

CANCER IN RURAL AMERICA

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SCOPE OF THE PROBLEM

- Healthy People 2010 had inadequate data available to determine urban versus rural disparities in overall cancer mortality for any cancer.¹
- Overall colorectal cancer screening rates in rural areas lag behind non-rural by ten percent.¹
- Rural women are ten to 49 percent less likely to have had a mammogram in the past two years, or a Pap test within the past three years.¹
- Rural versus non-rural cancer survival rates were not analyzed in Healthy People 2010.¹
- State cancer registries, and data from the Surveillance, Epidemiology, and End Results (SEER) program provide rural researchers and community planners with current data to evaluate cancer prevalence and mortality.²
- Tobacco was expected to account for about 30 percent of all cancer deaths in 2014.³
- An estimated 1,658,370 new cases of cancer will occur in 2015.⁴
- Breast and prostate cancer remain the most commonly occurring types of cancer in women and men, respectively.³
- Rural/urban disparities exist across the cancer continuum because access to health care continues to be a challenge for rural dwellers.⁵
- Rates of cancer are highest across the Southeast and Midwest with pockets of high rates in the extreme Northeast, Montana, and Wyoming.¹
- It is projected that costs associated with cancer care in 2020 will be \$157.77 billion, assuming current incidence, survival, and cost of health care treatment.⁶

Healthy People 2020 continued the Healthy People 2010 cancer goal to reduce the overall number of new cancer cases, as well as the illness, disability, and death caused by cancer.⁷ Although there was a 20 percent reduction in reported cancer deaths between 1991 and 2009,⁸ cancer remains the second leading cause of death in the United States^{4,9,10} accounting for one in every four deaths.⁸ It is the leading cause of death for both males and females between age 40 and 79.¹⁰ In 2015, it is projected that 1,658,370 new cases of cancer and 589,430 cancer-related deaths will occur.⁴ It is also projected that cancers of the prostate, lung and bronchus, and colorectal areas will account for about 50 percent of new cancer cases among men in 2015; prostate cancer will account for 26 percent of these new cases.⁴

Among women, it is projected that cancers of the breast, lung and bronchus, and colorectal area will account for 50 percent of new cases; breast cancer will account for 29 percent of the new cases.⁴ In the past five years for which data is available (2007-2011), there was a steady decline in cancer incidence among males while incidence rates among females did not change.⁴ The decline seen among males has been attributed to rapid declines in colorectal, lung, and prostate cancer.⁴ Although a decline in lung and colorectal cancer incidence has been observed among females, breast cancer incidence rates have remained stable.¹⁰

The costs of treating cancer continue to rise. National expenditure for cancer care in 2010 was \$124.57 billion; it is projected that assuming steady trends, the cost would rise to \$157.77 billion by year 2020.⁶

HEALTHY PEOPLE 2020 GOALS AND OBJECTIVES

This chapter discusses rural-urban variations and/or factors that may influence the following Healthy People 2020 goals⁷:

- **C-1** Reduce the overall cancer death rate
- **C-9** Reduce invasive colorectal cancer
- **C-10** Reduce invasive uterine cervical cancer
- **C-11** Reduce late-stage breast cancer
- **C-13** Increase the proportion of cancer survivors who are living five years or longer after diagnosis
- **C-15** Increase the proportion of women who receive a cervical cancer screening based on the most recent guidelines
- **C-16** Increase the proportion of adults who receive a colorectal cancer screening based on the most recent guidelines
- **C-17** Increase the proportion of women who receive a breast cancer screening based on the most recent guidelines

CANCER DISPARITIES IN RURAL AREAS

Rural disparities in cancer incidence and mortality exist throughout the United States with some regions experiencing significantly higher rates of cancers and higher mortality due to later stage of detection and poorer access to screening, care and clinical trials.

Mortality rates for all cancers combined is seven percent higher in Appalachian states compared to the rest of the nation, and five percent higher for all cancers combined for Appalachian counties compared to non-Appalachian counties.¹¹

Colorectal cancer mortality has also been reported to be 15 percent higher for rural Georgia residents compared to urban Georgia residents.¹² Although cervical cancer related deaths declined over the past four decades, women residing in non-metropolitan areas have had persistently higher mortality rates compared to those residing in metropolitan areas; in 2007, cervical cancer mortality rate was 22 percent higher among non-metropolitan residents compared to metropolitan residents.¹³ Cervical cancer mortality rates have also been reported to be two times higher for Black women compared to white women and

three times higher for Black women residing in rural areas compared to white women resident in metropolitan areas.¹³ Compared to urban residents, cervical cancer incidence rates are six to 15 percent higher among women residing in small urban and rural areas respectively, compared to residents of metropolitan areas.¹³

Routine screening reduces the occurrence of certain forms of cancer such as colorectal, breast and cervical cancers therefore; expert organizations such as the United States Preventive Services Task Force¹⁴ and the American Cancer Society¹⁵ recommend age-based screening guidelines for these cancers. However, sub-optimal adherence rates are still reported.¹⁶ These sub-optimal rates are more pronounced for rural residents. A study that utilized the Behavioral Risk Factor Surveillance Survey data, a nationally representative data, reported that although an increase in colorectal cancer screening for rural residents occurred between 1998 and 2005, rural residents were still less likely to be screened for colorectal cancer compared to their urban counterparts; this disparity increased with increasing rurality.¹⁷

A Utah study also reported that rural residents were less likely to be adherent to colorectal cancer screening guidelines compared to urban residents.¹⁸ Bennett et al. found that rural white residents had decreased odds of screening for colorectal cancer compared to urban white residents.¹⁹

A study conducted in rural Oregon found that patients with a positive family history of breast or colorectal cancer were more likely to be up-to-date with screening tests compared to those with no known family history.²⁰ Rural Kansas residents participating in an employee wellness program were less likely than urban or suburban residents to be adherent to breast and colorectal cancer screening.²¹ Nuño and colleagues, found that compared to their urban counterparts, Hispanic and American Indian females resident in rural Southwestern states were five percent less likely to report having a mammogram within the past year, seven percent less likely to report having a mammogram within the past three years, and four percent more likely to report that their last mammogram was within the previous five years.²² However, breast cancer screening among Medicaid enrollees has been reported to be highest among women resident in non-metropolitan rural areas compared to residents of non-metropolitan urban areas or metropolitan urban areas.²³ Cervical cancer screening using cytology has

also been reported to be lower among residents of the Appalachian Ohio region compared to their non-Appalachian Ohio counterparts.²⁴

Disparities in cancer diagnosis and treatment have also been documented. Compared to urban residents, women residing in rural areas have been reported to have lower biopsy rates following abnormal diagnostic mammography; rural women who had biopsies were more likely to have longer average time to biopsies compared to urban women.²⁵ Rural breast cancer patients have been reported to be less likely to receive conservative treatment compared to urban residents.²⁶ Breast cancer patients who had mastectomy in a rural hospital were found to be less likely to have immediate reconstruction surgery compared to their urban counterparts.²⁷

A study that utilized the National Cancer Institute's SEER data, a nationally representative dataset, found that rural breast cancer patients were less likely to receive radiation therapy compared to urban breast cancer patients.²⁸ Baldwin and colleagues also found that older and widowed rural cancer patients had the lowest rates of receipt of radiation therapy.²⁸ Although sentinel lymph node biopsy (SLNB) is currently preferred over axillary lymph node dissection for lymph node staging in patients with a breast cancer diagnosis, rural patients are less likely to undergo SLNB compared to urban patients; a lag in adoption of SLNB among rural physicians has also been reported.²⁹

Rural residents diagnosed with melanoma have been found to be less likely than their urban counterparts to receive a sentinel lymph node biopsy.³⁰ Prostate cancer patients resident in rural areas have also been reported to be less likely than their urban counterparts to receive definitive treatment.³¹ Compared to their urban counterparts, rural colorectal cancer patients have been reported to be less likely to undergo laparoscopic procedure.³² In their study which utilized the Georgia Cancer Registry, Johnson et al. report that rural and sub-urban residents with a diagnosis of non-small cell lung cancer had 63 percent and 23 percent increased odds of having un-staged disease respectively compared to their urban counterparts.³³ Johnson et al. also found that rural residents had 13 percent decreased odds of receiving any treatment following diagnosis for non-small cell lung cancer.³³ This study also found that rural residents had eight percent lower odds of receiving chemotherapy, and 11 percent decreased odds of receiving radiation therapy compared to urban residents.³³ However, Johnson et al. found that rural

residents diagnosed at stage I or II had nine percent and ten percent decreased odds of death compared to urban residents.³³ Markossian and colleagues, found that women residing in small and isolated rural areas were more likely to have un-staged breast cancer compared to urban residents.³⁴ They also found that compared to urban residents, rural residents were more likely (30 percent increased odds) to receive surgery after a breast cancer diagnosis but less likely (17 percent decreased odds) to receive radiotherapy.³⁴ Using SEER data, Martinez, et al. found that following lumpectomy for breast cancer, rural residents (OR=0.39) and residents of near metropolitan counties (OR=0.66) had decreased odds of receiving radiation therapy compared to urban residents.³⁵

Cancer outcomes and survival are also influenced by rural residence. Increased psychological and psychosocial problems have also been reported among rural breast cancer patients.²⁶ Rural cancer survivors are less likely to report availability of a psychologist or cancer support group within 30 miles distance than their non-rural counterparts.³⁶ Five-year cervical cancer survival rates have been reported to be 3.5 percent lower for non-metropolitan women compared to metropolitan women.¹³

A Kentucky study found that rural cancer survivors had poorer mental health outcomes.³⁷ Rural lung cancer patients have also been found to have poor mental health outcomes compared to urban patients.³⁸ Cancer survivors age 65 and above who reside in rural areas have been reported to be more likely to forgo medical and dental care due to cost.³⁹ Another cancer that has been found to have a poor outcome for rural residence is carcinoid tumor.⁴⁰

RURAL DISPARITIES ACCESSING CANCER CLINICAL TRIALS

Prior research has shown that clinical trials are an important resource for advancing new forms of cancer treatment, and for evaluating methods to improve pain management and palliative care as well as quality of life.⁴¹ The problem of differential access to cancer care for rural versus urban populations has been widely recognized.⁴¹⁻⁴³ It has also been shown that rural communities and the uninsured participate less than other groups in cancer clinical trials.

Rates of survival for cancer are lower in rural areas where there are fewer sub-specialists.⁴⁴ The reasons for lack of participation in clinical trials are numerous but include lack of availability of

oncologists and radiation oncologists in rural areas, as well as scarcity of information about available clinical trial opportunities. Another major barrier to rural physician participation in clinical trials is costs associated with compliance with clinical trials reporting criteria. Another common problem in cancer clinical trial participation are patients' inability to afford travel and hotel bills, as payment for these expenses is considered an inducement to participation by review boards, and cannot be covered by the investigator. Patient-related barriers also include lack of health insurance, transportation costs, feelings of uncertainty, mistrust, personal and cultural barriers, and lack of understanding.^{42,43} Provider barriers to recruitment include perceptions of lack of trust of participants, time constraints, lack of resources, inadequate knowledge of the community, selection bias, and trial design criteria.⁴²

VARIATION BY RURAL REGION

Regional variations have been demonstrated in both cancer incidence and mortality rates. **Figure 1** and **Figure 2** show the regional variations for the three most common types of cancer. It also shows the United States rates. Regional variations in receipt of care also exist. Cancer survivors in the South have been reported to be more likely to forgo medical care while cancer survivors who reside in the West are more likely to forgo medical and dental care.³⁹

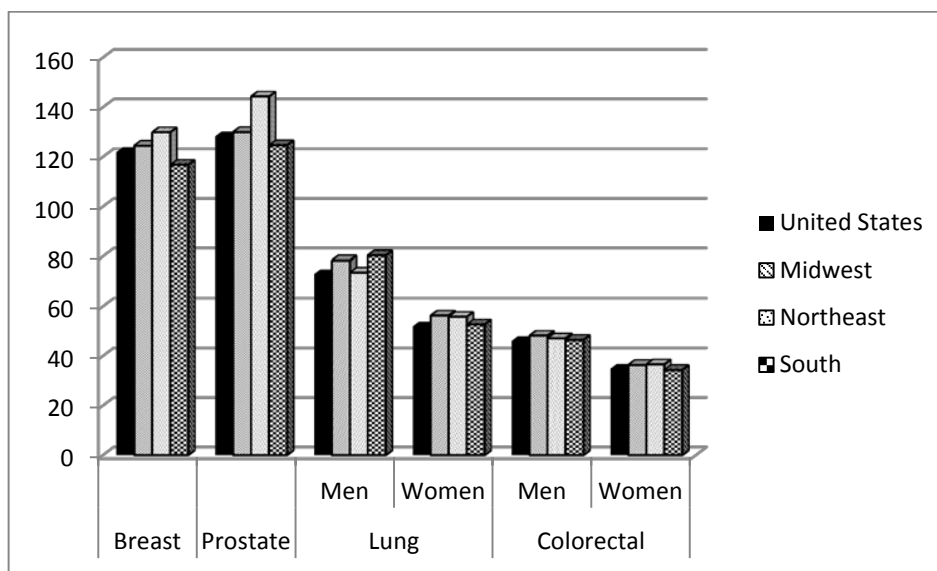
VARIATION BY RACE AND ETHNICITY

Cancer rates vary among the racial and ethnic groups. Asian Americans have the lowest cancer incidence and mortality rates while Blacks have the highest cancer incidence and mortality rates.¹⁰ Rate of cancer occurrence among Blacks is double that among Asian Americans.¹⁰ Whites have higher cancer incidence and mortality rates for all cancer sites combined compared to Asian Americans/Pacific Islanders, American Indians/Alaska Natives and Hispanics.¹⁰ Whites also have higher incidence rates for the four most common cancer sites which include cancer of the prostate, lung and bronchus, colon and rectum, and urinary bladder for males, and cancer of the breast, lung and bronchus, colon and rectum, and uterine corpus for females. However, whites have lower incidence and mortality rates for cancers caused by infectious agents such as cervical, liver, and stomach cancers.¹⁰ Breast cancer incidence is highest among white women; however, mortality rates are highest among Black women.¹⁰ Between 1999 and 2009, Hispanics had the highest incidence of cervical cancer; in 2010, Black women had the highest incidence of cervical cancer.⁴⁶ Cervical cancer death rates were highest among Black women between 1999 and 2010; Hispanic women had the second highest mortality rates from cervical cancer between 1999 and 2010 except for year 2008 when American Indians/Alaska Natives had the highest cervical cancer mortality rates.⁴⁶ Cervical cancer

mortality and incidence have been reported to be higher with increasing rurality for all racial/ethnic groups except for Hispanics, with women residing in small urban non-metropolitan and rural areas having increased mortality risk compared to urban residents.¹³ Rural non-Hispanic and Black women have higher cervical cancer incidence rates, compared to their urban counterparts.¹³

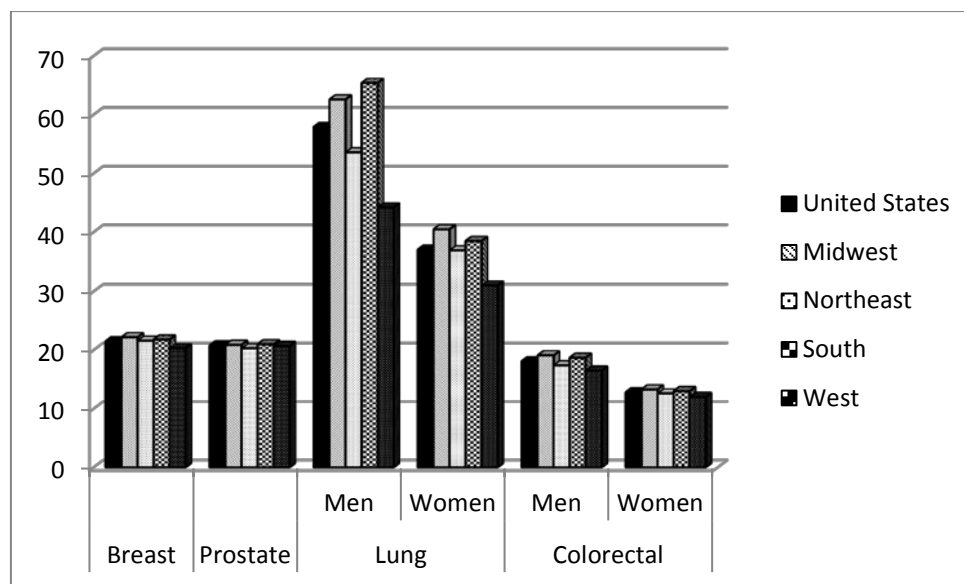
Compared to their urban counterparts, colorectal cancer screening rates have been found to be lower among, rural

Figure 1: Regional Incidence Rates of the Four Most Common Cancer Sites



Adapted from <http://www.cdc.gov/cancer/dcpc/data/geographic.htm>⁴⁵

Figure 2: Regional Mortality Rates of the Four Most Common Cancer Sites



Adapted from <http://www.cdc.gov/cancer/dcpc/data/geographic.htm>⁴⁵

whites, African Americans/Blacks and Hispanics, however, screening rates are lower among Asians and American Indian/Alaska natives resident in urban areas compared to those resident in rural areas.⁴⁷ African American females have been found to be more likely to report having had cervical cancer screening compared to whites.¹⁹

Race/ethnicity has also been reported to influence cancer diagnosis, treatment and survival. Blacks are less likely than whites to be diagnosed with cancers that are still at localized stage, thus, decreasing the likelihood of successful treatment.¹⁰ Black rural residents have been reported to have an increased likelihood of being diagnosed with cervical cancer at an advanced stage compared to non-Hispanic non-metropolitan residents and metropolitan residents.¹³ A Georgia study found that Hispanics were more likely to have a late stage diagnosis of breast cancer compared to non-Hispanics.³⁴ Markossian et al. also report that African Americans were more likely to have un-staged cancer and late stage cancer diagnoses compared to whites.³⁴ With regard to breast cancer treatment, Markossian et al. report that rural cancer patients are less likely to receive surgery and radiotherapy respectively compared to urban residents; African Americans were less likely to receive radiotherapy following diagnosis compared to whites.³⁴ Baldwin et al. found that African Americans and Hispanic/Latino women diagnosed with breast cancer were less likely to receive radiation therapy compared to other racial/ethnic groups.³¹

Markossian and colleagues also report that African Americans are more likely to die following their diagnosis compared to whites.³⁴ Press and colleagues report that African Americans and Hispanics are more likely to have delayed treatment following an abnormal mammogram.⁴⁸ Blacks have lower five-year survival rates than whites for most cancers.¹⁰ Singh found that cervical cancer survival rate was lower for non-metropolitan Blacks compared to metropolitan

Blacks.¹³ A South Carolina study found that African American women residing in rural South Carolina had decreased survival rate compared to their white counterparts.⁴⁹

IMPACT ON MORTALITY, MORBIDITY, AND OTHER HEALTH PROBLEMS

Barriers to Prevention, Screening, and Treatment

Barriers that have been found to contribute to cancer disparities can be classified as patient-level or system-level barriers.⁵⁰ Some patient-level barriers include fatalistic beliefs,⁵¹ lack of knowledge,^{52,53} embarrassment,⁵⁴ fear of a negative outcome following routine screening,⁵³ cost of care/lack of insurance coverage^{53,55} and fear of the screening procedure.^{53,55,56} System-level barriers include lack of physician recommendation, increased travel time and travel distance to nearest care facility,⁵⁷ inadequate physician/healthcare provider supply,⁵⁸ complexities of navigation.⁵⁹ Perceived barriers have also been reported to be influenced by rural-urban residence.^{51,55,57,58,60} These barriers have been found to impact cancer screening,⁵³ diagnosis,⁵⁹ and participation in clinical trials.⁵²

Befort and colleagues found that rural residents were more likely to have fatalistic beliefs such as believing that cancer recommendations are confusing, cancer is not preventable, and everything causes cancer.⁵¹ Lack of insurance, lack of transportation,

embarrassment, travel distance, and fear of having a cancer diagnosed have been reported as barriers to obtaining mammogram among rural residents.⁵⁷ A study conducted in a rural area in Washington found that perceived low risk, cost of screening, needing to take time off work, and fear of pain and finding cancer were barriers to screening mammography.⁶¹ An Appalachian study reported that embarrassment, lack of health insurance, and no physician recommendation for mammogram in the past 12 months were barriers to breast cancer screening.⁵⁴ Cost and lack of insurance has been associated with decreased likelihood of compliance with preventative mammography and Pap test screening recommendation.²² In their study, Nuño et al. found that visiting a health care provider within the past year was associated with increased Pap test and mammography screening among rural Hispanic women resident in southwestern region, however, cost was a statistically significant hindrance to visiting a health care provider.²²

Fatalism, lack of provider recommendation, having insurance coverage that did not pay for colonoscopy, and fear of a negative outcome are some of the factors that have been found to negatively influence colorectal cancer screening.⁶² A study which comprised of rural, low-income, and minority residents of North Carolina, identified cost of screening, fear of a cancer diagnosis, embarrassment and fear of the procedure as barriers to colorectal cancer screening.⁵⁵ A Georgia study in which all participants were rural residents reported that not having enough time with their physicians, cost, fear of complications, lack of transportation, anxiety about bowel preparation and procedure, and embarrassment were barriers to colorectal cancer screening.⁵⁶

A rural Appalachian study reported that lack of knowledge, confusing screening guidelines, lack of physician recommendation, and embarrassment were barriers to colorectal cancer screening.⁶³ Colorectal cancer screening has also been reported to be more likely among older patients, college graduates, and married individuals.⁶⁴ Greiner et al. also reported that patients who had adequate time for discussion during physician visit and those with a cancer diagnosis were more likely to be up-to-date with colorectal cancer screening.⁶⁴ Rural residents have also identified fear of a negative outcome and pain as hindrances to Prostate Specific Antigen test or digital rectal exam.⁶⁵ Lack of knowledge, travel distance, cost, discouragement from oncologist and

family physicians has been reported as barriers to participation in clinical trials by rural residents.⁶⁶ A rural Oregon study found that those who had at least one health maintenance visit within the previous two years were more likely to be up-to-date with colorectal cancer screening, Pap test, clinical breast exam, a mammogram or both clinical breast examination and mammogram compared to those who did not have a health maintenance visit.⁶⁷ Carney et al. also found that uninsured individuals were less likely to be up-to-date with colorectal cancer screening or Pap test compared to women with private insurance.⁶⁷ A study utilizing the Behavioral Risk Factor Surveillance Survey, a nationally representative dataset, found that rural Hispanic women who had health insurance were more likely to report being up-to-date with mammogram and Pap tests compared to rural Hispanic southwestern women who did not have health insurance; women who had visited a health care provider in the past year were more likely to report having a mammogram within the past one year compared to those who had not had a health care provider visit within the past year.²² Having a health care provider visit within the past year, current employment and higher household income were also associated with increased likelihood of Pap test use among rural American Indians resident in the Southwestern region.²²

With regards to health-system related barriers, an Iowa study found that travel time to nearest radiotherapy facility for rural residents was three times that of urban residents.⁶⁰ In an Appalachian study, Physicians reported that concerns about patients' inability to afford colorectal cancer screening tests, cultural barriers, inadequate reimbursement, and few physicians trained in colonoscopy were barriers to recommending colorectal cancer screening to patients.⁶³ An Alaskan study identified inadequate exchange of information between primary care physicians and gastroenterologists resulting in patients being uninformed about requirements was a barrier to colorectal cancer screening compliance.⁶⁸ A long wait time before appointments has also been identified as a barrier to colorectal cancer screening compliance.⁶⁸ A Pennsylvania study reported that primary physicians in rural Pennsylvania perceived insufficient physician supply as a contributing factor to decreased colorectal cancer screening.⁵⁸ The physicians reported that decreased physician supply resulted in increased patient load leading to time constraints when attending to patients.⁵⁸ The resultant

time constraints resulted in decreased likelihood of discussing preventive measures including colorectal cancer screening with patients.⁵⁸ A North Carolina study conducted in four rural counties with high rates of invasive cervical cancer found that inadequate reimbursement, cost, the burden of determining if patients' insurance company covered human papillomavirus (HPV) vaccine, cost of purchasing the vaccine, low demand for vaccine, and fear of expiration of vaccine were cited by providers as barriers to providing to patients an HPV vaccine.⁶⁹ Another study found that acculturated Hispanic women were significantly more likely than non-Hispanic whites to be compliant with Pap test while non-acculturated Hispanic women were less likely than non-Hispanic white women to be compliant with Pap test.⁷⁰ They also found that non-acculturated Hispanic women were more likely than acculturated Hispanic women and non-Hispanic whites to report barriers to cervical cancer screening.⁷⁰

Women residing in rural intermountain regions of California diagnosed with breast cancer and who have mental health illness have been found to have limited access to mental health services.⁷¹ Celaya et al. found that increased travel distance and increasing age was associated with decreased likelihood of receiving breast conserving surgery and radiation therapy among breast cancer patients.⁷² Celaya and colleagues also found that receiving a diagnosis in winter and being unmarried decreased the likelihood of receiving radiation therapy.⁷² Privately insured patients have also been reported to be more likely to receive laparoscopic surgery compared to individuals covered through government programs and uninsured individuals across all races/ethnicity.³² This study also found that patients receiving care in rural hospitals were less likely to have laparoscopic surgery compared to those receiving care in urban hospitals.³² Alnasser et al. also found that individuals receiving care in teaching hospitals were more likely to receive laparoscopic surgery compared to those receiving care in non-teaching hospitals.³²

Access to health care also contributes to the cancer disparities. Markossian et al. report that a unit-increase in per-capita rate of breast cancer care physicians was associated with a 13 percent decrease in the risk of death following a breast cancer diagnosis.³⁴ In their 2007 literature review, Bettencourt et al. reported that challenges experienced by rural breast cancer patients such as increased travel time required to access health care, disruption of family life, and employment impact their psychosocial and psychological problems.²⁶

KNOWN CAUSES OF THE PROBLEM

Although genetic predisposition plays a role in cancer incidence, factors such as poor lifestyle choices^{73,74} and inadequate access to health care services³⁴ have also been found to influence cancer disparities. Lung cancer is a type of cancer that is greatly influenced by life style choices such as smoking. Prevalence of smoking in Kentucky is more than twice that in Utah for both males (29.1 percent vs 10.4 percent) and females (28.0 vs. 9.3 percent).⁷³ Lung cancer incidence and mortality rates exhibit similar trends to smoking prevalence with highest rates in Kentucky and lowest rates in Utah.⁷³ Factors that have been associated with increased prevalence of smoking include not having a high school diploma⁷⁴ and lower tobacco tax.⁷³ The leveling off seen in lung cancer rates among females compared to the decline in males has been attributed to lower smoking cessation rates among women.⁷³ Jemal et al. 2008 found that states with higher smoking prevalence and lower tobacco excise tax had increased lung cancer deaths between 1999 and 2005 among females.⁷³ Other factors that have been found to influence state smoking prevalence include public awareness of the deleterious effects of smoking, acceptable tobacco practices, tobacco control activities, and educational levels of residents.^{73,75}

PROPOSED SOLUTIONS OR INTERVENTIONS

An Alabama study found that tailored counseling calls improved breast cancer screening guidelines adherence among rural African American women.⁷⁶ Thompson and colleagues found that following provision of culturally appropriate education and patient navigation using community health workers, 76.5 percent of women residing in New Mexico border counties who were previously not up-to-date with cervical cancer screening obtained Pap tests.⁷⁷ The use of patient navigators have also been shown to improve colorectal cancer screening rates,⁶⁸ and recruitment and retention of minority and low-income women in clinical trials.⁷⁸ An Iowa study found that mailed education letters and reminder phone calls improved colorectal cancer screening using fecal immunochemical tests (a.k.a. FIT) and colonoscopy among rural family medicine patients.⁷⁹ An Alaskan study found that training a physician assistant and a nurse practitioner increased colorectal cancer screening rates from ten percent to 47 percent.⁶⁸ A Wisconsin study found that awarding grants to health systems who worked with community partners improved access to colorectal cancer screening among underserved populations.⁸⁰

While few studies have examined interventions to improve enrollment into cancer clinical trials among patients within rural communities, there are a set of best practices for engaging communities in research that can be applied toward this effort.⁸¹ Additionally, emergent evidence that the use of patient navigators might help facilitate accrual of disadvantaged populations into clinical trials,⁸² supports prior research on the general value of community health workers in helping underserved populations get access to needed health care.⁸³

A randomized control trial in FQHCs in rural Louisiana with three arms: 1) women who received a recommendation for mammography and were scheduled at facilities in close proximity to their residence; or 2) who received health literacy intervention of videos featuring a) women discussing barriers and facilitators to screening, b) women recommending screening to other women, c) physicians recommending screening and a woman getting screened, and d) a fifth-grade level pamphlet highlighting breast cancer risk factors, benefits of routine screening and explanation of the test; or 3) women who received educational intervention, brief counselling and screening recommendation as well as scheduled and follow up reminder by a nurse including ensuring that they can locate the clinic, found that although screening rates increased among the three arms of intervention, screening rates were highest among the nurse support arm (study arm 3). However, this study pointed out that the cost of implementation might be a challenge in rural areas with limited resources.⁸⁴

Organizing screening events during which fecal occult blood test kits (a.k.a. FOBT) were distributed has also been shown to increase colorectal cancer screening rate with 80 percent of those who received test kits returning them; these screening rates were further improved by follow-up calls and use of incentives.⁸⁰

COMMUNITY MODELS KNOWN TO WORK

Texas Cancer Screening, Training, Education and Prevention

The Texas A&M Cancer Screening, Training, Education and Prevention program (**Texas C-STEP**)⁸⁵ was originally funded by the Texas Cancer Prevention and Research Institute (CPRIT) in 2011 to address barriers to colorectal cancer, and later breast and cervical cancer screening, in the largely rural Brazos Valley of Texas. Concurrently,

the project trains family medicine residents in colonoscopy and women's health procedures. The project enhanced the ability of the Texas A&M Physicians Family Medicine Center, clinical home to a family medicine residency program, to provide accessible, affordable, culturally relevant cancer screening and diagnostic services to uninsured and underinsured area residents.⁸⁵

The Texas C-STEP program has achieved significant success in meeting its original objectives and goals, conducting almost 1300 colonoscopies in its first 42 months, as a result of its education and outreach efforts by state-certified community health workers (a.k.a. promotoras). Individuals who self-reported as African American and Hispanic accounted for 20 percent and 44 percent of CPRIT-funded colonoscopies, respectively. Eighty-three percent of the CPRIT-funded colonoscopy recipients had never been screened before receiving colonoscopy. Perceived barriers to colorectal cancer using colonoscopy were identified by recipients; these barriers were found to exhibit demographic variations.⁸⁶

“Mountain Tops & Bottoms” in Grundy County, Tennessee⁸⁷

Nurse practitioner Darryl Adams initiated “Mountain Tops and Bottoms: A Women's Health Event”⁸⁷ in 2009 following the death of a patient with breast cancer. The 53-year-old woman came to see Adams because she thought she had a breast infection. Adams' examination revealed a large cancerous mass that had metastasized throughout the woman's body. The woman had never done a breast self-examination or had a mammogram. Mountain Tops and Bottoms now attracts 50 to 60 women each year, many of them driving from their sparsely populated mountain homes over rough, narrow roads from as far away as 50 miles. As the enthusiasm spread, other small communities have held their own outreaches, using Adams as their keynote speaker. Core to all events is what Adams calls “my simple and girly Power Point presentation,” which outlines how to access free screenings and why self-care and screenings are so important. The all-female atmosphere also gives Adams an opportunity to explain what women can expect. Some women are uncomfortable thinking a man might be looking at their breasts, others worry that screenings are painful. Once she is able to convince them to have that first screening, Adams said those worries dissipate.

Friend to Friend: Translating an Evidence-Based Program to Rural Texas

Women living in many parts of rural Texas are not meeting recommendations for mammogram or Pap tests. Treatment costs and mortality are often higher for rural and underserved women due, in part, to lack of access to preventive screening which is associated with later diagnosis and poorer survivorship. Friend to Friend⁸⁸ is a research tested, best practice program supported by Texas AgriLife Extension which aims at increasing screening rates for underserved, diverse women living in rural and frontier communities in 40 counties in Texas. Friend to Friend attracted a diverse population of women from rural and frontier areas whose current screening rates are lower than those seen in other Texas communities. It improved knowledge about best practices for mammogram screening although there is still some room for improvement. The majority of women who attended signed commitment cards for future screening. Community events such as Friend to Friend can be utilized to plan, market, and implement evidence-based intervention programs to diverse groups of Texas women living in rural and frontier areas. AgriLife Extension's extensive statewide outreach education system could further aid in partnering with healthcare professionals and obtaining resources for such initiatives. More than 1,000 participants were recruited in the first phase of this project.

Stanford University's Cancer Thriving and Surviving

Cancer survivors often experience late or long-term effects of the disease or its treatment. Examples of these long-term complications include depression, fatigue, pain, impaired physical function, and fear of recurrence.⁸⁹ The Cancer Thriving and Surviving (CTS) program⁹⁰ was developed to enable cancer survivors develop self-management skills that would help them combat these late or long-term effects. The CTS program is a modified version of the Chronic Disease Self-Management Program,⁹¹ an evidence based intervention (Stanford School of Medicine). The program consists of small group workshops. Each workshop lasts for six weeks and each once-a-week session lasts for two and half hours. After going through the program, participants were more likely to report better communication with their physicians and improved energy levels, and less likely to report sleep or stress problems. They were also less likely to report being depressed.

Programs for Cancer Survivors

The care and well-being of the estimated 13 million cancer survivors in the U.S. presents an enormous challenge to public health.⁹² Cancer survivors are at risk for recurrence and second cancers, and are more likely than the general population to experience co-morbid conditions such as cardiovascular disease, diabetes, and osteoporosis than the general population not only due to the late and long-term side effects of cancer and its treatment, but a common set of risk factors. Despite studies identifying physical inactivity and other lifestyle factors as having a negative impact on a wide variety of survivorship outcomes, relatively few cancer survivors meet established recommendations for physical activity, fruit and vegetable consumption, or weight management.⁹³⁻⁹⁶ Cancer survivors, as well as health care professionals, are often unaware of what types of health promotion programs are available for cancer survivors, or how to access them. Working with the Cancer Alliance of Texas, The Texas A&M School of Public Health surveyed organizations in Texas about the availability of psychosocial, physical activity, nutrition, and weight management program services. Results were compiled and displayed in google maps so that persons across the state could identify the location of different services. This type of locator service,⁹⁷ which will be especially helpful to those living in rural areas, is being further developed in a web-based application expanded to consider a variety of programs and services for those with chronic conditions.

SUMMARY AND CONCLUSIONS

Rural and minority populations are at risk for sub-optimal adherence to recommended screening guidelines, and receipt of evidence-based treatment. They are also more likely to receive a late stage cancer diagnosis. These disparities as well as, inadequate access to specialized cancer services, put rural residents at an increased risk for poorer outcomes. Community based models show that targeted and culturally relevant education and interventions could increase cancer awareness and screening rates. These models also show that expanding access to screening for those who cannot afford it also improves screening rates. These findings provide a template for stakeholders and organizations working to reduce cancer disparities. Efforts to identify other strategies that could improve awareness, access, screening rates, and use of evidence-based treatment among rural residents are recommended.

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