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Prostate Cancer and PSA Testing: Implications of Provider-Patient Communication and Shared-Decision Making on National Screening Recommendations

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by
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ABSTRACT

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The national recommendations for use of the prostate specific antigen (PSA) test for prostate cancer screening have been modified over the years as scientific evidence emerged. Current screening recommendations discourage widespread PSA screening for men at low to average risk, but provide specific guidelines for shared-decision making between men and their health providers about the benefits and risks of PSA testing. This study was an examination of relationships between men's assessment of the quality of their care and communication with their health providers, the extent to which providers engage men in recommended discussions about PSA testing, and factors associated with shared-decision making and PSA testing. Secondary data from the U.S. Health Information National Trends Survey 4, Cycle 2 that included men with no history of prostate cancer and in the recommended age ranges for prostate cancer screening were analyzed (N=777). Non-Hispanic white men rated their quality of care higher than men of other races (χ^2 (49, *n=635*) = 7.23, *p* = 0.0098), whereas Hispanic men gave the lowest ratings compared to other men (χ^2 (49, *n=635*) = 5.42, *p* = 0.024). Previous PSA testing was reported by 64% of the men, 56% of whom stated that they discussed screening with their provider and 80% reported that they were asked if they wanted to have the test done. However, only 21% - 39% reported having ever discussed the pros and cons of PSA testing. Discussing PSA testing with a provider was the strongest predictor of obtaining the test (OR=69.5, *CI = 23.6 – 204.6*), but the effect was significantly modified when providers and patients engaged in the shared-decision making process (OR = 47.42, *CI = 14.91 – 150.74*).

Age, education level, and perceived quality of care were consistent positive predictors of PSA testing. These results indicate there is a gap in provider-patient discussions about PSA screening and suggest that health providers may not be following the recommended guidelines for the content of the discussions needed to facilitate shared-decision making. Effective provider-based interventions to increase shared-decision-making about PSA testing are needed if the national objectives for prostate cancer screening are to be met.

DEDICATION

To my brothers Asquith Anderson Reece and Kevin Lawrence Reece

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ACRONYMS AND ABBREVIATIONS

ACS	American Cancer Society
ARC	Appalachian Regional Council
AUA	American Urological Association
BPH	Benign Prostatic Hyperplasia
CAHPS	Consumer Assessment of Health Providers and Systems
CDC	Centers For Disease Control And Prevention
CI	Confidence Interval
DRE	Digital Rectal Exam
HBM	Health Beliefs Model
HINTS	Health Information National Trends Survey
MSG	Management Systems Group
NCI	National Cancer Institute
OR	Odds Ratio
PSA	Prostate Specific Antigen
USPSTF	United States Preventive Services Task Force

CHAPTER 1

INTRODUCTION

Background

The prostate specific antigen test is one of the most important biochemical cancer tumor markers identified in the 20th century (Kuriyama et al., 1981). The prostate specific antigen (PSA) is a glycoprotein that is released by both normal and cancerous prostate tissue (Zelefsky, Eastham, & Sartor, 2011). Landmark achievements in prostate cancer research led to the detection of elevated levels of the prostate specific antigen in the blood serum of men with advanced stage prostate cancer and the acceptance of the PSA as a biomarker for prostate cancer in adult males (Chu, 1994; Balk, Ko, & Bubley, 2003; Stamey & Kabalin, 1989; Stamey et al., 1989). Also see Appendix A.

Since the mid 1980s the PSA test has been used as a screening tool for prostate cancer for older adult men and as a test to evaluate and monitor men previously diagnosed with prostate cancer to measure the effectiveness of their treatment (NCI, 2013d). The PSA test has been shrouded in controversy since the early stages of research that led to its identification, and this controversy continues today as many researchers, scientists, and cancer advocates argue about the use of the PSA as an efficacous screening test for prostate cancer (Barry, 2009; Hayes & Barry, 2014).

Even though there are other factors that could cause an elevation in a man's PSA level, numerous studies have repeatedly shown that prostate specific antigens are consistently expressed in nearly all types of prostate cancers. As a man's PSA blood level increases so does his likelihood of having an accurate diagnosis of prostate cancer (Stamey et al., 1989). There have been very few reported cases where men diagnosed with prostate cancer did not appear to

have elevated PSA level in their blood serum (Hoffman, 2013; Thompson et al., 2004; Zelefsky et al., 2011).

Epidemiology of Prostate Cancer in the USA

Prostate cancer screening and particularly the use of the PSA test is an important concern in public health globally and nationally. Prostate cancer is the most frequently diagnosed nonskin cancer and the second leading cause of cancer deaths in American men after lung cancer. Estimates from the National Cancer Institute (NCI) for incidence, mortality, and prevalence for 2014 indicate that there will be approximately 233,000 new cases of prostate cancer that account for over 14% of all new cancer cases in 2014 (Siegel et al., 2014). This figure indicates a decrease in the projected incidence from 2013 where it was estimated that there would have been approximately 238,590 new cases in 2013 (Siegel et al., 2013). Nearly 30,000 deaths will result from prostate cancer (5% of all cancer deaths). It is further estimated that there are currently over 2.62 million men living with prostate cancer in the US (NCI, 2013b). The lifetime risk for developing invasive prostate cancer is 15.3%. In other words nearly one in seven men will develop prostate cancer in their lifetime (Siegel et al., 2014).

In addition, significant racial disparities exist in prostate cancer incidence and mortality. African American men are 1.6 times more likely to be diagnosed with prostate cancer and are more likely to be diagnosed with advanced stage prostate cancer. They are nearly two and a half times more likely to die from the disease compared to white men and men of other races. Hispanic men and men of Asian descent are less likely to develop prostate cancer than white men (American Cancer Society (ACS), 2014).

Screening Recommendations

There is some disagreement among medical professionals and researchers about the risks, benefits, and efficacy of prostate cancer screening and whether or not this screening saves lives. The two existing procedures that are used to screen for prostate cancer are the prostate specific antigen (PSA) test and the digital rectal exam (DRE). Important questions have been raised about the accuracy, sensitivity, and specificity of these two tests. The uncertainty is based on the apparently conflicting results of two large-scale prospective studies. The first study, the European Randomized Study of Screening for Prostate Cancer (ERSPC) trial, indicated that PSA screening decreased deaths from prostate cancer by 20% even though there was significant increased risk for over diagnosis (Schröder et al., 2009). The second study, the U.S. Prostate, Lung, Colorectal, and Ovarian (PLCO) Cancer Screening Trial, reported that there was no observed mortality benefit from prostate cancer screening when the PSA Test was combined with the DRE (Andriole et al., 2009).

Subsequent to the publication of these studies, a number of other systematic reviews and meta-analyses were carried out to pool together information to provide additional insight into the controversy (Djulbegovic et al., 2010). A number of national public health organizations that provide evidence-based guidance and recommendations for disease screening, treatment, and other medical care have recommended against the widespread use of the PSA test to screen for prostate cancer. The main argument is that there is insufficient evidence to show that the potential benefits of PSA testing outweigh the potential harms of screening (Moyer, 2012; Qaseem, Barry, Denberg, Owens, & Shekelle, 2013; Slatkoff, Gamboa, Zolotor, Mounsey, & Jones 2011).

The Centers for Disease Control and Prevention (CDC), the United States Preventive Services Task Force (USPSTF), the American College of Physicians (ACP), and others recommend that medical providers should not screen for prostate cancer using the PSA test in men who are ambivalent (who do not indicate a clear preference) about obtaining prostate cancer screening, men less than 50 years of age or over 69 years of age or whose life expectancy is less than 10 to 15 years, and men who are considered to be at low to average-risk of developing prostate cancer (Moyer, 2012; Qaseem et al., 2013). The American Cancer Society recommends bi-annual prostate cancer screening for all men ages 50-70 with a life expectancy of at least 10 years, and starting at age 40 or 45 for those considered at high risk (African American men and men of any race or ethnicity with a family history of prostate cancer), in addition to engaging in a process of informed or shared decision-making (ACS, 2013a).

The American Urological Society (AUA) recommends no screening for men under 40 years old or over 70 years old, or men who have less than a 10 to 15 year life expectancy. They recommend screening for men at increased risk from ages 40 to 54 years on an individual basis and for men 55 years old to 69 years old with shared-decision making and based on the man's preferences and beliefs (Carter et al., 2013). The common recommendation across these groups is that if men are to be screened using the PSA test it must be done after a detailed discussion between the patient and his health provider about the basics of prostate cancer, the benefits and risks of prostate cancer screening, what the results could mean, and what follow-up tests might be deemed necessary. This discussion should then lead to men making an informed decision or shared-decision with their health provider about whether they should engage in prostate cancer screening.

Even though the common recommendation is that men should be encouraged to engage in discussions about screening with their health providers so that they can make informed or shared-decisions, very few studies have looked at whether medical providers are engaging men in these detailed discussions about prostate cancer and prostate cancer screening. Some studies suggest that providers may be ordering PSA tests without the shared-decision making process (Slatkoff et al., 2011; Wilkes et al., 2013).

In addition to the fact that men are much less likely to engage in preventive health behaviors than women and tend to delay seeking medical care throughout their life course, there is another major issue that relates to this recommendation (Gast & Peak, 2011; Smith, Braunack-Mayer, & Wittert, 2006; Wenger, 2011). Research indicates that men are less likely to report positive engaged relationships and discussions with their health providers, which impacts health behaviors, medical adherence, and is associated with their overall health outcomes (McCullagh, 2011). Various ideas have been advanced to explain this phenomenon. Some indicate that this is a result of the way men are socialized to deal with health matters as well as a function of their attitudes and beliefs about masculinity and the male role (Creighton & Oliffe, 2010; Griffith, Ober Allen, & Gunter, 2011; Ornelas et al., 2009; Sloan, Gough, & Conner, 2010). Others argue that poor provider patient relationships may stem from historical issues of trust among some racial groups (Cheatham, Barksdale, & Rodgers, 2008; Griffith et al., 2011).

Regional differences exist in prostate cancer incidence that may be a consequence of racial differences and prostate cancer screening up take (Seigel et al., 2014). Other research suggests that these problems are exacerbated in rural or geographically isolated areas. In many rural communities health outcomes are poorer and are often a result of the traditional definitions of masculinity that influences stigma about health care by equating engaging in preventive health

services and other recommended screenings with male weakness. This stigma is complicated by the relatively limited research that focuses specifically on men's health matters in the USA and more specifically in the area of rural men's health issues (Rural Assistance Center, 2012). The Appalachia Community Cancer Network (ACCN) reported that burden of cancer among the people of Appalachia is not getting the attention it deserves (ACCN, 2010; Behringer et al., 2007). No studies were found that specifically addressed prostate cancer screening rates and shared-decision making among men and their health providers in Appalachia or compared these behaviors with non-Appalachian men.

Purpose of the Study

The purpose of this study is to examine the extent to which health providers are engaging men in discussions about the benefits and risks of PSA testing that facilitate shared-decision making about prostate cancer screening 2 years since the release of the new screening recommendations and to identify what factors are associated with shared-decision making and with obtaining a PSA test. The study therefore addresses the implications of the national screening recommendations on prostate cancer screening, incidence, treatment, and mortality. A comparison between Appalachian and non-Appalachian men is included. To accomplish this, a secondary data analysis of the most current cycle of the Health Information National Trends Survey (HINTS) that is collected by the National Cancer Institute was conducted.

Significance of the Study

This study is significant for a number of reasons. First, the prevalence of prostate cancer, the existing disparities, and the controversial recommendations are relevant public health issues. Second, as part of the evidenced based process, it is also important to evaluate if or how well health providers have responded to the national guidelines for prostate cancer screening using the

PSA test. Third, the United States Department of Health and Human Services (HHS) *Healthy People* initiative establishes the national agenda for health priorities in the USA. *Healthy People 2020* included two objectives that specifically target this issue of prostate cancer and prostate cancer screening. The two objectives are (1) to reduce the prostate cancer death rate (Objective C-7) and (2) increase the ratio of men who discuss prostate cancer screening with their health care provider (Objective C-19) (HHS, 2010; Porsche, 2010). Fourth, it is important to examine men's attitudes towards cancer screening, their perceptions of personal risk, their health seeking behaviors, as well as the associated factors that significantly impact their health outcomes in this area. If we could better understand these factors, it may be possible to design more effective programs to encourage men to talk to their doctors about screening options and to actually obtain screening if screening were recommended and desired.

This information may help guide the development of community or provider based interventions to promote shared or informed decision-making for prostate cancer and increase awareness, education, and screening about this disease. Findings from this study may also provide insight into how to improve communication between male consumers and their health providers. It may also help identify health determinants that could lead to a reduction in prostate cancer disparities. It is known that lower levels of educational achievement and financial limitations including lack of health insurance were barriers that prevented some men from getting screened for prostate cancer (Emerson, Reece, Levine, Hull, & Husaini, 2009) but beyond these socioeconomic factors, other psychological, social, geographic, and cultural factors are not as well understood. This study will help address these gaps.

Research Aims

There are four specific aims for this study:

(1) To describe older adult male patients' perceptions of the quality of their care and communication with their health provider and determine whether these perceptions influence PSA screening behavior;

(2) To examine the extent to which health providers are engaging in a shared-decision making process by discussing prostate cancer screening according to the most recent national screening guidelines;

(3) To determine what factors are associated with shared-decision making and provider-patient discussion about PSA testing; and

(4) To estimate the association between male patients' perceptions of the quality of their care, provider patient discussion about prostate cancer, and other factors with PSA testing.

CHAPTER 2

LITERATURE REVIEW

The Prostate Gland: Development, Location, and Function

All men are at some risk for developing prostate cancer, yet there are many men who do not possess correct knowledge about the location and function of this organ that contributes significantly to male development, health, sexual function, and general quality of life (Winterich et al., 2009). The prostate gland is a secondary sex, exocrine organ that is an integral part of the human male reproductive system (Lang, Frame, & Collins, 2009). Prostate development begins before birth but rapid growth occurs during puberty in preparation for the production of semen. An enzyme called 5-alpha reductase converts testosterone into a more potent form known as dihydrotestosterone that signals prostate growth (Hudak, Hernandez, & Thompson, 2006). Stimulated by these androgens the prostate gland continues to grow until adulthood (Hamilton & Freedland, 2011). A healthy prostate gland is chestnut shaped and usually the size of a walnut. The prostate gland secretes a low alkaline fluid that forms approximately 70% of the volume of the seminal fluid that nourishes and protects sperm during ejaculation (Zelefsky et al., 2011).

The prostate gland is located between the bladder and the penis and is anterior to the rectum. The urethra passes through the center of the prostate gland. See Figure 1. The prostate is partly muscular and partly glandular. It is made up of four lobes, four major zones, and ducts that open in to the prostatic part of the urethra. The anterior lobe, also known as the isthmus of prostate, is the narrow middle area of the prostate gland that lies anterior to the urethra (in front). This anterior lobe is mostly nonglandular and is made up of fibromuscular tissue. The median lobe is a cone-shaped portion of the gland located between the urethra and the two ejaculatory ducts. The lateral lobes are located to the right and left of the prostatic urethra and form the

largest mass of the prostate gland and are continuous toward the posterior lobe. The posterior lobe is that part of the lateral lobes that the health provider palpates through the rectum during digital rectal exam (DRE). It lies inferior to the ejaculatory ducts and posterior to the urethra (NCI, 2012).

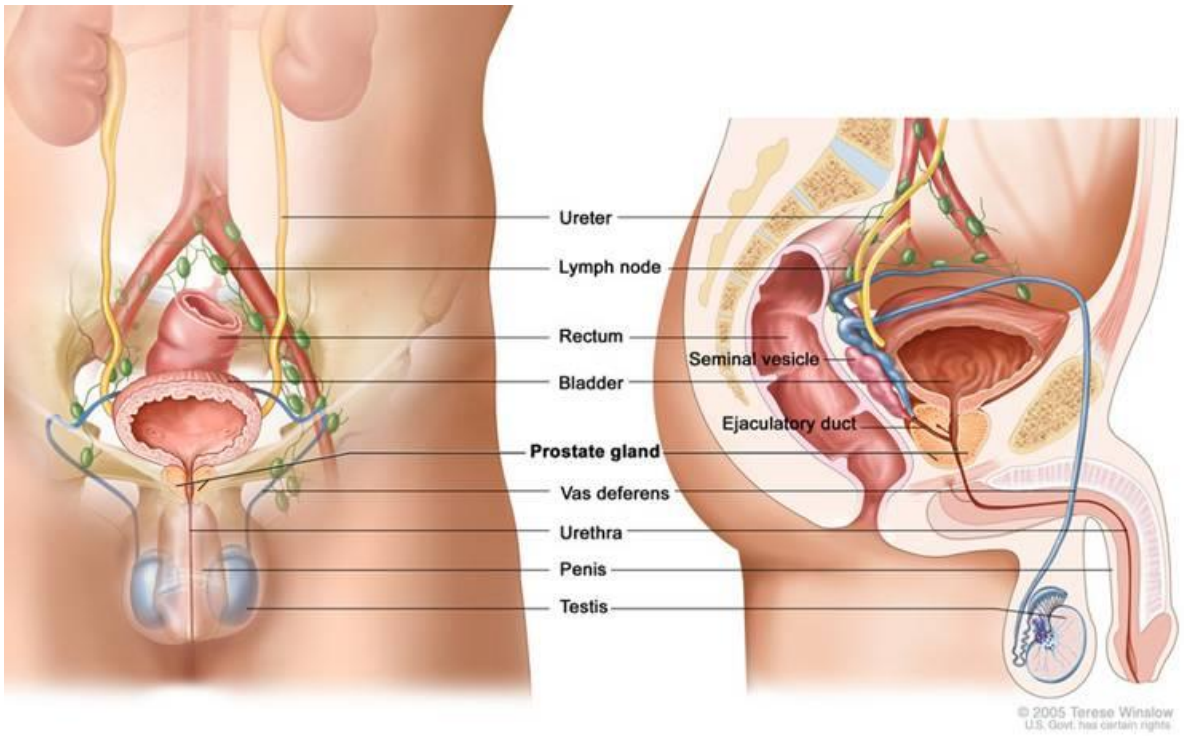

Figure 1. Anatomy of the Human Male Genitourinary Tract and Pelvic Area

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Within the lobes of the prostate there are four zones, the peripheral, transitional, central zones, and anterior fibromuscular stroma (Zelefsky et al., 2011). The peripheral zone, which is the largest area, contains about 75% of the glands in the prostate. The peripheral zone is in the outer most part of the prostate, and the lower peripheral zone is fairly close to the rectal wall. The majority of prostate adenocarcinomas originate in this area accounting for 70%-80% of all prostate cancers (Zelefsky et al., 2011). The transition zone surrounds the urethra and is anterior

to the central zone. It is mostly made up of smooth muscle and occupies about one third of the prostate. Approximately 15% of prostate cancers originate in this region. The central zone is in the center of the prostate and holds most of the remaining glands and surrounds the ejaculatory ducts. Infrequently cancer would originate in this central zone. However, some research has shown that carcinomas originating in this zone tend to be more aggressive and have poor prognoses (Cohen et al., 2008). The anterior fibromuscular zone is nonglandular and consists of a band of smooth muscle fibers and connective tissue that adjoins the smooth muscle of the bladder and the external sphincter and that prevents the back flow of semen into the bladder (Zelefsky et al., 2011).

Pathology of the Prostate

The prostate remains functional and at adult size as long as androgens are present. As men age they have an increasing chance of developing diseases of the prostate. There are three main diseases of the prostate: prostatitis, benign prostatic hyperplasia, and prostate cancer. Prostatitis is inflammation of the prostate gland caused by infection and is most often characterized by swelling, various urinary problems such as hesitancy, discomfort when passing urine (dysuria), and increased frequency at night (nocturia). Other symptoms include pain in the groin, pelvic, or genital area and painful ejaculation, and may sometimes be accompanied by fever. The peripheral zone of the prostate is the most common site for chronic prostatitis (Zelefsky et al., 2011).

Benign prostatic hyperplasia (BPH) is a common occurrence in older men and mainly occurs in the transition zone of the prostate gland. BPH is a nonmalignant enlargement of the prostate gland. Sometimes the inner section of the prostate that is located around the urethra continues to grow and can lead to this common condition that is serious prostate problem, but it

is not cancer. When the prostate gland becomes enlarged, it can easily restrict the flow of urine due to compression of the urethra leading to some of the same symptoms described above (dysuria, nocturia, hesitancy, incomplete emptying of the bladder). BPH is a common problem that affects the quality of life in approximately one third of men older than 50 years and is histologically noticeable in approximately 90% of all men 80 years and older. As many as 14 million men in the United States have symptoms of BPH (Cunningham & Kadmon, 2013; McVary et al., 2011; Paolone, 2010). These two prostate conditions are important to note because often these are problems that get men to the doctor for prostate examinations and prostate cancer screening because some of the symptoms of these nonmalignant conditions are similar to those of prostate cancer (Hale, Grogan, & Willott, 2007).

Prostate Cancer Development and Symptoms

Prostate cancer develops as a result of uncontrolled tumor growth in the prostate gland. Most prostate cancers occur within the peripheral zone of the prostate gland as noted previously, and it is from this area that most needle biopsies are taken. Prostate cancer develops after an initial transformation event, followed by mutations of various genes, including the genes for tumor protein p53 that can lead to tumor progression and metastasis. The enzyme 5-alpha reductase has been implicated in the development of prostate cancer (Hamilton & Freedland, 2011). Several types of cells are found in the prostate, but approximately 95% all prostate cancers develop from the gland cells and are therefore termed prostate adenocarcinomas (the term for cancer that develops in glandular cells). The other 5% of prostate cancers are typically rare and may include transitional cell carcinomas, small cell carcinomas, and squamous cell sarcomas (NCI, 2013).

Grading and Staging of Prostate Cancer

The Gleason grading system was developed by Donald Gleason as a method for categorizing prostate cancer based on the microscopic appearance of cancer cells (Gleason & Mellinger, 1974). There have been some adaptations to the staging system, but this has been the conventional basis for research on the assessment, prognosis, and treatment of prostate cancer (Epstein, Allsbrook Jr., Amin, Egevad, & ISUP Grading Committee, 2005; Pierorazio, Walsh, Partin, & Epstein, 2013). The characteristic Gleason scoring illustration in Figure 2 depicts five tissue patterns that are technically referred to as the grades of the prostate tumor. The Gleason grade is based upon the degree of loss of the normal glandular tissue architecture (i.e. shape, size, and differentiation of the glands). The determination of this loss of normal glandular structure caused by the cancer is represented by a numeric grade, ranging from 1 to 5, where the number 5 represents the worst grade (See Figure 2) (NCI, 2013).

The Gleason score is then calculated based on the two most prevalent histologic grades of the tumor (grade 1 to grade 5). The primary grade represents the appearance of the majority tumor and a secondary grade which represents the minority of the tumor. The total Gleason scores range from 2 to 10 and indicate how likely it is that a tumor will spread. A lower Gleason score indicates the cancer tissue resembles normal prostatic tissue, whereas a high Gleason score indicates that the cancer tissue is very different from normal tissue and the tumor is more likely to metastasize (Epstein, 2011; Epstein et al., 2005). Recent research shows that the differences in the differentiated grades of a biopsy specimen could provide different prognostic information so the Gleason score is often reported with its separate components (e.g., Gleason score 3 + 4 = 7; or 4 + 3 = 7) (Amin, Partin, & Epstein, 2011; Helpap, Ringli, Shaikhibrahim, Wernert, & Kristiansen, 2013; Lavery & Droller, 2012; Pierorazio et al., 2013). Higher Gleason scores are

associated with increased levels of PSA in the blood serum and several studies have confirmed that PSA levels were directly proportional to clinically advancing prostate cancer and cancer volume (Stamey & Kabalin, 1989; Stamey et al., 1989).

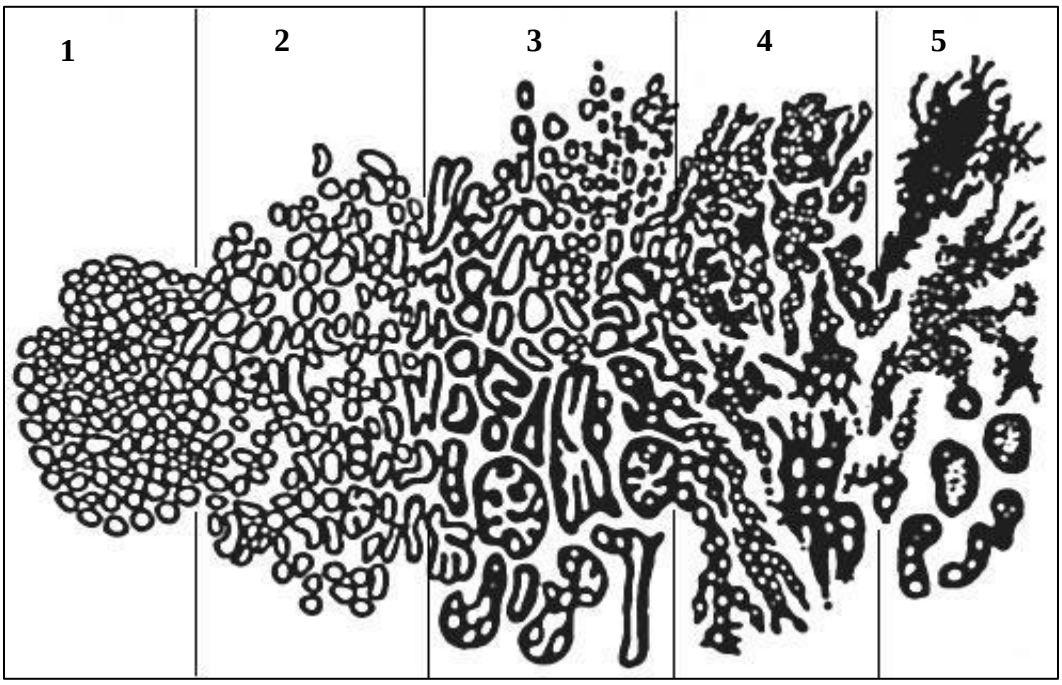

Figure 2. Gleason Grading System Depicting Microscopic Appearance of Cancer cells

Early-stage prostate cancer is localized prostate cancer. This means that the cancer has not metastasized to local tissues or to other body parts, such as bone, and is still completely contained within the prostate gland (See Figure 3, Stages I, II, and IIA). Like many cancers, in the early stages of prostate cancer they are usually no unusual symptoms. When symptoms develop they may mimic those of BPH that include urinary difficulties and problems achieving and erection or experiencing painful ejaculation. These issues worsen with increasing stage of disease (Kurian, Shergill, & Mammen, 2005).

Stage III prostate cancer is called locally advanced cancer. The cancer has spread just beyond the prostate gland and may be found in the seminal vesicles and/or nearby tissue but not

reached the bladder, rectum, lymph nodes, or distant organs. When these cancers are locally invasive, the transitional-zone carcinomas typically first spread to the neck of the bladder, while the peripheral-zone tumors extend into the seminal vesicles and ejaculatory ducts (Kurian et al., 2005). Recurrent cancer can occur at this stage, and as the name suggests refers to cancer that has been previously treated but that has come back in the previously treated area. A return of prostate cancer is detected by an increase in PSA in the blood after radiation therapy or radical prostatectomy (NCI, 2013c).

Stage IV or metastatic cancer refers to late stage prostate cancer that occurs when the cancer cells have spread through the bloodstream or the lymphatic system to other parts of the body such as the pelvic bone. Prostate cancer has a tendency to metastasize to the bone, in partly because of the two way interaction between tumor cells and the surrounding bone stroma (Zelefsky et al., 2011). Numerous studies continue to try to explain the mechanisms for distant prostate cancer metastasis (Drake et al., 2013; O'Hurley et al., 2013). Advanced stage prostate cancer often causes additional symptoms such as pain in the regional bones such as pelvis, vertebrae, and ribs. If prostate cancer metastasizes to the spinal cord, compression can occur that may cause weakness in the legs as well as fecal and urinary incontinence (O'Hurley et al., 2013).

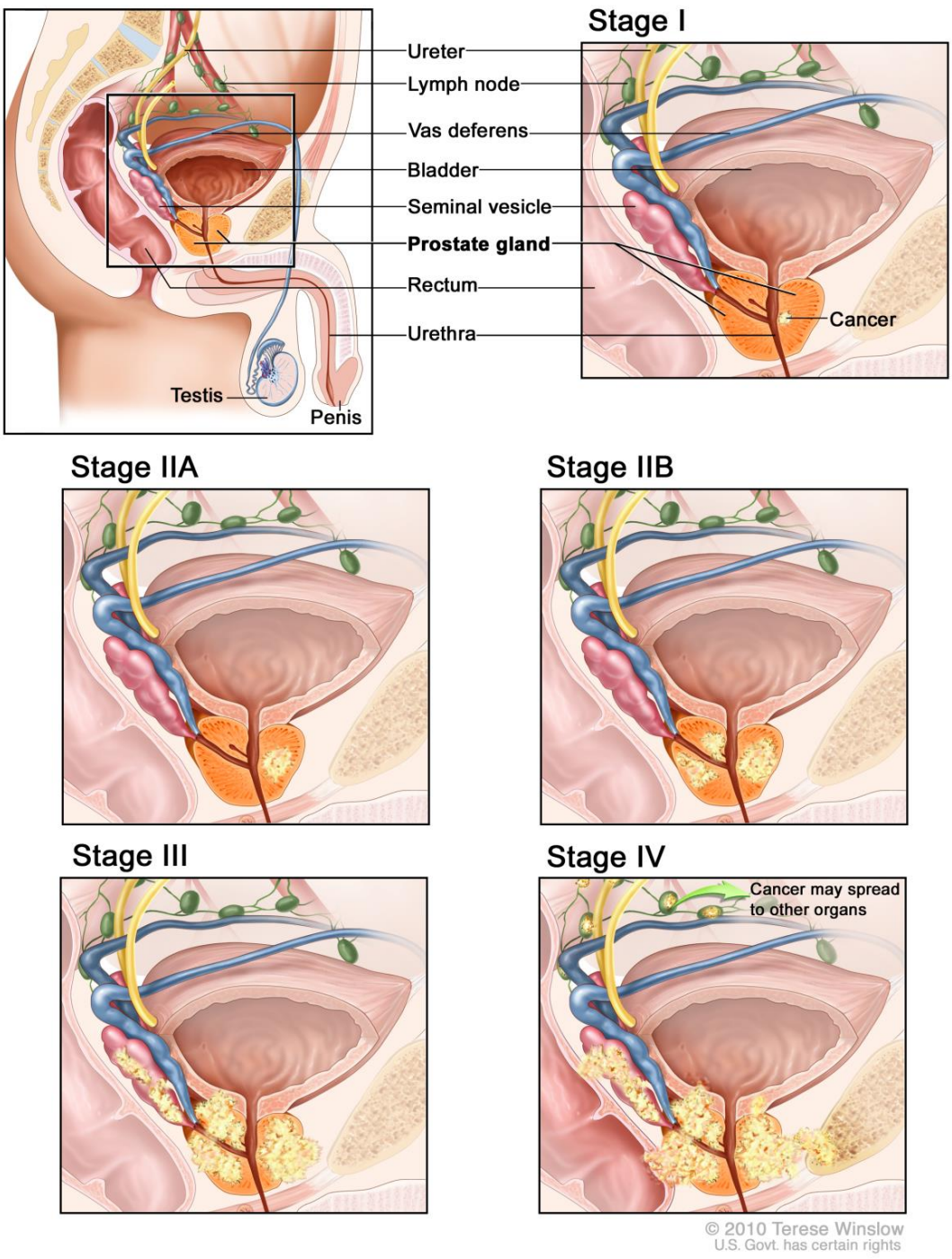

Figure 3. A depiction of prostate cancer development through Stages I to IV.

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Relationship between PSA Levels and Prostate Cancer Progression

Both normal healthy and neoplastic prostate cells secrete PSA (Vickers et al., 2007) and an increase in the PSA level can at times be attributed to other benign conditions such as acute prostatitis, benign prostatic hyperplasia, and other conditions. Even though the level of PSA expressed on a per cell basis varies, there is no debate on the fact that PSA is consistently expressed in nearly all prostate carcinomas (Stamey et al., 1989). The absolute value of serum PSA is useful for determining the extent of prostate cancer and assessing the response to prostate cancer treatment; its use as a screening method to detect prostate cancer is common but controversial. In normal healthy males PSA is secreted into prostatic alveoli. It is then pumped into the prostatic urethra during ejaculation by means of fibromuscular tissue contractions of the prostate and expelled into seminal fluid. Because PSA is primarily released in prostatic secretions, only very small amounts of PSA are expected to be found circulating in the blood serum of a healthy individual. However, in the presence of prostate cancer, the concentration of PSA in the blood increases significantly (See Figure 4) (Kulasingam, Diamandis, & Vega, 2008).

PSA blood serum levels are generally measured in nanograms per milliliter (ng/mL). The American Cancer Society reports that the risk of prostate cancer increases as the PSA level increases, from about 8% with a PSA level of 1 ng/mL to about 25% with a PSA level of 4-10 ng/mL (ACS, 2013). PSA levels that are greater than 10 ng/mL suggest a more than 67% increased risk of the presence of disease (Ross & Pawlina, 2011). As indicated in Figure 4, increase in clinical stage leads to an increase in blood PSA levels. Typically healthy men with no pathological prostate problems display blood serum PSA levels in the range 0.5-2 ng/ml. These minimal levels of PSA enter the circulation by the process of diffusion through a number of anatomic barriers. In early development of prostate cancer these PSA levels may increase to

4-10 ng/ml as a result of destruction of the prostatic tissue. As prostate cancer advances and becomes invasive, significant amounts of PSA escape into the bloodstream. With advanced staged cancer these PSA levels may range from 10 ng/ml to 1,000 ng/ml (Kulasingam et al., 2008).

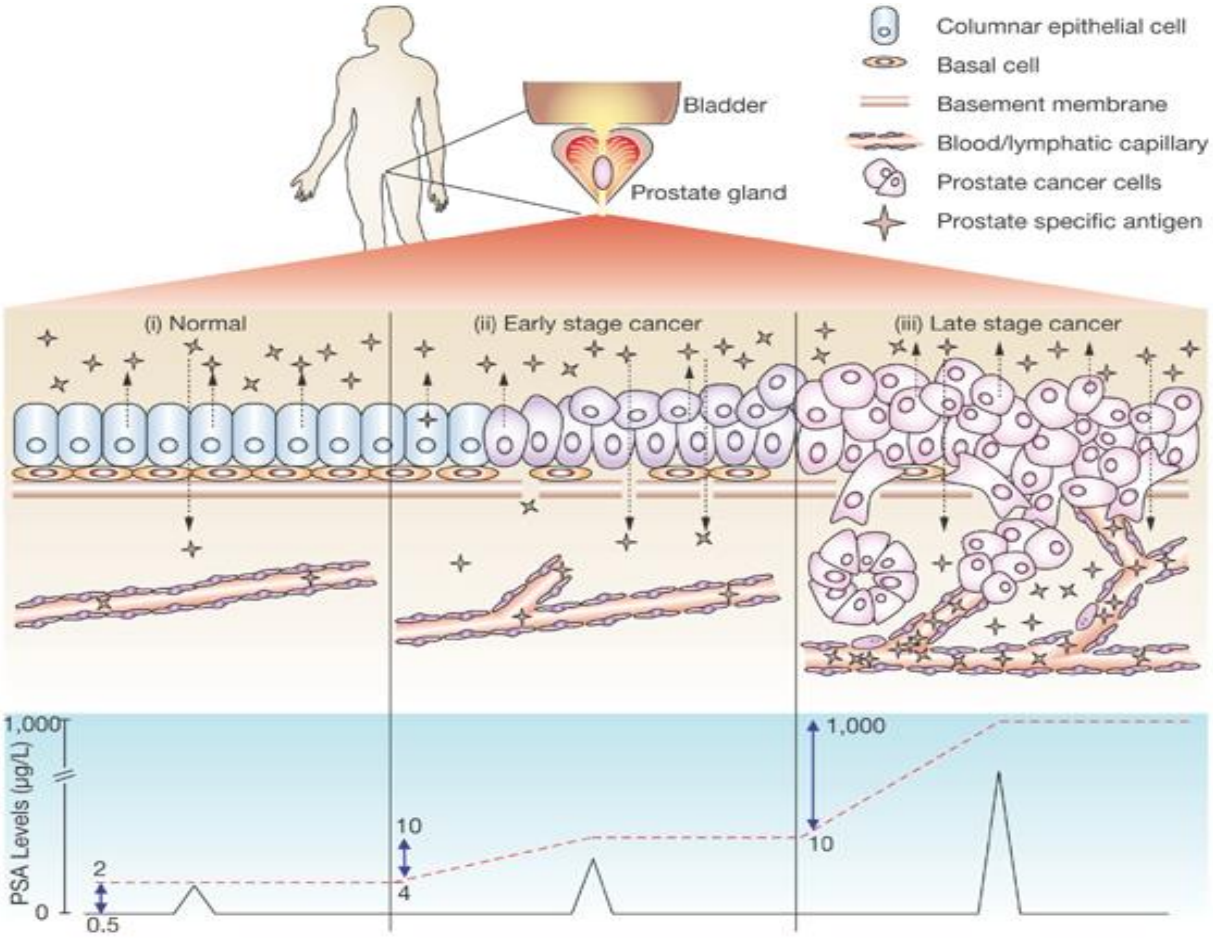


Figure 4. Prostate cancer invasion and tissue destruction as a measure of PSA elevation. Reprinted by permission from Macmillan Publishers Ltd: Nature Clinical Practice Oncology (Kulasingam, Diamandis, & Vega, 2008) See Appendix C.

The Prostate Specific Antigen (PSA) Test

In 1986 the US Food and Drug Administration (FDA) approved the use of the blood serum PSA test as a mechanism for tracking the progress of disease and treatment. Eight years later in 1994, the FDA authorized the PSA test as a screening tool for prostate cancer along with the use of the standard digital rectal exam (NCI, 2013d). This endorsement of the PSA test led to a dramatic increase in prostate cancer incidence because of the ability to detect very early stage prostate cancer in asymptomatic men. However, as alluded to previously, there was and continues to be concern about the large number of false positive test results and the widespread attempts to treat prostate cancers that may have not been life threatening that lead to significant negative side effects and poor quality of life for men (Barry, 2009; Welch & Albertsen, 2009). Because of the controversy regarding the accuracy and efficacy of the use of the PSA, additional factors are being studied to attempt to increase the accuracy of PSA testing (NCI, 2013c). These include:

1. Age-associated reference ranges – As men age the PSA level will naturally increase so that a recorded PSA should be compared to the what is considered normal for men in that age range or age group. However, one important drawback is that most of these studies have been conducted among predominantly Caucasian men and do not necessarily account for possible variations based on ethnicity and other factors (NCI, 2013c).
2. PSA density – PSA levels also increase with increasing prostate size as the benign cells make PSA. PSA density is the calculated ratio of PSA levels and prostate volume measured by transrectal ultrasound (TRUS) (Catalona et al., 2000).

3. Free PSA to Total PSA ratio – PSA can be measured in two serum types, either total conjugated (which is bound to other proteins) or free PSA. The percentage of free PSA tends to increase in benign prostatic hypertrophy compared with prostate cancer, and increasing size of the prostate correlates with an increase in the percentage of free PSA. However, a lower percentage of free PSA is associated with increased prostate cancer risk. Research studies suggest that measuring the conjugated or free PSA increases the accuracy of diagnosis (El Melegy, Aboulella, Abul-Fadl, & Mohamed, 2010; Killick, Bancroft, Kote-Jarai, & Eeles, 2012). The percentage of free PSA relative to the total PSA can be informative as a high ratio is considered favorable while a low percentage PSA is more commonly associated with more aggressive prostate cancer (Catalona et al., 2000; Pal, Maitra, Mellon, & Khan, 2013).
4. PSA velocity – This refers to changes in PSA level over time. Sometimes studies consider PSA doubling time. Although some increase with age is expected, a substantial change in PSA velocity has been used to predict prostate cancer and to prompt prostate biopsy. However, some recent research on PSA velocity indicates that biopsy should not be prompted in the absence of other symptoms (Vickers et al., 2007).

Each of these factors is important and should be included as part of the discussion and education that men receive to increase their ability to make an informed decision about getting screened for prostate cancer using the PSA test. Inadequate or incorrect knowledge about the PSA test and what the values mean have been shown to influence men's decisions about getting screened (Ukoli et al., 2013).

The Digital Rectal Exam

The Digital rectal examination (DRE) is one common component of prostate cancer screening. The DRE is useful to help establish the clinical stage of prostate cancer (Zelefsky et al., 2011). The DRE is insufficient on its own but helps to provide an estimation of the location, size, and pathologic stage of the primary cancer. Through the palpation of the prostate via the rectum this examination can lead to the detection of abnormal prostate conditions such as induration, asymmetry of the gland, the presence of nodules, and tumors in the posterior and lateral regions of the prostate gland (Chodak, Keller, & Schoenberg, 1989). Even though the DRE helps provide prognostic information on prostate cancer and is essential for treatment planning there are limitations of using the DRE alone to screen for prostate cancer. For example most Stage I prostate cancers are nonpalpable and may not be felt or discovered using the DRE. In addition, 15% or more prostate cancers occur in nonperipheral areas and therefore cannot be detected with a finger examination. Most cancers that are detected by the DRE alone are often in a clinically or pathologically advanced stage. The greatest value of the DRE is in combination with the PSA test (Chodak et al., 1989; Hoffman, 2013).

Risk Factors for Prostate Cancer

Age

Even though prostate cancer is very prevalent, other than age, race, and family history there are very few confirmed risk factors for this disease. Age is, however, the number one risk factor for developing prostate cancer (ACS, 2014). Figure 5 depicts the proportions of prostate cancer diagnoses and deaths across the lifespan by age group. Young men are not likely to be diagnosed with prostate cancer or to die from the disease, but as age increases risk increases significantly. Nearly 70% of all prostate cancers are diagnosed in men over 55 years of age. It is estimated that prostate cancer may occur in as many as 80% of all men over 80 years of age.

Studies show that latent prostate cancers have been found during autopsies performed on older men who died from other causes even though the number of latent cancers detected at autopsy declined in the 1990s as a result of the prevalence of screening (Konety, Bird, Deorah, & Dahmoush, 2005; Zare-Mirzaie Balvayeh Imamhadi & Lotfi, 2012).

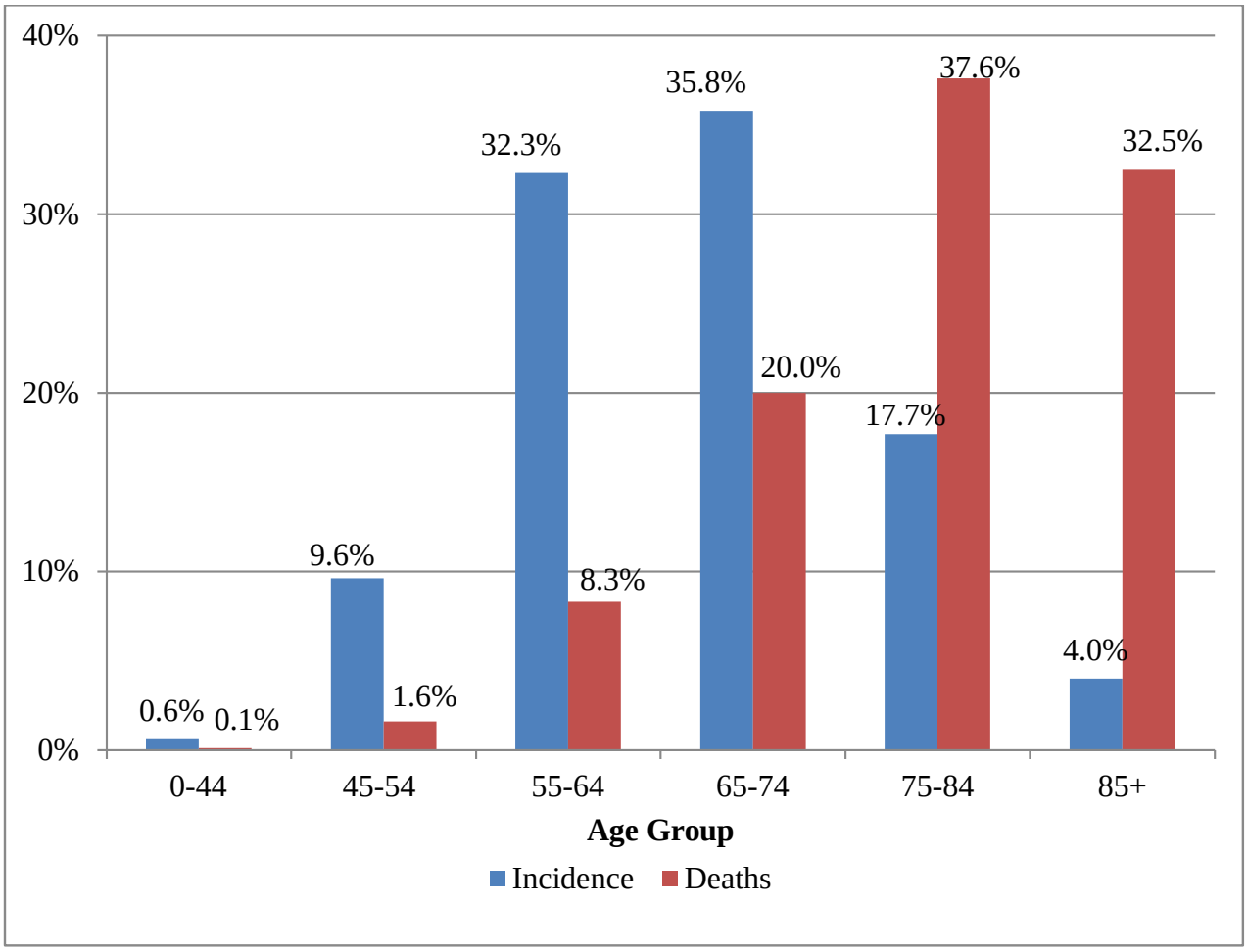


Figure 5. Proportions of prostate cancer incidence and deaths by age group

Race

Race is the next most important risk factor for developing prostate cancer (ACS, 2014). Incidence and mortality rates of prostate cancer remain significantly higher among African-American men as compared to white men. Incidence and mortality rates among Hispanic men are similar to those of white men, whereas rates of men of Asian origin are lower than in white

men. Even though there has been a decline in mortality rates among white and African-American men, prostate cancer deaths in African American men continue to be more than twice as high as in white males (Sassani et al., 2011; Siegel et al., 2014). Table 1 below shows the age adjusted incidence and mortality rates by race or ethnicity for the US based on SEER data (NCI, 2013f).

Table 1.

Age-Adjusted Prostate Cancer Incidence and Mortality Rates by Race or Ethnicity 2006-2010

Race or Ethnicity	Incidence per 100,000	Mortality per 100,000
All Races	152.0	23.0
White	144.9	21.2
White Hispanic	124.9	19.8
White Non-Hispanic	148.2	21.3
Black	228.5	50.9
Asian or Pacific Islander	81.8	10.1
American Indian or Alaska Native	77.8	16.9
Hispanic	125.8	19.2

Many attempts have been made to try to unravel these racial differences in prostate cancer incidence and mortality. Studies examined differences in tumor grade and stage of disease at diagnosis (Tewari et al., 2005; Xiao, Tan, & Goovaerts, 2011). African American men and Hispanic men tend to present with more advanced stages of prostate cancer at initial diagnosis. African American men also appear to have more aggressive forms of prostate cancer than men of other racial groups (Kim et al., 2011; Powell, Bock, Ruterbusch, & Sakr, 2010).

Some studies have examined racial and ethnic differences in male testosterone levels and the implications for racial differences in the prevalence of clinical prostate cancer (Gann, Hennekens, Ma, Longcope, & Stampfer, 1996; Makridakis & Reichardt, 2001). Studies have shown that young African-American men have testosterone levels that are 15% higher than in their young white counterparts. In addition, there is evidence that 5-alpha reductase appears to be more active in young African Americans men than in white men, which implies that hormonal differences may play a role in the differences in prostate cancer development in these two races (Gill, Wilkens, Pollak, Stanczyk, & Kolonel, 2010). Prostate cancer is an androgen dependent tumor. Testosterone and dihydrotestosterone are responsible for regulating the epithelial growth of the prostate and promote metastasis of prostate cancer and it is known that hormones and growth factors stimulate cell proliferation and have been linked to other cancers. Not only does androgen administration promote tumor growth in patients with metastatic prostate cancer, androgen suppression is used in prostate cancer treatment to slow the growth of prostate cancer. However, studies have not found any consistent association with race and androgen levels in men with advanced stage prostate cancer (Gill et al., 2010).

Other studies focused on issues related to psycho-social barriers to prostate cancer screening, health seeking behaviors, as well as differences in access to treatment to try to explain these disparities (Cheatham et al., 2008; Ferrante, Shaw, & Scott, 2011; Harvey & Alston, 2011; Mitchell, 2011; Xiao et al., 2011). It is important to note that the independent role or function of race as a major risk factor for prostate cancer or any other type of cancer is difficult to separate from the effects of other associated determinants such as education, income, insurance status, and health-care access (Institute of Medicine, 1999).

Geographic Disparities in Prostate Cancer Incidence and Mortality

Other disparities in prostate cancer incidence and mortality exist. It is clear that there are some geographic differences in prostate cancer incidence and mortality (Coleman et al., 2008; Xiao et al., 2011). Figure 6 depicts the age-adjusted mortality rate for prostate cancer across the USA for January 1, 2010 (NCI, 2013g). Men living in the southern black belt, the central and southern Appalachian region, Washington DC, and northwest states have higher prostate cancer death rates than the rest of the USA. No studies were found that specifically examined prostate cancer screening in the Appalachian region.

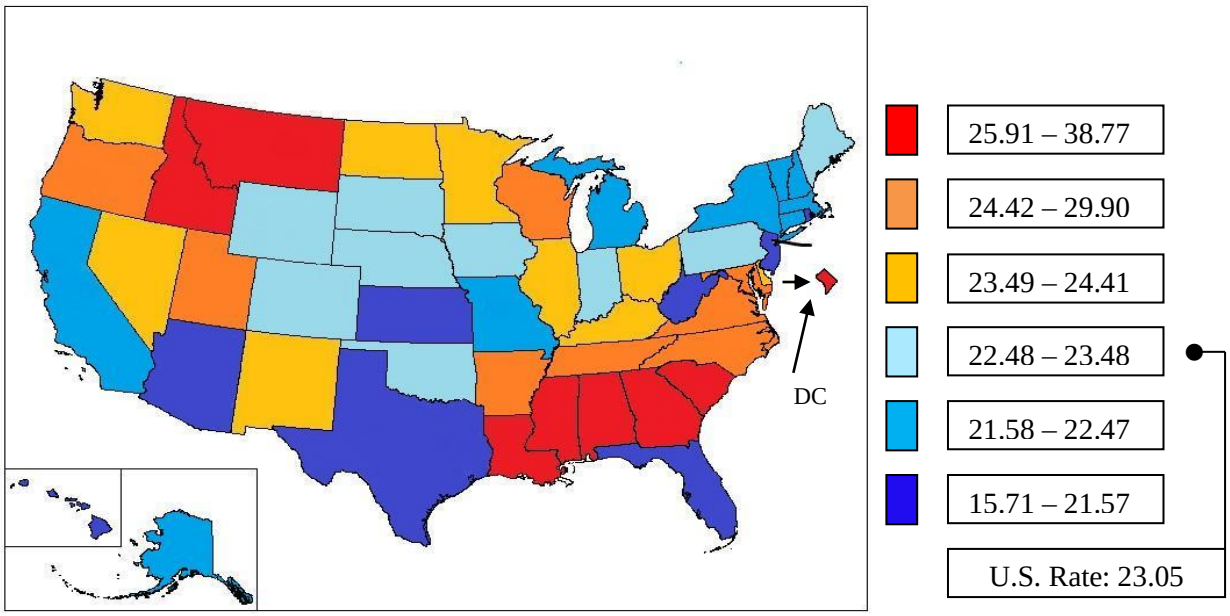


Figure 6. Age-Adjusted Mortality Rates by State, All Races 2006-2010 per 100,000 (NCI, 2013e)

Appalachia

The Appalachian region of the USA has seen cancer rates that are significantly higher than the rest of the US population particularly in lung cancer, cervical cancer, and colorectal cancer (Katz, Pennell, Dignan, & Paskett, 2012; Wingo et al., 2008). A recent epidemiological

report indicates that cancer is the leading cause of death in the Appalachian region (Blackley, Behringer, & Zheng, 2012). Appalachia is a 205,000-square-mile region in the USA that follows the Appalachian range of Mountains from southern New York in the north to northern Mississippi in the south. Parts of 12 states (New York, Pennsylvania, Maryland, Virginia, Ohio, Kentucky, Tennessee, North Carolina, South Carolina, Georgia, Alabama, and Mississippi) and the entire state of West Virginia make up this region. There are 428 counties that are home to over 25 million residents. Over 40% of the region's population lives in rural areas as compared to 20% of the national population. Poverty rates in Appalachia are higher than the national average at 16.1% (NCI, 2013f). Even though significant development and socioeconomic gains have occurred in the region within recent years, the Appalachian Regional Council (ARC) reports that there are still nearly 100 counties that are considered economically distressed, experience significant poverty with limited infrastructure, resources, and very poor health outcomes (ARC, 2009). These are social determinants that have been shown to impact preventive health behaviors and help drive health disparities (Wingo et al., 2008).

Within Appalachia there are subregions that are contiguous counties that have relatively homogeneous characteristics in terms of their demographic profiles, economic status, and topography (Figure 7). This classification that was developed in the early history of the ARC and provides a basis for subregional analysis was reclassified in 2009 into smaller areas using more recent economic and transportation data to provide greater analytical detail for research purposes (ARC, 2009). Interestingly, cancer incidence also varies to a large extent between these subregions (Blackley et al., 2012). However, there is very limited published research that specifically investigates prostate cancer screening behavior, incidence, and death rates within the Appalachian Region. Wingo and colleagues argue that from a historical perspective, this dearth

may be a consequence of the unavailability of reliable data across the region. Their study was among the first to publish cancer incidence rates for a large Appalachian sample. They were able to identify some differences in incidence rates between Northern, Central, and Southern Appalachia (Wingo et al., 2008). As these researchers point out, further research is needed to figure out how these variations within Appalachia may be correlated with access to care and other socioeconomic factors, or with lifestyle factors or other geographic (urban/rural residence) factors (Wingo et, al 2008).

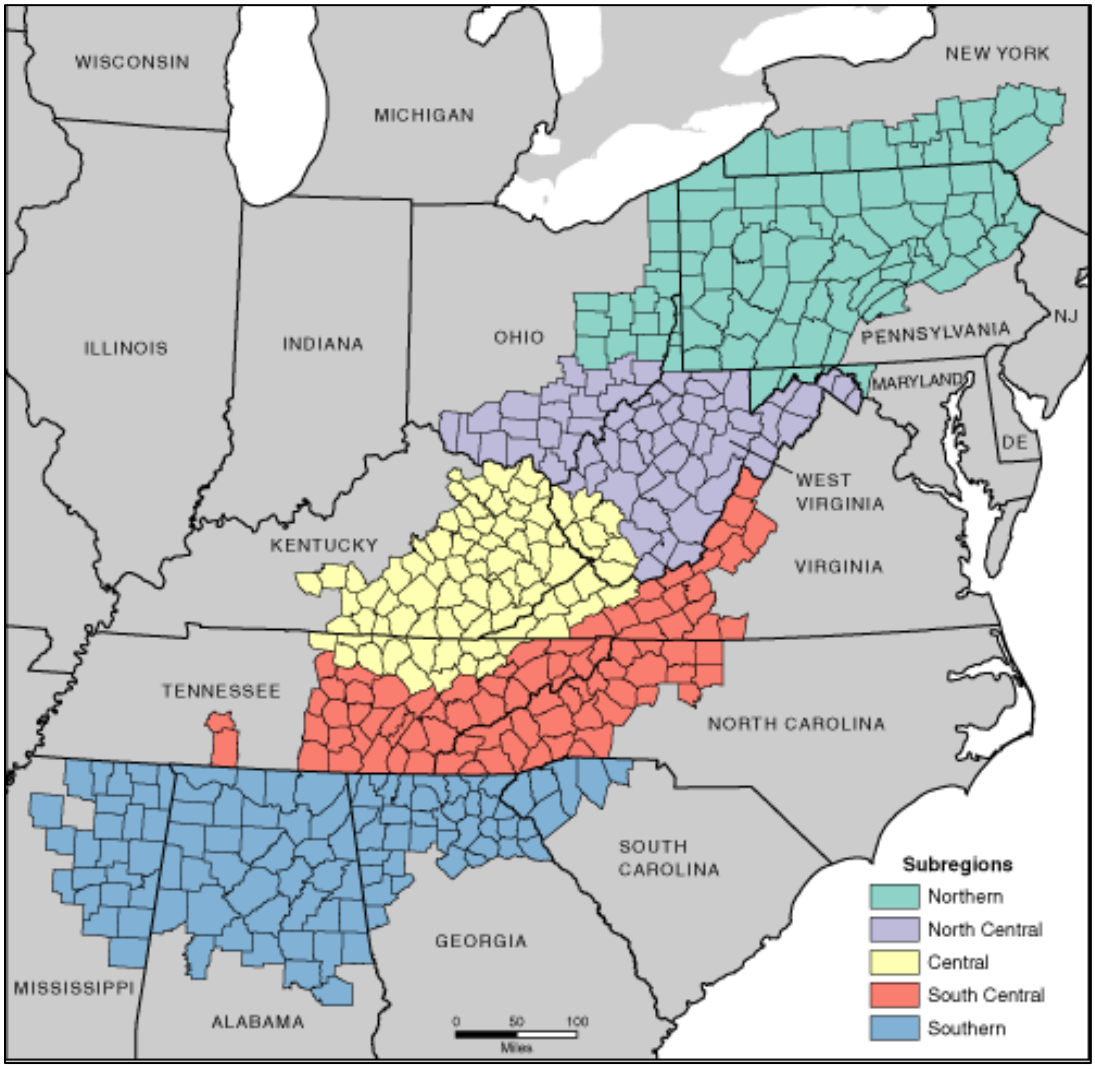


Figure 7. Map of Appalachian Subregions (Appalachian Regional Commission, 2009)

Factors Influencing Prostate Cancer Screening

Several factors have been advanced as barriers and facilitators of prostate cancer screening. Studies have shown that low literacy and limited prostate health knowledge impede prostate cancer screening (Blocker et al., 2006; Friedman, Corwin, Dominick, & Rose, 2009; Reynolds, 2008; Ukoli et al., 2013).

One major barrier in a general sense is men's attitudes towards health seeking. Research shows that men are significantly less likely than women to engage in preventive health behaviors and tend to delay seeking medical care throughout their life course (Gast & Peak, 2011; Smith et al., 2006; Wenger, 2011). There has also been a proliferation of work that attempts to address beliefs and attitudes about health and health seeking as well as the gender constructions that impact the negative health outcomes that men have been experiencing (Blocker et al., 2006; Broom & Tovey, 2009; Cheatham et al., 2008; Creighton & Oliffe, 2010;). Various ideas have been advanced to explain this phenomenon. Some indicate that this is a result of the way men are socialized to deal with health matters as well as a function of their attitudes and beliefs about masculinity and the male role (Creighton & Oliffe, 2010; Griffith et al., 2011; Ornelas et al., 2009; Sloan, Gough, & Conner, 2010).

Prostate cancer screening and general health seeking is also complicated by the fact that men are also less likely to report positive engaged relationships with their health providers (McCullagh, 2011). Positive provider–patient interactions and relationships have been shown to positively impact health behaviors and medical adherence and are associated with improved health outcomes. Griffith and colleagues in their study (2011) indicated that African American men indicated that they generally did not go to the doctor and that they were typically afraid to do so. Some men reported that when they actually got to the doctor they were uncomfortable

with the way the health provider spoke to them or were demanding in their medical recommendations. Others commented that health providers made recommendations but often stopped short of informing them on how to engage in critical behavior changes. Issues of limited trust in doctors were reported in other studies (Cheatham et al., 2008) as well as fear of what a diagnosis of a serious health condition may mean. The implications of what an elevated PSA level and the possibility of a diagnosis of prostate cancer means are among the major issues related to prostate cancer screenings. Fear of the harms associated with screening include impact on patient quality of life, impact on family, fear about treatment options, and debilitating side effects of treatment (Friedman et al., 2009; Ukoli et al., 2013). Perceived threats to masculinity and aversion to the DRE exam have also been advanced as reasons for not obtaining prostate cancer screening (Ukoli et al., 2013).

These issues relate directly to the quality of care provided in the health seeking experience. Lee and colleagues reported that issues with inconvenience in accessing heath care and their perception of difficulty in obtaining quality health care were significant barriers to prostate cancer screening among minorities. These issues must be addressed as part of the process to help men decide about screening (Lee, Consedine, Gonzalez, & Spencer, 2012).

In theory, the constructs of the Health Belief Model (HBM) (Figure 8) have often been advanced in the discussion of health seeking and health screening behavior. This well known theory (first used to examine why some individuals were reluctant to participate in health screenings such as for tuberculosis) has been used as a guiding framework for identifying factors that promote or detract from health seeking is typically a good foundational model for these types of studies for understanding screening behavior (Glantz, Rimer, & Lewis, 2002). The HBM is a psychological model that focuses on the attitudes and beliefs of individuals. The

theory suggests that health seeking is influenced by the individual's perception of the level of threat that is posed by the particular health problem and the value person associates with what it takes to reduce or eliminate the threat (Becker, 1976; Glantz et al., 2002) that makes it relevant to the issue of prostate cancer screening.

The HBM explains and predicts health behaviors by exploring constructs such as a person's perceived susceptibility of a disease or illness, the perceived severity of that condition, perceived benefits of engaging in certain behaviors, perceived barriers to action, cues to action and self-efficacy. This theory is founded on the idea that an individual will take a health-related action if he or she perceives that he or she is at risk; feels that an outcome is severe enough to warrant action; has a confident expectation that by taking a particular action the negative health condition can be avoided; and believes that he or she has the ability and/or resources to successfully take action (Glanz et al., 2002; Hayden, 2014).

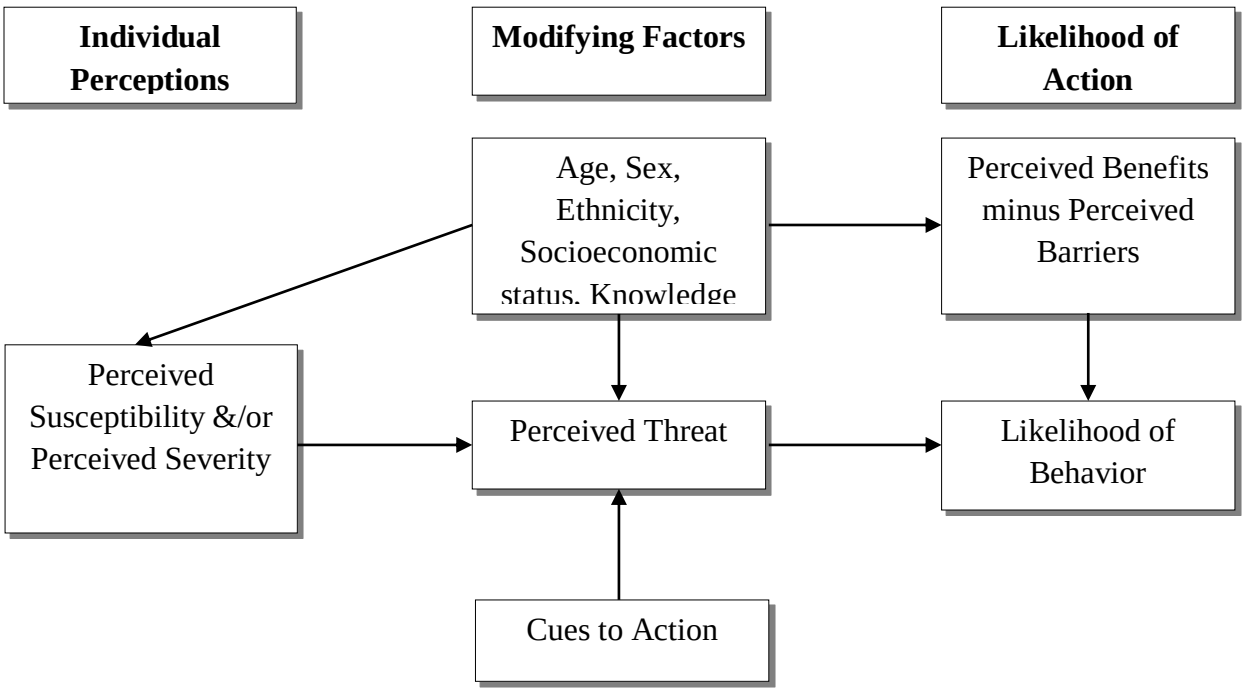


Figure 8. The Health Belief Model (Hayden, 2014).

The constructs of the HBM have also been used to examine prostate cancer screening behavior and was shown to useful in assessing men's perception of their prostate cancer risk, the severity of the disease, what would motivate them to get screened, as well as their perception of benefits and barriers to screening (Çapık & Gözüm, 2011, Odedina et al., 2011). The strongest cues to action or reasons for obtaining prostate cancer screening even prior to the new guidelines by the USPSTF was a recommendation or an order for the exam by a physician, personal knowledge and perceived risk for getting prostate cancer (Emerson, et al., 2009; Ferrante et al., 2011; Finney Rutten et al., 2005; Odedina et al., 2011). The perceived quality of care and interactions with the doctor, whether the patients are being provided with accurate and balanced information on prostate health, the benefits and harms of screening, individual patient's risk, in the context of their personal values and other modifying factors of prostate cancer risk is the focus of this study. In other words are health providers following the recommendations for prostate cancer screening given by the USPSTF.

Provider-Patient Communication

Communication is commonly defined as the exchange of information from one source to another. The effectiveness of communication is impacted by the content of the information, the relationship or dynamics between the source and recipient, and the methods used to convey the information (Corcoran, 2007). Health communication is the transactional discussion between the health provider or health educator and the patient in relation to some form of health promotion, the prevention of illness and disease, and medical decision making (Corcoran, 2007). Communication and interpersonal relationships and are among the core clinical competencies required of physicians (Duffy et al., 2004). In the medical setting the health provider's communication skills not only include the ability to conduct a clinical interview to obtain the

information needed for an accurate diagnosis or to provide therapeutic information but also their ability to form a trusted, caring relationship with the patient. Effective communication can help patients make informed decisions, cope with possible medical diagnoses, and better manage their health whereas ineffectual communication contributes to breakdown in care and undermines the overall doctor-patient relationship (Ha & Longnecker, 2010).

Factors Influencing Provider-Patient Communication

Several individual patient factors impact the quality of communication between the patient and the health provider. Epstein and colleagues (2005) identified four major categories of factors influencing the quality of the communication between health providers and their patients. These are patient factors, provider factors, relationship factors, and health clinic factors. Patient factors include the individual's personality, self-efficacy, culture, values, family background, socioeconomic status, previous illness and medical care experiences, attitudes toward health providers, and perception of severity of the current illness (Epstein et al., 2005).

Characteristics of the health provider also play a critical role. These may include personality, supportiveness of the patient's autonomy, cultural competence, risk aversion, the presence or absence of a patient-centered orientation, and knowledge of the patient as a person. This knowledge is often developed over time and can be impacted by the length of the relationship or number of times the patient has seen the particular provider or attended the healthcare facility. Stronger relationships are built when patients experience trust, when expectations of care are met, and when there is concordance or understanding of values and beliefs (Epstein et al., 2005).

Clinic factors or issues with the health system can also impact the provider-patient interaction. In addition to the general issues of health care access and medical insurance, the

quality of communication between patient and provider is affected by satisfaction or frustration with wait times, ease of obtaining appointments, and length of time in the clinical encounter with the doctor and the physical environment of the office, clinic, or health center (Epstein et al., 2005).

Impact of the Quality of Patient Physician Communication

In general, the quality of patient provider communication critically impacts health seeking behavior and overall health outcomes. It has been shown that patients who experience better interactions with their providers tend to be more informed patients, are more actively involved in their medical care, make better health decisions, have a shared understanding of the circumstances of their health with their physicians, and are often more adherent to their medical treatment (Epstein, Alper, & Quill, 2004). On the other hand barriers and break downs in communication have been shown to lead to patient dissatisfaction, complaints of lack of caring, and concern about their problems on the provider's part that as some researchers point out also contribute to increased likelihood of medical malpractice law suits (Ha & Longnecker, 2010; Levinson, Lesser, & Epstein, 2010). These factors also contribute to racial disparities in the health care experience of different groups (Saha, Arbelaez, & Cooper, 2003).

Other studies have found that health providers tend to communicate differently with patients based on their demographic differences such as age, race, level of education, and income (Siminoff, Graham, & Gordon, 2006). It is important that providers understand the importance of racial, cultural, and socioeconomic diversity among their consumers and may need to tailor their attempts to educate and inform their patients. Inappropriate differences in communication may lead to disparities in patient health outcomes. Minority patients report experiencing poorer communication between them and their health providers. Unquestionably, quality patient-centered communication is associated with increased trust of health providers that is associated

with medical adherence and continuity of care (Cooper et al., 2003; Zolnierek & Dimatteo, 2009). Successful doctor-patient communication is crucial to developing an effective therapeutic doctor-patient relationship and is critical to the delivery of the optimal health care.

Epstein and Street (2007) devised a model (as seen in Figure 9) to show the relationships between patient-centered communication and health outcomes. The model includes six basic functions of provider-patient communication (1) foster healing relationships; (2) exchange information; (3) respond to patients' emotions; (4) manage uncertainty; (5) make informed decisions; and (6) enable patient self-management. One of the goals is to assess patients' self-rating of the quality of this type of communication with their providers in their most recent encounters. These key constructs are the basis for a number of questions in the HINTS Survey.

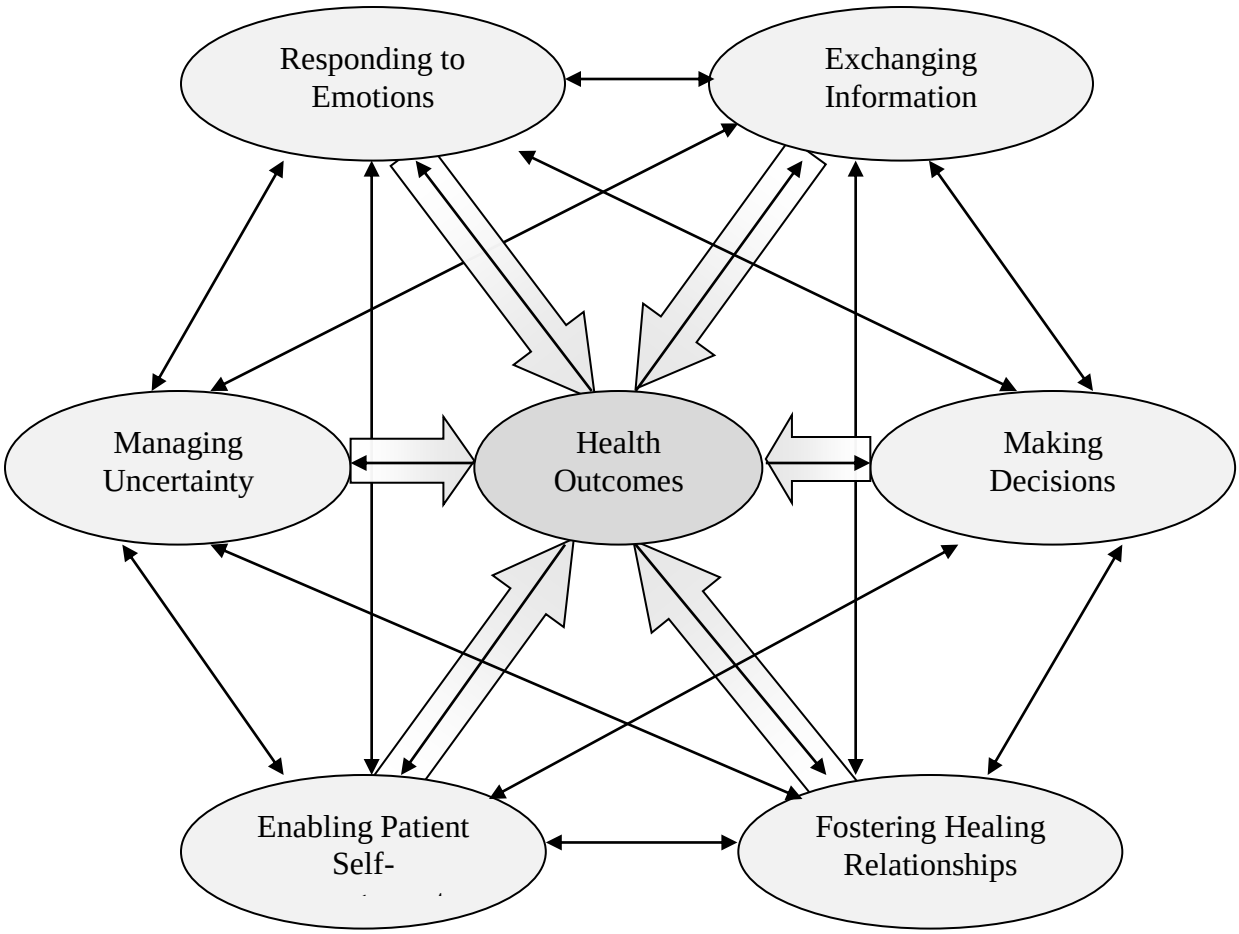


Figure 9: Patient-centered communication and health outcomes in cancer care (Epstein & Street, 2007). Source: Epstein, & Street, Jr. (2007) *Patient-centered communication in cancer care: Promoting healing and reducing suffering.* Bethesda, MD: National Cancer Institute.

Shared-Decision Making and PSA Testing

Shared-decision making is a process that allows patients and their providers to work in partnership to make health care decisions that not only considers the best scientific evidence and methods available for medical care but also considers the patient's beliefs, values, concerns, and personal preferences (Elwyn et al., 2012). Shared-decision making honors the patients' rights to be fully informed of all possible options and potential harms and benefits of each option so that they can maintain their sense of personal autonomy. The potential outcomes must be discussed

so that patients can fully grasp the implications of their decisions regarding their course of action (Charles, Gafni, & Whelan, 1997; Politi & Street, 2011). In this process the health provider's knowledge and expertise is balanced with providing support to the patients to help them make the best possible decisions about their health care (Elwyn et al., 2012).

In order to achieve this, relationships between health providers and patients must be built and nurtured through positive clinical encounters. When information is shared, patients should be encouraged to carefully consider and reflect on the impact that the information could have on their health, general wellbeing, and lifestyle and be able to express their views, seek additional opinions and consult with family members or significant others throughout the decision-making process (Elwyn et al., 2012). Shared-decision making is especially important when it comes to sensitive conditions and screening methods such as prostate cancer screening using the PSA test and the digital rectal exam. Research has shown that patients often experienced pressure in their decisional guidance. This is influenced by the health provider's preferences or possible biases toward certain option, their communication styles and approaches, as well as patients' own ideas about the level of personal concern exhibited by the providers (Thorne, Oliffe, & Stajduhar, 2013). However, most often patients participate in decisions about medical procedures and treatments without a complete understanding of their options and without appropriate decisional support materials (Fowler Jr., Levin, & Sepucha, 2011; Hoffman et al., 2009).

Epstein et al. (2004) describe the following important steps for effective sharing of clinical evidence with patients facing medical decisions. These include (1) building the partnership; (2) understanding the patient's expectations and experience; (3) appropriate framing and communicating the clinical evidence; (4) having a balanced discussion on the uncertainties,

risks and benefits; (5) providing recommendations and obtaining feedback ; and (6) double checking with the patient for understanding and agreement.

With the ongoing debate about the use of the PSA test much of the emphasis on prostate cancer screening is now centered on informed and shared-decision making. In this process men who meet the criteria for screening should be educated about prostate cancer, the harms, benefits, limitations of screening, and what the results of a PSA test could mean for their health before they are offered or asked if they want to be screened (ACS, 2013; AUA, 2013; Ukoli et al., 2013). Given the uncertainty around the use of the PSA test, careful discussions are necessary to ensure that patients do not experience lower levels of satisfaction in the decision making process (Politi, Clark, Ombao, Dizon, & Elwyn, 2011). Research shows that shared-decision making is even more critical when there is inadequate clinical evidence or there is ambivalence about medical procedure (Epstein & Gramling, 2013; Politi, Lewis, & Frosch, 2013; Politi & Street, 2011).

Based on the USPSTF recommendations for shared-decision making, a number of issues must be discussed. Consequently to determine if shared-decision making is happening in the clinical setting shared-decision making must be seen not as a clear-cut, dichotomous variable, but should be considered a continuous measurement of the various components suggested by the USPSTF (Sheridan, Harris, & Woolf, 2004; Woolf & Krist, 2009).

Conceptual Framework

Based on the preceding discussion on the Health Belief Model, the theory behind patient centered communication and shared-decision making a mixed model was devised for this proposal (See Figure 10 below). This model incorporates constructs from the various approaches as they influence shared-decision making about PSA testing and actual PSA testing. What the

model presupposes is that social determinants impact patient factors that, along with certain health provider factors, impact patient perceptions of provider patient communication that then is associated with, determines or predicts whether shared-decision making occurs. The model shows how these factors impact current screening guidelines objectives and the national objectives for prostate cancer outcomes in America. In other words if shared-decision making is occurring then we can determine if national recommendations are being followed by health care providers and if the Healthy People 2020 C-19 objective is being met.

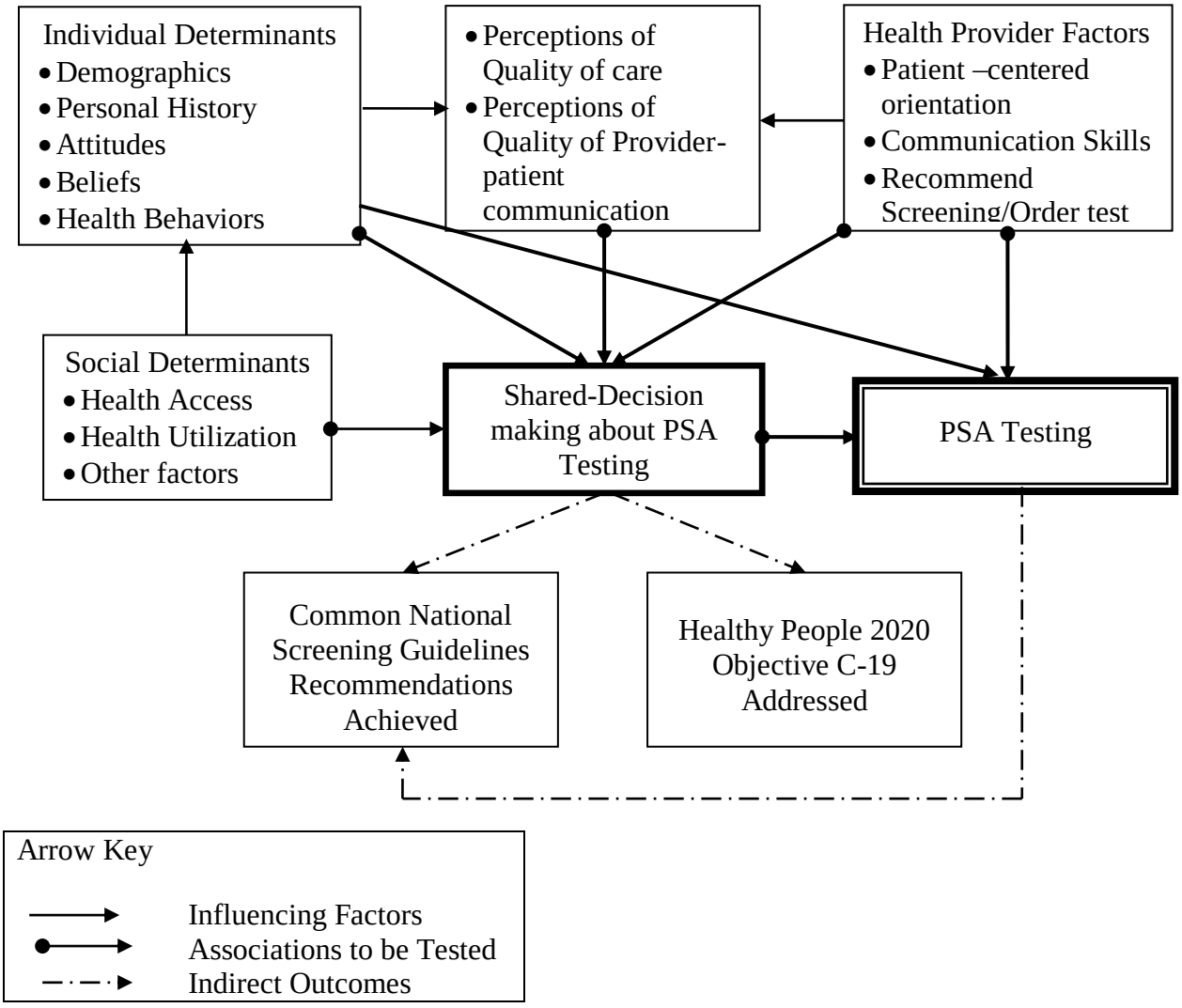


Figure 10: Conceptual Model of Factors impacting Shared-decision Making and PSA Testing

CHAPTER 3

METHODS

The aims of this study were to: (1) describe older adult male patients' perceptions of the quality of their care and communication with their health provider and determine whether these perceptions influence PSA screening behavior; (2) examine the extent to which health providers are engaging in a shared-decision-making process by discussing prostate cancer screening according to the most recent national screening guidelines; (3) determine what factors are associated with shared-decision making and provider-patient discussion about PSA testing; and (4) estimate the association between male patients' perceptions of the quality of their care, provider patient discussion about prostate cancer, and other factors with PSA testing. The variables were also examined to identify whether there were regional or racial differences in any of these factors.

Study Design

This study used secondary, publicly available data from the U.S. Health Information National Trends Survey 4 (HINTS 4) Cycle 2, 2013. HINTS 4 is a cross-sectional survey of a nationally-representative sample of adults living in America. The survey is conducted every 2 years and is used to assess the general impact of the health information environment on adult health behaviors. HINTS 4 measures how the public accesses and uses health information. It assesses the extent to which people participate in preventive health and other promoting behaviors. It examines how information technology is used to manage health and health information. The HINTS 4 survey also includes several measures that specifically focus on cancer prevention and control (NCI, 2013b).

Data Collection

Data collection for HINTS 4 Cycle 2 began on October 9th, 2012, and was completed on January 11th, 2013. The Cycle 2 survey was conducted exclusively by mail. A minimal $2 monetary incentive was provided to potential respondents to encourage participation. The survey was self-administered and respondents returned their survey via a preaddressed envelope included in the survey packet. The sampling strategy for the HINTS Cycle 2 survey comprised a two-stage or two-step design. First a stratified random sample of household addresses was selected using available lists of US residential addresses, and then at the second-stage, a sample of adults 18 years and older within the sampled households was obtained (NCI, 2013b).

The household addresses included in the sampling frame were provided by the Marketing Systems Group (MSG). Addresses were divided into three groups or strata. The first stratum included addresses in high minority population areas. The second stratum included addresses in areas with low minority population areas. The third stratum included addresses located in counties located in the Central Appalachia region regardless of minority population or concentrations. All occupied residential addresses in the United States that were present in the MSG household database, including seasonal addresses, post office boxes, and redirected mail addresses were eligible for inclusion in the sampling frame. The questionnaire was first mailed. If there was no response a follow-up post card was sent as a reminder. Up to two more questionnaires were mailed to nonresponders. Households that were identified as potential Spanish speaking households received both English and Spanish versions of the survey. More extensive information regarding the sampling procedures are detailed in the HINTS 4 Cycle 2 Methodology Report (NCI, 2013b).

Sample Selection

There were 3,630 respondents included in the total HINTS 4 Cycle 2 sample. Sample weights were calculated to estimate a national sample using the HINTS 4 Cycle methodology for sample weights described in the HINTS 4 Cycle 2 Methodology Report (NCI, 2013b). This data analysis featured only men in the recommended age brackets for prostate cancer screening based on the American Cancer Society's recommendations (N = 777). This included all African American men 40 to 75 years old who are considered at an increased risk for prostate cancer. Men from other racial groups between ages 50 and 75 years were included in the sample (Smith, Brooks, Cokkinides, Salsow, & Brawley, 2013). This study does not account for men with an increased risk for prostate cancer because of the familial risk of having a first degree male relative with a history of prostate cancer. While this HINTS data set asks a general question about having a family history of cancer, it does not specifically query what type of cancer and the degree of relationship.

Research Questions and Survey Items

The aims of this study were addressed by the following four research questions: (1) how do older adult male patients rate their perceptions of the quality of their care and communication with their health provider? (2) To what extent are health providers engaging in the shared-decision-making process by discussing prostate cancer screening according to the most recent national screening guidelines? (3) What factors are associated with level of shared-decision making and provider patient discussion about prostate cancer screening? (4) What is the relationship of male patient's perceptions of the quality of their care, shared-decision making, and other putative factors on PSA testing?

Demographic items included in the analysis included age, race or ethnicity, marital status, level of education, household income, employment status, and residence in the Appalachian region. These personal characteristics that have been shown to impact health awareness, beliefs, attitudes, health seeking behaviors, and other health interactions were first used to describe the sample and also served as covariates in multivariate analyses and to adjust for possible confounding.

Perceptions of Quality of Care and General Provider-Patient Communication

Research Question 1: How do older adult male patients rate their perceptions of the quality of their care and communication with their health provider?

To address this question respondents were asked to assess the quality of the interaction they had with their health providers (doctors, nurses, or other health professionals) in the 12 months prior to completing the survey. These questions were not specific to prostate cancer screening but were a broad assessment of the general quality of their provider-patient communication. Respondents were asked how often did their health provider:

(a) Give them the chance to ask all the health-related questions they had;

(b) Give them the attention they needed regarding their feelings and emotions;

(c) Involve them in decisions about their health care as much as they wanted;

(d) Make sure they understood the things they needed to do to take care of their health;

(e) Explain things in a way they could understand;

(f) Spend enough time with them; and

(g) Help them deal with feelings of uncertainty about their health or health care?

The answer choices ranged from 1 = always; 2 = usually; 3 = sometimes; 4 = never. These scores were reverse coded and then summed to create a continuous variable of level of

satisfaction with provider patient communication with a minimum score of 7 and maximum score of 28. Higher scores represent higher perception of the level of provider engagement and interaction. The mean of these seven items was used as a measure of the quality of the communication that is similar to the method used in previous research (Rutten, Auguston, & Wanke, 2006; Underhill & Kiviniemi, 2012). Cronbach's alpha reliability for this created scale was $\alpha = 0.93$, which indicates very high internal consistency in this sample. Five items in this measure are adaptations of five similar items developed for the Consumer Assessment of Health Providers and Systems (CAHPS, previously called Consumer Assessment of Health Plans). The responses to these items were categorized as either "always" or "not always" (usually, sometimes, never). For most of these items between 43% and 67% of the participants responded 'always'. These responses were dichotomized to 'always' or 'not always' to be used in the regression analyses addressing research questions 3 and 4. This method has been used in previous research studies using previous HINTS data sets (DeVoe, Wallace, & Fryer, 2009; Wallace, Chisolm, Abdel-Rasoul, & DeVoe, 2013).

Respondents were also asked to rate the quality of the care they received from their providers in the last 12 months. Responses ranged from 1 to 5 (where 1 = excellent and 5 = poor). This scale was also reverse coded to reflect that higher scores indicate greater satisfaction with quality of care in the respondents' most recent health encounters. These two ratings were subsequently used as predictors of shared-decision making and PSA testing.

For research question 1, bivariate analyses including cross tabulations with chi squares (χ^2) estimated associations between (a) perceptions of quality of care and (b) level of interaction with their health provider questions and demographic variables (age group, marital status, education level, etc), residence in Appalachia, and ever having a PSA test.

Provider Communication about Prostate Cancer and PSA Testing

Research Question 2: To what extent are health providers engaging in shared-decision making process by discussing prostate cancer screening according to the most recent (2011) screening guidelines?

Informed and shared-decision making are key issues that relate to PSA screening and form the common recommendations among the various agencies with opinions on the use of the PSA test. Seven questions were used to assess respondents' experience of an informed discussion regarding the use of the PSA test with their health provider. These seven questions (Q1 to Q7) are:

Q1. Have you ever had a PSA test" (1 = Yes; 2 = No)? All male respondents were also asked to respond to the following questions that examine conversations they may have had with their doctors or other health care providers regarding the PSA test:

Q2. Has a doctor ever discussed with you whether or not you should have the PSA test (1 = Yes; 2 = No)? If participants responded yes to this question, they moved to the next question, otherwise they skipped to the next three questions.

Q3. Did the doctor ask you whether or not you wanted to have the PSA test (1 = Yes; 2 = No)?

Q4. Did a doctor ever tell you that some experts disagree about whether men should have PSA tests (1 = Yes; 2 = No)?

Q5. Has a doctor or other health care professional ever told you that the PSA test is not always accurate (1 = Yes; 2 = No)?

Q6. Has a doctor or other health care professional ever told you that some types of prostate cancer are slow growing and need no treatment (1 = Yes; 2 = No)?

Q7. Has a doctor or other health care professional ever told you that treating any type of prostate cancer can lead to serious side effects, such as problems with urination or having sex (1 = Yes; 2 = No) (NCI, 2013a)?

Questions 4 through 7 (Q4 to Q7) were used to create a summated scale for measuring shared-decision making of PSA testing. Each question was recoded so that all 'No' responses were given a score of zero. Yes responses to the questions were scored one. (0=No; 1=Yes). Summated scores ranged from 0 to 4. Higher scores represent increased shared-decision making with patient about PSA testing. The Cronbach's alpha reliability score was calculated for the shared-decision making variable ($\alpha = 0.78$). This continuous variable was used as the measure for shared-decision making in the multivariate models in research questions 3 and 4. This method is suggested by previous research examining shared decision making for PSA testing (Woolf & Krist, 2009).

Means and standard errors were reported. Bivariate analyses including cross tabulations with chi squares (χ^2), and univariate regressions estimated associations between age, race or ethnicity, marital status, level of education, employment status, household income, health insurance status, general health rating, history of cancer, and informed decision making about prostate cancer screening with history of PSA screening.

Predictors of Shared-Decision Making

Research Question 3. What factors are associated with level of shared-decision making and provider patient discussion about prostate cancer screening?

Several variables including demographic and other independent variables were examined in relation to this continuous dependent variable, shared-decision making. The demographic items that included in these analyses are age, marital status, education, work status, household income, and health insurance status. These personal characteristics that have been shown to impact health awareness, beliefs, attitudes, health seeking behaviors, and other health interactions were also used to describe the sample but were also included as covariates in multivariate analyses and to adjust for possible confounding.

Other covariates include general health status and number of chronic medical conditions. General health status was measured using a standard five-point scale where responses ranged from 5 = poor to 1 = excellent (Ware, Kosinski, & Keller, 1996). The number of major chronic conditions were calculated based on participants' responses to the question of whether they were ever told by a doctor or other health professional that they had any of the following medical conditions: diabetes, high blood pressure, any heart condition such as heart attack, angina, or congestive heart failure; chronic lung disease, asthma, emphysema, or chronic bronchitis; arthritis or rheumatism; and depression or anxiety disorder (1= Yes; 2=No) (NCI, 2013a). The number of chronic medical conditions a person has is associated with number of physician visits (Ashman & Beresovsky, 2009) and increased likelihood of PSA testing (Halpern et al., 2013). A continuous variable for the sum of the number of chronic conditions was created and included to adjust for possible impact PSA testing.

The measurement of health care use included four variables: having a regular doctor or medical home; health insurance; estimate of time since their last nonemergency medical visit; and the total number of medical visits within past year. Each of these questions was used previously on other national validated surveys such as the Behavioral Risk Factor Survey

(BRFSS) (CDC, 2011). Respondents were first asked if they had a usual source of health care. The question queried if they had a particular doctor, nurse, or other health professional who they saw most often not including psychiatrists and other mental health professionals (1=Yes, 2=No). The subsequent question asked the respondents if they had any kind of healthcare coverage, including health insurance, prepaid plans such as HMOs, or government plans such as Medicare (1=Yes, 2=No).

A third question asked respondents to provide an estimate of time since their last visit to a doctor for a routine checkup or general physical exam that was not because of a specific injury, illness, or condition. Responses ranged from: 1 = Within past year (anytime less than 12 months ago); 2 = Within past 2 years (1 year but less than 2 years ago); 3 = Within past 5 years (2 years but less than 5 years ago); 4 = 5 or more years ago; 5 = don't know; and 6 = never (NCI, 2013a).

The fourth question asked respondents to report how many times they sought medical care from a doctor, nurse, or other health professional for themselves, excluding emergency room visits. Responses ranged from: 0 = none; 1 = 1 time; 2 = 2 times; 3 = 3 times; 4 = 4 times; 5 = 5 to 9 times; and 6 = 10 or more times (NCI, 2013a). This variable was used as a continuous measure to examine relationships between number of medical visits, levels of satisfaction with provider-patient communication, shared-decision making, and screening behavior.

Perception of disease risk has been shown to impact preventive health behaviors (Becker, 1976) and screening for cancer. Respondents were asked to report their perceived likelihood of getting cancer in their lifetime. Likert scale responses for the variable measuring cancer risk perception ranged from 1 = Very unlikely to 5 = Very likely. They also rated their likelihood of getting cancer in comparison to other people their age. These responses ranged from 1 = much less likely to 5 = much more likely. A third question asked respondents to select the option that

best reflected their opinion on the statement "I feel like I could easily get cancer in my lifetime." Options for this were (1) I feel very strongly that this will NOT happen; (2) I feel somewhat strongly that this will NOT happen; (3) I feel I am just as likely to get cancer as I am to not get cancer; (4) I feel somewhat strongly that this WILL happen; and (5) I feel very strongly that this WILL happen. Participants were also asked if any family members ever had cancer (1 = Yes; 2 = No; 4 = Not sure). A history of cancer in family members may influence a person's perceived risk. Respondents were also asked how much they agreed or disagreed with the statement: "I'd rather not know my chance of getting cancer." 1 = strongly agree, to 4 = strongly disagree. A multivariate linear regression analysis tested the independent associations between the putative independent variables and shared-decision making while adjusting for age, race, marital status, insurance status, and other potential confounders.

Predictors of PSA Testing

Research Question 4. What is the relationship between male patient's perceptions of the quality of their care, provider patient discussion about prostate cancer, and PSA testing?

Four multivariate logistic regression models were used to estimate the strength of the associations of various predictor variables on PSA testing. The various independent predictors have been described above. In Model 1 the various demographic variables were regressed on the PSA testing variable along with the variables assessing quality of care, perceived cancer risk, feelings about wanting to find out about a cancer diagnosis, number of chronic medical problems, and having had a recent medical visit. This model is the basis for comparison for subsequent models. Model 2 includes all variables from model 1 and adds the shared-decision making variable. Model 3 includes model 1 variables and the variable assessing if the doctor had ever discussed PSA testing. In Model 4 each of the variables of interest was regressed on PSA

testing. A test for an interaction effect was conducted between shared-decision making and the variable that addressed the question of whether the doctor discussed PSA testing.

Statistical Analysis

All data were analyzed using SAS 9.2 statistical software (SAS Institute; North Carolina). Sample weights were used in the survey analysis to assign an increased relative value to some members of the sample as compared to others. Weights are necessary when the sample is selected by unequal probability sampling. They are also used in poststratification and to adjust for nonresponse (Kalton, 1983). Sample weights were applied to all analyses in order for more accurate inferential statistics to be calculated and to estimate the values for a national sample. This is one of the analytic recommendations given by the National Cancer Institute for the HINTS data because of biases introduced through planned over-sampling and differential response rates. The specific analytic method used was the jackknife procedure with 50 replicate weights (NCI, 2013a). This procedure provides a method of reducing bias and obtaining standard errors in situations where the standard methods might underestimate errors and lead to type-1 errors (Severiano, Carriço, Robinson, Ramirez, & Pinto, 2011).

Descriptive analyses summarized the general characteristics of the sample and their encounters with their health providers. These included frequencies, means, and standard errors. Standard errors were reported instead of standard deviations because while standard deviations are most frequently used as a measure of the dispersion of a characteristic in a sample, the standard error is used as an inferential statistic to estimate a population characteristic (Biau, 2011). These univariate and bivariate analyses were calculated for each variable of interest to provide descriptive data for the sample. Unadjusted univariate logistic regression models were used to clarify any within group differences.

Multivariate regression analyses estimated the effects of the independent variables (health care visits, number of chronic medical conditions, having a regular provider, perceived quality of care and provider patient communication, perceived cancer risk, and no desire to know if cancer is present) on shared-decision making (linear regression), and PSA screening (logistic regression). These regression models adjusted for sociodemographic factors such as age, race, marital status, education, income, insurance status, and other covariates described above. The descriptive summary of the sample and the findings from the multivariate analyses are reported in the following chapter. Where appropriate, analyses are represented in tables and graphs.

Human Subjects Protections

This study is a secondary data analysis of data collected by the National Institutes of Health. It does not contain any identifiable health information and is publicly available. Appendix E contains the HINTS data use agreement obtained for this study. The East Tennessee State University Institutional Review Board (IRB) determined that this research study met the criteria for being exempt from IRB review because it did not meet the conditions that would represent human subject's research. See Appendix F.

CHAPTER 4

RESULTS

Secondary data from the U.S. Health Information National Trends Survey 4 (HINTS 4 Cycle 2) were used for this study. The sample consisted of 777 men who met the criteria for inclusion based on the American Cancer Society's recommendations for PSA screening (Smith et al., 2013). African American men between the ages 40 to 75 years and all other ages 50 and 75 years were included in the sample. This study did not account for men with an increased risk for prostate cancer due to a familial risk of having a first degree male relative with a history of prostate cancer because this information was not included in the HINTS 4 Cycle 2 dataset. Men with a previous history of prostate cancer were excluded from the sample. The data were weighted to estimate the results to the national population represented by this sample (NCI, 2013a).

Descriptive Characteristics of the Sample

Descriptive analyses were conducted to measure the frequencies and distribution of demographic characteristics and the variables of interest for the men in the sample. The weighted average age for the men was 59.42 years *(SE = 0.20; CI 59.02 – 59.81)*. About 4% of the black men fell in that lowest age category (40-49 years) for recommended screening based on increased risk for prostate cancer. Approximately two thirds of men were non-Hispanic white men (67%), nearly 12% were non-Hispanic black men, 9 % were Hispanic, and the other 12% did not identify their race. About 70% reported being married or living as married. Approximately 63% of the men had more than a high school education. Just over half the men reported being currently employed. Half of the men reported having an annual household

income that was $50,000.00 or higher. More specific details of these descriptive statistics are presented in Table 2 below.

Table 2.

Sample Characteristics with Weighted Percentages for Total Sample by History of PSA Testing

Variables Subcategories	Total Sample N=777		Ever Had PSA *n=503*		Never Had PSA *n=258*	
	n	Weighted %	n	Weighted%	N	Weighted%
Age Categories**						
40-49 years	27	4.28	7	33.88	20	66.12
50-59 years	316	49.10	166	52.71	142	47.29
60-69 years	320	34.37	244	76.98	72	23.02
70-75 years	114	12.27	86	84.91	24	15.08
Ethnicity						
Hispanic	85	8.97	51	63.76	32	36.24
Non-Hispanic White	480	67.66	330	67.80	141	32.20
Non-Hispanic Black	109	11.38	61	54.59	46	45.41
Other Race or Not Ascertained	103	11.98	61	53.56	39	46.44
Marital Status**						
Married or Cohabiting	473	70.93	342	71.52	123	28.47
Single never married	107	12.10	104	53.28	78	46.72
Separated/Divorced/Widowed	188	16.24	51	35.47	54	64.52
Not Ascertained	9	0.72	6	76.50	3	23.50

*Within Group Differences based on Chi Square Analyses: ** p < .01; ** p < .001*

Table 2. (Continued)

Variables	Total Sample		Ever Had PSA		Never Had PSA	
Subcategories	N=777		*n=503*		*n=258*	
	n	Weighted %	n	Weighted %	n	Weighted %
Education**						
Less than High School	80	15.15	41	63.18	36	36.82
High School Graduate	167	21.17	83	47.67	77	52.33
Some College	233	34.37	154	65.77	76	34.23
Bachelor's Degree	177	17.55	128	69.53	48	30.47
Graduate Degree or Higher	117	11.31	96	82.59	19	17.41
Not Ascertained	3	0.45	1	76.86	2	23.14
Work Status**						
Employed	367	51.72	225	59.25	133	40.75
Unemployed	57	6.16	23	42.27	31	57.73
Retired	265	28.38	208	80.44	54	19.56
Disabled	66	11.35	35	55.22	30	44.78
Other or Not Ascertained	20	2.19	12	73.63	10	26.37
Household Income**						
Less than $20,000	145	15.97	61	39.62	79	60.38
$20,000 to < $35,000	97	12.69	62	67.85	33	32.15
$35,000 to < $50,000	90	11.20	53	59.83	34	40.17
$50,000 to < $75,000	120	16.49	88	68.33	28	31.67
$75,000 or more	236	33.94	179	72.71	55	27.29
Not Ascertained	89	9.69	60	67.27	29	32.73

*Within Group Differences based on Chi Square Analyses: ** p < .01; ** p < .001*

Unfortunately, fewer than 10% of the men in the final weighted sample lived in the regions of Appalachia. Table 3 below includes the weighted percentages for demographic and other factors showing the differences between Appalachian and Non-Appalachian men. Even though variables with very small numbers of valid responses typically yield unreliable estimates, it is noteworthy that a larger proportion of Appalachian men (61.32%) reported never discussing the shared-decision-making topics than Non-Appalachian men (46.65%). However, based on Chi-squared tests of independence there are no statistically significant differences (p-value < 0.05) between these two groups.

Table 3

Demographics and Other Comparisons between Appalachian and Non-Appalachian Men

Variables	Appalachian *(n=58)*		Non-Appalachian *(n=719)*	
	Weighted %	Standard Error of %	Weighted %	Standard Error of %
Ages 50-69 years	89.87	4.67	83.34	1.67
non-Hispanic White	81.06	9.36	67.64	2.08
Married or Cohabiting	75.56	7.79	71.05	2.22
> High School Education	59.16	10.54	66.21	2.09
Employed	49.68	10.26	45.44	2.65
Household Income ≥ $50,000	55.77	9.23	55.70	2.67
Health Insurance	79.00	8.85	89.62	1.45
Regular Provider	72.53	10.66	72.83	2.54
Recent Visit	82.60	7.94	83.74	1.71
YES - Had a PSA Test	60.23	10.35	64.12	2.67
Never Discussed 4 SDM Issues	61.32	8.32	46.65	3.01

Descriptive Data on PSA Testing and Other Covariates

Sixty-four percent of the men reported ever having a PSA test. One in three black men 40-49 years ever had a PSA test. Fifty-two percent of the men 50-59 years old and more than 75% of all men 60 years and older reported ever having a PSA test. The rates of PSA testing differed between men in the different age groups. Older men were more likely to have had a PSA test. For example, men in the 60-69 and 70-75 age categories were significantly more likely to have obtained a PSA test than men in the 50-59 years age group (*Unadjusted ORs = 3.00; CI = 1.94-4.63; OR = 5.05; CI = 2.65-9.16 respectively*).

White men had the highest rates of PSA testing, but these rates were not statistically significantly different from men of other race or ethnic groups. Men who were married or living as married had significantly higher PSA testing rates than other men. These differences were significant χ^2 (49, *n=751*) = 21.74, $p < 0.0001$. In fact, these men were three times more likely to obtain PSA test than men who were not married or cohabiting (*Unadjusted OR = 2.99; CI = 1.90 - 4.70*). Screening rates were higher in men with more than a high school level of education than among men with a high school education or lower education level (χ^2 (49, *n=758*) = 9.19, $p = 0.004$). Men with some college, bachelor's, or higher degrees were more likely to obtain screening than men a high school education (*Unadjusted ORs = 2.12, CI = 1.19 – 3.79; OR= 2.60 CI = 1.22-5.52; OR = 4.79; CI = 2.34-9.79 respectively*). Retired men were three times more likely to have had a PSA test than working men (*Unadjusted OR = 3.16; CI = 1.77-5.65*). Men in the lowest income bracket were more than two to four times less likely to obtain screening than all higher income groups with unadjusted odds ratios and confidence intervals ranging from 2.26 to 3.99 and 1.02 to 7.99 respectively. See Table 2.

The percentage men with medical insurance with history of PSA testing was significantly higher than men with no insurance (χ^2 (49, *n=750*) = 7.22, *p* = 0.009). Men who reported having a regular provider or medical home also had significantly higher rates of PSA testing than men who did not have a medical home; (χ^2 (49, *n=744*) = 17.83, *p* = 0.0001). The percentage of men who had a PSA test was also higher among those who reported at least one medical visit within the past 2 years than men who did not have a visit within the past 2 years (χ^2 (49, *n=758*) = 16.87, *p* = 0.0002). See Table 4. These figures represent crude associations and are unadjusted for other covariates that are addressed in subsequent regression models.

Health Care Use and Health Status

Seventy four percent of the men reported having a regular medical provider and about 83% reported having had at least one medical visit within the past 2 years. In terms of their general health status, 40% of men rated their health as very good or excellent, 41% rated their health as good, and just below 20% rated their health as fair or poor. The number of chronic medical conditions reported by survey respondents ranged from 0 to 7 conditions (M = 1.69, *Standard Error = 0.08; 95% CI = 1.53 – 1.86).* Twenty two percent reported having no chronic medical problems. About 50% reported having either one or two medical conditions, and 28% reported having three or more chronic medical problems. See Table 3.

Risk Perception and Attitude Toward Cancer Screening

In terms of absolute cancer risk perception 36 % of men indicated that they felt they were likely or very likely to get cancer in their lifetime; 42% indicated that they were neither unlikely nor likely to get cancer; and 22% percent indicated that they felt unlikely or very unlikely that they would get cancer in their lifetime. Over 40 % of men sampled indicated that they agreed or strongly agreed that they would rather not know their chances of having cancer (not specific to

prostate cancer). Approximately 57% of men surveyed stated that they disagreed or somewhat disagreed that some cancers were slow growing and needed no treatment. There was a negative association with prostate cancer screening for men who indicated that they strongly or somewhat agreed that some cancers were slow growing and needed not treatment *(Unadjusted OR = 0.47; CI = 0.30 - 0.74).* There were no significant differences by race or by region.

Table 4.

Weighted Percentages for Health Care Utilization, Health Status and Medical problems

Variables	Total Sample N=777		Ever Had PSA *n=503*		Never Had PSA *n=258*	
	n	Weighted %	n	Weighted%	n	Weighted%
Other Variables						
Health Insurance**	671	88.91	458	67.12	198	32.87
Regular Health Provider***	568	73.52	413	70.80	144	29.20
Recent Medical Visit***	652	83.47	456	69.15	183	30.85
Health Status*						
Poor	27	4.33	15	3.33	12	6.07
Fair	108	14.17	52	12.35	56	17.37
Good	286	41.22	185	38.77	101	45.53
Very Good	244	31.14	181	34.79	63	24.71
Excellent	76	9.15	56	10.75	20	6.33
Chronic Medical Problems*						
0 medical problems	156	22.48	84	16.94	72	32.35
1 or 2 medical problems	259	48.97	253	53.85	106	40.28
3 or more medical problems	206	28.54	137	29.21	69	27.36

*Within Group Differences based on Chi Square Analyses: ** p < .01; *** p < .001*

Outcomes of Research Questions

Research Question 1. *How do older adult male patients rate their perceptions of the quality of their care and communication with their health provider?*

Figure 11 shows the racial variations in the percentages of men who rated their perceived quality of care as very good or excellent, good, or fair or poor. Overall, 58% to 84% of men perceived the quality of the care they received as very good or excellent. Significantly more Non-Hispanic white men rated their perception of quality of care higher (very good or excellent) than men of other races based on Chi squares analysis (χ^2 (49, n=635) = 7.23, p = 0.0098). On the other hand Hispanic men rated their perceptions of quality of care significantly lower than men of other races (χ^2 (49, n=635) = 5.42, p = 0.024).

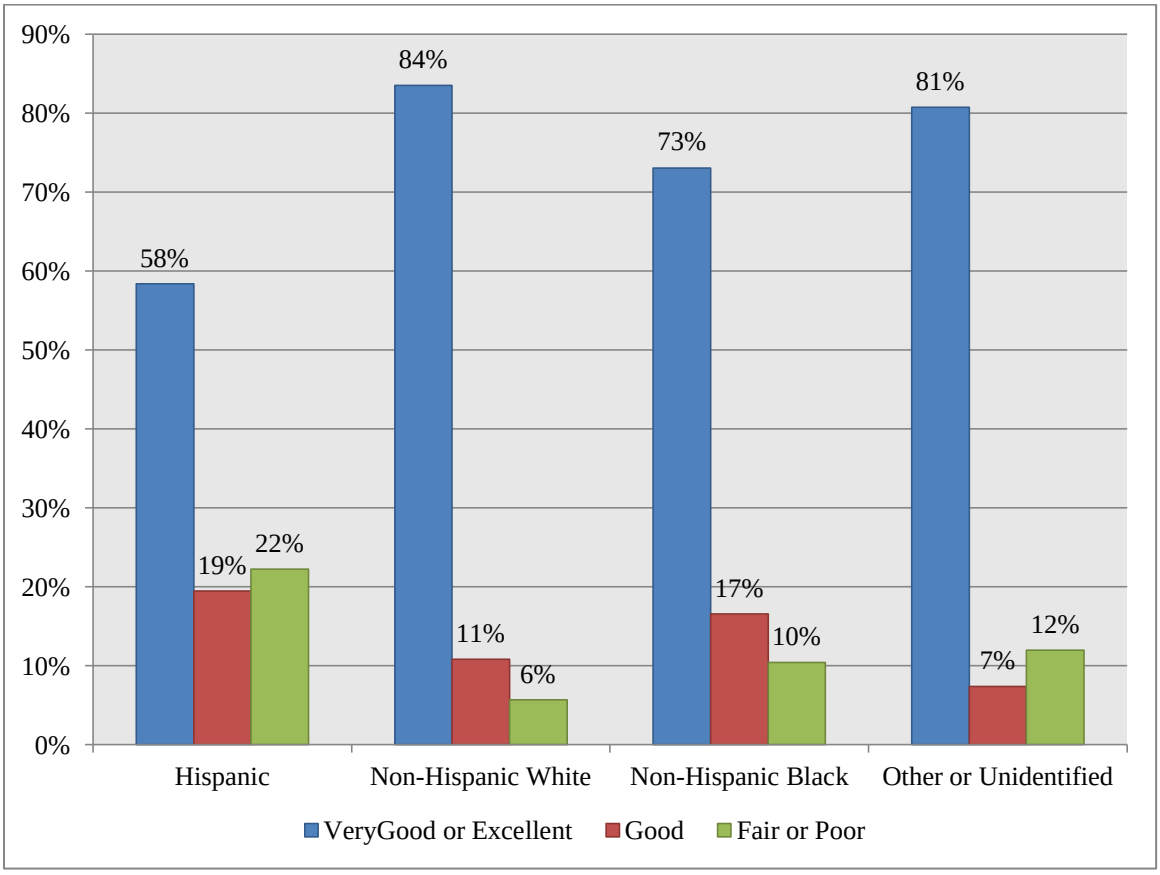
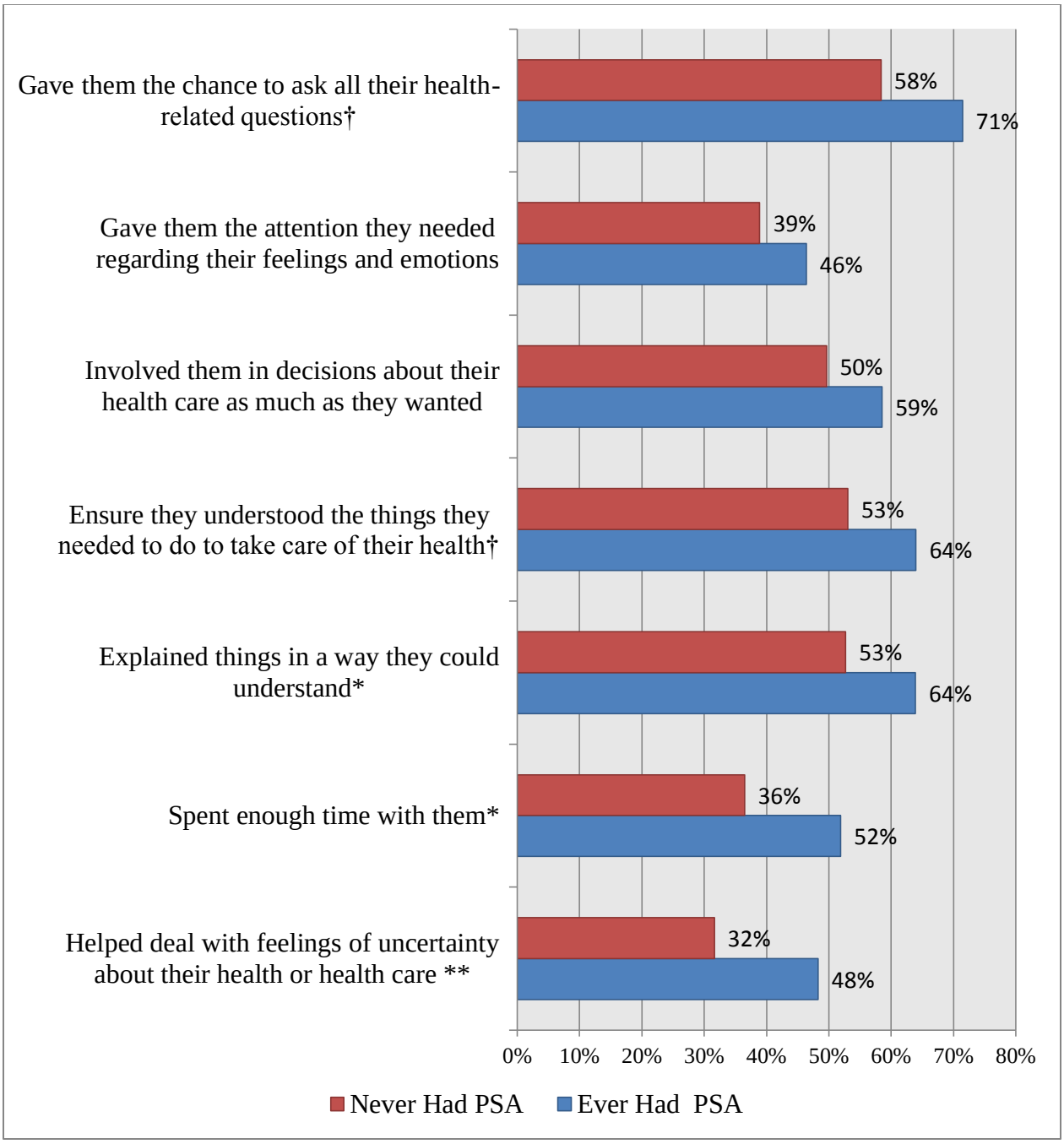


Figure 11. Ratings for Perceived Quality of Care by Race

There was some variation in the ratings men had for their interactions with their providers on the individual provider-patient interaction questions or scale. See Figure 12. There were no statistically significant racial or regional differences in these ratings or percentages. However there were significant differences in proportions between men who previously had a PSA test and those who reported that they never had a PSA test based on Chi Square tests. A significantly higher percentage of men who ever had a PSA indicated that their provider always helped deal with feelings of uncertainty about their health or health care (χ^2 (49, *n=604*) = 7.30, *p* = 0.0094); spent enough time with them (χ^2 (49, *n=599*) = 6.92, *p* = 0.011); and explained things in a way they could understand, (χ^2 (49, *n=611*) = 4.16, *p* = 0.046). There were marginally significant differences for ensuring they understood the things needed to do to take care of their health (χ^2 (49, *n=614*) = 3.15, *p* = 0.082) and being given the chance to ask all their health-related questions (χ^2 (49, *n=618*) = 3.86, *p* = 0.055). See Figure 12. The seven items for general patient provider communication were summed. Scores ranged from a minimum of 7 to a maximum of 28. Average score for summated scale measuring provider patient communication was 23.63 (*SE = 0.25; 95% CI = 23.11 – 24.14*).



*Within group differences based on Chi Square Analyses: ** p < .01; *** p < .001*

Figure 12. Percent of men giving a rating of 'Always' for Provider-patient communication by PSA Screening

Research Question 2. *To what extent are health providers engaging in shared-decision- making process by discussing prostate cancer screening according to the most recent national screening guidelines?*

This analysis provided the self-reported rates on if health providers were discussing prostate cancer screening, whether men wanted to be screened, as well as the implications, pros, and cons of prostate cancer screening. Table 4 shows the weighted percentages of the number of positive responses to the seven questions assessing for the total sample and for men who reported having a nonemergency primary care visit within the past two years. Scores for the variable shared-decision making (Q4 through Q7) ranged from 0 to 4 (Mean = 1.18; *Standard Error = 0.08; 95% CI = 1.02 – 1.33)*.

Table 5 illustrates that 64% of the total men sampled reported having ever had a PSA test. Fifty six percent stated that they discussed the screening with their doctors and over 80% of the men stated that in that conversation the doctor or health provider asked them if they wanted to have the test done. When asked if the doctor or health provider ever discussed the other four key issues regarding PSA testing, comparatively few men reported ever discussing these issues with their health provider (See Table 5, Q4 through Q7). Less than one in four men reported that a physician or health provider ever told them that some experts disagree about whether men should have a PSA test. Just over 30% indicated ever being told that the PSA test is not always accurate or that some prostate cancers are slow growing and do not need treatment. However, about 40% of the respondents indicated that they were told that prostate cancer treatment can cause problems with urination and having sex. These figures were similar among men who reported having had a nonemergency medical visit within the past 2 years as shown in Table 5.

Table 5

Weighted Percentages of Yes Responses to the Shared-Decision-Making Questions (N=777)

	Total Sample *(N=777)*	Primary Visit in 2 years *(n=625)*
Questions about PSA testing	% *(n)*	% *(n)*
Q1. Have you ever had a PSA test?	64.21 *(503)*	69.21 (458)
Q2. Has a doctor or health provider ever discussed with you whether or not you should have the PSA test?	56.13 *(441)*	61.22 (401)
Q3. In that discussion, did the doctor or health provider ask you whether or not you wanted to have the PSA test?	83.84 *(357)*	83.97 (327)
Q4. Did a doctor or health provider ever tell you that some experts disagree about whether men should have PSA tests?	21.05 *(171)*	23.73 (158)
Q5. Has a doctor or health provider ever told you that the PSA test is not always accurate?	29.32 *(232)*	32.26 (208)
Q6. Has a doctor or health provider ever told you that some types of prostate cancer are slow-growing and do not need treatment?	28.25 *(222)*	30.75 (198)
Q7. Has a doctor or health provider ever told you that treating any type of prostate cancer can lead to serious side-effects, such as problems with urination or having sex?	38.55 *(295)*	40.98 (258)

Bivariate analyses using Cross-tabulations with Chi squares showed that there were no statistically significant effects by race or ethnicity, or region. However, from Figure 13 we can see the same trend as described above. Non-Hispanic black men had lower screening rates than white or Hispanic men and fewer reported having discussed prostate cancer screening. However, among those who reported having a discussion Non-Hispanic black men were the largest percentage of men reporting that they were asked if they wanted to have the PSA test.

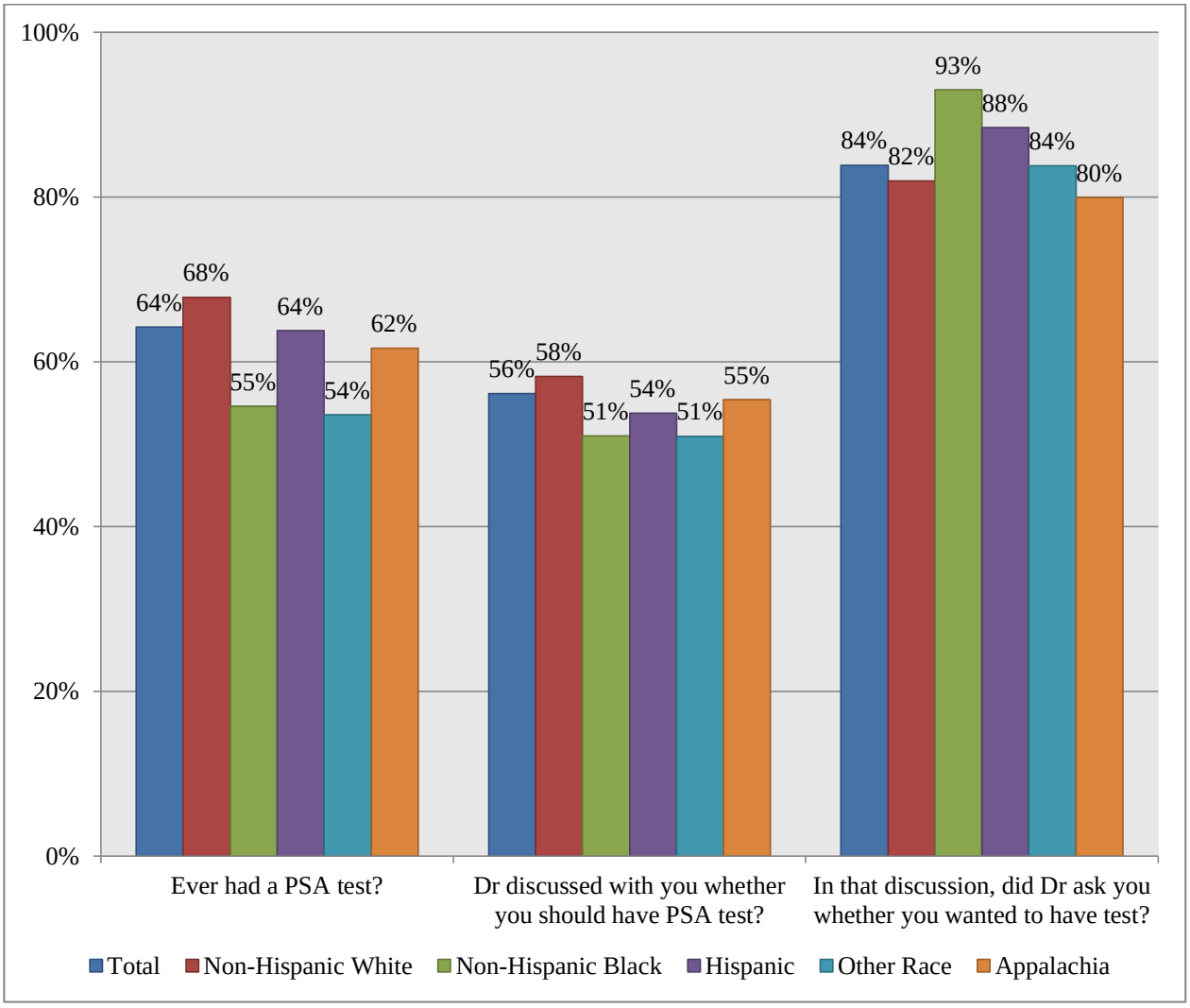


Figure 13: Frequencies of Positive Responses about PSA Testing By Race & Region

More Non-Hispanic white men reported having been told by their doctor or health provider that some experts disagree about PSA testing, that the PSA test is not always accurate and that some cancers are slow growing and do not need treatment when compared to Non-Hispanic black men. A more detailed description of the responses to these questions is provided in Figure 14 below.

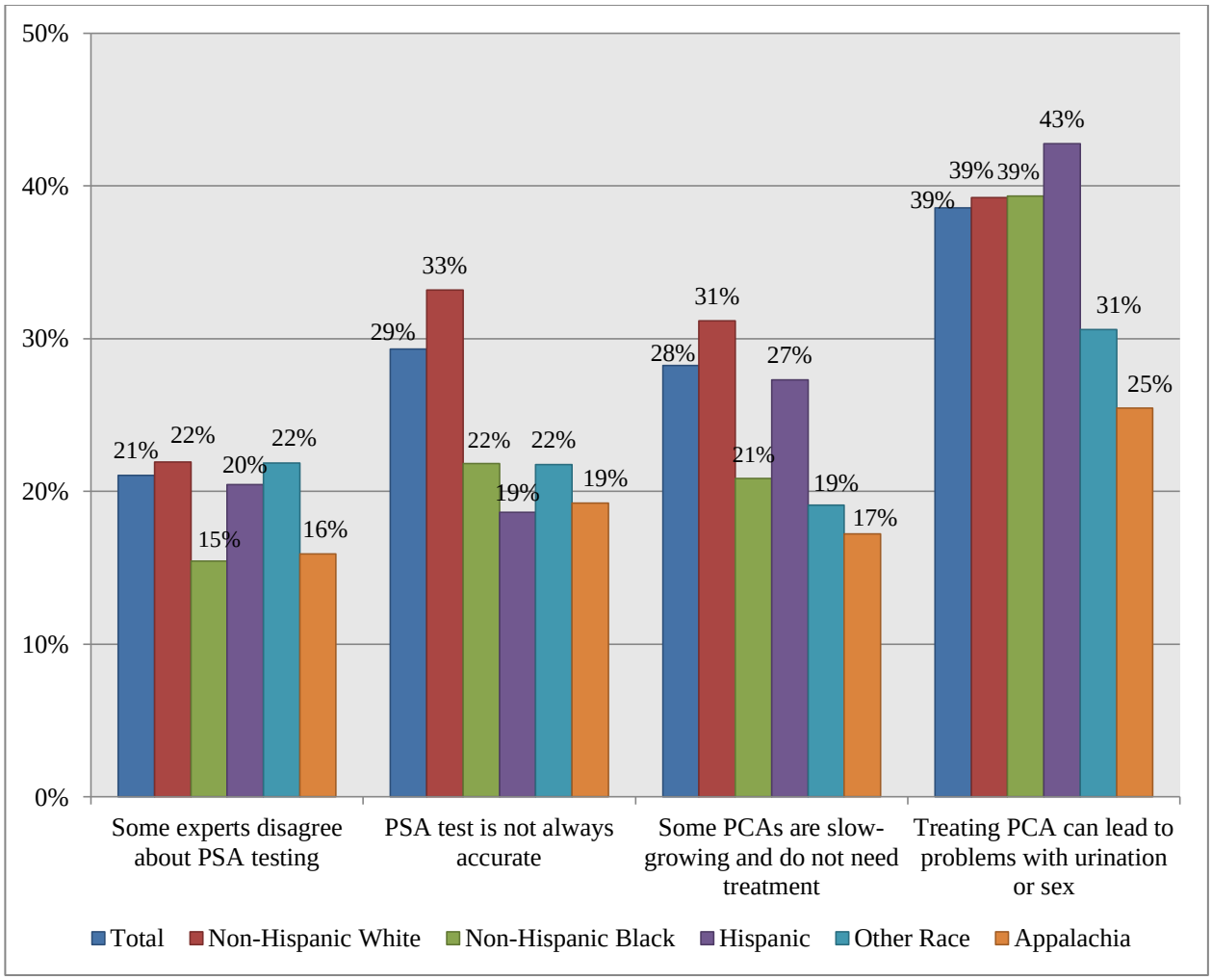


Figure 14: Frequencies of Positive Responses about PSA Testing By Race & Region

The number of Appalachian respondents was small and consequently most analyses including the Appalachian variable lacked statistical power; however, men living in the Appalachian region were less likely to report having had these discussions than men from other

regions. In general, based on Figures 13 and 14 that describe the proportions of positive responses to questions about PSA testing, we can see the same general trends as described above.

Research Question 3. *What factors are associated with shared-decision making about PSA testing?*

The predictors showing a significant linear association with whether men discussed the key areas for shared decision making about PSA testing are included in Table 6. Age, household income, having a regular provider level of communication and having had a recent medical visit were significant positive predictors of shared-decision making. Men who strongly agreed that they would rather not know their chances were less likely to engage in shared-decision making than men who preferred to know their chances of getting cancer. These variables accounted for approximately 12% of the variance in shared-decision making.

Table 6.

Multiple Linear Regression Estimates for the Predictors of Shared-Decision Making (n = 457).

Variables	Estimate	SE	t-value	p-value
Age	0.39	0.16	2.42	0.02
Household income	0.04	0.02	2.16	0.04
Regular Provider	0.41	0.19	2.15	0.04
General Communication	0.03	0.01	2.21	0.03
Rather not Know	-- 0.37	0.18	-2.04	0.05
Recent Visit	0.61	0.21	2.90	.001
R^2 (R Squared)		*0.12*		
F		*8.54*		*<.0001*

Research Question 4. *What is the relationship between male patient's perceptions of the quality of their care, provider patient discussion about prostate cancer and PSA testing?*

The results of four separate multiple logistic regression models used to estimate the strength of the association of the various predictors of PSA testing in the sample are reported in Table 7. Model one examined demographic factors such as age (10-year category), marital status, race or ethnicity, education level, and other correlates such as perception of cancer risk, number of chronic medical problems, perceived quality of care received, having a regular provider, and having had a medical visits in the past 2 years. As expected age was a significant predictor of PSA testing in this model and across all four models (ORs ranged from 2.51 – 2.97). For every 10-year increase in age the likelihood of having a PSA test increased by 2.5 times to 2.97 times. Men who were married or living as married were twice as likely to have obtained PSA testing (OR = 2.41 *95% CI = 1.21 – 4.80)* when compared to men who were not cohabiting. Having had a nonemergency medical visit in the past 2 years positively predicted PSA testing (OR 4.41; *95% CI = 1.57 – 12.42*). Higher perception of quality of care was a significant predictor of PSA testing. However, men who indicated that they would rather not know if they had cancer were less likely to have obtained screening compared to men who cared to know (OR = 0.49; *95% CI = 0.28 – 0.85*).

The variable addressing the four key questions about pros and cons of prostate cancer screening that define shared-decision making was added in model 2. Discussions of the four key controversial issues related to shared-decision making positively predicted prostate cancer screening. For a one unit increase in level of discussion of key issues the odds of having had a PSA test (versus not having a PSA test) increases by a factor of 3.35. Age, education level,

married or cohabiting, and perceived quality of care remained positive predictors of PSA testing in this model.

Model 3 examined the effect of general discussion about PSA testing while controlling for the other variables. The strongest predictor of PSA testing was the doctor or health provider having ever discussed whether the respondent should have the PSA test. Men whose doctor talked with them about PSA testing were 69.5 times more likely to have had the PSA test compared to men who indicated that they had not ever discussed PSA testing with their doctor (OR = 69.45; *CI = 23.60 – 204.61*). Age (OR = 2.51; *CI =1.16 – 5.45*), having more than a high school education (OR = 3.61; *CI = 1.17 – 11.17),* and quality of care (OR = 1.83; *CI = 1.01 – 3.31*) remained significant predictors of PSA testing in this model.

In model 4 when the shared-decision making variable was added patients who discussed general PSA testing were only 47 times more likely to obtain prostate cancer screening with the PSA test (OR = 47.42; *CI = 14.91 – 150.74*). Shared-decision making also significantly predicted PSA testing (OR = 47.42; *CI = 14.91 – 150.74*). In other words, both variables predicted PSA testing but discussing the four key issues required for shared-decision making significantly modified the effect of having a general talk about prostate cancer screening. Age (OR = 2.66; *CI =1.14 – 6.24*), having more than a high school education (OR = 4.01; *CI = 1.14– 14.18)* and quality of care (OR = 2.04; *CI = 1.10 – 3.78*) also remained significant predictors of PSA testing in the fourth model.

Table 7

Logistic Regression Estimates for the Predictors of PSA Testing

	Model 1 (n = 437)	Model 2 (n = 427)	Model 3 (n = 437)	Model 4 (n = 427)
Covariates	Estimate *(95% CI)*	Estimate *(95% CI)*	Estimate *(95% CI)*	Estimate *(95% CI)*
Age (10-year increase)	2.67 *(1.44 – 4.95)**	2.97 (1.56 – 5.65)**	2.51 *(1.16 – 5.45)**	2.66 *(1.14 – 6.24)* *
Married or Cohabiting =1	2.41 *(1.21 – 4.80)**	3.44 *(1.52 – 7.79)**	2.11 *(0.81 – 5.56)*	2.84 *(0.94 –8.58)* †
> High School =1	2.05 *(1.06 – 3.95)**	2.39 *(1.08 – 5.28)**	3.61 *(1.17 – 11.17)**	4.01 *(1.14–14.18)**
Quality of Care	1.63 *(1.15 – 2.32)**	1.91 *(1.23 – 2.95)**	1.83 *(1.01 – 3.31)**	2.04 *(1.10 – 3.78*)*
Rather not know = 0	0.49 *(0.28 – 0.85)**	0.51 *(0.23 – 1.10)*	0.65 *(0.22 – 1.90)*	0.70 *(0.19– 2.66)*
Recent Visit =1	4.41 *(1.57 – 12.42)**	3.80 *(0.93 – 15.48)* †	3.16 *(0.90 – 11.13)*†	3.29 *(0.90 –12.01)* †
Shared-decision		3.35 *(1.94 – 5.80)****		1.93 *(1.11 –3.56)**
Dr. Discussed PSA			69.49 *(23.60 – 204.61*)***	47.42 *(14.91 – 150.74)****
Testing =1				

*Note: *p < .05; ** p < .01; *** p < .001; †p < .10*

CHAPTER 5

DISCUSSION

The recommendations for use of the PSA test have been modified over the years as new scientific evidence emerged making it necessary to continually evaluate the impact of these evidence based recommendations on medical and public health practice and on the lives and health of the population. Even though prostate cancer is the second leading cause of cancer deaths in men after lung cancer and has a higher mortality rate than many other types of cancer the controversy relating to early detection and the efficacy of PSA screening remains unrelenting (Barry, 2009; Slatkoff et al., 2011). The most current prostate cancer screening recommendations discourage wide spread PSA screening for men at low to average risk but encourages shared-decision making between adult men and their health providers regarding the possible benefits and risks of PSA testing and gives guidelines for what topics are to be included in shared-decision making (Carter et al., 2013; Moyer, 2012). This study assessed men's perceptions of the quality of care and the level of communication they have with their health providers, the extent to which these recommendations are being followed, and what factors are associated with shared-decision making and PSA testing in a nationally representative sample.

Perceptions of Communication with Health Providers and Quality of Care

In general, most men rated their general communication with their health providers as very good or excellent. There were no demographic or regional differences in these ratings. However, men who had a previous PSA test were more likely to rate their level of communication higher than men who did not have a PSA test. This association is supported by previous research that suggests that higher quality communication that is patient-centered, that addresses concerns, and that helps patients to feel respected and understood leads to more

informed health decisions, improves adherence to medical recommendations, and helps patients deal with existing or potential medical conditions (Epstein & Street, 2011; Ha & Longnecker, 2010; Politi, Lewis, & Frosch, 2013; Zolnierek & Dimatteo, 2009). This suggests that there may be a need for additional to investigate what can be done to facilitate better communication among the men who give a lower rating for their level of communication or if there were other factors that prompted their poorer rating.

Among the men who never had a PSA test only about one third indicated that the provider always spent enough time with them or helped them deal with their feelings of uncertainty about their health. This finding might be suggesting, as did some previous research, that patients feel rushed in their medical encounters that may not provide enough time for them to address their issues and concerns about their health. This also impacts the patients' ability to develop a trusting relationship that in turn impacts overall patient satisfaction ratings (Dugdale, Epstein, & Pantilat, 1999; Fiscella et al., 2004).

Hispanic men rated their quality of care lower than men of other races. Previous research indicates that Hispanics in America are faced with a number of barriers to culturally and linguistically appropriate care in some areas. These barriers may include issues with lower socioeconomic factors that might impact health care use, language proficiency, and other communication factors, as well as other sociocultural factors (Escarce & Kapur, 2006; Gast & Peak, 2012). Continued efforts are needed to identify and address the conditions that negatively impact quality of care and the poorer health outcomes experienced by minority men.

Prevalence and Predictors of PSA Testing

In this study the percentage of men who reported ever having a PSA test is comparable to data from other national samples (Finney Rutten et al., 2005; Hoffman et al., 2009). As

expected, older men were more likely to report ever having had a PSA test. The strongest predictor of PSA testing was having had a discussion about testing with their physician. Education and being married or cohabiting were also significant predictors of PSA, which is consistent with previous reports on predictors of prostate cancer screening (Emerson et al., 2009; Finney Rutten et al., 2005).

Another factor associated with PSA testing was men's perception of the quality of care received. This was highly correlated with level of general communication with the health provider but this separate variable was a strong independent predictor of PSA testing even when regression models were adjusted for other factors. In other words, men who rated the quality of their care high were much more likely to have obtained the PSA test than men who had lower ratings for quality of care. Lee and colleagues (2012) reported poor quality of care as a barrier to prostate cancer screening in urban dwelling African American and Afro-Caribbean men.

There are still a significant number of men who did not want to find out if they had cancer and this was negatively associated with PSA testing. This finding supports previous research that indicates that men who fear cancer or the implications of a prostate cancer diagnosis may be less likely to obtain screening (Friedman et al., 2009; Ukoli et al., 2013).

Prevalence and Factors Associated with Shared-Decision Making

About 60% of the men in the study who had a preventive health visit in the past 2 years reported having discussed PSA testing with their health provider. However, in these 2 years post the updated USPSTF recommendations approximately only 2 to 4 out of 10 men in the recommended age for screening for prostate cancer report having ever been told by their health provider that some experts disagree about whether men should have PSA tests, that the PSA test is not always accurate, some cancers are slow growing and do not need treatment, or that prostate

cancer treatment can lead to serious sexual and urinary side effects. These are the four key issues that national health organizations indicate must form part of the discussion necessary to facilitate shared- or informed-decision making. While a provider recommendation of a PSA test was the largest predictor of screening, discussing these issues had a substantive moderating effect on screening. In other words, discussing the controversial issues reduces the likelihood of PSA testing among older adult men. This finding suggests that more work needs to be done to encourage shared-decision making about prostate cancer screening in the clinical setting. It is understood that health providers are constrained for time in individual clinical encounters but it might be useful to identify other ways of communicating accurate and balanced information regarding PSA testing in that setting.

One unanswered question derived from this finding concerns the nature of discussions and topics covered among the men who report having discussed prostate cancer screening with their health provider. In this study between 51% and 58% of men of all races reported having ever discussed PSA testing with their health provider, but most men indicated that they had not engaged in shared-decision making with their providers. It is likely that physicians are continuing to order PSA tests without informing their patients about the pros and cons of screening and engaging in the shared-decision making process as recommended as reported previously (Ferrante et al., 2011; Hoffman et al., 2009; Wilkes et al., 2013). Shared-decision making allows health providers to work in partnership with their male patients in a way that promotes their autonomy to make decisions about their health that is informed by the best available evidence, their personal beliefs and preferences, and which provides accurate information on all options available (Elwyn et al., 2010; Frosch, 2012). Because of the potential risks associated with prostate cancer screening such as false positives that can lead to undue

stress, unnecessary biopsies of the prostate that can in turn lead to unwanted side effects, it is necessary to have these discussions so that men can come to terms with the implications and consequences of their decision to screen or not screen. Failure to have these discussions robs men of the opportunity to have their fears and concerns about screening addressed by their provider (Charles, Gafni, & Whelan, 1997). While this does not necessarily mean that because men are not having these discussions with their providers that they are completely uninformed about issues regarding PSA testing as there are other sources of information. However, previous studies suggest that this sometimes leads to misinformation and lack of preventive health screenings based on inaccurate or incomplete information (Ferrante et al., 2011).

Limitations

The HINTS survey did not provide data on whether men were asymptomatic for prostate cancer or other prostatic diseases. Other benign prostate conditions might prompt physician visits and could signal need for prostate examinations and prostate cancer screening (Cunningham & Kadmon, 2013; McVary et al., 2011; Paolone, 2010). The data also did not measure intent to obtain screening nor whether the discussion with the physician specifically influenced their decision to screen or not to screen. This information would have been useful to help delineate reasons for obtaining or refusing prostate cancer screening.

The Appalachian region had the highest nonresponse rate to the survey. Consequently the number of Appalachian male respondents is small and even with the sample weighting could lead to potential errors in statistical estimates because the respondents may not accurately represent Appalachian men in the national population. Future studies or subsequent iterations of HINTS should include methods to increase sample size for Appalachian residents in population-based studies.

More generally, cross-sectional studies do not reflect changes in the phenomena being studied over time and are therefore limiting in inferring causation. However, this study estimates the prevalence of shared-decision making in a nationally representative sample at this point in time. Future time series designed studies can use these questions and variables to determine trends in shared-decision making about prostate cancer screening as the USPSTF recommendations and the recommendations of the other guiding organizations become more widely distributed.

Implications and Recommendations for Future Research

The majority of studies examining discussions about PSA testing were conducted prior to the most recent (2011) national screening recommendations. This study adds to the literature that examines the impact of public policy decisions on prostate cancer screening on provider interactions with adult male patients and their screening decisions. These decisions will consequently impact future prostate cancer incidence rates. Just as increased use of the PSA test in the 1990s led to significantly higher incidence rates of prostate cancer, it is expected that reduced screening rates will lead to fewer prostate cancers being detected. Even though there are likely to be decreased incidence rates nationally, this outcome may lead to a false sense of success in prostate cancer prevention, screening, and treatment. It is therefore imperative that the clinical, epidemiological and behavioral research is continued to further reduce the burden of this disease and the existing disparities.

This evidence shows that most health providers are not following the recommended screening guidelines and are not discussing important issues that impact men's decisions to be screened, which suggests that there is a need for various types of interventions to improve these numbers in the clinical setting. This information might help inform the design of more effective

provider based interventions to increase shared-decision-making about PSA testing and increase facilitation of PSA screening, if screening is recommended and desired by older adult males. Additionally, interventions at the community level to increase knowledge about prostate cancer and the benefits and risks of screening as well as how to initiate these discussions with their health provider may increase the likelihood of shared-decision making in the clinical setting.

In addition it may be useful to evaluate the feasibility of using trained prostate cancer health or nurse educators in the clinical setting to provide accurate information on the pros and cons of prostate cancer screening. Making decisional aids and checklists readily available to men (wherever they seek health information) to help them determine their prostate cancer risk along with questions to ask their provider may help boost the shared-decision making process. Further to this, it would be useful to identify and include other approaches that might lessen the perils associated with screening. Hayes and Barry (2014) indicate that having a PSA test every 2 years instead of annually, increasing the PSA level that would trigger a biopsy as well as providing less aggressive treatment for newly diagnosed prostate cancer cases may be options to consider. Future studies could also examine the impact that this type of medical and scientific skepticism has on patient decision making as suggested by Politi and colleagues (2011).

These findings may be used to increase public awareness, education, and screening about this critical public health the disease. If we are to make similar strides in prostate cancer as we have done in breast and cervical cancer screening and outcomes, early detection may still be one of the most critical issues. Improvements in prostate cancer education, screening methods, along with more effective and efficacious treatment modalities will increase the chances of a successful outcome.

Conclusion

Overall most men reported very good or excellent overall communication with their health provider and indicated satisfaction with the quality of care they received. However, Hispanic men reported lower perceptions of quality of care than men of other races and non-Hispanic white men reported the highest ratings for quality of care received. Quality of provider-patient communication and quality of care received were associated with PSA testing and with shared-decision making. Age, marital status, and level of education were also significant predictors of PSA testing. While having a discussion with a doctor about PSA testing was the biggest independent predictor of PSA testing, the effect was significantly modified when those discussions included information that some experts disagreed with PSA testing, that the test may not always be accurate, that some prostate cancers are nonaggressive and do not need treatment, or that prostate cancer treatment can lead to serious sexual and urinary side effects. Even though a majority of older adult men received the PSA test and reported good provider-patient communication, only a marginal number reported having discussed the pros and cons of prostate cancer screening with their health providers. This means that health providers are falling short of the USPSTF recommendation for the use of the PSA test in the clinical setting and may be continuing to order the PSA test as part of routine testing for older adult men. Consequently, there is need for continued efforts to increase awareness of prostate cancer and PSA testing in the clinical and community setting so that men can be equipped to make informed decisions about prostate cancer screening and be able to initiate these discussions with their providers. Until more rigorous scientific evidence becomes available, these challenges will continue as patients, providers, researchers, advocates, and other stakeholders deal with this important health concern.

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APPENDIXES

APPENDIX A

Historical Achievements in Prostate Cancer Research & PSA Testing

The following list includes some important dates in the study and treatment of prostate cancer and the development and use of PSA test as presented by Denmeade & Isaacs (2002).

1. 1904 – Hugh Hampton Young from Johns Hopkins develops the radical prostatectomy
2. 1913 – Prostate Cancer is treated with direct implantation of radium into the prostate
3. 1936 – Ethel Gutman describe elevated acid phosphatase activity in prostate cancer
4. 1938 – Robert Moore and Allister McLellan use oestrogen injections for medical castration
5. 1941 – Charles Huggins reports on the beneficial effects of castration and oestrogen in men with advanced prostate cancer
6. 1947 – Terrence Millin introduces radical retropubic prostatectomy
7. 1962 – Malcolm Bagshaw describes megavoltage radiation for localized prostate cancer
8. 1966 – The Gleason Grading system is developed
9. 1971 – The National Prostatic Cancer project is initiated (completed in 1988)
10. 1973 – The Veterans Administration Study (VACURG) shows the benefit of hormonal therapy
11. 1975 – WW Scott and colleagues report the results of the first national randomized chemotherapy study for prostate cancer
12. 1980 – Prostate-specific antigen is found to be elevated in serum of men with prostate cancer
13. 1980-1984 – in 1980's PSA was determined to be more sensitive for detecting prostate cancer than DRE but less specific

14. 1981 – Luteinizing hormone-releasing hormone analogues are first used to treat prostate cancer
15. 1983 – Patrick Walsh reports on nerve-sparing prostatectomy to preserve erectile function
16. 1983 – H. Holm develops ultrasound guided trans perineal implantation of radioactive seeds
17. 1985 – Leuprolide is approved by the Food and Drug Administration (FDA) for treatment of Prostate cancer
18. 1986 – FDA approves the use of the PSA for monitoring prostate cancer
19. 1988 – Ultrasound biopsy device is developed
20. 1989 – Flutamide receives FDA approval
21. 1990 – Three dimensional conformal radiation therapy is developed
22. 1994 – FDA approves PSA screening for the detection of early prostate cancer
23. 1995 – A meta-analysis trial of combined androgen blockade concludes that no significant benefit is achieved by combining these drugs
24. 1997 – Randomized studies show the benefits of combining radiation and androgen ablation (Denmeade & Isaacs, 2002)
25. 2008 – The USPSTF recommends against PSA-based screening for prostate cancer in men aged 75 years and older and concluded that the evidence was insufficient to make a recommendation in younger men
26. 2009 – Reports from two major randomized controlled studies published in New England Journal of Medicine
27. 2011 – The USPSTF recommends against PSA-based screening for prostate cancer in all age groups.

APPENDIX B

Permission to use Copyrighted Materials – Terese Winslow

Terese Winslow Oct 11
to me
Dear Michelle,

Thank you for contacting me. You have my permission to use my Stages of Prostate Cancer illustration in your dissertation review chapter and PowerPoint presentations. When you know where the dissertation will be published, contact me again and I will email you my Journal Permissions form. Or does East Tennessee State U. have a journal?

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On Oct 11, 2013, at 12:08 PM, Michelle Reece wrote:

Dear Terese Winslow
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Thank you for your attention and I await your response.
Very Respectfully,
Michelle C. Reece

<CDR442273-571.jpg>
--

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APPENDIX C

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APPENDIX D

HINTS 4 Cycle 2 Data – Terms of Use

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It is of utmost importance to ensure the confidentiality of survey participants. Every effort has been made to exclude identifying information on individual respondents from the computer files. Some demographic information such as sex, race, etc., has been included for research purposes. NCI expects that users of the data set will adhere to the strictest standards of ethical conduct for the analysis and reporting of nationally collected survey data. It is mandatory that all research results be presented/published in a manner that protects the integrity of the data and ensures the confidentiality of participants.

In order for the Health Information National Trends Survey (HINTS) to provide a public-use or another version of data to you, it is necessary that you agree to the following provisions.

1. You will not present/publish data in which an individual can be identified. Publication of small cell sizes should be avoided.
2. You will not attempt to link nor permit others to link the data with individually identified records in another database.
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4. If the identity of any person is discovered inadvertently, then the following should be done;
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10. You may receive periodic e-mail updates from the HINTS administrators.

☑ Marking this box indicates that I agree to comply with the above stated provisions.

Please enter your email: _____

Accept

APPENDIX E

Health Information National Trends Survey Questions

A7. Overall, how confident are you that you could get advice or information about cancer if you needed it? (CancerConfidentGetHealthInf)
1. Completely confident
2. Very confident
3. Somewhat confident
4. A little confident
5. Not confident at all

Questions on Healthcare Utilization

C1. Not including psychiatrists and other mental health professionals, is there a particular doctor, nurse, or other health professional that you see most often (1= Yes; 2 = No)? (RegularProvider)

C2. Do you have any kind of health care coverage, including health insurance, prepaid plans such as HMOs or government plans such as Medicare (1= Yes; 2 = No)? (HealthInsurance)

C3. About how long has it been since you last visited a doctor for a routine checkup? A routine checkup is a general physical exam, not an exam for a specific injury, illness, or condition. (MostRecentCheckup)
1. Within past year (anytime less than 12 months ago)
2. Within past 2 years (1 year but less than 2 years ago)
3. Within past 5 years (2 years but less than 5 years ago)
4. 5 or more years ago
5. Don't know
6. Never

C4. In the past 12 months, not counting times you went to an emergency room, how many times did you go to a doctor, nurse, or other health professional to get care for yourself? (FreqGoProvider)
1. 0 None GO TO D1 on the next page
2. 1 time
3. 2 times
4. 3 times
5. 44 times
6. 5-9 times
7. 10 or more times

C5. The following questions are about your communication with all doctors, nurses, or other health professionals you saw during the past 12 months. How often did they do each of the following: 1 =Always; 2=Usually; 3= Sometimes; 4= Never
1. Give you the chance to ask all the health-related questions you had? (ChanceAskQuestions)
2. Give the attention you needed to your feelings and emotions? (FeelingsAddressed)
3. Involve you in decisions about your health care as much as you wanted? (InvolvedDecisions)

4. Make sure you understood the things you needed to do to take care of your health? (UnderstoodNextSteps)
5. Explain things in a way you could understand? (ExplainedClearly)
6. Spend enough time with you? (SpentEnoughTime)
7. Help you deal with feelings of uncertainty about your health or health care? (HelpUncertainty)

C6. In the past 12 months, how often did you feel you could rely on your doctors, nurses, or other health care professionals to take care of your health care needs? (DrTakeCareNeeds)

C7. Overall, how would you rate the quality of health care you received in the past 12 months? (QualityCare)

Questions on Overall Health

F1. In general, would you say your health is (GeneralHealth)
1. 1 Excellent
2. 2 Very good
3. 3 Good
4. 4 Fair, or
5. 5 Poor?

F2. Overall, how confident are you about your ability to take good care of your health? (OwnAbilityTakeCareHealth)
1. 1 Completely confident
2. 2 Very confident
3. 3 Somewhat confident
4. 4 A little confident
5. 5 Not confident at all

F3. Has a doctor or other health professional ever told you that you had any of the following medical conditions: 1= Yes; 2=No
1. Diabetes or high blood sugar? (MedConditions_Diabetes)
2. High blood pressure or hypertension? (MedConditions_HighBP)
3. A heart condition such as heart attack, angina, or congestive heart failure? (MedConditions_HeartCondition)
4. Chronic lung disease, asthma, emphysema, or chronic bronchitis? (MedConditions_LungDisease)
5. Arthritis or rheumatism? (MedConditions_Arthritis)
6. Depression or anxiety disorder? (MedConditions_Depression)

Questions on Screening for Prostate Cancer Using PSA Test

The following questions are about discussions doctors or other health care professionals may have with their patients about the PSA test that is used to look for prostate cancer.

L8. Have you ever had a PSA test? (EverHadPSATest) 1 = Yes; 2 = No

L9. Has a doctor ever discussed with you whether or not you should have the PSA test? (DrShouldPSATest) 1 Yes; 2 No GO TO L11 below

L10. In that discussion, did the doctor ask you whether or not you wanted to have the PSA test? (DrWantedPSATest) 1 Yes; 2 No

L11. Did a doctor ever tell you that some experts disagree about whether men should have PSA tests? (SomeDisagreePSATests) 1 Yes; 2 No

L12. Has a doctor or other health care professional ever told you that:
   a. The PSA test is not always accurate? (ProstateCa_PSATest) 1 Yes; 2 No
   b. Some types of prostate cancer are slow-growing and need no treatment? (ProstateCa_SlowGrowing) 1 Yes; 2 No
   c. Treating any type of prostate cancer can lead to serious side-effects, such as problems with urination or having sex? (ProstateCa_SideEffects) 1 Yes; 2 No

Questions on Cancer History

M1. Have you ever been diagnosed as having cancer? (1= Yes; 2 = No) No GO TO N1 on the next page. (EverHadCancer)

M2. What type of cancer did you have? Mark all that apply.
   a. Bladder cancer (CaBladder)
   b. Bone cancer (CaBone)
   c. Breast cancer (CaBreast)
   d. Cervical cancer (cancer of the cervix) (CaCervical)
   e. Colon cancer CaColon
   f. Endometrial cancer (cancer of the uterus) (CaEndometrial)
   g. Head and neck cancer (CaHeadNeck)
   h. Hodgkin's lymphoma (CaHodgkins)
   i. Leukemia/Blood cancer (CaLeukemia)
   j. Liver cancer (CaLiver)
   k. Lung cancer (CaLung)
   l. Melanoma (CaMelanoma)
   m. Non-Hodgkin lymphoma (CaNonHodgkin)
   n. Oral cancer (CaOral)
   o. Ovarian cancer (CaOvarian)
   p. Pancreatic cancer (CaPancreatic)
   q. Pharyngeal (throat) cancer (CaPharyngeal)
   r. Prostate cancer (CaProstate)
   s. Rectal cancer (CaRectal)
   t. Renal (kidney) cancer (CaRenal)
   u. Skin cancer, non-melanoma (CaSkin)
   v. Stomach cancer (CaStomach)
   w. Other-Specify (CaOther_OS CaOther Cancer_Cat)

M3. At what age were you first told that you had cancer? (WhenDiagnosedCancer)

Survey Questions on Beliefs about Cancer

Think about cancer in general when answering the questions in this section.

N1. How likely are you to get cancer in your lifetime? (ChanceGetCancer)
   1 = Very unlikely; 2 = Unlikely; 3 = Neither unlikely nor likely; 4 = Likely; 5 = Very likely

N2. Compared to other people your age, how likely are you to get cancer in your lifetime? (CompareChanceGetCancer)

1. 1 Much less likely;
2. 2 Less likely;
3. 3 About the same;
4. 4 More likely;
5. 5 Much more likely

N3. Select one answer that best represents your opinion about the statement: "I feel like I could easily get cancer in my lifetime." (EasilyGetCancer)
1. I feel very strongly that this will NOT happen
2. I feel somewhat strongly that this will NOT happen
3. I feel I am just as likely to get cancer as I am to not get cancer
4. I feel somewhat strongly that this WILL happen
5. I feel very strongly that this WILL happen

N4. How much do you agree or disagree with the statement: "I'd rather not know my chance of getting cancer." (RatherNotKnowChance)
1. Strongly agree
2. Somewhat agree
3. Somewhat disagree
4. Strongly disagree

N5. How much do you agree or disagree with each of the following statements?
1. It seems like everything causes cancer. (EverythingCauseCancer)
2. There's not much you can do to lower your chances of getting cancer. (PreventNotPossible)
3. There are so many different recommendations about preventing cancer, it's hard to know which ones to follow (TooManyRecommendations)
4. Some cancers are slow growing and need no treatment (CancerSlowGrowing)
5. In adults, cancer is more common than heart disease. (CancerMoreCommon)
6. In women, breast cancer is more common than lung cancer. (BreastCancerMoreCommon)

N6. As far as you know, who has a greater chance of getting cancer - a person with a 1 in 1,000 chance of getting cancer, or a person with a 1 in 100 chance? (WhichRatioCancerChance)
2 = 1 in 1,000 is a greater chance of getting cancer
1 = 1 in 100 is a greater chance of getting cancer

N7. Have any of your family members ever had cancer? (FamilyEverHadCancer)
1 = Yes; 2 = No; 4 = Not sure

Sociodemographic Questions

O1. What is your age? (Age)

O2. What is your current occupational status? (OccupationStatus) Mark only one.
1. 1 Employed (Employed)
2. 2 Unemployed (Unemployed)
3. 3 Homemaker (Homemaker)
4. 4 Student (Student)
5. 5 Retired (Retired)
6. 6 Disabled (Disabled)
7. 91 Other-Specify (OccupationStatus_OS) (OtherOcc) (MultiOcc)

O5. What is your marital status? (MaritalStatus)

1. 1 Married
2. 2 Living as married
3. 3 Divorced
4. 4 Widowed
5. 5 Separated
6. 6 Single, never been married

O6. What is the highest grade or level of schooling you completed? (Education)

1. Less than 8 years
2. 8 through 11 years
3. 12 years or completed high school
4. Post high school training other than college (vocational or technical)
5. Some college
6. College graduate
7. Postgraduate

O10. Are you of Hispanic, Latino/a, or Spanish origin? One or more categories may be selected. Mark one or more.

1. No, not of Hispanic, Latino/a, or Spanish origin (NotHis)
2. Yes, Mexican, Mexican American, Chicano/a (Mexican)
3. Yes, Puerto Rican (PuertoRican)
4. Yes, Cuban (Cuban)
5. Yes, another Hispanic, Latino/a, or Spanish origin (OthHisp) (Hisp_Cat)

O11. What is your race? One or more categories may be selected. Mark one or more.

1. White (White)
2. Black or African American (Black)
3. American Indian or Alaska Native (AmerInd)
4. Asian Indian (AsInd)
5. Chinese (Chinese)
6. Filipino (Filipino)
7. Japanese (Japanese)
8. Korean (Korean)
9. Vietnamese (Vietnamese)
10. Other Asian (OthAsian)
11. Native Hawaiian (Hawaiian)
12. Guamanian or Chamorro (Guamanian)
13. Samoan (Samoan)
14. Other Pacific Islander (OthPacIsl) (Race_Cat2)

O18. Thinking about members of your family living in this household, what is your combined annual income, meaning the total pre-tax income from all sources earned in the past year? (IncomeRanges).

1. $0 to $9,999
2. $10,000 to $14,999
3. $15,000 to $19,999
4. $20,000 to $34,999
5. $35,000 to $49,999
6. $50,000 to $74,999
7. $75,000 to $99,999
8. $100,000 to $199,999
9. $200,000 or more

APPENDIX F

ETSU Institutional Review Board (IRB) Determination

East Tennessee State University
Office for the Protection of Human Research Subjects • Box 70565 • Johnson City, Tennessee 37614-1707
Phone: (423) 439-6053 Fax: (423) 439-6060

October 18, 2013

Michelle C. Reece
2926 Chestnut Lane, Apt #1
Johnson City, TN 37601

Dear Ms. Reece,

Thank you for recently submitting information regarding your proposed project "Patient-physician communication, shared decision making, and attitudes about prostate cancer screening."

I have reviewed the information, which includes a completed Form 129.

The determination is that this proposed activity as described meets neither the FDA nor the DHHS definition of research involving human subjects. Therefore, it does not fall under the purview of the ETSU IRB.

IRB review and approval by East Tennessee State University is not required. This determination applies only to the activities described in the IRB submission and does not apply should any changes be made. If changes are made and there are questions about whether these activities are human subject research in which the organization is engaged, please submit a new request to the IRB for a determination.

Thank you for your commitment to excellence.

Sincerely,
Chris Ayres
Chair, ETSU IRB

Full AAHRPP Accreditation

Accredited Since December 2005

VITA

MICHELLE C. REECE

Education:	Public Schools, Barbados
	Bachelor of Arts in English & Behavioral Sciences, Andrews University, Berrien Springs, MI, 1994
	M.S. Counseling Psychology, Tennessee State University, Nashville, TN 2004
	Master's Certificate in Health Care Administration and Planning, College of Public Service & Urban Affairs, Tennessee State University, Nashville, TN 2007
	Dr.P.H., Community and Behavioral Health, College of Public Health, East Tennessee State University, Johnson City, TN 2014
Professional Experience:	Research Assistant – Center for Prevention Research, Tennessee State University, 2002-2005
	Research Associate – Center for Prevention Research, Tennessee State University 2005 – 2011
	Research Analyst, Vanderbilt University School of Medicine, Dept. of Epidemiology May – Aug. 2012
	Teaching Associate – ETSU College of Public Health 2011 – 2014
Selected Publications:	Hull, P. C., **Reece, M. C.,** Patton, M., Williams, J., Beech, B. M., Canedo, J. R., & Zoorob, R. (2013). A Community-Based Oral Health Self-Care Intervention for Hispanic Families. *International Journal of Public Health,* (DOI) 10.1007/s00038-013-0470-5
	Hull, P. C., Canedo, J. R., **Reece, M. C.,** Lira, I., Reyes, F., Garcia, E., Juarez, P., Williams E, & Husaini, B. A. (2010). Using a Participatory Approach to Address Disproportionate Hispanic Cancer Burden. *Journal of Health Care for the Poor and Underserved*, Suppl. *21*(1) 95-113
	Emerson, J. S., **Reece, M. C.,** Levine, R. S., Hull, P.C., & Husaini, B. A. (2009). Predictors of New Screening for African American Men Participating in a Prostate Cancer Educational Program. *Journal of Cancer Education*, *24*(4), 341-345
	Husaini, B. A., **Reece, M. C.,** Emerson, J. S., Scales S, Hull, P. C., & Levine, R. S. (2008). A Church-Based Education Program on Prostate Cancer Screening for African American Men: Reducing Health Disparity. *Ethnicity and Disease*, *18,* 179-184

Selected Presentations:	Roach, R. R., Duvall, K. L., **Reece, M. C.,** & Geraci, S. A. "Strategies for Teaching Effective Provider-Patient Communication in Appalachia and Beyond." Oral Presentation. Department of Internal Medicine Quillen College of Medicine, April 21, 2014
	Reece, M. C., Quinn, M. "Racial differences in radiation methods for first course of treatment for localized-regional prostate cancer." Oral Presentation: The Appalachian Student Research Forum, Johnson City, Tennessee, April 2014
	Reece, M. C., Brown, T., Cain, V. A., Husaini, B. A., & Hull, P.C., "Predictors of Men's Help Seeking for Urinary and Erectile Problems". Presented at The 21st Annual American Men's Studies Association (AMSA) Conference. Ann Arbor Michigan, April 2013
	Reece, M. C., Hull, P. C., Atchison, C., Brown, T. & Husaini, B. A., "Racial Differences in Men's Health Seeking Behavior." Presented at the American Public Health Association (APHA) Annual Meeting, Denver, Colorado, November 2010
	Reece, M. C., Hull, P. C., Atchison, C., Lambert, M. & Husaini, B. A. "Race and Prostate Cancer Screening: Nashville Men's Preventive Health Survey" American Association for Cancer Research (AACR): The Science of Cancer Disparities Carefree, Arizona 2009
Honors and Awards:	Graduate Student Excellence in Teaching Award, ETSU College of Public Health, Department of Community and Behavioral Health, April 25th, 2014
	Tennessee Public Health Training Center LIFEPATH Field Scholar Award, June 1st 2013
	T.J. Wu Memorial Student Research Scholarship, ETSU College of Public Health, April 5th, 2013
Professional Service:	2014 Tennessee Men's Health Report Card Advisory Panel Member
	American Men's Studies Association 2014 Conference Abstract Reviewer
	American Public Health Association 2014 Abstract Reviewer Men's Health Caucus
	American Cancer Society Cancer Prevention Study-3 Recruiter NE Tennessee & SW Virginia region 2013
	Women against Prostate Cancer (WAPC) Advocacy Group, Washington DC, 2013