UCLA UCLA Previously Published Works

Title

Better Off at Home — How We Fail Children with Complex Medical Conditions

Permalink

https://escholarship.org/uc/item/6vx4r5cx

Journal

New England Journal of Medicine, 388(3)

ISSN 0028-4793

Author Newcomer, Charles A

Publication Date 2023-01-19

DOI 10.1056/nejmp2213657

Peer reviewed

eScholarship.org

340B-covered hospitals without surveying hospitals on their acquisition costs. The result of the ruling is that reimbursement rates for all hospitals must be uniform. This decision has effectively caused CMS to revert to a reimbursement calculation of the ASP plus 6% and ended current attempts at cost control for 340Bcovered providers.

CMS will have to repay covered entities an estimated \$3.8 billion for lost Medicare revenue from 2018 and 2019, the years covered by the case. The agency's 2024 Hospital Outpatient Prospective Payment System rule will detail a remedy for underpayments for 2018 to 2022 and could result in an estimated \$13.2 to \$14.1 billion in total payments by CMS to 340B-covered providers.

Now that taxpayers will once again bear billions of dollars in payments related to the 340B program, it's worth evaluating whether this provision still confers a meaningful benefit for the public. When the program was established more than 30 years ago, it represented a limited remedy for a selected group of providers. Although advocates have imputed broad policy goals for the 340B program based on its original focus on safety-net providers, none of these goals were translated into statutory obligations for participating providers. Considering the broad and perverse effects this program has had on the organization and cost of health care, there seems to be little justification for maintaining it in its current form. At a minimum, we believe Congress should restore the lower payment rates for 340B-covered providers. Rather than set an arbitrary payment rate for 340B-participating hospitals, CMS could continue to base payments on the ASP but calculate the ASP separately for 340B-covered and noncovered providers, using data that it collects from manufacturers.

Beyond this change, policymakers could require providers to use 340B-related profits to address health disparities and improve care for underserved populations.⁵ Congress could also consider imposing obligations to remedy the program's financial harms, including addressing the toxic financial effects associated with cancer care by requiring 340B-covered providers to fully comply with hospital price-transparency requirements and restricting their ability to refer patients with cancer to debt collectors. Absent these changes, we believe policymakers should consider disbanding the 340B program. Given its negative reverberations for patients and markets, this approach may be the best path forward.

Disclosure forms provided by the authors are available at NEJM.org.

From the School of Medicine (W.K., K.S.), the Clinical Excellence Research Center (K.S.), and the Graduate School of Business (K.S.), Stanford University, Stanford, CA.

This article was published on January 14, 2023, at NEJM.org.

1. Conti RM, Bach PB. The 340B drug discount program: hospitals generate profits by expanding to reach more affluent communities. Health Aff (Millwood) 2014;33: 1786-92.

2. Fein AJ. The 340B program climbed to \$44 billion in 2021 — with hospitals grabbing most of the money. Drug Channels. August 15, 2022 (https://www.drugchannels .net/2022/08/the-340b-program-climbed-to -44-billion.html).

3. Conti RM, Bach PB. Cost consequences of the 340B drug discount program. JAMA 2013;309:1995-6.

4. Desai S, McWilliams JM. Consequences of the 340B drug pricing program. N Engl J Med 2018;378:539-48.

5. Nikpay SS, Buntin MB, Conti RM. Relationship between initiation of 340B participation and hospital safety-net engagement. Health Serv Res 2020;55:157-69.

DOI: 10.1056/NEJMp2212972 Copyright © 2023 Massachusetts Medical Society.

Better Off at Home — How We Fail Children with Complex Medical Conditions

Charles A. Newcomer, M.D.

"My child would be better off at home." At the outset of my career as a pediatric hospitalist at a major children's hospital, I would have dismissed a statement like that from a parent. While I would have admitted that improvements could always be made

at our hospital, I would have defended the wonderful care we provided. I would have attributed such a sentiment to the simple fact that hospitalizations were always going to be stressful for children and their families.

But 3 years ago, my husband

and I became fathers to a little boy with end-stage renal disease. Our son was on daily peritoneal dialysis in our home for more than 2 years before he received a deceased-donor kidney transplant. He was hospitalized 16 separate times before he turned 4 years old.

N ENGL J MED 388;3 NEJM.ORG JANUARY 19, 2023

The New England Journal of Medicine

Downloaded from nejm.org by Andy Newcomer on January 18, 2023. For personal use only. No other uses without permission.

Copyright © 2023 Massachusetts Medical Society. All rights reserved.

My husband, who is not a medical professional, expressed concerns about our son's care long before I did. Things that appeared to me to be routine mistakes seemed outrageous to him. Medications would be ordered incorrectly because the dialysis clinic's records weren't visible to the inpatient team. At times, rounds were conducted without our input. Doctors who didn't know our son well would provide conflicting explanations for complicated problems.

In spite of those issues, so many things were going right, and I knew how hard the team was working. "These things happen," I told my husband. Rather than trying to champion changes that would improve our son's care, I would instead try to help my husband work through his frustrations with mindfulness exercises. I would ask the social worker to talk to him. "He just needs more support," I would say. But then a few difficult experiences changed my perspective.

There was the time we were discharged home with the wrong concentration of Epogen (epoetin alfa) because our home concentration wasn't on the hospital's formulary. The numbers on the bottle were so small I didn't notice the change. To achieve the correct dose, we would have had to inject a significantly larger volume. Instead, we continued injecting the same volume we had given before the admission. When we checked our son's labs weeks later, his hemoglobin had dropped so low he was at risk for needing a transfusion. Fortunately, that didn't happen.

The next time he was hospitalized, we brought our home Epogen with us, but the pharmacist said she couldn't confirm that it had been stored properly in our house and insisted that we use the hospital's supply. But there was no way I could inject our son with such a large volume, so I secretly used our home supply and wasted the pharmacydispensed doses. I felt like a criminal doing it, especially because I myself had strongly advised my own patients' parents against giving medications that hadn't been verified by our pharmacy. It was, I'd told them naively, a patient-safety issue.

Months later, our son was admitted to the pediatric ICU for urgent dialysis to clear a toxic medication. We waited for several hours for the dialysis team to connect him, a delay that the dialysis staff would eventually blame on the pharmacy and that physicians would blame on the dialysis unit. The next morning, the attending discharged us after I pleaded with her to please let us go home, where I believed we could do dialysis more safely and efficiently. "He'll be better off with us," I told her.

It's true that children's hospitalizations are always difficult for families to bear. But the frequent and often prolonged hospitalizations faced by families of children with complex medical conditions have additional stressors: financial challenges, an increased risk of medical errors,¹ a substantial loss of privacy, and a constant upending of family routines. But one stressor that's perhaps the most painful is also one that is invisible to many physicians. We task families with keeping these fragile children safe at home, yet when they are sick enough to require hospitalization, we ask families to entrust their care to a network of providers who are not as familiar with

their needs and to an array of services and hospital policies that sometimes seem designed to do them harm.

My family's experiences have profoundly influenced my own practice of medicine and have shown me how we, as individual practitioners, need to change. They have also underscored the need for broader reforms that are critical to improving the care of children like my son. Some changes are admittedly simpler than others.

For instance, we as clinicians should always begin our rounds by asking parents about their concerns. We know that patientand family-centered rounds that take family concerns into account can reduce the risk of medical errors.² Family involvement in rounds is especially critical for children with complex medical conditions, who are disproportionately at risk for being harmed by such errors.³ The risk seemed particularly acute for our son when he was hospitalized with a respiratory illness and cared for by a team that was unfamiliar with his care. We were thankful for physicians who took the time to ask for our input, allowing us to correct errors or misunderstandings. Participating in this way also significantly reduced the stress we felt about the risk of harm.

We should also strive to spend more time with our patients and their families. My son gets better care when the team routinely comes to see him more than once a day. I still remember the pediatric intern who came to sit with us in the afternoons during his first prolonged hospitalization. Her visits were brief, but free from the pressure of rounds, we would remember to share de-

The New England Journal of Medicine

Downloaded from nejm.org by Andy Newcomer on January 18, 2023. For personal use only. No other uses without permission.

Copyright © 2023 Massachusetts Medical Society. All rights reserved.

tails with her that helped her better understand our son and his needs.

In addition, caregiver support programs should be continued during hospitalizations. Programs like California's In-Home Supportive Services (IHSS) provide families with critical financial relief that allows a family member to care for a child at home without a burdensome loss of income. Yet when children in the program are admitted to the hospital and are at their most vulnerable, IHSS stops paying and doesn't resume this financial support until discharge. Many of these families are already experiencing financial hardship, and this policy robs them of critical support at the precise time they need it most.

teams and hospitals caring for children like my son also need more support. It is long past time to increase reimbursement rates for Medicaid, which covers more than one third of children nationwide. Although Medicaid reimbursement rates vary by state, they are substantially lower than those for Medicare. This longstanding inequity has many downstream effects that disproportionately affect children with complex medical conditions. Although children lack the political power wielded by patients covered by Medicare, they need and deserve the same high-quality health care that Medicare patients receive.

Our son is now a joyful, thriving preschooler, but we know future hospitalizations are inevitable. It is our hope that we can be part of improving care for families like ours, so that the next time our son needs to be admitted, we can feel confident that he will truly be better off in the hospital.

Disclosure forms provided by the author are available at NEJM.org.

From UCLA Mattel Children's Hospital, Los Angeles.

This article was published on January 14, 2023, at NEJM.org.

1. Blaine K, Wright J, Pinkham A, et al. Medication order errors at hospital admission among children with medical complexity. J Patient Saf 2022;18(1):e156-e162.

2. Rosen P, Stenger E, Bochkoris M, Hannon MJ, Kwoh CK. Family-centered multidisciplinary rounds enhance the team approach in pediatrics. Pediatrics 2009;123(4): e603-e608.

3. Huth K, Vandecruys P, Orkin J, Patel H. Medication safety for children with medical complexity. Paediatr Child Health 2020;25: 473-4.

DOI: 10.1056/NEJMp2213657 Copyright © 2023 Massachusetts Medical Society.

Hope — Beyond Firearm Trauma

At the same time, health care

Selwyn O. Rogers, Jr., M.D., M.P.H.

s a trauma surgeon on the South Side of Chicago, I too often have to tell a parent, a child, a sibling, or a best friend that a bullet killed their loved one. In a sterile, eggshell-colored box of a room, I crowd in a chaplain, sometimes one of our violence-recovery specialists, and always a security officer, with no more than two family members or close friends. Why the security officer? We've learned that sometimes grief-stricken people become enraged and lunge at us or try to throw something - anything — maybe a chair. For that reason, the only furniture in the quiet room is four chairs; we have entertained the option of bolting them to the floor. Why

only two relatives or friends? We've found that the intensity of the grief is difficult enough to manage with two people, never mind a large clan.

Other times, a distraught mother or sister will let out the unmistakable shriek of despair, drop to her knees, and pound her fist into the concrete floor. One of the more surreal responses I get is silence: just a faraway stare, as if the person is looking past me. I have just told them in clear, succinct language that their son, daughter, father, mother, or friend is dead. I ask if there are any questions, and they mumble "no." Then they get up and walk out of the quiet room, and I never see them again.

Remarkably and fortunately, much more often than sharing the news of someone's death, I am informing people that their loved one was struck by bullets and suffered damage to organs, arms, or legs but will survive. I try to explain the anatomy of the liver or the small or large bowel. I explain what an ostomy is or how we fix a broken femur with a nail down its long axis. Sometimes I have to explain the nature of critical illness or how a ventilator works. In these interactions, I use every ounce of my skills and intuition to communicate clearly and to judge what the family's response is.

Sometimes, still, I'm faced with blank stares. Or raised eye-

N ENGL J MED 388;3 NEJM.ORG JANUARY 19, 2023

The New England Journal of Medicine

Downloaded from nejm.org by Andy Newcomer on January 18, 2023. For personal use only. No other uses without permission.

Copyright © 2023 Massachusetts Medical Society. All rights reserved.