A Patient's Perspective on Decision-making for the Adoption of Digital Care Pathways

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Abstract: Healthcare Information Systems (HIS) are implemented to provide high-quality, patient-centred care. Yet, there is little evidence about the decision-making role patients play for the adoption of HIS nor what factors patients deem essential in the adoption of HIS. To guide healthcare practitioners in decision-making for the adoption of HIS, this study reports on the key factors which influence patients' perception and use of HIS. Specifically, a qualitative study was conducted with 15 patients to understand the phenomenon of patient decision-making for the adoption of HIS. Our findings identify the concept of 'Digital Care Pathways' and indicate that there are four primary decision factors which influence the adoption of HIS: (i) trust; (ii) fear; (iii) ease of use; and (iv) accessibility. To synthesise the findings, we present the patients decision-making framework for digital care pathways as a first step to encapsulate the patients' perspective of decision-making factors associated with adopting innovations for digital care pathways.

1 INTRODUCTION

Healthcare delivery systems throughout the world have been made possible by the advancement of Information System (IS). Increasing attention has been given to implementing healthcare information systems (HIS) in hospitals, particularly regarding the need to consider the acceptance and usage of HIS among healthcare professionals (Ismail et al., 2015).

We coin the phrase 'Digital Care Pathways' to refer to online services provided by hospitals. Digital Care Pathways can provide a digital solution to the patients, and it may bring other benefits, such as standardized care and greater control over the delivery of care. HIS is one of the applications that can be used to provide a digital solution for patients. By adopting HIS applications, hospitals also gain significant benefits, ranging from improved diagnosis, thereby delivering better patient care and improved the support of clinical decision-making. This enhances hospital productivity, lowers costs, and reduces medication errors (Aron et al., 2011). Technological advancements made in medical science have offered new choices which are upgrading outcomes of care, yet it has inadvertently dissociated clinicians from the patients. Therefore, a healthcare environment has

been established where, often, patients and their families are not involved in their significant treatment decisions and discussions. Patients can be left in obscurity about how their issues are being handled and further on how to direct the profound range of diagnostic choices accessible to them (Epstein et al., 2011).

1.1 Patient-centred Care

The term, "patient-centred care", was introduced by the Picker/Commonwealth Program for Patient-Centred Care (now the Picker Institute) to present the significance of having a better understanding by clinicians of the patient and family experience of illness. Additionally, patient-centred care should support patients' needs during their time in a very difficult and often complex care delivery system (Barry and Edgman-Levitan, 2012). Over the past few decades, renewed focus had emerged around patientcentred care as an attempt to avert the trend away from focusing on diseases and reverting back to the patient's needs and satisfaction (Gerteis et al., 1993).

The most significant characteristic of patientcentred care is the dynamic commitment of patients when healthcare choices must be made — moreover,

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when an individual patient lands at an intersection of medicinal possibilities, diverging pathways have extraordinary and significant results with lasting ramifications. These include, for instance, decisionmaking in major surgeries, prescriptions to be taken for the rest of a patient's life, and screening and symptomatic tests that can trigger upsetting interventions. The procedure by which the optimal decision might be reached regarding a patient is termed as shared decision-making. It includes, at least, a clinician and the patient, while other members from the medical team or households might be allowed to participate. Every member is in this way outfitted with a better comprehension of the pertinent factors and wisely shares responsibility in the choice about how to pursue treatment (Delbanco and Gerteis, 2012).

The adoption of HIS is similarly an essential decision in a hospital, and central to this is the decision-making process. However, despite an accumulation of best practices, frameworks and research which has identified success factors, the function of hospital decision-makers, especially patients, in the adoption process of new technologies remains unreported (Yang et al., 2013).

1.2 Problem Statement

The objective of this paper is to report on an empirical study conducted with patients on the role they play in decision-making for the adoption of HIS. We look particularly at the assumptions around 'patientcentric' technology and the role of patients in decision-making.

There is an apparent lack of insight into what role patients play in the decision-making for the adoption of HIS and whether they should be involved in the decision-making process. To address these gaps, we formulate the following research questions:

- *RQ1*. What role do patients have in decision-making for the adoption of HIS?
- *RQ2*. From the patient's perspective, what are the decision-making factors for the adoption of HIS?

2 BACKGROUND

2.1 Patient-centred Care

The Institute of Medicine (IOM) defined patientcentred care as "care that is respectful of and responsive to individual patient preferences, needs, and values" by thus ensuring "that patient values guide all clinical decisions" (Barry and EdgmanLevitan, 2012). This definition highlights the importance of clinicians and patients working together to produce the best outcomes possible.

Patient-centred care depends on the nature of individual, professional and organizational connections. In this manner, endeavours to advance patient-centred care ought to consider the patientcenteredness of patients (and their households), clinicians, and wellbeing systems (Epstein, 2010, Epstein et al., 2011). Helping patients to be progressively dynamic in consultations changes years of doctor-commanded communications to those that draw in patients as active about what patient-centred care truly implies, however, can create endeavours that are specious and implausible.

Despite the discussions around patientcenteredness, hospitals have been adopting technologies without having discussions with the patients (Barry and Edgman-Levitan, 2012). Besides, while adopting technologies may upgrade the patient's experience, they have failed to accomplish the objectives of patient-centred care. Calls for patientcentred care have frequently stressed the execution of infrastructural changes (Epstein et al., 2011). These changes, such as adopting HIS, may be necessary to move medical care into the 21st century, but they should not be conflated with achieving patient-centred care. Simply implementing HIS in itself is not patientcentred unless it strengthens the patient-clinician relationship, promotes communication about things that matter, helps patients know more about their health and facilitates their involvement in their care (Epstein and Street, 2011).

2.2 Impact of HIS

Lippeveld et al., (2000) defines HIS as "a set of components and procedures organized to generate information which will improve healthcare management decisions at all levels of the health system". HIS has the potential to address many of the challenges that healthcare is currently confronting. For example, it can improve information management, access to health services, quality and safety of care, continuity of services, and costs containment (Lippeveld et al., 2000).

Technological advances have encouraged the development of new technologies that drive connectivity across the healthcare sector such as software apps, gadgets and systems that personalise, track, and manage care using just-in-time information exchanged through various patient and community connections (Leroy et al., 2014; Carroll, 2016). This paradigm shift has contributed to advancing healthcare

practice, highlighting our growing reliance and need of digital care pathways to support healthcare decisions. However, without involving patients in the decisionmaking process, it may impact how patient-centred care is received (Epstein and Street, 2011).

Digital care pathways provide the opportunity for healthcare providers to meet the demands of highquality patient care and makes all-encompassing healthcare support possible, thereby playing a dominant role in improving health processes and in the provision of patient care services worldwide.

2.3 Involvement of Patients in Decision-making – Does it Matter?

Policies to encourage shared decision-making have become prominent in the United States, Canada, and the United Kingdom (Elwyn et al., 2010). This is partly because of a recognition of the ethical imperative to properly involve patients in decisions about their care (Mulley, 2009). Shared decision-making is an approach where clinicians and patients make decisions together using the best available evidence. By doing so, they likely know the benefits or harms of each so that they can communicate their preferences and help select the best course of action for them. Shared decision-making respects patient autonomy and promotes patient engagement (Elwyn et al., 2014).

Despite considerable interest in shared decisionmaking, implementation has proved difficult and slow (Légaré et al., 2008). At the minimum, three conditions must be set up for shared decision making to be part of mainstream clinical practice: provide access to evidence-based information about medication choices; direction on the best way to weigh up the impact of various choices; and a strong clinical culture that may encourages patient involvement (Elwyn et al., 2010). In addition, Carroll et al. (2016) outlined the importance of community care and the need for more patient-centric focus in decision-making. These authors outline some options for creating a sustainable decision support platform for patients that may facilitate wider adoption of shared decision making in clinical practice.

2.4 Need for Patients Decision-making Framework for Digital Care Pathways

According to Baker et al. (2002) "decision-making is regarded as the cognitive process resulting in the selection of a belief or a course of action among several alternative possibilities". Technology adoption decisions in hospitals may occur through planned acquisitions or uncontrolled changes in medical practice. They reflect a complex set of dynamics and incentives (Gelijns, 1992).

There are different decision-making models and theories used to define a hospital's decision to adopt the technology. The first set of models include the profit-maximization model (Focke and Stummer, 2003), and the fiscal managerial system (Lennarson Greer, 1985). These theories presume that hospitals assess new advancements from the viewpoint of clinical gains, and advances obtained when the estimated regular estimation of income surpasses the expected expense over the valuable lifetime of the item. Hospitals embrace capital-concentrated advancements unrelated to their expense to accomplish technological prevalence and to upgrade their reputation. It helps hospitals as pioneers in the technical domain, tempting patients, doctors, and scientists (Anderson et al., 1994).

Nonetheless, medical administrators may often choose to put resources into monetary loss activities that can enhance medical exposure and draw in patients for other parts of the hospitals (Teplensky et al., 1995). The medical-unorthodox viewpoint (Lennarson Greer, 1985) centres around the delivery of services as per the requirements of doctors or medical administrations. Its likelihood depends on elementary presumptions that the doctors and the clinic receive new technologies dependent on the medical needs of the population they serve, regardless of whether monetary limitations, competition, or estimation of hospital repute recommend alternative conducts. In contrast, hospitals do not embrace innovation, regardless of its exceptionally beneficial nature, if patients cannot procure significant advantages from it.

Several other theories such as Technology– Organization–Environment (TOE) framework (Tornatzky et al., 1990), and Human-Organization-Technology–fit (HOT-fit) (Yusof et al., 2008) have been suggested to describe hospital behaviour and adoption of new technology, yet none of these perspectives has tried to explain technology adoption decisions from the patient's perspective or has considered patients as a stakeholder (Yang et al., 2013).

3 METHODOLOGY

This study aimed to comprehensively analyse the decision-making factors on the adoption of digital care pathways in a hospital setting. For this purpose, we performed a literature search, which focused on the decision-making about the adoption of IS in general and HIS in particular. The detailed protocol and results of the literature review are available in our technical

report (Abbas et al., 2019). Following the literature review, we conducted exploratory interviews with fifteen patients who were undergoing treatment in the hospital and using HIS as part of their care pathway.

The hospital we studied is the second largest maternity hospital in Ireland, with an average of 5,000 births per year and the sole provider of obstetrical, midwifery and neonatal intensive care to the Mid-West region. It is managed by the Irish Government's Health Service Executive (HSE) within a hospital group. This hospital moved from phone consultation for diabetic pregnant patients to virtual clinics which includes video consultation with patients.

We used the methodical approach of qualitative semi-structured interviews since they not only provide an interviewing process that targets the identification of the relevant determinants of the role patients can play in the decision-making process, but it also allows new viewpoints to emerge freely (Britten, 1995).

All the 15 interviews were recorded and subsequently transcribed. Interviews were conducted between February 2019 and August 2019. The ethical approval was granted for these interviews through the ethics committee.

Data analysis was undertaken using thematic analysis (Guest et al., 2011). Initially, in thematic analysis, we coded data according to key themes and its various subcategories. All the interview transcripts were analysed and coded, according to the guidelines suggested by Saldaña (2015).

In the first cycle, the entire transcript was read in detail line-by-line. We performed descriptive coding, bearing in mind our research questions. This was followed by relating categories to their subcategories. We then mapped our findings according to the literature while remaining open to the identification of alternative and new categories of concepts. Once a relationship was determined, the focus returned to the data to question the validity of these relationships to decision-making factors. Thus, by blending the strengths of our analysis and coupling them with our literature review, concept mapping offered a way to represent meaning to the decision-making concept.

4 PATIENT DECISION-MAKING FRAMEWORK FOR DIGITAL CARE PATHWAYS

Lennarson Greer (1985) suggests that that the clinicians and the hospital adopt new technologies based on the clinical needs of the patients. While the decision to adopt healthcare technology is based on

patients need is described, the patients are not involved in the decision-making process. As a first step for involving patients in the decision-making process for the adoption of HIS, we developed the 'Patient Decision-Making Framework for Digital Care Pathways' (Figure 1) that captures different decision-making factors from the patient's perspective. Central to this is the idea that patients need to be aware of the advancements in Digital Care Pathway and how it helps them in improving their care. In the norm, a Digital Care Pathway does not alter how healthcare is delivered to the patients but alters the medium of the care.

Based on the interviews, we identify patients' key decision-making factors for the adoption of digital care pathways and present them through our framework. The main contribution from our framework is that we have identified four main patients' decision-making factors for the adoption of digital care pathways - trust in the adoption of the digital care pathways, fear of privacy and safety, ease of use of the digital care pathways, and accessibility to healthcare. As described earlier, there is a growing consensus that hospitals are setup with a view to patient-centred care and one should involve the patients in the decision-making. Yet, we have observed a lack of involvement of patients in decision-making for digital care pathways. Our framework and the four factors provide an approach to define the context of digital care pathways adoption to support patients' decision-making. We describe each of the four factors and how literature supports our framework.

4.1 Trust in Adoption of Digital Care Pathways

Trust in technology influences the use or adoption of a technology (Abbas et al., 2017). Trust is defined by Amoroso et al. (1994) as a "level of confidence or degree of confidence" and trust in technology is defined as a "degree of confidence that the technology satisfies its requirements". Since the definition is expressed as a "degree of confidence", Amoroso et al. illustrate that trust is dependent upon management and technical decisions made by individuals or groups of individuals evaluating the technology. Trust in digital care pathways is expressed in terms of a set of requirements, where the 'set' is variable. For example, HIS trust may be dependent on the set of functional requirements or maybe a critical subset of functional requirements, or it may be some set of requirements that include non- functional assurance requirements like accuracy or reliability (Amoroso et al., 1994).



Figure 1: Patient Decision-Making Framework for Digital Care Pathways.

Patients described three sub-factors of trust that they deemed to be an important of the decisionmaking process - reliability, accuracy and efficiency.

Van Velsen et al. (2016) discussed trust in a rehabilitation portal technology, which was mainly determined by its reliability. They defined reliability for the rehabilitation portal technology as: "*That it works properly; is not constantly offline. But also scientifically reliable*". For patients, reliability is the probability of the technology delivering results that are consistent with their clinicians' understanding. Carbone et al. (2013) defined Accuracy for HIS as "information generated to the extent to which test results, diagnoses and treatments are error-free".

For patients, the accuracy of digital care pathways was one of the decision-making factors that should be looked into before its adoption. One of the patients mentioned: "my first thoughts to decide virtual clinics would be its accuracy because else I don't want to use virtual technology that is giving error generated results".

Efficiency and quality have been discussed regularly in the literature. The efficiency of technology is one of the decision factors defined by (Egea and González, 2011) for a clinician's acceptance to use and trust technology. They explain, "a clinician who uses healthcare technology is concerned by the quality and efficiency of the system which impacts the patient's care. Effectiveness of the technology is that it can give a quick response or reaction with minimal resources and/or time taken".

Patients thought the efficiency of virtual clinics is one of the decision factors that supported the hospital in adopting it. One patient stated that: *"How can* (hospital) decide to use virtual clinics if it was not efficient enough while managing their time and patients as well".

4.2 Fear of Loss of Privacy and Safety

Fear of lack of regulations around privacy and safety of patient's data was another factor that was mentioned by patients as one of the main decisionmaking factors to adopt virtual clinics. Researchers who have published on this topic, advocate for regulations to protect privacy and ensure safety. However, patients continue to have a fear of a data breach. For example, Hsieh (2015) describes privacy as the potential loss of confidential patient data in Electronic Medical Record exchange systems as a reason for low adoption by the hospitals. Patients interviewed were concerned by the change of General Data Protection Regulation (GDPR) regulations and the impact it may have on their privacy of data. When asked about the virtual clinics decision-making factor that they think was considered, one patient mentioned that: "my concerns around virtual clinics decisionmaking will always be around privacy of my data and the lack of awareness given to me around it ... no one briefed or talked about it".

Similarly, patients considered that the safety of their treatment as one of the Hospitals decisionmaking factors to adopt virtual clinics. One of the patients had concerns around the usage and safety of virtual clinics stating that: "this is all government doing to facilitate hospital, they have fewer resources, and this is all to utilize that else why would you implement something virtually when physical consulting is safer and makes sense to the patient".

4.3 Ease of Use of Digital Care Pathways

Ease of use of digital care pathways refers to how patients see ease of use and comfort in using as leading to the adoption of digital care pathways. Almost every patient mentioned ease of use as a leading decision-making factor in adopting virtual clinics. Patients see virtual clinics as a means to provide comfort in treatment, or as a means to ease staff workload. Barry and Edgman-Levitan (2012) advocate for this, stating that "patients need to be involved in determining the management strategy most consistent with their preferences and comfort".

It was noticed that long waiting times could be minimized from both the patients and the healthcare professional's perspective. One of the patients stated that "I have small kids, going to the hospital with them is tough. Through virtual clinics, I have specific time with my clinician, and I don't have to wait in long queues".

4.4 Accessibility to Healthcare

The fourth patient decision-making factor that our framework captures is accessibility. Accessibility covers the connectivity to the resources as well as access to the resources. Access to resources describes how patients think implementing virtual clinics has helped to end long queues and wait time by utilizing less staff and space in the hospital. One of the concerns patients had with the implementation of virtual clinics was the thought process behind the connectivity to access virtual clinics. Patients living in remote areas were concerned by their internet speed and how these virtual clinics can be assessed.

Patients who had to travel a long way applauded virtual clinics and how it solved their problem of travelling. Also, it was noticed that long waiting times could be minimized from both the patients and the healthcare professional's perspective. One of the patients stated that "As a virtual entity given that our geographic area is quite big, I find it very difficult to come to the hospital, it makes sense to introduce this service and to do everything virtually".

5 DISCUSSION AND CONCLUSIONS

Globally, patient-centred care is talked about in modern healthcare, yet challenges remain to regularly engage patients in decision-making. This is echoed by Barry and Edgman-Levitan (2012), who claim that engaging clinicians and patients in decision-making can help to achieve quality and trust: "Recognition of shared decision making as the pinnacle of patientcentred care is overdue". To build a truly patientcentred healthcare system, we need to involve patients in decision-making, not only about their treatments, but also about the decisions to adopt digital care pathways.

We also studied the role which patients play in the decision-making for the adoption of digital care pathways. In the case study we conducted, one of the decision factors from hospital perspective for the adoption of virtual clinics was on patient-centred care and making the experience better for patients, but we found that patients themselves did not play any role in the decision-making for the adoption of the virtual clinic.

Although patients were happy with the care and did not express an interest in participating in the decision-making for the adoption of virtual clinics, they did contest the decisions to adopt virtual clinics as not being patient-centred. One patient stated "I see virtual clinics as help to midwives, it has nothing to do with patients. If I was on private insurance, would they have adopted virtual clinics?".

Generally, patients were satisfied with the care hence less concerned with the involvement in the decision-making process. One patient stated that "I am happy with my care so yes it makes sense that my involvement is minimal and having no experience in decision-making, what would I suggest anyways". Another patient stated that "I am not an expert so consulting me with decision-making is not a good option, I am happy the way my treatment has gone and for me, the care is the only factor that matters".

There is some evidence that when patients have made well-informed decisions, they also follow better treatment routines (Joseph-Williams et al., 2010). Patients are encouraged to think about the available screening, treatment, or management options and the likely benefits and harms of each so that they can communicate their preferences. As stated by Stacey et al. (2017) "when informed patients face discretionary treatment, they make more conservative decisions, often deferring or declining interventions". These effects seem to be strengthened when patients are given decision coaching (a brief discussion with a trained facilitator) to help them with the process of discussion (Joseph-Williams et al., 2010).

We have identified that there is a gap, as different theories such as TOE, HOT-fit or the medicalindividualistic perspective do not involve patients in the decision-making for the adoption of digital care pathways. Therefore, we introduce the patient decision-making framework for digital care pathways which covers the patient's perspective in the decision-making process.

5.1 Future Work

Having established a foundation for the patient decision-making framework for digital care pathways, we will continue to build on this to establish key processes and factors to further develop the decision-making framework that includes both the hospital staff and patient perspective of decisionmaking factors for the adoption of digital care pathways. The concept of a digital care pathway may broaden the concept of how the medium of care for the patients be enhanced.

We present the framework as a first step that encapsulates research developments across patientcentred care and recognise a need for empirical research to validate patient decision-making. Our subsequent focus will be on extending and modifying existing techniques based on the identified patient factors during our analysis. Furthermore, we will test and refine it on a large scale with the healthcare sector.

One of the limitations of this study is the limited number of patients interviewed. As this is a project in progress, we are interviewing additional patients to strengthen our findings.

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454