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Assessing Patient Barriers to Cancer Screening in Safety-Net Health Systems

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Bachelor of Science
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2014

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An abstract of
A thesis submitted to the Faculty of the
Rollins School of Public Health of Emory University
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Abstract

Assessing Patient Barriers to Cancer Screening in Safety-Net Health Systems

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Objective: We assessed patient needs and resources for colorectal cancer (CRC) and breast cancer screening at nine safety-net health systems that participated in the Community Health Initiatives CHANGE Grant program run by the American Cancer Society. Methods: Fifty-two key informant interviews were conducted by ACS staff during routine site visits to each of the nine safety-net systems in the summer of 2013. Questions were asked about intervention implementation, including successes, challenges, and lessons learned. A team of researchers from ACS and the Emory Preventive Research Center (EPRC) used constructs from the Consolidated Framework for Implementation Research (CFIR) to code transcripts and examine emerging themes using each primary care setting as a case. Segments on patient needs and resources were further analyzed using a constant comparative approach. Results: The needs and resources of patients varied by system and by type of cancer screening. Common patient barriers to screening included cost of services, lack of knowledge, fears of testing and diagnosis, transportation, language differences, and low literacy levels. To address these barriers, health systems made changes to informational materials, provided referrals and partnered with organizations providing free or low-cost services, or employed patient navigators or community health workers to help patients understand and navigate the health system. Conclusions: Patient barriers to accessing and receiving preventive care services arise at all levels of health care delivery, including patient, provider, organizational, and policy levels. CFIR constructs are useful for capturing this information, but changes to construct definitions could improve the data analysis process. By addressing patient barriers, safety-net health systems can play a critical role in improving access to cancer screening for underserved populations, thereby helping to reduce the burden of disease on underserved populations and potentially lowering cancer mortality rates.

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Contents

Chapter 1: Introduction

Cancer is a group of diseases characterized by the uncontrolled growth and spread of abnormal cells (National Cancer Institute, n.d.-b). The uncontrolled growth of cells can be caused by external factors such as tobacco use, infectious organisms, and unhealthy diets, internal factors such as inherited genetic mutations, hormones, and immune conditions, or a combination of internal/external factors. Exposure to such cancer-causing or cancer-triggering factors is not immediate, and sometimes ten or more years can pass between exposure and detectable cancer (National Cancer Institute, n.d.-b).

Cancer is the second-most common cause of death in the United States, exceeded only by heart disease (National Cancer Institute, n.d.-a) and it accounts for almost 1 in 4 deaths among Americans. In 2016, about 1.6 million Americans are expected to be diagnosed with cancer (National Cancer Institute, n.d.-a). Approximately 595,000 Americans are expected to die from cancer in 2016, an average of 1,627 people per day. Progress has been achieved in reducing the cancer burden in the U.S. with declining rates of overall cancer deaths since the 1990s (U.S. Preventive Services Task Force, 2008).

Cancer is also a very expensive disease. The AHRQ estimates that direct medical costs for cancer in the United States in 2011 were $88.7 billion (American Cancer Society Inc., 2015b). Lack of insurance and other barriers may prevent Americans from receiving optimal health care.

Colorectal and breast cancer are two of the most common types of cancers in the United States, and the intervention in this study focused on providing screenings for both types of cancer among various populations.

Colorectal Cancer

Colorectal cancer (CRC) develops in the colon or rectum, also known as the large intestine (Centers for Disease Control and Prevention, n.d.-a). It begins as a noncancerous growth, called a polyp, in the inner lining of the colon or rectum, and it develops slowly over a period of 10 to 20 years. Early CRCs do not cause symptoms, which is why screening is so important. CRC is the third most common type of cancer and the second leading cause of cancer deaths in the United States (Centers for Disease Control and Prevention, n.d.-b; Health Resources and Services Administration; U.S. Preventive Services Task Force, 2008). Approximately 5% (1 in 20) of Americans are affected by it at some point in their lifetime (National Cancer Institute, 2016b). An estimated 136,000 people were diagnosed with CRC in 2012, including 71,000 men and 65,000 women (Centers for Disease Control and Prevention, n.d.-b). For that same year, it is also estimated that there were over 50,000 deaths among Americans due to CRC.

Major modifiable risk factors for CRC include obesity, diabetes, smoking, and high consumption of red/processed meats and alcohol (Centers for Disease Control and Prevention, n.d.-c). Non-modifiable risks include personal or family history of adenomatous polyps or CRC and a personal history of chronic inflammatory bowel disease (Crohn’s or ulcerative colitis).

Breast Cancer

The majority of breast cancers begin in parts of breast tissue made up of glands for milk production, called lobules, and ducts that connect lobules to nipple. Breast cancers which originate in the ducts (ductal carcinomas) are the most common, and they are considered invasive when they spread into lobules or other surrounding tissues

(Centers for Disease Control and Prevention, 2014a). Breast tumors are typically detected first as palpable masses, which most often turn out to be benign. If screening images identify the presence of a tumor, a biopsy is needed to determine a final diagnosis (American Cancer Society Inc., 2015a).

In 2012, there were an estimated 224,000 new cases of invasive breast cancer in women (U.S. Cancer Statistics Working Group, 2015). Approximately 41,000 breast cancer patients died in that same year, making breast cancer the 2nd highest cause of cancer death among women (2015).

A woman living in the United States has a 12.3% (1 in 8) lifetime risk of being diagnosed with breast cancer (American Cancer Society Inc., 2015a). This risk has increased over the past four decades due to longer life expectancy, changes in reproductive patterns, menopausal hormone use, rising prevalence of obesity, and increased detection through screening (American Cancer Society Inc., 2015a).

Importance of Cancer Screening

Cancer screening is important for early detection and prevention. A substantial portion of cancers can be prevented through the use of screening. Cancer screening refers to testing individuals who are asymptomatic for the particular disease, and it is important because early detection reduces mortality by finding cancer early, when tumors or metastases are smallest and there is the best chance for cure (Health Resources and Services Administration; National Cancer Institute, 2015a). Screening has been known to reduce mortality for cancers of the breast, colon, rectum, cervix, and lung (National Cancer Institute, 2016a). Use of screening to detect cancer early provides better opportunities for patients to obtain more effective treatment with fewer side effects

(Health Resources and Services Administration; National Cancer Institute, 2015a). Patients whose cancers are found early and are treated in a timely manner are more likely to survive these cancers than those whose cancers are not found until symptoms appear (Health Resources and Services Administration; National Cancer Institute, 2015a).

The USPSTF makes recommendations about preventive care service for patients without recognized signs or symptoms of the target condition based on systematic reviews of evidence, weighing the benefits and harms of tests, and an assessment of the net benefit of each service (U.S. Preventive Services Task Force, 2008). Clinicians and policymakers need to understand the evidence provided by those who write recommendations, but they should assess each individual patient's condition as a new case and make decisions accordingly (2008).

Colorectal Cancer Screening. CRC is a disease that is largely preventable. If detected early, 65-80% of CRC cases can be prevented through screening and the removal of polyps (American Cancer Society Inc., 2014; Daly, Levy, Moss, & Bay, 2014; Health Resources and Services Administration). Currently, only about 60% of U.S. adults are up-to-date with CRC screening guidelines that are set by the American Cancer Society (ACS) and the USPSTF (National Cancer Institute, 2015b), and less than half of adults are screened at the recommended intervals (Health Resources and Services Administration). Levels of CRC screening lag behind those of other effective cancer screening tests, and it is estimated that an attainment of goals for population CRC screening could save 18,800 lives per year (U.S. Preventive Services Task Force, 2008).

The USPSTF recommends CRC screening for adults beginning at age 50 and continuing until age 75, excluding patients with specific inherited syndromes and inflammatory bowel disease (U.S. Preventive Services Task Force, 2008). For adults who have not previously been screened for CRC, decisions about first-time screening should be made in context of individuals' health status and competing risks (2008).

National guidelines promote any of several tests for CRC screening, using tests that detect occult bleeding and endoscopic tests that visualize all or part of the colon (American Cancer Society Inc., 2014; Daly et al., 2014; U.S. Preventive Services Task Force, 2008). USPSTF recommends screening for CRC through an annual stool test (Fecal Occult Blood Test, FOBT), sigmoidoscopy every five years (combined with a FOBT every 3 years), or colonoscopy every ten years (National Cancer Institute, 2015a; U.S. Preventive Services Task Force, 2008).

Endoscopic tests. Recommended tests to directly visualize colorectal cancer and precancerous polyps are colonoscopy and flexible sigmoidoscopy (U.S. Preventive Services Task Force, 2008). Flexible sigmoidoscopies involve the insertion of a small, lighted tube into the rectum to examine the lower one-third of the colon and can be performed without sedation, but it does not allow for the direct removal of polyps (American Cancer Society Inc., 2014). Like a sigmoidoscopy, a colonoscopy allows for direct visual examination of the colon and rectum. It involves a longer and more complex instrument and usually requires sedation, but it also allows for the immediate removal of polyps. Both procedures require the patient to use laxative agents to cleanse the bowel beforehand. Colonoscopy is the more sensitive test and is considered the "gold standard" of CRC screening (Redwood et al., 2014). Although colonoscopy is considered to be the reference standard against which the sensitivity of other colorectal screening tests are compared, it is not perfect (U.S. Preventive Services Task Force, 2008). There are associated risks with having a colonoscopy, but the risk of harm is very low (2008).

FOBT/FIT. Because many cancerous tumors and polyps bleed intermittently into the intestine, the use of FOBTs, which detect blood in the stool that is not visible and that indicates possible cancer, can be used to detect CRC (Centers for Disease Control and Prevention, 2014b). The guaiac-based fecal occult blood test and the fecal immunochemical test (FIT) are obtained by patients from health providers for use at home (Daly et al., 2014). After collecting stool samples for the test, patients return the kit to their provider or laboratory for evaluation. Patients with positive results are referred for colonoscopy to rule out the presence of polyps or cancer. The FIT is typically preferred because it requires the patient to provide fewer samples and does not require dietary restrictions in preparation of testing. FOBTs are much less expensive compared with colonoscopy and are often preferred by patients. In many safety-net settings, FOBTs are the primary option for patients because of their lower cost as well as limited availability of colonoscopy (Daly et al., 2014). An undeniable benefit of less invasive screening tests is that they may reduce the number of colonoscopies required by patients, thereby lowering the risks associated with invasive screening methods (U.S. Preventive Services Task Force, 2008).

There is emerging evidence which suggests that offering patients a choice between the traditional colonoscopy and an at-home FOBT or FIT could increase overall rates of compliance with screening recommendations (Sarfaty et al., 2013). A study published by Inadomi et al. found that offering patients the ability to choose between the two screening types significantly increased screening rates among racial/ethnic minorities and non-English-speaking patients (Inadomi et al., 2012). Findings such as this suggest the need for further exploration of practice changes which could increase screening rates and improve access by reducing costs and structural barriers.

Breast Cancer Screening. Breast cancer does not typically produce symptoms when tumors are small and most easily treated (American Cancer Society Inc., 2015a; Centers for Disease Control and Prevention, 2014c). This makes screening very important for detection and early treatment. Breast cancer is typically detected either during a screening exam—before there are symptoms—or after a woman notices a lump. Early detection of breast cancer by mammography can lead to a greater range of treatment options, including less-extensive surgery and the use of chemotherapy (American Cancer Society Inc., 2015a).

Screening recommendations vary based on the age and risk of each individual patient (American Cancer Society Inc., 2015a). USPSTF recommends that women aged 45-74 receive a mammography at least once every 2 years and continue screening as long as their overall health is good and they have a life expectancy of 10 years or more (National Cancer Institute, 2015a).

Mammography. Mammography screening involves a low-dose x-ray procedure that produces a visualization of the internal structure of the breast to look for disease in women who do not have symptoms (American Cancer Society Inc., 2015a). It allows for early detection of breast cancer, helping to increase survival, especially for women 50-69 (National Cancer Institute, 2015a). However, just like any other screening test, mammography is not perfect, and it is not uncommon for tests to produce false positives and create an unnecessary sense of fear or worry (American Cancer Society Inc., 2015a).

Despite any limitations, mammography is still the single most effective method of early detection because it can identify cancer several years before symptoms develop.

Despite a full body of research on why breast cancer screening is critical, many women continue to go unscreened. According to the National Health Interview Survey in 2013, the percentage of women 50 years of age or older who reported having a mammogram within the past two years was only 72% (National Cancer Institute, 2015b).

All screening tests are merely tools, and the most important step is their acutal use by patients. Further research into systems approaches to promoting the use of CRC screening could have a large impact on increasing the use of the tools that are available (U.S. Preventive Services Task Force, 2008). Eliciting patient preferences is one step in improving adherence (2008). Ideally, shared decision making between clinicians and patients would incorporate information on local test availability and quality as well as patient preference (2008).

Disparities in Cancer Burden and Access to Screening

In the United States, various sub-populations are disproportionately affected by cancer and experience unique barriers to accessing cancer screening services. Namely, racial/ethnic minorities and disadvantaged groups such as low-income, undereducated, low-literacy, and uninsured populations suffer the most from these disparities. Below is a brief description of the disparities experienced by two racial/ethnic groups (African-American and Hispanic) that were the focus of safety-net settings that participated in this study. This is followed by a brief description of the disparities faced by other disadvantaged populations, including low-income, uninsured, and undereducated groups.

Racial and Ethnic Minorities. Analyses of the cancer rates among racial and ethnic populations shows that cancer disproportionately affects minority groups. The reason why different types of cancer affect some ethnic minorities more than others is unknown, but researchers hypothesize that differences in geographic location, income, and educational background might be associated (National Cancer Institute, n.d.-a).

African Americans. African Americans account for about 13% of the total population in the United States, according to the U.S. Census Bureau (Rastogi & U.S. Bureau of the Census, 2011), and they have the highest death rate and shortest survival of any racial and ethnic group for most cancers (American Cancer Society Inc., 2013). Compared to non-Hispanic whites, the death rate from cancers among African Americans is 29% higher in men and 14% higher in women (American Cancer Society Inc., 2015b). For 2007-2011, African American men had the highest cancer death rate (269.3 per 100,000 men) of any racial or ethnic group (Kohler et al., 2015).

CRC incidence and mortality rates show health disparities with a disproportionate burden occurring in certain minority populations, including African Americans (American Cancer Society Inc., 2014; U.S. Preventive Services Task Force, 2008). Decline in breast cancer incidence has stabilized among white women, while rates continue to increase among black women (Kohler et al., 2015). The increase for black women may be partially because of increased mammography screening among black women, although latest data show mammography rates have been fairly constant (2015).

The reasons why cancer affects African Americans disproportionately are unknown. Some of these disparities may be due to hormonal factors that are related to cancer pathogenesis (Kohler et al., 2015). However, there are other important differentiating social risk factors that contribute to this disparity, including variation in screening access and use, behavioral and environmental exposure patterns (2015). For example, people without health insurance and those with Medicaid are more likely to be diagnosed with advanced cancers. These factors disproportionately affect African Americans because 20% of African Americans are uninsured, compared to only 11% of whites, and 25% of African Americans live below the poverty threshold, compared to 10% of whites (Kaiser Family Foundation, 2016).

Hispanics. Hispanics account for more than 17% of the total population in the United States, making them the largest racial/ethnic minority group (Dominguez et al., 2015). They are also the youngest minority in the United States, with the average age being almost 15 years younger than whites. Early cancer screening interventions targeted at this minority group could have a significant impact by preventing chronic diseases that manifest later in life (2015).

Over one-third (35%) of Hispanics living in the U.S. are foreign born (American Cancer Society Inc., 2015c). It is important to note that collecting and reporting health statistics is challenging for Hispanic populations because they are typically reported as an aggregate group, which does not account for differences in degree of acculturation or country of origin (2015c). It is also important to note the differences between groups of Hispanic origin because public health programs that are tailored to them will need to be sensitive to cultural and linguistic differences.

Within an average lifetime, one in three Hispanic men and women will be diagnosed with cancer (American Cancer Society Inc., 2015c). About 22% of deaths among Hispanics are due to cancer, which ties cancer with cardiovascular disease as the leading cause of death among Hispanics (Dominguez et al., 2015). Rates of cancer screening among Hispanics fall far below the rates of whites. Hispanics are 28% less likely to get screened for CRC than whites, and are less likely to be aware of the importance of CRC screening (2015). For Hispanic women, screenings for breast and cervical cancer are 7% lower than whites. This is an important disparity because breast cancer accounts for 16% of cancer deaths among Hispanic women, making it the most common cancer death for Hispanic women, followed by lung and colorectal cancers (American Cancer Society Inc., 2015c).

Genetics, environment, and medical history all influence cancer screening rates for Hispanic men and women, but there are many socioeconomic factors that play an important role as well. Chief among these are income (including access to health insurance), education, and cultural factors related to language, beliefs, values, and traditions (American Cancer Society Inc., 2015c). Across all age groups and self-reported countries of origin, Hispanics are 20 times less likely to speak English proficiently than whites (Dominguez et al., 2015). Language differences serve as an obstacle in school, work, and health care settings. Hispanics are four times more likely than whites to not have completed high school (Dominguez et al., 2015). In 2013, more than one-third (35%) of Hispanics living in the U.S. did not have a high school diploma or equivalent (American Cancer Society Inc., 2015c). Many Hispanics work low-wage jobs in the agriculture, construction, and food service industries, making them twice as likely to live below the poverty line (Dominguez et al., 2015). These occupations rarely provide health insurance benefits, which creates another disparity for this population. Approximately 41% of Hispanics lack access to health insurance and/or a usual source of care, and over

15% report delaying medical care as a result of cost concerns (2015). This impedes access to preventive services such as cancer screenings. With the rollout of the ACA, the number of uninsured Hispanics in the U.S. has greatly declined, but there is a large population of undocumented Hispanic immigrants who are still unable to benefit from it.

Disadvantaged Populations. Research shows that cancer screening rates are particularly low among sub-populations of Americans who are underinsured or uninsured, low-income, undereducated, low-literacy, or non-English-speaking (Almufleh et al., 2015; Ross, Bernheim, Bradley, Teng, & Gallo, 2007). The high cost of screening services is a barrier for many patients who lack health insurance. Research has shown that regardless of racial or ethnic status, people without insurance have much lower CRC screening rates (15-29%) compared to the insured (45-60%) (American Cancer Society Inc., 2014). Patients with literacy or language barriers are also less likely to receive screening services, especially for CRC screening which involves understanding complex instructions for screening preparation and at-home testing through FOBTs and FITs (Arnold et al., 2012; Carcaise-Edinboro & Bradley, 2008; Gwede et al., 2015). A sub-population of interest includes recent immigrants, who are significantly less likely to receive CRC and breast cancer screening (Adams, Choi, Eberth, et al., 2015; American Cancer Society Inc., 2014).

There are many reasons for these low screening rates, including patient access barriers, limitations of facilities, and inadequate communication from providers on the importance of screening (Almufleh et al., 2015; Carcaise-Edinboro & Bradley, 2008). Clinicians and health systems can play a major role in increasing utilization and quality of screening for cancer by understanding patient barriers to care and implementing patient-level initiatives to address these barriers within the communities they serve.

Safety-Net Health Systems

Safety-net clinics are designed to meet the needs of people in poor, underserved communities by providing primary care services, regardless of patients' abilities to pay (Katz, Felland, Hill, & Stark, 2011). The most common types of safety-net systems are Federally Qualified Health Centers (FQHCs), FQHC look-alikes (which are similarly structured but are not officially accredited as FQHCs), and Patient Centered Medical Homes (PCMHs), all of which have gained much publicity in recent years after the passing of the Patient Protection and Affordable Care Act in 2010.

Research has demonstrated the essential impact of primary care on improving access to care, narrowing disparities, and improving patient outcomes (Shi, Chen, Nie, Zhu, & Hu, 2014). Studies have shown that the availability of safety-net health systems improves access to medical care for vulnerable populations by helping to eliminate racial/ethnic and SES disparities in access to care and quality of care (Adams, Choi, Eberth, et al., 2015; Adams, Choi, Khang, et al., 2015; Emmons et al., 2011; Shi, Tsai, Higgins, & Lebrun, 2009). Nearly two-thirds of patients in FQHCs are ethnic minorities, low income, and uninsured, living in either underserved rural or urban areas (Adams, Choi, Eberth, et al., 2015; Adams, Choi, Khang, et al., 2015).

There is a large, growing body of literature on how safety-net systems meet the quality, access, and cost barriers of their patients. Previous literature has examined the types of barriers experienced by patients in FQHCs, and there is a small, growing body of literature on how FQHCs and PCMHs in particular are trying to focus on cancer screening for underserved patients (Shi et al., 2014). Despite advances in prevention, screening, diagnosis, and treatment of cancer, disparities by race/ethnicity and socioeconomic status remain due to a variety of patient- and system-level barriers (Krok-Schoen et al., 2015). It is important to understand the causes of barriers that patients experience when trying to access cancer screenings, how they affect screening rates, and how safety-net health systems can help patients to overcome these barriers.

The Consolidated Framework For Implementation Research

Throughout the past several decades, social scientists have begun to emphasize the importance of interactions between dimensions of health care intervention content, context, and the process of implementation (Damschroder et al., 2009). Influences on implementation come from many levels, from external influences to organizational processes and to key individuals who drive intervention success, and these must all be examined together in order to identify and understand important relationships (2009).

The Consolidated Framework for Implementation Research (CFIR) was developed in 2009 as a framework that “offers an overarching typology to promote implementation theory development and verification about what works where and why across multiple contexts” (Damschroder et al., 2009, para. 1). The goal of its development was to consolidate common constructs from published implementation theories and develop a theoretical framework that makes use of the meaningful contributions from a breadth of existing research related to implementation science.

Barriers to implementation arise at all levels of health care delivery, including patient, provider, team, organizational, and policy levels (Damschroder et al., 2009). It is important for researchers to understand this in order to evaluate intervention implementation effectiveness, sustainability, and the dissemination of findings (Damschroder et al., 2009; Robins et al., 2013).

The Outer Setting domain of CFIR contains the construct “Patient Needs and Resources.” This construct describes “the extent to which patient needs, as well as barriers and facilitators to meet those needs, are accurately known and prioritized by the organization” (Damschroder et al., 2009). The current study used data coded with this construct to examine how safety-net systems identified patient barriers to cancer screening, which barriers were identified by clinic staff, and how systems strategized to help patients overcome such barriers. Systems were part of the American Cancer Society’s Community Health Initiatives (CHI) CHANGE Grants Program, which funded safety-net health systems to use evidence-based approaches to cancer screening.

Research Question

This study aims to examine patient barriers to cancer screening that were identified in safety-net health systems participating in the American Cancer Society’s Community Health Initiatives CHANGE grant program. Specifically, we hope to understand which barriers were identified by clinic staff and how systems strategized to help patients overcome such barriers.

Chapter 2: Literature Review

Patient Barriers to Cancer Screening Services

Despite advances in prevention, screening, diagnosis, and treatment of cancer, disparities by race/ethnicity and socioeconomic status remain due to a variety of patient- and system-level barriers. Patient barriers to care are any obstacles which patients must overcome in order to access and receive care. Barriers can be tangible (e.g. lack of transportation to get to clinic) or intangible (e.g. fear of going to the doctor's office). Barriers that prevent patients from accessing cancer screenings can differ based on the individual patient, physical setting, or type of screening. The health care field is changing quickly and dramatically, especially with the passing of the Affordable Care Act and the expansion of Medicaid (Choi et al., 2015). These changes are meant to increase access for those who face barriers to care, but not all people are able to access services with equal levels of ease yet, and barriers still exist for many people. Avoiding or delaying screenings can result in more advanced stage at diagnosis, lower survival rates, and higher death rates for populations who have historically been underserved by the medical system (Health Resources and Services Administration; National Cancer Institute, 2015a). Understanding patients' experiences with different types of barriers to preventive care will help health care service organizations work to overcome them.

Organizational and policy-level changes can be made in order to overcome patient barriers to care, such as burdensome amounts of paperwork, lack of availability of services, and increased funding for special populations who cannot afford high out-of-pocket costs (Palmer, Samson, Batra, Triantis, & Mullan, 2011). Allowing patients to speak for themselves can help clinical organizations identify the most pressing barriers and barriers that are not always observable from an outsider's point of view (Ragas et al., 2014). Continuing to develop an understanding of barriers and monitoring these differences has the potential to impact social, geographic, and racial disparities, which will be important as preventive services become more widely available throughout the country (Choi et al., 2015).

Recent trends in patient-centeredness have prompted new studies on barriers that prevent patients from accessing colorectal and breast cancer screenings. Studies generally examine either barriers to a type of screening test (i.e. mammogram, colonoscopy) or they examine barriers based on the level at which they occur (i.e. individual, organization, or community level) (Krok-Schoen et al., 2015; Palmer et al., 2011). Below is a discussion of existing literature on patient-level barriers to cancer screenings based on type of cancer, either colorectal or breast, as well as a discussion of the barriers faced by different disadvantaged populations.

Barriers to Colorectal Cancer Screening

Barriers to CRC screening exist on patient- and system-levels, as well as across the continuum of care from outreach to follow-up. Studies show that many patients are unaware of opportunities for CRC screening (McLachlan, Clements, & Austoker, 2012), especially patients with low literacy levels (Arnold et al., 2012). Many patients are also unaware of the importance of CRC screening (Gwede et al., 2015), and this lack of awareness contributes to low cancer screening rates across the country in all types of health settings. Studies examining patient-provider interactions have found that patients who receive inadequate education and explanations of CRC screening from providers are less likely to be screened for CRC (Carcaise-Edinboro & Bradley, 2008; Gwede et al., 2015). Kimura and colleagues found that provider recommendations and increased patient knowledge of CRC and CRC screening act as major facilitators for CRC screening (Kimura, Sin, Spigner, Tran, & Tu, 2014), highlighting the importance of the provider’s role in patient engagement and education.

In 2012, McLachlan et al. conducted a systematic review of literature on patient barriers to CRC screening (McLachlan et al., 2012). They analyzed 47 studies which addressed patient-reported barriers to an anticipated primary colonoscopy (as opposed to colonoscopies used as follow-up to abnormal screening results). The most significant barrier identified by patients across all studies was the laxative bowel prep (2012). The preparation for colonoscopy is generally perceived by patients as complicated, time-consuming, and embarrassing, and there are concerns over the pre-test fasting requirement and diet restrictions related to prep (Gwede et al., 2015; McLachlan et al., 2012). Existing literature points to other procedure-related barriers including fear of pain, sedation, perforation, bleeding, and vulnerability associated with colonoscopies (Gwede et al., 2015; Kimura et al., 2014; McLachlan et al., 2012). There were major concerns over the fear of finding cancer as well (Gwede et al., 2013; Gwede et al., 2015; McLachlan et al., 2012). Providers should be aware of this concern and be prepared to address patient fears during clinical encounters.

Perceived system-level barriers to CRC screening include difficulties with transportation and scheduling appointments (Darsie, Rico, Gadgil, & Tootoo, 2015; McLachlan et al., 2012), as well as financial cost and access (McLachlan et al., 2012). The high cost of colonoscopy is a barrier to CRC screening for many patients (Coronado, Petrik, et al., 2015; Gwede et al., 2015). Associated costs include cost of screening, follow-up care, and hiring specialists to perform exams.

As a way to alleviate these concerns, providers can offer at-home screening tests to patients, including the FOBT and FIT. These tests reduce many patient barriers by offering a faster, less-invasive way to screen for CRC (McLachlan et al., 2012). Because of the high costs associated with colonoscopies, many patients who are uninsured or insured through public insurance rely on at-home screening tests like FOBTs and FITs because they are more affordable (Carcaise-Edinboro & Bradley, 2008; Gwede et al., 2013). This suggests that the FOBT could play an important role in increasing screening rates across SES groups because it is both lower-cost and less invasive than other screening options (Carcaise-Edinboro & Bradley, 2008).

Though at-home testing is a promising way to raise screening rates for those with significant access barriers, there are still barriers associated with at-home tests which cause concern. In 2015, Coronado et al. conducted interviews with English- and Spanish-speaking patients to explore reasons for not returning FIT kits in the mail. Reasons included cost of a follow-up colonoscopy, not having received the test in the mail, concerns about mailing fecal matter, and being too busy or forgetful (Coronado, Schneider, Sanchez, Petrik, & Green, 2015). To overcome this obstacle, one study demonstrated how providing clinical outreach to patients can increase the likelihood that patients will complete and return FIT kits (Goldman et al., 2015). This makes evident the various important roles that clinical settings can play in providing patient cancer screenings, from outreach and education to testing and follow-up. More research needs to be done to examine other barriers to screening through at-home CRC screening tests.

Literacy as a barrier to CRC screening. Literacy has been identified as one of the most important patient barriers to receiving CRC screening (McLachlan et al., 2012). Smith et al. conducted a study on how literacy affects a patient's ability to understand colonoscopy prep instructions (Smith et al., 2012). They gave a colonoscopy prep pamphlet to patients from FQHCs in Chicago. When they assessed patients' literacy levels at the beginning of the study, they found that most (71%) patients were deemed to be at an adequate literacy level. At the conclusion of the study, they found that comprehension scores for bowel prep were very low (3.2 out of 5). This was especially true for participants with low-literacy levels but included those with adequate reading levels as well. Socio-economic factors (e.g. education, income) were also associated with comprehension, but the authors concluded that literacy was by far the most important factor associated with comprehension.

The effects of patients' literacy levels on the ability to complete at-home CRC screening tests have been examined in few studies. A study by Arnold et al. found that level of literacy is a factor in a patient's CRC knowledge, beliefs, and confidence in obtaining an FOBT (Arnold et al., 2012). They found that low-literacy patients had more perceived barriers to FOBT completion, were less confident in their ability to obtain an FOBT, and agreed that FOBTs were confusing, embarrassing, and too much trouble (2012). Coronado determined that literacy was also a major patient barrier to completing FIT kits for CRC screening (Coronado et al., 2014). They found that patients preferred wordless instructions for completing at-home screening tests, such as those which utilized visuals and pictures, instead of those that included lengthy text descriptions.

Barriers to Breast Cancer Screening

Breast cancer is the second leading cause of cancer-related death among American women (Centers for Disease Control and Prevention, 2014c). National efforts to reduce mortality have emphasized early detection through mammography, but rates of screening remain low, especially among disadvantaged populations (Davis et al., 2012; Nguyen, Tran, Kagawa-Singer, & Foo, 2011; Nonzee et al., 2015). Identifying barriers to breast cancer screening is important. Past studies have shown that women who experience more barriers to accessing mammograms perceive less benefit from being screened and are therefore are less likely to seek screening services (Hatcher-Keller, Rayens, Dignan, Schoenberg, & Allison, 2014). Narrowing disparities and increasing screening rates requires an in-depth understanding of the factors that influence women's access to care and decisions to seek and/or follow-through with care.

Studies have been done to examine patient barriers to mammography, but there is a need for more literature on the subject. In particular, there has been much research done on perceived patient barriers from the provider perspective, but more studies on barriers perceived from the patient perspective could add to knowledge about what barriers exist and how patients feel they are affected by them, especially given recent economic changes and revisions to insurance coverage plans. Nonzee et al. interviewed providers in safety-net settings and identified lack of awareness and limited knowledge about cancer screening, denial or fear, competing priorities (e.g. child care), language, cultural beliefs, low educational attainment, poor health literacy, and embarrassment as barriers to receiving breast cancer screening (Nonzee et al., 2015). Some participants in the study emphasized that many patients who were motivated to get a mammography were deterred by lack of understanding the clinical processes and financial resources available to facilitate screening. This highlights the importance of clinical education and the need for interventions which help clinical staff guide patients around personal-level barriers. Palmer et al. also studied patient barriers from the provider perspective, focusing on racial and ethnically diverse, uninsured, and low-income women (Palmer et al., 2011). They identified high out-of-pocket costs, burdensome amounts of patient paperwork, and lack of care coordination as major barriers to breast cancer screening. In their discussion, they emphasized that it is critical for clinical organizations to understand such barriers faced by patients in order to plan interventions which can help them overcome such obstacles.

Women in rural areas face unique barriers to accessing mammography services. In 2012, Davis et al. did a qualitative study and interviewed women who were past due for mammograms in order to assess patient knowledge, beliefs, barriers, and experiences (Davis et al., 2012). In general, they found that many participants were unclear about when they should begin routine mammography, and as a result, did not seek screening. Specifically, for rural participants there were fewer reported barriers to mammography, and among these patients, positive beliefs, high self-efficacy, and more physician recommendations were reported. However, screening rates were lower for rural participants, and more research is needed to explore why this could be the case.

To add to literature on breast cancer screening from the patient perspective, Ragas et al. interviewed women who had received abnormal breast screening results and asked about perceived barriers and recommendations for improving care (Ragas et al., 2014). In their study, participants who had access to free or low-cost screening and diagnostic services discussed how costs and insurance barriers were still difficult to overcome. Additionally, a shortage of linguistically and culturally diverse providers was identified as a barrier to both screening and follow-up. Women in the study recommended that community-based health education focus on revising health messages, forming partnerships, and increasing patient engagement as ways to build capacity to overcome such barriers.

Facilitators to breast cancer screening identified in the literature include identification of abnormalities (e.g. “finding a lump”), provider-initiated actions, and motivation from family or friends (Nonzee et al., 2015; Ragas et al., 2014). The presence of cancer screening facilities, short traveling distance and commute time to the facility, the neighborhood characteristics of the facility, and the availability of public transportation are all factors that can positively influence a women’s intention to be screened for breast cancer (Adams, Choi, Eberth, et al., 2015; Nguyen et al., 2011). Additionally, access to patient navigators has been shown to break access barriers commonly experienced by low-income, non-English-speaking, and immigrant women (Nguyen et al., 2011). More information is needed on how to tailor breast cancer screening interventions to meet the needs of these populations. With the emergence of new health care reform provisions that target financial barriers, more attention should be paid to non-financial barriers to care for women in need of breast cancer screenings.

Barriers to Cancer Screening for Disadvantaged Populations

Barriers for Minorities. Despite efforts to improve access in recent years, screening is suboptimal and disparate among minority groups (Carcaise-Edinboro & Bradley, 2008). Studies show that racial and ethnic minority patients are more likely to delay or miss follow-up appointments (Krok-Schoen et al., 2015; Nguyen et al., 2011). Reasons for delaying or avoiding care differ among groups based on ethnicity and race, and are often linked to socio-economic differences such as educational background, income, and insurance status.

Literature suggests that the channels of communication used to relay messages about CRC screening often differ among minority populations, and they have an important effect on patients' screening rates, particularly for men. It has been demonstrated that improving communication between providers and minority patients can reduce CRC screening disparities for racial and ethnic minorities, who are screened less often than non-Hispanic whites (Carcaise-Edinboro & Bradley, 2008). One study identified that African American and Hispanic men receive health care messages about CRC screening through different communication channels than white men, typically through television and radio (Powe et al., 2009). A study done later added to the implications of this finding when it discovered that Latino patients receiving outreach from safety-net clinics were significantly more likely to complete FIT kits than others (Goldman et al., 2015). These studies suggest that providers within safety-net systems provide culturally and educationally appropriate intervention techniques in order to reach minority patients.

There are important disparities to note for low-income and immigrant women, who often lack information (e.g. knowing pertinent medical information and how to navigate health system), logistics (transportation, interpretation), and affective interpersonal skills (understanding the language of providers, trust in providers) that are needed to access services such as breast cancer screening (Nguyen et al., 2011). A survey assessing women's perceived risk, benefits, and barriers to mammography found that women who experienced more barriers to mammography services also perceived less benefit from being screened for breast cancer (Hatcher-Keller et al., 2014). This was particularly true for African American women. This highlights the importance of addressing the barriers experienced by patients, as well as providing adequate education on the importance of cancer screening, in an effort to increase screening rates.

Insurance and low socio-economic status. Studies have shown that the inability to afford costs of health care services is one of the greatest factors associated with safety-net underutilization and underutilization of cancer screenings (Almufleh et al., 2015; Ross et al., 2007). There is high cost burden on uninsured patients, which contributes to non-adherence with cancer screenings. One study examining time-to-resolution for patients with abnormal CRC screening results in FQHCs found that in addition to having a college education and higher income, insurance status had a major influence on how quickly patients were able to access follow-up testing services (Krok-Schoen et al., 2015). For patients with positive test results, there is often limited funding to assist with the payment of follow-up testing. This contributes to underscreening, especially for CRC. Combined with a lack of access to specialists to perform such follow-up tests, authors have found that the burden on patients can be so great for CRC screening that even insured patients are often non-adherent with testing guidelines (Coronado, Petrik, et al., 2015).

In recent years, Medicaid coverage has been expanded in many parts of the country, providing access to health services for millions of people. However, gaps in coverage for many people still remain. Choi et al. studied patient barriers to colorectal, cervical, and breast cancer screening in states that did not expand Medicaid coverage (Choi et al., 2015). They found that patients living in states without Medicaid expansion had lower cancer screening rates, especially among patients in safety-net settings.

Low-Literacy and Language. Literature shows that low literacy levels and low English proficiency serve as common barriers to accessing and understanding cancer screenings, particularly for CRC screening, which requires patients to understanding complex instructions for at-home testing for FIT kits or bowel preparation before colonoscopies (Arnold et al., 2012; Carcaise-Edinboro & Bradley, 2008; Gwede et al., 2015). Educational materials or testing instructions that include medical terminology can be hard for patients to understand, even if they are proficient English speakers (Kimura et al., 2014). Gwede et al. found that educational materials in plain language toward a low-literacy population and in a variety of languages beyond English (e.g. Spanish) could be a major help to CRC promotion (Gwede et al., 2013).

McCarthy et al. studied literacy and recall of health care instructions among patients 55 years of age and older (McCarthy et al., 2012). After giving verbal care instructions to patients, they found that within fifteen minutes, most patients could only recall up to half of the care instructions that had been given to them. This was regardless of literacy level, though those patients with lower literacy levels had lower rates of recall over time. A similar study examined comprehension scores for bowel prep instructions among older individuals (Smith et al., 2012). Their study also found that literacy was a significant predictor of comprehension levels, with low-literacy patients experiencing more barriers to understanding.

The authors of these studies described providers’ obligations to understand literacy barriers for patients in order to provide the best care possible, including spending more time explaining pertinent health information face-to-face with patients and providing comprehensive written instructions that are appropriate for all literacy levels. Findings suggests that literacy barriers can be addressed by providing appropriate materials to low-literacy or non-English-speaking populations (Coronado et al., 2014; Gwede et al., 2015). The authors also suggested that taking literacy barriers into account could help raise screening rates among disparate populations.

Previous research has identified several patient-level barriers that impact cancer screening rates among disadvantaged populations, but there is still a need for further in-depth research on the subject, particularly in safety-net settings (Gwede et al., 2015; Shi et al., 2014). In addition to the barriers previously discussed, patients can experience barriers including poor knowledge about screening, fear of cancer diagnosis, lack of motivation, embarrassment, inadequate transportation, and poor availability of screening facilities (Allen et al., 2014; Davis et al., 2012; Gwede et al., 2013; Gwede et al., 2015). Narrowing these disparities requires an in-depth understanding of the factors that influence patient access to care and decisions to seek and/or follow-through with care (Krok-Schoen et al., 2015; Nonzee et al., 2015).

Innovations for Improving Access to Cancer Screenings

Studies are actively being done on innovations that could allow safety-net systems to overcome barriers for patients lacking access to cancer screening services. Patient navigators have emerged as one such promising innovation for helping non-English-speaking patients overcome cultural, religious, and language barriers to both CRC and breast cancer screenings (Honeycutt et al., 2013; Lasser et al., 2011; Nguyen et al., 2011). They do so by coordinating interpretation services, providing culturally-competent care, and helping patients build trust in providers. One study demonstrated that they were particularly effective at breaking access barriers commonly experienced by low-income, non-English-speaking, and immigrant women (Nguyen et al., 2011). For non-English-speaking patients, navigation has increased the likelihood of undergoing CRC screening and to be screened by colonoscopy (Lasser et al., 2011).

Some literature points to outreach efforts within safety-net systems' communities as a potential way of engaging and educating patients to increase cancer screening rates (Goldman et al., 2015; Honeycutt et al., 2013). To overcome access barriers, one study demonstrated that providing clinical outreach to patients increases the likelihood that patients will complete and return FIT kits (Goldman et al., 2015), and another study demonstrated that outreach is effective at engaging low-income adults in rural settings for preventive health screenings (Honeycutt et al., 2013).

The Guide to Community Preventive Services (Community Guide), created by the non-federal Community Preventive Services Task Force, has conducted systematic reviews on the effectiveness of various interventions to increase breast, cervical, and colorectal cancer screenings (Community Preventive Services Task Force, 2013). Recommended client-level interventions for improving access and quality of breast and colorectal cancer screening services include client reminders, one-on-one education, group education (for breast cancer), small media, reduction of client costs, and reduction of structural barriers. They have found sufficient evidence that these types of interventions can increase community demand for screening services. They advocate for continued research on how such interventions can be implemented in various settings and among different populations, and they advise that health systems seeking to improve cancer screening rates select interventions based on local populations, needs, barriers, and available resources.

Role of Safety-Net Systems in Addressing Patient Barriers to Screening

Since the 1990s, the number of uninsured Americans has grown more rapidly than the general population, and the willingness of private physicians to provide charity care has greatly declined (Katz et al., 2011). Safety-net clinics fill this gap in care by serving poor, uninsured, and publicly insured (e.g. Medicaid) populations regardless of a patient's ability to pay (Jones & Sajid, 2009). They also reach large numbers of homeless, low-income, and immigrant patients. Existing literature demonstrates that geographic proximity to a safety-net clinic such as an FQHC improves access for uninsured and underserved populations (Richards, Saloner, Kenney, Rhodes, & Polsky, 2014) and decreases preventable hospitalizations, especially for Medicare and Medicaid beneficiaries (Wright, Potter, & Trivedi, 2015).

Safety-net clinics' ability to provide coordinated, comprehensive primary care and support services in an efficient manner is particularly important to people with complex medical and social needs (Jones & Sajid, 2009). They are typically community-based organizations, run by providers from hospitals, community groups, or local governments (Agency for Healthcare Research and Quality, 2013). Their strategies for helping uninsured people enroll in public insurance could be helpful to state outreach efforts, and their experience in providing culturally-competent care and coordinating multi-disciplinary services could be useful to private medical groups (Katz et al., 2011).

In recent years, safety-net systems have faced increasing financial pressures due to rising cost of health care services, shortages of providers who accept Medicaid reimbursement, and facility closures (Jones & Sajid, 2009). Resources are also becoming constrained as demand for services increases, especially since the economic recession. These pressures and demands have called safety-net clinics to develop new innovations for increasing access and lowering cost of care for the disadvantaged communities they serve.

Cancer disproportionately affects many of the underserved populations that safety-net clinics target and treat (Agency for Healthcare Research and Quality, 2013). To help reduce these disparities, safety-net clinics provide many preventive care services, including screenings for breast and colorectal cancers. These screening services are provided directly to patients or through referrals to other clinics or health service providers. Safety-nets differ on what types of funding they receive and what types of cancer screenings they are able to offer. Some forms of CRC screening are available in most safety-net clinics (e.g. FOBT) but other forms are not (e.g. colonoscopy). Expansion of services provided at such clinics in the future could help to reduce cancer disparities in the United States (Adams, Choi, Eberth, et al., 2015; Adams, Choi, Khang, et al., 2015).

The underserved populations that FQHCs are designed to reach present many unique access challenges to accessing preventive care like cancer screenings, including transportation, language, literacy, and lack of insurance (Agency for Healthcare Research and Quality, 2013). It is critical that these disadvantaged populations receive screening services because underuse of cancer screening is frequently associated with higher latestage cancer rates and mortality. To enhance cancer screenings, health systems must understand the barriers, needs, and available resources of their target populations.

Federally Qualified Health Centers

One type of safety-net system that has gained much attention in the past few decades is the Federally Qualified Health Center (FQHC). The original designers of FQHCs were physicians who wanted to meet the needs of people in poor communities by providing primary care services regardless of patients' ability to pay (Katz et al., 2011). By design, the centers were not just meant to provide medical care to individuals, but they also strived to improve the overall health of the community.

The numbers of FQHCs and patients who visit FQHCs have increased exponentially in the past decade (Adams, Choi, Khang, et al., 2015; Katz et al., 2011; Richards et al., 2014). From 1996 to 2010, federal funding for FQHCs increased from $750 million to $2.2 billion, helping to increase the number of FQHCs from 700 to 1,200 systems (Katz et al., 2011; Wright & Nice, 2015).

The majority of FQHCs are private non-profit or publicly-owned community health centers that accept all patients regardless of ability to pay (Ko, Cummings, & Ponce, 2015; Rothkopf, Brookler, Wadhwa, & Sajovetz, 2011). FQHCs mainly serve patients whose income is below 200% of the federal poverty level and who are uninsured or covered by Medicaid and other public programs (Allen et al., 2014; Katz et al., 2011; Richards et al., 2014). In 2012, FQHCs served 21 million patients, of whom 36% were uninsured and 92% were living below the 200% poverty level (Adams, Choi, Eberth, et al., 2015; Adams, Choi, Khang, et al., 2015; Daly et al., 2014). Specific to FQHCs, system-level barriers to cancer prevention include competing priorities, inadequate patient insurance, and lack of reimbursement (Allen et al., 2014).

FQHCs receive funding from HRSA (Adams, Choi, Khang, et al., 2015; Allen et al., 2014). HRSA requires them to report specific outcomes in their Uniform Data System (UDS) to maintain funding (Allen et al., 2014), including CRC screening rates (Health Resources and Services Administration). Approximately 1,198 FQHCs receive operating grants from the Public Health Service Act and thus qualify for reimbursement from Medicare and Medicaid (Daly et al., 2014). In the past three years, HRSA has added several types of cancer screenings to UDS measures, which increases documentation and awareness of cancer prevention in FQHCs (Allen et al., 2014; Gwede et al., 2013). This documentation helps improve the accuracy of cancer incidence and mortality statistics that guide research efforts and policy design and implementation.

FQHCs attempt to provide comprehensive, quality primary health care services to underserved communities and vulnerable populations (Daly et al., 2014; Emmons et al., 2011; Katz et al., 2011; Richards et al., 2014; Rothkopf et al., 2011). They offer a variety of services including laboratory testing, radiology, pharmacy, dental care, behavioral health, and sometimes medical specialty care (Katz et al., 2011). Some can also assist with language translation and transportation. FQHCs can alleviate gaps in access to care for rural minority communities (Ko et al., 2015). In rural areas, FQHC availability has been associated with lower rates of preventable hospitalizations and higher rates of receipt of preventive services (Ko et al., 2015; Wright et al., 2015).

FQHCs provide primary health care services to populations with limited access to health care services, including cancer screenings (Gwede et al., 2013; Gwede et al., 2015;

Martinez-Gutierrez et al., 2013). FQHCs' ability to provide coordinated, comprehensive primary care and support services in an efficient manner is particularly important to people with complex medical and social needs (Katz et al., 2011). Studies have shown that the availability of FQHCs improves access to medical care for vulnerable populations by helping to eliminate racial/ethnic and SES disparities in access to care and quality of care (Adams, Choi, Eberth, et al., 2015; Adams, Choi, Khang, et al., 2015; Emmons et al., 2011; Shi et al., 2009). Nearly two-thirds of patients in FQHCs are ethnic minorities, low income, and uninsured, living in either underserved rural or urban areas (Adams, Choi, Eberth, et al., 2015; Adams, Choi, Khang, et al., 2015).

Medically underserved populations are much more likely to depend on urgent care, emergency rooms, and/or FQHCs for their routine medical care (Krok-Schoen et al., 2015; Rothkopf et al., 2011). Studies have shown that uninsured and publicly insured Americans who visit FQHCs receive more preventive services, including cancer screenings, compared to those who do not visit FQHCs (Adams, Choi, Eberth, et al., 2015; Adams, Choi, Khang, et al., 2015). Rothkopf et al. found that community health center users are about one-third less likely than other groups to have emergency department visits, inpatient hospitalizations, or preventable hospital admissions (Rothkopf et al., 2011). Research has demonstrated the essential impact of primary care on improving access to care, narrowing disparities, and improving patient outcomes (Shi et al., 2014). People with chronic conditions are in need of comprehensive, continuous, and coordinate care (Shi et al., 2014), and FQHCs are designed to provide this type of care for underserved populations, especially those with chronic illness (Gwede et al., 2015; Martinez-Gutierrez et al., 2013).

Research suggests that FQHCs need assistance in planning and implementing cancer prevention programs (Allen et al., 2014). Partnering with academic institutions and other affiliated organizations can help support the goal of providing more comprehensive health care services for underserved populations in FQHCs (Adams, Choi, Khang, et al., 2015).

Patient Centered Medical Homes

Many government entities, private payer groups, and specialty provider groups agree that one of the best ways to address patient barriers, especially for chronically ill patients, is adopting a model of care called the patient centered medical home (PCMH) (Henderson, Princell, & Martin, 2012). Introduced in the 1960s by the American Academy of Pediatrics to help serve patients with complex health needs, the PCMH is a type of primary care setting that aims to serve patients by improving health outcomes and lowering costs through coordinating the medical care, including a wide range of social and mental health services (Henderson et al., 2012; Lipson, Rich, Libersky, & Parchman, 2011).

Due to the many adaptations which have been made to the model in the various settings where it has been implemented, the definition of a PCMH varies according to the organizations that adopt the model (Crabtree et al., 2010; Jackson et al., 2013). The Agency for Healthcare Research Quality (AHRQ) defines the PCMH as a model which emphasizes comprehensive, coordinated, accessible, continuous, team-based, and patient-driven primary care (Lipson et al., 2011). In a 2010 study, Stange et al. conducted an extensive review of literature on PCMHs with the goal of writing a formal definition of the model and a way to measure its success (Stange et al., 2010). They defined a PCMH as people within a community who are dedicated to improving the health of their own community through optimizing the fundamental attributes of primary care and merging them with new, innovative ideas for health service and practice improvement (2010). These two definitions share little in common, reflecting how much the model's definition changes among researchers and entities. Results from the National Demonstration Project on PCMH implementation suggested that more studies need to be done on how to define a PCMH within varying contexts (Crabtree et al., 2010).

The goal of the PCMH is to provide a "home" where patients can go to see the same, trusted medical provider and health care team who will coordinate care for their complex, evolving needs (Henderson et al., 2012; Lipson et al., 2011). Coordinated care is a hallmark of PCMHs, and it is believed to improve health outcomes, increase patient satisfaction, and decrease costs of care (Calman et al., 2013; Henderson et al., 2012; Sarfaty, Wender, & Smith, 2011). Mid-level providers, such as nurses, nurse practitioners, and physician assistants are ideal care coordinators within the PCMH setting because they are trained to provide more "whole person" care (Henderson et al., 2012).

A patient's care team within a PCMH includes this care coordinator, as well as other nurses, pharmacists, mental health care providers, physical therapists, nutritionists, and social workers (Henderson et al., 2012). This team collaborates to take into account the patient's physical, social, emotional, and behavioral needs, and they actively work to obtain the resources necessary to remove any barriers to care for patients, including lack of transportation, inadequate housing, and social support (Henderson et al., 2012; Lipson et al., 2011; Sarfaty et al., 2011). A study done in 2012 across 26 safety-net clinics suggested that patients’ experience of care coordination was better among clinics that implemented PCMH improvements and that patients in such clinics reported better quality of care as well (N. Cook et al., 2015). For patients with chronic disease, coordinated care is an important part of managing disease. In 2011, Lasser et al. studied the effects of replacing physicians with patient navigators to promote education and screening for colorectal cancer in PCMHs (Lasser et al., 2011). They found that patient navigation was successful in increasing completion of CRC screening among ethnically diverse patients, providing social and emotional support to patients. Another study done in 2008 demonstrated that the relationship-centered aspects of PCMHs were highly correlated with the delivery of preventive services (Ferrante, Balasubramanian, Hudson, & Crabtree, 2010). A growing body of research supports this finding and hypothesizes that team-based care and relationships between patients and providers that will be the future of primary care (Bodenheimer, 2011; Mead, Andres, & Regenstein, 2013; Nutting et al., 2011).

Though coordinated care teams are essential to PCMH structure, gathering feedback and including patients’ preferences, needs, and resources during decision-making sets PCMHs apart from other safety-net settings. This is especially important for patients with chronic illnesses like cancer (Henderson et al., 2012; Nutting et al., 2011), who often feel excluded from the decision-making process (Barry & Edgman-Levitan, 2012). In the PCMH setting, the concept of “patient centeredness” shifts attention away from the disease and back to the patients (Barry & Edgman-Levitan, 2012; N. Cook et al., 2015). Emphasis is put on activating and engaging patients; a space is given to them to ask for care they need, when and how they want it, and they are given the information and resources they need to make choices that appropriate for them (Calman et al., 2013; Nutting et al., 2011; Sarfaty et al., 2011).

Many researchers, policy makers, and providers highlight the PCMH's ability to lower costs for patients, ultimately affecting health outcomes. Despite reforms in access and availability of health insurance, many adults in the U.S. find it difficult to maintain health care insurance coverage and gain access to high-quality preventive care (Berenson, Doty, Abrams, & Shih, 2012). Evidence has shown that the PCMH model reduces costs by lowering or eliminating the number of unnecessary visits to hospitals, emergency departments, and other acute care services (Berenson et al., 2012; Lipson et al., 2011; Sarfaty et al., 2011). Additional evidence shows that patients rate the quality of their experiences more positively when healthcare settings adopt PCMH-related attributes (Berenson et al., 2012; N. Cook et al., 2015; Jackson et al., 2013).

The PCMH model has been widely adopted throughout the past several decades, but only recently has it become a key focus of health care reform. The model still has many flaws and leaves major gaps in care for some patients (Tuepker et al., 2014). For this reason, much research still needs to be done to understand how PCMHs can be better used for increasing access to cancer screenings and improving health outcomes for chronic disease patients (Jackson et al., 2013; Porter et al., 2015; Sarfaty et al., 2011) and increasing access to care for low-income, disadvantaged patients (Mead et al., 2013).

Summary of Safety-Net Systems. Patients who have poor access to health services have poorer health outcomes. This is especially true for cancer mortality for patients with little or no access to cancer screening services. Patients' experiences in the healthcare setting should be regularly evaluated in order to understand the necessary practice-level changes that need to be made in order to eliminate barriers to care and lower the burden of disadvantaged populations (N. Cook et al., 2015).

Understanding patterns of preventive care use is important for targeting private and public sector policies to ensure that recommended preventive care is available for all populations. Improving the nation's health will require ensuring access to care and quality of care across all population groups, and safety-net systems are a promising modality for achieving such equity.

There is a growing body of literature on how safety-net systems meet the quality, access, and cost barriers of their patients. Previous literature has examined the types of barriers experienced by patients in safety nets, and there is a small, growing body of literature on how FQHCs in particular are trying to focus on cancer screening for underserved patients. There has been some research done to examine organizational factors which have a major impact on rates of breast and colorectal cancer screenings, but more studies specific to FQHCs, PCMHs, and other safety-net settings need to be done (Martinez-Gutierrez et al., 2013). Research in the literature is mostly quantitative in nature, which often fails to capture nuanced details of patient experiences or stories of intervention implementation.

Consolidated Framework For Implementation Research

Throughout the past several decades, implementation scientists have begun to emphasize the importance of interactions between aspects of intervention characteristics and the process of implementation (Damschroder et al., 2009). Influences on implementation come from many levels, from external influences to organizational process components and key individuals who drive intervention success. These must be examined together in order to identify and understand important relationships which affect implementation of key interventions (Damschroder et al., 2009).

The Consolidated Framework For Implementation Research (CFIR) is a theory that "offers an overarching typology to promote implementation theory development and verification about what works where and why across multiple contexts" (Damschroder et al., 2009; para. 1). The goal of its development was to consolidate common constructs from a breadth of existing implementation theories and develop a single, comprehensive framework that utilizes the most important contributions of each theory for use across a wide range of implementation studies (Damschroder et al., 2009). CFIR is composed of five domains: intervention characteristics, outer setting, inner setting, characteristics of the individuals involved, and the process of implementation (2009). These domains, and the constructs within them, are used to capture data on almost all aspects of an intervention and the implementation process.

The CFIR was first published in 2009 by Damschroder and colleagues, and due to its recent publication, relatively few studies have been completed to date to evaluate its usefulness, applicability, or comprehensiveness as an evaluation tool (Abbott, Foster, Marin Hde, & Dykes, 2014; Breimaier, Heckemann, Halfens, & Lohrmann, 2015). In their 2013 study, Damschroder et al. found CFIR definitions to be sufficient for coding all qualitative interview responses relevant to the intervention (Damschroder & Lowery, 2013). Ilott et al. concluded from their study of 11 health care innovations that CFIR facilitates comparisons of interventions, no matter the differences in health care setting, context, geographical location, timeframe, or intervention components (Ilott, Gerrish, Booth, & Field, 2013).

Other studies examining the comprehensiveness of CFIR have pointed out limitations in the framework (Breimaier et al., 2015; Rojas Smith, Ashok, Morss Dy, Wines, & Teixeira-Poit, 2014; Sorensen & Kosten, 2011). In 2014, AHRQ and a selected panel of experts applied CFIR to case studies in order to examine its comprehensiveness and applicability (Rojas Smith et al., 2014). Some experts felt the framework could be more comprehensive and could better capture the unique needs of patient needs, preferences, and characteristics. They suggested alternative models for CFIR which would have separate domains for patient needs and preferences. A study done by Breimaier et al. found that CFIR constructs fail to capture stakeholder involvement and engagement, sustainability, and pre-existing measures or activities related to interventions (Breimaier et al., 2015). Suggestions were made on how to make CFIR more comprehensive by adding additional constructs to capture these crucial aspects of implementation. Given the recent debut of CFIR into the field of implementation science, its limitations are understandable, and future research can be done to improve the model as necessary.

Patient Needs and Resources. Barriers to implementation arise at all levels of health care delivery, including patient, provider, team, organizational, and policy levels. It is important for researchers to understand this in order to perform the most thorough evaluations for assessing implementation effectiveness and sustainability (Damschroder et al., 2009; Robins et al., 2013).

The construct “Patient Needs and Resources” is part of the Outer Setting domain of CFIR (Damschroder et al., 2009). The outer setting of an intervention typically includes the economic, political, and social context within which an organization resides.

Changes in the characteristics of the outer setting often have great impact on, and are mediated through, changes in the inner setting, thus having great impact on the potential success or failure of an intervention.

The “Patient Needs and Resources” construct describes “the extent to which patient needs, as well as barriers and facilitators to meet those needs, are accurately known and prioritized by the organization” (Damschroder et al., 2009). Many theories on implementation science recognize the importance of acknowledging patient characteristics, but CFIR considers patient needs and resources to be an absolutely critical part of the implementation process for interventions seeking to improve patient outcomes.

Many studies have found CFIR to be useful for evaluating the implementation of health care interventions (Abbott et al., 2014; C. Cook & Rockwood, 2013; Damschroder & Hagedorn, 2011; Damschroder & Lowery, 2013; Forman et al., 2014; Hartzler, Lash, & Roll, 2012; Ilott et al., 2013; Lash, Timko, Curran, McKay, & Burden, 2011; Luck et al., 2014; Midboe, Cucciare, Trafton, Ketroser, & Chardos, 2011; Robins et al., 2013; Williams et al., 2011). However, few studies have examined or drawn conclusions about the importance of the construct “Patient Needs and Resources” as part of the CFIR. In 2011, Damschroder and Hagedorn compared CFIR to other implementation theories and their usefulness for evaluating substance use disorder (SUD) programs, asserting that more knowledge is needed about the delivery of evidence-based practices for patients who are most likely to benefit (Damschroder & Hagedorn, 2011). They advocated for the inclusion of the “Patient Needs and Resources” construct within the Outer Setting domain because an intervention’s success in meeting the needs of targeted patients depends largely on the extent to which an organization prioritizes and understands the needs of those patients. They also argued that the importance of understanding patient needs will only continue to increase due to the recent interest in patient centered medical homes.

In 2013, Damschroder et al. published an evaluation of a weight management program that used CFIR to guide tool development and data analysis (Damschroder & Lowery, 2013). The study aimed at using CFIR to compare sites participating in the intervention and to distinguish between sites with high and low implementation effectiveness. They used 31 CFIR constructs in their evaluation, and their analysis revealed 10 constructs which distinguished between high and low implementation effectiveness. One of these 10 constructs was “Patient Needs and Resources,” which was used to identify staff’s knowledgeability of the program, how patients were cared for in different ways depending on different needs, and how the program design was responsive to patient feedback. The construct was also used to identify patient barriers to participation in the program, such as a co-pay that was too expensive for some patients.

A major trend in CFIR literature involves studies which use the theory to conduct literature reviews on important aspects of intervention implementation, and several have drawn specific conclusions using the construct “Patient Needs and Resources.” Hartzler et al. used CFIR to conduct a literature review on contingency management in substance abuse treatment and found that characteristics of the Outer Setting only appeared to be the focus in 4 of the 49 articles on the subject (Hartzler et al., 2012). These four studies used Outer Setting characteristics to examine the impact of client ethnicity, income, and psychiatric severity on implementation, as well as client preferences in treatment. The authors concluded that more research needs to be done on the subject with a focus on client needs and preferences. Lash et al. used CFIR to review literature on continuing care treatment and monitoring interventions. They found that the “Patient Needs and Resources” construct was useful for identifying patterns in the literature on interventions which addressed patient barriers to care, including inconvenience of meetings, lack of resources, the importance of religious beliefs, and distinguishing demographic factors (e.g. sex, race) (Lash et al., 2011). These findings were used to suggest further research around implementing interventions which focused on key patient characteristics associated with continued care. Similarly, Williams et al. used CFIR to review literature on alcohol screening and brief interventions, finding that patient needs were only discussed in 2 of 8 studies (Williams et al., 2011). The authors concluded that Outer Setting characteristics were important for describing successful implementation, but there was not enough evidence to draw conclusions about the importance of patient needs, suggesting a focus for future research.

Several studies which have used CFIR as the guiding framework for intervention planning and evaluation have also drawn conclusions about the “Patient Needs and Resources” construct. In 2014, Forman et al. used CFIR to gain understanding of patient experiences within a leadership development and team engagement intervention within primary care clinics (Forman et al., 2014). A reduced list of CFIR constructs was used to analyze key informant interviews with participating staff. Interestingly, though the intervention was patient-centered, “Patient Needs and Resources” was not included as a construct for evaluation. Instead, the team only used codes which would help describe the internal challenges that would be associated with implementation, such as “Complexity” and “Networks and Communication.”

In a study by Ilott et al., “Patient Needs and Resources” emerged naturally as an important concept for implementation in 9 of 11 health care innovations (Ilott et al., 2013). It was found to be most relevant for innovations which addressed the absence of critical services or clinical practice changes. Robins used the “Patient Needs and Resources” construct to find that patients who lacked computer skills had difficulty participating in a blood pressure monitoring program (Robins et al., 2013). Both of these studies found the “Patient Needs and Resources” to be useful for drawing conclusions about relevant patient barriers to care or trends in implementation.

It has been demonstrated that CFIR can be a useful tool for evaluating complex health interventions. Literature has discussed its usefulness for programs involving blood pressure monitoring, substance use addiction, and other topics. This suggests that it could also be useful for other complex health programs such as cancer screening interventions. A review of the literature shows that to date, no studies have been done using CFIR to evaluate the implementation of interventions for cancer screening within safety-net settings or for assessing patient barriers to cancer prevention services. To fill this gap, this study used the CFIR construct “Patient Needs and Resources” to examine patient barriers to cancer screening services that were identified during the routine evaluation of a cancer prevention program.

Chapter 3: Methods

Introduction

Beginning in 2014, a group of researchers from the Emory Prevention Research Center in Atlanta, Georgia began a qualitative analysis of the American Cancer Society's Community Health Initiatives (CHI) CHANGE Grants Program. Team members used the Consolidated Framework For Implementation Research (CFIR) to examine factors that affected intervention implementation (Kegler et al. 2016; Liang et al. 2016). This study used data that was coded under the CFIR construct "Patient Needs and Resources" to identify patient barriers to care that were identified by each safety-net setting throughout the intervention.

Program Description

The American Cancer Society, Inc. is a 501(c)(3) nonprofit corporation that works with nearly 3 million volunteers to save lives and create a world with less cancer by helping people stay well and get well, by finding cures, and by fighting back against the disease (American Cancer Society Inc., 2016). An overarching goal of the American Cancer Society (ACS) is to eliminate disparities in cancer burden among different segments of the US population, defined in terms of socioeconomic status (income, education, insurance status, etc.), race/ethnicity, geographic location, sex, and sexual orientation.

The American Cancer Society's Community Health Initiatives (CHI) CHANGE Grants Program was designed to promote evidence-based approaches to cancer screening from the Community Preventive Services Task Force and the National Colorectal Cancer Roundtable. The program required grantees to implement a cancer screening intervention using both client- and provider-oriented strategies recommended in “The Guide to Community Preventive Services” by the Community Preventive Services Task Force (Community Preventive Services Task Force, 2013). Health system grantees set goals for increasing breast and colorectal cancer screening in their communities. Possible evidence-based interventions included:

Table 1. Recommended Cancer Screening Interventions from The Community Guide

Type of Intervention	Description
Client-Oriented Interventions	
Client Reminders	Written (letter, postcard, email) or telephone messages (including automated messages) advising people that they are due for screening
	Can be tailored or untailored to each individual
	Sometimes include follow-up reminders, additional text or discussion of information about ways to overcome barriers to screening, and assistance in scheduling appointments
Small Media	Videos and printed materials such as letters, brochures, and newsletters
	Can provide information tailored to specific individuals or targeted to general audiences
Group Education	Presentations or other teaching aids in a lecture or interactive format conducted by health professionals or trained laypeople
	Conveys information on ways to overcome barriers to screening with the goal of informing, encouraging, and motivating participants to seek recommended screening
One-on-One Education	Telephone or in-person messages delivered by healthcare workers or professionals, lay health advisors, or volunteers in a variety of settings

	Conveys information on ways to overcome barriers to screening with the goal of informing, encouraging, and motivating participants to seek recommended screening
	Messages can be tailored or untailored to individuals or target populations
	Often accompanied by supporting materials delivered via small media or client reminders
Reduction of Structural Barriers (including use of screening navigators and transportation assistance, as well as other activities)	Reducing time or distance between service delivery settings and target populations
	Modifying hours of service
	Offering services in alternative or non-clinical settings (e.g. mobile mammography vans)
	Eliminating or simplifying administrative procedures and other obstacles (e.g. scheduling assistance, patient navigators, transportation, translation services)
Reduction of Client Out-of-pocket Cost	Attempt to minimize or remove economic barriers that make it difficult for clients to access cancer screening services
	Can include vouchers, reimbursements, reduction in co-pays, or adjustments in federal or state insurance coverage
Provider-Oriented Interventions	
Provider Assessment and Feedback	Evaluate provider performance in delivering or offering screening to clients (assessment) and present providers with information about their performance in providing screening services (feedback)
	Feedback may describe the performance of either an individual provider or a group of providers, which can be compared with a standard or goal
Provider reminder and recall systems	Reminders inform health care providers it is time for a client's cancer screening test (reminder) or that the client is overdue for screening (recall)
	Examples include reminders in patient charts, email alerts, or pop-up alerts in EMR systems

Source: Community Preventive Services Task Force. (2013). Cancer Prevention and Control. Retrieved from http://www.thecommunityguide.org/cancer/index.html

Grants ranged from $40,000 to $80,000, with the majority funded at $50,000. The grant proposals were written collaboratively by regional American Cancer Society and safety-net system staff. The evaluation collected both quantitative and qualitative data. The interviews conducted with program staff, leadership, and ACS support staff during site visits produced the data that were used for the current study.

Study Sample

There were 68 safety-net health systems receiving a grant as part of the CHANGE program in 2013. Nine sites were selected for site visits as part of the program evaluation. Sites were chosen purposively based on type of cancer addressed by intervention (breast or colorectal), targeted population, and geographic location.

In the summer of 2013, Society evaluators conducted semi-structured interviews with 3-9 key informants from each of the nine sites. Evaluators identified and selected interviewees from a list of all clinic staff involved in project implementation which was provided by clinic leadership at each site. The evaluators attempted to conduct individual interviews with all identified staff, but in some cases staff were not available during the scheduled site visit. Two evaluators attended each site visit, and one-on-one interviews with clinic staff were conducted. In some cases, interviews were conducted with 2-3 staff simultaneously, depending on clinic staff availability. Interviewees came from all levels of intervention implementation, and their roles included executive directors, chief medical officers, IT staff, quality improvement coordinators, medical assistants, nurses, community health workers, and patient navigators. Fifty-two interviews were conducted in total with an average of six interviews per site. By the end, sixty-one individuals were interviewed as part of the program evaluation. Qualitative data were collected from these interviews for use in the program evaluation.

Interview Guide

Evaluation staff from the American Cancer Society developed semi-structured interview guides and tailored them to each type of respondent (i.e. leadership, staff). See Table 2 below for a list of interview questions that were used to guide this study. The interview guide was designed to capture a range of intervention aspects, including start-up activities, implementation, practice-level changes, policy changes, staffing structure, and challenges and facilitators of the intervention. On average, interviews lasted 45-90 minutes. All interviews were recorded and transcribed verbatim to aid with future analysis. These transcripts served as the data source for this study. Table 2 presents the evaluation questions used to guide the evaluation, and the data source used to address each question.

Table 2. Interview Guide Questions and Indicators

Question	Indicator
Qualitative Data – Site Visits—Questions from Program Leadership Interview Guide	
Intro question: About how many patients does your clinic serve annually?	• Information on patient population
Qualitative Data – Site Visits—Questions from Program Staff Interview Guide	
Q3.a. Can you describe in detail what activities you are doing with the ACS grant funds?	• Description of patient needs that prompted selection of intervention activities • Intervention-specific activities done to overcome patient barriers to care
Q5.b. What factors influenced you to select this intervention?	• Description of patient needs that influenced decision to implement intervention

Q7. Please describe the steps you took to implement the grant-funded intervention.	- Description of assessments or evaluations done to gauge patient needs, barriers to care, and available resources
Q14. What were some of the challenges in implementing the intervention? What steps did you take to overcome the challenges?	- Patient needs or barriers to care that affected intervention implementation - Strategies employed to overcome patient barriers
Q15. What were some factors that helped you implement the intervention?	- Available resources that helped clinic overcome patient barriers to care
Q35. How would you describe the program's capacity to ensure that patients who get a positive test result are followed up with a colonoscopy?	- Description of patient needs outside of clinic (such as access to phone for scheduling follow-up appointment)
Q41. Do you know what estimated wait times are for follow-up colonoscopy?	- Description of patient barriers to screening beyond the intervention and clinical setting

Data Analysis

Each safety-net system is considered a case in this analysis. A deductive approach was used to construct a codebook based on the CFIR constructs and definitions, including a code for Patient Needs & Resources. Codes which were generated from the interview guide questions and new themes that emerged from the data were also included. All coders (N=6) participated in testing the codebook by coding two transcripts from one system and through multiple research team meetings to refine and reach consensus on code definitions. After the codebook was finalized, the analysis for this study involved two phases.

The goal of the first phase was to apply CFIR codes to each of the transcripts and build the foundation for case-based analysis (Yin, 2003). For each transcript, a pair of coders coded the transcript independently and then met to resolve discrepancies. After consensus was reached, final codes were applied to the transcripts using NVivo 10 (a qualitative analysis software) to prepare for the next phase of analysis. For each case (system), a coder was assigned as an “expert” who was responsible for coding all the transcripts within that case and for reviewing its project proposal and evaluation reports. This was done so that at least one team member could gain the fullest possible understanding of that system’s intervention activities. All coders created a brief memo for each transcript they coded, and after all memos were completed, they were compiled by the expert for each case to facilitate future analyses. The study team had bi-weekly meetings to resolve any questions or issues that emerged from this phase of coding.

The goal of the second phase was to conduct a cross-case analysis to identify patient needs, barriers, and strategies for overcoming barriers across different safety-net systems. A query was run using NVivo to pull all segments coded under the CFIR construct Patient Needs & Resources. The code was applied to statements representing what respondents identified as patient needs, barriers to care, or available resources for cancer screening. After the query was pulled, two team members reviewed all segments from the query. As they read, they took notes on emerging themes in the data and met afterward to review their lists, identify the most salient themes, and resolve any disagreements.

For the next step, each coded segment from the query was entered into a matrix with safety-net systems as rows and “Patient Barriers/Needs Identified” and “Strategies to Overcome Barriers and Meet Needs” as columns (see Table 3). Each segment was marked to indicate from which respondent the comment was made. For example, if the second interviewee from Site A made a comment about the site having a very transient population, the comment was marked “A2” in the table. In this matrix, specific themes were not yet broken out by row, but rather grouped within a site.

Table 3. Sample of Site-Based Coding Matrix

Site	Patient Barriers/Needs Identified	Strategies to Overcome Barriers and Meet Needs
Site A (CRC)	A2,A4,A10-language (Eng/Span, different dialects); need interpretive services; materials at appropriate reading level A2,A4,A5-unfunded patients; no insurance A8,A10-embarrassment (of discussing, of bringing in fecal samples) A2-large population of high risk patients A2-transient population; changing addresses A3-patients are unaware of importance of testing; lack of education; they don't always understand instructions, don't ask questions; they are overwhelmed with info when they go to doctor A5-cost; too expensive A8-at beginning, patients didn't understand that test was free;	A2,A10-patient-centered culture; PCMH; frequent huddles to discuss patient needs; "hustled" free colonoscopies when they were unavailable A2-sent postcards, called patients individually; they are dedicated to reaching high-risk patients; contracted with delivery service to track addresses A2-worked with outside non-profit to find free colonoscopies; this organization provides interpreters A3-scheduled all appointments for patients A3-walked patients through testing process, explained all instructions, did demonstrations, answered questions; provided direct extensions in case of questions A4-using PDSA cycles A4-made sure there were enough appointment slots for patients who

	didn't mail back because they didn't want to be charged	needed testing A5-FIT test made it easier and more affordable; convenient because it can be mailed back A5-pre-screened patients before appointment and booked necessary services to save time A8-reacted to patients not returning test in mail; put up posters

The following step involved re-organizing segments into a matrix with themes as rows and “Patient Barriers/Needs Identified” and “Strategies to Overcome Barriers and Meet Need” as columns (See Table 4). In this step, responses from each site were combined to help visualize salience across respondents and sites. For example, if two respondents from Site C discussed making language-appropriate brochures for patients, the two responses were aggregated and labeled “C(2)” to represent the site (C) and number of respondents (2). Similar themes from each site were then combined into a final column. This allowed for visualization of which themes were most salient within and across sites and for an audit trail to increase validity of the findings.

Table 4. Sample of Theme-Based Coding Matrix

Theme	Sites Where Theme Appears	Barriers/Needs Identified (by site)	Barriers/Needs Identified (combined, all sites)	Solutions to Barriers (by site)	Solutions to Barriers (combined, all sites)
Literacy	Site B Site C Site E Site F Site I	B(1)-health communication language too difficult for patients (e.g. plan A, plan B for Medicare) C(1)-low literacy/reading level E(1)-low literacy I(1)-need materials that are comprehensive, accurate, appropriate, understandable	B(1)/C(1)/E(1)/I(1)-literacy issues among population; need better materials	C(2)-brochures in Spanish & English; written at low reading level F(1)-patient navigator makes class curriculum flexible to adjust for different levels of understanding, existing knowledge, language; if patient comes in more than once for same class, has 1-1 chat about what they're retaining and why	C(2)/F(1)-addressed literacy issues through changes to curriculum and development of new materials

Chapter 4: Results

Introduction

The CFIR construct “Patient Needs and Resources” was used to code statements made by key informants regarding patient needs, available patient resources, and how safety-net staff prioritized and strategized overcoming these barriers for patients. Responses that were coded using this construct elicited many types of patient barriers to care as well as strategies for overcoming them. The major types of patient barriers mentioned by interviewees included cost, lack of knowledge or awareness, fears regarding screening and diagnosis, transportation, scheduling conflicts, language, culture, and low literacy levels. Of these themes, two were mentioned in all nine safety-net systems: cost and lack of knowledge/awareness. Patient fears were mentioned in eight of the nine sites, while transportation was important for five sites. Scheduling, language, and literacy were also mentioned as important barriers in four of the nine sites. Patient navigation was mentioned as an important strategy for addressing barriers in five of the nine sites, and as the strategy that stood out the most in the data, it is described in its own section.

Cost

Cost as a Barrier. Cost was mentioned as a barrier to care for patients in all nine sites. Cost barriers mentioned by respondents fell into two main categories: lack of adequate health insurance and cost of screening services.

First, being uninsured or underinsured was identified as a major barrier for patients seeking cancer screening services in all nine sites. For many of these sites, uninsured or underinsured patients comprise a significant portion of the safety-net system's patient population. Many respondents spoke at length about how difficult it was for patients to access preventive health services without adequate insurance or with no insurance at all. Overall, respondents agreed that lack of adequate insurance serves as a barrier to care for patients, not only for cancer screening, but for accessing all types of health care.

Respondents in three sites spoke about specific eligibility gaps that prevented patients in their systems from accessing preventive services. At Site I, respondents noticed that many Native American patients within their system had trouble obtaining health care coverage, and the coverage that some patients were able to obtain was often insufficient for covering needed services, such as breast cancer screening. Sites D and F noted that changes to Medicaid coverage in recent years have left many people ineligible for financial assistance to access screening, particularly for childless adults. In their local area, patients had limited options for accessing low-cost or free mammograms, and many of the available services had so many eligibility requirements that most patients were unable to utilize the programs. Site D also experienced trouble with securing funding through grants or other state financial assistance programs for giving diagnostic screenings to symptomatic patients. They were able to provide screening for patients who had no signs or symptoms of colon cancer, but any patient who came to the safety-net system with symptoms of CRC had to be turned away or referred to another facility. This was a stressor and burden on the system because they were unable to provide the patient-centered care that is expected of them, and it meant denying many patients a potentially life-saving diagnosis.

Second, there were seven sites that identified the cost of screening services as a barrier for patients. Respondents from these sites (A, B, C, D, F, G, and H) reported that screening services and/or their associated copays were often too expensive for many patients. At these sites, the costs associated with screenings deterred patients from seeking care, scheduling appointments, or attending recommended follow-up appointments. Site H noted that many patients did not get screened because of competing financial needs, such as cost of shelter or food. Patient awareness of financial aid to pay for screenings was an important barrier for Site A. A respondent from Site A recounted that at the beginning of their CHANGE grant intervention, many patients would not return their CRC at-home testing kits because they did not understand that it was free. They would take the kits home but not return them out of fear of being charged for the laboratory processing. At Site F, cost of services served as a barrier not only for patients, but also for providers. A respondent from this site shared that many doctors would not make referrals for patients to get CRC screening because they knew neither the clinic nor the patients could pay for the screening.

Cost of services was an important barrier to care for patients at all participating grant sites, and many of these sites turned to outside sources for financial assistance. However, respondents from Sites F and H noted that the number of charity hospitals and other services in their areas that provide low-cost or free screenings have diminished in recent years. This leaves many patients uncovered and without access to important preventive health services.

Strategies for Overcoming Cost Barriers. To help patients overcome cost barriers, grantee systems took many different approaches. Sites A, C, F, G, and H provided low-cost or free breast and CRC screening services through grants or by partnering with outside organizations such as GI specialists. Sites A and C formed partnerships to provide CRC screening, and Sites F, G, and H partnered with outside providers or mobile clinics to provide breast cancer screening. Specifically, Site F changed their referral system and started making blanket referrals for mammograms in order to cut-down the number of required office visits for patients.

Sites D, E, and I offered a sliding-scale fee to help lower costs for patients with lower incomes. A respondent from Site F offered this comment about the approach:

> We don’t want to just say well, I’m sorry, we don’t have any resources for you, so we’re just going to neglect that part of your care. We really want the care that you receive here, whether you’re insured or not insured, to be identical as if you have Blue Cross Blue Shield or any commercial [insurance]. So that’s been our goal. (Site F)

Sites A and H decided to focus on offering patients a FOBT or FIT as a way to provide low-cost screening alternatives for CRC screening. They felt that at-home CRC screenings cut costs by reducing the number of appointments necessary for patients, and because tests can be mailed back to clinics, it reduced the number of times patients needed to travel to the clinic. A respondent from Site A made this comment on the approach:

> Of course, the uninsured patients, they wouldn’t go in for a colonoscopy because it was just entirely too expensive. So using FIT test for prescreening or for screening made all the difference in the world, I think, in the success of the program and then identify the people who really did need a colonoscopy as

> opposed to referring everybody who is over the age of 50 for a colonoscopy automatically, I thought was very successful. (Site A)

Overall, respondents felt that providers and staff within their safety-net systems were aware of patient financial barriers to screening, and they were willing to learn more about interventions and approaches to addressing such barriers.

Knowledge

Lack of Knowledge as a Barrier. Respondents from all nine sites identified lack of knowledge or awareness as a patient barrier to cancer screening. The most common knowledge barrier discussed was patients not understanding how to navigate the health care system. Respondents at six sites (A, B, C, D, G, and H) reported that many patients within their safety-net systems experienced difficulty with understanding insurance plans, the availability (or lack) of health resources, or how primary care systems functioned overall. The language and ideas involved in understanding health care applications and insurance plans were sometimes too complicated for patients, as noted by respondents in Sites B and D. These patients often fell through “gaps” in care and were less likely to be screened. A respondent from Site G noted that many patients did not understand how to find a primary care doctor within their safety-net system or in their insurance network. Patients at Sites F and H were unaware of what types of screening services were available within their health systems, and respondents from these sites felt that this lack of awareness sometimes prevented patients from seeking necessary services.

Another common theme within knowledge barriers for patients was not being educated or aware of the signs and symptoms of different types of cancers. This was reported by respondents from Sites A, D, E, F, and G. These sites discussed that lack of knowledge about the symptoms associated with different types of cancer acted as a barrier to screening because patients were not aware that they might need medical attention and/or were not convinced that screening was necessary. A respondent from Site G noted that patients arriving to their clinic had different levels of understanding and background knowledge of cancer. This made it difficult to provide group education sessions because they had to engage patients on many different levels, ensuring that material was neither too complicated nor too uninteresting. Sites C and H identified a need for improving patient education on healthy behaviors that protect against cancers as well. The respondents from Site C who spoke about this need spoke in detail about the barriers to hosting group education for CRC, noting that many patients were afraid to speak about personal bowel problems in a group setting. They advocated for providing different options for patient education in the future, including one-on-one and over-the-phone sessions.

Similarly, respondents from Sites A, D, E, and F identified lack of knowledge or awareness about the importance of cancer screening and different types of screening as a major patient barrier. These respondents reported that many patients were simply unaware of the importance of cancer screening, making it difficult to motivate them to book appointments. They discussed patients being unaware of what the screening process involved and why it was important. For example, as was mentioned in an earlier section, Site A experienced issues with patients not returning FIT kits in the mail because they did not fully understand the testing process and were afraid of being charged a fee for mailing the kit to the lab. Other patients at this site were unable to understand instructions for testing, and because they were too afraid to ask for help or clarification, at-home tests and/or bowel prep for colonoscopies were completed insufficiently. At Site E, women reacted negatively to myths about the importance of cancer screening (e.g. cervical cancer is only necessary for women who are sexually active), and as a result, did not feel it was necessary.

Strategies for Overcoming Education Barriers. Respondents from all nine sites identified potential ways of overcoming patient knowledge barriers. Staff at Sites C, G, and I made it an overall goal to emphasize autonomy and informed decision-making for their patients, and they found that this improved attendance and follow-up rates. One respondent commented:

> If we empower the patients with knowledge and give them the information up front and establish that accountability, then we'll see a reduction in lost patients. (Site B)

As part of their CHANGE grant, Sites F, G, and I made efforts to improve the content and administration of their group education sessions. Sites A, D, E, F, and G improved or began offering one-on-one education sessions to improve individual understanding of cancer screening, and they found that this allowed patients a space to safely ask intimate questions and maintain privacy. There were seven sites (A, B, C, D, E, H, and I) that made adjustments to written and printed materials to improve understanding. Some sites developed new, personalized educational materials and instructions for patients, and others improved upon existing materials by making them more comprehensive or adding visual aids.

Fears

Fear as a Barrier. Safety-net system staff who participated in this study described patient fears associated with cancer screening, and in eight (A, B, C, D, E, F, G, and H) of the nine sites, fears were mentioned as a barrier to screening for patients. The patient fears that staff described fit into three categories: fear of testing, embarrassment, and myths/misconceptions.

Patients' fear of testing was observed by respondents from Sites B, D, E, F, and G. Fear of pain was a barrier to screening for patients at Site D. For patients at Sites B, D, and F, the fear of a cancer diagnosis was described as a real fear that prevented patients from scheduling or following-up with screenings. Other testing fears observed by respondents included fear of crowds (Site E), fear of doing colonoscopy prep (Site D), and fear of infection from testing procedures (Site B). Fear of interacting with the health care system was a barrier unique to Site G, and respondents from this site discussed patients being afraid to go into a clinic and interacting with health workers. One respondent reflected on this barrier:

> I think it has everything to do with just – it's like a fear of taking that step. It does take some personal responsibility to follow-up, you learn about it, you hear about it, you know it's free, but now you've got to make the appointment and actually go. And I think there's a little bit of fear [associated] with that as well, especially for those who don't traditionally have access to healthcare. It's a little bit daunting. So I think that probably is the main barrier. (Site G)

Respondents at Sites A, C, and F linked patient fears to embarrassment. Patient fears at Sites C and F were viewed as more general fears of discussing sensitive topics and personal information with strangers, including health care workers or other patients during group education sessions. At Site A, respondents noted that patients were often embarrassed of bringing in stool samples for at-home CRC testing kits, and for this reason some patients did not want to complete tests or participate in free screening programs.

Myths and misconceptions about cancer and cancer screening were viewed as the cause of patient fears in Sites C, D, E, and H. Respondents from Site E reported that misinformation or circulating myths about breast cancer acted as barriers to screening for some women in their system. For example, they noted that some patients believed that women with smaller breasts were less likely to get breast cancer, making the need for mammography less urgent. Other patients reported to staff a fear that if they were to be diagnosed and treated for breast cancer, men would not be interested in them anymore, and for this reason, they avoided screening as a way to avoid diagnosis. At Site H, myths and misconceptions were observed as important barriers for men, especially Hispanic men, within the system. Myths in the community linked homosexuality to CRC testing, and the fear of being associated with such labels prevented some men from seeking screening services. At Site C, men were also resistant to CRC testing for fear of being stigmatized or judged.

Strategies for Overcoming Fear Barriers. Sites B, C, E, and F employed strategies to help patients overcome fears and anxieties around screening for cancer. Workers at Site B began offering one-on-one counseling to help answer individual questions and ease patient fears pertaining to CRC screening. Site C also addressed the fears of male patients toward CRC screening. To reach men in their population, they emphasized the privacy of screening through FOBTs at home, and they spoke with patients' wives to schedule in-house appointments when necessary. Sites E and F addressed patient fears toward breast cancer screening by offering reassurance. Staff at these sites focused on taking time to ease patient fears by sharing personal stories, personally accompanying patients to exams, and answer any questions that came up about the screening process. At Site F, the patient navigator was particularly integral to this effort.

Transportation

Transportation as a Barrier. Transportation was mentioned as a patient barrier in five of the nine sites (B, C, E, F, and G). Patients in Sites B, E, F, and G had trouble accessing transportation to the safety-net clinics because their communities did not have adequate public transportation services (or did not have public transportation at all). Respondents from Sites B and C noted that the costs associated with transportation and/or parking served as a patient barrier to accessing services. A respondent from Site C made the following comment:

> Transportation is definitely a little bit of an issue for some of our patients, in terms of having someone with them to go to the colonoscopy... Even getting here sometimes is tough for this patient population if they don't live in walking distance. (Site C)

For patients at Sites B and E, the long distance required to travel to or between clinical sites served as a barrier to cancer screenings and follow-up appointments. Respondents from Site E reported that patients sometimes have to travel more than an hour to clinical sites, and when patients are required to attend multiple appointments at such a distance, they become hesitant and dissuaded, leading to poor follow-up and attendance for screening appointments.

Strategies for Overcoming Transportation Barriers. To help address patient transportation barriers to screening, Sites A, C, E, and H made system and practice changes that would reduce the number of necessary clinical visits for patients. Site A used FIT kits to pre-screen patients for CRC, in order to reduce the number of times patients would have to travel to clinical sites as well as reduce the number of unnecessary colonoscopy visits. They also pre-booked necessary appointments to save time, and when such appointments were not needed, they simply cancelled them and made space for other patients. Site C also reduced the number of necessary appointments for patients by combining one-on-one patient education and counseling with pre-screening and referral appointments. Likewise, Site E began pairing mammograms with other exams, such as PAP smears, in order to “kill two birds with one stone.” Site H recognized that many patients had difficulty traveling between sites, so they began offering patients information on site locations, available services, and the types of insurance or financial assistance available at each location. They then gave patients the option to schedule screening services at a location of their choice. This facilitated attendance because patients were empowered to make their own decision about where, when, and how they receive screening services.

To assist patients who experienced issues with accessing public transportation, Sites E and F connected patients with transportation services or provided information on how to access public transportation. Site E provided bus tickets and taxi cards to patients who needed assistance with paying for public transportation services. These cards were mailed to patients ahead of time to ensure that patients would not have to pay out-of-pocket or experience reimbursement issues. Site F provided information and helped patients plan routes on public buses and trains to get to clinical locations.

Scheduling

Scheduling as a Barrier. Four sites identified specific patient access barriers for cancer screening that were due to scheduling issues. Respondents at Site C reported that patients experienced challenges with scheduling CRC screening because scheduling for appointments typically happened six months ahead of time, making it difficult to remember, or “at the last minute,” which left no time for patients to correctly complete bowel preparation. Patients from Site I also experienced issues having to wait weeks for a referral appointment, during which time many patients forgot or changed their minds about screening. At Site H, the demand for screenings was so high that the FQHC ran out of spaces, making services unavailable to patients who requested them. Site B experienced an issue with accidentally scheduling patients for services they did not need or could not receive due to conflicting health conditions or medications.

Strategies for Overcoming Scheduling Barriers. All nine safety-net systems employed some type of strategy to help patients overcome access barriers that were due to scheduling. Six of the nine sites (A, C, E, G, H, and I) began scheduling screening appointments together (e.g. mammogram with Pap smear) or eliminating unnecessary appointments. For example, while the patient navigator from Site C was waiting for patients to get scheduled for a colonoscopy, she did one-on-one education sessions with patients and taught them about colon cancer and at-home testing methods. Respondents from this site felt that this change was crucial for breaking-down scheduling barriers for patients.

Site I implemented standing orders so Medical Assistants and nurses could provide referrals for future screenings. In order to ensure patients were able to get scheduled for appropriate services, and to prevent attrition, three sites (A, D, and F) appointed specific staff members (e.g. patient navigators) or made other booking system changes to schedule appointments for patients. Three different sites (B, C, and H) employed patient reminders, which involved personally calling patients before screening appointments to verify their attendance and check that patients had made plans for bowel prep, if relevant. These sites were very focused on identifying patient-level barriers and considering them during the scheduling process. A respondent from Site B stated:

> It was just the mentality that the patient needs to come first, the convenience of what's convenient for the patient. This process, this procedure is already difficult enough. What can we do to make it easier on the patient, to make it not such a hardship for the patient to have to go through all these processes? There's no need for them to have so many stops. … So they just worked out, just working it out and understanding that it was for the patient and to make the patient more compliant. (Site B)

Language

Language as a Barrier. Language was mentioned as a patient barrier in Sites A, B, F, and H. All four of these sites identified important subpopulations within their health systems that spoke different languages (Creole, Spanish, Vietnamese), which meant they required special services, such as health care interpreters or separate printed materials.

Some sites faced an additional obstacle when patients spoke different dialects within a language and thus required separate services. Language barriers occurred when patients were unable to read printed materials (such as bowel prep instructions) or were too afraid to ask for assistance with interpretation and translation. Sites A, B, and F noted that patients within these subpopulations varied in their understanding of how to read and write, both in English as well as their own language(s). This made it more complicated for safety nets to address individual barriers and needs.

Strategies for Overcoming Language Barriers. Four sites identified strategies for overcoming patient language barriers. Sites B, C, and F created or improved existing printed materials, such as instructions and informational brochures. Improvements were made by accounting for different dialects and using language at a lower reading level. A respondent from Site C who was involved in making these changes offered this comment:

> We wanted to make sure that even though they said “Oh, I speak a little bit of English,” I say “I’ll be respectful and make sure you can get as much information as possible in your most comfortable language.” (Site C)

Sites A, B, and F enlisted the help of health care interpreters to reduce language barriers for patients. Site A partnered with an outside non-profit organization that provided interpreters. Site B employed a bilingual patient navigator who could simultaneously interpret for patients while helping them to navigate the complex safety-net health system. The patient navigator at Site F was also bilingual and tailored group education classes that accounted for varying levels of health literacy, dialect of language, levels of understanding, and existing knowledge about cancer and cancer screenings.

These sites all commented that accounting for challenges with the English language during interventions greatly reduced barriers for patients.

Literacy

Literacy as a Barrier. Literacy was mentioned as a patient barrier by respondents from Sites B, C, E, and I. All four of these sites mentioned that many patients within their health systems were low-literacy and were in need of comprehensive, accurate information sources written at a low, understandable reading level. A respondent from Site I commented on the challenge of accessing such resources:

> It’s a big challenge…with any handouts and materials we give out on any topic. They need to be at an appropriate level of literacy and health literacy, and this is certainly not limited to any one area of health education or any one source for materials. But so often they’re written in a way that I think people aren’t going to read…They’re not at a fifth grade reading level. (Site I)

Site B noted that many medical information brochures and instruction guides use complicated medical terms and jargon, and this acts as a barrier to understanding for patients.

Strategies for Overcoming Literacy Barriers. Respondents from Sites C and F discussed using strategies aimed at addressing literacy barriers for patients. Health workers within Site C used brochures written at low reading levels to educate patients about CRC and different types of screening. They printed these brochures in both English and Spanish as well. At Site F, the patient navigator who taught group education sessions made the curriculum flexible enough to adjust for different literacy levels and languages.

Respondents from both of these sites felt that accounting for varying levels of literacy helped patients overcome barriers to screening.

Culture

Culture as a Barrier. Culture was mentioned as a patient barrier in three of the nine sites. Respondents from Sites H and I discussed cultural differences between the health providers in the safety-net systems and the patients in their systems' reach. Site H identified particular cultural barriers for Hispanic men served by their system in regard to CRC screening. These patients often resisted CRC screening due to myths and fears surrounding the process of receiving a colonoscopy within the Hispanic community, including the fear of being associated with homosexuality.

> …at the beginning, there was a lot of resistance from men, in general, men from minority races and cultures, African Americans, Middle Eastern and Asian descent, just because they had this idea that…"Colon cancer can't affect me" or "Colon cancer affects a part of the body that I'm uncomfortable with admitting that there could be something wrong…" (Site C)

Site I served a large Native American population, and one respondent commented that this population faced "historical trauma" regarding access and use of medicine in the United States. A respondent from Site B identified a cultural barrier to care associated with religion at their site. There were patients in their safety-net who could not eat jello for religious reasons, but jello was listed as a suggested part of bowel prep for colonoscopy. This had to be taken into consideration so as not to be insensitive to patients' needs. Respondents from these sites commented that their approaches to cancer screening education involved a great deal of cultural sensitivity in order to be successful.

Strategies for Overcoming Cultural Barriers. There were two sites that implemented strategies to help patients overcome cultural barriers. Sites F and I both made adjustments to health education curriculum to make it more culturally-appropriate for their respective cultural minority groups. As part of the CHANGE grant, Site F held group education classes to talk about breast cancer screening. The patient navigator in charge of teaching the classes made the curriculum more flexible so it could be adjusted for different levels of medical understanding, existing levels of knowledge, and different languages spoken by patient groups. Further, if patients attended the same group education presentation more than once, the patient navigator engaged those patients in one-on-one sessions to investigate matters that seemed confusing or troublesome for them. Site I addressed cultural barriers experienced by their Native American patient population by providing health education sessions at powwows, in a setting where they felt more comfortable discussing health issues.

Patient Navigation

Patient Navigation as a Strategy for Overcoming Patient Barriers. To help patients overcome barriers to care, five of the nine sites in this study employed patient navigators. Sites B, C, D, F, and G utilized patient navigators in a variety of ways to help identify and reduce barriers for patients. At Sites C, D, and G, they addressed scheduling barriers by scheduling exams and appointments for the patients, and they played an important role by coordinating referral appointments and the delivery of lab results with partner organizations. Respondents from Site C felt this was particularly important to the success of the intervention as a whole because working directly with the patients improved attendance. One respondent reflected on this idea:

> And that’s what [the patient navigator] and the program have been able to do, has been taking [patients] from ordering the colonoscopy and getting them on the schedule to going [to the appointment] because we know that if you schedule someone six months out, their chances of getting to that appointment will be minimal compared to the guy you’re going to put in in two weeks. (Site C)

Additionally, patient navigators at Sites C and D were able to simultaneously help reduce transportation, knowledge, and scheduling barriers. At these sites, patient navigators combined pre-screening questions with one-on-one education sessions, which reduced the number of necessary appointments. They also helped patients schedule screening colonoscopies weeks in advance, and they offered at-home FOBTs in the meantime. If patients completed the FOBT and results were not positive, patients were able to cancel their colonoscopy screening appointment, which saved them time and money. If results of the FOBT were positive, patients already had a colonoscopy appointment scheduled and did not have to re-navigate the system to manage a referral or contact partner organizations. Both sites found this approach to be effective at addressing the needs of their populations.

Sites also found patient navigators to be useful for providing culturally-competent and appropriate education for patients. Patient navigators at Sites B, C, D, and F shaped educational content for patients by offering visual aids and pictures to explain complex health concepts or testing instructions and procedures. Sites B and F employed patient navigators who were bilingual and able to provide more culturally-competent care and coordination for patients in their populations. The patient navigator at Site F also tailored the safety-net system’s group education curriculum to be more flexible and able to adjust for varying levels of understanding, literacy, and dialects of language. Each of these sites felt that employing a patient navigator was an important key to the success of their interventions.

Summary

Respondents from each site identified multiple barriers and strategies for overcoming patient barriers to care. The major themes that emerged from the “Patient Needs and Resources” code included cost, knowledge, fears, scheduling, transportation, language, literacy, and culture as the main patient barriers to care, and patient navigation emerged as an important theme for addressing patient barriers. The importance of these findings will be discussed in the following chapter.

Chapter 5: DISCUSSION

We examined patient needs, available resources, and how safety-net staff identified and strategized to overcome patient barriers to cancer screening. Themes highlighted key patient barriers and strategies for overcoming barriers. Major themes included high costs of services, lack of knowledge or awareness, and fears associated with testing, screening, and diagnosis. Common strategies for overcoming barriers included partnering with outside organizations to provide free or low-cost screening, adjusting health curricula for comprehensiveness and cultural competence, and providing patient navigation services.

Financial Barriers

Respondents from all nine sites identified cost of screening services, lack of adequate health insurance, and eligibility gaps for public insurance as important barriers to care. This is consistent with the literature on financial barriers to screening for both breast (Nonzee et al., 2015; Palmer et al., 2011; Ragas et al., 2014; Ross et al., 2007) and colorectal cancer (Coronado, Petrik, et al., 2015; Gwede et al., 2015; McLachlan et al., 2012). Findings support studies which demonstrate that even when patients are motivated to get screened, the high costs associated with screening, follow-up care, and appointments with specialists deter patients from seeking preventive screening services (Nonzee et al., 2015; Ragas et al., 2014). This is also supported by The Community Guide, which recommends reducing client out-of-pocket costs as a way to reduce barriers to care and increase screening rates (Community Preventive Services Task Force, 2013).

Although the CHI grant program did not require grantees to specifically address patient cost barriers, many sites identified system practices meant to help patients afford screening services. Respondents felt that these approaches (providing low-cost or free screening, forming partnerships with outside organizations, offering sliding-scale fees, and offering FOBTs or FITs as alternatives to colonoscopies) were successful for helping patients overcome cost barriers. Intervention approaches such as these should be explored further as a way to reduce out-of-pocket costs for patients.

Overall, the providers and staff within safety-net systems were aware of patient cost barriers to care. After studying patient barriers to breast cancer screening, Palmer et al. emphasized that it is critical for clinical organizations to understand financial barriers faced by patients in order to plan interventions which can help improve access to preventive care services (Palmer et al., 2011). Findings from the data in this study support this recommendation for improved awareness of patient financial barriers, especially in safety-net settings where many patients lack health insurance and cancer screening rates suffer as a result (Ross et al., 2007).

Knowledge Barriers

In all nine grant sites, respondents identified lack of knowledge about cancer and cancer screening services as an important barrier for patients. Patients experienced difficulty understanding informational pamphlets, financial plans, and how to navigate primary care systems in general. Many patients were not familiar with the signs and symptoms of cancer, nor were they aware of what types of screening services were available to them and what each test involved. These responses support the results of other studies which have found that lack of knowledge or awareness about cancer screening contributes to low rates of screening (Arnold et al., 2012; Gwede et al., 2015; Hatcher-Keller et al., 2014; McLachlan et al., 2012; Nonzee et al., 2015).

To help patients overcome knowledge-based barriers to screening, safety-net systems in this study updated and improved health education curricula, offered additional education services (e.g. one-on-one classes), and adjusted printed materials to improve understandability. The perceived success of these approaches complements to the findings of previous studies which have addressed patients' lack of understanding by improving communication and provider interactions with patients (Carcaise-Edinboro & Bradley, 2008; Hatcher-Keller et al., 2014; Kimura et al., 2014; Nguyen et al., 2011; Powe et al., 2009; Ragas et al., 2014). These studies demonstrated increased screening rates and improved patient engagement, suggesting that more attention needs to be paid to interventions and approaches for improving patient-provider communication.

Patient Fears

Previous studies on barriers to cancer screenings have found that fear is one of the most significant factors in a patient's decision to seek preventive care services (Allen et al., 2014; Coronado, Schneider, et al., 2015; Davis et al., 2012; Gwede et al., 2013; Gwede et al., 2015; Kimura et al., 2014; McLachlan et al., 2012). In this study, fear of testing, embarrassment, and myths and misconceptions all acted as barriers to screening for patients in eight of the nine sites. Fear was sometimes the determining factor for patients deciding whether or not to seek screening services. In Site A, patients were too afraid to participate in CRC screening, even when services were free, culturally-appropriate, and interpreters were available to eliminate other potential access barriers. Respondents from Site C found it difficult to conduct group education sessions about CRC screening with patients due to the sensitive nature of discussing bowel problems with strangers in an unfamiliar setting. This finding can contribute to the ongoing discussion and review by the Community Preventive Services Task Force regarding group education as a recommended client-oriented intervention for increasing CRC screening rates (Community Preventive Services Task Force, 2013). Health care providers need to be aware of patient concerns, and they should be prepared to address fears and anxieties during clinical encounters.

To help patients overcome their fears of screening, one site offered one-on-one educational counseling sessions to address individual concerns or questions. Staff at another site made a change to the culture of their practice by making a concerted effort to slow down and take more time to listen to patients' concerns, offer reassurance, share personal stories, and accompany patients to exams when possible. These patient-centered approaches were perceived as effective for addressing patient fears, improving appointment attendance, and increasing returns of at-home screening kits (FOBT and FIT). Findings support the recent movement for more patient-centered interventions, and they suggest a need for more research on identifying and addressing patient fears to screening.

Patient Navigation

To help patients overcome barriers to care, five of the nine sites in this study employed patient navigators. Though this approach is not listed as a standalone evidence-based intervention by The Community Guide (it is listed as a strategy for reducing structural barriers), many sites included it as part of their CHANGE Grant intervention program (Community Preventive Services Task Force, 2010). Patient navigators coordinated referrals and communication with partner organizations, scheduled appointments, carried-out patient reminders for appointments, and provided culturally-competent educational services, including group sessions and one-on-one counseling with patients. Sites which utilized patient navigators as part of their programs found that they were particularly integral in helping patients overcome personal fears of testing or screening. Patient navigators are emerging in the literature as important members of the primary care team, and the success of using patient navigators in this study adds support to the argument being made by other authors (Honeycutt et al., 2013; Lasser et al., 2011; Nguyen et al., 2011). Exploring the use of patient navigators as a standalone intervention for increasing access to screening services for patients is a possibility for future research.

Use of CFIR Construct to Assess Patient Needs and Resources

Researchers in this study used the CFIR construct “Patient Needs and Resources” to code segments about patient barriers to care, available resources, and strategies for overcoming barriers. The code captured a wide variety of comments made by respondents about the type of patient barriers that were identified, how safety-net systems prioritized addressing patient access needs, and how providers and staff chose to address barriers to care.

The “Patient Needs and Resources” code was useful for capturing many different types of data from a very large data set. However, the lengthy amount of data produced in the coding query was unorganized and cumbersome, and researchers had to take extra steps to separate segments for analysis given the breadth of the comments categorized under this construct. It took considerable time to identify comments about which patient barriers were identified by each site, and then we separated them from comments addressing how clinical staff chose interventions that might help meet patients’ access needs. We also interpreted the importance of each comment and determined whether or not it should be included in analysis (i.e. whether or not it truly addressed patient needs and resources).

Patients experience barriers to care on many different levels. Some of these barriers occur within the patient's home, outside of the clinical setting, and therefore may be too difficult for health care workers to tackle. Other barriers occur within the clinical setting and are easier for staff to identify and address. For example, safety-net staff may identify unemployment as a cause of barriers to care when patients are unable to get health insurance or do not have the money to afford food and shelter. This is an issue that is probably too large for one health clinic to solve, whereas something like literacy or language needs can be more easily addressed by employing an interpreter.

Previous studies have examined the comprehensiveness and utility of CFIR as a qualitative evaluation tool. Authors agree that CFIR is useful for capturing a wide range of data and organizing important implementation themes (Breimaier et al., 2015; Rojas Smith et al., 2014; Sorensen & Kosten, 2011). However, many researchers suggest that some construct definitions are not specific enough. These authors suggest narrowing definitions or splitting constructs into sub-constructs in order to capture and organize data more efficiently. A review of CFIR from a panel of experts at the Agency for Healthcare Research and Quality (AHRQ) suggested the framework could better capture the unique needs of patient needs, preferences, and characteristics (Rojas Smith et al., 2014). Alternative models of CFIR have been proposed, consisting of separate domains for patient needs and preferences.

To help improve the utility of the "Patient Needs and Resources" construct, future researchers should consider creating sub-codes in order to capture and distinguish different types of data. For example, researchers hoping to examine different types of strategies used to overcome patient barriers can create a code such as “Strategies for Overcoming Barriers” or even “Successful Strategies” versus “Unsuccessful Strategies.” Those looking to examine barriers that occur within a clinical setting versus those which occur in the home, work, or community setting might separate codes into “Extramural Barriers” and “Intramural Barriers.”

Limitations

This study has several limitations. First, this study only used interviews from safety-net system staff and leadership. No interviews were conducted with patients; therefore, data is limited to the barriers which were perceived by providers. Next, participants in the study were not directly asked about patient barriers to care, health needs outside of the clinical setting, or strategies for directly addressing patient barriers for screening. Comments regarding these subjects were made organically while answering other, possibly un-related, questions. For this reason, safety-net clinic staff may have identified additional barriers to care or strategies for overcoming barriers that were critical to providing cancer screening, but they may not be mentioned in this study. The qualitative analysis in this study involved a degree of subjectivity that may have resulted in some key comments being left out of the final analysis of results. To minimize this potential limitation, after the first analysis of results was completed independently by one researcher, a second researcher reviewed the major themes that were identified (Yin, 2003). Discrepancies were addressed through consensus.

Implications and Recommendations

Given the increased attention and focus on patient centeredness in the primary care field (Barry & Edgman-Levitan, 2012; N. Cook et al., 2015), safety-net systems should put more emphasis on identifying patient needs and putting them at the center of each practice in order for cancer screening programs to be effective at reaching those in need (Damschroder & Lowery, 2013). Patient barriers to accessing and receiving preventive care services arise at all levels of health care delivery, including patient, provider, team, organizational, and policy levels (Damschroder et al., 2009). Existing research focuses mainly on organizational factors which influence rates of breast and colorectal cancer screenings (Krok-Schoen et al., 2015; Palmer et al., 2011). More studies specific to FQHCs, PCMHs, and other safety-net settings could to be done to identify the strengths and limitations of each model in addressing patient barriers to care (Martinez-Gutierrez et al., 2013).

Safety-net systems can pay more attention to the concept of health literacy, which is defined by the Affordable Care Act as the degree to which an individual has the capacity to obtain, communicate, and understand basic health information in order to make appropriate health decisions (Centers for Disease Control and Prevention, 2015). There is a growing body of literature available to support organizations wishing to improve health literacy (Agency for Healthcare Research and Quality, 2016; Joint Commission, 2007; National Institutes of Health, 2016; Office of the Surgeon General & Office of Disease Prevention Health Promotion, 2006). The Institute of Medicine and Department of Health and Human Services have recommended that health systems wishing to address health literacy barriers investigate existing health curricula and materials which have been shown to reduce literacy barriers (Kindig, Panzer, & Nielsen-Bohlman, 2004; U.S. Department of Health Human Services, 2010). They recommend that systems begin by engaging patients within their target population as well as members and leaders within the community to gather ideas and input for making culturally- and linguistically-appropriate changes. Insights from these populations may offer valuable perspective on how community members receive and interpret important health messages. Additional suggestions in the literature to help guide health systems include making changes to health communications an organizational priority, analyzing communication needs across the continuum of care, implementing policy changes which promote patient-provider interaction, and exploring the use of technological applications or software which allow for tailored communications based on language and literacy levels (Joint Commission, 2007; Office of the Surgeon General & Office of Disease Prevention Health Promotion, 2006). Safety-net systems can take advantage of these tools in an effort to address patient barriers to care in their communities, especially those due to literacy, knowledge and awareness, language, and fear.

Further, more attention can be focused on community- and patient-level barriers that patients experience, particularly among disadvantaged populations. To fill gaps in research and understanding, safety-net systems should consider gathering feedback on a regular basis directly from patients within their communities regarding access barriers, as well as suggestions for how to address and overcome such barriers (N. Cook et al., 2015; Ragas et al., 2014). Gathering data and conducting research which involves patients and community members in the planning, implementation, and evaluation of interventions could also help tailor interventions to meet local needs and effectively address specific community barriers. Using CFIR constructs can be helpful for gathering and organizing such data. Narrowing the definitions of constructs such as “Patient Needs and Resources” will allow organizations to collect data which is more specific to the unique barriers which safety-net systems are trying to address. Safety-net systems can specifically seek funding to support their efforts from grant programs aimed at reducing patient access barriers. Throughout this process, it will be important for systems to weigh the needs and preferences of patients with existing limitations on available resources, focusing on obstacles which can be addressed realistically and most effectively.

References

Abbott, P. A., Foster, J., Marin Hde, F., & Dykes, P. C. (2014). Complexity and the science of implementation in health IT-knowledge gaps and future visions. *Int J Med Inform, 83*(7), 13.

Adams, S. A., Choi, S. K., Eberth, J. M., Friedman, D. B., Yip, M. P., Tucker-Seeley, R. D., . . . Hebert, J. R. (2015). Is availability of mammography services at Federally Qualified Health Centers associated with breast cancer Mortality-to-Incidence Ratios? An Ecological Analysis. *J Womens Health (Larchmt)*. doi: 10.1089/jwh.2014.5114

Adams, S. A., Choi, S. K., Khang, L., D, A. C., Friedman, D. B., Eberth, J. M., . . . Hebert, J. R. (2015). Decreased cancer Mortality-to-Incidence Ratios with increased accessibility of Federally Qualified Health Centers. *J Community Health, 40*(4), 633-641. doi: 10.1007/s10900-014-9978-8

Agency for Healthcare Research and Quality. (2013, May 2013). Module 2. Working With Safety Net Practices. Retrieved 02 April 2016, from http://www.ahrq.gov/professionals/prevention-chronic-care/improve/system/pfhandbook/mod2.html

Agency for Healthcare Research and Quality. (2016, March 2016). AHRQ Health Literacy Universal Precautions Toolkit. Retrieved from http://www.ahrq.gov/professionals/quality-patient-safety/quality-resources/tools/literacy-toolkit/index.html

Allen, C. L., Harris, J. R., Hannon, P. A., Parrish, A. T., Hammerback, K., Craft, J., & Gray, B. (2014). Opportunities for improving cancer prevention at federally qualified health centers. *J Cancer Educ, 29*(1), 30-37. doi: 10.1007/s13187-013-0535-4

Almufleh, A., Gabriel, T., Tokayer, L., Comerford, M., Alaqeel, A., & Kurlansky, P. (2015). Role of community health outreach program "living for health" in improving access to federally qualified health centers in Miami-dade County, Florida: a cross-sectional study. *BMC Health Serv Res, 15*, 181. doi: 10.1186/s12913-015-0826-z

American Cancer Society Inc. (2013). Cancer Facts & Figures for African Americans 2013-2014. Atlanta: American Cancer Society.

American Cancer Society Inc. (2014). Colorectal Cancer Facts & Figures 2014-2016. Atlanta: American Cancer Society.

American Cancer Society Inc. (2015a). Breast Cancer Facts & Figures 2015-2016. Atlanta: American Cancer Society.

American Cancer Society Inc. (2015b). Cancer Facts & Figures 2015. Atlanta: American Cancer Society.

American Cancer Society Inc. (2015c). Cancer Facts & Figures for Hispanics/Latinos 2015-2017. Atlanta: American Cancer Society.

American Cancer Society Inc. (2016). About Us. 2016, Retrieved from http://www.cancer.org/aboutus/index

Arnold, C. L., Rademaker, A., Bailey, S. C., Esparza, J. M., Reynolds, C., Liu, D., . . . Davis, T. C. (2012). Literacy barriers to colorectal cancer screening in community clinics. *J Health Commun, 17 Suppl 3*, 252-264. doi: 10.1080/10810730.2012.713441

Barry, M. J., & Edgman-Levitan, S. (2012). Shared decision making—the pinnacle of patient-centered care. *New England Journal of Medicine, 366*(9), 780-781.

Berenson, J., Doty, M. M., Abrams, M. K., & Shih, A. (2012). Achieving better quality of care for low-income populations: the roles of health insurance and the medical home in reducing health inequities. *Issue Brief (Commonw Fund), 11*, 1-18.

Bodenheimer, T. (2011). Building blocks of the patient-centered medical/health home: comment on "colorectal cancer screening among ethnically diverse, low-income patients". *Arch Intern Med, 171*(10), 912-913.

Breimaier, H. E., Heckemann, B., Halfens, R. J., & Lohrmann, C. (2015). The Consolidated Framework for Implementation Research (CFIR): a useful theoretical framework for guiding and evaluating a guideline implementation process in a hospital-based nursing practice. *BMC Nurs, 14*(1), 43.

Calman, N. S., Hauser, D., Weiss, L., Waltermaurer, E., Molina-Ortiz, E., Chantarat, T., & Bozack, A. (2013). Becoming a patient-centered medical home: a 9-year transition for a network of Federally Qualified Health Centers. *Ann Fam Med, 11 Suppl 1*, S68-73. doi: 10.1370/afm.1547

Carcaise-Edinboro, P., & Bradley, C. J. (2008). Influence of patient-provider communication on colorectal cancer screening. *Med Care, 46*(7), 738-745. doi: 10.1097/MLR.0b013e318178935a

Centers for Disease Control and Prevention. (2014a, 21 July 2014). Are There Different Kinds of Breast Cancer? (2016) Retrieved from http://www.cdc.gov/cancer/breast/basic_info/kinds-of-breast-cancer.htm

Centers for Disease Control and Prevention. (2014b, 17 February 2016). Colorectal Cancer Screening Tests. Retrieved from http://www.cdc.gov/cancer/colorectal/basic_info/screening/tests.htm

Centers for Disease Control and Prevention. (2014c, 07 October 2014). What Is Breast Cancer? Retrieved from www.cdc.gov/cancer/breast/basic_info/what-is-breast-cancer.htm

Centers for Disease Control and Prevention. (2015, 30 September 2015). Learn About Health Literacy. Retrieved from http://www.cdc.gov/healthliteracy/learn/index.html

Centers for Disease Control and Prevention. (n.d.-a, 17 February 2016). Basic Information About Colorectal Cancer. 2016, Retrieved from www.cdc.gov/cancer/colorectal/basic_info/index.htm

Centers for Disease Control and Prevention. (n.d.-b, 23 March 2016). Colorectal Cancer Statistics. 2016, Retrieved from www.cdc.gov/cancer/colorectal/statistics/index.htm

Centers for Disease Control and Prevention. (n.d.-c, 01 December 2014). What Are the Risk Factors for Colorectal Cancer? 2015, Retrieved from http://www.cdc.gov/cancer/colorectal/basic_info/risk_factors.htm

Choi, S. K., Adams, S. A., Eberth, J. M., Brandt, H. M., Friedman, D. B., Tucker-Seeley, R. D., . . . Hebert, J. R. (2015). Medicaid coverage expansion and implications for cancer disparities. *Am J Public Health, 105 Suppl 5*, S706-712. doi: 10.2105/ajph.2015.302876

Community Preventive Services Task Force. (2010, 19 April 2016). Increasing Cancer Screening: Reducing Structural Barriers for Clients. Retrieved from http://www.thecommunityguide.org/cancer/screening/client-oriented/ReducingStructuralBarriers.html

Community Preventive Services Task Force. (2013, 17 December 2013). Cancer Prevention and Control. Retrieved from http://www.thecommunityguide.org/cancer/index.html

Cook, C., & Rockwood, K. (2013). Knowledge translation: an overview and recommendations in relation to the Fourth Canadian Consensus Conference on the Diagnosis and Treatment of Dementia. *Alzheimers Res Ther, 5*(Suppl 1), 8.

Cook, N., Hollar, L., Isaac, E., Paul, L., Amofah, A., & Shi, L. (2015). Patient experience in health center medical homes. *J Community Health, 40*(6), 1155-1164.

Coronado, G. D., Petrik, A. F., Spofford, M., Talbot, J., Do, H. H., & Taylor, V. M. (2015). Clinical perspectives on colorectal cancer screening at Latino-serving federally qualified health centers. *Health Educ Behav, 42*(1), 26-31. doi: 10.1177/1090198114537061

Coronado, G. D., Sanchez, J., Petrik, A., Kapka, T., DeVoe, J., & Green, B. (2014). Advantages of wordless instructions on how to complete a fecal immunochemical test: lessons from patient advisory council members of a federally qualified health center. *J Cancer Educ, 29*(1), 86-90. doi: 10.1007/s13187-013-0551-4

Coronado, G. D., Schneider, J. L., Sanchez, J. J., Petrik, A. F., & Green, B. (2015). Reasons for non-response to a direct-mailed FIT kit program: lessons learned from a pragmatic colorectal-cancer screening study in a federally sponsored health center. *Transl Behav Med, 5*(1), 60-67. doi: 10.1007/s13142-014-0276-x

Crabtree, B. F., Nutting, P. A., Miller, W. L., Stange, K. C., Stewart, E. E., & Jaén, C. R. (2010). Summary of the National Demonstration Project and recommendations for the patient-centered medical home. *The Annals of Family Medicine, 8*(Suppl 1), S80-S90.

Daly, J. M., Levy, B. T., Moss, C. A., & Bay, C. P. (2014). System strategies for colorectal cancer screening at Federally Qualified Health Centers. *American Journal of Public Health, 105*(1), 212-219. doi: 10.2105/AJPH.2013.301790

Damschroder, L. J., Aron, D. C., Keith, R. E., Kirsh, S. R., Alexander, J. A., & Lowery, J. C. (2009). Fostering implementation of health services research findings into practice: a consolidated framework for advancing implementation science. *Implement Sci, 4,* 50. doi: 10.1186/1748-5908-4-50

Damschroder, L. J., & Hagedorn, H. J. (2011). A guiding framework and approach for implementation research in substance use disorders treatment. *Psychol Addict Behav, 25*(2), 194-205. doi: 10.1037/a0022284

Damschroder, L. J., & Lowery, J. C. (2013). Evaluation of a large-scale weight management program using the consolidated framework for implementation research (CFIR). *Implement Sci, 8*, 51. doi: 10.1186/1748-5908-8-51

Darsie, B., Rico, J., Gadgil, M., & Tootoo, J. (2015). Colorectal cancer burden and access to Federally Qualified Health Centers in California. *Prev Chronic Dis, 12*, E169. doi: 10.5888/pcd12.150162

Davis, T. C., Arnold, C. L., Rademaker, A., Bailey, S. C., Platt, D. J., Reynolds, C., . . . Wolf, M. S. (2012). Differences in barriers to mammography between rural and urban women. *J Womens Health (Larchmt), 21*(7), 748-755. doi: 10.1089/jwh.2011.3397

Dominguez, K., Penman-Aguilar, A., Chang, M. H., Moonesinghe, R., Castellanos, T., Rodriguez-Lainz, A., & Schieber, R. (2015). Vital signs: leading causes of death, prevalence of diseases and risk factors, and use of health services among Hispanics in the United States - 2009-2013. *MMWR Morb Mortal Wkly Rep, 64*(17), 469-478.

Emmons, K. M., Cleghorn, D., Tellez, T., Greaney, M. L., Sprunck, K. M., Bastani, R., . . . Puleo, E. (2011). Prevalence and implications of multiple cancer screening needs among Hispanic community health center patients. *Cancer Causes Control, 22*(9), 1343-1349. doi: 10.1007/s10552-011-9807-7

Ferrante, J. M., Balasubramanian, B. A., Hudson, S. V., & Crabtree, B. F. (2010). Principles of the patient-centered medical home and preventive services delivery. *The Annals of Family Medicine, 8*(2), 108-116.

Forman, J., Harrod, M., Robinson, C., Annis-Emeott, A., Ott, J., Saffar, D., . . . Greenstone, C. L. (2014). First Things First: Foundational requirements for a medical home in an academic medical center. *J Gen Intern Med, 9*, 9.

Goldman, S. N., Liss, D. T., Brown, T., Lee, J. Y., Buchanan, D. R., Balsley, K., . . . Baker, D. W. (2015). Comparative effectiveness of multifaceted outreach to initiate colorectal cancer screening in community health centers: a randomized controlled trial. *J Gen Intern Med*. doi: 10.1007/s11606-015-3234-5

Gwede, C. K., Davis, S. N., Quinn, G. P., Koskan, A. M., Ealey, J., Abdulla, R., . . . Meade, C. D. (2013). Making it work: health care provider perspectives on strategies to increase colorectal cancer screening in federally qualified health centers. *J Cancer Educ, 28*(4), 777-783. doi: 10.1007/s13187-013-0531-8

Gwede, C. K., Koskan, A. M., Quinn, G. P., Davis, S. N., Ealey, J., Abdulla, R., . . . Meade, C. D. (2015). Patients' perceptions of colorectal cancer screening tests and preparatory education in federally qualified health centers. *J Cancer Educ, 30*(2), 294-300. doi: 10.1007/s13187-014-0733-8

Hartzler, B., Lash, S. J., & Roll, J. M. (2012). Contingency management in substance abuse treatment: a structured review of the evidence for its transportability. *Drug Alcohol Depend, 122*(1-2), 1-10.

Hatcher-Keller, J., Rayens, M. K., Dignan, M., Schoenberg, N., & Allison, P. (2014). Beliefs regarding mammography screening among women visiting the emergency department for nonurgent care. *J Emerg Nurs, 40*(2), e27-35. doi: 10.1016/j.jen.2013.01.015

Health Resources and Services Administration. (n.d.) Colorectal Cancer Screening. Retrieved from http://www.hrsa.gov/quality/toolbox/measures/colorectalcancer/

Henderson, S., Princell, C. O., & Martin, S. D. (2012). The patient-centered medical home. *AJN The American Journal of Nursing, 112*(12), 54-59.

Honeycutt, S., Green, R., Ballard, D., Hermstad, A., Brueder, A., Haardorfer, R., . . . Arriola, K. J. (2013). Evaluation of a patient navigation program to promote colorectal cancer screening in rural Georgia, USA. *Cancer, 119*(16), 3059-3066. doi: 10.1002/cncr.28033

Ilott, I., Gerrish, K., Booth, A., & Field, B. (2013). Testing the Consolidated Framework for Implementation Research on health care innovations from South Yorkshire. *J Eval Clin Pract, 19*(5), 915-924. doi: 10.1111/j.1365-2753.2012.01876.x

Inadomi, J. M., Md, Vijan, S., Md, Ms, Janz, N. K., . . . et al. (2012). Adherence to colorectal cancer screening: a randomized clinical trial of competing strategies. *Arch Intern Med, 172*(7), 575-582. doi: 10.1001/archinternmed.2012.332

Jackson, G. L., Powers, B. J., Chatterjee, R., Bettger, J. P., Kemper, A. R., Hasselblad, V., . . . Kendrick, A. S. (2013). The patient-centered medical home: a systematic review. *Ann Intern Med, 158*(3), 169-178.

Joint Commission. (2007). *What did the doctor say?: Improving health literacy to protect patient safety*: Joint Commission on Accreditation of Healthcare Organizations.

Jones, A. S., & Sajid, P. S. (2009). A primer on health care safety nets. *Robert Wood Johnson Foundation, Princeton (NJ).*

Kaiser Family Foundation. (2016). Poverty Rate by Race/Ethnicity. Retrieved 02 April 2016, Retrieved from http://kff.org/other/state-indicator/poverty-rate-by-raceethnicity/

Katz, A. B., Felland, L. E., Hill, I., & Stark, L. B. (2011). A long and winding road: federally qualified health centers, community variation and prospects under reform. *Res Brief*(21), 1-9.

Kegler, M., Beasley D., Liang, S., Cotter, M., Phillips, E., Hermstad, A.,…Riehman, K. (2016). *Using the Consolidated Framework for Implementation Research to understand safety net system efforts to increase colorectal cancer screening rates.* Manuscript submitted for publication.

Kimura, A., Sin, M. K., Spigner, C., Tran, A., & Tu, S. P. (2014). Barriers and facilitators to colorectal cancer screening in Vietnamese Americans: a qualitative analysis. *J Cancer Educ, 29*(4), 728-734. doi: 10.1007/s13187-014-0646-6

Kindig, D. A., Panzer, A. M., & Nielsen-Bohlman, L. (2004). *Health Literacy: A Prescription to End Confusion*: National Academies Press.

Ko, M., Cummings, J. R., & Ponce, N. A. (2015). Changes in the supply of US rural health centers, 2000-2011: Implications for rural minority communities. *J Rural Health*. doi: 10.1111/jrh.12147

Kohler, B. A., Sherman, R. L., Howlader, N., Jemal, A., Ryerson, A. B., Henry, K. A., . . . Penberthy, L. (2015). Annual report to the nation on the status of cancer, 1975-2011, featuring incidence of breast cancer subtypes by race/ethnicity, poverty, and state. *Journal of the National Cancer Institute, 107*(6). doi: 10.1093/jnci/djv048

Krok-Schoen, J. L., Kurta, M. L., Weier, R. C., Young, G. S., Carey, A. B., Tatum, C. M., & Paskett, E. D. (2015). Clinic type and patient characteristics affecting time to resolution after an abnormal cancer-screening exam. *Cancer Epidemiol Biomarkers Prev, 24*(1), 162-168. doi: 10.1158/1055-9965.epi-14-0692

Lash, S. J., Timko, C., Curran, G. M., McKay, J. R., & Burden, J. L. (2011). Implementation of evidence-based substance use disorder continuing care interventions. *Psychology of Addictive Behaviors, 25*(2), 238-251. doi: 10.1037/a0022608

Lasser, K. E., Murillo, J., Lisboa, S., Casimir, A. N., Valley-Shah, L., Emmons, K. M., . . . Ayanian, J. Z. (2011). Colorectal cancer screening among ethnically diverse, low-income patients: a randomized controlled trial. *Arch Intern Med, 171*(10), 906-912. doi: 10.1001/archinternmed.2011.201

Liang, S., Kegler, M., Cotter, M., Phillips, E., Beasley, D., Hermstad, A.,…Riehman, K. (2016). *Integrating evidence-based practices for increasing cancer screenings in safety net health systems: A multiple case study using the Consolidated Framework For Implementation Theory.* Manuscript submitted for publication.

Lipson, D., Rich, E., Libersky, J., & Parchman, M. (2011). Ensuring that patient-centered medical homes effectively serve patients with complex health needs. *Prepared by Mathematica Policy Research under Contract No. HHSA2902009000191TO2). AHRQ Publication* (11-0109).

Luck, J., Bowman, C., York, L., Midboe, A., Taylor, T., Gale, R., & Asch, S. (2014). Multimethod evaluation of the VA's peer-to-peer Toolkit for patient-centered medical home implementation. *J Gen Intern Med, 29 Suppl 2,* S572-578. doi: 10.1007/s11606-013-2738-0

Martinez-Gutierrez, J., Jhingan, E., Angulo, A., Jimenez, R., Thompson, B., & Coronado, G. D. (2013). Cancer screening at a federally qualified health center: a qualitative study on organizational challenges in the era of the patient-centered medical home. *J Immigr Minor Health, 15*(5), 993-1000. doi: 10.1007/s10903-012-9701-8

McCarthy, D. M., Waite, K. R., Curtis, L. M., Engel, K. G., Baker, D. W., & Wolf, M. S. (2012). What did the doctor say? Health literacy and recall of medical instructions. *Med Care, 50*(4), 277-282. doi: 10.1097/MLR.0b013e318241e8e1

McLachlan, S.-A., Clements, A., & Austoker, J. (2012). Patients' experiences and reported barriers to colonoscopy in the screening context—a systematic review of the literature. *Patient Educ Couns, 86*(2), 137-146.

Mead, H., Andres, E., & Regenstein, M. (2013). Underserved patients' perspectives on patient-centered primary care: does the patient-centered medical home model meet their needs? *Medical Care Research and Review*, 1077558713509890.

Midboe, A. M., Cucciare, M. A., Trafton, J. A., Ketroser, N., & Chardos, J. F. (2011). Implementing motivational interviewing in primary care: the role of provider characteristics. *Transl Behav Med, 1*(4), 588-594. doi: 10.1007/s13142-011-0080-9

National Cancer Institute. (2015a). NCI self-generated report on Cancer Trends.

National Cancer Institute. (2015b, 26 May 2015). Screening Rates for Several Cancers Miss Their Targets. Retrieved from http://www.cancer.gov/news-events/cancer-currents-blog/2015/screening-targets

National Cancer Institute. (2016a, 01 April 2016). Cancer Screening Overview-Health Professional Version (PDQ). Retrieved from http://www.cancer.gov/about-cancer/screening/hp-screening-overview-pdq

National Cancer Institute. (2016b). SEER Stat Fact Sheets: Colon and Rectum Cancer. 2016, Retrieved from http://seer.cancer.gov/statfacts/html/colorect.html

National Cancer Institute. (n.d.-a, 14 March 2016). Cancer Statistics. 2016, Retrieved from www.cancer.gov/about-cancer/what-is-cancer/statistics

National Cancer Institute. (n.d.-b, February 9, 2015). What is Cancer? Retrieved March 23, 2016, Retrieved from http://www.cancer.gov/about-cancer/what-is-cancer#how-cancer-arises

National Institutes of Health. (2016, 24 February 2016). Health Literacy. Retrieved from https://www.nih.gov/institutes-nih/nih-office-director/office-communications-public-liaison/clear-communication/health-literacy

Nguyen, T. U., Tran, J. H., Kagawa-Singer, M., & Foo, M. A. (2011). A qualitative assessment of community-based breast health navigation services for Southeast Asian women in Southern California: recommendations for developing a navigator training curriculum. *Am J Public Health, 101*(1), 87-93. doi: 10.2105/ajph.2009.176743

Nonzee, N. J., Ragas, D. M., Ha Luu, T., Phisuthikul, A. M., Tom, L., Dong, X., & Simon, M. A. (2015). Delays in cancer care among low-income minorities despite access. *Journal of Women's Health, 24*(6), 506-514.

Nutting, P. A., Crabtree, B. F., Miller, W. L., Stange, K. C., Stewart, E., & Jaén, C. (2011). Transforming physician practices to patient-centered medical homes: lessons from the national demonstration project. *Health affairs, 30*(3), 439-445.

Office of the Surgeon General, & Office of Disease Prevention Health Promotion. (2006). Proceedings of the Surgeon General’s Workshop on Improving Health Literacy: September 7, 2006, National Institutes of Health, Bethesda, MD.

Palmer, R. C., Samson, R., Batra, A., Triantis, M., & Mullan, I. D. (2011). Breast cancer screening practices of safety net clinics: results of a needs assessment study. *BMC Womens Health, 11*, 9. doi: 10.1186/1472-6874-11-9

Porter, A. C., Fitzgibbon, M. L., Fischer, M. J., Gallardo, R., Berbaum, M. L., Lash, J. P., . . . Tulley, J. (2015). Rationale and design of a patient-centered medical home intervention for patients with end-stage renal disease on hemodialysis. *Contemporary clinical trials, 42*, 1-8.

Powe, B. D., Cooper, D. L., Harmond, L., Ross, L., Mercado, F. E., & Faulkenberry, R. (2009). Comparing knowledge of colorectal and prostate cancer among African American and Hispanic men. *Cancer Nurs, 32*(5), 412-417. doi: 10.1097/NCC.0b013e3181aaf10e

Ragas, D. M., Nonzee, N. J., Tom, L. S., Phisuthikul, A. M., Luu, T. H., Dong, X., & Simon, M. A. (2014). What women want: patient recommendations for improving access to breast and cervical cancer screening and follow-up. *Womens Health Issues, 24*(5), 511-518. doi: 10.1016/j.whi.2014.06.011

Rastogi, S., & U.S. Bureau of the Census. (2011). *The black population: 2010*: US Department of Commerce, Economics and Statistics Administration, US Census Bureau.

Redwood, D., Provost, E., Asay, E., Roberts, D., Haverkamp, D., Perdue, D., . . . Espey, D. (2014). Comparison of fecal occult blood tests for colorectal cancer screening in an Alaska Native population with high prevalence of Helicobacter pylori infection, 2008-2012. *Prev Chronic Dis, 11*, E56. doi: 10.5888/pcd11.130281

Richards, M. R., Saloner, B., Kenney, G. M., Rhodes, K., & Polsky, D. (2014). Access points for the underserved: primary care appointment availability at federally qualified health centers in 10 States. *Med Care, 52*(9), 818-825. doi: 10.1097/mlr.0000000000000184

Robins, L. S., Jackson, J. E., Green, B. B., Korngiebel, D., Force, R. W., & Baldwin, L. M. (2013). Barriers and facilitators to evidence-based blood pressure control in community practice. *J Am Board Fam Med, 26*(5), 539-557. doi: 10.3122/jabfm.2013.05.130060

Rojas Smith, L., Ashok, M., Morss Dy, S., Wines, R. C., & Teixeira-Poit, S. (2014). *AHRQ Methods for Effective Health Care: Contextual Frameworks for Research on the Implementation of Complex System Interventions*. Rockville (MD): Agency for Healthcare Research and Quality (US).

Ross, J. S., Bernheim, S. M., Bradley, E. H., Teng, H. M., & Gallo, W. T. (2007). Use of preventive care by the working poor in the United States. *Prev Med, 44*(3), 254-259. doi: 10.1016/j.ypmed.2006.11.006

Rothkopf, J., Brookler, K., Wadhwa, S., & Sajovetz, M. (2011). Medicaid patients seen at federally qualified health centers use hospital services less than those seen by private providers. *Health Aff (Millwood), 30*(7), 1335-1342. doi: 10.1377/hlthaff.2011.0066

Sarfaty, M., Doroshenk, M., Hotz, J., Brooks, D., Hayashi, S., Davis, T. C., . . . Wender, R. (2013). Strategies for expanding colorectal cancer screening at community health centers. *CA Cancer J Clin, 63*(4), 221-231. doi: 10.3322/caac.21191

Sarfaty, M., Wender, R., & Smith, R. (2011). Promoting cancer screening within the patient centered medical home. *CA Cancer J Clin, 61*(6), 397-408.

Shi, L., Chen, C. C., Nie, X., Zhu, J., & Hu, R. (2014). Racial and socioeconomic disparities in access to primary care among people with chronic conditions. *J Am Board Fam Med, 27*(2), 189-198. doi: 10.3122/jabfm.2014.02.130246

Shi, L., Tsai, J., Higgins, P. C., & Lebrun, L. A. (2009). Racial/ethnic and socioeconomic disparities in access to care and quality of care for U.S. health center patients compared with non-health center patients. *J Ambul Care Manage, 32*(4), 342-350. doi: 10.1097/JAC.0b013e3181ba6fd8

Smith, S. G., von Wagner, C., McGregor, L. M., Curtis, L. M., Wilson, E. A., Serper, M., & Wolf, M. S. (2012). The influence of health literacy on comprehension of a colonoscopy preparation information leaflet. *Dis Colon Rectum, 55*(10), 1074-1080. doi: 10.1097/DCR.0b013e31826359ac

Sorensen, J. L., & Kosten, T. (2011). Developing the tools of implementation science in substance use disorders treatment: applications of the consolidated framework for implementation research. *Psychol Addict Behav, 25*(2), 262-268. doi: 10.1037/a0022765

Stange, K. C., Nutting, P. A., Miller, W. L., Jaén, C. R., Crabtree, B. F., Flocke, S. A., & Gill, J. M. (2010). Defining and measuring the patient-centered medical home. *Journal of General Internal Medicine, 25*(6), 601-612.

Tuepker, A., Kansagara, D., Skaperdas, E., Nicolaidis, C., Joos, S., Alperin, M., & Hickam, D. (2014). “We’ve Not Gotten Even Close to What We Want to Do”: a qualitative study of early patient-centered medical home implementation. *Journal of General Internal Medicine, 29*(2), 614-622.

U.S. Cancer Statistics Working Group. (2015). United States Cancer Statistics: 1999-2012 Incidence and Mortality Web-based Report. Atlanta (GA).

U.S. Department of Health Human Services. (2010). National action plan to improve health literacy. *Washington, DC: Department of Health and Human Services*.

U.S. Preventive Services Task Force. (2008). Screening for colorectal cancer: U.S. Preventive Services Task Force recommendation statement. *Ann Intern Med, 149*(9), 627-637.

Williams, E. C., Johnson, M. L., Lapham, G. T., Caldeiro, R. M., Chew, L., Fletcher, G. S., . . . Bradley, K. A. (2011). Strategies to implement alcohol screening and brief intervention in primary care settings: a structured literature review. *Psychol Addict Behav*, *25*(2), 206-214.

Wright, B., & Nice, A. J. (2015). Variation in local health department primary care services as a function of health center availability. *J Public Health Manag Pract*, *21*(1), E1-9. doi: 10.1097/phh.0000000000000112

Wright, B., Potter, A. J., & Trivedi, A. (2015). Federally Qualified Health Center use among dual eligibles: Rates of hospitalizations and emergency department visits. *Health Aff (Millwood), 34*(7), 1147-1155. doi: 10.1377/hlthaff.2014.0823

Yin, R. (2003). Qualitative research methods: Thousand Oaks, CA: Sage.