E-HEALTH, HEALTH PROMOTION AND WELLNESS COMMUNITIES IN CYBERSPACE

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Lay health competence and democratization of medical knowledge

The integration of medical knowledge with information knowledge is one of the most fascinating scientific and transdisciplinary breakthroughs of our times and may well lead to cultural changes and new individual and collective attitudes, competences, communication and cooperation in fighting or preventing disease, in protecting or enhancing health and in promoting wellness. As far as health information, health care, and health communication is concerned, the internet already provides a wealth of information and advice, establishes new cyberspace communities concerned with health and health care, and allows for distributing previously privileged medical knowledge, 24 hours, 7 days a week, accessible around the globe. New information networks change and promote medicine and health care in two ways: *E-medicine uses the internet to improve and to modify traditional forms of diagnosis, therapy, quality control, and biomedical research via competence networks in medicine. E-health uses the internet to communicate health information and advice to lay people in an easy to understand language, to promote individual health care competence by de-professionalizing vast areas of previously privileged knowledge, to create new global rooms for interactive cyberspace communities, and thus change individual and cultural attitudes towards health and disease and traditional systems of providing and financing the treatment of sickness; e-health addresses issues of individual wellness and wellbeing, not just medical issues in health care.*

E-health, according to Gunther Eysenbach, the editor of the Journal of Medical Internet

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Research, the leading professional journal in this new field, is 'an emerging field in the intersection of medical informatics, public health and business, referring to health services and information delivered or enhanced through the internet, and related technologies. In a broader sense, the term characterizes not only a technical development, but also a state-of-mind, a way of thinking, an attitude, and a commitment for networked, global thinking, to improve health locally, regionally, and worldwide by using information and communication technology'. He proposes 3 criteria for good e-health platforms: 'easy to use, entertaining (no-one will use something that is boring), and exciting'. Quality standards for e-health need to include the following 10 'E's: 'efficiency, enhancing quality, evidence based, empowerment, encouragement, education, enabling, extending, ethics, equity' [8]. Thus, medical information provided in e-health sites will differ essentially from medical information given in medical textbooks and professional medical journals; e-health needs to avoid professional jargon. While established traditional so called health care systems, for a variety of reasons, have more and more become disease treatment systems, their medical success has also medicalized quite a number of issues of health and wellbeing related to lifestyle, stress and frustration.

Empowering people

E-health sites do not only address medical issues, they discuss medical aspects within the wider framework of health, protection or even enhancement of health, wellbeing and wellfeeling and actually emphasize health and lifestyle attitude over medical treatment. The rise of e-health sites has occurred outside the established health care system is driven by the consumer and the market [23]. The central and yet to be evaluated role of e-health seems to be the empowerment of the lay person to take control of her or his own health risk and health care. If information and knowledge is a precondition for self-determination, independence and power, then literacy - including health literacy - allows individuals to make their own choices, including choices in regard to lifestyle, quality of life and wellness. Literacy programs supported by UNESCO and other agencies have indirectly improved living conditions and health conditions of millions of

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people. The promotion of health literacy by e-health and other means is the logical next step to empower people to take better care of their health and the health of their loved ones. Health literacy, as defined by the US NIH' website [http://www.healthypeople.gov] is 'the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions'.

Our generation has learned a lot about predictable risk to health, about prevention of disease and management of chronic disease, about individual proteonomics and drug metabolism. - and we have the communication and education tools available to provide individuals with risk information and risk prevention, with health care management and disease management. But so far traditional health care systems have failed to translate the new wealth of information into knowledge tools for the individual citizen and for the promotion of individual health care competence and new models of lay-expert partnerships in the care for health. Information and advice provided by e-health seems to be more successful than public health education initiatives [7;12].

We seem to appreciate and value more what we actively search or surf by our own initiative than what comes to us by authorities [23;7]. More and more health information more and more becomes available outside of the traditional sickness care system of hospitals or physicians offices. Health food stores, health clubs, new age stores provide more health care information that can be found in the traditional sickness treatment system. Easy to understand and easy to use sites such as http://www.healthypeople.gov, hosted by the US Department of Health and Human Services and the Center for Disease Control, http://www.majoclinic.com, provided by the Mayo Foundation for Medical Education and Research under the logo 'reliable information for a healthier life', or www.webmd.com with over 20 million visitors per week are just a tip of an iceberg representing an information revolution on health care matters including but going far beyond information and advice for treating diseases. We have no information form other countries, but in the United States more people go to the internet for health advice than go to doctors or hospitals.

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A German medical journal, Aerztezeitung, presented a study reviewing German citizens' expectations for medical information additional to the existing health care system. 59% wanted the most recent information on their particular disease or disorder, 53% a 'second opinion', 42% on alternative medicine, 41% information about specialized local physicians, 39% advice on how to deal with health insurance [17]. According to a poll by the Kaiser Family Foundation, in the United States 75% of young adults, age 15-24, have searched the internet for health related issues; health information was more often asked for than copying music (72%) or sports information (46%). 15% of these 'online health seekers' look into health related sites once a week, 24% once a month; cancer, diabetes and health care related to sexual activity were the most searched places [11].

E-health sites are traveled by all citizens, healthy people and patients. Some go to the internet for advice on how to stay healthy, get information or second opinions on the disorders of loved ones. Reliable and easy-to-understand predictive, preventive and enhancing lifestyle information either supplements or replaces advice from a personal physician. A number of health care insurers already cooperate with providers of health information on the internet or with physicians advising patients on attitudes, medication, and treatment via the internet [18] and patients and insurers are willing to pay for those services, sometimes saving money and getting better results or at least 'a second opinion' from another physician [1;17].

E-health empowers people to understand the importance of being and staying healthy and to find advice and support to reduce health risk. As far as the right to literacy is a human and civil right, the promotion of health literacy is one of the most basic requirements to support autonomy and wellbeing of citizens. Health education by e-health vehicles 'challenges individuals, communities, and professionals - indeed all of us - to take specific steps to ensure good health, as well as long life, are enjoyed by all' [www.healthypeople.gov]. Dutta-Bergmann in a recent population based survey documented that customers seeking medical news on the internet were 'more health conscious and health information oriented, held stronger health beliefs, and were more likely to engage in healthy activities'[7:8]

New roads and rooms for health seekers and health care

The internet provides new roads and new rooms for information, education, communication and advice, including medical news, medical services, drugs and medications, specific diseases, healthy lifestyles, discussion groups on health. Called 'portals' these sites provide different services to different communities, including the following eight: (a) internet based or internet supported medical education, medical-ethical education, continuing education for health care professionals, (b) medical expert competence networks and cyberspace rounds for individual patient management of complex nature, (c) general health information and health care sites for lay people to educate themselves on basic or specific matters of health care, healthy exercise, lifestyle and nutrition and on how to deal with basic health risks and ordinary disease such as the common cold, stomach pain etc, (d) specialized interactive sites for individual medical checkups with or without a personal advisor or physician involved, (e) cyberspace visits to a doctor for a brief diagnosis or a 'second opinion' referring to already existing personal clinical or laboratory data, (f) sites provided by insurers, drug companies or other stakeholders in health care management for information or advice to their constituency, (g) sites to order or review prescriptions and medicinal drugs, (h) sites for cyberspace based health-care communities of self-selected communication seekers such as patients suffering from diabetes, obesity, hypertension, drug abuse, or genetic disorders of various kind.

Some sites provide more than one service, others are open only to paying subscribers or licensed personnel [2;14;18]. Many portals, particularly those specialized in specific medical disciplines such as oncology or diabetes also provide 'self-test' questionnaires for lay visitors; some e-health portals are integrated with 'private consultation' links and professional 'competence-nets' have two levels. Private consultation requires registration and fee for service. Self-diagnosis test sites such as www.real-age.com do not charge for service; they combine advice on lifestyle modification, nutrition and physical exercise with medical information and encouragement and refinance themselves by advertising wellness products, physical exercise

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equipment and vitamins, and advise on how to deal with specific issues and where to turn for more and personal advice.

Health literate citizens going to www.realage.com get a free diagnosis, specific individual prognosis and advise on how to lower their real age for free; this site sends updates every few weeks, those updates include references to new drugs and prescription free medication and refinance themselves this way; they also offer additional checkups and education on nutrition, exercise, and lifestyle as this seems to be that way they refinance themselves as their diagnosis and counseling is free of charge to customers. Other sites, such as www.cyberdocs.com provide for-fee consultation, available for virtual 'house calls' 24 hours, 7 days a week.

Reliability of information, potential fraud and exploitation are and will be an issue on these new roads and in these new rooms as they were and are in traditional rooms of providing health information and services. A report by the European Commission stresses both, the economic and the health benefits of e-health: 'When combined with organizational changes and the development of new skills, e-health can help to deliver better care for less money within citizen-centered health delivery systems... There are many examples of successful e-health developments including health information networks, electronic health records, telemedicine services, wearable and portable monitoring systems, and health portals. Today, at least four out of five European doctors have an internet connection, and a quarter of Europeans use the internet for health information'[5].

Success and reliability of different ways and rooms of e-health will depend on two requirements: technical skills and moral authority. Ratzan, Payne and Massett [20] called for new quality standards in 'health message design' in order to make health information more effective. But in e-health as in all other forms of health service, important that lay people, as famous Confucian physician Gong Tingxian required, 'choose enlightened physicians [ming-i] and thereby receive help in their ailment; they have to be careful, because life and death follow each other closely' [19:296]. Thus, e-health has to integrate ethics and expertise, humaneness [ren] and skills [ji], not different to any other technology and service.

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Building cyberspace communities

Of particular cultural, philosophical, and ethical importance are new forms of communities in cyberspace, beyond the limits of time and geography. These new health oriented communities have developed outside of the established medical system and 'create global communities'. Establishing a global community for patients and families of a rare genetic disorder of the kidney, called 'von Hippel-Lindau syndrom', was the vision of Joyce Graff, widow of a victim of this genetic disorder [9], inherited by 3 in 100.000 people. Www.vhl.org does not only provide information on most recent research, advice on treatment, nutrition and lifestyle; this site actually is a global friendship network; friends sending greetings to birthdays and recipes for cakes and cookies. Carriers and their families become neighbors and friends, support each other and share sentiments, good and bad news, visions and fears; most know each other better than their neighbors next door who have no idea what the VHL disorder means [25].

A similar, but much larger site is the pdkcure.org site, for the community of carriers of kidney cysts. Impressed by the polycystic kidney disease site and with support by the German Forschungsgemeinschaft, the Bochum Center for Medical Ethics built a German language site www.zystennieren.de for information and interactive communication. This site was build primarily for bioethics research in order to find out whether or not e-health sites would be accepted in German language and culture. To our surprise, without much fanfare, we had over 18.000 hits within the first 18 months, mostly from young carriers who have no symptoms yet, do not see a doctor, but surfed for and found a place to get information and to communicate with others on issues such as getting married, having children etc. These sites such as <pdkcure.org> and <zystennieren.de> are for relative small groups of carriers of kidney cysts; they establish new rooms, not only for information, also for sharing emotion and communication; they support individuals, patients, families and form various kind of cyberspace based communities and neighborhoods; they provide services not available in traditional physician-patient interaction. We had an extensive, sometimes emotional and controversial debate among youngsters on truth-

telling to one's fiancé about being a carrier, prior or after engagement or not telling at all. These were hotly debated and very personal ethical issues, not those of medicine or health care. The room we provided did not exist anywhere else; we had no 'ethicist' on call to direct the debate as bulletin boards do not accept paternalism or tutelage. The zystennieren.de site has a second feature, an e-mail address of a clinician, who himself is not only a medical expert but himself a carrier of ADPKD. This medical expert and webmaster discusses issues in total privacy; sometimes, at a later stage or at the end of the private discussion, the counselee and the counselor might agree to put their mail-exchanges in an anonymized version into one of the public rooms of the site where exemplary discussions are preserved. Our site, of course, also contains basic information on ADPKD understandable for the lay person, a review of the most recent medical literature, advice for lifestyle such as to avoid contact sports and to avoid the development of hypertension, to be aware of symptoms for ruptured cysts or other risks associated with this disorder and which are described in detail [25].

Summarizes Dutta-Bergmann [7:7] in a survey: 'individuals who sought out health-based discussion groups on the internet were more likely to be health-information oriented than individuals who did not seek out discussion groups on the internet'. Our experiences include that they also found new neighbors in cyberspace and sometimes friends, that they discussed issues they would rarely discuss with their neighbors next door and that they shared emotions, concern, and company not possible outside of cyberspace. E-health community sites are more than self-help sites in the traditional sense; they are real communities, developing their own cultures and customs; a US clearinghouse for a large number of these sites can be found in www.mentalhelp.net/selfhelp.

Should e-health be regulated?

As in all areas of human activity, new techniques and instruments face the fate of old ones. They can be used in two ways, to promote or to hurt human culture, fellow humans and society. Why should it be different with such powerful new tools as the combination of research

and results in biomedicine and information technology?

The wealth of information and communication developing around the internet naturally is seen as a competitive force by the existing players in the fields of disease management. Without much interface, so far it is growing parallel to the existing sickness care system, often not quality-controlled, sometimes primarily profit-oriented, but these temptations are well known to the existing sickness care system also. Some voices have called for internet rules of good behavior and proposed a set of ethics rules for professional conduct of stakeholders in e-health information and communication. Certification of websites is under consideration by various professional organizations and governments. The Commission of the European Communities [4] has published preliminary guidelines for quality control criteria related to websites. Certification probably is the preferred tool over regulation, but even certification may not be strong enough to promote and to protect professional and ethical quality standards in websites for the lay as well as for the experts. Self regulation, soft forms of certification, and the powers of competition, consumer choice, and the market, - they all will have to contribute towards the development of true avenues and networks in the individual care for health. A study by the Kaiser-Family-Foundation found, that software filters used in schools and libraries to protect juveniles from going to pornographic sites, when tightly configured, also make e-health sites inaccessible [Publication No 3294].

Codes of Conduct have been proposed by the 'Health on the Net Foundation' [www.hon.ch/honcode/conduct.html] and others [www.hiethics.org;15;24]; the American Medical Association has issued guidelines [26]. E-health culture and customs have yet to develop. As ten Have puts it: 'the only feasible approach, precisely because of the nature of the internet, is self-regulation and self-binding of providers and consumers' [10:119]. Quality standards in e-health have already been defined [8; 5; 24] and strong players in the market such as well build government supported sites in competition with private providers such as Harvard School of Public Health or the Mayo Clinic group will have to provide good examples. Dutta-Bergmann [7:8] observes that e-health sites offer great potential for pharmaceutical companies

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and treatment providers to reach out to health-active groups. But as these groups are well educated and well informed, information 'must be cogently constructed and strong arguments must be provided because of searchers are actively engaged in their health decisions'.

Only rarely has the internet yet been used in public health education by health care providers or been supported by public finances, nor has it been made ready for emergency health communication during a mega crisis or terrorist attack [13]. Even in countries with low levels of internet access, in the area of public health the internet can be used to communicate with 'health ambassadors', health care providers and social service agencies. The internet's increasing power of health information, communication, and advice could become a great contribution to promote health literacy and health competence. Independent certification boards or agencies need to support quality control and issue quality certificates without hampering competition and the diversity of information, support, and communication provided via the internet. As the 'eEurope 2002' report by the Commission of the European Communities writes: 'it is critical that e-health content and services are developed efficiently, are available for all, and health related web sites comply with established quality criteria'[4]. It will depend on good cooperation and integration of the experts and sources of medicine, informatics, and education to serve the people in protecting and enhancing health, in avoiding, managing and healing diseases, and in supporting those who are frail, old confused, and suffering from various illnesses.

But it will need more than the merging of technologies and certification oversight; it will need, as the famous Confucian scholar Yang Chuan said, *experts 'who have the heart of humaneness and compassion, are clever and wise, sincere and honest'* [19:286]. Yang Chuan spoke about virtuous and trustworthy physicians; today and in the future we have to see that all experts involved in health care and disease management have these character traits and virtues. E-health certainly has all the properties to enrich individuals and their families and friends with and without the help of professional health care experts to develop health literacy and competence, to enjoy healthy lifestyles, protection and even enhancement of health as never before.

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While e-health has all the properties to emancipate lay people from unnecessary expert paternalism and from dominance of protected and privileged knowledge, only honest and virtuous physicians can take the lead to develop the new cyberspace rooms for new cyberspace communities and health care information seekers [23]. These and other new rooms of communication and cooperation certainly need to be open to the competitive forces of the markets of values and valuables, but certain level of quality assurance and quality control are necessary in order to protect people from fraud and disinformation and to make communication-in-trust possible. A contemporary Chinese bioethicist, Ni Peimin, wrote that health care is 'not a matter of biology alone', but 'a never ending journey towards the highest perfection of human being' [16:42]. The merging of medical knowledge, common-sense lifestyle advice and information technology, integrated in e-health, certainly becomes a new tool for information, advice, compassion, and solidarity in the concern and care for health. But, as all tools, it can be used for unhealthy, immoral and inhuman purposes also and therefore needs more cooperation, attention, and critical evaluation by bioethicists.

References

1. Bennett J (2002) Patients skip the waiting room for virtual visit to the doctor. Wall St J Dec 26, 2002

2. Carns A (2002) Online doctor-patient consulting shows promise in California, Wall St J 10-24-02

3. Collste G (2002) The Internet doctor and medical ethics Medicine, Health Care and Philosophy 5:121-125

Sass HM (2004): E-Health, Health Promotion and Wellness Communities, online im Internet: URL: http://www.e-health-ethics.org/eh-pub-sass-healthpromotion.pdf [PDF veröffentlicht am 2006-10-18] [gesehen am: JJJJ-MM-TT].

4. Commission of the European Communities (2002) eEurope 2002: Quality Criteria for Health related Websites. J Med Internet Res 4(3):e15 [www.jmir.org]

5. Commission of the European Communities (2004) e-health - making healthcare better for European citizens: An action plan for a European e-Health Area. COM (2004)356, 2004-04-30]

6. Diefenbach MA, Butz BP (2004) A multimedia interactive education system for development and preliminary evaluation J Med Internet Res 6(1):e3

7. Dutta-Bergmann MJ (2004) Health attitudes, health cognitions, and health behaviors among internet health information seekers: a population based survey. J Med Internet Res 6(2):e15

8. Eysenbach G (2001) What is e-Health? J Med Inernet Res 3(2):e20 [www.jmir.org]

9. Graff, J: Creating global communities, www.vhl.org/supportgrps/

10. Have H ten (2002) Cybermedicine and e-ethics (Editorial) Medicine, Health Care and Philosophy 5:117-119

11. Kaiser Family Foundation (2001) Generation Rx.com. How Young People use the Internet for Health Information

12. Kielstein R, Sass HM (2002) Genetics in Kidney Disease. How much do we want to know? Am J Kidney Dis 39:637-652

13. Kittler AF, Hobbs J, Volk LA, Kreps GL, Bates DM (2004) The internet as a vehicle to communicate health information during a public health emergency. J Med Internet Med 6(1):e8

Sass HM (2004): E-Health, Health Promotion and Wellness Communities, online im Internet: URL: http://www.e-health-ethics.org/eh-pub-sass-healthpromotion.pdf [PDF veröffentlicht am 2006-10-18] [gesehen am: JJJJ-MM-TT].

14. Landro L (2003) Family doctors lead the pack, ready to embrace e-records. Wall St J Jan 16, 2003

15. Marwick C (2000) Ensuring ethical internet information JAMA 283:1677-1678

16. Ni Peimin (1999) Confucian virtues and personal health. Confucian Bioethics, ed R Fan, London: Kluwer, 27-44

17. NN [HD Noiting, J Wasem] (2002) Was muendige Patienten erwarten. Deutsche Aerztezeitung 15.05.2002

18. Parker-Pope T (2003) Can't get in to see that famed MD? Top docs now keep office hours online. Wall St J, Jan 7, 2003

19. Qiu R (1988) Medicine, the art of humaneness. J Med Philos 13(3):277-300

20. Ratzan SC, Payne JG, Massett HM (1994) Effective health message design. Am Behav Sc 38(2):294-309

21. Reagan B (2002) Handle with Care. What works on e-commerce sites won't necessarily work in health care., Wall St J 10-21-02

22. Ross SE, Moore LA, Earneswt MA, Wittenvogel L (2004) Providing a web-based online medical record with electronic communication capabilities to patients with congestive heart failure. J Med Internet Res 14; 6(2):e12 [May 14]

23. Sass HM (2003) New options for health care policy and health status insurance: citizens as customers. Croatian Med J 44(5):562-567

24. Schroeder P (2002) Vom Sprechzimmer zum Internetcafe, Bochum: ZME

25. Schroeder P (2003) Patientenaufklaerung und Gesundheitskommunikation im Internet. Patientenaufklaerung bei genetischem Risiko, ed HM Sass, P Schroeder, Muenster: Lit, 57-78

26. Winkler MA et al (2000) Guidelines for medical health information sites in the internet. JAMA 283:1600-1606

Sass HM (2004): E-Health, Health Promotion and Wellness Communities. Eubios J of Intern Asian Bioethics, 14:170-174.