ARE THERE CHARACTERISTICS OF INFECTIOUS DISEASES THAT RAISE SPECIAL ETHICAL ISSUES?¹

CHARLES B. SMITH, MARGARET P. BATTIN, JAY A. JACOBSON, LESLIE P. FRANCIS, JEFFREY R. BOTKIN, EMILY P. ASPLUND, GRETCHEN J. DOMEK AND BEVERLY HAWKINS

ABSTRACT

This paper examines the characteristics of infectious diseases that raise special medical and social ethical issues, and explores ways of integrating both current bioethical and classical public health ethics concerns. Many of the ethical issues raised by infectious diseases are related to these diseases’ powerful ability to engender fear in individuals and panic in populations. We address the association of some infectious diseases with high morbidity and mortality rates, the sense that infectious diseases are caused by invasion or attack on humans by foreign micro-organisms, the acute onset and rapid course of many infectious diseases, and, in particular, the communicability of infectious diseases. The individual fear and community panic associated with infectious diseases often leads to rapid, emotionally driven decision making about public health policies needed to protect the community that may be in conflict with current bioethical principles regarding the care of individual patients. The discussion includes recent examples where dialogue between public health practitioners and medical-ethicists has helped resolve ethical issues that require us to consider the infected patient as both a victim with individual needs and rights and as a potential vector of disease that is of concern to the community.

¹ This paper was presented for discussion at the 2003 American Society for Bioethics and Humanities Conference, ‘Bioethics across Borders.’
INTRODUCTION

Historically, infectious diseases such as plague, smallpox, typhoid, cholera, tuberculosis and leprosy have been the cause of enormous fear and social distress. Because most of these diseases were thought to be contagious and often occurred in dramatic epidemics, societies addressed these diseases as public health problems, and the needs and rights of populations and communities for protection by improved sanitation, quarantine, immunisation, disease screening and directed therapy have typically been the primary ethical concerns of public health practitioners and legislators. In contrast, the field of bioethics that emerged in the late 1960s has increasingly emphasised the rights of individual patients to autonomous decision making, the avoidance of harm, and the obligation of the practitioner to act in the best interests of the individual patient. Generally, bioethicists have focused on cases that involved chronic, debilitating and life-ending diseases such as cancer, organ failure, congenital abnormalities and addictions, while little attention has been given to the discussion of ethical issues related to the control and management of infectious diseases.

With the appearance of AIDS in the early 1980s the separation between the population-wide concerns of public health and the individual practitioner/patient orientation of bioethics began to close. Zuger\textsuperscript{2} identified AIDS as the ‘first disease on record to spawn a huge, vocal, visible, angry grass-roots patients’ rights movement that changed the course of history.’ AIDS activists have been very effective in forcing public health officials and legislators to consider the rights of patients to privacy, autonomous decision making regarding their care, and the rights of infected patients to justice in the distribution of healthcare resources. Conversely, the relation of AIDS communicability to specific human behaviours has forced individual practitioners to be more open about questioning patients’ private behaviours, to be more concerned with educating patients and the public about high risk behaviours, and to consider classical public health methods for reducing communicability. In many ways, AIDS and many other infectious diseases require us to consider the patient as both a \textit{victim} with individual needs and rights, and as a potential \textit{vector} of disease that is of concern to the community.\textsuperscript{3}


Unfortunately, AIDS, and possibly the often-associated infectious disease tuberculosis, are among the very few examples of infectious diseases where public health policy makers and modern bioethicists have begun to have useful dialogue to explore new ethical paradigms. The purpose of this paper is to examine the characteristics of infectious diseases that raise special medical and social ethical issues, and to explore the ways that current bioethics and classical public health ethics might integrate to meet the needs for ethical ways to manage infectious diseases in the community and for individual patients.

In the following discussion, we will propose that the ethical issues raised by infectious diseases are often related to these diseases’ powerful ability to engender fear in individuals and panic in populations. This fear and panic often leads to rapid, emotionally driven decision making about the care of individual patients and about public health policies, even when these decisions challenge generally accepted medical-ethics principles such as patient autonomy, non-maleficence, beneficence and justice.

I HIGH MORBIDITY AND MORTALITY

The high morbidity and mortality rates for many infectious diseases mean that there is a lot at stake when diagnosing, treating, and preventing them, and pressing ethical concerns are bound to emerge whenever large numbers of human lives are in the balance. While the same could be said for other, non-infectious diseases with high morbidity and mortality rates, such as cancer and heart disease, infectious diseases have this quality to a greater degree than most other types of diseases. Infectious diseases in the 21st century continue to be the leading world-wide causes of death and disability, despite dramatic 20th century advances in the eradication, control, and treatment of infectious diseases such as smallpox, polio, and bacterial infections. Generally, what sparks ethical debate as a result of the high morbidity and mortality of infectious diseases are fearful reactions to outbreaks, with government organisations, health professionals, and individuals altering their own behaviour or requiring altered behaviour in ethically questionable ways. When fear of these diseases becomes a principal force in clinical and public health decision-making,

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serious ethical issues concerning just distribution of resources and human rights can arise.

For example, government support for programmes of high social value such as education, nutrition, and economic development may be subordinated to the need for public health and medical funding to control and treat these infections. The highly fatal and contagious Ebola virus, although only rarely transported out of Africa, has been a cause of worldwide fears that have influenced local economic, travel, and immigration policies. The highly fatal viral disease SARS, both in and outside China, has threatened to bring economic havoc to whole cities as resources have been diverted to meet needs for intensive hospital care, and commerce has been brought to a halt because of quarantine and travel restrictions. Our relative ignorance about the reservoir and source of SARS and the methods of transmission has generated fear of the unknown, and possible over-reaction by public health officials in the use of isolation and quarantine. In attempts to control the SARS epidemic in Taiwan, more than 130,000 individuals were placed in quarantine for 10 or more days with the threat of fines and jail time for violators. Less than 0.3% of quarantined persons were subsequently diagnosed as suspect or probable SARS, and the net effectiveness of the quarantine programme is still under evaluation.

Human rights such as privacy and autonomy may come in conflict with the perceived needs of the community to utilise quarantine and forced therapies to control potentially fatal infectious diseases such as AIDS and tuberculosis. The decision of the New York City public health officials to move from a patient free-choice approach to therapy of tuberculosis, to mandatory directly observed therapy was in large part motivated by the recognition that new strains of TB were highly resistant to antibiotics and many patients, including a high proportion of healthcare workers, were dying from this normally treatable infection. The management of the antibiotic-resistant TB outbreak in NYC has been a rare example of good ethical policy arising from extensive dia-

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logue between the public health officials, infectious disease specialists, and patient advocacy groups.\textsuperscript{9}

Although the World Health Organization declared worldwide eradication of smallpox in 1980, the 30\% mortality and the potential for reintroduction of smallpox as a bioterrorism agent has introduced fear-driven discussions about public policies for quarantine, and the public versus individual risks and benefits of widespread immunisation.\textsuperscript{10} Physicians, nurses and other hospital clinical employees have been particularly conflicted about their public duty to take a vaccine to protect themselves, and subsequently their patients and the public, from the spread of smallpox. The conflict has arisen because of the well-defined potential risks of this live-virus vaccine causing serious and even fatal illness in the recipients of the vaccine or of spreading the vaccine to immune deficient patients at high risk of developing serious complications.

Recent European outbreaks of the fatal neurologic disease, bovine spongiform encephalopathy, in cattle have been associated with over 130 cases of variant Creutzfeldt-Jakob Disease, a similar fatal neurologic disease in humans,\textsuperscript{11} and the resulting attempts to control these diseases have led to widespread slaughter of hundreds of thousands of cattle and embargoes on the import of beef from infected herds and countries. Although the number of human cases has been very small, the universal mortality of humans with CJD has been a powerful force for drastic methods of control.

The continued high prevalence of potentially fatal infectious diseases can in part be attributed to the ability of micro-organisms to rapidly mutate to become resistant to anti-microbials and vaccines.\textsuperscript{12} The steady increase in the prevalence of these resistant pathogens has been attributed to increasing and often inappropriate use of antimicrobials in patient care and by the agriculture industry. This association has stimulated discussions of the ethical


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conflicts between the desires of individual patients for maximum antibiotic therapy and the interests of the community in reducing inappropriate antimicrobial use. Similarly, public policy debates are stimulated by the desires of the meat and poultry industries to speed animal weight gain by using antibiotics in animal feed, and the public health needs to control the development of resistant microbial pathogens.

II INVASIVENESS

Whereas many diseases arise from within the individual’s own genetic makeup in interaction with some aspects of their lifestyle or environment, infectious diseases are caused by invasion or attack on humans by foreign micro-organisms. The common use of war-related words to describe infectious diseases (killer-viruses, flesh-eating strep, invasiveness, attack, and Black Death) reflects the fear that is associated with these diseases. This notion of enemy attack raises ethical questions similar to those faced in discussions of actual warfare. For example: what rights do individuals and communities have in defending themselves against such attacks? To what extent are these defence measures justified? Can individuals refuse to defend themselves if this refusal endangers others? Is a paternalistic response ever justified to force people to defend themselves? The rights of the individual and of the community to protection from attack are at stake when an outbreak occurs, as we can see in the following examples.

For millennia, militarists have attempted to utilise microbial pathogens or their toxins to kill or immobilise their enemies either through the direct effects of these agents or by engendering fear and disruption of social and public health programmes. Recent experience with anthrax bio-terrorism in the US raised policy and ethics questions concerning the justice of decisions about who should be screened for infection, who should receive the limited supply of prophylactic antibiotics, who should receive a vaccine of uncertain effectiveness and safety profile, and what services, such as the mail, should be shut down to protect the public.13 While some have welcomed this bioterrorism-fear-induced infusion of public funds to support public health laboratories and programmes,14 others have expressed concern that

the lack of truth telling and possible exaggeration of the risks of bio-terrorism by military, FBI and other government officials may ultimately damage public confidence in public health agencies, a confidence that is necessary for these agencies to be effective.\textsuperscript{15}

The idea of enemy attack may also suggest innocence on the part of the victim; however, in the case of diseases such as HIV/AIDS, public opinion may see the infected individual as a victim not of some foreign attacker, but of her own behaviour.

III ACUITY

Infectious diseases can be the most quickly progressing of any diseases; many infectious diseases, such as meningitis, pneumonia, bacterial septicaemia, and haemorrhagic viral infections can develop and progress to a rapidly fatal outcome in less than a 24 hour period. This acuity leads to fear and the need for rapid decision-making before a definitive diagnosis is available, and this fear may lead to hasty decisions that may be poor public health policy or deprive infected individuals of their autonomous rights.

Meningococcus is among the most rapidly invasive of bacterial pathogens; the time between first symptoms and death may be less than 24 hours. In outbreaks of meningococcal meningitis and septicaemia, fear of this rapidly fatal infection has sometimes led school leaders and parents to close schools and leave the community, making it difficult for public health officials to conduct needed prophylaxis and immunisation programmes.

The autonomous rights of the individual to maximum therapy may be in conflict with the rights of the community to discourage prescription practices that increase the prevalence of resistant pathogens. For example, a patient with acute and rapidly progressive pneumonia of unclear aetiology may initially be treated with multiple antibiotics, a practice that has been shown to increase the prevalence of multiple drug resistant pathogens in the community.\textsuperscript{16} Recently, physicians and patient advocacy groups have collaborated to educate physicians about the need to change antibiotic therapy to a single, effective drug based on subsequent laboratory reports, and to educate patients about the lack of effectiveness of antibiotics in treating common viral


infections.17 This collaboration is a good example of effective integrative ethics where public health officials, individual practitioners and patients communicate to arrive at policies that meet the needs of individuals and communities.

IV COMMUNICABILITY

The fact that infectious diseases are often passed from one individual to another through contact of some kind raises questions of responsibility, since the infected individual poses a risk to others and is in some sense responsible if the infection is spread. In communicable disease, the patient is both the victim and vector. There are at least three sorts of communicability that raise specific ethical questions: first, when the patient is a risk to the community in general; second, when the patient is a risk to healthcare providers; and third, when healthcare providers pose a risk to their patients. In each of these scenarios we must identify who bears the responsibility for communicating infection and who should therefore take measures to prevent it.

Communicability essentially involves the ways human beings interact, the various levels of intimacy they have with one another. When this intimacy becomes a serious threat, it is necessary to change these interactions if the danger of infection reaches a certain threshold. But what is this threshold? And which behaviours may we justifiably require to be altered? And what degree of force ought we to use to achieve this altered behaviour? Once again, difficult questions of autonomy versus public health and safety come to the fore at the threat of infection.

For example, the decisions of some communities to require patients with tuberculosis to accept therapy under strict observation, and in extreme cases to quarantine infectious patients who refuse therapy, are examples of decisions that engender considerable debate among medical ethicists and political leaders.18 Sometimes the public’s fear of communicable infections far exceeds the actual risk. Although the communicability of leprosy from person to person has yet to be proven, since biblical times the public has tended to drive lepers from their communities and

to exile them to remote islands and villages. It is only recently, since antimicrobial therapy has been shown to control leprosy, that the practice of isolation and exile of these patients has ceased in the US.

Some social behaviours, such as unprotected sex with multiple partners and intravenous drug use, are highly linked with susceptibility to infectious diseases such as hepatitis and AIDS. These behavioural associations with infectious diseases have led to considerable discussion around the ethical issues of autonomy vs. community moral values and vs. effective but controversial public health practices. For example, the regular use of condoms has been shown to effectively reduce the spread of many venereal diseases such as syphilis, gonorrhoea, and HIV infections. However, this effective public health practice may conflict with community religious and moral values, and the spread of these diseases may not be adequately controlled because of the conflict. Similarly, the public health practice of providing clean needles and syringes to drug addicts, which has been shown to decrease the spread of HIV and hepatitis virus infections, has been discouraged in many communities because of conflict with local cultural and moral values.19

The current worldwide AIDS epidemic has appropriately sensitised the public to the risks of being exposed to contaminated blood and body secretions. However, the fear of communicability is scientifically inappropriate, and an ethical injustice to infected individuals when HIV infected children are barred from schools and when some physicians and other healthcare workers refuse to care for AIDS patients. The concept that the patient may also be the vector of a potentially lethal infectious disease becomes particularly complicated when the patient is a physician, nurse or other caregiver. Physicians, dentists and nurses are at an increased risk of becoming infected with hepatitis viruses and the HIV viruses that cause AIDS because of their exposure to blood and body fluids from infected patients.20 The ethics of professionalism are challenged when these caregivers refuse to treat infected patients because of this risk, and when caregivers infected with these viruses continue to practice their profession.


in ways that increase the risk of transmission of their infections to patients.\textsuperscript{21}

A recent smallpox scare in a major US city illustrates that institutions as well as individuals may react inappropriately due to fear of communicable diseases. An airline passenger was detained at the airport upon landing because he had developed a generalised rash that resembled smallpox. The patient and the possibly exposed passengers were appropriately temporarily detained on the aircraft while expert clinical opinion was obtained. In the process of evaluating the patient, public health officials contacted the major hospitals in the city to determine which hospital would accept the patient for care should the diagnosis be confirmed. All hospitals refused to accept the patient. This episode illustrated the need to identify and equip hospitals in each community to care for suspected smallpox patients as part of bio-terrorism planning. It also illustrated the conflict between hospitals’ missions to care for the sick, and their fear that accepting such a patient would expose other patients to smallpox. It is possible that they were also concerned that accepting this patient would be costly and would hurt their business by discouraging patients from coming to their hospital.

Communicable diseases typically have no respect for political boundaries, and the need for international co-operation to control the spread of these diseases has been a powerful force in the development of international public health programmes, such as the World Health Organization, and in the evolution of international quarantine laws. Epidemic communicable diseases, such as cholera, tuberculosis and AIDS, have required negotiating common public health policies, rules and regulations between communities that may have quite different values and ethical principles.

V TREATABILITY AND PREVENTABILITY

Most infectious diseases are treatable or preventable. While we currently have no therapy or effective method for preventing some infectious diseases such as Ebola and SARS, we do have effective therapies or preventive measures for most of those infectious diseases that are the greatest cause of mortality worldwide. This poses a dilemma that is at the root of many of the

most heated discussions over ethical and social resource issues related to infectious diseases: if we have effective therapies and preventive measures, why are these diseases still major causes of mortality?

Even though effective preventive measures and therapies exist, individuals and communities may choose not to employ them for various reasons. Religious convictions are sometimes cited as the reason for refusing immunisation; individuals may value their religious practices more than they value the decreased risk of infection that inoculation provides. Personal fears about side effects or concerns about the actual effectiveness of immunisations can also be reasons for refusal. Populations that would benefit from preventive measures against infectious diseases are not always ready or willing to employ such measures, and the extent to which more developed nations ought to impose these measures is a compelling question. Improvements in sanitation, availability of clean water, and relieving poverty/crowding conditions have all been major factors in the control of infectious diseases in developed countries. In developing countries, the need for resources to achieve these environmental improvements is often in competition with the need for resources for education, industrial development, military actions and, unfortunately, in some cases, the support of unethical rulers. Although recently improving, financial support from developed countries to those in need in the developing world still lags far behind what the World Health Organization and other agencies perceive as reasonable contributions to improve world health.

The relatively high cost of antimicrobials is a continuing reason that many patients in developed nations do not receive appropriate therapy for their infections. The recent, heated dialogue over availability of much less expensive generic (non-patented) anti-HIV medications in developing countries is rooted in the ethical dilemma over the conflicting needs of patients in poor countries for these medicines and the needs of drug manufacturers to protect their patents and related profits to fund future research. The patent antibiotics vs. generic antibiotics issue has also been a major cause of ethical argument in the US. Recently, a major drug company stopped manufacturing oral Cefixime, an antimicrobial that had a valuable unique application in treatment of venereal diseases, because its patent had expired and profits were no longer attractive.22 As noted before, excessive and

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inappropriate use of antimicrobials by patients and clinicians has been a major cause of development of resistance to antimicrobials. One cause of this excessive use has been an increasing aggressive commercial advertising campaign by many drug companies to promote the use of the newest, most expensive, and most profitable patented antimicrobials.

Vaccines for infectious diseases such as polio, measles, chickenpox and smallpox have been effective in nearly eradicating these diseases from the developed world. These vaccines are effective not only for the individual recipients, but importantly also to create ‘herd immunity’, that is, to also reduce the incidence of these infections in whole communities. This dual effect has raised ethical issues when selected individuals, families, or religious groups assert their autonomous rights to refuse vaccination and as a result increase the risks of the remaining population to infection.23

VI HOST SUSCEPTIBILITY

The general health of the host determines susceptibility to many infectious diseases. While some infectious diseases, such as the Ebola virus and smallpox, are so virulent that they will attack all humans regardless of their general health status, susceptibility to most infectious diseases is highly linked to the general health of the host. Susceptibility to infection and the resulting morbidity and mortality to such common infectious diseases as tuberculosis, enteric pathogens, and acute respiratory tract diseases is highly correlated with nutrition and general health status. The relatively high mortality rates for the common infant diarrhoeas and childhood respiratory tract infections seen in malnourished children in poor African nations and in wartime refugee camps dramatically illustrate this association. This realisation leads to frequent debate about the just and ethical distribution of community resources. It has been argued that available but limited resources should first of all go to providing adequate nutrition before resources are spent on more expensive and possibly less effective medical services.

Ethical discussions about treatment of infectious diseases may also be involved in end of life cases. With many non-infectious

conditions, the effectiveness of giving treatment to individuals whose health is already poor may not outweigh the costs of such treatment. In these instances, the cost and burdens may be very high, while the health benefit is low. Patients dying of cancer and other debilitating diseases are often more susceptible to infectious diseases, such as pneumonia. With a patient who is near the end of life, who then develops a treatable infectious disease, the cost and burdens of treatment may be quite low, but the benefit also remains low. With treatment of the infection, the result may be simply a prolongation of the status quo, which is already a deteriorating, unsatisfactory condition.

VII COMMUNITY SUSCEPTIBILITY

The general health of the community environment determines susceptibility to many infectious diseases. The social and environmental health status of communities includes the provision of sanitation, hygiene, availability of clean air, water, and food, adequate nutrition and control of mosquitoes and other vectors of infectious diseases. This social infrastructure has significant effects on the susceptibility of community members to infectious diseases. The strong association of poverty and poor environmental health with infectious diseases raises the ethical issues of justice and human rights. In a sense, the patient is both the individual and the community.

The World Health Organization estimates that at least two thirds of the world’s population lacks safe sanitation and one quarter lacks access to safe water. It is not surprising then, that in these undeveloped communities infantile diarrhoea is a major contributor to those infectious diseases that continue to be the major cause of death worldwide. The poverty-associated crowding and lack of hygiene in central Africa has for more than 100 years been associated with a very high rate of meningococcal meningitis. In the 1996 outbreak, more than 15 000 Africans died of this acute and often fatal infection.

Poverty-related lack of hygiene and associated increased susceptibility to infectious diseases continues to be a problem even

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25 Ibid. p. 2.
in highly developed countries such as France and the US. Outbreaks of tuberculosis, diphtheria and louse-borne trench fever have recently been observed in the homeless populations of several US cities.²⁷

In most wars, morbidity and mortality from infectious diseases has exceeded that of military actions, and war-associated refugee camps continue to suffer from high attack rates and mortalities from measles, cholera, infantile diarrhoeas, acute respiratory tract diseases and malaria.²⁸ This phenomenon illustrates the effect of war-related disruptions of community socio-economic conditions on infectious diseases. The public realisation that this link exists can generate considerable fear and influence decisions to abandon communities during times of war and create refugee crises. Although not a direct form of bio-warfare, the military strategy of disrupting social, economic and public health systems and encouraging refugee migrations has the same effect of precipitating outbreaks of infectious diseases and killing large numbers of civilians.

VIII HIGH SOCIO-ECONOMIC IMPACT

Infectious diseases may lead to deterioration in community socio-economic status. In this regard, there is a tremendous amount at stake. The link between low community economic status and susceptibility to infectious diseases goes both ways. For centuries we have been aware of the devastating effect that worldwide epidemics, such as the plague and influenza, can have on local and even world economies. The outbreak of bubonic plague in Europe in the mid-14th century killed one third of Europe’s population, and the effects on local and regional commerce were devastating.²⁹ The 1918 worldwide influenza epidemic killed 21 million people, an effect on mortality and economic development that rivalled that of the First World War.³⁰ This raises issues of the economic responsibility of societies to maintain conditions that discourage infections and to treat outbreaks.

²⁸ Whitman, op. cit. note 24, Chapter 6 (Refugee Infections).
Most recently, we have come to realise and to fear the destructive effect the AIDS epidemic is having on the economies of countries where as many as 25% of the working age population can be taken out of the work force by this infection. The fear of continued spread of the HIV infection and resulting AIDS mortality has been compounded by the realisation and fear that the resulting decline in socio-economic and public health services is associated with epidemics of tuberculosis and other infectious diseases. These fears have led some community leaders to publicly deny the existence of some infectious disease epidemics, such as AIDS and SARS, a violation of the truth-telling ethic that has seriously delayed and obstructed needed community public health control measures.

The recent Macroeconomics and Health report to the World Health Organization recognised the synergy between economic development and infectious diseases by emphasising the principal point that economic growth is not possible without a healthy population. This realisation may hopefully generate a more just distribution of resources between the rich and poor nations. In the 2002 meeting of the World Health Assembly, the Commission on Macroeconomics and Health reported that the world now has the capability of ending poverty and poverty-associated diseases for the first time in history. The cost to the rich developed countries would only be one cent out of every $10 of gross national product.

CONCLUSION

Although many of the characteristics of infectious diseases mentioned in this paper might be present in non-infectious diseases, taken together they comprise a group of traits that raise distinctive ethical concerns. Our historical attitudes toward infectious diseases have been shaped by countless years of public health officials contending with them; but they have not been central in recent bioethics. Only now, as diseases like HIV/AIDS, multi-drug resistant tuberculosis, SARS, West Nile virus, and other emerging and re-emerging diseases come to the fore, are we pressed to re-examine the ethical principles to which we have been appealing. We believe that a new paradigm for ethics of infectious diseases

32 Ibid.

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will evolve as public health policy makers and ethicists give increased consideration to the rights of individuals, and bioethicists give increased consideration to the competing needs to prevent spread of communicable diseases.

Charles B. Smith, Margaret P. Battin, Jay A. Jacobson, Leslie P. Francis, Jeffrey R. Botkin, Emily P. Asplund, Gretchen J. Domek, Beverly Hawkins
Division of Medical Ethics
University of Utah
Salt Lake City, Utah 84112
USA
battin@utah.edu