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Analyzing cancer disparities: A new policy landscape calls for new approaches to research

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In 2010, the Patient Protection and Affordable Care Act (PPACA) was signed into law. Through its many provisions, the PPACA has the potential to substantially impact patterns of cancer screening, treatment, and outcomes, and therefore cancer-related disparities.

The primary intent of the PPACA was to provide health care coverage to millions of uninsured individuals.¹ In states that witnessed Medicaid expansion, individuals with incomes up to 133 percent of the Federal Poverty Level (FPL) have been able to obtain health care coverage through the Medicaid program. For individuals with incomes 133-400% of the FPL, the PPACA has made coverage accessible through the *Health Benefit Exchanges* (hereafter referred to as the *Exchange*).

Four benefit categories are available through the *Exchange*. While all categories provide the essential health benefits and limit out-of-pocket expenditures, the percentage of health care costs covered is 60%, 70%, 80%, and 90% under each of the *Bronze*, *Silver*, *Gold*, and *Platinum* plans, respectively.² In addition, people may be eligible to obtain federal subsidies for premium and/or cost-sharing.

Cancer screening tests recommended by the U.S. Preventive Services Task Force are mandated through the PPACA without cost-sharing. While this is a positive development for cancer prevention, the PPACA provides mandated coverage only for initial screening and not for subsequent diagnostic testing that follows abnormal findings.^{1, 3}

This poses important cost-related barriers to receive timely diagnostic resolution and treatment initiation, all of which contribute to treatment delays and adverse outcomes. This policy is in sharp contrast with the provisions of the Breast and Cervical Cancer Early Detection Program (BCCP), which, while reaching only 15% of the target population,⁴ provides coverage for diagnostic testing and ensures subsequent referral of women with confirmed breast or cervical cancer diagnosis to Medicaid for full coverage.

Detailed studies to evaluate the independent and interactive effects of each of Medicaid expansion, BCCP, and purchasing insurance plans through the Exchange are urgently needed to evaluate the effect of these changes on cancer disparities.

First, the new studies must be designed to identify specific subgroups of the population that benefited from, or continued to experience disparities despite the PPACA. Compared to previous studies, these studies need to be considerably more detailed in their approach. For example, it can no longer be considered adequate to account for uninsured status in a

dichotomous fashion. Rather, it is necessary to closely examine the benefit structure of a given insurance plan to determine the extent to which such a plan is able to remove cost-related barriers to care. Indeed, given the steep cost-sharing provisions of certain exchange plans, such as the *Bronze* plan purchased through the *Exchange*, an individual with low incomes facing competing needs and deciding between food or rent versus diagnostic testing for a condition that may still be asymptomatic, might opt to delay tests until symptoms develop -- at which point prognosis may be poor.

Second, these studies need to account for the availability of programs that may have sprouted at local community levels to provide coverage to low-income uninsured individuals even prior to Medicaid expansion or the implementation of the PPACA should be the subject of case studies, yielding invaluable lessons from natural experiments. One such program is *Care Plus*, a Medicaid Waiver Demonstration program that was designed and implemented collaboratively by the Ohio Department of Medicaid and the MetroHealth System, the largest provider of Medicaid services in the state of Ohio, and the principal safety net healthcare provider in Northeast Ohio.⁵ *Care Plus* was launched in February 2013 and discontinued at the end of that year, as the state's Medicaid coverage expansion went into effect on January 1, 2014 and *Care Plus* enrollees transitioned to Ohio Medicaid.

The above considerations call for novel approaches in cancer disparities research. With regard to data sources, there is a need to access data beyond the conventional sources of Medicare or Medicaid in conjunction with data from cancer surveillance systems. Additional necessary data sources include (but are not limited to): a) data originating from BCCP programs; b) private insurance data, especially for plans purchased through the *Exchange*, that provide a detailed characterization of benefit structure; and c) data from programs originating at the local community level, such as *Care Plus*, as described above.

In parallel, our study designs must evolve to incorporate new perspectives and techniques. Our focus needs to shift from the analysis of endpoints to that of processes of care. Applying a methodical and systematic approach, akin to checklists described by Atul Gawande in his book titled the *Checklist Manifesto*,⁶ suboptimal process-of-care measures at specific junctures along the cancer care continuum, or *points of failure*, must be catalogued – from upstream influences to prevention, screening and diagnostics, to treatment, survivorship, and end-of-life care. In addition, these points of failure should be analyzed to determine their origin at the individual-, community-, or system-levels, and to evaluate their contribution to endpoints.

Last but not least, new analytic strategies (e.g., classification tree approach, and/or simulation techniques) must be employed to account for the fact that individuals are likely to experience a combination of points of failure, rather than one at a time. In addition, these points of failure occur in an environment in which policy changes may have occurred simultaneously and at multiple levels (i.e., Medicaid expansion co-existing with the BCCP program, and co-occurring with the implementation of the PPACA, while additional programs are in place at local community levels). Unless we adopt novel perspectives and new analytical techniques, our approach to cancer disparities research will remain as fragmented as our health care system.

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