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Cancer Screening Practices Among Amish and Non-Amish Adults Living in Ohio Appalachia

Abstract

Purpose—The Amish, a unique community living in Ohio Appalachia, have lower cancer incidence rates than non-Amish living in Ohio Appalachia. The purpose of this study was to examine cancer screening rates among Amish compared to non-Amish adults living in Ohio Appalachia and a national sample of adults of the same race and ethnicity in an effort to explain cancer patterns.

Methods—Face-to-face interviews focusing on perception of risk, cancer screening behaviors, and screening barriers were conducted among Amish (n=134) and non-Amish (n=154) adults living in Ohio Appalachia. Cancer screening rates were calculated and then compared to a national sample of adults.

Findings—More Ohio Appalachia non-Amish males (35.9% vs 14.5%; $P = .022$) and females (33.3% vs 12.5%; $P = .008$) reported that they would probably develop cancer in the future compared to Amish males and females. Amish adults had significantly lower prostate (13.5% vs 63.1% vs 44.6%; $P < .001$), colorectal (males: 10.3% vs 40.0% vs 37.2%, females: 8.6% vs 31.6% vs 42.9%; $P < .001$), cervical (48.0% vs 84.0% vs 80.0%; $P < .001$), and female breast (24.8% vs 53.7% vs 56.9%; $P < .05$) cancer screening rates compared to Ohio Appalachia non-Amish participants and a national sample of adults, respectively. Barriers to cancer screening were similar among the 2 Ohio groups; however, Amish males reported that prostate cancer screening was not necessary more often than did Ohio Appalachia non-Amish males (78.6% vs 16.7%; $P = .003$).

Conclusions—Lower rates of cancer screening were documented among the Amish and may be a contributing factor to the reduced cancer incidence rates reported among this population.

Keywords

Amish; Appalachia; health disparities; health promotion; medical care

The Amish, a unique cultural, ethnic, and religious community, live mostly in the rural areas of Midwestern states.^{1,2} The largest Amish settlement in the world is located in Ohio Appalachia. Some characteristics of the Amish lifestyle include their plain clothing, less use of tobacco and alcohol, increased physical activity levels, and avoidance of modern-day conveniences like using electricity, telephones, and the automobile.^{1,2} This chosen lifestyle, which is a result of their religious beliefs, may have implications for health, specifically related to preventable chronic diseases like cancer.

In Ohio Appalachia, cancer incidence rates (all sites) are 389.5 per 100,000 among the Amish compared to 646.9 per 100,000 among the non-Amish ($P < .001$).³ Cancer incidence rates among the Amish may be lower because of their chosen lifestyle, differences in exposures to environmental carcinogens, genetics, or a combination of these factors.^{4–6} Since current cancer mortality rates are not available for the Amish, an analysis of cancer surveillance data (1993–2003) was initiated to compare the distribution of stage of disease at diagnosis for colorectal cancer (CRC), female breast cancer, and prostate cancer for Amish vs non-Amish adults living in Ohio Appalachia. Significant differences between the Amish and the non-Amish in Ohio were found, with the Amish having higher rates of advanced

stage for CRC (males and females): 24.0% vs 14.5% ($P < .05$); female breast cancer: 18.5% vs 3.8% ($P < .001$); and prostate cancer: 10.7% vs 3.8% ($P < .001$).⁷

Early detection of cancer by completing a cancer screening test has been associated with early stage at diagnosis and decreased cancer mortality rates.⁸ Based on lower cancer incidence rates coupled with higher rates of late-stage disease at diagnosis among the Amish, an important issue to consider is cancer screening behaviors. Lower cancer screening rates were previously documented among residents of Ohio Appalachia compared to residents in non-Appalachia Ohio.⁹ However, information about cancer screening rates specifically among the Amish is not available. The purpose of this study was to conduct face-to-face interviews to document cancer screening rates among the Amish and then to compare their cancer screening rates to the Ohio Appalachia non-Amish and a national sample of adults.

METHODS

This analysis used data that were collected as part of a larger cancer-related lifestyle cross-sectional survey conducted among Amish and non-Amish adults living in Ohio Appalachia. The study was approved by the Institutional Review Board at The Ohio State University.

Setting

At the time of the study, the Appalachian region of the state of Ohio included 29 of Ohio's 88 counties, or 33% of the state in square miles, accounting for approximately 13% of Ohio's total population.¹⁰ The participants interviewed for this study lived in Holmes and Tuscarawas counties, which are located within Ohio Appalachia and include the largest Amish community in the world.¹¹

As compared to other sections of Ohio, the Appalachian region has been characterized by low socioeconomic status, including lower household incomes, higher poverty rates, less education, and lower paying occupations.^{10,12,13} The population was 41,567 in Holmes County and 91,944 in Tuscarawas County in 2005, with a median household income (2003) of \$38,640 for Holmes County and \$36,722 for Tuscarawas County compared to \$43,119 for Ohio (all counties).^{14,15} The percentage of adults (age ≥ 25 years) in 2000 without a high school diploma was 48.5% in Holmes County and 19.7% in Tuscarawas County, compared to 16.0% for Ohio (all counties).^{14,15} The significantly higher percentage of adults without a high school diploma in Holmes County is a reflection of the large Amish community where, by law, children are required to attend school only through the 8th grade.²

In addition, Ohio Appalachia residents have barriers to overcome in accessing health care. There are only 33 registered hospitals and 1,665 physicians for more than 1.4 million residents (2000).¹⁶ Ohio Appalachia residents are more likely to travel greater distances to obtain health care, and there is limited public transportation available. This health care barrier is especially difficult for the Amish, who must travel long distance by horse and buggy or rely on paid non-Amish drivers to access health care services. The risk of being uninsured among Ohio residents is highest in the Appalachian counties. There are nearly 200,000 uninsured Ohio Appalachian residents with 14.7% of adults and 6.3% of children lacking health insurance.¹⁷ The estimated percentage of Holmes and Tuscarawas County residents without health insurance is 9%–11%, which is similar to the rate in Ohio.¹⁸ The Amish usually do not subscribe to insurance plans from health insurance companies. There is a church fund within each Amish church district and the funds may be used in case of emergency or to take care of expensive health care costs.^{1,2} Less expensive health care costs (usually $< \$1,000$) among the Amish are paid by the individual or family. There is 1 hospital

in Holmes County and 2 hospitals in Tuscarawas County, with 21 primary care physicians located in Holmes County and 68 primary care physicians in Tuscarawas County, for a ratio of population to primary care physician of 1,923:1 in Holmes County and 1,345:1 in Tuscarawas County, compared to a 852:1 ratio for Ohio.^{19,20}

Participant Selection

The cancer-related lifestyle survey study was a follow-up to a cancer incidence study where members of the research team worked with Amish leaders to gain trust and approval for the research. For this study, because of the lack of telephones among the Amish, we mailed a letter of introduction about the study to the adult heads of households who participated in the original cancer incidence study. The original study participants were randomly selected from the Holmes County, Ohio, Amish Directory.^{3,11} A co-investigator of the study went to each household to explain the study in more detail and to arrange a convenient time for the interview. Each adult male and female was asked to complete a face-to-face interview that lasted approximately 2 hours and focused on a variety of cancer-related lifestyle factors. Among the Amish participants, if the individuals had died or moved out of the state, then the current residents of the household were recruited if they were Amish. An attempt was made to locate individuals who had moved within the state of Ohio. For households that were no longer Amish and for Amish households who refused to participate, replacements were randomly selected from households listed in the same Amish church district in the Amish Directory to maintain the target sample size.

The Amish participants were compared to 2 groups of adults. One group was a non-Amish sample randomly selected from Holmes County and Tuscarawas County. These participants lived close to the Amish and therefore this comparison group provided some information about whether the Amish cancer screening patterns were similar to those of the non-Amish individuals who lived near them. The Ohio Appalachia non-Amish households were randomly chosen from the publicly available county auditors' databases, and the same methods that were used to recruit Amish respondents were used for the non-Amish participants. For this study, the non-Amish sample included only individuals who did not grow up in Amish households.

The Amish cancer screening rates were also compared to screening rates for the general population in the United States using data obtained from the 2005 National Health Interview Survey (NHIS) conducted annually by the National Center for Health Statistics.²¹ The cancer supplement data file was used for the analysis. Only data from non-Hispanic white males and females were used in the comparison because the Amish are non-Hispanic white and cancer screening rates have been shown to differ by racial and ethnic groups.²²

Survey

The survey used in this study included many lifestyle characteristics. For this report, we include data collected on the individual's demographic characteristics, perceived personal risk for developing cancer ("How likely do you think it is that you will develop cancer in the future?") and cancer screening behaviors.²³ The section of the questionnaire that focused on cancer screening tests was modeled after those suggested for ascertaining the use of colorectal cancer screening in behavioral research.²⁴ After each female participant was asked if she knew if there was a test to check for cervical, breast, or colorectal cancer, she was asked to name the corresponding cancer screening test. After each male participant was asked if he knew if there was a test to check for prostate or colorectal cancer, he was asked to name the corresponding cancer screening test. Following those items, the interviewer provided a brief description and picture of each screening test to reduce measurement error. Additionally, the participants indicated the date and reason for their last test as well as the

reasons for the lack of screening within recommended cancer screening guidelines (lack of knowledge, lack of doctor recommendation, fear, no symptoms, costs, lack of transportation, etc.).^{8,25} In addition, each participant was asked if they ever had a dentist or doctor look or feel under their tongue or inside their cheeks to check for oral cancer.

Following the completion of the interview each participant was provided a \$25 gift card for appreciation of their time. The questionnaire used in the interviews of the Amish adults was slightly modified (religion and education items were revised) for the non-Amish participants. The Amish adults were interviewed during 2004 and the Ohio Appalachia non-Amish adults during 2005.

The male and female heads of household were usually interviewed at the same time by different interviewers. In most cases men were interviewed by male interviewers and women by female interviewers. Couples were asked to complete the interviews in different rooms without other family members present. In a few cases, couples either insisted on being interviewed in the same room or within earshot of each other. The interviewers documented the presence of additional family members during part of or the entire interview or if the other interviewer and participant could be heard.

Statistical Analyses

Descriptive statistics were computed for Amish and non-Amish by gender. The age-adjusted prevalence of self-reported cancer screening tests within screening guidelines (see definitions below) were calculated separately for the Amish and each comparison group by gender. All reported estimates were age-adjusted using the direct method and the 2000 US Standard Population.²⁶ Only individuals of the appropriate age for each cancer screening test were included in that analysis.

For males and females 50 years of age and older, being within CRC screening guidelines (American Cancer Society) was determined by fecal occult blood test in the past year, flexible sigmoidoscopy in the past 5 years, or colonoscopy in the past 10 years. For males 50 years of age and older, being within recommended screening guidelines for prostate cancer was having received a prostate specific antigen test (PSA) and digital rectal examination (DRE) within the past year. For women, cervical cancer screening rates were calculated (21 years and older) within the past year and within the past 3 years, and breast cancer screening within recommended guidelines was calculated as having had a mammogram in the past 24 months for women 40–49 years of age and within the past 12 months for women 50 years and older. Oral cancer screening rates (for ever been screened) were calculated for all participants.

Because we were interested in comparing age-adjusted rates and standard errors, a Z test was used to test for significant differences between the Amish and each comparison group. A chi-square test was used to compare the Amish to the Ohio non-Amish comparison group with respect to beliefs about cancer and cancer-related worry. The stratification and clustering features of the sampling plan were accounted for in analyses using NHIS data, and all data were analyzed using SAS v9 software (SAS Institute, Cary, North Carolina).

RESULTS

Letters introducing the study and its purpose were sent to a total of 112 eligible Amish households. Amish adults (n=134) from 75 households agreed to participate, resulting in a household response rate of 67%. Interviews of all Amish women were conducted by female interviewers, while 75% of Amish men were interviewed by male interviewers. With respect to privacy during the interview among the Amish participants, 45% of the interviews were

conducted without another family member present and without interruption, 21% were conducted in private but were periodically interrupted by another family member, and 34% were conducted when another family member was either in the room the entire time or close by so that the other person could hear the interview.

Introductory letters were sent to a total of 422 Ohio Appalachia non-Amish eligible households. Adults were available in only 266 households when a co-investigator went to schedule an interview at the non-Amish households. Non-Amish participants (n=154) from 98 households participated, giving a 23% household response rate and a 37% agreement rate. Non-Amish women were interviewed by a female interviewer in 99% of the interviews and a male interviewer interviewed non-Amish men in 93% of the interviews. The non-Amish participants were interviewed alone and without interruption in 58% of the interviews, 13% were conducted in private but were periodically interrupted by another family member, and 29% were conducted when another family member was either in the room the entire time or close by so that the other person could hear the interview.

Table 1 lists the descriptive statistics for the Ohio Amish and Ohio Appalachia non-Amish participants. The Amish males were younger (mean age: 52.4 years vs 58.8 years), were more often currently married (95.2% vs 82.5%), had less formal education (high school graduate or more: 1.6% vs 87.5%), and were more likely to have always lived in the same county (61.3% vs 31.3%) compared to the non-Amish males. The Amish females were younger (mean age: 52.9 years vs 56.8 years), were more often currently married (93.1% vs 74.2%), had less formal education (high school graduate or more: 0% vs 87.8%), and were more likely to have always lived in the same county (61.1% vs 34.4%) compared to the non-Amish females.

There was a significant difference regarding personal cancer risk perception, with Ohio Appalachia non-Amish males (35.9% vs 14.5%; $P = .022$) and females (33.3% vs 12.5%; $P = .008$) reporting it was more likely that they would develop cancer in the future compared to the Amish males and females. The prevalence estimates of cancer screening rates within guidelines for the males are listed in Table 2 and for females in Table 3. The Amish males (4.1%) were significantly ($P < .01$) less likely to be within recommended prostate cancer screening guidelines (PSA and DRE) compared to local Ohio Appalachia non-Amish males (37.2%). For PSA only, Amish males (13.5%) were significantly ($P < .001$) less likely to have been screened compared to local Ohio Appalachia non-Amish males (63.1%) and the national sample of white males (44.6%). The Amish males were also significantly ($P < .001$) less likely to be within recommended screening guidelines for CRC (10.3%) compared to non-Amish males (40.0%) and the national sample of white males (37.2%). In addition, Amish males (2.7%) self-reported ever being screened for oral cancer significantly ($P < .001$) less than Ohio Appalachia non-Amish males (32.0%).

The Amish females were significantly ($P < .001$) less likely to be within recommended screening guidelines (within the past year and 3 years) for cervical cancer (24.7% and 48.0%, respectively) compared to local Ohio Appalachia non-Amish females (66.1% and 84.0%, respectively) and the national sample of white females (62.4% and 80.0%, respectively). The Amish females were also significantly ($P < .05$) less likely to have had a mammogram within recommended guidelines (24.8%) compared to Ohio Appalachia non-Amish females (53.7%) or a national sample of white females (56.9%; $P < .001$), and they were significantly ($P < .001$) less likely to have had screening within recommended guidelines for CRC (8.6%) compared to Ohio Appalachia non-Amish females (31.6%) and the national sample of white females (42.9%). In addition, Amish females (1.2%) self-reported ever being screened for oral cancer significantly ($P < .001$) less than Ohio Appalachia non-Amish females (22.0%).

Cancer screening barriers (eg, lack of knowledge, costs) were similar among the Ohio participants, except that Amish males reported that prostate cancer screening was not necessary more often than did the Ohio Appalachia non-Amish males (78.6% vs 16.7%; $P = .003$).

DISCUSSION

In this study, significantly lower cancer screening prevalence within recommended guidelines was documented for all cancers (prostate, colorectal, breast, cervical) among the Amish compared to a local geographic sample of Ohio Appalachia non-Amish adults and a national sample of adults of the same race and ethnicity. Lower cancer screening rates may be a contributing factor to the higher rates of late stage at diagnosis (colorectal, female breast, and prostate cancer) documented among this distinct population living in Ohio Appalachia.⁷

Studies of other religious groups have also documented their lower cancer incidence rates compared to other individuals living in the same geographic region.^{6,27,28} In previous reports, the lower cancer incidence rates among these religious subpopulations have been attributed to cultural factors, such as the lower use of tobacco and alcohol, and differences in sexual and reproductive behaviors.^{6,27,28} For example, these lifestyle factors may explain the absence of cervical cancer that has been documented among Amish females.^{3,4} The notable exception was a study documenting increased prostate cancer incidence among male members of the Church of Jesus Christ of Latter-day Saints (LDS) compared to non-LDS males.²⁹ The investigators of this study suggested that the increased prostate cancer incidence may be partly due to the adoption of cancer screening behaviors among LDS males.²⁹

The Amish are an underserved population living in Ohio Appalachia who have a history of a limited use of preventive healthcare.^{1,2} Many of the barriers to preventive healthcare among the Amish are similar to barriers cited by other rural populations and include lack of knowledge about cancer screening tests, costs, lack of health insurance, and restricted access to care.^{30,31} The unique cultural aspects of the Amish population add additional barriers associated with limited transportation, less education, less access to media (educational information), and their religious beliefs and practices.^{1,2,32,33} Most Amish do not have any form of health insurance and pay for medical expenses out of pocket or from a church fund depending on the amount.^{1,2} The lower prevalence of unhealthy behaviors (use of tobacco and alcohol) by the Amish and their strong religious beliefs may also partially explain the differences in their perception about their risk for cancer documented in this study.³⁴ Amish religious beliefs do not forbid them from seeking healthcare services, like cancer screening tests; however, the Amish are cautious about accepting preventive services.^{1,2} In addition, Amish religious beliefs emphasize communal rather than individual health.^{1,2,32,33} Thus costly procedures to extend life, such as cancer screening tests, may be rejected because of the associated expense and their perception of modern medicine's attempt to replace the will of God.

The Amish lifestyle, however, provides unique opportunities to develop strategies to increase the use of cancer screening tests in this population. The principles associated with community-based participatory research could be useful to plan interventions to increase cancer screening among the Amish.³⁵ For example, acknowledging the community as a unit of identity, developing a collaborative and equitable partnership, including the Amish perspective in any educational materials/programs, sharing the results of the intervention with the community, and maintaining a long-term relationship with the community are important principles when working with isolated medically underserved communities. Many

of the same cultural factors were recently identified in a focus group study on breast and cervical cancer screening that included Amish women living in Pennsylvania.³⁶

Although the differences reported between the Amish and non-Amish in this study are striking, caution must be exerted in interpreting these results. First, the response rate among the Amish households was moderate (67%), and it was lower (23%) among the non-Amish living in Ohio Appalachia. Unlike the Amish who were usually at home and mostly refused to participate because of lack of time, the non-Amish individuals were more difficult to reach in person to arrange the interviews. Limited resources allowed us to make only a maximum of 3 attempts to reach each household. Usually low response rates create selection bias in that those who participate may in some way not be representative of the population from which they are selected. In this case, because of the lower response rate among the non-Amish, we used data from the NHIS to assess how representative our sample was in terms of the use of screening tests. We found that for males, the reported screening rates were higher (prostate and colon cancer tests), suggesting that men who were more likely to be screened participated in this study. For women, however, it was not as clear to determine if selection bias was present, as women in the study were more likely to report cervical cancer screening but less likely to report breast and colon cancer screening compared to women in the NHIS. There is, however, established reports that women over-report cervical cancer screening, compared to other screening tests, so our sample might be more representative of the population we sampled than these data indicate.^{38,39} Lower response rates to survey research are becoming more common,³⁷ and strategies to overcome this limitation are important for future community-level behavioral research.

Additionally, the Amish community in Ohio is the largest Amish community in the world; however, other Amish communities may differ and variation in cancer screening practices may exist. On a related note, one strict Amish order that accounts for about one-fifth of the Amish living in Ohio Appalachia was not part of the sampling frame because its members are not listed in the Holmes County Amish Directory.¹¹ It is not known what the cancer screening rates are among this strict order of Amish. Finally, this study was based on the self-report of completing cancer screening tests within a specific time frame, which has been shown to be less accurate compared to the review of medical records.^{38,39}

The strengths of this study are that participants were randomly selected and face-to-face interviews were conducted, enabling pictures and definitions of screening tests to be used to decrease measurement error. Furthermore, the results among the Amish were compared to local Ohio Appalachia adults and a national sample of individuals of the same race and ethnicity.

In conclusion, this study provides a glimpse into how Amish lifestyle factors may potentially play a role in impacting cancer incidence rates and rates of late stage at diagnosis. Our data add to the evidence that screening rates may potentially influence cancer incidence rates, stage at diagnosis, and possibly cancer mortality rates.

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Table 1
Demographic Characteristics of Ohio Amish and Ohio Appalachia Non-Amish Participants by Gender

	Males		Females		P value
	Amish (n=62)	Non-Amish (n=64)	Amish (n=72)	Non-Amish (n=90)	
Age (years)					.071
Mean \pm SD	52.4 \pm 13.8	58.8 \pm 15.9	52.9 \pm 15.1	56.8 \pm 15.3	
Range	22–84	24–92	21–89	22–90	
Marital Status					.004
Never Married	3.2%	1.6%	0%	2.2%	
Married	95.2%	82.5%	93.1%	74.2%	
Divorced/Sep	0%	14.3%	0%	9.0%	
Widowed	1.6%	1.6%	6.9%	14.6%	
Education					<.001
< High school	98.4%	12.5%	100%	12.2%	
High school graduate	1.6%	46.9%	0%	52.2%	
> High school	0%	40.6%	0%	35.6%	
Always lived in county	61.3%	31.3%	61.1%	34.4%	<.001

Table 2

Cancer Screening Age-Adjusted Prevalence Estimates for Ohio Amish, Ohio Appalachia Non-Amish, and U.S. White Males[†]

Screening Test	Percent Reporting Within Screening Guidelines		
	Ohio Amish	Ohio Appalachia Non-Amish	NHIS
PSA	13.5	63.1 ^{***}	44.6 ^{***}
DRE	17.6	48.9 ^{**}	n/a
DRE + PSA	4.1	37.2 ^{**}	n/a
FOBT or Endoscopy	10.3	40.0 ^{***}	37.2 ^{***}
Oral (ever screened)	2.7	32.0 ^{***}	n/a

[†] Age-adjusted prevalence estimate computed among individuals who were eligible for a screening test

n/a = not available

** $P < .01$

*** $P < .001$; comparing to Amish estimate

PSA = Prostate Specific Antigen Test within past year; age ≥ 50 years, DRE = Digital Rectal Examination within past year; age ≥ 50 years, FOBT = Fecal Occult Blood Test in past year or Endoscopy (flexible sigmoidoscopy in past 5 years or colonoscopy in past 10 years); age ≥ 50 years NHIS = National Health Interview Survey (2005); 69% response rate

Table 3

Cancer Screening Age-Adjusted Prevalence Estimates for Ohio Amish, Ohio Appalachia Non-Amish, and U.S. White Females[†]

Screening Test	Percent Reporting Within Screening Guidelines		
	Ohio Amish	Ohio Appalachia Non-Amish	NHIS
Pap Smear			
Within past year	24.7	66.1***	62.4***
Within past 3 years	48.0	84.0***	80.0***
Mammography	24.8	53.7*	56.9***
FOBT or Endoscopy	8.6	31.6***	42.9***
Oral (ever screened)	1.2	22.0***	n/a

[†] Age-adjusted prevalence estimate computed among individuals who were eligible for a screening test

n/a = not available

* $P < .05$

** $P < .01$

*** $P < .001$; comparing to Amish estimate

Pap smear; age ≥ 21 years

Mammography in past 2 years for 40–49 years, and past year for ≥ 50 years

FOBT = Fecal Occult Blood Test in past year or Endoscopy (flexible sigmoidoscopy in past 5 years or colonoscopy in past 10 years); age ≥ 50 years

NHIS = National Health Interview Survey (2005); 69% response rate