Proceedings of the 18th International Symposium on Health Information Management Research

Patient Empowerment and its Connection to Trust

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Patient Empowerment (PE) allows patients to be more active in managing their own health and quality of life. The aim of this paper is to analyze how trust affects PE, in the context of healthcare information systems. An interview study was conducted concerning patients' online access to electronic healthcare records. Results show that PE requires that patients trust the information that healthcare professionals and their electronic health record systems provide. Without trust, patients cannot control their own participation in relation to the healthcare professionals. This may result in a diminished ability to participate in the healthcare processes regarding their own care. Practical implications include acquired knowledge about and awareness of how trust influences PE, with particular emphasis on healthcare professionals. A trust model is presented that illustrates the trustor-trustee dimensions of PE. This model has both theoretical and practical implications in its illustration of how trust and PE connect.

Keywords

EHR, online medical records, patient empowerment, trust

1. Introduction

This article focuses on Patient Empowerment (PE) and trust in healthcare. Regarding healthcare information systems, PE requires a new approach, how to manage the patient information, in order to strengthen patient participation. The PE concept allows patients to take a more active role in the management of their own health and quality of life [1]. The focus of healthcare researchers is often on the providers' needs and requirements rather than on the patients' needs and requirements [2]. If the goal is to allow patients a more active role in their healthcare, both they and their providers require relevant and trustworthy information. The trust concept, which is somewhat vaguely defined and used in various research disciplines, is often treated as an objective factor in research at the same time that it is treated as a subjective concept [3]. As a consequence, the connection between people and technology is lost. To maintain this connection, a renewed focus on the patient perspective is needed that emphasizes the importance of trust in PE [1]. Björvell [4] p. 4816 writes: "Patient empowerment is a prerequisite for fully considering the patient's views of his/her illness and ability to contribute to the best possible health and life quality for the patient."

Yet, empowering patients is not a simple task, especially since there is disagreement on the definition of the PE concept. Gibson [5] p. 359 offers the following definition of PE: ''A social process of recognizing, promoting, and enhancing people's abilities to meet their own needs, solve their own problems and mobilize the necessary resources in order to control their lives.'' Thus, according to Castro [1], PE allows patients to exert more influence over their health by giving them more control over issues they consider important.

The argument in this article is that trust, including trustworthy patient information, (oral or digital) is essential for the empowerment of patients. In healthcare research, trust (which is sometimes associated with mutuality) is rarely grounded in a solid theoretical base. If trust is a prerequisite for PE, then trust requires a thoroughly worked-out structure that supports individuals, healthcare professionals, and decision-makers who want to empower patients.

ISBN: 978-91-89081-09-3
DOI: https://doi.org/10.15626/ishimr.2020.06

This article complements previous research with its integration of PE and trust. The aim of this article is to analyze how patient empowerment is affected by trust as a concept, in the context of healthcare information systems. The article seeks to answer two research questions: 1) How can the understanding of patient empowerment be clarified in order to frame the trust concept? 2) How can patient empowerment and the trust theory be explained and integrated in order to enhance the knowledge and understanding of patient empowerment? From a theoretical perspective, the article presents a conceptual model that connects the two concepts. From a practical perspective, the article addresses the healthcare community's attention to how trust (including trustworthy information) influences PE.

2. Patient Empowerment

A significant development in healthcare is the increasing focus on patient involvement in healthcare design, policy, and delivery that is intended to lead to greater PE. This development occurred concurrently with the trend towards a more participatory healthcare system. However, as Anderson and Funnell [6] observe, the PE concept is still somewhat surrounded by "myths and misconceptions" when used by various healthcare researchers and actors. Castro et al. [1] note that the absence of theoretical and conceptual clarity on PE has resulted in poor understanding and communication of the measurements and comparisons made in various studies of healthcare organizations. In a systematic review of measures used in PE, Barr et al. [7] conclude that PE is a complex concept that can be addressed from various perspectives: the patient, the healthcare provider, or the healthcare system. This article takes the public healthcare system perspective.

Healthcare researchers use various models to describe care concepts: patient-centered medicine, patient-centered care, patient-focused care, and patient empowerment care. These models have slightly different meanings, are used in slightly different contexts, and, according to Funnell [8], their implementation is unclear. However, the models all reflect the concern of the healthcare community with patients' health problems as well as with patient involvement in dealing with those problems.

In Patient-Centered Medicine (PCM), "the doctor and patient influence each other and cannot be considered separately" [9], p. 13. In the physician-patient relationship, which is the foundation of the care, the physician's approach influences the extent of the patient's trust in the physician and the information provided [10].

Patient-Centered Care (PCC) refers to the individualized care that is provided according to established standards [11]. Patients seek an integrated understanding of their world-as-it-is: of their whole person, their emotional needs, their life issues, and their relationship with physicians and nurses [12]. Holmström and Röing [13] describe the PCC model as a prerequisite for empowering patients.

Patient-Focused Care (PFC) may be used interchangeably with PCC [14]. PFC refers to the restructuring and redesigning efforts to free healthcare delivery from the constraints of existing methods, people, or departments [15]. The patients' needs in the focus rather than the providers' needs. This focus requires that patients trust the organization(s), healthcare professionals, and the associated technology. While each concept was dominant in the literature during the years indicated, none was a replacement concept. Over time, more actors were included in patient care. Trust that is created, exists, and is developed via relationships increasingly became more complicated as the concepts evolved.

Influential developments in healthcare in the 21st century are changing the landscape of healthcare delivery and information dissemination. These developments became particularly evident with the advent of healthcare technological information systems and the greater organizational focus on patient involvement in their own care. Two of these developments are described below.

Electronic Healthcare Record (EHR) systems digitally collect patient healthcare information and allow patients to view their healthcare information online. In this way, patients have more opportunity to become involved in their care. Patient empowerment is a complex process, as patients may feel empowered in one context but not in another. The European Patient Forum (EPF) works to promote patient involvement, empowerment, and health literacy among organizations at the European and national level. They define empowerment as follows [16], p. 4): Patient empowerment is "a multi-dimensional process that helps people gain control over their own lives and increases their capacity to act on issues that they themselves define as important." Empowerment is not a simple process, nor is it necessarily linear. It is important to understand that a patient can feel empowered in a particular context, and disempowered in another.

PE is rooted in a healthcare philosophy based on principles of patient autonomy and freedom of choice [17]. An empowered patient has the information needed to take responsibility for the healthcare services that aim to maintain his/her healthy mind and body. As the title of Kane's article states [18], "information is key to patient empowerment." For Degoulet et al. [19], the PE philosophy recognizes the "increasing ability of patients to actively understand, participate in and influence their health status." Kuijpers et al. [20] agree that that the PE philosophy is based on the understanding that patients need knowledge, skills, and motivation if they are to exert a positive influence on their own well-being.

Ûnver and Atzori [21] identified four dimensions of PE: patient knowledge, patient control, patient participation and patient support. These dimensions (see Figure 1) are useful in understanding what PE really is:

- Patient Knowledge –The patients' understanding of health information and their ability to use it. This knowledge includes most elements traditionally viewed as part of "health literacy" although the latter concept includes elements other than understanding of health information [2] .
- Patient Control –The patients' role in the management of their health and well-being. This dimension includes patient responsibility for their health management and treatment progress [22].
- Patient Participation – The involvement of patients with health professionals as together they explore the changing role of patients vis à vis the medical decision-making process. This relationship involves patient preparation for healthcare consultations on treatment [22].
- Patient Support – The health professionals' support for patients in the "empowering process". For example, these professionals may explain the EHR system to patients and whether patients understand their health information in the EHR [6].

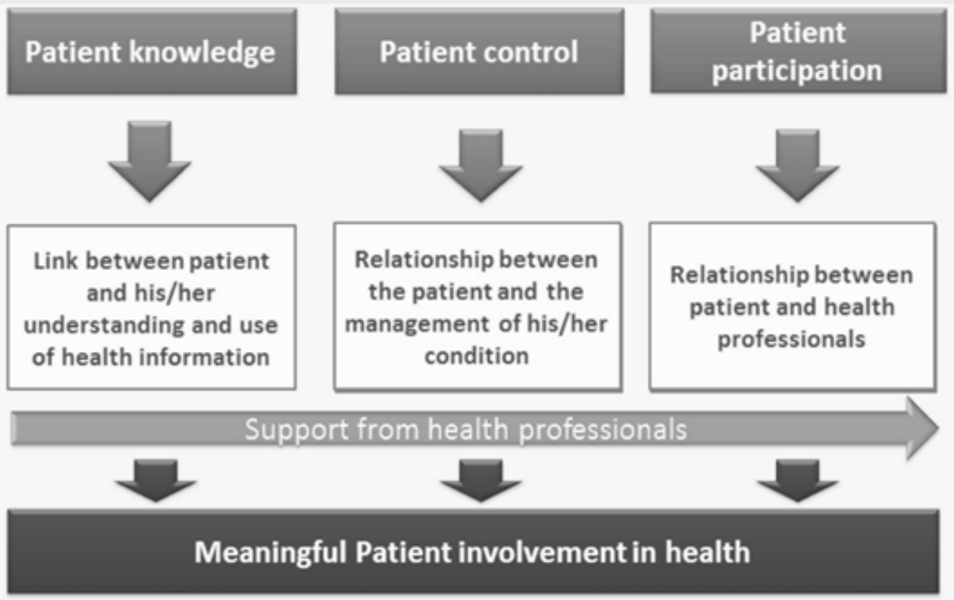

Figure 1 Illustration of the four dimensions of patient empowerment from Ûnver & Atzori [21].

As Figure 1 illustrates, a relational perspective exists for the first three concepts, all of which refer to the relationship between the patient and something or someone else. These three concepts all lead to support for the patient and for the patient's involvement in his/her healthcare and quality of life.

A key feature in these relationships is trust. To achieve full PE, trust is essential. As researchers have observed, access to their health records by patients enhances their communications with healthcare professionals [23]. Improved communications, in turn, lead to improved mutual trust, which motivates patient self-care and self-responsibility.

3. Trust and Trust Relationships

Trust is a widely used concept for a variety of purposes and in a variety of settings. Trust is sometimes defined as the willingness to accept vulnerability or personal risk [24]. This willingness is the foundation of trust relationships. Pourshahid and Tran [25] describe a trust relationship as the Trustor X-Trustee Y interaction that is intended to generate a shared gain (at the risk of loss to Trustor X). See Figure 2. The trust relationship creates relational capital that derives from the parties' social interaction, shared norms, and mutual goals. The trust relationship assumes a reduction in the risk of opportunistic behavior [26]. The parties' reputations are key factors in the establishment and development of the trust relationship.

Trust relationships (see Figure 2) can be direct or indirect. Indirect trust derives from the recommendations of independent parties while direct trust derives from the direct interactions between the parties [27]. Recommender trust, which is a form of direct trust, derives from sources that a party (or parties) trust [28], meaning there is a direct interaction between request and recommendation.

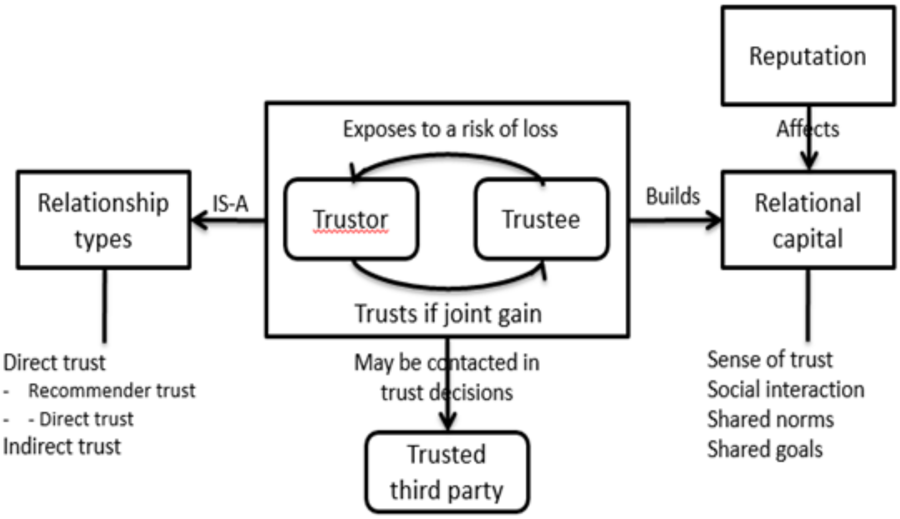

Figure 2 Trust relationships.

Trust may be described as each party's perception of the other party's ability, benevolence, and integrity [29, 30]. These attributes are also known as the trusting beliefs [31]. Ability refers to a set of skills, competencies, and characteristics that enable either party to exert influence within some specific domain of expertise [30]. Benevolence refers to the extent to which either party believes that the other party acts in a positive manner with the will do well without egocentric or profit considerations [32, 3]. Integrity refers to each party's perception of the other party's devotion to a set of generally accepted principles [30].

Trust relationships may exist at different levels: organizational, personal, and technological. Organizational trust is the trust that underpins, for example, the sharing of vital systems knowledge [33]. This trust is a governance mechanism that is necessary for conflict resolution, intra- and inter-organizational goal setting, and the creation of shared values that enable employees to work together more productively [34, 3]. Personal trust is the trust between parties based on words, actions, and decisions [35].This trust increases the parties' vulnerability to the actions of others whose behavior cannot be controlled [36]. Technological trust is the trust derived from the parties' belief that the underlying website technology infrastructure and control mechanisms can facilitate the transmittal of reliable information [32].

3.2 Research on Trust in Healthcare

Researchers have not deeply investigated the connection between PE and trust, many of them have examined various aspects of trust in healthcare in a variety of healthcare settings. Several studies discuss trust in healthcare but do not connect trust to PE. Gordon et al. [24] rated their pre-visit and post-visit trust in physicians and in the healthcare system at follow-up outpatient visits. They found that post-visit trust in the physicians was significantly higher than pre-visit trust. Li et al. [29], examined how patients can participate in the management of their digital health information proposed a trust-enabled fair social contract model. The model is designed to test whether patients' intention to use digital health information is driven by trust. Lord et al. [33] assessed the effect of patient-physician trust when patients are diagnosed with cancer. Trust in the hospital, the general practitioners, and the National Health Service was very high. McAlearney et al. [34] explored perceptions of trust and distrust of healthcare providers and the medical care system. Patient-centered communication and healthcare provider encouragement increased the women's trust in their physicians and the medical care system. In previous research, Söderström et al. [35], used a trust matrix to analyze trust issues related to EHR. This matrix contrasts the three levels of trust (organization, personal, technological) with the three trusting beliefs (ability, benevolence, integrity). The study revealed flaws in current practice and highlighted the need for different levels of trust perspectives. The study also identified three areas where challenges exist: the need for greater trust in patient-focused healthcare, for improved communications between patients and healthcare professionals, and for the use of clearer terminology. Although Söderström et al [35] touch on PE with the reference to patient-focused healthcare, and do not identify relevant research issues related to PE. This article will take the analysis one step further: to connect central trust concepts to central PE concepts.

4. Research Approach

The empirical material included in this research origins from DOME, an extensive healthcare information systems project [36] as presented in Rexhepi et al [41], where the methodology applied in this study is also described. The entire study underpinning this paper builds on interviews with patients with access to their EHRs online, with a purpose of improving patient opportunities to access sufficient information and thus enabling PE. The quotations presented were extracted directly from their interviews with 30 cancer patients. We rephrased some passages to make them easier to understand.

Our data analysis was inspired by autoethnographic studies. We used the Rexhepi et al. [37] interview quotations as stories that use the trust model and the four PE dimensions. Our analysis follows Maréchal [38] p. 43) as a "form or method of research that involves self-observation and reflexive investigation in the context of ethnographic fieldwork and writing." The connection between PE and trust is evaluated in the context of digital health information.

Qualitative data-analysis is an iterative process. The primary-level interpretation in the data collection process, allowed interviews to expand on relevant themes and topics, and enabled data collection to become more fruitful in relation to the aim of the study [39]. Secondary-level interpretations were performed when all data had been collected and consisted of a qualitative conventional content analysis [40].

5. Connecting Patient Empowerment and Trust

In this section we present the results of our analysis in which patients' comments are used to illustrate the connections between PE and trust. The quotations selected come from several different respondents, and they mirror the views of the majority.

5.1 The Relationship between PE Concepts and Trust

This section is structured according to the four PE dimensions (Patient Knowledge, Patient Control, Patient Participation, and Patient Support). The primary focus is PE and trust that results from patient access to their healthcare information on an EHR system.

Patient Knowledge

Patients require knowledge about their own health. Ready access to relevant and understandable information is a prerequisite for the other three PE dimensions. Traditionally, patients only received information orally during the patient meeting. Today, however, with the possibility of access to EHR systems, many patients can also read this information online. This technological development increases the pressure on healthcare professionals to express themselves in ways that patients can understand. The possible risk of misunderstandings should not be ignored.

"...the more information/knowledge one can get, the better I feel ... the only concern about it is that one could misinterpret something because you do not understand. But you should be able to call the doctor if you do not understand.... "

Patient knowledge develops in trust relationships. Patients (the trustors) trust the healthcare professionals (the trustees) and the healthcare information available on the EHR systems. The ability to access EHR information can provide valuable knowledge that increases trust. However, patients who access knowledge from EHR entries may not always understand what they read or may not always trust what they read. Additional communication is often necessary when direct information from healthcare professionals is too skimpy, too vague, or too complex with its use of professional jargon.

"I want to know even if it's bad news. It does not get any easier just because you get the same information two days later verbally from a doctor or because someone says, it is not so dangerous and so on. No, I want clear answers. "

These complementary ways of communicating healthcare information can strengthen the trust of patients in their healthcare providers and in the healthcare information systems. Trust that builds over time is powerful, experience-based trust. Patients who receive reliable information at one interaction are more inclined to trust the information provided at the next interaction.

Patient Control

Patients are more empowered if they have some control over their health. Access to an EHR system allows patients to review and confirm their diagnosis and treatment plan. They need not rely on memory to recall what was explained orally to them often explained in stressful circumstances.

"I read mainly because I want to double check that I understood everything correctly."

"Yes, it is clear that it has given me more safety, [...] before, one could not read it. When I could, I started to read all about it."

With access to their health information that they can monitor online, patients may take more responsibility for managing their health. This sense of control over their health (and lives, in some cases) reinforces the trust patients place in healthcare professionals and their information systems.

Patient Participation

Patients who are allowed to participate in decisions related to their healthcare feel more empowered [41]. For example, they are better prepared when they meet with their healthcare providers if they have reviewed their files in an EHR system.

"I feel more prepared for the doctor's visit. I can ask more appropriate questions based on what I've read."

Patients with access to an EHR system may identify gaps in the information entered. They may then request that additional information be made available at their next physician or nurse meeting. A less positive outcome, however, may be that patients who identify information gaps may experience some loss of trust. Patients may think they were not properly listened to or were assumed unable to understand the information. PE means that patients trust that information is not withheld from them and that their participation is welcomed.

Patient Support

Healthcare professionals support patients in numerous ways. One important way to provide support is to give patients adequate, relevant information. Patients need more than crumbs of information. They require comprehensive access to their health information (in part, from EHR systems) so that they can help make decisions. Trust in such support empowers patients.

Healthcare professionals are sometimes reluctant to share too much information with patients. They do not want to scare patients unnecessarily or to confuse them needlessly with the complexity of medical terminology. These concerns may prevent some healthcare professionals from providing the support that empowers patients. Lack of adequate patient support can threaten PE.

"... now it almost seems like they (healthcare professionals) are a little afraid that people (patients) will be frightened to death in some way, and I don't think so, because then they underestimate the patient ... and I mean ... if we actually have all these cancer diseases, then we are also able to read about it."

Therefore, it is essential to establish and maintain the physician-patient trust relationship if patients are to be empowered. Close attention should be paid to the four PE dimensions described above. PE is a process in which a culture of trust is cultivated over time. In such a culture, patients' needs and wants must be supported. Distrusting situations should be identified and managed.

The recent digitalization of patient information removes any physical information sharing obstacle, there is nothing to hide behind anymore. The cultural shift regarding EHR needs to include healthcare professionals viewing patients as being equal and able. As Edwards and Elwyn [44] write, patients who are empowered can be trusted to participate in their own care.

5.2 Analysis of PE and the Trust Model

The principal idea behind PE is that patients should (and should be allowed) to take a more active role in making decisions on their health. PE is more likely achievable when trust is taken into consideration. Understanding the role trust plays in empowering patients can, for instance, facilitate required cultural shifts (see Figure 3).

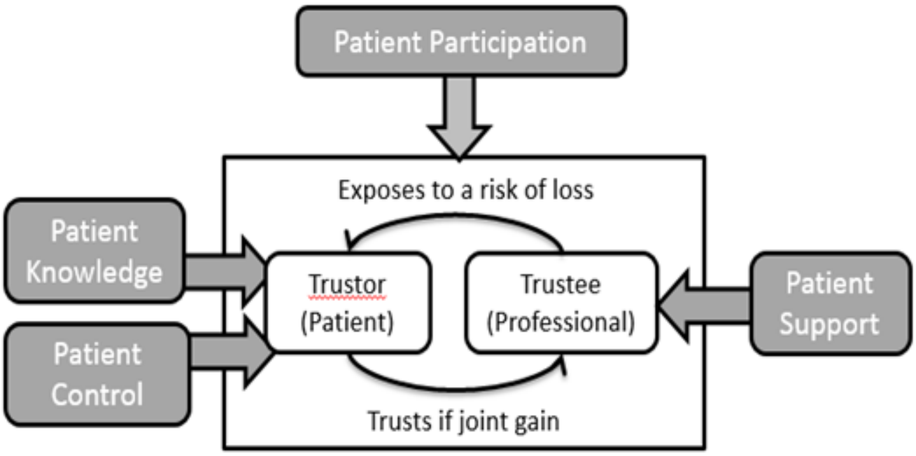

Figure 3 PE versus trust relationships.

As the trust model in Figure 3 illustrates, the two dimensions of Patient Knowledge and Patient Control refer to the trustor's role in the trust relationship. If patients are to be empowered, they must have sufficient knowledge about their health and sufficient control over decisions related to their health. The dimension of Patient Support refers to the trustee's role in the trust relationship. The trustee (i.e., the healthcare professional) should ensure that the trustor (i.e., the patient) receives personalized interventions as needed. Mutual trust is essential. Patient Participation is the umbrella dimension that can expose trustor and trustee to the risk of loss or can benefit them with the possibility of joint gain. The relational capital is a concept of trust. Patients and physicians get to know each other, know how to expresses themselves and in what way to address a subject to get clear answers. Patients must believe in physician abilities in order to trust them, in their benevolence in acting in the patient's best interest, as well as in the physician's integrity [30].

When the trust relationship functions well, both trustor and trustee thrive. The patient is empowered by knowledge of and control over his/her health. The healthcare professional benefits from the active role the patient takes in participating in decisions and in monitoring his/her health. The part that health information systems plays in this relationship is essential for supplementing, reinforcing, and explaining physician-nurse communications. Such technology cannot be seen as merely peripheral to the physician-nurse oral communications.

A higher degree of empowerment requires an understanding of the complexities of trust. Using a trust lens in Figure 3, it becomes apparent that trust is present and necessary in all parts of healthcare. If a patient is to make good use of healthcare information, s/he must trust that the information is correct, as well as trust that the technology storing the information is solid and safe. Also, the relationship between patients and healthcare professionals is built on interpersonal trust [35]. Understanding and examining trust in a healthcare setting is therefore vital in order to take patient empowerment to the next level.

It is noteworthy that this is like two sides of the same coin - there are advantages and disadvantages with both perspectives. What is clear is that the trust model and research into trust must be clarified and complemented with a person's trust in him-/herself, regarding both patients and healthcare professionals. Good care is more difficult to achieve if the patient does not trust him-/herself.

6. Discussion and Conclusions

Society is currently striving to become more digital, but the full potential thereof will not be achieved unless trust becomes an integral part. True PE, participation and inclusion require considering and building trust into the context of healthcare information systems.

The aim of this article is to analyze how patient empowerment was affected by trust as a concept, in the context of healthcare information systems. The historical context of this article is the placement of patients at the center of healthcare that has evolved and strengthened in subsequent decades. The analytical tools used to explore this relationship were the four PE dimensions of Patient Knowledge, Patient Control, Patient Participation, and Patient Support. Based on this analysis, a trust model was created that illustrates the connections between these dimensions with the focus on the roles of the trustor and the trustee. Trust in healthcare and related systems is essential in order for patients to feel and become empowered, as well as for enabling healthcare personnel in the provision of high quality care. Patients, as trustors must believe in the abilities of the healthcare professionals and systems to provide them with the best possible care, as well as in their inclination to act trustworthy and in their integrity to adhere to common set principles. Without trust, patients cannot control their own participation in relation to the healthcare professionals. This lack can also result in diminishing the ability to participate in the healthcare processes including the healthcare information systems regarding their own care.

The questions posed in this research were the following: What is the relationship between the patient empowerment concept and the trust concept? 2) How can the trust concept be integrated with the patient empowerment concept in a way that increases our understanding of patient empowerment?

In response to the first question, our analysis, building on an empirical study, reveals that empowering patients requires that a mutually beneficial trust relationship be established and maintained between patients and healthcare providers. Patients must trust that healthcare professionals and systems can provide them with the best possible care. They must also trust that healthcare information systems provided them (whether by professionals or by technology) is reliable, relevant, and comprehensive. Without trust, patients cannot control their own participation in their own healthcare decisions.

In response to the second question, our analysis supports the claim that one promising ways to connect trust and PE is to make electronic health records (EHR) available to patients. These healthcare information systems allow patients to read and examine their medical histories, diagnoses, treatment plans, radiology images, and much more. Using such technology, patients may better understand physician-nurse oral communications as they review past physician-nurse consultations and prepare for future physician-nurse consultations. This analysis reinforces the importance of PE with trust at its core. One of the important aspects of PE is the patient's access to and use of digital healthcare information systems. Such an approach is not primarily technical, but rather involves culture, work processes and issues concerning healthcare professionals. In the overall evaluation, the use of healthcare information systems have considerable potential for enabling PE [43].

This article explores the relationship between PE and trust to an extent not previously discussed in the literature. The results of this study have both theoretical and practical implications. The trust model can be used to explain and promote trust incentives in healthcare at the organizational, personal, and technological levels.

This article also concludes that the "hard" perspective (the technological element) of trust provides practical support for the "soft" perspective (the human element) of trust. From a practitioner perspective, this study emphasizes the importance of how PE is enhanced when the four PE dimensions are considered as trust-creating tools. This study provides support to healthcare providers as they develop patient trust in their practices and system.

Practical implications include acquired knowledge about and awareness of how trust influences PE, with particular emphasis on healthcare professionals. If such actors use the results from this study, they will have a more solid base for taking action and implementing changes based on the new knowledge that will foster creation and maintenance of trust throughout the healthcare organization. Their enlightenment will also, to a greater extent, enable patients to become participative, and thus empowered. The softer aspects of trust that extend the concept beyond technology ought to be included when developing systems, services and trust.

We offer the following suggestions for future research: Empirical studies on trust in digital patient-related information (e.g., case studies). Such studies should result in a model for patient safety from a trust perspective that encompasses all levels of trust; Investigation of how the trust model can be used in practice (e.g., with the use of guidelines, checklists, etc.), in collaboration with healthcare organizations for practical viability; Standardization of EHR templates (e.g., for healthcare plans for specific diagnoses). These will not have the desired impact, however, without also focusing on how to organize educational efforts to achieve structured security functions; and Evaluation of education programs that teach the use of healthcare technology designed for patient use.

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