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AUTONOMY AND DECISION-MAKING IN AMERICAN HEALTHCARE

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ABSTRACT

Although tens of millions of healthy people in the United States of America seek medical care every year, few stop to think about what a privilege it is to have the ability to make autonomous medical decisions. Whether these decisions are made alone or with family advice, cognitively sound adults have the right to choose. Problems arise, however, when people who are not able to make their own decisions (children, intoxicated individuals, elderly adults, etc.) present for treatment. This essay, written from the perspective of a philosophically minded premedical student, seeks to discuss the right to medical decision making as it pertains to these people. It will examine autonomy, decision-making, and informed consent from a fundamental perspective as well the relationship between these processes and doctors, patients, and families. Overall, the mission is to answer questions such as: Who has the right to determine my healthcare? Who has the right to determine the healthcare of my children? How will my fate be determined when I am no longer able to decide for myself? The research culminates in a concise guide that physicians, nurses, and other healthcare professionals can use to structure discussions regarding patient autonomy and decision-making in American healthcare today.

TABLE OF CONTENTS

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Chapter 1

Preface

Although much of the focus surrounding American healthcare in recent years seems to concern health insurance and patient access, autonomy and informed consent are equally important yet often overlooked subjects. This essay will investigate the application of rules and concepts concerning autonomy in hospitals and clinics across the country and will address current right-to-choose regulations in America. Specifically, I want to discuss the right to medical decision-making as it pertains to doctors, patients, and families. Overall, this project will answer the question: Who has the right to dictate my healthcare and why do they have this right?

It is important to note that I am not writing this essay from the point of view of either a physician or a professional bioethicist-I profess to be neither. I have never had to advise a mother on what treatment to seek for her child, nor have I ever comforted a family whose loved one is in the final stages of hospice care. Rather, my stance is that of an aspiring pre-medical student who happens to be both educated, and have a deeply vested interest, in philosophy and ethics. I have had the privilege of working for well over a year in the emergency department at Mount Nittany Medical Center where the exposure to informed consent, personal autonomy, and medical ethics has been constant. My goal has been to analyze the situations that I have seen in the clinical setting, and apply the philosophy and ethics that I have learned in the classroom, in order to reach

what I think are the most important conclusions in autonomy in decision-making and American healthcare today.

Although the main focus of this essay will steer away from textbook examples of autonomy and medical decision-making, it is nevertheless important to mention the basic federal, state, and local laws regarding ideal medical care. I will then outline the philosophical background for my arguments before moving into practical and clinical experiences. End-of-life decision-making and hospice care will follow, and then we will move into the doctor's perspective and what a physician can expect to encounter with regard to medical decision-making. This necessarily will lead into the conclusions, where I give my suggestions as to how physicians can manage a patient's medical decision-making while maintaining the patient's personal autonomy.

Chapter 2

Federal, State, and Local Healthcare Regulations

Before we begin to examine autonomy in decision-making in the clinical healthcare setting, we must first recognize that federal, state, and local governing bodies closely regulate the healthcare industry. In order to study the gray areas around these regulations, it is important to examine some of the basic, current laws and precepts. Furthermore, it is neither vital nor feasible to touch on every major healthcare policy at each of the three levels. For this reason, we will focus on the ones that are pertinent to this discussion.

Federal Regulations

Perhaps the main legal document governing patient autonomy at the federal level is "The Health Insurance Portability and Accountability Act of 1996" or HIPAA. This act, signed into law by President Bill Clinton in 1996, was introduced in order to protect the privacy of patients and confidential health information. As a result of HIPAA and associated privacy laws, medical patients are assured total confidentiality with regard to their medical records and history.[1] This means that doctors and hospitals are not permitted to disclose any patient information to anyone without the explicit permission of

[1] "Health Information Privacy." *Health Information Privacy*. U.S. Department of Health and Human Services, 2014. Web. 26 Feb. 2014. See Appendix for a more in-depth summary of HIPAA and the HIPAA Privacy law.

the patient. The only exceptions to this rule are the parents of minors (parents have a legal right to know) and other medical professionals who are directly involved in a patient's care (e.g. a patient's emergency physician may consult a cardiologist without the patient's consent if the patient has a sudden cardiac event in the emergency department).

In terms of informed consent for healthcare, the general framework of the laws that have been drafted and interpreted by the United States government asserts that consent for healthcare must be derived from the one who has the proper legal authority to do so. As is the case with most of the laws in America, the federal government sets forth a series of general laws and regulations which are then further interpreted, refined, and enforced by the states. In the majority of states where the legal age of consent is 18 years old, legal adults (18 years of age and older) have the right to make medical decisions on their own behalf. Likewise, adolescents who become legally emancipated prior to age 18 also have the right to consent for themselves.[2]

State Regulations

In addition to the many federal health regulations, each state has its own unique laws to supplement those of the national government. Although the general principles of privacy conservation, personal autonomy, and informed consent apply to each state, the

[2] In many cases these regulations do not apply to family planning because these services can often be sought under the age of 18 and without parental consent.

differences reside in the way these statutes are regulated. States tend to take more of an enforcer role in terms of federal regulations, but they also self-govern with respect to some of the more intricate subjects such as vaccinations, age of consent, and informed consent policies.

An important hot button issue in healthcare today deals with vaccinations and whether parents should be legally obliged to have their children immunized. This is a great illustration of a matter in which the state takes over where the federal government does not have clear guidelines. In the case of minors under the age of 18, an article published by the Official Journal of the American Academy of Pediatrics outlines the general standard for consent:

> State law is generally the controlling authority for whether parental consent is required or minors may consent for their own health care, including vaccination. At the federal level, no vaccination consent law exists; however, federal law requires that vaccine information statements be given to the parent or another person who is qualified under state law to consent to vaccination of a minor.[3]

Essentially, this means that although a parent need not give direct consent for their dependent to be immunized, they must at least be given adequate information about those immunizations. The Commonwealth of Pennsylvania, for example, does not require informed consent for vaccinations. Although people are generally informed as to when they will receive a vaccination, if a person were to have a fall that resulted in both unconsciousness and a large laceration, he or she may be given a tetanus shot without

[3] English, Abigail, JD, et. al. "Legal Basis of Consent for Health Care and Vaccination for Adolescents." *Pediatrics* 121.1 (2008): 585-87. American Academy of the American Academy of Pediatrics. Web. 13 Mar. 2014.

explicit consent. This does not mean that people can be vaccinated against their wills-there are many sub-cultures within the state that abstain from vaccination-it simply means that informed consent is not legally required for one to receive a vaccination.

Local Regulations/Hospital Policies

When we break the subject down even further to examine hospital policy, we find that many physician groups and healthcare institutions have their own codes of conduct regarding patient autonomy. Hospitals as well as independent physician groups have various ways of documenting and therefore each will approach informed consent in medical decision-making from a different angle. Generally, the patient will sign a waiver upon arriving at a hospital or doctor's office with which he or she agrees to receive healthcare at that institution. This usually does not permit the hospital to perform any type of treatment, but rather allows the hospital to bill the patient and release information to insurance companies. In some facilities, a social worker or case manager is employed by the hospital to work with patients and healthcare providers to make sure the patients and their families stay informed about, and are in agreement with, treatment plans. In other places, the responsibility of informing the patient falls solely on the shoulders of the nurses and physicians. Regardless of the particular policies, it is up to the hospitals to enforce the state and federal regulations in such a way that patients retain personal autonomy and rights to medical decision-making. Necessarily, state and federal laws mean nothing if they are not interpreted and subsequently put into practice by individual

institutions. Hospital policies, although they still tend to be quite general, are nevertheless much more specific and practical than government regulations, and they form the basis of healthcare code as it pertains to autonomy and consent.

Chapter 3

Autonomy and Ethics in Philosophy

To be an autonomous being implies that one rejects any ultimate authority outside of him or herself, that is, everyone but the self. As an autonomous being, an individual has the power of self-government; therefore every action and choice is made, theoretically, with the full consent of the human being.[4] A vigorous defense of personal autonomy is perhaps the most vital piece of American healthcare, simply because the aforementioned laws and regulations alone are not entirely effective in providing the complete protection of that right for the patient. The Stanford Encyclopedia of Philosophy indicates that, "the autonomous individual acts freely in accordance with a self-chosen plan, analogous to the way an independent government manages its territories and establishes its policies."[5] Roughly put, this indicates that one who is truly autonomous will act according to his or her own desires, regardless of the situation or outside regulations. In terms of healthcare, then, an autonomous being will decide exactly what level of care he or she needs to have, despite the paternalistic wishes of physicians or the government. Before we move into healthcare, however, it is necessary to discuss

[4] Buss, Sarah, "Personal Autonomy", *The Stanford Encyclopedia of Philosophy* (Spring 2014 Edition), Edward N. Zalta (ed.).

[5] Eyal, Nir, "Informed Consent", *The Stanford Encyclopedia of Philosophy* (Fall 2012 Edition), Edward N. Zalta (ed.).

the philosophical "father" of autonomy (Immanuel Kant) and his argument that moral necessities are grounded on a standard of rationality.[6]

The notion of a categorical imperative refers to Kant's method of evaluating why an individual should perform a certain action. Kant's perspective was that each person has a motive behind every action he or she takes, but only some actions are considered to be "morally good." In order to determine whether or not an action is "good," Kant developed the categorical imperative. The strict formula of the categorical imperative from Kant's *Groundwork to the Metaphysics of Morals* states that one should act in such a manner that he or she can will his or her maxim (action) to become a universal law. In other words, a categorical imperative is an obligation that is both unconditional and absolute, and is the same and unwavering for all people. This follows Kant's philosophy on laws, which also deals with morality. Kant argued that a law is only a good law if it applies universally to everyone.

According to Kant, self-law is the ultimate form of law. When one imposes the law on him- or herself, the law is imposed with reason which gives the person a universal law. Furthermore, one is not truly a "good person" or exercising "good will" unless he or she has the discipline to self-impose the law. This means that autonomy in terms of healthcare would have to apply universally to everybody to be considered a good law under the Kantian approach. It follows, then, that because some people are incapable of exercising good will in that they cannot impose the law on themselves, we must consider autonomy and healthcare from a more utilitarian point of view.

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[6] Kant, Immanuel. Mary J. Gregor, ed. and trans. *Groundwork of the metaphysics of morals*. Cambridge, U.K.: Cambridge University Press, 1998. Print.

Utilitarianism and the Social Contract Theory

Now obviously we would hope that physicians would always act with some idea of the categorical imperative in mind, because doctors should treat patients universally, that is equally. In some cases, however, patients who are unable to impose the law on themselves properly present a problem: How can autonomy be afforded universally when some individuals are incapable of autonomy, and furthermore, how can we know that autonomy is in the best interest of society?

Utilitarianism as introduced by Jeremy Bentham and John Stuart Mill contends that government and society should act in such a way that affords the highest amount of good to the greatest number of people. This presupposes, then, that a group of people actually have an ultimate maxim that can be universally applied or agreed upon. The social contract theory as explicated by the Stanford Encyclopedia of Philosophy is such that, "in some way, the agreement (or consent) of all individuals subject to collectively enforced social arrangements shows that those arrangements have some normative property (they are legitimate, just, obligating, etc.)."[7] In healthcare, affording personal autonomy to cognitively-sound individuals provides the highest ideal of treatment for the general population.

Given that agreement is the core of the social contract theory, it follows that a person's personal autonomy presupposes that he or she agrees to this contract in the first place. That is, in order for one to argue that competent humans deserve autonomy in healthcare, he or she must necessarily agree that this is in the greatest interest of society.

[7] D'Agostino, Fred, Gaus, Gerald and Thrasher, John, "Contemporary Approaches to the Social Contract", *The Stanford Encyclopedia of Philosophy* (Spring 2014 Edition), Edward N. Zalta (ed.).

Further, agreement as a conditional state of thinking requires that one has used reason to determine that the cognitively competent individual has the best grasp of personal medical decision-making. In other words, if the greatest number of people did not believe personal autonomy in healthcare is the best policy, there would not be such a strong societal push towards individual medical decision-making in America today.

While social contract theory does help to ensure that patients are in control of their own medical decision-making, it excludes those patients who simply do not fit within the status quo. Rather than try to generalize healthcare, it is important that these unordinary situations be evaluated on a case-by-case basis. This means that healthcare providers should approach each person as if he or she does fall under the social contract of autonomy, and they should employ reason and the wisdom of experience to treat non-typical patients. I will touch on many of these extenuating circumstances in the following chapters.

Informed Consent

Before these concepts can be applied to healthcare in America, an important distinction needs to be made between the ideas of autonomy and informed consent. Autonomy, as indicated above, refers to one's individual right to determine a healthcare plan. Informed consent, on the other hand, has to do less with the patient and more with the provider. It involves the patient's right to be informed on matters regarding his or her health.

The Stanford Encyclopedia of Philosophy contains extensive reviews on informed consent, especially as it relates to research and medical ethics. In this article, the author, Nir Eyal contests that, "Consent is considered fully informed when a capacitated (or "competent") patient or research subject to whom full disclosures have been made and who understands fully all that has been disclosed, voluntarily consents to treatment or participation on this basis." Furthermore, it is largely impermissible to take any invasive action towards a subject when he or she either explicitly denies consent, or fails to provide adequate consent. It is imperative that we explore the different types of informed consent and the methods by which consent is obtained in the clinical setting.

In *Rethinking Informed Consent in Bioethics*, renowned bioethicists Neil C. Manson and Onora O'Neil state that informed consent goes beyond the patient's right to choose in that it allows patients to make reasonable and thoughtful choices which in turn reflect rational personal autonomy. Their approach to the application of informed consent is significant in that they argue: "since clinical treatment cannot and will never reach standards for legitimate consent in every single aspect of care, we must rethink informed consent as a whole." They advocate two new models of informed consent, the disclosure-based account and the transactional-based account, each of which have qualities that are useful to medicine and medical decision making.

A disclosure-based account of informed consent, "requires those who seek consent to ensure that relevant information flows/is disclosed to those who have to choose whether or not to consent." This means that doctors are ethically, and in some cases legally, required to adequately inform patients of medical status and treatment plan. Disclosure-based informed consent also suggests that physicians should not sugarcoat or

water-down information when relaying it to the patient.[8] Patients have the right to know clearly what is going on in terms that they can understand; however, the asymmetry of knowledge that typically exists between doctors and patients presents an obstacle in terms of trust and accountability.[9] It is important, then, for doctors to learn how to speak to patients in a way that reduces difficult medical jargon while maintaining the seriousness of the message or condition.

The transactional-based account of informed consent places an emphasis on the words and actions of those who request consent and those who consent/refuse.[10] That is, we should view informed consent less as a downward flow of information and more as a series of interactions between patient and provider. With the transactional-based account, patients not only have the choice to undergo a procedure, but they are also afforded the opportunity to elect not to have the procedure. This builds on the disclosure-based model of informed consent by ensuring that patients are not only informed, but also engaged in thoughtful discussions with providers. It is not enough that physicians provide autonomy to their patients; informed autonomy is far more valuable and just.

Another problem regarding informed consent in healthcare is documentation and determining exactly how to obtain informed consent and how to record these transactions. Clearly, not every situation warrants the same methods for informed

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[8] Manson, Neil and Onora O'Neill. *Rethinking Informed Consent in Bioethics*. Cambridge: Cambridge University Press, 2007. Print. 69.

[9] Manson, Neil and Onora O'Neill. *Rethinking Informed Consent in Bioethics*. Chapter 7. Manson and O'Neill admit that it is difficult for non-medically trained patients to hold medical professionals accountable because of the information gap between doctors and patients. They suggest that a good mix of transparency, professional/peer evaluation, and managerial forms of accountability help to ensure the doctors are practicing effectively and are being held accountable for their work. *Press Ganey* surveys and other related patient-satisfaction studies can also be useful evaluation tools.

[10] Manson, Neil and Onora O'Neill. *Rethinking Informed Consent in Bioethics*. 69.

consent, so it is important to make some distinctions. Although the catch-all release forms some institutions require one to sign before seeking treatment and/or undergoing medical research may hold some legal merit in terms of preventing lawsuits, they do little to augment trust. If a patient feels as if he or she is signing away rights before even receiving treatment, this may lead to a very negative healthcare experience. Certainly, there are situations where detailed conference and medical consent forms are necessary. If the patient seeks to undergo a surgery or some other type of invasive procedure, the doctor has a responsibility to counsel the patient and obtain several levels of both verbal and written consent. On the other hand, during a physical exam when a doctor dons his stethoscope and asks to listen to the patient's heart, is hardly necessary to obtain in-depth formal consent. Rather it is much more likely that the patient will nod and lean back in the bed to signify consent to the doctor's examination. Likewise, if a patient requires blood work or intravenous fluids, it is not efficient for the nurse or phlebotomist to sit down to discuss every single risk and benefit of the needle stick, because it is such a low-risk procedure. When the nurse tells the patient that he or she is ready to insert the needle, once again a simple affirmative motion such as extending one's arm or nodding suffices for informed consent. Healthcare providers must use reason and good judgment in determining which levels of informed consent are needed in various situations. These varying degrees and methods of informed consent allow hospitals to treat patients in a timely manner while the patients still maintain rights to informed consent, which reflects personal autonomy.

Chapter 4

In Practice

In an ideal society, there would be individual, clear-cut treatment plans that allow physicians to maintain perfect autonomy for every patient, in every aspect of medicine. Unfortunately, there are many situations in modern healthcare that complicate the provision of autonomy, especially in emergency care.

Because many physicians are not well-versed in the philosophical implications behind autonomy, informed consent, and medical decision making, it is important that this information be more widely distributed and also presented in a way that is both comprehensible and practical for present-day clinicians. Before graduating from medical school almost every aspiring doctor takes a medical oath of integrity. In this oath, healthcare professionals pledge to treat all patients with honesty and care, and they promise to never intentionally cause any undue harm to the patient. It follows that doctors confront an ethical paradox when an autonomous patient wishes to act in a way that may bring harm to him- or herself.

For example, I have seen on more than one occasion a patient present to the Emergency Department acutely altered by either alcohol or other drugs. These patients are often belligerent, thrashing about, and threatening their own safety and that of others. At times these patients are not clothed, and at other times they may or may not be covered in any number of substances or bodily fluids. For the majority of patients, there is no security, sedation, or restraint necessary; so does that mean we should also refrain

from those measures with the altered patients? It seems irrational to allow a psychotic or intoxicated patient to run freely around the hospital (or the streets, for that matter), solely in the name of autonomy. In the same manner as heteronomous law prevents criminals from roaming about, a sort of heteronomy does exist in the healthcare setting. In other words, if these people are taken into custody against their wills when they are caught running around the streets naked, screaming obscenities, and trespassing on private property, why should they have instant autonomy the second that they step into a hospital?

A physician at Mount Nittany Medical Center who wishes to remain anonymous has a simple yet sensible idea regarding the autonomy of these individuals. He believes that, "the patients put themselves in these situations when they choose to drink to excess, so in a way they maintain autonomy because they choose the states that they are in." Indeed the problem of intoxicated patients who "forfeit" their rights to autonomy presents an interesting situation for providers. If, however, we consider that particular group of individuals in accordance with this physician's remark, we can act in accordance with a universal law. This is made possible because those who are intoxicated have autonomously placed themselves in a special group. Therefore, healthcare professionals have the right and the responsibility to act in the best interests of the patient and themselves by using sedation, restraints, emergency procedures, and other treatments as necessary.

I have heard more than once that people claim that physicians have no right to force treatment, and to an extent I fully agree. In many cases, able-minded patients will refuse such tests as blood transfusions, CT-scans, and certain medications, citing cost

constraints, religious limitations, and sometimes fear as the reasons. In these situations, it is very reasonable to grant these people autonomy, as they are fully capable of choosing how much care they wish to receive: if someone cannot afford a CT-scan, why force them to have one done? This situation is further exacerbated in the case of cultural or spiritual restrictions where patients may present themselves for basic care such as intravenous fluids but refuse any sort of secondary treatments due to their beliefs.

Perhaps the strictest sect of religious conservatives is the Christian Scientists. This group of people believes that prayer will heal any ailment. Although there are certainly varying degrees of obedience within the church, some members will not even use ice on minor bumps and bruises. They argue that medical care is entirely unnecessary when they can appeal to God for healing.

Although there is rarely any dissent regarding these beliefs from within the religion, occasionally "rogue" or former members expose some of the destructive and traumatic experiences which these sorts of restrictions can introduce. An example of this is the writer Josy Fox, who is a former Christian Scientist. She has written several short essays on her life and her experiences with the church of Christian Science. As a child, Fox claims that she was denied access to all medications, immunizations, and medical treatment because her parents were able to refuse care on her behalf. She explains how she suffered through various illness and pains, and in one instance was even forbidden to use an ice pack after a serious head injury. She argues, "To ignore alternative health procedures when a dependent child is languishing at home, weak and despondent, and

whose condition remains unreported to a judicial agency, is a blatant violation of a basic human right."[11]

Despite the fact that Christian Scientists act on the basis of what they believe is the best course of action for their families, it is nevertheless difficult to excuse the unnecessary suffering (and at times, deaths) of children who are not given the right to choose. The Christian Scientist home of Herbert and Catherine Schaible, for example, lost two sons in the course of four years due to failure to seek medical attention for curable ailments. The first, Kent, a two-year-old toddler, died after his parents refused to take him to the doctor when he contracted bacterial pneumonia. Instead, the couple turned to prayer and healing as allowed by the Christian Science faith, which were seemingly ineffective in efforts to save the child. As a result of Kent's death, the parents were found guilty of involuntary manslaughter and sentenced to 10 years of probation. The parents made headlines again in the spring of 2013 when their 8-month old son, Brandon, died of complications from diarrhea and breathing difficulties after, once again, the parents refused to take their child to see a doctor.[12] After pleading no contest to third-degree murder in the death of Brandon, the couple was sentenced to 3-and-a-half to 7 years in a state penitentiary with 30 months of probation to follow their release from prison.

It may seem as if a possible solution in these instances is to force parents to allow their children to receive medical care if such care is deemed to be of utmost benefit to the child. Difficulties arise, however, in terms of the United States Constitution and freedom

[11] Fox, Josy. *Medical Care: A Child's Right?*

[12] Radford, Benjamin. "Faith-Healing Parents Arrested for Death of Second Child." *Discovery News.* Discovery Communications, LLC., 24 Apr. 2013. Web. Fall 2013.

of religion. Admittedly, it is cumbersome to force a family to act against their religious views in a country that was founded on the belief that each citizen should have the right to practice religion as they see fit. Nevertheless, adherence to the Constitution should not be an excuse for blatant child neglect. In the words of Dr. Steven Novella, a neurologist at Yale University, "Forgoing proven medical care for serious treatable conditions is never a good idea, but it is criminal neglect when such decisions are made on behalf of defenseless children."[13]

Moreover, it would be unfair to generalize that Christian scientists are the only religious group causing debate in today's healthcare system. In the rural northeastern part of the United States of America, for example, there is a high concentration of the American Amish.[14] The Amish are a very traditionalist population of the Christian faith who are concentrated mainly in states such as Pennsylvania, Delaware, Ohio, and Indiana. These people live very simply, and reject many of the conveniences that most Americans consider to be commonplace based on modern technology. Notably, the Amish live in houses without electricity, dress in plain clothing, speak English as well as a regional dialect (such as Pennsylvania Dutch), and travel by horse and buggy rather than motorized automobiles.

In terms of healthcare, Amish people are generally more receptive than Christian scientists to receiving treatment; however they are far more conservative than their modernized English neighbors. Because Amish are often farmers, builders, or mechanics,

[13] Radford, Benjamin. "Faith-Healing Parents Arrested"

[14] It is important to note that there are many groups of people with beliefs and traditions similar to the Amish. I have chosen to highlight this particular group because as a native of Pennsylvania, I come in contact with the Amish on a semi-regular basis. In addition, Mount Nittany Medical Center serves a small but considerable Amish population, a circumstance that has fueled investigation into their customs.

they depend on their hands for this manual labor. For this reason, Amish as a whole are mostly receptive to sutures and orthopedic procedures such as fractured bone casting and ligamentous repair. They understand that the situations are typically not life or death, and in my personal experience they seem to have no problem with treatments necessary to their hands-on way of life.

Health insurance exists as one of the constraints that the Amish encounter when seeking medical care. Although Amish people do not generally have health insurance in the commercial sense, most participate in a type of church aid where each member of the community gives a certain amount of money to the church on a regular basis, and then this pool of money is used as a sort of emergency fund that can be tapped in times of need. Consequently, without private health insurance, if a member of the Amish community were to go to the hospital, he or she would take on the full expense of the visit. It follows then, that the Amish generally try to avoid traditional healthcare and will take a minimalist approach rather than undergoing extensive testing.

In the fall of 2013, a story broke about Sarah, a 10-year-old Amish girl with leukemia, whose parents left their home in Ohio (and for a short time, the United States entirely) to avoid court-ordered chemotherapy treatments. Apparently, the child had been started on chemotherapy but the parents decided that these treatments were making their daughter too sick. Rather than subject their daughter to these treatments, they chose to take her home and care for her using traditional Amish practices as best that they could. Doctors, on the other hand, argued that Sarah’s cancer was treatable with

chemotherapy.[15] Sarah's father has claimed that he was threatened and berated by Sarah's doctors for his decision to discontinue the chemotherapy, even after he offered to bring Sarah to the hospital regularly so the doctors can monitor the progress of her home remedies. The hospital allegedly allowed Sara to return home after her family hired a physician to consult on a regular basis, but shortly thereafter the hospital decided to take further action.[16]

This case did make its way into the legal realm, which led to a series of decisions and appeals within the Ohio courts. Initially, a court sided with the family and stated that the family had the right to refuse care for their daughter. The hospital, however, countered that Sarah would die without chemotherapy and there was a moral as well as a legal obligation to treat her. Eventually, an appeals court appointed an attorney-nurse with Sarah's guardianship rights such that this person could act as her liaison for medical decision-making.[17]

When the legal guardian sent a vehicle to the family home so that Sarah could be brought back to the hospital for treatment, it was discovered that her family had fled their home in order to avoid the treatment. In an interview with the father several months after the family left Ohio, Sarah's parents claim that she is 100% cancer free using their home remedies.[18] The family wishes to be able to return to their home without the threat of

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[15] Seewer, John. "Ohio Amish Girl, Family Flee to Avoid Forced Chemo." *MSN News*. Borrowed from the Associated Press, 27 Nov. 2013. Web. 15 Mar. 2014.

[16] Michael, David. "Full Story: Ohio Amish Girl Being Forced into Experimental Chemotherapy; Fled U.S. for Natural Treatments–Said to Be Free of Cancer." *Journal of Natural Food and Health*. 18 Nov. 2013.

[17] Michael, David. "Full Story: Ohio Amish Girl Being Forced into Experimental Chemotherapy"

[18] Michael, David. "Full Story: Ohio Amish Girl Being Forced into Experimental Chemotherapy"

persecution or legal action. Sara's parents, like the Schaibles, contend that they have the right to dictate their own medical care based on religious beliefs.

Such a problem exists within the medical ethics community in that physicians and courts must try not to undermine the trust of traditionalist cultural communities like the Amish by forcing medical treatments on them. For example, if Amish or Christian Scientist children are required to undergo certain test or tests when they are brought to the emergency room or other medical setting, families might be reluctant to bring the children in altogether. Likewise, if a family with a sick child has views similar to Sarah's family's sentiments, why would they take the little one to a doctor knowing that they might be bullied into unwanted treatment? Certainly, there is an obligation to treat children in a way that promotes their health and well-being; but if traditionalist families shy away from seeking treatment altogether, what have we to gain by forcing the proverbial hand of medicine? After all, families generally feel that they should be able to seek the care that they need without being coerced into treatment that goes against their beliefs. Despite the fact that states do tend to award great freedoms to parents regarding medical care of their children, the lines become extremely blurred in life-and-death situations. These are situations, therefore, where case law, rather than federal or Constitutional law, seems to be the best forum for legal reasoning.

The greatest shame in these situations is that they revolve around helpless young children. At a time when the focus should be on healing (or dying) comfortably, ill young patients are subjected to long and arduous legal battles that pit the families that love them against the doctors on whom they depend for treatment. This is a source of undue stress not only for the healthcare professionals, but also the patients. If we deem it morally

impermissible for parents to refuse care for their children at all costs on the basis of religious or moral principles, then case-by-case evaluation is necessary to determine when the parents are legally obligated to seek medical attention. The inconsistency surrounding this aspect of American healthcare is the groundwork for largely avoidable conflicts moving forward.

Chapter 5

End-of-Life Decision Making

Although the majority of healthy adults like to think that complete personal autonomy will be an option throughout life, the realities of aging complicate the matter. As humans age, we become more susceptible to mental illness and abnormal memory loss which delay cognitive ability and hinder a person's ability to make good decisions regarding health. One such illness, Alzheimer's disease, "is an irreversible, progressive brain disease that slowly destroys memory and thinking skills, and eventually even the ability to carry out the simplest tasks." According to the National Institute of Aging, as many as 5.1 million Americans (2.5% of the United States population) are thought to have Alzheimer's disease in America.[19] The Center for Disease Control further indicates that while only around 5% of Americans aged 65-74 have the disease; almost one-half of Americans over the age of 85 exhibit some signs of dementia or Alzheimer's.[20] Such a high prevalence of mental inhibition presents many problems in terms of an elderly person's medical autonomy and ability to make informed decisions.

Much like the aforementioned examples of intoxicated patients who cannot be entrusted with the responsibility of making good decisions about their healthcare and treatment plans, persons with dementia and other degenerative mental illnesses are often stripped of their medical autonomy. This is obviously not done as a malicious neglect to

[19] "Alzheimer's Disease Fact Sheet." *National Institute on Aging*. U.S. Department of Health and Human Services, Sept. 2012. Web. Fall 2013.

[20] "Alzheimer's Disease Fact Sheet."

their rights, but rather it is necessary to ensure that the elderly receive adequate care. In some cases, adults will sit down later in life and devise a legal document that outlines their wills should the situation arise where they are no longer able to decide safely on a proper medical plan. Although this seems like a viable solution that allows patients to maintain autonomous right, complications emerge when situations change. In other words, nobody has a detailed plan for every medical situation that could present itself after a person has lost his or her ability to make decisions safely. A better way to maintain control of one's self-governing right, then, seems to be that one should designate a trusted family member (or close friend) as their healthcare agent[21] to make medical decisions should he or she lose that capacity.

Ideally, this designated individual should act in a way that respects the ultimate well-being of the patient. Assuredly, this can introduce extremely difficult situations, because the representative is forced to abandon all personal goals and act in accordance with the patient's maxim. An example that is particularly trying is when a patient states while he or she is still cognitively intact that, should they become ill, they do not want any advanced life-saving treatment (blood transfusions, intubations, ventilators, invasive procedures, etc.). Many times this wish appears to be solid in theory, but when the person who is the appointed decision maker actually arrives at the bedside and sees the patient start to die, the desire to save the life becomes greater. In these cases, priority must be given to the patient's wishes before he or she lost personal autonomy. That is, if he or she

[21] One appoints this agent in his or her living will, specifically in a health care proxy, which is the term used for the specific document in which a patient identifies who will make his or her medical decisions if he or she is cognitively or physically unable to do so.

explicitly stated that only comfort measures should be taken, medical professionals and family members are generally expected to oblige.

In February of 2014 I had the privilege of speaking with Dr. Debra Wiegand, PhD, RN, who is a nursing instructor at the University of Maryland, School of Nursing. Dr. Wiegand is an expert on end-of-life decision-making; she also specializes in palliative and hospice critical care including the family's role in the withdrawal of life-sustaining therapy. We discussed the roles of the physician, patient, and family in critical and emergent situations, specifically those instances when the patient is unable to communicate an autonomous treatment plan. Dr. Wiegand stressed the importance in having a plan ready for these situations, and she highlighted the most proven and effective criteria for these situations. In her experience, when healthcare professionals are confident and consistent in terms of the methods involved in obtaining consent, the outcomes tend to be much more favorable for patients and their families.

According to Dr. Wiegand, there are three levels of consent and decision-making that warrant our attention in an emergent setting. The first of these levels is the patient's written wishes. Most often, this is in the form of a will or other legal document. The idea is that a person should draft this document while he is she is still mentally capable of doing so; this becomes especially important if a terminal illness or degenerative cerebral disease is present. Furthermore, if a physician is able to access this advance directive, he or she has concrete evidence of the patient's conscious decision making.

The primary problem with written documentation is that it lacks portability and can be very difficult to obtain in an emergency setting. For example, if a person presents

with an acute cardiac event, time is very limited. To contact the proper sources and obtain legal documentation may take hours, and this sort of timeframe is not feasible in the emergency room. Doctors are obligated to treat the patient as if they are a full code status[22] until information to the contrary is received. It is important, therefore, that a patient have a copy of their advance directive available to a primary contact person (family member, close friend, etc.). This serves to expedite the hospital's recovery of the patient's legal and medical desires.

Another issue that arises in terms of written documentation is that the wording is often very vague and does not apply to specific situations. Often, people will state: "I never want to be placed on a ventilator," or, "I never want to receive a blood transfusion," because at the end of life, this type of care unfortunately serves to prolong inevitable death. A situation may arise, however, where a person may only need such advanced care for a short amount of time in order to turn around an acute event. For example, if a demented patient has a written will stating that they do not want a blood transfusion, but they fall in a nursing home and lose blood due to a large laceration, it would seem barbaric to deny transfusion based on the written will. After all, the blood will serve as a comfort measure and not solely as a means of prolonging life. It can be nearly impossible to interpret exactly how a patient would want to be treated when all the medical professional has is a few pages of legal documentation. In these situations, then,

[22] Full code status refers to the patient's desire to have life-sustaining therapy in a life-threatening event. In contrast, patients who have a DNR (Do Not Resuscitate) code status wish not to have any advanced treatment in end-of-life situations.

a prudent doctor will take advantage of his or her wisdom of experience to supplement the patient's written directive.

The second level of consent and decision-making deals with the verbal wishes of the patient. It is important here to make a distinction: this refers only to patients who are cognitively able to devise a plan by themselves. Healthcare providers use a set of criteria to determine mental cogency, but this criterion is very subjective and can vary from physician to physician. According to Dr. Edmund Howe, MD, JD, the general criteria that a psychiatrist would recommend evaluates the patient's ability to:

1) Understand alternatives
2) Appreciate how these alternatives apply to him or herself
3) Reason regarding these alternatives
4) Express a choice[23]

The idea is that if the patient exhibits an understanding of the treatment plan and alternative treatment plans, has the capacity to reason through these different options, and is able to make what appears to be an informed and thoughtful choice, he or she is cognitively sound enough to retain the right to autonomy. Once a doctor determines that the patient is capable of providing verbal consent, this capacity is more advantageous than written advance directives, because it is portable and a physician does not need to search for a document; the doctor just simply asks the patient.

The third and final level of consent and decision-making deals with the wishes of the family and/or other loved ones who may be present either in person at the bedside or via electronic means. This level should be held in the lowest regard compared to the

[23] Howe, Edmund, MD, JD. "Ethical Aspects of Evaluating a Patient's Mental Capacity." *Psychiatry* 6.7 (2009): 15-23. *National Institutes of Health*. Web. 27 Feb. 2014.

written and/or verbal wishes of the patient, because by involving sources outside of the individual, the patient loses a great part of personal autonomy. This third level should be used primarily when the patient is physically or mentally incapable of relaying their medical wishes to the professionals, usually in the absence of prior written documentation. This is a common occurrence in end-of-life situations when patients become lethargic, listless, confused, and otherwise disoriented.

Ideally, when the patient was conscious or mentally competent, they would have documented, either in writing or verbally, wishes to allow the family to intervene on their behalf. In these instances, the first and/or second levels of consent and decision-making will be used because the patient is actually in control of his or her decision-making by actively passing the responsibility to family. This is the ideal clinical consent situation, because it allows for the most personal autonomy.

Problems arise when a patient did not previously give family the right to intervene, and the physician is unsure that the family is acting considerately on the patient's behalf. Because people generally do not have much experience with death, especially the death of close family members, it can be hard to predict how someone will act in these situations.[24] A person who is normally levelheaded and logical in decision-making can become erratic in times of grief and mourning secondary to the stress. This presents an ethical crossroads for the provider as he struggles to manage what he thinks is best for the patient, what he thinks the patient would choose, and what the family

[24] "Informal Discussion with Dr. Debra Wiegand, PhD, RN."

requests. It can also be cumbersome to determine if the family members are selflessly relaying the patient's wishes, or if they are interjecting their own selfish ideas.

The ideal strategy for autonomy in decision-making is a mixture of the patient's wishes and those of the family. Especially in situations where the patient is incapable of relaying his desires, a written will with family support is the most effective and provides the best results. According to Dr. Wiegand, it is the responsibility of the medical team to make sure the family understands the patient's desires. This means that when at all possible, and especially upon the removal of (or decision not to use) life-sustaining therapy, the physician should move the family towards the desires of the patient and not the patient towards the desires of the family. Admittedly, this can be a daunting task given the unpredictability and persistence of stressed and frightened family members. Indeed, there may be times when the family is so forceful (some will even threaten legal retribution), that the physician has no choice but to give in to their desires.[25]

In the vast majority of cases, end-of-life decision-making, though often a group effort, should ultimately be the choice of the conscious individual. If a family is able to provide medical professionals with the patient's written directive and then support these wishes selflessly, geriatric and end-of-life care can run much more smoothly. According to the abstract of a seminar that Dr. Wiegand gave to the American Academy of Hospice and Palliative Medicine based on a study she performed regarding the family experiences

[25] Here we are talking primarily about those patients who have not secured a legitimate legal will. If the doctor does have written documentation that supports the desires of the patient, he or she has a greater legal foundation on which to carry out the patient's individual wishes. If all that the doctor has to go on is verbal desires, the door is more open for he-said she-said controversies that may compromise the integrity of the verbal consent.

during the dying process, "Families need to be prepared, guided, and supported through the dying process. Healthcare providers need to provide quality end-of-life care to patients and families before and after the withdrawal of life-sustaining therapy."[26] This obviously requires teamwork and acceptance on the family's part as well as patience, empathy, and compassion on the part of the doctor.

Hospice Care

In contrast with palliative care which is the treatment of patients at all stages of disease, hospice care focuses on pain relief and other comfort measures in end-of-life patients. Generally insurance companies require that a patient is told by a doctor that they have less than six months to live before that patient is able to be placed on hospice care. There are generally fewer problems with advance directives when a patient is on hospice care, because the majority of people on hospice are concerned with passing peacefully and not unnecessarily sustaining life. Nevertheless, the aforementioned stress and anxiety when one watches a family member die can lead to erratic decision-making towards the end.

At times, family members who notice that their loved one in hospice care is exhibiting signs of active death will bring him or her to the hospital for treatment. In many cases this is not because they can accept that their loved one will die, but rather because they panic because they are not sure what else to do. In these cases it is the

[26] Wiegand, Debra, PhD, MBE, RN, CCRN, CHPN, FAHA, FAAN. "Family Experiences During the Dying Process After Withdrawal of Life-Sustaining." Lecture. AAHPM & HPNA Annual Assembly. San Diego. 12 Mar. 2014. *American Academy of Hospice and Palliative Medicine*. Web.

responsibility of the healthcare provider to comfort and reassure the family, and also to make certain that the patient is comfortable until he or she dies. Physicians who become angry or irritated when families bring in a patient on hospice care only compound the tension of the situation.

Along the same lines, most hospice programs in the United States have a system in place that allows family members to call a hotline for support towards the end of the patient's life. These programs provide grief counselors and other healthcare professionals who help guide the family through the patient's final hours or minutes.[27] Primary physicians, social workers, and the hospice organizations themselves need to be diligent when informing the patients and families of these services. Such measures, if taken well prior to the end-of-life, provide more peaceful endings for patients and loved ones, and less frustration for emergency healthcare workers.

[27] "Informal Discussion with Dr. Debra Wiegand."

Chapter 6

The Doctor's Perspective

Although autonomy as it pertains to the patient is frequently visited as a topic in discussions about proper healthcare, such discussion is useless without the support of the medical community as a whole. After all, a patient can draft a plan that describes exactly what he or she wants in terms of medical care, but it will be effective only if the physician is on board with the plan. The problem is not that doctors are inherently opposed to patient autonomy; in fact, most are more than happy to act in accordance with the will of the patient. It is, rather, that the intricacies and regulations surrounding personal autonomy and informed consent are so cumbersome that many doctors simply do not have time to sit back and deeply reflect on the personal rights of every patient. Furthermore, it is the responsibility of medical ethicists and philosophically-trained healthcare professionals to provide fellow physicians, nurses, and other providers with easy access to concise guidelines that they can follow to ensure that a patient's autonomy is preserved to the fullest extent in every situation.

One may not consider the skill of deliberation to be a vital characteristic of the physician; however, this trait is extremely important with respect to his or her effectiveness in communicating with patients. Physicians, despite the paternalistic role that they sometimes take on in society, need to be true advocates of autonomy in community in that they encourage people both to think for themselves and to discuss possible plans with the doctor. According to Eugene Garver, "a good person must be

good at deliberation and persuasion." He goes on to argue further that, "because practical wisdom requires persuasive power, such persuasive ability is a sign of practical wisdom." Physicians additionally must be trained in rhetoric, given that, "rhetoric shows how reason can be contingent, emotional, and interested without ceasing to be rational." Necessarily, wise physicians should be less interested in bullying patients into choosing a certain plan and more concerned with discussion and deliberation with patients and families.[28] Such rhetoric and deliberation, as long as it is good and ethical, improves the moral character of the physician.

One of the potential challenges to autonomy that doctors must face is to how to treat those patients who are incapable of determining, or agreeing to, an autonomous plan. This includes the situations with the intoxicated patients, as well as unconscious victims of accidents, elderly people, and many other situations. For this specific discussion, we will exclude those instances where the individual in question has a family member or friend present who is able to advise the situation (or a person with power of attorney who has legal power as signed over by the patient). It seems as though, in my experience, each doctor has an idea of an ideal end, which is to live by means of reasonable measures. In order to reach this end, physicians have a certain standard of care that is composed of critical care measures tailored to the individual. This means that doctors should act in such a way as to do everything in their powers to save the patient.

Certainly there cannot be an absolutely universal treatment plan, because each patient needs to be cared for in a manner that best treats him or her. When doctors have

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[28] Garver, Eugene. *For the Sake of Argument: Practical Reasoning, Character, and the Ethics of Belief*. Chicago: University of Chicago, 2004. 2-3.

an unconscious patient come in with an unknown code status and no power of decision, they seemingly use this “universal principle to preserve life” as a rule to guide action, in order to save the patient. Furthermore, it is imperative that we condense these discussions into a series of conclusions that doctors can then put into action.

Chapter 7

Conclusions

When we combine the philosophical implications of autonomy, informed consent, and medical decision-making we can draw conclusions that form a general set of guidelines medical professionals can use to ensure that patients and families are treated ethically. These guidelines are certainly subject to amendment as each situation one encounters in medicine is fully unique. Nevertheless, these principles should be considered as a starting point when considering how to treat a patient.

Healthcare providers need to remember that each person does have the right to autonomy and a right to make his or her own medical decisions. Because the majority of Americans agree that individuals should have control of personal healthcare (with the exception of the unique cases mentioned above that are still under debate), social contract theory suggests that autonomy is in the best interest of the greater population. Until a patient loses cognitive ability as described by the criteria in Chapter 5, he or she is morally entitled to take charge of personal healthcare. Patients also have the right to receive information from providers in a manner than neither overshoots nor under-estimates their general knowledge, and likewise physicians must be mindful to provide the best information possible to the patients. Patients should not only be able to determine their own healthcare plans, but they should also be properly informed as to the treatments to which they consent or do not consent. When considering the implementation of

healthcare laws and policies, it is vital to draft legislation that keeps the greatest good of the majority at the forefront while still considering those incapable of autonomy.

Naturally, situations will arise where a patient who would normally be able to provide the physician with their wishes for treatment is unable to do so. In these cases (e.g. the patient is unconscious or intoxicated), the physician must use the wisdom of experience to act in a way that best benefits the patient. This means that the doctor must rely on judgment and knowledge from past experiences to devise a plan in the patient's best interests. In the case of the intoxicated patient, I contend that the person does maintain a sense of personal autonomy because he or she chooses to put him- or herself in the intoxicated state. In terms of the unconscious patient, although personal autonomy is seemingly forfeited, patients can avoid a total loss of autonomy by devising a plan and carrying in on their person or leaving it with a close family member.

Perhaps the most difficult situations that arise with regard to medical decision making deal with the various American cultural groups. It is generally accepted that a cognitively sound adult has the right to make medical decisions for him- or herself. When the case involves a child, however, the boundaries are not as clear. Parents should be afforded the right to make medical decisions on behalf of their children (under the age of 18) so long as these decisions are made in the best interests of the child. Physicians must be conscious of religious restrictions while also ensuring that the child's right to live is not neglected. In situations where the ailment is clearly treatable, parents should be required to seek treatment for their child, and physicians are morally, and in some cases legally, required to report those situations where parents fail to seek treatments. If the disease or injury is more complex, further discussion and reasoning between providers

and parents is needed. Much of the confusion surrounding religion, medical care, and dependents is resolved or at least diminished when physicians take the time to sit down and discuss matters with the parents. A clear line of communication between healthcare providers and parents signifies trust, openness, and empathy, which are vital in ensuring that child welfare extends beyond religious boundaries.

Finally, it is important for healthcare providers to have a clear plan of action in place when tackling end-of-life and hospice care situations. Physicians, nurses, and home-health delegates must be aware that the situations are emotionally and physically taxing for both patients and families, and the focus must be primarily on comfort and smooth transitions. In terms of decision-making, the aforementioned order of precedence should be adopted:

1) Legal or written directives
2) Verbal wishes of the patient
3) Family demands/desires

This sequence affords the patient the greatest opportunity for personal autonomy while also giving families a say in the decision-making. Necessarily, the process operates much more smoothly if the patient drafts a living will or healthcare proxy prior to reaching the point when he or she loses personal autonomy (cognitively, physically, etc.). Nevertheless, physicians demonstrate – and grow in – moral character through honest discussion and deliberation with patients and their families.

Healthcare is more than a government policy, a system of hospitals, or research. It goes further than a physical exam, a CT-scan, or even an advanced experimental procedure. It is impossible to categorize every patient that one will encounter. Healthcare and the medical profession in general is about the treatment of the person. It presupposes

a level of trust that must be established when one human decides to put his or her life into the hands of another. With every advance in medical technology and every breakthrough device, professionals must be aware that they, and not some machine, are responsible for the holistic care of the autonomous human being. At the end of the day, real, intimate contact separates the good clinicians from the great providers:

> Dear Mr. (removed),
>
> I am the Emergency Medicine physician who treated your wife Mrs. (removed) last Sunday in the Emergency Department at (hospital). I learned only yesterday about her passing away and wanted to write to you to express my sadness. In my twenty years as a doctor in the Emergency Room, I have never written to a patient or a family member, as our encounters are typically hurried and do not always allow for more personal interaction.
>
> However, in your case, **I felt a special connection to your wife** (removed), who was so engaging and cheerful in spite of her illness and trouble breathing. I was also touched by the fact that you seemed to be a very loving couple. You were highly supportive of her, asking the right questions with calm, care, and concern. From my experience as a physician, I find that the love and support of a spouse or a family member is the most soothing gift, bringing peace and serenity to those critically ill.
>
> I am sorry for your loss and I hope you can find comfort in the memory of your wife's great spirit and of your loving bond. My heartfelt condolences go out to you and your family.
>
> (removed), MD[29]

[29] Hudson, Hayley. "Unexpected Letter From ER Doctor May Make You Tear Up (PHOTO)." *The Huffington Post*. TheHuffingtonPost.com, 09 Feb. 2013. Web.
This letter was originally written in pen by an emergency room physician. It demonstrates exactly the type of intimate relationship that can truly affect the lives of patients and their families. To treat a person one has never met before fulfills a physician's job description, but to truly care for them goes above and beyond the call of duty.

Appendix

HIPAA Privacy Rule and Public Health

Summary

New national health information privacy standards have been issued by the U.S. Department of Health and Human Services (DHHS), pursuant to the Health Insurance Portability and Accountability Act of 1996 (HIPAA). The new regulations provide protection for the privacy of certain individually identifiable health data, referred to as protected health information (PHI). Balancing the protection of individual health information with the need to protect public health, the Privacy Rule expressly permits disclosures without individual authorization to public health authorities authorized by law to collect or receive the information for the purpose of preventing or controlling disease, injury, or disability, including but not limited to public health surveillance, investigation, and intervention.

Public health practice often requires the acquisition, use, and exchange of PHI to perform public health activities (e.g., public health surveillance, program evaluation, terrorism preparedness, outbreak investigations, direct health services, and public health research). Such information enables public health authorities to implement mandated activities (e.g., identifying, monitoring, and responding to death, disease, and disability among populations) and accomplish public health objectives. Public health authorities have a long history of respecting the confidentiality of PHI, and the majority of states as well as the federal government have laws that govern the use of, and serve to protect, identifiable information collected by public health authorities.

Introduction

The shift of medical records from paper to electronic formats has increased the potential for individuals to access, use, and disclose sensitive personal health data. Although protecting individual privacy is a long-standing tradition among health-care providers and public health practitioners in the United States, previous legal protections at the federal, tribal, state, and local levels were inconsistent and inadequate. A patchwork of laws provided narrow privacy protections for selected health data and certain keepers of that data.

The U.S. Department of Health and Human Services (DHHS) has addressed these concerns with new privacy standards that set a national minimum of basic protections, while balancing individual needs with those of society. The Health Insurance Portability and Accountability Act of 1996 (HIPAA) was adopted to ensure health insurance coverage after leaving an employer and also to provide standards for facilitating health-care--related electronic transactions. To improve the efficiency and effectiveness of the health-care system, HIPAA included administrative simplification provisions that

required DHHS to adopt national standards for electronic health-care transactions. At the same time, Congress recognized that advances in electronic technology could erode the privacy of health information. Consequently, Congress incorporated into HIPAA provisions that mandated adoption of federal privacy protections for certain individually identifiable health information.

The HIPAA Privacy Rule (Standards for Privacy of Individually Identifiable Health Information) provides the first national standards for protecting the privacy of health information. The Privacy Rule regulates how certain entities, called covered entities, use and disclose certain individually identifiable health information, called protected health information (PHI). PHI is individually identifiable health information that is transmitted or maintained in any form or medium (e.g., electronic, paper, or oral), but excludes certain educational records and employment records. Among other provisions, the Privacy Rule:

- gives patients more control over their health information;
- sets boundaries on the use and release of health records;
- establishes appropriate safeguards that the majority of health-care providers and others must achieve to protect the privacy of health information;
- holds violators accountable with civil and criminal penalties that can be imposed if they violate patients' privacy rights;
- strikes a balance when public health responsibilities support disclosure of certain forms of data;
- enables patients to make informed choices based on how individual health information may be used;
- enables patients to find out how their information may be used and what disclosures of their information have been made;
- generally limits release of information to the minimum reasonably needed for the purpose of the disclosure;
- generally gives patients the right to obtain a copy of their own health records and request corrections; and
- empowers individuals to control certain uses and disclosures of their health information.

The deadline to comply with the Privacy Rule is April 14, 2003, for the majority of the three types of covered entities specified by the rule [45 CFR § 160.102]. The covered entities are

- health plans,
- health-care clearinghouses, and
- health-care providers who transmit health information in electronic form in connection with certain transactions.

At DHHS, the Office for Civil Rights (OCR) has oversight and enforcement responsibilities for the Privacy Rule. Comprehensive guidance and OCR answers to hundreds of questions are available at http://www.hhs.gov/ocr/hipaa.

Impact on Public Health

Public health practice and research, including such traditional public health activities as program operations, public health surveillance, program evaluation, terrorism preparedness, outbreak investigations, direct health services, and public health research, use PHI to identify, monitor, and respond to disease, death, and disability among populations. Public health authorities have a long history of protecting and preserving the confidentiality of individually identifiable health information. They also recognize the importance of protecting individual privacy and respecting individual dignity to maintaining the quality and integrity of health data. CDC and others have worked to consistently strengthen federal and state public health information privacy practices and legal protections.

DHHS recognized the importance of sharing PHI to accomplish essential public health objectives and to meet certain other societal needs (e.g., administration of justice and law enforcement). Therefore, the Privacy Rule expressly permits PHI to be shared for specified public health purposes. For example, covered entities may disclose PHI, without individual authorization, to a public health authority legally authorized to collect or receive the information for the purpose of preventing or controlling disease, injury, or disability [45 CFR § 164.512(b)]. Further, the Privacy Rule permits covered entities to make disclosures that are required by other laws, including laws that require disclosures for public health purposes.

Thus, the Privacy Rule provides for the continued functioning of the U.S public health system. Covered entities should become fully aware of the scope of permissible disclosures for public health activities as well as state and local reporting laws and regulations. Moreover, a public health authority may also be a covered entity. For example, a public health agency that operates a health clinic, providing essential health-care services and performing covered transactions electronically, is a covered entity. This report provides guidance to public health authorities and their authorized agents, researchers, and health-care providers in interpreting the Privacy Rule as it affects public health. CDC recommends that public health authorities share the information in this report with covered health-care providers and other covered entities and work closely with those entities to ensure implementation of the rule consistent with its intent to protect privacy while permitting authorized public health activities to continue.[30]

[30] Thacker, Stephen B., MD, MSc. "HIPAA Privacy Rule and Public Health." *Centers for Disease Control and Prevention*. Centers for Disease Control and Prevention, 11 Apr. 2003. Web. 19 Mar. 2014.
This is an excerpt of a summary of the HIPAA Privacy Rule, and is provided by the Centers for Disease Control and Prevention and the US Department of Health and Human Services as a short guide to the legislation. The material in this report originated in the Epidemiology Program Office, Stephen B. Thacker, M.D., M.Sc., Director.

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Wiegand, Debra, JA Deatrick, and K Knafl. Family management styles related to withdrawal of life-sustaining therapy from adults who are acutely ill or injured. *Journal of Family Nursing*, 14 (2008):16-32.

Academic Vita
Cody Allan Pepperday

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EDUCATION

The Pennsylvania State University — University Park, PA
Bachelor of Arts in Philosophy, May 2014

- Minor in Spanish
- Schreyer Honors Scholar
- Paterno Fellow

Westminster College — New Wilmington, PA
Bachelor of Arts in Philosophy candidate, 2010-11

- Minor in Spanish
- All-College Honors Scholar

HONORS SOCIETIES

- Westminster Honors College — 2010-2011
- Westminster OKS Honors Society — 2010-2011
- Penn State Paterno Fellows — 2012-present
- Schreyer Honors College — 2012-present

PRESENTATIONS/RESEARCH

April 2011, Westminster College

- Undergraduate Research and Arts Celebration
- *The "Freshman Fifteen": Debunking the Myth of First-Year College Weight Gain*
- Runner up: Best First-year Research Presentation

Fall 2012, Penn State Pacific Institute for Research and Evaluation (PIRE)

- Research Assistant
- Surveyed participants and compiled results on the effects of anti-DUI campaigns
- Training in HIPAA regulations and research ethics

CLINICAL EXPERIENCE

May 2012, Dr. Thomas Ellis, DO, Shadowing

- Orthopedic surgery
- Spent time in both the clinical and surgical settings

2012-present, Mount Nittany Medical Center, Volunteer

- Assisted patient movement within the medical center
- Interacted with patients, nurses, and physicians, and facilitated care

2013-present, ScribeAmerica at Mount Nittany Medical Center, Physician Scribe

- Worked directly with the emergency department physician
- Assisted in non-clinical duties of the medical staff
- Informed the physician when laboratories and radiographic studies were available

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WORK EXPERIENCE

- Clear-Centre Community Pool, Lifeguard 2008-2009
- Philipsburg-Osceola Little League, Statistician 2008-2010
- DelGrosso's Amusement Park 2009-2010
- Westminster College Newspaper, Sportswriter 2011
- PA Department of Transportation, GSI 2011-2013
- The Hite Company, Laborer 2012-present
- ScribeAmerica Physician Scribe 2013-present

ATHLETIC ACTIVITIES

- Westminster College Varsity Football 2010-2011
- Westminster College Varsity Track and Field 2010-2011
- Westminster College Varsity Letterwinner 2011
- Penn State Archery Club Team 2012-present
    - Nationally Ranked Indoor Collegiate Archer (14^{th} in 2014)

EXTRACURRICULAR ACTIVITIES

- First Church of Christ (Philipsburg, PA) 2007-present
- Centre County YMCA Member 2007-present
- Philipsburg Heritage Days 2010-present
- Vessels of Mercy Praise Band 2011-present
- Penn State Pre-Medical Society 2012-present
- Penn State Dance Marathon Committee Member 2012-2013

ACADEMIC/CAREER GOALS

West Virginia School of Osteopathic Medicine Lewisburg, WV

Doctor of Osteopathic Medicine candidate, May 2018

- Prospective interests in Orthopedic Surgery, General Surgery, Plastic Surgery, and Emergency Medicine

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