Re-thinking Models of Patient Empowerment

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Abstract. The empowerment of citizens in relation to personal healthcare management includes consideration of a multi-faceted collection of elements. Simplistic forms of understanding which link empowerment to access provide limited acknowledgement of the requirement to facilitate a greater sense of health ownership in patients and collaborative working practices in practitioners. More complex attitudes to the delivery of empowered patients encompassing knowledge development, technological awareness and partnership approaches to healthcare delivery are steps in the right direction, but strain to fit currently emerging ideas around patient centered care. This paper posits that existing frameworks aimed at empowering patients for a patient centered ehealth system are insufficiently presented. The frameworks, which are mostly premised on an inequitable focus, fail to factor in the invaluableness of holism and technological innovation. Through a review of existing frameworks and an articulation of patient demands, weaknesses in current structures to support empowerment are explored, and key constituents of a framework for patient empowerment are determined. Consequently, the paper articulates a model focused around delivering an empowered patient in the 21st century healthcare system.

Keywords. E-health, empowerment, patient empowerment, patient empowerment frameworks, holism, iteration, technology support

Introduction

The presence and increase of challenges to ehealth in today's society have begun to generate doubts about the capability of technology [2], especially with regards to issues of empowering patient [1,4]. Patient empowerment is roughly believed to be integral to any modern healthcare system [4]. Indeed, progress has been made with the development of models aimed to support the delivery of 'empowered patients' for better healthcare. Nevertheless, some patient empowerment frameworks/models have limited functionality through solely focusing on singular aspects of empowerment [5] and showing sign of age in an increasingly technological healthcare environment [1] (be this telehealth focused or part of wider technological reforms).

The contribution of this paper focuses around establishing weaknesses with current patient empowerment structures through critical analysis. A taxonomic analysis is used to explore current frameworks and connections are drawn between existing structures. The critical analysis provides a platform for presenting a new framework for patient empowerment, which builds on the strength of existing structures, but seeks to combine

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patient efficacy, provider support, health management, and technological infrastructure (including more sophisticated telehealth services) in innovative ways to provide societal benefits.

The next section explores patient empowerment through a focus on information access, patient involvement, and self-management. This work includes critical analysis of existing state of the art frameworks and models. Limitations highlighted within these models coupled with an understanding of their strongest features are used in the development of a new model of patient empowerment, as presented in Figure 1.
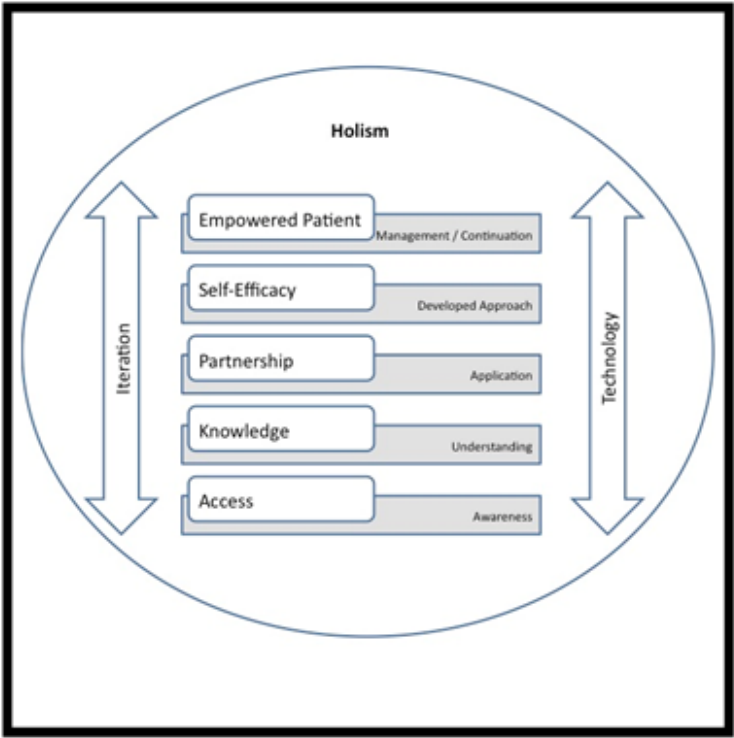

Figure 1. Framework for patient empowerment

This new model draws on aspects of systems theory such as holism, and iteration. In the final section of the paper we conclude by describing next steps and further work.

1. Patient Empowerment

In the health and medical literature, there is no consistent definition of patient empowerment [2]. Yet the concept universally carries a positivist function. Patient empowerment is generally about patients taking control or responsibility over their health, illness and treatment care [1] as well as the ability to participate in the consultation and decision making process [8].

In addition, patient empowerment facilitates patient self-management of not only specific periods of illness or long term conditions, but also of their health as a whole [5]. Furthermore, patient empowerment encourages pro-active health awareness and an expectation that patients will adhere to treatment. This contrasts with the traditional doctor-patient relationship, which is built on the concept of 'compliance' in which patients are required to do as they are told [9]. Here we find the hallmark of patient empowerment, it being a non-paternalistic approach to healthcare services. Thus a large amount of literature in the effort to explain patient empowerment stresses the difference between 'adherence' and 'compliance' [2,3,6,9].

Patient empowerment, however, is also linked to many functional elements such as access to information, patient involvement, and self – management. In this paper, we initially explore patient empowerment with respect to these functional elements.

1.1. Information Sharing

Information has been considered to have a vital role in the performance of healthcare systems around the world [2]. It is asserted that patient empowerment depends on the flow of health information [6]. There is no doubt that the act to provide greater public information sharing provides patients with a greater awareness and evidence about their health. Nonetheless, information alone may eventually disempower the patients by making them recipients thereby compromising the stated goal of patient empowerment.

1.2. Patient Involvement

Ensuring that patients' views are heard at all levels and across all parts of the healthcare system is essential for delivering empowered patients for better health and care services [1]. The doctors are expected to engage patients in their treatment, which will encourage patients to get involved in their healthcare and treatment [2].

1.3. Self-Management

One of the functional elements that is most often linked to patient empowerment is self-management [2]. This may in some cases be referred to as patient personal development. This involves a range of activities that improve awareness about disease to support end of life pain management [3]. Undoubtedly, self-management facilitates a greater sense of health ownership in patients [1]. It may not place the patient as the facilitator of their own care, but it does increase their value in the care relationship [5].

2. Frameworks of Patient Empowerment

Existing frameworks regarding patient empowerment are often constructed in relation to a multitude of different categories. For example, frameworks exist related to community empowerment for health purposes, the empowerment of carers, family health empowerment, and individual health empowerment. Disease specific models have also been introduced to encourage empowerment in disease management and control circumstances, e.g. in the areas of diabetes [2], mental illness [3] and many more. We can break these categorizations down into the following generic themes:

Health-Centred; Patient-Centred; Provider-Centred; Technology-Centred and Hybrid models.

2.1. Health-Centred

A collection of empowerment frameworks [3,5,7] that guide patient empowerment through a focus on health related or disease focused conditions can be broadly defined as health-centred. Such health-centered frameworks present pathways through to patient empowerment as connected primarily to the management of health related conditions that arise from serious illness and disease, through to generic health condition management.

Undoubtedly, health-centred frameworks enable opportunities for the development of mechanisms designed to better support patients in coping with chronic illnesses like diabetes and many more [4]. However, they are restricted to chronic disease and can be limited to knowledge about specific illnesses [9].

2.2. Patient-Centred

Second-generation patient empowerment frameworks evolved from global health policy transformation in the early 21st Century [2]. The limitations of health-centred models required different approaches to be developed which shift the balance of power within healthcare relationships to enable patients to be seen as an expert with respect to their own health management [3]. Within this framework an important criterion of successful adherence to treatment is that a patient's willingness, and experience with illness should be included in consultations.

From this perspective, patients have more control over their healthcare. Nevertheless the patient-centred framework can offer an illusory empowerment to patients with chronic disease [8].

2.3. Provider-Centered

The key concept behind provider-centred frameworks is on better enabling the empowerment process. Provider-centred frameworks seek to do this through promoting participation in the patient empowerment goal with providers and increasing provider willingness to participate in the implementation of patient empowerment. This can encourage providers to be active in helping the patient to understand their health and medical treatment, but at the same time a provider's perspectives on care may often overrule patient self-efficacy and continue existing power relationships.

2.4. Technology-Centred

Technology-centred frameworks originated in the midst of substantial technological change [5]. These are generally centred on utilizing technology (both telehealth and wider computer based technologies) to deliver personalized healthcare. Technology-centred frameworks open avenues for continuous and readily accessible health data and can help to facilitate self-monitoring. However, current digital divides limit the full potential of technology to support patient empowerment [5].

2.5. Hybrid

A hybrid framework involves the integration of two or more of the above categories of framework, and the ideas presented therein, with the focus on developing a more holistic perspective on patient empowerment. Hybrid solutions can provide a balanced patient:provider:technology:health approach in line with their integration focus [3]. However, it can be argued that each perspective above has a role to play in patient empowerment – therefore an integrated framework encapsulating each idea may deliver a stronger solution.

3. Limitations of Existing Models

Current models/frameworks capturing health, patient, provider and technology roles provide a better understanding of the efficacy of patient empowerment in the healthcare system and influence utilization of approaches to deliver patient empowerment and greater ehealth integration. However, the above analysis indicates that the balancing of stakeholder roles in healthcare systems is unlikely to be addressed effectively by singularly focused initiatives; hybrid approaches combining conceptual ideas are a preferred option. The primary issue is that an over focus on singular areas may prevent optimum ehealth integration and use. Hence they have limited functionality and strength through: solely focusing on a singular aspect of empowerment whilst neglecting others [3]; missing vital elements [1]; and showing signs of age in an increasingly technological healthcare environment [2]. Consequently, a different approach is needed to have a clearer understanding of the patient empowered ehealth system. A number of studies have begun to establish the main elements of a framework for understanding this basis in the context of holism (looking at the system as a whole, rather than singular parts or singular stakeholders). The aim of this paper is to articulate a model, which would consider systems theory ideas to present a robust framework of patient empowerment for better ehealth integration. A robust framework is key to ensuring an empowered patient in the 21st century e-health system.

4. Developing a New Framework

In this section, we present a unified model of patient empowerment that is centred on understanding perspectives of multiple stakeholders in healthcare systems and vital aspects of empowerment. In this model, patient empowerment is understood as a shared and iterative process, whereby all stakeholders in the healthcare system work in partnership to enhance personalized healthcare management. Such partnerships seek to facilitate a greater sense of health ownership in patients and promote collaborative working practices through a series of iterative steps (towards an increasingly developed relationship) to maximize excellence. This more complete framework of empowerment brings together separate categories of patient empowerment models, contributing an integrated structure of empowerment. Consideration of the whole, in terms of aspects of empowerment, is more than merely the sum of its parts [5]. In this regard, all stakeholders in the healthcare system affect patient empowerment, and technology (including telehealth provision) is incorporated in every stage of the empowerment process. This model, presented in Figure 1, also acknowledges the importance of

iterative development in maximizing patient involvement in the development process and the promotion of empowerment for personalized healthcare.

4.1. Awareness-Access

The empowerment of citizens in relation to personal healthcare management has been linked primarily to an access to knowledge or services issue [2]. Such access provides a basic form of understanding patient empowerment [3]. Patient empowerment depends on access to the healthcare system and all health resources but access is not in itself enough to deliver patient empowerment. In the proposed framework, Figure 1, access and awareness are coupled as significant concerns at the base of the patient empowerment framework. There is no point in access if the patient is not aware, similarly awareness alone may promote requirements for access.

4.2. Understanding-Knowledge

Knowledge development is vital to the delivery of empowered patients, providing citizens with the information they need for their health decision-making processes. Development of patient knowledge involves a relationship between patients and their understanding of health information, as well as the ability to make effective use of the knowledge [3]. Understanding knowledge is about the degree to which a patient has the ability to obtain, process, and understand the health related information needed to make informed decisions [2]. This contributes to patients understanding in becoming active participants in the management of their health, which eventually has been shown to result in more efficient partnership work between patient and practitioner groups [3].

4.3. Partnership Application

One of the common functional elements to support the empowerment of patients is partnership care. This means the patient and provider should work in partnership to enhance patient involvement in their health and healthcare, illnesses, and treatment plan [8]. Partnership development can also contribute to enhance self-management, improve healthcare utilization and promote a greater sense of empowerment, which can boost patient self-efficacy and/or confidence to have more control of their care [3]. Thus partnership is not only vital to the development of a treatment care plan, but can also lead to a developed approach for empowering the patient [5].

4.4. Developed Approach of Self-Efficacy

Patient self-efficacy, which can be referred to as the extent of a patients' belief in their own ability to take responsibility for their own healthcare, complete required tasks [5] and reach goals developed in their treatment plan (either personal or provider focused) [3], is one of the ingredients for patient empowerment to occur. For instance, it can enable personal initiative to be taken in one's healthcare and may help patients to make beneficial choices that are more relevant to their personal care [7]. Thus the ultimate goal of personalized care is not just to improve the quality of life, but also to create a developed approach to care. Thus continuity is vital as it enhances an empowered patient.

4.5. Technology Including Telehealth as an Underlying Support Mechanism

Technology has been acknowledged for its potential in the delivery of the empowered patient [5]. However, technology does not exist as a singular aspect, it is multi-faceted and supports many different areas towards patient empowerment. For example, basic web access promotes patient engagement with health literature and can connect together patients with services. At the level of self-management, telehealth tools including mobile applications can help patients to understand their health conditions, engage in personal health monitoring, and construct dialogues for communication with their health providers for more developed partnership care. Therefore technology exists as an enabler within the framework supporting all aspects and increasing in maturity as the patient / provider relationships develop overtime. For example, a patient who decides to monitor their own healthcare through technology will increase over time their understanding and sophistication of use.

Conclusion

Patient empowerment approaches involve multiple elements that cannot be determined or explained by their component parts alone. Component parts in systems designed to support patient empowerment are intimately connected and can be understood only by reference to the whole. Thus the entire system should be considered in frameworks constructed to support the empowerment of patients. Iteration and technology are vital in empowerment processes, which require frequent monitoring of progress. Further work will focus on additional support for the proposed framework through healthcare stakeholder analysis, including exploration through qualitative questionnaires around patient empowerment principles. This will enable further levels of complexity to be analyzed and taken into consideration.

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