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Autonomy and Paternalism in Medicine

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Introduction

Ethics in medicine and research has been developed throughout time to meet an ever-changing world. One principle of bioethics, respect for autonomy is something that has been developed and fought for overtime. Autonomy is a way in which one displays their capacity for making informed decisions, a capacity that healthcare professionals have a duty to respect (Engelbrecht, 2014). A critical way in which patients display autonomy is through the process of informed consent (Sylvestre et al., 2021), which is a "freely-given decision or agreement following disclosure of relevant information" (O'Sullivan et al., 2020). However, medical paternalism, which is doctors making decisions in their patient's best interest without the patient's consent, is a practice that has been seen throughout history (Drolet & White, 2012). As this practice lacks informed consent, it also shows a lack of respect for autonomy. Paternalism and autonomy are on two different ends of the spectrum on ethical decision-making in medicine. Ethically and morally, the respect for an individual's autonomy should always take precedence, however, there are certain circumstances in which paternalism is justified, even as the space between the two remains gray.

Autonomy

Autonomy is being aware and capable of making informed decisions for oneself. Being aware that one can make their own choices, and having others recognize that ability in oneself is a cornerstone in decision making. Informed consent, which was first developed as a legal obligation in medical practice, and then developed into an ethical principle is based on autonomy (Nelson-Marten & Rich, 1999). These two ideas cannot be separated (Engelbrecht, 2014), as taking away an individual's right to informed consent means taking away their right to autonomous decision-making. Even though informed consent is based upon an individual's choice, there is also another key player in this process. Part of informed consent is obtaining the information, and the provider of this information is oftentimes the doctor or physician.

Providing information and appropriate assistance is an ethical responsibility of healthcare workers in terms of autonomy and informed consent (Engelbrecht, 2014). Examples of unethical behavior include: not giving patients all the necessary information, withholding information about effective treatments (O'Sullivan, et al., 2020), and not presenting the risks of deciding not to partake in a treatment option (Cocanour, 2017). A doctor must respect the autonomy of an individual, and with this ensure truly informed consent from them. Truly informed consent involves both the consent from the patient on the treatment option, but also making sure this consent comes from them having all the necessary information, that they are not blindly agreeing to this option. While doctors do face difficulties such as understandably framing information (Sylvestre et al., 2021), ensuring the patient understands everything being said (O'Sullivan, et al., 2020), and making certain the patient is aware of how to apply this information (Engelbrecht, 2014), it is all to fulfill their ethical duty as a medical professional.

Seeing as medical professionals play an important role in informing the patient, it is also a part of this commitment that they respect the ability of patients to make decisions for themselves (Engelbrecht,

2014). How can one decide for themselves if they are not seen as capable of making an independent decision? Autonomous decision-making and informed consent happen daily in healthcare and are engraved in medical law (Cocanour, 2017). The multitude of different medical specialties has the requirement for informed consent tying them together, despite individual differences in opinions of patient autonomy. In a 2001 study, Norwegian physicians were asked to self-report their opinions on statements regarding the physician-patient relationship and autonomy. It was discovered that surgeons scored lowest on the patient autonomy dimension, whereas psychiatrists scored the highest (Falkum & Førde, 2001). This is notable because looking at the areas of a patient each profession is concerned with is vastly different. Surgeons are concerned with the body; objective problems they find often have a determinable cause and designated solution. It is easy to make a medical choice regarding surgery, as the options presented to one by the surgeon often have solid data to support a particular course of action, a course of action the surgeon could have easily chosen for one and would not have been refuted. However, the field of psychology is much more difficult. With it being concerned about the patient's mind, their thoughts, their feelings, and every aspect of their life, for a psychological patient to improve their health, it rests on the choices of the individual themself. In this instance, the professional is there to provide them with the necessary information, tools, and support, for improvement but the real change comes from within the patients themselves. Recognizing that it is up to their patient to decide to improve on their own, it is of no surprise that psychiatrists value patient autonomy most. In surgery, the patient is placed into the hands of the surgeon, and oftentimes the surgeon is the only one with the knowledge or experience to make the needed medical decision.

Regardless of how autonomy is viewed in patients, all healthcare workers subtly influence patient autonomy. However, because autonomy is something that can be developed and changed within an individual, the physician-patient relationship can help to foster the capacity for autonomous choice in an individual (Sylvestre et al., 2021). As informed consent is legally and ethically required, the final decision will rest upon the patient, and choices should not be decided upon without all the necessary information available. "The important component of autonomy is to allow patients to make their own informed decisions" (Engelbrecht, 2014), and it is the duty of the healthcare provider to not only respect autonomy, but to cultivate it.

Paternalism

While autonomous decision-making is the prevalent practice in modern-day medicine, it hasn't always been this way. The growth of consumerism and liberalism from the 19th to 20th century led to a questioning of authority by society, including authority in medicine (O'Sullivan et al., 2020). Patients who were treated under a paternalistic model of care wanted to be able to "act without controlling constraints imposed by others" (Cocanour, 2017), which was achieved as seen by the required respect for autonomy today. The desired display of autonomy conflicted with the paternalistic mindset of the time which involved the doctor asserting their knowledge and making decisions for the patient in what they believed to be the patient's best interest (O'Sullivan et al., 2020). In theory, there isn't a problem with doctors making decisions for their patients, especially considering all the knowledge and experience they have. However, in reality,

this practice disregards one of their most important ethical responsibilities, informed consent.

The realization of lack of consent can be seen through court cases and the legal system from the early to mid-1900s. In 1905, as a result of Mohr v Williams, "the opinion from the court was that when entering into a contract, the physician can operate to the extent of the consent given, but no further" (Cocanour, 2017). In this case, a doctor was tried as he operated on both ears of the patient, after only receiving consent to operate on one, leaving the patient with impaired hearing. Another case in 1957 resulted in the first use of the term "informed consent". In Salgo v Stanford a doctor was charged with professional negligence as their patient underwent a procedure without being aware of all the potential risks and became paralyzed as a result (Cocanour, 2017). This demonstrated a lack of informed consent as the patient was not truly informed about potential risks, and had he been would have decided differently. These two examples are vital to demonstrating paternalism and the issues that can arise from it, primarily a lack of informed consent.

In order to fully understand paternalism, it is necessary to look at the reasoning behind the doctor's actions. Both of these doctors were acting with the intent to help the patient and wished to cause them no harm, which is what justifies paternalism in a way. "Beneficence requires that the physician must promote the welfare of their patient and to do or promote good" (Cocanour, 2017) and nonmaleficence, where they protect the patient from harm (O'Sullivan et al., 2020) are two more principles of bioethics. Treating the patient with respect and ensuring the well-being of the patient are the key elements of paternalism (O'Sullivan, et al., 2020). While paternalistic actions taken by doctors strip patients of their informed consent and do not respect autonomy, whether it was done with beneficence and nonmaleficence is of the utmost importance.

A notable point about paternalism today is that it is still an 'integral value in ethical decision-making… as a balance to other values" and serves as a reminder of the responsibility to patients. Paternalism also acknowledges that the position the doctor holds, as an educated professional, is vital to making decisions (Drolet & White, 2012). The doctor has the medical knowledge of what symptoms may mean, treatment options, and the disease. The patient, on the other hand, knows their bodies, along with their values and beliefs that affect the course of treatment (Skirbekk, et al., 2011). In a paternalistic doctor-patient relationship, the patient is the subordinate; modern-day this has changed, as patients are not only in an equal position but have power as the ultimate decision-maker (Lepping, et al., 2016). It must be recognized that while the autonomy of patients is the most important aspect of a medical decision, doctors still have authority through their knowledge and experience. A reassuring principle to patients comes from 1980, when the American Medical Association's Principle of Medical Ethics, stated that physicians must deal honestly with their patients, which was truly recognized and later described as a fundamental element of the patient-doctor relationship (Nelson-Marten & Rich, 1999).

The doctor-patient relationship is a complicated one and has a complex history. It began as a paternalistic relationship but soon evolved, as the demand for autonomy grew. As respect for autonomy is the prevalent practice today, there are still expectations of informed consent and in turn autonomy which paves way for the justifiable use of paternalism by doctors.

Exceptions to informed consent include medical emergencies, public health emergencies, therapeutic privilege, patient waiver, and patient incompetence (Cocanour, 2017). In these examples, respect for autonomy must be balanced against the other bioethical principles: beneficence, nonmaleficence, and justice. Oftentimes, in many of these situations, when the autonomy of the patient is unable to be respected, it is a paternalistic relationship that comes into play as seen by not obtaining informed consent, and the doctor practicing with nonmaleficence and beneficence.

Balancing the Bioethical Principles

A point brought up when looking at autonomy and paternalism involves the differences between the two. It is stated that "paternalism is about the doctor-patient relationship whereas autonomy is an ethical value. These relationships in healthcare exist in parallel to principles of ethics" (Lepping, et al., 2016). This statement questions how autonomy and paternalism can be associated together when they "exist in parallel", meaning they don't intersect, or even interact directly with each other. However, one of the main features of paternalism is that it involves the healthcare professional acting with beneficence and nonmaleficence (O'Sullivan, et al., 2020). The ethical responsibilities of paternalism, while they do not involve respect for autonomy, can be compared and balanced with it.

These ethical principles must be balanced within the healthcare field (Drolet & White, 2012), but respect for autonomy, nonmaleficence, and beneficence will be the primary focus. The five exceptions discussed above all demonstrate a balance; as one can not be justified or respected, another takes precedence. In the example of a medical emergency, a notable factor in the decision-making process of the doctor is time. They must judge if there is enough time to retrieve informed consent and if taking the time to obtain it would further endanger the patient's health (Falkum & Førde, 2001). A similar situation would be in the case of public health emergencies, primarily if one were to have a highly deadly and infectious disease. If an individual were to have one, they could be placed into quarantine without consent, but the determining factor is that with no action taken, great harm to the public would happen (Buchanan, 2008). In both cases, the doctor would be upholding their ethical responsibilities to protect the patient's well-being, and not cause harm to them or to others, which balances not being able to respect autonomy.

Therapeutic privilege, which is when the doctor chooses not to disclose information to the patient as they would believe it would cause them harm, is another example of finding balance. Today, this practice is rarely used, and if it is, it is often done in the psychiatric field and with extreme caution. In the past, it was common for doctors to conceal information, as Hippocratic medicine encouraged doctors to inform their patients with as much constraint as possible (Nelson-Marten & Rich, 1999). As respect for autonomy became ethically necessary, so did honesty in the doctor-patient relationship, and therapeutic privilege is only used following nonmaleficence.

Patient waiver and patient incompetence are two more exceptions to informed consent, where the decision-making power is either voluntarily or involuntarily transferred from the patient. With a waiver, the patient is asking not to be informed, they want the doctor to have all decision-making power, and the choice to not exercise autonomy is theirs alone. When

a patient is declared incompetent it is often due to psychiatric illness, brain injury, or neurodegenerative disease. For this to happen, “all adults are presumed to be competent unless they are determined by a court to be incompetent” (Cocanour, 2017) and the decision-making power moves to someone else and maybe a family member. Whether by patient waiver or legally declared incompetence, it is always in the best interest of the patient, to protect them from harm and promote their well-being.

When autonomy is unable to be respected it must be justifiable and is justifiable by practicing under the other bioethical principles. Autonomy is arguably the moral and ethical choice, one should always respect an individual's right to make their own decisions. Yet there are instances in which autonomy has the potential to be dangerous or harmful; harmful to the individual, to another person, or society as a whole. When a person does not have the best interest of themselves or others in mind there needs to be interference in their decision-making process. This is where the other bioethical principles: beneficence and nonmaleficence, come into play, as a doctor should promote the well-being of others and protect them from harm if they are unable to respect autonomy. Oftentimes these exceptions lead back to a paternalistic relationship, but what is different than the past is the goal of paternalism when in use today, is to practice it until the patient can regain their autonomous decision-making abilities if possible (Lepping, et al., 2016).

In taking a closer look at healthcare ethics, it is clear to see that the four principles are capable of working alone or together (Gillon, 2003). The clearly defined exceptions mentioned show ethical guidelines, as in each case the patient’s health, or the health of the population is at risk. There is a clear situation in which harm can be prevented, while their health is still being protected. But what happens when ethical conflict arises, and the patient’s welfare is not at risk, or there is a chance of harm no matter what ethical decision the healthcare professional makes?

The Nocebo Effect

While the process of informed consent is ethically and legally necessary, some problems arise with it, problems that come up from being truly informed. Part of the doctor's process of informing the patient includes telling them about possible side effects they could experience. Informing them of this increases their risk of experiencing the side effects, known as the nocebo effect (Faasse & Petrie, 2013). This raises an ethical dilemma between respecting autonomy and nonmaleficence. If a healthcare professional fully informs their patient, fulfilling their duty to respect the autonomy and provide informed consent, this increases the chance of suffering harm through the side effects, which is not following nonmaleficence (Gelfand, 2020).

Unlike a medical or public health emergency, there is no harm present in this situation (Cohen, 2014). The patient does not have an infectious disease, they are not bleeding out, or have any other life-threatening injury. The issue is that informing the patient creates the risk of harm, by simply mentioning potential side effects (Cohen, 2014). If the patient does experience these side effects, there can also be many potential explanations for it. It could be a preexisting symptom not realized or unrelated to the treatment, an actual symptom because of the nocebo effect, or an increase in symptom reporting through the “expectation–guided search process”; which happens by people selectively searching for the mentioned potential side effects (Faasse & Petrie, 2013).

The nocebo effect presents the perfect opportunity to narrow in on the ethical decisions of doctors. With the patient not facing immediate danger, the doctor can reflect on their duty and the impacts of their choices, because whatever they choose will affect their patient's well-being. Selecting the path of nondisclosure will include prioritizing nonmaleficence over respect for autonomy and truly informed consent. It also demonstrates the return of a paternalistic doctor-patient relationship (Gelfand, 2020), a relationship that has already been done away with by patients. As autonomy is something that has been fought for and reinforced by the people themselves, it is something they believe to be natural and essential. Which involves being informed and involved in everything, despite the risks (Gelfand, 2020), something they expect doctors to respect.

Respecting patient autonomy is something involved in the role of being a doctor, and in turn, something patients expect of them. Through the expectations patients have of their physicians, they create a role the physician takes and as long as the physician does not stray from the idealized role, the patient can trust the physician (Skirbekk, et al., 2011). This information was discovered in a 2011 Norwegian study that researched trust in the physician-patient relationship. The main findings were that the trust one has in their physician is implied, and is not something that is explicitly discussed, however concerning the boundaries of trust, it was limited to a certain degree and was restricted if the patient felt uncertain (Skirbekk, et al., 2011). This relates to the nocebo effect and one potential solution of it in particular. Choosing to prioritize nonmaleficence and withholding information will decrease trust in physicians (Gelfand, 2020). If a patient were to find out their doctor withheld information about side effects, even if it was done with their best interests in mind, the trust they have in the medical field is damaged.

In preventing the possible harm of experiencing side effects, is it worth ruining the trust patients have in their doctor, a trust relationship that has developed so much over time it is rarely discussed between the two? If a doctor chose to follow the standard of care and disclose information about side effects, and then the patient did experience these side effects to some degree, they can respect the honesty of the professional in fulfilling their duty to provide information necessary for informed consent. If a doctor chooses to withhold information about potential side effects, and the patient then experiences those side effects, there are more serious consequences to the relationship that has been built. The trust on the end of the patient is gone, as they did not have all the information necessary to give informed consent, and the doctor strayed from their societal role and returned to a more paternalistic relationship. However, human relationships are complicated and they play a role in the decision-making process (Lepping, et al., 2016). Most doctors carefully make their decisions based on what they have learned from getting to know the patient about their wishes and requests.

It has been found that people who exercise autonomy to the greatest degree have the best health (Buchanan, 2008), so perhaps it may be beneficial to prioritize it, especially after it has historically been wanted by patients. What it comes down to is the doctor figuring out the patient's needs, and responding to those needs by respecting their views (Gillon, 2003). The nocebo effect is an ethical conflict where most solutions to it have been found to create the same amount of risk, or a greater amount of risk, than simply disclosing the potential side effects to the patient. The "right"

decision is often situation-specific and is not always clear or feasible to follow through on. In cases where the nocebo effect is at play, the determining factor is often the physician and patient values (Gelfand, 2020). If something were to go wrong, they both would know the patient's wishes were respected, and the doctor did their duty in following their patient's request.

Conclusion

Doing no harm has been doctors' priority for the duration of time, but as seen through the nocebo effect it has come into conflict with their more modern-day duty to respect autonomy. Paternalism has shown that while it is possible to promote good and prevent harm in the patient's best interest, it may only work in certain situations where the patient is unable to make their own choices for the time being, oftentimes situations where life is at risk. In a time when there is no serious health threat to the patient, what should be done? The answer will be different depending on who one asks, as many different healthcare professions view autonomy differently. Choosing to protect the patient jeopardizes the doctor-patient relationship but choosing to respect the autonomy and ensure informed consent could jeopardize the patient's health. With the nocebo effect any choice made leads to a series of "what-ifs," there is no definite lineup of what to expect and it varies from patient to patient, doctor to doctor.

To follow a patient's beliefs, wishes, and values, the patient must first know what they are. Deciding who one is and how one wants to live their life stems from being an autonomous individual, as autonomy makes morality possible (Gillon, 2003). This doesn't just apply to patients, but all professionals in the healthcare field. While paternalism was once the standard of care there is a reason it isn't anymore. There is a reason nonmaleficence, beneficence, and justice aren't the only principles of bioethics. Respect for autonomy is something that hasn't always been seen, not just in the medical field but everywhere in the world. If a person can make their own medical decisions while being provided with the necessary information, it helps them to grow and develop as autonomous decision-makers in every aspect of their life. Their autonomous decision may be a request for nondisclosure, it may be a request for full disclosure, or it may be undecided as they wish to ponder their values a while longer; whatever the decision, all healthcare providers have a duty to respect it.

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