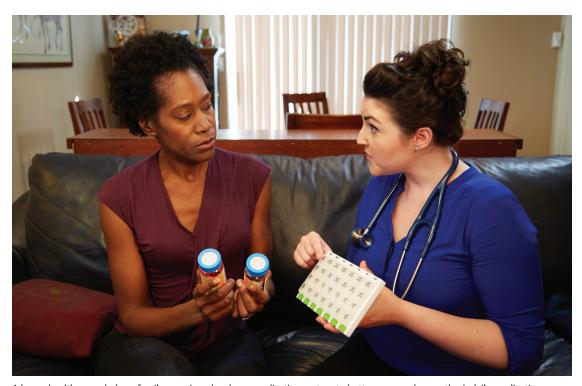
BACKGROUND AND EVIDENCE

Although there is a growing body of research about interventions to improve medication adherence in older adults, only a handful of studies focus on the role of the family caregiver. In a systematic review of medication adherence, only three of 63 studies included the family caregiver as a target of the intervention.³ Researchers didn't report specifically on the caregiver's role in adherence in any of these studies.

ajn@wolterskluwer.com AJN ▼ May 2017 ▼ Vol. 117, No. 5



NO LONGER HOME ALONE



A home health nurse helps a family caregiver develop a medication system to better manage her mother's daily medications. Photo courtesy of the AARP Public Policy Institute.

A qualitative study by Travis and Bethea explored family caregiver management of medications. 4 Many caregivers reported using primary sources for information regarding medication management. These primary sources included physicians, pharmacists, home health nurses, and package inserts. Some caregivers also reported using secondary sources, such as the Internet and a health insurance company information hotline. Although most caregivers didn't have to ask for information from primary sources—it was offered by their family members' clinicians—this information was often limited and not fully explained, so that the family caregiver didn't fully understand the medication directions. One caregiver recalled being left with a prescription that said "Take as directed," but couldn't recall what the physician had specified during their conversation. Caregivers who reported using secondary sources had a more sophisticated understanding of the medications and regimen and could engage in better problem solving when questions or problems arose.

In a study by Travis and colleagues, four categories of "medication administration hassles," which the authors described as "minor irritants of daily living," were identified, including information seeking and sharing, scheduling logistics, safety issues, and polypharmacy.⁵ In a separate study, increased

complexity of the medication regimen was associated with greater medication administration "hassles" for family caregivers.⁶

The below considerations, which can be used by RNs to enhance a family caregiver's ability to manage complex medication regimens, address these issues.

CONSIDERATIONS WHEN DEVELOPING A MEDICATION SYSTEM

In developing the following suggestions for nurses, we drew on the principles of the "just culture" movement in health care, which is supported by the American Nurses Association. This concept discourages blaming individuals for errors that result from systemic problems, and encourages the reporting of mistakes, so their causes can be discovered and addressed. Even competent family caregivers find medication management frustrating and complicated. Instead of blaming family caregivers for making errors, the goal should be to help them develop systems that reduce the likelihood of mistakes. We also want to create open communication, so that errors can be recognized, corrected, and ameliorated, if need be.

When working with family caregivers, it is recommended that nurses consider the following general

S4 AJN ▼ May 2017 ▼ Vol. 117, No. 5 ajnonline.com

suggestions. These can help to reduce the number of problems and challenges caregivers face when managing medications for an older family member.

Information seeking and sharing. Family caregivers need to understand how to access additional information to answer questions that arise during care. They also need to understand the importance of talking to the provider before stopping, starting, or changing medications and of showing each provider the complete medication list, including over-the-counter medications or supplements, during each encounter. Family caregivers should use a single pharmacy to fill prescriptions, so potential interactions can easily be assessed.

They should also be given information on potential changes in the care recipient's condition that might be related to a medication (especially if the person is taking a new medication or the dosage has changed), illness, or disease that should be communicated to the provider. Family caregivers need to know what resources are available (for example, a consulting pharmacist or care provider, medication instruction materials, or helpful Web sites, such as www.fda.gov). When in doubt about a medication, the family caregiver should consult with a pharmacist, nurse, or other health care provider.

Scheduling logistics and simplification. It is important that family caregivers understand that decisions regarding medication management should be made within the context of the goals of care. For example, some regimens can be simplified by eliminating medications that don't contribute significantly to the patient's goals or quality of life.

The chance of errors increases when regimens become more complex; for example, when there is a need for multiple doses each day, special considerations in regard to timing or food, or frequent symptom-related adjustments. Using some system—pillboxes or a detailed checklist, for instance—to organize the medications, document the timing, and ensure regular intervals between medications is better than relying on memory.

Family caregivers may benefit by setting up the medications in front of a nurse, who can monitor this process and provide feedback. Written instructions that are clear and understandable may also be helpful when family caregivers are at home and managing medications on their own.

Safety issues. It is important that nurses ensure family caregivers understand the name (both brand and generic), dose, timing, route, purpose, and any special instructions associated with each medication. They should also understand the desired and therapeutic outcomes of each medication, as well as the potential adverse effects. Family caregivers need to be aware of the importance of keeping medications

safely stored out of reach of children, pets, and older adults with cognitive impairment.

While caring for a family member at home, the caregiver needs to know how to give the medications correctly and how to cope with missed doses and mistakes (for example, when and who to call). In general, it's better to skip a dose that has been missed than to double up on the dose. This is particularly important regarding medications that have a narrow therapeutic window, such as warfarin, or those that can result in dose-related adverse effects, such as insulin.

Older adults often take their medications with just enough fluid to swallow the pills. However, some medications, such as nonsteroidal antiinflammatory drugs, need to be taken with enough water to ensure passage through the stomach for optimal absorption or to avoid gastric irritation. Nurses should encourage family caregivers to give a full eight ounces of water with medications.

To avoid choking or aspiration, family caregivers should make sure that the older adult is in a full upright position when swallowing medications.

Polypharmacy. A contributing factor to medication errors is polypharmacy. The increased complexity of managing several medications can lead to these errors. In addition, adverse effects are more likely when an older adult is taking more than five medications or over-the-counter preparations in addition to prescribed medications.⁸

Nurses can encourage caregivers to ask their family member's provider how to simplify the medication regimen by discontinuing medications that offer limited therapeutic benefit.

VIDEO CASE EXAMPLE

Go to http://links.lww.com/AJN/A74 to watch a video demonstrating the work of one home health nurse, Jessica Randolph, as she helps a family caregiver, Atim Washington, better manage medications for her mother, who was recently discharged from the hospital.

In the video, Ms. Randolph has just finished changing a wound dressing and asks Ms. Washington about

How to Use This Series

- Read the article, so you understand how best to help family caregivers manage medications.
- Encourage the family caregiver to watch the video at http://links. lww.com/AJN/A74.
- Ask the caregiver if she or he has any questions.

ajn@wolterskluwer.com AJN ▼ May 2017 ▼ Vol. 117, No. 5



SUPPORTING FAMILY CAREGIVERS

NO LONGER HOME ALONE

the home management of her mother's medications. Ms. Washington admits that her system for medication management—a set of plastic bags filled with the day's medications—isn't working well. Ms. Randolph gives Ms. Washington an alternate management option, a pillbox organizer, to better manage her mother's daily medications. She also answers Ms. Washington's questions about any special considerations regarding the administration and scheduling of medications and provides her with a list of resources that includes contact information for all of her mother's caregivers and additional online resources. \blacksquare

Theresa A. Harvath is the associate dean for academics in the Betty Irene Moore School of Nursing, University of California, Davis, in Sacramento. Allison Lindauer is an assistant professor at Oregon Health and Science University, Portland. Kathryn Sexson is a family NP at Denali Family Healthcare and an assistant professor in the School of Nursing, University of Alaska, Anchorage. The authors would like to acknowledge Susan C. Reinhard and Heather M. Young, leaders of the No Longer Home Alone video project, and the contributions of Carol Levine, who conducted focus groups with family caregivers regarding the challenges of medication management. Contact author: Theresa A. Harvath, tharvath@ucdavis.edu. The authors have disclosed no potential conflicts of interest, financial or otherwise.

REFERENCES

- AARP Public Policy Institute and the National Alliance for Caregiving. Caregiving in the U.S. 2015. Washington, DC; 2015 Jun. http://www.aarp.org/content/dam/aarp/ppi/2015/ caregiving-in-the-united-states-2015-report-revised.pdf.
- Reinhard SC, et al. Home alone: family caregivers providing complex chronic care. Washington, DC: AARP Public Policy Institute; 2012 Oct. http://www.aarp.org/content/dam/aarp/ research/public_policy_institute/health/home-alone-familycaregivers-providing-complex-chronic-care-rev-AARP-ppihealth.pdf.
- Ruppar TM, et al. Medication adherence interventions for older adults: literature review. Res Theory Nurs Pract 2008; 22(2):114-47.
- Travis SS, Bethea LS. Medication administration by family members of elders in shared care arrangements. *Journal of Clinical Geropsychology* 2001;7(3):231-43.
- Travis SS, et al. Development of the family caregiver medication administration hassles scale. Gerontologist 2003;43(3):360-8.
- Travis SS, et al. Factors associated with medication hassles experienced by family caregivers of older adults. *Patient Educ Couns* 2007;66(1):51-7.
- American Nurses Association. *Just culture*. Silver Spring, MD; 2010 Jan 28. Position statements; http://nursingworld.org/ psiustculture.
- Gnjidic D, et al. Polypharmacy cutoff and outcomes: five or more medicines were used to identify community-dwelling older men at risk of different adverse outcomes. J Clin Epidemiol 2012;65(9):989-95.

S6 AJN ▼ May 2017 ▼ Vol. 117, No. 5 ajnonline.com