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Sustainable Health Informatics: Health Informaticians as Alchemists

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Abstract

The digital transformation of health care delivery remains an elusive work in progress. Contextual variation continues to be a significant barrier to the development of sustainable health information systems. In this paper we characterize health informaticians as modern alchemists and use this characterization to describe informatics progress in addressing four key healthcare challenges. We highlight the need for informaticians to be diligent and loyal to basic methodological principles while also appreciating the role that contextual variation plays in informatics research. We also emphasize that meaningful health systems transformation takes time. The insight presented in this paper helps informaticians in our quest to develop sustainable health information systems.

Keywords

Sustainability; Health informatics; Decision support; Ontologies; standards; Work practice; Usability; Context

1. Introduction

In the middle ages Alchemists used mixture of science, philosophy and mysticism to find the philosopher's stone that would enable them to develop:

1. A formula for the elixir of immortality – a mythical portion that would cure all diseases and grants the drinker with eternal life
2. A universal alkahest which is a solvent having the power to dissolve every other substance including gold

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3. An elusive substance that was believed to make the transmutation of common substances into gold.

To find the elixir of immortality became more of a theological religious task and the trials to prove the effect has probably taken the lives of more alchemists that it has cured. The search for the universal alkahest faced the fundamental problem that, if it dissolves everything, then it cannot be placed into a container because it would dissolve the container.

The English alchemist James Price had demonstrated to lay audiences that he could turn mercury into silver or gold by mixing borax, potassium nitrate, and a red or white powder – the white powder produced silver while the red produced gold. Challenged by other members of the Royal Society he reluctantly accepted to demonstrate his capability, but when they turned up to watch his transmutation, he in their presence drank a flask of Laurel water (contained hydrocyanic acid) and promptly died before the audience could do anything. Price was supposedly terrified by peer review [1].

The original alchemists can be divided into two categories, tricksters who fooled thousands of gullible people to obtain gold and jewels, and obsessed, but enthusiastic men who spent all their lives occupied by the science of alchemy. The latter were the early chemist pioneers who discovered numerous substances and chemical elements, which eventually led to the drawing up of the periodic table.

Health informaticians can be characterized as the present-day alchemists. We have all seen examples of well-hyped health information technology (HIT) systems that fail to live up to the promised functionalities when implemented in complex clinical work settings. However, many informaticians are also diligent scientists who have been striving for years to achieve useful and sustainable solutions for healthcare's most pressing issues. This paper describes informatics progress in addressing four key healthcare challenges. We focus on the contextual aspects of these contributions in keeping with the theme of the Context Sensitive Healthcare Informatics Conference.

2. Areas in focus

In the following sections, we will describe the state of science of four specific areas where health informaticians have developed meaningful solutions to key healthcare challenges including interoperable health systems, redesigning clinical work practices, the development of algorithms to enable safe and efficient decision making, and the design of interfaces to support the entire user experience continuum.

2.1. Ontologies and standards

Interoperable data interchange needs the backbone of clinical data exchange and the substrate for all large-scale big data analytics and predictive modeling [2]. We have made considerable progress over the last thirty years in advancing interoperability [3]. We have come from looking at basic science informatics questions regarding the quality of standards (terminological, messaging and transport), NLP [4], Health Information Exchange [5] and data warehousing [6] to studies of the impact of these implementations on clinical outcomes and business measures of health and healthcare [7, 8].

To define the problem more clearly, we need to define interoperability. Here Robert Heinlien's concept of "Grocking" can be instructive [9]. This is described as where one person or in our case healthcare organization when receiving information understands it exactly as the person who sent the information understands the information exchanged. To break this down further we need to define syntactic interoperability where the way that the information is structured is well defined. Semantic Interoperability implies that one has syntactic interoperability and in addition has defined in a computable fashion the information in the content of the information being exchanged or stored for reuse [10].

We have made great progress on defining standards to support all the layers of the model that define true semantic interoperability. However, there is still work to be done. To date, we have transport standards and great examples of syntactic interoperability such as HL7 v2.X for many use cases including admission, discharge and transfer messages used in many and perhaps most hospitals and NCPDP Script [11] for prescription information which has empowered ePrescribing and is one of the few parts of the EHR that has improved the safely of healthcare. For semantic interoperability we have strong upper level ontologies such as the Basic Formal Ontology (BFO) [12], we have domain ontologies such as HL7 FHIR [13] and the Ontology of General Medical Sciences [14] and we have large scale clinical ontologies for naming such as SNOMED CT for diagnoses and findings, LOINC for laboratory Test Results, RxNorm and ATC for drug codes. There is a new effort by the US Department of Veterans Affairs to create a merged ontology of SNOMED CT, LOINC and RxNorm, named SOLOR, which is focused on greater interoperability among and between these individual standards. There is ongoing work to make the terminological standards conformant with the domain models and the domain models conformant with the upper level ontologies. Good work has already been accomplished which encapsulates terminological standards into messages and then the transport layers [15].

Some studies have already been published showing the importance of these methods and that their use leads to important clinical outcomes [16, 17]. This can improve the quality of data for input into predictive analytics to improve both the efficacy of healthcare and the safety of the care that we provide [18, 19]. More work is needed to use these integrated pipelines to represent large portions of our healthcare data which will improve our clinical decision support, our biosurveillance and help to move healthcare from a cottage industry into a systematized practice of health and healthcare [2, 20–22].

2.2. Redesigning work practices in healthcare

When we think about how technology will change work practices it is not a matter of if it will happen but rather how it will happen. Technology such as electronic medical record (EMR) systems enables new connections across patients, providers and settings and we need to understand the nature of these connections to enable better redesign of work practices [23]. One on hand, technology can enhance existing processes. Healthcare practitioners spend a substantial amount of time documenting and doing information retrieval tasks. Artificial intelligence (AI), Natural Language Processing or speech recognition-based tools such as digital scribes can automate some of these documentation tasks, allowing providers to spend more time delivering true patient centered care [24].

Technology can also support new or evolving processes. Collaborative care delivery is a fundamental part of healthcare transformation initiatives worldwide but collaboration is still not well operationalized in front line care delivery. We need to better understand the transition from macro level collaborative processes to front line micro level collaborative work practices. However, this transition is challenging because collaborative care delivery takes place within a complex and dynamic system of people, processes, care delivery settings and technologies. Further, we cannot understand collaboration by focusing on individual aspects of care deliver. Redesigning work practices to support collaboration requires the development of collaborative competencies that enable the transition between individual and collaborative work practices [25]. One such competency is common ground, which is essential to ensure that all agents engaging in collaboration have shared knowledge of the processes, technologies and terminologies that will operationalize collaborative care delivery [23, 25]. Another evolving process enabled by connected health technologies is patient engagement. Patients can play active roles not only in the planning and delivery of their care, but also in informatics tasks such as the development and implementation of HIT [26].

Regardless of whether we are redesigning work practices for existing or evolving processes, we must understand that technology alone will not transform healthcare delivery into a collaborative patient centered system. Rather we need to ensure that redesigned work practices are contextually grounded in the needs of all users (e.g. patients, practitioners and providers) in the sociotechnical ecosystem where HIT will be used.

2.3. Decision support

Expert systems use heuristics that employ methods of reasoning with only partial evidence. This requires experts in the field to encode knowledge about how they reason and put it into a computable format. This is accomplished by specifying weightings such as Evoking Strength which is defined as given the manifestation (finding, test result, etc.) how strongly should you think of the diagnosis. The other method used frequently is feature selection in a machine learning algorithm. Bayesian approaches employ conditional probabilities in the form of sensitivity and specificity to define and combine probabilities of for example a diagnosis being present. For many years, leaders in medicine have felt that there was something special about the heuristics doctors use to create a differential diagnosis.

In 1959, Ledley and Lusted reported that computers could help doctors in the diagnostic process [27]. Many papers have been published demonstrating the accuracy of computational medical diagnosis, generally in a very limited field such as thyroid disease or congenital heart disease. Only a few of these early systems were used outside the environment of their developers' institutions due to their specific coding against their local databases, limited knowledge bases, poor user interfaces and the many obstacles to sharing computer systems developed in the early 1960's. In the current environment of the Internet and widespread availability of personal computers and smartphones, the potential for routine use of decision-support systems to assist health professionals in the diagnostic process has become a reality.

Tim de Dombal at the University of Leeds created the first abdominal pain diagnosis program using Bayesian probability theory. The system helped users differentiate between appendicitis, diverticulitis, perforated ulcers, cholecystitis small-bowel obstruction, pancreatitis and non-specific abdominal pain using data acquired from thousands of patient presentations [28]. Ted Shortliffe at Stanford University developed a program MYCIN, that provided decision support regarding the empiric antibiotic management of infectious diseases [29]. MYCIN used production rules consisting of conditional statements [30]. This is one methodology that falls under the general category of artificial intelligence [31].

Homer Warner at the University of Utah developed the HELP system which was integrated with the hospital information system (HIS) and provided clinicians with clinical decision support [32, 33]. The HELP system incorporated a complete electronic medical record within an HIS. The rules in the HELP system were written in the Arden Syntax [34]. Each complete rule set is a medical logic module and each such module has its own conclusions [35]. Homer Warner also built the Iliad system that used a pure Bayesian approach calculating the post-test odds for each disorder.

Randy Miller and Jack Myers created the quick medical reference (QMR) system, that was developed as a diagnostic decision support system in support of all of general medicine [36]. QMR was employed at the University of Pittsburgh for use on a consult service which functioned under the model that a physician with a computerized clinical diagnostic decision support system was more effective at making diagnoses than the physician alone [37]. In QMR, manifestations are associated with diagnoses and the positive association of these manifestations are graded by their frequency of occurrence and by their evoking strength (i.e. how often should a clinician think of this diagnosis if one has a particular manifestation). Manifestations and diagnoses are both graded by their importance and this information is used as part of the weightings to provide a ranked list of the differential diagnoses for a given set of manifestations [38].

DXplain, a computer-based decision support system, was developed in the early 1980’s by Octo Barnett, MD from the Laboratory of Computer Science (LCS) at Massachusetts General Hospital (MGH) [39, 40]. DXplain has been employed as an electronic medical textbook, a medical reference system and a decision support tool. In the role of a medical textbook, DXplain can provide a comprehensive description with selected references for over 2,300 diseases. Descriptions include the etiology, the pathology, and the prognosis for the diagnosis. As a clinical decision support tool, DXplain uses its knowledge base of probabilities of approximately 6,000 clinical manifestations (History, PE findings, Lab data, X-ray data and elements of the past medical history) and generates a differential diagnosis [41]. The system uses an interactive format to collect clinical information and makes use of a modified form of Bayesian logic to produce a ranked differential diagnose list. The system also provides references and disease descriptions for each of the diagnoses in its database [42].

Over the past nineteen years, DXplain has been used by thousands of physicians and medical students. Eleven years ago, LCS began to make DXplain available over the Internet to hospitals, medical schools, and medical organizations [43]. Elkin, et al compared the predictive accuracy if using Evoking Strength as compared with Sensitivity in arriving at the correct diagnosis computationally [2].

Zhou et al, developed machine learning algorithms for disease phenotypes for primary care using electronic health records which she tested in Rheumatoid Arthritis [44]. Qureshi et al, reported a hierarchical machine learning method for distinguishing types of Attention Deficit disorder from structural MRI data [45]. Ye et al, used support vector machines to predict cancer type from full text articles from the biomedical literature [46].

CDS has had variable uptake in the practice of medicine and override rates continue to be quite high. Vendors and healthcare institutions continue to work to find a balance between efficiencies in the practice and patient safety.

We are working toward a learning health system organized with the infrastructure to facilitate continuous practice improvement by incorporating data from our practice and our clinical outcomes to improve our next day's clinical practice [47]. This data driven continuous quality improvement employing a human-computer partnership can lead us to a future of safer and more effective health and healthcare.

2.4. From usability to user experience

Problems in usability of health information technology (HIT) systems are well acknowledged in research [48]. The vast investments in the adoption of HIT in the United States as well as in Europe have been driven by expectations reflecting key usability goals, particularly increased effectiveness and efficiency in health care [49]. Usability is defined by the International Organization for Standardization (ISO) as "the extent to which a user can use a product to achieve specific goals with effectiveness, efficiency and satisfaction in a specified context" [50]. The term human factors is described by the American National Standards Institute and the Association for the Advancement of Medical Instrumentation as "the application of knowledge about human capabilities (physical, sensory, emotional, and intellectual) and limitations to the design and development of tools, devices, systems, environments and organizations" [51]. In the US, the Food and Drug Administration (FDA) and the Agency for Healthcare Research and Quality, and in Europe, the European Commission have called for usability and human factors evaluation of HIT systems and medical devices during the design process, requiring evidence of end user involvement during the design process.

User-centered design (UCD) is a design philosophy that seeks to place the end user at the center of the design process. The term was coined in the 1980s by Donald Norman [52] who put forward guidelines that designers could follow in order for their interfaces to achieve good usability outcomes. From that point on, many designers, researchers, and policy makers have proposed various methodologies and techniques that seek to involve the end user in the design process. In their 2010 standard ISO 9241–210 [53], the ISO extended the definition of UCD to "address impacts on a number of stakeholders, not just those typically considered as users," referring to the design approach as human-centered design (HCD) and defining human-centered design as "an approach to systems design and development that aims to make interactive systems more usable by focusing on the use of the system and applying human factors/ergonomics and usability knowledge and techniques.” The main goal of HCD is to increase the usability of the product in order to create maximum user satisfaction and increase the safety performance of the device. There are six requirements that a process must meet if it is to be considered an HCD process: (1) The design is based upon an explicit understanding of users, tasks, and environments; (2) Users are involved throughout design and development; (3) The design is driven and refined by user-centered evaluation; (4) The process is iterative; (5) The design team includes multidisciplinary skills and perspectives; (6) The design addresses the whole user experience (UX).

UX is an intriguing phenomenon that has been widely disseminated and speedily accepted in the Human-Computer Interaction (HCI) community. The immense interest in UX in academia and industry can be attributed to the fact that HCI researchers and practitioners have become well aware of the limitations of the traditional usability framework, which focuses primarily on user cognition and user performance in human-technology interactions. In contrast, UX highlights non-utilitarian aspects of such interactions, shifting the focus to user affect, sensation, and the meaning as well as value of such interactions in everyday life. UX is defined as the perceptions and responses of users that result from their experience of using a product or service [53]. It reflects the overall experience related to usability, usefulness, function, credibility, and satisfaction with the technology [54]. To show evidence of significant quality and productivity gains with technology, appropriate measures need to be used integrating long term usability and user experience collection [55].

3. Discussion and Conclusion

The vision of HIT being a key player in health care delivery has existed for a long time and has consumed many individuals and organizations. However, this grand vision remains elusive and HIT implementation continues to be a struggle with very few systems proving to be sustainable solutions when implemented in complex health care contexts. In looking at our field, we see a clear parallel to the alchemists where viability over time can be attributed to a set of basic methodological principles. Health informatics involves basic knowledge about the empirical world as well as specific knowledge on the plethora of evolving and constant contextual issues that influence human health. This knowledge must be acquired in a systematic way using transparent logic so that others can replicate an experiment or observation. True alchemists also highlight that finding the right mix of chemicals that lead to real scientific discoveries and societal benefit takes time. Similarly, health system transformation will not happen overnight but rather is an ongoing process and we must continue to be diligent and methodological in our approaches while also being patient in our quest for meaningful outcomes. Formative evaluation and concepts from learning health systems [47] must be an integral part of health informatics research.

Health informaticians can become modern day alchemists by:

- Turning leaden software into usable, responsive and efficient software;
- Weaving golden and usable threads out of the vast number of chaotic data formats and contexts;

- Using HIT to improve work processes that were/are often inchoate or informally arranged - usually formed by history, past privilege, old technologies, legacy systems, etc.
- Making decision support systems more responsive and available to the right user at the right processes at the right time. This requires incorporating AI and machine learning approaches for the benefit of all concerned - patients, providers, administrators and research and science.

Our work as informatics alchemists is frequently influenced by the political and economic contexts of where health care is being delivered. In societies with a liberal market-controlled economy, the criteria of full transparency and replicability can be difficult to satisfy because vendors want to protect their proprietary product to maintain their market share. Political policy can also impact how health care is designed and governed, including the role that informatics will play in health care delivery. Despite these challenges we implore health informaticians to strive to honor basic methodological principles in our overall quest to develop and evaluate innovative and sustainable health information systems.

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