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A Matter of Life and Death

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"It is a matter of life and death." This common expression is used to convey the urgency of a given situation by juxtaposing what can be argued as two of society's most significant experiences. It is perplexing how there can be such a fine line between two states of being that suggest the exact opposite of one another. First, there is the gift of life that can be seen as the greatest gift of all, because without it everything we know would not be. Secondly, there is death which is the thing that takes away from us the greatest gift of all. "It is a matter of life and death." This common expression replays in my head as it is also the phrase the doctor so sullenly used to express the serious consequences of my grandmother refusing medical treatment for early stages of kidney disease. In my paper I will discuss the ethical challenge physicians face when balancing autonomy and beneficence, and how this ethical challenge lead me to be skeptical of the efficacy of the HIPAA privacy rule in all medical cases. I will discuss this in the context of my own experiences regarding a loved one refusing medical treatment that could have saved her life.

What is it like to not be alive? None of us know the answer to this question, thus making it hard for people not only to accept the inevitability and uncertainty of death, but also making it hard for people to come to terms with the fact that they will not live forever. I think this is how my grandma felt; she had been alive, strong, and healthy for so long she was almost in denial of her own mortality. The first time she was diagnosed with kidney disease (a notably curable condition when caught in its early stages) she brushed it off like it was nothing. She did not like doctor's office visits and underestimated her own condition as well as her own body's strength, despite doctors' countless efforts to explain her condition to her. Months, years, and various doctor appointments passed as her kidneys got worse. My grandma expressed no discomfort, was not verbal about her symptoms, and never even gave us the slightest inkling that she had any medical issues. It was later revealed that this was because she “did not want to worry anyone” and “hated visiting the doctor.” She instead chose to live in denial of her condition. Her doctors had to struggle with the ethical tension between respecting my grandma’s autonomy and her right to refuse treatment, and their duty to ensure beneficence and patient privacy protection.

But what exactly do the principles of autonomy and beneficence have to do with anything in the context of research and medicine? Patient autonomy and public beneficence are two ethical principles discussed in the Belmont Report that provide guidance to researchers dealing with ethical issues presented in human research. Patient autonomy falls under the category of “respect for persons” and emphasizes that patients have the right to be treated as autonomous agents as well as to have their autonomy acknowledged by researchers or other medical professionals (*Belmont Report*). One medical website defines patient autonomy as, “The right of patients to make decisions about their medical care without their health care provider trying to influence the decision” and states that it allows for, “health care providers to educate the patient but does not allow the health care provider to make the decision for the patient” (“Medical Definition of Patient Autonomy”). On the other hand, the Belmont Report describes the principle of beneficence as researchers treating their subjects “in an ethical matter” which can be done by respecting subjects’ decisions, protecting them from harm, and making efforts to ensure their well being (*Belmont Report*). This principle encourages researchers to do no harm and to “maximize possible benefits and minimize possible harms” (*Belmont Report*). This principle of doing no harm has been a long standing principle in medical ethics as seen in the Hippocratic Oath. In taking this oath, physicians vow to uphold certain ethical standards in their practice. Here the close relationship of ethical principles and guidelines in both research and medicine can be seen. The understanding of these ethical principles can now be applied to the difficulties physicians face in dealing with “matter of life or death” issues, not only with the case of my grandma, but also with other people who refuse medical treatment.

These ethical principles can cause tension among doctors, researchers, and healthcare providers in situations where patients, for whatever reason, refuse some sort of treatment that could save their life. Physicians want to do what is best for the patient, which normally entails saving their lives, but have to respect patients’ decisions to refuse treatment at the same time. Although these two ethical principles are often in conflict with one another, the issue is not deciding which principle is more important than the other because I do not think either one takes precedence over the other. Rather, I am focusing on the interesting dynamic that both of the principles play a part in that affects my views on patient privacy rules.

In my grandma’s case, autonomy trumped beneficence as her doctors were obliged to respect her healthcare decision to refuse kidney treatment. However, this did not come without a struggle among her doctors and their countless efforts to try to abide by the principle of beneficence. They wanted to ensure her well being and felt the best way to do this was to encourage her to receive treatment, as it would save her life. As stated in the Belmont Report, the Hippocratic Oath, “requires physicians to benefit their patients 'according to their best judgment'”, which is what the doctors in my grandma’s case were trying to do. It must also be noted that my grandma never shared with any of us, her family, that she had kidney issues until her condition reached a point where she needed to be hospitalized and on life-sustaining equipment for kidney failure. The fact that the doctors were unsuccessful in relieving my grandma’s stubbornness and in convincing her to receive treatment for a condition so easily curable and over so many years makes me raise questions and have doubts for patients' privacy rights and the HIPAA privacy rule.

The HIPAA privacy rule protects patients' rights to private medical records and other personal health information by establishing national standards which allow patients to have authorization over their medical records. Under this rule, physicians cannot share a patient's medical information with others without the patient's consent (U.S. Department of Health & Human Services). Before having a firsthand experience of doctors abiding by rules and regulations in order to respect my grandma's autonomy and privacy, it was easy for me to say that of course all patients should have the right to have their medical records private under all circumstances. However, after my grandma's case, my views have now been changed and I believe there needs to be some sort of revision or exception to the HIPAA privacy rule that allows for leniency in physicians respecting patient both autonomy and privacy. Was the doctor-patient relationship between the physicians and my grandma not strong enough for my grandma to be able to trust their suggestions? Would hearing the same suggestions from her family rather than from doctors have been able to persuade my grandma to accept treatment? After the loss of my grandma I cannot help but think that if the doctors were able to justify making exceptions to the HIPAA privacy rule and disclosing my grandma's health records to my family that we might have been in a better position to persuade my grandma to receive treatment than her doctors were. While I believe it is important and ethical for physicians to value and respect autonomy and privacy rules, I believe it would be equally as ethical for physicians to attempt to save patients' lives even if that includes disclosing health information to family members or other designated people. As the doctor stated, this was "a matter of life and death", so does the value of someone’s life not count as substantial enough justification to at least be open to different alternatives or variations of the HIPAA privacy rule?

While some may argue that it would be unethical to violate the HIPAA privacy rule, I think there are some cases in which it would be unethical to *not* violate this privacy rule. My own experiences have lead me to better understand that balancing beneficence and autonomy is a struggle that directly puts the risks and benefits of always abiding by privacy rights into question. Considering revisions to the guidelines of the HIPAA privacy rule in crucial medical situations, for some patients, is a matter of life or death.

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