ORIGINAL ARTICLE

A Challenge to e-Health: The Need for Ethical Guidelines in Developing Countries

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INTRODUCTION

Telemedicine/e-Health that includes communication through telephone, fax, email, internet, and videoconferencing between the users and providers, is a highly valuable tool in medical, therapeutic and diagnostic services (transmission of digital images, vital signs, e.g. cardiac sounds, ECGs, etc.), disease monitoring from distant places, preventive medicine, biomedical research, health education, business of medical products, medical insurance and other related fields. Regarding provision of clinical services, in contrast to traditional face-to-face patient- physician contact at one geographical location (i.e. in a consultation room), in the telemedicine services the two partners are at a distant location from one another, and may be in different cities of one state, two states of same country, different countries on continent or even on two different continents thousands of kilometers apart.

This provides many advantages over the traditional medical practice and research model, for example quickness and cost effectiveness. It also enhances patients' health education, but generates some ethical issues as well.[1,2] These originate due to built-in demerits of the basic technology, communication problems arising from linguistic and cultural differences, an altered physician patient relationship, or involvement of vulnerable consumers such as people of limited mental capability or with borderline mental disorders. Other causes leading to ethical issues are attractive and alluring advertisements about healthcare services on the internet, which are sometimes misleading, failure to protect the privacy and confidentiality of patients' personal data and health information, record keeping of patients' details, jurisdictional and licensure issues,[3] process of acquisition of informed consent from the patient and the conflict of interest which arises from some e-health services being sponsored by commercial organizations and some of those enterprises being solely or partly owned by physicians. In the following paragraphs a discussion and analysis will be made of these issues from an ethical perspective. Some of the issues are legal but their ramifications overlap with ethical issues, thus these will also be discussed here. The aforementioned issues are jointly encountered by both the developed and the developing countries, but the developed world has to some extent addressed these issues or is in the process of resolving the remaining in an ethical manner.

On the other hand, in less developed parts of our globe most of the relevant problems either have not been addressed or have not been properly identified altogether. In addition, the developing countries have their own issues due to non-acquisition of equivalent technology, less expertise of healthcare professionals and service providers and less familiarity of consumers with this service. These issues create a dilemma as to what extent is it ethical to introduce and employ these sophisticated technologies in the areas where basic human necessities are still unavailable and diseases like tuberculosis and malnutrition are still rampant, such things that can be eradicated with judicious use of smaller budgets than are required for the establishment of e-Health services. Moreover, the already existing imbalance of authority between physician and patient will be aggravated by the establishment of e-health in those areas where technology providers or physicians have the required knowledge and expertise while patients or consumers in general are ignorant of this technology.

Even more troublesome in developing countries is the frequent power breakdown and not uncommon telecommunication faults that might lead to sudden interruption in e-Health processes such as telemedicine consultation. Moreover it is feared that the introduction of e-health services would increase the continuing migration of physicians and other health-care providers from regions of low physician-patient ratio to affluent regions within the same country or other countries hosting the telecommunication and e-health bases, and this will subsequently increase existing inequities in the availabilities of proven and more familiar traditional health services.[4] Even some authors object upon the excessive use of telemedicine and tele-assistance (with exception of emergency and medical isolation) and term it dangerous and against the medical ethics.[3,5] In any way, if one initiates to provide services like telemedicine or e-Health in developing countries he ought to follow certain ethical guidelines commensurate with local conditions and demands for the greater good of the people. In the following paragraphs I would like to highlight important ethical issues that may be encountered in e-health practice and discuss some problems specific to developing countries.

PHYSICIAN PATIENT RELATIONSHIP

The physician-patient relationship is a fiduciary one where a bond of mutual trust and respect is built between the two. The direct and close interaction in traditional face-to-face or in-person therapeutic encounters between physician and patient helps in the development of this trust and further interaction between them cements that bondage. In traditional practice, a physician's credibility and goodwill plays a part in solidifying a patient's confidence in the physician. This factor is altogether missing if both are sitting at different places, unfamiliar with each other and more importantly if they have different cultural and linguistic backgrounds. While practicing

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e-Health it is necessary that physicians be non-judgmental, give respect to professional confidentiality and that both physician and patient reliably identify each other.[6] In contrast to telephonic and email communication, the video-conferencing builds a better relationship between patient and physician but does not break the cultural and linguistic barriers,[7] which can further worsen the quality of interaction. In view of the above factors it is to be decided whether the e-Health services should be confined to those between a physician and patient who are already familiar with each other such as for follow up meetings about already known disorders or for preliminary contact between patient and physician. In this regard the guidelines of the World Medical Assembly[8] emphasize face-to-face consultation between patient and physician and stress that services of telemedicine / e-Health should be restricted to emergency situations, when the physician can't be physically available within a reasonable timeframe and in cases where the physician and patient have an existing relationship.

Studies have revealed that the traditional in-person consultation is patient centered because the patient has verbal dominancy,[9-11] while in the telemedicine consultation (including videoconferencing) physicians talk about 20% more than the patients and thus it is deemed physician centered. Moreover, in-person consultations often involve a discussion of psychosocial and lifestyle issues in addition to medical ones. Plus, a hands-on patient examination is possible and this results in more patient satisfaction than telemedicine consultation.

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In the telemedicine consultation, with the patient being more passive and having little or no knowledge of the employed technology, together with having a perception of physician detachment and concerns about privacy and confidentiality ultimately results in a diminished resolution of their problems[11], this all resulting in a doubtful therapeutic outcome. Positive impact created by non-verbal communication during an in-patient clinical consultation is lessened in distant consultation9 and this adversely affects the outcome and expected needs of the patient. Use of internet or other electronic services as the only source of health guidance is not without demerits and thus it is discouraged.[3]

E-Health services have the potential to be involved in ethically doubtful or unethical activities such as abortion, physician assisted suicide or organ trade, because often the consumers are willing to pay generously for these services. The issue of organ trade is most relevant to developing countries as most of the supply comes from poor countries while demand is fueled by the more developed ones, and as a result this creates long term health problems for poor countries.

CONFIDENTIALITY AND PERSONAL PRIVACY

It is an ethical demand that patients' personal information, their health and treatment data, and information about their psychological condition is not disclosed without authorization. Moreover it should not be accessed by or released to a third party without the patient's consent. Failure to protect these factors disrespects the fundamental principles of bioethics[12] especially autonomy of the patient and her privacy and confidentiality. It is mandatory that technical persons involved in the transmission of the information from patient to physician and vice versa are trustworthy and maintain the secrecy of this information. In e-Health services some patients and consumers have apprehension about un-permitted disclosure of their information,[2] but the onus of this responsibility lies on the shoulders of physicians and technical personnel involved in the process. In e-Health besides consultations, digital images from radiology and pathology are transmitted from one to another site. The E-Health code of ethics recommended by the World Health Organization[13] demands that there should be reasonable measures to prevent unauthorized access or use of personal data of the patients and relevant digital images should be transmitted by such means as 'encrypting' the acquired information. Also to facilitate the users it is required that there should be a mechanism whereby patients can easily review and update their data. To regulate the system and prevent unauthorized access, there should be mechanism to trace how and when the data was used and physicians should have knowledge as to how the site stores the data and for how long. Providers should ensure the safety of consumers so that when the personal data is 'de-identified' it is not linked back to the user.

INFORMED CONSENT

The already problematic issue of informed consent is more complicated in e-Health. When a person accesses a health care site on the Internet or participates in a videoconference, should it be considered that by doing so he has expressed his implied consent, similar to the visit of a patient to a consultant for face-to-face medical advice? If so, should it be inferred that this is equivalent to informed consent obtained in traditional medical practice? One can pose strong arguments against these assumptions. It could be justifiably presumed that an average patient has limited knowledge about modern communication technology and this is even more true when the patient is from a less developed country. If the mere act of accessing the website of a medical service does not amount to acquisition of informed consent then how could a valid informed consent be obtained for e-Health services? A complete explanation to the patient about the process of consent presented by the attending physician, the patient's full mental competency (also physical maturity) and his comprehension of the details are the requirements of informed consent.[12] To accomplish these requirements with the new technology, incomplete technical understanding on the part of the patients, language differences and inadequate mental capability of the patient all pose problems. Therefore, it is imperative

to formulate some ethical guidelines in fulfilling one of the important requirements in patient management and which also has important legal ramifications.

RECORD KEEPING

Who is responsible for keeping the record of the patient? The physician, the patient, or a third party such as the website provider? These are the questions which need to be dealt with seriously so as to meet ethical requirements. It is advised by the Finnish Medical Association that the physicians practicing telemedicine have responsibility for keeping all patients' relevant records along with their identification. It is considered essential that non-medical personnel who are involved in collecting and transmitting the data should maintain confidentiality of the patients' record.[4]

ISSUES OF JURISDICTION

The license of traditional face-to-face medical practice is limited to particular geographical areas. If one's license is valid for one state, the physician is legally prohibited from practicing in another state unless she has a valid license in that state as well. Though e-Health practice breaks the geographical barriers of the communication, the barrier of licensure jurisdiction still exists. Can and should a competent physician practice telemedicine beyond his area of jurisdiction? If for the time being, the reply is affirmative, which locality will decide the issues of litigation or malpractice, the physician's or patient's area of residence? There could be differences of opinion in this respect but quite plausible is the argument offered by Briggs[14] that "a wrong is done where its effects are felt", consequently the patient's jurisdiction will take action in cases of omission or acts of malpractice. However there should be consensus of opinion among different regions of a country and amongst various countries internationally. Moreover, medical organizations should act proactively to resolve this important issue faced by e-Health practitioners. As suggested by the Finnish Medical Association,[6] the doctors practicing telemedicine are only allowed to do so in the country where they are residing and authorized to practice usual medicine. If the patient is a resident of another country then they should have license to practice medicine in that country or through an internationally accredited license.[4]

ETHICAL ISSUES IN DEVELOPING COUNTRIES

In developing countries, which are already resource strained, have meager and proportionally less funds to allocate to health services than do developing countries, initiation of e-Health services will not be without ethical concerns, especially in remote or rural areas, where face-to-face traditional health services are lacking. It is a fact that the outcome of this modern technology in the health care services domain is still unproven and employment of these controversial services to populations having no existing alternate mode of health service will be riddled with ethical issues.[15] Moreover, if these services are provided in financially poor countries where many of the people have no computers and other required devices needed to utilize these services, people would need to use the computers of friends, relatives, schools and public libraries, and this will result in a necessary breach of confidentiality and privacy of information.[15] Specifically in developing countries, there are ramifications of the above mentioned issues and some additional issues as well.

There is an imminent danger that e-Health service providers might disrespect these ethical issues by offering to health services-poor areas in developing countries and there is a possibility that profit-oriented organizations might succeed in alluring those populations. Privacy and confidentiality are globally recognized ethical values, but their value-strength is more important in affluent societies and developed countries. Populations where basic human needs such as potable water, shelter for living and food for eating are not adequately available will be less careful and less sensitive to issues of confidentiality and privacy and it is feared that they might be lured to sacrifice and barter these values for the availability of health services in the form of e-Health. Would it not look strange to provide tele-medical services through the investment of millions of dollars to areas which are still plagued by tuberculosis and malaria, diseases that could easily be diagnosed and treated by such simple means as examination of X-ray films or microscopic sputum or blood samples, things that require much lesser expense?

There is already an extreme shortage of medical doctors and specialists in most of the developing countries and a huge disparity between available physicians in these countries and developed ones. Most of the sub-Saharan African countries have less than 10 doctors per 100,000 people, while Italy has 606, the U.S. 509 and Australia 249.16 Quite a significant number of physicians prefer to migrate to Western countries due to higher salaries and good living standards. With the development of tele-medicine and the availability of this service in the developing countries in remote and rural areas, physicians would not be obliged to physically travel there to provide medical services. This will create an inequity of the usual face-to-face medical services (which have a proven success record) between these areas and more developed areas. The results will consequently be a mushrooming of e-Health services in rural areas whose success is yet to be evaluated and whose outcome is yet to be assessed.

Additionally, how much of the population of developing countries has a clear understanding and knowledge of the pros and cons of e-Health services? Some of the developed countries have devised guidelines regarding tele-medicine such as the U.K., U.S.A. and Finland, and many others are in the process of formulating them.[17-20] But to the best of the author's knowledge none of the developing countries have formulated their guidelines for this rapidly growing tool in the field of medicine. Thus there is a dire need for the formulation of guidelines in these countries.

CONCLUSION AND SUGGESTIONS

Regarding the above issues, guidelines have been formulated by many of the developed countries and minimum required standards have been set by leading organizations of such as the American Psychiatric Association, American Medical Informatics, the American College of Radiology, the American Telemedicine Association, the Canadian National

Initiative for Telehealth, and the Internet Health Coalition. But much less has been discussed about this new technology in developing countries with exception of India and South Africa[16] and to some extent Pakistan.

To initiate this service in developing countries there is need to make all of the stakeholders aware of this tool and to familiarize them with its pros and cons. Initial steps might be the identification of ethical issues relevant to e-Health by service providers including physicians, medical researchers, health educators, and national medical organizations of each respective country. The various groups might then take responsibility to become proactively involved in resolving these issues[21] according to their problems and needs. It can comfortably be suggested that the major role of e-Health services appears in the event when one physician seeks an opinion from another physician about the patient under her supervision. E-health might be highly valuable and even a life saving tool in emergencies and disasters when face-to-face medical services are not available within a reasonable timeframe or the level of required expertise is not available. Moreover, this service may complement established in-person medical services, for example in follow up cases when both physician and patient are already familiar with each other and the nature of the disease is identified. In this regard the process of setting minimum standards and guidelines is primarily a governmental responsibility with the participation of leading medical organizations.

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RESEARCH HIGHLIGHTS

WHO Greatly Underestimates Malarial Fatalities

Caroline Melhado

A new study published in the *Lancet* found that World Health Organization estimates for malarial deaths in India are inaccurate. WHO reports only 15,000 cases of deaths due to malaria (10,000 adult and 5,000 children) per year, while researchers found that India probably has closer to 200,000 deaths from malaria a year.

The vast majority of deaths in India, especially rural India, take place at home without any medical intervention. These deaths often go largely unnoted in data collection when studying infectious diseases that cause about 1-3 million deaths in India per year. Researchers used interviews that where then coded by two independent physicians to ascertain whether death with a fever was due to malaria. Of the 122,291 deaths that were available for analysis from the Million Death Study, 3657 deaths were inevitably accepted by both coders (in the case that they did not agree the coders could converse to try and persuade the other), and 2122 deaths were identified by both coders immediately as malaria. The study used the latter number in drawing estimates of nationwide malaria death rates. Of these deaths 90% were in rural areas and 86% were not in health care facilities.

The district rates, calculated from the prevalence of malaria death from the interviews, were then used to find a nationwide figure of death from malaria. Researchers found that about 200,000 people under the age of 70 die from malaria each year in India, nearly 20 times the amount estimated by WHO. These new statistics elucidate certain problems of rural healthcare in accounting for and preventing infectious diseases both in India and worldwide.

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