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Re-Thinking Technology and its Growing Role in Enabling Patient Empowerment

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Abstract

The presence and increase of challenges to ehealth in today's society have begun to generate doubts about the capability of technology in patient empowerment, especially within the frameworks supporting empowerment. Through the review of existing frameworks and articulation of patient demands, weaknesses in the current application of technology to support empowerment are explored, and key constituents of a framework for patient empowerment are determined. This paper argues that existing usage of technology in the design, development and implementation of patient empowerment in the healthcare system, although well intentioned, is insufficiently constituted, primarily as a result of fragmentation. System theory concepts such as holism and iteration are considered vital in improving patient empowerment frameworks for the modern healthcare system.

Keywords

e-health, frameworks, health informatics, patient empowerment, technology

1. Introduction

Technology is arguably an integral part of modernity. The potential of technology to facilitate the activities of modern society is well recognised [1], and there is hardly any facet of contemporary society that is devoid of modern technology. The relevance of technology to patient empowerment was readily apparent from the early advocacy of ehealth in health systems. The nexus between technology and patient empowerment is such that the latter could not be imagined without the former. Patient empowerment, being a product of the modern age, is not sustainable without technology, although technology in and of itself is also not a panacea to empowerment facilitation [1]. The

requirements for patient empowerment such as vast access to health information and knowledge [2], self-management programmes [2], new health policy construction for patient involvement [3], and the use of mobile and wearable devices [3] cannot be harnessed and efficiently managed without effective technology. However, the presence and increase of challenges to some technological utilities like health information technologies (HIT) have begun to generate doubts about the capability of information and communication technologies (ICT) [1-2, 5], especially with regards to patient empowerment.

Facilitating patient empowerment is integral to any modern healthcare system and corresponds to developments towards a greater level of liberty. Progress has been made with the conceptualization and development of models and frameworks aimed to support the delivery of the empowered patient [1]. Technological products are being extensively utilised and integrated in the design, development and implementation of these frameworks. Nevertheless, some patient empowerment frameworks and models have concealed their expansion and strength through: disconnected elements [5]; and are showing signs of age in an increasingly technological healthcare environment [6]. Additionally, the vast application of technology in both the discourse and modelling of patient empowerment is yet to deliver the prized goal of an empowered patient [14].

This paper discusses patient empowerment and critiques the application of technology in the design, development and implementation of infrastructure to support it. The contribution of the paper is to suggest a more sustainable technology-driven framework of patient empowerment. Patient empowerment as a concept is discussed and existing patient empowerment frameworks are critically analysed. Limitations highlighted within these frameworks coupled with an understanding of their strongest features are used in the development of a new model of patient empowerment, as presented in Section 4, Figure 1. This new model draws on aspects of systems thinking such as holism, and iteration, to propose a new approach to thinking about the impact of technology on patient empowerment. In the final section of the paper we conclude by describing next steps and further work.

2. Patient Empowerment and Patient Empowerment Frameworks

Today there exists many definitions of patient empowerment but essentially patient empowerment is about patients taking control or responsibility over their health, illness and treatment care [5], as well as the ability to participate in the consultation and decision making process [6]. Patient empowerment also encourages adherence, with the expectation of a patient to follow treatment guidance. This contrasts with traditional doctor-patient relationships, which accept the concept of 'compliance' in which patients are required to do as they are told [6]. Here we find the hallmark of patient empowerment as a non-paternalistic approach to healthcare services. Thus the majority of literature in the effort to explain patient empowerment stresses the difference between 'adherence' and 'compliance'[5-7, 10]. Adherence connotes partnership [10] with this contrasting with compliance, which denotes subservience [11].

Anderson and Funnell (2010), in a study about patient empowerment and its common misconception, reconsidered patient empowerment as an interactive process that may be facilitated by healthcare providers, which will yield positive results. In their case this involved helping patients make self selected changes related to physical activity. In contrast, Schulz and Nakamoto (2011), asserts that patient empowerment is the active participation of the citizen in his or her health and care pathway, with the interactive use of information and communication technology, and also as a continuous process. In this context patients are responsible drivers of their own health, in which the healthcare system values them as partners. Thus this views patient empowerment as provider-patient interaction, which is the process of communication and sharing of knowledge through partnership using technology assessment. Regardless of differences among definitions, a unifying theme is present in all the descriptions of empowerment throughout the healthcare literature. This unifier is "self-determination" characterized by the need to change a prevailing situation. Patient empowerment, however, is also linked to many functional elements such as information access, knowledge development, technology support, partnership work, and self – management.

Existing frameworks regarding patient empowerment are often constructed in relation to a multitude of different terms and aims. For example, frameworks exist related to community empowerment [5] for health purposes, the empowerment of carers [6], family health empowerment [7], provider empowerment [10] (described as doctors as facilitators of empowerment), patient centric [8] viewing the patient as the most crucial element), or disease management [5, 7] for long-term condition care. Patient empowerment frameworks and models can be regarded as a philosophy in patient care [5], describing approaches (rooted in different care practices and ideologies) to structuring healthcare systems in order to provide better patient care, through a belief that empowered patients lead to enhanced health and wellbeing [6]. Frameworks and models help to advance patient empowerment to occur [6]. Thus it can be argued that frameworks and models improve the scalability and effectiveness of patient empowerment implementation [12].

In a number of existing frameworks, patient empowerment is guided through a focus on psychological assumptions [11] and the doctor-patient relationship [12]. This emphasis on how healthcare providers could help patients be more confident and involved in their health care and treatment plan [6-8] through understanding patients as experts in their own lives.

3. Role of technology in Patient Empowerment

Technology is by far the most prominent tool concerning development of an approach to patient empowerment [14]. Many patient empowerment frameworks and models are developed, designed, and implemented with the aid of various technologies [14]. Technology has proven to be extremely useful to patient empowerment not only as a tool to aid the empowerment process, but also as a facilitator of learning about patient empowerment. The delivery of an empowered patient is increasingly becoming

contingent on such technological roles as communication, access provision, interpretation, real-time connectivity, coproduction between patients and health system etc. For example, technological means to aid effective communication between all healthcare stakeholders can increase knowledge generation and exchange between all stakeholders in the healthcare system. Another important point is the use of technology for collaboration among patients and providers. Indeed technology in relation to patient empowerment allows patients to share ideas about health information with different groups of people. Technology driven frameworks for patient empowerment are being constructed in which the most crucial elements profoundly depend on technology. Conversely, technologies in some frameworks may also be arranged such that their role in delivering patient empowerment is obscured. This could result in today's patient empowerment models not being effective in the near future, as technologies such as mobile devices and social networks are rapidly changing patient expectations of involvement in their own health care.

3.1 Technology- Driven Frameworks and Concerns

More complex approaches to the delivery of empowered patients rely on technology and the way it is utilised [15]. There are a wide number of technologies empowering patients. For example, web services have been used for information sharing, interactive portals, and remote data access [14-15]. Another technology, which is growing in usage, is mobile applications both on mobile phones and tablets applied to ease communication among healthcare stakeholders (i.e. providers, patients, systems). Some of these mobile apps include: the MedXCom app [14], which lets patients request appointments, enables them to store and manage all of their health information, and to instantly share important data and updates with their doctors [16]; Apple's health apps [17] which allow patients to put all their health data in one place and enable data from a patient's health app to be automatically shared with their doctors. An interesting technology applied in empowering patients is the use of forums, blogs, and social networks for online support. These are suitable tools to convert support groups from physical life to the electronic world, thus generating knowledge from healthcare stakeholders, which then strengthens the continuity of care beyond treatment.

Technology-driven frameworks have been used primarily in reference to application of technological tools to support patient empowerment [14]. These technological tools (i.e Internet, mobile phones, mobile applications, web portals, social networks, and many more) are increasingly and broadly integrated in the design and implementation of some patient empowerment frameworks. This has the effect of portraying technology-driven frameworks as a technical effort, which guides patient empowerment through a focus on the potential of technology to deliver personal healthcare management [16]. With this growing acceptance of the application of technology in patient empowerment, some medical scholars and health organisations have proposed technology-focused frameworks, which can be broadly classified thus: Access centred; Knowledge based centred; Participative technologies; Assistive technologies... Therefore, these four significant categories of technology-driven patient empowerment frameworks will be reviewed.

3.2 Access framework

A collection of technology- driven frameworks that guide patient empowerment through a focus on access technologies can be broadly defined as access framework. Access framework sees the problem of patient empowerment as that of inaccessibility. Consequently, technology models are framed to address this problem. Various strategies are thus devised to present pathways and points of contact through which patient empowerment could be attained. The issues of interfaces and connectivity form key elements of access frameworks [17]. Access framework offers many benefits such as enabling patients and communities to use appropriate healthcare services in promotion of their medical services needs [3]. However, the framework fails to aid a greater sense of health ownership in patients, and collaborative working practices in practitioners. Furthermore, its emphasis on access as the major impediment to the realisation of an empowered patient oversimplifies the problem of patient empowerment.

3.3 Knowledge based framework

Knowledge based frameworks recognise the value of knowledge to patient empowerment. Information is conceived as singularly important within health care system to enable patients understand their own health [7]. Within this framework an important criterion of successfully empowering patient is the awareness of health information that directly aids their needs [18]. Technology is thus utilised chiefly to address the issues of knowledge and information. Examples of technological devices and apps used within the knowledge-based framework are SGH Diabetes Pal and Patient Pal, which severally seek to provide necessary knowledge to patients. Nonetheless, knowledge framework alone cannot guarantee positive result.

3.4 Participative framework

The key concept behind participative frameworks is on enabling patient support process. The participative frameworks seek to do this through promoting participation in the patient empowerment goal with patients. This idea offers many benefits, which include encouraging and enabling patients to be more actively involved in managing their own health through the use of technology to exchange ideas and information with other patients. It also offers significant productivity improvements in the development and implementation of patient empowerment. This can encourage patient to be active in helping other patient to understand their health through sharing their experience, but at the same time a patient perspectives on their health may overrule providers' expert. **3.5** Assistive framework

Assistive framework directs patient empowerment to achieving a balance of technology support in line with health needs [20]. These are generally centred on utilising assistive technologies to provide greater independence by enabling patient to perform task outside practitioner's intervention. Assistive framework open avenues for continuous readily accessible health care and can help to facilitate self-monitoring [14]. However the lack of comprehensive understanding of how these various assistive technologies needs fit together to provide patient with complete independence.

Table 1 shows a summary of existing technology driven patient empowerment frameworks. Models and frameworks open avenues for better understanding of the efficacy of technology in the implementation of patient empowerment.

Framework	Role	Concerns(s)
Access framework	Shapes patient	Lack of acknowledgement for
	empowerment around	the capability of technology
	access technologies (i.e	to facilitate a greater sense of
	web services);	health ownership in patients,
	connecting health	and collaborative working
	system.	practices in practitioners.
	Utilising the potential	Accessibility (such as the
Knowledge based	of knowledge-based	degree to which distribution
framework	technology (i.e patient	of health information or apps
	record, health	is open to as many people as
	resources) to deliver	possible in terms of their
	informed patient.	needs).
Participative	Directs patient	Trivialisation of a provider's
framework	empowerment to	role.
	achieving a social	
	support.	
Assistive framework	Patient Empowerment	Creates an atmosphere of
	here is modelled on	illusory idea of patient's
	technologies that	faultless discernment.
	incorporate cultural and	
	individual preferences.	

Table 1 Summary of technological-driven frameworks for patient empowerment.

4. A Unified Technology-Driven Framework of Patient Empowerment

Current technology driven frameworks already allow for the establishment of initial steps towards the delivery of an empowered patient [14-15]. However, while a wide number of technology driven frameworks have claimed to support patient empowerment, the misapplication of technology in the design, implementation and development of these has lead to results not forthcoming from the current usage of technology [18]. Therefore, it is apparent that, if technologies role were to be assigned differently positive results may occur. This section proposes one single unifying model that articulates the role of technology in patient empowerment.

Building on the existing models and frameworks for patient empowerment, this section presents a unified technology driven (UTD) framework (Figure 1) of patient empowerment. The proposed framework focuses on aspects of technologies empowering patients and their effect on patient attitudes towards empowerment. In this framework patient empowerment is appreciated as an iterative process whereby every step in the empowerment process is repeated, to understand the system as a whole, and to arrive at a desired result. Furthermore, the proposed patient

empowered technology framework brings together disparate elements of existing technology driven frameworks, offering a more comprehensive account of the role of technology in delivering an empowered patient. More importantly, the framework highlights the role that technology plays in every phase of the empowerment process. In this regard, technology is a useful tool, which can make the practical implementation of patient empowerment possible. The model presented in Figure 1 also highlights impact related to the promotion of empowerment for all healthcare stakeholders.

One of the distinguished characteristics of the proposed technological driven framework is its employment of the principle of holism, which broadens the scope of the patient empowerment process to include as many stakeholders and technological roles as can be conceived. Some patient empowerment models exclude some patient groups, often leaving them unable to get a greater sense of health ownership. For example, models that do not concentrate on groups of patients who are not chronically ill or who use health services infrequently. The unified technology-driven framework, which has the most general purpose, supports empowerment to diverse patient groups who otherwise would be virtually invisible to the mainstream healthcare system.



Figure 1 Unified Technology Driven (UTD) Framework.

4.1Components of Unified Technology-Driven (UTD) Framework

The proposed framework identifies five roles where technology will be critical to improvement and change in the patient empowerment model. Over the last five to ten years [14,18], there has been a significant amount of effort put into the application of technology to empower patients, although, little attention is paid on its role in patient empowerment. Based on review of the patient empowerment literature, there are five overlapping themes in the literature that can be considered key classes of technologies involved in the empowerment of the patient, that is: access technologies, knowledge-based technologies, participative technologies, assistive technologies, and personalised technologies.

Access technologies- Access technology is one of the key mechanisms used for empowering patients. Its application covers several approaches such as interface(s), computerized patient records, formatting (i.e disk, USB), health card, summary care record, and many more. This is the electronic provision of health and treatment information to all healthcare stakeholders (providers, patients etc.). For example, the summary care record provided by the NHS in the UK aids to interact with database searching for suitable information to connect providers at emergency wards. This effort is based on data management, which is a means that enables data storage and sharing between all healthcare stakeholders. Access technologies also allow patients and healthcare providers to access health information and services. For many, access technologies play an important role in delivering the empowered patient, while for others access alone is not adequate to empower a patient. True patient empowerment requires that patients are not just recipients of information but also partners who can also generate and process information. The role access technology plays here is in connecting to the healthcare system as a whole including all stakeholders (patients, providers etc.). However, existing frameworks are not designed to enable patient input, as they don't automatically have access to their records [7]. The proposed framework includes patient access at its core, expecting patients to be connected in the first stage of the process of patient empowerment. This is considered to allow the establishment of the connected patient and could be used in achieving the next stage of the empowerment process through iteration. Thus establishing a connected healthcare system (i.e. national, cross- national, and global).

Knowledge-based technologies-Knowledge-based technologies allow the collection and displacement of useful health information to healthcare stakeholders such as patients, providers for reading, viewing, study, or reference. Knowledge-based technology includes health portals, knowledge banks, health libraries, Web Information Systems, email, and many more. The main functions of these technologies are to provide resources and inquiry support for patients, providers, and other healthcare stakeholders. Thus, knowledge based technology is crucial in the delivery of the empowered patient. The importance of knowledge-based technology in patient empowerment has also been recognized by many health organisations such as the World Health Organisation (WHO), which initiated free and open access to medical literature through the Health InterNetwork Access to Research Initiative (HINARI). However, there is the case of 'dangerous knowledge', which means that having unlimited health knowledge may lead patients to act on, unproven science [10]. For example, a patient with high blood pressure could access health information, which concludes that caffeine is not a risk factor for cardiovascular disease. Acting on such information alone could lead to the patient's continued use of coffee. However, other research into the effects of coffee on human health may have provided a contrary result. Such studies may strongly argue that coffee increases blood pressure. This shows the existence of inconclusive views on the effect of caffeine on cardiovascular conditions. Thus knowledgebased technology in this context may not automatically yield absolute positive results, which are important for patient empowerment. In the proposed framework knowledge-based technologies are recognised specifically for their ability to deliver informed patients. Informed patients' are enlightened about their own health and their negotiating agents [12] whose health responsibility is both a matter of increasing knowledge [15] about everyday experience as part of a reflexive plan and a matter of locating this plan within a broader informational environment.

Participative technologies- Participative technologies allow patients to get and share information easily and give them straightforward access to knowledge traditionally held by doctors, but that does not inherently empower patients [14]. This involves social media (i.e skype, twitter, facebook), web portals, health forums, dialogue construction, email, and many more. For example, suppose a patient with mental issues joined a social media group such as Depression Alliance for peer support, visits 10 top online health forums to discuss their health problem and has a video chat on Skype with his doctor for clarification of the information he received from other sources. Is that patient empowered? This will no doubt transform the paternalistic relationship between a patient and the healthcare system into a partnership care process. Partnership care is one of the central mechanisms available to support the development of patient empowerment [16] and is essential for the delivery of the empowered patient with a high

quality of health care diagnosis, and treatment of disease. Thus providing patients with an opportunity to get involved and take an active role in their own health. The application of participative technologies in the proposed framework is argued as a means by which inherent problems in empowering patients (including support asymmetry between healthcare stakeholders and willingness to share information) can be solved through a developed approach that leads to an involved patient.

Assistive technologies- One of the technologies that best facilitate the implementation of patient empowerment is assistive technologies [14]. This encompasses a range of devices from mobile to wearable devices. It may involve health apps; mobile phones with installed apps; memory aids such as reminder messages, medication aids, clocks and calendars, locator devices, aids for leisure; Sensors around the home to detect situations that can be a potential hazards such as floods, gas, absence from a bed, leaving home; and other technologies associated with dementia. Assistive technologies may not necessarily place the patient in the control seat [15]. However, it does help the patient with everyday living, that allows the patient to perform a task that they would otherwise be unable to do, or increases the safety with which the task can be done [20]. For example, a person who is a sleepwalker could trip over breakable, or harmful objects, and be injured, or could open the door and leave the home without knowing, but with assistive technology a sensor could raise an alarm in such a situation, thereby waking the sleepwalker. Therefore assistive technologies can help to promote independence for patients and promote liberty. Thus this would help create patients' general feeling of confidence in managing and treating their own health. In this regard, the proposed framework appreciates the role of assistive technologies in empowerment to deliver or enhance a confident patient.

Personalised technologies- Inclined to the level of complexity of personal healthcare management in modern healthcare system and the differences in patients (whether they be caused by variation in disease, lifestyles, or preferences) personalised technologies are becoming increasingly necessary in healthcare and a vital element in the patient empowerment model. Personalised technologies are tools or approaches that may enable a patient to design to meet his original specifications, preferences, and needs. This involves self-diagnosis, personal alerts, self-monitoring, self-care, self-treatment, self-protection, self-assessment, self- efficacy, and self-management. Personalised technologies help patients prevent some disease (diabetes, heart disease, kidney disease or heart failure) or reduce the risk of having one. For example, the NHS health and symptom checker app allows patients to check symptoms if feeling unwell, which will then automatically provide them with assessment, information about their condition and advice on how to look after their own health. This helps spot early signs and helps prevent a condition getting worse. In addition this may help patients make beneficial choices that are more relevant to their own circumstances and preferences [25]. The proposed framework understands personalised technologies as self-health, which allows patients to modify, control their own health to individual expectation. This helps patient more control over their health, well being, and treatment plan that promote personal initiative and a greater sense of health ownership in patients. Furthermore, the ultimate desired goal of patient empowerment is not limited to single aspect such as connected, informed, engaged, confident, or empowered patient, but rather all ingredients working together as one whole system (complete).

Iterative Process - As seen in Figure 1, the idea of an iterative process is inherent in the proposed framework. The framework suggests that activities in the empowerment process can be repeated aspects to support approaching a desired goal, target or result (empowered patient). Each repetition of the process is expected to produce a result that can be used as the starting point for the next iteration. For example, access technologies can aid to deliver a 'connected health system' (i.e practitioner, provider, patient, hospitals, GPs, organisations), which could be used as a starting point to guide the use of knowledge based technologies to produce a more 'informed patient'. In addition the framework emphasises that there is no starting point or end point during the process. Hence, it is continual iterative processes as one can really only know whether there is a mitigated risk after repeated trial to build something and put the pieces together. And each

successive iteration process should generate new creative thinking until a desired goal of the 'empowered patient' is achieved.

5. Conclusions and Future Work

As our healthcare systems move to patient centred care models there is a tendency that a patient's role will change from a paternalistic to a more adherence focused approach [7]. There is a clear quest in the effort to understand patient empowerment methods for the delivery of empowered patients, and the development of models for patient empowerment have been an on-going global research issue over the past few decades [14]. With the emergence of ehealth services, most of the recent research assumed that any push for technology should focus on access to health information [15] and services, to enable partnership care [17], and for knowledge development [19] in order to yield patient empowerment [19]. However, the slight misunderstanding of technology in the design, development, and implementation of some of the current models of patient empowerment has underrated the strength of the role that technology can play in helping to deliver the empowered patient and as such results are not forthcoming [14,20]. The presented technology driven framework of patient empowerment in this paper could successfully cope with the demands of a patient empowered technology system, as in this framework the role of technology is re-designed to take into account holistic perspectives and an iterative process. In this regard, re-application of the role technology presently has in the effort to deliver empowered patients, in accord with the proposed framework (figure 1) as the potential to yield positive results. In the patient empowerment approach all its properties cannot be determined or explained by its component parts alone. Thus the entire system should be considered a whole. Therefore there is need for the unified application of homogeneous technology in patient empowerment. Iteration is vital in empowerment processes, which require frequent monitoring of progress.

Further work will focus on developing additional support for the framework through healthcare stakeholder analysis, including exploration through a qualitative questionnaire to have a complex, holistic picture, and detailed views of information around patient empowerment principles. This will enable a further level of complexity to be analysed and taken into consideration. The proposed framework of patient empowerment recognises access across various different forms as a core to successful patient empowerment development, whilst understanding that there are other elements that can be utilised to greater improve empowerment outcomes. The UTD framework proposed in this paper does not just have the potential to be integrated into the UK health system, it also has the potential to be integrated on an International scale into other environments. Some of the aspects of the framework could also be applied to a health information application, service, or design. The literature identifies a number of barriers, which may hinder such an implementation process. If the barriers of the implementation are identified early then actions can be taken to overcome these barriers. Some possible barriers that may be encountered are administrative practice and perhaps the availability of software but through knowledge and awareness these can be overcome.

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