Empowering Patients through Information Technologies

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SP169 - Self Engagement, Patient Empowerment and mHealth
patient empowerment

a process where patients are encouraged to think critically and act autonomously

promotes self-regulation, self-management and self-efficacy in order to achieve maximum health and wellness

empowerment: a process by which people, organizations, and communities gain mastery over their affairs
“why” empower

- **sustain** good health and **prevent** health deterioration
  - lifestyle related disease, e.g. cancer, cardiovascular and respiratory chronic disease

- **recognize** early **signs** of disease
  - new disease or disease progression or transition to comorbid situation

- **manage** every day practical issues
  - manage a common, chronic, progressive, costly, health burden at home

- **gain** control and **co-decide** on treatment and disease management options
“who” is to be empowered

- healthy citizens
  - to adopt and sustain a healthy lifestyle and detect disease early
- chronic patients
  - autonomously manage everyday practical issues
  - adhere to therapy and monitoring
  - detect disease progression and transition to comorbidities
- all patients
  - cope with disease
  - co-decide on treatment and disease management

also involved

- family and social environment: to cope and to be able to care
- healthcare providers: to be aware and support when needed
“how”

input data  ➔  processing  ➔  delivery
“how”

input data ➔ processing ➔ delivery

- educational resources for patients
- medical evidence
- quantified self
- personal sensors
- personal health records
- intentions, plans, beliefs, etc.

- data integration
- analytics
- semantics
- predictive systems
- decision support systems

- web pages
- social media
- personal health applications
- ...
so, we have a good grasp of...

the context

- **who**: healthy citizen, chronic patients, all patients, family, healthcare providers
- **why**: prevent, detect, manage, decide

the process:

- **how**: educational content, medical evidence, sensors, personal health and other systems, data integration, semantics analytics, predictive systems, decision support systems, web technologies, mobile devices, smart phones, ...

but, it is still unclear...

the content:

- **what** is to be designed and evaluated in a patient empowerment intervention

Symons’ evaluation onion, Context-Process-Content (Symon 1991 & Pettigrew 1985)
R. Bengoa, Regional Minister for Health and Consumer Affairs for the Basque Country of Spain (2012):

“Suppose I am a patient:

I have 12,000 apps about chronic disease, access to my records and a battery of gadgets for home support.

Am I more empowered?”

The WHO, Empowering Patients, 17-4-2012
patient empowerment so far ...

- cooperate with health professionals
- actively engage in disease self-management

- maintain or improve health
- know how to care for themselves

actively participate in health related decisions
searching PubMed

- patient education
- patient engagement
- patient empowerment

The graph shows the number of published papers per year from 1960 to 2013. The x-axis represents the year of publication, and the y-axis represents the number of published papers per year. The red line indicates the increase in patient education publications, with a notable peak around 2008. The green line represents patient engagement, and the blue line represents patient empowerment. The graph highlights the growing interest in these areas over the years.
empowerment as a cognitive process

empowerment ⇔ control on one’s own actions

↓

complex construct that involves various cognitive processes and skills

 gestures

- knowledge acquisition, through perception
- thinking and learning
- awareness of one’s own current conditions and /or needs
- active participation in the management of the current or future condition and in the relevant decision making

thus, following the overall approach of cognitive psychology...
empowerment as a cognitive process

- understanding: personal health condition awareness
- knowledge: relevant, structured information with a purpose
- information: data and information aggregation

- emotional support
- suitable, supportive physical environment
- enabling technological framework
- feedback mechanisms

- action, participation

- shared decision
- mindchange
- social
- emotional
- cognitive

- control
- engagement
- awareness
awareness: understand own health condition

- combine personal data with generic medical evidence
- ability to realize medical evidence in relation to their personal condition understanding
- semantic linking to produce concept maps of educational data
- visual analytics to simplify complex expert information
- structuring and organizing information with a particular purpose
- links to relevant educational content on on-line educational repositories (MedLinePlus, wikipedia)
- access to information

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## Engagement

### Participation & Action

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control: decision making

collaborative spaces
personal health records
decision support systems

shared decision
control: mind change

modify one’s own mental states, e.g. beliefs, emotions, intentions, and thus achieve and maintain a healthy behavior

- identify motivation, attitude, habits
- design interventions to change first representations then behaviours

requires highly interdisciplinary research

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a case example: empowering the chronic comorbid patient

facts:

- significant increase in the prevalence and incidence of chronic disease
- ½ of all chronic patients present comorbidities
- the chronic patient is mostly an outpatient
  - needs to care for herself at home
  - mainly away from continuous professional care
  - while trying to lead a normal life
cardiorenal disease & comorbidities

some numbers...

- hypertension $\Rightarrow$ 1/3 of adults (US 2008)
- diabetes $\Rightarrow$ 8% of overall population
- chronic kidney disease $\Rightarrow$ 9-16% of overall population
- 44% of chronic kidney disease is due to diabetes
- 86% of chronic kidney disease has at least 1 comorbidity
- most patients with chronic kidney disease develop cardiovascular disease

- chronic heart failure $\Rightarrow$ 1-2% of total healthcare costs
- end-stage renal disease (dialysis) $\Rightarrow$ >2% of total healthcare costs
CARRE
Cardiorenal comorbidity management via empowerment and shared informed decision

FP7-ICT-2013-611140
consortium: 6 partners from 4 EU countries
coordinator: Eleni Kaldoudi (DUTH)
budget: 3,210,470€
http://carre-project.eu/

DUTH
The Open University, UK
Univ. of Bedfordshire
Vilnius Univ. Hospital
Kaunas Univ.
Industrial Research Institute for Automation & Measurements

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CARRE approach

- foster understanding of comorbid condition
- calculate informed comorbidity progression
- compile personalized empowerment services
- support shared informed decision and integrated management
CARRE approach

- Medical evidence aggregation
- Medical evidence
- Evidence based medical literature
- Personal health information
- Social media
- Quantified self

Private data harvesting & interlinking

Public data harvesting & interlinking

Patient empowerment & decision support services

Comorbidity model visualization (generic and personalized)

Intention extraction: G. Drosatos, A. Arampatzis, E. Kaldoudi, IUPESM WC2015
risk factor as a central concept

risk factors derived from clinical studies and reported in medical literature
(top level evidence: systematic reviews with meta-analysis)
risk factor as a central concept

under condition related to observable x

disorder 1 (as a risk factor)

leads to

disorder 2

with a probability y

conceptual model

CARRE ontology published in NCBO BioPortal
http://bioportal.bioontology.org/ontologies/CARRE

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some of the major related conditions

1. Acute kidney injury
2. Acute myocardial infarction
3. Age
4. Albuminuria
5. Anaemia
6. Angina pectoris
7. Asthma
8. Atrial fibrillation
9. Chronic kidney disease
10. Chronic obstructive pulmonary disease
11. Cholelithiasis
12. Colorectal Cancer
13. Coronary and carotid revascularisation
14. Death
15. Depression
16. Diabetes
17. Diabetic nephropathy
18. Drugs
19. Dyslipidemia
20. Family history
21. Heart Failure
22. Hyperkalemia
23. Hypertension
24. Hyperuricemia
25. Hypoglycaemia
26. Ischemic heart disease
27. Ischemic stroke
28. Left ventricular hypertrophy
29. Obesity
30. Obstructive Sleep Apnoea
31. Myocardial infarction
32. Osteoarthritis
33. Pancreatic Cancer
34. Peripheral Arterial Disease
35. Physical activity
36. Smoking
37. ...
Obesity causes diabetes when $23 \leq \text{BMI} \leq 34$ with a risk ratio of 1.61.

Obesity causes heart failure when $25 \leq \text{BMI} \leq 30$ and sex = female with a risk ratio of 2.50.

Obesity causes hypertension when $99.4 \leq \text{Waist Circumference} \leq 106.2$ and sex = male with a risk ratio of 2.50.
hypertension causes chronic renal disease when systolic BB ≥ 140mmHg AND/OR diastolic BB ≥ 90 mmHg

risk ratio = 2.00

smoking causes chronic renal disease when smoking status = current AND sex=male

risk ratio = 2.40

so far... 268 major risk associations (identified in medical literature)
(which involve 45 health conditions and 47 related observables)
as included in the CARRE risk factor database and predictive model
CARRE risk factor database and predictive model
a partial view of the graph...
intuitive presentations for patients

work in progress
interactive risk prediction and planning

- weight
- exercise
- blood pressure
- blood glucose

work in progress
empowerment in CARRE

advanced decision support services and mindchange interventions based on the real-time coupling of medical evidence, personal health status and intentions and beliefs, as deduced from social web data mining

enabling framework:
interactive model to allow planning and a set of alarms to enable patient engagement and give feedback

personalized, interactive risk model of disease progression and transition

generic model of disease progression pathways and comorbidities trajectories, based on current medical evidence
to summarize...

1. health education for the public

2. customization for relevant and meaningful health information

3. medical evidence

- self awareness for engagement & control in health and disease prevention & management

- quantified self

- personal decision support system

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to summarize...

1. general health information for the public
2. customized health information and guidelines for the individual
3. self-awareness for informed decision and control

but, are we still missing out on something?
change of paradigm: making environments work for people

medical evidence

quantified self

personal decision support system

via
descriptions & participatory sensing

health content
of the environment
acknowledgment

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CARRE: Personalized patient empowerment and shared decision support for cardiorenal disease and comorbidities

http://www.carre-project.eu/
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