

Representation of People's Decisions in Health Information Systems*

A Complementary Approach for Understanding Health Care Systems and Population Health

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Keywords

Population health, learning health systems, health information systems, complex systems thinking, social theory

Summary

Objectives: In this study, we aimed: 1) to conceptualize the theoretical challenges facing health information systems (HIS) to represent patients' decisions about health and medical treatments in everyday life; 2) to suggest approaches for modeling these processes.

Methods: The conceptualization of the theoretical and methodological challenges was discussed in 2015 during a series of interdisciplinary meetings attended by health informatics staff, epidemiologists and health professionals working in quality management and primary and secondary prevention of chronic diseases of the Hospital Italiano de Buenos Aires, together with sociologists, anthropologists and e-health stakeholders.

Results: HIS are facing the need and challenge to represent social human processes

based on constructivist and complexity theories, which are the current frameworks of human sciences for understanding human learning and socio-cultural changes. Computer systems based on these theories can model processes of social construction of concrete and subjective entities and the interrelationships between them. These theories could be implemented, among other ways, through the mapping of health assets, analysis of social impact through community trials and modeling of complexity with system simulation tools.

Conclusions: This analysis suggested the need to complement the traditional linear causal explanations of disease onset (and treatments) that are the bases for models of analysis of HIS with constructivist and complexity frameworks. Both may enlighten the complex interrelationships among patients, health services and the health system. The aim of this strategy is to clarify people's decision making processes to improve the efficiency, quality and equity of the health services and the health system.

1. Introduction

Health systems face increasing challenges to achieve a proper balance between efficiency, effectiveness, quality and accessibility [1, 2]. Undoubtedly, the social cost-benefit balance is related to three levels of decisions: the system as a whole (policies), health services (professionals) and patients (treatment compliance, behavior and lifestyle).

Information and knowledge at these three levels are at the core of health systems. At a healthcare level, professionals obtain information from anamnesis, physical examination, complementary studies and patient opinions. Relating this information to previous knowledge, experiences, training and scientific evidence, they make decisions that impact patient and health system outcomes [3, 4].

The health system level also relies on information and evidence to make health policy decisions impacting both the health system and society and to attempt to achieve the desired triangle of efficiency, equity and quality [1, 2].

Patients also make decisions about their health and treatments based on disparate sources of information (doctors, nurses, pharmacists, internet, media, friends, etc.), their culture and context, personal experiences and material resources at hand [5]. These decisions, which fit or do not fit with scientific evidence, medical knowledge or professional recommendations, translate into concrete actions, for example, prevention, treatments, procedures, behaviors, and lifestyle changes.

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Several information technologies have been designed to assist the system and physicians in dealing with data and to improve decision making (e.g., Electronic Health Record (EHR), Personal Health Records (PHR), Regional Healthcare Information Systems (RHIS), and Learning Health Systems (LHS)). The EHR and clinical decision support systems help practitioners and patients make clinical decisions [4, 6]. The LHS aims to help at a system level to make decisions, e.g., to help policymakers or community decision makers measure the performance of health services and healthcare providers, to evaluate the effects of interventions, and to provide measurable improvements to achieve greater value in healthcare and a better system as a whole [7, 8, 9, 10].

The LHSs are designed to be fed with routine data from health care processes in a broad spectrum of health care settings (e.g., primary care, emergency department, transitional care, and in-home care). These systems provide real-time evidence from the analysis of population databases through observational and quasi-experimental designs (comparative effectiveness research). Thus these platforms “learn” from the experiences of routine care processes and return these real-world experiences to the decision-making processes of doctors, health services and the health system [7, 11, 12].

However, health information systems (HIS) do not always consider the decisional process, procedures, technologies and contexts by which patients make their decisions. The incomplete representation of the patient's health decision processes in computer systems causes decision makers, such as physicians, politicians and administrators, to not have information about the realm of the patient's decision making process, not only at the individual level but also at familiar and community levels, e.g., the values and resources based on which patients adhere (or not) to medical indications, completely or incompletely, or even abandon treatments [13]. The lack of this information in the decision making process hinders the interpretation of the impact of health interventions on the everyday life of people and on the health system itself.

More and better informatics approaches are needed to represent the way in which patients make every day decisions in health promotion, primary care, chronic diseases and at-home care [13].

Some strategies and technologies aim to put into practice some of these functionalities, e.g., surveying patients between visits, deploying systems with the ability to provide registry data back to patients [14], implementing PHR [15], gathering data from social media, mobile-phone apps as a method of disease management intervention [16] and tracking tools, such as built-in pedometers, diet management aids, and weight and blood pressure logs [9, 17, 18].

However, the ongoing evaluations of some of these implementation experiences show similar results to the evaluations of disease management interventions. These types of programs reach a small group of empowered people and those who take a pro-active approach to everyday problems [19, 20, 21]. Moreover, these experiences are difficult to transfer to those who should benefit, that is, vulnerable populations. Overall, these interventions cannot be applied to these groups of people [22]. This suggests the need to conceptualize patient decisions about health care and the treatment of chronic diseases under new theoretical frameworks. The aim of this paper is to communicate the conceptualization that was generated.

2. Methodology

The Hospital Italiano de Buenos Aires (HIBA) is a university hospital that has a health care network with two hospitals, one of high and another of medium complexity, as well as a network of primary care in the metropolitan area of Buenos Aires, Argentina. The HIBA performs 3 million outpatient visits and 45,000 surgical procedures annually, of which 50% are ambulatory patients. The gradual development and the implementation of an in-house HIS began in 1998 [23]. Since 2003 an institutional chronic disease program was implemented [21], and since 2010 a total quality program, that achieved in 2015 the accreditation from the Joint Commission International. Based on these experiences,

the teams that were involved recognized the need to rethink and conceptualize other frameworks for decisions made by patients that occurred beyond the scope of the hospital institution. This conceptualization took place in 2015 at meetings with interdisciplinary discussions of these teams, together with epistemologists, sociologists, anthropologists and consultations with national and international e-health stakeholders.

3. Results

3.1 The Need for Representation of the People Decision-making Process in Health Information Systems

Because of demographic and epidemiological changes, patients have increased their autonomy. In this scenario, patients' decisions are the cornerstone of the health system because they might make decisions that challenge the logic of evidence and health services [13]. The gap between what health professionals recommend and expect from people and the decisions people make in their everyday life is well known, as it can impact individual health outcomes as well as system level outcomes as a whole [21].

The decision makers, such as physicians, politicians, and administrators, need to understand and anticipate the rationale of patient decisions to align the strategies of all of three levels of healthcare, that is, the health system, health providers and patients [24].

Various studies have shown that the effects of social and behavioral determinants of health on mortality, such as social isolation, sometimes exceed those of genetic factors and clinical indicators, such as blood pressure and cholesterol level [25, 26]. These determinants include objective, subjective and relational aspects of life that the people consider to be more significant, such as whether the person lives alone, their educational level, the breakdown of a relationship, financial hardship, employment status, violence, and other stressors over the course of a life [25, 27]. For example, a recent study in the United States showed that most of the variation in life ex-

pectancy at the age of 40 years related more to lifestyles and habits on health, such as smoking, obesity and physical exercise, than with access to health care [28].

Additionally, studies have shown that the more complex the conditions and needs of patients, the greater the variability in decisions [29, 30] and also the greater the likelihood that the treatment plan is ineffective or impractical [29].

Such examples suggest that, to reduce costs; improve the quality of physical, psychological and spiritual care; and increase accessibility to medical care, it is necessary to understand the objective, subjective and relational factors involved in decisions people make in the context of their daily lives.

To date, the main approach for anticipating decisions of patients in HISs, is to include data on the social determinants of health (SDH), which are known to be associated with many of the attitudes of people toward health care [25, 26, 27].

In this regard, the IOM has defined a set of SDH that should be included in EHR, including social relationships, living conditions, and neighborhoods, as well as sociodemographic, psychological, behavioral and community domains [25].

A registry of SDH could be very useful for health services and the health system in several ways (e.g., profiling patients to develop educative, communicative, behavioral or social interventions [25, 27], identification of high-risk patients, identification of the population's needs [25, 30], etc.). But it might be necessary to go a step further and consider the process by which people make their decisions in context, as people decide based on the rules of sociocultural systems in which they have interdependence, self-organization and freedom of choice, which are the fundamental determinants of complex systems [31, 32].

Studies such as the previously cited of life expectancy in the US show us that pieces of a "cultural system" are not mechanistic pieces with predictable responses. They "think and choose" to adopt the new system or recommendation and how they will do this. The recognition of this added complexity will lead us to acknowledge the decision process itself, taking into consideration that people are not passive re-

ceptacles of information; instead, they transform the information and its meanings based on their experiences, beliefs and social context [33].

There is scarce evidence on how these dynamics operate in the field of health systems and in particular in health informatics projects [34].

These observations led us to argue for the incorporation of the decision processes of patients in HISs, as these systems must go beyond the registry of patient data and deepen the understanding of the processes in which patients, families and community practices are based, i.e., how patients read and process the information and how they make decisions in the context of their daily lives.

We propose the consideration of other theoretical and methodological approaches to represent the reality that could complement current information system strategies (EHR, PHR, RHIS, LHS, controlled clinical trials approaches, etc.). Such strategies could provide information on how people and health care processes behave and perform in society, that is, how people make decisions about their health and diseases beyond the radar of the health services and, consequently, how to gather this information to learn how people work and how this impacts community health.

3.2 Challenges for the Representation of People's Decisions in Health Information Systems

This change of focus represents a substantial challenge for HISs, LHSs, and their ambition for transformation and change, as they need to understand the patient's behavior, social changes, their complex interrelationships and the temporality in which the events unfold, including process time lapses.

We suggest that this challenge involves reconsidering the positivist clinical research framework that is based on the recording and analysis of objective and mostly biomedical variables [35].

The positivist epistemology rests on an ontology that assumes that it is possible to objectively describe reality, regardless of the values that guide the viewer, which means that it is possible to discover general

and universal causality laws independent of time and context (regarded by some authors as "naive realism" [36]). Since the beginning of the XX century and the paradigm of infection diseases [37], methods in medicine have relied on the isolation of an objective "causal" effect of a single factor (or "exposure") so that the causal effect can be properly identified [38].

In clinical research, from the positivist paradigm, it is assumed that scientific rigor is achieved through methodological clinical decision-making based on the examination of evidence derived from the latest clinical research [35]. This "causal reductionism" could be a dangerous shortcut for the development of sophisticated HISs that need to understand, represent and model "not only the trees but also the forest", namely, the natural environment of the daily life of people and communities. This implies the necessity to complement the understanding of isolated units (reductionism) with the understanding of the whole picture to achieve a broader view of all of the system units and simultaneously perceive the interrelationship dynamics between units.

The positivist paradigm is under review by the current epistemology [35, 36], and each day more scientists and scholars are willing to abandon the idea that knowledge is a description of the world that is completely independent of the observer. For new epistemologies, knowledge is not taken as a representation of the facts of nature, or as the product of a rational subject who observes an independent nature of it, but as a generative activity in which human beings participate together with their productions and technologies in processes that are always open to productions that transform the world and human beings themselves [36, 39].

In the example of the US research on life expectancy, to study and understand the relationships between people's behaviors and life expectancies, these behaviors were previously conceptualized as objective factors ("physical activity", "obesity" or "smoking"). Therefore, the analysis strategy was to study the contribution of each of these factors to the life expectancy in the population [28]. The authors of this research noted in the conclusions that it will

be necessary, at the local level, to develop policies to reduce these differences because the research discovered a wide diversity in life expectancies among the different U.S. regions, states and counties. However, when decision makers have to think about and develop these policies, further complex studies are needed to understand the behavior of the population. Indeed, we believe that it will be necessary to adopt other perspectives of analysis because studies on the relationship between lifestyles and mortality have shown that both are linked by complex interactions [21, 30, 38] that involve socio-cultural, environmental and economic processes. In this regard, traditional studies of causation will be insufficient to understand these processes with the depth and breadth required to develop effective actions [21, 35].

The constructivist framework may be useful for understanding these types of processes, how and why individuals integrate and apply new knowledge in clinical and health decisions, and how behaviors may change as a result of interventions [33].

In the medical field, classical studies of sociology and anthropology have shown changes in the relationships of patients with their family, labor and social environment because of the interactions between the social environment, health services and subjective experiences of a particular disease [33, 40]. Even more, these experiences modify not only patient knowledge about the disease and the attitudes to treatment but also individual competences (objective and subjective) and the capacities of communities and families, as well, in many cases, their legal situations [40].

These interactions also shape the identity of people who are suffering and, in consequence, the way they live in their world, whether it be cancer, HIV/AIDS, obesity, dementia, substance abuse, learning difficulties, aging, or alcoholism [33]. Consequently, the responses of individual patients and communities are very diverse and more complex than anticipated, especially in our hyper-connected current context in which changes in one part of the world can have global repercussions.

The theoretical foundations of constructivism are diverse; however, as posited

by Berger and Luckmann in 1966 [41], interaction between individuals generates mental representations about the actions and habits of others and their reciprocal roles, which become shared meanings. As these representations remain stable over time, they become stable (rules, expectations and speeches on how to understand the world), and in turn, they produce social norms, institutions and organizations. These structures build common meanings and collective realities, that is, behaviors, interests and identities, that are collectively considered legitimate. Therefore, they are social constructs that are not created individually, but reproduce themselves. In other words, they are the result of complex interactions between individual decisions and power relations in society [33, 36, 41]. Patient activism that mobilizes the support of relevant public policies is an example of people who actively shape the parameters of their illness and the meaning of selfhood in relationship to them [33], while they construct creative responses for collective care.

The constructivist framework could probably lead us to unravel novel strategies developed by social actors at the individual level of practitioners or patients, or at group levels, such as communities or associations, to address the burden of diseases and treatments [36].

Additionally, the theories of complexity with systemic perspectives should be incorporated to analyze and understand the complex decision-making processes on the health and treatment of people in their daily lives. These theories assume that the effect of a particular factor depends on the state of the other factors and that these factors affect others and are affected by feedback loops and interdependence. Therefore, understanding the basic principles of a social system involves understanding the interactions between each other, between people and the environment, and between social and biological processes [31, 32, 38].

This indicates taking a step further beyond the risk factor framework [42] and the understanding of the environment, (e.g., families, communities, schools, and the health care system) in which the target population lives, functions and decides. It

also means understanding the relationships within the system and the positive and negative feedback loops between individuals, individuals and environments over time, as well as between social and biological processes. This knowledge is essential for identifying appropriate interventions and anticipating the potential impact when a new program is introduced into a specific community [38, 43].

Successful implementation of public health interventions requires an understanding of the environment (e.g., families, communities, schools, and health care system) in which the target population lives and functions.

Within these frameworks, according to constructivism and the theory of complexity, health informatics, and particularly LHSs, face the challenge of identifying, representing and registering new entities that emerge from social realms and that are directly or indirectly related to health care processes. These systems also face the challenge of modeling the transformations and complex relationships among those entities.

3.3 Future Directions: Some Basic Proposals

To address these challenges, health information systems will need to draw on different disciplines and methodological approaches. In this section, we discuss three possible approaches for implementing the constructivist frameworks and theories of complexity: a) health assets mapping, b) community clinical trials, and c) system simulation tools.

a) HISs may include the approach of "Health Assets" [44], which are considered to be innovations that people and communities adopt as tools for health care, e.g., formal or informal networks of caregivers, neighborhood associations, patients associations, physical shared places, and cultural activities. The same people regard these assets as promoters of their health or facilitators of health care [45]. These concrete resources reflect "things" that people construct with and because of the information in the context of their capacities and restrictions; what they do with and from their strengths and weaknesses, e.g., as-

sociations, institutions, virtual platforms, physical facilities and connections are resources that communities develop and mobilize to foster local opportunities [44].

It is possible to identify health promoting/protecting assets at individual, community and population levels from across all of the domains of health determinants.

These types of resources may be captured from patients and disparate sources (internet, media, etc.) to understand the strengths of a community. They can also be identified for constructing community health asset maps [45]. These may help people, and also physicians, discover positive factors in their community and construct a network of relationships and mutual support for improving well-being and health [46].

b) HISs, such as LHSs, can develop analytical capabilities to identify such assets and determine their effectiveness for certain groups and in certain local contexts through comparative research at the level of social groups, based on social native groups (schools, companies, communities or even virtual networks), independently of the possibility to physically interview people for the study at health service institutions that may be far from their home.

These community trials portray the natural settings of health practices, which are suitable for interventions that operate at a group (not individual) level [47]. In these cases, it is expected that the environment itself promotes improved health status on people involved in the group. Hence, the change is expected at the level of the entire group, instead of each person individually. The analysis at a social group level did not only identify differences in the expected outcomes but also enlightened key elements promoting the change process in the natural context of peoples' every-day life.

Several examples of community trials are emerging, especially in health promotion and primary care, e.g., an intervention at the school level to improve cardiac health for students with cardiovascular risk factors [48] or an intervention at the health service level to improve breastfeeding practices [49], among others. A community trial determined that a peer group intervention can improve community HIV

prevention. This trial also identified a diffusion effect that fostered this outcome at a community level [47]. This type of analysis may support population strategies, e.g., control of HIV.

c) HISs may also add value to the learning process from real routine care practice incorporating complexity theory in the analytic methods. This way, these systems may include the complexities of the environments and conditions in which populations live and work, the regional context, and the complicated delivery systems within which programs are implemented [38].

The complex system disciplines may help in data modeling and analysis. Various system simulation tools can be used to explore how the system is functioning and evaluate the impact of different interventions, as well as how the impact may be modified by other factors or features within the system itself [38, 50]. Qualitative analysis may be encouraged to model systemic relationships [43].

For example, estimating the plausible impact of a complex program for improving the end-of-life of dementia patients may require the consideration of several feedback loops and dependencies. The educational level may help physicians to communicate the adverse effects of the interventions (gastrostomy, nasogastric tube, etc.) to relatives and caregivers. This trustworthy physician-family relationship may encourage caregivers to care for patients at home. An advantageous economic situation may help relatives to hire caregivers, which will relieve the family from the burden of the disease. A community with many active residents in the neighborhood may encourage others to engage in supportive networks and, for instance, create claims for new facilities for older people. Using this example, initiatives to improve the comfort of end-of-life for dementia patients and their families could result in a reinforcing feedback loop that triggers further beneficial changes in the community.

A deeper understanding of the dynamic relationships in the whole system can help anticipate and monitor the effectiveness of a program or intervention, as the complex systems framework recognizes multiple levels, feedback loops and dependencies,

which also lead to the identification of macro-level patterns [38, 43].

Beyond these three proposals, health informatics could study how to represent and to model current and non-traditional research designs that are suitable for analyzing social health processes, such as qualitative research and community-based participatory research. In the people-decision field and in community level research, qualitative methodologies (alone or in combination with quantitative ones) are sometimes the keystone of the analytic rationale [51]. The community-based participatory projects encourage the development of collaborative relationships across research institutions, health care providers and community-based organizations to jointly address long-standing public health issues among vulnerable populations [52]. In this collaborative framework, the research is carried out alongside the concomitant intervention, in an action-research design, where most of the data, which is mainly qualitative, are emerging from the research setting. It would be a challenge for the informatics domain to continue addressing and deepening within this type of unstructured and changing information.

4. Conclusions

Changes in demographics, epidemiology, sociology and information technology incite professionals and researchers to rethink how to understand and evaluate healthcare systems and population health. Longevity, autonomy, chronic conditions, accessibility to health information, and personal and social disparities and changes reinforce the role of patient's decisions and the context in which they were made.

From our point of view, this means moving toward computer systems that embrace entities and relationships at social group levels, that represent the partially constructed nature of reality, and that also model the complexity of natural scenarios where people make decisions in their daily lives.

This proposal faces several limitations, including the fact that, although at present the human sciences are based on epistemo-

logical post-positivists theories [36], the dominant paradigm of scientific research oriented to technology development remains mostly positivist. Therefore, it will be difficult (and possibly expensive) to enact the initial stage of development of methods and models based on these social science research theories. However, Internet developments, such as Facebook and Twitter, which continually learn from the real life of people, encourage us to think that these approaches are feasible to implement.

Even more, these approaches have been encouraged by several authors from different backgrounds and disciplines [30, 35, 38, 39, 42, 43, 44] and share the vision that health information systems need to represent what people-in-context do with information, recommendations and interventions instead of the traditional approach, which is what information, recommendations and interventions do with people.

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