Targeting Patient Empowerment via ICT interventions: An ICT-specific Analytical Framework

Emergent Research Forum (ERF)

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Abstract

Empowerment of patients is today often an explicit goal of various ICT interventions where the patients themselves use ICT tools, often via the internet. This study is proposing a framework model for ICT interventions aiming to empower patients. Our new model includes different aspects of the Empowerment concept, general possible strategies to achieve Empowerment using different ICT services. Finally, the ICT services and the underlying strategic model can be used to define evaluations of such interventions where the aim is to demonstrate Empowerment. Our model is based on a review of various general models of Empowerment and the Behavioral Intervention Technology Model (BIT). The implications of our model are discussed using two case studies projects, the C3-Cloud EU project about empowering patients with 4 chronic diseases and the EMPARK project about Internet-of-Things sensors based real time feedback to Parkinson patients.

Keywords

Empowerment, ICT-Intervention, Framework model.

Introduction

Information technology has already transformed most aspects of healthcare. There are several types of motivation for these ICT developments, to improve clinical outcomes, to possibly contain costs that are increasing but in many cases, there is also an explicit goal to empower patients (Lee et al. 2015). There is a need to make explicit what such empowerment can entail and not the least to perform evaluations of the interventions that specifically address the issue of empowerment. The scope of this article is to present a framework for patient empowerment that can be useful both for construction and for evaluation of ICT interventions including patients as actors.

ICT Services and eHealth with patients as users

Early ICT development for health targeted health professionals as primary users. While such applications as Electronic Health Records, communication and planning of services and decision support continue to be important, many new ICT interventions specifically target patients as the users, often in a communicative partnership with the professional care. Our analysis is primarily concerned with such services. The following is a non-exhaustive set of typical ICT services where empowerment may be an important aspect:

a) Static advice for self-management for different health issues
b) AI-based advice for self-management based on information provided by the patient/citizens on the current health issue
c) Access to the Personal Electronic Health Record from the professionals (PAEHRs)
d) Chat-based interaction between patient and professionals with near real time response
e) Messaging between professionals and patients
f) Virtual online video consultations
g) Form-based patient reported outcome measures (PROMs)
h) Education programs for patients as agreed with professionals. This includes many aspects of online Cognitive Behavioral Therapy that has a rapidly increasing demand.
i) Online communities and social media.

The actual use of such ICT services depends on the users having a certain degree of eHealth literacy and access to required technology (smart phones, network, sensors, etc). In this paper, we will not deal further with this prerequisite for empowerment.

**Empowerment conceptualization for intervention studies**

ICT interventions targeting patient empowerment are growing in both number and magnitude. Despite many models that deal with empowerment in general, we think there is a lack of a simple pragmatic model that can guide the design of interventions and an integrated evaluation. Existing empowerment models are not having the specific needs of intervention design in focus and are contextual. Below we introduce a novel model of the patient empowerment concept that is suitable for ICT intervention studies. It is beyond the scope of this paper to provide a full literature coverage, only selected other studies are discussed.

Empowerment as a concept has various meanings related to the context. In healthcare, patient empowerment often refers to or is used in conjunction with the patient-centered and patient-equality mentality as a contrast to the paternalistic model where patients were considered as passive recipients under the supremacy of physicians. Although most scholars agree that patient empowerment should be viewed as a composite of different dimensions, models of patient empowerment differ in how the content and borders of patient empowerment are defined. For instance, the Consumer-Directed Theory of Empowerment (Kosciulek 2005) was developed and later validated within the framework of patient rehabilitation programs. Bravo et al. (2015), by reviewing 67 articles with different definitions on patient empowerment, suggested a novel conceptualization model for patient empowerment. The advantage of this model is that it provides a broad contextual map. However, it circumvents the problem of patient empowerment definition by suggesting “indicators of patient empowerment” by combining what patients feel/think/possess (capacities, states, resources) and what patients do (behavior). This model implicates that patient engagement is a behavioral component of empowerment. It is a pragmatic approach and interventions that target empowerment often have a patient engagement in focus. However, internal, perceived empowerment, which reflects an individual’s state of mind, does not necessarily translates into a desired action, a behavioral change. Internal empowerment may fail or be insufficient to induce behavioral changes due to a variety of reasons. For example, better knowledge and understanding about the disease may prompt patients to engage more actively with a care plan, but this could be inhibited by negative attitudes of the physician or lack of communication channels between the patient and health provider (Salmon and Hall 2004). Such barriers could be the specific target of both evaluation and ICT interventions. Therefore, interventional studies should rely on patient empowerment conceptualization, which makes the distinction between genuine empowerment, something that patients perceive, and a behavior, which it promotes. It would also allow intervention designs that specifically addresses the potential barriers between internal empowerment and patient engagement. The lack of consensus on definitions of empowerment prompted us to turn our attention to studies that try to conceptualize patient empowerment from a patient, rather than a scholarly perspective. Agner and Braun (2018) reviewed publications that qualitatively assessed the concept of patient empowerment as perceived and described by patients. Patients with different chronic diseases from different countries with different socio-economical and health provider background seem to share thoughts on empowerment: knowledge about, control over and coping with the disease and the process of health provision along with the feeling of support and legitimacy were unequivocally mentioned by patients.

Our empowerment concept clearly differentiate between the internal characteristics of empowerment (i.e., control, coping etc) and the potential consequences of it. We define these consequences broadly in
accordance with the demonstrated benefits of patient empowerment. At the patient level, increased empowerment may translate into the perception of, better Quality of Life (QoL) or satisfaction, and/or positive behavioral change in form of deeper engagement and therapy adherence, or improved disease related clinical outcomes. Consequences may be also at the healthcare system level (i.e., reduced utilization, increased efficacy, reduced costs). Figure 1 presents the conceptual model of Intervention Patient Empowerment that we propose as the conceptual basis and integral part of the ICT Patient Empowerment Model (ICT-PEM).

<table>
<thead>
<tr>
<th>Patient Empowerment</th>
<th>Empowerment consequence</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Control</td>
<td>• Patient Specific</td>
</tr>
<tr>
<td>• Psychological Coping</td>
<td>- Perception (QoL, satisfaction)</td>
</tr>
<tr>
<td>• Legitimacy</td>
<td>- Behavioral (engagement, compliance)</td>
</tr>
<tr>
<td>• Support</td>
<td>• Clinical Outcomes</td>
</tr>
<tr>
<td>• Knowledge</td>
<td>• Healthcare System Outcomes</td>
</tr>
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**Figure 1. Intervention Patient Empowerment**

**ICT Patient Empowerment Model (ICT-PEM)**

We propose a new model to provide a framework for the design and evaluation of ICT interventions that aim to empower patients (Figure 2). In this model, the conceptual model of Intervention Patient Empowerment helps to define the *Aims* of the intervention regarding both its targeted design and for the evaluation. We propose that one or several internal empowerment characteristics should be selected as the primary aims of an intervention whenever an explicit goal is the improvement of empowerment.

Using the ICT-PEM model requires that the project explicitly selects a *Strategy* for influencing the empowerment characteristics or empowerment consequences that the specific intervention addresses. For the ICT design strategy, our model merits most from the elements of the model of BIT (Mohr et al. 2014). BIT defines behavioral interventional technology broadly including all ICTs that support users in changing behaviors and cognitions related to health, mental health and wellness. Although several prior ICT design models have been published, such as Ritterband’s ‘Internet Intervention Model’ (Ritterband et al. 2009), ‘Fogg Behavioral Model’ (Fogg 2009) and the Persuasive System Design (Oinas-Kukkonen and Harjumaa 2018) to aid eHealth related ICT interventions, they provide insufficient theoretical background for integration with the ill-defined and broad concept of patient empowerment. Our choice to integrate elements of the BIT model is based on (1) its similarity to the core concept of ICT-PEM in its distinction of a conceptual and instantiation domain, (2) its concept of defining ICT developments as a chain of developmental phases with each having a well-defined specific target. However, in contrast to the BIT, ICT-PEM does not intend to provide a detailed recipe for the technological instantiation of each ICT intervention steps, as it is unnecessary for the overall goal of the ICT-PEM and would pose unnecessary limitations to the applicability of ICT-PEM.

Important examples of Strategies that need to be specified in the specific context of patient empowerment intervention are Education, Feedback, Monitor, Communicate, Analyze and Engage. Education, Feedback and Monitoring are presented as conceptual approaches to achieve behavioral change in the BIT model. We believe that the Engagement strategy for behavioral change in our model corresponds well and combines what is described as Goal setting and Motivation in the BIT model. Engagement as a strategy may be achieved by various *ICT services* and can consequently be coupled to multiple internal empowerment characteristics, such as Control, Legitimacy, Support and Coping. We added Communicate and Analyze to the strategies in our model as both of these approaches, once targeting the patients, should lead to improvement in Knowledge, Legitimacy, and Control, respectively. Monitoring disease activities and providing patients with Feedback are additional strategies that may be chosen to increase Knowledge, Control and Coping as internal empowerment characteristics. As described above, our model requires the chain-like coupling of each targeted internal empowerment characteristic with one or several Strategies,
which in turn should be coupled to specific ICT services that should be delivered by well-defined ICT Technologies/Tools. Our model emphasizes the importance of understanding how the Workflow processes function in the healthcare process to be able to design an ICT Service for patient empowerment. An incomplete list of current and emerging ICT Services that can be applied in interventional trials to improve patient empowerment were provided in the first chapter. We are aware that available ICT Services will expand along with the constant development and believe it would be contra productive to include a rigid list. Similarly, our model does not intend to define or provide a list of specific Technologies and Tools as they are subject to continuous development. This chain of determination ensures a targeted approach for an ICT intervention that facilitates both the design of the intervention and the evaluation. However, we give examples for the application of our model in the next chapter that describes two of our ongoing ICT intervention projects. Finally, the model emphasizes that the Intervention project should develop a strategy for Evaluation that considers the defined empowerment aims right from the start using suitable Empowerment characteristics or consequences indicators. Noting that no ICT intervention can achieve the desired empowerment unless the technology is used and accepted, we point out the need to separately assess the technology acceptance.

![Figure 2. The ICT Patient Empowerment Model](image)

Importantly, ICT-PEM defines a workflow in accordance with the BIT model, which allow the temporal coupling of the specific sub-intervention to clinical or patient-related workflows. Both patients and their closest health providers may be essential partners in designing such workflows.

**Case Study C3Cloud**

The C3-Cloud project focuses on elderly patients with diabetes, heart failure, renal failure and depression in different comorbidity combinations (C3-Cloud 2019). Three European pilot sites are included: Osakidetza (Basque Country, Spain), RJH (Region Jämtland Härjedalen, Sweden) and SWFT (South Warwickshire NHS Foundation Trust, UK). The C3-Cloud system consists of a variety of components: the Coordinated Care and Cure Delivery Platform (C3DP), the Patient Empowerment Platform (PEP) and the Clinical Decision Support Module (CDSM). Empowerment was an important goal of the application. Using our model, the Aims selected are the Knowledge and Control characteristics using our Interventional Patient Empowerment concept. The Strategies selected in the design using ICT-PEM is on Education with special attention given as part of the ICT-PEM Workflow planning to the physician-patient interaction and also the strategy of giving Feedback to patients on their recorded data and to allow Monitoring by connecting some devices for home monitoring (Glucose meters, balance and blood pressure). The ICT services used by patients are reached through the Patient Empowerment Platform. Finally, an extensive Evaluation program is planned where patient use and views on the various components are assessed.

**Case Study EMPARK**

The EMPARK project is focusing on empowering patients with Parkinson’s Disease using ICT. The intervention was designed using ICT-PEM with the main Aim of providing Knowledge and Control to the
patients employing the Strategy of Monitoring and Feedback. The ICT-Services include a tablet based user interface where the data from the recordings communicated to a central server is presented to the patients in an easy to understand and comprehensive way. Among the Technologies/Tools used is an Internet-of-Things sensor based system to measure motor function, sleep, and medication intake as well as other patient reported measures on exercise and symptom assessment. The Evaluation completed included several iterations of testing the usability of the technology with patient groups but the real clinical test where the perceived Control and measured Knowledge remain to be studied (Memedi et al. 2018).

Discussion

In this paper, we presented a new framework model for design and evaluation of ICT interventions where patients are the users and where there is an explicit aim to empower patients. The ICT-PEM model utilizes and builds on the elements and achievements of previous models, mostly on the empowerment conceptualization by Bravo et al. (Bravo et al. 2015) and Agner et al. (Agner and Braun 2018), and Mohr et al. BIT model as an eHealth ICT intervention model (Mohr et al. 2014). However, our model integrates, modifies and amend these elements to achieve its primary goal of integration between empowerment conceptualization and ICT intervention design. It is also intended to provide a stable theoretical, conceptual background for the design of evaluations for the ICT interventions targeting empowerment.

Acknowledgements

The C3-Cloud work was financed by the European Commission, and the EMPARK project is financed by the Swedish Knowledge Foundation, Sensidose AB, Cenvigo AB, and Nethouse AB. Liran Karni is the recipient of a PhD. grant from the Örebro University Successful Ageing program.

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