

CANCER AND HEALTH LITERACY: ESTABLISHING A CONCEPT OF CANCER LITERACY

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THE IHA'S 10th ANNUAL
HEALTH LITERACY
CONFERENCE
IRVINE, CA: 4-6 MAY 2011

THEORETICAL BACKGROUND

Information about health is overwhelming, it is often difficult for non-medical persons to be adequately informed about issues that are essential to their health (Viswanath, 2005).

Health literacy cannot be defined anymore only as reading and writing skills in a healthcare context, but should include other abilities, e.g. declarative knowledge or procedural knowledge (Nutbeam 2000; Schulz & Nakamoto, 2005).

Existing measures of health literacy (e.g. TOFHLA, REALM) only assess basic reading and writing skills (Mancuso, 2009).

Need for content and context-specific measures of health literacy (Nutbeam, 2008).

OBJECTIVE and HYPOTHESIS

Objective of the project was to operationalize and to specify a usable and defined concept of **Cancer Literacy**, i.e. to understand what knowledge and abilities make a person cancer literate.

We hypothesize that **specific cancer-related health outcomes** can be better explained and predicted by using the concept of **Cancer Literacy** than by using general health literacy alone.

METHODS

1. A Delphi study in three consecutive rounds among a panel of Swiss cancer experts (Table 1), including oncologists, GPs, nurses from oncology wards, social workers, and public health experts to operationally define the concept of **Cancer Literacy**.

	Accepted	1st round	2nd round	3rd round
	n (%)	n (%)	n (%)	n (%)
Oncologists	20 (27)	16 (34)	18 (38)	14 (34)
GPs	20 (27)	5 (11)	7 (15)	6 (15)
Nursing staff (oncology wards)	15 (19)	12 (26)	14 (29)	12 (29)
Social services / other experts	20 (27)	14 (30)	9 (19)	9 (22)
Total	75 (100)	47 (100)	48 (100)	41 (100)

2. Development, pre-test and validation of a measure of **Cancer Literacy**. Assessment of its internal consistency, test-retest reliability and construct validity.

3. Assessment of the **Cancer Literacy** and the **cancer information-seeking behavior** of the Ticino population (Survey, N = 639).

MAIN RESULTS

1. The result of the Delphi process is a **first operational definition of the concept of Cancer Literacy**, i.e. a list of the aspects of cancer that, in the experts' view, laypeople should know to be considered cancer literate (Table 2) We can now say, by systematically building upon the professional experience of health care providers, what the key competences are that a layperson should possess in order to be considered cancer literate. Both the aspects of cancer chosen by the participants in our study to be included in the concept of cancer literacy, and those that were excluded seem to confirm the **higher importance attributed to the first part of the cancer continuum** (i.e. prevention and early detection). People should in this view **only know as much about cancer as it is necessary to prevent it and to manage it in the best possible way**, but it seems that knowing everything about it would not be necessary nor expected.

Table 2 First operational definition of the concept of cancer literacy

Aspects of cancer risks
Individual behaviors related to cancer
Importance of behavioral risk factors
How to reduce cancer risk by changing behaviors
Environmental factors related to cancer
Importance of environmental risk factors
Strength of the relationship between risk factors and cancer development
Aspects of information
Trustworthiness of information sources about cancer
Aspects of detection and diagnosis
Existing screenings
Benefits of the screenings
Goals of the screenings
Aspects of treatment
Types of treatments
Right of the patient to choose the treatment
Aspects of coping with the disease
Existing support services
How to contact support services
Types of supporting services offered

2. The **Cancer Literacy** scale (CLS) showed **acceptable internal consistency** (overall Cronbach's alpha .769) and 4-week **test-retest reliability** (Pearson's correlation .721, $p < .001$). Independent-samples t-tests confirmed that known groups, as women, non-foreigners, people with higher educational level, people with medical background, and active caregivers of a cancer patient all presented significantly **higher CLS scores**, providing **evidence for construct validity** (Table 3).

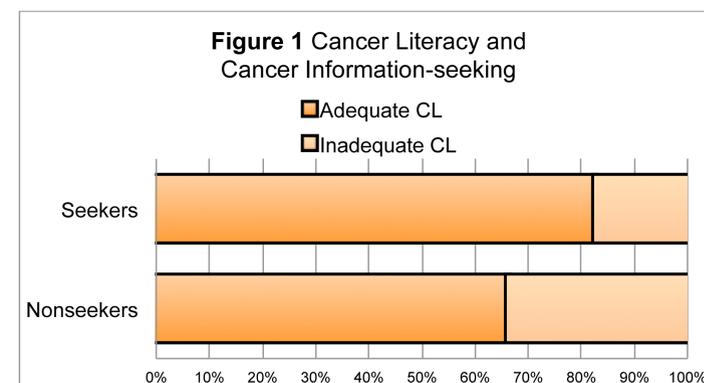
3. (early results) The survey highlighted some **major deficiencies as regards knowledge** about some aspects of cancer, showing for instance that more than 60% of the respondents are not aware of the relationship between overweight and cancer. Moreover, the survey revealed some **significant knowledge disparities among people with different educational levels**: just to mention one, almost 20% of women with lower education vs. only 2% of

Table 3 Cancer Literacy score means for different groups

	Mean CLS	SD	t	df
<i>Gender</i>				
Men	47.6	13.6	-7.34***	637
Women	55.5	13.6		
<i>Educational level</i>				
No college	50.8	14.7	-2.49*	629
College	53.9	12.5		
<i>Nationality</i>				
Swiss	52.4	14.6	2.18*	637
Other	49.7	12.7		
<i>Medical background</i>				
No	50.8	13.9	-5.56***	634
Yes	62.6	13.4		
<i>Caregiver status</i>				
No	51.3	13.8	-3.68***	478
Yes	56.1	13.9		

* $p < .05$; *** $p < .001$

highly educated women ($p < .01$) had never heard of a Pap test. **Cancer Literacy** was significantly associated with cancer information-seeking, with **higher percentages of people with adequate Cancer Literacy among seekers than among nonseekers** (see Figure 1, $p < .001$). Moreover, **Cancer Literacy** was found to predict self-



reported engagement in health promoting behaviors. Binary logistic regressions showed that, controlling for gender, age, educational level, and medical education, **people with adequate Cancer Literacy were more likely than the others to report not smoking** (OR = 1.728; CI = 1.214-2.574; $p < .01$), **exercising** (OR = 1.929; CI = 1.311-2.837; $p < .01$), and **undergoing preventive medical examinations** (OR = 2.777; CI = 1.215-6.345; $p < .05$) as personal ways of staying healthy. Participants with adequate **Cancer Literacy** were also found being almost **five times more likely than participants with limited Cancer Literacy to have been screened for cancer** (OR = 4.781; CI = 3.057-7.477; $p < .001$). The total **Cancer Literacy** score was positively correlated with general attitude towards cancer screenings participation ($p < .001$).

CONCLUSIONS and IMPLICATIONS FOR PRACTICE

1. We have now an idea of **what should be known about cancer** and, consequently, of what should be **communicated to the public**.
2. The newly developed scale provided us with **evidence of the validity of our conceptual attempt** to go in the direction of a content- and context-specific concept of health literacy.
3. The study helped **defining the most cancer illiterate segments of the Ticino population** and will produce information on the best ways to reach these segments in communication campaigns.

NEXT STEPS

Analysis of the **specific role of health and cancer information-seeking** (or non-seeking), **trust**, and **choice** of different information sources in the relationship between Cancer Literacy (or its components) and health outcomes.

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