



IBSA FOUNDATION
for scientific research

Università
della
Svizzera
italiana



SAPIENZA
UNIVERSITÀ DI ROMA

INTRODUCTION TO HEALTH LITERACY

October 12-13, 2016

Milan – Rome, Italy

Peter J. Schulz

Institute of Communication & Health

Sothern Switzerland University, Lugano, Switzerland

Michaela Liuccio

Biomedical Scientific Communication Program

La Sapienza University, Rome, Italy

CONTENTS

- 1. Health Literacy Definitions**
- 2. Relevance of Health Literacy**
- 3. Health Literacy Concepts**
- 4. Dimensions of Patient Empowerment**
- 5. Health Literacy Measurement Tools**
- 6. Health Literacy and Web-Based Resources**
- 7. Future Health Literacy Interventions**
- 8. Discussion**

1. HEALTH LITERACY DEFINITIONS

“Health literacy is a constellation of skills, including the ability to perform basic reading and numerical tasks required to function in the healthcare environment. Patients with adequate health literacy can read, understand, and act on healthcare information.”

1. HEALTH LITERACY DEFINITIONS

“The degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions.”

(NLM, Healthy People 2010)

The degree to which individuals have the capacity to obtain, process, and understand health information, services and skills needed to make informed health decisions and actions.”

(Paasche- Orlow, 2012)

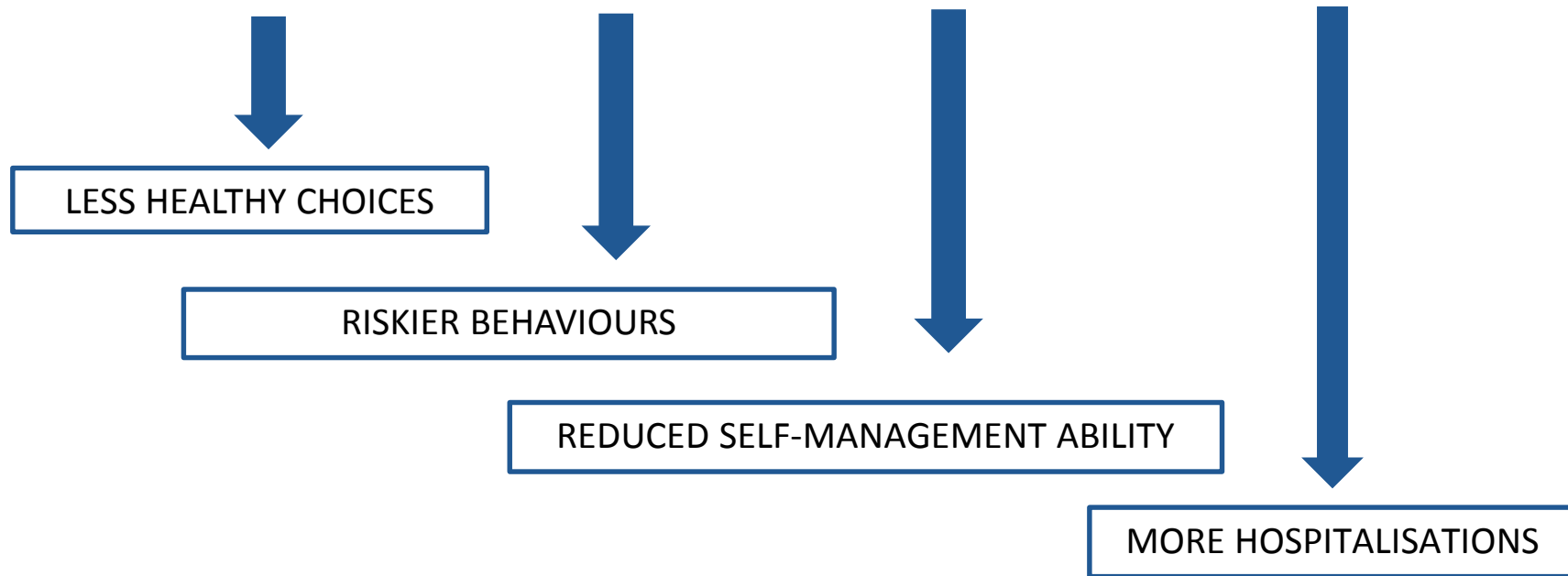
1. DEFINIZIONI DI HEALTH LITERACY

“... the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health. Health Literacy means more than being able to read pamphlets and successfully make appointments. By improving people's access to health information and their capacity to use it effectively, health literacy is critical to empowerment.”

(WHO, 2009)

2. RELEVANCE OF HEALTH LITERACY

WHAT ARE THE CONSEQUENCES OF POOR HEALTH LITERACY?



3. HEALTH LITERACY CONCEPTS

BASIC/ FUNCTIONAL LITERACY

Sufficient basic skills in reading and writing to be able to understand and function effectively in everyday situations.

COMMUNICATIVE LITERACY

More advanced skills which enable individuals to extract information, derive meaning from different forms of communication, and to apply new information to changing circumstances.

CRITICAL LITERACY

More advanced skills which can be applied to critically analyse information and to use this information to have greater control over life events and situations.

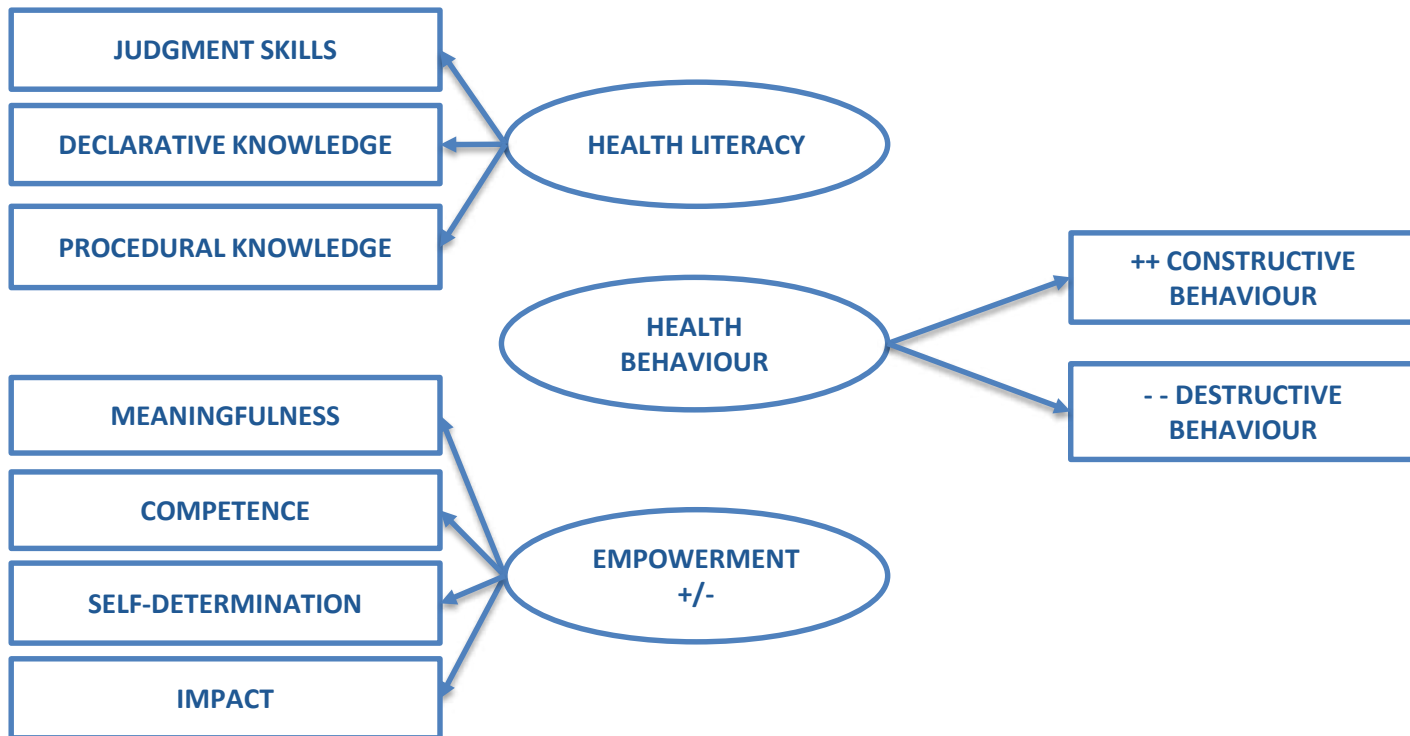
3. HEALTH LITERACY CONCEPTS

		EMPOWERMENT	PSYCHOLOGICAL
		LOW	HIGH
HEALTH LITERACY	LOW	HIGH-NEEDS PATIENT	DANGEROUS SELF-MANAGER
	HIGH	NEEDLESSLY DEPENDENT PATIENT	EFFECTIVE SELF-MANAGER

4. DIMENSIONS OF PATIENT EMPOWERMENT

- **MEANINGFULNESS:** importance of managing one's disease
- **COMPETENCE:** skills for management of one's disease
- **SELF-DETERMINATION:** autonomy in management of one's disease
- **IMPACT:** control over outcomes of disease management

4. HEALTH EMPOWERMENT MODEL (SCHULZ & NAKAMOTO, 2013)



5. HEALTH LITERACY MEASUREMENT TOOLS

- **WORD RECOGNITION TESTS**
 - Wide Range Achievement Test (WRAT)
 - Medical Achievement Reading Test (MART)
 - Rapid Estimate of Adult Literacy in Medicine (REALM)
- **READING COMPREHENSION AND NUMERACY TESTS**
 - Newest Vital Sign (NVS)
 - Test of Functional Health Literacy in Adults (TOFHLA)
- **HEALTH LITERACY SCREENING QUESTIONS**

5. HEALTH LITERACY MEASUREMENT TOOLS: REALM

RAPID ESTIMATE OF ADULT LITERACY IN MEDICINE (REALM)

- Word recognition test:
 - Long version : 125 items (3-5 min.)
 - Short version : 66 items (1-2 min.)
 - REALM-R: 8 items (1-2 min.)
- Participants are asked to read medical words out loud
- 4 Health Literacy levels based on total score

Medscape®		www.medscape.com
Fat	Fatigue	Allergic
Flu	Pelvic	Menstrual
Pill	Jaundice	Testicle
Dose	Infection	Colitis
Eye	Exercise	Emergency
Stress	Behavior	Medication
Smear	Prescription	Occupation
Nerves	Notify	Sexually
Germs	Gallbladder	Alcoholism
Meals	Calories	Irritation
Disease	Depression	Constipation
Cancer	Miscarriage	Gonorrhea
Caffeine	Pregnancy	Inflammatory
Attack	Arthritis	Diabetes
Kidney	Nutrition	Hepatitis
Hormones	Menopause	Antibiotics
Herpes	Appendix	Diagnosis
Seizure	Abnormal	Potassium
Bowel	Syphilis	Anemia
Asthma	Hemorrhoids	Obesity
Rectal	Nausea	Osteoporosis
Incest	Directed	Impetigo

5. HEALTH LITERACY MEASUREMENT TOOLS: NVS

NEWEST VITAL SIGN (NVS)

- Comprehension of a nutrition label from an ice cream container
- 6 questions used for assessment (3 min.)
- Available in English and Spanish

Medscape® www.medscape.com

Nutrition Facts			
Serving Size			½ cup
Servings per container			4
Amount per serving			
Calories	250	Fat Cal	120
			%DV
Total Fat	13g		20%
Sat Fat	9g		40%
Cholesterol	28mg		12%
Sodium	55mg		2%
Total Carbohydrate	30g		12%
Dietary Fiber	2g		
Sugars	23g		
Protein	4g		8%

*Percentage Daily Values (DV) are based on a 2,000 calorie diet. Your daily values may be higher or lower depending on your calorie needs.

Ingredients: Cream, Skim Milk, Liquid Sugar, Water, Egg Yolks, Brown Sugar, Milkfat, Peanut Oil, Sugar, Butter, Salt, Carrageenan, Vanilla Extract.

5. HEALTH LITERACY MEASUREMENT TOOLS: SCREENING QUESTIONS

564

Chew et al.: Validation of Screening Questions for Limited Health Literacy

JGIM

Table 2. Areas Under the Receiver Operating Characteristic Curve and 95% CI for the Health Literacy Screening Questions (N=1,796)

Screening Questions	S-TOFHLA		REALM	
	Health Literacy		Health Literacy	
	Inadequate	Inadequate or Marginal	Inadequate	Inadequate or Marginal
	(N=123)	(N=255)	(N=75)	(N=381)
How confident are you filling out forms by yourself? ("Confident with Forms")	0.74 (0.69–0.79)	0.72 (0.69–0.76)	0.84 (0.79–0.89)	0.71 (0.68–0.74)
How often do you have someone help you read hospital materials? ("Help Read")	0.67 (0.62–0.72)	0.63 (0.59–0.66)	0.72 (0.67–0.79)	0.62 (0.60–0.65)
How often do you have problems learning about your medical condition because of difficulty reading hospital materials? ("Problems Reading")	0.66 (0.61 – 0.71)	0.63 (0.61–0.67)	0.72 (0.65–0.78)	0.63 (0.60–0.66)

(Chew et al., 2004, 2008)

5. HEALTH LITERACY MEASUREMENT TOOLS: HLS-EU

EUROPEAN HEALTH LITERACY SURVEY (HLS-EU)

- 12 dimensions, 47 items
- Tested in 8 European countries
- Perceived Health Literacy measure

HLS-EU-Q47

© HLS-EU Consortium

Item no.	Relation to HLS-EU matrix	On a scale from very easy to very difficult, how easy would you say it is to: ...	1 Very difficult	2 Difficult	3 Easy	4 Very easy	5 (Don't know - to be used by interviewer only)
1	Healthcare/ Access information	find information about symptoms of illnesses that concern you?					
2	Healthcare/ Access information	find information on treatments of illnesses that concern you?					
3	Healthcare/ Access information	find out what to do in case of a medical emergency?					
4	Healthcare/ Access information	find out where to get professional help when you are ill?					
5	Healthcare/ Understand information	understand what your doctor says to you?					
6	Healthcare/ Understand information	understand the leaflets that come with your medicine?					
7	Healthcare/						

5. HEALTH LITERACY MEASUREMENT TOOLS: S-TOFHLA

YOUR DOCTOR HAS SENT YOU TO HAVE A _____ X-RAY (A1).

- a) *stomach*
- b) *diabetes*
- c) *stitches*
- d) *germs*

5. HEALTH LITERACY MEASUREMENT TOOLS: S-TOFHLA

YOU MUST HAVE AN _____STOMACH (A2) WHEN YOU COME FOR_____(A3).

- a. asthma*
- b. empty*
- c. incest*
- d. anemia*

- a. is*
- b. am*
- c. If*
- d. It*

5. HEALTH LITERACY MEASUREMENT TOOLS: S-TOFHLA

THE X-RAY WILL _____ (A4) FROM ONE TO THREE _____ (A5).

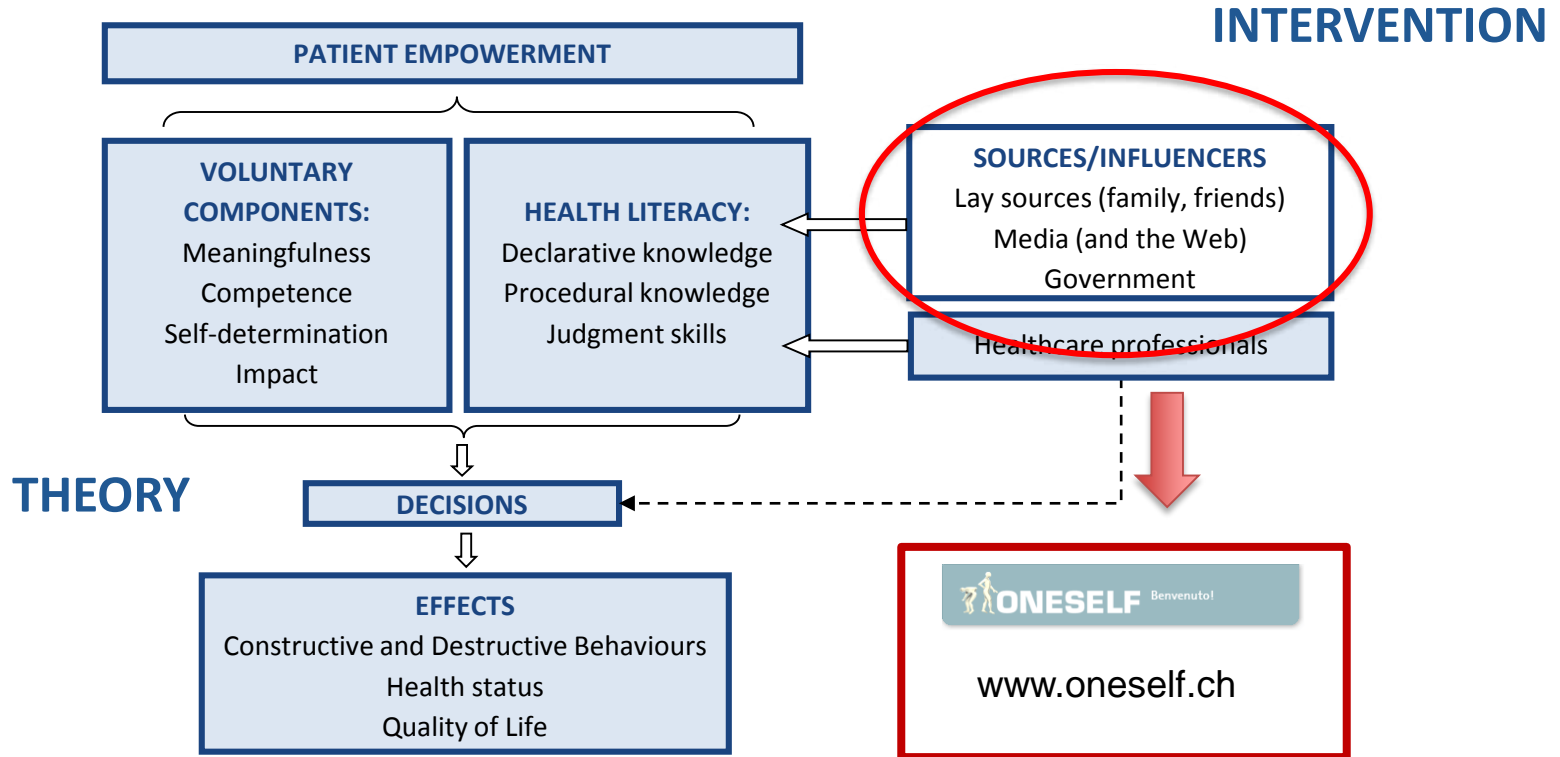
- a. take*
- b. view*
- c. talk*
- d. look*

- a. beds*
- b. brains*
- c. hours*
- d. diets*

6. CAN WEB-BASED RESOURCES IMPROVE HEALTH LITERACY AND INCREASE PATIENT EMPOWERMENT?



6. CAN WEB-BASED RESOURCES IMPROVE HEALTH LITERACY AND INCREASE PATIENT EMPOWERMENT?



ONESELF

WELCOME TO  **ONESELF**

www.oneself.ch

PHYSICIANS

SEE ALSO

- Area: Back pain
- Area: Fibromyalgia
- Link
- Contact the newsroom
- Contact the Ticino League Against Rheumatism

WELCOME TO ONESELF. CHOOSE YOUR AREA



AREA
BACK PAIN

ENTER



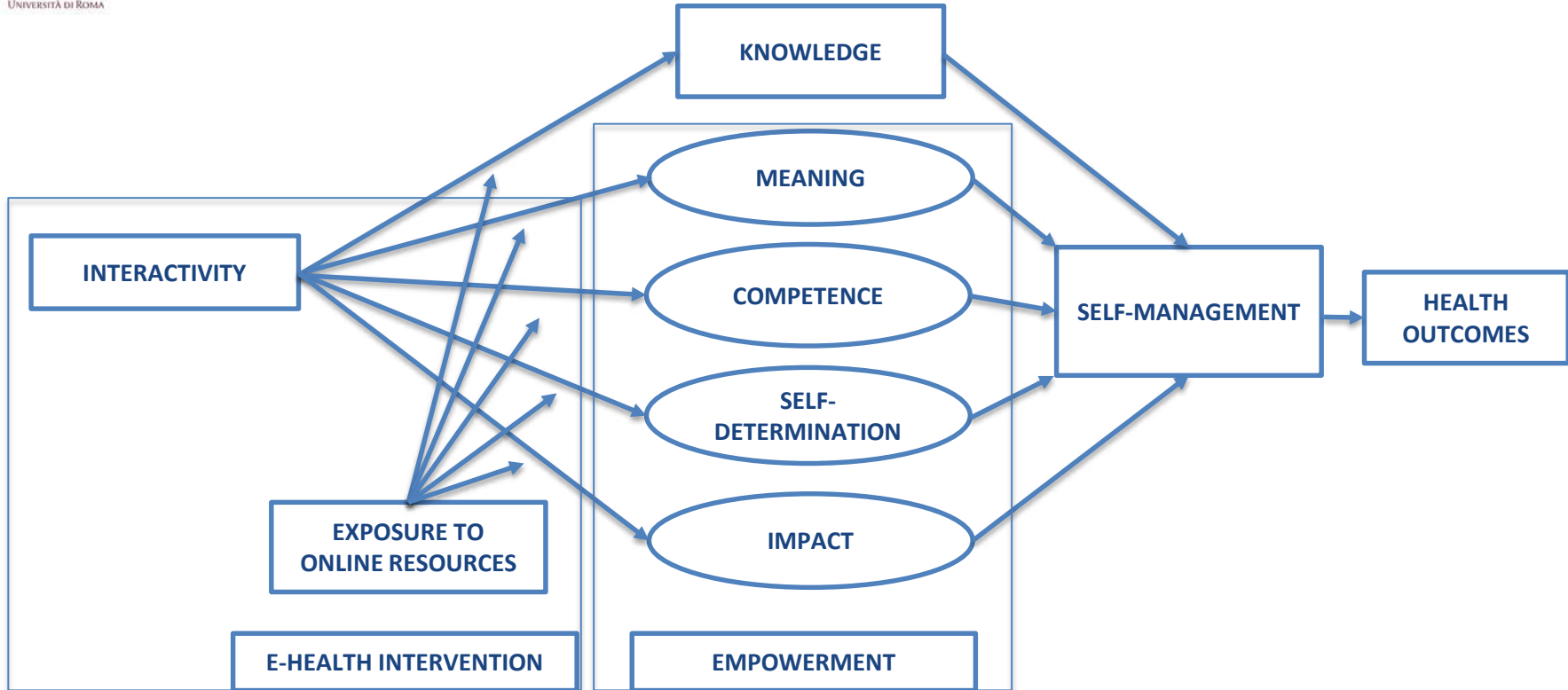
AREA
FIBROMYALGIA

ENTER

6. IMPLEMENTATION OF THE HEALTH LITERACY MODEL

SECTIONS	HEALTH	LITERACY	LEVELS
	Declarative knowledge	Procedural knowledge	Integration with life and goals
Radio	X		
Library	X	X	
Virtual Gym		X	
Web Forum			X
Chat room			X
Answers from medical experts			X
Patient stories			X

6. EFFECTS OF E-HEALTH INTERVENTIONS ON HEALTH LITERACY AND EMPOWERMENT



6. METHODS

EXPERIMENTAL STUDY

- 165 patients with fibromyalgia syndrome (FMS) were randomised into 3 groups:
- Group 1: patients who were given a static version of ONESELF (control group)
- Group 2: patients who were given an interactive-only version of ONESELF
- Group 3: patients who were given the full version of ONESELF
- These patients had a pre-test and a post-test after 5 months of web navigation

CROSS-SECTIONAL STUDY

- 209 patients who had registered on ONESELF were asked to fill out a questionnaire
- The cross-sectional study was conducted 5 months after the end of the experimental study

*“I expect you all to be independent, innovative,
critical thinkers who will do exactly as I say!”*



*“I expect you all to be independent, innovative,
critical thinkers who will do exactly as I say!”*

6. THE INTERNET AND HEALTH LITERACY LIMITS

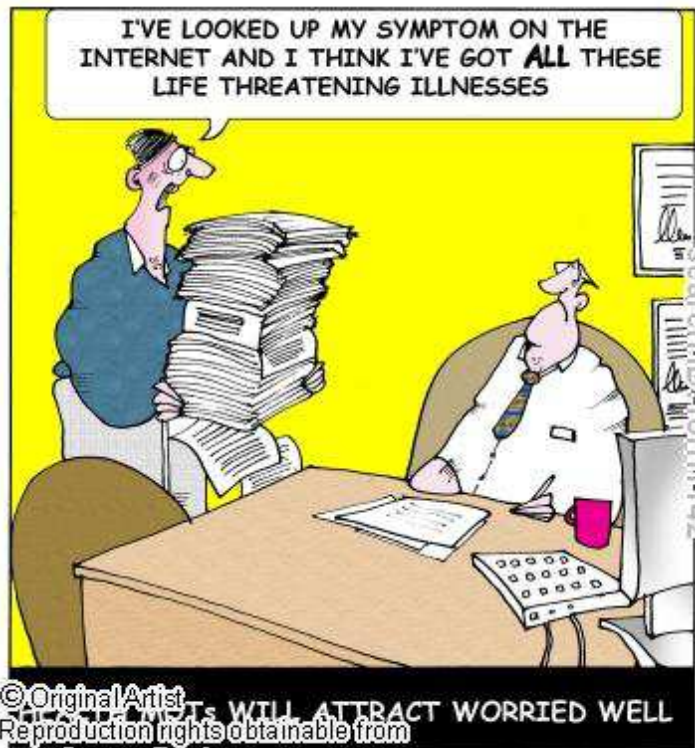
- Information which is available on the internet helps patients and consumers make decisions about their health
- Even when of good quality, the information provided is not universal nor tailored to the individual patient
- Medications are not indicated for all patients, and even when they are, they do not have the same efficacy in all patients
- The information given does not reflect the likelihood of efficacy in individual patients

6. THE INTERNET AND PATIENT COMPETENCE

- Patients have competence with respect to their specific symptoms, experience and health goals
- Issues arise when patients receive information whose reliability they are unable to determine
- The web is not well-designed to support patient choices: its flexibility makes it a dangerous tool
- When searching the internet, people are driven by their preferences, wishes and predilections, and this may lead patients to built their knowledge around their wishes rather than based on reality

6. THE INTERNET AND PATIENT EMPOWERMENT

- Need: searching websites that set out criteria to be used when making health decisions rather than websites that deceptively claim to support users in making their health decisions
- Example: medication description. Information should include details about:
 - reasons for treating a certain condition with medications or other measures (e.g. diet, exercise)
 - reasons for prescribing certain types of medicines
 - reasons for choosing a specific medicine
- Avoid easy choices, easy choices can be harmful



6. USER SEARCHES: 'BAD' LITERACY AND DIRECTED WEB NAVIGATION

- Experiment to determine the effects of quality vs. biased information found online
- Subject: knowledge, beliefs and behaviours regarding immunisation (MMR)
- Three groups:
 - (1) standard Google;
 - (2) Google configured to yield only quality information from websites meeting HONcode criteria (<http://www.hon.ch/HONcode/Patients/>) as search results;
 - (3) Google configured to yield only web pages featuring anti-immunisation arguments as search results
- Pre/post-test design, experiment conducted in 39 students who were given 12 minutes for their online searches
- Measures: trust, knowledge, attitude, perceived information quality and bias

6. USER SEARCHES: 'BAD' LITERACY AND DIRECTED WEB NAVIGATION

- Students whose web searches were directed to yield good quality web pages (group 2) learned more...
- ... and judged the importance of vaccination and the effectiveness of immunisation against swine flu more highly than the other groups did
- Students whose web searches were directed to yield biased, anti-vaccination web pages (group 3) became more worried about the side effects of immunisation and more convinced it is harmful compared to the other groups

EXPERIMENT 1 RESULTS

- Knowledge significantly increased in group 2 (good quality pro-immunisation websites, $p < .03$), and did not increase in groups 1 and 3. No difference was found compared to pre-test knowledge, $H(2) = 4.02$, $p = .13$
- Attitude:
 - Group 2 (good quality websites) showed significantly increased recognition of the importance of flu vaccination in adults ($z = -2.326$, $p < 0.02$) and of the effectiveness of immunisation against swine flu ($z = -2.230$, $p < .03$)
 - Group 3 (poor quality anti-immunisation websites) showed increased concern about the side effects of vaccination in adults ($z = -2.582$, $p < .01$) and increased belief that vaccination causes more harm than good ($z = -2.200$, $p < .02$)

EXPERIMENT 1 RESULTS (CONTINUED)

ONE-WAY ANOVA AND KRUSKAL WALLIS TESTS SHOWED NO DIFFERENCE AMONG THE THREE GROUPS IN TERMS OF:

- Trust in information found ($F(2,36)=1.83, p=.17$) ($\chi^2=2.54, p=.28$),
- Satisfaction with information found ($F(2,36)=1.84, p=.17$) ($\chi^2=1.21, p=.54$),
- Persuasiveness of information ($F(2,36)=0.99, p=.38$) ($\chi^2=0.76, p=.68$),
- Relevance of information ($F(2,36)=2.97, p=.06$) ($\chi^2=5.44, p=.06$)
- Trust in Google ($F(2,36)=3.07, p=.06$) ($\chi^2=4.20, p=.12$)

EXPERIMENT 2

- Hypothesis: the greater the share of anti-vaccination web pages yielded as web search results the more critical and wary of vaccination users become
- 5 experimental groups + 1 control group. Changes in the ratio of pro-vaccination to anti-vaccination web pages yielded as web search results (0:10, 4:6, 6:4, 8:2, 10:0)
- Experiment conducted on Mturk, (n =197). Mean age=37.3 years (SD 11.4).
- Measures: persuasion, 9 items; socio-demographic items (as in Experiment 1)

7. FUTURE HEALTH LITERACY INTERVENTIONS

- Enhancing written materials (Patient Information Toolkit: www.nhsidentity.nhs.uk/patientinformationtoolkit)
- Using videos as educational material to improve Health Literacy
- Web-based interventions? Mixed evidence (Cortner 2006)
- Training of healthcare professionals to address low health literacy among patients (Coleman et al. 2013)
- Initiatives to tackle low literacy: the California Health Literacy Initiative (CHLI), a resource centre for health literacy information and training (<http://cahealthliteracy.org>)
- Media campaigns

7. FUTURE HEALTH LITERACY INTERVENTIONS

- Three goals:
 - providing patients with appropriate, current information materials to improve their knowledge, skills and behaviour and enable them to make informed choices about their health
 - encouraging an appropriate, effective use of healthcare services, including expansion of disease prevention and screening programs
 - fighting inequalities in health and access to healthcare through targeted information and health literacy efforts directed especially to those who are most disadvantaged and hard to reach

7. PRODUCING APPROPRIATE MATERIALS

- Engage patients in the development and assessment of health information materials
- Prior to preparing information materials, consider the information needs of the intended audience; if possible, provide tailored information of interest to individual patients
- Write information using clear language and in a way that is appropriate to the readability level of the intended audience
- Provide accurate, unbiased, evidence-based information using language that does not cause alarm and is not patronising; use active voice
- Avoid using needlessly long words, jargon and acronyms
- If possible, use diagrams and other visuals

7. PRODUCING APPROPRIATE MATERIALS

- Present information clearly and in small blocks of text; Q&As, underlining, bulleted or numbered points help break down long texts
- Include date of publication so that readers can know if the information is current
- Provide a list of contacts patients can turn to for information should they need it
- Provide information from multiple sources and through multiple channels
- Time is crucial for effectiveness of information communication; keep in mind that patient needs change during the course of a disease

8. DISCUSSION

EXISTING HEALTH LITERACY MEASURES:

- lack cultural sensitivity and may be relevant only to certain populations
- are limited to assessment of skills
- are not theory-informed
- are not consistently applied
- have not undergone rigorous psychometric testing

8. DISCUSSION

Health Literacy Universal Precautions Toolkit



Ask
Me³

Good Questions
for Your
Good Health

 NPSF
National Patient Safety Foundation®


8. DISCUSSION



HEALTH LITERACY IN ORDER TO:

- Identify important information
- Communicate with the healthcare community
- Understand and fight against diseases, etc.

8. DISCUSSION



Why should
we tackle it?

ONCE WE HAVE CLEAR WHAT PEOPLE UNDERSTAND AND DO NOT UNDERSTAND, WE CAN:

- Create adequate communication materials
- Identify the most appropriate communication strategy
- Structure interventions that improve knowledge and bridge gaps
- Possibly communicate more effectively

→TAILORING TO THE INTENDED AUDIENCE IS NEEDED