

# Q&A: Where are the patient advocates? The negative effect of social isolation on older patient care during COVID

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A new study by researchers at the University of Michigan School of Nursing found that social isolation of older adult patients from their families and providers during the pandemic compromises the quality of patient care in all settings: hospital, outpatient and assisted living.

Clinical faculty members Karen Harden, Deborah Price, Heidi Mason and April Bigelow, clinical associate professor, discuss their findings and offer ideas to offset the negative effects of the ongoing COVID-related social isolation. Their study, COVID-19 Shines a Spotlight on the Age-Old Problem of Social Isolation, appears in the *Journal of Hospice and Palliative Nursing*.

## **Can you give a couple examples from your study of how the state-mandated social isolation restrictions hurt patient care?**

Price: In the inpatient example, the 83-year-old male patient was admitted to the hospital for chemotherapy for abdominal cancer. The patient was in terrible pain and wasn't tolerating the treatment. He suffered alone while hospitalized, without any [family members](#) allowed to be present to support him. The patient's advance directive included a DNR (do not resuscitate) order. The hospital staff did not follow the directive, and CPR was performed on the patient against his wishes.

In the outpatient setting, the patient lived at a child's home, but still felt isolated because she was unable to see her provider as much or have several [family](#) members present when at a clinic visit. Much of the family support had to be done via a phone conversation with the provider. This patient was exploring palliative care options which aligned with her values and goals, so the personal connection with her provider was very important to her.

We also looked at a long-married couple in assisted living. During quarantine, their daughters could no longer visit daily, and within three months, both parents declined rapidly. The wife had dementia, and she was confused and agitated because she couldn't see her daughters. Her husband and chief caregiver developed hearing problems, which made phone calls very difficult. He did not understand the progression of Alzheimer's disease, and therefore lost patience with his wife. He became very depressed and confused, calling the staff or his family late at night. The family eventually had to move the mother to a higher level of care, and moved the father to live with family members.

### **If social distancing means I have to stay away from my older adult loved ones, how can I still advocate from a distance?**

Bigelow: It is still possible to advocate for your family or loved one even if you can't go with them to office appointments, or visit them the way you did before COVID. They can ask to be added to a Zoom visit during medical appointments, attend by conference call or submit questions to the provider in advance. Often, family or friends of the patient know information that could be helpful to the providers, so we value their input. Additionally, they are aware of and usually aligned with their overall care goals and can confirm that the treatment options discussed support the patient's wishes.

### **What changes can the health care system implement to ensure good communication and patient advocacy? Won't this be expensive?**

Mason: Part of this is just a shift of mindset or paradigm. Although the patient portal and virtual visits are relatively young in terms of health

care delivery, the utilization of these tools will increase and help shape the way we deliver care and interact with our patients.

Many specialties have historically used nontraditional visits—for example, virtual surgical follow-ups or group visits for chronic disease management—and these types of visits will continue to evolve as the health care climate changes to adapt to our current world. Staying open to new ways of doing things or interacting with providers/patients allows for the implementation of new science, new technology and new uses of existing resources that may not use a lot of extra health care dollars. We're fortunate to be able to collaborate with our colleagues in other disciplines to try to limit these increased costs.

## **How can older adults better advocate for themselves?**

Bigelow: One of the easiest ways to advocate for yourself is to establish a good relationship with a provider. Often, this starts in the primary care office, but extends to other specialties that you see regularly. A relationship with your provider allows your health care team to really know your goals, desires and wishes. Armed with this knowledge, they can help direct your care and talk through your options as they relate to your overall goals.

A good primary care provider will be a strong advocate for you as you transition through different stages of health. Often, patients are worried to advocate for themselves or disagree with their provider, because they're worried they may disappoint the provider. But the goal of most providers is to help patients live as well as possible for as long as possible, in a way that's aligned with your own goals and values.

## **Are there other ways to help older adults break through the isolation and loneliness caused by social**

## distancing?

Harden: Create a sense of purpose, daily structure or routine for each and every day.

Patients need to get up in the morning and feel they are productive, and they need to interact with others beyond their home environment. Recognizing milestones and special events helps them feel connected, and engagement in social activities that were previously important to them. It's important to stay connected with family, but also to providers, through televisits to stay on top of medical issues.

## **Your work draws heavily from the field of palliative care, which is a scary term for many people, and implies "giving up." What is a healthier way for patients and advocates to view palliative care?**

Harden: Palliative care is often misunderstood. Palliative care embodies holistic care and evaluates people in their physical, psychosocial and spiritual domains. The goal of palliative care is for people to be comfortable and to live as well as they can for as long as they can. This may come in the form of symptom control during an acute illness, management of expected complications from chronic or serious illness, or issues that arise at end-of-life. Outside of the management of these physical issues, palliative care will help patients and families evaluate and communicate their desires, values and overall goals of care. These wishes can then be used to drive the discussions about potential treatments and determine which resources may be most beneficial.

**More information:** Karen Harden et al. COVID-19 Shines a Spotlight on the Age-Old Problem of Social Isolation, *Journal of Hospice & Palliative Nursing* (2020). [DOI: 10.1097/NJH.0000000000000693](https://doi.org/10.1097/NJH.0000000000000693)

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