Cancer and the Medicare Disabled

A DISSERTATION
SUBMITTED TO THE FACULTY OF THE GRADUATE SCHOOL
OF THE UNIVERSITY OF MINNESOTA
BY

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IN PARTIAL FULFILLMENT OF THE REQUIREMENTS
FOR THE DEGREE OF
DOCTOR OF PHILOSOPHY

Dr. Beth A. Virnig, Dr. Patricia McGovern

November 2008

Acknowledgements

I would like to thank many people for their help and support throughout my dissertation work. I would especially like to thank my advisor, Dr. Beth Virnig, for her inspiration, generous support and encouragement.

I owe many thanks to Dr. Patricia McGovern and the National Institute for Occupational Health and Safety (NIOSH) for directing and funding my doctoral education and training grant in Occupational Health Services Research and Policy.

I am also very grateful for having an exceptional doctoral committee, and in addition to Drs. Virnig and McGovern, thank you to Dr. Bruce Alexander, Dr. Michael Davern, and my chair, Dr. A. Marshall McBean.

To my colleagues and friends in the Division of Health Policy and Management in the University of Minnesota, including Dr. Virnig's workgroup of Sara Durham, Stephanie Jarosek, and Helen Parsons, and Eric Barrette and Lindsay Bockstedt—thank you. I would also like to thank the University of Minnesota Surgical Outcomes Workgroup, especially Dr. Todd Tuttle and Dr. Waddah Al-Refaie, and the Health Outcomes group at Memorial Sloan-Kettering Cancer Center for their comments and suggestions.

Finally, I would like to thank my family. My parents, Jeff and Jeanne Butzer, have always supported me in my education and my adventures, and I would not have had the foundation necessary to complete this dissertation without their constant encouragement. I will always be grateful to my husband Tim for his support, his humor, and his love throughout my graduate school career.

Dedication

This dissertation is dedicated to my husband, Tim, my parents, Jeff and Jeanne Butzer, and my sister, Ellen Kaye.

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Introduction

One in two men and one in three women will be diagnosed with cancer within his or her lifetime,[1] and approximately 41% of these cancer diagnoses occur in people under age 65.[2] Upon being diagnosed with cancer, working-age adults, like other cancer patients, face choices in treatment and fears about survival, but they must further consider if and to what extent they are able to return to work. If a working-age cancer survivor is unable to work due to the morbidity of cancer and related treatments, he or she may apply for federal disability benefits, which include Social Security Disability Insurance (SSDI) payments and Medicare health insurance. Furthermore, working-age adults who are permanently disabled for non-cancer reasons should be screened for cancer according to guidelines, because despite their other health issues, they remain at risk of developing cancer. This work evaluates three different relationships between cancer in working-age adults and enrollment in Medicare due to permanent disability:

(1) Does a cancer diagnosis affect whether a working-age adult enrolls in Medicare due to disability?

(2) Does pent-up demand for cancer diagnosis exist for the permanently disabled in the pre-Medicare waiting period?

(3) Upon cancer diagnosis, do working-age disabled Medicare beneficiaries receive quality diagnostic workup and treatment?

By examining these relationships, federal policymakers, health care practitioners, advocates for the disabled, and others will have greater knowledge of the relationships between cancer and enrollment in Medicare due to disability and how the status quo can be improved.

Cancer incidence, screening, diagnosis, care, and outcomes in working-age adults

As stated above, 41% of cancer diagnoses occur in patients under the age of 65.[2] Cancers with a median age of diagnosis of less than 65 include Hodgkin lymphoma, melanoma, and cancers of the female breast, oral cavity and pharynx, bones and joints, soft tissue (sarcomas), ovary, cervix, uterus, testis, eye, brain, and thyroid.[3] While common cancers such as lung, prostate, and colorectal have a median age of diagnosis of over 65, the large number of cases diagnosed each year make these important health concerns for working-age adults.

Cancer screening is important, because the earlier stages of cancer diagnosis are associated with the best odds of survival. Screening tests exist for many types of cancer, including, breast, cervical and colorectal. Guidelines exist for how often screening should be completed. See table below.

Table 1: Cancer Screening Tests and Guidelines

Cancer	Screening Tests	Guidelines[4, 5]	
Prostate	Prostate Specific Antigen Test	Should be offered annually to men age 50 and older with a life expectancy of at least 10 years	
	Digital Rectal Exam		
Female Breast	Self Exam	Women age 20 or older should be comfortable with how their breasts feel normally and be able to identify any changes.	
	Clinical Breast Exam	Every 3 years for women age 20 through 39; annually for women age 40 through 60	
	Mammograms	Every 1-2 years for women 40 and older	
Cervical	Papanicolaou Test	Every 1-3 years, beginning at age 21 or within 3 years of onset of sexual activity	
Colorectal	Fecal Occult Blood Test	Every year	One of these options for adults adults age 50-75
	Fecal Immunochemical Test	Every year	
	Flexible Sigmoidoscopy	Every five years	
	Colonoscopy	Every ten years	
	Virtual Colonoscopy	Every five years	
	Barium Enema	Every five years	

Once cancer is diagnosed, through either screening or a reaction to symptoms, a patient should undergo a quality diagnostic workup. For example, if a woman is diagnosed with breast cancer, she should be tested for estrogen receptor (ER) status, progesterone receptor (PR) status, node positivity, and tumor size and grade. A quality diagnostic workup enables the physician to properly stage the patient and determine the best course of treatment.

As with screening, guidelines have been set for cancer treatments. For example, breast conserving surgery (BCS) followed by radiation therapy is the standard treatment for women with curable, invasive breast cancer (stages I-III). Patients may be adequately treated, undertreated, as in a breast cancer patient does not receive recommended radiation following surgery, or undergo a more aggressive surgery than is clinically indicated, such as contralateral prophylactic mastectomy for unilateral breast cancer. Whether a patient is appropriately treated is an important quality of care issue.

Cancer-related permanent disability in working-age adults

Cancer survivors may be unable to work due to effects from their treatments or other late effects.[6] One study found that 16.8% of cancer survivors under the age of 65 were unable to work compared to 5.0% of other working-age adults without a chronic illness.[7] The same study found that cancer survivors without an additional chronic illness were 3.22 times as likely to be unable to work due to their health status; cancer survivors with other chronic illness were 11.80 times as likely to be unable to work.[7] Predictors of cancer-related work disability include stage at cancer diagnosis,[6, 8] age at

cancer diagnosis,[7] level of physical work required by the job,[6] lower time discretion at work,[6] urban residence[6] race,[7] marital status,[7] and lower levels of education.[6-8]

Working-age cancer survivors who are unable to work may apply for federal disability benefits, which include access to health care through the Medicare insurance program. According to a 2003 study, the Social Security Administration (SSA) provided Social Security Disability Insurance (SSDI) disability benefits to 19.5% of cancer patients who were unable to work due to their health status.[7]

Enrollment in Medicare due to disability

People with disabilities who meet specific criteria are eligible to enroll in Medicare prior to age 65. In order to receive disability benefits, a person must have earned twenty credits by paying Social Security tax in the last ten years if age 31 or older. For persons disabled prior to turning 24, the general requirement is six credits earned in the previous three years. For persons aged 24-30, the general requirement is an average of two credits per year between the age of 21 and the time of disability. [9] Widows of disabled workers may receive benefits upon their disabled spouses' deaths. Alternatively, children of persons who paid into Social Security may receive disability benefits under their parent's earnings record if: (1) the child is unmarried and age 18 or older; (2) the disabling impairment began prior to the child turning 22; (3) the child meets the same definition of disability as required by adult applicants.[10]

Enrolling in Medicare due to disability is a long and complicated process. First, a person must be ruled "disabled" by the Social Security Administration (SSA). The SSA defines disability as inability to do work that one could do before and inability to

"adjust to other work" due to one's medical condition(s).[10] The disability "must also last or be expected to last for at least one year or to result in death." The SSA uses a five-question process[10] to determine whether a person is disabled:

1. Are you working?

   If a person averages earnings more than $940 a month through work in 2008 then he or she is ineligible.

2. Is your condition "severe"?

   The condition must interfere with basic work-related activities.

3. Is your condition found in the list of disabling conditions?

   The SSA maintains a list of medical conditions that are so severe that disability status is automatic.

4. Can you do the work you did previously?

   If so, the claim will be denied.

5. Can you do any other type of work?

   If so, the claim will be denied.

Of workers applying for disability status in 2005 (the most recent year with available data), 33.4% were awarded disability benefits. This percentage rises to 49.3% if pending applications are excluded. The most common reason for denial for workers is "able to do other type of work," followed by "able to do usual past work," "impairment is not severe," "other" and "impairment did not or is not expected to last 12 months."[11]

Cases will be reviewed from time to time; a beneficiary will continue to receive benefits as long as he or she remains disabled. Periodicity of review is dependent on whether a beneficiary's condition is "expected" to improve, or whether improvement is "possible" or "not expected." Benefits will end when health improves to an extent that the disability ends or a beneficiary chooses to return to work.[10]

Persons who meet the SSA's definition of disability may apply for Social Security Disability Insurance (SSDI) and, if awarded, will receive monthly cash benefits following a 5-month waiting period. Medicare benefits begin 24 months following continuous receipt of cash benefits, which results in a minimum total waiting period of 29 months between application for disability benefits and enrollment in Medicare due to disability.[11] Within this 29-month waiting period, a beneficiary may not average earnings of more than $940 per month. It has been estimated that 1.4 million persons receiving SSDI were within the waiting period for Medicare benefits,[12] of whom one-quarter[12] to one-third[13] are uninsured. Due to the length of this waiting period, persons enrolled in Medicare due to disability likely have long-term, chronic conditions, not high-mortality conditions. One study found a 2.4% death rate in one-year for disabled Medicare beneficiaries; death rates were higher in those with diseases of the respiratory system and diseases of the circulatory system.[14]

There are many potential causes of disability. People may have intellectual disabilities (ID), physical disabilities (PD), or both. They may have been disabled at birth or as a young child, or may have been actively involved in the workforce for years prior to a disabling event. There are both work-related and non-work-related causes of disability. The most common causes of enrollment due to disability for former workers

are mental disorders (other than mental retardation), diseases of the musculoskeletal system and connective tissue, diseases of the nervous system and sense organs, and diseases of the circulatory system.[11]

In 2007, disability benefits were awarded to 8.1 million people. Of those, 87% were former workers, 10% were disabled children of workers and 3% were disabled widows of deceased workers.[15] Of the 8.1 million, 7.1 million (87.7%) were enrolled in Medicare.[16]

In 2006, 9.5% of new awards for disability (10.3% of those to disabled workers) were given to those disabled from neoplasms. Disability due to neoplasms accounts for 2.4% of the Medicare disabled and 2.6% of disabled workers. The percentage was higher for female disabled workers than for males (3.3% vs. 2.6%).[15]

The demographics of persons who enroll in Medicare due to disability differ from those of the general working-age population. Males accounted for 52% of disabled beneficiaries. The percentage of disabled-worker beneficiaries increases with age, with the lowest rate in persons under 25 and the highest rate for persons aged 60-64. This trend is observed for both men and women. The percentage of disabled beneficiaries aged 18-64 varied by state; Utah's percentage was the lowest (2.4%), and West Virginia's percentage was the highest (8.4%). The following twelve states had 5% or more disabled workers within the working-age population: Alabama, Arkansas, Kentucky, Louisiana, Maine, Mississippi, Missouri, North Carolina, Oklahoma, South Carolina, Tennessee, and West Virginia.[15]

Medicare Benefits

Medicare beneficiaries may choose to enroll in either traditional fee-for-service (FFS) Medicare (The Original Medicare Plan) or managed care (MC) Medicare (Medicare Advantage Plans). The Original Medicare Plan allows a beneficiary to visit any practitioner or hospital that accepts Medicare, but the beneficiary must pay co-insurance, co-payments and deductibles. The Medicare Advantage Plans may cover more services than the Original Medicare Plan, and may have lower out-of-pocket costs, but the beneficiaries are often restricted to certain practitioners and hospitals. MC Medicare beneficiaries' benefits will depend on their individual plans and may include prescription drug coverage; all beneficiaries enrolled in The Original Medicare Plan share the same benefits.[17]

Some Medicare beneficiaries are also enrolled in other public programs, including Medicaid and the Veterans Affairs medical benefits program. Low-income Medicare beneficiaries may be eligible for enrollment in Medicaid. These beneficiaries are known as "Dual Eligibles." Those who qualify for Supplemental Security Income (SSI) in addition to SSDI are eligible for full Medicaid coverage, which will pay the Part B premium and any co-pays or deductibles. Medicaid additionally provides long-term care coverage. SSDI beneficiaries who do not qualify for SSI due to income limits may qualify for partial Medicaid benefits, including payment of the Part B premium but not always Medicaid cost sharing.[18] Additionally, veterans may qualify for health benefits from the Department of Veterans Affairs; however, it is recommended that veterans enroll in Medicare regardless of VA status. Being enrolled in both programs offers a veteran more options for healthcare.[19]

Medicare insurance is separated into four sections: Part A, Part B, Part C, and Part D. Parts A and B relate most to this research; Part C is Medicare Advantage and Part D is a prescription drug benefit plan.

Medicare Part A is hospital insurance. Part A is free to Medicare enrollees who earned at least 40 credits by paying Medicare taxes. Part A pays for inpatient hospital care, critical access hospitals, skilled nursing facilities, hospice care and some home health care. The 2007 Part A deductible is $992 (since 1/1/2007); co-insurance is required starting the 61st day of coverage within the benefit period (or the 21st day for skilled nursing facilities).[17]

Medicare Part B is medical insurance and is not free. Most people pay a monthly premium of $93.50 (since 1/1/2007) for Part B coverage. The deductible is $131 and enrollees pay 20% co-insurance on any amount above the deductible (excluding certain preventive services). Part B benefits include doctors' services, outpatient care, and other medical services not paid by Part A.[16]

Since 2005, new Medicare beneficiaries who are enrolled in Part B have been entitled to a one-time "Welcome to Medicare" physical exam within the first six months of enrollment. During this exam, the enrollee will have his or her medical history, height and weight recorded, blood pressure tested, immunization history reviewed, and may also have a vision test or Electrocardiogram (EKG). Physicians will give the enrollee a written plan that will outline which preventive services, including screenings, are needed.[17]

Medicare covers the following preventive services at no out-of-pocket cost for the beneficiary: cholesterol tests, lipid panels, Pap lab tests, fecal occult blood tests,

prostate specific antigen (PSA) tests, influenza immunizations, and pneumococcal pneumonia immunization. Preventive services that are available with the enrollee paying co-insurance include mammography, Pap test collection, pelvic exams, flexible sigmoidoscopy, screening colonoscopy, barium enemas and digital rectal examinations. The following preventive services are covered (with or without co-insurance) for those enrollees at risk: Hepatitis B immunizations, bone mass measurements for those women at risk of osteoporosis, diabetes screening, supplies, and self-management training, and glaucoma tests.[17]

Studies of cancer screening, diagnosis and outcomes in the non-elderly disabled

As mentioned above, this body of work not only includes analyses of cancer survivors enrolling in Medicare due to disability, but also analyses of cancer care in people who are enrolled in Medicare due to non-cancer-related disability. It is important to ensure that people with permanent disabilities have access to cancer screening, quality diagnostic workups, and appropriate cancer treatment.

A number of studies have been conducted on the relationships between disability and cancer screening, diagnosis, and outcomes, both here in the United States[6, 7, 20-28] and abroad.[8, 29-36] Data sources have included the SEER-Medicare database,[22, 23] the Medicare Current Beneficiary Survey (MCBS),[37] the National Health Interview Survey (NHIS),[7, 26, 27] the Medical Expenditure Panel Survey (MEPS),[38] the Fred Hutchinson Cancer Research Center's registry,[6] Western Australia's State Cancer Registry,[29] hospital patient series,[8] other administrative data records,[33] chart reviews,[28] qualitative interviews,[8, 21] and questionnaires.[20, 34, 35] Studies have focused on persons

with intellectual disabilities,[29, 33, 34] physical disabilities,[20, 21, 27, 28, 35] or both.[7, 22, 23, 26, 37, 38]

Site-specific cancer incidence may be higher or lower in the disabled relative to the general population. Males with intellectual disabilities were found to have higher rates of leukemia, brain and stomach cancers, but lower rates of prostate cancer.[29] Women with intellectual disabilities were found to have higher rates of leukemia, uterine, and colorectal cancers.[29] These differences could be due to biologic factors, such as links to Down syndrome, environmental factors such as weight or diet, or other, more social, factors such as nulliparity as a risk factor for breast cancer or lower rates of prostate cancer screening in the disabled.

Studies of cancer screening in the disabled have shown decreased rates of mammography,[27, 37, 38] pelvic exams,[20] and Pap tests[27, 33, 37] relative to the general population. In one study, lower rates of mammography and Pap tests were observed only for disabled women with major lower extremity mobility difficulty.[26] Reasons for lower rates of screening include difficulty getting onto an exam table[20, 21, 35] or into the correct position,[20, 21] finding the right physician,[20] not being recommended screening by the physician,[20, 35] transportation issues,[21] need for an alternate format of educational materials (Braille or audiotape),[21] or belief that they were at a low risk of cancer.[20, 35] Physicians may not recommend screening tests even if they are indicated for an array of reasons. For example, a major risk factor for cervical cancer is sexual activity; physicians may incorrectly believe that disabled women are not sexually active.[20, 33, 34]

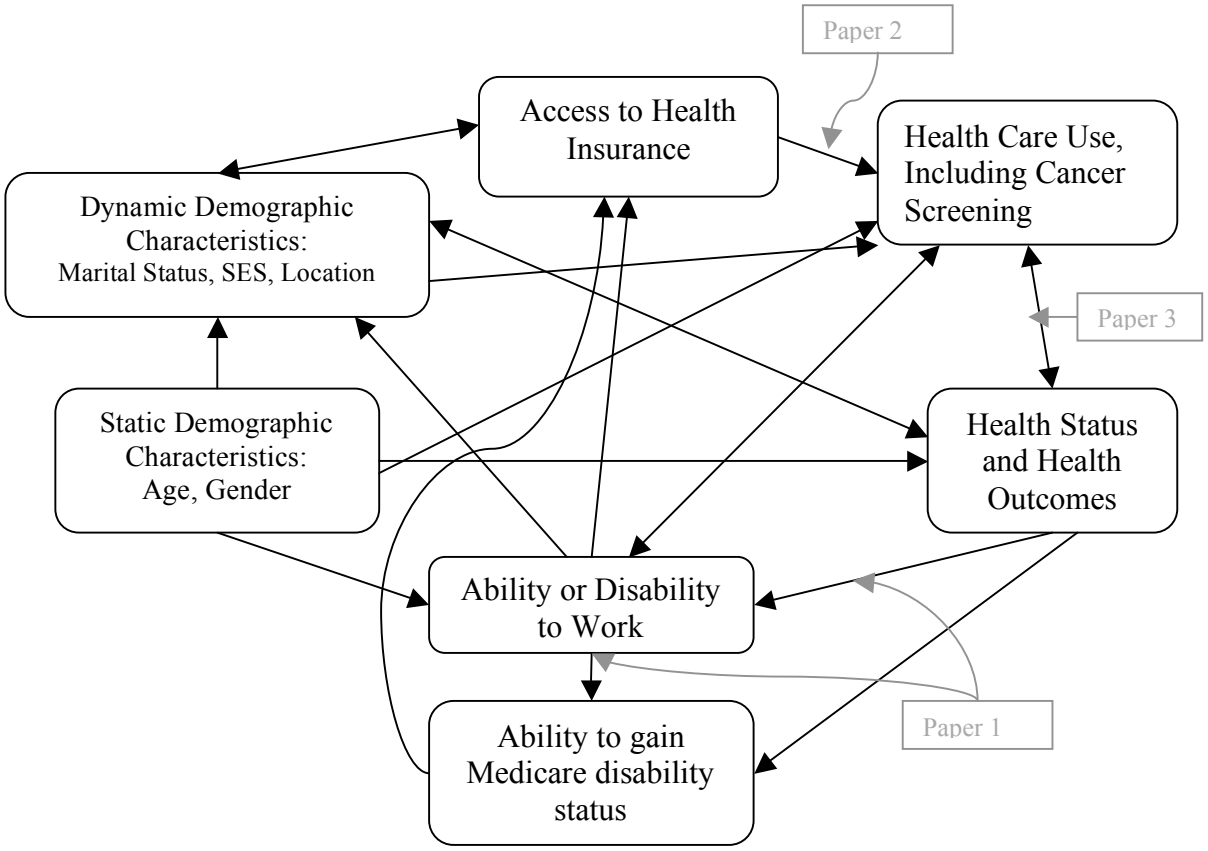
On the other hand, many studies have shown that women with disabilities receive mammograms[20, 26] and Pap tests[26] as often as women without disabilities or that

the disabled are diagnosed at comparable stages to the general population.[22, 28] In some cases, the disabled are diagnosed at earlier stages, such as for lung or prostate cancer.[22] It has been suggested that disabled women may use more health services than other women[28] and therefore have more opportunities to undergo mammography[20] or other screening tests.[22]

Differences in cancer treatment exist for those enrolled in Medicare due to disability and the non-disabled. Studies have found lower rates of surgery for non-small cell stage I lung cancer,[39] breast conserving surgery (BCS),[23, 40] radiation following BCS,[23, 40] and standard breast cancer care[23] in people enrolled in Medicare due to disability, compared to the non-disabled. In addition, poorer overall and cancer-specific mortality in the disabled, compared to the non-disabled, has been documented.[22, 40]

The three papers included below examine cancer's contribution to enrollment in Medicare due disability, pent-up demand for cancer screening during the 29-month waiting period prior to Medicare enrollment, and quality of cancer diagnosis and treatment in the working-age disabled enrolled in Medicare. Results from these three studies expand the knowledge of the relationships between disability, cancer, and cancer care. Public policy recommendations to improve the quality of care in this vulnerable population will follow.

Figure 1: Conceptual Model



The above model displays the conceptual framework for this study, which is applied to all three papers below. The relationships explored by each individual paper are identified with the grey arrows. Paper 1 identifies the effect of a cancer diagnosis on enrollment in Medicare due to disability. Paper 2 focuses on the phenomenon of "pent-up demand" for cancer diagnosis in people with disabilities within the 29-month waiting period prior to receipt of Medicare benefits. Paper 3 focuses on the quality of cancer diagnosis and treatment for women diagnosed with breast cancer while enrolled in Medicare due to non-cancer-related disability.

The Effect of a Cancer Diagnosis on Enrollment in Medicare Due to Disability

Abstract

Background

People who enroll in Medicare due to disability face a 29-month waiting period between initial application and enrollment. We identify working-age adults diagnosed with lung, prostate, colorectal or female breast cancer who later enroll in Medicare due to disability (inability to work) and compare them to general population cohorts of people diagnosed with one of the four cancers. We then determine the length of time from diagnosis to enrollment, for those disabled cancer patients who do enroll, expecting that enrollment will spike just after 29 months post-diagnosis. Finally, we identify the demographic and tumor characteristics of cancer survivors associated with enrollment in Medicare due to disability.

Patients and Methods

The Surveillance, Epidemiology, and End Results (SEER) and SEER-Medicare data were used for this analysis. We included lung, prostate, colorectal, and female breast cancer cases diagnosed between 1992 and 2002.

We constructed line plots of time-to-enrollment for people who enrolled in Medicare due to disability. Bivariate analyses were conducted, comparing demographic and tumor characteristics in the disabled and the general populations. Logistic regression models predicted enrollment in Medicare from 29 to 35 months post-diagnosis.

Results

We identified 359,049 working-age adults who were diagnosed with prostate, lung, colorectal, or female breast cancer; 4.4% later enrolled in Medicare due to disability.

The vast majority of cancer survivors who enrolled in Medicare due to disability did so between 29 and 31 months post-diagnosis. Later stage at diagnosis, being unmarried, Hispanic or African American race/ethnicity, older age, and male gender were associated with higher odds of enrollment in Medicare due to disability.

Conclusions

Cancer treatment and its associated morbidity contribute to enrollment in Medicare due to disability. Medicare policy, which only offers health care benefits to people with disabilities 29 months after application, should be re-evaluated. The possibility that a cancer diagnosis gives an already disabled person the resources needed to enroll in Medicare due to disability should be investigated.

Introduction

One in two men and one in three women will be diagnosed with cancer within his or her lifetime[1] Approximately 41% of cancer diagnoses occur in people under age 65.[2] Working-age cancer patients face decisions on whether, when, and to what extent they will return to work.

Cancer survivors may be unable to work due to effects of their treatments or their disease.[6] Working-age cancer survivors were over three times as likely to be unable to work due to their health status compared to people of the same age without cancer or another chronic disease, while cancer survivors who also had other chronic illness were almost twelve times as likely to be unable to work.[7] Predictors of cancer-related work disability include later stage at cancer diagnosis,[6, 8] older age at cancer diagnosis,[7] higher level of physical work required by the job,[6] lower time discretion at work,[6] urban residence,[6] black race,[7] single, divorced, widowed, or separated marital status,[7] and lower levels of education.[6-8]

Cancer survivors who are unable to work may apply for Social Security Administration (SSA) disability benefits. The SSA defines disability as an inability to do work that one could do before and inability to "adjust to other work" due to one's medical condition(s). The disability "must also last or be expected to last for at least one year or to result in death." In order to receive these benefits, a person must have paid into Social Security while previously employed.[10]

Persons who meet the SSA's definition of disability may apply for Social Security Disability Income (SSDI) and, if awarded, will receive monthly cash benefits following a five-month waiting period. For those who do receive SSDI, Medicare health

insurance benefits may begin after twenty-four months of continuous cash benefits, resulting in a minimum of twenty-nine months from initial disability application to Medicare enrollment. [11]

In 2006, disability benefits were awarded to 7.8 million people.[11] Disability due to neoplasms accounts for ten percent of new awards for disability and three percent of existing awards for disabled former workers.[11] Of those with disability benefits in 2006, 88.5% were also enrolled in Medicare. [41] According to a 2003 study, the SSA provided SSDI disability benefits to 19.5% of cancer patients who were unable to work due to their health status.[7]

We identify persons enrolled in Medicare due to disability who were diagnosed with one of four types of cancer prior to enrollment. If disability is due (at least in part) to a cancer diagnosis, a person will enter Medicare a minimum of 29 months following cancer diagnosis (the minimum waiting period). Recent publications have called attention to the people who are within the waiting period and have suggested modifying, shortening, or eliminating it.[12, 13] We hypothesized that (1) there is a spike in enrollment in Medicare due to disability beginning 29 months following cancer diagnosis; (2) younger survivors are more likely to enroll; (3) men are more likely to enroll; (4) unmarried survivors are more likely to enroll; (5) groups other than non-Hispanic whites are more likely to enroll; (6) survivors of later-stage cancers are more likely to enroll; (7) patients who receive more radical treatments are more likely to enroll, after adjusting for stage.

Methods

Data

We utilized the Surveillance, Epidemiology, and End Results (SEER) and SEER-Medicare databases for this analysis. SEER, a set of population-based cancer registries sponsored by the National Cancer Institute, collects information on cancer incidence and survival from 16 population-based cancer registries; these registries currently include cancer cases diagnosed within areas containing about 26% of the U.S. population.[4242] Twelve of these registries have data for the entire time period of our study (1992-2002); four registries, Greater California, Kentucky, Louisiana and New Jersey, began collecting data in 2000. The information collected by SEER includes patient characteristics, county of residence, primary tumor site, tumor characteristics, cancer treatments (excluding chemotherapy), and follow-up for vital status.[42]

The SEER-Medicare database links the information from the SEER cancer registries with Medicare enrollment and claims. Medicare provides comprehensive health care for approximately 98% of the United States population age 65 or older as well as younger disabled beneficiaries who meet enrollment criteria. The Medicare enrollment information is available through 2006 for people diagnosed with cancer through 2002; using these data we can identify month of initial enrollment and reasons for enrollment (age, disability, or end-stage renal disease). By accessing Medicare records, in addition to having detailed records of cancer diagnosis, care, and survival from the SEER database, we also have health plan enrollment data.

Sample

The sample includes all persons aged 21-59 when enrolled in SEER-Medicare due to disability who have previously been diagnosed with colorectal, lung, prostate or female breast cancers. A cancer diagnosis must have been the enrollee's first cancer diagnosis and must have occurred between 1992 and 2002. Patients who were diagnosed by death certificate or autopsy were excluded. A similarly-created population cohort of all SEER cases aged 21-59 was used as a comparison group. Members of the disabled cohort are also represented in the general population cohort; therefore we refer to it as the "general population cohort" rather than the "non-disabled cohort."

Measures

Patients were classified as either disabled (in the SEER-Medicare cohort) or as members of the general population (in the SEER cohort). The number of months from cancer diagnosis until enrollment in Medicare due to disability was measured for the disabled cohort. Other variables include age at diagnosis (continuous and categorical), sex, race/ethnicity (non-Hispanic white, African American, Hispanic white, Asian, and American Indian/other/unknown), marital status (single, married, separated/divorced/widowed, unknown), cancer site (lung, prostate, colorectal, female breast), treatment type, and stage at diagnosis (in situ, localized, regional, distant, unstaged). The stage at diagnosis variable is based on collapsing the detailed extent of disease information collected by SEER.[43] For prostate cancer cases, there are only four stage categories: in situ, localized/regional, distant and unstaged. We collapsed information on urban/rural residence, zip-code level income and education into

categories for the disabled cohort only; these variables were only available in the SEER-Medicare, and not the SEER, data.

Analysis

Time to enrollment was plotted for all cancer survivors who later enrolled in Medicare due to disability. Line plots of time to enrollment were constructed, stratified by cancer site, stage at diagnosis, cancer treatment, age at diagnosis, sex, marital status, and race/ethnicity, with patient counts on the vertical axis and time in months on the horizontal axis.

Bivariate analyses (disabled vs. general population) by cancer site, age at diagnosis, sex, marital status and race were completed using chi-square tests for significance. We also compared stage at diagnosis and surgical treatment for each of the four cancers.

Logistic regression models were constructed, predicting whether a person enrolls in Medicare due to disability in the period 29-35 months post cancer diagnosis. The predictors include cancer site, stage at diagnosis, cancer treatment, age at diagnosis, sex, marital status, race, and geographic location by registry. Separate logistic regression models for each cancer site were constructed, and stage at diagnosis and surgery type were added to the models. For the logistic regression analyses, the cohort was limited to patients who survived at least 29 months following cancer diagnosis to exclude those who do not survive the length of time necessary to enroll. We additionally excluded in situ cancers.

Results

We identified 359,049 working-age adults who were diagnosed with prostate, lung, colorectal, or female breast cancer between 1992 and 2002. Of these, 15,724 (4.4%) later enrolled in Medicare due to disability (Appendix A). Plots of time from cancer diagnosis to enrollment showed that enrollment peaked at 30 months post-cancer diagnosis for all four cancers (Figure 2). We then stratified figures by cancer stage to examine whether stage had an effect on time to enrollment but found similar patterns. Enrollment continued to spike at month 30 for all breast cancer stages at diagnosis and types of surgical treatment (Figures 3 and 4).

We then compared those who enrolled in Medicare due to disability to the general population and found that the disabled cohort was more likely to be older, male, African American, and separated, divorced or widowed than the general population (Table 2). Women in the SEER cohort were more likely to be diagnosed with in situ or localized breast carcinoma than women in the Medicare cohort, and less likely to be diagnosed with regional or distant disease. Men in the SEER cohort were more likely than Medicare to be diagnosed with localized or regional prostate cancer, and less likely to be diagnosed with distant cancer. Localized colorectal cancer was diagnosed more often in the general population, while regional colorectal cancer was diagnosed more often in the disabled cohort. Finally, the proportion of lung cancers diagnosed at a distant stage was higher in the general population, while proportions of localized and regional lung cancers were higher in the population later enrolled in Medicare due to disability (Table 3).

Surgery type also varied across disability status. Women diagnosed with breast cancer who later enrolled in Medicare due to disability were more likely to undergo mastectomy and less likely to undergo lumpectomy than the general population. Men in the general population were more likely than those who later enrolled in Medicare due to disability to have a prostatectomy. Colorectal cancer patients who later enrolled in Medicare due to disability were more likely to have a radical resection than the general population after taking into account clinical factors that would influence treatment. Those lung cancer patients who later enrolled in Medicare due to disability were more likely to undergo surgery, whether a resection of less than one lobe, a resection of a whole lung, or a radical resection, than lung cancer patients in the general population (Table 4).

In multivariate analysis of the entire cohort, we limited the analysis to invasive cancer patients who survived at least 29 months post-diagnosis. The disabled cohort, N=6,965, represented 3.0% of all SEER patients meeting the criteria (N=231,435). Lung, colorectal, and female breast cancer survivors were all more likely to enroll in Medicare due to disability than prostate cancer survivors (OR: 2.93-13.21, all $p<0.0001$). The oldest group (55-59) was more likely than the youngest group (21-29) to enroll, and male, single, separated/ divorced/ widowed, African American and Hispanic white patients were more likely to enroll than their counterparts (Table 5).

In multivariate analysis of prostate cancer survivors, distant-stage cases were more likely to enroll than localized/regional cases. Separated, divorced, or widowed survivors were more likely to enroll than married survivors, and African Americans and Hispanic whites were more likely to enroll than non-Hispanic whites (Table 6). When

surgery was added to the model, we found no differences in enrollment by known surgery type.

Enrollment in Medicare due to disability following a lung cancer diagnosis was increased for persons diagnosed at a later stage, but did not differ by age, marital status, or race/ethnicity. Male lung cancer survivors were more likely to enroll than females (Table 7). When looking at surgery for lung cancer, those patients who did not undergo surgery, those who underwent radical resection, and those who had whole lung resection were more likely to enroll than those who had less than one lobe removed.

Survivors of colorectal cancer had increased odds of enrolling in Medicare due to disability with later stages at diagnosis. Male colorectal cancer survivors and single, separated, divorced, or widowed survivors were more likely to enroll than female or married survivors, respectively. Again, African American or Hispanic whites had higher odds of enrollment than non-Hispanic whites (Table 8). Patients who underwent radical resection for colorectal cancer and those who did not undergo surgery were more likely to enroll than those who underwent local resection.

Multivariate analysis of female breast cancer survivors also showed increased odds of Medicare enrollment due to disability with later stage at diagnosis. Patients in the oldest age group were more likely to enroll than those in the youngest. Single, separated, divorced, or widowed survivors were more likely to enroll than married survivors, and African American or Hispanic white survivors were more likely to enroll than non-Hispanic whites (Table 9). Female breast cancer patients who received mastectomy or did not undergo surgery were more likely to enroll than those who

underwent lumpectomy, and those who had no nodes removed were more likely to enroll than those who had 1-4 nodes removed.

Discussion

It was estimated that at least 1.4 million persons receiving SSDI are waiting for Medicare benefits,[12] and an estimated ten percent of these patients have cancer. We determined the length of time from diagnosis to enrollment, for those disabled cancer patients who do enroll, and identified the demographic and tumor characteristics of cancer survivors who enroll in Medicare due to disability.

We hypothesized that there would be a spike in enrollment in Medicare due to disability 29 months post-diagnosis, which would be the earliest month in which a survivor could receive Medicare benefits if cancer was part of his or her application. We found dramatic spikes in enrollment, peaking at 30 months post-diagnosis, as seen in our figures. We expected the spikes to shift by cancer stage or treatment, with peaks at varying months post-diagnosis associated with differing onsets of morbidity and disability. For example, chemotherapy-related long-term disability would be expected to manifest 3-4 months after diagnosis. However, we found that the vast majority of all patients enrolled in Medicare between 29 and 31 months post-diagnosis.

It is possible that a cancer diagnosis is something that pushes someone "over the edge" into qualifying for SSDI/Medicare benefits. Being diagnosed with cancer could put an already disabled person in touch with the right social worker or advocate who can assist him or her with the paperwork and process involved in enrolling in Medicare due to disability. If a person is already disabled enough for SSDI enrollment pre-cancer

diagnosis, but unable to navigate the system, there are systemic issues that should be addressed. If a person's cancer diagnosis, combined with other chronic medical conditions, pushes him or her into SSDI eligibility, then the system may be working properly. We were unable to assess the above given our data but think it is an important area for future research.

We hypothesized that younger patients would be more likely to enroll than older patients, because they may be treated more aggressively, but found the opposite. Cancer survivors who were diagnosed between the ages of 21 and 29 were less likely to enroll than those who were diagnosed at age 55-59. Possible explanations could be that the older survivors had more pre-existing comorbidities, greater skills at navigating the process for enrollment, or greater needs for financial support.

As we hypothesized, male survivors were more likely to enroll than female survivors, and African American and Hispanic whites were more likely to enroll than non-Hispanic whites. Males may experience more pressure to financially contribute to their household income than females. Consequently, when males are unable to work due to health status, they may be more likely to apply for disability. African American and Hispanic whites are more likely to be socio-economically disadvantaged than non-Hispanic whites, which would support our finding that they are more likely to enroll. Survivors of later stage diagnoses were more likely to enroll in Medicare due to disability than those who survived earlier stages. Since increased morbidity is observed with later stage diagnoses, our findings are as expected.

We were initially surprised to find that patients who did not undergo surgery for lung, colorectal, or female breast cancer were more likely to enroll in Medicare due to

disability than patients who underwent surgeries, after adjusting for stage. However, our finding can be explained when thinking about what types of cancer patients do not undergo surgery. These patients may be uninsured, or they may have more comorbidities, which would make them more likely to enroll. Similarly, female breast cancer patients who had surgery but no nodes removed were more likely to enroll than others; these women may not have been given the appropriate diagnostic workup.

We did find that patients who underwent more aggressive surgeries for lung, colorectal, or female breast cancer were also more likely to enroll than those who underwent less aggressive surgeries. This was expected, since aggressive surgeries are more likely to interfere with work-related activities. While it is clear that more aggressive treatment may be necessary to improve survival for an individual, it may also increase the individual's risk of permanent disability. Providers must continue to take post-treatment quality of life and productivity into account when determining the proper course of cancer treatment.

The 29-month waiting period between cancer diagnosis and enrollment in Medicare due to disability should be reconsidered and is currently under discussionat the federal level. There has been a bill introduced in the United States Senate, S. 2102, "Ending the Medicare Disability Waiting Period Act of 2007," but this bill remains in committee for the duration of the 110th Congress.[44] A similar bill has been introduced in the United States House, H.R. 154, and was referred to the Subcommittee on Health over a year ago.[45] While the criteria for SSDI includes an expectation of disability to last for "at least one year,"[10] which should dissuade temporarily-disabled people from

applying, Medicare benefits are not awarded until a person has been disabled for almost two-and-a-half years.

The waiting period was put in place to ensure that people receiving benefits are permanently disabled; perhaps there is another way to ensure only the permanently-disabled receive health insurance benefits other than withholding access to care for the approximately twenty-five percent who are uninsured during the waiting period.[12] While eliminating or shortening the waiting period for only the uninsured would be "difficult," other possibilities include reducing the waiting period to one year, eliminating the waiting period for certain subgroups of beneficiaries, or allowing SSDI beneficiaries to buy in to Medicare during the waiting period.[12]

While it is important for patients and providers to minimize disability associated with cancer diagnosis and treatment, it is also important for policymakers to ensure that disabled cancer survivors and other people with disabilities are not prohibited from receiving needed health insurance benefits and access to health care.

Strengths and Limitations

This study is a large, population-based analysis of the time from cancer diagnosis to enrollment in Medicare due to disability. To our knowledge, it is the first study to plot time from diagnosis to enrollment and to identify which cancer survivors enroll in Medicare due to disability. Interpretation of these results should consider the following limitations.

The SEER-Medicare data do not report information such as individual-level socio economic status (SES), occupational history, or medical history (other than claims

once enrolled). While the SEER-Medicare data does contain information on census tract and zip code-level income and education statistics, the lack of these variables in the SEER data prevent us from including them in our bivariate or multivariate analyses. All of these factors can affect whether a person needs to enroll in Medicare due to disability: persons of lower SES may have less savings or other support and need SSDI and health insurance more than those of higher SES, and persons with more co-morbidities are more likely than others to have cancer be the "last straw" and cause application to SSDI/Medicare. The SEER-Medicare data do not include people who applied for SSDI but were denied.

We were unable to identify the SEER-Medicare disabled patients in the SEER data; these datasets are not linked due to privacy concerns. Therefore, some of our estimates may be biased toward the null as we compared the disabled to the general population rather than the disabled to the non-disabled.

We were unable to study chemotherapy use due to limitations of the SEER. (Medicare does include chemotherapy use in its claims, but we did not utilize claims in this study). While chemotherapy may be disabling, we do not believe that it had a large effect on enrollment in Medicare due to disability, because disability from chemotherapy would mean that a person would apply for disability benefits later than the actual month of diagnosis. We did not see a separation of enrollment curves by stage; since chemotherapy is most often given to regional-staged cancers, we would expect a delayed or wider peak of enrollment around months 33-35 post-diagnosis, which was not observed.

Additionally, the definition of "disability" for the purposes of this dissertation is an administrative definition used by the SSA. Results may not be generalizable to all persons with disabilities, as there are multiple definitions of "disability."[46]

Conclusion

Cancer treatment and its associated morbidity contribute to enrollment in Medicare due to disability. Medicare policy, which only offers health care benefits to people with disabilities 29 months after application, should be re-evaluated. The possibility that a cancer diagnosis gives an already disabled person the resources needed to enroll in Medicare due to disability should be investigated.

Figures:

Plots of months-to-enrollment from cancer diagnosis.

X-axis: 0 to 60 months post- cancer diagnosis

Y-axis: number of cases enrolled

Figure 2

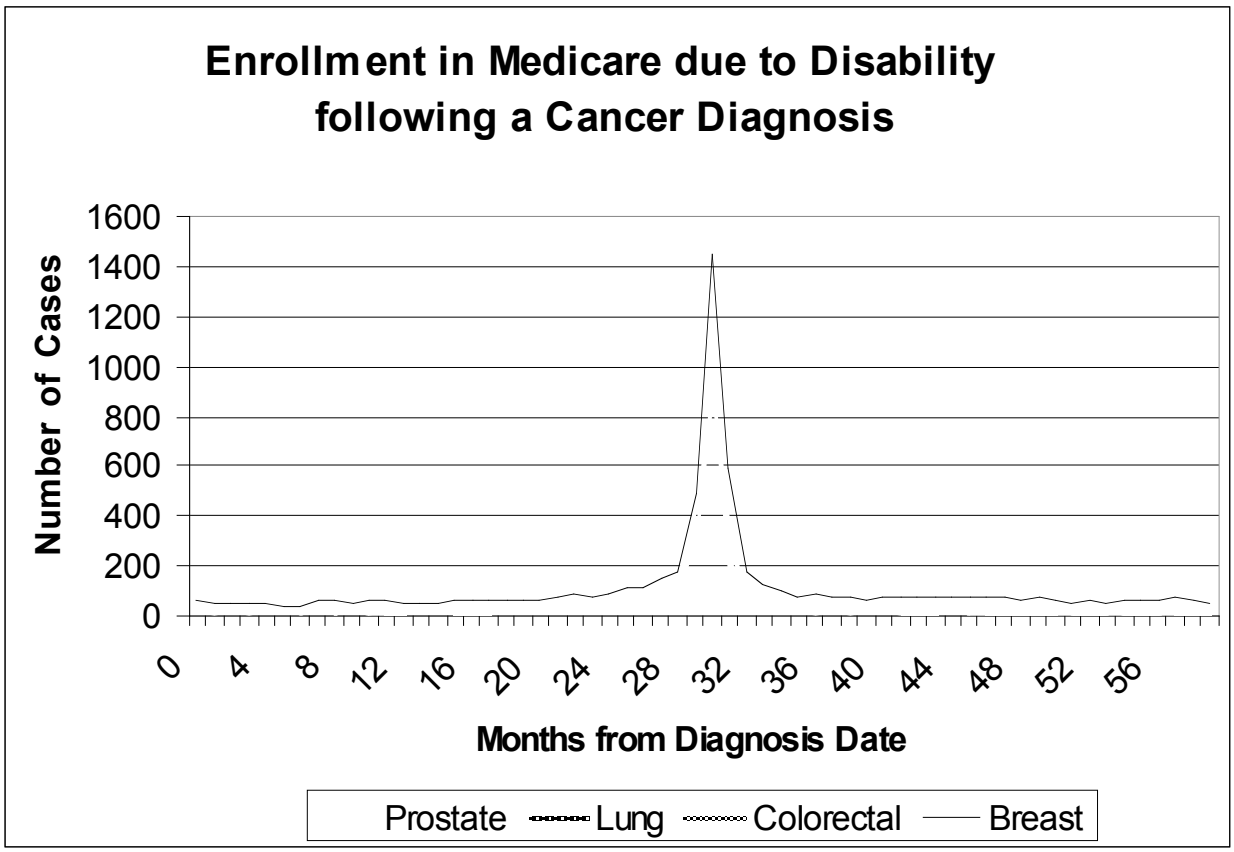


Figure 3

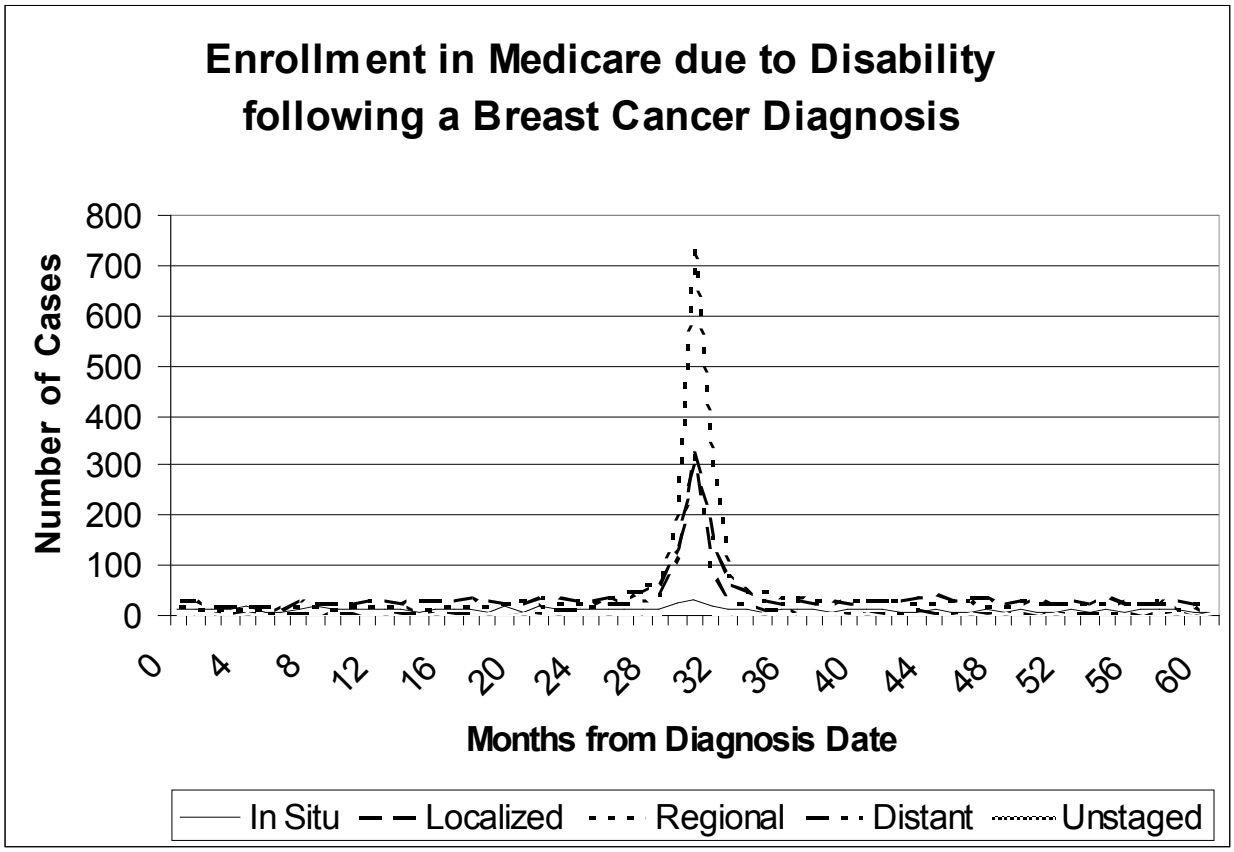

Enrollment in Medicare due to Disability following a Breast Cancer Diagnosis
Number of Cases
800
700
600
500
400
300
200
100
0
0
4
8
12
16
20
24
28
32
36
40
44
48
52
56
60
Months from Diagnosis Date
In Situ
Localized
Regional
Distant
Unstaged

Figure 4

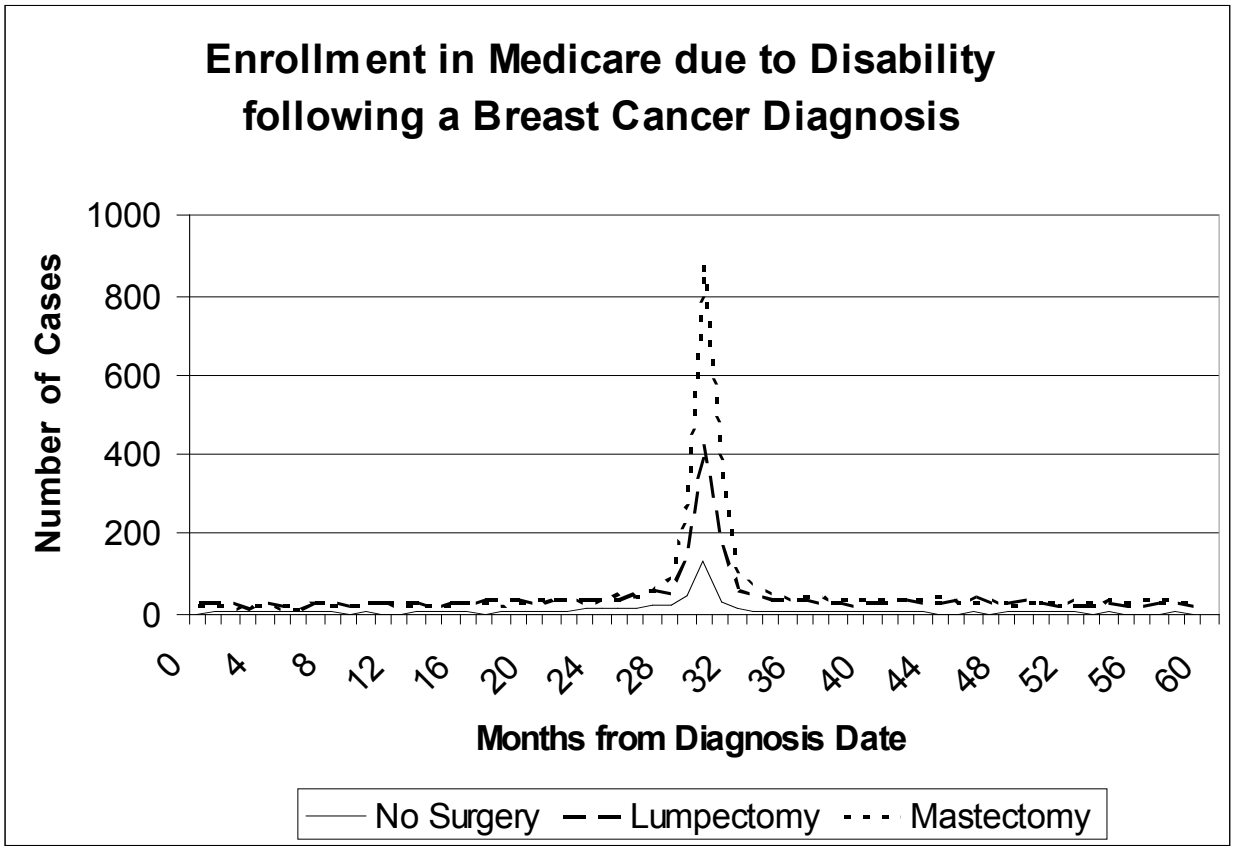

Enrollment in Medicare due to Disability following a Breast Cancer Diagnosis
Number of Cases
1000
800
600
400
200
0
0
4
8
12
16
20
24
28
32
36
40
44
48
52
56
60
Months from Diagnosis Date
No Surgery
Lumpectomy
Mastectomy

Table 2: Demographic Characteristics of the Disabled and General Population Cohorts

		Disabled (SEER-Medicare)	General Population (SEER)	p-value
N		15,724	359,049	
Cancer Site	Prostate	2,346 (14.9%)	65,550 (18.2%)	<0.0001
	Lung	3,409 (21.7%)	59,987 (16.7%)	
	Colorectal	3,350 (21.3%)	55,881 (15.6%)	
	Female Breast	6,619 (42.1%)	177,631 (49.5%)	
Age at Diagnosis	21-29	125 (0.8%)	3,110 (0.9%)	<0.0001
	30-39	1,006 (6.4%)	27,195 (7.6%)	
	40-44	1,410 (9.0%)	41,062 (11.4%)	
	45-49	2,383 (15.1%)	66,832 (18.6%)	
	50-54	4,139 (26.3%)	96,698 (26.9%)	
	55-59	6,661 (42.4%)	124,152 (34.6%)	
Sex	Male	6,231 (39.6%)	131,912 (36.7%)	<0.0001
	Female	9,493 (60.4%)	227,137 (63.3%)	
Marital Status	Single	2,674 (17.1%)	55,332 (15.4%)	<0.0001
	Married	8,969 (57.0%)	232,256 (64.7%)	
	Sep./Div./Wid.	3,348 (21.3%)	55,329 (15.4%)	
	Unknown	733 (4.7%)	16,132 (4.5%)	
Race	Non-Hisp White	10,413 (66.2%)	254,483 (70.9%)	<0.0001
	African. American	2,911 (18.5%)	45,960 (12.8%)	
	Hispanic White	1,401 (8.9%)	28,279 (7.9%)	

		Disabled (SEER-Medicare)	General Population (SEER)	p-value
	Asian	846 (5.4%)	25,531 (7.1%)	
	Am.Ind./Oth./Unk.	153 (1.0%)	4,796 (1.3%)	
Urban/Rural	Big Metro	10,327 (65.7%)	Not Available	
	Metro	3,599 (22.9%)		
	Urban	766 (4.9%)		
	Less Urban	845 (5.4%)		
	Rural	187 (1.2%)		
Zip Code Median Household Income	0-24,999	927 (5.9%)		
	25,000-49,999	7,678 (48.8%)		
	50,000-74,999	4,128 (26.3%)		
	75,000-99,999	818 (5.2%)		
	100,000+	204 (1.3%)		
	Unknown	1,969 (12.5%)		
Zip Code % with < 12 Years of Education	0.0-19.9%	2,664 (16.9%)		
	20.0-29.9%	5,181 (33.0%)		
	30.0-39.9%	3,092 (19.7%)		
	40.0%+	2,818 (17.9%)		
	Unkown	1,969 (12.5%)		

Table 3: Stage at Diagnosis: Disabled vs. General Population

		Disabled (SEER-Medicare)	General Population (SEER)	p-value
Female Breast	In Situ	561 (8.5%)	32,583 (18.3%)	<0.0001
	Localized	2,298 (34.7%)	82,935 (46.7%)	
	Regional	2,730 (41.2%)	51,417 (29.0%)	
	Distant	921 (13.9%)	8,049 (4.5%)	
	Unstaged	109 (1.7%)	2,647 (1.5%)	
Prostate	In Situ	2 (0.1%)	13 (0.0%)	<0.0001
	Localized/Regional	2,034 (86.7%)	61,006 (93.1%)	
	Distant	215 (9.2%)	2,283 (3.5%)	
	Unstaged	95 (4.0%)	2,248 (3.4%)	
Colorectal	In Situ	108 (3.2%)	3,548 (6.4%)	<0.0001
	Localized	885 (26.4%)	19,397 (34.7%)	
	Regional	1,551 (46.3%)	19,676 (35.2%)	
	Distant	701 (20.9%)	11,403 (20.4%)	
	Unstaged	105 (3.1%)	1,857 (3.3%)	
Lung	In Situ	2 (0.1%)	33 (0.1%)	<0.0001
	Localized	752 (22.1%)	8,138 (13.6%)	
	Regional	1,648 (48.3%)	19,660 (32.8%)	
	Distant	867 (25.4%)	29,151 (48.6%)	
	Unstaged	140 (4.1%)	3,005 (5.0%)	

Table 4: Surgery Type: Disabled vs. General Population

		Disabled (SEER-Medicare)	General Population (SEER)	p-value
Female Breast	No Surgery	450 (6.8%)	7,343 (4.1%)	<0.0001
	Lumpectomy	2,590 (39.1%)	95,598 (53.8%)	
	Mastectomy	3,505 (53.0%)	73,415 (41.4%)	
	Unknown	74 (1.1%)	1,275 (0.7%)	
Prostate	No Surgery	1,016 (43.3%)	23,390 (35.7%)	<0.0001
	Local Tumor Destruction	123 (5.2%)	2,087 (3.2%)	
	Prostatectomy	1,134 (48.3%)	38,936 (59.4%)	
	Unknown	73 (3.1%)	1,137 (1.7%)	
Colorectal	No Surg./ Local Ex.	213 (6.4%)	5,277 (9.4%)	<0.0001
	Local Resection	1,618 (48.3%)	29,381 (52.6%)	
	Radical Resection	1,469 (43.9%)	20,546 (36.8%)	
	Unknown	50 (1.5%)	677 (1.2%)	
Lung	No Surgery	1,776 (52.1%)	43,963 (73.3%)	<0.0001
	Resection < 1 Lobe	1,205 (35.4%)	11,856 (19.8%)	
	Resection of Whole Lung	250 (7.3%)	1,817 (3.0%)	
	Radical Resection	103 (3.0%)	668 (1.1%)	
	Unknown	75 (2.2%)	1,683 (2.8%)	

Table 5: Logistic Regression Models
Predicting enrollment in Medicare due to disability 29-35 months post-diagnosis
Cohorts limited to those who survived at least 29 months post-diagnosis
Disabled N= 6,965
SEER N= 231,435

		Odds Ratio	95% Confidence Interval	p-value
Cancer Site	Prostate	1.00 (ref)		
	Lung	13.21	11.96-14.60	<0.0001
	Colorectal	4.78	4.33-5.28	<0.0001
	Female Breast	2.93	2.62-3.29	<0.0001
Age at Diagnosis	21-29	1.00 (ref)		
	30-39	1.17	0.90-1.51	0.2536
	40-44	1.12	0.86-1.45	0.3961
	45-49	1.13	0.88-1.46	0.3442
	50-54	1.22	0.95-1.57	0.1283
	55-59	1.45	1.12-1.86	0.0042
Sex	Female	1.00 (ref)		
	Male	1.23	1.15-1.32	<0.0001
Marital Status	Married	1.00 (ref)		
	Single	1.27	1.18-1.36	<0.0001
	Sep./Div./Wid.	1.49	1.39-1.58	<0.0001
	Unknown	1.08	0.95-1.22	0.2491
Race/Ethnicity	Non-Hisp White	1.00 (ref)		
	African. American	1.63	1.52-1.74	<0.0001
	Hispanic White	1.45	1.33-1.59	<0.0001
	Asian	1.03	0.92-1.16	0.5621
	Am.Ind./Oth./Unk.	1.06	0.83-1.34	0.6454

*Adjusted for Registry

Table 6: Prostate Logistic Regression Models
Predicting enrollment in Medicare due to disability 29-35 months post-diagnosis
Cohorts limited to those who survived at least 29 months post-diagnosis
Disabled N= 619
SEER N= 57,340

		Odds Ratio	95% Confidence Interval	p-value
Stage at Diagnosis	Localized/Regional	1.00 (ref)		
	Distant	8.10	6.38-10.27	<0.0001
	Unknown	1.19	0.77-1.83	0.4368
Age at Diagnosis	21-39	1.00 (ref)		
	40-44	0.48	0.09-2.44	0.3746
	45-49	0.78	0.18-3.34	0.7412
	50-54	0.97	0.23-4.03	0.9631
	55-59	1.26	0.30-5.23	0.7512
Marital Status	Married	1.00 (ref)		
	Single	1.01	0.78-1.31	0.9321
	Sep./Div./Wid.	1.47	1.16-1.86	0.0012
	Unknown	1.20	0.87-1.64	0.2662
Race/Ethnicity	Non-Hisp White	1.00 (ref)		
	African. American	1.91	1.56-2.33	<0.0001
	Hispanic White	1.65	1.22-2.23	0.0010
	Asian	0.88	0.51-1.51	0.6305
	Am.Ind./Oth./Unk.	0.75	0.37-1.53	0.4251

*Adjusted for Registry

Adjusted Surgery OR, predicting disability 29-35 months post-dx
No Surgery 1.00 (ref)
Local Tumor Destruction 1.10 (0.74-1.64); p= 0.6363
Prostatectomy 0.84 (0.70-1.00); p= 0.0544
Unknown Surgery 1.77 (1.14-2.75); p= 0.0118
(Adjusted for all variables in above table plus registry and stage at diagnosis)

Table 7: Lung Logistic Regression Models
Predicting enrollment in Medicare due to disability 29-35 months post-diagnosis
Cohorts limited to those who survived at least 29 months post-diagnosis
Disabled N= 1,818
SEER N= 14,193

		Odds Ratio	95% Confidence Interval	p-value
Stage at Diagnosis	Localized	1.00 (ref)		
	Regional	2.66	2.33-3.03	<0.0001
	Distant	3.82	3.29-4.43	<0.0001
	Unknown	1.45	1.09-1.93	0.0100
Age at Diagnosis	21-29	1.00 (ref)		
	30-39	1.30	0.61-2.80	0.4995
	40-44	1.59	0.76-3.34	0.2195
	45-49	1.72	0.83-3.57	0.1473
	50-54	1.80	0.87-3.72	0.1125
	55-59	1.96	0.95-4.04	0.0691
Sex	Female	1.00 (ref)		
	Male	1.15	1.04-1.28	0.0054
Marital Status	Married	1.00 (ref)		
	Single	0.86	0.74-1.01	0.0653
	Sep./Div./Wid.	1.07	0.94-1.21	0.3285
	Unknown	0.96	0.74-1.25	0.7532
Race/Ethnicity	Non-Hisp White	1.00 (ref)		
	African. American	1.11	0.95-1.30	0.1872
	Hispanic White	1.04	0.81-1.34	0.7456
	Asian	1.07	0.85-1.36	0.5526
	Am.Ind./Oth./Unk.	0.87	0.46-1.63	0.6544

*Adjusted for Registry

Adjusted Surgery OR, predicting disability 29-35 months post-dx
No Surgery 2.19 (1.94-2.48); p<0.0001
Radical Resection 2.49 (1.91-3.26); p<0.0001
Resection of <1 Lobe 1.00 (ref)
Resection of Whole Lung 1.97 (1.62-2.40); p<0.0001
Unknown Surgery 1.79 (1.27-2.52); p= 0.0008
(Adjusted for all variables in above table plus registry and stage at diagnosis)

Table 8: Colorectal Logistic Regression Models
Predicting enrollment in Medicare due to disability 29-35 months post-diagnosis
Cohorts limited to those who survived at least 29 months post-diagnosis
Disabled N= 1,610
SEER N= 35,684

		Odds Ratio	95% Confidence Interval	p-value
Stage at Diagnosis	Localized	1.00 (ref)		
	Regional	3.08	2.69-3.51	<0.0001
	Distant	8.96	7.68-10.44	<0.0001
	Unknown	1.83	1.31-2.56	<0.0001
Age at Diagnosis	21-29	1.00 (ref)		
	30-39	0.85	0.54-1.34	0.4750
	40-44	1.06	0.68-1.65	0.8148
	45-49	1.04	0.67-1.61	0.8615
	50-54	1.19	0.77-1.83	0.4301
	55-59	1.47	0.96-2.25	0.0769
Sex	Female	1.00 (ref)		
	Male	1.24	1.11-1.37	<0.0001
Marital Status	Married	1.00 (ref)		
	Single	1.30	1.13-1.50	0.0003
	Sep./Div./Wid.	1.40	1.21-1.61	<0.0001
	Unknown	1.05	0.80-1.37	0.7260
Race/Ethnicity	Non-Hisp White	1.00 (ref)		
	African. American	1.39	1.19-1.62	<0.0001
	Hispanic White	1.54	1.29-1.84	<0.0001
	Asian	0.93	0.74-1.17	0.5338
	Am.Ind./Oth./Unk.	1.26	0.80-1.99	0.3261

*Adjusted for Registry

Adjusted Surgery OR, predicting disability 29-35 months post-dx
No Surgery/ Local Excision 1.40 (1.09-1.80); p= 0.0097
Local Resection 1.00 (ref)
Radical 1.15 (1.03-1.28); p = 0.0128
Unknown 1.83 (1.24-2.70); p= 0.0023
(Adjusted for all variables in above table plus registry and stage at diagnosis)

Table 9: Female Breast Logistic Regression Models
Predicting enrollment in Medicare due to disability 29-35 months post-diagnosis
Cohorts limited to those who survived at least 29 months post-diagnosis
Disabled N= 2,918
SEER N= 124,218

		Odds Ratio	95% Confidence Interval	p-value
Stage at Diagnosis	Localized	1.00 (ref)		
	Regional	3.25	2.97-3.55	<0.0001
	Distant	15.10	13.49-16.90	<0.0001
	Unknown	2.19	1.64-2.92	<0.0001
Age at Diagnosis	21-29	1.00 (ref)		
	30-39	1.15	0.80-1.65	0.4486
	40-44	1.04	0.73-1.49	0.8296
	45-49	1.07	0.75-1.52	0.7212
	50-54	1.17	0.82-1.66	0.3995
	55-59	1.44	1.01-2.06	0.0428
Marital Status	Married	1.00 (ref)		
	Single	1.47	1.33-1.63	<0.0001
	Sep./Div./Wid.	1.75	1.59-1.92	<0.0001
	Unknown	1.27	1.04-1.56	0.0214
Race/Ethnicity	Non-Hisp White	1.00 (ref)		
	African. American	1.97	1.77-2.20	<0.0001
	Hispanic White	1.35	1.18-1.54	<0.0001
	Asian	1.02	0.86-1.21	0.8423
	Am.Ind./Oth./Unk.	1.22	0.85-1.76	0.2790

*Adjusted for Registry

Adjusted Surgery OR, predicting disability 29-35 months post-dx
No Surgery 1.68 (1.41-2.00); p<0.0001
Lumpectomy 1.00 (ref)
Mastectomy 1.67 (1.53-1.82); p<0.0001
Unknown 1.09 (0.73-1.63); p=0.6798
(Adjusted for all variables in above table plus registry and stage at diagnosis)

Adjusted Surgery OR, predicting disability 29-35 months post-dx
No Surgery 1.31 (1.08-1.57); p=0.0049
Lumpectomy 1.00 (ref)
Mastectomy 1.70 (1.56-1.85); p< 0.0001
Unknown 1.00 (0.67-1.51); p=0.9846
/
1-4 Nodes Removed 0.89 (0.76-1.04); p=0.1464
5-90 Nodes Removed 1.00 (ref)
No Nodes Removed 1.60 (1.41-1.83); p<0.0001
Unknown # of Nodes 1.16 (0.91-1.49); p=0.2410
(Adjusted for all variables in above table plus registry and stage at diagnosis)

Pent-up Demand for Cancer Diagnosis Prior to Entering Medicare Due to Disability

Abstract

Introduction

People who enroll in Medicare due to disability face a 29-month waiting period between initial application and enrollment. During this waiting period, some people without insurance may delay needed or recommended diagnostic or preventive service until Medicare enrollment (pent-up demand).

We designed this study to assess whether pent-up demand for cancer diagnosis exists in this population by comparing stage at diagnosis for women with breast cancer (a screening-related disease) and women with lung cancer (a non-screening related disease) who were diagnosed within the first four years of enrollment. We performed similar analyses for a cohort of elderly women who aged into Medicare on their 65th birthdays.

Sample

The Surveillance, Epidemiology, and End Results (SEER)-Medicare data were used for this analysis. We identified 1,715 women between the ages of 50 and 59 who were diagnosed with breast or lung cancer in the first four years of enrollment in Medicare due to disability, from January 1, 1992 through December 31, 2002; we identified 33,922 elderly women age 65-69 who met the same criteria.

Study Design

We assessed whether pent-up demand for cancer screening existed by assessing stage at diagnosis in the first two years of enrollment, compared to the third or fourth years of enrollment, using both bivariate and multivariate (ordered logistic regression) analyses.

Results

The highest proportions of disabled breast and lung cancer cases were diagnosed in the first year of enrollment in Medicare due to disability; this phenomenon was not observed in the age-eligible. We did not find evidence of pent-up demand in stage or tumor size, for cancer diagnosis for either the disabled or elderly cohorts. Demographic and tumor characteristics did not vary across enrollment time categories (diagnosed in first or second year of enrollment, compared to diagnosed in third or fourth year of enrollment). Stage at diagnosis was similar for the two enrollment time groups, in both unadjusted and adjusted analyses.

Conclusions

We found potential evidence of pent-up demand for cancer diagnosis: the proportions of breast and lung cancer cases diagnosed in the first year of enrollment following the 29-month waiting period were higher than in other years. However, we did not find evidence of pent-up demand in stage at diagnosis or tumor size. We found no evidence of pent-up demand for breast or lung cancer diagnosis in women aging into Medicare.

Introduction

Persons enrolling in Medicare due to disability must wait 29 months from their initial application until they are eligible to receive Medicare benefits. During this waiting period, some people without insurance may delay needed or recommended diagnostic or preventive services until Medicare enrollment (pent-up demand).

The pent-up demand phenomenon has been documented in studies of the near-elderly who are uninsured prior to entering Medicare at age 65. The effect is manifested as higher demand for physician visits in the previously uninsured[47] or an increase in doctor visits for the uninsured compared to those who were insured prior to entering Medicare if they had a history of hypertension, diabetes, heart disease or stroke.[48]

Insurance status impacts cancer screening rates and outcomes. Insured adults ages 18-64 may be three to four times as likely to have undergone breast cancer screening as the long-term uninsured.[3] Age-eligible (age 65) Medicare enrollees who were uninsured prior to enrollment have been shown to have higher utilization of mammography, cholesterol testing, and prostate examination after enrolling, compared to those who were continuously insured.[4]

These findings could suggest important unmet need for cancer screening in the 25.8% of people with disabilities who were uninsured during the Medicare waiting period. These uninsured are more likely to be under 55, male, non-veterans, of black race, or below the poverty threshold than other beneficiaries in the waiting period. The uninsured were five times as likely as the insured to need "care but not able to get it"

and six times as likely to delay "medical care because of costs"; these effects likely translate to a lesser use of cancer screening.[5]

To assess pent-up demand for cancer diagnosis we evaluate screening services for breast and lung cancer in non-elderly (age <65) women who enroll in Medicare due to disability and women who age into Medicare on their 65th birthdays. We include two cancer sites, breast and lung, with different hypotheses for each cancer. While biennial mammograms are recommended, we hypothesize that non-elderly women with disabilities and in the 29-month waiting period may delay mammography and clinical breast exams until Medicare enrollment; we expect that this unmet need will result in later stages at diagnosis and larger tumors soon after enrollment compared to cancers diagnosed after at least two full years of Medicare benefits. Conversely, there is no recommended screening test for lung cancer, and a lung cancer diagnosis usually arises from a reaction to symptoms. We expect that women with lung cancer symptoms will seek care even while in the waiting period and there will be little to no disparity in stage at diagnosis for women diagnosed within the first two years of enrollment, compared to those diagnosed in year three or four. We will conduct the same analyses in women aging into Medicare on their 65th birthdays to determine whether the evidence for pent-up demand for physician visits and hospitalizations in the near-elderly transitioning into Medicare translates to pent-up demand for cancer diagnosis.

Methods

Dataset

We compare demographic and tumor outcomes for the newly-enrolled elderly women and non-elderly disabled women using the Surveillance, Epidemiology, and End Results (SEER)-Medicare database. SEER, a set of population-based cancer registries sponsored by the National Cancer Institute, collects information on cancer incidence and survival from 16 population-based cancer registries; these registries include about 26% of the U.S. population. SEER collects data on patient characteristics, tumor characteristics, cancer treatments (excluding chemotherapy), and follow-up for vital status.[42] The SEER-Medicare database links the information from the SEER cancer registries with Medicare beneficiary claims. Medicare provides comprehensive health care for approximately 7.1 million[16] non-elderly disabled beneficiaries who meet enrollment criteria as well as 98% of the United States population age 65 or older. By accessing Medicare records, in addition to having detailed records of cancer diagnosis, care, and survival from the SEER database, access to health plan enrollment information and all inpatient and outpatient health service data exists. While the cancer diagnosis data are available from 1973-2002, the Medicare enrollment information is available from 1986 through 2005.

Sample

Women who first enrolled in Medicare due to disability and were diagnosed with breast or lung cancer in the first four years of enrollment, from January 1, 1992 through December 31, 2002 were included in our cohort. We excluded male patients so

we could eliminate any confounding when comparing female breast cancer outcomes and lung cancer outcomes. Patients must have been age 50 to 59 years old at time of Medicare enrollment, because clinical guidelines recommend biennial mammography for women age 40 through 69, and pent-up demand is more likely in women who are well within the guidelines. We similarly identified a cohort of women who entered Medicare at age 65 and were diagnosed with cancer within the first four years of enrollment.

Women with a history of cancer, those diagnosed at autopsy or death certificate, those diagnosed with in situ lung cancers, those with a missing month of diagnosis, women of unknown race, those who were not continuously enrolled in Medicare for four years from becoming eligible or until death, and those from the Rural Georgia SEER registry (due to small cell sizes) were excluded from the disabled and elderly cohorts (Appendix B).

Measures

Stage at breast cancer diagnosis and stage at lung cancer diagnosis within two time periods (in the first two years of enrollment in Medicare and the third or fourth year of enrollment) were our dependent variables. The stage at diagnosis variable is "produced by collapsing the detailed extent of disease information collected by SEER."[43] Independent variables included age at diagnosis (continuous), race/ethnicity (categorical), marital status (categorical), and geographic location by registry (categorical).

Analysis

Bivariate analyses of stage at diagnosis were completed using chi-square tests for significance. We also conducted analyses stratified by age, marital status, and race/ethnicity.

We plotted the number of cases diagnosed each year, for the disabled and the elderly, stratified by cancer site.

We used ordered logistic regression models to predict earlier stage at diagnosis, stratified by cancer site. The independent variable of interest was time period; we hypothesized that late-stage diagnosis will be higher in the first time period than the second time period for breast cancer diagnoses but not lung cancer diagnoses. The models were adjusted for age at enrollment, marital status, race, and geographic location by registry.

Results

Cancer Diagnosis in Women with Disabilities

We identified 1,715 women who were diagnosed with breast (1,148, 66.4%) or lung cancer (580, 33.6%) within their first four years of enrollment in Medicare due to disability. Equal percentages of breast cancer patients (N=658, 57.8%) and lung cancer patients (N=330, 57.2%) were diagnosed within the first two years of enrollment (p=0.8035). Demographic and tumor characteristics did not vary across enrollment periods, for women diagnosed with breast or lung cancer. Both women with breast cancer (p=0.2821) and women with lung cancer (p=0.9771) were diagnosed at similar

stages for each of the two time periods (Table 10) and had similar-sized breast cancer tumors (p=0.7330) (Table 12).

The highest proportion (30.0%) of breast cancer cases in our cohort of women with disabilities was diagnosed within the first year of enrollment; the proportions of cases diagnosed in year two, three, or four of enrollment were 23.2%, 28.9%, and 17.9%, respectively (Figure 5). We saw a continuous decline in the proportion of lung cancer cases diagnosed from year one (29.5%) through year four (20.3%) (Figure 6).

Using our ordered logistic regression models, we found that disabled women were no more likely to be diagnosed at earlier stages of breast cancer in the first two years of enrollment, compared to the third or fourth years of enrollment (OR=1.08, p=0.4870). We found similar results for women diagnosed with lung cancer (OR=1.07, p=0.6789) (Table 13).

Cancer Diagnosis in Women Who Age into Medicare

We identified 33,922 women who were diagnosed with breast (24,377 , 71.9%) or lung (9,545 , 28.1%) cancer within the first four years of entering Medicare when age-eligible at 65. Of the elderly breast cancer patients, 12,213 (50.1%) were diagnosed within the first two years of enrollment, compared to 4,493 (47.1%) of elderly lung cancer patients (p<0.0001). As with the disabled cohort, demographic and tumor characteristics, including stage at diagnosis and breast cancer tumor size, did not vary across enrollment period (Tables 11 and 12).

The proportion of breast cancer cases in each year of enrollment stayed constant (all years between 24.5% and 25.4%) (Figure 5). The proportion of lung cancer cases

consistently rose from 22.8% in the first year of enrollment through 27.6% in the fourth year of enrollment (Figure 6).

Elderly women diagnosed with breast (p=0.3939) or lung (p=0.9152) cancer in the first two years of enrollment were no more likely to be diagnosed at an early stage than those diagnosed in years three or four (Table 13).

Discussion

This study examines whether unmet need for cancer screening and diagnosis exists for persons enrolling in Medicare due to disability and facing a waiting period of approximately 29 months between applying for Social Security Disability Income/Insurance (SSDI) and eligibility for Medicare benefits. We hypothesized that pent-up demand for breast cancer diagnosis, but not necessarily lung cancer diagnosis, occurs during this waiting period because recommended screening may be delayed until enrollment. Pent-up demand could present itself as more cases diagnosed, later stages of diagnosis or larger tumor sizes in the first two years of enrollment than when diagnosed after two full years of coverage. While we did find greater numbers of breast and lung cancer cases diagnosed in the first year of enrollment, our results show no difference in stage at diagnosis for women diagnosed with breast or lung cancer or breast cancer tumor size soon after enrolling in Medicare due to disability or age compared to those diagnosed in their third or fourth year of enrollment.

Interestingly, the proportions of breast cancer cases diagnosed in women with disabilities were higher in years one and three of enrollment than in years two and four. It is possible that women who enter Medicare due to disability have unmet need, receive

breast cancer screening in the first year of coverage and are diagnosed, resulting in the high proportion of cases diagnosed in the first year. The higher proportion found in the third year compared to the second or fourth year could be due to biennial screening. We did not find any variation in the proportion of elderly women diagnosed with breast cancer over the four years of enrollment and therefore no evidence for pent-up demand for breast cancer diagnosis.

We found differing trends for those enrolling in Medicare due to disability and age when looking at the proportion of lung cancer diagnoses in each of the four years of enrollment. The proportion decreased over the years for women with disabilities but increased over time for those who aged into Medicare. We believe that the trend for elderly women is due to increasing rates of lung cancer as women age from 65 through 69. The downward trend for women with disabilities could signify pent-up demand for lung cancer diagnosis in women in the 29-month waiting period.

Within the disabled, the higher proportions of breast cancer diagnoses in the first and third year of enrollment and the decrease in lung cancer cases over the four years did not translate to poorer breast cancer outcomes. We suggest further research to identify screening rates over the first four years of enrollment and to suggest causes for our findings.

While previously published studies have found evidence for pent-up demand for doctor visits in the near-elderly,[48] and we found potential evidence of pent-up demand in the number of cases diagnosed, this pent-up demand does not appear to translate to breast or lung cancer outcomes, including stage at diagnosis and tumor size. There are a few potential reasons for our null findings. First, our study found no evidence for pent-

up demand for cancer diagnosis in the disabled waiting for Medicare eligibility, but we were unable to stratify by insurance status. Approximately 74% of women had access to other insurance while waiting for Medicare eligibility, through a spouse, dual eligibility, or other sources.[12] It is possible that a study of solely the uninsured would find evidence of pent-up demand. Second, women may have had access to mammograms through other sources—including the National Breast and Cervical Cancer Early Detection Program.

Policy Implications

Research has shown that approximately 26% of those waiting for coverage are uninsured; the reasons for uninsurance include the expense, job loss, and inability to obtain due to health status, illness, or age.[12] While one option would be to reduce or eliminate the waiting period for the uninsured, while keeping it in place for the insured, Riley[12] has said that such a policy would be difficult to design and implement. Another option would be to use financial subsidies to assist the uninsured in purchasing insurance during the waiting period; this may be an effective choice as 77.7% of uninsured in the waiting period listed affordability as a barrier.[12]

While a large proportion of those in the waiting period are insured, there may be sufficient reason to reduce or eliminate it for all people in the waiting period. Research has shown that uninsured near-elderly adults with a history of hypertension, diabetes, heart disease or stroke report fewer doctor visits and hospital stays than the insured near-elderly once enrolled in Medicare.[48] It would likely follow that pent-up demand for physician visits and hospital stays would exist for the chronically disabled.

Another study found that self-reported health trends increased at age 65 for the previously uninsured more than for the previously insured;[51, 52] this should also translate to the disabled. Additionally, it has been shown that the near-elderly who were uninsured prior to entering Medicare at age 65 cost the Medicare program more money than those who were insured prior to enrollment,[48] and universal coverage for all adults 55-64 prior to entering Medicare at age 65 would potentially reduce short-term Medicare spending for newly eligible Medicare beneficiaries.[52] Perhaps reducing or eliminating the waiting period would both benefit the disabled beneficiary and save Medicare money. Finally, it is possible that pent-up demand for other cancer diagnosis, such as colorectal cancer, exists.

Limitations

While not all people with disabilities in the 29-month waiting period are uninsured, those who are underinsured or even fully insured may delay physician care until Medicare benefits are awarded. Future research should focus on whether pent-up demand for cancer diagnosis exists for uninsured people with disabilities in the Medicare waiting period. We were unable to solely study the uninsured given our data limitations, but surveys linked to Medicare data for the non-elderly disabled may provide the data needed to complete the suggested analysis.

Since we are unable to identify whether cancer screening occurred in the year or two years prior to enrollment given our dataset, it is impossible to compare screening rates before and after Medicare enrollment due to disability. Instead, stage at diagnosis was assessed.

Conclusion

We found potential evidence of pent-up demand for cancer diagnosis: the proportions of breast and lung cancer cases diagnosed in the first year of enrollment following the 29-month waiting period were higher than in other years. However, we did not find evidence of pent-up demand in stage at diagnosis or tumor size. We found no evidence of pent-up demand for breast or lung cancer diagnosis in women aging into Medicare.

Table 10: Demographic and Tumor Characteristics of the Disabled Cohort * p<0.05

		Breast		Lung	
		Diagnosed in 1st or 2nd Year of Enrollment	Diagnosed in 3rd or 4th Year of Enrollment	Diagnosed in 1st or 2nd Year of Enrollment	Diagnosed in 3rd or 4th Year of Enrollment
N		658	480	330	247
Demographic Characteristics					
Age	50-54	28* (42.6%)	175 (36.5%)	106 (32.1%)	69 (27.9%)
	55-59	378 (57.4%)	305 (63.5%)	224 (67.9%)	178 (72.1%)
Marital Status	Single	115 (17.5%)	78 (16.2%)	42 (12.7%)	37 (15.0%)
	Married	272 (41.3%)	200 (41.7%)	127 (38.5%)	86 (34.8%)
	Sep./Div./Wid.	239 (36.3%)	184 (38.3%)	140 (42.4%)	110 (44.5%)
	Unknown	32 (4.9%)	18 (3.8%)	21 (6.4%)	14 (5.7%)
Race/ Ethnicity	Non-Hisp. White	418 (63.5%)	315 (65.6%)	250 (75.8%)	187 (75.7%)
	Black	162 (24.6%)	96 (20.0%)	55 (16.7%)	46 (18.6%)
	Hispanic White	57 (8.7%)	45 (9.4%)	18 (5.4%)	10 (4.1%)
	Asian	21 (3.2%)	24 (5.0%)	7 (2.1%)	4 (1.6%)
Tumor Characteristics					
Stage at Diagnosis	In Situ	113 (17.2%)	77 (16.0%)	n/a	n/a
	Localized	336 (51.0%)	240 (50.0%)	62 (18.8%)	44 (17.8%)
	Regional	165 (25.1%)	142 (29.6%)	115 (34.9%)	84 (34.0%)
	Distant	37 (5.6%)	17 (3.5%)	136 (41.2%)	106 (42.9%)
	Unstaged	7 (1.1%)	4 (0.8%)	17 (5.2%)	13 (5.3%)
Tumor Grade	1	98 (14.9%)	66 (13.7%)	13 (3.9%)	6 (2.4%)
	2	203 (30.8%)	156 (32.5%)	43 (13.0%)	30 (12.1%)
	3	207 (31.5%)	139 (29.0%)	95 (28.8%)	72 (29.2%)
	4	26 (4.0%)	23 (4.8%)	40 (12.1%)	45 (18.2%)
	Unknown	124 (18.8%)	96 (20.0%)	139 (42.1%)	95 (38.1%)

Table 11: Demographic and Tumor Characteristics of the Elderly Cohort

		Breast		Lung	
		Diagnosed in 1st or 2nd Year of Enrollment	Diagnosed in 3rd or 4th Year of Enrollment	Diagnosed in 1st or 2nd Year of Enrollment	Diagnosed in 3rd or 4th Year of Enrollment
N		12,348	12,300	4,755	5,353
Demographic Characteristics					
Marital Status	Single	997* (8.1%)	840 (6.8%)	359* (7.6%)	344 (6.5%)
	Married	7,524 (61.0%)	7,290 (59.4%)	2,378 (50.1%)	2,608 (48.8%)
	Sep./Div./Wid.	3,416 (27.7%)	3,768 (30.7%)	1,821 (38.4%)	2,180 (40.8%)
	Unknown	393 (3.2%)	384 (3.1%)	184 (3.9%)	208 (3.9%)
Race/ Ethnicity	Non-Hisp. White	10,05 (81.2%)	10,109 (82.3%)	3,949 (83.3%)	4,475 (83.8%)
	Black	815 (6.6%)	792 (6.4%)	412 (8.7%)	431 (8.1%)
	Hispanic White	724 (5.9%)	648 (5.3%)	169 (3.6%)	207 (3.9%)
	Asian	776 (6.3%)	733 (6.0%)	212 (4.5%)	227 (4.2%)
Tumor Characteristics					
Stage at Diagnosis	In Situ	2,053 (16.6%)	2,021 (16.4%)	n/a	n/a
	Localized	6,875 (55.8%)	6,965 (56.7%)	941 (19.8%)	1,047 (19.6%)
	Regional	2,756 (22.3%)	2,639 (21.5%)	1,637 (34.5%)	1,865 (34.9%)
	Distant	529 (4.3%)	539 (4.4%)	1,915 (40.4%)	2,140 (40.1%)
	Unstaged	117 (1.0%)	118 (1.0%)	249 (5.3%)	288 (5.4%)
Tumor Grade	1	2,098 (17.0%)	2,076 (16.9%)	187 (4.0%)	199 (3.7%)
	2	4,239 (34.4%)	4,225 (34.4%)	618 (13.0%)	702 (13.1%)
	3	2,959 (24.0%)	2,900 (23.6%)	1,391 (29.3%)	1,496 (28.0%)
	4	418 (3.4%)	428 (3.5%)	624 (13.2%)	707 (13.2%)
	Unknown	2,616 (21.2%)	2,653 (21.6%)	1,922 (40.5%)	2,236 (41.9%)

* $p<0.05$

Table 12: Breast Cancer Tumor Size

	Disabled		Elderly	
	Diagnosed in 1st or 2nd Year of Enrollment	Diagnosed in 3rd or 4th Year of Enrollment	Diagnosed in 1st or 2nd Year of Enrollment	Diagnosed in 3rd or 4th Year of Enrollment
No Mass	26 (3.9%)	25 (5.2%)	435 (3.5%)	406 (3.3%)
0-1 cm	130 (19.8%)	92 (19.0%)	3,415 (27.7%)	3,421 (27.8%)
1-2 cm	211 (32.1%)	163 (34.0%)	4,016 (32.6%)	3,950 (32.2%)
2-5 cm	166 (25.2%)	123 (25.6%)	2,527 (20.5%)	2,553 (20.8%)
5+ cm	33 (5.0%)	23 (4.8%)	427 (3.5%)	422 (3.4%)
unknown	92 (14.0%)	55 (11.5%)	1,510 (12.2%)	1,530 (12.5%)
p=0.7330			p=0.8822	

Table 13: Multivariate Analysis
Using Ordered Logistic Regression, Predicting Earlier Stage at Diagnosis

		Disabled		Elderly	
		Breast	**Lung**	**Breast**	**Lung**
Time to Diagnosis	1st or 2nd Year	1.08 (0.86-1.36)	1.07 (0.77-1.48)	0.98 (0.93-1.03)	1.00 (0.92-1.07)
	3rd or 4th Year	1.00 (ref)	1.00 (ref)	1.00 (ref)	1.00 (ref)
Age	50-54	1.00 (ref)	1.00 (ref)	**	**
	55-59	1.15 (0.91-1.44)	0.78 (0.55-1.11)	**	**
Marital Status	Single	1.11 (0.80-1.53)	1.07 (0.64-1.80)	0.79 (0.72-0.87)	0.94 (0.81-1.10)
	Married	1.00 (ref)	1.00 (ref)	1.00 (ref)	1.00 (ref)
	Sep./Div./Wid.	1.05 (0.82-1.36)	0.97 (0.68-1.40)	0.80 (0.76-0.84)	0.93 (0.86-1.01)
	Unknown	1.02 (0.57-1.84)	1.54 (0.72-3.26)	1.10 (0.95-1.27)	0.88 (0.71-1.09)
Race/ Ethnicity	Non-Hisp. White	1.00 (ref)	1.00 (ref)	1.00 (ref)	1.00 (ref)
	Black	1.17 (0.87-1.57)	1.16 (0.73-1.83)	0.82 (0.74-0.91)	0.93 (0.81-1.08)
	Hispanic White	0.97 (0.64-1.47)	2.39 (1.11-5.16)	0.93 (0.83-1.04)	0.78 (0.63-0.95)
	Asian	0.82 (0.42-1.59)	1.98 (0.43-9.08)	1.22 (1.08-1.38)	0.79 (0.64-0.98)

*Adjusted for registry
** n/a: one age category only

Figure 5:

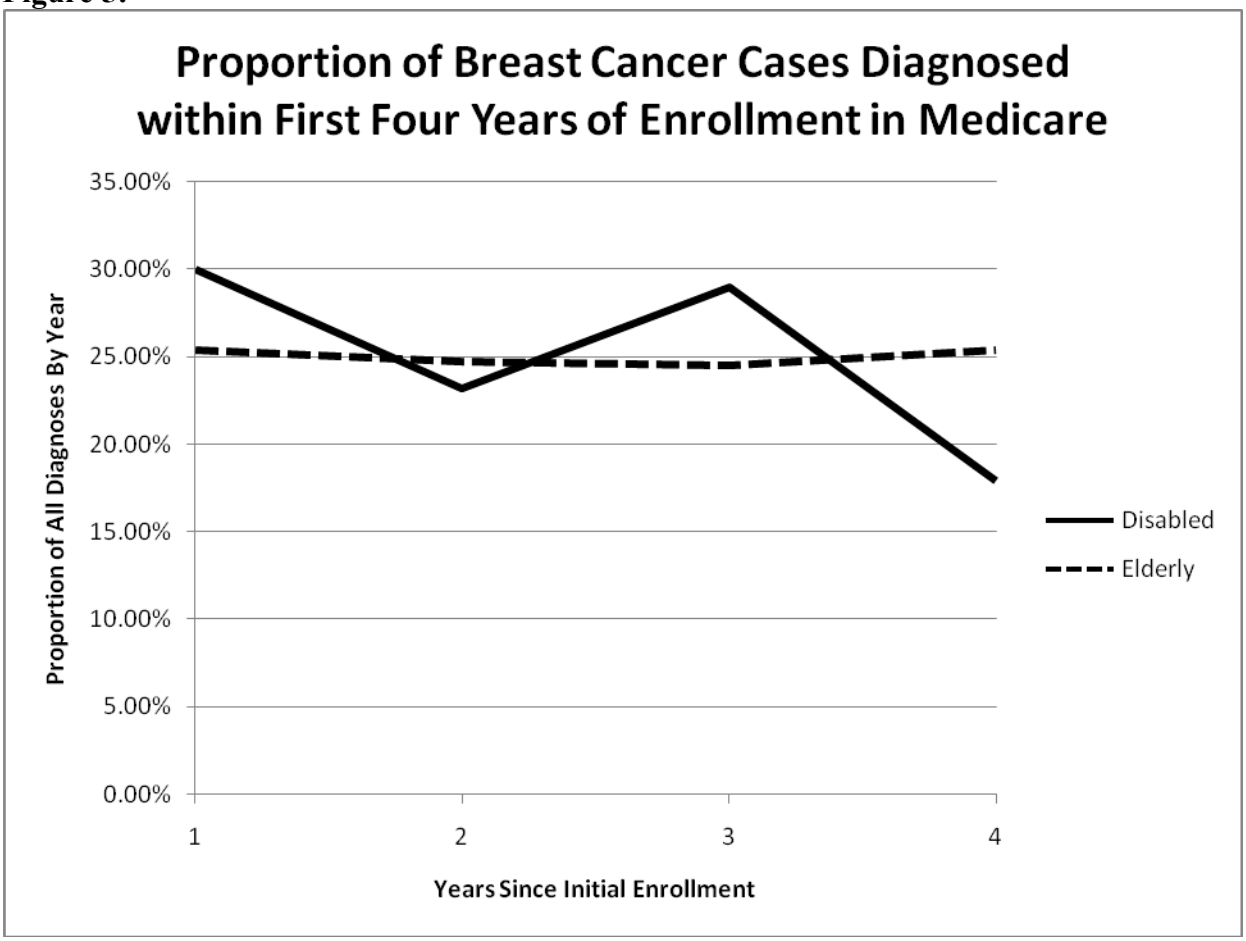
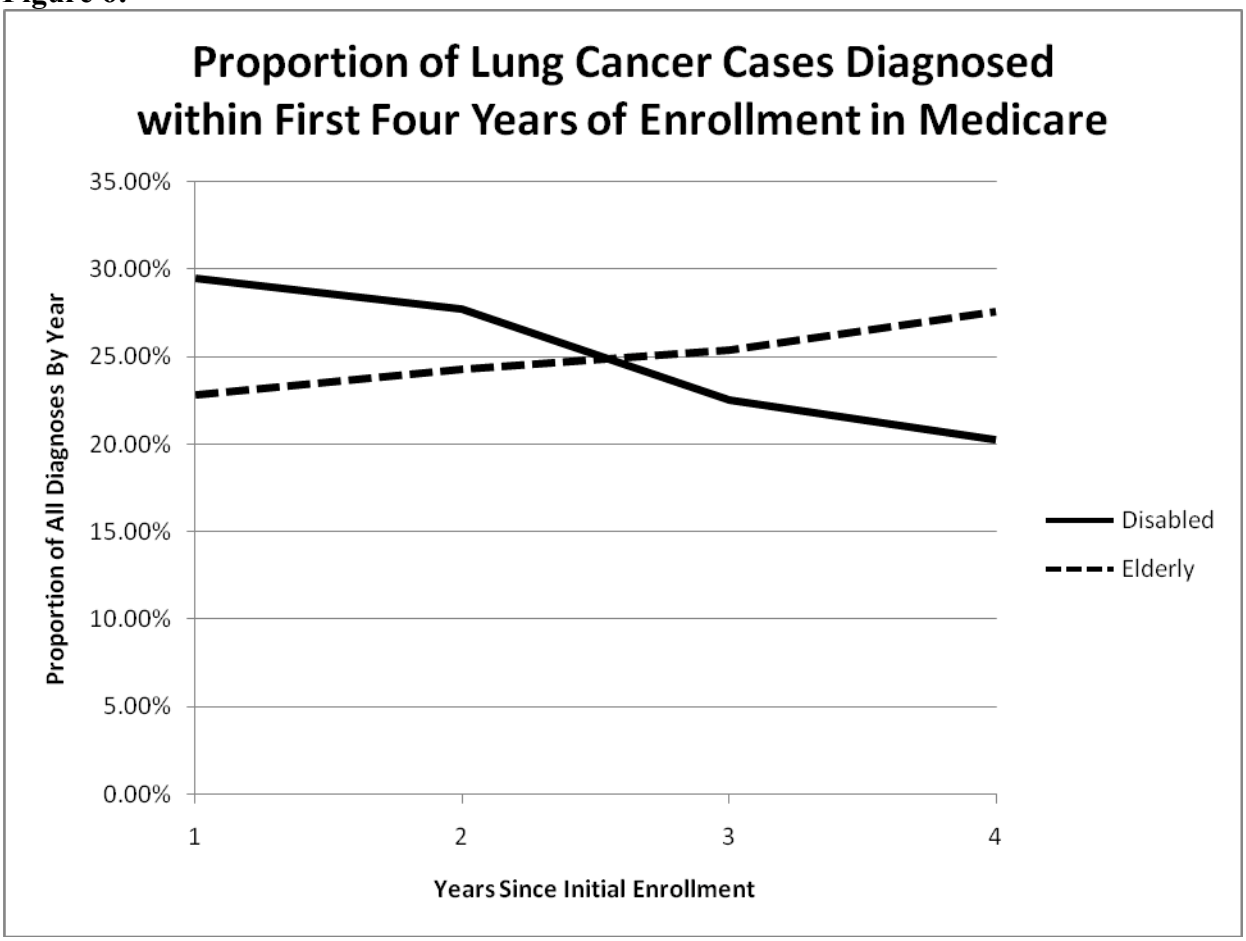

Proportion of Breast Cancer Cases Diagnosed within First Four Years of Enrollment in Medicare
35.00%
30.00%
25.00%
20.00%
15.00%
10.00%
5.00%
0.00%
Proportion of All Diagnoses By Year
1
2
3
4
Years Since Initial Enrollment
Disabled
Elderly

Figure 6:


Proportion of Lung Cancer Cases Diagnosed within First Four Years of Enrollment in Medicare
35.00%
30.00%
25.00%
20.00%
15.00%
10.00%
5.00%
0.00%
Proportion of All Diagnoses By Year
1
2
3
4
Years Since Initial Enrollment
Disabled
Elderly

Quality Care for a Vulnerable Population?

Cancer Diagnosis and Treatment in the Disabled

Abstract

Introduction

We compare cancer diagnosis and treatment in female breast cancer patients who are enrolled in Medicare due to disability to that of the general population. We investigate the quality of diagnostic workups and treatments in the Medicare disabled and the general population.

Sample

The Surveillance, Epidemiology, and End Results (SEER) and SEER-Medicare databases were used to identify women ages 30-59 diagnosed with female breast cancer from 1992 through 2002.

Study Design

We used chi-square tests to determine whether differences in demographic and tumor characteristics, diagnostic workup, and treatment varied between women with disabilities and those in the general population. Logistic regression models were used to determine whether women with disabilities were more or less likely to receive appropriate treatment than women in the general population.

We plotted proportions of treatment type received over time, from 1992 through 2002, for women with disabilities and women in the general population and used Cochran-Armitage tests for trends.

Results

Women in the general population were slightly more likely than those enrolled in Medicare due to disability to be diagnosed with in situ disease and less likely to be diagnosed with late-stage breast cancer. Breast cancer patients with disabilities received superior or similar quality diagnostic workups compared to those in the general population. However, they were less likely to receive recommended radiation therapy (RT) following breast conserving surgery (BCS). Between 1992 and 2002, the percentage of women receiving standard care for breast cancer decreased for both women with disabilities and those in the general population.

Discussion

The similarity in rates of standard care is due to higher rates of mastectomy in the disabled. They were less likely to receive RT following BCS, which is of concern. It is of great importance that practitioners take care in counseling women with disabilities in choosing the best form of standard care for breast cancer treatment. Communication between the patient, the surgical, radiation, and medical oncologists, along with other practitioners overseeing care of the disabled woman, should take place to ensure that she receives the best care for her situation.

Conclusions

We did not find any large differences in diagnostic workup or treatment between women with disabilities and those in the general population. Between the years of 1992 and 2002, rates of standard treatment for breast cancer fell for both groups. While standard treatment occurs at similar rates, a disparity in RT following BCS exists. It is important for providers to take care in suggesting the best treatment for women with disabilities to ensure they receive adequate treatment.

Introduction

A quality diagnostic workup is necessary for properly staging and treating a cancer patient. For example, breast cancer patients should have their estrogen receptor (ER) and progesterone receptor (PR) status assessed, as well as evaluation of nodal involvement and tumor size and grade. A quality diagnostic workup should result in proper cancer staging and will allow a healthcare provider to suggest the best course of treatment.

Currently, guidelines state that the standard treatment for women with stage I or II breast cancer is breast-conserving surgery (BCS) followed by radiation therapy (RT).[53] However, some women undergo BCS without radiation, which could be considered undertreatment, or undergo mastectomy, which has similar outcomes to BCS with radiation but is less preferred. Over the time period of 1992-2005, mastectomy use decreased while BCS use increased.[54] Interestingly, use of radiation therapy that should follow BCS has decreased over the same period, which results in lower overall rates of standard care (defined as BCS with RT or mastectomy).

Recent studies have examined breast cancer stage at diagnosis[22] and treatment[23, 40] in working-age women enrolled in Medicare due to disability. They report that working-age women enrolled in Medicare due to disability are less likely than others to receive BCS or to receive RT following BCS.[23, 40] To date, they have not analyzed the quality of diagnostic workup or treatment trends.

We designed this study to assess whether working-age breast cancer patients enrolled in Medicare due to disability are more or less likely than the general population to have quality diagnostic workups or to receive standard treatment for breast cancer

when BCS plus adjuvant radiotherapy is recommended. We also investigate whether the trends toward less standard care for breast cancer over time are observed for women with disabilities and whether treatment-related disparities are changing.

Methods

Data

The Surveillance, Epidemiology, and End Results (SEER) and SEER-Medicare databases were used for this study. SEER, a set of population-based cancer registries sponsored by the National Cancer Institute, collects information on cancer incidence and treatment from 16 population-based cancer registries; these registries currently include about 26% of the U.S. population. The information collected by SEER includes patient characteristics, county of residence, primary tumor site, tumor characteristics, cancer treatments (excluding chemotherapy), and follow-up for vital status.[42]

The SEER-Medicare database links the information from the SEER cancer registries with Medicare beneficiary claims. Medicare provides comprehensive health care for approximately 6 million working-age (under 65) disabled beneficiaries who meet enrollment criteria. By accessing Medicare records, in addition to having detailed records of cancer diagnosis and care from the SEER database, access to health plan enrollment information and all inpatient and outpatient health service data exists.

Sample

Our sample includes all women ages 30-59 and diagnosed with female breast cancer between the years of 1992 and 2002 after enrollment in Medicare due to disability. Patients with a prior cancer diagnosis and those who were diagnosed at

autopsy or on a death certificate were excluded as were those located in the Alaska and Rural Georgia SEER registries (due to not being population-based and small cell sizes, respectively). A general population cohort was similarly constructed using SEER data (Appendix C).

Measures

We measured adequacy of diagnostic workup by measuring testing (known or unknown) for ER and PR status, tumor stage, tumor size, tumor grade, and nodal involvement for women diagnosed with breast cancer. We additionally measured ER and PR status (negative, positive, or unknown), tumor size (0-1cm, 1-2cm, 2-5cm, 5+cm, or unknown), tumor grade (low, high, or unknown), and nodal involvement (negative, positive, or unknown) because the results of the tests are used in treatment decisions.

Treatment variables included surgery type (no surgery, BCS, mastectomy, or unknown) and radiation (no radiation, radiation, or radiation status unknown). For women with localized or regional breast cancer, BCS without radiation was considered undertreatment, and standard care included BCS with radiation or mastectomy.

Other variables included age (continuous), race/ethnicity (white non-Hispanic, white Hispanic, black, or other/unknown), marital status (single, married, separated/divorced/widowed, or unknown), tumor registry, and stage at diagnosis. The stage at diagnosis variable was "produced by collapsing the detailed extent of disease information collected by SEER."[43]

Analysis

Bivariate analyses of age at diagnosis, marital status, race, tumor stage at diagnosis, tumor grade, ER and PR testing and status, nodal involvement, and treatment type were conducted using chi-square tests for significance.

We plotted receipt of standard care (BCS with RT or mastectomy) over time, from 1992 through 2002, for women with disabilities and women in the general population. We also constructed plots for receipt of RT for women who underwent BCS. We tested for trends using the Cochran-Armitage test. For the plots, we categorized the 11 years of our data into 5 year categories, 1992-1993, 1994-1995, 1996-1998, 1999-2000, and 2001-2002.

Logistic regression models were used to determine whether women with disabilities were more or less likely to receive standard care (BCS with RT or mastectomy) than women in the general population. We limited this analysis to women with localized or regional breast cancer who underwent surgical treatment. We constructed additional models predicting RT in association with BCS, limiting to women who received BCS. We adjusted for age at diagnosis, marital status, race, and geographic location by registry for all regression models.

Results

Demographics

We identified 174,014 working-age women diagnosed with breast cancer from 1992-2002. Of these, 6,051 (3.5%) were enrolled in Medicare due to disability. The disabled patients were more likely to be older, unmarried, and of black race (Table 14).

Diagnosis:

We found a few indicators of higher quality of diagnostic workups in women with disabilities compared to those in the general population. The disabled were more likely to be tested for ER status (70.9% vs. 68.4%, p<0.0001), PR status (69.0% vs. 66.5%, p<0.0001), and tumor grade (81.6% vs. 80.0%, p=0.0031), but less likely to have tumor size recorded (16.1% vs. 15.1%, p=0.0399). Overall, women with disabilities were less likely to have nodal involvement tested (74.8% vs. 76.6%, p=0.0011), but this difference was likely due to differences in surgical treatment. There were no statistical differences in being staged (98.4% vs. 98.5%, p=0.2376) (Table 15).

Women in the general population were more likely than those with disabilities to be diagnosed with in situ disease (18.8% vs. 14.9%, p<0.0001) and less likely to be diagnosed with regional or distant breast cancer (34.0% vs. 40.9%, p<0.0001, excluding unknown stage). When tested, women with disabilities were less likely than those in the general population to have positive ER status (69.5% vs. 71.4%, p=0.0086) or PR status (61.0% vs. 64.1%, p<0.0001) (Table 15).

Treatment

Women with disabilities were less likely than those in the general population to undergo surgical treatment for their breast cancer (93.9% vs. 95.9%, p<0.0001) and were more likely to undergo mastectomy when surgically treated (50.9% vs. 43.4%, p<0.0001). Of women who underwent BCS, those with disabilities were less likely to receive RT than women in the general population (66.2% vs. 70.8%, p=<0.0001). Those with disabilities were less likely to receive standard treatment, which we defined as either mastectomy or BCS with RT (87.0% vs. 88.1%, p=0.04) (Table 16). Results

from our multivariate analysis showed no difference in standard care between women with disabilities and the general population (OR=1.06; Table 17). However, of women who underwent BCS, those in the general population were more likely than those with disabilities to receive RT after adjusting for confounders (OR=1.21, 95% CI= 1.11-1.32) (Table 18).

Trends in Treatment

Between 1992 and 2002, rates of mastectomy declined and BCS increased among women surgically treated for breast cancer. We observed these phenomena in both women with disabilities (Figure 7) and women in the general population (Figure 8). In 2001-2002, women with disabilities remained more likely to undergo mastectomy than BCS, but women in the general population had similar rates of BCS and mastectomy. The percentage of women undergoing BCS who also received RT fell throughout the study period (Figure 9). The level of RT following BCS fell from 71.1% in 1992 to 63.3% in 2002 ($p=0.0342$) in the disabled and from 72.9% in 1992 to 67.3% ($p<0.0001$) in the general population. As a result, the percentage of surgically-treated women receiving standard care fell over time, as mastectomy use decreased but increasing use of BCS was accompanied by decreasing use of RT (Figure 10). The proportion of women receiving standard care fell from 89.9% in 1992 to 82.3% in 2002 ($p<0.0001$) in the disabled and from 88.1% in 1992 to 80.6% ($p<0.0001$) in the general population.

Discussion

In our analysis of breast cancer diagnosis and treatment in working-age women, we found that those in the general population were more likely than those enrolled in Medicare due to disability to be diagnosed with in situ disease and less likely to be diagnosed with late-stage breast cancer. Our results mirror those of a recent study, although theirs were not statistically significant.[22] As in situ breast cancer disease is closely related to use of mammography, it is possible that the lower proportion of in situ disease found in the disabled is related to lower documented use of breast cancer screening[27, 37, 38] in women with disabilities.

We found that the quality of a breast cancer diagnostic workup tended to be better in working-age women with disabilities than women in the general population, although differences were small. Women enrolled in Medicare due to disability were more likely to have their estrogen receptor (ER) and progesterone receptor (PR) status tested, as well as tumor grade, than women in the general population. Working-age women with disabilities who underwent surgery were as likely to have nodal involvement tested as those in the general population. The only diagnostic measure that was less known for women with disabilities was tumor size. We cannot determine reasons for more thorough diagnostic workups in women enrolled in Medicare due to disability with our data; however, one possible explanation is that all women who are enrolled in Medicare due to disability are insured, unlike women in the general population.

A study of breast cancer treatment in women enrolled in Medicare due to disability found that these working-age women were less likely than the non-enrolled to undergo breast conserving surgery (BCS) than the general population, and of those who

did undergo BCS, use recommended radiation therapy (RT) was not as common from 1988-1999.[23] We found similar results.

We found similar rates of standard care in women with disabilities and those in the general population, which seems like a positive finding. However, the only reason that the rates of standard care are similar is because the rate of mastectomy is much higher in women with disabilities. The equivalence of standard care masks the disparity in receipt of RT following BCS. The lower RT rates in the disabled are of great concern and should be targeted as a way to improve breast cancer care in this population.

We further examined the trends in BCS vs. mastectomy and use of RT in association with BCS over time to see whether trends observed in the general population[54] exist for women with disabilities. We did find that women enrolled in Medicare due to disability became less likely to undergo mastectomy, significantly less likely to receive standard care (BCS with RT or mastectomy), and significantly less likely to receive RT when undergoing BCS over the period 1992-2002.

Women with disabilities may be affected differently by breast cancer treatment than other women. For example, mastectomy may inhibit proper use of wheelchairs, walkers, or crutches.[23] Conversely, women with disabilities may have greater problems completing the six-week post-BCS radiotherapy treatment due to getting into the correct position for RT, having access to transportation, or other issues than women without disabilities. Therefore, it is of great importance that practitioners take care in counseling women with disabilities in choosing the best form of standard care (BCS with RT or mastectomy) for breast cancer treatment. Communication between the patient, the surgical, radiation, and medical oncologists, along with other practitioners overseeing

care of the disabled woman, should take place to ensure that she receives the best care for her situation.

Strengths and Limitations

This study is a large, population-based analysis of the quality of cancer diagnosis and care in working-age women enrolled in Medicare due to disability. To our knowledge, this is the first study that quantifies the quality of diagnostic workup in female breast cancer patients enrolled in Medicare due to disability or examines trends in standard treatment over the past decade.

The definition of "disability" for the purposes of this research is an administrative definition used by the SSA. Results may not be generalizable to all women with disabilities, as there are multiple definitions of "disability."

Conclusions

We did not find any large differences in diagnostic workup or treatment between women with disabilities and those in the general population. Between the years of 1992 and 2002, rates of standard treatment for breast cancer fell for both groups. While standard treatment occurs at similar rates, a disparity in RT following BCS exists. It is important for providers to take care in suggesting the best treatment for women with disabilities to ensure they receive adequate treatment.

Table 14: Breast Cancer Patient Demographic Characteristics

		General Population (SEER)	Disabled (SEER-Medicare)	p-value
N		167,954	6,051	
Age at Diagnosis	30-39	11.5%	6.8%	<0.0001
	40-44	16.5%	12.2%	
	45-49	23.4%	20.9%	
	50-54	25.2%	26.6%	
	55-59	23.6%	33.5%	
Marital Status	Single	15.6%	28.8%	<0.0001
	Married	65.3%	40.7%	
	Sep./Div./Wid.	15.5%	26.4%	
	Unknown	3.6%	4.0%	
Race	Non-Hisp White	71.2%	66.1%	<0.0001
	Hispanic White	9.1%	8.7%	
	Black	10.0%	19.6%	
	Oth./Unk.	9.7%	5.6%	

* limited to localized or regional cancers who underwent BCS or mastectomy

Table 15: Breast Cancer Diagnosis and Tumor Characteristics

		General Population (SEER)	Disabled (SEER-Medicare)	p-value
N		167,954	6,051	
Staged	Staged	98.5%	98.3%	0.2376
	Unstaged	1.5%	1.7%	
Stage at Diagnosis	In Situ	18.5%	14.6%	<0.0001
	Localized	46.6%	43.5%	
	Regional	29.0%	31.6%	
	Distant	4.5%	8.6%	
	Unstaged	1.5%	1.7%	
ER Tested	Tested	68.4%	70.9%	<0.0001
	Untested	31.6%	29.1%	
ER Status	Negative	19.6%	21.6%	<0.0001
	Positive	48.8%	49.3%	
	Untested	31.6%	29.1%	
PR Tested	Tested	66.5%	69.0%	<0.0001
	Untested	33.5%	31.0%	
PR Status	Negative	23.4%	26.9%	<0.0001
	Positive	42.6%	42.1%	
	Untested	33.5%	31.0%	
Nodes	None Examined	23.1%	24.9%	0.0028
	Examined	75.5%	73.8%	
	Unknown	1.5%	1.3%	
Size Assessed	Assessed	84.9%	83.9%	0.0399
	Unassessed	15.1%	16.1%	
Tumor Size	0-1 cm	18.0%	15.5%	<0.0001
	1-2 cm	29.5%	27.1%	
	2-5 cm	30.3%	31.7%	
	5+ cm	7.1%	9.6%	
	unknown	15.1%	16.1%	
Tumor Grade Assessed	Assessed	80.0%	81.6%	0.0031
	Unassessed	20.0%	18.4%	
Tumor Grade	Low	43.1%	43.4%	0.0105
	High	37.0%	38.1%	
	Unknown	20.0%	18.4%	

Table 16: Breast Cancer Treatment Characteristics

		General Population (SEER)	Disabled (SEER-Medicare)	p-value
N		167,954	6,051	
Treatment	No Surgery	4.1%	6.0%	<0.0001
	BCS Alone	15.2%	14.9%	
	BCS with RT	36.8%	29.3%	
	Mastectomy	41.3%	47.3%	
	Surgery or RT Unknown	2.7%	2.5%	
Standard Treatment*	BCS without RT	11.9%	13.0%	0.0424
	BCS with RT or Mastectomy	88.1%	87.0%	
BCS and RT	BCS without RT	29.2%	33.8%	<0.0001
	BCS with RT	70.8%	66.2%	

* limited to localized or regional cancers who underwent BCS or mastectomy

Table 17: Predicting Standard Care for Breast Cancer Using Logistic Regression
Limited to surgically-treated women diagnosed with localized or regional breast cancer
Disabled N= 4,361
SEER N= 121,709

		Odds Ratio	95% Confidence Interval	p-value
Cohort	Disabled	1.00 (ref)		
	SEER	1.06	0.97-1.16	00.2299
Age at Diagnosis	30-39	1.00 (ref)		
	40-44	0.98	0.91-1.04	0.0212
	45-49	0.96	0.90-1.02	
	50-54	0.96	0.90-1.02	
	55-59	1.03	0.97-1.10	
Marital Status	Married	1.00 (ref)		
	Single	0.83	0.78-0.87	<0.0001
	Sep./Div./Wid.	1.03	0.98-1.08	
	Unknown	0.65	0.59-0.71	
Race/Ethnicity	Non-Hisp White	1.00 (ref)		
	African. American	0.79	0.75-0.84	<0.0001
	Hispanic White	1.01	0.95-1.08	
	Other/Unknown	1.12	1.05-1.20	

*Adjusted for Registry

Table 18: Predicting RT with BCS using Logistic Regression
Limited to BCS and known radiation status
Disabled N= 2,671
SEER N= 87,212

		Odds Ratio	95% Confidence Interval	p-value
Cohort	Disabled	1.00 (ref)		
	SEER	1.21	1.11-1.32	<0.0001
Age at Diagnosis	30-39	1.00 (ref)		
	40-44	0.96	0.91-1.02	<0.0001
	45-49	0.95	0.90-1.01	
	50-54	1.01	0.96-1.07	
	55-59	1.13	1.07-1.20	
Marital Status	Married	1.00 (ref)		
	Single	0.82	0.78-0.85	<0.0001
	Sep./Div./Wid.	1.06	1.02-1.10	
	Unknown	0.49	0.45-0.53	
Race/Ethnicity	Non-Hisp White	1.00 (ref)		
	African. American	0.83	0.79-0.87	<0.0001
	Hispanic White	0.91	0.86-0.96	
	Other/Unknown	0.85	0.80-0.90	

*Adjusted for Registry

Figure 7

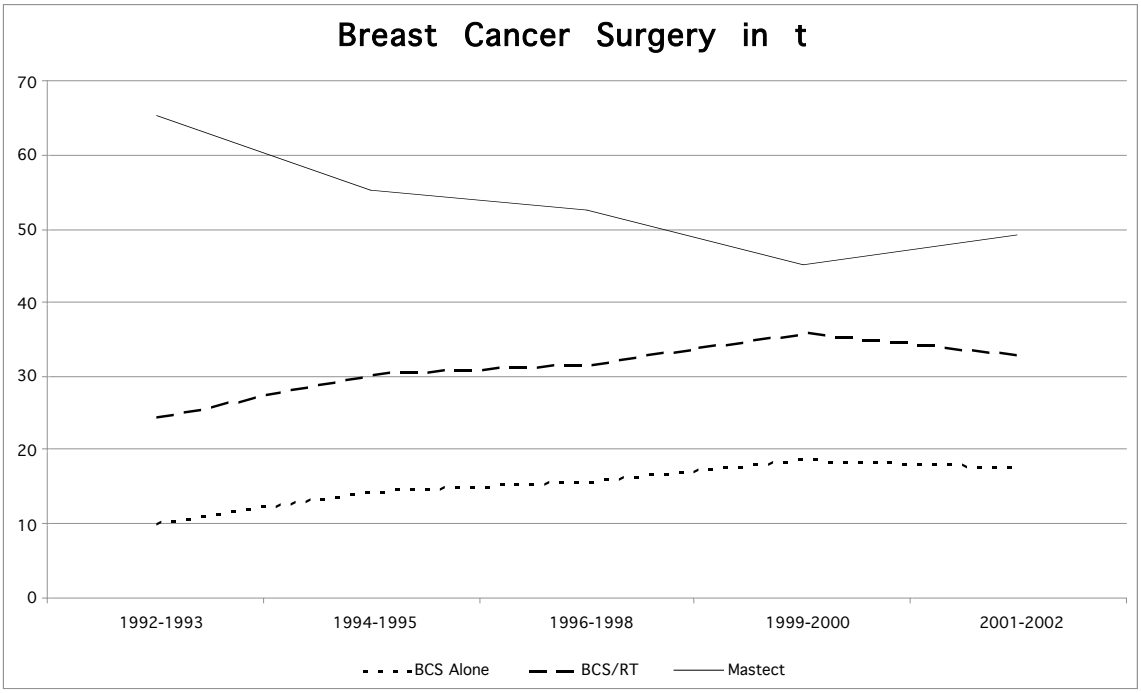


Figure 8

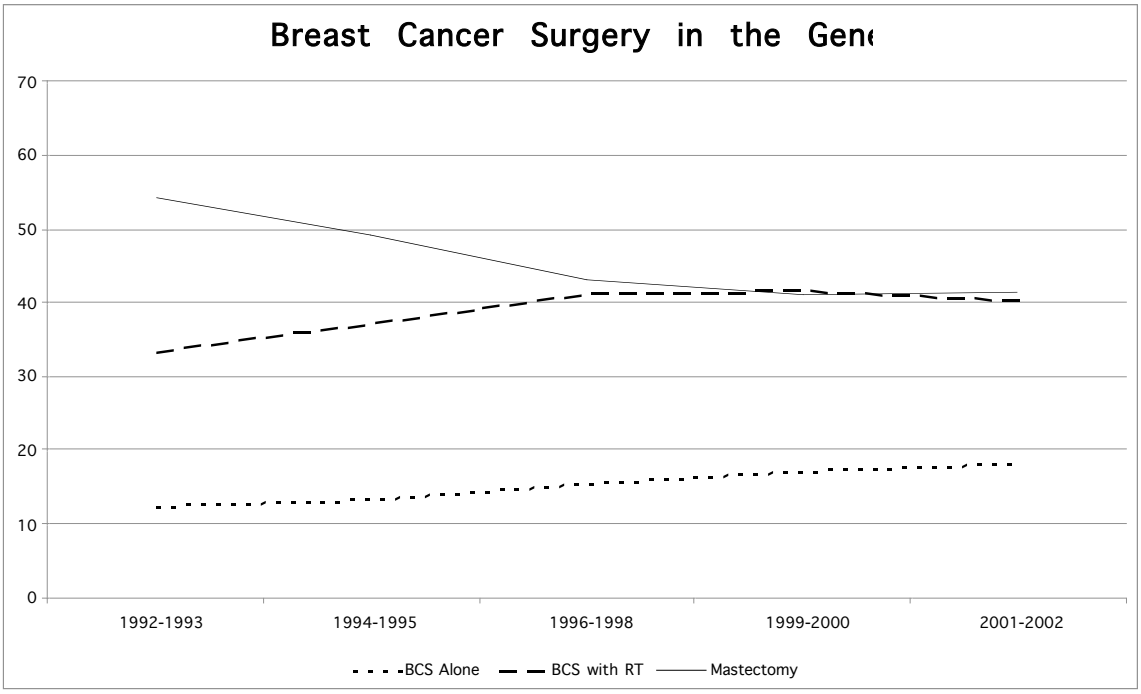


Figure 9

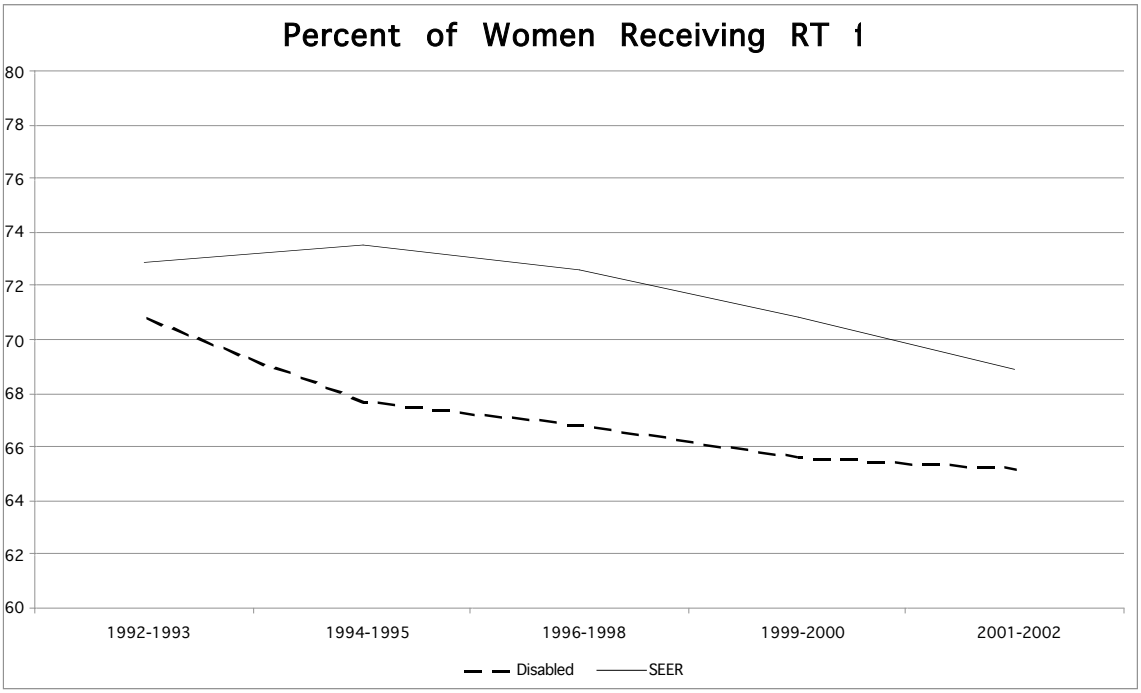
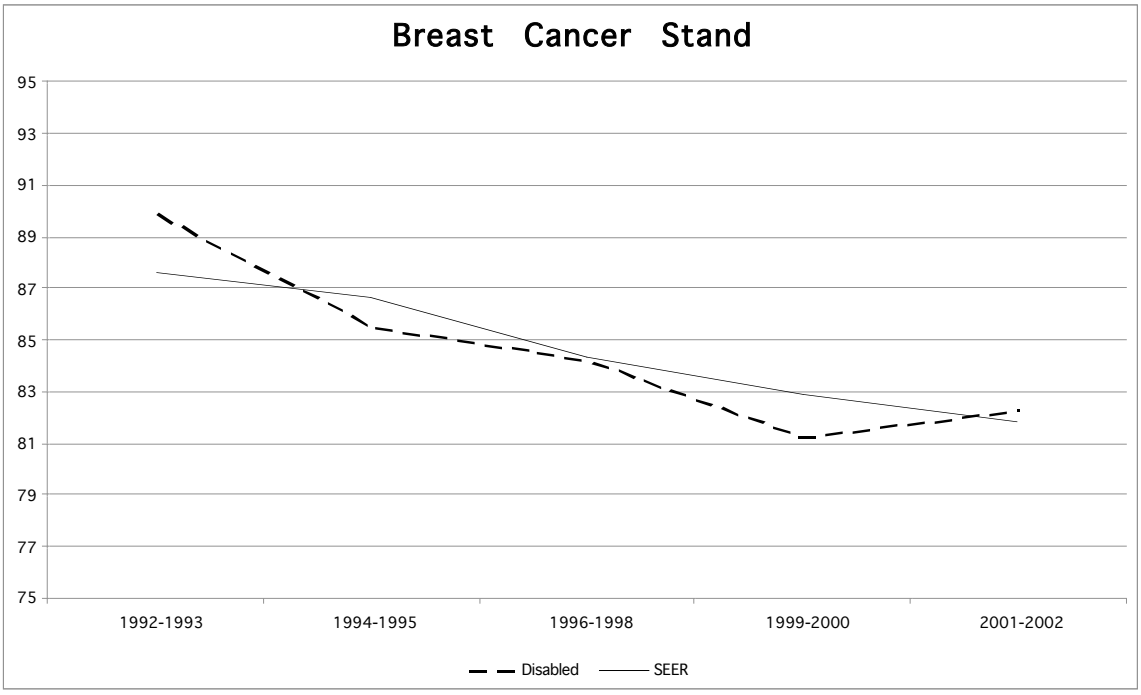


Figure 10



Discussion

The three papers above examine relationships between cancer in working-age adults and enrollment in Medicare due to disability. We have established that cancer is an important health issue for working age adults; 41% of these cancer diagnoses occur in people under age 65.[2] Unlike most elderly cancer survivors, working-age adults must assess whether they are able to return to work, and if not, whether they will qualify for federal disability benefits.

The literature has shown that cancer diagnosis and treatments can leave a working-age adult unable to work; our study shows that working-age adults who are unable to work following cancer diagnosis and treatment do enroll in Medicare due to disability, and they seem to enroll as soon as possible. The immediacy with which one applies for federal disability benefits (almost all patients applied within 2 months of diagnosis) shows that these disability benefits are important and necessary. It is imperative that people with disabilities are aware of these federal benefits, that they understand whether they qualify for them, and that they have any resources necessary to apply for benefits that they deserve. After all, those who receive SSDI and enroll in Medicare due to disability earned these benefits by paying payroll taxes when employed.

The 29-month waiting period is of concern, and efforts to reduce or eliminate it should be supported. While only a quarter of people within the waiting period are uninsured,[12] we do not know how many of the insured are underinsured or face access issues. The Social Security Administration (SSA) requires that a disabling condition must be expected to last at least a year or until death in order to qualify for benefits. We

understand that this requirement is put in place to prohibit the temporarily disabled from receiving benefits designed for the permanently disabled. However, we fail to understand why the waiting period could not be reduced to match the five months of waiting that exists prior to receipt of Social Security Disability Insurance (SSDI) payments, especially since it seems that if a person were to apply for benefits in order to profit from a program for which he or she did not qualify, the income payments would be the target more than health insurance benefits. As a result, we strongly support efforts to reduce or eliminate the 29-month waiting period.

We did find evidence of pent-up demand in the number of cases diagnosed soon after the 29-month waiting period ended, although this pent-up demand was not manifested in cancer outcomes. The lack of evidence for pent-up demand in outcomes, given the potential evidence for pent-up demand in cancer cases diagnosed, was surprising. In the future, we would like to examine actual screening rates for women upon enrolling in Medicare due to disability. Further research could additionally identify whether pent-up demand exists for other cancer diagnoses or other chronic disease diagnosis and care.

While some have stated that the disabled is a "vulnerable population," we found that diagnostic workup and treatment for breast cancer was at least as good in those enrolled in Medicare due to disability as in the general population. It is possible that the superior care could be due to 100% insurance within our disabled subjects, and future studies could compare outcomes in the Medicare disabled to the insured non-disabled. We did find concerning evidence that appropriate breast cancer treatment is decreasing over time in the disabled, mostly due to a decreasing use of radiation therapy following

breast conserving surgery. It is important that healthcare providers adequately assess whether a woman with disabilities will be able to complete radiation therapy following breast conserving surgery so that the woman receives recommended care. As seen elsewhere in healthcare, communication between the patient and provider is necessary in ensuring the best course of treatment for an individual.

Our research has expanded the knowledge of the relationships between cancer and those patients enrolled in Medicare due to disability. It is important to assess the use and quality of federal programs such as those (SSDI and Medicare) available to working-age adults with disabilities. We encourage future research in this population, including expansion of our methods to analyses of other cancers, and building on our research by measuring screening use. Additional data on the level of health service use and health status for the patients within the 29-month waiting period would provide the foundation for other exciting research. The greater the knowledge base, the better the understanding we will have about the quality of cancer-related enrollment and cancer screening, diagnosis, and care in the 8.1 million[15] working-age people enrolled in Medicare due to disability.

Bibliography

1. National Cancer Institute. Cancer facts & the war on cancer. <http://training.seer.cancer.gov/module_cancer_disease/unit5_war_on_cancer.html >. Accessed 2007 September 29.

2. Edwards BK, Howe HL, Ries LA, Thun MJ, Rosenberg HM, Yancik R, Wingo PA, Jemal A, Feigal EG. Annual report to the nation on the status of cancer, 1973-1999, featuring implications of age and aging on U.S. cancer burden. Cancer 2002 May 15;94(10):2766-92.

3. Ries LAG, Harkins D, Krapcho M, Mariotto A, Miller BA, Feuer EJ, Clegg L, Eisner MP, Horner MJ, Howlader N, Hayat M, Hankey BF, Edwards BK (eds). 2005 November. *SEER cancer statistics review, 1975-2003*. <http://www.seer.cancer.gov/csr/1975_2003/results_single/sect_01_table.11_2pgs.pdf>. Accessed 2008 October 13.

4. American Cancer Society. 2008 March 5. American Cancer Society guidelines for the early detection of cancer. <http://www.cancer.org/docroot/PED/content/PED_2_3X_ACS_Cancer_Detection_Guidelines_36.asp>. Accessed 2008 November 7.

5. Agency for Healthcare Research and Quality. 2008 Guide to clinical preventive services. <http://www.ahrq.gov/clinic/cps3dix.htm#cancer>. Accessed 2008 November 7.

6. Greenwald HP, Dirks SJ, Borgatta EF, McCorkle R, Nevitt MC, Yelin EH. Work disability among cancer patients. Soc Sci Med 1989;29(11):1253-9.

7. Hewitt M, Rowland JH, Yancik R. Cancer survivors in the United States: Age, health, and disability. Journals of Gerontology Series A-Biological Sciences & Medical Sciences 2003 Jan;58(1):82-91.

8. Vartanian JG, Carvalho AL, Toyota J, Kowalski IS, Kowalski LP. Socioeconomic effects of and risk factors for disability in long-term survivors of head and neck cancer. Archives of Otolaryngology -- Head & Neck Surgery 2006 Jan;132(1):32-5.

9. Social Security Administration. How you earn credits. Baltimore, MD: Social Security Administration; 2007 January. Report nr 05-10072.

10. Social Security Administration. 2007 August 29. Disability planner: Social security protection if you become disabled. <http://www.ssa.gov/dibplan/>. Accessed 2007 September 25.

11. Social Security Administration. 2007 August. Annual statistical report on the Social Security Disability Insurance program, 2006. <http://www.ssa.gov/policy/docs/statcomps/di_asr/>. Accessed 2007 September 25.

12. Riley GF. Health insurance and access to care among Social Security Disability Insurance beneficiaries during the Medicare waiting period. Inquiry 2006;43(3):222-30.

13. Dale SB, Verdier JM. Elimination of Medicare's waiting period of seriously disabled adults: Impact on coverage and costs. New York: The Commonwealth Fund; 2003 July 7. Report nr 660.

14. Riley GF, Lubitz JD, Zhang N. Patterns of health care and disability for Medicare beneficiaries under 65. Inquiry 2003;40(1):71-83.

15. Social Security Administration. 2008 September. Annual statistical report on the Social Security Disability Insurance program, 2007. <http://www.ssa.gov/policy/docs/statcomps/di_asr/2007/index.html>. Accessed 2008 October 13.

16. Centers for Medicare & Medicaid Services. 2008. 2007 CMS statistics. <http://www.cms.hhs.gov/CapMarketUpdates/Downloads/2007CMSstat.pdf>. Accessed 2008 October 13.

17. Centers for Medicare & Medicaid Services. 2007 September 27. Medicare.gov - the official U.S. government site for people with Medicare. <http://www.medicare.gov>. Accessed 2007 September 28.

18. Kaiser Family Foundation. 2005 February 7. Navigating Medicare and Medicaid: Resource guides for people with disabilities, their families, and their advocates. <http://www.kff.org/medicare/med020705pkg.cfm>. Accessed 2008 November 7.

19. United States Department of Veterans Affairs. 2008 July 28. Information for veterans eligible to enroll in Medicare. <http://www.va.gov/healtheligibility/costs/MedicareDEligibility.asp>. Accessed 2008 November 7.

20. Nosek MA, Howland CA. Breast and cervical cancer screening among women with physical disabilities. Archives of Physical Medicine & Rehabilitation 1997 Dec;78(12 Suppl 5):S39-44.

21. Mele N, Archer J, Pusch BD. Access to breast cancer screening services for women with disabilities. JOGNN - Journal of Obstetric, Gynecologic, & Neonatal Nursing 2005 Jul-Aug;34(4):453-64.

22. McCarthy EP, Ngo LH, Chirikos TN, Roetzheim RG, Li D, Drews RE, Iezzoni LI. Cancer stage at diagnosis and survival among persons with Social Security Disability Insurance on Medicare. Health Serv Res 2007 Apr;42(2):611-28.

23. McCarthy EP, Ngo LH, Roetzheim RG, Chirikos TN, Li D, Drews RE, Iezzoni LI. Disparities in breast cancer treatment and survival for women with disabilities. Ann Intern Med 2006 Nov 7;145(9):637-45.

24. Ramirez A, Farmer GC, Grant D, Papachristou T. Disability and preventive cancer screening: Results from the 2001 California Health Interview Survey. Am J Public Health 2005 Nov;95(11):2057-64.

25. Roetzheim RG, Chirikos TN. Breast cancer detection and outcomes in a disability beneficiary population. Journal of Health Care for the Poor & Underserved 2002 Nov;13(4):461-76.

26. Iezzoni LI, McCarthy EP, Davis RB, Harris-David L, O'Day B. Use of screening and preventive services among women with disabilities. American Journal of Medical Quality 2001 Jul-Aug;16(4):135-44.

27. Iezzoni LI, McCarthy EP, Davis RB, Siebens H. Mobility impairments and use of screening and preventive services. Am J Public Health 2000 Jun;90(6):955-61.

28. Caban ME, Nosek MA, Graves D, Esteva FJ, McNeese M. Breast carcinoma treatment received by women with disabilities compared with women without disabilities. Cancer 2002 Mar 1;94(5):1391-6.

29. Sullivan SG, Hussain R, Threlfall T, Bittles AH. The incidence of cancer in people with intellectual disabilities. Cancer Causes & Control 2004 Dec;15(10):1021-5.

30. Verger P, Aulagnier M, Souville M, Ravaud JF, Lussault PY, Garnier JP, Paraponaris A. Women with disabilities: General practitioners and breast cancer screening. Am J Prev Med 2005 Feb;28(2):215-20.

31. Rietman JS, Dijkstra PU, Debreczeni R, Geertzen JH, Robinson DP, De Vries J. Impairments, disabilities and health related quality of life after treatment for breast cancer: A follow-up study 2.7 years after surgery. Disability & Rehabilitation 2004 Jan 21;26(2):78-84.

32. Kitamura Y, Ohno Y, Kasahara S, Murata K, Sugiyama H, Oshima A, Tsukuma H, Ajiki W, Hasegawa T. Statistical estimation of the number of breast cancer patients with disabilities resulting from surgery. Breast Cancer 2005;12(2):130-4.

33. Stein K, Allen N. Cross sectional survey of cervical cancer screening in women with learning disability. BMJ 1999 Mar 6;318(7184):641.

34. Davies N, Duff M. Breast cancer screening for older women with intellectual disability living in community group homes. Journal of Intellectual Disability Research 2001 Jun;45(Pt 3):253-7.

35. Cooper NS, Yoshida KK. Cancer screening behaviors among Canadian women living with physical disabilities. Archives of Physical Medicine & Rehabilitation 2007 May;88(5):597-603.

36. Patja K, Eero P, Iivanainen M. Cancer incidence among people with intellectual disability. Journal of Intellectual Disability Research 2001 Aug;45(Pt 4):300-7.

37. Chan L, Doctor JN, MacLehose RF, Lawson H, Rosenblatt RA, Baldwin LM, Jha A. Do Medicare patients with disabilities receive preventive services? A population-based study. Archives of Physical Medicine & Rehabilitation 1999 Jun;80(6):642-6.

38. Schootman M, Jeffe DB. Identifying factors associated with disability-related differences in breast cancer screening (United States). Cancer Causes & Control 2003 Mar;14(2):97-107.

39. Iezzoni LI, Ngo LH, Li D, Roetzheim RG, Drews RE, McCarthy EP. Treatment disparities for disabled Medicare beneficiaries with stage I non-small cell lung cancer. Archives of Physical Medicine & Rehabilitation 2008 Apr;89(4):595-601.

40. Iezzoni LI, Ngo LH, Li D, Roetzheim RG, Drews RE, McCarthy EP. Early stage breast cancer treatments for younger Medicare beneficiaries with different disabilities. HSR 2008 October;43(5, Part I):1752-67.

41. Centers for Medicare & Medicaid Services. 2007. 2006 CMS statistics. <http://www.cms.hhs.gov/CapMarketUpdates/Downloads/2006CMSstat.pdf>. Accessed 2007 September 25.

42. National Cancer Institute. Overview of the SEER program. <http://seer.cancer.gov/about/>. Accessed 2007 August 21.

43. National Cancer Institute. 2007 August 29. Scientific data documentation . <http://wonder.cdc.gov/wonder/sci_data/seer/type_txt/seer.asp>. Accessed 2007 September 30.

44. S. 2102, 110th Congress Sess. (2007) .

45. U.S. House of Representatives. H.R. 154, 110th Congress Sess. (2007) .

46. Iezzoni LI. Using administrative data to study persons with disabilities. Milbank Q 2002;80(2):347-79.

47. Chen LW. 2004 June 6. The pent-up demand for health care of the uninsured near elderly approaching age 65: Presentation at the 2004 AcademyHealth annual research meeting. <www.academyhealth.org/2004/ppt/chen3.ppt>. Accessed 2007 September 30.

48. McWilliams JM, Meara E, Zaslavsky AM, Ayanian JZ. Use of health services by previously uninsured Medicare beneficiaries. N Engl J Med 2007 Jul 12;357(2):143-53.

49. Ayanian JZ, Weissman JS, Schneider EC, Ginsburg JA, Zaslavsky AM. Unmet health needs of uninsured adults in the United States. JAMA 2000 Oct 25;284(16):2061-9.

50. McWilliams JM, Zaslavsky AM, Meara E, Ayanian JZ. Impact of Medicare coverage on basic clinical services for previously uninsured adults. JAMA 2003 Aug 13;290(6):757-64.

51. McWilliams JM, Meara E, Zaslavsky AM, Ayanian JZ. Health of previously uninsured adults after acquiring Medicare coverage. JAMA 2007 Dec 26;298(24):2886-94.

52. Hadley J, Waidmann T. Health insurance and health at age 65: Implications for medical care spending on new Medicare beneficiaries. Health Serv Res 2006 Apr;41(2):429-51.

53. Scarth H, Cantin J, Levine M. Clinical practice guidelines for the care and treatment of breast cancer: mastectomy or lumpectomy? The choice of operation for clinical stages I and II breast cancer (2002 update). CMAJ 2002 July 23;167(2):154-5.

54. Virnig BA, Jarosek S, Habermann EB, Al-Refaie W, Jensen E, Yee D, Tuttle TM. Decreased use of radiation therapy after breast-conserving surgery: A concerning trend in the United States. Working Paper, University of Minnesota.

Appendices

Appendix A: Stepwise Cohort Ascertainment for "The Effect of a Cancer Diagnosis on Disability Status"

Disabled Cohort

Start: All persons with a colorectal, breast, prostate, or lung cancer diagnosis in SEER-Medicare data, diagnosed 1973-2002: 1,447,460
After excluding persons whose first cancer diagnosis was not one of the big four: 1,383,892
After excluding persons not originally enrolled for disability or disability/ESRD: 155,864
After excluding persons with a prior cancer diagnosis: 147,301
After excluding cases diagnosed prior to 1992: 99,506
After excluding cases with age ge 60 at diagnosis: 37,753
After excluding persons diagnosed at death or autopsy: 37,588
After excluding male breast cancer patients: 37,587
After excluding people with a missing month of diagnosis: 37,481
After excluding persons enrolled in Medicare prior to diagnosis OR more than five years post-cancer diagnosis: 15,724

General Population Cohort

Start: All persons with a colorectal, breast, prostate, or lung cancer diagnosis in SEER data, diagnosed 1973-2002: 2,215,648
After excluding persons with a prior cancer diagnosis: 1,906,490
After excluding cases diagnosed prior to 1992: 1,145,610
After excluding cases with age ge 60 at diagnosis: 361,723
After excluding persons diagnosed at death or autopsy: 360,599
After excluding male breast cancer patients: 359,803
After excluding people with a missing month of diagnosis: 359,803
After excluding persons from the Alaskan Native registry (SEER only; not population-based): 359,049

Appendix B: Stepwise Cohort Ascertainment for "Pent-up Demand for Cancer Diagnosis Prior to Entering Medicare Due to Disability"

Disabled Cohort
Start: Female breast and lung cancer patients who were at one time (before or after diagnosis) enrolled in Medicare due to disability: 55,377
After excluding patients diagnosed prior to 1992: 37,249
After excluding patients who are not 50-59 at time of diagnosis: 11,738
After excluding patients with a prior cancer: 11,061
After excluding patients diagnosed at autopsy or death certificate: 11,031
After excluding patients with a missing month of diagnosis: 11,009
After excluding patients who were not diagnosed within four years of enrolling in Medicare due to disability: 1,755
After excluding patients who were not continuously enrolled for the first four years or until death: 1740
After excluding patients from the Rural Georgia registry: 1,732
After excluding patients of unknown race: 1,715
After excluding in situ lung cancer patients: 1,715

Elderly Cohort
Start: Female breast and lung cancer patients originally enrolled in Medicare due to age: 425,351
After excluding patients diagnosed prior to 1992: 256,240
After excluding patients who are not 65-69 at time of diagnosis: 51,332
After excluding patients with a prior cancer: 48,032
After excluding patients diagnosed at autopsy or death certificate: 47,840
After excluding patients with a missing month of diagnosis: 47,739
After excluding patients who did not enroll when immediately eligible: 44,704
After excluding patients who were not diagnosed within four years of enrolling in Medicare due to disability: 34,991
After excluding patients who were not continuously enrolled for the first four years or until death: 34,970
After excluding patients from the Rural Georgia registry: 34,895
After excluding patients of unknown race: 34,699
After excluding in situ lung cancer patients: 34,694

Appendix C: Stepwise Cohort Ascertainment for "Quality Care for a Vulnerable Population? Cancer Diagnosis and Treatment in the Disabled"

Disabled Cohort
Start: All females with a breast cancer diagnosis in SEER-Medicare data, diagnosed 1973-2002, and originally enrolled for disability or disability/ESRD: 38,829
After excluding patients with a prior cancer diagnosis: 36,592
After excluding cases diagnosed prior to 1992: 23,749
After excluding cases with age ge 60 at diagnosis: 14,416
After excluding persons diagnosed at death or autopsy: 14,398
After excluding patients enrolled after diagnosis: 6,079
After excluding the Rural Georgia and Alaska registries: 6,051

General Population Cohort
Start: All females with a breast diagnosis in SEER data, diagnosed 1973-2004: 774,955
After excluding patients with a prior cancer diagnosis: 659,997
After excluding cases not diagnosed 1992-2002: 347,947
After excluding cases not 21-59 at diagnosis: 168,846
After excluding persons diagnosed at death or autopsy: 168,659
After excluding the Rural Georgia and Alaska registries: 167,594