



# The role of ethics in information technology decisions: a case-based approach to biomedical informatics education

James G. Anderson\*

*Sociology and Anthropology Department, Purdue University, Room 353, Stone Hall-Office, 700 West State Street, West Lafayette, IN 47907-2059, USA*

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**Summary** The purpose of this paper is to propose a case-based approach to instruction regarding ethical issues raised by the use of information technology (IT) in healthcare. These issues are rarely addressed in graduate degree and continuing professional education programs in health informatics. There are important reasons why ethical issues need to be addressed in informatics training. Ethical issues raised by the introduction of information technology affect practice and are ubiquitous. These issues are frequently among the most challenging to young practitioners who are ill prepared to deal with them in practice. First, the paper provides an overview of methods of moral reasoning that can be used to identify and analyze ethical problems in health informatics. Second, we provide a framework for defining cases that involve ethical issues and outline major issues raised by the use of information technology. Specific cases are used as examples of new dilemmas that are posed by the introduction of information technology in healthcare. These cases are used to illustrate how ethics can be integrated with the other elements of informatics training. The cases discussed here reflect day-to-day situations that arise in health settings that require decisions. Third, an approach that can be used to teach ethics in health informatics programs is outlined and illustrated.

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## 1. Ethics in health informatics education

Academic programs are rapidly developing in health information administration, healthcare information technology (IT), medical and nursing informatics. At the same time, medical, nursing and allied health schools are incorporating informatics into their curriculum [1,2]. However, a recent survey of medical informatics in American medical schools found that ethical issues raised by information

technology were addressed in about one-third of the schools surveyed [3]. Also a similar review of 10 graduate nursing informatics programs found that only two programs required ethics courses [4].

At the same time the rapid growth of information technology in health care is transforming the delivery of healthcare. Information technology simultaneously changes clinical practice and challenges existing values. The introduction of information technology into health care raises a host of ethical and social issues. Yet these issues are rarely addressed in graduate degree and continuing professional education programs. At the same time, healthcare professionals need good clinical and

\*Tel.: +1-765-494-4703; fax: +1-765-496-1476.

E-mail address: andersonj@soc.purdue.edu (J.G. Anderson).

technical education as well as appropriate ethical education. There are important reasons why ethical issues need to be addressed in informatics training. Ethical issues raised by the introduction of information technology affect practice and are ubiquitous. These issues are frequently among the most challenging to young practitioners who are ill prepared to deal with them in practice. Second, as Friedman and Dev [5] have pointed out, education in the health professions is intertwined with practice since informatics is concerned with access to and use of information. The case-based approach proposed in this paper articulates well with the teaching of informatics. Third, examination and discussion of real-life cases provide practical guidance in recognizing ethical issues and dealing with them when they arise.

This paper first will provide an overview of methods of moral reasoning that can be used to identify and analyze ethical problems in health informatics. Second, it will provide a framework for defining cases that involve ethical issues and a priority list of issues common to health informatics. Third, it will outline an approach that can be used to teach ethics in health informatics programs.

## 2. Ethical principles

A useful framework for ethical analysis is based on the principles of beneficence, non-maleficence, autonomy and justice [6]. The principle of beneficence requires the potential benefits to individuals be maximized and potential harm be minimized. The second principal, non-maleficence is related. This is the injunction to do no harm. Tang [7] has pointed out that in responding to the Health Insurance Portability and Accountability Act that health care providers need to balance protection of patient data with the need to use these data to make decisions about treatment and quality of care. Autonomy requires us to honor the individual's right to self determination including privacy. Finally, the principle of justice requires an equitable distribution of the potential benefits and harm from an action. However, there are several theories of distributive justice. One approach is egalitarian and requires that each individual receive equal benefits. A utilitarian approach holds that our moral obligation is that an action should benefit the most people. While a libertarian approach leaves decisions to the marketplace and eschews regulations. However, some issues involve ethical conflicts between these principles. For example, privacy and security of patient data (based on the principles of autonomy and non-maleficence) conflict with the benefit

to society from using these data for research and public health (the principle of distributive justice) [8].

## 3. Ethical Issues in health informatics

Some issues that arise in the use of health informatics are issues of judgment or best practice. For example, whether or not to implement an electronic medical record, e-prescribing or a point-of-care decision support system in a practice. While these decisions may be used for other instructional purposes, situations that arise in health informatics that involve high levels of moral uncertainty or involve conflict between competing values and duties are ideal for teaching ethical principles in decision-making. For example, traditionally health care professionals have been the gate keepers to health information. Online sources of health information offer immediate information to consumers. An important ethical issue is what responsibility does the health professional have in assisting consumers to recognize the difference between good and bad information [9]? Anderson and Goodman [10] provide a compendium of case material that illustrates ethical concerns in health informatics. These materials can be used for case-based instruction in health informatics courses and continuing professional education.

In this paper we will outline some of the major ethical issues raised by information technology. Cases will be used to illustrate how ethics can be integrated with the other elements of informatics training. Cases discussed reflect day-to-day situations that arise in health settings that require decisions [11]. Issues such as privacy and confidentiality, conflicts of interest, and the nature of the physician-patient relationship are fundamental and pervade the US health care system.

Biomedical ethics provides a common frame of reference to address these issues. First, ethics helps us to identify issues that involve questions of right or wrong, appropriate or inappropriate actions on the part of individuals and organizations. Second, actual cases are ideal for identifying and analyzing ethical issues that arise in practice as a result of information technology. Cases can be selected and used to identify, discuss and debate controversies and challenges raised by informatics applications. Third, bioethics also provides a framework and tools to address controversies involving ethical issues and resolve conflicts that arise in practice. Fourth, discussion of challenges, problems and issues can lead to the development of institutional policies and procedures that balance potential harm and

benefits of uses of information technology and the development of professional standards and codes of ethics.

Below we have outlined some of the major social and ethical issues raised by the use of information technology in health care.

### 3.1. Consumer health information

Consumers in developed countries increasingly are using the Internet to obtain health-related information, goods and services [12]. Use of the Internet makes available to consumers a vast body of health-related information but at the same time potentially exposes them to out of date, inaccurate and fraudulent information. It also changes the doctor patient relationship and raises possibilities of conflict when the parties fail to agree on diagnosis and/or treatment decisions. While there is increasing evidence that IT applications can improve efficiency and the quality of care, their implementation in practice raises a host of social and ethical issues that need to be resolved. Some of the major issues are outlined below and illustrated by cases.

#### 3.1.1. Inaccurate health information

Information obtained from Web sites may be inaccurate, out of date or fraudulent [13]. For example, an analysis of 371 Web sites that contain information on Ewing's sarcoma, a bone cancer that afflicts children and young adults found that one out of three sites contained information that did not come from peer-reviewed sources [10]. Some of the sites proposed treatment using alternative medicine. Estimated survival rates varied from 5 to 85%. This situation raises important ethical questions such as: are consumers able on their own to effectively distinguish between peer-reviewed information and less reliable sources? Do health care providers have a responsibility to assist consumers to effectively interpret and act upon contradictory Web-based information such as this? What is the likelihood that parents who use the Web to obtain treatment information will delay or fail to consult their physician?

#### 3.1.2. Conflicts of interest

An additional problem that arises with Web sites that provide health-related information is potential conflicts of interest. The blurring of commercial content and professional information on these sites is a major problem for consumers. Questions that need to be addressed include: do health-related Web sites that advertise health care products and services have a responsibility to make the distinc-

tion clear between advertising and health education? In what ways, if any, is a Web site like or unlike newspapers, radio and television in terms of the differences between news and advertising?

#### 3.1.3. Physician-patient relations

Consumers are assuming more responsibility for their own health care decisions. Some worry that patients who use the Internet to obtain specific disease related information might not consult their doctor about serious health problem. Also, some physicians feel threatened when patients come to them with information gathered from the Internet about alternative diagnoses and treatments. Use of the Internet in this fashion raises a number of difficult questions [14]. While patients are encouraged to learn more about their diseases and treatments and to assume greater responsibility for their care and treatment, how should physicians respond to "clinical trial fishing" when this information is used to second-guess the professional's treatment plan? Should patients and family members be encouraged to question and even challenge decisions made by their health care providers? Or is shopping for additional opinions and protocols on the Internet counterproductive?

### 3.2. Online health services

All manner of health services are available online from virtual health calls to the sale of pharmaceutical products to mental health services [15]. Below we review some of these online services and the ethical issues that they raise.

#### 3.2.1. Virtual house calls

A number of Web sites provide patient-specific health information for a fee. Consumers can also shop online for surgery. On some sites the consumer enters his/her medical profile and the surgical procedure he/she wants on a Web site. Physicians and dentists can bid on the procedure and patient and physician can negotiate the fee [10]. The proliferation of these online services raises a host of new issues. Do virtual house calls treat medical care as a commodity like other goods and services that can be purchased online? Can advice and diagnosis really be effective and safe without any physical contact between online physicians and patients? What guarantees should providers of online medical services be required to supply that the health care providers are qualified to perform the services that they advertise online? Is it unethical for physicians to advertise services online without explicitly stating their qualifications?

### 3.2.2. Online pharmaceutical products

A survey by Forrester Research estimated that by the year 2004 consumers will use the Internet to purchase \$15 billion worth of prescription drugs [16]. Web sites that provide prescription medications to patients who have not first seen a physician in person raise important issues. Questions raised by this practice include: is it ethical for a physician to prescribe a drug over the Internet without actually seeing a patient in person?

### 3.2.3. Behavioral health services

Behavioral health services are beginning to move onto the Web [10]. Questions raised by the use of the Internet to provide behavioral health services include: is there a danger that online screening and counseling may aggravate a sense of isolation and depression in some patients? Can patients receive adequate evaluations and treatments online? Will some patients who use the online service avoid seeing a therapist in person?

### 3.2.4. Electronic medical records

Physicians in Europe and the US increasingly are using electronic medical records [17]. At the same time, accidental breaches of security have occurred at a number of health care organizations who have implemented EMRs [18]. The ready access to patient data raises a number of questions. If a breach of security occurs, is the health care organization obligated to inform all of their patients whose records may have been affected? Will breaches of security result in patients withholding sensitive information from their health care provider? Who should be held responsible for any harm to a patient that occurs because of violations of confidentiality?

Privacy violations also occur when confidential patient data is used for inappropriate purposes. For example, medical students sold health records to malpractice attorneys. State employees in the state of Maryland sold patient information from the state's medical database to HMOs [10]. These violations of patient confidentiality raise issues such as should certain patient records or portions of the record that contain sensitive information such as substance abuse or mental illness be made off-limits to employees not directly involved in care of the patient? At the present time there are few restrictions on what states can do with medical information that they collect. Is it appropriate for states to use these data to identify potential criminals, to monitor family members suspected of child abuse, to detect drug users, etc?

Secondary use of health information is growing. Third-party payers use patient-specific data to pro-

cess claims and to manage pharmacy benefit programs. Self-insured employers have legal access to employees' medical records. Data mining companies acquire medical information and link it to other sources of patient-specific information. The sale of personal information from these databanks for marketing purposes is widespread. Some of the issues that these practices raise are: should the consent of the individual patient be necessary before his/her medical data is included in shared databases? Who should be held accountable if patient data contained in these shared data bases is used inappropriately? If a patient requests that sensitive information such as his/her HIV status not be made part of the medical record, is it ethical for a health care provider to comply with the patient's wishes?

### 3.2.5. Bioinformatics

Bioinformatics involves the use of information technology to acquire, analyze, store, manage, and transmit genetic data [19]. In the future gene chips will be used to acquire genetic data; data mining will be used to extract data from large data bases and warehouses; and decision support systems will be used to analyze data and to make clinical decisions. The rapid growth of bioinformatics presents additional social and ethical issues. Acquiring and using genetic data for clinical purposes will raise issues concerning consent and appropriate use of these data. Questions that need to be raised include: is it ethical to use genetic data collected from patients for clinical purposes in research without first obtaining their express consent? Who can appropriately access and use patient-specific genetic data? Should certain uses of these data be prohibited? For example, insurance companies may use this information to determine eligibility for coverage. Employers may use genetic information to hire and assign employees to specific jobs.

## 4. A framework for teaching ethical decision-making

Biomedical ethics provides a framework and tools to address controversies involving ethical issues and resolve conflicts that arise in practice. This process can be taught in informatics training programs. For example, ethical issues arose when a firm that develops medical information system contracted with a large teaching hospital to develop a decision support system termed a "bedside assistant" [10]. By using the system, physicians will be able to gain immediate access to information contained in the patient's chart through computer terminals located

in each patient's room. The information contained in the system will alert physicians to potential side effects of medications and drug interactions. The decision support system will propose differential diagnoses and critique treatment plans. The hospital administration wants the bedside assistant implemented as soon as possible, since a lot of money has been invested in the system development. Administrators anticipate that providing physicians with immediate access to the medical information and decision-support tools will lead to better diagnoses, improved treatment, and reduced costs. The hospital hopes to prevent potentially dangerous adverse drug events. The engineers developing the decision support, however, have major concerns about its safety. They worry that the system may malfunction because of a bug in the software or because incorrect data has been entered into the patient's record. Though the development team consulted published sources and medical experts in the field, there is no guarantee that they fully understand the information on which the system is based.

The following six steps can be used to analyze and resolve the ethical problems involved in this case [20]. First, data needs to be collected on the controversy or challenges that arise from using the bedside assistant. To begin with the following questions might be raised: (1) what are the major anticipated benefits from implementing the "bedside assistant?"; (2) how long a testing period would be required to determine its safety and reliability?; (3) what are the major risks to the patient from using the system for decision-making?

The second step is to determine the type of ethical problems raised. The following questions could be considered: (1) since no information system is perfect, what levels of risk are acceptable?; (2) what safeguards need to be built into the system to protect the patient from medical errors?; (3) since there are risks to patients involved, to what extent should physicians who will be using the new decision support system be involved in designing, testing, and implementing the bedside assistant?

The third step is to use ethical theories or approaches to analyze the problem. In this case health care providers might debate two approaches. One approach views the health professional's duty and responsibility as being primarily to the individual patient. This is the principle of beneficence. Accordingly, the practitioner may decide that the bedside assistant should not be implemented as long as there are risks to the individual patient. A second approach from a utilitarian standpoint is for the professional to be guided by a desire to bring about the best consequences for the most patients. In this case he/she might view some risk as acceptable as

long as most patients are helped by using the "bedside assistant."

The fourth step is to explore practical alternatives. The health professional might confer with colleagues regarding options and the best decision in this instance. This might help in creating a consensus as to how much risk is acceptable when implementing the "bedside assistant." The fifth step is to take action based on decisions made in steps 1 through 4. Failure to do so may result in harm to patients.

The final sixth step is to evaluate the process and outcome. The practical goal of ethics training is to teach health care professionals to resolve ethical problems such as this one. Questions to ask include: what was the result of my actions? Were they beneficial to the patient? How does this situation compare to others that I have encountered or may encounter? This overall process helps strengthen the health care professional's ability to confront and resolve other ethical problems that arise in the course of practice.

## 5. Conclusion

The International Medical Informatics Association (IMIA) Group on Health and Medical Informatics Education [21], the American Medical Informatics Association (AMIA), 1999 Spring Conference on Informatics Education [22], and the American Nurses Association (ANA) [23] have all identified the ethical use of information technology and ethical decision-making as core competencies for health care providers. Health care practitioners involved in using health care information technology are expected to apply moral principles to particular situations to make decisions. When these principles clash as they frequently do, they must balance one principal against the others. At present health informatics curricula lack ethics training needed so that health care professionals can resolve conflicts and make decisions in situations involving ethical issues. The case-based approach outlined here is ideal to teach practitioners to identify, analyze and make decisions in situations involving ethical issues. This approach needs to be integrated more fully into informatics training programs in the health professions.

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