Ending Cervical Cancer Screening: Attitudes and Beliefs from Ethnically Diverse Older Women

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ABSTRACT

Background Guidelines support ending cervical cancer screening in women aged 65 or 70 years and older with prior normal testing, but little is known about women's attitudes and beliefs about ending screening.

Methods We recruited and interviewed 199 women aged 65 years and older from primary care clinics. All had prior cervical cancer screening and no prior hysterectomy. In face-to-face interviews conducted in English, Spanish, Cantonese or Mandarin, women were asked about various aspects of cervical cancer screening and their plans to continue lifelong screening. **Results** Most interviewees (74.4%) were non-White (44.7% Asian, 18.1% Latina and 11.6% African-American). Most (68%) thought that lifelong screening was either important or very important, a belief held more strongly by African-American (77%) and Latina (83%) women compared to women in other ethnic groups (p<0.01); most (77%) had no plans to discontinue screening or had ever thought of discontinuing (69%). When asked if they would end screening if recommended by their physician, however, 68% responded "yes." In multivariable analyses, older age (OR=1.25 per year; CI=1.09-1.44), having public insurance (OR=3.84; CI=1.56-9.46) and having no personal (OR=3.13; CI=1.12-8.73) or family (OR=3.06; CI=1.19-7.89) history of cancer remained independent predictors of ending screening if recommended by their physician. **Conclusions** The majority of these ethnically diverse women believe that lifelong cervical cancer screening is important. Many women, however, reported they would end screening if recommended by their physician, underscoring the important role of clinicians in informing women about screening guidelines designed to maximize screening benefits and minimize harms.

Introduction

Since the widespread implementation of cytology-based cervical cancer screening, cervical cancer incidence and mortality have fallen dramatically in the United States ¹. For many decades, all women were encouraged to have annual testing and efforts were directed toward increasing screening rates. Although under use of screening in certain populations remain a problem, increased enthusiasm for screening among physicians and women alike has resulted in over-screening among women at low risk for cervical neoplasia. Among low-risk women, the chance that a positive test represents true disease is substantially lower ^{2, 3}, and false-positive testing can generate worry and trigger unnecessary and possibly harmful interventions including colposcopy, biopsy and invasive cervical treatments.

In an effort to maximize screening benefits and minimize screening harms, several national organizations have examined the evidence to determine appropriate ages after which women can safely end cervical cancer screening. Citing a lack of high-quality evidence to guide screening cessation in older women, the American College of Obstetricians and Gynecologists (ACOG) recommends lifelong testing in women who have a cervix ⁴. The American Cancer Society (ACS), on the other hand, supports ending screening in women aged 70 years and older with 3 or more prior normal cytology tests and no abnormal cytology tests within the past 10 years ⁵. The US Preventive Services Task Force (USPSTF) has a stronger position and actively discourages screening in women aged 65 years and older who have had prior normal Pap testing and who are not otherwise at high risk for cervical cancer ⁶. The USPSTF gives this preventive service a "D" recommendation, indicating that screening this population is either ineffective or that the harms outweigh the benefits.

Despite the ACS and USPSTF recommendations, studies of physicians and patients conducted after release of the new guidelines indicate that most American obstetrician/gynecologists still screen low-risk women over age 65 years often and indefinitely ⁷, and that most women prefer lifelong screening ⁸. While women from ethnic minority groups have a disproportionate incidence of cervical cancer ¹ and hence have been targeted to improve participation in screening programs, little is known about how older women in these groups perceive the importance of cervical-cancer screening and how they view contemporary recommendations to end screening. To address these issues, we sought to examine attitudes and beliefs on ending cervical cancer screening from an ethnically diverse group of women aged 65 years and older.

Methods

Participants and recruitment

Between October 2002 and December 2005, we interviewed women from 4 racial/ethnic groups to assess their perceived risk across three cancer prevention scenarios: a) general screening for colon cancer, b) chemoprevention of breast cancer, and c) ending cervical cancer screening. Women were randomly assigned to answer one of the 3 scenario questions, but all women older than 65 years without prior hysterectomy were assigned to answer the cervical cancer screening section; those with prior hysterectomy were given either breast or colon cancer scenarios. Women were asked during a face-to-face interview about their understanding of cancer risk, knowledge about screening, communication with their physician about screening risk and benefits, and trust in their doctor's recommendation about cancer screening. In the current analysis, we report outcomes related only to ending cervical cancer screening.

After approval from the University of California, San Francisco (UCSF) Committee on Human Research, we recruited women from 3 primary care practices at the UCSF Medical Center and community-based public clinics. Eligible women included those who were aged 50 to 80 years, who self-identified as White, Latina, African-American or Asian (mainly Chinese), and had seen a clinician at the clinical site at least once in the previous 2 years. Using these criteria, we used administrative data to generate a list of potentially eligible women. We then contacted the clinicians involved in their care and requested permission to contact their patients. We excluded women who no longer had the same physician within the participating practices and those with current cancer or with cognitive impairments identified by their physician.

Personalized letters were sent to potential participants in English, Spanish or Chinese. Two weeks after the introductory letter was sent, eligible and willing participants completed a 20-

minute telephone-screening questionnaire in English, Spanish, Cantonese or Mandarin and were scheduled for a 60-minute face-to-face interview.

Survey description

The face-to-face interview included items derived from standard questions developed and used in previous surveys and from formative focus groups. The questionnaire was developed simultaneously in English, Spanish, and Chinese using bilingual research assistants and was pretested in each of the four racial/ethnic groups, specifically testing for cultural, linguistic, and literacy appropriateness. The cervical cancer screening interviews focused on risk perception, based on the Weinstein conceptual framework ⁹ and included the nature and probability of harm and the factors that influence individual susceptibility. Other questions included health status as measured by the Medical Outcomes Study Short Form 12v2 (2).

Predictors and outcomes about cervical cancer screening

We asked women questions about the importance of regular cervical cancer screening (very important, important, not important), plans to continue screening for the rest of their lives (yes/no), whether they had ever thought about not getting Pap tests any more (yes/no), and whether based on their doctor's recommendation they would stop getting Pap tests (yes/no). Women were subsequently given quantitative estimates of benefits and harms associated with ending screening ^{2,3}. Women were told that about "3 out of every 10,000 65 year-old women with 3 or more normal Pap tests will get cervical cancer, but about 200 women out of 10,000 per year will be told they have an abnormal Pap test result which will turn out to be OK after further testing. The more Pap tests you get, the more likely you will be told you have an abnormal Pap test." After providing women with this information, we asked the same questions about the importance of and plans to continue lifelong cervical cancer screening.

Data analysis

Descriptive statistics were generated for all variables and summarized using frequency distributions. Variables and demographics were compared for differences among ethnic groups. Comparisons were made using either the chi-squared test or the Fisher's exact test for categorical variables and analysis of variance models for continuous data. Multivariate logistic regression with forward and backward stepwise modeling was used to examine the association of demographic factors and personal characteristics with the conditional decision to end cervical cancer screening if recommended by their physician. Statistical Analysis System (SAS, version 8.2) was used to analyze data. All analyses were two-sided (alpha=0.05).

Results

Interviews were completed by 199 women aged 65 years and older (mean age, 70.9 years) who had no prior hysterectomy and who had previous regular cervical cancer screening. Other demographic characteristics are listed in Table 1. Most interviewees (74.4%) were non-White (44.7% Asian, 18.1% Latina and 11.6% African-American), had been or were currently married, had at least a high school education and reported "good" to "excellent health. All characteristics differed significantly by ethnicity (p < 0.05), except age.

We asked several questions related to screening attitudes (Table 2). Most women (68%) thought that lifelong screening was either important or very important, a belief held more strongly by African-American and Latina women compared to women in Asian and White groups (p<0.01). Over three quarters (77%) planned to be screened for the rest of their lives and about 60% had never thought of ending screening. Being provided with quantitative information about benefits and harms of continued cervical cancer screening did not change subjects' belief that lifelong Pap testing was either important or very important (68% pre-information *versus* 65% post-information) nor did it change their plans to continue screening for the rest of their lives (77% pre-information *versus* 77% post-information, p>0.05 for both comparisons).

About two thirds (68%) of women stated they would end screening if it were recommended by their physicians. Ethnicity was a significant factor in this decision (p=0.05), and over three fourths of Asian women would accept this recommendation. Table 3 shows proportion of women responding "yes" to this question stratified by variables; women who were older, had less than a high school education, had only public insurance, were born outside of the US and/or had no personal or family history of cancer were more likely to end screening based on their physician's

recommendation. Perceived risk of cervical cancer, trust in physicians and the belief that doctors should make important medical decisions, not patients, were not significant factors in this decision (Table 3). In multivariate analyses, older age, having public insurance and having no personal or family history of cancer, but not ethnicity, remained independent predictors of ending screening (Table 4).

About 20% (n=40) of women reported having ever discussed discontinuing screening with their clinicians (Table 5). In bivariate analyses, these women were less likely to be married and more likely to have attained higher educational levels and report better overall health status compared to women who did not discuss discontinuing with their clinicians (p<0.05 for all; data not shown). Most conversations about ending screening were instigated by clinicians and lasted less than 5 minutes. Fewer than a quarter of these conversations included information about risks and benefits. Over half of women (n=23) who had participated in these conversations reported that their doctors recommended ending screening and, of these women, 87% (n=20) reported that they had ended screening.

Conclusions

The majority of women in this ethnically diverse sample believed that lifelong cervical cancer screening was important; African-American and Latina women were more likely to hold this view compared to Asian and White women. Most women had no plans to discontinue screening or had never thought of discontinuing. Regardless of ethnicity, however, most women reported they would end screening if their physician recommended it.

While our finding that women in older age groups and those with no personal or family history of cancer are more likely to end screening based on physician recommendation is logical, the reasons behind having public insurance being a predictor are less clear. We attempted to determine if perception of physicians played a role but were unable to demonstrate trust or beliefs about who should be making decisions as independent risk factors for ending screening. This observation may be due to factors we were not able to measure adequately or control for.

While several prior studies have explored general attitudes and beliefs about cancer screening in older individuals ¹⁰, our study uniquely focused on elucidating ethnic differences in ending cervical cancer screening. Prior studies have shown that women believe cervical cancer screening is important and 75% of women have come to expect an annual Pap test ¹¹. Current data indicate that women have mixed attitudes about risk-based screening schedules. Some studies indicate that the majority of women plan to continue cervical cancer screening indefinitely and want annual screening even if their physicians recommend otherwise ⁸, perhaps due to mistrust of physicians' rationales for recommending less frequent testing ^{12, 13}. However, in a study of younger and middle-aged, educated, White women conducted in New England, women identified patient education and clinician-patient reasons (such as feeling comfortable with the clinician and being taken seriously) as more important in the annual exam than getting a

Pap test, leading investigators to conclude that in that population, biennial or triennial screening would be acceptable ¹⁴.

Although there is a dearth of information about older women's attitudes about ending cervical cancer screening, some studies have revealed their attitudes about ending other types of cancer screening. Women over age 70 express a disinclination to end breast cancer screening, though they identify increasing age, poor health, and physicians' recommendations as potential reasons for ending screening ¹⁰. Nevertheless, rates of mammography do decrease with age, as do rates of cervical cancer screening ¹⁵.

Our study has both strengths and limitations. We were able to recruit a sizable group of women aged 65 and older most of whom were non-White, allowing us to compare many outcomes by ethnicity. Power to detect differences in some subgroups, however, was limited. While the setting of a structured interview allowed us to gather more complete data than a self-administered survey, the presence of an interviewer may have influenced how some women responded. We also realize that stated beliefs may not reflect actual clinical behaviors. While part of our survey included quantitative information about risk of cervical cancer, we could not assume that women understood these risks, especially since risk were on such a small scale.

Some authors have suggested that elderly patients be given quantitative information to facilitate shared informed decision making ¹⁶. Whether or not risks of such a small magnitude, such as those associated with cervical cancer incidence in low-risk older women, lend themselves to the shared informed decision-making model remains unclear.

While our study indicates that many women indicate that they would indeed end screening if their physician recommended it, a substantial proportion would want lifelong testing.

Recent decision analyses indicate that lifelong screening of low-risk women is not cost-effective

¹⁷ and is associated with harms that eclipse benefits as women age ². Such findings support the USPSTF guideline that encourages screening cessation in low-risk women after the age of 65 years in an effort to maximize screening benefits and minimize harms. While clinicians often respect the desires of individuals to continue lifelong screening, it is unclear if such decisions sit squarely within the purview of individual women. It may well be that low-risk women who insist on annual, lifelong screening are requesting care outside the limits of what is reasonable to offer and that other models of care should be considered (e.g., paying out of pocket for cost-ineffective services). Future studies should focus on best ways to explain the rationale behind ending cancer screening in older individuals to facilitate satisfaction with ultimate decisions.

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contact their patients.

Table 1: Study participant demographic characteristics (N=199), San Francisco 2002-2005

Characteristic		Ethnicity				
	White	African-	Latina	Asian	N=199	
		American				
	N=51	N=23	N=36	N=89		
	(25.6%)	(11.6%)	(18.1%)	(44.7%)		
Age, years						
65-69	29 (56.9%)	10 (43.5%)	9 (25.0%)	39 (43.8%)	87	
					(43.7%)	
70-74	14 (27.5%)	8 (34.8%)	16 (44.4%)	34 (38.2%)	72	
					(36.2%)	
75+	8 (15.7%)	5 (21.7%)	11 (30.6%)	16 (18.0%)	40	
					(20.1%)	
Mean age, years	70.3 (3.8)	70.4 (3.9)	73.0 (4.3)	70.6 (4.1)	70.9 (4.1)	
(std)						
Marital status						
Married	17 (33.3%)	5 (21.7%)	12 (33.3%)	49 (55.1%)	83	
					(41.7%)	
Formerly married	27 (52.9%)	16 (69.6%)	18 (50.0%)	38 (42.7%)	99	
					(49.7%)	
Never married	7 (13.7%)	2 (8.7%)	6 (16.7%)	2 (2.3%)	17	
					(8.5%)	

Education					
Less than high	2 (3.9%)	3 (13.0%)	25 (69.4%)	47 (52.8%)	77
school graduate					(38.7%)
High school	15 (29.4%)	10 (43.5%)	8 (22.2%)	16 (18.0%)	49
graduate or some					(24.6%)
college					
College graduate	34 (66.7%)	10 (43.5%)	3 (8.3%)	26 (29.2%)	73
or graduate school					(36.7%)
Insurance†					
Public	15 (30.0%)	11 (47.8%)	26 (76.5%)	63 (74.1%)	115
					(59.9%)
Private	35 (70.0%)	12 (52.2%)	8 (23.5%)	22 (25.9%)	77
					(40.1%)
Health Status					
Poor or fair	7 (14.0%)	10 (43.5%)	21 (58.3%)	54 (60.7%)	92
					(46.5%)
Good, very good	43 (86.0%)	13 (56.5%)	15 (41.7%)	35 (39.3%)	106
or excellent					(53.6%)
Income#					
≤ \$15,000/year	8 (17.8%)	4 (21.1%)	12 (48.0%)	26 (36.1%)	50
					(31.1%)
Born in the United	42 (84.0%)	23 (100.0%)	1 (2.8%)	5 (5.6%)	71
States					(35.9%)

Family history of	19 (38.0%)	11 (50.0%)	16 (45.7%)	21 (23.8%)	67
cancer					(34.3%)
Personal history of	19 (37.3%)	4 (17.4%)	7 (19.4%)	12 (13.5%)	42
cancer					(21.1%)

p<0.05 for differences in proportions across all race/ethnicity strata except for age as a categorical variable.

#based on 2003 Health and Human Services poverty guidelines for households of 3 (\$15,260)

[†]excludes 7 uninsured women

Table 2: Attitudes about screening indefinitely: women who have had prior screening and who have not had a hysterectomy (N=199), San Francisco 2002-2005

Question		Ethni	city		Total	P value
	White	African-	Latina	Asian	N=199	
	(n=51)	American	(n=36)	(n=89)		
		(n=23)				
How important	to you is it	to continue ge	etting Pap te	ests for the res	at of your life?	
Important or	25	17	30	61	133/199	< 0.01
very	(50.0%)	(77.3%)	(83.3%)	(68.5%)	(67.5%)	
important*						
Do you plan to	get Pap test	s regularly fo	r the rest of	your life?		
Yes	37	20	28	66	151/199	0.36
	(74.0%)	(90.9%)	(80.0%)	(74.1%)	(77.0%)	
Have you ever	thought abo	out not getting	Pap tests an	ny more?		
Yes	22	4	7	28	61/199	0.05
	(43.1%)	(17.4%)	(19.4%)	(32.9%)	(31.3%)	
Based on your	doctor's rec	ommendation	s would you	stop getting	Pap tests?	
Yes	24	13	19	63	119/199	0.05
	(57.1%)	(59.1%)	(61.3%)	(78.8%)	(68.0%)	
*aammarad ta "nat	4 11	1				

^{*}compared to "not at all or somewhat important"

Table 3: Proportion of all participants answering "yes" to the question "Based on your doctor's recommendations would you stop getting Pap tests?" (N=175*)

Characteristic	Number that would end	P value	
	screening (%)		
Demographic variables			
Age, years			
65-69	43 (55.1%)	0.002	
70-74	53 (74.7%)		
75+	23 (88.5%)		
Marital status			
Married	49 (62.8%)	0.3326	
Formerly married	61 (73.5%)		
Never married	9 (64.3%)		
Education			
Less than high school graduate	58 (81.7%)	0.0057	
High school graduate or some college	27 (57.5%)		
College graduate or graduate school	34 (59.7%)		
Insurance†			
Public	81 (79.4%)	0.0003	
Private	36 (52.9%)		
Health status			
Poor or fair	61 (72.6%)	0.1902	
Good, very good or excellent	57 (63.3%)		

Income#		
≤ \$15,000/year	33 (78.6%)	0.0508
>\$15,000/year	61 (61.6%)	
Country of birth		
Born in the US	35 (56.5%)	0.017
Non US born	83 (74.1%)	
Clinical history		
Family history of cancer		
Yes	31 (55.3%)	0.0148
No	85 (73.9%)	
Personal history of cancer		
Yes	16 (47.1%)	0.004
No	103 (73.1%)	
erceptions and attitudes		
Perceived risk of cervical cancer		
No risk, very low, somewhat low or low	100 (69.0%)	0.323
Moderate, high or very high	16 (59.3%)	
Agree that important medical decisions should	ld be made by doctors,	, not
patients+		
Strongly disagree or somewhat disagree	37 (59.7%)	0.080
Somewhat agree, agree or strongly agree	82 (72.6%)	
Trust in doctors to make the best medical dec	cisions on patients' bel	nalf§
Not at all, a little or somewhat	20 (71.4%)	0.705

Mostly or completely

99 (67.8%)

†excludes 7 uninsured women

#based on 2003 Health and Human Services poverty guidelines for households of 3 (\$15,260)

+Subject agrees with the statement: "The important medical decisions should be made by doctors, not patients."

§Subject responds "mostly or completely" to the question: "How much do you trust doctors to make the best medical decisions on your behalf?"

^{*}information missing for 24 participants.

Table 4: Predictors of answering "yes" to the question "Based on your doctor's recommendations would you stop getting Pap tests?": multivariable analysis*

Variable	Adjusted odds ratio	95% confidence interval
Age, per year	1.25	1.09-1.44
Public health insurance (vs. private)	3.84	1.56-9.46
No family history of cancer	3.06	1.19-7.89
No personal history of cancer	3.13	1.12-8.73

^{*}adjusted for all variables in Table 3 (race, education, marital status, income, health status, non-US born, perceived risk of cervical cancer, agree that important medical decisions should be made by doctors not patients, trust in doctors to make the best medical decisions on patients' behalf)

Table 5: Women's discussions with clinicians about not getting any more Pap tests (N=40)

Variable	N (%)
Who initiated the conversation about not getting any more Pap	
tests?	
Doctor	22 (53.6%)
Patient	10 (24.4%)
Both doctor and patient	8 (20.0%)
Number of minutes talked with doctor about not getting any	
more Pap tests	
≤ 5 minutes	34 (85.0%)
> 5 minutes	6 (15.0%)
Doctor ever discussed risks of not getting any more Pap tests	10 (23.8%)
Doctor ever discussed benefits of not getting any more Pap tests	9 (21.95%)
Doctor ever recommended stopping Pap tests	23 (57.5%)
Of these, % who actually stopped getting Pap tests	20 (87.0%)

^{*}Data missing in 1 participant for each variable.

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