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The Clinical and Economic Impact of the Early Detection and Diagnosis of Cancer

Peter J. Deckers,[*] Richard Manning,[*] Tricia Laursen, [*] Stacey Worthy,[*] and Shruti Kulkarni[*]

Many detectable cancers are often undiagnosed, misdiagnosed, or diagnosed too late. Recently developed early detection technologies can be costly and inaccessible. In contrast, low-cost, practical solutions are needed now. This article advocates for "Early Detection and Diagnosis (EDD)," a method where practitioners 1) teach patients to self-assess abnormal symptoms, see their practitioner promptly, and accurately describe symptoms; and 2) make diagnoses in response. Despite EDD's effectiveness, barriers including low health literacy, symptom misinterpretation and minimization, and inadequate patient-provider communication have impeded wide adoption in the United States. Widespread education and awareness efforts, including state legislative and regulatory activity, can overcome these barriers.

This article explains EDD's clinical and economic impact and challenges associated with its adoption in the United States. It recommends state legislatures enact laws requiring that 1) medical boards develop guidelines on how providers can train patients to detect cancer signs early and promptly seek a diagnosis; 2) medical boards offer continuing medical education courses on the training guidelines; and 3) state health plans cover these services. These actions make patients more likely to detect their cancer symptoms and promptly report relevant information to their provider. In turn, providers will be able to make an earlier and more accurate diagnosis.

* Dr. Deckers serves on the board of directors of 15-40 Connection, a 501(c)(3) not-for-profit organization whose mission is to educate and empower people about early cancer detection. Dr. Deckers also serves as a surgical oncologist at *UConn Health* and as Professor of Surgery and Dean Emeritus at *UConn School of Medicine*.

* Dr. Manning is a Partner in the Life Sciences Practice at Bates White, LLC in Washington, DC. He provides consulting services and expert testimony on matters relating to economics for clients in government, law firms and other private enterprises.

* Ms. Laursen is the President of 15-40 Connection, a 501(c)(3) not-for-profit organization whose mission is to save lives by teaching people how to detect cancer early and be active partners in their healthcare.

* Ms. Worthy is a partner at DCBA Law & Policy LLP in Washington, DC. She provides counsel to not-for-profit health policy and patient advocacy organizations, health care programs and providers, and pharmaceutical and biotechnology companies in various aspects of their legal, regulatory, and business affairs.

* Ms. Kulkarni is an associate at DCBA Law & Policy LLP in Washington, DC. She provides counsel to pharmaceutical, biotechnology, and medical device companies. She offers insight on federal and state legal, legislative, regulatory, and enforcement matters.

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INTRODUCTION

Cancer is currently the leading cause of life years lost in the United States, and many easily detectable forms of cancer are often undiagnosed, misdiagnosed, or diagnosed too late, leading to avoidable deaths.[1] Moreover, cancer is one of the most expensive diseases to treat and can result in considerable financial burden.[2] Patients and their families can experience financial hardship from high out-of-pocket expenses, which can significantly diminish quality of life and even interfere with delivery of quality care.[3]

Ahead of the 2020 presidential election, improving the detection and treatment of cancer and lowering the cost of health care have been two bipartisan focal points for elected officials and presidential candidates alike.[4] In June 2019, former Vice President Joe Biden stated that he wanted to "cure cancer" during his presidency.[5] Similarly, in March 2018, President Trump called for Americans to speak to their health care providers to learn more about cancer prevention measures that can save their lives.[6] As the President encouraged various stakeholders, including government agencies, to increase awareness to help more Americans survive cancer, the American people have called on the government to lower health costs.[7] Twenty-eight percent of respondents in a recent Kaiser Family Foundation poll reported that lowering health care costs should be a top health care priority for elected Democratic officials.[8] While these two goals are seemingly at odds with each other, it is possible to achieve them both at once. State legislators and medical boards have the opportunity to put policies in place that encourage low cost, practical solutions to detect and diagnose cancer earlier, thereby improving care and saving the health system money.

Diagnosing cancer at earlier stages, before it metastasizes, can significantly increase survival rates and reduce costs to both the patient and the general public.[9] Yet, while

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[1] *Years of Life Lost*, Nat'l Cancer Inst., https://progressreport.cancer.gov/end/life_lost#field_additional_information (last updated Feb. 2019); Cancer Research UK, Saving Lives, Averting Costs: An Analysis of The Financial Implications Of Achieving Earlier Diagnosis Of Colorectal, Lung And Ovarian Cancer (2014), https://www.cancerresearchuk.org/sites/default/files/saving_lives_averting_costs.pdf.

[2] S. Yousuf Zafar & Amy P. Abernethy, *Financial Toxicity, Part I: A New Name for a Growing Problem*, 27 Oncology 80, 80 (2013).

[3] *Id.* at 81.

[4] Shefali Luthra, *Promising to Cure Cancer is Easy Politics. The Science is Much More Difficult,* LA Times (June 22, 2019, 7:00 AM), https://www.latimes.com/science/la-sci-cure-cancer-politicians-science-20190622-story.html.

[5] Tal Axelrod, *Biden says as president he wants to 'cure cancer,'* The Hill (June 11, 2019, 3:04 PM), https://thehill.com/homenews/campaign/447982-biden-says-as-president-he-wants-to-cure-cancer.

[6] *President Donald J. Trump Proclaims April 2018 as Cancer Control Month*, Executive Off. of the President (Mar. 29, 2018), https://www.whitehouse.gov/presidential-actions/president-donald-j-trump-proclaims-april-2018-cancer-control-month.

[7] *Id.*

[8] Ashley Kirzinger et al., *KFF Health Tracking Poll–June 2019: Health Care in the Democratic Primary and Medicare-for-All*, KFF (June 18, 2019), https://www.kff.org/health-reform/poll-finding/kff-health-tracking-poll-june-2019.

[9] Hyunsoon Cho et al., *When Do Changes in Cancer Survival Mean Progress? The Insight from Population Incidence and Mortality*, 2014 J. Nat'l Cancer Inst. Monographs 187, 187–97 (2014); Zafar & Abernethy, *supra* note 2.

diagnostic tests exist to detect cancer early on, such tests can be costly or inaccessible for certain patients.[10] Additionally, these tests are only available for a limited number of cancers, such as cervix, colon, breast, prostate, endometrial, and lung cancer, even though more than one hundred types of cancer exist.[11] While investors continue to fund innovative technology, practitioners need a low-cost, practical solution that they can use now. One practical solution is a method referred to herein as "Early Detection and Diagnosis" (EDD)—a combination of teaching patients the Three Steps to Early Detection ("Three Steps") and the provider making an early and accurate diagnosis based on the information received.[12] The Three Steps are: 1) establishing a personal health baseline; 2) detecting health changes that last for more than two weeks; and 3) reporting signs and symptoms to a practitioner.[13]

EDD has been widely adopted in the United Kingdom but not in the United States, partly due to barriers such as low health literacy, misinterpretation and minimization of symptoms, inadequate patient-provider relationship and communication, cognitive biases, and insufficient time spent with patients.[14] These barriers can be overcome with widespread education and awareness efforts, including through state legislative activity and regulatory activity by medical boards.

This article explains the clinical and economic impact of EDD. It identifies challenges that patients and practitioners face in implementing EDD. Finally, it proposes legislative and regulatory solutions that promote EDD. These solutions are intended to improve care for the patient while reducing costs to the healthcare system.

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[10] Susan G. Komen, Understanding Cost and Cost Coverage Issues with Diagnostic Breast Imaging 3 (2019), https://ww5.komen.org/uploadedFiles/_Komen/Content/What_We_Do/Advocacy/komen-understanding-cost-coverage-with-dbi-final-report.pdf.

[11] *Guidelines for the Early Detection of Cancer*, Am. Cancer Soc'y (last revised May 30, 2018), https://www.cancer.org/healthy/find-cancer-early/cancer-screening-guidelines/american-cancer-society-guidelines-for-the-early-detection-of-cancer.html.

[12] *3 Steps Detect*, 15-40 Connection, https://www.15-40.org/3-steps-to-early-detection/ (last visited Mar. 27, 2020).

[13] *Id.*

[14] Thomas E. Kottke, *Overcoming the Barriers to Cancer Screening*, 73 Mayo Clinic Proc., 386, 387 (1998); Minjoung M. Koo et al., *Symptom Signatures and Diagnostic Timeliness in Cancer Patients: A Review of Current Evidence*, 2 Neoplasia 165, 166 (2018). *See generally* Claire Jones et al., *A Systematic Review of Barriers to Early Presentation and Diagnosis with Breast Cancer Among Black Women* 4 BMJ Open 1, 2, 7–8 (2014).

I. BACKGROUND

A. Overview of EDD

EDD allows practitioners to identify cancer at an early stage and administer effective treatment sooner than would have otherwise been possible.[15] There are two generally accepted methods of early detection. First, practitioners can screen asymptomatic individuals for the presence of cancer.[16] Second, patients can identify signs and symptoms that suggest a change to their health, promptly seek care, and obtain a clinical diagnosis.[17] While screening interventions can detect asymptomatic cancer, they are only available for a limited number of cancers and their effectiveness is often constrained by cost and lack of use due to low patient adherence and unwillingness to undergo screening.[18] Given that most patients are diagnosed with cancer after they present with symptoms, this article focuses on the second method of detection—self-identification.[19]

1. The role of the patient

Patients with cancer who are aware of persistent health changes and promptly seek an evaluation of such changes are more likely to receive an early diagnosis and treatment.[20] "Persistent health changes" are subtle changes in an individual patient's normal health that last longer than two weeks.[21] Many forms of cancer are at least subtly symptomatic.[22] Though patients present with different symptoms, some of the most common cancer symptoms include persistent cough or hoarseness, an unexplained lump, unexplained weight loss, change in the appearance of a mole, persistent change in bowel habits, persistent change in bladder habits, abdominal bloating, unexplained pain, extreme fatigue, fever, difficulty swallowing, blood in urine, rectal bleeding, other unexplained bleeding, changes to the breast, or a sore that does not heal.[23]

Not all patients experience the same symptoms, and some may decide not to report experiencing a symptom if the symptom is not one that is commonly associated with

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[15] *Guide to Early Cancer Diagnosis* 8, World Health Org., (2017), http://apps.who.int/iris/bitstream/handle/10665/254500/9789241511940-eng.pdf;jsessionid=1E6CC8FBDE89690115E632DEB7BCCB1D?sequence=1;%20; *Cancer Screening*, Nat'l Cancer Inst. (last updated Apr. 9, 2018), https://www.cancer.gov/about-cancer/screening.

[16] *Guide to Early Cancer Diagnosis*, *supra* note 15, at 9.

[17] *See 3 Steps Detect*, *supra* note 12 (suggesting that if a patient experiences a subtle change in their health that lasts two weeks or more, they should contact their doctor).

[18] R.N. Battista & S.A. Grover, *Early Detection of Cancer: An Overview*, 9 Ann. Rev. Pub. Health. 21, 22, 39–40 (1988).

[19] Katriina L. Whitaker et al., *What Prompts Help-Seeking for Cancer 'Alarm' Symptoms? A Primary Care Based Survey,* 114 Brit. J. Cancer 334, 334 (2016).

[20] Koo et al., *supra* note 14, at 165–66.

[21] *Use the Two-Week Rule: Know When It's Time to Talk to Your Doctor*, 15–40 Connection, https://www.15-40.org/3-steps-to-early-detection/2-week-rule (last visited Mar. 27, 2020).

[22] Whitaker et al., *supra* note 19, at 334, 336.

[23] Kelly Winstanley et al., *The Impact of Body Vigilance on Help-Seeking for Cancer 'Alarm' Symptoms: A Community-Based Survey*, 16 BMC Pub. Health, 1172, 1173 (2016).

a particular condition.[24] Without practitioner-patient dialogue and ongoing education about EDD, patients may mistakenly rely on common symptoms lists as comprehensive and decide to ignore or not report subtle and persistent health changes that are not listed as a common cancer symptom. This issue further emphasizes the need for improved ongoing patient education and practitioner-patient dialogue.

2. The role of the physician

Once a patient has identified a persistent health change, the practitioner and patient must work together so that the patient receives a timely and accurate diagnosis. Such diagnoses depend on sufficient communication and accurate patient history, patient-reported symptoms, and a physical examination.[25] The practitioner must have "an appropriate index of suspicion" and conduct a clinical evaluation of any screening tests, procedures, and other clinical data before the cancer progresses.[26] Practitioners who are trained to detect less obvious signs of certain cancers are more likely to make an earlier diagnosis.[27] Trained practitioners acting alongside engaged patients can improve care beyond what either could have achieved alone.

II. ECONOMIC IMPLICATIONS OF EDD VS. DELAYS IN DETECTION AND DIAGNOSIS

A. The Direct Economic Impact of EDD

EDD of cancer can significantly reduce both direct and indirect costs to patients and the health system. In 2014, the U.S. health system spent roughly $87.8 billion on direct cancer-related health care, $4 billion of which was spent directly by patients and their families.[28] Such spending included approximately 58% for hospital outpatient or office-based provider visits, 27% for hospital inpatient stays, 12% for prescribed medicines, 2% for home health, and 1% for emergency room visits.[29] Much of this cost is undoubtedly associated with expensive multi-disciplinary treatments for advanced stages of cancer.

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[24] Tracy L. Finlayson et al., *Assessing Symptoms, Disease Severity, and Quality of Life in the Clinical Context: A Theoretical Framework*, 10 Am. J. Managed Care 336, 336 (2004). *See generally* Minjoung M. Koo et al., *Typical and atypical presenting symptoms of breast cancer and their associations with diagnostic intervals: Evidence from a national audit of cancer diagnosis,* Cancer Epidemiology 140, 140–46 (2017).

[25] Jerome P. Kassirer, *Imperatives, expediency, and the new diagnosis,* 1 Diagnosis 11, 12 (2014).

[26] *Guide to Early Cancer Diagnosis*, *supra* note 15, at 14.

[27] National Academy of Sciences, Fulfilling the Potential of Cancer Prevention and Early Detection 294 (2003).

[28] *The Costs of Cancer: Addressing Patient Costs*, Am. Cancer Soc'y: Cancer Action Network 1, 1–2 (2017), https://www.fightcancer.org/sites/default/files/Costs%20of%20Cancer%20-%20Final%20Web.pdf.

[29] *Id.*

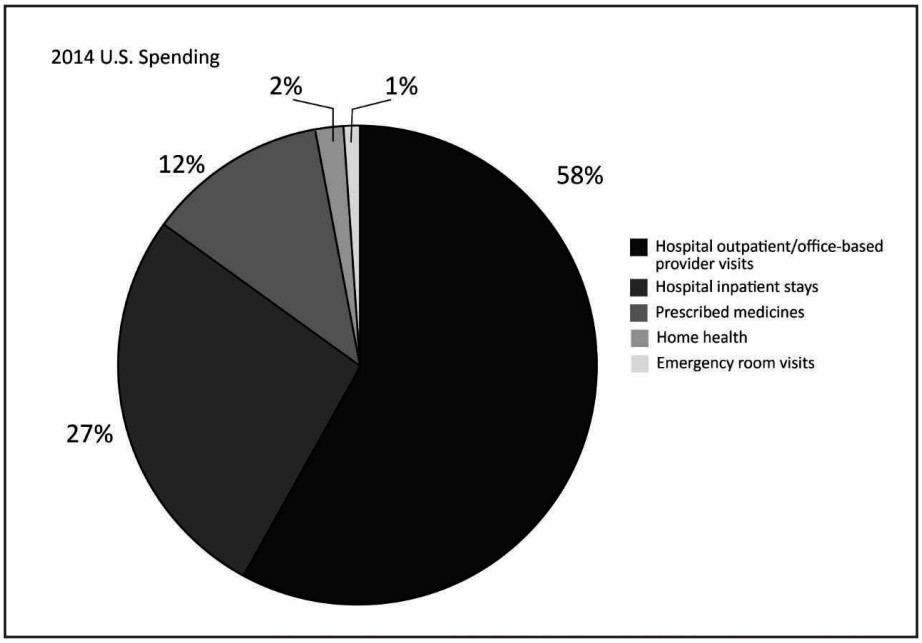

Fig. 1. 2014 Patient costs for cancer related health care in the U.S. Image shows a pie chart depicting the distribution of patient costs for cancer related health care in the U.S. in 2014.

With the cost of cancer care continuing to rise, EDD can ease financial strain and result in significant cost savings.[30] A 2017 study estimated that earlier diagnosis of all cancer types could save an estimated $26 billion annually on treatment costs alone in the U.S.[31] The study also noted that early diagnosis of the top five cancers—breast, lung, prostate, colorectal, and melanoma—could result in cost savings of over $10.7 billion a year.[32] Moreover, early diagnosis may reduce the need for expensive novel drug therapies for advanced stages.[33]

Treatment in later stages of many types of cancer are associated with much higher treatment costs, despite diminished survival rates. For example, treatment costs for lung cancers diagnosed at stage I averaged $7,239 a month, compared to $21,441 for those diagnosed at stage IV.[34] A 2018 study found that costs for the first year of treatment for gastric cancers diagnosed at stage I averaged $8,900, while treatment for such cancers

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[30] Elizabeth Goss, *The State of Cancer Care 2018*, Nat'l Coalition for Cancer Survivorship (2018).

[31] Zura Kakushadze et al., *Estimating Cost Savings from Early Cancer Diagnosis*, Data 1, 2, 13 (Sept. 4, 2017).

[32] *Id.* at 13.

[33] *See Early cancer diagnosis saves lives, cuts treatment costs*, World Health Org., https://www.who.int/news-room/detail/03-02-2017-early-cancer-diagnosis-saves-lives-cuts-treatment-costs (last visited Mar. 27, 2020) (asserting that the cost of cancer treatment is much less in cancer's early stages).

[34] Thomas R. Gildea et al., *A Retrospective Analysis of Delays in the Diagnosis of Lung Cancer and Associated Costs*, 9 ClinicoEconomics & Outcomes Res. 261, 261 (2017).

diagnosed at stage IV averaged over $25,000.[35] A breast cancer study published in 2017 found that the average per-patient cost during the first two years following diagnosis was $71,909 and $97,066 when diagnosed at stage 0 and I/II, respectively, but rose to $159,442 for a stage III diagnosis and $182,655 for a stage IV diagnosis.[36] Similarly, another study revealed average treatment costs in the first year following colorectal cancer diagnosis to be $49,189, $66,613, $83,980, and $108,599 when diagnosed at stage I, II, III, and IV, respectively.[37] The same study found similar, yet less dramatic, cost trends for breast, prostate, and lung cancer.[38]

B. The Indirect Economic Impact of EDD

Delayed cancer diagnoses also impose substantial indirect costs on society. Although these costs are not as directly observable as the direct costs of care, they are nonetheless real. While the largest indirect costs of cancer are associated with years of life lost and diminished quality of life, EDD may result in improved survival, quality of life, patient experience, and reduced costs.[39]

The potential impact of early diagnosis is particularly illustrative for breast, skin, colon and rectal, lung, and prostate cancers. Symptoms of breast cancer (e.g., nipple discharge) can appear as early as stage I.[40] A patient with a diagnosis at stage I has a five-year survival rate of approximately 99%, compared to 27% during stage IV.[41] Skin cancer also presents with visible changes to the skin in early stages.[42] According to one study, the five-year survival rate for early stage melanoma is 99% compared to 20% at stage IV.[43] The five-year survival rate for early stage colon and rectal cancer is 90% compared to 14% for late stages, 56% for early stage lung cancer compared to 5% in late stages, and 99% for early stage prostate cancer compared to 30% in late stages.[44]

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[35] Jie-Hyun Kim et al., *Early Detection is Important to Reduce the Economic Burden of Gastric Cancer*, 18 J. Gastric Cancer 82, 86 (2018).

[36] Helen Blumen et al., *Comparison of Treatment Costs for Breast Cancer, by Tumor Stage and Type of Service*, 9 Am. Health & Drug Benefits 23, 23 (2016).

[37] *Cancer Care Spending in California: What Medicare Data Say,* Cal. Healthcare Found. 1, 10 (2015), https://www.chcf.org/wp-content/uploads/2017/12/PDF-CancerCareSpendingMedicare.pdf.

[38] *Id.*

[39] K. Robin Yabroff et al., *Economic Burden of Cancer in the United States: Estimates, Projections, and Future Research,* 20 Cancer Epidemiology, Biomarkers & Prevention 2006, 2006, 2008 (2011).

[40] *Cancer Facts & Figures*, Am. Cancer Soc'y, 1, 10 (2018), https://www.cancer.org/content/dam/cancer-org/research/cancer-facts-and-statistics/annual-cancer-facts-and-figures/2018/cancer-facts-and-figures-2018.pdf.

[41] *Id.* at 11–12, 21.

[42] *Id.* at 23.

[43] *Id.* at 24.

[44] *Id.*

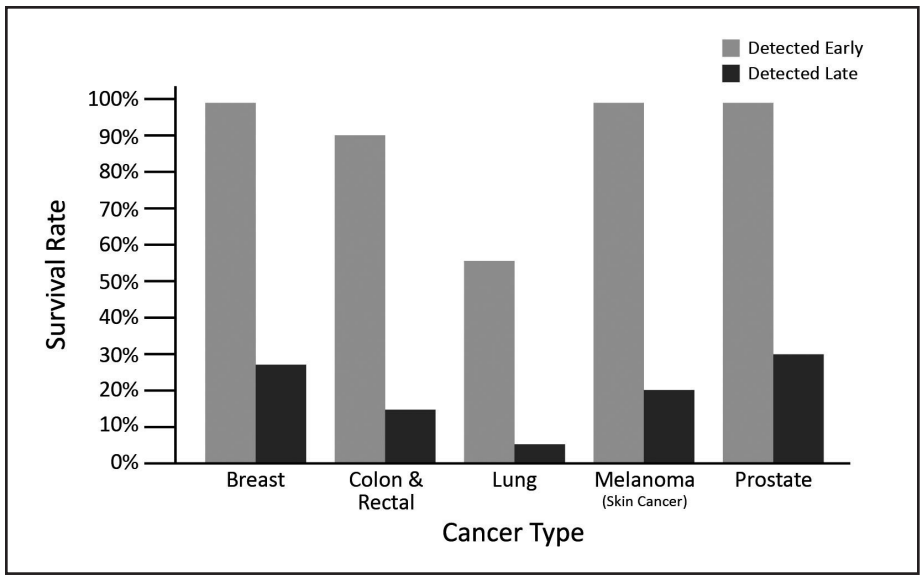

Fig. 2. Comparison of survival rates for cancer that was detected early and cancer that was detected late.[45] Data sourced from studies on survival rates for breast, colon and rectal, lung, melanoma, and prostate cancers from 2017 to 2018.[46]

Other indirect costs of cancer include reduced productivity and absenteeism. One study estimated that annual productivity lost due to cancer mortality (which increases with delayed diagnosis) was estimated to rise to $148 billion by 2020.[47] An additional study noted that the cost of cancer-related employee absenteeism between 2004 and 2008 was $8.1 billion, with a median cost per state of nearly $116 million.[48]

Additionally, delayed diagnosis can increase the risk of costly malpractice lawsuits.[49] Medical malpractice claims may arise out of delayed diagnosis or misdiagnosis, resulting from a physician's conduct or inaction, that increases the risk of recurrence or spread of the patient's cancer and results in sustained injuries.[50] A 2015 study showed that a majority of medical malpractice lawsuits involving breast cancer were due to delayed diagnosis stemming from inadequate patient self-assessment.[51] EDD can improve assessments and reduce these risks and expenses.

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[45] *Id.*

[46] *Id.* at 21.

[47] Alison Pearce et al., *Projecting Productivity Losses for Cancer-Related Mortality 2011–2030*, 16 BMC Cancer 1, 2 (2016).

[48] Florence K. Tangka, *State-Level Estimates of Cancer-Related Absenteeism Costs*, 55 J. Occupational Envtl. Med. 1015, 1015, 1019 (2016).

[49] Alicia Gallegos, *Delayed Diagnosis Tops Breast Cancer Malpractice Claims*, MDEdge (Oct. 20, 2015) https://www.mdedge.com/obgyn/article/103656/breast-cancer/delayed-diagnosis-tops-breast-cancer-malpractice-claims.

[50] *Id.*

[51] Penny Greenberg, *Navigating Risks in Breast Cancer Diagnosis and Treatment: How Physicians Can Enhance Patient Safety*, Patient Safety and Quality Healthcare (Oct. 12, 2015), https://www.psqh.com/analysis/navigating-risks-in-breast-cancer-diagnosis-and-treatment.

III. BARRIERS TO EDD

Cancer is one of the most commonly missed diagnoses in the US.[52] Inaccurate or delayed cancer diagnoses have been described as "a blind spot in the delivery of quality care."[53] Both patients and practitioners contribute to this phenomenon.

A. Patient Barriers

Though some patients may recognize persistent and subtle health changes, many delay seeking medical help.[54] According to one study, over a third of individuals with cancer who reported a persistent health change in the past three months chose not to seek help from a practitioner.[55] These delays are due to a number of factors, including misinterpretation and minimization of symptoms in which patients do not recognize they need medical intervention, poor health literacy, psycho-social factors, and lack of access to a practitioner.[56]

1. Misinterpretation and minimization of symptoms

Two barriers to timely diagnosis of cancer include misinterpretation and minimization of symptoms.[57] Patients may dismiss ambiguous symptoms of cancer as less serious ailments, or simply feel that they do not rise to the level of requiring medical intervention.[58] Women with ovarian cancer may mistakenly attribute early symptoms, such as abdominal distension, pelvic or abdominal pain, and frequent urination, to irritable bowel syndrome, aging, or stress.[59] Patients may confuse symptoms of lung cancer (e.g., coughing, shortness of breath, and tiredness) with

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[52] Laura Landro, *The Key to Reducing Doctors' Misdiagnoses,* Wall St. J. (Sept.12, 2017), https://www.wsj.com/articles/the-key-to-reducing-doctors-misdiagnoses-1505226691.

[53] *Id.*

[54] S.L. Quaife et al., *Recognition of Cancer Warning Signs and Anticipated Delay in Help-Seeking in a Population Sample of Adults in the UK.,* 110 Brit. J. of Cancer 12, 12–16 (2014).

[55] Whitaker et al., *supra* note 19, at 1.

[56] *See, e.g.*, Nancy S. Morris et al., *The Association Between Health Literacy and Cancer-Related Attitudes, Behaviors, and Knowledge*, 18 J. Health Comm. 223, 225 (2013); Stephanie Smith et al., *'I know I'm not invincible': An interpretative phenomenological analysis of thyroid cancer in young people*, 23 Brit. J. Health Psychol. 352, 361, 363 (2018); Jascha de Nooijer et al., *A Qualitative Study on Detecting Cancer Symptoms and Seeking Medical Help: An Application of Andersen's Model of Total Patient Delay*, 42 Patient Educ. & Counseling 145, 148, 152–55 (2001); *Five Ways Tech-Savvy Millennials Alter Health Care Landscape*, Cision PR Newswire (Mar. 23, 2015), https://www.prnewswire.com/news-releases/five-ways-tech-savvy-millennials-alter-health-care-landscape-300054028.html.

[57] Grace McCutchan et al., *Barriers to Cancer Symptom Presentation Among People from Low Socioeconomic Groups: A Qualitative Study*, 16 BMC Pub. Health 1052, 1054–55 (2016).

[58] *See generally* Robert A. Simmons et al., *Health Literacy: Cancer Prevention Strategies for Early Adults,* 53 Am. J. Preventative Med., 73, 73–74, 76 (2017). *See also* Jennifer Ann Fish et al., *Understanding Variation in Men's Help-Seeking for Cancer Symptoms: A Semistructured Interview Study,* Psychol. of Men & Masculinity 1, 4 (Apr. 2018).

[59] Kate E. Brain et al., *Ovarian Cancer Symptom Awareness and Anticipated Delayed Presentation in a Population Sample*, 14 BMC Cancer 1, 2 (2014).

other ailments, particularly if they have a history of smoking, thereby delaying the diagnosis of lung cancer.[60]

Even when a patient properly identifies symptoms, psycho-social factors such as feelings of fear, worry, shame, and embarrassment can cause a delay in seeking treatment.[61] For example, studies have shown that patients may wait to seek medical advice for symptoms associated with sex organs due to the private nature of the symptoms or feelings of embarrassment and shame.[62] Others conform to a cultural mindset that if they simply "tough it out," their symptoms will subside.[63] They may wait for their symptoms to worsen or accumulate before seeking medical attention.

Individuals experiencing persistent health changes may downplay the seriousness of those symptoms because they do not know that these changes could indicate a serious health condition or because patients do not know about or apply the two-week rule to evaluate causes such as diet or stress.[64] A study of individuals diagnosed with colorectal cancer found that 52% displayed at least one cognitive barrier to diagnosis, and of those, 40% minimized the seriousness of those symptoms, attributing the symptoms to aging, diet, stress, or ulcers rather than to cancer.[65] This downplaying of seriousness delayed diagnosis by an average of two months.[66]

2. Health literacy

Evidence suggests that individuals with lower health literacy may be more likely to forego cancer screenings, avoid physician visits, and have higher mortality rates.[67] Health literacy is "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions."[68] Health literacy includes the ability to read, understand spoken information, and understand numbers.[69]

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[60] *Signs and Symptoms of Lung Cancer*, Am. Cancer Soc'y (last revised Oct. 1, 2019), https://www.cancer.org/cancer/lung-cancer/detection-diagnosis-staging/signs-symptoms.html.

[61] *See* Jascha de Nooijer et al., *supra* note 56, at 148, 152, 153–55.

[62] Mohamadreza Neishaboury et al., *Does Embarrassment Contribute to Delay in Seeking Medical Care for Breast Cancer? A Review,* 2 Archives of Breast Cancer 75, 75–77 (2015); Chantal Balasooriya-Smeekens et al., *The Role of Emotions in Time to Presentation for Symptoms Suggestive of Cancer: A Systematic Literature Review of Quantitative Studies*, 24 Psycho-Oncology 1594, 1594–97 (2015).

[63] Lee M. Ellis et al., *Losing "Losing the Battle with Cancer,"* 1 JAMA Oncology 13, 13 (2015).

[64] *See supra* notes 12–13 and accompanying text.

[65] Janette L. Vardy et al., *Cognitive Function in Patients with Colorectal Cancer Who Do and Do Not Receive Chemotherapy: A Prospective, Longitudinal, Controlled Study,* 33 J. Clinical Oncology 4085, 4088 (2015).

[66] *Id.*

[67] Nancy S. Morris et al., *The Association Between Health Literacy and Cancer-Related Attitudes, Behaviors, and Knowledge,* 18 J. Health Comm. 223, 225 (2013).

[68] *Id.*; Levent Dumenci et al., *Measurement of Cancer Health Literacy and Identification of Patients with Limited Cancer Health Literacy,* 19 J. Health Comm. 205, 206 (2014).

[69] *Health Literacy*, Nat'l Inst. Health, https://nnlm.gov/initiatives/topics/health-literacy (last visited Mar. 27, 2020).

Patients with low health literacy may not recognize signs and symptoms of cancer, may delay screenings, and may have difficulty distinguishing credible scientific and medical evidence from misconceptions.[70] For example, low health literacy has been associated with cancer fatalism, or the general belief that cancer outcomes are predetermined by fate.[71] Lower awareness of and negative beliefs about cancer have been associated with delays in reporting cancer symptoms, advanced stage diagnosis, and lower survival rates.[72]

3. Barriers more common among young adults

Young adults may delay seeking a diagnosis due to the perception of invincibility.[73] A 2018 study that interviewed young adults aged nineteen to thirty-four with thyroid cancer found that a majority stated that they were shocked by their diagnosis because they felt they were too young to have cancer.[74] Another study concluded that the youth of individuals aged twenty to forty-three contributed to delays in cancer diagnosis because they experienced a feeling of invincibility or a state of denial.[75]

Lack of strong patient-provider relationships could also lead to delayed or inaccurate diagnoses in young adults. Millennials tend to view health care as a transaction that should occur quickly and efficiently.[76] They are twice as likely as baby boomers to prefer walk-in clinics or retail health facilities over traditional primary care physicians because of their efficient health care delivery.[77] Consequently, millennials may be less prone to develop a strong patient-provider relationship, and providers may not have a comprehensive understanding of the patient's health, resulting in a delayed or inaccurate diagnosis.

B. Clinical Barriers

The diagnostic process is fundamentally dependent on the personal interaction between the provider and the patient, the sufficiency and accuracy of information shared and gathered through the patient's history and exams, and the practitioner's clinical

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[70] Julia L. Halverson et al., *Health Literacy and Health-Related Quality of Life Among a Population-Based Sample of Cancer Patients,* 20 J. Health Comm.1320, 1322 (2015).

[71] McCutchan et al., *supra* note 57, at 1058.

[72] *Id.* at 1053 (suggesting that poor knowledge, negative beliefs, and barriers to help-seeking result in a long-patient interval). *See also* L.S. Karliner et al., *Language Barriers, Location of Care, and Delays in Follow-Up of Abnormal Mammograms,* 50 Med. Care 171, 172 (2012) (contending that poor communication between minority women and physicians leads to less knowledge and subsequently a barrier to follow-up care).

[73] *See* Smith et al., *supra* note 56, at 361, 363.

[74] *Id.* at 355, 363.

[75] *See* Baukje B. Miedema et al., *Young Adults' Experiences with Cancer: Comments from Patients and Survivors*, 52 Can. Fam. Physician 1447, 1449 (2006).

[76] Kristin Kovesdy, *7 Ways Millennials are Changing the Healthcare Industry (and What it Means to You)*, HFA, https://teamhfa.com/insights/7-ways-millennials-are-changing-the-healthcare-industry-and-what-it-means-to-you/ (last visited Mar. 12, 2020).

[77] *Five Ways Tech-Savvy Millennials Alter Health Care Landscape*, *supra* note 56.

evaluation of that information.[78] Various barriers can prevent practitioners from promptly diagnosing cancer, such as diagnostic errors, inadequate practitioner-patient communication, and insufficient time with the patient.

1. Cognitive biases

Diagnostic errors, or inaccurate or delayed diagnoses, "persist throughout all settings of care and continue to harm an unacceptable number of patients."[79] According to one study, 75% of diagnostic errors are due to cognitive biases such as 1) confirmation bias, or the tendency to seek only as much information as necessary to form an initial clinical impression; and 2) anchoring, or the tendency to stick with initial impressions even as new information becomes available.[80] In other cases, the selection of the first "diagnosis that comes to mind because it is common, serious, recently encountered, or otherwise noteworthy;" and unpacking, or the "failure to elicit all relevant information," prevents a timely diagnosis.[81]

Just as a patient may dismiss a subtle health change associated with cancer, a practitioner may not accurately identify such a change. Cancer is one of the most frequently missed diagnoses, often due to commonality of symptoms combined with cognitive biases.[82] These misdiagnoses have been attributed to anchoring and other cognitive biases.[83]

2. Inadequate practitioner-patient communication

Inadequate practitioner-patient communication can prevent an accurate diagnosis. Practitioners may not educate or train patients on identifying subtle and persistent health problems or convey the need for them to seek medical intervention promptly. As a result of this lack of training, patients may not deem subtle and persistent health changes important enough to bring to their physicians' attention.

Practitioners may confuse patients by using medical jargon that patients are unable to comprehend.[84] Individuals with a limited understanding of the information that their practitioners convey to them are consequently more likely to experience treatment delays.[85] Additionally, practitioners may not adequately convey the risks of a cancer

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[78] Erin P. Balogh et al., Improving Diagnosis in Health Care, The National Academies Press 37 (2015).

[79] *Id.* at 1.

[80] Edward Etchells, *Anchoring Bias with Critical Implications*, Agency for Healthcare Res. & Quality, Patient Safety Network (June 2015), https://psnet.ahrq.gov/webmm/case/350/anchoring-bias-with-critical-implications.

[81] Alexis R. Ogdie et al., *Seen Through Their Eyes: Residents' Reflections on the Cognitive and Contextual Components of Diagnostic Errors in Medicine*, 87 Acad. Med., 1361, 1363, 1365 (2012).

[82] *Id.* at 1361.

[83] *Id.*

[84] Suzanne Graham & John Brookey, *Do Patients Understand?*, 12 Permanente J. 67, 67–68 (2008).

[85] B. Noonan, *Understanding the Reasons Why Patients Delay Seeking Treatment for Oral Cancer Symptoms from a Primary Health Care Professional: An Integrative Literature Review,* 18 Eur. J. Oncology Nursing *118 (2014). See* Halverson et al., *supra* note 70, at 1328.

diagnosis or the benefits of certain procedures and treatments.[86] A study on patients' perspectives of colorectal cancer screenings found that at least 77% of eligible patients said it was important for physicians to explain the purpose of screening, risks and benefits, test accuracy, and alternatives when considering whether to participate in screening.[87] Yet, not enough patients received such information.[88]

3. Lack of sufficient time

Practitioners may be unable to make an early diagnosis because they do not have enough time during patient visits to properly assess symptoms.[89] Many practitioners, under pressure to be efficient, multitask when patients are speaking and may miss important information.[90] Failure to sufficiently investigate patient symptoms and complaints correlated with more than a six-month delay in the diagnosis of colorectal cancer.[91] Yet, it is not unusual for primary care doctors' appointments to be scheduled at fifteen-minute intervals; during that short period of time, the patient may not even have the practitioner's undivided attention.[92]

IV. RECOMMENDATIONS TO IMPROVE RATES OF EDD

In light of recent statements from the current Administration encouraging improved cancer care, it is important for states to retain control over the practice of medicine and find their own ways to reduce health care costs while also improving cancer care.[93] As such, states should take steps to encourage practitioners to implement EDD education and training programs for patients. To overcome adoption barriers, states should require medical boards to develop guidelines for training practitioners on EDD in primary care settings. Additionally, states should require medical boards to ensure that continuing medical education (CME) courses are available, which would educate primary care physicians and other practitioners on the guidelines and encourage them to adopt practical, low-cost solutions to detect cancer sooner and more accurately. Finally, states should require health plans to provide coverage of these services as an essential

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[86] M Finch, et al., *Women's Experiences With Ovarian Cancer: Reflections on Being Diagnosed,* 12. J. Oncology Nursing 152, 158 (2002).

[87] M. K. Barton, *Physician-Patient Communication Regarding Colorectal Cancer Screening is Lacking,* 62 Cal. Cancer J. Clinicians 1, 1 (2012).

[88] *See id.* (explaining that, of patients valuing test accuracy information, only seven percent received that information).

[89] *See generally* Roni Caryn Rabin, *15-minute Doctor Visits Take a Toll on Patient-Physician Relationships*, Kaiser Health News (Apr. 21, 2014), https://khn.org/news/15-minute-doctor-visits/ (suggesting that shorter, rushed interactions between practitioners and patients is increasingly common).

[90] *Id.*; G.P. Guy, *Visit Duration for Outpatient Physician Office Visits Among Patients with Cancer*, 8 J. Oncol Prac. 2 (2012).

[91] *See* Amanda L. Thorne et al., *Reduction in Late Diagnosis of Colorectal Cancer Following Introduction of a Specialist Colorectal Surgery Service,* 88 Annals Royal C. Surgeons Eng. 562, 563 (2006) (showing that some patients were delayed in diagnosis because of their own refusal or delay in participating in investigations).

[92] Guy, *supra* note 90.

[93] *See* Exec. Office of the President, *supra* notes 6–7 and accompanying text.

health benefit—encouraging patient-practitioner collaboration by ensuring practitioners receive adequate compensation and additional time to implement EDD. These legislative and regulatory efforts would not only decrease cost of treatment and life years lost, but also lower the risk of malpractice lawsuits stemming from missing or delaying such diagnoses.

A. Guidelines and Professional Education

Patients often play a key role in diagnosing their cancer. Unless a patient is able to detect signs and symptoms of cancer and share that information with a health care provider promptly, a provider may not be able to make a diagnosis or begin treatment. As such, practitioners must start the process that leads to diagnosis by training patients to identify subtle and persistent health changes and seek prompt medical attention. Consequently, it is imperative that health care providers are aware of the barriers to EDD of cancer and how to overcome them. Pursuant to state legislation requiring such, state medical board and voluntary medical associations should develop guidelines and offer educational courses for primary care providers and others aimed at increasing adoption rates of EDD. Guidelines and educational courses should identify the treatment barriers discussed herein and offer training in treatment strategies that will help patients to recognize and understand persistent health changes and practitioners to be mindful of cognitive biases that may unnecessarily delay diagnoses.

One such educational tool is the Three Steps.[94] Practitioners and other medical professionals, such as nurse practitioners, medical assistants, patient advocates, and even first responders, can utilize the Three Steps to help patients engage more meaningfully with their health and recognize symptoms of cancer quickly.[95] First, patients must establish a personal health baseline by being aware of when they feel "normal" or at their best.[96] This includes understanding normal energy levels, presence and intensity of pain, weight, sleep patterns, motor control and reflexes, bowel habits, and appearance.[97] Patients can establish their baseline health by conducting self-examinations; taking photographs, making notes, or using a calendar to track changes to their health, pain, and energy levels; and undergoing regular physical examinations.[98]

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[94] *3 Steps Detect*, *supra* notes 12–13 and accompanying text.

[95] *See generally id.* (explaining the Three Steps method).

[96] *Remember What Great Feels Like*, 15-40 Connection, https://www.15-40.org/3-steps-to-early-detection/remember-your-great/ (last visited Mar. 27, 2020).

[97] *Id.*

[98] *Id.*

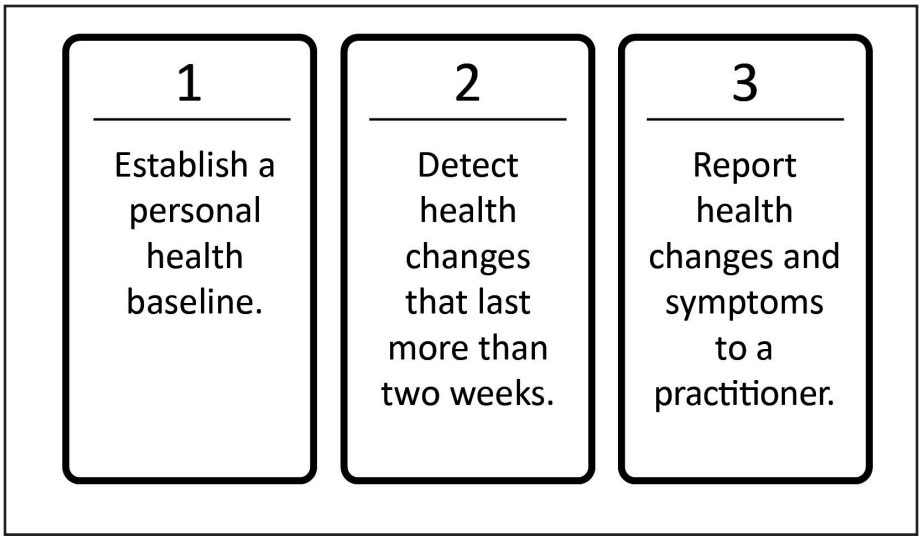

Fig. 3. Outline of the three steps of early detection of cancer.[106]

Second, patients must detect changes to their health that last for longer than two weeks.[99] Patients should be educated to understand what potential cancer symptoms can look and feel like.[100] Rather than dismissing ambiguous symptoms, patients should learn to keep track of any persistent health change, no matter how subtle.[101]

Third, patients must promptly and thoroughly report signs and symptoms that last longer than two weeks to a practitioner.[102] To facilitate this process, they should bring the practitioner a list of health changes or items for discussion, including the dates and duration of which the signs and symptoms were present.[103] Patients should trust their instincts, even if their practitioners dismiss their concerns, and ask for help in determining the underlying reason for the health change or obtain a second opinion.[104] Once the patient receives a diagnosis and a treatment plan, he should 1) ask the practitioner what to expect; 2) continue to monitor his health; and 3) follow up with the practitioner if his health deviates from what is expected.[105]

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[99] *Use the Two-Week Rule*, 15-40 Connection, https://www.15-40.org/3-steps-to-early-detection/2-week-rule/ (last visited Mar. 27, 2020).

[100] *Id.*

[101] *Id.*

[102] *Share With Your Doctor*, 15-40 Connection, https://www.15-40.org/3-steps-to-early-detection/share-with-your-doctor/ (last visited Mar. 27, 2020).

[103] *Id.*

[104] *Id.*

[105] *Id.*

[106] *3 Steps Detect*, *supra* notes 12–13.

Training medical school students, residents, and fellows can help ensure that future practitioners are aware of how to teach patients the Three Steps.[107] According to the National Cancer Institute, "[p]rimary care physicians, physician assistants, and nurse practitioners are the major sources of health information related to prevention of cancer in health care settings for [most] patients."[108] Research also shows that improved communication between practitioners and patients with breast cancer has been associated with "a sense of choice, improved actual treatment, and patient satisfaction with care."[109] Because health care professionals and organizations are responsible for creating environments in which patients and their families can learn about and engage in the diagnostic process, professional education resources on improving the quality of patient-provider communication, the patient-provider relationship, and patient engagement will be imperative in improving rates of EDD.[110]

For example, programs may focus on how practitioners can tailor their communications for low health-literacy adults to ensure that patients know the value of the information they share and that they are able to comprehend the information that they receive.[111] To counter patient tendencies to forget information or retain incorrect information, training may be offered on information retention and comprehension tools, such as the teach-back method, in which practitioners ask the patient questions to determine whether the patient recalls and understands any information or instructions conveyed.[112]

Education should also extend to printed and digital patient materials. This would ensure that patient educational materials, instructions, and consent forms are written in plain language, for a sixth-grade reading level or less, without using medical jargon.[113] Programs can highlight the use of plain English such as "cancer-causing" rather than

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[107] *See generally* Anjali Choudhary & Vineeta Gupta, *Teaching Communications Skills to Medical Students: Introducing the Fine Art of Medical Practice*, 5 Int'l J. Applied Basic Med. Res. 41 (2015) (suggesting that teaching medical students communication skills will improve practitioner-patient interactions, which correlate with improved healthcare outcomes).

[108] Ronald M. Epstein & Richard L. Street Jr., *Patient-Centered Communication in Cancer Care: Promoting Healing and Reducing Suffering*, Nat'l Cancer Inst., 71 (2015).

[109] Daniel J. Oates & Rebecca A. Silliman, *Health Literacy: Improving Patient Understanding*, 23 Oncology J. (2009).

[110] *The Patient-Provider Relationship Study: The Ripple Effect Starts with Boomers*, Solutionreach, https://www.solutionreach.com/rethinking-the-patient-provider-relationship (last visited Mar. 27, 2018) (emphasizing the importance of communication for the patient-provider relationship and patient satisfaction).

[111] *Quick Guide to Health Literacy*, Dep't of Health and Human Servs., https://www.centralwestgippslandpcp.com/assets/files/pre-2019/projects/health-literacy/guide/Quickguide.pdf (last visited Mar. 27, 2020) [hereinafter "*Quick Guide*"]; Shaghayegh Vahdat et al., *Patient Involvement in Health Care Decision Making: A Review*, 16 Iran Red Crescent Med. J. 1, 1–3 (2014).

[112] *Quick Guide*, *supra* note 111; Epstein & Street, *supra* note 108.

[113] Richard S. Safeer & Jann Keenan, *Health Literacy: The Gap Between Physicians and Patients*, 72 Am. Fam. Physician 463, 467 (2005); Adam E. M. Eltorai et. al., *Readability of Patient Education Materials on the American Association for Surgery of Trauma Website*, 3 Archives of Trauma Res. 1, 2 (2014).

"carcinogen," "into your vein" rather than "intravenous," or "related to the lungs" rather than "pulmonary."[114]

Treating patients as "equal partners" in their care leads to better adherence to recommended prevention and treatment processes and improved clinical outcomes.[115] It is crucial that primary care practitioners establish strong relationships with patients to build trust and motivate patients to report symptoms. Educational programs on participatory decision-making can help practitioners develop protocols to establish such relationships. Participatory decision-making establishes "a partnership among practitioners, patients and their families" that helps patients to understand their health care "wants, needs and preferences" and make informed decisions.[116] Training on such practices will be beneficial to increasing rates of early diagnosis because these practices build trust between patients and providers and empower patients to understand their health. Practitioners with a participatory decision-making style are thirty percent less likely to have patients leave their care.[117] This may be particularly beneficial for young adults, who are more prone to go to urgent care clinics or frequently change primary care providers.

Professional education programs should also focus courses on cognitive biases and the associated risks of diagnostic errors. Courses should train practitioners on how to recognize cognitive biases and how they can broaden their diagnostic thinking process. For example, practitioners can be trained on how to broaden differential diagnoses by participating in case discussions with colleagues that work through their thought processes, sharing uncertainty and techniques to avoid narrowly framing cases.[118] Clinicians can be trained to reduce confirmation bias by actively seeking information that could diverge from the current impression.[119] They can seek additional information during the physical examination or about a patient's history that may lead to an alternative diagnosis.[120]

Moreover, practitioners can utilize patient communication training to avoid cognitive biases by asking their patients how their health has changed since their last visit and whether those changes have lasted longer than two weeks. They can also encourage their patients to report symptoms by explaining that they cannot test for all changes in the patient's health and that consequently, it is critical for patients to accurately report persistent health changes.

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114 *See generally Quick Guide*, *supra* note 111.

115 *See generally* Epstein & Street, *supra* note 108; Institute of Medicine, Improving the 21st Century Healthcare System, Crossing the Quality Chasm: A New Healthcare System for the 21st Century (2001).

116 Kristin L. Carman et. al., *Patient and Family Engagement: A Framework for Understanding the Elements and Developing Interventions and Policies*, 32 Health Affairs 223, 224 (2013).

117 *Id.*

118 *See* Ogdie et al., *supra* note 81, at 1367 (encouraging discussion among physicians about cognitive biases and diagnostic error).

119 *See generally id.* at 1365 (explaining confirmation bias).

120 *Id.*

Programs may also highlight the benefits of increasing physicians' time spent with patients. While shorter patient visits may increase the number of patients seen in a practice, longer visits may be more effective by allowing time for cancer screenings and health education discussions, potentially lowering future treatment costs.[121] Conversations between physicians and patients build trust and can uncover helpful information in making a diagnosis and improving patients' overall health.

B. Coverage of EDD

To further encourage the adoption of EDD, including the training that practitioners must offer to patients, it is imperative that practitioners receive adequate reimbursement for their time and efforts. Given that short patient visits, often influenced by health plans, are already a barrier to accurate and timely diagnosis, providing sufficient coverage of such services may reduce this barrier. Qualified health plans governed by the Patient Protection and Affordable Care Act are required to offer coverage of essential health benefits, including preventive services.[122] Additionally, states may add additional services to the list of essential health benefits that plans must cover.[123] As such, states should add EDD to their list of essential health benefits. The increase in patient satisfaction, quality of life, and cost-savings actualized by this low-cost method should offset the cost of covering this benefit.[124]

CONCLUSION

Detecting and diagnosing cancer at earlier stages can increase survival rates and reduce costs to the patient and the general public. To improve rates of EDD, state legislatures should require medical boards to develop guidelines that encourage patient-practitioner collaboration and education on EDD, ensure CME courses are available to incentivize practitioners to adopt such practices, and require health plans to cover such services. These legislative solutions can facilitate partnerships between practitioners, patients, caregivers, and communities. In turn, such actions will improve education, patient satisfaction, and quality of care; lower health care costs; and reduce the risk of medical malpractice for providers.

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121 Guy, *supra* note 90.

122 *Health Coverage Rights and Protections*, HEALTHCARE.GOV, https://www.healthcare.gov/health-care-law-protections/ (last visited Mar. 27, 2020).

123 *Information on Essential Health Benefits (EHB) Benchmark Plans*, CTR. FOR MEDICARE AND MEDICAID SERV., https://www.cms.gov/CCIIO/Resources/Data-Resources/ehb (last visited Mar. 27, 2020).

124 *See* Kakushadze et al., *supra* note 31, at 13 (discussing cost savings from early diagnosis of cancer).

DISCLOSURE STATEMENTS

Dr. Deckers serves on the board of directors of 15-40 Connection, a 501(c)(3) not-for-profit organization whose mission is to educate and empower people about early cancer detection. A list of 15-40's funders can be found on its website. Dr. Deckers also serves as a surgical oncologist at UConn Health and as Professor of Surgery and Dean Emeritus at UConn School of Medicine.

Ms. Laursen is the President of 15-40 Connection, a 501(c)(3) not-for-profit organization whose mission is to save lives by teaching people how to detect cancer early and be active partners in their healthcare.

Dr. Manning is a Partner in the Life Sciences Practice at Bates White, LLC in Washington, DC. He provides consulting services and expert testimony on matters relating to economics for clients in government, law firms, and other private enterprises.

Ms. Worthy is a partner at DCBA Law & Policy LLP in Washington, DC. DCBA's clients include not-for-profit health policy and patient advocacy organizations, health care providers and programs, and biotechnology manufacturers, and not-for-profit organizations. To avoid conflicts of interest, DCBA adheres to the District of Columbia Rules of Professional Conduct.

Ms. Kulkarni is an associate at DCBA Law & Policy LLP in Washington, DC. DCBA's clients include health care providers, device and drug manufacturers, and not-for-profit organizations. To avoid conflicts of interest, DCBA adheres to the District of Columbia Rules of Professional Conduct.

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AMERICAN UNIVERSITY
WASHINGTON, DC

American University Washington College of Law

4300 Nebraska Avenue, NW

Washington, D.C. 20016

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