



Community Health Worker Navigation for Patients With Cancer: It Is Time to Scale up

Kerin Adelson, MD, MHCDS¹  and Gabrielle Rocque, MD, MSPH^{2,3} 

DOI <https://doi.org/10.1200/JCO.23.01723>

Cancer negatively affects health-related quality of life (QOL). The diagnosis itself is associated with fear and anxiety. Interactions with the health care team are often uncoordinated and confusing. Communication often fails so that there is discordance between provider intent and patient comprehension. Cancer treatment can result in physical burdens and side effects, time toxicity associated with treatments and procedures, financial toxicity related to medical expenses and income reduction, and emotional challenges as the ability to maintain personal and familial responsibilities is diminished. Furthermore, when physical symptoms or social stressors progress beyond a patients' coping ability, she or he may turn to emergency departments for relief, where about 70% of the time they will be admitted to the hospital (three times higher than the noncancer population).¹ In the inpatient environment, personal autonomy may be subjugated by rigid hospital systems and schedules, further harming QOL. Near the end of life, acute care drives up cost, too often with little or no clinical benefit. Interventions that break this cycle are critically needed.

These challenges are compounded for low-income, minority, and non-English speaking patients. Social determinants of health have a profound impact on cancer care outcomes. From 2016 to 2020, 216 Black patients per 100,000 died of cancer in the United States compared with 149 White patients, despite lower overall cancer incidence.² Furthermore, individuals living in counties with persistent poverty have higher mortality in multiple cancer types.³ Although these disparities are long-standing, multifactorial, and challenging to address, a key first step is recognition that health is not only defined by disease and treatment but also the complex interplay between biological, behavioral, built environment, sociocultural environment, and the health care system (National Institute of Minority Health and Health Disparities Research Framework).⁴ There is an urgent need to reduce burdens of cancer treatment by overcoming structural barriers to care—ensuring QOL is maintained and patients with cancer can live, work, and have meaningful social interactions with their family and community.

In the accompanying article by Patel et al,⁵ patients recently diagnosed with a new or recurrent hematologic malignancy or solid tumor and belonging to an employer union health fund serving low-income racial and ethnic minority low-wage workers in Atlantic City and Chicago were randomly assigned to usual care or a community health worker (CHW) intervention. Usual care included outpatient oncology services and case management by a union-employed nurse. The CHW intervention group received usual care plus weekly telephonic contact for 4 months, followed by monthly for 12 months or until death. This included advanced care planning education in the patients' preferred language, the Edmonton Symptom Assessment System with triage to a union nurse for intervention, and screening for health-related social needs with referral to community-based programs. Study results were impressive; intervention patients had significantly improved health-related QOL, reduced frequency of emergency department and hospital use, and lower total cost of care than the usual care arm. This result must be considered in the context of additional work by this group, which has demonstrated equally impressive results for similar interventions in other populations, including Medicare Advantage,⁶ privately insured,⁷ and a predominantly White Veteran population.⁸

What is the recipe that explains these trials' success? Surely, assigning a patient a CHW alone is not a magic bullet for overcoming all of the ills in health care. In this trial, there were two main interventions: First, both the intervention and control arm received a redesign of their health insurance benefit to encourage patients to visit a single academic health system in their city. Second, for patients in the intervention arm, CHWs focused their time on proactive symptom

ACCOMPANYING CONTENT

 [Article, p. 518](#)

Accepted September 20, 2023

Published January 4, 2024

J Clin Oncol 42:491-493

© 2024 by American Society of
Clinical Oncology



[View Online
Article](#)

THE TAKEAWAY

In the article that accompanies this editorial, Patel et al⁵ demonstrate that low-income minority patients with cancer randomly assigned to a community health worker intervention had significantly improved health related quality of life (QOL), reduced frequency of emergency department and hospital use, and lower total cost of care than patients who did not receive this additional support. In recognition that community-based navigation interventions such as Patel's can greatly improve patient outcomes, Centers for Medicare & Medicaid Services recently established a new billing mechanism for this service, in turn creating a moral obligation for cancer care delivery organizations to implement similar programs that will improve QOL, empower patients, and reduce acute care use and cost.

screening, advanced care planning, and community resource navigation. The incorporation of these elements into one intervention builds on concepts shown to be effective in previous trials. Basch et al⁹ showed that proactive collection of patient-reported outcomes (PROs) led to improved QOL, reduced acute care utilization, and improved survival. Temel et al¹⁰ showed that early use of palliative care lead to better QOL, lower health care utilization at the end of life, and improved survival. At the University of Alabama at Birmingham, patients working with a nonclinical navigator had declines in emergency room visits, hospitalization, and intensive care unit admissions, as well as reduction in costs, when compared with non-navigated patients.¹¹ Ultimately, symptom monitoring, palliative care, and navigation are naturally aligned, and Patel et al⁵ should be applauded for successfully blending these into one multilevel intervention.

What went on in the interactions between the CHWs and the patients? It would be fascinating to see a qualitative thematic analysis of these conversations. However, by reporting on patient activation and decision satisfaction scales, the authors do provide a viewing window. The CHW group had substantial increases in patient activation scores (4 v 24 points). Intervention patients had three times higher odds of overall satisfaction with decisions, feeling adequately informed and that their decisions were the best possible, consistent with their personal values, and were theirs to make. This suggests that the CHWs improved communication by facilitating understanding of diagnosis, treatment, and options—ultimately enhancing patients' sense of empowerment and control. Of note, the symptom screening was completed directly by the CHW over the telephone. Telephonic care management can bridge travel barriers and allow for more proactive and timely responses than when care is limited to in-person appointments. Although many PRO interventions are attempting to automate collection electronically, this study begs the question whether PROs administered by a trusted advocate may provide a meaningful alternative.

With this wealth of evidence, one might expect that adoption of programs like this one would be rapid. This has not been the case. Why not? Deploying complex multilevel interventions is hard. Success requires attention to intractable

patient-level, cultural, economic, and governmental policy issues. This often requires developing new infrastructure and systems. Specifically, to improve the feasibility of this intervention, Patel et al⁵ redesigned the health insurance benefit to financially support CHW services and encourage patients to get care from a single academic center in their city, enhancing coordination between the CHW and cancer care team. Such benefit redesign is not feasible for most patients. For patients living in rural areas, there is often not a single cancer center but a collection of small practices within a broad geographic radius. We must ask whether pulling a patient out of their local care delivery network is optimal? Could this lead to loss of coordination between the patient and his or her primary care team and other providers?

Scaling this intervention to an entire cancer population will present challenges to intervention fidelity. In this study, only 80 patients received the intervention. Population-level expansion would require exponential increase in staffing, which will make oversight more difficult. This program provided the intervention in patients' native language, which inevitably contributed to the impressive improvements in patient activation. To scale this nationally, identifying CHWs proficient in all languages will be critical. Large-scale implementation work is needed to provide a blueprint for how this intervention can be delivered not only to diverse patients but also across diverse health systems with unique cultures and resource limitations.

Perhaps the most important implementation barrier is financial. Historically, there has been no payment mechanism that would support navigation. Although using nonclinical members of the health care team can free up time for clinical team members to work at the top of their license, investing in FTEs without a direct revenue stream remains a challenging business case for today's cash-strapped hospitals and practices. A solution may come in the coming year; Centers for Medicare & Medicaid Services (CMS) has developed a new billing code for health system coordination, promoting patient self-advocacy and facilitating access to community-based resources to address unmet social needs.¹² However, single payer interventions are challenging in real-world practice where clinician adoption requires an understanding that any complex new process can be used by all patients. Thus, it will be

critical that commercial payers and self-insured employers also support CHW and navigation services.

We are hopeful that CMS' new support for community health and navigation will facilitate dissemination and adoption of models like Patel's.⁵ Once this payment mechanism is in

place and assuming it is adequate to support the intensity of coordination services needed, cancer care delivery organizations will have a moral obligation to implement programs that have been shown to improve QOL, empower patients, and reduce acute care use and cost—all essential to helping close the disparity gap.

AFFILIATIONS

¹University of Texas, MD Anderson Cancer Center, Houston, TX

²University of Alabama at Birmingham, Department of Medicine, Division of Hematology and Oncology, Birmingham, AL

³O'Neal Comprehensive Cancer Center, Birmingham, AL

CORRESPONDING AUTHOR

Kerin Adelson, MD, MHCDS, University of Texas, MD Anderson Cancer Center, 1515 Holcombe Blvd, Houston, TX 77030; e-mail: kbadelson@mdanderson.org.

SUPPORT

G.R. is supported by a National Institute of Nursing Research R01 grant (1R01NR019058-01).

REFERENCES

- Christodoulou I, Ukert B, Vavuranakis MA, et al: Adult cancer-related emergency department utilization: An analysis of trends and outcomes from emergency departments in Maryland and New York. *JCO Oncol Pract* 19:e683-e695, 2023
- Cancer Stat Facts. National Cancer Institute. <https://seer.cancer.gov/statfacts/html/all.html>
- Moss JL, Pinto CN, Srinivasan S, et al: Persistent poverty and cancer mortality rates: An analysis of county-level poverty designations. *Cancer Epidemiol Biomarkers Prev* 29:1949-1954, 2020
- National Institute on Minority Health and Health Disparities. 2017. NIMHD Research Framework. <https://nimhd.nih.gov/researchFramework>
- Patel MI, Kapphahn K, Wood E, et al: Effect of a community health worker-led intervention among low-income and minoritized patients with cancer: A randomized clinical trial. *J Clin Oncol* 42:518-528, 2024
- Patel MI, Ramirez D, Agajanian R, et al: Lay health worker-led cancer symptom screening intervention and the effect on patient-reported satisfaction, health status, health care use, and total costs: Results from a tri-part collaboration. *JCO Oncol Pract* 16:e19-e28, 2020
- Patel MI, Kapphahn K, Dewland M, et al: Effect of a community health worker intervention on acute care use, advance care planning, and patient-reported outcomes among adults with advanced stages of cancer: A randomized clinical trial. *JAMA Oncol* 8:1139-1148, 2022
- Patel MI, Agrawal M, Kapphahn K, et al: Engagement of Patients with Advanced Cancer (EPAC) randomized clinical trial: Long-term effects on survival and healthcare use. *J Clin Oncol* 41, 2023 (suppl 16; abstr 1513)
- Basch E, Deal AM, Kris MG, et al: Symptom monitoring with patient-reported outcomes during routine cancer treatment: A randomized controlled trial. *J Clin Oncol* 34:557-565, 2016 [Erratum: *J Clin Oncol* 34:2198, 2016; *J Clin Oncol* 37:528, 2019]
- Temel JS, Greer JA, Muzikansky A, et al: Early palliative care for patients with metastatic non-small-cell lung cancer. *N Engl J Med* 363:733-742, 2010
- Rocque GB, Pisu M, Jackson BE, et al.: Resource use and Medicare costs during lay navigation for geriatric patients with cancer. *JAMA Oncol* 3:817-825, 2017
- CMS physician payment rule advances health equity. Centers for Medicare & Medicaid services. 2023. <https://www.cms.gov/newsroom/press-releases/cms-physician-payment-rule-advances-health-equity>

AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

Disclosures provided by the authors are available with this article at DOI <https://doi.org/10.1200/JCO.23.01723>.

AUTHOR CONTRIBUTIONS

Conception and design: All authors

Manuscript writing: All authors

Final approval of manuscript: All authors

Accountable for all aspects of the work: All authors

AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

Community Health Worker Navigation for Patients With Cancer: It Is Time to Scale Up

The following represents disclosure information provided by authors of this manuscript. All relationships are considered compensated unless otherwise noted. Relationships are self-held unless noted. I = Immediate Family Member, Inst = My Institution. Relationships may not relate to the subject matter of this manuscript. For more information about ASCO's conflict of interest policy, please refer to www.asco.org/rwc or ascopubs.org/jco/authors/author-center.

Open Payments is a public database containing information reported by companies about payments made to US-licensed physicians ([Open Payments](#)).

Kerin Adelson

Employment: Emilio Health/Brightline Health (I)

Leadership: Emilio Health/Brightline Health (I)

Stock and Other Ownership Interests: Lyra Health (I), MindNest Health (I), Carrum Health, Emilio Health/Brightline Health (I), Kynnyx

Consulting or Advisory Role: AbbVie (\$10,000 USD or above in a single calendar year), Quantum Health (\$10,000 USD or above in a single calendar year)

Patents, Royalties, Other Intellectual Property: Genentech

Other Relationship: Genentech/Roche

Gabrielle Rocque

Consulting or Advisory Role: Pfizer (\$10,000 USD or above in a single calendar year), Gilead Sciences (\$10,000 USD or above in a single calendar year)

Research Funding: Genentech, Pfizer, Daiichi Sankyo/Astra Zeneca

Travel, Accommodations, Expenses: Gilead Sciences

No other potential conflicts of interest were reported.