

Links Between Financial Hardship and Out-of-Pocket Drug Costs

PAN'S POSITION ON COST SHARING AND ACCESS TO PRESCRIPTION MEDICATIONS

The Patient Access Network Foundation believes that cost sharing should not prevent anyone from obtaining medically necessary treatment.

Access to medically necessary healthcare is critical for successful patient outcomes, yet access is often impeded or blocked entirely by cost sharing. Despite its value as a tool to limit discretionary healthcare spending, cost sharing can create insurmountable barriers between patients and medications, diagnostic tests, office visits, surgery and other needed services. There are significant concerns that cost sharing limits access to medically necessary treatment for seriously ill and economically vulnerable patients and families.

This *Issue Brief* examines how out-of-pocket (OOP) drug costs cause financial hardship among economically vulnerable patients, and how financial assistance and other supports help alleviate some of these challenges.

STRATEGIES TO INCREASE ACCESS TO MEDICATIONS AMONG MEDICARE BENEFICIARIES

- » Put a “hard cap” on OOP costs once beneficiaries reach Part D’s catastrophic threshold.
- » Distribute OOP costs more evenly throughout the calendar year.
- » Ensure that health conditions have at least one effective drug that is not on a specialty tier.

Out-of-Pocket Drug Costs Cause Financial Hardship for Many Americans

Although advances in biotechnology have facilitated development of exciting new treatments for many health conditions, accessing these medications leads to financial hardship for some patients because of

high OOP costs. These patients must often choose between paying OOP costs for life-saving medications, or covering the costs of basic needs like food, rent and utilities.

Data from the National Center for Health Statistics showed that in 2013, 7.8% of adults who took prescription medications reported not taking their medications as directed to save money, with adults aged 18–64 being about twice as likely as adults over the age of 65 to report saving money by not taking their medications as prescribed (8.5% vs. 4.4%).¹ High OOP medication costs have a disproportionate impact on economically vulnerable families. A 2015 report from the Kaiser Family Foundation showed that overall, 24% of all Americans reported having problems paying for their prescription drugs. This figure increased to 33% among people with low incomes, and to 43% among those in poor health.²

Research on the financial hardships associated with accessing prescription medications has addressed many areas of clinical care, and the concept of “financial toxicity” has been a particular focus in cancer research.^{3,4,5} A review of 45 studies on financial hardship among cancer survivors showed that as many as 62% of survivors reported being in debt because of their treatment, nearly 50% of survivors reported experiencing some form of financial distress, and as many as 45% of survivors did not adhere to recommended prescription medication because of cost.⁶ Nationally representative studies of cancer patients show that those who do not receive all necessary cancer care are more likely to be publicly insured or uninsured, and that financial pressures place younger patients at especially high risk of needing to make changes in their prescription drug use such as skipping doses, taking less medication or delaying filling a prescription.^{7,8} It is important to emphasize that medications are only one source of OOP cancer costs, and many patients are concerned about these costs across the life of their treatment. Addressing these concerns will almost certainly require new ways of thinking about how care is provided and paid for.⁹

Financial hardships associated with OOP drug costs are not limited to patients with cancer. Burdens associated with OOP drug costs have been described for a multitude of other conditions such as multiple sclerosis, hemophilia, and hepatitis C, among others.^{10,11,12} These hardships force patients to make difficult decisions about their health. Kaiser Family Foundation data show that among Americans who reported problems paying household medical bills in the past 12 months, 32% reported skipping doses of medication or cutting pills in half, 38% reported choosing a less expensive treatment than the one their doctor recommended and 41% reported they chose not to fill a prescription.¹³ Although the Affordable Care Act resulted in a sharp drop in OOP drug costs between 2010 and 2011, these costs are once again on the rise, with particularly high burdens among people who need brand name drugs.^{14,15}

Sources and Impact of Assistance for Out-of-Pocket Drug Costs

Some patients who have trouble covering their OOP medication costs can ease the burden of these costs by securing financial assistance or other help from outside sources. Without this support, these patients would be unable to access treatment, or they would need to forgo basic necessities to pay for their prescription drugs. When insurance is inadequate to cover OOP drug costs, alternate sources of financial support provide a much-needed safety net for people who would otherwise be unable to access needed treatment.¹⁶

Medicare Low Income Subsidies

Medicare beneficiaries with very few assets (savings, investments and real estate valued at <\$28,150 for a married person or <\$14,100 for a single person) can qualify for a low-income subsidy (LIS, sometimes called “Extra Help”) to help cover OOP costs for prescription drugs.¹⁷ The purpose of the LIS is to shield low-income beneficiaries from high OOP healthcare costs—especially costs related to prescription medications.¹⁸ Research has shown that Medicare beneficiaries who qualified for the LIS are more likely to initiate an expensive, life-saving cancer treatment compared to beneficiaries who do not qualify for this assistance.¹⁹ Importantly, the beneficial impact of the LIS on access to prescription medications is not limited to expensive medications; it is also evident for health conditions that are treated with less expensive drugs such as diabetes.²⁰

State Pharmaceutical Assistance Programs

Many states offer State Pharmaceutical Assistance Programs (SPAPs), and these are often coordinated with Medicare Part D drug plans to help eligible people pay for prescription drugs. SPAPs work differently in each state, and in many cases, these programs focus on supporting residents’ coverage of drug costs for certain illnesses like HIV/AIDS or end stage renal disease.²¹ These programs were facilitating access to medications in many states before Medicare began offering coverage for prescription drugs,²² and they continue to provide a much-needed safety net that allows older and disabled adults to access prescription medications.²³

340B Program

The Health Resources and Services Administration works with the American Pharmacists Association to help safety net providers—hospitals and health systems that provide a significant amount of care to low-income, uninsured and otherwise vulnerable people—to deliver pharmacy services through the 340B program.^{24,25} These programs support patients by facilitating access to prescription medications that

are available to the providers at a discounted price.²⁶ Although needy patients do not interact with this program directly, when they receive care from a 340B provider, patients receive programmatic benefits through significantly lower medication costs. There is ample evidence that this program facilitates access to medications, even for conditions like cancer that often require costly medications.^{27,28}

Pharmaceutical Manufacturer Coupons

Pharmaceutical companies sometimes offer coupons or other discounts for certain drugs, but these coupons cannot be used by people with government-sponsored insurance like Medicare.²⁹ Despite these restrictions, coupon programs facilitate access to costly medications, and many advocacy organizations assist their constituents in accessing needed medications by connecting patients with these programs.^{30,31,32} Recently, third-party payers and pharmacy benefit managers have started “accumulator adjustor” programs that prevent the application of drug manufacturer coupons and discount cards toward patient OOP costs, thereby creating additional financial hardship by limiting the OOP cost protections that these coupons are intended to provide.

Charitable Foundations

Certain charitable organizations can provide financial support to people who have problems covering their OOP drug costs.^{33,34} Unlike pharmaceutical coupon programs, these charitable organizations are able to provide financial support to anyone—including people with federal insurance—through targeted, disease-specific funds. As a result, they can facilitate access to needed medications for low-income people of all ages, including people who are insured by Medicare and Medicaid. These charitable organizations are a last resort for many patients who were unable to cover their OOP medication costs in other ways. They are especially important for patients with cancer and other conditions whose treatment calls for expensive medications for which less expensive alternatives are not available.^{35,36} A survey of nearly 1,900 patients conducted by the PAN Foundation showed that among patients who received financial support for their OOP medications, 59% reported that the support allowed them to continue on their treatment, 54% reported that the support helped them focus more on their health and 51% reported that it reduced their level of stress.³⁷

Community-based Resources

In some areas, needy patients receive support from local organizations like hospitals or health systems where they receive care, and this support can include help with prescription medications. Although there are many examples of these hospital-based patient assistance programs,^{38,39,40} these programs are often

relatively small, and they are therefore able to help only a few patients. Some religious organizations also offer modest levels of support to cover the cost of prescription medications, but the level of this support is also relatively modest.^{41,42,43}

Financial Navigation

Patient navigators with expertise in the financial aspects of healthcare access can also be a resource to patients who have problems affording their medications. These financial navigators are increasingly found in settings that provide care for cancer patients, but financial navigation services are also available through some patient advocacy organizations.^{44,45,46,47} The growing importance of financial navigation is reflected in the increased availability of online programs designed to train people to fulfill this important role.⁴⁸

NeedyMeds

NeedyMeds is a national nonprofit organization that maintains a website of free information on programs that help people who can't afford medications and healthcare costs. More than 1.3 million patients, family members, healthcare professionals, social workers and patient advocates use the NeedyMeds website each year. The organization provides information and education on a wide variety of programs that assist uninsured and underinsured Americans. These include pharmaceutical patient assistance programs, diagnosis-based assistance, help with completing patient assistance program applications, diagnosis-based assistance and government programs.⁴⁹

The PAN Foundation

The PAN Foundation is an independent, national 501 (c)(3) organization dedicated to helping federally and commercially insured people living with life-threatening, chronic and rare diseases with the OOP costs for their prescribed medications. PAN provides the underinsured population access to the healthcare treatments they need to best manage their conditions and focus on improving their quality of life. Since its founding in 2004, PAN has provided nearly 1 million underinsured patients over \$3 billion in financial assistance through more than 60 disease-specific programs.

For more information about this *Issue Brief*, contact Amy Niles, Vice President of External Affairs, at aniles@panfoundation.org.

Supporting Literature

- ¹ Cohen RA, Villarroel MA. Strategies used by adults to reduce their prescription drug costs: United States, 2013. NCHS data brief, no 184. Hyattsville, MD: National Center for Health Statistics. 2015.
- ² Kaiser Health Tracking Poll: August 2015. Available at: <https://www.kff.org/health-costs/poll-finding/kaiser-health-tracking-poll-august-2015/> (accessed February 6, 2018).
- ³ de Souza JA, Yap BJ, Hlubocky FJ, Wroblewski K, Ratain MJ, Cella D, Daugherty CK. The development of a financial toxicity patient-reported outcome in cancer: The COST measure. *Cancer*. 2014 Oct 15;120(20):3245-53
- ⁴ de Souza JA, Yap BJ, Wroblewski K, Blinder V, Araújo FS, Hlubocky FJ, Nicholas LH, O'Connor JM, Brockstein B, Ratain MJ, Daugherty CK, Cella D. Measuring financial toxicity as a clinically relevant patient-reported outcome: The validation of the COverprehensive Score for financial Toxicity (COST). *Cancer*. 2017 Feb 1;123(3):476-484.
- ⁵ de Souza JA, Conti RM. Mitigating Financial Toxicity Among US Patients With Cancer. *JAMA Oncol*. 2017 Jun 1;3(6):765-766.
- ⁶ Altice CK, Banegas MP, Tucker-Seeley RD, Yabroff KR. Financial Hardships Experienced by Cancer Survivors: A Systematic Review. *J Natl Cancer Inst*. 2016 Oct 20;109(2).
- ⁷ de Moor J, Virgo KS, Li C, Chawla N, Han X, Blanch-Hartigan D, Ekwueme DU, McNeel TS, Rodriguez JL, Yabroff KR. Access to Cancer Care and General Medical Care Services Among Cancer Survivors in the United States
An Analysis of 2011 Medical Expenditure Panel Survey Data. *Public Health Rep*. 2016 Nov-Dec; 131(6): 783–790.
- ⁸ Zheng Z, Han X, Guy GP Jr, Davidoff AJ, Li C, Banegas MP, Ekwueme DU, Yabroff KR, Jemal A. Do cancer survivors change their prescription drug use for financial reasons? Findings from a nationally representative sample in the United States. *Cancer*. 2017 Apr 15;123(8):1453-1463.
- ⁹ Zafar SY, Newcomber LN, McCarthy J, Nasso SF, Saltz LB. How Should We Intervene on the Financial Toxicity of Cancer Care?. ASCO Connection. Available at: <https://connection.asco.org/magazine/current-controversies-oncology/how-should-we-intervene-financial-toxicity-cancer-care>. (accessed February 13, 2018).
- ¹⁰ Owens GM. Economic Burden of Multiple Sclerosis and the Role of Managed Care Organizations in Multiple Sclerosis Management. *Am J Manag Care*. 2016;22:S151-S158.
- ¹¹ Elder-Lissai A, Hou Q, Krishnan S. The Changing Costs of Caring for Hemophilia Patients in the U.S.: Insurers' and Patients' Perspectives. Presented at: American Society of Hematology Annual Meeting; December 6-9, 2014; San Francisco, CA. Reviewed at: <http://www.raredr.com/news/cost-hemophilia-care> (accessed February 6, 2017).
- ¹² Hoadley J, Neuman T, Cubanski J. The cost of a cure: Revisiting Medicare Part D and hepatitis C. Health Affairs Blog, November 3, 2016. DOI: 10.1377/hblog20161103.057356
- ¹³ Cost-sharing Roundtable: Improving Patient Access to Critical Therapies. Proceedings Report. Available at: https://panfoundation.org/files/PAN_CostSharingRoundtable_FullReport.pdf (accessed February 6, 2018)
- ¹⁴ <https://www.kff.org/infographic/10-essential-facts-about-medicare-and-prescription-drug-spending/> (accessed January 25, 2018).
- ¹⁵ Hoadley J, Cubanski J, Neuman T. Medicare Part D in 2016 and Trends over Time. Available at: <http://files.kff.org/attachment/Report-Medicare-Part-D-in-2016-and-Trends-over-Time> (accessed February 2, 2018).
- ¹⁶ Johnson PE. Patient assistance programs and patient advocacy foundations: Alternatives for obtaining prescription medications when insurance fails. *Am J Health Sys Pharm* 2006;63(21 Supplement 7):S13-S17.
- ¹⁷ Extra Help with Medicare Prescription Drug Plan Costs <https://secure.ssa.gov/i1020/start> (accessed February 6, 2018).
- ¹⁸ Briesacher BA, Ross-Degnan D, Wagner AK, et al. Out-of-Pocket Burden of Healthcare Spending and the Adequacy of the Medicare Part D Low-Income Subsidy. *Medical care*. 2010;48(6):503-509.
- ¹⁹ Doshi JA, Li P, Huo H, Pettit AR, Kumar R, Weiss BM, Huntington SF. High cost sharing and specialty drug initiation under Medicare Part D: a case study in patients with newly diagnosed chronic myeloid leukemia. *Am J Manag Care*. 2016 Mar;22(4 Suppl):s78-86.
- ²⁰ Stuart Bruce, Xianghua Y, Davidoff A, Simoni-Wastila L, Zuckerman I, Shoemaker JS, Doshi J. Impact of Part D Low-income Subsidies on Medication Patterns for Medicare Beneficiaries With Diabetes. *Med Care*. 2012 Nov;50(11):913–919.
- ²¹ <https://www.medicareinteractive.org/pdf/SPAP-Chart.pdf> (accessed February 6, 2018)
- ²² Safran DG, Neuman P, Schoen C, Kitchman MS, Wilson IB, Cooper B, Li A, Chang H, Rogers WH. Prescription drug coverage and seniors: findings from a 2003 national survey. *Health Aff (Millwood)*. 2005 Jan-Jun;Suppl Web Exclusives:W5-152-W5-166.

- ²³<https://www.medicareinteractive.org/pdf/SPAP-Chart.pdf> (accessed February 7, 2018).
- ²⁴340B Drug Pricing Program. Available at: <https://www.hrsa.gov/opa/index.html> (accessed February 7, 2018).
- ²⁵<http://www.pharmacist.com/change-air-apha-awarded-hrsa-contract> (accessed February 7, 2018).
- ²⁶America's Essential Hospitals. <http://essentialhospitals.org/wp-content/uploads/2016/03/Our-View-340B-March-2016.pdf>. (accessed February 7, 2018).
- ²⁷Castellon YM, Bazargan-Hejazi S I, Masatsugu M, Contreras R. The impact of patient assistance programs and the 340B Drug Pricing Program on medication cost. *Am J Manag Care* 2014 Feb;20(2):146-150.
- ²⁸Kantarjian H, Chapman R. Value of the 340B Drug Discount Program. *JAMA Oncol*. 2015;1(8):1029-1030.
- ²⁹Office of the Inspector General, Department of Health and Human Services. https://oig.hhs.gov/fraud/docs/alertsandbulletins/2014/sab_copayment_coupons.pdf (accessed February 6, 2017).
- ³⁰American Cancer Society. <https://www.cancer.org/treatment/finding-and-paying-for-treatment/understanding-health-insurance/if-you-have-trouble-paying-a-bill/prescription-drug-assistance-programs.html> (accessed February 7, 2018).
- ³¹Hemophilia Federation of America. <http://www.hemophiliafed.org/resource-library/additional-resources/navigating-patient-assistance-programs/> (accessed February 7, 2018).
- ³²American Diabetes Association. <http://www.diabetes.org/living-with-diabetes/health-insurance/prescription-assistance.html?referrer=https://www.google.com/> (accessed February 7, 2018).
- ³³Patient Access Network Foundation. <https://panfoundation.org/index.php/en/> (accessed February 7, 2018).
- ³⁴Healthwell Foundation. <https://www.healthwellfoundation.org/> (accessed February 7, 2018).
- ³⁵Patient Access Network Foundation. <https://panfoundation.org/files/PAN-Issue-Brief-3.pdf> (accessed February 7, 2018).
- ³⁶Resnick HE, Barth B, Klein D: Charitable Assistance Among Economically Vulnerable Cancer Patients: Patient Access Network Foundation Summary Statistics 2011-2015. Evidence-based Oncol Available at: <http://www.ajmc.com/journals/evidence-based-oncology/2016/august-2016/charitable-assistance-among-economically-vulnerable-cancer-patients-patient-access-network-foundation-summary-statistics-2011-2015/p-1> (accessed February 7, 2018).
- ³⁷Patient Access Network Foundation. <https://panfoundation.org/files/PAN-Issue-Brief-3.pdf> (accessed February 7, 2018).
- ³⁸Passavant Hospital Foundation. Patient Assistance Fund. Available at: <http://www.passavanthospitalfoundation.org/resources/patient-assistance-fund>. (accessed March 13, 2018).
- ³⁹Craig Foundation Patient Assistance Funds. Available at: <https://craighospital.org/foundation/patient-assistance-funds>. (accessed February 13, 2018).
- ⁴⁰St. Clair Hospital Patient Assistance Fund. Available at: <https://www.stclair.org/giving/support/patient-assistance-fund>. (accessed March 13, 2018).
- ⁴¹Catholic Charity financial assistance. Available at: http://www.needhelpayingbills.com/html/catholic_charities_financial_a.html (accessed March 13, 2018).
- ⁴²St. Pius X Catholic Church Medication Assistance Program. Available at: <https://stpiusxc.org/77>. (accessed March 13, 2018).
- ⁴³Jewish Federations of North America assistance programs. Available at: http://www.needhelpayingbills.com/html/jewish_federation_financial_as.html. (accessed March 13, 2018).
- ⁴⁴Yezeffski T, Steelquist J, Watabayashi K, Sherman D, Shankaran V. Impact of Trained Oncology Financial Navigators on Patient Out-of-Pocket Spending. Available at: <http://www.ajmc.com/journals/supplement/2018/the-patient-assistance-safety-net-how-many-need-help-how-many-are-helped/impact-of-trained-oncology-financial-navigators-on-patient-outofpocket-spending>. (accessed February 13, 2018).
- ⁴⁵JCP Editors: Financial navigators to address cancer cost concerns. *Journal of Clinical Pathways*. 2017;3(7):21-22.
- ⁴⁶Sherman D. Oncology financial navigators: Integral members of the multidisciplinary cancer care team. Available at: <https://www.accc-cancer.org/docs/Documents/oncology-issues/articles/SO14/so14-oncology-financial-navigators>. (accessed February 13, 2018).
- ⁴⁷National Multiple Sclerosis Society. Resources and Support. Available at: <https://www.nationalmssociety.org/Resources-Support>. (accessed March 13, 2018).
- ⁴⁸Hagen T: A boot camp opens for oncology financial navigators. Available at: <http://www.onclive.com/web-exclusives/a-boot-camp-opens-for-oncology-financial-navigators>. (accessed February 13, 2018).
- ⁴⁹<https://www.needymeds.org/> (accessed February 13, 2018).