

Blueprint

SPRING 2019

Difficult Decisions: UHF Looks at Challenges of Choosing Post-Acute Care

Donna was helping her elderly mother care for Donna's sister, Paula, who has amyotrophic lateral sclerosis (ALS). The mother also looks after Paula's young daughter. After Paula was hospitalized with severe pneumonia, her condition declined. A sudden decision loomed: Where would Paula go for post-hospital care if she couldn't go home? Donna recalled that a social worker handed her mother a list of 12 facilities and told her to "pick one."

But "picking one" was not so simple. "This is a situation that's very, very difficult," Donna told United Hospital Fund staff who interviewed her for a recent report.

Welcome to the complex world of post-acute care. Each year, one in five hospital patients in the U.S. need ongoing care after discharge, including some 300,000 New Yorkers. And with continued pressures to shorten hospital stays and move patients to lower-intensity care settings, the demand for post-acute care is likely to increase.

UHF conducted a year-long project, *Difficult Decisions About Post-Acute Care*, supported by the New York State Health Foundation,

to better understand why hospital discharge planning sometimes falls short. The UHF team interviewed patients and family caregivers, hospital staff, nursing home administrators, policymakers, and experts in the field. The result is a series of four reports: an overview of the issues, a focus on the perspective of patients and their families, an examination of the views of hospital and nursing home personnel, and recommendations for a way forward.

ONUS PLACED ON PATIENTS AND FAMILIES

The main takeaway? While patients and their family caregivers should ideally be able to choose a post-acute care provider based on their own priorities and circumstances—and informed by performance data that can help them understand quality differences among providers—the reality is far different. Instead, they often must make this critical decision quickly, while still in frail health, and without adequate information or guidance. The wrong choice can lead to regret and dissatisfaction, or more devastating consequences: readmission to the

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DID YOU KNOW?



Each year, 300,000 New Yorkers require continued care following

hospital stays for major surgery or serious illness.

■ **Carol Levine, UHF's Director of the Families and Health Care Project, is a co-author of a new AARP report, "Home Alone Revisited: Family Caregivers Providing Complex Care."** The report, which shares the results of a nationally representative survey of family caregivers, expands on a 2012 report on family caregivers jointly published by UHF and the AARP Public Policy Institute. The authors found that today's caregivers are diverse with diverse experiences, provide intense and complex care (including medical tasks and managing multiple health conditions that are often accompanied by pain), and are in need of much greater support. To read the report, including the full findings and recommendations, please visit: <https://uhfnyc.org/publications/>.

■ **New York City Mayor Bill de Blasio in March 2019 named UHF President Anthony Shih, MD, to the advisory board for OneNYC,** an initiative created to examine long-term strategies for challenges facing the city. The 39-person board comprises experts from a number of disciplines and includes civic leaders, businesspeople, academics, and community

leaders. Dr. Shih brings to the board his experience working for better, more equitable health care for all New Yorkers.

■ **UHF has selected Pooja Kothari, program manager in the Quality Institute, as the 2019 Patricia S. Levinson fellow.** The fellowship was established in 2017 with the generous support of the Robert A. and Patricia S. Levinson Award Fund at the New York Community Trust to advance UHF's work improving health care for vulnerable populations.

Ms. Kothari joined UHF in 2017 and plays a central role in developing and managing projects on quality measurement and improvement. In addition to recently co-authoring a report in UHF's "Difficult Decisions" series about post-acute care, she collaborates with the New York State Department of Health on quality measurement, monitoring, and alignment issues. She will soon be working on a new project funded by the New York State Health Foundation called "How's My Health Dashboard," which aims to help patients create a dashboard of measures they can use to partner with providers in their health care. ■



Barbara J. Yastine

UHF Board Welcomes Barbara Yastine

United Hospital Fund is delighted to welcome veteran financial services executive Barbara Yastine to the Board of Directors. Ms. Yastine's election was announced in December 2018.

"Barbara Yastine brings a wealth of knowledge and financial expertise to our board, and we are thrilled to work with her," said UHF President Anthony Shih, MD. "She will expand the depth and breadth of our leadership as we strive to build a more effective health care system for all New Yorkers."

With significant experience in financial services, management, and governance, Ms. Yastine today serves as a director of four financial firms: First Data Corporation, Primerica Corporation, Axis Capital Holdings Limited, and Zions Bancorporation. She is an

active investor in and advisor to early- and growth-stage companies.

Ms. Yastine served as chairman and CEO of Ally Bank from 2012 to 2015 and as chair of the Bank and chief administrative officer of the Bank's parent, Ally Financial, from 2010 to 2012. She previously held the role of chief financial officer of Credit Suisse First Boston and spent 15 years at Citigroup and its predecessors in a variety of roles, including chief administrative officer of the Global Consumer Group and chief financial officer of the Corporate and Investment Bank. She is a director of the parent corporation of nonprofit Charles Stark Draper Laboratory and recently stepped down after 12 years as vice chairman of the addiction treatment provider Phoenix House.

She received an MBA and a BA in journalism from New York University. ■

"I am honored to join the Board of United Hospital Fund and to work with Tony Shih, the Board, and the very dedicated staff to advance health care quality in New York."

Price Transparency and Patient Empowerment

One of my board members recently asked what I thought about a new federal proposal to increase price transparency in health care. The proposal specifically relates to the public disclosure of negotiated rates between providers and insurers and would go one step further than the Affordable Care Act's requirement that hospitals publish their standard charges to the public, which just went into effect this January. I wish I could have given a simple response, such as: "I think it's great—this would empower patients to make more appropriate choices and drive down health care costs."

But of course, like almost everything else in health care, this complex issue does not lend itself to an easy answer.

COMPLEXITIES AND RISKS

In general, greater transparency in health care is a worthy goal that most people can support, including policymakers on both sides of the aisle. Indeed, when enough useful information is available, increased transparency can lead to greater patient empowerment. But there are numerous steps between greater price transparency and a more empowered patient, and several risks can emerge along the way. One major concern is that responsibility and accountability for choices may be pushed down to the patient, without providing the appropriate knowledge, tools, and support to make informed decisions.

PERPLEXING PRICE LISTS

For the most part, hospital price lists—even if they are insurer-negotiated rates and not standard charges—do not match how health care is used from a patient perspective. A patient generally experiences hospitalization as an episode of care, such as a hip surgery procedure or treatment for a bout of illness like pneumonia. In contrast, a bill for one of these hospitalizations comprises dozens, if not more, of individual line items that patients have no way of deciphering or predicting ahead of time. Further, even if the total price were foreseeable, the patient would also need to know about the provider's quality of care before making an informed decision. And here, patients may encounter yet another dimension of complexity: what they define as "quality" is not necessarily what we in health care are currently measuring and reporting. A comprehensive 2017 study by United Hospital Fund found that most publicly reported quality measures were not precise or meaningful enough to consumers and their families to adequately inform health care decisions. And of course, price and quality information for patients is only useful for

decision-making if there is time to make a decision—clearly, not in the case of common reasons for hospitalizations like heart attacks or strokes.

UNINTENDED CONSEQUENCES

Greater price transparency may also lead to unintended consequences. For instance, proponents assume that consumers will choose the lower-priced provider if there are no apparent differences in quality. However, this may not always be true, particularly if the patient's health insurance plan design largely guards against price differences or diminishes their impact, especially after a deductible is met. In addition, in the absence of other information, patients may sometimes use prices as a proxy for quality. Likewise, when providers see how much payers are reimbursing competitors, they might attempt to increase prices to match their peers rather than lowering them to attract patients. These potential unintended consequences warrant careful study as price transparency efforts continue to gather steam.

This is not to say that greater price transparency is not desirable—it certainly is, but we should temper our immediate expectations. Further, we should acknowledge that hospital price transparency is only one step along the path to patient empowerment. There are fortunately other areas in health care decision-making that yield a clearer, more direct way forward.

POST-ACUTE CARE DECISION-MAKING

UHF recently completed a study that highlights one such area, decision-making around post-acute care (see cover story). Even though one in five hospital patients require medical care after discharge, large gaps in information and decision support prevent patients and families from making the best choices about post-acute care. The potential health and financial consequences are significant. Much of this information is, in fact, readily accessible and considerably less complex than hospital prices; the challenge is that keeping patients and families actively engaged and providing them with useful, timely information means working across multiple stakeholders and overcoming communication breakdowns and other systemic problems. Sometimes, guidance around these difficult decisions is not only needed, but welcome. And perhaps this is the lesson: although transparency may be desirable, it is not enough to achieve patient empowerment and more informed health care decision-making. ■



Anthony Shih, MD
UHF President

We should acknowledge that hospital price transparency is only one step along the path to patient empowerment.

Difficult Decisions: UHF Looks at Challenges of Choosing Post-Acute Care

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1 in 5

U.S. hospital patients need ongoing care after discharge each year

hospital, permanent disability, sub-optimal recovery, or worse.

In addition, the whole concept of post-acute care can be unfamiliar to patients. While many know about nursing homes or home care agencies in their communities, they are less familiar with the full range of available care settings and what types of services are offered at home, in the community, or in facilities.

As a result, patients often end up choosing a facility most convenient to where they live, rather than one where they would receive higher-quality care. Even then, there may not be a bed available, forcing the patient to start the process over.

HOSPITAL STAFF FACE LIMITATIONS IN ASSISTING PATIENTS

Hospital personnel involved in discharge planning are under immense pressure to minimize length of stay and to respond to the demand for new patient admissions, often resulting in the need for hospitalized patients and their families to make rushed decisions. Further complicating the discharge process, interpretation of federal regulations prohibiting hospital staff from steering patients to individual facilities can limit the type of guidance providers can offer. In addition, some staff may not be familiar with the quality of care at specific facilities or may not be comfortable making suggestions.

Hospital staff interviewed by the Difficult Decisions team said they try to discuss post-discharge care with patients and family caregivers at the start of the hospital stay. But there are many barriers to such discussions—patients may be too sick to engage, family members are stressed from dealing with the medical crisis at hand, or it may be too early in a patient’s recovery to know what the best options will be.

Discharge planners also found that patients were often surprised by the limits of their insurance coverage for post-acute care. All the hospital teams interviewed for the project reported delays in insurance authorizations for care at skilled nursing facilities, making it difficult to release a patient to their choice of care in a timely fashion. “Patients get their hearts set on certain places...and because of

insurance barriers, you kind of have to break their heart,” one provider said.

Hospital teams talked about working with patients who were frail or confused or not fluent in English. Finding and assessing quality data that is available is another challenge, especially when it may not be relevant to an individual’s situation or preferences. Although the Centers for Medicare and Medicaid Services (CMS) and New York State Department of Health both maintain websites on nursing home quality, those resources don’t sufficiently distinguish between short-stay and long-stay care and can be difficult to navigate, even for hospital staff.

A WAY FORWARD

The Difficult Decisions reports make it clear that change is necessary at all levels, from the regulatory framework, to individual staff interactions with patients and family caregivers, to the information needed to support informed decisions. Several recommendations were put forward. Among them:

- Bring relevant information about post-acute care options to the bedside through videos, tablets, and apps.
- Pinpoint communication gaps during the discharge planning process and ensure that patients and caregivers are updated.
- Better prepare patients and families about what to expect at a skilled nursing facility.
- Train hospital staff on the information and support they can and cannot provide and help patients use data to identify high-quality providers.

“We need a new way of looking at post-acute care,” said Lynn Rogut, leader of the Difficult Decisions project and director, Quality Measurement and Care Transformation, of UHF’s Quality Institute. “To start, this would mean that patients and families are placed at the center of hospital discharge planning and their priorities are identified and respected and that evidence-based, coordinated care becomes a reality.”

All four reports can be downloaded from UHF’s [website](#). ■

Some names have been changed to protect the individuals’ privacy.

Voices of New York's Uninsured

With the support of the Health Foundation for Western and Central New York, UHF has published a profile of the uninsured in 16 counties of western and central New York—particularly those eligible for free or low-cost coverage who still lack it.

Peter Newell, director of UHF's Health Insurance Project, prepared a report pairing UHF's policy and statistical analysis with a closer look at the day-to-day consequences of not having health insurance—putting a human face on broad policy issues, where discussions usually center around numbers in the thousands or millions.

In late 2018, UHF convened several discussion groups of current or recently uninsured individuals in western and central New York State, soliciting their direct experiences and fears about being uninsured, and their insights

on barriers to coverage. Some quotes from these sessions appear below.

“The stories amplify and enrich the data analysis,” said Mr. Newell. “I know from the research that the largest share of uninsured in most counties falls into the income group that is not eligible for free or low-cost coverage, but is eligible for subsidies for qualified health plans bought on the Exchange. But when someone sits across a table from you and explains why they still can't afford coverage because of other expenses, or why it isn't worth it because of the high deductibles, and what lacking coverage actually means, that is extremely powerful.”

The full report, *Reaching the Five Percent: A Profile of Western and Central New Yorkers Without Health Coverage*, is available on UHF's website. ■



UHF spoke with nearly 40 New Yorkers from four spots in western and central New York—from the village of Gowanda (population 2,709) straddling Erie and Cattaraugus Counties to Syracuse, the fifth-largest city in the state. Names have been changed to protect participants' privacy.

■ “Between all the day-to-day stuff with starting my new business, and getting the house ready for the kid, I barely have time to relace my boots. I guess you could say it's something I'm being ignorant about. But I have some coverage through my business, and there's the urgent care thing. Down the road I will probably look into insurance, but it doesn't seem like the most important thing for me to worry about.”

—Derek (26)

■ “I have never, never taken anything from anybody. I've never taken any handouts. Anxiety medicine, checkups, I took care of myself. I've been working since I was 15 years old. I paid my dues, I guess. Now, I don't want to take [public insurance], but I'll take what I can. I guess it gets a bad rap. There's so many people that take advantage of something.”

—Harriet (58)

■ “When it came to the end of the year and they were going to fine me, they said I didn't make enough to be fined, but I made too much for any subsidies. I got sick one time, urgent care was \$100. They paid for my X-rays, and they paid for my medication. So it was way cheaper than paying two or three hundred bucks for insurance.”

—Shirley (33)

■ “If I'm at a point where I have to be hospitalized, obviously I'm not going to be working so I'm not going to have any income. And same goes for my husband. If he's hospitalized and can't work, our income is totally going to change and it's going to go from this, to it's going to be nothing. And then hopefully and eventually, we would be eligible for some kind of health insurance help. So that's where we're at right now. You never know. Right now, he's driving on icy roads into New England. You never know. That's a sad way of looking at things.”

—LouAnn (50)

Celebrating Health Care Excellence

United Hospital Fund will celebrate the New York metropolitan region as a center of health care excellence at a new special event this spring. At the first Tribute to Excellence in Health Care at Cipriani 42nd Street on May 6, UHF will honor outstanding personal leadership to improve the quality of care, patient safety, and patient experience.

The event will recognize 57 quality improvement champions who were selected by 51 participating hospitals and long-term care organizations. Singled out for their vision and accomplishment, the honorees will receive the Excellence in Health



Tribute to Excellence in Health Care

RECOGNIZING QUALITY IMPROVEMENT CHAMPIONS

Care Award. They include 31 physicians, 17 nurses and nurse practitioners, and a number of other medical professionals.

Carolyn Clancy, MD, Deputy Under Secretary for Health at the U.S. Department of Veterans Affairs, is providing a keynote address. The longtime head of the Agency for Healthcare Research and Quality, Dr. Clancy is one of the nation's most respected quality improvement leaders.

For more information, please visit: www.uhfnyc.org/events ■



J. Barclay Collins II with his grandson, Kai, on his boat, "India."

"UHF provides an independent voice on issues of policy that are extremely important. It also provides a place for people from a variety of disciplines within the health care community to come together."

Legacy Society Profile: Helping Sustain UHF's Future

UHF's Legacy Society honors and recognizes those who have included a bequest or other type of planned gift arrangement for UHF in their long-range financial plans.

Throughout an influential career that has taken him from London to Venezuela, from board rooms to oil fields, from a top New York City law firm to the senior management team of a global energy company, **J. Barclay Collins II** has always made time for one thing—and it's not golf.

"Throughout my life, I've been a volunteer," notes the Gettysburg, Pennsylvania native. "It has been a deep privilege for me to help nurture organizations that serve the public good." This has meant devoting his time, talents, and resources to numerous nonprofit organizations that support the causes he cares about—United Hospital Fund is lucky to be among them.

The former Executive Vice President and General Counsel of the Hess Corporation, Mr. Collins has served on the UHF board since 1984 (the same year he started at Hess). He has been Board Chairman since 2006.

Mr. Collins recently joined UHF's Legacy Society, making a planned gift to help sustain

UHF's future. "I think it's important, in your testamentary relationships, to support in perpetuity the organizations that have been important to you," he says.

His commitment to improving health care was shaped, in part, by his belief that it is intrinsically related to the other causes he supports, which include environmental preservation, the arts, and education. "I think it's important to focus on these broader issues and make an effort to find solutions that could be related," he says.

His schedule hasn't slowed since retiring from Hess: in addition to UHF, he chairs the New York Botanical Garden and Mystic Seaport Museum boards and is actively engaged in other nonprofits. He does make time for his favorite hobby, sailing. And for a week or two every summer, his grandchildren visit him in Mystic, Connecticut, where they stay on their grandfather's 50-foot mahogany ketch, "India." Helping them learn to sail is perhaps emblematic of another of his philanthropic priorities: passing the torch to the next generation of volunteer leaders.

Mr. Collins is bullish on UHF's future and believes its role in New York is critical. ■

Suzanne Brundage

Director of UHF's Children's Health Initiative



Suzanne Brundage is Director of UHF's Children's Health Initiative. She spoke to Blueprint about UHF's recent series of reports on harnessing value-

based payments to improve children's health, which she co-authored with Chad Shearer, UHF's Vice President for Policy and Director of the Medicaid Institute. The reports were supported by a cooperative agreement awarded to ChangeLab Solutions and funded by the U.S. Centers for Disease Control and Prevention.

Q: Why are the early years of a child's life so important to his or her health?

There's a T.S. Eliot line that I love: "In my beginning is my end." Everyday experiences and interactions, especially before a child's third birthday, literally help build a child's brain and can affect a kid's physiology. This is why early adversity has been linked to increased risk for chronic conditions, behavioral problems, and even early death. So, the key to promoting lifelong health is surrounding kids with the factors that support their health and development and limiting consistent, high stress during those critical years.

Q: Why did you choose to focus on how children's health is paid for?

Children's primary care has a huge opportunity to ensure kids stay healthy—not just by providing medical services but by working with the family, promoting developmental services and coordinating care with social services. But the current payment system does not support those essential activities. We want to strengthen pediatric primary care and give it the tools to improve outcomes for kids—but in order to do that, you have to make the money work.

Q: You indicate that children's health champions and Medicaid agencies need to work together to seize opportunities to improve children's health—what are the benefits of this kind of collaboration?

There are many unresolved issues related to how to strengthen pediatric primary care, collaborate across sectors to promote child health, and pay for it all. Part of the reason why so many issues are unresolved is because children are not 'little adults'; the care strategies that work well for adults—better managing chronic conditions, reducing length of stay—are less applicable to kids. Developing strategies uniquely for children requires Medicaid leaders reaching out to the children's community for ideas and greater bandwidth. And children's champions need Medicaid agencies to harness payment reform to drive toward better outcomes for kids.

Q: One of the recent reports addresses "integrated family health care"—what is this and why is it important?

It's our vision for health care. We need to shift the delivery system so providers can seamlessly address the health needs of the entire family, including helping the family with non-medical needs—like accessing nutritious foods—that will impact the health of every family member.

Q: You acknowledge that implementing some of the recommendations laid out in these reports will be challenging—why is it worth pursuing (beyond being the right thing to do)?

We are the stewards of our children's futures. We must invest in them. But beyond that, it's in our self-interest. Promoting the health and development of young children will lead to a healthier country, lower health care costs, and greater school success.

To view the reports, please visit: www.uhfnyc.org/publications. ■



Blueprint

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United Hospital Fund is an independent, nonprofit organization working to build a more effective health care system for every New Yorker.

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Blueprint

ON THE CALENDAR



MAY 6, 2019

UHF's Tribute to Excellence in Health Care Recognizing Quality Improvement Champions

Cipriani 42nd Street

JULY 18, 2019

UHF's annual Medicaid Conference

New York Academy of Medicine

OCTOBER 7, 2019

UHF's annual Gala

Presenting the Health Care Leadership and Distinguished Community Service Awards, and Special Tributes

Cipriani 42nd Street

NOVEMBER 19, 2019

UHF/Greater New York Hospital Association Annual Research Symposium

CUNY Graduate Center

PUBLICATIONS *These and other UHF reports are available at www.uhfnyc.org*



Achieving Payment Reform for Children through Medicaid and Stakeholder Collaboration looks at how value-based payment reforms can be harnessed to improve children's health. This is one of three UHF reports that were supported by a cooperative agreement awarded to ChangeLab Solutions and funded by the U.S. Centers for Disease Control and Prevention.

Evaluation of a Continuum-Based Behavioral Health Integration Framework Among Small Primary Care Practices in New York State examines how primary care practices can integrate behavioral health screening and treatment into the delivery of care. The report was released by Montefiore Health System, the New York State Health Foundation, and UHF.

Pathways to Progress on Difficult Decisions in Post-Acute Care is the fourth report in UHF's "Difficult Decisions" series examining patient and family caregiver preferences and experiences related to decision-making options following a hospital stay.

Be sure to visit UHF's newly redesigned website at uhfnyc.org. Find information on our programs, sign up for email alerts, or make a tax-deductible gift. You can also follow us at:



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