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Families Must Provide More Medical Care at Home, but with Little Training

Howard Gleckman, May 23, 2022

More than ever, family members are required to play a major role in caring for their loved ones. But they are being asked to do increasingly complex medical tasks with little or no training. The result: Greater risk to patients and enormous avoidable stress for those family caregivers.

A new study attempts to identify the barriers to good caregiver training. And it turns out to be like the old Agatha Christie novel Murder on the Orient Express; Everybody did it. The barriers infect the entire system.

The study, by Julia Burgdorf of VNS Health and co-authors, looked at home health care after hospital discharge. But many of its conclusions likely apply just as much to home-based long-term care. In both cases, family members are required to perform tasks they simply don't know how to do. And often, if this work is done incorrectly, it is dangerous to both the caregivers and those they are caring for.

Consequences

Imagine changing bandages after surgery, keeping a port or drain sterile, or managing oxygen machines or other medical devices. Do it wrong, and a patient could easily require a trip to the emergency department, a hospital readmission, or worse.

When it comes to personal care, imagine helping someone bathe or get to and from the bathroom. Mess that up, and a loved one could fall and land in the ED.

To avoid those outcomes, Medicare requires hospitals and home health agencies to train family caregivers (bet you didn't know that). But it generally doesn't pay for it. And most states have enacted the Caregiver Advise, Record, and Enable (CAR AR -11.7%E) Act that requires hospitals to identify and train family caregivers.

Yet, many family members likely don't get training at all. And half report the training they do get is either insufficient or inappropriate. When caregivers or care receipts are Black or low income, their chances of getting training are even lower.

To understand what is happening, Burgdorf and her colleagues asked home health agency-based nurses and therapists why the system is so broken. The agencies were rural and urban, for-profit and not-for-profit, and local, regional, and national companies. Here are some of the problems they identified:

Poor communication between hospitals and home health staff, and between hospitals and families. This is yet another example of the larger, long-standing communications mess when patients are discharged. Hospital administrators have known for years about the dangers of bungled communication when patients are transferred—even within a hospital. It is worse when they go home.

One huge challenge: The discharge process often is rushed. Payors, including Medicare, encourage hospitals to discharge patients as quickly as possible. And patients and their families just want to get home. In that situation, that all-important training never gets much past an incomprehensible written description that is stuffed a pile of papers handed to a patient at discharge.

There is a fix: Training could begin as soon as a patient is admitted. Hospitals could supplement hands-on training with videos—a vast improvement over the mindless TV bored patients usually watch from their hospital beds. Some hospitals do this. Many don't.

The discharge problems never seem to get fixed. And family members often have no idea what they are supposed to do when the patient comes home.

Strict rules by payors, including Medicare and private insurance, limit the flexibility home care nurses need to train family members. For example, payors often restrict the number of home care visits. There is good reason for this. Without these limitations, some unscrupulous providers would bill for bottomless visits.

But those constraints often limit the time nurses have to teach. They go to the home, get their clinical work done, and leave. Proper caregiver training falls by the wayside. Or it becomes little more than perfunctory.

Anybody who has tried to do this clinical work—say, sterilizing a port—knows you can't just be told what to do or handed a sheet of paper that describes it. You need to actually do it, with an expert closely observing and correcting your mistakes. And that takes time.

Poor communication. It also takes good communication. And home care nurses and therapists acknowledged that they struggle to explain clinical information to family members. Clinicians need to be trained to have those conversations. And that takes time and money.

The survey also describes how important these conversations can be when family dynamics get complicated. What do you do, for example, when a patient does not want a spouse or adult child to change his bandages?

Covid-19. Not surprisingly, the study also identified how the challenges of family caregiver training were made worse by covid.

The list is long, but it includes: Sicker patients being care for at home because they are unwilling to get care in a skilled nursing facility, the limits on family visitors to patients in the hospital that reduce training opportunities, and the enormous challenges of doing training while masked.

It is inevitable that family members will be asked to do more, and more complex, caregiving as more post-hospitalization care migrates to home. And without necessary training, it is inevitable that the outcomes for patients will worsen, and the cost to the system will rise.

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