

"A Wealth of Information: Catholic Social Thought and the Ethics of the Dissemination of Health Information "

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Perhaps one of the most significant changes of the past millenium that will have profound implications for the future is the increasing complexity of our information technology. Developments in computers, and information infrastructures have changed the way in which we are able to access, collect, and use information. Both the technology and the information itself must increasingly be thought of in terms of wealth.

Presently, according to *Forbes*, the world's richest person is William H. Gates, III, founder of Microsoft, who has a net worth of approximately \$92.73 Billion¹. What is particularly fascinating about this is that this wealth comes largely from the ability to control and process information. As opposed to previous ages, wealth in our time comes not so much from the ability to exploit natural resources, but rather in the ability to use information. The raw materials for computers, silicon, sand and some metals, are not especially valuable as natural resources. It is in the use of these materials to create machines that can process information that they have some value.

With this wealth comes a plethora of individual and social justice issues. For individuals, concerns about privacy predominate.² Employees may presently be monitored for e-mail use, and some businesses are taking steps to regulate at work behavior³. As private citizens, individuals fear a loss of privacy, as witnessed by the strong response to the data collection features of the Intel Pentium III chip. Worldwide, nations have begun to consider the possible ways in which the needs of the individual person intersect with the common good.

On a broad, social level, control of the resources for collecting information and distributing it, the channels by which the information is collected, and the ultimate end uses of the information are all areas where ethical conflicts can occur. If some groups are able to monopolize the ability to collect information, it could mean that only some people in the world would have the means by which they can control resources, perhaps to the detriment of others. A coherent theory of the ethical use of information is therefore essential.

This paper will attempt to address this concern thorough the Catholic Social tradition. Using the issue of access to health care information as a focal point, it will assess the interrelationship between the development of a market for health care information and the rights of individuals to data protection. Using the principles of subsidiarity, the common

good, and preferential option for the poor, it will assess the current uses of health information in insurance, public health, and individual decision making, and will offer some direction on what, ideally, ought to be our perspective on such uses. Ultimately, in this view, the person enjoys no absolute right to privacy with regard to medical information, but justice and prudence demand appropriate safeguards of the person's best interests.

Health Information and Its Uses

In the 1998 American film, *Gattaca*, the fortunes of the citizens of a futuristic society are dictated by the vicissitudes of their genetic code. The genetically superior are guaranteed a comfortable life, while the rest are allowed a minimal existence. While we are not today at such a level of diagnostic sophistication, the specter of the misuse of information is rapidly emerging. The Human Genome Project, a scientific research study that is funded by the National Institutes of Health in order to "create an encyclopedia of the human genome--a complete map and sequence," has already begun to effect our lives.⁴ Recent discoveries have shown a relation of genetic abnormalities to cystic fibrosis and other diseases.

With the ability to have such information also comes the potential for misuse. Particularly within American society, insurance is one area where genetic information can have serious repercussions, both for the private citizen as well as the private corporation. Genetic information, is, after all, information, and that is the basis on which funding decisions for health care must be made. Individuals desire insurance coverage in order adequately prepare for unforeseen events. At the same time, insurance is also a business. Private corporations provide coverage only when it is to their economic advantage. If companies are not permitted to make rational decisions regarding a level of appropriate risk, insurance cannot be offered. There is therefore an ethical conflict between the insurance companies and the consumer about this medical information, and how it is to be used.

Although many persons would like an absolute right to privacy, it does not exist. Due to our nature as social and individual beings, a conflict will always exist between personal desires and social needs. While most of us would wish for some degree of control over our own lives, we recognize compelling social needs which override our individual right to self determination, free speech, and many other basic human rights. The same applies to the issue of access to medical information.

The growing development of computer technology in medicine has forced us to more carefully delineate the origins and applications of limitations to privacy and confidentiality, and their influence on the justice of providing adequate access to health care. As computers enable us to collect and to manage information more productively, it also allows persons to make decisions which were impossible in past years.

In the case of insurance, this means that the process of underwriting some types of policies, that is of assessing the potential risk of loss with the prospective profit, can be

profoundly influenced by additional information. Individually underwritten policies, in which a person must be "qualified" in order to complete the contract, as opposed to simplified issue policies, where a class of persons are given a group policy, will be most effected.⁵ In the former, specific personalized information is used to more assess the potential risk to the insurance company. In simplified policies, this information is not required. With the increased risk for the insurance company comes an increased cost for the prospective insured person. Yet, even this simple distinction between individual and simplified policies understates the varieties of ethical conflict which is inherent in insurance coverage. As one source figures it, when we consider that there are three basic forms of insurance (health, life and disability), and three categories for each (private, group and social), with four additional criteria on one's genetic risk, there are possibly "fifty-four different situations where there are (potentially) different ethical, social and legal problems" in insurance coverage.⁶

Underwriting such risks involves assessing four criteria:

1. A sufficient number of homogenous risks
2. A definite and measurable loss
3. A fortuitous loss
4. A loss should not be catastrophic⁷

When these criteria are thrown into imbalance, insurance no longer present a profitable business. The first means that a pool of similar people must share the risk. If, for example, a group of persons who are tested, and who are shown to be genetically positive for a particular form of cancer, it would not be in the insurance company's best interest to insure them, since the risk is not shared equally by all. Actuaries provide a statistical basis for the second criterion. The third means that the loss and subsequent payment of benefits should be random. Finally, the nature of the loss should be such that it will not bankrupt the company.

At the heart of the issue from the insurance company's point of view is what is known as "adverse selection."⁸ This is when a person is aware of information which would indicate that they are more likely to make an early claim on their policy, but withhold such information from the insurance company. Obviously, widely available genetic testing would also make it possible for a person who receives a positive report on their susceptibility for a particular disease or condition to make such an "adverse selection" much more accurately. In essence, in order for insurance to be both profitable and obtainable, both parties must aware of the risks and the prospective benefits of the insurance policy.

The relationship between an individual policyholder and the insurance company will be significantly affected by the availability of genetic information. In many ways, it resembles the relationship between a card dealer and a player at a blackjack table. The

house, and the dealer, know that the odds are in their favor. The player, however, is willing to take a small risk in order to achieve certain possible benefits. If either the player or the dealer have additional information, it is impossible to play the game in the same way. Genetic information creates an imbalance of power between the insurance company and the person. Whoever has access to the information would have an advantage over the other party.

Changing the nature of the relationship between the person and the insurer would have significant social implications in the United States, which relies upon a free market mechanism to insure some adequate health care. As opposed to other countries with a national health system, in the United States insurance plays a key role in providing some adequate amount of health care. In Canada, and the member nations of the European Union, insurance is only for supplemental coverage.⁹ We, however, require insurance to meet basic needs.

The conditions for access to medical information are thus at the heart of the issue. As medical databases become more common, it will be technologically possible (and probable) to link many different kinds of information very accurately. Individuals, as well as companies, and possibly even the government will want access to the information. Already today there are ethical conflicts concerning the use of medical information, which will be exacerbated by genetics.

As Richard Turkington has pointed out, however, American laws that govern the limits of confidentiality and the use of medical information are a patchwork of federal and state authority.¹⁰ The U.S. Supreme has recognized a constitutional right to informational privacy with regard to health information, but it applies only to federal agencies.¹¹ Since most medical information is maintained in the private sector, the vast majority of medical information is not covered by this decision.

Some states have enacted legislation which is based upon the National Association of Insurance Commissioner's' NAIC Insurance Information and Privacy Protection Model Act. As Turkington notes, however, these statutes have difficulties:

The NAIC Model Act allows redisclosure of information by insurers to a large number of persons and institutions, if the disclosure furthers a business function. Redisclosure is also allowed for marketing purposes. Redisclosures are authorized for research, but only if the publication based on the research does not identify individuals.¹²

The recent furor over a drug store's release of medical records to a drug company to facilitate marketing points both to the willingness of many businesses to use this information and the public's ignorance of the depth of the problem. States have also enacted various kinds of "special" confidentiality laws, which protect the release of information on specific diseases, like HIV status and mental health records, without a clearly justifiable reason, which directly relates to the common good. Examples of such exceptions include imminent danger to a third party, and statutory reporting requirements for child abuse.¹³

Laws which protect patient health confidentiality on the state level tend to be applications of broader principles which recognize a professional privilege. The record itself is not protected, only the information which is gained in a privileged relationship. When the information is placed in the record, it is "privileged" because of the way in which the information was obtained. In and of itself, the record is not considered to be confidential, but the means of obtaining it is, and thus the record becomes protected vicariously.

The difficulty with this method of assuring confidentiality is that there is no broad principle of the confidentiality of a record. The implications become most apparent when one considers the blanket consent form which most insurance companies require of their prospective policyholders. The Medical Information Bureau, a private association which is sponsored by approximately 700 insurance companies, contains vast amounts of medical information which is obtained by the use of blanket consent forms. In order to apply for insurance, an applicant must agree to the release of information to the MIB. Information obtained by the insurance company by applicants is often not routinely given to the individual unless a specific request for it is made in writing. According to Turkington, the MIB maintains records on approximately 15 million Americans.¹⁴ For the most part, the exchange of information by the MIB is unregulated on either the federal or the state level. Although the individual gives "consent", it is so broad that its only purpose is to legally protect the insurance company. The discretion of who has access to the information is left to the insurance company. In no sense is the information subject to the control of the person.

At the present time, medical information is largely unprotected from potential corporate misuse and it puts the individual at risk. Especially in a society where health care is subject to market forces, this is a very dangerous precedent. Care must be taken to level the playing field, but not by enacting legislation which would effectively prevent the insurance companies from making informed decisions about potential risks, nor by concentrating complete power in the hands of the consumer, who may use it create social disadvantage.

On what ethical grounds, then might we find a way to balance both the concerns of the individual and that of the insurance company? Does the person have a natural law right to privacy with regard to medical information?

The Catholic Tradition on Privacy, Wealth and the Common Good

To interpret the present situation in light of Catholic social teaching, it will be necessary to understand how "privacy" as a concept both converges and diverges from its common use. The Second Vatican Council, for example, addresses the right to privacy, in *Gaudium et Spes*. In the context of defining the nature of the common good, the Council Fathers wrote of the right of the human person "...to his good name, to respect, to proper knowledge, the right to act according to the dictates of conscience and to safeguard his privacy..."¹⁵ In the post-conciliar instruction, *Communio et Progressio*, The Pontifical Commission for the Means of Mass Communication also makes reference to this right, when it speaks of the responsibilities of news organizations: "But the right to information

is not limitless. It has to be reconciled with other existing rights. There is the right of truth which guards the good name both of men and of societies. There is the right of privacy which protects the private life of families and of individuals... This right to information is inseparable from freedom of communication."

A Catholic understanding of a right to privacy must be understood within the broader categories of the nature of the human person and his or her relation to the common good. In this context, the meaning of freedom is also a critical focal point. Implicit in American concepts of the term is the beliefs in the almost absolute autonomy of individual liberty and self-determination.¹⁶ The philosophical basis of American claims about rights differs greatly from the Catholic use of the same terms. As David Hollenbach, S.J. has noted: "Catholic rights theory is far removed from individualistic or libertarian rights theory. The theory presented in the encyclicals is personalist, and not individualist, and it recognizes that persons are essentially social and institution building beings. Because of this fact, the personal rights which belong to every human being in an unmediated way create duties which bind other persons, society and the state."¹⁷

The Catholic understanding of the right to privacy, then, is founded upon a theological understanding of personhood which differs from that of American society. One of the hallmarks of the present pope, John Paul II, has been to consistently address this understanding of the human person and to apply this concept to compelling issues.¹⁸ In his first encyclical, *Redemptor Hominis*, he began his pontificate with a clear statement of the nature of the person:

The man who wishes to understand himself thoroughly-and not just in accordance with immediate, partial and often superficial and even illusory standards and measures of his being-he must with his unrest, uncertainty, and even his weakness and sinfulness, with his life and death, draw near to Christ. He must, so to speak, enter into Him with all his own self, he must "appropriate" and assimilate the whole of the reality of the Incarnation and Redemption in order to find himself. If this profound process takes place within him, he then bears fruit not only of adoration of God, but also at deep wonder of himself.¹⁹ It is only through Christ, through a reflection on the Incarnation and the Redemption that the profound meaning of the person may be understood, he argues. The Incarnation and the Redemption point both to our creation by God in his image, and the unconditional love which he has for us, which saves us from our own sinfulness.²⁰ The person in the community...as a fundamental factor in the common good, constitute(s) the essential criterion for all programs, systems and regimes," John Paul II said elsewhere.²¹

Our inability, or unwillingness, to recognize the person is one, if not the, weakness of our contemporary society. Speaking to bishops in Puebla, Mexico in 1979, he said

Perhaps one of the most obvious weaknesses of our present day civilization lies in an inadequate view of man. Without doubt, our age is the one in which man has been most written and spoken of, the age of the forms of humanism and anthropocentrism. Nevertheless, it is paradoxically also the age of man's abasement to previously unsuspected levels, the age of human values trampled on as never before.²²

A proper anthropology then, sees the human person as both individual as well as social by nature. Created in the image and likeness of God, we find our purpose in community. Any right to privacy, then, supposes that the right must be interpreted in light of the common good.

The freedom to act one way or another, then, is conditioned by the natural goals which have already been given to us by God. We may not act in a way which is violative of our individual or our social nature without acting unethically.

Catholic thought on the use of wealth has been well documented in many places. The distribution and use of wealth is understood to be both individual as well as social. The common good also influences our understanding of the right to private property and its use for others' needs. In terms of the specific issue of this paper, the use of health information, it can be realistically argued that the information record itself ought to be understood as a form of wealth, and is therefore, subject to the same ethical guidelines as those for private property. A balance must be achieved between the protection of individual privacy interests and legitimate social needs.

Conclusion

In the United States, recent legislative efforts have begun to address this balance. On the Federal level, the Health Insurance Portability and Accountability Act (HIPAA) was signed into law by President Clinton in August 1996. The Act directed the Secretary of Health and Human Services to issue guidelines on health record confidentiality by August 21, 1997. It also mandated that Congress must adopt legislation by two years later, August 1999. If Congress fails to act, the Department of Health and Human Services is required to adopt a national health record policy by the year 2000.²³ Any legislation or federal regulation is supposed to address three key issues in the confidentiality of medical records: the rights of subjects to the information; the procedures for exercising the rights; and probable disclosures which will preempt these rights. It is clear that the Department of Health and Human Services takes these concerns seriously and is moving to correct the problems.²⁴

While this is clearly a move in the right direction, it is difficult to see how several significant issues will be resolved. With new federal law, one consideration is whether the federal law will supersede existing state statutes on health record confidentiality. As mentioned earlier, presently federal regulations apply only to federal agencies, with the private sector being largely unregulated. Preemption of state statutes is really the only effective way of adopting a cohesive national policy on health record confidentiality.

Recent moves in Congress to introduce legislation on health record confidentiality tend to simply reinforce the present situation. Clearly, insurance companies are lobbying for a continuation of the status quo. The NCAIC Model Act, for example, stipulates that individuals should have the right of notice that the information is accessed, but that they have limited rights to prohibit access to the information.²⁵ In that way, the proposal is reminiscent of contemporary legislation on credit reports. Although consumers have a

right to view the information, they may not prohibit its dissemination. The credit bureaus may sell the information to any qualified purchaser. Individual rights of the person whom the record describes are effectively limited to correcting erroneous information.

Although it may be conceded that for most Americans, the credit bureau system seems to work, one could argue that a higher standard ought to prevail with regard to health care information. One model for American legislation might be the Canadian system. There, access to personal health information is severely restricted. Since Canada has a national health system, most of the information is not in private hands. The technological ability to link records and to access information is more easily accomplished than in the United States. Since the Canadian government requires statistical data, and even has established a national agency, Statistics Canada, to obtain such data, procedural safeguards have been developed. Policies on microdata release, discretionary release and record linkages limit access to information to qualified researchers. Care is taken to ensure individual privacy, and compelling social reasons are necessary to access the information.²⁶

Although the American system could not completely duplicate the Canadian system simply because of where the information is located; we could adopt key parts of the model. Significant highlights would include a presumption of individual privacy and the need for a compelling social interest to release information. A mechanism also needs to be developed by which exceptions to this presumption could be overridden. Depending upon the Courts to micromanage this issue will only lead to a diminishment in the effect of the law.

Individuals are very concerned about the growing ability to access all kinds of personal information. While one can clearly see that some of this fear may be due to ignorance about the technology, there is a legitimate issue which underlies this problem. Americans are very wary of intrusions into their private lives. As the film *Gattaca* dramatically illustrates, we can envision a world where information can become prejudicial to the individual. Any resolution to the question of who may access health care information will ultimately need to balance the need for privacy with legitimate social concerns. To move too much in one direction or another, without a radical overhaul of the American health system to a national model, will result in an imbalance of power. Persons have a right to ordinary health care, and insurance companies need to make just economic decisions on how they can provide social benefits while maintaining profitability. Just how a balance will be achieved in other cultures, is also another issue, and must be addressed.

Overall, a Catholic approach to the issue of the use of health information would be built upon an understanding of the nature of the human person and the individual rights and duties which flow from that nature. There is no absolute right to privacy, but there is a presumptive one. Legitimate social goods may outweigh the right to privacy, but these must be compelling enough to overturn the personal right. How these principles will be enacted still remains to be seen.

ENDNOTES

¹Clint Willis, "100 Richest," *Forbes* (29 Nov. 1999) 1.

²The use of the term, "privacy" may be misleading. In the United States, the term connotes not only a right to non-interference in personal liberty but also a limitation on the use of information. In Europe, the preferred legislative term for privacy rights in relation to information has been "data protection." An excellent survey of the American notion of privacy may be found in Philip A. Smith, O.P., "The Right to Privacy: *Roe v. Wade* Revisited," *The Jurist* 43(1983): 289-317. Smith outlines the diverse meanings of the term and how it has been judicially adjudicated from the time of Louis Brandeis and Samuel Warren's foundational article on "The Right to Privacy," *Harvard Law Review* 4(1890): 190-96 until the time of the article.

³*The Wall Street Journal* 21 October 1999, B1

⁴V. McKusick, "Mapping and Sequencing the Human Gene," *New England Journal of Medicine*, 320 (6 April 1989): 910.

⁵Robert J. Pokorski, "A Test for the Insurance Industry," *Nature* 391 (26 February 1998): 835-836.

⁶Ray Mosely, Lee Crandall, Marvin Dewar, David Nye and Harry Oster, "Ethical Implications of a Complete Human Gene Map for Insurance," *Business and Professional Ethics Journal* 10 (Winter 1991): 73.

⁷*Ibid.*, 75.

⁸Pokorski, 835.

⁹Janet Hagey, "Privacy and Confidentiality Practices for Research with Health Information in Canada," *Journal of Law, Medicine & Ethics* 25 (1997): 130-38

¹⁰Richard Turkington, "Medical Record Confidentiality Law, Scientific Research, and Data Collection in the Information Age," *Journal of Law, Medicine & Ethics* 25 (1997): 113-29 It should be noted that the United States is quite deficient in this area in relation to other nations. As far back as 1970, Germany instituted a data protection law in the state of Hesse. The leading international privacy law at the present time is the European Union's "Directive on the Protection of Individuals with Regard to the Processing of Personal Data and on the Free Movement of Such Data," 95/46/EC, 1995 O.J. (L281) 31. In March 2000, The U.S. Department of Commerce reached a tentative agreement of "safe harbor" principles with the EU to allow U.S. companies the means by which they can abide by the conditions of the directive. See www.ita.doc.gov/td/ecom/menu.htm .

¹¹*Ibid.*, 115. The pertinent case is *Whalen v. Roe* 429 U.S. 589 (1977).

¹²Ibid.

¹³See, for example, *Tarasoff v. Regents of the University of California*, 17 Cal. 3d425, 551 P.2d334, 131 Cal. Rptr. 14(1976).

¹⁴Ibid., 115

¹⁵Vatican II, *Gaudium et Spes, Pastoral Constitution*, in Austin Flannery, ed., *Vatican II: The Conciliar and Post-Conciliar Documents*, 1988 Revised Edition, (Grand Rapids, MI: Eerdmans, 1988), 26, p. 927.

¹⁶How these rights are understood, is, of course, a matter of great controversy. See, for example, Ralph F. Gaebler, "Is there a Natural Law Right to Privacy?" *American Journal of Jurisprudence* 37(1992): 319-336 and Walter Murphy, "The Right to Privacy and Legitimate Constitutional Change," in *The Constitutional Bases of Political and Social Change in the United States* (1990): 213-14.

¹⁷David Hollenbach, *Claims in Conflict: Retrieving and Renewing the Catholic Human Rights Tradition*, (New York: Paulist Press, 1979), 97.

¹⁸Much has been written on John Paul II's understanding of the person. His writings, both before and after his election to the papacy, are voluminous, numbering over one hundred articles, and seven books. According to George H. Williams, [*The Mind of John Paul II: Origins of his Thought and Action*, (New York: Seabury, 1981) 354] the definitive pre-papal bibliography on Karol Wojtyla was edited in Polish by Barbara Eychler in *Chrzescianin Swiecie* 74 (February 1979): 67-91. Another bibliography was edited in 1980 under the title *Karol Wojtylaw swietle publikacji: Karol Wojtyla negli scritti*, ed. by Wiktor Gramatowski, S.J. and Zofia Wilinska, (Vatican City: Liberia Editrice, 1980). Representative articles and books which deal with John Paul II's understanding of the person are: J. Brian Benestad, "The Political Vision of Pope John Paul II: Justice through Faith and Culture," *Communio* 8 (1981): 3-19; Ronald Lawler, *The Christian Personalism of John Paul II*, (Chicago: Franciscan Herald Press, 1982); James V. Schall, *The Church, the State and Society in the Thought of John Paul II*, (Chicago: Franciscan Herald Press, 1982); George Hunston Williams, "John Paul II's Concepts of Church, State and Society," *Journal of Church and State* 24 (Autumn 1982): 463-96; and *The Mind of John Paul II*; Elzbieta Wolicka, "Participation in Community: Wojtyla's Social Anthropology," translated by Alice Manterys, *Communio* 8 (1981): 108-118; and Andrew Woznicki, *A Christian Humanism: Karol Wojtyla's Existential Personalism* (New Britain, CT: Mariel, 1980). Obviously, however, Karol Wojtyla's works before he became pope would afford a much more nuanced appreciation for his ideas. Yet, given the immense discussion of his pre-papal conception of the person, particularly with regard to his book, *The Acting Person* [see George H. Williams, "John Paul II's Concepts of Church, State and Society," 468, fn. 17 for a sense of the debate about three competing English translations of the meaning of chapter 7 in that book] it will be necessary to limit this analysis

¹⁹John Paul II, Encyclical, *Redemptor hominis*, 4 March 1979, English translation, (Boston, MA: Daughters of St. Paul, 1979) 18-19, § 10; original Latin text published in *AAS* 71 (1979): 257-324.

²⁰*Ibid.*, 17, § 9.

²¹*Ibid.*, 36, § 17

²²John Paul II, Address, *Amados hermanos*, 28 January 1979, English translation in *Origins* 8 (8 February 1979): 534; original Spanish text in *AAS* 71 (1979): 195.

²³*Ibid.* 122

²⁴See Department of Health and Human Services, "Health Insurance in the Age of Genetics," <http://www.nhgri.nih.gov/NEWS/insurance>

²⁵National Association of Insurance Commissioners, NAIC Insurance Information and Privacy Protection, Model Act, (Kansas City: National Association of Insurance Commissioners, 1992

²⁶Janet Hagey, 131-32.