

Ian Brown and Andrew A. Adams:

The ethical challenges of ubiquitous healthcare

Abstract:

Ubiquitous healthcare is an emerging area of technology that uses a large number of environmental and patient sensors and actuators to monitor and improve patients' physical and mental condition. Tiny sensors gather data on almost any physiological characteristic that can be used to diagnose health problems. This technology faces some challenging ethical questions, ranging from the small-scale individual issues of trust and efficacy to the societal issues of health and longevity gaps related to economic status. It presents particular problems in combining developing computer/information/media ethics with established medical ethics. This article describes a practice-based ethics approach, considering in particular the areas of privacy, agency, equity and liability. It raises questions that ubiquitous healthcare will force practitioners to face as they develop ubiquitous healthcare systems. Medicine is a controlled profession whose practise is commonly restricted by government-appointed authorities, whereas computer software and hardware development is notoriously lacking in such regimes.

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Introduction

Modern medicine is a highly technological field. No modern hospital is without its plethora of “machines that go ping”. As these machines get smaller, cheaper and more powerful, they present some challenging ethical questions, ranging from the small scale individual questions of trust and efficacy to the societal issues of health and longevity gaps related to economic status. Thus the ethical issues raised by *ubiquitous healthcare* (see the next section for a definition) present particular problems in combining developing computer/information/media ethics with established medical ethics. The common ground between these areas includes:

- Confidentiality (medical ethics); privacy (information ethics)
- Responsibility (medical); liability and professionalism (information)
- Informed consent (medical); professionalism (information)
- Enforced treatment (public health); surveillance, censorship etc (information)

In addition, medicine is a controlled profession whose practise is restricted by government-appointed authorities in the developed world, whereas computer software and hardware development is notoriously lacking in such regimes. Medical technology, alongside drugs, must be individually approved for medical use, and is covered by much stricter liability laws than the average business computer.

Medical ethics is principally presented and studied as practise and outcome based,¹ with central authorities typically dealing with the hard cases and only time-sensitive decisions needing sole individual judgement, whereas information ethics

¹ Frank, A. W.: Ethics as process and practice. 355—357

tends to stress individual responsibility and judgement as the primary means to acting in a professional and ethical manner.

These apparently diametrically opposed approaches are not uncontroversial in their own fields²³ nor do they preclude the rich variety of ethical practice in both fields. However, the divergent norms in the two fields present extra difficulties in developing the necessary common understanding in the light of increasing reliance on computing technology for medical purposes.

In this article we present a practise-based ethics approach, raising the questions to which medical and computing professionals will be forced to face up, as they collaborate to develop and deploy ubiquitous healthcare systems.

Ubiquitous healthcare

Ubiquitous healthcare is an emerging field of technology that uses a large number of environmental and patient sensors and actuators to monitor and improve patients' physical and mental condition. Tiny sensors are being designed to gather information on bodily conditions such as temperature, heart rate, blood pressure, blood and urine chemical levels, breathing rate and volume, activity levels, and almost any other physiological characteristic that provides information that can be used to diagnose health problems. These sensors are worn on⁴ or implanted in the body, or installed in patients' homes and workplaces. Actuators go further and trigger actions such as the release of small quantities of pharmaceuticals into the bloodstream or the electrical stimulation of brain areas (e.g. those implicated in conditions

² Shildrick, M. and Mykitiuk, R.: Ethics of the Body.

³ Hughes, C. and Thompson, C.: The International IT Professional Practice Programme.

⁴ Roggen, D., Arnrich, B. and Troster, G.: Life Style Management using Wearable Computer.

such as Alzheimer's disease and Parkinson's disease⁵ or those associated with depression⁶).

The main purpose of these sensors and actuators is to help patients and their carers monitor health status and design and implement interventions to improve that status. Initially, they are likely to be used by family doctors to remotely monitor patients, and provide general health advice while saving patients a trip to their offices. This is particularly useful for mobility-impaired patients, including many older people. In time, the technology is intended to support greater self-monitoring and care by all individuals, not just those with chronic conditions.⁷ Less capable patients, such as young children and those with cognitive impairments, will need more intensive support from healthcare workers and family members. Ubiquitous healthcare technologies can monitor and advise on longer-term health factors such as diet and exercise, presaging a shift towards "well-being management" that incorporates social as well as physical and mental health.⁸

Technologies are also being developed to support the activities of healthcare workers, in hospitals and other critical care settings as well as primary care contexts. Examples include patient record systems that modify the information presented to hospital workers based on their current context;⁹ support for improved information flow between

nurses during shift changes;¹⁰ and the collection and pre-transmission of information from accident scenes to hospitals.¹¹ Systems have also been developed to support the training of doctors.¹²

Finally, ubiquitous computing technologies are being used to improve the performance of patient support devices — such as helping cognitively impaired wheelchair users avoid impact with objects, and especially with other people in crowded areas,¹³ and to provide feedback such as verbal descriptions of objects for visually impaired users.¹⁴

Ethical issues

How far should individuals be held directly responsible for the state of their body? Biological theories swing to and fro on how much of an individual's state of health is determined by nature (genetics) or nurture (lifestyle). Gradually, statistical norms are providing some of the answers, which are usually a combination of both genetic disposition and environmental factors that cause serious disease, whether that is heart disease, breast cancer or diabetes.

Health care in the industrialised world is generally provided on an insurance basis, but the funding mechanism for the insurance varies substantially: almost all public (e.g. UK), private/public (e.g. France) or almost all private (e.g. the US). Both public and private health insurance organisations

⁵ Boockvar, J.A. and others: Long-term deep brain stimulation in a patient with essential tremor: clinical response and postmortem correlation with stimulator termination sites in ventral thalamus.

⁶ Aouizerate, B. and others: Deep brain stimulation of the ventral caudate nucleus in the treatment of obsessive-compulsive disorder and major depression.

⁷ Komninos, A. and Stamou, S.: HealthPal: An Intelligent Personal Medical Assistant for Supporting the Self-Monitoring of Healthcare in the Ageing Society.

⁸ World Health Organization: Preamble to the Constitution of the World Health Organization as Adopted by the International Health Conference.

⁹ Tantori, M., Favela, J. and Gonzalez, V.: Towards the Design of Activity-aware Mobile Adaptive Applications for Hospitals.

¹⁰ Tang, C. and Carpendale, S.: Healthcare Quality and Information Flow during Shift Change.

¹¹ Massey T., Gao, T., Bernstein, D., Husain, A., Crawford, D., White, D., Selavo, L. and Sarrafzadeh, M.: Pervasive Triage: Towards Ubiquitous, Real-time Monitoring of Vital Signs for Pre-hospital Applications.

¹² Fishkin, K., Consolvo, S., Rode, J., Ross, B., Smith, I., and Souter, K.: Ubiquitous Computing Support for Skills Assessment in Medical School.

¹³ Mihailidis, A., Elinas, P., Gunn, D., Boger, J. and Hoey, J.: Pervasive Computing to Enable Mobility in Older Adults with Cognitive Impairment.

¹⁴ Coroama, V. and Rothenbacher, F.: The Chatty Environment - Providing Everyday Independence to the Visually Impaired.

face difficulties in dealing with the new information available about patients. While knowing genetic risk factors can allow public health insurance to focus preventive measures/diagnosis on those most at risk (early prescription of cholesterol lowering drugs for those genetically at risk of heart disease and regular scans for those most at risk of cancer) they also face calls for the freedom of those at risk of costing the publicly funded system large sums to be curtailed. Ericson and Haggerty¹⁵ used Beck's¹⁶ concept of the "Risk Society" to describe moves toward actuarial styles of policing and criminal "justice". Health care systems already use actuarial approaches a good deal more than policing has ever done. So, as more becomes known about disease factors and as it becomes easier to gather information about patients, what ethical questions are raised about the ubiquitous healthcare technologies discussed above?

Privacy

Who owns health information, and how restricted is access to it? Medical information is classed as "sensitive" by the EU Data Protection Directive,¹⁷ and yet the UK government's National Health Service IT programme will place medical records onto a single system, much more vulnerable to mass access than the distributed data storage of today. Accessible by all medical personnel over the NHS' network and by the patient (and anyone capable of cracking into it) over the internet, it requires strong opt-out action to prevent every last detail being added from the relative security of a doctor's paper files and internal network, onto a system controlled at five regional centres. In collecting the massive amounts of health and lifestyle information gathered by ubiquitous healthcare systems, close attention will need to be paid to who controls what is gathered, who has

¹⁵ Ericson, R. V. and Haggerty, K.D.: Policing the Risk Society.

¹⁶ Beck, U.: Risk Society: Towards a New Modernity.

¹⁷ European Parliament and Council of the European Communities: Directive 95/46/EC of the European Parliament and of the Council of 24 October 1995 on the protection of individuals with regard to the processing of personal data and on the free movement of such data.

access to it, and where/how/whether that information is stored.

Private health insurance companies often require a physical examination before insuring individuals. In the ubiquitous healthcare technology world would they be at liberty to require a trial period for gathering "total health information awareness" about patients before starting cover? Would they be allowed to require all patients to report all "risky" activity, backed up by monitoring showing exactly how much alcohol one had that last weekend before suffering a stomach ailment?

Agency

With great information comes the potential for behaviour modification. So thought Bentham¹⁸ and Foucault,¹⁹ at least. Will our bodies become our Panoptic prison, and our behaviour be dictated by health insurance limitations? Will technology gradually reshape and modify unhealthy behaviours?²⁰ Will mood-altering drugs (already appetite suppressant drugs are being marketed to both the obese and the anorexic) take this a stage further and "programme" our reactions to avoid disease? Will the robot nurse of the present Japanese old folks' home become the robotic Nurse Ratched of the future?

Equity

The health gap between rich and poor (and the associated life expectancy gap) is already significant in many developed countries. In the UK for example, life expectancy between rich and poor differs by 5% of lifespan²¹. Government responses have included suggestions to "force" the poor to take up healthier lifestyles to make up for their economic disadvantage. More advanced healthcare is already available if one has the money. Will the development of ubiquitous technologies exacerbate this trend and if so, should the lack of

¹⁸ Bozovic, M.: The Panopticon Writings.

¹⁹ Foucault, M.: Discipline and Punish.

²⁰ Intille, S.: Ubiquitous Computing Technology for Just-in-Time Motivation of Behavior Change.

²¹ Shaw, M., Smith, G.D. and Dorling, D.: Health inequalities and New Labour: how the promises compare with real progress.

availability to all prevent those who can afford it from spending their money on the greatest prize of all — a longer healthier life?

Responsibility for errors

The largest payments in civil court cases in the US tend to be for medical mistakes, due to both the impact and need of patients put at great risk by faulty procedures, and by the reaction against “betrayed trust” when medical personnel get it wrong. The history of healthcare informatics is littered with examples of software failure producing grievous harm (e.g. the Therac 25 case²²). If automated ubiquitous systems go wrong and harm results, who is to blame, and how will consequent costs be covered in already financially stretched systems? As technology becomes ever more complex, what will “informed consent” look like?²³

Ethical Discussions

In this section, we consider first the most significant basic ethical principles which must inform the ethical debate about ubiquitous healthcare, and then some initial normative responses to the ethical questions raised above.

Relevant Principles

The two primary (though not the only) ethical principles applied in healthcare are beneficence and autonomy²⁴. The progress made in the twentieth century in requiring informed consent to medical procedures is often characterised (or, it might be claimed over-simplified) as a battle between beneficence attitudes and respect for autonomy in medical settings. Of course this dichotomy (whether actual or only perceived) is far too simple to adequately describe real medical ethics in practice. It ignores broader questions of social justice that arise in a resource-limited system. It ignores questions of agency and their link to autonomy (from whether heavy drinkers should

be provided with liver transplants to whether heavy smokers should have to pay for their anti-cancer drugs). The autonomy/beneficence dichotomy also ignores the balance of rights in the smaller sense such as is at stake with questions of family consent to organ donation or in questions of late term abortion. It ignores questions of the medicalisation of “difference” such as occurs with human hermaphroditism (one of a number of situations described in the medical literature as “abnormalities of sex determination”). There are many other issues at stake and the clean representation of an emerging ethics of ubiquitous healthcare as presented in this paper should be taken only as a starting point.

In Information ethics, autonomy has emerged as the primary principle in many areas. Privacy rights, for example, are justified on the basis of autonomy, when they are justified at all instead of taken as *sui generis* rights.

Social justice is beginning to emerge as a significant factor in discussion of digital divides²⁵. Beneficence (or its more extreme cousin paternalism) is used as the justification for a variety of information policy decisions, particularly including decisions on what, how and from whom to censor access to information online.

Privacy

Information privacy guidelines, clearly based on the principle of autonomy, are one of the most well developed areas of agreement between information and medical ethicists. In general terms, information about an individual must be processed with clear respect for the individual. The beneficence principle is also at work, here, however, as may be seen in the statements of the UK Information Commissioner’s response to the case of George and Gertrude Gates in December 2003. Following the claims of British Gas that the UK’s Data Protection Act prevented them from passing details of the withdrawal of the couple’s energy supply to social services, the Information Commissioner made it clear that the right to information privacy must be interpreted with due attention to a duty of care owed to customers, particularly those vulnerable to significant negative consequences without information sharing.

²² Leveson, N. G. and Turner, C. S.: An Investigation of the Therac-25 Accidents.

²³ Faden, R. and Beauchamp, T.: A History and Theory of Informed Consent.

²⁴ *Ibid.*

²⁵ Baskaran, A. and Muchie, M.: Bridging the Digital Divide.

So, in developing appropriate ethical approaches to the massively increased volume and sensitivity of data that will be generated by ubiquitous healthcare devices, a balance must be struck between preserving the autonomy of individuals, and preserving their life and good health. In general terms, access to information should be under the control of the patient or their appointed guardian (for those deemed legally incompetent to make such decisions).

Further work is needed on the issue of access to information either for statistical research purposes, or where resources allocation questions are at stake (see normative responses on equity questions below).

Agency

Medical ethics is perhaps the one area of life in which beneficence is routinely allowed to override autonomy. Even the most liberal of governments have laws against extreme forms of self-harm (such as taking regular doses of highly addictive drugs). In most countries, even many relatively mild substances are heavily controlled in their application. Similarly, certain attitudes are generally taken as indicative of incompetence (the most obvious being suicidal tendencies). Medical ethics already struggles with the question of enforced treatment of those with personality disorders, and legal questions abound about the deprivation of liberty of those diagnosed with untreatable disorders who have yet to commit violent acts, but for whom this is regarded as (almost) inevitable by qualified personnel. These questions will become ever more difficult as ubiquitous healthcare develops, alongside related physical and chemical advances. Should a pessimistic individual be permitted to undergo the implantation of deep brain stimulation devices, or should these be restricted only to those with deep depression?

If one takes the current normative view of drugs, then such treatments are only to be used where the consequences of non-use are appalling. However, alcohol is almost universally and caffeine universally available. The definition of ability and disability, normality and abnormality, difference and deviance, are socially defined. As one might literally be able to "turn on the waterworks" or "turn one's frown upside down", society will have to struggle further with questions of allowed self-determination. When the self is effected by the treatment, in a deliberate and planned way, which self should decide on the initiation and/or cessa-

tion of treatment comes to the fore as the central question to be addressed.

Equity

The cost of new cancer drugs is bringing the stark realities of healthcare divides into the cosy world of the UK's NHS. Private insurance regimes in countries like the US have been faced with these dilemmas for longer, but have seemed powerless to prevent them growing ever larger, particularly with an ageing population coinciding with the demographic wave of the baby boomer generation reaching old age.

Ubiquitous healthcare will bring these questions into ever-starker relief. The exponential increase in computing power, combined with the linear decrease in the cost of hardware systems has not prevented a growing digital divide from opening up. So, although the ubiquitous healthcare divide may not be as wide as the cancer drug divide, and the length of time from development to affordability may be shorter, the diversion of resources from traditional healthcare to ubiquitous devices may severely exacerbate the difficulties already facing healthcare systems worldwide.

Preventing patents from becoming the usual profit-making centre of ubiquitous healthcare devices (either for hardware or software) would seem to be a priority for avoiding the kind of inequities in drug availability we are now seeing²⁶. Using market forces to provide incentives not only for ameliorating the symptoms of the rich, but for curing the disabling health problems of all would seem a necessary (but not sufficient) step in reducing the contribution of ubiquitous healthcare to existing social inequities.

Responsibility for Error

It is clear that the warranty disclaimers of the software industry cannot easily be merged into the litigious world of medical (mal)practise. However, the demand for ever-greater health benefits from new technology may well force a less rigid standard of liability in ubiquitous healthcare markets. An acceptance of the fallibility of human action is already built into the professional standards of the medical profession, and the rapid pace of techno-

²⁶ Drahos, P. and Braithwaite, J.: Information Feudalism.

logical transformation may well force an even lower standard to prevail for ubiquitous healthcare technologies than is acceptable for other elements of health care. This, too, will remain an area in need of both ethical consideration and practical and legal application.

Conclusion

The ethical implications of ubiquitous healthcare are many and varied. They cannot be answered by medical ethics or information ethics alone. Nor can they be answered now, once and for all. They will require constant consideration, discussion, evolution and occasionally revolution.

Different social settings may produce different answers, just as a multiplicity of views exists today on questions of reproductive ethics and freedom of speech. The extreme globalisation required of information ethics is not (yet at least) required of ubiquitous healthcare ethics, bounded as it is by the physical embodiment of the patient. However, the impact of access to technology and self-diagnosis (even self-treatment) and a more internationally mobile population, require a more internationally aware approach in the ethics of ubiquitous healthcare than has been the case for medical ethics to date, where significant differences have been easily tolerated, even for close neighbours such as the UK and the Republic of Ireland (who have radically different reproductive ethics stances).

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