Self-Reported Reasons Men Decide Not to Participate in Free Prostate Cancer Screening

Sally P. Weinrich, PhD, RN, FAAN, Martin C. Weinrich, PhD, Julie Priest, MSPH, and Cathy Fodi, RN

Purpose: To determine the reasons why men fail to participate in a free prostate cancer screening.

Design: Survey and secondary analyses using correlational design.

Setting: Community sites in the Southeastern United States.

Sample: The sample (N = 241) ranged in age from 40–68 years. Mean age was 50 years (SD = 7.4). Most of the men were African American (79%) and married (70%). Almost half of the subjects (44%) earned between $9,601 and $25,020 per year.

Method: Telephone survey of men who did not participate in initial prostate cancer screening after educational program.

Main Research Variables: Demographics, self-reported reasons men decided not to participate in a free screening following a prostate cancer educational program, and predictors for subsequent participation in screening.

Findings: The main self-reported reason for not participating in a free prostate cancer screening opportunity was time problems. A significant relationship between income and physician problems existed among the men who did not participate. Twenty-one percent of the 241 men participated in a second opportunity for free prostate cancer screening. Men who cited "lost packet" as their reason for not participating in the first free screening were more than twice as likely to go for the second opportunity for free screening when offered another packet or voucher for a free screening with their physician of choice.

Conclusions: "Time problems" was the most frequent self-reported reason men gave for failure to participate. Providing a follow-up phone call and vouchers a second time for reimbursement of the cost associated with a screening increased participation. Men often need assistance with locating physicians and nurse practitioners who will file for financial reimbursement. Appointment reminders are critical.

Implications for Nursing: The findings of this study of the significant relationship between income and "physician problems" for not participating has implications for healthcare providers. Future programs could provide telephone follow-up with men and remail vouchers, as needed. In addition, men could be encouraged to designate one place in their households for health-related papers (for safekeeping).

African American and low-income men, who are at high risk for prostate cancer incidence and mortality, often do not participate in prostate cancer screening. Little information is known about the reasons for failure to participate from the perspective of the men.

Key Points . . .

- Economic cost and lack of knowledge of prostate cancer screening are major barriers to regular screening.
- The most frequent reason given for not participating in first screening opportunity was "time problems."
- Men with low incomes are more likely to report "physician problems" as the reason for not participating in the first screening.
- African American men and men with low incomes often need assistance with accessing health care even when the cost of the health care is covered.

Literature Review

Prostate cancer screening increased significantly nationwide in the 1990s. However, African American men were less likely than Caucasian men to participate in prostate cancer screening (Mettlin, Murphy, Rosenthal, & Mench, 1998). Unfortunately, African American men have the highest incidence and mortality from prostate cancer, with an incidence rate of 234.2 in African Americans versus 144.6 in Caucasians per 100,000 (Jemal, Thomas, Murray, & Thun, 2002; Ries et

Sally P. Weinrich, PhD, RN, FAAN, is a professor in the School of Nursing at the University of Louisville in Kentucky and a research professor in population studies at the University of South Carolina's Cancer Center in Columbia; Martin C. Weinrich, PhD, is a professor of internal medicine at the University of Louisville; Julie Priest, MSPH, is a programmer analyst at Inveresk Research in Cary, NC; and Cathy Fodi, RN, is a primary care nurse practitioner at the VA Hospital in Asheville, NC. *This research was funded by the National Cancer Institute (R01 CA60561-01) and the South Carolina Cancer Institute. This article is based on the authors' viewpoints and is not representative of the National Cancer Institute's opinion. (Submitted January 2001. Accepted for publication July 1, 2002.)*

Digital Object Identifier: 10.1188/03.ONF.E12-E16

al., 2002). In the 1992 National Health Interview Survey, significant differences existed in participation in screening that used a digital rectal examination (DRE). Lower income and African American men were least likely to participate. Significantly fewer African American men (between the ages of 40 and 70) with family incomes of less than $20,000 had had a DRE in their lifetimes in contrast to African American men with a household income of $20,000 or more (32% versus 51%, p = 0.05) (M. Brown, personal communication, February 18, 1997).

Disagreement exists about the effectiveness of prostate cancer screening, in terms of lives saved, among experts who both support and oppose prostate cancer screening (Etzioni et al., 1999; Feuer, Merrill, & Hankey, 1999; Johansson, Holmberg, Johansson, Bergstrom, & Adami, 1997; Labrie, 2000; Mettlin, 2000; Weinrich, 2001). Agencies that support screening advocate informed decision making, in which the men are educated regarding the benefits and limitations of prostate cancer screening (Smith et al., 2001; Weinrich). Priority groups for prostate cancer education and research need to be at-risk populations, which include African American (Eyre & Feldman, 1998; Myers, 1999) and low-income men (Weinrich, Ellison, et al., 2000; Weinrich, Weinrich, et al., 2000).

Increased participation in prostate cancer screening has been reported when the barriers of cost and lack of knowledge are removed (Abbott, Taylor, & Barber, 1998; Demark-Wahnefried et al., 1995; Myers et al., 2000; Powell, Gelfand, Parzuchowski, Heilbrun, & Franklin, 1995; Powell et al., 1997; Weinrich, Weinrich, Boyd, & Mettlin, 1998). Men most likely to participate in prostate cancer screening are those who have higher education, favorable views of early detection, and strong physician support for early detection (Myers et al.). Unfortunately, decreased participation among African American and low-income men has been documented (Weinrich, Reynolds, et al., 2000; Weinrich, Weinrich, Boyd, & Atkinson, 1998; Weinrich, Weinrich, Atwood, & Cobb, 1999). No published studies are available that examine reasons for the failure to participate in prostate cancer screening when the barriers of cost and education are removed for low-income and African American men, two groups at highest risk for prostate cancer mortality. Previous published research on the South Carolina Prostate Cancer Study has documented some barriers, including embarrassment, lack of transportation, procrastination, inconvenient hours for physicians, and lack of knowledge of where to go for medical assistance (Shelton & Weinrich, 1999; Weinrich, Reynolds, Tingen, & Starr, 2000).

Three research questions were formulated based on the literature.

- What were the self-reported reasons for failure to participate in a free prostate cancer screening?
- What is the association between the self-reported reasons for failure to participate and demographic variables?
- What predicts subsequent participation in prostate cancer screening?

Methods

Design and Study Sample

This descriptive, correlational study, which recruited subjects in three stages, was a secondary analyses from a larger study (Weinrich, Weinrich, Boyd, & Mettlin, 1998). The sample included men who did not participate in a free prostate cancer screening following an educational program, were contacted by telephone to elicit self-reported reasons for not participating, and were given a second opportunity for a free screening.

In the first stage of the larger study, conducted between 1995 and 1996, 1,901 men at 222 different community sites completed a survey, participated in an educational program on prostate cancer, and were offered free prostate cancer screening from their physicians of choice (Weinrich, Weinrich, Boyd, & Mettlin, 1998). The educational program included information on signs and symptoms of prostate cancer, the American Cancer Society's prostate cancer screening guidelines, and benefits and limitations of prostate cancer screening (Weinrich, Weinrich, Boyd, & Mettlin). A total of 1,060 (56%) men went to their physicians of choice for the free prostate cancer screening. The physicians billed those who were conducting the research study for the cost of the screening. African American and low-income men were the least likely to have participated in the first phase of the larger study (Weinrich, Weinrich, et al., 2000). No record of screening was obtained from the remaining 841 men. Follow-up calls to a random list of 275 of the 841 men revealed that 18% of the men had gone to their individual physician of choice, but the physicians had not billed the research study for the cost.

In the second stage of this study, conducted in 1997, the remaining 566 men were called and asked why they had not participated. Of the 566 men, 153 men (27%) could not be reached after repeated calls. Of the 566 men, 105 men (19%) reported that they had obtained the prostate cancer screening. Calls to their physicians revealed that 102 of them had indeed been screened, although their physician had not billed the research study. The physicians for the remaining men (n = 3) found no record of prostate cancer screening. Six of the 566 men "did not know" whether they had gone for a prostate cancer screening examination.

During the second stage, the 241 men who stated that they had not yet had a prostate cancer screening examination were sent another voucher to use at their physician of choice. Standardized telephone procedures, which included a script and key areas to discuss, were developed and followed for stages 2 and 3.

In the third stage of this study conducted in 1997, 302 (53%) men out of the 566 men who were reached by telephone were given a second opportunity for a free screening with their individual physician of choice. Among the 302 men, 241 men gave at least one reason for not accepting their first free screening opportunity and were included in this research study. This article reports on reasons for not participating given by these 241 men.

Instrument

The researcher for the telephone survey in stage 2 developed an open-ended question to obtain data on reasons men did not participate in the first offer for free prostate cancer screening. It was developed by S. Weinrich, the author, who is an expert in prostate cancer education and screening among African American and low-income men (Trossman, 2000; Weinrich, Boyd, & Powe, 1997). The question was pilot tested with 15 men. Minor changes in wording were made to improve readability and adapt it to an eighth-grade reading level. Reasons given by some men were cited as part of the

telephone interview. The final wording of the question was "Several men have told us why they chose not to go for a prostate checkup. Some men did not go because they did not have time, some men had problems with their doctor, and some men did not want to have the digital rectal exam. Can you tell us why you decided to not have a prostate checkup?"

Data Analyses

Analyses for this secondary study was performed using data from stages 2 and 3. The reasons men gave in stage 2 for not going for the first screening opportunity were recorded and categorized into seven categories: (a) time problems, (b) lost the voucher for the first offer of free screening, (c) physician problems, (d) forgot, (e) intended to go, (f) personal problems, and (g) a variety of other individual reasons.

Descriptive statistics were performed using SAS® version 6.12 software to examine self-reported reasons for failure to participate in a free prostate cancer screening. Chi-square tests of significance, Fisher's exact test, univariate tests, and multiple logistic regression were used to test the self-reported reasons for failure to participate, and demographic variables predicted subsequent participation based on self-reported reasons.

Results

Demographics

The 241 men from stages 2 and 3 ranged in age from 40–68 years ($\overline{X}$ = 50 years; SD = 7.4). Most of the men were African American (79%) and married (70%). When education was condensed into three categories (less than high school, some high school or graduated from high school, and more than high school), 57% of the sample had attended or graduated from high school. More than half of the subjects (62%) had low incomes, defined in this study as a family income of less than $25,020 per year. Statistically significant differences existed by race in the distributions of income and age categories ($p < 0.001$). The distribution of demographic variables, including age, race, education, income, and marital status, is summarized in Table 1.

Table 1. Description of Sample

	African American Men (N = 190)		Caucasian Men (N = 51)	
Demographics	**n**	**%**	**n**	**%**
Age* (years)				
40–49	121	64	–	–
50–59	48	25	38	75
60–69	21	11	13	25
Education				
Less than high school (HS)	23	12	4	8
Some HS/HS graduate	106	56	31	61
More than HS	61	32	16	31
Income*				
$9,600 or less	39	21	4	8
$9,601–$25,020	92	48	14	27
$25,021 or more	59	31	33	65
Marital status				
Married	130	68	38	75
Single, widowed, divorced, or separated	60	32	13	25

N = 241

*p = 0.001

Self-Reported Reasons Men Did Not Participate

There were different reasons given by the men in stage 2 of the study for not accepting the first offer of free prostate cancer screening. The most frequent reason given for not going for the first screening opportunity was "time problems" (46%). The remaining reasons included lost the packet (17%), physician problems (16%), forgot (11%), intended to go (6%), and personal reasons (6%) (see Table 2). A "variety" category included individual reasons such as "do not like exam," "do not need it," expressed fear, procrastination, apathy, "did not know to go," and other reasons (n = 65). The percentages sum to more than 100% because many men (57) gave more than one reason for not participating in the first screening opportunity. Examples of responses that were coded in the category of "time problems" (n = 110) were "too busy" and "did not take the time to go." Examples of responses that were coded in the category of "physician problems" (n = 39) were "need a new doctor," "need to change doctors," and "doctors refused to accept the free voucher packet or to perform the prostate exam." Specific comments for the "forgot" category (n = 26) in addition to "forgot" were "could not remember." Men who had personal or health problems were listed as personal problems (n = 14). No significant differences by race were seen in the distribution of reasons given for not participating.

Associations Between Self-Reported Reasons for Failure to Participate and Demographic Variables

A statistically significant relationship was found between the income variable and "physician problems" for not participating in the first screening. The middle-income group ($9,601–$25,020 per year) was more likely to cite physician problems as their reason for not participating than men in the lower-income (≤ $9,600 per year) or higher-income (≥ $25,021 per year) categories ($p = 0.03$). Physician problems included refusal of physicians to invoice for payment or the lack of a physician. No other statistically significant relationships between the demographic variables and the self-reported reasons for failure to participate existed. Race was not significant.

Predictors for Acceptance of Second Opportunity for Free Prostate Cancer Screening

Twenty one percent (n = 51) of the 241 men accepted the second opportunity for free prostate cancer screening. No significant differences were seen in race during the second opportunity for free screening (22% of African American men versus 18% of Caucasian men).

Reasons given by the men for not accepting the first opportunity for free prostate cancer screening were examined as predictors for acceptance of the second opportunity. Predictors, based on the men's self-reported reasons, were time problems, lost the invoice packet, doctor, forgot, intent, and personal reasons.

A significant difference in participation in the second free prostate cancer screening was found in the group who said

Table 2. Self-Reported Reasons for Not Participating in Free Prostate Cancer Screening Following an Educational Program

Reasons Given	n	%[a]
Time problem	110	46
Lost the voucher	41	17
Physician problems	39	16
Forgot	26	11
Intended to go	14	6
Personal or health problem	14	6
Other (apathy, procrastination, do not like exam)	65	27

[a] Percents total more than 100% because some subjects listed more than one reason for not participating.

N = 241

they had lost the voucher packet. More than one third (37%) of the 41 men who said they did not go for the first offer for free screening because they lost the voucher packet *did* participate in the second opportunity for a free screening. This was statistically significant ($p = 0.008$). These men were more than twice as likely to go for the second opportunity of free screening when offered another voucher (OR = 2.62, $p = 0.01$). No other significant predictors were found.

Discussion

Limitations

Results can be generalized to men in southern community settings who received education on prostate cancer screening. These self-reported reasons cannot be generalized to men who decide not to be screened but who have *not* received education on prostate cancer screening.

The age of the data, which were first collected in 1995 and 1996, is a limitation. However, the lack of other studies in the literature on self-reported reasons for failure to participate in prostate cancer screening following education merit this publication. The design of this secondary analyses, which collected data from the men two years after they received prostate cancer education, is a strength. Currently, the answer for the national debate on the efficacy of prostate cancer screening is for each nurse practitioner or physician to inform and actively involve each man in the decision-making process for or against prostate cancer screening after the benefits and limitations are discussed. This is the only article published on the self-reported reasons, by a cohort of men who received prostate cancer education, for failure to participate in free screening. Similarly, no other published data are available on men who have been given a second opportunity for free screening.

Nursing Implications

The significant relationship between income and "physician problems" has implications for healthcare providers regarding why men decide not to participate in prostate cancer screening. Men often need assistance with accessing or making appointments for health care even when the cost for the care is free. The assistance can include access to phone numbers, reminders such as calendars to keep the appointments, and transportation.

Specifically, the middle-income group of men was more likely to cite physician problems as their reason for not participating. In contrast, the low-income men were less likely than the middle-income men to participate in the free prostate cancer screening (Weinrich, Weinrich, et al., 2000). Nurses need to recognize that men with middle or low incomes may need assistance with navigating the healthcare system.

The problem of the physicians refusing the invoice highlights the need for the payor of the invoice to intervene directly with the healthcare provider to ensure that service is provided. The problem of "did not have a physician" highlights the need to provide names, addresses, and phone numbers of healthcare providers who accept vouchers. Indeed, the South Carolina Prostate Cancer Study demonstrated that when men are provided assistance using the Client Navigator Method, increased screening occurs (Weinrich, Weinrich, Boyd, & Mettlin, 1998). The Client Navigator Method consisted of a nurse or social worker who contacted the men by telephone, identified barriers, and assisted with individual problems. The method also included three reminders: a key ring, calendar, and refrigerator magnet to record a physicians' name and telephone number.

The lack of association with race with any of the self-reported reasons is a mystery that needs additional research. African American men in both this study (Weinrich, Weinrich, Boyd, & Mettlin, 1998) and nationwide (Mettlin et al., 1998) are less likely to participate in prostate cancer screening in contrast to Caucasian men. Additional research using qualitative methodology is needed to identify the reasons.

Before the opportunity for free screening, all of these men had received a prostate cancer educational program that discussed different treatment options, including watchful waiting. The potential side effect of sexual dysfunction from some prostate cancer treatments was discussed in the question and answer session. Of interest, none of the men reported potential incontinence or erectile dysfunction from treatment as reasons for not participating in the prostate cancer screening.

Another implication for healthcare providers working with at-risk men is the low participation with the second opportunity—approximately one man in five participated. The predictor for subsequent participation of "losing the voucher" has implications for healthcare providers. Issuing a new voucher led to improved participation. Future programs could benefit from this information by providing telephone follow-up with the men and remailing vouchers for men who fail to participate. Also, men could be encouraged to designate one place in their household for health-related papers and keep their voucher in this place until their appointment with the healthcare provider. Healthcare providers need to explore a more effective manner of payment for the examination. Lost vouchers for reimbursement were a significant reason that the men did not participate. Direct communication with the men's physicians of choice is an option.

The healthcare barriers identified in this research may apply to other populations. Future research should continue to focus on prostate cancer mortality rates for high-risk groups: African American (Eyre & Feldman, 1998) and low-income men (American Cancer Society, 1990). A qualitative study could further clarify reasons for failure to participate in prostate cancer screening.

Author Contact: Sally P. Weinrich, PhD, RN, FAAN, can be reached at sally.weinrich@louisville.edu, with copy to editor at rose_mary@earthlink.net.

References

Abbott, R.R., Taylor, D.K., & Barber, K. (1998). A comparison of prostate knowledge of African American and Caucasian men: Changes from prescreening baseline to post intervention. *Cancer Journal from Scientific American, 4,* 175–177.

American Cancer Society. (1990). Report to the nation: Cancer in the poor. *CA: A Cancer Journal for Clinicians, 39,* 263–265.

Demark-Wahnefried, W., Strigo, T., Catoe, K., Conaway, M., Brunetti, M., & Rimer, B.K. (1995). Knowledge, beliefs, and prior screening behavior among blacks and whites reporting for prostate cancer screening. *Urology, 46,* 346–351.

Etzioni, R., Legler, J.M., Feuer, E.J., Merrill, R.M., Cronin, K.A., & Hankey, B.F. (1999). Cancer surveillance series: Interpreting trends in prostate cancer—Part III: Quantifying the link between population prostate-specific antigen testing and recent declines in prostate cancer mortality. *Journal of the National Cancer Institute, 91,* 1033–1039.

Eyre, H.J., & Feldman, G.E. (1998). Status report on prostate cancer in African Americans: A national blueprint for action. *CA: A Cancer Journal for Clinicians, 48,* 315–319.

Feuer, E.J., Merrill, R.M., & Hankey, B.F. (1999). Cancer surveillance series: Interpreting trends in prostate cancer—Part II: Cause of death misclassification and recent rise and fall in prostate cancer mortality. *Journal of the National Cancer Institute, 91,* 1025–1032.

Jemal, A., Thomas, A., Murray, T., & Thun, M. (2002). Cancer statistics, 2002. *CA: A Cancer Journal for Clinicians, 1,* 23–47.

Johansson, J.E., Holmberg, L., Johansson, S., Bergstrom, R., & Adami, H.O. (1997). Fifteen-year survival in prostate cancer: A prospective, population-based study in Sweden. *JAMA, 277,* 467–471.

Labrie, F. (2000). Screening and early hormonal treatment of prostate cancer are accumulating strong evidence and support. *Prostate, 43,* 215–222.

Mettlin, C.J. (2000). Screening and early treatment of prostate cancer are accumulating strong evidence and support. *Prostate, 43,* 223–224.

Mettlin, C.J., Murphy, G.P., Rosenthal, D.S., & Mench, H.R. (1998). The national cancer database report on prostate carcinoma after the peak in incidence rates in the U.S. *Cancer, 83,* 1679–1684.

Myers, R.E. (1999). African American men, prostate cancer early detection examination use, and informed decision-making. *Seminars in Oncology, 26,* 375–381.

Myers, R.E., Hyslop, T., Wolf, T.A., Burgh, D., Kunkel, E.J.S., & Oyesanmi, O.A. (2000). African American men and intention to adhere to recommended follow-up for an abnormal prostate cancer early detection examination result. *Urology, 55,* 716–720.

Powell, I.J., Gelfand, D.E., Parzuchowski, J., Heilbrun, L., & Franklin, A. (1995). A successful recruitment process of African American men for early detection of prostate cancer. *Cancer Supplement, 75,* 1880–1884.

Powell, I.J., Heilbrun, L., Littrup, P.L., Franklin, A., Parzuchowski, J., & Gelfand, D. (1997). Outcome of African American men screened for prostate cancer: The Detroit education and early detection study. *Journal of Urology, 58,* 146–149.

Ries, L.A.G., Eisner, M.P., Kosary, C.L., Hankey, B.F., Miller, B.A., Clegg. L., et al. (Eds.). (2002). *SEER cancer statistics review, 1973–1999.* Bethesda, MD: National Cancer Institute.

Shelton, P., & Weinrich, S. (1999). Barriers to prostate cancer screening in African American men. *Journal of Black Nurses Association, 10*(2), 14–28.

Smith, R.A., von Eschenbach, A.C., Wender, R., Levin, B., Byers, T., Rothenberger, D., et al. (2001). American Cancer Society guidelines for the early detection of cancer: Update of early detection guidelines for prostate, colorectal, and endometrial cancers. *CA: A Cancer Journal for Clinicians, 51,* 38–75.

Trossman, S. (2000, March/April). Health for all: RN fights to level the playing field. *American Nurse, 32,* 8–9.

Weinrich, S.P. (2001). The debate about prostate cancer screening: What nurses need to know. *Seminars in Oncology Nursing, 17,* 78–84.

Weinrich, S.P., Boyd, M., & Powe, B. (1997). Tool adaptation for socioeconomically disadvantaged populations. In M. Stromborg & S. Olsen (Eds.), *Instruments for clinical nursing research* (pp. 20–29). Pittsburgh: Oncology Nursing Society.

Weinrich, S.P., Ellison, G., Boyd, M.D., Hudson, J., Bradford, B., & Weinrich, M.C. (2000). Participation in prostate cancer screening among low-income men. *Psychology, Health, & Medicine, 5,* 439–450.

Weinrich, S.P., Reynolds, W.A., Tingen, M.S., & Starr, C.R. (2000). Barriers to prostate cancer screening. *Cancer Nursing, 23,* 117–121.

Weinrich, S.P., Weinrich, M., Atwood, J., & Cobb, M. (1999). Cost for prostate cancer educational programs by race and educational method. *American Journal of Health Behavior, 23,* 144–156.

Weinrich, S.P., Weinrich, M.C., Boyd, M.D., & Atkinson C. (1998). The impact of prostate cancer knowledge on cancer screening. *Oncology Nursing Forum, 25,* 527–534.

Weinrich, S.P., Weinrich, M.C., Boyd, M.D., & Mettlin, C. (1998). Increasing prostate cancer screening in African American men with peer educator and client navigator educational interventions. *Journal of Cancer Education, 13,* 213–219.

Weinrich, S.P., Weinrich, M.C., Ellison, G., Hudson, J., Reeder, G., & Weissbecker, I. (2000). Contrasting cost of a prostate cancer educational program by income. *American Journal of Health Behavior, 24,* 422–433.

For more information . . .

- National Prostate Cancer Coalition
  www.4npcc.org
- Prostate Cancer InfoLink
  www.comed.com/Prostate
- Prostate Cancer Research Institute
  www.prostate-cancer.org

Links can be found using ONS Online at www.ons.org.