Published in final edited form as:

J Community Health. 2013 August ; 38(4): 753–758. doi:10.1007/s10900-013-9675-z.

Health Literacy Among the Amish: Measuring a Complex Concept Among a Unique Population

Mira L. Katz,

Division of Health Behavior and Health Promotion, College of Public Health, The Ohio State University, Suite 525, 1590 North High Street, Columbus, OH 43201, USA. College of Medicine, The Ohio State University, Columbus, OH, USA. Comprehensive Cancer Center, The Ohio State University, Columbus, OH, USA

Amy K. Ferketich,

Division of Epidemiology, College of Public Health, The Ohio State University, Cunz Hall, Columbus, OH, USA

Electra D. Paskett, and

College of Medicine, The Ohio State University, Columbus, OH, USA. Comprehensive Cancer Center, The Ohio State University, Columbus, OH, USA. Division of Cancer Prevention and Control, The Ohio State University, Columbus, OH, USA

Clara D. Bloomfield

College of Medicine, The Ohio State University, Columbus, OH, USA. Comprehensive Cancer Center, The Ohio State University, Columbus, OH, USA

Mira L. Katz: mira.katz@osumc.edu

Abstract

The Amish have cultural practices that include formal education through the 8th grade. This study's purpose was to compare the health literacy among Amish to non-Amish adults living in Ohio Appalachia to understand its potential contribution to poorer health behaviors (e.g. lower cancer screening rates). Amish ($n = 143$) and non-Amish ($n = 154$) adults completed interviews as part of a lifestyle study. The rapid estimate of adult literacy in medicine (REALM) instrument (score range 0–66) was used and mean REALM scores were compared (t test) and correct pronunciation of each word was compared (Chi square test). Significance was considered at $p < 0.001$ because of multiple comparisons. Mean REALM scores among Amish males (53.3 ± 13.1) and females (56.2 ± 8.6) were significantly ($p < 0.001$) lower compared to non-Amish males (61.2 ± 9.8) and females (63.0 ± 6.2). Twelve percent of Amish participants read at or lower than a 6th grade level compared to 2.6 % of non-Amish participants. This study provides a glimpse into how culture may influence health literacy. Many Amish participants had limited or marginal health literacy. Innovative strategies that address inadequate health literacy and specific cultural characteristics are needed to improve health-related behaviors and outcomes among the Amish.

Keywords

Health literacy; Health education; Amish; Rural communities

Introduction

There is increasing evidence that inadequate health literacy may be a contributing factor to lower health knowledge, poor health status, and improper use of health services resulting in health disparities [1]. Health literacy is defined as “the degree to which individuals have the capacity to obtain, communicate, process, and understand basic health information and services needed to make appropriate health decisions” [2]. Due to the multiple skill domains required to obtain health information and receive appropriate health services, health literacy is conceptualized as the intersection of education, culture, health systems, and other diverse factors [2].

The Amish, a unique cultural and religious community, live mostly in the rural regions of the Midwest section of the United States (US) [3, 4]. About one-fourth of the approximately 275,000 Amish adults and children in North America live in Ohio [5]. The Amish lifestyle includes attending an Amish school until the 8th grade, and avoidance of modern-day electrical devices including communication devices such as the television, radio, and computers [3, 4]. This chosen lifestyle may have implications for health literacy as well as poorer health behaviors and outcomes. For example, Amish males and females have lower cancer incidence rates, however the Amish have higher rates of advanced stage at diagnosis and lower screening rates compared to non-Amish adults [6–8]. To understand how the Amish culture may affect health literacy, this study examined the difference in health literacy among Amish and non-Amish adults living in Ohio Appalachia. The results of this study provide an initial prevalence of health literacy among the Amish to inform the development of health education materials and future health promotion programs.

Methods

This report 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, about one-third of the state in square miles, accounting for approximately 13 % of Ohio’s population [9]. 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 [10].

The Appalachian region of Ohio has been characterized by low socioeconomic status, including lower household incomes, higher poverty rates, less education, and lower paying occupations [9, 11, 12]. The population was 41,567 in Holmes County and 91,944 in Tuscarawas County; with a median household income (2003) of \$38,640 for Holmes County and \$36,722 for Tuscarawas County compared to \$43,119 for all Ohio counties [13]. 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 all Ohio counties [13]. 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 only required to attend school only through the 8th grade [3, 4].

Participant Selection

The cancer-related lifestyle survey study was conducted as a follow-up to a cancer incidence study which estimated an age-adjusted cancer incidence rate for all cancers of 55 % of the age-adjusted adult rate in Ohio [14]. For this study, we mailed an introductory letter to the

households who participated in the original cancer incidence study that were randomly selected from the Holmes County, Ohio Amish Directory [10, 14]. A study investigator went to each household to explain the study in more detail and to arrange a convenient time for the interview. Adult males and females were asked to complete a face-to-face interview that lasted approximately 2 h and focused on a variety of cancer-related lifestyle factors.

In most cases men were interviewed by male interviewers and women by female interviewers. 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 a non-Amish sample randomly selected from Holmes County and Tuscarawas County. These participants lived in the same Ohio counties as the Amish and therefore this comparison group provided some information about whether the Amish had similar health literacy rates as 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 the Amish were used for the non-Amish participants. The non-Amish sample included only individuals who did not grow up in Amish households.

Survey

The survey used in this study collected data on demographic characteristics including health literacy and a variety of cancer-related behaviors. For this report, we included data about the individual's demographic characteristics and health literacy.

The rapid estimate of adult literacy in medicine (REALM) was the health literacy instrument used in the study [15]. The REALM is a medical word recognition and pronunciation test. On average, it takes less than 3 min for participants to read the list of 66 health-related words. The words are arranged in three columns based on the number of syllables and pronunciation difficulty. Each correctly pronounced word is scored as one and the range of scores is from 0 to 66. Words pronounced with a dialect or accent are counted as correct, as long as there are no additions or deletions to the beginning or ending of a word (e.g. no credit for a person who states "attacks" instead of "attack"). Total scores are converted to the following four reading grade levels: 0–18 words (grades 0–3 limited health literacy); 19–44 words (grades 4–6 limited health literacy); 45–60 words (grades 7 and 8: marginal health literacy); and 61–66 words (grade 9+: adequate health literacy). The REALM has a high intra-subject reliability (0.97).

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.

Statistical Analyses

Descriptive statistics were computed for Amish and non-Amish by gender. The mean total REALM scores were compared between groups using a *t* test and the correct pronunciation of each word was compared using a Chi square test. Significance was considered at $p < 0.001$ because of multiple comparisons.

Results

Letters introducing the study and its purpose were sent to 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 422 Ohio Appalachia non-Amish eligible households. Adults were available in only 266 households when an 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 most (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 a family member, and 29 % were conducted when a family member was either in the room or close by so that the other person could hear the interview.

Demographic characteristics for the Ohio Amish and Ohio Appalachia non-Amish participants are listed in Table 1. The Amish males were younger (mean age 52.4 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 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.

Total REALM scores were significantly ($p < 0.001$) lower among Amish males (53.3 ± 13.1) compared to non-Amish males (61.2 ± 9.8) and among Amish females (56.2 ± 8.6) compared to non-Amish females (63.0 ± 6.2). Sixteen (11.9 %) Amish participants read at or below the 6th grade (REALM score: 0–44; limited health literacy) compared to only 4 (2.6 %) non-Amish participants. Additionally, over half of the Amish participants ($n = 77$; 57.5 %) had marginal health literacy (REALM score: 45–60) compared to 19 (12.3 %) non-Amish participants. Adequate health literacy (REALM score: 61–66) was measured among 41 (30.6 %) Amish participants and 131 (85.1 %) non-Amish participants.

The REALM words pronounced correctly by Amish and non-Amish participants are listed in Table 2. Significant differences ($p < 0.001$) between Amish and non-Amish participants, respectively, in the pronunciation of words on the REALM instrument were as follows: herpes (39.6 vs. 96.8 %); asthma (76.1 vs. 96.1 %); incest (56.7 vs. 90.3 %); fatigue (77.6 vs. 96.8 %); arthritis (86.6 vs. 98.1 %); syphilis (20.9 vs. 93.5 %); nausea (74.6 vs. 94.8 %); allergic (60.5 vs. 81.2 %); menstrual (73.1 vs. 96.8 %); alcoholism (75.4 vs. 93.5 %); gonorrhea (29.1 vs. 93.5 %); diagnosis (74.6 vs. 92.2 %); potassium (79.9 vs. 96.8 %); obesity (28.4 vs. 92.2 %); and osteoporosis (34.3 vs. 83.8 %).

Discussion

Limited health literacy has been shown to contribute to poorer health knowledge and health behaviors, less ability to communicate with health care providers and manage chronic illness, and adds to health care costs [1, 16–18]. This may be through many mechanisms because health decisions and activities are made within a broad health or social context. Social contextual factors are defined as the “structural forces that shape the texture of people’s day-to-day realities, including an array of social and material resources that ultimately have profound effects on health” [19]. One contextual factor, health literacy, has a significant effect on an individual’s health [1]. Due to the multiple skill domains required to obtain health information and receive appropriate health services, health literacy is conceptualized as the intersection of education, culture, health systems, and other diverse factors [2]. A framework for health literacy includes the following components: cultural and conceptual knowledge, print literacy (ability to read, write, and understand text), numeracy (capability to complete numerical tasks), oral literacy (listening, speaking, communication), and media literacy (ability to access and evaluate media information) [2, 20, 21]. Not only can culture influence health literacy development, it can also have an influence on factors that mediate health literacy and health behaviors and/or outcomes [21, 22].

Culture primarily refers to shared meanings, values, and ideas within a community that may influence many health-related factors. The unique cultural aspects of the Amish lifestyle may contribute to the lower rates of health literacy as measured by the REALM instrument. In addition to having less formal education, Amish use English mainly outside the home (Pennsylvania German is the primary language), and have less access to media exposure which decreases the opportunity to hear the correct pronunciation of many words [3, 4, 23]. This is evident from this study because a few of the words that were commonly mispronounced by the Amish were related to sexual behaviors (e.g. syphilis, gonorrhea, incest) that are not usually discussed within the Amish community.

The strengths of this study are that participants were randomly selected and face-to-face interviews were conducted, enabling the measurement of health literacy. Furthermore, the results among the Amish were compared to local Ohio non-Amish Appalachian adults. Our study does have some limitations. The Amish community in Ohio is the largest Amish community in the world; however, other Amish communities may differ in health literacy rates. 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 [10]. It is not known what the literacy rates are among this strict order of Amish. The measurement of health literacy is challenging because it encompasses knowledge, multiple skills, and previous personal experiences [2]. Any health literacy instrument does not measure the full complexity of health literacy and the REALM instrument does not measure comprehension or numeracy skills.

In conclusion, this study provides a glimpse into how culture may influence health literacy among a unique population. In this study, Amish participants have limited health literacy based on the REALM test. These results suggest that cultural issues may contribute to limited health literacy and many Amish adults may have difficulty with patient education materials that are not written at a low grade level. Innovative strategies that address limited literacy levels and specific cultural characteristics are needed to improve health-related behaviors and outcomes among the Amish and should be considered when working with other communities.

Acknowledgments

Authors received funding sources from: (1) NIH P50 CA015632; (2) NIH P30 CA16058; (3) NCI K07 CA107079 (MLK); and (4) Coleman Leukemia Research Foundation.

References

1. Dewalt DA, Berkman ND, Sheridan S, Lohr KN, Pignone MP. Literacy and health outcomes: A systematic review of the literature. *Journal of General Internal Medicine*. 2004; 19(12):1228–1239. [PubMed: 15610334]
2. Institute of Medicine of the National Academies. *Health literacy: A prescription to end confusion*. Washington, DC: Institute of Medicine; 2004.
3. Hostetler, JA. *Amish society*. Baltimore, MD: The Johns Hopkins University Press; 1993.
4. Donnermeyer, JF.; Kreps, GM.; Kreps, MW. *Lessons for living. A practical approach to daily life from the Amish community*. Sugarcreek, OH: Carlisle Press; 1999.
5. Kraybill, DB. *Amish studies*. 2012. Retrieved 4 Jan 2012, from <http://www2.etown.edu/amishstudies/Index.asp>
6. Ferketich, AK. Distribution of stage of disease among Amish and non-Amish living in Ohio. Columbus, OH: Personal Communication; 2008.
7. Ferketich AK, Katz ML, Kauffman RM, et al. Tobacco use among the Amish in Holmes County, Ohio. *Journal of Rural Health*. 2008; 24(1):84–90. [PubMed: 18257875]
8. Katz ML, Ferketich AK, Paskett ED, et al. Cancer screening practices among Amish and non-Amish adults living in Ohio Appalachia. *Journal of Rural Health*. 2011; 27(3):302–309. [PubMed: 21729158]
9. Appalachian Regional Commission. *The Appalachian regional commission*. 2012. Retrieved 28 Dec 2012, from <http://www.arc.gov/>
10. Ohio Amish Directory. Holmes County and vicinity. Walnut Creek, OH: Carlisle Press; 2000.
11. Haaga, J. *Educational attainment in Appalachia*. Washington, DC: Appalachian Regional Commission; 2004.
12. Abramson, R.; Haskell, J. *Encyclopedia of Appalachia*. Knoxville, TN: The University of Tennessee Press; 2006.
13. United States Census Bureau. *State and county QuickFacts*. Holmes County, OH and Tuscarawas County, OH: U.S. Department of Commerce; 2006. <http://quickfacts.census.gov/qfd/index.html>
14. Westman JA, Ferketich AK, Kauffman RM, et al. Low cancer incidence rates in Ohio Amish. *Cancer Causes and Control*. 2010; 21(1):69–75. [PubMed: 19779840]
15. Davis TC, Long SW, Jackson RH, et al. Rapid estimate of adult literacy in medicine: A shortened screening instrument. *Family Medicine*. 1993; 25(6):391–395. [PubMed: 8349060]
16. Baker DW, Gazmararian JA, Williams MV, et al. Functional health literacy and the risk of hospital admission among medicare managed care enrollees. *American Journal of Public Health*. 2002; 92(8):1278–1283. [PubMed: 12144984]
17. Howard DH, Gazmararian J, Parker RM. The impact of low health literacy on the medical costs of medicare managed care enrollees. *American Journal of Medicine*. 2005; 118(4):371–377. [PubMed: 15808134]
18. Baker DW, Wolf MS, Feinglass J, Thompson JA, Gazmararian JA, Huang J. Health literacy and mortality among elderly persons. *Archives of Internal Medicine*. 2007; 167(14):1503–1509. [PubMed: 17646604]
19. Sorensen G, Emmons K, Hunt MK, et al. Model for incorporating social context in health behavior interventions: Applications for cancer prevention for working-class, multiethnic populations. *Preventive Medicine*. 2003; 37(3):188–197. [PubMed: 12914824]
20. Christ WG, Potter WJ. Media literacy, media education, and the academy. *Journal of Communication*. 1998; 48:5–15.
21. Squiers L, Peinado S, Berkman N, Boudewyns V, Mc-Cormack L. The health literacy skills framework. *Journal of Health Communication*. 2012; 17(Suppl 3):30–54. [PubMed: 23030560]

22. Paasche-Orlow MK, Wolf MS. The causal pathways linking health literacy to health outcomes. *American Journal of Health Behavior*. 2007; 31(Suppl 1):S19–S26. [PubMed: 17931132]
23. Kraybill, DB. The riddle of Amish culture. 2. Baltimore, MD: The Johns Hopkins University Press; 2001.

Table 1
Demographic characteristics of Amish and non-Amish Ohio Appalachia participants by gender

	Males		Females		p value
	Amish (n = 62)	Non-Amish (n = 64)	Amish (n = 72)	Non-Amish (n = 90)	
Age (years)					0.071
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					0.004
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

REALM words pronounced correctly by Amish and non-Amish participants

Word	Amish (n = 134) n (%)	Non-Amish (n = 154) n (%)
Fat	133 (99.3)	152 (98.7)
Flu	133 (99.3)	153 (99.6)
Pill	131 (97.8)	152 (98.7)
Dose	132 (98.5)	150 (97.4)
Eye	132 (98.5)	152 (98.7)
Stress	130 (97.0)	152 (98.7)
Smear	129 (96.3)	150 (97.4)
Nerves	129 (96.3)	151 (98.1)
Germes	129 (96.3)	151 (98.1)
Meals	129 (96.3)	151 (98.1)
Disease	132 (98.5)	151 (98.1)
Cancer	132 (98.5)	151 (98.1)
Caffeine	127 (94.8) *	153 (99.4)
Attack	126 (94.0) *	152 (98.7)
Kidney	130 (97.0)	150 (97.4)
Hormones	124 (92.5)	148 (96.1)
Herpes	53 (39.6) ***	149 (96.8)
Seizure	116 (86.6)	138 (89.6)
Bowel	116 (86.6) *	145 (94.2)
Asthma	102 (76.1) ***	148 (96.1)
Rectal	118 (88.1) *	148 (96.1)
Incest	76 (56.7) ***	139 (90.3)
Fatigue	104 (77.6) ***	149 (96.8)
Pelvic	118 (88.1) *	148 (96.1)
Jaundice	95 (70.9) **	134 (87.0)
Infection	130 (97.0)	153 (99.4)
Exercise	129 (96.3)	152 (98.7)
Behavior	129 (96.3)	151 (98.1)
Prescription	124 (92.5)	149 (96.8)
Notify	124 (92.5) *	152 (98.7)
Gallbladder	126 (94.0)	150 (97.4)
Calories	130 (97.0)	151 (98.1)
Depression	124 (92.5) *	152 (98.7)
Miscarriage	132 (98.5)	151 (98.1)
Pregnancy	123 (91.8) *	150 (97.4)
Arthritis	116 (86.6) ***	151 (98.1)

Word	Amish (n = 134) n (%)	Non-Amish (n = 154) n (%)
Nutrition	124 (92.5)	148 (96.1)
Menopause	114 (85.1) **	149 (96.8)
Appendix	125 (93.3)	146 (94.8)
Abnormal	126 (94.0)	149 (96.8)
Syphilis	28 (20.9) ***	144 (93.5)
Hemorrhoids	116 (86.6) *	147 (95.5)
Nausea	100 (74.6) ***	146 (94.8)
Directed	118 (88.1)	144 (93.5)
Allergic	81 (60.5) ***	125 (81.2)
Menstrual	98 (73.1) ***	149 (96.8)
Testicle	105 (78.4) **	143 (92.9)
Colitis	105 (78.4)	131 (85.6)
Emergency	128 (95.5)	151 (98.1)
Medication	131 (97.8)	151 (98.1)
Occupation	127 (94.8)	152 (98.7)
Sexually	100 (74.6) *	132 (85.7)
Alcoholism	101 (75.4) ***	144 (93.5)
Irritation	123 (91.8)	149 (96.8)
Constipation	114 (85.1) *	145 (94.2)
Gonorrhea	39 (29.1) ***	144 (93.5)
Inflammatory	104 (77.6)	129 (83.8)
Diabetes	113 (84.3) **	145 (94.2)
Hepatitis	114 (85.1) *	145 (94.2)
Antibiotics	119 (88.8) *	147 (95.5)
Diagnosis	100 (74.6) ***	142 (92.2)
Potassium	107 (79.9) ***	149 (96.8)
Anemia	102 (76.1)	129 (83.8)
Obesity	38 (28.4) ***	142 (92.2)
Osteoporosis	46 (34.3) ***	129 (83.8)
Impetigo	39 (29.1)	62 (40.3)

*
 $p < 0.05$;

**
 $p < 0.01$;

 $p < 0.001$