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# Association between cancer literacy and cancer-related behaviour: evidence from Ticino, Switzerland

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**Significance for public health**

From a public health perspective, our findings underscore the importance of adapting informational and educational communication interventions designed to improve cancer prevention and screening to different audiences, which could differ not only in their functional health literacy, and in particular to put into place strategies to evaluate their success, including the actual transformation of information in relevant knowledge that can be used as a basis for health decision making. Moreover, the cancer literacy score is able to provide researchers and public health officials with detailed information on which are the main gaps in cancer knowledge and to identify the segments of the population that are more at risk. This information could be used to design and develop targeted informational campaigns for low health literate citizens.

## Abstract

*Background*. This paper details the role of different dimensions of health literacy in the relationship between health literacy and cancer-related health behaviours. In particular, *Cancer Literacy* is studied as an exemplar of a dimension of health literacy beyond basic reading and writing skills. The link between functional health literacy, *Cancer Literacy* and cancer-related health behaviours is investigated in a sample of Ticino (Switzerland) residents (n=639).

*Design and methods*. Detailed data is collected about respondents' functional health literacy, *Cancer Literacy*, cancer information seeking behaviour, engagement in cancer preventive behaviours, participation to cancer screenings, and intention to adhere to current screening recommendations.

*Results*. Results confirm the added value of *Cancer Literacy* – compared to functional health literacy – in explaining people's cancer information seeking behaviour, their participation to several cancer screenings and their screening intention, underscoring the need to take into account dimensions of health literacy beyond basic functional skills.

*Conclusions*. From a public health perspective, findings provide further evidence on the importance of adapting informational and educational communication intervention designed to improve cancer prevention and screening to different audiences.

## Introduction

Health literacy has been defined as *the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions*.[1] The concept has gained widespread acceptance,[2] because of the evidence of a positive relationship between health literacy and health-related behaviours.[3-5] One of the main limitations of research on the relationship between health literacy and behaviour resides in the fact that it relies on measures of functional health literacy (*FHL*), or people's ability to read and understand medical information,[6] which does not fully capture the complexity of the concept, and could thus let existing literacy gaps undetected.[7] Even though a large number of empirical studies has been devoted to assess the role of *FHL*, less is known about the role played by other dimensions of health literacy in explaining health behaviour. [2,6,8-11]

The existence of several dimensions of health literacy has been widely acknowledged.[8,11] Most definitions underscore the important role not only of the simple mechanical acquisition of information, but also of other dimensions, such as the ability to process and transform it into relevant knowledge, which should therefore be taken into account.[1,6,12] Nutbeam,[6] for instance, distinguishes between three different dimensions of health literacy. A first dimension, *FHL*, refers to basic cognitive abilities (including reading and writing skills) enabling the individuals to understand relevant health information in everyday situations. A second dimension, *interactive health literacy*, encompasses more advanced cognitive and social skills enabling the individuals to undertake an active role within their social environment regarding their own health. A last dimension, *critical health literacy*, includes even more advanced cognitive abilities enabling the individuals to critically appraise health-related information and advice and to take appropriate health decisions. Schulz and Nakamoto also propose a three-tiered conceptualization of health literacy, stressing the importance of knowledge.[12] In addition to basic reading and numeracy skills, their multidimensional concept of health literacy comprises declarative knowledge (factual knowledge related to health issues to be able to learn how to approach a health condition) and procedural knowledge (*know-how* to apply factual knowledge and use health information in a specific context) and judgment skills (the ability to judge on the basis of factual knowledge necessary to deal with novel situations).

Since a clear picture of the casual pathways linking health literacy and health-related behaviours is still missing, a deeper understanding of the role played by different dimensions of the concept in this process would be greatly beneficial to the advancement of research in this field.[4,13,14]

### Cancer literacy

The main aim of this paper is to gain insights on the role played by a dimension of health literacy other than the functional one in explaining health behaviours. One of the main obstacles to research taking into account different dimensions is the fact that these have been theorized, but only rarely operationalized. One example of operational definition is the concept of *Cancer Literacy* (*CL*), which has been defined as *all the knowledge a layperson needs to possess to understand the information and advice the health system has to offer with regard to preventing, diagnosing and treating cancer*.[15] The operationalized dimensions are those of declarative and procedural knowl-

edge about cancer, as conceptualized by Schulz and Nakamoto.[12] The process of operationalization and validation of the measure of *CL* provides evidence of the fact that the concept actually captures components of health literacy other than *FHL*.[15] According to the authors of the measure, giving a correct answer to a specific pool of cancer knowledge questions also reflects people's interactive health literacy (*e.g.,* ability to find and interpret cancer information of varying levels of difficulty), and their critical and judgmental skills (*e.g.*, ability to assess appropriateness of information located).[16]

### Research question and hypotheses

The importance of people's health literacy in explaining a wide range of cancer-related behaviours has been widely recognized.[17-24] However, most of these studies have assessed health literacy using measures of *FHL* only. We thus decided to study *CL* as an exemplar of a dimension of health literacy encompassing more than basic reading and writing skills, and to investigate whether a measure that is specific to the field of cancer prevention could contribute to a deeper understanding of the link between health literacy and cancer-related health behaviours.

That said, our leading research question is: *What is the role of CL in explaining cancer-related health behaviours*? Two distinct but interrelated hypotheses were developed. First, since they are different dimensions of the same overarching concept, we expected *FHL* and *CL* to be associated (*Hypothesis 1a*). Moreover, based on the existing literature showing that health literacy is positively associated with being a female, being younger, having an higher educational level and having a personal history of disease,[13,25,26] we expected to find the same associations for both *FHL* and *CL* (*Hypothesis 1b*).

Second, since *CL* is a more complex and comprehensive dimension of health literacy explicitly conceptualized in the field of cancer prevention,[15] and in light of the evidence on the association between health literacy and cancer-related behaviours,[3,4,17-19,21,26,27] we expected *CL* to present a stronger association with cancer information seeking and cancer-related health behaviours than *FHL* (*Hypothesis 2*).

The two hypotheses were tested in a sample of Ticino (Switzerland) residents, by collecting detailed data about their *FHL*, *CL*, cancer information seeking, and cancer-related health behaviours.

## Design and methods

### Data collection and sample

The cross-sectional data analysed in this study was collected face-to-face in an opportunity quota sample of 639 Ticino residents by a team composed by undergraduate and graduate communication students. Interviewers were systematically trained to ensure knowledge of the questionnaire and of the criteria for the recruitment of the respondents. Interviewers were instructed to conduct 10-20 interviews in their extended social circle, including respondents evenly distributed as regards gender, age, and education. Interviewers could interview only one member of their own nuclear family (parents and siblings) and only one person per household. To ensure representation of people with personal experience with cancer, each interviewer was required to include at least one person who had already received a cancer diagnosis.

### Measures

#### Functional health literacy

Respondents' *FHL* was assessed by means of an Italian translation of the screening questions developed and validated by Chew and colleagues.[28,29] To assess the applicability of the screening questions to the Swiss health system, they were informally discussed with a group of healthcare providers, who agreed in suggesting not to use the question *How confident are you filling out medical forms by yourself?* because this is not common practice in Swiss hospitals. The questions were also informally pretested using the think-aloud technique among a group of Italian-speaking Swiss citizens,[30] who confirmed what had been pointed out by the healthcare providers. For this reasons only the two questions *How often do you have someone help you read hospital materials*? and *How often do you have problems learning about your medical condition because of difficulty understanding written information?* were included in the questionnaire.

#### Cancer literacy

Cancer literacy was assessed using the *Cancer Literacy Score* (CLS), an index formed by 37 knowledge items regarding different aspects of cancer,[15] grouped in 5 subscales (cancer risk, detection and diagnosis, treatment, coping, and information). The measure has been shown to present acceptable overall internal consistency, test-retest reliability and construct validity, and is a continuous variable ranging from 0 to 100, reflecting the percentage of correct answers.[16]

#### Cancer-related health behaviours

Four different cancer-related health behaviours were assessed. The first was cancer information seeking: respondents were asked if they had ever searched for cancer information. As it has been done in the past,[31,32] people answering *yes, once* or *yes, several times* were categorized as *cancer information seekers* and people answering *no* as *cancer information non-seekers*. Second, participants were asked to provide details about their engagement in four behaviours known for being associated with diminished cancer risk: not smoking, eating fruits and vegetables, exercising, and using a sunscreen. For analytical purposes an index was created by assigning a value of 1 for a healthier answer and a 0 for a less healthy answer, and by summing the values of these four items. Third, past cancer screening participation was assessed by seven questions asking respondents whether they had ever had a colonoscopy or endoscopy, a FOBT (Fecal Occult Blood Test), a skin exam, a PSA (Prostate-Specific Antigen) exam, a rectal exam, a Pap test, or a mammography. The choice of the screenings was related to the Swiss Cancer League screening guidelines (www.cancerleague.ch). Lastly, in order not to take into account only actual behaviors, all respondents, irrespectively of screening history, gender and age, were asked to rate on a 7-point Likert scale their intention to adhere to the current screening recommendations.

#### Control variables

The associations between *FHL*, *CL* and cancer-related health behaviours might be an artefact of the effect of some well-known common predictors, such as gender, age, educational level, personal cancer history, and having played an active role in the care of a third person suffering from cancer.[13,25,26] Data about these aspects were thus collected and used to highlight group differences and as control variables in multivariate analysis.

### Statistical Analysis

Basic frequency analyses were used to describe the characteristics of the whole sample. Hierarchical multivariate regression models were used to estimate the independent relationships between respondents' characteristics, FHL, CL and cancer-related behaviours (controlling for all covariates). All analyses were performed on the whole sample, except those aiming at investigating past screening behaviour, which were conducted on separate sub-samples including only respondents belonging to the target group for each of the different screening test. In order to take into account a slight overrepresentation of people below 30 years and of those with a secondary education in the sample and to be representative of the Ticino population estimates,[33] data were weighted for education and age.

## Results

### Sample characteristics

Slightly more than half of the sample (53.8%) was female. Fifteen percent of the respondents were less than 30 years old, 22.5% were 30-44, 33.2% were 45-64, and 29.5% were over 65. The mean age of the sample was 51 years (SD=18.4 years). About 68% of the respondents were Swiss, non-Swiss respondents had been living in Switzerland for 26.6 years on average (SD=19.3). Forty-one percent of the sample had only completed compulsory education (9 years), 46.2% had a secondary school degree (*e.g.* high school, professional school), and 13.1% had a college degree or higher. Eleven percent of the respondents reported having ever been diagnosed with cancer, and 33.8% reported having played an active role in the cancer experience of a third person, and were thus labelled as *caregivers*.

### Functional health literacy

In the first screening question for *FHL* – *i.e.* how often one needs help reading hospital materials – the majority of the respondents (42%) reported never needing help, one quarter (25%) occasionally, 16% sometimes, 8.6% often, and very few of them always. Multivariate analysis showed that, controlling for all covariates, only educational level was significantly associated (B=0.314, P<0.001, β=0.191) with how often people need help (Model $R^2$=0.064).

The second screening question – *i.e.* how often one has problems learning about his/her medical condition because of difficulties reading written materials – yielded similar results. The majority of the respondents (35.2%) reported that it never happens to them, slightly more than one third (31.9%) occasionally, around 20% sometimes, 6.4% often, and very few of them that it happens all the time (3.4%). Multivariate regression showed that not only educational level (B=0.199, P<0.01, β=0.127), but gender (B=-0.191, P<0.05, β=-0.089) and having a personal history of cancer (B=-0.265, P<0.05, β=-0.078) as well were significantly associated with having problems learning about one's medical condition (Model $R^2$=0.033). The two questions showed acceptable internal consistency (*Cronbach's alpha* = 0.727) and were thus merged into a single index which was used in further analyses.

### Cancer literacy

The CL scale presented satisfactory internal consistency (*Cronbach's alpha*=0.769). Respondents scored on average 51.04 (SD=14.49) on the scale, meaning they answered correctly on average to around 50% of the knowledge items. Multivariate analysis showed that, controlling for all the other covariates, only gender (B=5.531, P<0.001, β=0.191), educational level (B=0.953, P<0.001, β=0.112), and caregiver status (B=7.353, P<0.001, β=0.241) were significantly associated with *CL* (Model $R^2$=0.114). As hypothesized, when added to the model, both the screening questions for *FHL* were shown to be significantly associated with *CL* (*Help read*: B=2.269, P<0.001, β=0.176; *Problems understanding*: B=2.036, P<0.001, β=0.150).

### Cancer-related health behaviours

#### Cancer information seeking

Almost forty percent of the respondents answered positively when asked whether they had ever searched for cancer-related information. A logistic regression showed that, controlling for covariates, educational level (P<0.001), personal cancer history (P<0.001), and caregiver status (P<0.001) were significantly associated with cancer information-seeking (Table 1, *Model 1* for details). As shown in Table 2 (*Model 2*), when *FHL* was added to the baseline logistic model, no significant effect was found. On the other hand, when *CL* was added to the model in a subsequent step, it was shown to be significantly associated with of cancer information seeking (P<0.001, Table 1, *Model 3* for details).

#### Preventive behaviours

Respondents reported engaging on average in 2.3 (SD=0.87) behaviours out of the 4 included in the preventive behaviour index. A multivariate analysis highlighted a significant independent effect of educa-

**Table 1. Hierarchical logistic regression analysis with cancer information seeking as dependent variable, predicted by respondents' characteristics, functional health literacy and cancer literacy (n=639).**

| Variable | Cancer information seeking | | | | *Model $R^2$* | |
|---|---|---|---|---|---|---|
| | B | SE | Wald | Exp(B) | Cox and Snell | Nagelkerke |
| Model 1 | | | | | | |
| Gender | 0.125 | 0.191 | 0.427 | 1.133 | 0.187 | 0.255 |
| Age | -0.011* | 0.006 | 3.827 | 0.989 | | |
| Educational level | 0.588*** | 0.153 | 14.824 | 1.801 | | |
| Cancer history | 1.807*** | 0.308 | 34.525 | 6.093 | | |
| Caregiver | 1.636*** | 0.202 | 65.358 | 5.133 | | |
| Model 2 | | | | | | |
| Gender | 0.159 | 0.193 | 0.676 | 1.172 | 0.191 | 0.259 |
| Age | -0.012* | 0.006 | 4.032 | 0.988 | | |
| Educational level | 0.554*** | 0.155 | 12.800 | 1.739 | | |
| Cancer history | 1.861*** | 0.311 | 35.770 | 6.428 | | |
| Caregiver | 1.629*** | 0.203 | 64.654 | 5.098 | | |
| Functional health literacy | 0.162 | 0.104 | 2.399 | 1.175 | | |
| Model 3 | | | | | | |
| Gender | -0.222 | 0.210 | 1.113 | 0.801 | 0.266 | 0.361 |
| Age | -0.017*** | 0.006 | 6.768 | 0.984 | | |
| Educational level | 0.339** | 0.161 | 4.409 | 1.404 | | |
| Cancer history | 2.032*** | 0.341 | 35.532 | 7.633 | | |
| Caregiver | 1.455*** | 0.215 | 45.924 | 4.285 | | |
| Functional health literacy | 0.042 | 0.113 | 0.135 | 1.043 | | |
| Cancer literacy | 0.060*** | 0.009 | 50.030 | 1.062 | | |

SE, standard error; Wald, wald statistics, Exp(B), the Odds Ratio for the IV and DV. *P<0.05; **P<0.01; ***P<0.001.

tional level only (B=0.115, P<0.05, β=0.092) on the preventive behaviour index. When *FHL* and *CL* were added to the baseline model, no significant effect of either variable was found.

### Past screening participation

More than half of the respondents (54.7%) reported having been screened for cancer. Multivariate logistic regressions were performed in selected subsamples (corresponding to the target groups of the different screening test) to investigate the association between respondents' characteristics, *FHL* and *CL* and past participation to cancer screening. Different personal characteristics were associated with participation to the different screening tests: among female respondents aged 50+, older respondents (B=-0.110, P<0.001, Exp(B)=0.896) and those with an higher education level (B=-0.942, P<0.05, Exp(B)=0.390) were significantly less likely to have been screened for breast cancer, among male respondents aged 50+, older respondents were significantly less likely to have been screened for prostate cancer (B=-0.047, P<0.05, Exp(B)=0.954) and, in the whole sample, caregiver of a cancer patient were significantly more likely to have been screened for skin cancer (B=-0.436, P<0.05, Exp(B)=0.646). None of the personal characteristics taken into consideration were shown to be independently associated with cervix cancer and colon cancer screening. When *FHL* was added to the models, it was shown not to be significantly associated to completion of any of the screening tests. *CL*, on the contrary, was shown to be significantly associated to participation to all the screenings but the one for prostate cancer (*Skin*: B=0.034, P<0.001, Exp(B)=1.034; *Cervix*: B=0.035, P<0.001, Exp(B)=1.035; *Colon*: B=0.076, P<0.001, Exp(B)=1.079; *Breast*: B=0.033, P<0.05, Exp(B)=1.033).

### Screening intention

Respondents showed an overall moderate intention to adhere to current screening recommendations (M=4.84, SD=1.99), the modal response being 7, chosen by 29.3% of them. As shown in Table 2 (*Model 1*), a multiple regression highlighted significant independent effects for gender (P<0.001), age (P<0.001), and personal cancer history (P<0.05) on the intention to get screened. When *FHL* was added to the baseline regression model, no significant effect was found (Table 2, *Model 2*). However, when *CL* was added to the model in a subsequent step, both *FHL* and *CL* were shown to be significantly associated with the respondents' intention to get screened (P<0.001, Table 2, *Model 3* for details).

## Discussion

Aim of this study was to get a deeper understanding of the role played by a dimension of health literacy other than basic functional skills in explaining cancer-related behaviours. The results will be discussed in light of the hypotheses derived from our literature review.

*FHL* and *CL* have been shown to be correlated, thus confirming *Hypothesis 1a*. However, data showed that the two dimensions of health literacy are only partially associated with the same individual characteristics, thus partly disconfirming *Hypothesis 1b*. As expected, educational level and gender were associated with both *FHL* and *CL*. However, having a personal history of cancer was significantly associated only with *FHL* and being a caregiver only with *CL*. Contrarily to our hypothesis, at a multivariate level age was not found to be associated neither with *FHL* nor with *CL*. This result could be interpreted as evidence of the fact that age should not be considered a predictor of literacy in itself: *CL* could increase with age because the older people get, the more occasions they have had to get in contact with people suffering from cancer. As regards our second hypothesis (*Hypothesis 2*), data showed that *CL* was independently positively associated with cancer information seeking, participation to cancer screening, and intention to undergo cancer screening, while *FHL* was not. None of the two constructs, however, was found to be significantly associated with engagement in preventive behaviour. This could be explained by the fact that, unlike participation to cancer screening or intention to get screened, the preventive behaviours under investigation were not specific to cancer. There are indeed several personal or environmental factors other than *CL*, *e.g.* body image issues,[34] that could play an important role in the decision for example not to smoke or to eat fruit and vegetables every day. It has to be stressed that, even if *CL* was shown to be associated with most of the behaviours under investigations, the strength of this association was in most cases very weak. As regards past screening participation, we advance two possible explanations for these results. First of all, most of the existing screening tests can be used for both preventive and diagnostic purposes. Our data do not allow to make a distinction between the two cases and part of the respondents reporting having completed one or more of the screening tests could have done so because of specific health problems and not for preventive reasons. In such a case it is plausible that *CL* would play only a limited role in their decisions. Secondly, the tests considered are very different as regards for instance the barriers associated with completing them, their popularity, and the amount of promotion surrounding them. A very popular test conducted in regular medical consultations (such as the PSA test for men or the mammography for women) could therefore be more likely to be completed by people with low *CL*, whereas a test which is less widely known would require a more active involvement, and therefore a higher level of *CL*, in order to be completed.

## Limitations

It has to be acknowledged that this study suffers from some measurement-related limitations. First of all it relies on an opportunity quota sample, which is not representative of the population and limits

**Table 2. Hierarchical regression analysis with screening intention as dependent variable, predicted by respondents' characteristics, functional health literacy and cancer literacy (n=639).**

| Variable | Screening intention | | |
|---|---|---|---|
| | B | SE | β |
| Model 1 | | | |
| Gender | 0.513*** | 0.164 | 0.127 |
| Age | -0.017*** | 0.005 | -0.159 |
| Educational level | 0.064 | 0.128 | 0.022 |
| Cancer history | 0.523* | 0.251 | 0.084 |
| Caregiver | 0.254 | 0.172 | 0.060 |
| *Model $R^2$* | 0.048 | - | - |
| Model 2 | | | |
| Gender | 0.483*** | 0.164 | -0.120 |
| Age | -0.017*** | 0.005 | -0.159 |
| Educational level | 0.109 | 0.130 | 0.037 |
| Cancer history | 0.474 | 0.251 | 0.076 |
| Caregiver | 0.274 | 0.171 | 0.065 |
| Functional health literacy | -0.185 | 0.085 | -0.088 |
| *Model $R^2$* | 0.056 | - | - |
| Model 3 | | | |
| Gender | 0.224 | 0.160 | 0.056 |
| Age | -0.016*** | 0.005 | -0.152 |
| Educational level | -0.051 | 0.125 | -0.017 |
| Cancer history | 0.348 | 0.240 | 0.056 |
| Caregiver | -0.038 | 0.169 | -0.009 |
| Functional health literacy | -0.291*** | 0.082 | -0.139 |
| Cancer literacy | 0.044*** | 0.006 | 0.319 |
| *Model $R^2$* | 0.142 | - | - |

SE, standard error. *P<0.05; **P<0.01; ***P<0.001.

the generalizability of the results. Secondly, *FHL* was measured by two of the three self-report screening questions validated by Chew and colleagues.[28,29] The reason behind the choice of screening questions over other established health literacy measures is mainly practical. To date no validated Italian versions of the commonly used health literacy measures, *e.g.* REALM or TO*FHL*A, exists.[35,36] Even an informal validation of an Italian version of such instruments, as the one that was conducted with the screening questions for the purposes of the present research (see above), was not deemed feasible within the timeframe of the study. Nevertheless, each one of the three screening questions was proven by their authors to be a valid measure of functional health literacy and to be correlated with other health literacy measures. It has to be noted that the validity was assessed in the clinical setting and no conclusive evidence exists of their validity in a different context. Third, past screening participation was measured by single indicators not taking into account the motivation for completing the test (preventive *vs*. diagnostic). Fourth, our cancer information-seeking measure was dichotomous, and no distinction between modes of acquisition (*e.g.* seeking *vs*. scanning) or between sources used was made, limiting the depth of our examination. In particular, this measure did not allow us to get a full understanding of the process how individuals seek and evaluate health information and apply it to their healthcare decisions. Last, the cross-sectional nature of our study did not allow us to make any causal claims. Our results would therefore need to be tested in an experimental setting to have a clearer picture of the casual pathways linking health literacy and health behaviours.

## Conclusions

Despite these limitations, this study offers an important perspective on the communication processes involved in the individuals' health decision making. Communication scholars can profit from a deeper understanding of the potential consequences of an unsuccessful search for information: indeed people's ability to read health information (*FHL*) does not seem to be crucial in itself in predicting behaviour, while a more important role is played by the extent to which this information has been internalized (people's *CL*). Moreover, the findings have important implications for our theoretical model of health literacy, providing evidence of a link between *CL*, cancer information-seeking and cancer-related health behaviours and stressing once more the need to go beyond considering (and measuring) health literacy as mere functional literacy skills and to take other dimensions of health literacy (*e.g.* knowledge) into account.[8,15]

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