Enhancing the Patient Empowerment Due to ICT and Ethical Aspects Involved

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Abstract: - Health education informatics systems (HEIS) can provide structured and quality-controlled access to a wide variety of health knowledge, information and services. The potential benefits of using ICT for disseminating health information are numerous. However, there are ethical implications inherent in using ICT for health education which must be taken into consideration during the implementation of HEIS. Aging well in the modern society is a social necessity and ICT responds positively to the demographic challenge. “Multidisciplinary Complex System for the Efficient Management of the Anti-Aging Information” is a complex system that demonstrates that the information technologies have a deep integrator character, both at the level of the information management and at the one of the development of the modern health systems. “Informational Centre of Dermatology” has as target to achieve a modern informatics tool able to centralize in a single point a variety of web services and information addressed to the average citizens or to the dermatologists. This paper describes the enhancing of the patient empowerment due to ICT and the ethical aspects involved through the two health informatics systems; namely, AgingNice and CID, developed at the Romanian National Institute for R&D in Informatics.

Keywords: - ethical problems, health education, HEIS, aging, dermatology

1 Introduction

Information is a basic need. With growing interdependence of human life, access to information becomes crucial for people who have to adapt their way of living to continuously changing conditions. Access to information has become a prerequisite in the modern world that is characterized by global economic and political dynamics relevant for each and everybody.

Access alone is, however, not sufficient. Making adequate use of information, transforming it and creating knowledge out of it requires competence and opportunity. The Internet is a vast resource for consumers, but to realize its full potential it is necessary to ensure the quality of information, or at least to help consumers to assess the quality of information.

Since many years, Information and Communication Technology (ICT) is used in health care. ICT can enhance in different ways the dissemination of health information and knowledge. The Internet boom has provided many benefits for society, allowing the creation of new tools and new ways for people to interact. As with many technological advances, however, the Internet has not been without negative aspects. For example, it has created new concerns about privacy, and it has been hampered by spam and viruses. Moreover, even as it serves as a medium for communication across the globe, it threatens to cut off people who lack access to it. Citizens are increasingly using the Internet for their own health education and participation in healthcare. They are becoming the consumers of a wide range of health information, goods and services offered on the Internet.

Health education is a process by which individuals and groups of people learn to behave in a manner conducive to the promotion, maintenance or restoration of health [1]. In a broad sense, health
education is represented by all learning and teaching experiences that lead to improve and maintain the state of health. In a restrictive sense, health education strongly involves the development of cognitive, social and emotional skills that have a protective role on health and also the development of a healthy way of living by consolidating the healthy behaviors and decreasing the risky ones.

Knowledge is the sine qua non of informed decisions in health care, education, and research. HEIS can make the relevant information more accessible for doctors and other health care professionals and they can make the patients or the average citizens more informed about their own state of health and about the means to preserve it. It is necessary to examine the health education informatics systems in the light of the ethical values. For instance, it is obvious that the Internet offers unprecedented power to provide users of healthcare information - patients, professionals, families, educators, researchers - with data of unprecedented timeliness, accuracy, depth, and diversity. The very qualities that make the Internet such a rich marketplace of ideas - its decentralized structure, global reach, levelling of access to the tools of publication, immediacy of response, and ability to facilitate free-ranging interchange - also make it an exceptional channel for potential misinformation, unethical use, fraudulent practices, and evasion of legitimate regulation[2]. A risk for privacy violations will eventually lead to mistrust among both care providers and patients. This could eventually lead to a "censuring" of information, which, in its turn, will decrease the reliability of the systems.

In the context of promoting health in the dermatology domain, different types of health education are necessary, intended for individuals, groups, organizations and communities. This approach is linked to the awareness of the causality relations existing among the environment, economic and social factors and the state of health. This evolution represents a carrying off from the traditional role of health education, which was mainly orientated towards the changing of the individual deviating behaviours and which is playing now the role of a potential force for changing[1].

HEIS are changing the way health information is disseminated and managed, but implementation is a difficult task in which social and cultural issues must be addressed. Empowering the citizens through readily-available health information is a valuable use of the Internet, but the nature of the Internet environment raises the spectre of abuse of vulnerable persons [3].

2 Ethical Implications

Most ethical issues related to the HEIS concern the control of information provided. A defining characteristic of the Internet is the lack of an overriding governing or quality management authority controlling either the content that is provided to consumers or access to that information. The Internet has the following advantages:

a) permits very broad dissemination not otherwise possible,

b) provides more-or-less unhindered access to information (for those who can afford computers and connection charges) without the intervention of a medical professional,

c) disseminates information from sources whose credentials cannot easily be checked by consumers and

d) can provide for consumers’ anonymity so that if errors are detected and corrections made after original dissemination there, is no guarantee that the consumer will, or even can, be made aware of the corrections.

The ethical issues that arise when control over information is the central point of contention are: quality control and error avoidance, Internet governance and Web site responsibility, and intellectual property and control [4].

2.1 Public Concerns

- The pervasiveness of a technology which many people do not understand.

- The lack of basic health knowledge of the average citizen and its effects on the doctor/patient relationship.

- Finding the correct health information is a problem on the Internet.

- The lack of adequate infrastructure in certain regions.

- The absence of computer literacy in certain sections of the population which may reinforce existing inequalities.

- The differences along five demographic dimensions: race, income, educational attainment, community type (rural, suburban, or urban) and age.

- The necessity that the various systems in use can communicate with each other (technical interoperability).

- Internet access has grown all over the world, but clear demographic gaps remain, as it is shown in Figure 1.
2.2 Value Conflicts

- **Effectiveness versus confidentiality**: The need to know and share patient personal health data, in order to provide good quality of care, creates a situation of shared secrecy which may compromise confidentiality.
- **Privacy versus the collective good**: Privacy may be traded for certain collective goods (research, administration, planning, prevention...) that benefit the community or population at large.
- **Quality assurance versus professional autonomy**: In order to offer reliable information, the content available in health education informatics systems should respect some quality rules, but that might diminished or restrict the autonomy of the authors.
- **Efficiency versus beneficence**: While beneficence indicates giving the best possible care for every patient, this may be very expensive and not feasible. In the context of limited resources, to give a patient expensive care could deprive another patient of much needed basic.

2.3 The Citizen And Standardization

- The design of HIES which personal health data are collected, stored and maintained and who should or could have access to them via the Internet or via inter- or intra-hospital networks or who should have access to the patient data card.
- The standardization of terminology used in the HIES is a must. Language is not used uniformly in medicine. Clinicians often use different phrases to mean the same thing or the same phrase to mean different things. Standardization, using a concept-based clinical terminology, largely resolves this situation by creating a common platform for practitioners to which allows a better comparison and communication.
- The variety and diversity of health information technology currently employed within and across care settings presents an added problem which is overcome by using a standardized clinical terminology to enable system interoperability, i.e. the ability for unambiguous data to be exchanged between systems, regardless of the technology used.

2.4 The Citizens as a Stakeholder

- Patients, who should be the primary beneficiaries of these health education informatics systems, must become active partners in managing their healthcare information.
- Consumers need to be educated on how to "filter" information, i.e. how to discriminate trustworthy information from less trustworthy information. Some basic criteria consumers could look at include authorship, sources of information, potential bias, and date of publication.
- The concern is that Internet non-users will have, among other things, less power as consumers and fewer economic opportunities, less access to high-quality health information, and less opportunity to interact with others.
- ICT can be used to improve the citizen’s access to health information, to provide the citizen with tools that could enhance her/his choices (such as Internet-based information on healthcare services and providers) and increase her/his demand for healthcare.
- HIES empower the citizen to become a stakeholder in her/his own health, who seeks greater participation in her/his healthcare and therefore greater access to her/his own health information. Guidelines for ethical and unethical behaviour are provided in codes of ethics. The terms "shall and shall not" are used as a basis for setting high standards for behaviour. A code of ethics cannot guarantee ethical behaviour; it sets forth values and ethical principles, and offers ethical guidelines to which professionals aspire and by which their actions can be judged. Ethical behaviours result from a personal commitment to engage in ethical practice [5].

There are established organizations with the aim of setting and observing ethical standards of using ICT in medicine, e.g. “The Health On the Net Foundation (HON)”.

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Fig. 1 The demographic gaps of the Internet access
3 Multidisciplinary Complex System for the Efficient Management of the Anti-Aging Information – AgingNice

Anti-aging represents a new concept that tackles the body health from another perspective – the one of preventing and treating the degenerative diseases with a therapeutic protocol elaborated by a team containing all of medical specialties. The result consists in the delaying of the aging process and restoring the vitality of the mature body, but also an aesthetic appearance. Health promotion for the increasing aging population is an urgent and essential task because evidence indicates that health promotion interventions can extend longevity and improve quality of life. Health informatics systems can play an important role in achieving wellbeing, independent living and delaying of the aging process and restoring the vitality of the mature body. [7]

The multidisciplinary complex system AgingNice belongs to the health informatics systems with particularization in the anti-aging domain and allows the sharing of the knowledge concerning the specific research and the promotion of the theoretical and practical information, both among the stakeholders from the medical area and at the person level. AgingNice is a research project developed inside the National Research, Development and Innovation Plan for the period 2007-2013 (NP II) is the main instrument by which the Romanina National Authority for Scientific Research (NASR) is implementing the National Strategy for RDI.

3.1 Objectives

- creating an environment able to facilitate the knowledge, information and date circulation aiming an efficient management of the anti-aging domain;
- supporting and motivating the actuality of the anti-aging concept and increasing the quality in health systems;
- developing the informational space of the Romanian state of health;
- putting into value the advantages offered by ICT regarding the accessibility of the information in the anti-aging domain.

3.2 Methods

AgingNice respects the main tendencies of developing informatics solutions for the health system, emphasizing the interoperability as a must be demand to have an efficient exchange of health data and knowledge. It respects the quality criteria established by European Commission applied to health informatics products: transparency and honesty, authority (sources of information), confidentiality and data safety, updating information, receptivity and responsibility, accessibility [6].

The used architecture is a Client Server type organized in three tiers and it has a structure composed from elements that can function autonomously, and which architectural requirements were developed both different types of users. Each module comprises several applications structured on levels for an optimal organization of information, according to the specific aimed objectives and it was qualitatively evaluated for its ability to be linked with the others and for its coverage.

The graphic user interface has an intuitive, ergonomic and friendly feature; it has a unique structure and it allows an easy access to the functions and applications of the system.

AgingNice is at the designing phase. There have been evaluated till now the use and impact of ICT on physicians and citizens concerned about their own state of health, the role of HEIS in improving the efficiency and quality of healthcare and the technical, functional and organizational demands for the system.

3.3 Results

AgingNice comprises tools and information concerning anti-aging methods and strategies, clinical and laboratory investigations for aging preventing, anatomical modifications, educational models, self-evaluation tests, defining a personalized demeanor, tendencies in the anti-aging biomedicine, anti-aging campaigns and applications for facilitating the dissemination of the therapeutic protocol, study cases and recent research among the specialists.

3.4 Discussions

The use of the information technology in Romania in the anti-aging domain is insignificant and it doesn’t cover the specialists’ demands and the citizen’s need of informing. By presenting cosmetics products, the existing web applications in this area center with propagandistic goals, and they don’t have access to recent and centralized information. The stakeholders at the society level haven’t elaborated yet a perspective strategy concerning the prevention in this domain.

4 The Health Education Informatics System “Informational Centre of Dermatology” (CID)

In last years it has become more and more obvious that the value of dermatological information grows
while more people have access to it, because they can use it in their own habitat, confer it new interpretations, broadening thus the potential of information. The use of ICT in the dermatology domain can be considered having at least two major objectives. The first one consists in facilitating the permanent updating of the dermatologist’s knowledge and the sharing with the patient the responsibility regarding this one’s health, due to a more performing exchange of information. The second objective is related with improving the basic dermatology knowledge of a person, with consequences on long term in adopting a healthier lifestyle and making better the relation with the physician.

The complex integrated system “Informational Centre of Dermatology” (CID) belongs to the newest types of health educational applications that comprise the users’ motivation concerning educational content and its new promoting methods, obtaining better results in the learning process, developing new capacities (as the communication capacities), cognitive skills determined by digital information, like observing, viewing, a systematically approach and the information processing. [8]

4.1 Objectives
CID is an informatics system that allows the collaboration among health professionals and with the citizens and it was designed to be easily accessible to all groups of users due to specialized information expressed in a simple and clear language, functions and modules easily to understand and use.

CID is an efficient tool for promoting health, which facilitates the co-operation between the dermatologist and the patient by making the latter becomes aware about the implications of dermatological diseases, and how he can maintain and improve his own state of health. The information offered by CID aims to supply, not to replace, the existing relation between a patient/user of this Internet application and his/her doctor.

In the same time, CID can be a modern tool that facilitates the access of the dermatologists to the updated information and knowledge in the domain, in order to make them familiar with the latest approaches and trends of dermatology. Having at their disposal an informatics system with authorized access and reliable information, the physicians can establish efficacious dialogues and collaborations.

4.2 Methods
CID is a web-accessible informatics product which comprises an inter-connected database system in the dermatology domain, having a modular structure. The implemented solution has as its main objectives the performance, scalability, platform independence and accessibility of the complex integrated system. The performances of this system take into consideration the user-friendly interface, safety functioning and data, high response time.

Security controls are a part of the integrated system design. Users must register with the authentication procedure and obtain a login ID and password to access the system.

The system is characterized by updating in real time the data and information. The primary source of information used to fill the relational database comes from dermatologists. For that, they have at their disposal friendly web-based forms adapted to the structure and demands of each module. The accessed information is analyzed periodically in order to make a fast conformation to the users’ demands.

Evaluation of the system was done both objectively using automatically created log files and stored messages, and subjectively by using paper questionnaires from patients and health professionals. There have been also evaluated the ethical issues of CID (including online health information, forum of discussions).

4.3 Results
CID is structured into modules for: specialists (clinical cases, informational leaflets, medication news, scientific events, legislation), patients (healthy behaviour, risk factors, monitoring the inter-connections of dermatology with other medical specialties, preventing dermatological diseases, little encyclopedia), cosmetic dermatology, centres of specialized consultancy, preventing campaigns, discussion forum (see Figure 2).

The most important ones are “For Patients” – provides information for the ordinary citizen, concerning the novelties in dermatology, dermatological organizations and specialists, “Preventing Dermatological Diseases” – aims to foster the knowledge, the comprehension and the habits that encourage a person to change his behavior. It presents the aggravating factors for health, the clinical and paraclinical investigations, a healthy behaviour, “Leaflets for Patients” – offers leaflets with dermatological information that can be used by the specialists to increase their patients’ level of health education and “For Specialists” – creates an environment for information and collaboration, dedicated to the specialists so that they can find out the news in dermatological medication, scientific events, clinical cases.
4.4 Discussions
Implementing CID solves the aspects concerning:
- the integration and fortifying of the data coming from multiple sources;
- the setting up of the access rights so that the proper user might receive the proper information, at an opportune moment, with the help of the tools used everyday;
- a better understanding of the users’ needs, that will ultimately lead to make them stand to and to a better anticipation of the coming necessities.

5 Conclusion
Citizens, healthcare providers and industry are all making increasing use of the Internet. More and more Internet users become aware of the risk induced by accessing online the health information and they admit how difficult it is to have access to reliable information. It is expected that the average citizen should have a greater role in ensuring his own state of health and that he will look for high quality, updated, reliable dermatological information. All these will lead to an increased online availability of trustful specialized information and to the forthcoming of new easy-accessible web applications.

HEIS, for being more accessible, should be designed in a manner from which the user can easily find out if it’s useful to him, and the style, the nature of offered information and its presentation must be adapted to the targeted user. The quality of the health content is also an important issue that must be taken into consideration at the designing, implementation and managing of a health informatics system.

There are many ethically significant and complex issues relating to human health and health informatics systems. It should be emphasized that there are a number of initiatives to develop tools and guidelines to evaluate the quality of health information on the Internet.

Ethical and regulatory questions and national and international legislation addressing the many issues related to quality of information in the Internet, and telemedicine are a matter of present concern of many international organizations, like the United Nations, UNESCO, the International Telecommunications Union (ITU), the World Health Organization (WHOEthical) etc.

In the ever-evolving information age, we need continually to assess developing health information systems and related health policy against such key values as security, privacy, accessibility, and accuracy.

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