

## Ethical aspects of eHealth - systematic review of open access articles

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### Abstract

The Internet has changed the way of receiving health information and health care services. Improving health care locally, regionally and globally by using information and communication technology is an important goal of eHealth and its applications. The aim of this review is to describe different ethical aspects of eHealth applications. This article is a systematic review. Relevant literature was searched from databases and 18 chosen articles were analyzed by using a data based qualitative content analysis. Six ethical aspects concerning eHealth and its applications were found from the reviewed literature: autonomy, privacy, confidentiality, consent, equality of service availability and beneficence. eHealth applications have a potential to improve health care services comprehensively, especially in remote areas. There are still ethical concerns that need to be addressed as the technology continues to develop. eHealth can be an effective addition to traditional health care services as long as the health and wellbeing of patients remain as the central point and eHealth applications are not used only to gain financial savings.

**Keywords:** eHealth, ethics, telemedicine, telecare, health care information technology, systematic review

### Introduction

Receiving health information and health care has been changed by the Internet [1]. In today's world all public service providers, including health care providers, are expected and pressured to improve their processes and lower their operational costs. Minimizing duplicate processes and response time and improving decision making are part of the progress [2]. eHealth provides new methods for using health resources such as information, money and medicines. It is expected that in time eHealth should help to improve efficient use of these resources [3]. Eysenbach [4] says that the term eHealth does not only characterize technical development, but also a state-of-mind, a way of thinking, an attitude and a commitment for networked, global thinking. The main idea is to improve health care locally,

regionally and globally by using information and communications technology (ICT) [4].

eHealth applications are an important resource in northern sparsely populated areas where distances between towns are long and all health care services are not available on the spot. For example in Finland experiences of using telemedicine have been encouraging [5]. Utilizing eHealth applications enables people to be treated or nursed in their local environment, or in their homes, by using digital information technology to transfer patient information between hospitals and other health care centers. The idea of providing equal health services for all patients in sparsely populated countries where distances to the nearest hospital or medical expert are long is the main reason why eHealth has been adopted in many circumpolar countries [6].

eHealth has many applications and telemedicine is probably the most well-known of them. Terms such as telecare, telehealth, telepractice etc. are also used when speaking of applications that utilize ICT. The term eHealth applications is used in this review as an umbrella term for these different kinds of applications, but also other above-mentioned terms are used interchangeably. In this review the term ethical aspect means values and principles that should be considered when using eHealth applications as a part of health care services. Generally in medicine and nursing basic principles of ethics are respecting human life, respecting human dignity, autonomy, care, justice and maximizing beneficence [7] From the ethical point of view eHealth involves new forms of patient-physician interaction as well as new challenges and threats to informed consent, privacy and equity issues and online professional practice [4]. It is important to acknowledge that eHealth applications bring out unique ethical questions and problems which they need to be discussed and evaluated to ensure ethical and secure health care services. The aim of this review is to describe different ethical aspects of eHealth.

## Materials and Methods

The research design was a systematic review. Relevant literature regarding ethical aspects of eHealth applications was searched from four different databases in March and April 2013: CINAHL, Ovid MEDLINE®, PubMed and Scopus. Keywords were: ethics/ethical (ethic\*), eHealth, telecare, telehealth, telemedicine. All articles published before April 2013 were included in the searches. First search results were: Scopus n=18, CINAHL n=2, Ovid MEDLINE® n=75 and PubMed n=18. Three to five searches were made in every database and the number of search results varied between 1 and 310. All chosen literature was in English and they were published between years 2000 and 2012. An essential criterion for selection was that the article had to discuss ethical problems or questions dealing with eHealth applications. Only articles that had free full text available online for free via the network of the University of Oulu were used in this review. Because of this, the lack

of abstracts and free full texts was the most common reason for disqualification of articles. Other reasons for disqualification were language (other than English or Finnish) and the lack of information in the article about the addressed topic.

Articles were chosen by reading their abstracts. When the abstract was not available then the whole article was read. After an initial selection 61 articles were chosen. These articles were read twice and finally 18 articles were chosen for the systematic review. The chosen articles and their content were analyzed by using a data based qualitative content analysis. The articles were read with question "How ethical aspects of eHealth are described" in mind and notes were made according to them. Based on these notes relevant expressions from the articles were written down and they were simplified. These simplified expressions were sorted and they formed six groups. These six groups were a basis for the manuscript.

## Results

Six ethical aspects concerning eHealth and its applications were found from the reviewed literature. They are: autonomy, privacy, confidentiality, consent, equality of service availability and beneficence.

### *Autonomy*

Respecting the autonomy of the patient is one of the ethical fundamentals of all health care, including eHealth [8], and it should be remembered when using assistive technology (AT), especially with the elderly and people with different kinds of disabilities. Using AT, such as fall detectors, can give a peace of mind to the caregivers of the patient, but the patient who is monitored can feel that his/hers autonomy and independence are threatened by the technology. Some patients may feel that their personal vulnerability is highlighted if their fallings are being monitored. It can also raise a question whether the patient is able to take care of him/herself and for that reason not all older people want others to know that they have fallen [9]. When

managing risks and hazards in patients' home environment their autonomy must be respected, independence and self-determination should be promoted and maximum usefulness of AT ensured. Other means of monitoring, such as frequent visits from caregivers, should also be offered. From the patient's point of view the usefulness of telecare and AT could easily be confirmed by trials of chosen technology, and this could ensure that telecare is accepted by the user [10].

Although AT can be seen as a resource that promotes independence and autonomy of e.g. elderly people, there are also worries it can in fact diminish or undermine their autonomy. Promise of freedom and autonomy by using AT is based on the system's ability to monitor and secure. In some cases this could lead to unnecessary interventions and restrictions of access or mobility. It is possible that elderly people can feel that their autonomy is being invaded if they are restricted from making their own decisions about taking risks [11]. Increasing patients' autonomy and allowing them to become more involved in their own health care is an assumption of AT and other telehealth applications, but at the same time they can increase patients' dependence on the technology. There is a possibility that choice and control are removed from the users of AT and other applications if they learn to rely on automation [12].

### **Privacy**

Privacy and principles of basic privacy protection are universal. Collecting, processing, storing and disclosing personally identifiable information bring forth concerns of information privacy [13]. Patients have the right to control the use and dissemination of their personal health information [12]. The professional has the responsibility to choose the eHealth application that best protects the privacy of patient-professional communication and client information since there is a degree of insecurity in all telecommunications strategies [14]. When using eHealth applications for communicating directly with the patient, professionals should always first ensure that the person they are speaking with is

indeed the patient, e.g. in telephone consultations. They should also make sure that the conversation with the patient is not heard by others. In case the patient is not alone or he/she is using speakerphone, the professional should inform the patient that the privacy may not be maintained [15]. The use of telepractice, e.g. telepsychiatry, enables a situation where there are also other people present in the session and this is a unique privacy concern for eHealth applications. These non-clinical persons can be present either physically or via the technology they support at the place of the consultation [16].

The use of AT may be a privacy concern to many professional caregivers but mostly the information the monitoring device shares about an elderly patient does not differ from a social alarm system that one might already have. Monitoring devices can also be seen as supporting devices that make everyday life easier rather than as an invasive intrusion of one's privacy. It is important that the opinion of the elderly is taken into account when planning the introduction of AT and there is an appropriate balance between needs and privacy. This way it is possible to make sure the elderly do not feel that their privacy is violated [11].

### **Confidentiality**

Confidentiality has been regarded historically as the central principle of medical ethics [17]. This basically means that a doctor/other health care professional must preserve absolute confidentiality in all he/she knows about his/her patient, and this continues even after the patient's death. Any personal information about a patient must not be disclosed in any situation without the patient's permission. Confidentiality assurance secures that patients will inform health care professionals about matters that affect their treatment. This enables health care professionals to provide good care to their patients [8]. Personal identifiable information should always be protected, and both technological and personal safeguards are needed for ensuring it. Secure encrypted systems are essential for promot-

ing patient confidentiality and the use of Internet stresses the importance of them [18].

### **Consent**

Consent to a procedure is usually given orally or for example by offering an arm for taking a blood test, but this kind of assumed consent only applies to the procedure in question. When patients give information about themselves to health care professionals, an assumption can be made that they also give consent to the use of the information as well if the information is used for the direct provision of the treatment [8]. The use of telehealth technology is always a clinical intervention and it can potentially, both positively and negatively, impact the health and welfare of the patient. This should be remembered when using e.g. videoconferencing, email consultations etc. An authorization from the patient or his/hers surrogate is always needed when e.g. sharing photos of patient's skin lesions or personal historical information [18]. Getting an informed consent from a patient who has a cognitive impairment is particularly challenging. The patient may not fully understand why telecare device is needed, how it may affect them and how it is used. Sometimes people close to the patient and their professional caregivers can be more eager for him/her to accept the use of telecare technology [10].

Kluge [19] reminds that getting an informed consent from patients is impossible unless they have appropriate and relevant information, i.e. access to information about the proposed treatment modalities and to their own medical records, in many cases nowadays Electronic Health Records. Emerging patient rights challenge the structure of existing software and communication protocols and services and unless these are not adjusted to the current development, it can lead to a situation where telehealth and the outsourcing of informatics services are becoming a significant legal and ethical risk to the health care professionals and services [19]. Denton [20] suggests that following steps should be made when introducing telepractice as a possible way of treatment; professionals should always describe equipment and services that are used in telepractice,

how services via technology differ from traditional services, what kind of consequences, positive or negative, using technology may have and how telepractice may have limits concerning confidentiality. The purpose of the remote contact should be discussed with the patient and the risks and benefits of working electronically should be detailed. Also the possible interference of diagnosis or treatment caused by deficiencies or failure in electronic equipment should be described to the patient [20].

### **Equality of service availability**

eHealth applications can offer patients a better access to a higher quality of services and at the same time it makes offering these services more cost effective to the provider. There is a prospect that more reliable and safe medical care can be achieved through an appropriate use of centers of excellence. More efficient use of health care resources will probably enable a fairer access to services by patients [17]. eHealth applications can help medical professionals to provide medical treatment in remote areas where physicians are not otherwise available. Also medical specialists can make their skills obtainable in other countries and continents. This way the shortage of medical professionals in remote areas and other underserved regions and countries can be mitigated by eHealth applications. Yet there is a possibility that technological advancement increases migration of medical specialists from areas that have fewer resources [21]. When speaking of health care sites and other Internet-based applications, Demiris et al. [12] state that it is likely that the digital divide will remain when the availability of new technologies emerges. Even though lower socioeconomic groups are also increasingly gaining internet access, the meaning of broadband may become greater with the usability of more demanding services [12].

### **Beneficence**

Preventing and removing harm and promoting the good of the patient by minimizing possible harms and maximizing possible benefits are the core of the principle of

beneficence. Nonmaleficence, i.e. prohibition of infliction of harm, injury and death upon others, is also part of beneficence. eHealth applications can reduce health care costs, increase patient access to health care services, improve the quality and continuity of health care and reduce the loss of work time, travel and costs from the patients' point of view. They can also improve the patient satisfaction, provide a sense of security to patients and help patients suffering from chronic illness and disease to empower themselves and be more active in their care [22]. E.g. AT can increase autonomy and independence of patients by decreasing their dependence on on-site support [23]. Time and physical and geographical constraints are reasons that can justify the use of eHealth applications as a part of the treatment plan [18].

Even though eHealth applications retain lots of potential in the field of medicine and health care, some guidelines underline the importance of health care professionals establishing a real-world face-to-face relationship with the patient before using telemedicine applications [24]. Stanberry [25] ponders the possibility of us becoming prisoners of our own technology. By this he means that telemedicine applications should not prevent people from going to see a health care professional in person in case they wish to do so. He sees that one of the most dangerous consequences of the telemedicine revolution would be that eventually people lose the personal choice over how they want to receive health care services [25]. There are concerns about the use of telepractice, how it can possibly have dehumanizing effects on patients and that the quality of nursing care would suffer from it. Although at least one study has shown that a quicker access provided by telepractice actually enhanced patients' involvement in their care and strengthened the patient-professional relationship [15].

The lack of human touch is a significant disadvantage of eHealth applications. Therapeutic touch is a very important part of nursing and it cannot be accomplished when the patient and health care professional are not in the same location. This fact also supports the idea that eHealth applications should be used as a supple-

ment of traditional health care, not as a replacement [12]. Opponents of eHealth applications argue that the disadvantages of eHealth outweigh the advantages. Examples of disadvantages are the loss of personal care by a professional, the risks of depersonalization and replacement of actual visits by virtual visits just to save money and time [22].

## Discussion

Basic ethical principles of eHealth applications retell ethical principles of medicine and health care. Yet there are some special features that need to be especially taken into account when using eHealth applications. In this review ethical aspects of eHealth were mainly examined from the point of view of telemedicine, telecare and telehealth. The point of view of research and business did not appear on the data that often. The data used in this review was quite constricted from the point of view of number of articles. The main reason for this was the fact that only open access articles were used in this study. Quality of the used data was satisfactory. Yet more articulate and broad definition of the subject would have probably given a better coverage of data.

When speaking of patients' autonomy, it should always be respected, their independence and self-determination should be promoted by minimizing the restrictions of their own decision making concerning risks they want to take. Special ethical problems concerning privacy and confidentiality relate much to the used technology. Overhearing and eavesdropping of telephone consultations as well as eavesdropping of information networks are a threat to patients' privacy. Also the use of non-clinical personnel, e.g. technical support, is a privacy concern and patients must be informed if such persons are present in a session. All personal identifiable information must be protected and secured with technological and personal safeguards.

From the point of view of consent, it is crucial that patients have access to all relevant information, including their own health records, to make an informed consent. The reason for using eHealth application as a part of a

treatment as well as the whole process, the used technology and possible consequences of it should be thoroughly explained to the patients. eHealth applications can improve availability of health care in remote areas, but at the same time they can lead to a situation where professionals concentrate in larger cities and this is an ethical dilemma that should be resolved. The lack of human touch is an undeniable disadvantage of eHealth applications and to minimize it professionals should use eHealth applications as an addition to a traditional face-to-face patient-professional relationship. Patients should have a possibility to choose whether they see a professional in person or via technology and professionals should ensure that quality of health care does not suffer from the use of technology. Beneficence of eHealth applications also include increased access to services and improved quality and continuity of care. The use of eHealth applications reduces patients' costs of care and losses of work time and travel. Yet eHealth applications should not be used just to save time and money and the use of them should be well considered and validated. Even though there are a lot of questions that challenge the usefulness of eHealth applications, they will very likely be a significant help for conventional health care. In the best scenario eHealth applications allow patients to become more involved in their own health care and they also improve equal access to health care services.

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