Optimal Care Coordination Model for Lung Cancer Patients on Medicaid

Environmental Scan–Six Key Findings

June 2016

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Each year more than 220,000 Americans are diagnosed with lung cancer and about 160,000 die of the disease, making it the leading cause of cancer deaths in the nation.[1] These dismal statistics are worse for minorities and those who are socioeconomically disadvantaged, who not only have a higher incidence of lung cancer but also higher mortality rates.[2]

The reasons for these outcome disparities are the subject of much research and debate. The stage of diagnosis and treatment are clearly factors—socioeconomically disadvantaged patients are more likely to be diagnosed with later-stage cancer and less likely to receive any treatment, surgery, and chemotherapy for lung cancer.[3] But other variables are likely at play; for example, these patients may have poorer overall health, a higher prevalence of comorbid conditions, and greater life stress. The disparate outcomes may also be a function of the challenges they face navigating the healthcare system, including the financial and logistical barriers they encounter when accessing care and historic distrust of a system that is not designed around their needs. They are also less likely to have a usual source of primary care and may face more problems in gaining access to oncology subspecialty providers.

While researchers parse the causes, the nation's cancer centers have been working hard to close the gaps for socioeconomically disadvantaged and minority patients through participation in the National Cancer Institute Community Cancer Centers Program (NCCCP) initiative and other efforts. The Bristol-Myers Squibb Foundation has funded a three-year effort by the Association of Community Cancer Centers (ACCC) to develop an Optimal Care Coordination Model for Lung Cancer Patients on Medicaid with the goal of supporting cancer programs in their efforts to improve lung cancer care for Medicaid beneficiaries. Approximately 20,000 cancer care professionals from 2,000 hospitals and practices nationwide are members of ACCC—together serving an estimated 60 percent of the nation's cancer patients.

The reason for focusing on Medicaid beneficiaries is twofold. First, smoking rates are staggering in this population: 29 percent of adults who are covered by Medicaid smoke—nearly twice the national average—putting them at high risk for lung cancer.[4] (While tobacco use is the leading cause of lung cancer, it is important to note some 20 percent of lung cancer patients have never smoked. Exposure to environmental carcinogens and genetic mutations are other risk factors.[5]) And second, as outcome disparities among low-income populations demonstrate, they are also at higher risk for poor treatment outcomes.[6]

We know for example that patients with Medicaid or no insurance consistently have worse outcomes than other patients with lung cancer. Both groups have higher risks of death than privately insured patients. Moreover, African-Americans and Hispanics—groups that are disproportionately represented in Medicaid programs—have higher lung cancer incidence and higher lung cancer mortality rates when compared with non-Hispanic whites and those with higher socioeconomic status. Lung cancer patients in rural areas are also at a disadvantage relative to their urban peers. Further, Medicaid beneficiaries are often in poor health before their lung cancer diagnosis—making their treatment much more complex. More than a third are obese,

more than 20 percent are being treated for depression or high blood pressure, and 9 percent have diabetes.[7]

Developing an Optimal Care Coordination Model

In developing an optimal care coordination model to serve Medicaid beneficiaries with lung cancer, ACCC will focus on building effective partnerships among community organizations, patients, and primary care and specialty providers. To advance this work, ACCC has convened an Advisory Committee of physicians; an oncology nurse, a social worker, and a patient navigator; cancer program executives; patient advocates; and researchers—all experts in lung cancer care, disparities, and/or Medicaid.

To lay the foundation for this effort, ACCC completed an environmental scan with a focus on efforts to coordinate care after lung cancer diagnosis in order to improve experiences and outcomes for Medicaid beneficiaries. The scan included a literature review as well as the insights of the project's Advisory Committee members, a lung cancer survivor and patient advocate, and staff from two ACCC-member cancer programs, gathered in a series of interviews conducted in April and May 2016.

During year one of the Optimal Care Coordination for Lung Cancer Patients on Medicaid effort, the scan report will help guide work with the project's five Development Sites. The report describes common barriers providers encounter when trying to support Medicaid beneficiaries and highlights some promising solutions, including:
- financial and social barriers
- access to care
- patient engagement strategies
- patient navigation
- value of multidisciplinary teams
- role of supportive services.

Six key findings from the environmental scan report are summarized below.

 1. The financial and social barriers that Medicaid beneficiaries face in pursuing lung cancer treatment are significant, detrimental to outcomes, and largely unaddressed. These include:

- Accessing reliable transportation
- Taking time off from work/lost income
- Procuring child care or other family support
- Covering out-of-pocket expense of services and drugs

2. Medicaid beneficiaries have unequal access to high-quality care.

- Medicaid beneficiaries' typical points of entry into the healthcare system often differ from those insured by Medicare or private plans and may put them at a disadvantage. Many use emergency department and urgent care facilities as their first point of care;

staff there may be unfamiliar with diagnostic and referral pathways for lung cancer and unprepared to educate patients about the risks they face and the importance of timely follow-up.

- Similarly, patients presenting to community health centers are dependent on existing referral relationships, which may not include partnerships with cancer programs that treat a high volume of lung cancer patients, emphasize strong care coordination, provide access to supportive services, and have board-certified thoracic surgeons and other specialists.
- Medicaid beneficiaries are often limited to restrictive provider networks, which may not include providers with a specialization in lung cancer. The restricted networks are due in part to the fact that some oncology providers are unwilling to accept Medicaid patients because of the program's low reimbursement levels for specialists compared with Medicare and commercial insurance.
- They also lack access to and participate less frequently in clinical trials that may lead to improved outcomes.

3. Increasing patient engagement is critical to improving outcomes but will require a tailored approach given the unique challenges Medicaid beneficiaries face.

- Low levels of health literacy among Medicaid beneficiaries affect shared decision-making, particularly around adjuvant therapy and the ability to adhere to treatment recommendations.
- There are significant misconceptions about the disease itself, its ability to be treated and in some cases cured, and the risks of treatment (e.g., the belief that surgery can spread tumors). There is a need for decision-making tools written in plain language and designed with Medicaid beneficiaries' needs in mind.
- There is a need to overcome beneficiaries' distrust of the healthcare system, evident in skepticism about clinical trials (e.g., a fear of being "guinea pigs").
- The stigma of lung cancer (i.e., the perception that it is self-inflicted) and pessimism about its ability to be treated are widespread and hinder efforts to engage patients in their treatment.

4. Integration of patient navigators into care teams can promote Medicaid beneficiaries' access to timely, high-quality care.

- Navigators may have clinical or non-clinical backgrounds. Lay navigators, including cancer survivors, may help people overcome cultural barriers and distrust.
- They play a key role in ensuring access to care, coordinating care across providers, and promoting adherence to treatment recommendations, particularly oral medication regimens.
- And they can identify when patients need help and provide them with services to cope with distress, behavioral health issues, and financial challenges.

5. Multidisciplinary teams are key to improving care coordination. There may be opportunities to strengthen and build on the team approach to lung cancer care.

- Teams reinforce best practices and encourage proactive and comprehensive care planning; they also help avoid delays in diagnosis and treatment by streamlining care and improving communication among providers.
- They provide a means of addressing comorbidities.
- They also help to ensure prehabilitation and rehabilitation services are part of the plan of care.
- There are opportunities to improve team care, for example by increasing the representation of specialists (thoracic surgeons, radiation oncologists, and interventional pulmonologists).

6. Improvement is needed in timely access to supportive services for Medicaid patients—including attention to biopsychosocial needs, palliative care needs, survivorship issues, hospice, and end-of-life care.

- There is insufficient attention to the impact of social isolation, distress, and depression caused or exacerbated by cancer.
- Lack of funding for supportive services is a barrier, as many services are not reimbursed. There are also shortages of palliative care physicians, counselors, and other professionals.
- Palliative care is underutilized in this population despite evidence that it improves outcomes and survival rates; having culturally competent providers can help overcome patient resistance to hospice care.
- There is a need for more frank discussions with patients about their prognoses.
- Survivorship services are not widely used despite the need to address low smoking-cessation rates and the lingering physical and psychosocial effects of treatment.
- Having a survivorship care plan is also critical, but putting it into practice may be hard when Medicaid beneficiaries do not have a regular primary care physician.

During year one of the Optimal Care Coordination for Lung Cancer Patients on Medicaid effort, the scan report will help guide work with the project's five Development Sites. Working with these sites, ACCC will document the current state of care coordination for Medicaid patients with lung cancer and formulate draft principles for the development of the optimal care coordination model for this patient population.

The full environment scan report will be available in August 2016. An annotated bibliography prepared in conjunction with this report can be accessed at accc-cancer.org/resources/careCoordination-Overview.asp.

References

[1]*Cancer Facts and Figures*, American Cancer Society, 2016, available at http://www.cancer.org/acs/groups/content/@research/documents/document/acspc-047079.pdf and Lung Cancer: Key Statistics, American Cancer Society, available at http://www.cancer.org/cancer/lungcancer-non-smallcell/detailedguide/non-small-cell-lung-cancer-key-statistics.

[2] See for example: Singh GK., Williams SD, Siahpush M, et al. Socioeconomic, Rural-Urban, and Racial Inequalities in US Cancer Mortality: Part I-All Cancers and Lung Cancer and Part II-Colorectal, Prostate, Breast, and Cervical Cancers. *J Cancer Epidemiol.* 2011:107497 and A.W. Blackstock, AW, Herndon JE, Paskett ED, et al. Similar Outcomes Between African-American and Non-African-American Patients with Extensive-stage Small-cell Lung Carcinoma: Report from the Cancer and Leukemia Group B. *J Clin Oncol.,* Jan. 2006 24(3):407–12.

[3] See for example: Woods LM, Rachet B, Coleman MP. Origins of Socio-Economic Inequalities in Cancer Survival: A Review. *Ann Oncol.* 2006 17:5–19 and Forrest LF, J. Adams JH, Wareham H, et al. Socioeconomic Inequalities in Lung Cancer Treatment: Systematic Review and Meta-analysis. *PLoS Med,* Feb. 2013 10(2):e1001376.

[4] Centers for Disease Control and Prevention, press release Nov. 12, 2015. Available at: http://www.cdc.gov/media/releases/2015/p1112-smoking-rates.html.

[5] See http://www.cancer.org/cancer/news/features/why-lung-cancer-strikes-nonsmokers.

[6] Medicaid beneficiaries are by definition very poor, with annual incomes even in states that have expanded eligibility for the program of no more than 133 percent of the federal poverty level, or $24,300 for a family of four in 2016. Minority populations are disproportionately represented in Medicaid: In 2014, African-Americans made up 19% of non-elderly Medicaid beneficiaries; 29% were Hispanic and 43% were white. Source: Distribution of the Nonelderly with Medicaid by Race/Ethnicity, Henry J. Kaiser Family Foundation, State Health Facts, 2014. See: http://kff.org/medicaid/state-indicator/distribution-by-raceethnicity-4/.

[7] See http://www.gallup.com/poll/161615/preventable-chronic-conditions-plague-medicaid-population.aspx and https://kaiserfamilyfoundation.files.wordpress.com/2013/01/8383_d.pdf.