




STUCK IN THE HOSPITAL

DISCHARGE DELAYS LEAVE CHRONICALLY ILL PATIENTS WAITING WEEKS AND MONTHS FOR LONG-TERM CARE

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BY YANICK RICE LAMB



In Washington, D.C., an elderly woman spent nearly four months, 116 days to be exact, in a bed at Howard University Hospital for multiple health issues. She had no insurance and no place to go. Each day, the hospital bore the cost of her treatment at \$2,000 a day. As a last resort, the hospital went to court to win legal guardianship and eventually placed her in a suburban nursing home. Another uninsured patient stayed in the hospital from March 2008 to October 2010 to the tune of \$3.1 million.

In Chicago, Northwestern Memorial decided to pay \$500 a month in rent so a terminally ill patient with heart disease and no insurance could have a place to stay and hospice care. That was on top of the thousands of dollars for his hospital bill. The man, who was in his 40s and didn't want to go to a nursing home, died two months later.

In Cleveland, an illegal immigrant with no insurance had been in MetroHealth Medical Center for more than a month after a motorcycle accident. The patient had severe brain trauma and extensive limb injuries. Hospital officials didn't know when he might be leaving. And for each day, they covered a cost of at least \$3,150.

These stories are being replicated in hospitals across America. In addition to the toll on patients, the cost to the nation's health-care system is about \$50 billion for the uninsured alone. Those costs are ultimately passed on to everyone who pays taxes and anyone who has a medical bill. The problem, health-care officials say, is that more people need long-term care and that fewer people have insurance because of downsizing and the recession. Consequently, these patients experience discharge delays in moving on to the next step in their care. They are stuck in hospitals, because it's hard to place patients with high medical needs and low benefits.

"The person is caught in the middle, because some facilities don't want to take them," says Carol Levine, director of the Families and Health Care Project at the United Hospital Fund in New York.

"It is a big, big problem," acknowledges Donald M. Berwick, M.D., administrator for the Centers for Medicare and Medicaid Services in the U.S. Department of Health and Human Services (DHHS).

In California, for example, patients in the state's Medicaid program (known as Medi-Cal), those on Medicare and the indigent averaged 26 hospital days in 2009 before being transferred to skilled-nursing and intermediate-care facilities. That's a 30.8 percent increase from the average length of stay of 18 days in 2005, ac-

ording to an analysis of hospital data from the Office of Statewide Health Planning and Development.

So, what should happen?

Although many people complain about being released from the hospital sooner than they would like, the new normal is staying in the hospital for as few days as possible with as few procedures as necessary. Over the last two decades, U.S. hospitals have reduced the average length of stay from 7.2 days in 1989 to 5.4 days in 2009, according to the American Hospital Association. However, hospital stays for hard-to-place patients are going up, not down.

"Hospitals are no longer a place where you stay until you get better and then go home," says Barbara Ozmar, director of patient care coordination at Piedmont Hospital in Atlanta. "The general public at large doesn't fully appreciate that we get you well enough to transition your care."

Ideally, the transition should be seamless. The team of doctors, nurses, social workers and others should start discharge planning upon admission, and a patient could be transferred to long-term care within 24 hours.

It's a different story for hard-to-place patients who must wait in hospitals a few extra days, weeks or even months before they can be discharged to rehabilitation centers, nursing homes, hospice or skilled home care—if they have homes. This problem has traditionally centered around sicker, older and poorer patients. However, in today's evolving economy, it can affect almost anyone who needs long-term care and has complicated medical needs or finances.

Patients could become underinsured or uninsured. They could be badly injured in a car accident or fall. They could end up waiting for a place that takes patients on dialysis, ventilators or intravenous medication. They could end up waiting for a bed, period.

"It cuts across all ages and backgrounds," says Elana Patton, a case manager at Piedmont Hospital. "We're seeing younger people." This includes patients who need organ transplants or have traumatic injuries, chronic gastro-intestinal issues, cancer or HIV/AIDS.

Delayed discharges place patients at greater risk of catching life-threatening infections like septicemia, a bacterial blood infection. Extended hospital stays also delay the time patients can receive medical treatment or rehabilitation in a setting that might be better suited to their needs. "A rehab facility can provide two to three hours a day of rehab," explains Mark V. Williams, M.D., chief of the Division of Hospital Medicine at Northwestern University. "A hospital is typically only going to have rehab capabilities for 30 minutes or so."

"It's a cost issue," Dr. Williams adds. "Hospitals are not set up to conduct long-term rehab. They can't provide that intensity of services for

patients." Williams notes that hospitals are typically paid by the diagnosis, not necessarily for the extra days and extra resources. "And so these patients end up costing significant amounts of money."

The average hospital charge for an uninsured person went up 88 percent from \$11,400 in 1998 to \$21,400 in 2007, according to the Agency for Healthcare Research and Quality (AHRQ). Hospital stays also grew by a third for the uninsured as well as for Medicaid patients. These costs contributed to the \$2.2 trillion the United States spent on health care in 2007—16 percent of the nation's Gross Domestic Product. "This is a growing national problem," Ozmar says. "It's huge, and it's going to get bigger."

SCOPE OF THE PROBLEM

Many Americans are in worse shape at earlier ages for a host of reasons, including health-care disparities, genetics, inadequate exercise, poor nutrition, obesity, or drug and alcohol abuse. Doctors say they are seeing patients in their 20s or 30s who are already candidates for hip replacements and other medical procedures more common to their grandparents.

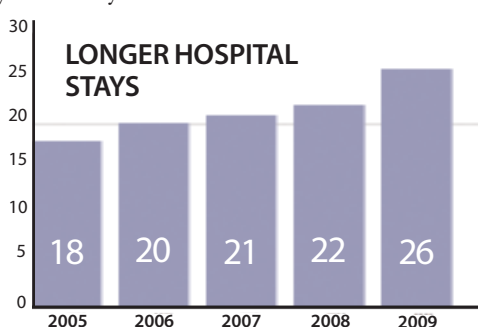
Add to this the graying of America, the increase in the level of care required as people age and the fragmentation of families that might have been on hand to support long-term care patients years ago. Unable or unwilling to provide care, some family members abandon relatives—even resorting to drive-by drop-offs at emergency rooms.

The percentage of people 65 and older is expected to rise from 13 percent to 20 percent by the middle of the century, according to a census report, "The Next Four Decades: The Older Population in the United States: 2010 to 2050." Of this group, those 85 and older are expected to increase from 14 percent to 21 percent. In addition, the pool of candidates for long-term care includes 50 million people who have disabilities—and their ranks are expected to grow, according to "The

Future of Disability," a 2007 report from the Institute of Medicine. The pool is overflowing with people who have multiple chronic conditions and account for a disproportionate share of health expenditures—much of it covered by federal dollars. From 1997 to 2008, the number of discharges to nursing homes and other long-term care facilities grew by 35 percent, according to the AHRQ's Healthcare Cost and Utilization Project. Discharges to home health care grew 69 percent over the same period.



"Stuck in the Hospital" is one of four projects produced through the Health Performance Fellowship sponsored by the Association of Health Care Journalists and the Commonwealth Fund. Go to heartandsoul.com for a multimedia version with bonus content on discharge, caregiving and other health-care issues. Learn more about caregiving on Saturday, June 18, during the Heart & Soul Awards weekend in Baltimore. TweetChat with us and share your stories at 8 p.m. Tuesday, June 21 (#heartandsoulchat).



Hospital stays rose 30.8 percent in five years for patients in California's Medicaid program (known as Medi-Cal), those on Medicare and the indigent.

Source: Office of Statewide Health Planning and Development

"Typical patients are the ones who come here with emphysema, diabetes out of control, heart failure and a whole host of other issues," says Jim Pile, M.D., the hospitalist at Metro-Health. "Many of our patients are on 10 to 15 medications."

With such a strong demand for long-term care, institutions can afford to be selective. Some avoid Medicaid patients, complaining about the reimbursements and lengthy review for new applicants. "Most of them try to decide what they're going to make off of you," says Alfred Chiplin Jr., managing attorney at the Center for Medicare Advocacy in Washington, D.C. "Everything is being driven by reimbursements. It's a real challenge."

In Prince George's County, Maryland, for example, a nursing home might make \$600 a day from a patient who has private insurance, but be reimbursed only \$200 for a Medicaid patient, according to Tracey Boseman, a representative of Capital Caring, which provides hospice and palliative care at area nursing homes, residences and other sites in the Washington area. The gap makes it tempting for long-term facilities to bypass patients who come with fewer dollars.

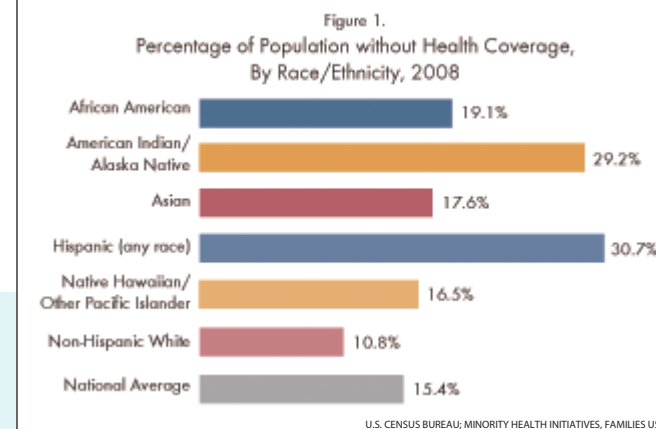
Chiplin says Medicare and Medicaid advise providers to accept a mix of cases across the income spectrum. "The no-

tion is that it should even itself out," he says. "That's theoretical, and I know the nursing homes and home-health agencies play games with that. Most of these facilities are way understaffed. They find ways to limit their exposure to the patients that are the most complicated."

Facilities that lack certified respiratory therapists may turn down patients who need ventilators to breathe. Patients who require long-term feeding tubes or dialysis to treat kidney failure also end up waiting in hospital beds while dis-

A QUESTION OF COLOR & COVERAGE

More than half of the uninsured are people of color. Here's a breakdown by race and ethnicity.



U.S. CENSUS BUREAU; MINORITY HEALTH INITIATIVES, FAMILIES USA

The Insurance Gap

For three weeks, Khary A. Matthews has watched fellow patients come and go in a three-bed ward at Howard University Hospital, where he says he's recovering from a seizure and meningitis. Like 50 million people nationwide, Matthews is uninsured. He also knows firsthand that the unemployment rate for African Americans is twice the national average.

Last June, he was laid off from his teaching job at a charter school. He has reached the marrow of his "bare bones" budget.

"The bills come in a shovel and go out in a teaspoon," Matthews says, quoting his grandmother. The 34-year-old actor cut back on plays and movies, sold his 2006 Audi, switched

to public transportation and signed up for food stamps. "I'm not ashamed of it," he says. "I've seen people with more degrees than me in line."

The scary part was giving up his insurance. He says he paid about \$30 a month for insurance through his job, but \$400 under COBRA, the Consolidated Omnibus Budget Reconciliation Act of 1985, which allows temporary coverage under an employer's group health coverage. Being sick worries him. He had another scare when he was hit by a car while riding his bike and ended up on the windshield. That's when the seizures started, he says.

"I'll be out grocery shopping, and I'll find myself in the back of an ambulance," says Matthews, who also

blacked out on a Metro rail platform. He hopes to find a roommate who can double as a sentinel in case he blacks out again—and a job with benefits. In the meantime, a social worker is helping him apply for Medicaid coverage.

Some people can't get insurance through their jobs. Studies show many can't afford the premiums or they squeeze out coverage for their children, but not for themselves. Most of the uninsured are in working families; 61 percent have at least one person with a full-time job and another 16 percent have someone working part time, according to a 2010 analysis by the Kaiser Commission. Among single people, the insurance gap is concentrated at the bottom

but cuts across income. About 25 percent of uninsured singles earned less than \$25,000 in 2008, reports Families USA. However, 8.2 percent took home \$75,000 or more.

It wasn't always this way. From 1968 to 1980, the majority of Americans younger than 65 had some type of private insurance. As more and more companies began to cut back on coverage, those with insurance fell from 79 percent to 67 percent in 2007, according to a half-century analysis by the National Center for Health Statistics. Employer-sponsored coverage dropped from 71 percent to 62 percent during this period. It's now at 57 percent, the Kaiser Commission reports.

charge planners and sometimes their families hunt for places that will accept them. "Ventilator care is generally more expensive, and a lot of nursing homes won't—or say they can't—provide it," Chiplin says. "It often causes delays, and it often requires people to be placed at facilities at considerable distance from where they reside and where their families live."

"It gets to be problematic; it sometimes has a racial component," Chiplin adds. "At one time, minorities, particularly African Americans, were having to go much farther from their homes in general, particularly when they had complicated care issues. That was particularly a problem in the South."

Health-care access and quality issues persist along racial and ethnic lines. "For blacks, Asians, Hispanics and poor populations, at least half of the core measures used to track access are not improving," the DHHS indicated in its 2008 National Healthcare Disparities Report. "The problem of persistent un-insurance is a major barrier to reducing disparities."

Uninsured people tend to be in worse health and are less likely to receive preventive or ongoing care, especially for chronic conditions. Some are in such bad shape that they are considered "train wrecks." Fifty million children and adults are uninsured in the United States, an increase of 5 million from 2007 to 2009, the height of the recession. Their ranks have swelled over the years, largely because of the drop in coverage by employers and a rise in the unemployment rate.

In some regions, the uninsured and underinsured overburden public and nonprofit hospitals that have a mission or mandate to admit them. For those who live in the nation's capital or deep into neighboring Virginia and Maryland, all roads lead to Howard University Hospital, says Vivien A. Fonjong, director of Utilization Review, Case Management and Social Work. "If you don't have insurance, this is where you come."

Sherry Aronson, vice president of Inpatient Operations at MetroHealth in Cleveland, says that's also the case in Cuyahoga County. "Our burden is extremely high, because there are not sufficient resources delivered by the county for care," she says. At MetroHealth, charity care rose from \$100 million in 2009 to \$109 million in 2010. "Are the other health-care systems as committed as we are to taking care of these patients?" Aronson asks. "I came from some of these places, and the answer is no. ... In fact, we should double-dog dare the other systems to step up and play their part."

The National Association of Public Hospitals (NAPH) reports the number of uninsured patients at member hospitals rose by 23 percent from the beginning of the recession through 2009. During this same period, uncompensated care went up 10 percent. This also includes thousands of dollars that some institutions pay to send a growing number of uninsured, undocumented workers to their home countries for long-term treatment, because it will cost less than absorbing the cost of continuous care in their hospitals.

Unreimbursed care drives down profit margins for public hospitals, which averaged 2.5 percent in 2009 compared to 5 percent for hospitals overall. The overflow of poor patients at safety-net hospitals also increased after neighboring hos-

pitals shut their doors or closed costly trauma centers in Detroit, Los Angeles, New Orleans, New York and Washington. The tragedy, Aronson adds, is that sick and injured residents sometimes die if their trip to a hospital is even a just a mile or two longer than it was previously.

THE DISCHARGE DILEMMA

For hospitals, hard-to-place patients remain a small yet significant subset of their populations. These patients occupy beds that could be turned over more rapidly amid regulatory and business pressures to control costs, reduce lengths of stay and avoid readmissions. "We've had a 3 percent change in our payer mix from privately insured to government coverage," says Matthew J. Schreiber, M.D., chief medical officer at Atlanta's Piedmont. And hard-to-place patients have added at least a day to his hospital's length of stay.

"They require a huge amount of time and human resources to deal with them," Dr. Williams says, especially when there's a pileup of complications. "It's frustrating for staff, frustrating for patients and their families."

And when ambulances drop off patients who are unconscious, social workers must double as detectives trying to ascertain not only their identities, but also the whereabouts of their families, says Janice Buildt, a social worker at the MetroHealth in Cleveland. Buildt says she often has to be creative since she works with a lot of trauma patients who are sedated with breathing and feeding tubes. But Buildt loves "the drama in the trauma" and welcomes a challenge. "I get to do a lot of 'CSI' work," she says, referring to the crime scene investigation series on television.

Social workers search wallets for identification cards, credit cards, business cards and scraps of papers with phone numbers scrawled on them. They surf the Internet. They check missing persons reports. Buildt gets excited when she finds a yellow and blue Blockbuster video card. She used one to find a patient's sister, who had renting privileges on her brother's card. The economy can make hot leads grow cold when a phone has been disconnected or when a house goes into foreclosure and neighbors can provide no clues.

If a patient remains incapacitated and no relatives can be found, hospitals may seek guardianship. "Once you are in the land of true guardianship, then you are into months because that process takes forever," says Jeffrey L. Greenwald, M.D., a hospitalist at Massachusetts General Hospital. Families can contribute to delays by blocking patient transfers to rehabilitation centers and nursing homes, or when the patients themselves are reluctant to move on. "A lot of patients are in complete denial that they need this kind of care," Ozmar says.

The decision to take this route and the lack of options can be daunting, Dr. Greenwald says. "Families want to explore multiple options—look for the nicest, closest, most friendly, environment for mom, dad, brother, sister. There is a lot of pressure to accept the offers, because the hospital needs to move that patient to an appropriate level of care."

WHAT HOSPITALS ARE DOING

Many hospitals are taking steps to address discharge issues overall, with some assembling senior-level strategic teams to expedite decisions on the most complicated cases. The Difficult Discharge Response Team at Northwestern Memorial came up with the idea to pay rent for the terminally ill man so that he'd have a place to receive Dobutamine infusions for heart failure, says Jessica Soos Palowski, senior social worker and case manager. The hospital also arranged long-term care for a young man whose insurance covered only his hospital stay. The man had fallen and injured his spinal cord.

Denver Health has a Complex Discharge Committee that meets every Friday to discuss patients who have been medically ready for discharge for at least 10 days. The committee's work along with the hospital's waste-cutting initiative, LEAN, have helped cut average hospital stays from six to four

days, says Philip Mehler, M.D., chief medical officer. But two patients have been there for about a year.

During any given week, the hospital has about 20 complex discharges at a combined cost of roughly \$3 million. Sometimes a solution can arise from the expertise of the administrators on the committee. A patient suffering from head trauma and respiratory problems had been in the hospital for 100 days, but couldn't be transferred to a skilled nursing facility because he needed to be suctioned three times a day. At Dr. Mehler's request, a physician was able to get the patient down to once a day, an acceptable limit for placement. In one case, the committee recommended the hospital install a video conferencing system so patients could "attend" guardianship hearings from a hospital bed rather than be taken to probate court.

Broader initiatives that show promise, medical professionals say, include:

Diagnosing Discharge

The devil is in the details when it comes to discharge. While a number of transitional care initiatives across the country show promise, discharge remains complicated—even when there are no medical or financial complications. With the advent of managed care in the 1980s, the consensus in the medical community was that the discharge process was in dire need of improvement.

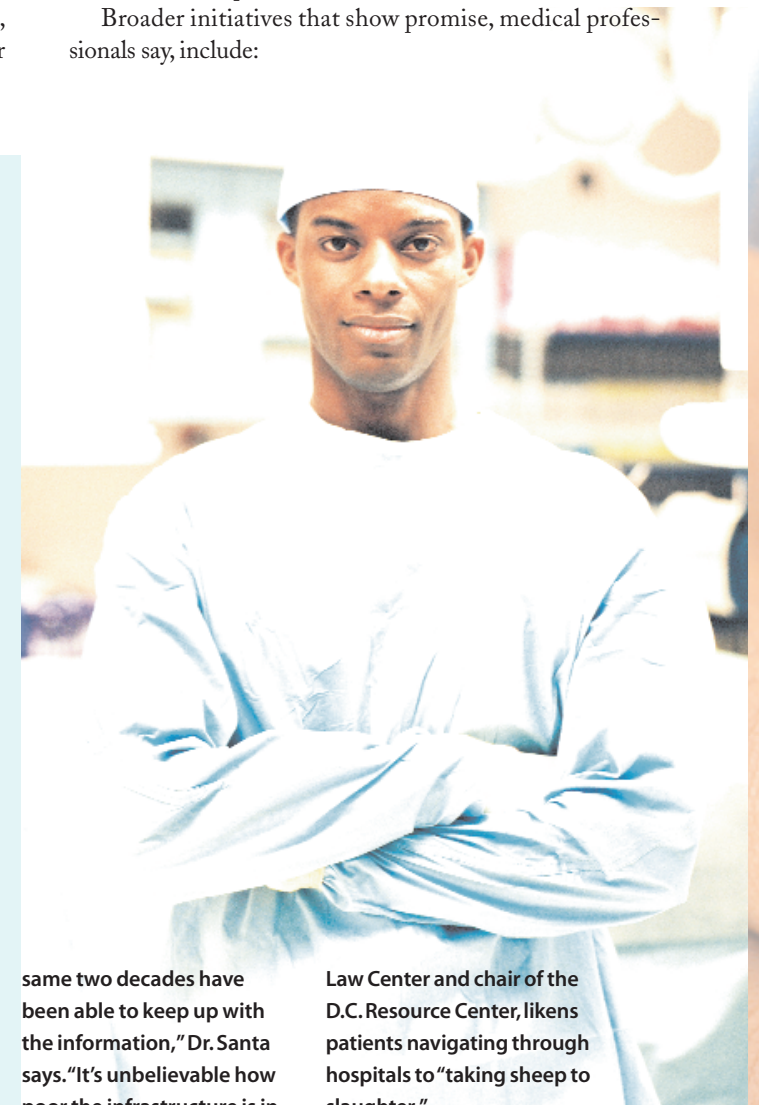
"Everybody agreed that the low-hanging fruit was discharge," says John Santa, M.D., director of the Consumer Reports Health Rating Center. "It's amazing to look at the stats and see what a mess it still is."

Dr. Santa and others criticize hospitals that send off caregivers with a list of long-term care facilities to contact quickly for a place for their relative or that simply hand patients and their families

sheets of paper with discharge instructions. Patients gave the lowest satisfaction ratings to 2,794 U.S. hospitals, or 82 percent of the 3,141 total, for discharge instructions. Consumer Reports' findings are based on federal data from the Hospital Consumer Assessments of Healthcare Providers and Systems Survey.

It's easy to see why the discharge process is convoluted. "You have more doctors who need to be coordinated about more problems, and many more drugs," Dr. Santa says. "There are many more opportunities for things to fall through the cracks."

Still, he insists, it's no excuse for present conditions. Electronic records, other innovations, partnerships and increased teamwork have improved discharge at many hospitals, but gaps persist. "Other industries in the



same two decades have been able to keep up with the information," Dr. Santa says. "It's unbelievable how poor the infrastructure is in health care."

Robert S. Bullock, an attorney for Elder & Disability

Law Center and chair of the D.C. Resource Center, likens patients navigating through hospitals to "taking sheep to slaughter."

"Consumers have to understand that they're inventory," Bullock says bluntly.

• **Transitional Care Model:** In this program, a nurse coordinates care that follows a patient—in the hospital, at a skilled-nursing facility, at home and even on follow-up doctor's appointments. "The goals of transitional care is to create a seamless transition," says Mary D. Naylor, Ph.D., TCM's founder and director of the New Courtland Center for Transitions and Health at the University of Pennsylvania School of Nursing. Studies have shown improvements in all quality measures, as well as fewer rehospitalizations and lower costs.

• **Project RED (Re-Engineered Discharge):** Brian Jack, M.D., created RED in 2006 to calm what he calls a "perfect storm" in discharge. Like TCM, it also designates a point person, in this case called a Discharge Advocate, so things don't fall through the cracks. For backup, there's a discharge checklist.

• **Project Boost:** "Boost is aimed at improving the overall discharge process for all patients," says Dr. Williams, co-chair. Started by the Society of Hospital Medicine, the program is being used in more than 60 hospitals, including Northwestern Memorial and Piedmont. It has shown early drops in readmissions by targeting high-risk patients and improving coordination and communication in all aspects of their care.

In addition to Project Boost, Dr. Schreiber says Piedmont also implemented a hospitalist program, a growing trend at hospitals nationwide intended in part to centralize care coordination and cut back on visits by primary-care physicians. Dr. Williams says hospitalists are also having an impact in making complicated discharges less complicated, although

this is largely anecdotal. "A lot of times the hospitalist can be helpful because they are interacting more with the social workers and the care managers than a busy office-based physician who may not be able to take the time to conduct family meetings and interact with the staff."

However, Toby S. Edelman, senior policy attorney for the Center for Medicare Advocacy Inc., cautions that hospitalists aren't created equally and that some don't want to do rounds. "Hospitalists work for the hospital," Edelman emphasizes. "Their primary loyalty is not to the patient. It just makes more fragmentation."

Hospitals are also trying to address health on the front end—before chronic illnesses become chronic—and throughout the spectrum of care. Some are doing this through partnerships with other health-care providers. Others have created their own networks with a pool of doctors to provide primary care and long-term-care units or free-standing facilities. "If we get to a diabetic earlier, they don't end up having kidney failure and all the intended consequences of it," Daniel Denton, M.D., says of the Community Services Expansion Plan at Northwestern Medical. Through the partnerships, patients have medical homes, and their medical, financial, transportation and housing issues are already known, minimizing the need for social workers to address them if they need to be admitted to the hospital. And if they need to be hospitalized, it can be planned rather than a sudden and costly visit to the emergency room.

Partnerships and expanded facilities help, but they still aren't enough in economically depressed areas such as Detroit or Northeastern Ohio, says Aronson, the vice president at MetroHealth in Cleveland, which has a 150-bed long-term nursing and rehabilitation center as well as community clinics. "It's a really challenging situation."

OUTLOOK FOR THE FUTURE

Dr. Berwick, the nation's Medicare and Medicaid administrator, has heard all of the complaints about inadequate and slow reimbursements to hospitals and nursing homes. He scoffs at the idea of throwing more money at the problem and says institutions have to learn to do more with less. "It's a tough time for everybody," he says. "The challenge is to use what we have to the very, very best advantage. Orienting hospitals and nursing homes and communities to continual improvement of their processes of care so they can afford to give great care under stringent circumstances, that's the job now."

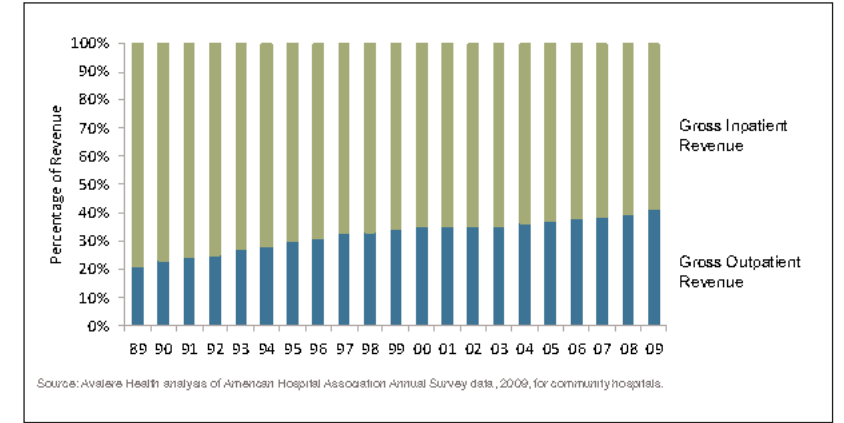
"If we could simply pay more, they'd be happy and that would be easy. But that wouldn't be changing care; that's just saying the system needs more to do what it does. We need health care that performs better." Dr. Berwick cites the efforts of CEOs Patricia Gabow at Denver Health and Gary Kaplan at Virginia Mason Hospital in Seattle in streamlining their operations and enhancing the discharge process. "They're reducing their costs while improving care. They're showing it's possible."

Gene Coffey, a staff attorney for the National Senior Citizens Law Center, cautions that long-term care is also being strained by cuts in Medicaid. It's a push-pull effect with growing eligibility for some Medicaid services on one hand, but cuts in the personal care benefit that he says could drive some people into institutions if they can no longer be cared for at home. "The District of Columbia, for example, cut its personal care benefit from an annual limit of 1,000 hours to 500 hours," Coffey says. "California, Minnesota, North Carolina and Washington State also made cuts."

Dr. Greenwald says Accountable Care Organizations show promise in coordinating care across providers and leveling out the financial burden. "You share the level of financial risk, and that will be a good thing," he says.

Many medical professionals are cautiously optimistic about reform. They say the Affordable Care Act doesn't go far enough in addressing long-term care, but the potential benefits outweigh any shortcomings. "After 100 years and seven presidents, it's a pretty historic law that will address significant access to care," says Herbert C. Smitherman Jr., M.D., assistant dean of Community and Urban Health at the Wayne State University School of Medicine in Detroit.

Buildt, the social worker at MetroHealth, says health reform is already making a difference for young people injured



ARE YOU REALLY IN THE HOSPITAL?

The growing reliance by hospitals on outpatient care over inpatient care has had a detrimental effect on Medicare patients who need more treatment. Medicare recipients are often ineligible for transfer to long-term care if they were outpatients and failed to meet the requirement of three days of inpatient hospitalization.

Outpatient care lasting at least two days has increased by 70.3 percent. Some people don't even realize they are in outpatient care—especially if they have received a hospital wristband, regular meals and a bed in a different area of the emergency room, says Toby S. Edelman, senior policy attorney for the Center for Medicare Advocacy Inc.

Medicare claims for outpatient care grew 22.4 percent, from 911,500 in 2006 to 1.12 million in 2008. The average length of time in outpatient care grew from 26 to 28 hours, but some people have been outpatients for as long as two weeks.

A Healthy Headstart

Issues related to health and aging can be overwhelming, says Irene V. Jackson-Brown, a certified care manager and senior advisor in Washington, D.C. It's never too early to get a handle on them.

- 1 Encourage family members to start thinking about life issues as soon as they turn 18, suggests Elana Patton, a case manager at Piedmont Hospital in Atlanta. Early on, people pay attention to vacation time, maternity leave, dental plan or 401(k), but they give short shrift to disability and long-term care.
- 2 Find out how to close the coverage gap if you're uninsured or underinsured.
- 3 Hold family meetings so everyone can answer the "what if?" questions and consider how much they can realistically handle, says Candice Carter, community outreach coordinator for Visiting Angels in Largo, Maryland.
- 4 Document your decisions, and designate a surrogate through a health-care proxy or living will. Check local laws through your health department.
- 5 Give copies to all doctors and specialists. Double-check to make sure the proxy or will is part of the record for

each hospital stay, along with current contact information.

- 6 Make sure family knows where to find these and other important papers.
- 7 Keep in mind a hospitalist, instead of your doctor, might be responsible for inpatient care.
- 8 Jot down questions as they occur to you, and keep the list on hand so you're prepared to talk to doctors, nurses and others.
- 9 Identify and meet the point person on the discharge team.
- 10 Talk to the social worker about special needs or concerns. If long-term care is likely, discuss options early.
- 11 Follow up with your primary care doctor.
- 12 Consider patient navigators, care managers or elder-care attorneys to help navigate the medical maze. One caregiver says having an advocate prevented her from being liable for her grandmother's unmet nursing home bills.
- 13 Research resources at Family Caregiver Alliance: caregiver.org, Next Step in Care: nextstepincare.org and the Area Agencies on Aging: eldercare.gov.
- 14 Start talking about end-of-life issues when you're healthy, advises Tracey Boseman of Capital Caring in Largo, Maryland.

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