Advancing Rural Cancer Control Research: National Cancer Institute Efforts to Identify Gaps and Opportunities

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ABSTRACT

Cancer mortality rates are approximately 8% higher in rural populations and mortality rates are falling more slowly in rural communities, resulting in widening rural-urban health disparities in the United States. The NCI has a long history of supporting health disparities research, including research to understand the health needs, strengths, and opportunities in rural communities. However, the portfolio analysis described in this article underscores the need to significantly accelerate rural cancer control research in partnership with state and local communities. This commentary outlines NCI's efforts over the last four years to address gaps in rural cancer control research and improve cancer prevention, control, and care delivery in rural populations. Future directions, challenges, and opportunities are also discussed.

Introduction

Through the dissemination of advanced medical innovations and the focused efforts of policymakers, the public health, and health care communities, overall cancer mortality in the United States is declining (1). While progress against cancer should be celebrated, cancer remains a leading cause of death in rural populations (2). According to analyses by the Centers for Disease Control and Prevention (CDC), age-adjusted mortality rates for all cancer sites combined decreased in both nonmetropolitan and metropolitan counties from 2006 to 2015, although death rates decreased at a slower pace in nonmetropolitan (rural) counties than in urban counties (3). This disparity likely reflects the care access, socioeconomic, environmental, and psychosocial factors that serve as barriers to cancer prevention and control in rural communities (4, 5). Recognizing the need and opportunity to address these cancer mortality disparities and related barriers through research, the NCI has worked to stimulate and support a new frontier of rural cancer control research efforts. This commentary outlines NCI's efforts over the last four years to address gaps in rural cancer control research and improve cancer prevention, control, and care delivery in rural populations.

While NCI has a long history of promoting rural cancer control research, a 2017 review was conducted of the NCI's Division of Cancer Control and Population Sciences (DCCPS) research portfolio, NCI's primary division that conducts rural health research. The portfolio analysis revealed that only 48 R-mechanism (research) grants focused on rural populations were awarded between fiscal years 2011 and 2016 (6). These awards represented 3% of the DCCPS portfolio during that time and only 29 of the 48 grants focused solely on rural areas. With this insight, NCI sought an opportunity to understand better the definitional and measurement challenges of rural health research. Therefore, NCI held a 1-day meeting titled "Understanding the Definitions of Rural/Rurality: Implications for Rural Cancer Control" in October 2017. This meeting brought together speakers and stakeholders from multiple agencies [e.g., U.S. Department of Agriculture (USDA), U.S. Census Bureau, Federal Office Rural Health Policy (FORHP), CDC] to discuss the different Federal definitions of "rural," strengths and limitations of each definition, and example use cases.

In addition, NCI also undertook several activities designed to further understand rural health research challenges, identify gaps in rural cancer control research, and build partnerships to address identified research opportunities. For example, NCI participated in a May 2017 workshop held at the University of Memphis focused on "Rural Cancer Control: Challenges and Opportunities." The workshop brought together researchers and other stakeholders to identify and discuss novel advances in cancer control research potentially relevant to rural populations. In alignment with this workshop NCI, led by DCCPS, also conducted a two-phase concept mapping survey in 2017 to understand opportunities for implementation science in rural cancer prevention and control research. Responses from 42 rural research leaders from academic, practice, nonprofit advocacy and government settings highlighted eight priority areas for dissemination and implementation research in rural areas. Priority areas included research examining and leveraging data and technology, efforts to define the rural cancer control research context, adapting research approaches to examine sustainability and longer-term project periods, using multilevel and systems approaches, engaging local rural partners and building trust, adapting models of care and definitions of access, identifying care and access issues, and coordination of preventive services and self-care. A detailed report discussing synthesis methods and each theme can be found on the NCI DCCPS Rural Cancer Control website: https://cancercontrol.cancer.gov/research-emphasis/rural.html.

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Efforts by NCI to identify challenges and priority areas also included hosting a Rural Cancer Control Research Conference in May 2018. The conference resulted in discussion and recommendations within five key thematic areas including: defining rural populations, surveillance and epidemiologic research focused on the multilevel granularity of regional data and heterogeneity across rural communities, methodologic challenges, multilevel interventions, and the role of implementation science in rural cancer control. Details of these meeting recommendations are discussed in Kennedy and colleagues (7).

Building Rural Cancer Control Research Capacity

The activities and conversations resulting from DCCPS's portfolio analyses and convening exercises spurred engagement from NCI's ongoing Cancer Centers Program, which supports 71 NCI-designated cancer centers through the P30 center core grant mechanism. In 2016, NCI's Population Health Assessment in Cancer Center Catchment Areas Initiative awarded supplemental funding to 15 NCI-designated Cancer Centers to enhance their capacity to acquire, aggregate, and integrate data from multiple sources in their respective catchment areas. A rural working group consisting of eight of the 15 cancer centers came together to streamline their data collection efforts and discuss ways in which NCI could continue to support rural cancer control research. This cross-institutional collaboration allowed awardees to reach a consensus on measures of rurality and other integral variables to bolster the reach and integrity of their research efforts. A special section of The Journal of Rural Health was published in 2019 to highlight work of the rural working group (8–12). The catchment area P30 supplement initiative was reissued in fiscal year 2018, and 14 additional cancer centers were awarded, with seven of the 14 centers participating in the rural working group. Details of the initiative can also be found online at: https://cancercontrol.cancer.gov/brp/hcirb/catchment-areas.html.

In addition to the catchment area supplements, NCI supported two rounds of competitive supplements to NCI-designated Cancer Centers in 2018 and 2019 specifically dedicated to strengthening collaborative research partnerships with rural communities. The impetus to provide funding to NCI-designated Cancer Centers was to promote collaboration with existing rural programs and create new research partnerships in rural areas that could leverage the center's existing research infrastructure. Building on this infrastructure was one method to attempt to accelerate research productivity once relationships were established and promote sustainability for these rural cancer control research programs. In total, NCI awarded supplements to 27 cancer centers to increase engagement and partnership with rural populations, rural health care providers, and rural stakeholders (13). With supplement funds for conducting research, awardees developed new or strengthened existing relationships with Federally Qualified Health Centers serving rural communities, Rural Health Clinics, state offices of rural health, community stakeholder groups, Indian Health Service facilities, and other community stakeholders. Awardees and their community partners have focused their efforts across the cancer continuum and come together annually to share progress, lessons learned, and to collaborate on joint projects. Several supplement awardees have also gone on to secure additional funding for research to support their rural cancer control research partnerships.

Improving the Reach and Quality of Cancer Care in Rural Populations

Data showing higher cancer mortality rates among rural communities and widening rural-urban mortality disparities have also spurred NCI's efforts to advance research focused on improving the reach and quality of cancer care in rural populations. In fiscal year 2019, NCI awarded four R01 grants focused on these issues through RFA-CA-18-026. The studies funded through these awards aim to develop and test interventions targeting the factors at multiple levels influencing care access and quality in low-income and/or underserved rural communities. Specifically, the awards focus on several issues, including: addressing financial hardship related to cancer-related care, developing the cancer survivorship knowledge and skills of rural primary care clinicians, advancing new models for delivering palliative care, and telehealth-enabled models for increasing rural provider access to molecular tumor boards and patient access to supportive care. These awards support partnerships with approximately 35 clinics and partner organizations located in or serving low-income rural communities in North Carolina, Kansas, Tennessee, and Mississippi, and in three American Indian reservations in South Dakota. Additional details of the grants awarded through this RFA can be found on the DCCPS Rural Cancer Control website (13). To continue stimulating this area of science, NCI reissued this announcement as RFA-CA-19-064 in Fall 2019 to continue stimulating research focused on improving cancer care reach and quality in rural populations. Awards are anticipated in fiscal year 2021.

The Cancer Moonshot℠

Funding through the Cancer Moonshot initiative also contributes to understanding and addressing rural cancer disparities. The goals of the Cancer Moonshot, passed as part of the 21st Century Cures Act (14) in December 2016, are to accelerate scientific progress and wider uptake of standard care in cancer, encourage collaboration, and enhance data sharing. Moonshot efforts are guided by recommendations from the Cancer Moonshot Task Force Blue Ribbon Panel Report (15). NCI supports several Moonshot-related funding opportunities and projects with rural components or a focus on rural populations, with DCCPS as its lead (https://cancercontrol.cancer.gov/research-emphasis/moonshot.html#approaches).

Prevention and screening

The Moonshot Blue Ribbon Panel identified as a key priority research examining implementation of evidence-based approaches to colorectal cancer (CRC) prevention and screening, particularly in areas where local uptake is exceptionally low. In support of this recommendation, NCI included as a funded Moonshot activity, the Accelerating Colorectal Cancer Screening and Follow-up Through Implementation Science (ACCSIS) initiative (16). ACCSIS involves five funded research centers and a coordinating center focused on identifying evidence-based interventions that can be scaled-up to reduce the burden of CRC in communities in greatest need. All five of the centers focus on underserved populations; three focus specifically on underserved rural populations in Appalachian Kentucky and Ohio, as well as North Carolina and Oregon. A parallel effort led by the universities of Arizona, New Mexico, and Oklahoma are focusing on CRC screening in underserved American Indian populations. Additional information about ACCSIS activities can be found at https://healthcaredelivery.cancer.gov/accsis/.

Symptom management

The Moonshot Blue Ribbon Panel also recommended efforts to minimize cancer treatment's debilitating side effects. Related to this recommendation, NCI, through DCCPS, supports the Improving the Management of symPtoms during And following Cancer Treatment (IMPACT) initiative (17). IMPACT is comprised of three research centers and a coordinating center focused on testing symptom management interventions that are integrated with electronic health record systems. Two of the three centers focus on engaging and recruiting from rural populations across 10 U.S. states and community health systems. Discoveries from individual centers and pooled findings across all centers will shed light on symptom control, treatment delivery, and health care utilization across the cancer continuum in underserved populations, including rural communities. Additional information about IMPACT can be found online at: https://healthcaredelivery.cancer.gov/impact/.

Partnerships for broadband and telehealth

In 2017, NCI and the Federal Communication Commission's (FCC) Connect2Health Task Force joined together in a multi-stakeholder collaborative – the L.A.U.N.C.H. initiative (Linking & Amplifying User-Centered Networks through Connected Health: A Demonstration of Broadband-Enabled Connected Health and Community-Based Co-Design; ref. 18). L.A.U.N.CH. sought to address one of the key challenges of rural cancer care: quality symptom management. The goal was to leverage connectivity and advanced technology to improve the lives of patients with cancer living in rural areas, who bear the double burden of having the highest cancer mortality rates and lowest levels of broadband access and adoption. The collaborative is currently working on pilot studies in Appalachian Kentucky focused on developing and delivering connected solutions for patients to be able to better manage their cancer symptoms (19).

Reexamining the Research Grant Portfolio

Following implementation of these strategic activities, NCI reanalyzed its DCCPS research grant portfolio to examine the number of rural cancer control research grants that were active in fiscal year 2019. Results indicated that 41 R- or U-mechanism awards (research grants or cooperative agreements) active that year focused on cancer control in rural populations. In addition, two P01 awards focused on cancer prevention and control interventions in rural communities. Of the 41 R- and U-mechanism awards, 34 were intervention studies (83%). Of these 34 intervention studies, 11 focused solely on detection/screening, 10 focused on prevention, five focused on survivorship, five focused on multiple parts of the cancer continuum, two focused on treatment, and one focused on end-of-life care.

Partners and Collaborators

Multiple partners and collaborators have been invaluable throughout NCI's work to strengthen its efforts in rural cancer control research and care delivery, including: FORHP and Health Resources and Services Administration (HRSA), FCC, the USDA's Economic Research Service, CDC, the U.S. Census Bureau, and others. NCI, for example, partnered with FORHP to cofund a cancer-related project led by its Rural Research Center located at the University of South Carolina. These projects include a rural colon and cervical cancer environmental scan focused on identifying opportunities for improving cancer screening uptake, follow-up of abnormal screening results, and timeliness and quality of treatment received among rural residents, as well as understanding how rural hospitals implement evidence-based cancer screening and treatment and related intervention strategies. NCI is grateful to all of its partners for openly and patiently continuing to share their expertise and vast rural experience.

Conclusions

Evidence suggests there are a number of barriers to effective cancer control research in rural communities (4, 20, 21). There is no single root cause, that if addressed, would solve all of these problems. Therefore, a multifaceted approach is critical to understanding and improving rural cancer control. For example, NCI's more recent rural-focused initiatives have focused on health care delivery challenges and coordination of care. Subsequently, the expectation is to address issues related to building the research evidence for cancer prevention programs in rural populations.

Many of these rural communities face deep and persistent poverty (22, 23) as well as health professional shortages, which make implementation of cancer control programs more challenging (24). NCI is trying to focus on these geographically underserved areas in a thoughtful way that is sensitive to local contexts and cultural values. For example, we have used the opportunity of the rural cancer control initiative to focus on American Indian communities. This has led us to, in some cases, to modify some of these initiatives, or to integrate these initiatives into other efforts in these communities. For example, projects focused on dissemination of colorectal cancer screening among American Indian communities have been integrated into the collaborative formed by awardees participated in the ACCSIS Moonshot initiative. Researchers with awards through NCI's DCCPS have also been mindful of the many differences among American Indian communities, sensitivity to tribal authority, governance, and recognition that sustaining strong collaborative relationships over a longer period of time is critical.

In addition, we recognize that while telehealth can play a significant role in rural cancer prevention and control, many rural communities and residents face very real barriers to using telehealth. We are encouraging applicants to seriously consider these challenges in the design and sustainability plans for the interventions they develop and are hopeful that new partnerships, like the collaboration with the FCC to implement connected health solutions in rural communities, will contribute to addressing some of these challenges. We are also hopeful that expansion of payment and support for telehealth services stimulated by the COVID-19 pandemic will continue.

We are looking forward to continuing to invest in research focused on rural cancer control, but this work continues to evolve (25). Concurrently, we are also seeking to expand the research specifically in geographically underserved areas, those with small populations living in persistent poverty counties that fall within the Health Professional Shortage areas (https://cancercontrol.cancer.gov/research-emphasis/underserved.html). We are still looking for ways to improve collaborations among organizations and institutions that serve, partner with, or are led by rural communities. We have been fortunate that NCI-designated Cancer Centers have eagerly hosted meetings of our rural cancer control consortium, which are important for growing this research community

and sustaining collaborative partnerships. We look to build on this collection of projects, in collaboration with other NCI initiatives, to continue to grow rural cancer control research efforts in the future.

Disclosure of Potential Conflicts of Interest

No potential conflicts of interest were disclosed.

Disclaimer

This commentary was prepared as part of the official duties of the authors as employees of the U.S. Federal Government. The views expressed are those of the authors and do not necessarily represent the official position of the NCI.

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