Patient Empowerment as a Cognitive Process

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Abstract: The concept of patient empowerment has emerged as a new paradigm that can help improve medical outcomes while lowering costs of treatment by facilitating self-directed behavior change. Patient empowerment has gained even more popularity since the 1990's, due to the emergent of eHealth and its focus on putting the patient in the centre of the interest. Current literature provides systematic reviews of the area, and shows that well defined areas (or dimensions) have eventually emerged in the field. In this paper we argue that patient empowerment should be treated formally as a cognitive process. We thus propose a cognitive model that consists of three major levels of increasing complexity and importance: *awareness*, *engagement* and *control*. We also describe the different constituents of each level and their implications for patient empowerment interventions, focusing on interventions based on information and communication technologies. Finally, we discuss the implications of this model for the design and evaluation of patient empowerment interventions.

1 INTRODUCTION

Patient empowerment has emerged as a new paradigm to improve medical outcomes through self-directed behavior change. Conceptually, 'empowerment' relates to (a) the goal of individuals to have control over their quality of life, and (b) the process via which individuals can achieve this goal. Patient empowerment seems particularly promising in the management of chronic diseases (Chatzimarkakis, 2010; Anderson and Funnel, 2010) and is directly connected with personalized patient services, education and preventive measures. The research community accepts that better health outcomes can be achieved by improving a person's ability to understand and manage his or her own health and disease, negotiate with different teams of health professionals, and navigate the complexities of health systems (The Lancet, 2012).

Empowerment appears in many different contexts, always as a cognitive process – that of enhancing the capacity of individuals or groups to make choices and to transform those choices into desired actions and outcomes. For example, human resource management research recognizes empowerment as a cognitive process; studies therein investigate interventions that are designed, developed and assessed following a cognitive model of the empowerment process (Robbins et al, 2002; Thomas and Velthouse, 1990).

In this paper we argue that patient empowerment should be treated as a cognitive process. We also propose a cognitive model and we describe its different constituents and their implications for the design and evaluation of patient empowerment ICT (i.e. information and communication technology) interventions. Finally, we discuss future work to deploy and validate the proposed model.

2 PATIENT EMPOWERMENT

Julian Rappaport (Rappaport, 1987) defined empowerment as *"a process, a mechanism by which people, organizations, and communities gain mastery over their affairs"*. Empowerment, in its most general sense, refers to the ability of humans to gain understanding and control over personal, social, economic and political forces in order to take action to improve their life (Israel et al, 1994). In health science, patient empowerment is understood as an enabling process or outcome (Freire, 1993; McAllister et al, 2012) by which patients are encouraged to autonomous self-regulation, self-

management and self-efficacy in order to achieve maximum health and wellness (Lau, 2002). Empowerment can therefore be described as a process where the purpose of an educational intervention is to increase patients' ability to think critically and act autonomously; while it can also be viewed as an outcome when an enhanced sense of self-efficacy occurs as a result of the process (Anderson and Funnell, 2010).

The concept of patient empowerment has emerged in 1970s in USA and UK as part of the rise of New Right politics (Traynor, 2003). The concept eventually evolved as a new paradigm that can help improve medical outcomes while lowering costs of treatment by facilitating self-directed behavior change. The concept seems particularly promising in the management of chronic diseases (Chatzimarkakis, 2010; Anderson and Funnel, 2010) and it is directly connected with personalized patient services, education and preventive measures. Patient empowerment has gained even more popularity since the 1990's, due to the emergent of eHealth and its focus on putting the patient in the centre of the interest. A recent review (Ajoulat et al, 2007) shows that patient empowerment services mainly aim at educational programs seeking patient reinforcement. Indeed, patient education interventions seem to have taken the lead in the early attempts to strengthen patients. To illustrate this we have searched PubMed database for the term 'patient education'. Figure 1 shows the results (red line), as a plot of number of papers per year for the last five decades. According to this graph, published works on "patient education" first started to appear during the 1960s, following an increasing curve from the mid-70s until 2006, when their yearly numbers started to decline. At the same time, research interest begun to focus on the related concepts of 'patient engagement' and 'patient empowerment'. PubMed searches with these terms (also plotted in Figure 1, with green and blue lines respectively) indicate an increasing research interest, especially during the last decade.

Reviews of the field reveal three basic dimensions of patient empowerment: *education*, *engagement*, and *control* (Ouschan et al, 2000, Unver and Atzori, 2013). Patient *education* is perceived as a set of planned educational activities designed to improve patient health behavior and health status. Its main purpose is to maintain or to improve patient health as well as to train the patient to become able to actively participate in his or her own healthcare treatment by increasing self-efficacy (Bandura, 1977). Patient *engagement* involves two different concepts: cooperation with health providers and an active engagement in managing one's own health status and disease. The *control* dimension refers to the patient's ability to actively participate in strategic decisions about his or her health and disease management.

Although there is a clear distinction between these three dimensions, often empowerment interventions include all three dimensions in their goal and, eventually, in their design. This has obvious implications for the methodology and tools that will be used to evaluate the specific intervention. For example, evaluation of patient education interventions should examine expected outcomes such as: understanding health information; ability to recognize new or warming signs or symptoms of disease progression and transition; and self-satisfaction of being well-informed on the treatment options of his or her condition or disease. The evaluation of interventions targeting patient participation should exam different outcomes such as: the degree of patients' involvement in treatment plans; lifestyle and behaviour changes; and the ability and willingness to share information and feelings. Finally, evaluation of interventions that attempt to increase patient control should take into account outcomes such as confidence in the ability to make decisions about treatment plans, maintaining a personal health record, and other major choices related to health management. Research so far has revealed interdependencies between these dimensions. For instance, Roter and Hall (1992), extensively researched the communication between doctors and patients and have noticed that patient education helped patients gain more control and management of their health, which in turn encourage patients to ask more questions and be more active regarding their health treatment. Moreover, researches revealed that the maintenance of control by obtaining information about health statuses, lead to an increased participation ratio in decision-making regarding treatment (Makoul et al, 1995). Furthermore, DiMatteo et al (1994) conclude that patient education or structural changes to the medical interaction (i.e. doctor and patient co-authoring medical records) have led patients to play. more active roles and develop a greater sense of control of their health and lives. Despite such findings, current literature lacks of a tiered, hierarchical approach towards patient empowerment.
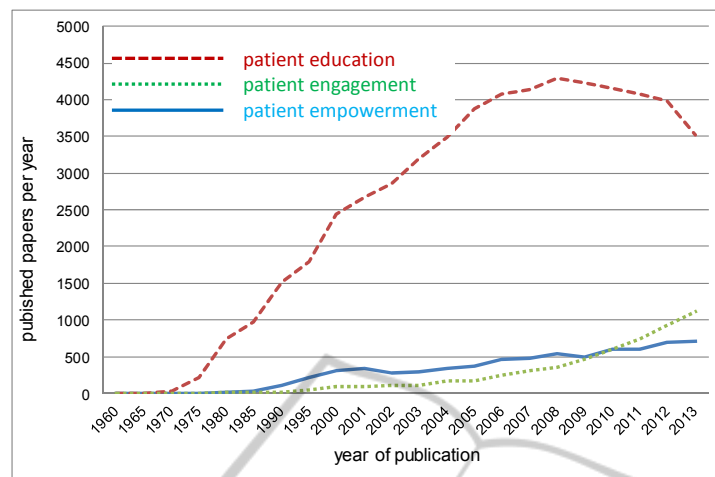
Figure 1: Plot of the PubMed search results for the terms "patient education" (red dashed line), "patient engagement" (green dotted line), and "patient empowerment" (blue compact line). The results of the 3 searches are plotted as number of published papers per year for the year range 1960 to 2013.

3 A COGNITIVE APPROACH TO PATIENT EMPOWERMENT

In its core meaning, empowerment is strongly related to the control on one's own action. In this respect, empowerment could be considered as a complex construct that involves various cognitive processes and skills (Falk-Rafael, 2001). Specifically, some of its basic elements include: 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. (Rappaport, 1984) Following the overall approach of cognitive psychology, we propose to treat patient empowerment in terms of three levels of increasing complexity and importance: awareness, participation and control (Figure 2).

3.1 Awareness

The first and most basic level refers to the complex task of health awareness. The patient (or the healthy citizen in general) should be aware of: his or her own health status; health related risks and lifestyle or environment induced hazards; potential disease progression to more severe stages; potential disease transition to other comorbidities; measures needed to stay healthy and/or prevent disease occurrence, progression or transition.

This level corresponds to the educational dimension as in current literature. However, we believe that it is more appropriate to treat it as a personal awareness of one's own health rather than the process of formal education. This underscores the fact that the patient should clearly understand the implications of the information provided and is able to act upon it. In any case, this level on its own can be viewed as an educational process with three sub-levels of increasing complexity (Davenport and Prusak, 2000): information gathering (i.e. simple facts), knowledge (i.e. information with a purpose), and understanding (i.e. conscious knowledge and achievement of explanation). Supporting access to information is the easiest and most straightforward task for patient empowerment interventions, be it via conventional channels of printed material, or via the nowadays more popular channels based on the internet and even mobile personal devices

Indeed, today there are many authoritative on-line databases that provide education material designed specifically for the patient. One notable example is the effort of the National Library of Medicine USA, who provides also the MedLinePlus (www.nlm.nih.gov/medlineplus/) service for patient information. Another important example is the EUPATI network funded by EU. which is a comprehensive collaborative effort towards educating the patients so that can take active part in their treatment and in the research towards new treatments.

Structuring and organizing information with a particular educational purpose refers to knowledge. Managing and supporting this second level of the
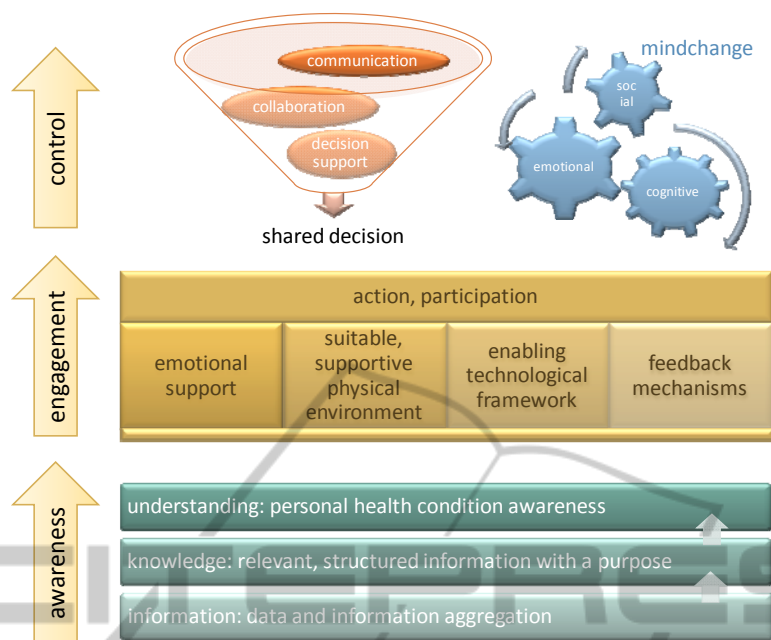
Figure 2: Patient empowerment modelled as a cognitive process. There are three distinct levels of increasing complexity and importance: awareness, engagement and control. Each level presents its own contributing factors.

educational process is a rather complex issue. Semantic eHealth interventions can certainly help by providing relevant semantic medical concept maps that will allow available medical evidence to be presented to the patient within context. Also, advanced visual analytics may offer alternative ways for patients to grasp difficult medical concepts. The final step of understanding relates to the patient's ability to realize his or her personal condition in relation to the medical evidence. This actually means achievement of health awareness. In order to support this, interventions should follow a combined approach of coupling medical knowledge to the personal characteristics of the patient. This personalization most often will require integration of personal health data, real-time biomedical sensor measurements, and data related to lifestyle and behaviour, beliefs and intentions as harvested via semantic analysis of unstructured personal data available in web based social networks.

3.2 Engagement

This second level of patient empowerment strives to achieve patient engagement in the health care process. Here we should emphasize active and proactive participation in managing the disease and its treatment and in preventing disease progression and transition. Successful patient participation can really be achieved only when the patient is health aware. However, this is not the only prerequisite. The patient additionally needs emotional strength, a suitable, supportive physical environment, an enabling framework and last but not least accurate feedback in order to be able to re-adjust participation

Emotional strength can generally be reinforced by easing the communication with health providers and most importantly within social groups. Both can be easily supported by common eHealth interventions that allow an easy and seamless communication with health providers or provide the environment for on-line social support groups. Creating a supportive physical environment may prove more intriguing. As we cannot easily alter physical environments to help patients, we could instead try to alter something equally important: the *perceived* environment. Here, future eHealth interventions should provide the means to identify resources and opportunities the environment already provides, which the patient (or its digital assistant) can exploit to increase the level and quality of participation in disease management. A simplistic example would involve an application that highlights a route within a city suitable for wheelchairs or places that offer salt free foods.

For the patient to be able to participate effectively in personal health management a number of other tools and services often need to be available – these comprise what we call the enabling framework. These may include specialized

equipment and/or digital interventions that provide the necessary prerequisites for the patient to be able to act. Fortunately, nowadays a wealth of such underline technologies are available, ranging from personal wearable health sensors to cloud based personal health applications and dedicated personal assistants. Finally, active participation requires improvement of the self-efficacy (Bandura, 1977). That is, it is necessary for the individual to know her own abilities and skills or to estimate accurately her needs for being able to be engaged in action. One of the most crucial tools for the formation of the self-efficacy is the accurate feedback, positive or negative, for individual's action that is received from the external environment. Only active engagement can be meaningful and effective in fulfilling its aims.

3.3 Control

Control in this context can include two different aspects: decision making and mind changing. Decision making refers to a collaborative process where patient and health professionals discuss and interact to reach a shared decision. A prerequisite for this is the patient to be health aware and also actively involved in her health management. Only then, the patients' participation in decision making should be effective. However, this aspect of control involves extensive communication and collaboration. Both are widely supported by current eHealth applications in a variety of ways, including also advanced collaboration environments and shared digital spaces. Some interesting examples include the emergent technology of personal health records, owned by the patients themselves, who however can give targeted access to their health providers when needed. Also considerable research work is available in the field of medical decision support systems, which can be generally viewed as either (a) the so-called 'strong' artificial intelligence systems whose behaviour is at some level indistinguishable from humans; or (b) an alternative approach that looks at human cognition and decides how it can be supported in complex or difficult situations, something like a form of 'cognitive prosthesis' that will support the human in a task (Coreira, 2003). In any case, shared decision support interventions need to take into account both patients and health professionals and integrate data and events from various sources of personal health data and medical evidence. On the other hand, control of action involves very internal cognitive processes – what we refer to as mind changing, that is the

capacity to modify one's own mental states like beliefs or intentions . This entails the representation of causal determinants of lasting behaviour change from the perspective of the individual, including perceptions, cognitions, and emotions. Together, they describe the personal-level motivational signature of direct goal-seeking behaviour (Piaget, 1976).

This level of empowerment is probably the most demanding, since it is based on highly interdisciplinary research which involves behavioural scientists, psychologists, behaviour simulation and experiments and finally information scientists. Attempts to support mind changing need to take into account individuals' motivations, attitudes and habits, understand them and then design an intervention which is aimed at changing representations first, and then behaviours. Mind changing is at the basis of human social interactions because it means that we can identify others' mental states and act upon them (Conte, 1995). This can be obtained by several means: communicative actions, like requests, commands, evaluations, assertions, etc. and non-communicative actions, which aim to modify the emotions, feelings, and beliefs of others without directly stating one's intentions.

4 CONCLUSIONS

The main point of this research is to justify how the precise distinction of the three levels of patient empowerment helps with its application, and help the patient receive it more smoothly and easily. The advantages of this process are that we can evaluate each level separately and not only the final outcome, identifying possible shortcomings and correcting them along the way. In other words, the evaluation and monitoring of patient empowerment have more clear targets, thus provide new opportunities for researchers to determinate where and when their strategy should change. We plan to test the validity of the model for the evaluation of a novel service environment for providing personalized empowerment and shared decision support services for cardiorenal disease and comorbidities, as part of the FP7-ICT project CARRE: Personalized Patient Empowerment and Shared Decision Support for Cardiorenal Disease and Comorbidities (Grant no. 611140). The project aims to create a set of empowerment interventions that address all level of the proposed empowerment model. In particular: (a) provide visual model of disease comorbidities trajectories, based on current medical evidence

(awareness: information aggregation and knowledge); (b) personalize the risk model based on his personal medical data and real-time sensors to support status awareness (awareness: understanding); (c) use the personalized model in conjunction with real time monitoring to create a set of alarms to enable patient engagement (engagement: enabling framework); and (d) provide advanced decision support services based on the real-time coupling of medical evidence, personal health status and intentions and beliefs, as deduced from social web data mining (control). The ultimate goal is to identify available evaluation tools for each different part of the model and thus provide a complete framework for the design and evaluation of patient empowerment interventions.

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