



## Optimal Care Coordination Model for Lung Cancer Patients on Medicaid

Environmental Scan  
2016



## INTRODUCTION

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.<sup>1</sup> 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.<sup>2</sup>

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.<sup>3</sup> 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 health care system, including the financial and logistical barriers they encounter when accessing care and historic distrust of a system that’s 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 high-quality oncology 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’s Community Cancer Centers Program and other efforts. The Bristol-Myers Squibb Foundation has funded a three-year effort by the Association of Community Cancer Centers (ACCC) to support centers in their efforts to improve lung cancer care for Medicaid beneficiaries. Approximately 23,000 cancer care professionals from 2,000 hospitals and practices nationwide are members of ACCC—together serving an estimated 65 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.<sup>4</sup> (While tobacco use is the leading cause of lung

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

2 See for example G. K. Singh, S. D. Williams, M. Siahpush 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,” *Journal of Cancer Epidemiology*, 2011:107497 and A.W. Blackstock, J. E. Herndon, E. D. Paskett 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,” *Journal of Clinical Oncology*, Jan. 2006 24(3):407-12.

3 See for example L. M. Woods B. Rachet, and M. P. Coleman, “Origins of Socio-Economic Inequalities in Cancer Survival: A Review,” *Annals of Oncology*, 2006 17:5-19 and L. F. Forrest, J. Adams, H. Wareham 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. See: <http://www.cdc.gov/media/releases/2015/p1112-smoking-rates.html>.

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.<sup>5</sup>) And as outcome disparities among low-income populations demonstrate, they are also at higher risk for poor treatment outcomes.<sup>6</sup>

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 (for details, see the literature review, Appendix A). What’s more, 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.<sup>7</sup>

ACCC will seek to create an optimal care coordination model to serve Medicaid beneficiaries with lung cancer—focusing 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 center executives; patient advocates; and researchers—all experts in lung cancer care, disparities, and/or Medicaid. This environmental scan is based on a literature review as well as the insights of the Advisory Committee members, a lung cancer survivor and patient advocate, and staff from two ACCC member cancer centers, which were gathered in a series of interviews conducted in April and May 2016 (Appendix B).

This report focuses on efforts to coordinate care after lung cancer diagnosis in order to improve experiences and outcomes for Medicaid beneficiaries. It describes common barriers providers encounter when trying to support Medicaid beneficiaries and highlights some promising solutions. In particular, it reviews:

- financial and social barriers
- access to care
- patient engagement strategies
- patient navigation
- value of multidisciplinary teams
- the role of supportive services.

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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](https://kaiserfamilyfoundation.files.wordpress.com/2013/01/8383_d.pdf).

# SUMMARY OF KEY FINDINGS

## **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 health care 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 centers 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., surgery can spread tumors). There's 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 health care system, evident in skepticism about clinical trials (e.g., a fear of being "guinea pigs").
- The stigma of lung cancer (i.e., 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. Cancer centers should ensure Medicaid beneficiaries have timely access to supportive services—including attention to biopsychosocial needs, palliative care needs, hospice services and end-of-life care, and survivorship issues.**

- There is insufficient attention to the impact of social isolation, distress, and depression caused or exacerbated by cancer.
- 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's 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.

# FINANCIAL AND SOCIAL BARRIERS

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

Treatment for lung cancer is a highly choreographed effort—requiring a series of diagnostic steps to determine the course of treatment, which then may encompass surgery, chemotherapy, and/or radiation therapy as well as new targeted drug therapies and/or clinical trials. Treatment thus requires a significant time and financial commitment and necessitates careful planning and timely follow-up. It can be onerous for all patients, but presents even greater challenges to Medicaid beneficiaries, given their social and financial challenges.

Reducing such barriers to care is crucial, says John Cox, MD, medical director of oncology services at the University of Texas Southwestern Medical Center. “I’m becoming more and more convinced that the drugs I’m giving, the actual care that a doctor is providing [are] not going to have the biggest bang for the buck for this population,” he says. “It is the connecting with the patients in some way, identifying their psychosocial needs and tying them to the food bank or to housing or getting rid of financial stress where you can.”

Lack of transportation is named by cancer center providers as one of the most significant barriers to treatment—it permeates every aspect of care and is an obstacle to timely diagnosis, consistent treatment, and follow-up care. Medicaid beneficiaries may not have reliable cars or gas money, may be too sick to take public transportation or lack access to it, and/or may not have friends or relatives able to take the time off of work to accompany them to treatment.

Gas cards, volunteer programs, and transport services paid for by Medicaid represent only partial solutions. Patients in remote areas may be left out, volunteer drivers are not consistently available, and pharmaceutical companies sometimes place restrictions on programs that pay for transportation. Lack of transportation also impedes access to clinical trials.

### **Potential solutions:**

- Expand partnerships with community-based organizations such as the American Cancer Society and recruit volunteer drivers through partnerships with faith-based communities or other volunteer networks.
- Provide temporary subsidized housing for patients traveling long distances. Sanford USD Medical Center in Sioux Falls, S.D., offers rental housing for \$20 a night.
- Consider solutions such as use of hospital van to deliver radiation/infusion therapy to patients.
- Advocate for policies to strengthen regional cancer programs so that patients can be treated close to home, where they have the support of family members and their communities.
- Consider use of technologies to expand access to care such as use of videoconferencing to consult with specialists during patients’ scheduled primary care visits and use of texting to send reminders and information to patients between visits.<sup>8</sup>

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8 The vast majority of Americans, including low-income and minority individuals, own smartphones and use them for texting. See A. Smith, *U.S. Smartphone Use in 2015*, Pew Research Center, April 2015, <http://www.pewinternet.org/2015/04/01/us-smartphone-use-in-2015/>.

- Getting time off of work for treatment is also an acute problem, especially for low-wage workers with hourly positions. So is arranging for child care. This is one reason lung cancer patients turn to emergency departments for symptom management.

### Potential solutions:

- Consider offering extended business hours.
- Offer small stipends to support patients' use of cell phones for text-based communication.

Medicaid beneficiaries also have significant concerns about the cost of treatment, given their precarious finances and the increasing cost of cancer care. Research has shown that cancer patients face higher out-of-pocket costs than those with other chronic conditions—with publicly insured patients more vulnerable than those in private group plans.<sup>9</sup> While there are pharmacy assistance programs available for some drugs, patients need a great deal of help in finding and applying for them, and the process can entail delays. In some states, higher copayments are applied for oral drugs than for intravenous therapies—putting them out of reach for many Medicaid beneficiaries, who thus must spend more time and potentially miss more work to come in for IV treatments.<sup>10</sup> Bankruptcy risk and fiscal insolvency have been shown to be risk factors for early mortality among cancer patients.<sup>11</sup>

### Potential solutions:

- Creating databases of financial and social supports, models of which include the *ACCC Patient Assistance and Reimbursement Guide* and tools from the ACCC Financial Advocacy Network (FAN), Healthify, and the University of Chicago's Community Rx database of community resources (being developed as part of a Center for Medicare and Medicaid Innovation project).
- Using technology to screen for financial barriers. City of Hope, a comprehensive cancer center near Los Angeles, uses a touch-screen system to assess these and other psychosocial challenges (described in detail below in the Supportive Services section) because it finds patients are more honest communicating with a computer than with a staff member. The tool itself has been user-tested widely, and the questions are written at a fourth-grade reading level and available in English and Spanish.
- Embedding financial counselors in clinics to help patients apply for financial assistance programs as needed—such as drug programs from pharmaceutical companies; non-pharmaceutical programs, foundations, and resources; and Meals on Wheels programs. Financial advisors can also help identify Medicaid managed-care plans that will best serve patients with lung cancer.
- Streamlining application processes for pharmaceutical assistance programs could help avoid delays.

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9 B. Bolwell, M.D., Chairman, Taussig Cancer Institute, Cleveland Clinic, Presentation to Association of Healthcare Journalists Conference, April 8, 2016.

10 B. N. Polite, J. J. Griggs, B. Moy et al., "American Society of Clinical Oncology Policy Statement on Medicaid Reform," *Journal of Clinical Oncology*, Nov. 17, 2014. States are allowed to charge higher copayments to Medicaid recipients with family incomes above 150% of the FPL (\$17,505 for one person and \$35,755 for a family of four in 2014). The amount of cost sharing cannot be more than 20% of the cost (Medicaid payment amount) of the drug. Total cost sharing cannot be more than 5% of the family's income.

11 S. D. Ramsay, A. Bansal, C. R. Fedorenko et al., "Financial Insolvency as a Risk Factor for Early Mortality Among Patients with Cancer," *Journal of Clinical Oncology*, Jan. 25, 2016.

## ACCESS TO CARE

### **Takeaway 2: Medicaid beneficiaries have unequal access to high-quality care.**

Where patients receive care appears to make a difference in treatment outcomes. Those using safety-net facilities face particular challenges—as research shows mortality rates are higher and patients there have worse access to specialists, including board-certified thoracic surgeons, which exposes them to significantly higher complication rates. “It’s an enormous challenge that we must study carefully to devise strategies to overcome,” says James Mulshine, MD, acting dean of Rush Graduate College in Chicago, Ill. He notes in particular that general surgeons may not be able to do video-assisted thoracoscopic surgeries.

Patients also lack the access commercially and Medicare-insured patients have to community-based providers and cancer centers. This may be a function of more limited provider networks—as fewer providers are willing to accept Medicaid rates—but it may also reflect a bias against Medicaid patients that emerges from a concern that they will be non-compliant and bring down performance ratings. (As providers are increasingly being held accountable for patients’ outcomes and health care costs, they may need to be given incentives or other assurances that they will not be financially penalized for taking on higher-acuity or more complex patients.) Medicaid managed-care plans, which oversee care for 75 percent of Medicaid beneficiaries, may exclude higher-cost but potentially higher-quality institutions and limit drug formularies.

Rural patients are at a disadvantage as well: specialists and in some cases the primary care physicians needed to treat confounding problems are clustered in metropolitan areas. Zanesville, Ohio-based Genesis Cancer Care Center reports having to handle many of their patients’ primary care needs because the local community health clinic is overwhelmed.

Addressing coverage and network capacity are beyond the purview of this project but cancer centers can focus on strengthening referral pathways to ensure that providers working in emergency departments, urgent care facilities, and community health centers, where Medicaid beneficiaries with lung cancer symptoms typically present, understand the benefits of using CT screening for high-risk patients. “The biggest delay is usually at the primary care level,” says Randall Oyer, MD, medical director of Lancaster General Health in Lancaster, Pa., citing primary care providers’ tendency to treat patients presenting with lung cancer symptoms first with antibiotics (for suspected infections), then X-rays, then scans, before finally referring them for biopsy.

### Potential solutions for improving access:

- Reaching out to primary care physicians to educate them about the importance of CT screening to enable early detection.
- Partnering with Medicaid managed-care plans, which enroll roughly three-quarters of all beneficiaries, to promote access to high-quality specialists and needed support services. “That is precisely what managed care is there to do—not just to pay doctors but to make sure that the systems of care are in place for the whole person, whether that’s patient navigators or other folks who can do the psychosocial supports,” says Kathleen Nolan, MPH, managing principal at Health Management Associates. While lung cancer specifically may not be on the radar of managed care plans’ improvement efforts—which tend to focus on chronic conditions that are more widespread and last over longer time periods—common comorbidities such as chronic obstructive pulmonary disease certainly are, Nolan says.<sup>12</sup>

The problem of access is very visible when it comes to clinical trials. Research data demonstrate that low-income and minority patients are less frequently included in trials, which not only deprives them of their potential clinical benefits but has significant ramifications for the generalizability of study results. This likely reflects a confluence of problems—inadequate education about the benefits of trials, mistrust of them, and financial barriers to participation. For example, Medicaid beneficiaries may be discouraged from participating in trials if doing so entails missing work, covering additional copayments, and/or needing to travel to more appointments.

### Potential solutions for increasing participation in clinical trials:

- Increasing provider awareness of the importance of access to clinical trials. For example, at Feist-Weiller Cancer Center in Shreveport, La., clinical trials coordinators visit primary care providers and patients to explain and enlist support.
- Tapping resources of patient advocacy groups like LUNGevity Foundation, the Lung Cancer Alliance, Cancer Support Community, and the Patient Advocate Foundation. The Lung Cancer Alliance, for example, offers a clinical trial matching service, patient education materials, and telephone support.
- Making use of practical resources for attracting clinical trial participants, including minorities, that are described in the ACCC/NCI Community Cancer Centers Program e-book, *Enhancing Access, Improving the Quality of Care, and Expanding Research in the Community*.
- Finding sources of funding to cover the cost of housing and transportation for Medicaid beneficiaries interested in participating in clinical trials.
- Partnering with research centers to send drugs to patients at local cancer centers, rather than sending patients to research centers.
- Making greater use of the National Cancer Institute’s Community Oncology Research Program (NCORP), which provides community sites with access to clinical trials.
- Promoting clinical trials in churches and at health fairs.

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<sup>12</sup> States such as Ohio are experimenting with episode-based payments and demonstration programs for dually insured beneficiaries to improve care and control costs for high-need patients. Such programs represent another lever for influencing access.

## PATIENT ENGAGEMENT STRATEGIES

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

Effectively engaging patients in decision making and behavior change are key to the success of lung cancer treatment, but there are many barriers when it comes to treating Medicaid patients. First, low levels of health literacy among Medicaid beneficiaries affect their ability to understand the risks and benefits of procedures and in particular may limit their willingness to undergo surgery. Genesis Cancer Care Center, which serves about 150 lung cancer patients each year in a poor region of Appalachia, has found 10 to 15 percent of Medicaid beneficiaries seeking care there are illiterate, and many other centers report that patients struggle to understand medical information. Some studies have also found that poor and black patients, among others, may have misconceptions about the risks of treatment such as a belief that surgery can spread tumors. “People often don’t have enough information about their disease,” says Maureen Rigney, MSW, director of community and support services at the Lung Cancer Alliance. “Many don’t know that there’s more than one type of lung cancer. They don’t know the questions to ask.” Rigney notes in particular the lack of support services for the minority of lung cancer patients (10% to 15%) with small cell lung cancer.

Medicaid beneficiaries may also have difficulty understanding how their benefits work, what their cost-sharing obligations may be, and what providers they have access to. This is understandable, given the variation in covered benefits and in out-of-pocket costs among states (and within states that have chosen to expand Medicaid to childless adults).

Medicaid beneficiaries may also be more likely to distrust the healthcare system. When faced with a life-threatening diagnosis, they may be tempted to conceal information they think might be held against them, says Matthew Loscalzo, LCSW, executive director of supportive services at City of Hope. “You’re going to be very careful talking about very specific things: things like money, things like insurance, things like drug addiction in the home, and things like personal substance abuse,” he says. It is important to routinely ask patients about such issues in a non-judgmental way so patients know it’s okay to talk about them.

The stigma associated with having lung cancer may also discourage patients from seeking care. Christopher Lathan, MD, faculty director for Cancer Care Equity at the Dana-Farber Cancer Institute, notes that it matters how providers talk to patients about the disease. Lung cancer patients are likely to receive their diagnosis from physicians in primary care or emergency department settings—and focus group research has found that these providers are more likely to tell those with lung cancer (as opposed to those with breast or colon cancer) that about 45 percent of lung cancer patients are metastatic and they should “get their affairs in order.” Hearing this at the outset—before meeting with oncologists and navigators who can carefully outline options—can contribute to patients’ fatalism, he says.

There is a lack of public awareness about the disease, the effectiveness of the new CT screening approach, and promise of new treatments; for example there’s a widespread belief that if you’ve smoked for years, the damage is done.<sup>13</sup> As Charles Florsheim, a lung cancer survivor and patient advocate points out, the disease lacks celebrity spokespeople and advocacy groups have difficulty garnering media attention, in contrast, for example, to the widespread public attention focused on breast cancer.

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<sup>13</sup> See <https://www.lungevity.org/support-survivorship/get-connected/blog/top-10-lung-cancer-myths-common-misconceptions-about-lung>.

In all cases, engagement strategies must be customized to meet the needs of the particular groups being served. For example, Hispanics—who represent about a third of Medicaid beneficiaries—are less likely to smoke than either whites or African Americans but are at risk for lung cancer because of their occupations (e.g., through contact with hazardous agricultural, mining, or building materials) and where they live (in highly polluted regions).<sup>14</sup> And like African Americans, Hispanics are more likely to present with later-stage lung cancer and less likely to undergo surgery, compared with whites. Interviews with Hispanic lung cancer patients point to miscommunication as a key barrier to treatment–related both to their lack of English proficiency and lack of understanding of the health care system.<sup>15</sup>

Particularly as more Hispanic adults gain coverage due to Medicaid expansions, it will important to engage high-risk individuals in lung cancer screening and, if diagnosed, to support them in navigating their treatment. The use of *promotoras*, or bilingual community health workers, has been shown to be effective in promoting screening for other cancers.<sup>16</sup> The University of New Mexico Cancer Center, an NCI-designated center, has long experience in training *promotoras* as well as Native American community health workers to deliver culturally appropriate cancer education and treatment navigation.<sup>17</sup>

### **Potential Solutions:**

- Paying greater attention to shared decision making, making use of free and/or low-cost patient education tools available. For example, the nonprofit HealthWise offers training and resources on how to encourage patient engagement and behavior change. The nonprofit Advance Care Planning Decisions provides videos and an app for advance planning.
- Addressing misconceptions about lung cancer treatment, particularly surgery, and the stigma around the disease head on.
- Proactively recruiting staff who have similar life experiences and empathy for coaching. Using community health workers may be effective.
- Putting educational material at a very low grade level; fifth or sixth grade reading level may be too high for patients under stress.
- Making broader use of peer-to-peer support groups specifically for lung cancer patients. (Given privacy regulations that prevent cancer centers from releasing the names of patients, providers may need to proactively encourage patients to join them.)
- Better and more meaningful use of patient advisory boards and the creation of guidelines for eliciting meaningful community input.

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14 See <https://www.asu.edu/courses/css335/q2.htm>.

15 See [http://cebp.aacrjournals.org/content/23/11\\_Supplement/C47.short](http://cebp.aacrjournals.org/content/23/11_Supplement/C47.short).

16 H. K. Koh, *Toward the Elimination of Cancer Disparities: Medical and Health Perspectives*, Springer, May 2009.

17 See <https://www.nmlegis.gov/lcs/handouts/TSROC%20082813%20Item%202%20UNM%20Cancer%20Center%20Update.pdf>.

# PATIENT NAVIGATION

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

The concept of patient navigation for cancer care dates to the 1990s, when Harold P. Freeman, MD, created a program in Harlem to train lay people to help socioeconomically disadvantaged patients gain access to timely cancer diagnoses and treatment. Since then, the functions of navigators in cancer care have evolved, with both clinical and non-clinical staff playing different roles. Nurse navigators are typically used to answer clinical questions, explain treatment recommendations, and communicate with other providers. Social workers may help identify patients' social and financial challenges and find resources to address them. And lay navigators may perform some of these functions, while also providing peer support to patients who may be overwhelmed by stress and struggling with treatment decisions and navigating the healthcare system.

In some, but not all cancer centers, navigators specialize in a particular cancer.

The NCI Community Cancer Centers Program (NCCCP) found that navigators are being used at community cancer centers in the following ways:

- Reaching out to community physicians and organizations to direct people to screening resources
- Helping patients with an abnormal finding move quickly through the diagnostic process
- Assisting patients from initial diagnosis through treatment completion
- Supporting patients during hospitalizations and helping them avoid future hospitalizations
- Supporting survivors as they experience late- or long-term effects and ensuring they receive follow-up care.<sup>18</sup>

A key role for navigators is streamlining the diagnostic process by arranging for tests and gathering medical information to develop and initiate a treatment plan; more than one expert noted that time is of the essence at this stage, but Medicaid beneficiaries frequently experience delays. A 2009 study in Dallas found the average time to lung cancer treatment at public hospitals was 76 days, compared with 45 days at private hospitals.<sup>19</sup>

During the course of treatment, navigators strive to make care as convenient and timely as possible. At Feist-Weiller Cancer Center, newly diagnosed patients are seen by multiple specialists in a dedicated lung cancer clinic. "You've got to get the patients in and treated as quickly as you possibly can," says Becky DeKay, MBA, executive director of the oncology service line. "Having it all done on one day eliminates the fact that a patient may go home and decide not to come back."

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18 See J. R. Swanson, T. Asfeldt, C. Kalaskie et al., "How the NCCP is Using Patient Navigation to Help Reduce Cancer Disparities," in ACCC/NCI Community Cancer Centers Program e-book, *Enhancing Access, Improving the Quality of Care, and Expanding Research in the Community*, see [http://www.nxtbook.com/nxtbooks/accc/ncccp\\_monograph/#/21/OnePage](http://www.nxtbook.com/nxtbooks/accc/ncccp_monograph/#/21/OnePage).

19 See <http://cancergrace.org/lung/2009/11/06/delays-in-treatment-for-lung-cancer-frustrating-but-do-they-impact-survival/>, citing study from the *Journal of Thoracic Oncology*.

Navigators can also help promote early integration of supportive care services, including screening for unmanaged pain and distress, and help ensure that patients' needs are continuously assessed throughout the course of treatment.

The use of navigators has increased in recent years, in part due to recommendations by organizations such as the American College of Surgeons' Commission on Cancer, which in 2012 made establishment of a navigation process a condition of accreditation.<sup>20</sup> However, finding reimbursement for this service can be challenging, and centers report that they have greater need for navigation than can be met by available resources. It may be important for centers to try to quantify the value of navigators' work, as places such as St. John Providence Health System in Detroit are now doing. Medicaid managed-care plans, in particular, are increasingly recognizing the benefits of using navigators for coordinating care and improving adherence to treatment recommendations and may be natural partners in efforts to quantify their value.

Below are examples of various navigation programs and their features:

- At the University of Texas Southwestern Medical Center and many other cancer centers, navigators are the main point of contact for all newly diagnosed patients. They communicate with primary care providers and make sure patients have access to specialty care and financial counseling.
- With funding from the Center for Medicare and Medicaid Innovation, the University of Alabama is partnering with its health system's Cancer Community Network sites to develop and test a patient navigation model for cancer patients, including those in medically underserved communities. At each of the sites, the navigation teams will be led by a nurse manager and staffed by specially trained lay navigators. They will provide information about treatment options, empower patients to make informed choices, and provide emotional and practical support.
- Lahey Hospital and Medical Center in Chelmsford, Mass., uses a lay screening navigator for screening and diagnosis and nurse navigators for treatment.
- At Genesis Cancer Care Center, nurse navigators meet patients when they receive their diagnosis and stay in the room after the physician leaves to offer comfort and help talk through their fears and needs. Because Genesis is located in Appalachia, providers have found it helpful to hire navigators who understand the local culture, are able to overcome patients' distrust, and are familiar with community resources.
- Sanford USD Medical Center, which serves many Native Americans in its Sioux Falls, S.D., location, found many benefits in using a Native American navigator.

### **Potential ways to strengthen navigation programs:**

- Developing metrics to quantify the value of navigation services to make a business case for their value (e.g., preventing readmissions, no-shows, and duplication of services).
- Training programs for medical assistants and/or lay people to act as navigators, in order to make them less expensive and enable centers to hire more of them.

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<sup>20</sup> See [https://www.washingtonpost.com/national/health-science/navigators-for-cancer-patients-a-nice-perk-or-something-more/2015/07/03/28c44930-1a9d-11e5-93b7-5eddc056ad8a\\_story.html](https://www.washingtonpost.com/national/health-science/navigators-for-cancer-patients-a-nice-perk-or-something-more/2015/07/03/28c44930-1a9d-11e5-93b7-5eddc056ad8a_story.html), the latter which cites evidence from Academy of Oncology Nurses and Patient Navigators that navigation programs/navigators are proliferating.

# VALUE OF MULTIDISCIPLINARY TEAMS

## **Takeaway 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.**

Since lung cancer treatment is complex and evolving, it makes intuitive sense for care to be delivered by a multidisciplinary team that can meet as a group to review patient cases to determine diagnoses and treatment and share responsibility for delivering care. The American College of Surgeons Commission on Cancer requires multidisciplinary team meetings as a condition of accreditation, and their use is widespread, though not uniform, in community cancer centers. In some, the teams include specialists in medical oncology, radiation oncology, pulmonary, interventional pulmonary, cardiothoracic surgery, interventional radiology, pathology, and pain and palliative care. Others include nurses, who may act as navigators, and involve social workers, financial counselors, clinical research staff, physical therapists, nutritionists, and pharmacists.<sup>21</sup> Some cancer centers have multidisciplinary teams and tumor boards specific to lung cancer.

At their best, multidisciplinary teams can ensure a treatment plan is coherent and consistent, especially when needs are complex and cases require the input of multiple specialists. They can also foster proactive management of symptoms and side effects and early detection of complications, while providing a means of addressing comorbidities and ensuring prehabilitation and rehabilitation services are part care plans. (While prehabilitation holds promise for improving lung cancer treatment outcomes, Medicaid patients may experience barriers in accessing it given that many programs require prior authorizations or limit coverage.<sup>22</sup> )

Other benefits include:

- Ensuring a rapid timeline from suspected symptoms and findings to diagnosis—by expediting treatment and helping ensure patients follow through.
- Reducing variation and ensuring latest scientific research findings are incorporated into the plan of care, including promising new immunologic and targeted drug treatments. As such personalized medicine becomes more of the standard of care for lung cancer treatment, outcomes could worsen for Medicaid beneficiaries if their access doesn't improve.<sup>23</sup>
- Discouraging the use of low-value care—such as use of older drugs that are not as effective or aggressive treatment when there are problems such as compromised kidney function.
- Ensuring supportive services—including screening for psychosocial problems, provision of behavioral health and palliative care, and a survivorship plan—are incorporated into the plan of care.
- Notably, team care has also been shown to increase lung cancer treatment rates, particularly for patients who may otherwise have been considered untreatable due to the stage of their disease or comorbidities.<sup>24</sup>

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21 H. A. Powell and D. R. Baldwin, "Multidisciplinary Team Management in Thoracic Oncology: More Than Just a Concept?" *European Respiratory Journal*, June 2014. See: <http://erj.ersjournals.com/content/43/6/1776>.

22 See <https://www.apta.org/PTinMotion/2016/2/Prehabilitation/>.

23 J. S. Kaur and D. G. Petereit, "Personalized Medicine: Challenge and Promise," *Journal of Cancer Education*, 2012 27:S12-7.

24 See A. E. Martin-Ucar, D. A. Waller, J. L. Atkins et al., "The Beneficial Effects of Specialist Thoracic Surgery on the Resection Rate for Non-Small-Cell Lung Cancer," *Lung Cancer*, 2004 46:227-32; L. M. Forrest, D. C. McMillan, C. S. McArdle et al., "An Evaluation of the Impact of a Multidisciplinary Team, in a Single Centre, on Treatment and Survival in Patients with Inoperable Non-Small-Cell Lung Cancer," *British Journal of Cancer*, 2005 93:977-78, and J. Wang, Y. F. Kuo, J. Freeman et al., "Increasing Access to Medical Oncology Consultation in Older Patients with Stage II-IIia Non-Small-Cell Lung Cancer," *Medical Oncology*, 2008 25:125-32.

These benefits are essential for Medicaid beneficiaries, who tend to present with later-stage lung cancer and have other conditions. “Lung cancer is always a disease that exists in a nest of other really severe challenges,” says Scott Wegner, MD, an oncologist at Genesis Cancer Care Center. “It requires really intensive multidisciplinary coordination to make it work in [the Medicaid] population. If you don’t have that concept from start to finish, you’re not going to succeed.”

More research is needed to determine how effectively multidisciplinary teams are functioning. Cancer centers report that the conversations involve discussions of the evidence-based guidelines as well as new research and typically lead to consensus as the best course of treatment. They also report that such collaboration tends to reduce delays in diagnosis and treatment. Given the significant resources required to convene multidisciplinary teams, safety-net facilities may struggle to include lung cancer subspecialists on care teams.

Below are details of multidisciplinary team approaches at three cancer centers:

*Sanford USD Medical Center*, in Sioux Falls, S.D., serves many rural patients, including many Native American patients who gain Medicaid coverage upon their lung cancer diagnosis.

- During the diagnostic phase, patients see a medical oncologist, pulmonologist, radiation oncologist, cardiovascular surgeon, and/or palliative medicine physician as needed during a single morning visit to Sanford’s dedicated, weekly lung cancer clinic. At noon, the specialists convene for a lunch meeting to decide on course of treatment.
- After lunch, the nurse navigator, sometimes joined by a physician, meets with the patient to discuss recommended treatment and next steps, some of which (e.g., scans, biopsies) can be delivered that afternoon.
- Uses telemedicine to provide genetic counseling or support by nutritionists or other specialists to patients at its satellite community cancer center.

*St. John Providence Health*, a community cancer center near Detroit, Mich., that treats about 60 percent Medicaid and/or Medicare patients.

- Holds weekly tumor boards attended by 12 to 15 providers with: two surgeons, two radiation oncologists, multiple medical oncologists, a nurse navigator, pulmonologists, radiologists, pathologists, and a cancer care coordinator.
- When the tumor board first convened in 2013, the specialists worked together to develop clinical pathways, which helped foster a culture of teamwork and shared decision making with patients.
- Today, the lung cancer clinic is “virtual,” with different specialists working in different areas of the center. St. John hopes to develop dedicated space for lung cancer patients to be seen by all specialists in an effort to streamline care.

*Lahey Hospital and Medical Center* in Chelmsford, Mass., which serves a suburban population and has been a pioneer in lung cancer screening.

- As part of its team approach, Lahey is piloting a lung cancer prehabilitation program to attempt to improve treatment outcomes, in partnership with the Survivorship Training and Rehab (STAR) program and a handful of other sites.
- All patients are assessed at a dedicated prehabilitation clinic for smoking cessation treatment, nutrition counseling, depression screening, breathing exercises, and other physical therapy. Having a dedicated clinic promotes comprehensive care and facilitates billing for a suite of services.

- Research has shown that prehabilitation can improve patients' quality of life as well as their outcomes. Shawn Regis, PhD, Lahey's patient navigator for lung cancer screening and an associate research scientist, emphasizes the importance of educating cancer providers that prehabilitation services are not just for those who have diminished lung capacity and may need extra help to be fit for surgery—they are beneficial for all patients. "No matter what condition they're in beforehand, if they do this prehab before their treatment, they're going to have better outcomes on the other end," he says. Despite the benefit, Regis says only physical therapy visits are reliably reimbursed, forcing the center to cover the other services.

### How to promote high-quality multidisciplinary care:

- Draw attention to what works and doesn't. For lung cancer care in particular, multidisciplinary team care has been shown to improve patients' experience and timeliness of care and adherence to evidence-based guidelines—though it has not been shown to demonstrably improve outcomes.<sup>25</sup> Studies have also found varying quality among teams, citing poor attendance at meetings, inadequate preparation for meetings, and poor-quality information about patients.<sup>26</sup>
- Ensure that social workers, lay navigators, and others who can advocate for beneficiaries' social, emotional, and financial needs are included in care planning.
- Use videoconferencing and other technology to enable clinicians working in medically underserved areas to consult with lung cancer specialists. The University of New Mexico's Project ECHO (Extension for Community Health Outcomes) has demonstrated how videoconferencing can enable effective partnerships between medical specialists and remotely located providers in safety-net institutions to manage complex conditions. Similarly, Duke University holds "virtual" lung cancer tumor boards via a Web conferencing platform to enable academic medical center experts to advise oncologists working in rural areas of North Carolina.<sup>27</sup>
- Build similar partnerships between primary care providers in community settings and cancer experts. Dana-Farber Cancer Institute in Boston, Mass., embeds medical oncologists in a local community health clinic to expedite workups and improve links between primary care doctors and specialists, which can be useful for management of comorbid conditions and survivorship care planning.
- Consider how new payment models, such as episode-based payment, could be adopted or adapted to promote team-based care, such as Medicare's Oncology Care Model, which provides episode-based payments for chemotherapy treatment, including new enhanced reimbursement for care management and performance-based incentives. "I think that the oncology care model is a step in the right direction," says Mark Soberman, MD, MBA, medical director of the oncology service line at the Frederick Regional Health System in Frederick, Md., and a thoracic surgeon. He notes that while such bundled payments are logistically challenging to implement they may discourage use of low-value care and help cancer centers pay for services such as navigation and counseling. It's unclear whether Medicaid plans will follow Medicare's lead in adopting bundled payments for cancer care.

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25 See M. Coory, P. Gkolia, I. A. Yang et al., "Systematic Review of Multidisciplinary Teams in the Management of Lung Cancer," *Lung Cancer*, 2008 60:14-21, and L. E. Horvath, E. Yordan, D. Malhotra et al., "Multidisciplinary Care in the Oncology Setting: Historical Perspective and Data from Lung and Gynecology Multidisciplinary Clinics," *Journal of Oncology Practice*, Nov. 2010 6(6):e21-e26.

26 Ibid.

27 See M. M. Stevenson, T. Irwin, T. Lowry et al., "Development of a Virtual Multidisciplinary Lung Cancer Tumor Board in a Community Setting," *Journal of Oncology Practice*, May 2013 9(3):77-80.

## ROLE OF SUPPORTIVE SERVICES

**Takeaway 6: Cancer centers should ensure Medicaid beneficiaries have timely access to supportive services—including attention to biopsychosocial needs, palliative care needs, hospice services and end-of-life care, and survivorship issues.**

### ***Psychosocial Support***

Lung cancer patients' psychological and social problems—including depression or distress that may be caused or exacerbated by cancer, as well as social challenges such as lack of stable housing or transportation and behavioral issues such as substance abuse—affect their ability to pursue treatment and manage their illness and recovery. In its 2008 report, *Cancer Care for the Whole Patient*, the Institute of Medicine recommended that oncology providers routinely screen patients for such psychosocial problems and make concerted efforts to link them to services that may help. And the American College of Surgeons' Commission on Cancer now requires its accredited centers to use psychosocial/distress screening tools for all patients.

Such screening can help identify serious mental health problems that could interfere with treatment and reveal whether patients are struggling to manage their personal or financial responsibilities, and may need a social worker's help to link them to community resources. While providers cannot solve all of their patients' problems, just identifying the sources of stress can help, says DeKay, who cited the example of rearranging chemotherapy treatment to accommodate child care or work schedules. Such relatively straightforward problems may not have surfaced without the screening tool, she says.

Screening efforts should include cancer patients' families and caregivers, who are also likely to need support, and should include clear pathways to refer patients to community resources and other sources of support.

Medicaid beneficiaries may have inadequate access to services to address their psychosocial needs because such services are not well reimbursed (or in some cases reimbursed at all) and because of workforce shortages (e.g., lack of social workers and counselors).

### **Potential solutions:**

- Routine and repeated use of screening tools to detect patients' financial barriers, substance abuse or other behavioral health problems, pain levels, goals for end of life, and advance directives. While the ACS guidelines recommend psychosocial distress screening at minimum during one "pivotal" medical visit, experts caution that this may not be sufficient, given that patients may struggle at any time during their treatment.
- City of Hope has developed a tool, *SupportScreen* ([www.supportscreen.com](http://www.supportscreen.com)), a 15-minute survey taken on a touch-screen tablet and written at a third-to-fourth-grade reading level. In addition to flagging potential issues it serves as a triage tool, routing responses and suggested referrals to appropriate team members (e.g., social workers, financial services staff, chaplains, and others) in real time. It also generates a summary report for physicians and educational information and a personalized list of resources for patients. City of Hope uses an electronic system because research has found that patients tend to be more honest when answering questions on a computer than when talking to their providers.

- The Distress Thermometer (<https://www.nccn.org/about/permissions/thermometer.aspx>) is a freely available, paper-based tool developed by the National Comprehensive Cancer Network used to detect distress. Research has also found that the widely used Picker System of Ambulatory Cancer Care Survey is able to identify lung cancer patients who have unmet needs for supportive care.
- Promoting better access to behavioral health counseling. St. John Providence created an on-site oncology psychologist program after it noticed that patients referred to off-site counseling programs were unlikely to attend them. Startup funding for the program came from physician donors who felt there was a need for such care.
- Building partnerships with local affiliates of the Cancer Support Community that offer psychosocial services.

## ONE PATIENT STORY

Cardinale B. Smith, MD, assistant professor in the division of hematology/medical oncology at New York's Mount Sinai School of Medicine, described one of her recent Medicaid patients, whose lung cancer was first detected through a CT scan at the emergency department. Though he was referred to Mt. Sinai's primary care clinic he was lost to follow-up. Nine months later, he finally came to the clinic. Unfortunately, by that time his cancer had progressed from stage 2B to stage 3A. It took another two months to schedule his workup because he would reportedly forget to come to appointments, which he attributed to a pending eviction. A social worker began to meet him at

his home to accompany him to appointments, and eventually helped him find stable housing. After his surgery was scheduled, however, he delayed it by a month, eventually revealing that the original date was the anniversary of his mother's death (she too had lung cancer.) After receiving surgery, Mt. Sinai's social worker continued to work with to get him to chemotherapy appointments, eventually using foundation funding to hire a private car service to pick him up and drop him off each day. Dr. Smith's view is that this patient's untreated depression and/or anxiety about dying the same painful death his mother did were key factors in his avoidance of treatment.

### **Palliative Care**

Palliative care services, intended to help patients with the severe physical and emotional symptoms that accompany lung cancer treatment, are underutilized by Medicaid patients despite evidence they can improve their quality of life, reduce depression, and lengthen their lives.<sup>28</sup> In addition to increasing suffering, poor pain and symptom management can lead patients to the emergency department, which in turn can lead to aggressive interventions that may be contrary to patients' wishes and drive up costs.

Part of the problem appears to be access: inpatient palliative care services are much less accessible in certain regions of the country (particularly in Southcentral states) and in certain types of hospitals (including public/safety-net hospitals).<sup>29</sup> While many patients would prefer to receive palliative care at home, Medicaid's home health care benefits have limitations (in New York State, for example, it covers

28 See for example C. C. Earle, L. N. Venditti, P. J. Neumann et al., "Who Gets Chemotherapy for Metastatic Lung Cancer?" *Chest*, May 2000 117(5):1239-46.

29 See for example M. Parrish, *In It Together: How Palliative Care Spread to All of California's Public Hospitals*, California Health Care Foundation, March 2013, and *America's Care of Serious Illness: 2015 State-by-State Report Card on Access to Palliative Care in Our Nation's Hospitals*, Center to Advance Palliative Care.

four hours a day/five days a week), placing burdens on family members and other caregivers, who may not be able to take off work or afford private help. And many cancer centers, especially regional cancer centers, do not have outpatient services capable of delivering early palliative care before patients get so sick they need to be hospitalized.<sup>30</sup> There are also widespread shortages of palliative care professionals.

The problem also appears to be related to patient education and engagement. The FDA's *Voice of the Patient* report, based on a public hearing among lung cancer patients and their caregivers, found that patients have difficulty distinguishing their disease symptoms from the side effects of treatment. Routine, structured approaches are needed to educate patients about what they can expect from their treatment and to flag any unmanaged pain, distress, anxiety, or depression.

### **Potential solutions:**

- Offer palliative care services as early as possible—ideally upon diagnosis and initiation of treatment. This may include automatic referrals for patients with lung cancer that has progressed to stage 3 or 4; anyone with advanced lung cancer who has additional comorbidities such as chronic obstructive pulmonary disease or a high body mass index; and anyone with unrelieved pain.
- Offer family meetings early in the course of treatment to discuss goals of care.
- For example, at Genesis Cancer Care Center, two board-certified palliative medicine physicians are embedded at the clinic. The physicians attend every visit with stage 3 or 4 patients and work proactively to manage their fatigue, depression, sleeplessness, pain, and appetite issues. They are available for same-day consultations if needed.
- Encourage the development and use of patient-reported outcome measures that take into account patients' goals for treatment (e.g., living long enough to make it to their son's wedding in six months), thus drawing greater attention to them and helping providers deliver patient-centered care.
- Partner with managed care plans to demonstrate the cost savings associated with timely palliative care in order to make the case for higher reimbursement.

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30 E. Bruera and S. Yennurajalingam, "Palliative Care in Advanced Cancer Patients: How and When?" *The Oncologist*, Feb. 2012 17(2):267-73.

## **Hospice and End-of-Life Care**

There's clear evidence of underuse of hospice services among Medicaid beneficiaries facing incurable lung cancer. Less than one-third of Medicaid-insured patients ages 21 to 64 enrolled in hospice after a diagnosis of stage 4 lung cancer; another study found more than half of patients diagnosed as having metastatic lung cancer had not discussed hospice with a provider within four to seven months after diagnosis.<sup>31</sup> As with underuse of palliative care services, underuse of hospice services may reflect lack of access, particularly in regions where hospice companies don't participate in Medicaid programs. Medicaid patients may be more likely to rely on hospitals than home hospice care services because many states require copayments for such care.<sup>32</sup>

Lack of access to good hospice services leads many patients to the Emergency Department (ED) for treatment of breakthrough pain and other symptoms. And as Dr. Cox notes, leaving patients with poorly managed symptoms damages their relationships with providers. Once that happens, he says, "It's really hard to engage and keep people's trust."

As with palliative care, there are also educational and cultural barriers to receipt of hospice services. African Americans, in particular, are less likely than white patients to use hospice services; a literature review pointed to their preference for more aggressive treatment (e.g., desire not to "give up"), lack of understanding of the role of hospice services, lack of racially diverse hospice staff, and mistrust of the healthcare systems as key factors (e.g., fear of physicians withholding life-saving treatment), in addition to lack of access.<sup>33</sup> There's a need for better shared decision-making around end-of-life care, and more frank and realistic discussions about prognoses including information on likelihood of response, the nature of response, and the adverse effects and risks of therapy. It is also important for providers to talk with patients about their out-of-pocket costs.

### **Potential solutions:**

- Use of culturally competent providers, including lay workers such as community health providers, to discuss end-of-life goals and advance directives with patients. Some systems, such as Montefiore Medical Center in the Bronx and Penn Medicine in Philadelphia, integrate lay workers into advanced cancer patients' care teams.
- Mt. Sinai's Dr. Smith notes that the Center for Medicare and Medicaid Innovation is funding development of a care model that would support concurrent provision of hospice services and cancer-directed therapies intended to prolong life. Such efforts may help patients and providers who don't want to choose between one course of action or the other.

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31 J. W. Mack, K. Chen, F. P. Boscoe et al., "Underuse of Hospice Care by Medicaid-Insured Patients with Stage IV Lung Cancer in New York and California," *Journal of Clinical Oncology*, July 10, 2013 31(20):2569-79; H. A. Huskamp, N. L. Keating, J. L. Malin et al., "Discussions with Physicians About Hospice Among Patients with Metastatic Lung Cancer," *Archives of Internal Medicine*, May 25, 2009 169(10):954-62.

32 See Medicaid Benefits Data Collection, 2012, Kaiser Family Foundation, see <http://kff.org/medicaid/state-indicator/home-health-services-includes-nursing-services-home-health-aides-and-medical-suppliesequipment/> and Medicaid's Home Care Benefits: Eligibility, Waivers, and Application Information, Paying for Senior Care, see <https://www.payingforseniorcare.com/medicaid-waivers/home-care.html>.

33 A. D. Spruill, D. K. Mayer, J. B. Hamilton, "Barriers in Hospice Use Among African Americans with Cancer," *Journal of Hospice and Palliative Nursing*, 2013 15(3):136-44.

## Survivorship

The Institute of Medicine has written that “an individual is considered a cancer survivor from the time of cancer diagnosis through the balance of his or her life.”<sup>34</sup> With more routine screening and more treatment options, more lung cancer patients may survive the disease or live longer after treatment. This means that cancer providers need to be prepared to help support survivors and partner with primary care practices in doing so. The National Cancer Institute estimates that a third of all cancer survivors experience physical or mental health problems—issues that may be even more common among Medicaid lung cancer patients, given their other vulnerabilities. A recent study found that cancer survivors who experience financial problems related to paying the bills for their treatment or having missed work are likely to experience ongoing depression and/or anxiety.<sup>35</sup>

Since 2015, the American College of Surgeons’ Commission on Cancer has required accredited cancer centers to give patients survivorship care plans, including a treatment summary and follow-up care plan.<sup>36</sup> Cancer centers should have protocols for monitoring survivors’ physical and mental health, including by offering services such as smoking cessation programs (quit rates are still low post-treatment, but frequent contact with patients can increase them). Physical and occupational therapy may be needed to address the lingering physical effects of lung cancer and treatment, and counseling may be needed to attend to its psychological impacts. Lung cancer survivor and patient advocate Charles Florsheim pointed, in particular, to patients’ need for emotional support between scans.

### Potential solutions:

- At Sanford USD Medical Center, patients see a nurse practitioner for a survivorship visit and receive a detailed care plan for their ongoing needs (e.g., for scans and medications) as well as a referral to a wellness center and pulmonary rehabilitation services.
- Encouraging STAR (Survivorship Training and Rehab) certification as a way of educating staff and integrating rehabilitative services within oncology treatment. This certification program, which is relatively low cost—about \$10,000 annually, after initial training—is used by some insurance companies in contracting decisions.<sup>37</sup>
- Embedding advanced practice nurses in primary care practices to advise providers on oncologic issues post-treatment.
- Coordinating with other disease communities to emphasize smoking cessation, given its collateral benefits on comorbid conditions such as COPD.

As this section makes clear, lung cancer patients—particularly vulnerable Medicaid beneficiaries—require supportive services from their time of diagnosis and on a continuing basis. To facilitate this, centers of excellence such as the City of Hope have integrated all supportive services under one department, including pain and palliative care, psychology, psychiatry, social work, education, and navigation. This may improve care and may also help centers achieve efficiencies related to staffing and resource sharing.

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34 Institute of Medicine, *From Cancer Patient to Cancer Survivor: Lost in Transition*; National Academies Press, 2005.

35 “Many Cancer Survivors Experience Financial Burdens,” *Medical Express*, March 14, 2016.

36 Centers have until January 1, 2019, to fully implement this requirement for all patients.

37 L. Landro, “Prescribing a New Kind of Rehab for Cancer Survivors,” *Wall Street Journal*, Jan. 28, 2013.



## CONCLUSION

As this environmental scan makes clear, Medicaid beneficiaries may struggle with unsafe or unstable housing, addiction, abuse, social isolation, stress, chronic and often poorly managed medical conditions, and many other challenges—all before they receive a devastating diagnosis of lung cancer. In shepherding beneficiaries through lung cancer treatment, cancer centers across the nation face evolving challenges as they seek innovative ways to coordinate care and offer logistical, emotional, and financial support to this vulnerable patient population.

ACCC and its membership are committed to health equity and ensuring patient access to quality cancer care. Through the Optimal Care Coordination Model for Lung Cancer Patients on Medicaid initiative, ACCC and engaged member programs are working to develop a comprehensive care coordination model that will provide a critical resource to address the unique needs of Medicaid patients with lung cancer. This environmental scan serves to lay a foundation for this multi-year effort.



# Appendix A

## Lung Cancer: Experiences of Medicaid Beneficiaries Review of the Professional Literature

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## OUTCOME DISPARITIES

A review of the professional literature uncovers troubling statistics about the care outcomes of lung cancer patients covered by Medicaid. 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, groups that are disproportionately represented in Medicaid programs—African-Americans, Hispanics, and those with low socioeconomic status—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.

Health system and non-health system (e.g., socioeconomic) factors contribute to disparities. Stage of diagnoses and differences in treatment are important—but do not fully explain disparities. Commonly suggested reasons for the disparities include:

- the possibility that these populations have poorer health and unhealthy behaviors;
- that they encounter financial and logistical barriers to receiving treatment and/or adhering to a treatment regimen (e.g., lack of transportation and time off of work);
- that they face challenges navigating the healthcare system and distrust it;
- and lack of access to high-quality providers.

Several studies suggest that outcomes disparities can be eliminated. One, for instance, found that when African-American patients were offered equivalent therapy, their survival outcomes were the same as non-African-American patients even though the African-American patients were more likely to present with significant weight loss and be Medicaid recipients—both features associated with worse survival rates. A retrospective review of lung cancer survival among nearly 1,000 patients treated at Walter Reed Army Medical Center also found no racial disparities in survival rates when access to medical care was universal. Instead, having incomplete resection and diagnosis at later stage were significant predictors of poor outcomes.

Suggested solutions for reducing disparities included building public health and health system capacity especially in underserved areas, improving preventive and chronic health care before a diagnosis of cancer, and helping patients navigate the health care system.

### ***Racial, Economic, and Geographic Disparities***

African-American men have a significantly higher incidence rate and are twice as likely to die of lung and bronchus cancer compared with whites. In addition, although African-Americans are only slightly less likely to present with localized disease compared with whites (14% versus 16%), their overall five-year survival is significantly lower (42% versus 50%). A. Jemal, R. Siegel and E. Ward et al., "Cancer Statistics, 2007," *CA: A Cancer Journal for Clinicians*, Jan/Feb 2007 57(1):43-66.

Those in more deprived groups and rural areas had higher cancer mortality than more affluent and urban residents, with excess risk for lung, colorectal, prostate, and cervical cancers. Deprivation and rural-urban continuum were independently related to cancer mortality, with deprivation showing stronger impacts. G. K. Singh, S. D. Williams, M. Siahpush 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," *Journal of Cancer Epidemiology*, 2011:107497.

This study compared survival outcomes (i.e., months lived) between late-stage African-American and non-African-American small-cell lung cancer patients. Even though African-American patients were more likely to present with significant weight loss, and be Medicaid recipients—both features associated with worse survival rates—when offered equivalent therapy their survival outcomes were the same as non-African-American patients. A.W. Blackstock, J. E. Herndon, E. D. Paskett 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," *Journal of Clinical Oncology*, Jan. 2006 24(3):407-12.

### **Effects of Insurance Coverage**

A study looking at cancer survival rates for four different cancers (colorectal, lung, breast, and prostate cancer) among all patients in Kentucky's Cancer Registry found lung cancer patients with public or no insurance had a significantly higher risk of death within three years compared with privately insured patients; for uninsured persons the risk was 19 percent greater. K. McDavid, T. C. Tucker, A. Sloggett et al., "Cancer Survival in Kentucky and Health Insurance Coverage," *Archives of Internal Medicine*, 2003 163:2135-44.

This large study reviewing data from nearly 300,000 lung cancer patients found that insurance status was a significant predictor of survival (i.e., years lived)—even after accounting for cancer stage, education, treatment delays, and other factors. Uninsured and Medicaid patients had the highest mortality rates. Multivariate analysis revealed that chemotherapy in addition to surgery provided the best five-year survival probability. R. Shi, R. Diaz, Z. Shi et al., "The Effect of Payer Status on Survival of Patients with Stage I/II Non-small Cell Lung Cancer: NCDB 1998-2011," *Anticancer Research*, Jan. 2016 36(1):319-26.

Patients insured through Medicaid after cancer diagnosis had higher disease-specific mortality than patients insured through Medicaid before cancer diagnosis and both Medicaid insured groups had significantly higher mortality than the non-Medicaid insured group. S. M. Koroukian, P. M. Bakaki, and D. Raghavan, "Survival Disparities by Medicaid Status: An Analysis of 8 Cancers," *Cancer*, 2012 118:4271-9.

### **Underlying Causes**

A review of research since 1995 examining the link between cancer survival and patients' socioeconomic status found that most research pointed to stage of diagnoses and differences in treatment as the most important explanations for the link—though neither fully explain this phenomenon. L. M. Woods B. Rachet and M. P. Coleman, "Origins of Socio-Economic Inequalities in Cancer Survival: A Review," *Annals of Oncology*, 2006 17:5-19.

Evidence suggests that addressing insurance- and cost-related barriers to care is a critical component of efforts to ensure that all Americans are able to share in the progress that can be achieved by access to high-quality cancer prevention, early detection, and treatment services. E. Ward, M. Halpern, N. Schrag et al., "Association of Insurance with Cancer Care Utilization and Outcomes," *CA: A Cancer Journal for Clinicians*, 2008 58:9-31.

This study examining survival rates among New Jersey cancer patients—including lung cancer patients—found that survival appears to be related to a complex set of demographic and clinical factors of which insurance status is a part. For example, for breast, colorectal, lung, non-Hodgkin lymphoma, and prostate cancer, uninsured and Medicaid insured patients had significantly higher risks of death than privately insured patients. X. Niu, L. M. Roche, K. S. Pawlish et al., "Cancer Survival Disparities by Health Insurance Status," *Cancer Medicine*, June 2013 2(3):403-11.

From the full text:

“Possible reasons for uninsured and Medicaid insured cancer patients' poorer survival compared with privately insured cancer patients, even after adjustment for other factors, may include: poorer health with more comorbidity and unhealthy behaviors; no or inadequate preventive health care and management of chronic conditions prior to cancer diagnosis; barriers to receiving treatment and adhering to a treatment regimen such as high cost, inability to navigate the health care system, misinformation about and mistrust of the health care system, lack of a usual source of health care, lack of transportation, lack of time off from work; no treatment or delay in receiving treatment; not all providers accept uninsured or Medicaid insured patients; and lower quality treatment by providers primarily serving the uninsured and Medicaid insured.”

“The finding that Medicaid insured cancer patients also have worse survival than privately insured cancer patients suggests that while ensuring that everyone has adequate health insurance is an important step, additional measures are needed to address cancer survival disparities. These include: building capacity in the U.S. public health and health care systems, especially in underserved communities; education about cancer prevention, detection, and treatment; preventive and chronic health care before a diagnosis of cancer; assistance to cancer patients in accessing and navigating the health care system; and workplace policies that encourage patients' attention to their health.”

Patients with Medicaid or no insurance consistently had worse outcomes than other patients with lung cancer. Some of the disparities may be secondary to residual confounding from smoking and other health behaviors, but available data suggest that patients with lung cancer with no or inadequate insurance do poorly because access to care is limited and/or they present with more advanced disease that is less amenable to treatment. C. G. Slatore, D. H. Au, M. K. Gould et al., “An Official American Thoracic Society Systematic Review: Insurance Status and Disparities in Lung Cancer Practices and Outcomes,” *American Journal of Respiratory and Critical Care Medicine*, Nov. 2010 182(9):1195-205.

A retrospective review used lung cancer survival among nearly 1,000 patients treated at Walter Reed Army Medical Center as a way of exploring whether universal access to care (as provided by the military health care system) ameliorates observed lung cancer survival disparities. It found no racial disparities in survival rates when access to medical care was universal; being male, having incomplete resection, and diagnosis at later stage were significant predictors of poor outcomes. C. R. Mulligan, A. D. Meram, C. D. Proctor et al., “Unlimited Access to Care: Effect on Racial Disparity and Prognostic Factors in Lung Cancer,” *Cancer Epidemiology, Biomarkers, and Prevention*, 2006 15:25-31.

Interviews among 32 African-American smokers with and without lung cancer found that African-American smokers are aware of the relationship between smoking and lung cancer and are interested in smoking-cessation treatment. These data also indicate that lung cancer disparities are unlikely to be associated with differential willingness to receive care but that African-Americans may perceive financial and insurance barriers to lung cancer treatment. C. S. Lathan, L. T. Waldman, E. Browning et al., “Perspectives of African-Americans on Lung Cancer: A Qualitative Analysis,” *Oncologist*, April 2015 20(4):393-9.

This article reports on how to use geocoding and U.S. Census Tract data to monitor health disparities related to socioeconomic status—a way to get around lack of socioeconomic data in most electronic health records. N. Krieger, J. T. Chen, P.D. Waterman et al., “Painting a Truer Picture of US Socioeconomic and Racial/Ethnic Health Inequalities: The Public Health Disparities Geocoding Project,” *American Journal of Public Health*, 2005;95:312-23.

This article provides an example of what's been dubbed "cells to society" research intended to understand how where people live—including measures of socioeconomic status, population density, racial residential segregation, ethnic enclaves, distance to hospitals, walkable destinations, and street connectivity—may relate to disparities in cancer incidence. S. L. Gomez, S. L. Glaser, L. A. McClure et al., "The California Neighborhoods Data System: A New Resource for Examining the Impact of Neighborhood Characteristics on Cancer Incidence and Outcomes in Populations," *Cancer Causes & Control*, 2011 22:631-47.

Area measures of socioeconomic status, including census tract and poverty, can help us understand the effect of people's environment on their disease outcomes. In this article Lathan argues that the next phase of cancer care disparities research should combine data on individuals' circumstances with measures exploring how their neighborhoods affect their cancer outcomes. The article describes delivery models in which oncology specialists partner with primary care providers as offering opportunities to improve access and care, and suggests in particular that collaborations between oncology specialists and community health clinics can improve underserved patients' access to the latest approaches in lung cancer treatment. C. S. Lathan, "Lung Cancer Care: The Impact of Facilities and Area Measures," *Translational Lung Cancer Research*, Aug. 2015 4(4): 385-91.

## TREATMENT VARIATION

While the use of recommended therapies for lung cancer is low, this problem is more pronounced among poor people of all racial backgrounds, who are even less likely than the general population to receive appropriate care for lung cancer. They are also more likely to experience treatment delays. In addition minority, uninsured, and Medicaid-insured patients are more likely than others to present with later-stage lung cancer. The perception of financial and access barriers to treatment may be a factor, as one study of black smokers with and without lung cancer found.

Finally, where you go for care matters: lung cancer patients treated at a National Cancer Institute-designated center had lower mortality rates while those with early stage non-small cell lung cancer treated at safety-net facilities were less likely to receive curative surgery.

### **Evidence of Variation**

This review of the literature found that racial and ethnic disparities in cancer treatment itself—in terms of receipt of definitive primary therapy, conservative therapy, and adjuvant therapy—explain some of the disparities in health outcomes, including more frequent recurrence, shorter disease-free survival, and higher mortality. V. L. Shavers and M. L. Brown, “Racial and Ethnic Disparities in the Receipt of Cancer Treatment,” *Journal of the National Cancer Institute*, Mar. 2002 94(5):334-57.

A literature review and meta-analysis of 23 studies found that patients in more socioeconomically deprived circumstances are less likely to receive any type of treatment, surgery, and chemotherapy (but not radiotherapy) for lung cancer than people who are less socioeconomically deprived. L. F. Forrest, J. Adams, H. Wareham, “Socioeconomic Inequalities in Lung Cancer Treatment: Systematic Review and Meta-analysis,” *PLoS Medicine*, 2013 10(2):e1001376.

Using a population-based sample of newly diagnosed non-small cell lung cancer (NSCLC) patients in 10 regions of the U.S., this study explored variation in use of recommended therapies for initial treatment. It found that overall use of recommended therapies for NSCLC is low. Large variations exist in the use of therapies according to age, race or ethnicity, and marital status. A. L. Potosky, S. Saxman, R. B. Wallace et al., “Population Variations in the Initial Treatment of Non-Small-Cell Lung Cancer,” *Journal of Clinical Oncology*, 2004 22:3261-8. Specifically:

- Just over half (52%) of NSCLC patients received recommended therapy.
- Approximately 69%, 48%, and 41% of patients with stages I and II, III, or IV lung cancer received recommended therapy, respectively.
- For all stages, the use of recommended therapy was inversely associated with age and stage at diagnosis.
- Recommended therapy also was more common in white versus black patients, and in married versus single patients.

### **Variation by Site of Care**

This retrospective cohort study compared mortality rates among cancer patients who attended NCI-designated cancer centers versus those who did not, using data for more than 211,000 patients. It found that NCI cancer center attendance was associated with a significant reduction in the odds of one- and three-year all-cause and cancer-specific mortality. The mortality risk reduction associated with NCI cancer center

attendance was most apparent in late-stage cancers and was evident across all levels of comorbidities. T. Onega, E. J. Duell, X. Shi et al., "Influence of NCI Cancer Center Attendance on Mortality in Lung, Breast, Colorectal, and Prostate Cancer Patients," *Medical Care Research and Review*, 2009 66:542-60.

This study using the Michigan tumor registry found that very few cancer services are provided to Medicaid-insured nursing home patients, despite the fact that many of these patients likely experienced cancer-related symptoms and marked physical decline before diagnosis and death. Nursing home residents diagnosed with cancer had a preponderance of late or unstaged disease (62%), high mortality within three months of diagnosis (48%), and low hospice use if they had distant-stage cancer (28%). Only 22% received cancer-directed surgery, 61% of which was confined to breast cancer patients, and only 6% of patients received chemotherapy and/or radiation. C. J. Bradley, J. P. Clement, and C. Lin, "Absence of Cancer Diagnosis and Treatment in Elderly Medicaid-Insured Nursing Home Residents," *Journal of the National Cancer Institute*, Jan. 2008 100(1):21-31.

In general, academic medical centers and large urban hospitals see larger proportions of the uninsured, Medicaid patients, and low-income patients than other care settings. This study shows that cancer patients with Medicaid were more likely to visit hospital clinics than privately insured patients. Yet the researchers found that setting of care did not affect whether anticancer treatment was prescribed or administered. L. C. Richardson and F. K. Tangka, "Ambulatory Care for Cancer in the United States: Results from Two National Surveys Comparing Visits to Physicians' Offices and Hospital Outpatient Departments," *Journal of the National Medical Association*, Dec. 2007 99(12):1350-8.

This study among more than 50,000 patients found that both black and white adult patients treated for early-stage NSCLC at high safety-net burden facilities are less likely to undergo curative-intent surgery than those treated at low safety-net burden facilities. K. S. Virgo, A. G. Little, S. A. Fedewa et al., "Safety-Net Burden Hospitals and Likelihood of Curative-Intent Surgery for Non-small Cell Lung Cancer," *Journal of the American College of Surgeons*, Nov. 2011 213(5):633-43.

### ***Diagnosis and Treatment Delays***

This study examined the timeliness of care for patients covered by Medicare (or dually covered by Medicare and Medicaid). M. T. Halpern and D. J. Holden, "Disparities in Timeliness of Care for U.S. Medicare Patients Diagnosed with Cancer," *Current Oncology*, Dec. 2012 19(6):e404-13.

Notable findings:

- Compared with Medicare-only patients, dual Medicare-Medicaid patients with breast or lung cancer were more likely to experience delays.
- Compared with white patients, black patients with any of the four cancers studied were very significantly more likely to experience delays in care.
- There were significant delays in treatment initiation for colorectal, lung, and prostate cancer patients whose initial treatment episode occurred in an outpatient setting (either a physician office or a hospital outpatient clinic) rather than as an inpatient episode.
- Surprisingly, greater availability of oncology care was not associated with more timely care. Greater numbers of thoracic surgeons in a county were associated with significantly increased likelihoods of delays in treatment initiation for lung cancer patients.

In this analysis, uninsured and Medicaid-insured patients, and those from ethnic minorities, had substantially increased risks of presenting with advanced-stage cancers at diagnosis. A large group—some 3.7 million patients—were included in the analysis and the findings were most prominent among patients whose cancers could potentially be detected by screening, including lung cancer. Black and Hispanic patients had an increased risk of advanced-stage disease (stage III or IV) at diagnosis, irrespective of insurance status, compared with white patients. M. T. Halpern, E. M. Ward, A. L. Pavluck et al., "Association of Insurance Status and Ethnicity with Cancer Stage at Diagnosis for 12 Cancer Sites: A Retrospective Analysis," *Lancet Oncology*, March 2008 9(3):222-31.

Times to diagnosis and treatment of lung cancer are often longer than recommended. This review of 49 studies looked at timeliness of lung cancer care, mostly in E.U. countries. It found that median time to diagnosis and median time to treatment often were longer than recommendations. Interventions that improved timeliness included nurse-led care coordination, multidisciplinary meetings via teleconference, and an expedited "two-stop" diagnostic process. J. K. Olsson, E. M. Schultz, and M. K. Gould, "Timeliness of Care in Patients with Lung Cancer: A Systematic Review," *Thorax*, Sept. 2009 64(9):749-56.

This study sought to examine the potential impact of Affordable Care Act health insurance expansion on cancer patients' stage of diagnosis. It did so by analyzing the relationship between stage at diagnosis and insurance status for patients who were nearly elderly (55-64 years old, i.e., not yet eligible for Medicare) and younger elderly (65-74 years old, i.e., eligible for Medicare). For eight common cancers including lung, uninsured, and Medicaid-insured patients had the highest proportion of stages III and IV cancers at diagnosis, and those with private insurance and Medicare plus supplemental insurance the lowest. E. M. Ward, S. A. Fedewa, V. Cokkinides et al., "The Association of Insurance and Stage at Diagnosis Among Patients Aged 55 to 74 Years in the National Cancer Database," *Cancer*, Nov./Dec. 2010 16(6):614-21.

This study examined the presurgical evaluation of suspected lung cancer patients in a community-based healthcare system to establish current benchmarks of care. The authors classified procedures into five steps: lesion detection, diagnostic biopsy, radiologic staging, invasive staging, and treatment—then analyzed the frequency of passage through each step, the time intervals between them, and the use of staging modalities. The authors suggest there is opportunity for improvement in the thoroughness, accuracy, and timeliness of preoperative evaluation of suspected lung cancer patients. N. Faris, X. Yu, S. Sareen et al., "Preoperative Evaluation of Lung Cancer in a Community Health Care Setting," *Annals of Thoracic Surgery*, Aug. 2015 100(2):394-400. It found:

- Of 614 eligible patients, 92% had lung cancer, 5% had a non-lung primary tumor, and 3% had a benign lesion. Six percent received preoperative therapy; 39% of resections were minimally invasive.
- Ninety-eight percent of patients had a preoperative computed tomography (CT) scan, 27% had no preoperative diagnostic procedure, 22% had no preoperative positron emission tomography (PET)/CT scans, and 88% had no invasive preoperative staging test.
- Only 10% had trimodality staging with CT, PET/CT, and invasive staging.
- Twenty-one percent of patients who had an invasive staging test had mediastinal nodal metastasis at resection.
- The median duration (interquartile range) from initial lesion identification to resection was 84 days (43 to 189) days; from lesion identification to diagnostic biopsy, 28 days (7 to 96); and from diagnostic biopsy to surgery, 40 days (26 to 69).

## THE ROLE OF SURGERY

Surgery to remove the cancer is the preferred treatment for stage I and stage II NSCLC. Despite evidence of its impact on survival rates, there is significant underuse of surgical resection for early-stage non small cell lung cancer among certain vulnerable groups—including blacks, Medicaid beneficiaries, and dually eligible beneficiaries. Some studies point to misconceptions about surgery reported more often by older, black, Southern, and less educated patients—most prominent among them that air exposure causes tumors to spread—as helping to explain why some patients refuse surgery. But other studies find that vulnerable patients, including blacks, are offered surgery less often.

Among all patients who pursue surgery, Medicaid patients, the uninsured, and minorities are less likely to receive care at high-volume hospitals or by specialist surgeons, both of which tend to have better outcomes from surgical resection.

### **Underutilization**

This study found patients with public insurance (Medicaid, Medicare, or both) were significantly less likely than patients with private insurance to undergo a lobectomy for early-stage NSCLC. S. S. Groth, W. B. Al-Refaie, W. Zhong et al., "Effect of Insurance Status on the Surgical Treatment of Early-Stage Non-Small Cell Lung Cancer," *Annals of Thoracic Surgery*, Apr. 2013 95(4):1221-6.

This study of more than 10,000 Medicare patients with early-stage NSCLC found that the rate of surgical resection was 12.7% lower in African-Americans compared with whites. The five-year survival rate was also lower for blacks (26.4% vs. 34.1%). However, among patients undergoing surgery, survival was similar for the two racial groups, as it was among those who did not undergo surgery. Furthermore, analyses in which adjustments were made for factors that are predictive of either candidacy for surgery or survival did not alter the influence of race on these outcomes. The findings suggest that efforts to increase the rate of surgical treatment for black patients are a promising way to improve survival in this group. P. B. Bach, L. D. Cramer, J. L. Warren et al., "Racial Differences in the Treatment of Early-Stage Lung Cancer," *New England Journal of Medicine*, Oct. 1999 341(16):1198-205.

This study analyzed the independent effect of African-American race on receipt of surgical resection in a racially diverse sample of patients with localized NSCLC, while controlling for other important demographic, clinical, socioeconomic, and tumor variables. It found that African-Americans in South Carolina were significantly less likely to undergo surgery compared with whites for localized, non-small cell lung cancer. N. F. Esnaola, M. Gebregziabher, K. Knott et al., "Underuse of Surgical Resection for Localized, Non-Small Cell Lung Cancer Among Whites and African-Americans in South Carolina," *Annals of Thoracic Surgery*, July 2008 86(1):220-7.

This report from the cancer registry at the Henry Ford Health System in Detroit found the rate of surgical resection among African-American patients with early-stage NSCLC was lower than among whites (58% versus 74%, respectively). After controlling for comorbidity, pulmonary function, and tumor stage, however, race had no apparent effect on the odds of being offered surgery, but did have a negative effect on the rate at which surgery was declined by patients (OR for African-American race, 4.1; 95% CI, 0.34 to 0.55). The study suggests that the lower surgical rate among black patients with early stage lung cancer is mainly due to low rates of acceptance of surgical treatment. J. McCann, V. Artinian, L. Duhaime et al., "Evaluation of the Causes for Racial Disparity in Surgical Treatment of Early Stage Lung Cancer," *Chest*, 2005 Nov 128(5):3440-6.

This study compared differences in treatment and survival among lung cancer patients insured by Medicare only and those insured by both Medicare and Medicaid (N=2,626). It found that dually eligible patients were half as likely to undergo resection as Medicare-only patients, and more likely to receive radiation. This finding held even after controlling for socioeconomic factors and comorbidities. However, if such patients were surgically treated, survival improved substantially—even though it remained inferior to the survival of Medicare patients. C. J. Bradley, B. Dahman, and C. W. Given, "Treatment and Survival Differences in Older Medicare Patients with Lung Cancer as Compared with Those Who Are Dually Eligible for Medicare and Medicaid," *Journal of Clinical Oncology*, Nov. 2008 26(31):5067-73.

### **High-Volume Hospitals and Specialist Surgeons: Impact and Access**

This review of the evidence from 1990 to 2011 explored the effects of procedural volume or surgeon specialty on outcomes of lung resections for cancer. Patients treated at high-volume hospitals had better outcomes (i.e., lower mortality rates). Those treated by general surgeons had significantly higher risks for mortality than those treated by thoracic or cardiothoracic surgeons. E. M. von Meyenfeldt, G. A. Gooiker, W. van Gijn, "The Relationship Between Volume or Surgeon Specialty and Outcome in the Surgical Treatment of Lung Cancer: A Systematic Review and Meta-Analysis," *Journal of Thoracic Oncology*, 2012 7:1170-8.

This study looked at the type of hospitals used by patients needing complex surgery, including lung cancer resection. It found that nonwhites, Medicaid patients, and uninsured patients were less likely to receive care at high-volume hospitals and more likely to receive care at low-volume hospitals when controlling for other patient-level characteristics. J. H. Liu, D. S. Zingmond M. L. McGory et al., "Disparities in the Utilization of High-Volume Hospitals for Complex Surgery," *Journal of the American Medical Association*, Oct. 25, 2006 296(16):1973-80.

An analysis from the Nationwide Inpatient Sample revealed that African-Americans who underwent lung resection were less likely to undergo surgery at high-volume hospitals compared with whites and were more likely to die during the perioperative period. C. J. Neighbors, M. L. Rogers, E. D. Shenassa et al., "Ethnic/Racial Disparities in Hospital Procedure Volume for Lung Resection for Lung Cancer," *Medical Care*, July 2007 45(7):655-63.

This study found that, taking into account tumor stage, dually eligible patients with non-small cell lung cancer were only half as likely to be evaluated by a surgeon as Medicare-only patients. C. J. Bradley, B. Dahman, C. W. Given, "Inadequate Access to Surgeons: Reason for Disparate Cancer Care?" *Medical Care*, 2009 47:758-64.

While several different surgical subspecialists perform lung resection for cancer, many believe that this procedure is best performed by board-certified thoracic surgeons. This study examined the effect of subspecialty training on operative mortality following lung resection. It found that operative mortality rates were lowest for cardiothoracic and noncardiac thoracic surgeons, compared with general surgeons (7.6% general surgeons, 5.6% cardiothoracic surgeons, and 5.8% noncardiac thoracic surgeons). P. P. Goodney, F. L. Lucas, and T. A. Stukel, "Surgeon Specialty and Operative Mortality with Lung Resection," *Annals of Surgery*, 2005 241:179-84

### **Underlying Causes**

Using a SEER-Medicare data analysis of health care claims data in the U.S., this review of the reasons that lung cancer surgery was not performed indicated that African-American patients had surgery recommended less often than whites and also refused surgery slightly more often than white patients. This finding has been replicated in state cancer registries. C. S. Lathan, B. A. Neville, and C. C. Earle, "The Effect of Race on Invasive Staging and Surgery in Non-Small-Cell Lung Cancer," *Journal of Clinical Oncology*, 2006 Jan 20; 24(3):413-8.

A survey of 181 racially diverse patients probed for reasons why so many people—23 percent of whites and 36 percent of blacks—do not undergo potentially curative surgery for NSCLC. The authors suggest that beliefs in a “cure” for lung cancer without surgical interventions may partially explain decisions not to pursue surgery. S. Cykert and N. Phifer, “Surgical Decisions for Early Stage, Non-small Cell Lung Cancer: Which Racially Sensitive Perceptions of Cancer Are Likely to Explain Racial Variation in Surgery?” *Medical Decision Making*, 2003 23:167–76.

This study investigated the prevalence of a belief that air exposure during lung cancer surgery might cause a tumor to spread among black and white patients at the VA. Thirty-eight percent of patients (61% of whom were African-American and 29% of whom were white) stated that they believe air exposure at surgery causes tumor spread. Nineteen percent of African-Americans stated that this belief was a reason for opposing surgery, and 14% would not accept their physicians’ assertion that the belief is false. M. L. Margolis, J. D. Christie, G. A. Silvestri et al., “Racial Differences Pertaining to a Belief about Lung Cancer Surgery: Results of a Multicenter Survey,” *Annals of Internal Medicine*, Oct. 2003 139(7):558–63.

This survey of nearly 1,000 adults who had not been diagnosed with lung cancer sought to determine the prevalence and racial/socioeconomic factors associated with several common misconceptions about cancer and its treatment. The most prevalent misconception, “Treating cancer with surgery can cause it to spread throughout the body,” was endorsed as true by 41% of the respondents. The second most prevalent misconception, “The medical industry is withholding a cure for cancer from the public in order to increase profits,” was identified as true by 27%. Respondents who were older, nonwhite, Southern, or indicated being less informed about cancer endorsed the most misconceptions. T. Gansler, S. J. Henley, K. Stein et al., “Sociodemographic Determinants of Cancer Treatment Health Literacy,” *Cancer*, Aug. 1, 2005 104(3):653–60.

## CARE COORDINATION

As lung cancer care has become much more complex, patients need help in understanding their treatment options, connecting to high-quality providers and support services, and managing their condition.

Studies have shown that both virtual and in-person multidisciplinary conferences can enhance care coordination and adherence to evidence-based care for cancer patients. While there is as yet limited evidence linking the use of multidisciplinary teams to improved survival rates, a team-based approach to care can result in timelier care and better patient satisfaction. Patient navigator programs, in which nurses or other staff help patients track appointments and educate them about their condition, also appear to improve care coordination.

Coordination between oncology providers and primary care providers is also important for managing lung cancer patients' comorbid conditions and providing support during and after treatment.

### ***Impact on Timeliness of Care***

This article describes a trial of the effects on patient care of Central Dupage Hospital's multidisciplinary clinic lung program, in which a team reviews a patient's case together, physicians see patients one at a time, and then reconvene to discuss. During this time, the patients are seen by the ancillary staff, such as nutritionists and social workers. The navigators document the comprehensive treatment plan. Then the patient has all recommended tests scheduled. Results of trial: this approach shortened time from initial referral to evaluation from two to three weeks to five days; improved access to palliative care; gave patients benefit of consultation by both an interventional radiologist and an interventional pulmonologist; and shortened time to treatment from 19 to 8.5 days. L. E. Horvath, E. Yordan, D. Malhotra et al., "Multidisciplinary Care in the Oncology Setting: Historical Perspective and Data from Lung and Gynecology Multidisciplinary Clinics," *Journal of Oncology Practice*, November 2010 6(6):e21-e26.

Rural North Carolina providers use a web-based conferencing platform to present lung cancer cases to a multidisciplinary group of experts at an academic medical center: radiologic and histologic images are presented; treatment guidelines and journal articles are reviewed; and coordinated care plans are formulated. This approach has been shown to shorten the time from evaluating a patient to having a definitive treatment plan. M. M. Stevenson, T. Irwin, T. Lowry et al., "Development of a Virtual Multidisciplinary Lung Cancer Tumor Board in a Community Setting," *Journal of Oncology Practice*, May 2013 May 9(3):e77-80.

This retrospective analysis of timelines of care for lung cancer patients at the VA found that—before initiating a care coordination program, which among other things introduced a multidisciplinary team approach—factors such as patients' having depression and comorbidities led to longer intervals between the diagnosis and initiation of treatment. The VA's care coordination program led to an average reduction between time of diagnosis and start of treatment of 25 days. S. Alsamrai, X. Yao, H. C. Cain et al., "The Effect of a Lung Cancer Care Coordination Program on Timeliness of Care," *Clinical Lung Cancer*, Sept. 2013 14(5):527-34.

### ***Impact on Use of Evidence-Based Guidelines***

This is a review of the evidence on the impacts of use of multidisciplinary teams in cancer care. It notes some studies (for breast cancer) that found use of teams led to more evidence-based recommendations and more timely treatment. Yet it also notes that teams' recommendations did not always take into account patients' preferences and comorbidities. In the U.K. and Sweden, teams were associated with improved five-year

survival rates for some cancers, but not lung. Having clear policies and commitment to team discussion of diagnostic and staging investigations has been associated with better management for lung cancer patients. Team care has also been associated with better patient experiences, including for lung cancer patients. C. Taylor, A. J. Munro, R. Glynne-Jones et al., "Multidisciplinary Team Working in Cancer: What Is the Evidence?" *BMJ*, March 23, 2010.

### **Impact on Patient Experience**

To explore lung cancer patients' experience in community healthcare settings, the authors held focus groups among patients and their informal caregivers on their experience of lung cancer care delivery. S. K. Kedia, K. D. Ward, S. A. Digney et al., "'One-Stop Shop': Lung Patients' and Caregivers' Perceptions of Multidisciplinary Care in a Community Health Care Setting," *Translational Lung Cancer Research*, Aug. 2015 4(4):456-64. Themes included:

- Patients reported that multidisciplinary care improved collaboration among providers, patient-physician communication, and convenience while reducing redundancy in testing.
- Patients said that such care coordination decreased their confusion, stress, and anxiety.
- Negative experiences included poor communication among physicians, insensitive communication about illness, delays in diagnosis and treatment, misdiagnosis, and mistreatment. Physician-to-physician communication and patient education were suggested areas for improvement in the multidisciplinary model.

### **Impact on Survival Rates**

This systematic review shows limited evidence linking use of multidisciplinary teams with improved lung cancer survival. The authors note that this does not mean that such teams do not improve survival, merely that currently available evidence of this is limited. They suggest the best way forward would be prospective evaluation of the effectiveness of multidisciplinary teams as they are implemented, paying particular attention to collecting data on potential confounders. M. Coory, P. Gkolia, I. Yang et al., "Systematic review of multidisciplinary teams in the management of lung cancer," *Lung Cancer*, 2008 60:14-21.

### **Profiles of Multidisciplinary Approaches**

This article reports on the efforts of the National Cancer Institute Community Cancer Centers Program (NCCCP), which launched in 2007 and sought to expand the use of multidisciplinary care in community cancer centers. Fourteen cancer centers were funded to develop multidisciplinary care (MDC) programs over two years, and used a standard tool to assess their progress. This tool (available here) can be used by cancer centers as a blueprint to design such programs and a tool to measure their progress in implementing them. A key change as sites moved toward mature MDC programs was that more cases were reviewed prospectively than retrospectively—this relied on early identification of patients appropriate for MDC planning and led to more active participation by care teams, provided a forum to focus on use of evidence-based guidelines, and enabled sites to monitor their adherence to quality measures (often in real time). Physician champions led the effort to promote MDCs and served as the institution's experts by remaining current with literature and the latest developments in the field. Sites also used care coordinators (to arrange treatment plans) and patient navigators (to identify cases, coordinate MDCs, and engage patients). Navigators also identify patient needs and coordinate appropriate ancillary services and individualized care (financial counseling, physical therapy, psychosocial services). E. L. Friedman, N. Chawla, P. T. Morris et al., "Assessing the Development of Multidisciplinary Care: Experience of the National Cancer Institute Community Cancer Centers Program," *Journal of Oncology Practice*, Oct. 21, 2014.

An academic medical center established a process for evaluating each geriatric cancer patient by a multidisciplinary team—including experts in medical oncology, geriatric medicine, pharmacy, social work, and nutrition—in order to assess patients' level of health (fit, vulnerable, or frail) and develop customized care plans. A. E. Chapman, K. Swartz, J. Schoppe et al., "Development of a Comprehensive Multidisciplinary Geriatric Oncology Center, The Thomas Jefferson University Experience," *Journal of Geriatric Oncology*, April 2014 5(2):164-70.

### ***Impact of Nurse Care Coordinators and Patient Navigators on Costs and Patient Experiences***

This study assessed the cost-effectiveness of a patient navigation program under capitated payment for Medicare beneficiaries diagnosed with lung cancer. It found that compared with usual care, navigation services incurred higher costs but also yielded better outcomes. The incremental cost and effectiveness was \$9,145 and 0.47 quality-adjusted life years (QALs), respectively, resulting in an incremental cost-effectiveness ratio of \$19,312/QALY. Y.-C. T. Shih, C.-R. Chien, R. Moguel et al., "Cost-Effectiveness Analysis of a Capitated Patient Navigation Program for Medicare Beneficiaries with Lung Cancer," *Health Services Research*, April 2016 51(2).

This randomized controlled trial found that nurse navigator support for patients with cancer—including lung cancer—early in their care course improves their experiences and reduces problems in care related to psychosocial issues and coordination or communication of information. E. H. Wagner, E. J. Ludman, E. J. Aiello Bowles et al., "Nurse Navigators in Early Cancer Care: A Randomized, Controlled Trial," *Journal of Clinical Oncology*, Jan. 1, 2014 32(1):12-8.

This article describes a telehealth-enabled program for VA cancer patients undergoing chemotherapy, which can lead to pain, nausea, fatigue, emotional distress, and other symptoms. Each day, such patients answered questions about their conditions on a touchpad device. The information is transmitted and reviewed by a nurse care coordinator; color-coded alerts are sent for patients experiencing problems. Nurses contact patients experiencing unusual or severe symptoms to provide support, education, referrals, or other services. A controlled trial found this approach significantly reduced unexpected use of the emergency department and clinic services and resulted in fewer missed chemotherapy treatments. Agency for Healthcare Research and Quality Innovation Profile, April 2016: Daily Remote Monitoring and As-Needed Nurse Contacts Reduce Unexpected Clinic Visits, Hospitalizations for Chemotherapy Patients.

### ***The Role of and Need for Primary Care in Care Coordination Models***

This study describes the prevalence of comorbid diseases as well as other "noncancer" issues (i.e., presence of poor health habits and use of preventive care measures) for four common, surgically related cancers (lung, prostate, breast, and colon). It found that among the cancer patients, 81% had a coexistent disease, with 59% reporting cardiovascular comorbidity and 17% reporting pulmonary comorbidity. Of note, 27% to 39% of cancer patients continued to smoke tobacco, of whom 85% continued to smoke daily. Finally, the rates of preventive care influenza vaccinations in high-risk individuals for the cancer cohort was no higher than the rate in controls, even though the cancer patients saw a health professional significantly more often. The authors suggest that to optimize cancer outcomes, successful treatment of both the cancer and the "noncancer" issues is required. C. Ko and S. Chaudhry, "The Need for a Multidisciplinary Approach to Cancer Care," *Journal of Surgical Research*, June 1, 2002 105(1):53-7.

A survey of Canadian cancer patients, primary care physicians, and specialists found that each group had different expectations in regards to how primary care physicians should be involved in cancer care. While most specialists did not expect PCPs to take part in coordinating patient care in

diagnosis and treatment phases, most patients and PCPs did. All parties agreed that PCPs should provide emotional support during these phases. During treatment, all parties agreed that PCPs should help with symptom relief. Researchers suggest there's a need to better define the PCP's role in order to achieve more collaborative and integrated cancer care. M. Aubin, L. Vezina, R. Verreault et al., "Patient, Primary Care Physician and Specialist Expectations of Primary Care Physician Involvement in Cancer Care," *Journal of General Internal Medicine*, Jan. 2012 27(1):8-15.

This article describes Dana Farber's clinical outreach program, launched in 2012, in which an oncology clinical facility was established in a local community health center to broaden access for vulnerable patients. Dana Farber's oncologists and a dedicated nurse navigator work at the center; and primary care providers refer patients to them for on-site diagnostic evaluations of suspected cancers with the goal of expediting evaluations and speeding time to treatment. An evaluation is ongoing to assess the impacts of this effort on use of Dana Farber's services by under-represented patients, no-show rates, and time from initial appointment to resolution. L. Tesler Waldman, L. Svoboda, B. F. Young et al., "A Novel Community-Based Delivery Model to Combat Cancer Disparities," *Healthcare*, Dec. 2013 1(3-4):123-129.

This article describes the implementation process for Dana Farber's clinical outreach program. L. Tesler Waldman, W. Bean, A. L. Levine et al., "Using FastTrack to Implement an Academic Medical Center and Community Health Center Collaborative for Cancer Care Delivery," *Healthcare*, Dec. 2013 1(3-4): 130-5.

In this study among Ohio adults, greater density of primary care providers decreased the incidence of late-stage cancer diagnoses (including for lung) among those with private insurance but not among those with public insurance (including Medicaid). J. J. Plascak, J. L. Fisher, and E. D. Paskett, "Primary Care Physician Supply, Insurance Type, and Late-Stage Cancer Diagnosis," *American Journal of Preventive Medicine*, Feb. 2015 Feb 48(2):174-8.

A survey of cancer survivors (including some lung cancer patients) treated at a large integrated delivery system fielded one year after their diagnosis found that most continued to regard their oncologists as their main providers—and about half were uncertain whether their oncologist communicated with their primary care provider, or if their primary care provider was knowledgeable in caring for survivors. J. Chubak, E. J. Aiello Bowles, L. Tuzzio et al., "Perspectives of Cancer Survivors on the Role of Different Healthcare Providers in an Integrated Delivery System," *Journal of Cancer Survivorship*, Jun. 2014 8(2):229-38.

## SUPPORTIVE SERVICES

Managing pain, emotional distress, and other symptoms are major concerns for lung cancer patients before, during, and after treatment. Many lung cancer patients report that symptoms such as shortness of breath and fatigue continue years after treatment.

Prehabilitative care—including exercise, nutritional counseling, and psychosocial screening/interventions—has been shown to improve patients' quality of life as well as their outcomes.

Lung cancer patients also require other types of supportive services—including psychosocial screening to identify and address issues that may interfere with treatment, palliative care to manage pain and other symptoms, and hospice care to help patients with advanced, incurable disease. Such supportive services are not used routinely in all settings, or are not offered early enough to patients. There is also evidence that Medicaid beneficiaries are less likely than those with other insurance to use palliative and hospice care. Improvement efforts have focused on early identification of poor-prognosis patients, education to teach them about their condition and prognosis, and proactive symptom management to avoid crises.

### ***The Goals and Benefits of Prehabilitation***

This is the first published review of cancer prehabilitation, defined as the process at the beginning and during acute treatment to assess patients' physical and psychosocial health, establish baseline functional levels, identify impairments, and provide targeted interventions to during and after treatment. The goal is to prevent or ameliorate treatment-related impairments. The body of evidence showing the beneficial effects of prehabilitation for lung cancer patients—detailed in article summaries below—is reviewed. It recommends further research to help clinicians customize the multiple types of prehabilitation therapies, which may include exercise, medical management, nutritional counseling, psychosocial strategies, and other interventions designed to better prepare patients for the challenges of forthcoming cancer treatments. J. K. Silver and J. Baima, "Cancer Prehabilitation," *American Journal of Physical Medicine and Rehabilitation*, 2013 92:715-27.

This study compared 22 lung cancer patients with comorbid COPD who had undergone rehabilitation before surgery with 60 historical controls. Patients with clinically and radiologically defined COPD underwent a prehabilitation exercise program for two weeks comprising inspiratory spirometry, breathing and coughing exercises with bronchodilator nebulizers (five times per day), and exercise (walking 95,000 steps per day). This program was continued until hospital admission and postoperatively until discharge. The control group received chest physiotherapy only during the postoperative period. The rehabilitation group had fewer complications and shorter length of stay than the control group. Y. Sekine, M. Chiyo, T. Iwata et al., "Perioperative Rehabilitation and Physiotherapy for Lung Cancer Patients with Chronic Obstructive Pulmonary Disease," *Japanese Journal of Thoracic and Cardiovascular Surgery*, May 2005 53:237-43.

This randomized controlled trial among 60 NSCLC patients provided intensive physical therapy to half of the patients before surgery, and routine physical therapy to both groups after surgery. Pre-surgical therapy appeared to increase patients' oxygen saturation, improve exercise capacity, and reduce hospital stays. E. Pehlivan, A. Turna, A. Gurses et al., "The Effects of Preoperative Short-Term Intense Physical Therapy in Lung Cancer Patients: A Randomized Controlled Trial," *Annals of Thoracic and Cardiovascular Surgery*, 2011 17:461-8.

This study found that short-term preoperative pulmonary rehabilitation could improve the exercise capacity of patients with chronic obstructive pulmonary disease who are candidates for lung resection for non-small cell lung cancer. A. Bobbio, A. Chetta, L. Ampollini et al., "Preoperative Pulmonary Rehabilitation in Patients Undergoing Lung Resection for Non-Small Cell Lung Cancer," *European Journal of Cardiothoracic Surgery*, 2008 33:95-8.

In this study patients who were not candidates for lobectomy because of impaired pulmonary function received prehabilitation—three hours a day/five days a week of intensive aerobic exercises, breathing exercises, education, and cigarette smoking cessation. Remarkably, pulmonary function improved significantly—allowing these patients to successfully undergo lobectomy. A Cesario, L. Ferri, D. Galetta et al., "Pre-Operative Pulmonary Rehabilitation and Surgery for Lung Cancer," *Lung Cancer*, 2007 57:118-9.

Stage 1 NSCLC patients' performance at a preoperative stair-climbing test was correlated with prognosis—with patients able to climb longer with significantly better prognoses after resection (lower mortality and higher five-year survival rates). A. Brunelli, C. Pompili, R. Berardi et al., "Performance at Preoperative Stair-Climbing Test Is Associated with Prognosis After Pulmonary Resection in Stage I Non-Small Cell Lung Cancer," *Annals of Thoracic Surgery*, 2012 93:1796-800.

UVA Health System thoracic surgeons trained as smoking cessation counselors counsel patients during pre and postsurgery visits to encourage them to quit smoking and offer help in doing so. The program led to a 35 percent quit rate—much higher than many other smoking cessation programs. Smoking Cessation Intervention by Thoracic Surgeons Achieves Above Average Pre- and Postoperative Quit Rates, Agency for Healthcare Research and Quality Innovation Profile, April 2016.

### ***Biopsychosocial Screening: The Need***

This authoritative report from the Institute of Medicine documents the growing body of scientific evidence demonstrating that psychological and social problems can prevent individuals from receiving needed health care, complying with treatment plans, and managing their illness and recovery. In spite of this, the report finds evidence that psychosocial services are not routinely or widely implemented in oncology care. The report articulates a vision for how psychosocial health services should be routinely incorporated into oncology care and makes 10 specific recommendations for how to do so. N. E. Adler and A. E. K. Page, Editors, *Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs*, Institute of Medicine, National Academies Press 2008.

This article from Stat magazine reports on how new targeted therapies for cancer patients are giving some of them more months and years of life, but causing emotional turmoil, too, as they pull back from the brink only to have cancer recur. The article shares the view of lung cancer patients and medical oncologists, palliative medicine clinicians, and medical ethicists. Suggests need for more routine and ongoing screening for distress, and more open discussions with patients about the potential effects and limitations of new cancer drugs. B. Tedeschi, "For Cancer Patients, Breakthrough Drugs Are Savings Lives But Wrenching Souls," *Stat*, Nov. 4, 2015.

This article notes that biopsychosocial screening has gained attention in cancer care because of a number of converging forces: patients and families expect to have a voice and some degree of control in their care; growing body of data supporting the benefits of supportive care interventions; new patient-friendly technologies; and universal cost concerns. The authors outline the benefits of screening both to patients and clinicians. M. Loscalzo, K. Clark, S. Pal et al., "Role of Biopsychosocial Screening in Cancer Care," *Cancer Journal*, 2013 19:414-20.

### **Biopsychosocial Screening: Tools**

This article describes a touch-screen automated program for biopsychosocial screening for cancer patients (SupportScreen, www.supportscreen.com) to identify, triage and offer referrals, and provide educational information. Used at Los Angeles' City of Hope cancer center. M. Loscalzo, K. Clark, J. Dillehunt et al., "SupportScreen: A Model for Improving Patient Outcomes," *Journal of the National Comprehensive Cancer Network*, April 2010 8(4):496-504.

This study finds that the Continuity and Coordination subscale of the widely used Picker System of Ambulatory Cancer Care Survey is able to identify lung cancer patients who have unmet needs for supportive care—particularly to address their psychosocial needs. A. Husain, L. Barbera, D. Howell et al., "Advanced Lung Cancer Patients' Experience with Continuity of Care and Supportive Care Needs," *Supportive Care in Cancer*, May 2013 21(5):1351-8.

### **Pain Management, Palliative Care, and Hospice Care: Variations in Use**

Even though early involvement of a palliative care team has been associated with better quality of care, quality of life, and longer survival for lung cancer patients, this has yet to be embraced as the standard of care. Interviews with clinicians pointed to factors likely to encourage them to make timely palliative care referrals: 1) Competence/skill—with referrers needing to be confident in the quality and capability of palliative care provision; 2) Care Coordination—the need to ensure integrated care, with defined lines of responsibility and clear team communication; 3) Ease of referral—the need for ready access to a palliative care provider in the lung cancer clinic; and 4) Perceptions—need to address clinicians' concerns that palliative care will lead patients to lose hope/be afraid. B. H Le, L. Mileshekin, K. Doan et al., "Acceptability of Early Integration of Palliative Care in Patients with Incurable Lung Cancer," *Journal of Palliative Medicine*, May 2014 17(5):553-8.

Data on 1,517 patients in a multi-region study found that many (53%) patients diagnosed as having metastatic lung cancer had not discussed hospice with a provider within 4 to 7 months after diagnosis. Patients who were black, Hispanic, non-English speaking, married or living with a partner, Medicaid beneficiaries, or had received chemotherapy were less likely to have discussed hospice. Increased communication with physicians could address patients' lack of awareness about hospice and misunderstandings about prognosis. H. A. Huskamp, N. L. Keating, J. L. Malin et al., "Discussions with Physicians About Hospice Among Patients with Metastatic Lung Cancer," *Archives of Internal Medicine*, May 25, 2009 169(10):954-62.

This study examined use of hospice services among Medicare beneficiaries. Although 53% (in CA) and 44% (in NY) of Medicare patients ages  $\geq 65$  years used hospice, less than one-third of Medicaid-insured patients ages 21 to 64 years enrolled in hospice after a diagnosis of stage IV lung cancer (CA, 32%; NY, 24%). Given low rates of hospice use among Medicaid enrollees and considerable evidence of suffering at the end of life, opportunities to improve palliative care delivery should be prioritized. J. W. Mack, K. Chen, F. P. Boscoe et al., "Underuse of Hospice Care by Medicaid-Insured Patients with Stage IV Lung Cancer in New York and California," *Journal of Clinical Oncology*, July 10, 2013 31(20):2569-79.

This study found that despite uniform health insurance coverage, there is wide variation in the utilization of palliative chemotherapy among Medicare patients, and nonmedical factors are strong predictors of whether a patient receives chemotherapy. In particular, African-Americans and those with lower socioeconomic status are less likely to receive chemotherapy for lung cancer compared with whites and those with high socioeconomic status. C. C. Earle, L. N. Venditti, P. J. Neumann et al., "Who Gets Chemotherapy for Metastatic Lung Cancer?" *Chest*, May 2000 117(5):1239-46.

### ***Pain Management, Palliative Care, and Hospice Care: Patient Experience***

This report is based on a public hearing among lung cancer patients, their caregivers, and advocates convened by the Food and Drug Administration as part of its Patient Focused Drug Development initiative. It focuses on lung cancer patients' experiences with care and chief complaints. Problems patients identified in the course of their treatment included: the stress of the diagnostic process; need for help understanding the short- and long-term goals of treatment especially for treatments that delay tumor progression but are not expected to cure; the need for providers to have a better understanding of patients' values; and need for early and routine follow-up after diagnosis and treatment. Patients say they have difficulty distinguishing their disease symptoms from the side effects of treatment, and need more help with the lingering effects of treatment. They also suggested efforts to encourage awareness of opportunities to participate in clinical trials and promote more transparency about the outcomes of clinical research. *The Voice of the Patient: Lung Cancer*, U.S. Food and Drug Administration, Dec. 2013.

Across nearly 28,000 cancer patients who visited an ED in North Carolina in 2008, the top three chief complaints were related to pain, respiratory distress, and GI issues. Lung, breast, prostate, and colorectal cancers were identified in 26.9%, 6.3%, 6%, and 7.7% of visits, respectively. D. K. Mayer, D. Travers, A. Wyss et al., "Why Do Patients with Cancer Visit Emergency Departments? Results of a 2008 Population Study in North Carolina," *Journal of Clinical Oncology*, July 1, 2011 29(19):2683-8.

Researchers interviewed lung cancer and COPD patients about their care experiences toward the end of life. They found that for lung cancer patients the role of nurse coordinator was valuable: such workers coordinated care between and within clinical settings, referred patients to community palliative care services, helped them with financial issues, and provided support. E. Epiphaniou, C. Shipman, R. Harding et al., "Coordination of End-Of-Life Care for Patients with Lung Cancer and Those with Advanced COPD: Are There Transferable Lessons? A Longitudinal Qualitative Study," *Primary Care Respiratory Journal*, March 2014 23(1):46-51.

### ***Pain Management, Palliative Care, and Hospice Care: Evidence of Impact on Quality of Life***

This randomized control trial at Massachusetts General Hospital demonstrated improved survival and quality of life for patients who receive palliative care referrals at the outset of their treatment. As compared with patients receiving standard care, patients receiving early palliative care had less aggressive care at the end of life but longer survival. J. S. Temel, J. A. Greer, A. Muzikansky et al., "Early Palliative Care for Patients with Metastatic Non-Small-Cell Lung Cancer," *New England Journal of Medicine*, Aug. 19, 2010 363(8):733-42.

There are few randomized controlled trials examining the effects of palliative care on the quality of care for advanced cancer patients. This was a randomized controlled trial examining the effects of Project ENABLE II (Educate, Nurture, Advise, Before Life Ends), which sought to educate cancer patients (including lung cancer patients) about their disease and to encourage their self-management and empowerment. The trial found that patients receiving such support had higher quality of life scores and higher mood scores, but did not have lower symptom intensity scores or reduced days in the hospital or ICU or lower emergency department visits. M. Bakitas, K. Lyons, and M. Hegel et al., "Effects of a Palliative Care Intervention on Clinical Outcomes in Patients with Advanced Cancer: The Project ENABLE II Randomized Controlled Trial," *Journal of the American Medical Association*, Aug. 19, 2009 302(7):741-9.

This randomized control trial tested the effects of a cancer support team on patients with advanced cancer, including lung cancer. The team offered individualized care coordination, symptom management, education, psychosocial and spiritual supports, and advanced care planning throughout the 15-month study period. Surviving subjects with higher survival expectancy (who also reported better baseline quality of life) in the intervention arm had the greatest improvement in health-related quality of life scores. B. J. Daly, S. L. Douglas, D. Gunzler et al., "Clinical Trial of a Supportive Care Team for Patients with Advanced Cancer," *Journal of Pain and Symptom Management*, Dec. 2013 46(6):775-84.

### ***Pain Management, Palliative Care, and Hospice Care: Models and Goals***

This article addresses the American Society of Clinical Oncology's (ASCO's) vision for improved communication with and decision making for patients with advanced cancer. This statement advocates an individualized approach to discussing and providing disease-directed and supportive care options for patients with advanced cancer throughout the continuum of care. Building on ASCO's prior statements on end-of-life care (1998) and palliative care (2009), this article reviews the evidence for improved patient care in advanced cancer when patients' individual goals and preferences for care are discussed. It outlines the goals for individualized care, barriers that currently limit realization of this vision, and possible strategies to overcome these barriers that can improve care consistent with the goals of our patients and evidence-based medical practice. J. M. Peppercorn, T. J. Smith, P. R. Helft et al., "American Society of Clinical Oncology Statement: Toward Individualized Care for Patients with Advanced Cancer," *Journal of Clinical Oncology*, 2011 29:755-60.

This article describes the Project ENABLE II (Educate, Nurture, Advise, Before Life End) approach to improve palliative care for rural cancer patients. Advance practice palliative care nurse specialists invited patients to enroll shortly after diagnosis of advanced or recurrent cancer. The nurses educated participants about key palliative care principles and crisis prevention via practice in problem solving/ decision-making skills, symptom management, communication, and advance care planning. Concurrent with anti-cancer treatment, they coordinated appropriate referrals to improve the patient and caregiver's quality of living with advanced cancer and the patient's end of life experience. The intervention was primarily conducted by telephone in order to be accessible to a rural population that was anticipated to become more dependent as illness progresses. The approach was essentially a "both-and" (as opposed to "either-or") model in which there would be a smooth transition from mostly anti-cancer treatment to mostly palliative care. M. Bakitas, K. Lyons, and M. Hegel et al., "Project ENABLE II Randomized Controlled Trial to Improve Palliative Care for Rural Patients with Advanced Cancer: Baseline Findings, Methodological Challenges, and Solutions," *Palliative and Supportive Care*, 2009 7(1):75-86.

A pilot effort in Australia to improve end-of-life planning for patients with end-stage heart failure and lung disease through in-person case conferences between general practitioners and specialists led to significant reductions in service utilization, apparently by improving case coordination, enhancing symptom management and assessing and managing caregiver needs. Findings may be relevant to end-of-life care for patients with lung cancer. G. Mitchell, J. Zhang, L. BurrIDGE et al., "Case Conferences Between General Practitioners and Specialist Teams to Plan End of Life Care of People with End Stage Heart Failure and Lung Disease: An Exploratory Pilot Study," *BMC Palliative Care*, May 5, 2014 13:24.

A VA demonstration program to improve end-of-life care for patients with inoperable lung cancer, advanced heart failure, and chronic lung disease focused on the following: early identification of poor-prognosis patients, interdisciplinary palliative assessment, and intensive nurse care coordination to optimize symptom management, continuity and coordination of services across providers and care settings, and support for families. The

program led to high rates of advance care planning, hospice enrollment, and death at home, and low end-of-life hospital and Intensive Care Unit (ICU) use. As a result of its success, the program will be expanded and its care model extended institution-wide. K. Rosenfeld and J. Rasmussen, "Palliative Care Management: A Veterans Administration Demonstration Project," *Journal of Palliative Medicine*, Oct. 2003 6(5):831-9.

This article reports on two pilot studies: one used a nurse-led educational effort to successfully reduce barriers to pain and fatigue management; and the other study demonstrated the feasibility of a nurse-led assessment followed by an interdisciplinary case conference intended to initiate supportive care to address patients' quality of life and symptom concerns. T. Borneman, M. Koczywas, M. Cristea et al., "An Interdisciplinary Care Approach for Integration of Palliative Care in Lung Cancer," *Clinical Lung Cancer*, Nov. 2008 9(6):352-60.

This study looked at the effects of the 2011 publication of the American Society of Clinical Oncology's goals for individualized care for advanced cancer patients on advanced care planning at the authors' institution. The results suggest that there is possible benefit from providing information on supportive care before first-line chemotherapy and informing patients about their prognosis in prolonging the duration of supportive care. T. Tokito, H. Murakami, K. Mori et al., "Implementation Status and Explanatory Analysis of Early Advance Care Planning for Stage IV Non-Small Cell Lung Cancer Patients," *Journal of Clinical Oncology*, March 2015 45(3):261-6.

# CLINICAL TRIAL PARTICIPATION

While some studies have found minorities, who are disproportionately represented among Medicaid beneficiaries, do not participate in cancer research trials as much as other groups, other studies suggest that income and social status may be as important as race in determining who participates.

In addition to lack of access to clinical trials in community settings, barriers include fear, mistrust of the medical community, and the financial and time burdens associated with participation.

The low rates of participation in clinical trials raise questions about the generalizability of study results.

## **Barriers to Participation**

This is a review of publications on recruitment of under-represented groups, including racial and ethnic minorities and low-income people, to cancer treatment or prevention trials. Barriers to recruitment/participation included lack of education; perceived harms of participation; distance to clinic; lack of transportation; loss of income; loss of control; mistrust of research/medical system; and cultural/language barriers. J. G. Ford, M.W. Howerton, G. Y. Lai et al., "Barriers to Recruiting Underrepresented Populations to Cancer Clinical Trials: A Systematic Review," *Cancer*, 2008 112: 228-42.

This study found that patient race/ethnicity was not associated with clinical trial enrollment after adjustment for socioeconomic covariates—suggesting that income/social status may be as important as race as a determinant of who joins clinical trials. Patients with advanced cancer endorsing less engagement in end-of-life planning were more likely to be enrolled in a clinical trial. R. Jimenez, B. Zhang, S. Joffe et al., "Clinical Trial Participation Among Ethnic/Racial Minority and Majority Patients with Advanced Cancer: What Factors Most Influence Enrollment?" *Journal of Palliative Medicine*, 2013 16:256-62.

Disparities in minorities' representation in cancer clinical trials have been shown only in adult populations, which suggest that the main causes of these disparities relate to health system-based barriers, including issues of poverty (e.g., lack of insurance), poor access to trials, and an inadequate number of clinical trials. Initiatives that increase the participation of community physicians in cancer clinical research trials and increase low socioeconomic status patients' access to cancer trials might ameliorate this problem. G. Colon-Otero, R. C. Smallridge, L. A. Solberg, Jr. et al., "Disparities in Participation in Cancer Clinical Trials in the United States: A Symptom of a Healthcare System in Crisis," *Cancer*, 2008 112:447-54.

This review of the literature on why minorities have low rates of participation in cancer clinical trials pointed to patients' fear, mistrust of the medical community, and the burdens associated with participation. Physicians' enthusiasm and communication skills, good relationships between providers and patients, patients' perceptions of benefits, and patients' altruism tended to promote participation. G. L. Schmotzer, "Barriers and Facilitators to Participation of Minorities in Clinical Trials," *Ethnicity and Disease*, 2012 22:226-30.

## **Impact**

The relatively low participation of African-Americans in phase III clinical trials has raised concerns about the appropriateness of generalizing study results to African-American populations. If African-American enrollment in clinical trials continues to be low, we may continue to see disparities in the treatment of diseases as well as unanswered questions as to why African-Americans fare less well than others when diagnosed with certain diseases such as cancer and diabetes. Additionally, more clinical trials are needed to explicitly

monitor the difference in outcomes across different populations. This article discusses the various reasons why African-American patient recruitment and participation is sub-optimal; the critical role of clinical trials in therapies; and a new practice model (Collaborative Care Model) designed to augment participation rates of African-Americans and other minorities in clinical trials. F. T. Shaya, C. M. Gbarayor, H. Keri Yang et al., "A Perspective on African-American Participation in Clinical Trials," *Contemporary Clinical Trials*, 2007 28:213-7.

Cancer research priorities are currently focused on specific biomarkers that can individualize patient treatments in the hopes of improving survival from cancer. But many minority communities have low rates of participation in clinical trials, due in part to mistrust. An NCI-led effort, described here, seeks to ensure genetic research includes different ethnic groups through a community-based participatory research model. J. S. Kaur and D. G. Petereit, "Personalized Medicine: Challenge and Promise," *Journal of Cancer Education*, 2012 27:S12-7.

# Appendix B

## Expert Sources

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A publication from the ACCC initiative, *Improving Care Coordination: A Model for Lung Cancer Patients on Medicaid* (formerly titled, *Optimal Care Coordination Model for Lung Cancer Patients on Medicaid*). Learn more at [acc-cancer.org/care-coordination](http://acc-cancer.org/care-coordination).

The **Association of Community Cancer Centers (ACCC)** is the leading education and advocacy organization for the cancer care community. Founded in 1974, ACCC is a powerful network of 25,000 multidisciplinary practitioners from 2,100 hospitals and practices nationwide. As advances in cancer screening and diagnosis, treatment options, and care delivery models continue to evolve, so has ACCC, adapting its resources to meet the changing needs of the entire oncology care team. For more information, visit [acc-cancer.org](http://acc-cancer.org) or call 301.984.9496. Follow us on Facebook, Twitter, LinkedIn, and Instagram; read our blog, ACCCBuzz; and tune in to our podcast, CANCER BUZZ.

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This publication is a benefit of ACCC membership.

Support provided by Bristol Myers Squibb Foundation.

