ETHICS AND HEALTH INFORMATICS: FOCUS ON LATIN AMERICA AND THE CARIBBEAN

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Abstract: Expanding use of computers in medicine continues to raise interesting and important ethical issues. After a brief review of the history of work in ethics in medical informatics, this introduction to this special issue of *Acta Bioethica* makes the case that this work must be applied in a Latin American and Caribbean context. From the use of intelligent machines to the evolution of the World Wide Web, the region presents vital –and under addressed– challenges to clinicians and policy makers. Sustained and regional debates, curriculum development and empirical and conceptual scholarship are among the means to ensure ethically optimized applications of health information technology in the region.

Key words: Bioethics, Caribbean, Health information technology, Latin America, Medical informatics, World Wide Web

ÉTICA E INFORMÁTICA EN SALUD: ENFOQUE SOBRE LATINOAMÉRICA Y EL CARIBE

Resumen: El creciente empleo de computadores en el área médica continúa planteando interesantes e importantes temas de salud. Después de una breve revisión de la historia de trabajos en ética de la informática en medicina, esta introducción al número especial de *Acta Bioethica* señala que este trabajo debe realizarse en un contexto latinoamericano y del Caribe. A partir del empleo de máquinas inteligentes hasta la evolución de la World Wide Web (WWW), la región presenta desafíos vitales –pero de muy poca atención– para los médicos y encargados de políticas públicas. Debates regionales continuos, desarrollo curricular y estudios empíricos y conceptuales figuran entre los medios que asegurarán en la región el uso éticamente óptimo de la tecnología de la información en salud.

Palabras clave: bioética, el Caribe, tecnología de la información en salud, Latinoamérica, informática en medicina, World Wide Web

ÉTICA E INFORMÁTICA EM SAÚDE: ENFOQUE SOBRA A AMÉRICA LATINA E O CARIBE

Resumo: O crescente emprego de computadores na área médica continua levantando interessantes e importantes temas de saúde. Após uma breve revisão da história de trabalhos em ética da informática em medicina, esta introdução ao número especial de *Acta Bioethica*, assinala que este trabalho deve realizar- se num contexto latino americano e do Caribe. A partir do emprego de máquinas inteligentes até a evolução da World Wide Web (WWW), a região apresenta desafios vitais, porem de muito pouca atenção, para os médicos e encarregados de políticas públicas. Debates regionais contínuos, desenvolvimento curricular e estudos empíricos e conceptuais figuram entre os médicos que asseguram na região uma utilização ótima, eticamente falando da tecnologia da informação em saúde.

Palavras chave: bioética, o Caribe, tecnologia da informação em saúde, América Latina, Informática em medicina, World Wide Web

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Foundations: Ethics and technology in health care

The past quarter century of bioethics has been shaped in large part by technology, and the most important questions have been about whether and when to use a machine or adopt a complex intervention. These questions have ranged from whether we should transplant solid organs or insert foreign genes, to what should count as an appropriate use of technology to prolong –or create– life. This is of course not to say there are no other ethical issues; it is only to say that bioethics itself has been weaned on post-industrial innovation and sustained by a diet of scientifically advanced devices, tools and techniques.

It was therefore inevitable that intelligent machines –that is, computers– would come to occupy a place in the bioethics curriculum. Indeed, many other innovations and machines would not be possible or would not work without computerized support.

Computers came to capture the attention, if not the imagination, of a growing number of health professionals, some of whom grew concerned about the consequences of health informatics. Would privacy and confidentiality be eroded or sacrificed? Would patients be harmed by inappropriate reliance on computers? Should doctors and nurses use a machine that analyzes data and makes decisions for them?

Before there was a World Wide Web, clinicians, scholars and others began to try to make sense of appropriate uses and users of computers in health care. Crucial early work in Pittsburgh[1,2] emphasized the importance of human cognition and judgment in the practice of medicine and other health professions. If medicine is essentially a human undertaking, then it is a mistake to hope or believe that computers could ever supplant or replace humans in its practice. Indeed, it would be a moral mistake to allow a computer to make a decision affecting patient care (at least without competent human oversight). It soon became clear that these ethical issues required sustained analysis, if for no reason other than that computers were becoming ubiquitous in health care and thus had joined the ranks of other technologies whose use engendered ethical challenges: "The future of the health professions is computational"[3, p. 1].

Then came the Web, promising universal access to information that would improve global health – but also threatening the health of those who were too desperate, hopeful or gullible to know better how to manage information filtered by industry, driven by commerce and supported by vast ensembles of proprietary interests. Health information on the Web shifted the focus from appropriate use and user to trust and reliability[4].

Throughout, and to the present, the use of computers in health care has posed challenges to privacy and confidentiality. Since antiquity, Hippocrates' "sacred secrets" have represented a tradeoff between confidentiality and an ever-broadening need-to-know. The growth of electronic patient records has made this tradeoff a high-stakes exchange, balancing (or attempting to balance) privacy, liability, public health and biomedical science. The best advice for those seeking to provide nontrivial protections for patient privacy has been a multi-pronged strategy of rules, education and electronic security[5].

Even these steps, however, are largely untested in an environment increasingly shaped by factors and forces unimagined by Hippocrates. How should we protect digitized genetic data when information about one person is also, in one degree or another, also information

about family members*(6)*? How strong is –and should be– our commitment to privacy when faced with public health emergencies including bioterrorism and bioterrorism preparedness*(7)*?

These challenges are exciting and important. They simultaneously reawaken us to the need to evaluate new tools through the lens of bioethics and demonstrate the utility of bioethics to clinicians and policy makers. Put differently, the expanded use of and reliance on health information technology places this technology squarely in the center of the stream of a century of scientific advances that raise ethical challenges. That is, use of computers in medicine is in many ways similar to use of other technologies that have changed practice and challenged morality. There remains, however, a very large and under-addressed problem:

It is not yet clear how any of this applies in contexts and countries in which the greatest challenges are not the use of diagnostic expert systems, but health equity; not appropriate use of very large data electronic bases, but access to care; not privacy of digitized genetic information, but genetics and public health. To prevent our fascination with machines from blinding us to the needs of global populations –to prevent the rise of what we should perhaps call "boutique ethics"– we must rethink the role of computers in health care in non-European and non-North American contexts.

Health information technology in Latin America and the Caribbean

Can information technology improve global health? Of course. The greatest challenge may be in finding a common denominator in wildly different venues. While we are glib about using descriptors such as "Latin America and the Caribbean," there is often little if anything in common between, say, Haiti, Honduras and Bolivia on one hand, and Argentina, Brazil and Chile on the other. Nevertheless, because use of health information technology is expanding in the region and because such use might be salutary where it is now lacking, we have a duty to examine the ethical issues that should inform such use.

Consider that one of the first insights by those studying ethics and informatics was that failure to use a computer might be as blameworthy as using one inappropriately*(1)*. That is to say, if there is reason to believe that a computer will improve medical care or public health, then it would be a moral mistake to fail to use it. Imagine a low cost system for connecting patients in one place to clinicians in another (…) would such a system improve access to care and therefore improve public health*(8)*? In many respects, such questions are simultaneously ethical and empirical. We cannot answer the former without answering the latter. It follows that one of the clearest moral imperatives we face in examining the use of health information technology in Latin America and the Caribbean is met by doing more research. If computational tools improve patient care or public health, we should use them; if not, not. This illustrates in stark relief the ways in which an evidence-based bioethics can inform and guide clinical practice, research and public health.

There is, further, the need to identify sound public policies, many of which will be shaped by unique local or regional circumstances. Moreover, policies imposed by those distant from the problem to be solved (or the application intended to solve it) are likely to fail or be ineffective. This means that accord, shared values and consensus are crucial if health information technology is to be useful in improving the health of populations, especially in the developing world. It is worth emphasizing that Latin America is already the source of important work along these lines*(9)*, work

which, incidentally, North Americans and Europeans should learn from if they seek ethically optimized health information technology policies.

Indeed, it will be a happy and useful irony when the North begins to learn from the South about best practices in the use of technology. We envision a day in which a clinician in the United States using a computer built in China follows a policy shaped by experts in Argentina, Brazil or Chile.

It is for these reasons that it is important to begin a sustained look at ethics and health informatics from a Latin American and Caribbean perspective. This is among the motivations and inspirations for this special issue of *Acta Bioethica*. While the contributions in this issue do not and could not present a comprehensive or systematic overview, they might in some small way be of service to those seeking to develop a context-sensitive ethics in the use of one of civilization's must important and exciting technologies.

Overview of the contributions

Telemedicine or "remote-presence healthcare" has excited some clinicians for more than a decade. With telemedicine technology, it is possible in principle for a patient in the provinces to be "treated" by a physician in the city – at least in principle. But the question whether optimism about such technology is well placed in Latin America and the Caribbean is difficult to answer. Dr. Sergio Litewka, an Argentine surgeon, addresses these and other issues in "*Telemedicina: Un Desafío para América Latina*". He is less than sanguine about the prospects, suggesting, ultimately, that, "Que la telemedicina sea un hecho positivo o un experimento lamentable en América Latina depende, en mucho, de los juicios y los valores que prevalezcan en las discusiones de cada sociedad y del modelo de

salud que esas comunidades decidan". This article is one of the first in any language to provide more than a cursory review of ethical issues that arise with the use of telemedicine. That it does so in a Latin American and Caribbean context underscores the importance of including, at a fundamental level, perspectives from those who are often identified as being the beneficiaries of new health information technologies.

In "Consumer Health Informatics: Ethics, Evaluation And Standards," Dr. Eta Berner, an educator and scholar in Alabama, and colleagues take an analysis about health information on the Web and apply it in a regional context. While concern about the accuracy and reliability of Web-based health information has led over the past decade to a suite of guidelines, codes of conduct and other oversight mechanisms, it remains to be seen what kinds of guidance is necessary or adequate to the many tasks before us. Since we are, in fact, talking about the World Wide Web, it makes little sense to suppose that mere regional or national rules will be adequate (although local rules of use might be appropriate in some contexts). Throughout, the tension here is as important as it is palpable. Dr. Berner and colleagues conclude: "Failure to use the best of health information technology will be a loss to the people of Latin America and the Caribbean. Failure to use this technology responsibly will allow the entire enterprise to be seen by some populations as a cruel trick." What remains now is to identify the best and most appropriate means to promote –if not ensure– such responsible use.

Both the North and the South face fundamental challenges at the intersection of privacy and informed consent, especially when electronic data are used for research. Dr. Gillian Bartlett and colleagues at McGill University in Canada share the results of a study linking these core ethical values in "Non-participation bias in health services research using data from an

integrated electronic prescribing project: The role of informed consent." Addressing the opportunities and challenges presented by electronic prescribing, this article is included to give a Canadian perspective on a technology that might be of special use for Southern Hemisphere health systems.

The conclusion – "Future research should focus on new models of patient consent that balance the rights of individuals for privacy and confidentiality with the requirements of public health research" – underscores a point made and emphasized earlier, namely, that evidence-based bioethics requires, well, evidence. Some regions present opportunities to integrate such evidence at the outset in the adoption of electronic tools.

Future directions

One of the beauties of teaching bioethics, or introducing it in the training of health professionals, is the opportunity to address larger, philosophical questions. These include the ancient problem of moral relativism, or the idea that rightness and wrongness are products of time, geographical region, religious tradition, political or national boundary, individual persons, and so on. Is informed (or valid) consent a universal value, or should we understand it as a mere local preference? Do all humans have a reasonable expectation of health privacy, or is this an indulgence of affluent societies? Are access to treatment and health care equity global duties, or is this, too, a value that changes or fluctuates with era, continent, religion or country?

We do not necessarily solve this noble philosophical problem by teaching bioethics, but we can, at the least, insist on and maybe even inspire attention to it. The use of computers in health care offers an especially interesting opportunity to advance this debate. This is no more true than when we use health information technology to test value systems and apply the critical skills of bioethics. The opportunity to ask the kinds of questions we ask in this special issue of Acta Bioethica is an opportunity to broaden the debate and apply the results in a region where some such issues have traditionally been under-addressed. Many of us would argue that moral relativism ill serves the people of Latin America and the Caribbean, making our inquiry all the more important and urgent. It also points the way to future research and future conceptual analysis. Thus there is a case to be made for sustained work in the following areas:

• Empirical research on the efficacy and acceptability of medical informatics tools in Latin America and the Caribbean.

• Bioethical analysis of traditional and new values and how they shape or guide expanding use of health information technology in the region.

• Ethically optimized policy development to link values to practice.

Each of these represents a major undertaking. But major undertakings are not new to Latin America and the Caribbean and, in any case, some of the necessary work has already begun. Our goal in this special issue is in part to make the case for regional leadership in a global debate and, if only in small part, to contribute to this debate. With goals that are modest enough, one can sometimes succeed merely by starting.

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