Patient Empowerment as a Cognitive Process

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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
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 ⇒ 1/3 of adults (US 2008)
- diabetes ⇒ 8% of overall population
- chronic kidney disease ⇒ 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 ⇒ 1-2% of total healthcare costs
- end-stage renal disease (dialysis) ⇒ >2% of total healthcare costs
CARRE

Cardiorenal comorbidity management via empowerment and shared informed decision

FP7-ICT-2013-611140

consortium: 6 partners
4 EU countries


budget: 3,210,470€
CARRE approach

- Foster understanding of comorbid condition
- Calculate informed comorbidity progression
- Compile personalized empowerment services
- Support shared informed decision and integrated management
CARRE methodology

- Dynamic generic and personalized cardiorenal comorbidities model
- Interactive visualization of the model
- Semantically interlinked data from heterogeneous sources
- Data/model driven decision support system

Patient empowerment
so, we have a good grasp of...

the context

◮ who: cardiorenal patients
◮ why: prevent and manage a common, chronic, progressive, costly, health burden

the process:

◮ how: data integration, semantic technologies, visual analytics, decision support systems

but, it is still unclear...

the content:

◮ what is to be designed and evaluated
patient empowerment so far ...

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

education

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

engagement

control

actively participate in health related decisions
searching PubMed

The graph shows the number of published papers per year from 1960 to 2013, categorized by different topics:

- Red line: patient education
- Green line: patient engagement
- Blue line: patient empowerment

The graph highlights a significant increase in publications starting around 2008, with a peak around 2010. There is also a noticeable drop after 2012.
empowerment as a cognitive process

empowerment ⇔ control on one’s own actions

↓

complex construct that involves various cognitive processes and skills

- 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

- communication
- collaboration
- decision support

- shared decision

- control
- engagement
- awareness

- mindchange
  - social
  - emotional
  - cognitive

- action, participation

- cognitive
- emotional
- social

mindchange
awareness: understand own health condition

- information
  - access to information
- knowledge
  - structuring and organizing information with a particular purpose
- understanding
  - ability to realize medical evidence in relation to their personal condition
awareness: understand own health condition

- combine personal data with generic medical evidence
- semantic linking to produce concept maps of educational data
- visual analytics to simplify complex expert information
- links to relevant educational content on on-line educational repositories (MedLinePlus, wikipedia)
engagement

participation & action

- emotional support
  - on-line social networks

- supportive physical environment
  - describe & exploit health content of the physical environment

- enabling technological framework
  - personal sensors and applications
    - smart alerts

- feedback mechanisms
  - feedback to the patient
control: decision making

- communication
- collaboration
- decision support

shared decision

collaborative spaces
personal health records
decision support systems
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
mapping CARRE services to the empowerment model.

<table>
<thead>
<tr>
<th>model level</th>
<th>CARRE service</th>
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</thead>
<tbody>
<tr>
<td><strong>awareness:</strong></td>
<td>provide visual and quantitative model of disease progression pathways and comorbidities trajectories, based on current medical evidence</td>
</tr>
<tr>
<td>information aggregation and knowledge</td>
<td>personalize the risk model to each individual based on his personal medical data and real-time sensor measurement to support disease status awareness</td>
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<tr>
<td><strong>engagement:</strong></td>
<td>use the personalized model in conjunction with real time monitoring to create a set of alarms to enable patient engagement and give feedback</td>
</tr>
<tr>
<td>enabling framework</td>
<td>provide 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</td>
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work in progress

based on the understanding of the “content” (the what”)

- design appropriate evaluation methodology that follows the various levels of the empowerment model

- make informed selection of and/or construct appropriate evaluation tools for each level of the empowerment model

Symons’ evaluation onion
(Symon 1991 & Pettigrew 1985)

context: who, why

process: how

content: what
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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