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Limited health literacy is a barrier to colorectal cancer screening in England: Evidence from the English Longitudinal Study of Ageing ☆

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ABSTRACT

Objective. To determine the association between health literacy and participation in publicly available colorectal cancer (CRC) screening in England using data from the English Longitudinal Study of Ageing (ELSA).

Methods. ELSA is a population-based study of English adults aged ≥50 years. Health literacy, participation in the national CRC screening programme, and covariates were interview-assessed in 2010–11. All those age-eligible for screening from 2006 to 11 were included in the present analysis (n = 3087). The association between health literacy and screening was estimated using multivariable-adjusted logistic regression.

Results. 73% of participants had adequate health literacy skills. Screening uptake was 58% among those with adequate and 48% among those with limited health literacy skills. Having adequate health literacy was associated with greater odds of CRC screening (multivariable adjusted OR = 1.20; 95% CI: 1.00–1.44), independent of other predictors of screening: age (OR = 0.92; 95% CI: 0.91–0.94 per one year increase), female sex (OR = 1.31; 95% CI: 1.11–1.54), and being in a higher wealth quintile (OR = 1.88; 95% CI: 1.43–2.49).

Conclusions. Limited health literacy is a barrier to participation in England's national, publicly available CRC screening programme. Interventions should include appropriate design of information materials, provision of alternative support, and increased one-on-one interaction with health care professionals.

Introduction

Colorectal cancer (CRC) is a leading cause of global cancer burden among men and women (Ferlay et al., 2010). In the United Kingdom (UK), CRC is the third most common incident cancer and cause of cancer death, with over 40,000 new cases and over 15,000 deaths in 2010 (Cancer Research UK, 2013). England is one of the first countries worldwide to implement a national, organised, publicly available screening programme using the faecal occult blood test (FOBT). The screening programme, entitled the National Bowel Cancer Screening Programme, is operated through the National Health Service (NHS) and was fully implemented in 2010. All adults aged 60–69 (currently being extended to 74) are eligible and receive a written screening invitation through the post with screening information and the home-based FOBT kit biennially beginning in the year of the 60th or 61st birthday.

Although the FOBT reduces mortality (Hewitson et al., 2008; Mandel et al., 1993), overall uptake of screening in England is low and substantially socially graded. An analysis of the first 2.6 million invitations to the programme from 2006 to 09 found that overall uptake was 54%, but was substantially lower among men and among adults living in deprived and ethnically diverse neighbourhoods (von Wagner et al., 2011). A further source of inequality in CRC screening participation in England may be low health literacy. Health literacy is defined as an individual's capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions (Institute of Medicine, 2004). Limited health literacy is associated with increased use of emergency care services, elevated risks for several chronic diseases and overall mortality, and poorer use of preventive health services such as cancer screening (Baker et al., 1998; Bennett et al., 2009; Berkman et al., 2011; Bostock and Steptoe, 2012). Health literacy has inconsistently been associated with CRC screening in three American studies (Arnold et al., 2012; Miller et al., 2007; Peterson et al., 2007), although higher health literacy has been associated with increased knowledge and positive attitudes toward the benefits of screening (Arnold et al., 2012; Miller et al., 2007; Peterson et al., 2007).

In England's Bowel Cancer Screening Programme, the primary mode of communication with eligible adults is through written screening information materials mailed through the post. Therefore, limited health literacy skills may in part explain the overall low uptake of screening and social inequalities in screening: they may inhibit some individuals' capacity to understand, and subsequently engage with the written screening information (Davis et al., 2001; Dolan et al., 2004; von

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Wagner et al., 2009a). Health literacy has not yet been investigated with respect to its role in participation in CRC screening when made publicly available, as in England.

Using data from the population-based English Longitudinal Study of Ageing (ELSA), we aimed to determine: 1) the prevalence and predictors of limited health literacy in an English population eligible for CRC screening, 2) the association between health literacy and participation in the FOBT-based NHS Bowel Cancer Screening Programme in England.

Methods

Study sample

The ELSA is a longitudinal cohort study of the English population aged ≥50 years (Taylor et al., 2007). Data are collected biennially through computer-assisted interviews. The 'core' ELSA study population consists of participants from the original sample established in 2002 and newer participants added at each wave of data collection to account for ageing of the original sample. Male and female core ELSA participants aged 60–75 at wave 5 (2010–11) who completed the health literacy assessment and the CRC screening questions were eligible for the present analysis. This age group covers those eligible for FOBT screening with the NHS Bowel Cancer Screening Programme at any point from its inception in 2006 to the time of data collection in 2010–11.

In total, 8741 core participants with non-proxy interviews completed data collection at wave 5. Of these, 5041 (58%) were aged 60–75 years. Due to fieldwork logistics, the interview questions about cancer screening were introduced partway through data collection and subsequently screening data are not complete for the entire sample. Of the 5041 eligible participants, 3087 (61%) were asked the cancer screening questions. Of these, 2995 (97%) completed the health literacy assessment. Refusals were due to: reading problems (n = 14), sight difficulties (n = 14), health problems (n = 15), other reasons including anxiety, impaired concentration, distress, etc. (n = 15), or an unknown reason (n = 34). Refusals were included and coded as limited health literacy, as these people are likely to perform with limited health literacy skills in real-life settings (e.g. at the doctor's office) because of their difficulties. Therefore, they were included to maintain the population-representativeness of the sample and capture a more accurate range of the health literacy skills of the English population. The present analysis thus included 3087 men and women aged 60–75 years (Fig. 1).

Health literacy assessment

Health literacy was assessed using a four-item comprehension test based on a fictitious medicine label from the International Adult Literacy Survey (Thorn, 2009) (Appendix A). Health literacy was categorised as 'adequate' (4/4 questions answered correctly) or 'limited' (<4/4 answered correctly) to capture the point at which adults begin to have difficulty with everyday health tasks. Although whether and how health literacy skills may change over time are uncertain, health literacy scores among our sample are expected to be stable between data collection and the times of reported CRC screenings (within one year of wave 5 data collection for 59% of those reporting screening and within two years for 96%). Health literacy was also measured at ELSA wave 2 (2004–5) and the scores did not change between waves 2 and 5 within individuals who remained in the study for both waves. Health literacy scores measured at wave 2 were not used for this analysis, as study attrition between waves was differential by health literacy score.

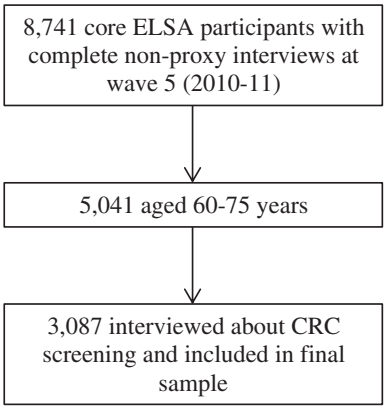

Fig. 1. Inclusion flow diagram, the English Longitudinal Study of Ageing, England, 2010–11 (n = 3087).

Colorectal cancer screening

Participants were asked if they had ever used a bowel testing kit (i.e. an FOBT kit) and whether the kit was part of the NHS Bowel Cancer Screening Programme. Only 49 out of the 1709 participants (<3%) who reported having completed an FOBT kit responded that the kit was not part of the NHS programme and 3 (<1%) responded that they did not know whether it was part of the programme; hence for this analysis we assume that completion of a FOBT kit equates with participation in the NHS programme. For convenience, the terms "completion of an FOBT kit" and "CRC screening" will hereupon be used synonymously.

Covariates

Sociodemographic covariates were: age, sex (male; female); educational attainment (no qualification; up to degree level; degree level or equivalent); net non-pension wealth (quintiles stratified at age 65 to account for changes in wealth following retirement) (Bostock and Steptoe, 2012); occupational class according to the 2010 National Statistics Socio-economic Classification (routine; intermediate; managerial or professional) (Office for National Statistics, 2010); and ethnic minority status (non-white; white).

Health-related covariates were: having a limiting long-standing illness (yes; no); having limitations in any one of six activities of daily living: dressing, walking across a room, bathing or showering, eating, getting in and out of bed, using the toilet (yes; no) (Bostock and Steptoe, 2012); having difficulty using the toilet including getting up and down (yes; no; this activity of daily living was also considered separately due to its specificity to completing an FOBT kit); having depressive symptoms, classified as scoring more than four on the eight-item Centre for Epidemiologic Studies depression scale (yes; no) (Radloff, 1977); self-reported general health (fair/poor; excellent/very good/good); and having ever been diagnosed with cancer (yes; no).

Statistical analysis

To achieve objective 1), the prevalence of adequate and limited health literacy were calculated. Unadjusted logistic regression modelling was used to generate odds ratios (ORs) and associated 95% confidence intervals (CIs) for the associations between health literacy and all covariates. Linear trend tests were used to assess graded relationships between ordered variables and health literacy. The same analyses were then conducted between participation in CRC screening and all covariates.

To achieve objective 2), the independent association between having adequate health literacy and participation in CRC screening was estimated using multivariable-adjusted logistic regression. Age, sex, educational attainment, and net non-pension wealth were forced into the model and all health-related covariates associated with screening with $p < 0.20$ in bivariate analysis were included in the initial model and retained if their deletion resulted in a ≥10% change in the OR for the association between health literacy and CRC screening (Rothman and Greenland, 1998).

Two sensitivity analyses were conducted. The first excluded those who refused to complete the health literacy assessment (n = 92) to ensure that these participants were not misclassified in a way to cause bias. The second excluded those who reported completing FOBT-based CRC screening outside of the national programme (n = 49). All regression modelling was performed with population weights applied to account for differential non-response across population subgroups (NatCen Social Research, 2012). All statistical tests were two-sided and performed at the 95% confidence level. All statistical analyses were conducted using StataSE 12.0 (StataCorp, College Station, TX).

Results

Nearly one in three ELSA participants eligible for CRC screening lacked adequate health literacy skills (Table 1). Health literacy was non-differential by gender, while those with higher educational

Table 1
Unadjusted associations between health literacy and covariates, The English Longitudinal Study of Ageing, England, 2010–11 (n = 3087).

	Health literacy level				
	Adequate (n = 2264; 73%)	Limited (n = 823; 27%)	Unadjusted OR for adequate health literacy	95% CI	p-Value
Age (mean (SD))	66.3 (4.5)	67.5 (4.7)	0.94[a]	(0.92, 0.96)	<0.0001
Sex					
Male	1010 (72%)	385 (28%)	1.00		
Female	1254 (74%)	438 (26%)	1.13	(0.95, 1.33)	0.17
Educational attainment					
No qualification	416 (57%)	319 (43%)	1.00		<0.0001[b]
Up to degree level	1168 (77%)	340 (23%)	2.78	(2.28, 3.38)	
Degree or equivalent	680 (81%)	164 (19%)	2.97	(2.34, 3.77)	
Occupational class					
Routine	769 (64%)	436 (36%)	1.00		<0.0001[b]
Intermediate	624 (76%)	201 (24%)	1.83	(1.49, 2.25)	
Managerial	859 (83%)	176 (17%)	3.00	(2.44, 3.69)	
Net non-pension wealth fifth					
1 (poorest)	309 (64%)	176 (36%)	1.00		<0.0001[b]
2	396 (70%)	172 (30%)	1.32	(1.01, 1.72)	
3	430 (76%)	133 (24%)	1.74	(1.31, 2.31)	
4	486 (75%)	159 (25%)	1.71	(1.30, 2.23)	
5 (richest)	532 (82%)	115 (18%)	2.77	(2.07, 3.69)	
Ethnicity					
Non-white	33 (43%)	44 (57%)	1.00		<0.0001
White	2231 (74%)	779 (26%)	3.33	(2.01, 5.53)	
Limiting longstanding illness					
Yes	656 (66%)	340 (34%)	1.00		<0.0001
No	1608 (77%)	483 (23%)	1.81	(1.52, 2.15)	
Limited activities of daily living					
Yes	279 (61%)	182 (39%)	1.00		<0.0001
No	1985 (76%)	641 (24%)	2.05	(1.65, 2.55)	
Difficulty using the toilet					
Yes	42 (55%)	34 (45%)	1.00		0.001
No	2222 (74%)	789 (26%)	2.21	(1.37, 3.56)	
Depressive symptoms					
Yes	161 (64%)	91 (36%)	1.00		<0.0001
No	2087 (75%)	709 (25%)	1.71	(1.28, 2.27)	
Self-reported general health					
Fair/poor	438 (59%)	303 (41%)	1.00		<0.0001
Excellent/very good/good	1826 (78%)	519 (22%)	2.47	(2.05, 2.97)	
Ever been diagnosed with cancer					
Yes	151 (73%)	56 (27%)	1.00		0.67
No	2113 (73%)	767 (27%)	1.08	(0.77, 1.51)	

[a] Per one year increase in age.
[b] p-Value for linear trend.

qualifications, of an intermediate or managerial occupational class, of any wealth quintile above the poorest, and of a white ethnicity were more likely to have adequate health literacy skills (Table 1). Not having a limiting long-standing illness, any limitations in activities of daily living, or depressive symptoms and having excellent, very good, or good general health were associated with having adequate health literacy skills. Having a previous cancer diagnosis was not associated with health literacy.

The overall participation rate in FOBT-based CRC screening was 55% (Table 2). Participation rates were 58% among those with adequate health literacy and 48% among those with limited health literacy (Table 2). In the unadjusted model, having adequate health literacy was associated with 50% greater odds of participating in CRC screening (OR = 1.50; 95% CI: 1.27–1.78). Other positive predictors of CRC screening participation in unadjusted models were female sex, having up to degree or degree level educational qualifications, being of managerial occupational class, being in any wealth quintile above the poorest, not having a limiting long-standing illness, limited activities of daily living, or depressive symptoms, and having excellent, very good, or good self-rated health. Older age was associated with being less likely to screen.

When adjusted for age, sex, educational attainment, and net non-pension wealth, the association between adequate health literacy and CRC screening was partly attenuated to borderline statistical significance (OR = 1.20; 1.00–1.44; Table 3). Occupational class and health-related covariates were not included in the model as they did not exert influence on the estimate for health literacy (Rothman and Greenland, 1998). In the multivariable model, female sex (OR = 1.31; 95% CI: 1.11–1.54) and being in any wealth quintile higher than the poorest (OR = 1.88; 95% CI: 1.43–2.49 for the richest quintile) were positively associated with CRC screening while age was negatively associated (OR = 0.92; 95% CI: 0.91–0.94 per year increase). Results were unaltered in sensitivity analyses removing those who refused to complete the health literacy assessment and those who reported FOBT-based CRC screening outside of England's national programme (not shown).

Discussion

Nearly one in three screening-aged adults lacked adequate health literacy skills in this large sample of older English adults. Limited health literacy was a barrier to participation in FOBT-based CRC screening available through England's National Bowel Cancer Screening Programme. Adults who responded correctly to all items on a four-item comprehension measure of a basic medicine label had 20% greater odds of participating in screening than those who responded incorrectly to at least one item. Younger adults within the screening-eligible age range, women, and those in richer wealth quintiles were also more likely to screen; these factors were stronger predictors of screening than health literacy. However, literacy barriers to screening are modifiable while these demographic factors are either not or not easily modified; hence literacy represents a more feasible intervention target. Given

Table 2
Unadjusted associations between CRC screening, health literacy, and covariates, The English Longitudinal Study of Ageing, England, 2010–11 (n = 3087).

	Participation in CRC screening				
	Yes (n = 1709; 55%)	No (n = 1378; 45%)	Unadjusted OR (Yes vs. No)	95% CI	p-Value
Health literacy					
Limited	391 (48%)	432 (52%)	1.00		<0.0001
Adequate	1318 (58%)	946 (42%)	1.50	(1.27, 1.78)	
Age					
mean age (SD)	65.8 (3.9)	67.7 (5.1)	0.92[a]	(0.91, 0.94)	<0.0001
Sex					
Male	727 (52%)	668 (48%)	1.00		0.001
Female	982 (58%)	710 (42%)	1.30	(1.12, 1.50)	
Educational attainment					
No qualification	346 (47%)	389 (53%)	1.00		0.0002[b]
Up to degree level	879 (58%)	629 (42%)	1.57	(1.31, 1.89)	
Degree or equivalent	484 (57%)	360 (43%)	1.47	(1.20, 1.82)	
Occupational class					
Routine	640 (53%)	565 (47%)	1.00		0.03[b]
Intermediate	468 (57%)	357 (43%)	1.16	(0.96, 1.29)	
Managerial	593 (57%)	442 (43%)	1.21	(1.02, 1.44)	
Net non-pension wealth fifth					
1 (poorest)	210 (43%)	275 (57%)	1.00		<0.0001[b]
2	324 (57%)	244 (43%)	1.79	(1.39, 2.31)	
3	342 (61%)	221 (39%)	2.08	(1.61, 2.70)	
4	378 (59%)	267 (41%)	1.92	(1.49, 2.46)	
5 (richest)	383 (59%)	264 (41%)	1.96	(1.53, 2.52)	
Ethnicity					
Non-white	34 (44%)	43 (56%)	1.00		0.09
White	1675 (56%)	1335 (44%)	1.55	(0.94, 2.56)	
Limiting longstanding illness					
Yes	512 (51%)	484 (49%)	1.00		0.001
No	1197 (57%)	894 (43%)	1.30	(1.11, 1.53)	
Limited activities of daily living					
Yes	218 (47%)	243 (53%)	1.00		0.001
No	1491 (57%)	1135 (43%)	1.44	(1.17, 1.77)	
Difficulty using the toilet					
Yes	36 (47%)	40 (53%)	1.00		0.21
No	1673 (56%)	1338 (44%)	1.36	(0.85, 2.18)	
Depressive symptoms					
Yes	126 (50%)	126 (50%)	1.00		0.02
No	1563 (56%)	1233 (44%)	1.37	(1.05, 1.80)	
Self-reported general health					
Fair/poor	356 (48%)	385 (52%)	1.00		<0.0001
Excellent/very good/good	1353 (58%)	992 (42%)	1.53	(1.29, 1.82)	
Ever been diagnosed with cancer					
Yes	118 (57%)	89 (43%)	1.00		0.61
No	1591 (55%)	1289 (45%)	0.93	(0.69, 1.25)	

[a] Per one year increase in age.
[b] p-Value for linear trend.

that the NHS primarily communicates CRC screening information through posted written information, interventions that are appropriate for the health literacy skills of screening-aged adults are needed to reduce literacy-based inequalities in CRC screening and to improve overall uptake.

Our findings are consistent with an American study that found lower health literacy, as assessed using a measure of medical vocabulary (the *Rapid Assessment of Adult Literacy in Medicine*; the REALM), was associated with lower self-reported FOBT screening (Arnold et al., 2012). However, two similar studies found no association (Miller et al., 2007; Peterson et al., 2007). One of these studies was statistically underpowered (Peterson et al., 2007), and use of the REALM may have limited all three studies: the REALM simply measures vocabulary, while the decision to undergo FOBT screening is dependent on a broader range of health literacy skills such as comprehension, reasoning, and judgement. Health literacy has, however, been associated with knowledge and positive attitudes toward CRC screening (Arnold et al., 2012; Dolan et al., 2004; Miller et al., 2007; Peterson et al., 2007). The pathways between health literacy, knowledge and beliefs about CRC screening, and screening uptake remain to be elucidated in empirical research, although useful theoretical frameworks exist (Davis et al., 2001; von Wagner et al., 2009b).

Consistent with our findings, an American study of a video intervention to communicate CRC screening information found that individuals with low health literacy were less likely to retain screening information (Wilson et al., 2010). A greater burden of CRC knowledge processing effort during information seeking by those with lower health literacy has also been shown (von Wagner et al., 2009a). Communication interventions to improve CRC screening rates must therefore be appropriate in terms of cognitive and health literacy demands. The current written materials in the NHS screening programme are difficult for individuals to process and understand (Smith et al., 2013), while trials of general practitioner endorsement and 'gist-based' information materials for individuals with low literacy are underway in the UK (Damery et al., 2012; Smith et al., 2013).

Strengths

This large analysis examined the role of health literacy in CRC screening participation in the context of the publicly-available NHS screening programme. Because overall programme uptake remains low and characterised by social inequalities, our results are valuable for understanding and addressing these problems. Although our measure of health literacy was not validated as a stand-alone measure, it was developed

Table 3
The associations between health literacy, covariates, and CRC screening, The English Longitudinal Study of Ageing, England, 2010–11 (n = 3087).

	Participation in CRC screening	
	Adjusted OR[a] (Yes vs. No)	95% CI
Health literacy		
Limited	1.00	
Adequate	1.20	(1.00, 1.44)
Age		
Per one year increase	0.92	(0.90, 0.94)
Sex		
Male	1.00	
Female	1.34	(1.14, 1.57)
Educational attainment		
No qualification	1.00	
Up to degree level	1.18	(0.96, 1.46)
Degree or equivalent	1.10	(0.87, 1.40)
Net non-pension wealth fifth		
1 (poorest)	1.00	
2	1.86	(1.43, 2.43)
3	2.13	(1.62, 2.80)
4	1.95	(1.50, 2.54)
5 (richest)	1.99	(1.51, 2.61)

[a] Adjusted for health literacy, age, sex, educational attainment, and net non-pension wealth.

using a framework defining literacy as a functional ability to complete goal-directed tasks (Thorn, 2009). This task represents a health management responsibility commonly faced by older adults that requires reading comprehension and judgement skills; this measure is a more comprehensive assessment of functional health literacy skills than simple vocabulary tests such as the REALM. In our statistical analysis we adjusted for important sociodemographic covariates and used population weights to increase the representativeness of our sample to the general English population.

Limitations

The ELSA study is not perfectly representative of the general English screening-eligible population. Only 2% of participants in our study sample were non-white, so we could not assess the impact of ethnicity. Cancer screening questions were delayed during ELSA fieldwork; subsequently, participants in our sample with no educational qualifications, in routine occupations, and in lower wealth quintiles were less likely to receive the cancer screening questions. Receipt of the questions was non-differential by all other variables, including health literacy. We used the appropriate statistical weights to account for differential non-response by these sociodemographic factors (NatCen Social Research, 2012). However, differential responses may still have an impact: participants in these more deprived groups were more likely to have low health literacy and were also less likely to have undergone screening. Finally, our CRC screening data were self-reported, although overall rates of screening were similar to those as recorded by the screening programme database after the first 2.6 million invitations in 2007 (von Wagner et al., 2011). Furthermore, self-report of FOBT screening has been well-validated against medical records in other studies with sensitivities ranging from 80% to 96% and specificities ranging from 71% to 86% (Baier et al., 2000; Gordon et al., 1993; Vernon et al., 2008).

Conclusions

Low literacy is an obstacle to control of colorectal cancer in England. Future research should examine literacy against screening participation rates recorded by the NHS and explore other constructs related to health literacy such as communicative skills and health numeracy. Health literacy interventions for older adults are a priority for improvement in screening rates and reduction in literacy-based inequalities. The potential modifiability of literacy-based screening inequalities relative to broad sociodemographic inequalities represents a route to improvement of health equity in the population that must not be missed by policymakers and the health system. Methods to communicate screening information must be appropriate for the health literacy skills of screening-aged adults. The upcoming introduction of flexible sigmoidoscopy screening in the UK programme provides an opportunity to reduce literacy barriers that should not be overlooked.

Conflict of interest statement

The authors declare that there are no conflicts of interest.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at http://dx.doi.org/10.1016/j.ypmed.2013.11.012.

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