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## Editorial

## Dying at home of Covid-19: Meeting the need for home-based care



## ARTICLE INFO

## Keywords

Older adults  
 COVID-19  
 Health care policy  
 Public health

## ABSTRACT

Despite the increased burden of Covid-19 on older adults, ethical and public health frameworks lack adequate guidance for elderly patients who manage severe, even fatal, illness at home. The U.S. Centers for Disease Control and Prevention (CDC) and World Health Organization (WHO) recognize the heightened risks of Covid-19 for older adults; however, both organizations presuppose that most cases of Covid-19 will be mild to moderate and recoverable at home. Yet, older adults are least likely to follow this trajectory. Older patients are more susceptible to experiencing severe illness at home from which they may not recover; and if they do seek medical care, they tend to suffer worse outcomes than younger patients in intensive care settings. Given their likelihood of severe illness, worse outcomes in intensive care settings, and potential difficulty accessing resources, frail, disabled, and otherwise vulnerable older patients may face Covid-19 at home without adequate resources, information, or support for home-based care. This editorial proposes three approaches to prevent needless suffering and ensure that this vulnerable population continues to receive needed care.

## 1. Introduction

Early in 2020, the World Health Organization (WHO) and U.S. Centers for Disease Control and Prevention (CDC) recommended that individuals with Covid-19 recover at home, emphasizing that most cases would be mild or moderate (U.S. Centers for Disease Control and Prevention, 2020; World Health Organization, 2020). Older adults, however, were far more likely than their younger counterparts to experience severe or fatal disease—infection fatality rates reached 15 to 20% for adults over 80, compared to less than 1% for those under 60 (Wu and McGoogan, 2020; Onder et al., 2020).

Ethical frameworks, meanwhile, established that those over 65, and especially those over 80, with comorbid conditions should be deprioritized if hospital beds or medical resources became scarce (Emanuel et al., 2020). Additionally, training resources for palliative and other healthcare providers focused on conversations with older patients about when to seek—or avoid—hospital-based care, but did not adequately address how home-based care might proceed. Healthcare providers and policy makers have since expanded guidance on managing Covid-19 in older adults, including characterizing clinical features and outcomes, addressing psychosocial stressors, and developing policies for long-term care facilities (Vrillon et al., 2020; Lithander et al., 2020; Strang et al., 2020a; American Geriatrics Society, 2020a; American Geriatrics Society, 2020b). Yet, managing severe disease in older adults who stay home during their illnesses remains understudied, and further attention to this population is merited.

Recognizing that older adults will continue to experience severe disease at home, identifying and closing gaps in available support systems is an essential ethical and public health duty. As such, this paper

considers the problem of severe illness at home amidst strained support networks early in the Covid-19 outbreak. It also explores three central approaches to ensuring that older patients and their caregivers receive necessary guidance, information, and resources. While the trajectory of the pandemic remains uncertain, the present moment represents an opportunity to improve in-home health care during—and beyond—the current health crisis.

### 1.1. Rising home deaths, strained support networks, and the importance of home care

During the spring of 2020, home deaths rose exponentially in hard-hit U.S. cities. In New York City alone, the Fire Department responded to 2192 home death calls between March 20th and April 5th, a 400% increase over the same period during the previous year (Tamman, 2020). Cities such as Detroit and Boston also noted the elevated home death toll (Gillum et al., 2020; Harris et al., 2020). Other U.S. counties, such as Miami-Dade, Florida, documented excess home deaths during Covid-19 surges compared to the same period in the prior year (Mazzei et al., 2020).

In addition, disabled, frail, and otherwise vulnerable older adults requiring in-home health support faced a range of obstacles in their ability to access care. Home health aides, nurses, and other home care workers endured shortages of personal protective equipment (PPE) and navigated difficult decisions about providing care, including whether to continue in-home visits for patients with Covid-19. Despite caring for 12 million Americans, home health aides remained largely unnoted in early public health guidance and continue to receive comparatively little attention from researchers and policy makers (Sterling et al., 2020a).

<https://doi.org/10.1016/j.ypmed.2020.106409>

Received 13 July 2020; Received in revised form 14 November 2020; Accepted 28 December 2020

Available online 31 December 2020

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Older adults were, and remain, disproportionately affected by Covid-19—as of early January, adults over 65 accounted for less than 15% of cases but more than 80% of deaths in the United States (U.S. Centers for Disease Control and Prevention, 2021). Among patients who remain at home despite severe symptoms, some may have disabilities or other limitations that prevent them from traveling to hospitals (Sterling et al., 2020b). Others may conclude that, inasmuch as older patients tend to fare poorly on ventilators and visitors continue to be restricted in many health systems, remaining at home may be preferable to entering the hospital. Still others face difficulties in accessing typical support networks. With cases rising across much of the U.S., including in already strained areas, attention to older adults managing Covid-19 at home remains needed.

## 2. Central lessons and approaches to caring for elderly at home

### 2.1. Increase attention to older adults and improve palliative and home care resources in public health recommendations

Initial CDC and WHO resources emphasized the mild to moderate trajectory of Covid-19 and the importance of recovering at home, with minimal discussion of in-home palliative care, management of severe disease at home, or even palliative care in medical settings (Lancet, 2020a). Notably, public health resources for older adults from the CDC evolved throughout May, and updates in late June provided information on advance care planning with respect to Covid-19. But beyond seeking urgent medical attention in the case of shortness of breath or other severe symptoms, little additional information was provided (Lancet, 2020b). Unfortunately, the needs of older adults for home health aides, in-home care visits, and other supports received minimal guidance early in the outbreak, and remain understudied nearly nine months on (Chan et al., 2020; Lebrasseur et al., 2020).

Aiming to reduce disparities and close potential gaps in support systems, public health organizations should emphasize the range of care services available to those who are particularly susceptible to morbidity and mortality from Covid-19. One step toward achieving this goal would be to ensure that resources developed by the National Association for Home Care & Hospice, American Academy of Hospice and Palliative Medicine (AAHPM), the International Association for Hospice and Palliative Care, and other organizations devoted to in-home care are included in public health guidance (National Association for Home Care and Hospice, 2020; International Association for Palliative Care, 2020; American Academy of Hospice and Palliative Medicine, 2020). Another step would be to incorporate information from a broad range of health providers, including nurses, home health aides, nursing home professionals, and organizations supporting individuals with disabilities in planning conversations and public guidance (Desroches et al., 2020; Behrens and Naylor, 2020; Mills et al., 2020).

### 2.2. Clarify in-home care for seriously ill patients

For patients who stay at home despite severe illness, whether due to disability, preference, anticipated prognosis, or other barriers to hospital-based care, there remains a critical need for further information about in-home care for severe Covid-19 cases. The AAHPM, for example, provides resources for clinicians on how to address Covid-19 with their patients. Links to Covid-ready communication materials include, for instance, a playbook developed by the clinician-run nonprofit, VitalTalk. The “COVID Ready Communication Playbook,” developed after the outbreak in Seattle, Washington, offers sample scripts for health care professionals. This “Playbook,” along with its accompanying illustrated guide, includes guidance for discussing resource limitations, triage, hospital and ICU admission, and healthcare proxies with patients (VitalTalk, 2020; Gray and Back, 2020). The Playbook and guide do not, however, examine what home care might look like for an elderly patient who is unable, or chooses not, to receive intensive care in a hospital.

Another organization—the Center to Advance Palliative Care (CAPC)—also provides resources and clinical training tools. Similar to those in VitalTalk’s “Playbook,” CAPC’s sample scripts for physicians caring for Covid-19 patients initially emphasized conversations surrounding a patient’s decision to seek or avoid hospital-based care. One sample script on receiving care at home, for instance, asked physicians to engage a patient with metastatic cancer in a discussion about staying home should the patient develop a severe or fatal illness. The script ended with the physician and patient agreeing that the patient would not go to the hospital if infected with Covid-19 (Center to Advance Palliative Care, 2020a). Yet, how might home-based care proceed? CAPC has since expanded and updated resources on home-based health planning, with more detailed guidance on Covid-19 crisis planning checklists. Still, additional information on the role of home health aides, in-home palliative care services, and the management of severe or fatal disease at home is warranted, along with integration into public health guidance (Center to Advance Palliative Care, 2020b).

Knowledge of home-based care is essential for patients and families deciding whether to seek outside medical attention for Covid-19 or to remain at home. Patients may wonder what “receiving care” at home will look like as their disease progresses. Are they entitled to a home health aide, telemedicine appointments with clinicians, medications—including opioids—to ease their pain or air hunger, or nothing at all? If an elderly person resides in the community rather than in an assisted living facility, how can they access care, especially if family members cannot be present? Moreover, how will staying at home with a potentially fatal illness unfold in different environments, such as rural versus urban settings?

Older adults deserve the opportunity to learn about alternatives to hospital-based care when facing the possibility of severe illness at home. To meet this need, research should further characterize and disseminate information about the range of options for symptom management in home environments, including the role of telehealth support when in-home services are disrupted (Strang et al., 2020b; Wu et al., 2020).

In order to promote informed decision-making, conversations between patients and their care team should address the tradeoffs of hospital-based versus home-based care and delineate the range of options for the latter. When counseling patients, healthcare workers should recognize that limitations may prevent patients from accessing adequate care and, to the extent possible, explore alternatives. For their part, palliative care organizations should develop resources and protocols to specifically support patients dying at home, beyond those intended for hospital-based and nursing home-based palliative care. Public health organizations should, in turn, connect clinicians and patients to these resources.

Importantly, disparities will limit patients’ options and shape their choices. Home-based care will also differ widely by a patient’s geographic region, social and economic status, the extent of the outbreak in a given community, and more. Special consideration should be given to older adults living in underserved communities to ensure access to home health aides, social workers, telemedicine, and other services.

### 2.3. Connect health care professionals and other workers with patients

Knowing that many older patients will experience severe illness at home, creative approaches to serving these patients in their homes are needed. For example, social workers or lawyers who specialize in living wills could be trained to help older adults with advance care planning or to provide counsel about how to access home-based care. This strategy could help alleviate additional demands on healthcare professionals during times of scarcity.

Home health aides have played an essential role in supporting patients throughout the pandemic. As one of the fastest-growing occupations in the U.S., home health aides should be integrated into response networks to support patients before their illnesses progress and end-of-

life care becomes necessary (Bureau of Labor Statistics, 2020). Ethical and public health recommendations would also benefit from incorporating information about home health aides and agencies into their resources for patients. Doing so could help older or homebound patients and their caregivers take steps to avoid reaching the point of needing end-of-life care.

Finally, while researchers have begun studying ways to relieve symptoms in patients dying of Covid-19 in hospital and nursing home settings, research efforts should also focus on how to best support at-home deaths (Strang et al., 2020c). Home care plans might address access to medications for pain and shortness of breath, the role of health-care workers and family members in patients' homes, directives for first responders if called, and postmortem procedures for handling the deceased. Training modules for families caring for older Covid-19 patients in-person or virtually would also be valuable.

### 3. Conclusion

The ongoing Covid-19 pandemic has revealed gaps in the support systems available to some of the most at-risk Americans. Given that age will remain a major risk factor for severe illness and death, it is essential that we identify—and learn from—past oversights. In doing so, we can work toward developing and implementing new approaches for ensuring that older patients and their caregivers receive necessary guidance, information, and resources. By centering the needs of an often-neglected population of frail, disabled, and vulnerable older adults managing Covid-19 at home, we can better meet our duty to care for all Americans, now and in the future.

### Acknowledgments

Dr. Fallon has nothing to disclose.

Dr. Kilbride was supported by a T32 training grant (no. HG009496) and a K01 career development award (no. HG010903) from the National Human Genome Research Institute (NHGRI).

### References

- American Academy of Hospice and Palliative Medicine, 2020. Resources to Address Coronavirus Disease 2019. <http://aahpm.org/education/covid-19-resources>.
- American Geriatrics Society, 2020a. American geriatrics society policy brief: COVID-19 and nursing homes. *J. Am. Geriatr. Soc.* 68, 908–911.
- American Geriatrics Society, 2020b. American geriatrics society policy brief: COVID-19 and assisted living facilities. *J. Am. Geriatr. Soc.* 68, 1131–1135.
- Behrens, L.L., Naylor, M.D., 2020. "We are alone in this battle": a framework for a coordinated response to COVID-19 in nursing homes. *J. Aging Soc. Policy.* 32 (4–5), 316–322. <https://doi.org/10.1080/08959420.2020.1773190>.
- Bureau of Labor Statistics, 2020. U.S. Department of Labor. Home Health Aides and Personal Care Aides, Occupational Outlook Handbook. <https://www.bls.gov/ooh/healthcare/home-health-aides-and-personal-care-aides.htm>.
- Center to Advance Palliative Care, 2020a. Covid-19 response resources. In: Proactive call to patients with COVID about receiving care at home: conversation script. <https://www.capc.org/toolkits/covid-19-response-resources/>.
- Center to Advance Palliative Care, 2020b. Setting-Specific Guidance for COVID-19: Home Care. <https://www.capc.org/covid-19/setting-specific-guidance-covid-19-home-care/>.
- Chan, E.Y.Y., Gobat, N., Kim, J.H., et al., 2020. Informal home care providers: the forgotten health-care workers during the COVID-19 pandemic. *Lancet.* [https://doi.org/10.1016/S0140-6736\(20\)31254-X](https://doi.org/10.1016/S0140-6736(20)31254-X).
- Desroches, M.L., Ailey, S., Fisher, K., Stych, J., 2020. Impact of COVID-19: Nursing challenges to meeting the care needs of people with developmental disabilities. *Disabil Health J.* <https://doi.org/10.1016/j.dhjo.2020.101015> ePub ahead of print.
- Emanuel, E.J., Persad, G., Upshur, R., Thome, B., Parker, M., Glickman, A., et al., 2020. Fair allocation of scarce medical resources in the time of Covid-19. *N. Engl. J. Med.* 382, 2049–2055.
- Gillum, J., Song, L., Kao, J., 2020. There's been a spike in people dying at home in several cities that suggests coronavirus deaths are higher than reported. In: ProPublica. <https://www.propublica.org/article/theres-been-a-spike-in-people-dying-at-home-in-several-cities-that-suggests-coronavirus-deaths-are-higher-than-reported>.
- Gray, N.A., Back, A.L., 2020. Covid-19 communication aids. *BMJ* 369, m2255. <https://doi.org/10.1136/bmj.m2255>.
- Harris, A., Cohen, H., Rabin, C., Teproff, C., 2020. At-home deaths are up in Miami-Dade, but ER visits are down. In: It could be COVID-19 fears. <https://www.miamiherald.com/news/health-care/article24253776.html>.
- International Association for Palliative Care, 2020. Resources Relevant to Palliative Care and COVID-19. <http://globalpalliativecare.org/covid-19/>.
- Palliative care and the COVID-19 pandemic. *Lancet* 395 (10231), 2020, 1168.
- Palliative care and the COVID-19 pandemic. *Lancet* 395 (10231), 2020, 1168.
- Lebrasseur, A., Fortin-Bédard, N., Lettre, J., Bussi eres, E.L., Best, K., Boucher, N., Hotton, M., et al., 2020. Impact of COVID-19 on people with physical disabilities: A rapid review. *Disabil Health J.* <https://doi.org/10.1016/j.dhjo.2020.101014>. Epub ahead of print.
- Lithander, F.E., Neumann, S., Tenison, E., et al., 2020. COVID-19 in older people: a rapid clinical review. *Age Ageing* 49, 501–515.
- Mazzei, P., Halleck, R., Oppel Jr., R.A., 2020. Found Unresponsive at Home: Grim Records Recount Lonely Deaths. *New York Times* (updated September 10, 2020). <https://www.nytimes.com/2020/05/08/us/coronavirus-florida-medical-examiner-records.html>.
- Mills, W.R., Sender, S., Lichtefeld, J., Romano, N., Reynolds, K., Price, M., Phipps, J., et al., 2020. Supporting individuals with intellectual and developmental disability during the first 100 days of the COVID-19 outbreak in the USA. *J. Intellect. Disabil. Res.* 64 (7), 489–496. <https://doi.org/10.1111/jir.12740>.
- National Association for Home Care & Hospice, 2020. Coronavirus Resources for Home Care & Hospice. <https://www.nahc.org/resources-services/coronavirus-resources/>.
- Onder, G., Rezza, G., Brusaferro, S., 2020. Case-fatality rate and characteristics of patients dying in relation to COVID-19 in Italy. *J. Am. Med. Assoc.* 323 (18), 1775–1776.
- Sterling, M.R., Tseng, E., Poon, A., Cho, J., Avgar, A.C., Kern, L.M., Ankuda, C.K., Dell, N., 2020a. Experiences of home health care workers in New York City during the coronavirus disease 2019 pandemic: a qualitative analysis. *JAMA Intern. Med.* 180 (11), 1453–1459.
- Sterling, M.R., Tseng, E., Poon, A., Cho, J., Avgar, A.C., Kern, L.M., Ankuda, C.K., Dell, N., 2020b. Experiences of home health care workers in New York City during the coronavirus disease 2019 pandemic: a Qualitative analysis. *JAMA Intern. Med.* 180 (11), 1453–1459.
- Strang, P., Bergstr om, J., Martinsson, L., Lundstr om, S., 2020a. Dying From COVID-19: loneliness, end-of-life discussions, and support for patients and their families in nursing homes and hospitals. A national register study. *J. Pain Symptom Manag.* 60 (4), e2–e13. <https://doi.org/10.1016/j.jpainsymman.2020.07.020>.
- Strang, P., Bergstrom, J., Lundstrom, S., 2020b. Symptom relief is possible in elderly dying COVID-19 patients: a national register study. *J. Palliat. Med.* <https://doi.org/10.1089/jpm.2020.0249> [Published online].
- Strang, P., Bergstrom, J., Lundstrom, S., 2020c. Symptom relief is possible in elderly dying COVID-19 patients: a national register study. *J. Palliat. Med.* <https://doi.org/10.1089/jpm.2020.0249> [Published online].
- Tamman, M., 2020. At-Home COVID-19 Deaths may be Significantly Undercounted in New York City. *Reuters*.
- U.S. Centers for Disease Control and Prevention, 2020. COVID-19 Guidance for Older Adults. <https://www.cdc.gov/aging/covid19-guidance.html>.
- U.S. Centers for Disease Control and Prevention, 2021. CDC Covid Data Tracker. Updated January 3, 12:16pm. <https://covid.cdc.gov/covid-data-tracker/#demographics>.
- Vital Talk, 2020. COVID Ready Communication Playbook. <https://www.vitaltalk.org/guides/covid-19-communication-skills/>.
- Vrillon, A., Hourregue, C., Azuar, J., Grosset, L., Boutelier, A., Tan, S., Roger, M., et al., 2020. COVID-19 in older adults: a series of 76 patients aged 85 years and older with COVID-19. *J. Am. Geriatr. Soc.* <https://doi.org/10.1111/jgs.16894>. Epub ahead of print.
- World Health Organization, 2020. Advice for Public. <https://www.who.int/emergencies/diseases/novel-coronavirus-2019/advice-for-public>.
- Wu, Z., McGoogan, J.M., 2020. Characteristics of and important lessons from the coronavirus disease 2019 (COVID-19) outbreak in China. *J. Am. Med. Assoc.* 323 (13), 1239–1242.
- Wu, R.I., Chou, T.J., Wang, Y.J., et al., 2020. Smartphone-enabled, telehealth-based family conferences in palliative care during the COVID-19 pandemic: pilot observational study. *JMIR mHealth uHealth* 8 (10), e22069. <https://doi.org/10.2196/22069>.

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