Improving Usability, Safety and Patient Outcomes with Health Information Technology
F. Lau et al. (Eds.)
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doi:10.3233/978-1-61499-951-5-70

Patient Empowerment: The Role of Technology

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Abstract. Patient empowerment is a buzzword that has gained much currency in recent years. It is defined as a process that helps people gain control over their own lives and increases their capacity to act on issues that they themselves define as important. This paper outlines the problems faced by the current medical model of patient empowerment and proposes a unique framework for patient empowerment that provides guidance on how health technology supports or detracts from empowering patients and families. The paper provides an ethical lens for physicians, policymakers, patients, and families in the health care system to consider the central role of the principles of autonomy and justice in patient empowerment. This paper also discusses how technology can be used to further patient empowerment and patient-centeredness of health care systems.

Keywords. patient empowerment, health technology, communication technology in patient empowerment

1. Introduction

Patient empowerment is a buzzword that seems to have gained much currency in the health care sector over the last decade [1, 2]. However, there does not appear to be a consistent definition of patient empowerment in the literature [3]. This varying terminology leads to confusion and disillusionment of the importance and role of patient empowerment [4]. Critically this leads to an inability to devise and test technological interventions effectively [5]. How can we implement a health technology, if we can't agree on a definition?

The Financing Sustainable Healthcare in Europe report provides a useful pointer to the underlying philosophy of patient empowerment [6]: "(1) the having and sharing of power, and (2) sources of power and ways to increase power. Empowerment can serve the goals of the empowered (e.g., greater pride and self-worth), and of the empowering agents (e.g., empowering employees as a way to foster productivity)."

Empowerment is the ability for individuals to have a voice at the table. It centres care around patients' preferences and increases their autonomy rather than their conformity [7]. This paper proposes some new ideas about what is necessary *and* sufficient for larger scale patient empowerment where information technology can play a transformative role.

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2. Problem Identification and Resolution Process

We conducted a scoping review of peer-reviewed and grey literature on patient empowerment in MedLine, Google Scholar and Google. We reviewed 32 articles until we reached saturation. We used the British Design Council's Double Diamond method [8] to identify key problems with patient empowerment and then narrowed them down to 5 major problems. We then explored potential solutions to the problems, noting that some problems were already being solved by other organizations, such as PCORI [1], but several were partially solved and one has not been addressed in any substantive manner.

3. Problems Patients Face in the Current Medical Model

In general, patients appear to face five major problems when attempting to self-manage their chronic disease or participate in the healthcare system.

1) They have little or no voice to influence the system for their own needs. Currently, services are negotiated by payers and providers, not patients or their advocates.
2) Patients have limited access to or control over their own medical information. Patients have limited transparency on who has access to their data.
3) Even if patients did have access and control of their data, they are still at a knowledge and information disadvantage when interacting or negotiating with payers and providers.
4) Patients have little say in how the main value creating activity in health care, research, is conducted, although efforts are underway to resolve this [1]. Patient data is controlled by the organizations that conduct the research.
5) Patients do not receive any of the benefits, including monetization of data, from the use of their data. In a world where data is increasingly an appreciating asset, this does not seem fair nor equitable [9].

These problems are not addressed by current empowerment models [3].

4. Initial Principles Development

The initial patient empowerment principles were developed through an iterative process of developing solutions for each of the above-mentioned problems. We identified several drivers for efforts to increase patient empowerment:

1) Cost reduction ("people need to look after themselves to lower costs")
2) Better health outcomes ("it's for their own good"),
3) Greater system efficiency ("less resources used if patients look after themselves")
4) Improve patient autonomy, control and participation in benefits (i.e., it's the right thing to do).

We quickly realized that cost reduction and system efficiencies are system benefits and can become coercive, if taken to their limits. Even achieving better health outcomes, while seemingly benign and positive, can also become coercive if those who have greater knowledge recommend interventions in the 'patient's best interest'. Any approach that can be coercive, by definition cannot lead to patient empowerment. Thus, we conclude that patient empowerment must come from an ethical driver [10, 11].

Ethical principles such as autonomy and justice should be the driving factors of patient empowerment. Patients must be autonomous agents of their own health and patient empowerment should be conducted through justice and equity for all patients. This approach has significant implications for how we approach patient empowerment and provides guidance about how technology can help patients control access to their data, level the playing field with regard to knowledge and information and help them participate in the benefits that are derived from the use of their data.

5. Principles of Patient Empowerment

We believe there are 3 areas where technology can support patient empowerment in keeping with an ethical approach that is not self-contradictory.

5.1 Access and Control

Access refers to the possession of one's own health care data. Access to data is important because without it, patients are unable to control interest in their own health care. People need to understand what needs improving before they can take steps to help themselves. Most patients are not even aware that they have the right to ask for their medical records [12]. The idea of ownership of data has been highlighted in Canada by the First Nations Information Governance Centre [13]. This group has implemented standards for how First Nations' data should be collected, used, and shared. The four parts of their framework are ownership, control, access, and possession (OCAP). OCAP® is part of the First Nation's efforts to exert self-determination. The principles of OCAP® also relate to all Canadians. All citizens have a right to access their own health data and exert self-determination for their health. The ethical principle of autonomy is strengthened by providing patients greater access and control over their own data, greater transparency on who has access to their information and how and for what purpose it is being used [14].

5.2 Knowledge and Information

Patient empowerment should give people the power to control their own health care. It needs to give them the knowledge, education and information to use that data in their own best interests. The current patient-provider relationship is paternalistic and needs a shift towards a more collaborative, two-sided relationship. This means that physicians need to help patients understand their condition and what they can do to treat it at home. Patients need tools to support health literacy, navigation of the health system and knowledge about their disease and its treatment. Patients want to be empowered and can be empowered in the process of treatment decision-making [13]. The principle of autonomy is furthered by helping patients level the information and power gaps inherent in healthcare, while ensuring safety from negative or highly stressful information [10, 11, 15].

5.3 Shareholding

Shareholding is a new idea in the health world which, to our knowledge, has not been previously described. What we propose is that all organizations that profit from a patient's data pay out a 'dividend' to the patient. This is already seen in the retail industry, where companies reward customers for their data through loyalty programs [16].

This concept encourages for-profit companies to compensate those who contribute to making their profits. People's information is currently being used by genomics companies and the pharmaceutical industry with no tangible benefit to those whose data was used. The monetization of data should go beyond paying for data when received. Rather, institutions should share the profits they make with the people whose data they used. Shareholding is a concept that is consistent with the ethical principle of justice in health care.

6. Role of Information and Communications Technology in Patient Empowerment

To improve patient access and control over data, patients need new technologies that allows them to download their data at will, that can tag and track their data to give them greater transparency over where their data goes, who uses it and for what purpose. They also need new technologies to allow them to give and revoke permissions for the use of their data. Although blockchain technologies are overhyped in healthcare, this is one area where they may have a role in providing transparency and control over data for patients. The blockchain, properly implemented, would allow patients to see who had a copy of their data, see who was requesting their data and for what purpose and grant or deny access to their data based on their own preferences and inclinations.

To enable greater knowledge and information, patients need access to tools that can improve their health literacy, their knowledge about their own diseases and what options they have to control them. To support patient autonomy, physicians need scalable and sustainable tools to help them understand a patient's readiness for change so that patients lead the way, rather than the other way around. Physicians also need tools to help them engaged in shared decision-making with their patients. Patients also need tools that can help them understand their own motivations and engage themselves in caring for themselves. Patients and caregivers also need access to technology that can help them navigate the health system so they can get the best care in the most efficient way.

To enable shareholding, the blockchain and other data tracking technologies may play an important role by allowing patients and companies to track where a patient's data went, by whom it was used and what benefit a company may have derived from it.

7. Conclusion

This paper makes a contribution to the patient empowerment literature by pointing out that patient empowerment must be approached from an ethical perspective, rather than from one driven by cost-cutting, system efficiency or even improved patient outcomes. This ethical perspective provides guidance about which technologies are required and how they could be used to promote patient empowerment. The transformative and forcemultiplicative role of technology in patient empowerment should not be underestimated, as it is the only way that patients can level the playing field and control their own health destinies.

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