HOME ALONE

Upending a common misperception, research from the AARP Public Policy Institute has found that family caregivers routinely perform complicated medical and nursing tasks for their loved ones, rather than simply helping with personal and household chores. What's more, these caregivers often are overwhelmed, afraid of making a mistake, and they have little or no professional backup. They are home alone.[1]

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Their plight represents a growing community health problem that health care organizations may be able to address through community benefit and other outreach programs.

The national study was produced by the AARP Public Policy Institute and the United Hospital Fund with support from the John A. Hartford Foundation. Described as "the first nationally representative population-based online survey of 1,677 family caregivers," it explored the complexity of tasks that family caregivers provide. The study documents that most of them deliver care requiring a set of skills for which they feel unprepared.

As quoted in the study, findings include:

- Almost half (46 percent) of family caregivers performed medical or nursing tasks for care recipients who have multiple chronic physical and cognitive conditions;
- Caregivers found wound care very challenging, and more than a third (38 percent) wanted more training;
- Three out of 4 family caregivers (78 percent) who performed medical or nursing tasks were managing medications, including administering intravenous fluids and injections;
- More than half of the family caregivers who reported they felt pressured to take on medical/nursing tasks said they had no choice, because there was no one else to do it or because insurance wouldn't pay for a professional;
- Most care recipients (69 percent) did not have home visits by a health professional. Twenty-seven percent of caregivers reported no additional help at home;
- Over half of the family caregivers served as primary care coordinators, and very few (3 percent) reported working with a care manager from an insurance company, government program or privately employed geriatric care manager.

The report says, "Family caregivers performing medical/nursing tasks were most likely to report feeling stressed and worried about making a mistake. They also were more likely to report talking to so many health care professionals and suppliers as a source of stress. More than half reported feeling down, depressed, or hopeless in the last two weeks, and more than a third reported fair or poor health. These negative impacts increased with the number of the care recipients' chronic conditions."

AARP says there is an urgent need to help family caregivers better cope with handling medical/nursing tasks at home. The organization calls for coordinated efforts of many sectors —hospitals, home care agencies, community agencies, nursing homes, hospices, physicians and others — to address this growing community health problem. It will take "a level of teamwork that challenges attitudes and behaviors firmly entrenched in the current system," the report's authors say.

The report recommends that health care professionals rethink and restructure how they interact with family caregivers: "Every health care clinician and social service professional must feel personally responsible for ensuring that the patients and families in their care understand how to perform the challenging tasks outlined in this report."

As the health care system shifts from an emphasis on acute care to chronic care, which is long term in nature, AARP's report recommends that caregiver training and support be long term, too: "The need does not end with discharge from any formal service, but extends to the community, where health care clinicians and social service professionals will need to address the challenge of assessment, instruction, and support, which must become integral to routine practice."

IMPLICATIONS FOR COMMUNITY BENEFIT

Hospital community benefit programs' com-

munity health needs assessments often identify needs of older persons and their caregivers. That means once family caregivers are identified as a need, hospitals and their partners could take an in-depth look: What tasks are they being asked to perform? Do they have the required knowledge and expertise? What kind of support do they need? Here are some suggestions:

- Collectively, community partners could work with family caregivers and design an implementation strategy to address unmet needs.
- Parish nurse or health ministry programs already focus most of their attention on older parishioners, but they may not have considered caregivers' needs. These programs might want to arrange for volunteer respite for caregivers and other support.
- Long-term care facilities teach basic nursing skills to their nursing assistants. They might be able to offer parallel sessions for family caregivers or make their education resources such as videos and other materials available to community members.
- Electronic health programs that offer 24-hour emergency consultation to other providers could make the services available to family caregivers.

These outreach activities can bring support and relief to the legions of family caregivers who need help. And, as the AARP report concludes, "at a time when federal and state health policy is driving changes to reduce hospitalizations and nursing home admissions, it is critical to consider who will care for people with multiple, chronic conditions who need substantial help with tasks that are often considered 'nursing' or 'medical' care. The default is the family, ready or not."

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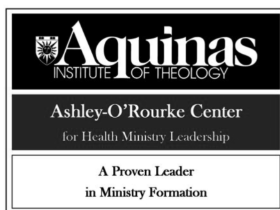
NOTE

1. Susan Reinhard, Carol Levine and Sarah Samis, *Home Alone: Family Caregivers Providing Complex Chronic Care*, (Washington, D.C.: AARP Public Policy Institute, 2012). www.aarp.org/content/dam/aarp/research/public_policy_institute/health/home-alone-family-caregivers-providing-complex-chronic-care-rev-AARP-ppi-health.pdf.



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