

Between the humanities and health sciences: Health literacy and patients' empowerment.

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Health Literacy

... “is the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.” (Healthy People 2010)

Identification and selection of literacy domains

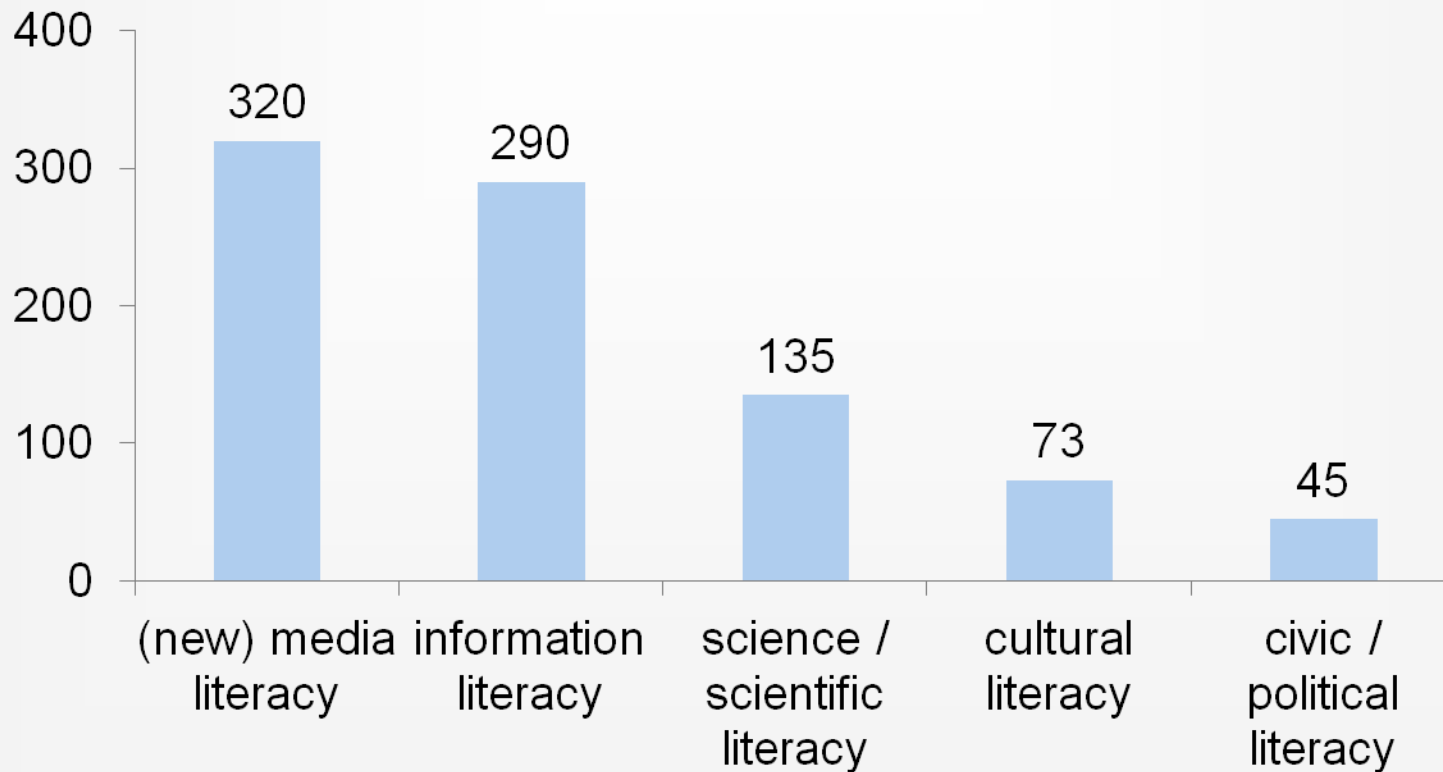
biological literacy	environmental literacy	multimedia literacy
civic literacy	family literacy	new media literacy
climate literacy	financial literacy	network literacy
computer literacy	health literacy	organizational literacy
consumer literacy	information literacy	political literacy
cultural literacy	internet literacy	religious literacy
dance literacy	legal literacy	science/scientific literacy
digital literacy	linguistic literacy	statistical literacy
ecological literacy	media literacy	technological literacy
economic literacy	multicultural literacy	television literacy

Literature review

- **Databases:** Pubmed, PsycINFO, Communication & Mass Media Complete, CINAHL, SAGE Full-Text Collection, Cochrane Library, GoogleScholar, GoogleBooks
- **Keywords:** “*kind of* literacy” together with “theory”, or “measurement”, or “model”, or “review” (where “*kind of*” was replaced with literacy domain)
- **Inclusion criteria:** English language; up to February 2010

Camerini A.L. et al., 2011

Results: Number of unique references*



* excluded are results from GoogleScholar and GoogleBooks

Results: Dimensions included in concepts of other literacy domains

	(new) media literacy	information literacy	science/ scientific literacy	cultural literacy	civic/ political literacy
functional literacy	X	X	X	X	X
factual knowledge	X	X	X	X	X
procedural knowledge	X	X	X		X
awareness	X	X	X	X	X
critical dimension	X	X			
affective dimension		X		X	
attitudes		X	X		X

Health Literacy

... “is the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.” (Healthy People 2010)

Definition of Health Literacy

... “is the degree to which individuals have the capacity to obtain, process, and understand **basic** health information and **services** needed to make **appropriate** health decisions.” Healthy People 2010, Institute of Medicine (2004)

What are **basic** health information?

How about '**skills**' instead of 'services'?

Why not '**informed**' instead of 'appropriate' health decisions?

Why does health literacy matter?



Literacy and Health Outcomes

Health Outcomes/Services

- General health Status
- Hospitalization & Rehospitalization
- Emergency department use
- Asthma Control
- COPD
- Depression
- Diabetes control*
- HIV control*
- Prostate cancer stage
- Mammography*
- Pap smear
- Pneumococcal immunization
- Influenza immunization
- STD screening
- Cost
- Mortality

Behaviors

- Substance abuse
- Breastfeeding
- Behavioral problems
- Adherence to medication*
- Smoking*
- Consent Process
- End-of-life decision making

Knowledge

- Birth control
- Pap screening
- Emergency department instructions
- Asthma
- Hypertension
- Diabetes
- And many more

Towards new concepts of Health Literacy

Consensus among scientists and policy makers:

- Health literacy is more than functional literacy (reading, writing, and numeracy skills) in the health domain.
- There is a need for validated measurements to reflect the extended conceptualizations of health literacy. (e.g. Mancuso 2009)

Health Literacy – a topic also in Europe?

- Several HL studies, including Switzerland – based on measurements different from S-TOFHLA or REALM
- Recently, validation studies of S-TOFHLA in German, French and Italian (Connor, Mantwill & Schulz, 2012) and in Dutch (PEC forthcoming). Also in the UK (von Wagner et al., 2007) and Serbia.
- So far, no direct comparison possible with results from the U.S.

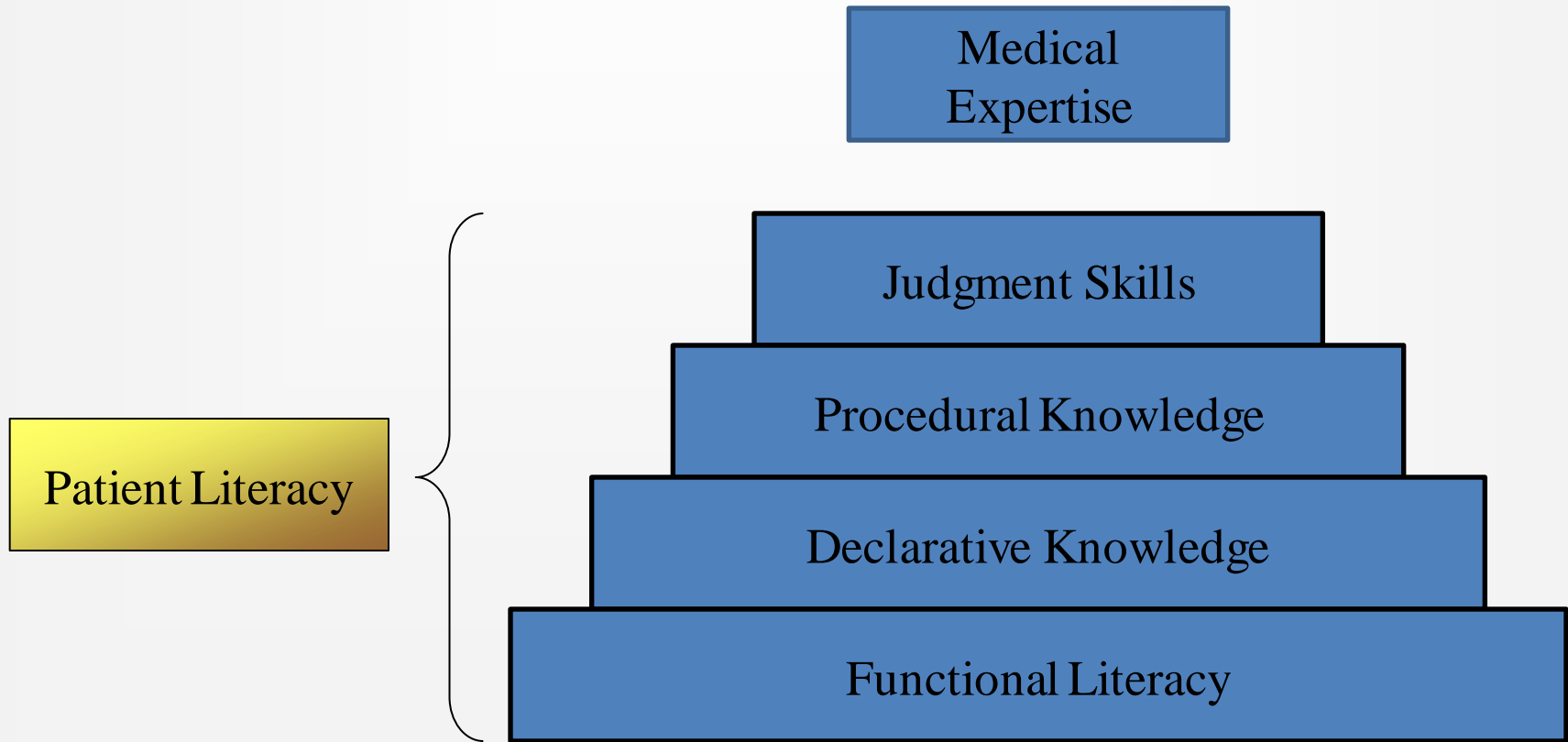
Expanding the concept of Health Literacy

What type of information does the patient need to build his health literacy?

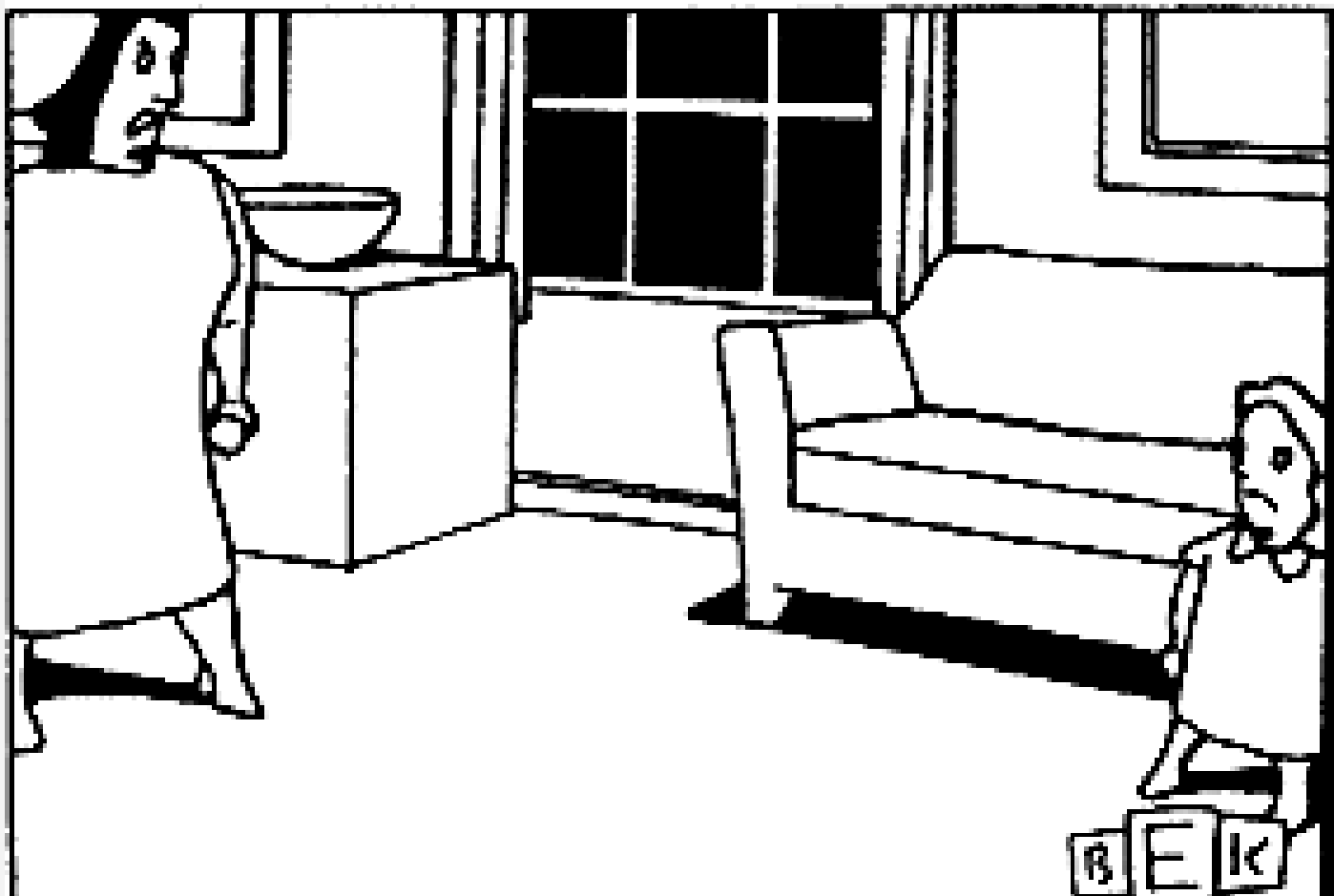
- **Declarative knowledge** (knowledge of the what) e.g. explanation of what a certain condition is (use of antibiotics)
- **Procedural knowledge** (knowledge of the how) e.g. how to maintain a healthy bodyweight through calorie restriction and exercise;
- **Judgment skills**: the ability to relate knowledge to her goals, particularly in novel situations (e.g. self-medication)

Broader concept of Health Literacy

Schulz & Nakamoto
2005



Limits of Health Literacy



“Someday, you’ll act like you understand.”

Patients' empowerment

Three views on empowerment

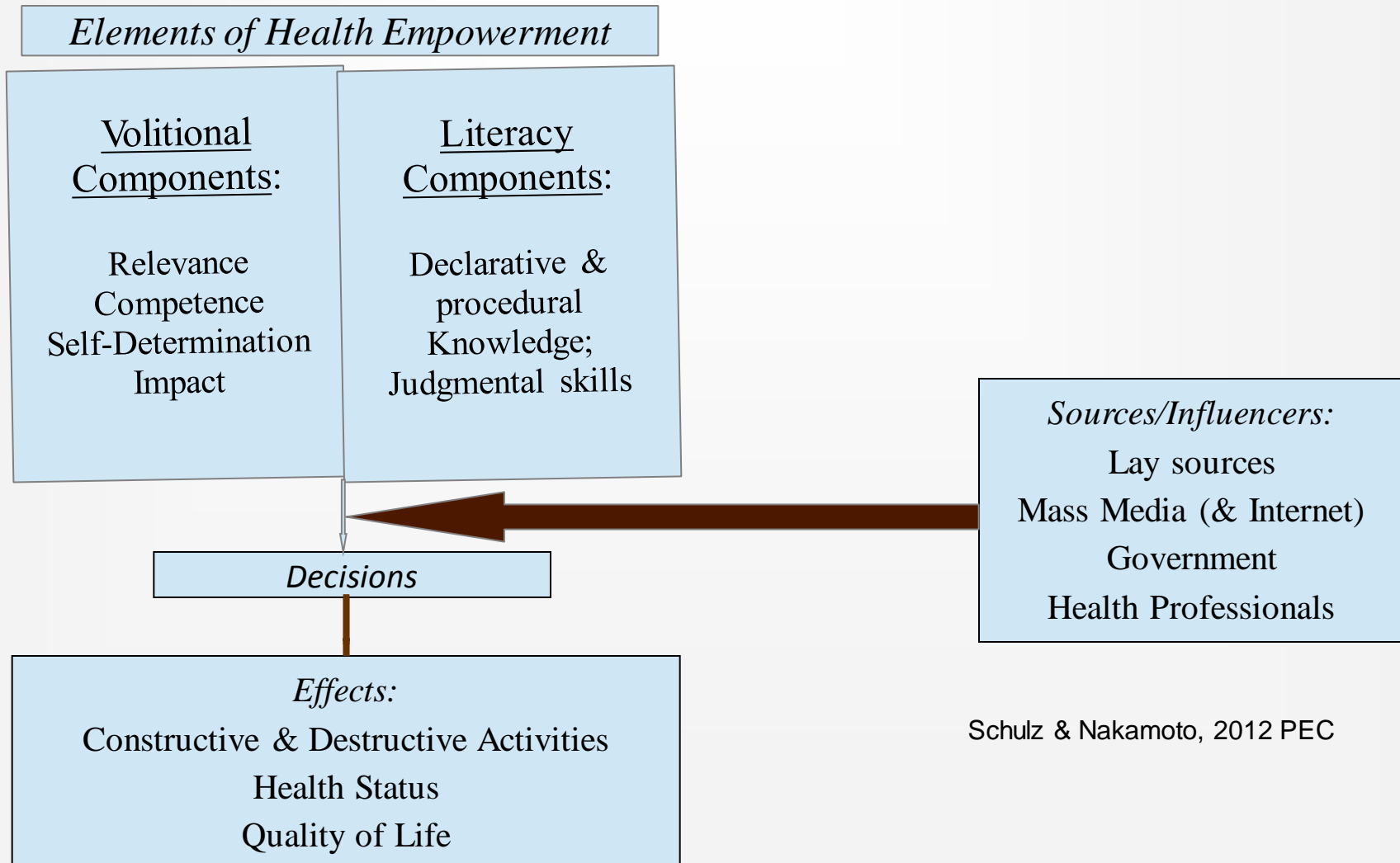
1. Normative view: through more egalitarian structures and a better distribution of power patients will increase their participation (Bhopal and White 1993; Sherwin 1992)
2. Health policy view: patients' empowerment will help to control healthcare costs (Neuhauser, 2003)
3. Medical view: Empowering patients will lead to better health outcomes (Edwards, Davies, and Edwards 2008).

Dimensions of patients' empowerment

- **Meaningfulness:** relevance of managing one's disease
- **Competence:** sense of competence to manage one's disease
- **Self-determination:** sense of autonomy to manage one's disease
- **Impact:** sense of control over the outcome of disease management

(Based on Thomas & Velthouse, 1990; Spreitzer, 1995)

Health Literacy & Empowerment

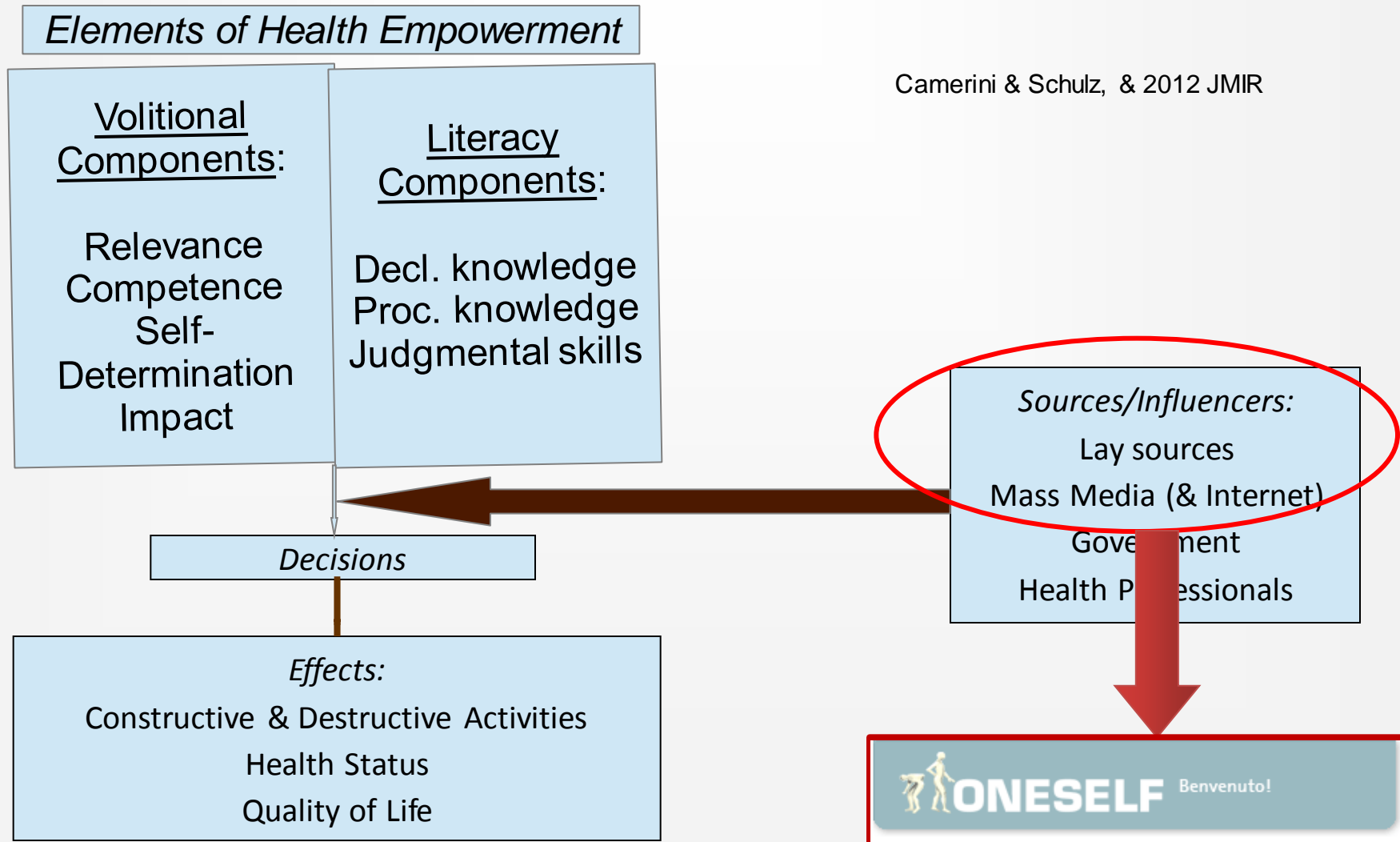


Can web-support increase the level of health literacy and empowerment?



The poor diabetic website, 2011

Health Literacy & Empowerment



Camerini & Schulz, & 2012 JMIR

 **ONESelf** Benvenuto!

Area medici

Vedi anche

- » Area: mal di schiena
- » Area: fibromialgia
- » Link
- » Contatta la redazione
- » Contatta la Lega ticinese per la lotta contro il reumatismo

Benvenuto in Oneself! Scegli la tua area:

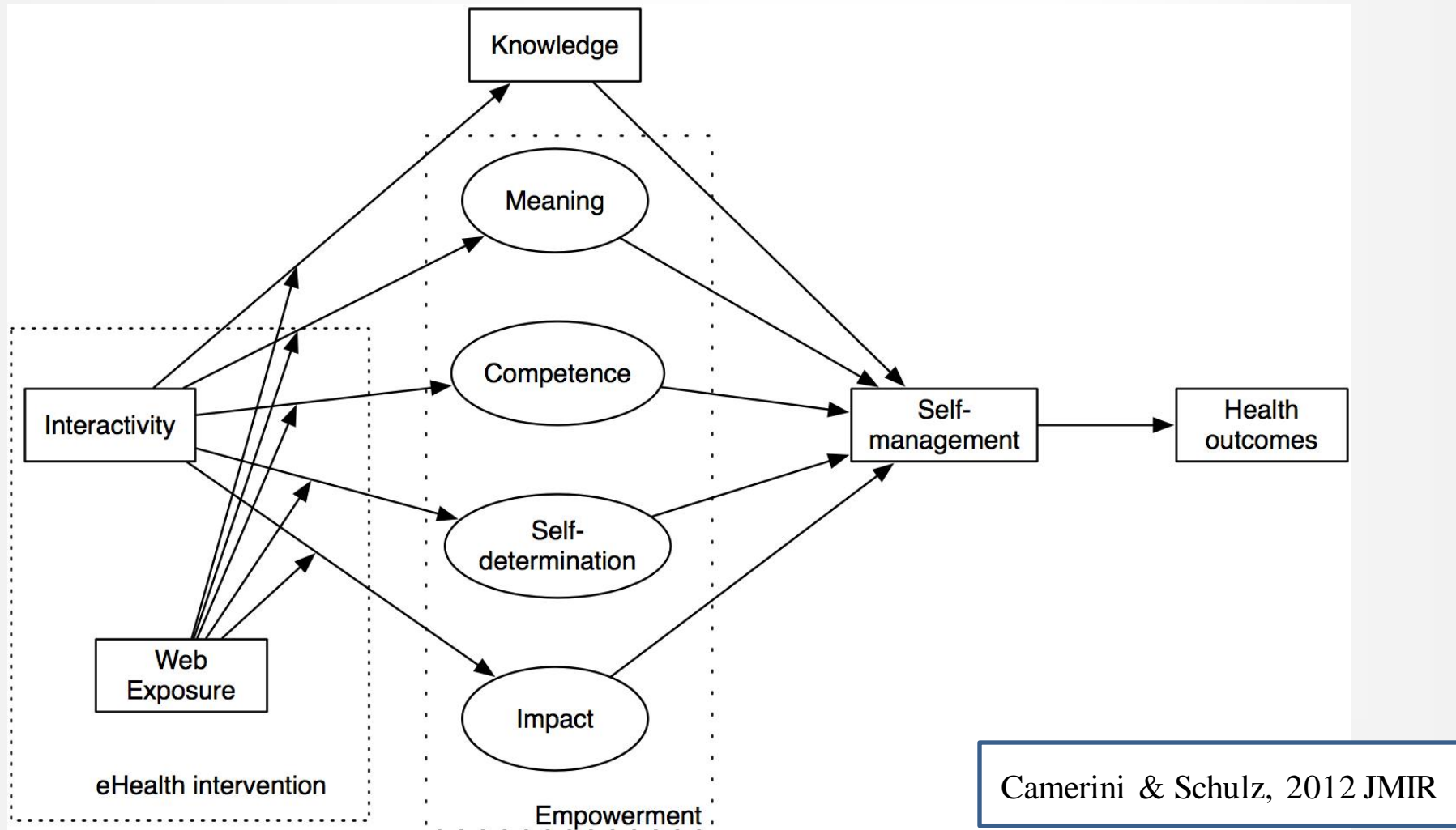
 **ONESelf** Area tematica
Mal di schiena **Entra**

 **ONESelf** Area tematica
Fibromialgia **Entra**

HL model implementation

Sections	Health literacy levels		
	Declarative knowledge	Procedural knowledge	Integration with existence and goals
Radio	x		
Library	x	x	
Gym		x	
Forum			x
Chat			x
The Specialist Answers			x
Tell-a-Story			x

eHealth effects on Health Literacy & Empowerment



Methods

Experimental study:

165 FMS patients were randomized in 3 groups/conditions:

Group 1: patients were provided with a static version of ONESELF (baseline)

Group 2: patients were provided with an interactive-only version of ONESELF

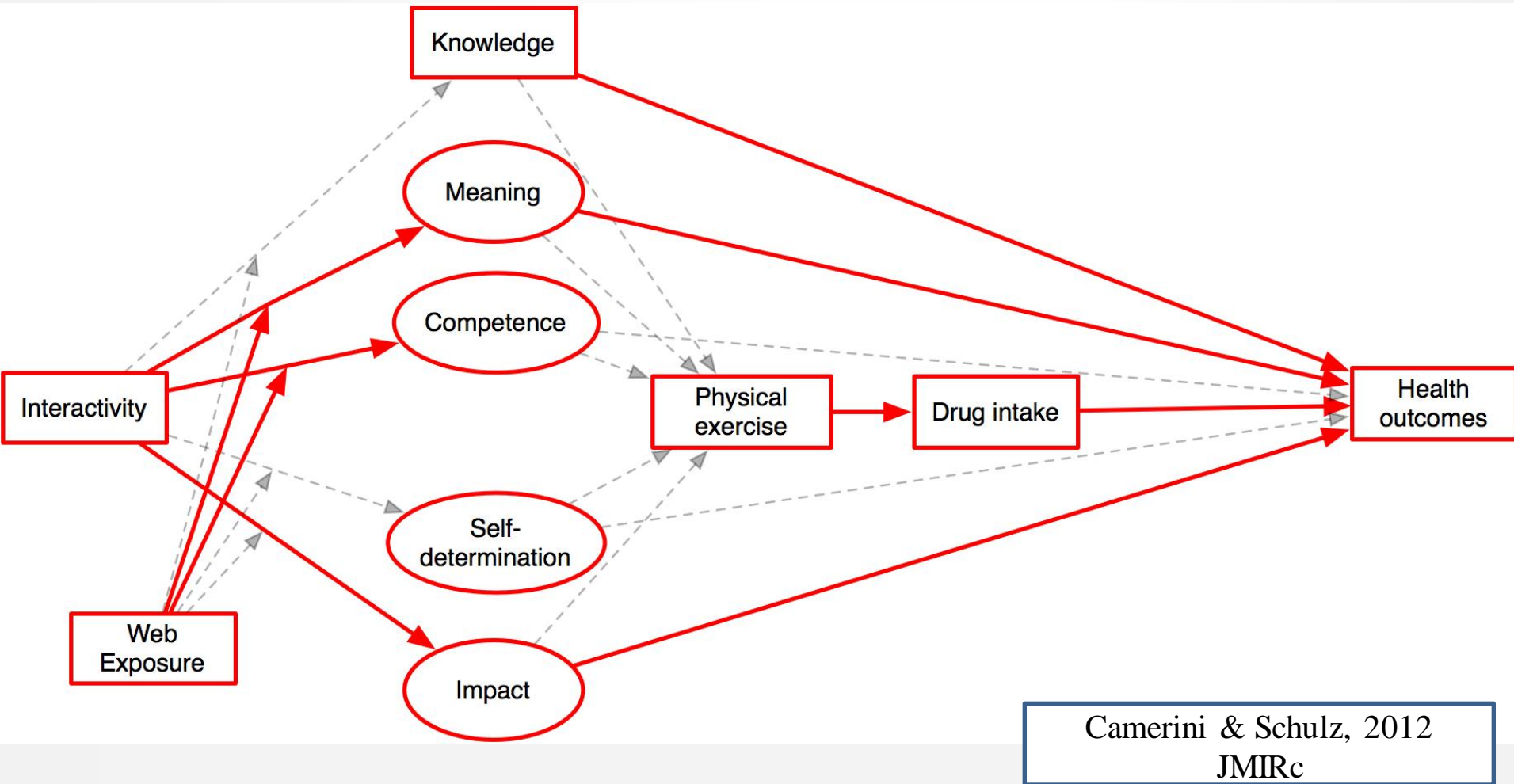
Group 3: patients were provided with the full-fledged version of ONESELF

They completed a pre-test and a post-test after 5 months of navigation.

Cross-sectional study

- 209 patients registered to ONESELF were recruited and asked to complete a cross-sectional survey.
- The cross-sectional study was conducted 5 months after the end of the experiment.

eHealth effects on Health Literacy & Empowerment



Direct effects of the eHealth intervention

- Strongest impact of the eHealth intervention was on the empowerment dimensions of meaning, competence, and impact.
- Knowledge and self-determination were not affected. This is likely due to the specific patients involved in the study:
 - FMS patients in the sample had been suffering for 6 years on average.
 - FMS is regarded as a fatality rather than as a causally predictable event.



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

Internet and the Limits of Health Literacy

Empowerment raises the problem of patient action based on:

- . Insufficient information
- . Inaccurate information
- . Misuse of information

Internet and the Limits of Health Literacy

- Available information on the Internet assists patients and consumers in making healthcare decisions.
- Even if the information is of high quality: it is neither universal (e.g. most side effects are rare) nor is it tailored to the patient.
- Medications are not suitable for all patients; even when they are, they will not be effective for all patients.
- Information lacks any calibration of probabilities of effectiveness etc. to specific patients.

The importance of background knowledge

- The utility of health information depends on the recipient's background knowledge that is necessary for understanding the new information and evaluating it adequately.
- Background knowledge is:
 - a form of non-declarative knowledge,
 - a form of individual dispositions such as experience specific to a field
 - necessary to assess situations adequately
 - required because related information has to be understood and considered in behavioral decisions.
- Information placed before a different background knowledge (physician versus patient) has a different impact.

Patients' expertise and the Internet

- Patient's unique expertise is in the specifics of their symptoms, their experience of the health condition, and their health goals.
- A problem arises when a patient receives information that she cannot assess adequately.
- The Internet is ill-constituted as a decision support for the patient: its flexibility makes it dangerous.
- The patient's own preferences, wishes, and predilections will govern information search: this might lead a patient to build a knowledge structure oriented to their wishes rather than reality.

Literacy, empowerment, and Patient Behavior

		Psychological Empowerment	
		Low	High
Health Literacy	Low	High-needs Patient	Dangerous Self-manager
	High	Needlessly Dependent Patient	Effective Self-manager

Concluding remarks

- Health Literacy – a topic that requires research in humanities as well as in social sciences
- Broader concept: the interplay between health literacy and volitional empowerment is critical to patients' autonomy.
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- Two different directions for future research in Health Literacy:
 - (1) Improving information material
 - (2) Focus on the patient as active consumer
- The guided literacy presents new challenges for health professionals and web content providers.

The ICH group



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