Community-Focused Health Care For The Seriously Ill

Experts offer a prescription for a health system that is centered on the community rather than traditional health care institutions.

BY JESSICA BYLANDER

The population of Americans with serious illness is large and growing. An estimated 60 percent of Americans have at least one chronic condition, 42 percent have several,1 and an estimated forty million people are limited in their usual activities as a result of one or more serious health conditions.2 The current health care workforce is not equipped to care for this growing population—particularly in the home and community settings where patients prefer to receive care—leading researchers and thought leaders warn. Building a workforce that can meet this population’s needs will require more than training, they say; it will require a radical redesign of the health system that is centered on the communities where patients live.

Participants offered a prescription for redesigning community-based care and workforce training for seriously ill patients at a December 6 summit in Washington, D.C., hosted by Health Affairs with support from the Gordon and Betty Moore Foundation.

“What we need to design is a Copernican health care system, where the patient and the family are the sun and everything revolves around them,” Diane Meier, director of the Center to Advance Palliative Care, said at the summit.

A Community-Focused Health System

When asked about their priorities, patients with serious illness say they want to remain independent and at home and want relief from distress. Living longer is the last of their priorities, yet the health care system is designed predominantly around that goal, Meier says.

A community-focused health ecosystem would shift resources away from traditional health care systems and into communities and community-based care. Such an ecosystem would prioritize support for families, community health workers, and direct care workers as the first line of care, Meier says. This community workforce would be supported by registered nurses and social workers in smaller numbers, and by even fewer advanced practice providers and physicians.

“You would have a pyramid of support that looks completely different than what we have today,” Meier says.

Some health systems have begun to execute a shift toward community-focused care. In 2018 Providence Health System in Washington, D.C., owned by St. Louis–based Ascension, announced that it would close its acute care services and focus on services to support community needs, such as home care and community-based behavioral health care.3

“We know that 15 percent of a person’s...
life is spent in actual health care, which means the remaining 85 percent is spent in other areas that either positively or negatively impact their overall well-being,” Keith Van Der Kolk, president and CEO of Providence Health System, said in a statement.

In the United Kingdom the National Health Service has announced new initiatives aimed at helping people live well with long-term conditions. One such initiative is the use of new community health teams whose goal is to support patients in their homes and keep them out of the hospital.4

Scope-Of-Practice Roadblocks
A key challenge to providing more care in the community and less in traditional health care settings is scope-of-practice rules.

“One of the things that needs to be predominately in the home, whoever is there needs a very broad scope of expertise,” says Joanne Lynn, director of the Program to Improve Eldercare at Altarum. “Everybody who is there needs to know 70 or 80 percent of anything that could come up.”

“It’s very different than in a hospital or even in a clinic setting, where there are all these resources down the hall,” Lynn adds. In a home or community-based setting, she says, workers are typically on their own: “You are there, and you are it.”

However, while lower-skilled providers may be technically capable of performing a variety of health care tasks in the home, scope-of-practice regulations—which vary from state to state5—can make it illegal for them to do so.

“A family member can give medicines, but not a hired aide,” Lynn notes.

Many entities, including the National Academy of Medicine, advocate for updating scope-of-practice laws to allow for more flexibility.5 But some state legislatures and regulatory bodies are in opposition, citing patient safety and liability concerns.

“I think scope of practice is low hanging fruit,” Joanne Spetz, associate director of research at Healthforce Center at the University of California San Francisco said at the December 6 summit. “We’ve been beating our head against the wall for so long, something’s going to give.”

A December 2018 report from the Department of Health and Human Services “recommends policies that will broaden providers’ scope of practice,” suggesting growing support for an overhaul of these regulations.7

Training The Community Workforce
In tandem with expanding scope of practice, attendees at the summit agreed that training for the community-focused health care workforce must improve.

According to Robyn Stone, senior vice president of research at LeadingAge, a research and advocacy organization for the aging, the existing community-based health workforce is “huge” but inadequately trained.

“It is highly undervalued and under-invested in,” Stone said at the summit. “There is very little training in terms of strong competencies around how do you actually do community-based care. A lot of these folks have just learned it on the fly.”

Stone recommended that the major payers of community-based health care services—namely, Medicaid and to a lesser extent Medicare—require workforce training as a condition of participation. Currently the federal government requires training only for nursing assistants and home health aides who work in Medicare- and Medicaid-certified nursing homes and home health agencies.8

“Shouldn’t we be requiring every state that does a dual-eligible program to put specific language [that] when those dollars are passed to a plan, they must have requirements for training workforce?” Stone suggested. “They have to demonstrate it, and if they can’t demonstrate it, then they have to use some of those dollars to train. If we did that, we would start to move the needle a little bit.”

In a November 2018 report the Bipartisan Policy Center recommends that Congress establish a grant program and direct two federal agencies, the Administration for Community Living and the Health Resources and Services Administration, to provide training grants for personal care aides and community health workers.9 In addition, the report recommends that the federal government identify and evaluate caregiver training models focused on specific chronic illnesses to determine when they are successful and how they might be scaled up.

Individual home care providers offer some examples of success in using training to increase retention. For instance, after a Home with Western Home, a private-pay home health service in Iowa, introduced a yearlong training program focused on communication, mentoring, and better relationships with supervisors, along with other initiatives, it reduced its staff turnover by 20 percent in the first five months of 2016.10

Attracting More Workers
Until the US places greater value on the care provided in the home and community by the lower-skilled workforce, and increases pay accordingly, it will be difficult to fill these crucial positions, summit attendees warned.

“We urgently need to have serious macroeconomic analysis of projections of what would happen to the country if you actually paid the workforce what they’re worth,” said Altarum’s Lynn. “This is the hardest job in the community, and we are paying less than a living wage.”

In 2012 the median hourly wage for all direct care workers—a category that comprises personal care aides, home health aides, and nursing assistants—was $10.63.11 All direct care workers assist older adults and people with disabilities who live at home with daily tasks such as eating, dressing, and bathing. Personal care aides also provide social supports, while home health aides and nursing assistants perform some clinical tasks under supervision. About 48 percent of direct care workers live in households earning less than 200 percent of the federal poverty level.8

While direct care is one of the fastest-growing job sectors, people aren’t willing to fill these roles, says Bianca Frogner, an associate professor of family medicine and director of the Center for Health Workforce Studies at the University of Washington.

“We compete with food services, other retail jobs, transportation, professional services,” Frogner said at the summit. “One of the things that needs to be thought of is who is filling in that pipeline, and what makes it attractive to somebody to work in these very hard
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jobs—what are the rewards beyond wages? Wages are one factor, but that’s not the easiest one to change.”

According to the National Home Health Aide Survey, conducted in 2007, the reasons that home health aides cited most frequently for continuing to work in their current jobs included career advancement opportunities, the opportunity to work overtime, working with a care team, and enjoying caring for others.

The Better Jobs Better Care research and demonstration program (funded for four years and $15.5 million by the Robert Wood Johnson Foundation and the Atlantic Philanthropies) sought to test new approaches for providing a stable and qualified long-term care workforce and reducing turnover. Unfortunately, none of the approaches improved direct care workers’ job satisfaction or reduced their likelihood of leaving their jobs.

Family caregivers, meanwhile, rarely are paid in the US. Several countries—Austria, England, Finland, France, Germany, Ireland, Italy, Spain, Sweden, and the Netherlands—have “cash for care arrangements,” which provide a set allowance rather than services to beneficiaries, who can then use the money to pay for home care. Some of the countries, such as Sweden and the Netherlands, allow relatives to be paid through the programs for the care they provide, and there’s evidence that families in other countries are using the benefit to pay for informal as well as formal care.

A special issue of *Health Affairs* that explores additional aspects of building the workforce to care for people with serious illness at home and in the community will be published in June 2019, with support from the Gordon and Betty Moore Foundation.

NOTES

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