Overlooking an Integral Lynchpin of Patient Care: The Caregiver at Home

Two health care trends have seemingly converged to underscore the pivotal importance of including the family caregiver as an integral member of the health care team. Those trends are the persisting requirement that hospitals reduce the number of Medicare patient readmissions and awakening recognition of the vast expanse of health care services already provided to patients in their homes primarily by untrained family members. At the intersection of these trends, we find the often completely overlooked family caregiver.

Why should critical care nurses direct any notable attention to family care providers? One reason is that they are the provider most responsible for executing the discharge plan of care developed in critical care to optimize patient recovery. A second is that if they do not follow that plan accurately or diligently, there is a much higher likelihood that the care recipient will reappear at our readmission double doors sooner and sicker.

Family Caregivers and Reducing Hospital Readmissions

Although critical care nurses are cognizant of the importance of preparing patients and families for discharge home, our historical focus has necessarily centered on the critical, acute, and subacute phases of care. With an average length of stay (LOS) in an intensive care unit in the United States continuing to decrease from 4.70 days in 1988 to 1990, to 4.53 days in 1993 to 1996,1 and 3.8 days today,2 our time interacting with patients remains brief and often punctuated by clinical events that tend to crystallize focus on current rather than future care. That rather myopic view was zoomed out in 2010 when the Center for Medicare and Medicaid Services launched the Hospital Readmissions Reduction Program to reduce patient readmissions, followed in 2012 by its imposition of escalating financial penalties on hospitals when readmission rates were deemed excessive.3

Since 2012, virtually all critical care units have been involved with implementation of measures designed to extend our clinical focus to embrace the potential consequences of acute care programs on optimizing the patient’s recovery following discharge. To the extent that readmissions are less likely if hospitals discharge patients only when they and their families are fully prepared to continue all requisite care at home, then thorough and thoughtful discharge planning comes to the fore as a high priority for all critically ill patients and their families. If that does not occur and readmission rates exceed the Center for Medicare and Medicaid Services thresholds, there are substantial penalties to be paid. For 2017, total Medicare hospital readmission rate penalties will rise to $528 million, or $108 million higher than in 2016, a financial hit intended to draw attention.4 To improve care quality and avoid those penalties, a substantial body of research and quality improvement initiatives have been generated to identify effective strategies for reducing readmissions. A number of those studies attest that
some of the activities effective in lowering readmission rates involve working closely with postdischarge care providers to clarify patient discharge instructions, coordinate care, and reduce medical complications. As I started working on this editorial, the first systematic review and metaanalysis of randomized controlled trials published between 1990 and 2016 that examined the effect of integrating home caregivers into discharge planning before discharge afforded the first hard evidence that inclusion of caregivers in discharge planning is associated with statistically significant reductions in readmissions at both 90 and 180 days. For the 15 studies meeting inclusion criteria, caregiver integration into hospital discharge planning was associated with 25% fewer readmissions at 90 days (relative risk = 0.75, 95% CI = 0.62-0.91) and 24% fewer readmissions at 180 days (relative risk = 0.76, 95% CI = 0.64-0.90). The majority of studies also reported statistically significant shorter times to readmission, shorter rehospitalization durations, and lower postdischarge care costs when discharge planning interventions included caregiver integration.

### Family Caregivers Current Contributions to Health Care

In 2012, the first nationally representative, population-based survey of family caregivers was undertaken by the AARP’s Public Policy Institute and the United Hospital Fund. The study was commissioned from increased recognition that in contrast to prior generations when younger family members assisted aging members primarily by supplanting personal care or basic household chores, today’s caregivers were increasingly performing therapeutic procedures that only trained health care professionals had previously provided. The reasons ascribed to this change were 3-fold: the prevalence of chronic conditions among an expanding aging population, financial penalties aimed at reduced hospitalizations, and availability of home care technology. The Home Alone: Family Caregivers Providing Complex Chronic Care study findings (Table 1) confirmed those anecdotal observations.

### Basis for Caregiving

The need for caregiving originates when a person requires assistance due to one or more physical, cognitive, or functional limitations. Although much of the literature related to caregiving concerns to those 65 years and older, the need for caregiving can be equal or greater in an adolescent trauma victim, so is less a function of age than of living with infirmities that typically accompany living longer and eventually impede living independently. In adults 85 to 89 years, 59% have health problems or functional deficits that require caregiver assistance, whereas 76% of those 90 and older need that help.

### Definition of Family Caregiver

The term family caregiver is somewhat of a misnomer because many persons who function in this capacity are not members of the recipient’s family. Nonetheless, this term refers to an unpaid family member, friend, or neighbor who provides care to an individual with an acute or chronic condition who needs assistance in managing tasks ranging from personal hygiene, to taking medications, to providing complex medical or nursing therapies such as ventilator care. The Family Caregiver Alliance defines this role as “any relative, partner, friend or neighbor who has a significant personal relationship with, and provides a broad range of assistance for, an older person or an adult with a chronic or disabling condition.” Other authoritative sources use comparable definitions for this role.

### Prevalence of Caregivers

An estimated 43.5 million adults in the United States provide unpaid care to an adult or a child. The estimated prevalence of caring for an adult is 16.6% (39.8 million Americans), with 34.2 million providing unpaid care to an adult age 50 or older in the last year.

### Profile of Caregivers

Need for a home caregiver has no bias or privilege, but cuts across all socioeconomic, educational, racial, ethnic, religious, and geographic strata. Caregivers reflect much the same diversity, except for a preponderance of women serving in that role. The profile of current caregivers shows they are 60% women, middle-aged (mean age 49 years), daughters or spouses, with 85% caring for a relative, 49% for a parent or parent-in-law, 10% for spouse. More men serve as caregivers in the lesbian, gay, bisexual, and transgender community.

### Scope of Caregiver Responsibilities

The traditional approach to identifying the assistance needed included categories such as activities of daily
living for personal care (bathing, dressing, eating, mobility, toileting, and transferring) and a more complex set of instrumental activities of daily living (eg, laundry, grocery shopping, managing finances, or using a telephone). More contemporary approaches group these activities into various domains that may more accurately recognize the complexity of assistance rendered (Table 2).

### Support Caregivers Need to Be Effective

One early outgrowth of the Home Alone report was AARP’s development of model state legislation that would begin to address these needs for caregiver involvement, training, and support. The Caregiver Advise Record and Enable (CARE) Act is enacted into law in 39 of 50 states (states yet to enact CARE Act into law are Alabama, Arizona, Florida, Georgia, Iowa, Missouri, North Carolina, South Carolina, Tennessee, Texas and Vermont, as of November 17, 2017). The CARE Act requires that hospitals undertake 3 actions regarding family caregivers:

1. Record the name of the caregiver in the patient’s medical record.
2. Inform the caregiver when the patient is to be discharged.
3. Provide the caregiver with education and live instruction in all medical/nursing tasks that will need to be provided for the patient at home.

### How Critical Care Nurses Can Support Home Caregivers

Since the CARE Act was first enacted into legislation in 2014, its progress remains laudable yet incomplete and uneven, so caregiver burdens persist. There are a

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<th>Key finding</th>
<th>Comment</th>
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<td>Caregivers provide complex medical/nursing tasks</td>
<td>The medical/nursing tasks performed most often: Medication management (78%) Using assistive mobility devices (43%) Food preparation for special diets (41%) Wound care (35%) Of the few (14%) who operate equipment such as mechanical ventilators or tube feeding systems, 49% find that hard to do.</td>
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<td>Caregivers administer multiple medications via multiple different routes</td>
<td>78% of caregivers managed medications, including intravenous fluids and injections. Nearly half administered 5-9 prescription medications daily. Medication management was difficult because it was time-consuming, generated anxiety over making errors, and some patients did not cooperate. Many caregivers learned how to manage medications on their own. Few received assistance or training from health professionals.</td>
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<td>Wound care training is limited</td>
<td>35% of caregivers provided wound care such as ostomy care and postsurgical dressing changes. 66% considered wound care difficult because of fear of making mistakes and discomfort with the bodily intrusiveness required. 33% received some training from a hospital nurse or physician, and 25% from home care nurses. Most received no training in wound care.</td>
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<td>Most recipients are not visited by health professionals</td>
<td>69% of patients were not visited at home by a health professional. 27% of caregivers had no additional help at home.</td>
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<td>Family caregivers are often primary care coordinators</td>
<td>53% of those who provided medical/nursing tasks needed to coordinate that care. Only 3% worked with a care manager.</td>
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<td>Caregivers feel they have no choice</td>
<td>57% of caregivers felt they had no choice in providing care. Of these, 43% felt a personal responsibility, because insurance did not cover it or there was no one else to do it. 12% felt pressure from another family member or the recipient.</td>
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<td>Provision of medical/nursing tasks may prevent nursing home placement</td>
<td>51% of caregivers who provided these tasks believed that they contributed to preventing nursing home placement. The more of these tasks they performed, the more likely they were to report this effect.</td>
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<td>Caregivers providing medical/nursing tasks reported negative effects on quality of life</td>
<td>These caregivers were most likely to report stress and worry over making mistakes; feeling down, depressed, or hopeless; and fair or poor personal health. The number of negative effects reported positively correlated with the number of care recipients’ chronic conditions.</td>
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number of strategies that critical care nurses can employ to facilitate fuller and faster support for integrating caregivers into patient care.

*Implement the CARE Act if your state has already enacted it into law.* The first step is recording the caregiver’s name and contact information into the patient’s record. A recent AARP CARE Act Summit<sup>29</sup> suggested this be completed by the admitting staff or unit nurse to ensure early and permanent entry.

<table>
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<th>Domain</th>
<th>Caregivers’ activities and tasks</th>
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| Personal self-care, mobility | Bathing and grooming  
|                         | Dressing  
|                         | Feeding  
|                         | Behavior management  
|                         | Time management  
|                         | Toileting, maintaining continence, managing incontinence  
|                         | Transferring  
|                         | Mobility within or outside                                                                 |
| Household tasks         | Grocery and necessary shopping  
|                         | Mail retrieval, disposition  
|                         | Meal preparation  
|                         | Laundry  
|                         | House cleaning  
|                         | Maintenance such as trash and yardwork  
|                         | Transportation                                                                                     |
| Emotional and social support | Provide social interaction, companionship  
|                         | Participate in leisure activities  
|                         | Assist with problem-solving, conflict resolution  
|                         | Manage emotional responses                                                                 |
| Health and medical care | Encourage independence and self-reliance insofar as possible  
|                         | Navigate across the health care system as an advocate to ensure patient needs are met  
|                         | Accompany recipients to medical appointments, speak as their advocate if they are unable to serve as valid historian of their health or symptoms  
|                         | Monitor to ensure treatment adherence  
|                         | Manage reminders or administer medications  
|                         | Provide medical therapies, treatments  
|                         | Provide wound care  
|                         | Operate necessary medical equipment  
|                         | Prepare food for special diets  
|                         | Recognize reappearance or worsening of health problems, drug side or untoward effects  
|                         | Recognize and respond to acute health needs and emergencies                                       |
| Advocacy and care coordination | Inquire and find answers to questions that arise  
|                         | Make appointments for services needed  
|                         | Communicate among health care providers as recipient needs warrant  
|                         | Facilitate understanding and collaboration among family members  
|                         | Obtain and coordinate other service providers  
|                         | Order and obtain prescription medicines, supplies                                                  |
| Surrogacy               | Manage insurance issues  
|                         | Handle financial matters (eg, paying bills) on recipient’s behalf  
|                         | Supervise legal matters on recipient’s behalf  
|                         | Maintain personal property  
|                         | Participate in advanced planning  
|                         | Actively participate in treatment decisions                                                         |

Revise policies and procedures to actively recruit and involve caregivers in ongoing patient care discussions. CARE Act Steps 2 and 3 will involve updating procedures related to visitation, rounds, huddles, patient and family conferences, discharge planning, etc, to institute invitation and meaningful participation of caregivers into patient care planning with implications for postdischarge care.

*Individualize assessment of the caregiver’s capability to provide postdischarge care.* Once the discharge plan and
therapies are identified, there needs to be an assessment of whether the caregiver is capable of providing that care so any deficiencies can be addressed before the patient is discharged. Caregiver assessment is not common in health delivery settings, so it may require explanation.\textsuperscript{19} Thorough assessments also inquire about caregivers’ health and well-being, stress level, and whether they feel overwhelmed. These assessments seek to identify the information, support, and training needed.\textsuperscript{31,32}

Tailor instructional strategies to support caregivers. Combinations of video and live demonstration with feedback and teach-back strategies may be used to refine satisfactory caregiver performance. Unit educators may lend assistance if challenges arise. Before patients are discharged, their nurses need to verify that caregivers are able to provide the care needed.

Take advantage of valuable resources that facilitate implementation of the CARE Act. In addition to journal articles and state updates posted on the AARP website (available at http://states.aarp.org/tag/care-act), other useful resources include a series of free AARP instructional videos for caregivers (available at www.aarp.org /ppi/initiatives/home-alone-alliance.html), links to the American Journal of Nursing’s Family Caregiving Series of articles for nurses (discharge planning, assessment of caregiver needs, teaching essential skills) and instructional videos for caregivers, and links to useful related reports\textsuperscript{33} and research. Another valuable resource is New York state’s CARE Act Toolkit for Hospital Staff,\textsuperscript{34} which provides strategies and tools for implementing this legislation. The Home Alone Alliance, a partnership of private, public, and nonprofit organizations to change the way health care professionals and organizations interrelate with home caregivers, identifies other organizations with resources devoted to this cause.

Closing

One of the lessons learned over the past decade has been the need for vigilance in adjusting our focus for critical care nursing. A few decades ago, disorder-centered care was superseded by patient-centered health care. We have since evolved to family-centered care that included the once novel idea of removing visiting hour restrictions, creating flexible definitions of what constituted a family, and letting patients define who they considered as their family. The current era requires that we once again widen our focus to capture an essential provider of health care who may lack a license or degree, but plays a pivotal and essential role in determining whether the patients we discharge from critical, acute, and subacute care units will remain and recuperate at home or return to hospitals sicker yet. Ignoring home caregivers is not an option. Respecting, interacting with, teaching, and learning from these providers are necessary elements in maintaining, recuperating, and optimizing patient recovery. Critical care nurses are up to this challenge. We look forward to hearing of and publishing reports of your successful programs in working with caregivers. CCN

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References