Since January 2020 Elsevier has created a COVID-19 resource centre with free information in English and Mandarin on the novel coronavirus COVID-19. The COVID-19 resource centre is hosted on Elsevier Connect, the company's public news and information website.

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Acute care of older people column




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Family caregiving for acute-critically ill older adults in the time of COVID-19

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I have the privilege of writing the final column for the Acute Care of the Elderly feature which began in 2008. The idea for the column was spawned, as good ideas often are, over dinner and wine at a Gerontological Society of America annual meeting. As I recall, we lamented the relative dearth of interest in the science of geriatric acute – critical care at the conference and worried about the assumptions held by many students, funders, and colleagues that gerontological nursing focused exclusively on long-term care. And so, Liz Capezuti, Sarah Kagan, Lorraine Mion, and I joined together at the invitation (or was it challenge?) of Editor-in- Chief, Barbara Resnick, to address and amplify issues of significance in the care of acute – critically ill older adults.

It is fitting that in this last year, we observed Geriatric Nursing's 40th anniversary with several columns that involved "taking stock" of acute-critical care for older people as well as review of progress on ageism, physical restraint use, and accommodations for patient communication impairment in acute-critical care. In the past 12 years, scientific and practice initiatives addressed the hazards of hospitalization and immobility with strong evidence regarding the development and outcomes of iatrogenic "geriatric" syndromes, such as delirium, myopathy, falls, and cognitive/physical functional decline, during acute-critical illness. Critical care rehabilitation is now a multidisciplinary specialty area promoting early intervention to prevent post-hospital functional decline. More adults are surviving critical illness[1] and, thanks to curricular improvements and programs such as Nurses Improving Care for Healthsystem Elders,[2] more nurses have specialty knowledge about gerontological assessment and care principles.

The anniversary year opened with the reminder that gerontological health care is no longer centered in the acute care hospital as it was 40 years ago but has shifted to home and community settings.[3] Nine months later, we are in the midst of a global pandemic that disproportionately sickens and kills older adults while seriously straining the acute-critical care workforce and resources. Vulnerable older patients enter acute-critical care settings without the supportive presence and advocacy of family caregivers. At the same time, the home setting has become a site for care across the continuum bolstered by telehealth for which family caregivers serve as technological support, interpreters, and implementers. Gerontological nurses are uniquely qualified to support family caregivers as they interact with acute-critical care in remote and creative ways during the COVID-19 pandemic.

Family Caregiving for Older Adults admitted to Acute – Critical Care

COVID-related family separation during acute-critical illness impacts older adult patients, family caregivers, and nurses on multiple levels and is likely to have long-term traumatic effects.[4] Restrictions on family visitation to prevent the spread of COVID-19 infection vary depending on local infection rates, institutional policies, and patient condition (e.g., allowances for end-of-life visitation). Information sharing, informed consent, treatment decision making, and end-of-life care may be impaired or inadequate in the absence of family caregivers. Disability advocates criticize and challenge hospital visitation restrictions as discriminatory toward persons with disability and promote policies permitting the "entrance of a designated support person for a patient with a disability and permitting family members, service-providers or other individuals knowledgeable about the needs of the person with a disability to serve as a designated support person."[5]

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Please consider the following recommendations adapted from Montauk and Kuhl[4] for how to support family caregivers during acute-critical illness:

(1) *Acknowledge the uniqueness of the situation.* This acknowledgement must, of course, be accompanied by information about how procedures, particularly visitation and communication, are handled differently during this very different time. Together, acknowledgement + information, communicates empathy and engenders trust which can help decrease anxiety for family caregivers.

(2) *Initiate family-patient video conferencing with mobile devices.* "Virtual" video visits between older patients and families should not be reserved only for end-of-life or life-sustaining treatment discussions. While acute-critically ill older persons may need some assistance or cueing in the use of these devices, the communication and connection is well worth the effort in terms of managing stress, anxiety and building trust both for patients and family caregivers. Case examples of the use of video communication are available at the Patient-Provider Communication Forum website. (https://www.patientprovidercommunication.org/covid-19-tools/case-examples/) The availability of iPads and mobile devices is a work-in-progress at many institutions. Nurses should continue to tell the poignant stories of patient-family connections through video communication, and work within their institutions to secure the provisioning of the mobile communication devices for patient use.

(3) *Be present and authentic.* Montauk and Kuhl[4] advise that nurses should not be afraid to show their emotions in an empathic way (that not burdensome or over-sharing). The goal here would be one of therapeutic use of self to provide human connection and caring that family caregivers may desperately need in a time of crisis, isolation, and, in some cases, grief.

(4) *Acknowledge and advise family caregivers that this is a traumatic experience.* Acute and critical care nurses play an important role in educating and advising family caregivers (a) of the symptoms of traumatic/post-traumatic stress; (b) that this is a common response to traumatic experience; (c) they are not alone in this experience; and (d) in providing resources to help family caregivers cope with post-traumatic stress, including referrals to counseling and hospital chaplaincy services. The following websites are excellent resources for ICU family caregivers: https://www.icusteps.org and https://www.sccm.org/MyICUCare/Thrive/Post-intensive-Care-Syndrome

Family Caregiving and Acute-Critical Illness in the Home Setting

I would be remiss if I did not acknowledge and address the acute-critical illness caregiving that occurs in the home. Prior to the pandemic, the extent of medical/nursing care activities provided by unpaid family caregivers raised concerns about burden and stress on an estimated 41.8 million family caregivers of adults over 50 years of age in the U.S.[6] The *Caregiving in the United States 2020* report shows a significant increase in the estimated number of persons serving as unpaid caregivers to older adults in the past 5 years.[6] Keeton and colleagues[7] examined data from the 2015 *Caregiving in the United States* survey ($N = 1,248$) in which 58% of caregivers reported performing medical/nursing tasks. The study found that caregivers performing medical/nursing tasks had higher risk of emotional stress, physical strain, and high burden of care than those who without those responsibilities.

In the midst of pandemic quarantine restrictions, family caregivers of home-dwelling older adults face limitations in assistance and respite as they take measures to protect older adults from infection while also managing or co-managing care for the older person's multiple chronic conditions and acute events. For example, a family who previously shared caregiving may now have limited caregiving to one individual due to daily exposures of members who work in essential services or travel restrictions. While more flexible work-from-home schedules are advantageous for some family caregivers, others have lost or relinquished jobs outside the home. Clearly, the strain and sacrifice that family caregivers experience have multiplied during the pandemic. In addition, many community-based programs and settings for older adults (e.g., adult day programs, senior centers) that provide essential services to support family caregivers have limited services (e.g., lunch pick-up) or remain closed.

Evidence suggests that these adult caregivers, most of who are over 50 years old, are also at risk for serious illness. A recent analysis of data from the *Understanding America Study* found higher proportions of poorer health during the pandemic across all outcomes among caregivers compared to noncaregivers.[8] Long-term caregivers reported the highest rates of poor health outcomes. Psychological distress was most common, reported by 46.5% of long-term caregivers vs 35.2% of noncaregivers. Somatic symptoms reported by long-term caregivers were also consistently much larger than noncaregivers (44%–60% higher).[8]

Health policy and programmatic initiatives are desperately needed to provide tangible support for family caregivers of frail older adults. Geriatric nurses must make our voices heard about this issue in policy arenas now and until we realize an age-friendly future, free of the preconceptions, stereotypes, and discrimination we find in healthcare today.

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