# **The Healthcare System of Strangers:**

# A Feminist Ethics of Care Correction to Autonomy in Western Healthcare

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To my friends and family, thank you for your love and listening throughout this project. I am forever grateful for you.

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#### INTRODUCTION

When I decided to dedicate the majority of my undergraduate studies to philosophy while still pursuing a career in healthcare, one of the first questions someone asked me was: "What do you plan to do... argue your way into dental school?" Although this was the first of the *many* questions or comments of concern directed at me regarding my choice of studies, it has nevertheless stuck with me. I thought about this question as I sat in my Values of Social Services and Healthcare philosophy class. I thought about it as I had conversations with my dentist about patient relationships and medical ethics; she encountered serious ethical dilemmas almost as much as she encountered a broken tooth. And I certainly thought about it as I have lived through the global COVID-19 pandemic for the last two years of my undergraduate experience.

With every news story, tweet, article, or research study published, I never stopped thinking to myself "How could philosophy *not* apply to everything happening in the world right now?" How could it *not* apply to healthcare or public health? How do people *not* see this?" In 2020, when I opened the *NY Times* it was likely that next to an article discussing COVID-19's bio-chemical impact in the human body, there was an article talking about peoples' pushback against lockdowns. In 2021, next to an article discussing the success of Pfizer and Moderna vaccines, there was an op-ed exploring why someone would refuse to follow the CDC-recommended mask mandates. In 2022, beside a graph illustrating the difference in hospitalizations for triple vaccinated and unvaccinated patients, there was likely a poll on why people choose not to get vaccinated or boosted despite the Department of Public Health's recommendation. All of this to say: philosophy, and specifically ethics, pervades our everyday lives. In the past two years, whether we are aware of it or not, philosophy, and specifically ethics, has been the topic of discussion right alongside the science of the pandemic.

Of all the ethical concerns of this pandemic, the one that has interested me the most is the one of autonomy. Are we truly autonomous, in the classical sense, when it comes to making health decisions that do not just impact ourselves? Although we may disagree with one's decision to not wear a mask or get vaccinated, how do we come to understand how they arrived at that autonomous decision? How does autonomy factor into all of the ethical debates we have watched, listened to, read, and participated in throughout this pandemic?

For the sake of personal curiosity, as well as for further contribution to the intersecting fields of philosophy and medicine, I chose to explore the role of autonomy in the Western healthcare system, specifically the United States, for this project. In this essay, I will argue that the notion of relational autonomy provides a more helpful lens than that of classical autonomy as an approach to healthcare ethics. I will begin in § I with an historical overview of autonomy; where did this term come from in the philosophical tradition? How did it develop from the ancient Greeks to modern day philosophers? In § II I will present how autonomy operates in medical ethics and bioethics, as well as in modern healthcare settings. My § III consists of three main aims: a recount of feminist ethics of care and its history, the introduction of relational autonomy in ethics and healthcare, and an argument for why relational autonomy in healthcare is a better alternative to classical autonomy. Finally, in § IV I discuss relational autonomy's corrections to the shortcomings of classical autonomy in Western medicine, especially with regard to the many health care injustices faced by marginalized communities across the United States. I will conclude with an overview of why this topic is so important to conversations today.

I

If you are too weak to give yourselves your own law, then a tyrant shall lay his yoke upon you and say:

"Obey! Clench your teeth and obey!"

And all good and evil shall be drowned in obedience to him.<sup>1</sup>

#### A HISTORY OF CLASSICAL AUTONOMY AND HOW WE UNDERSTAND IT

It is unclear whether we truly know today what it means to be autonomous, or what autonomy truly is. At its roots, autonomy derives its meaning from the Greek language; "auto" comes from "self", whereas "nomos" translates roughly to "law." Autonomy, as classically understood and defined, means self-rule. An autonomous individual is someone who makes decisions in accordance with their own will. The basis of autonomy translates to individuals making decisions for themselves, rather than some external being or power making the decision for them.

Ancient Greek philosophers and the birth of reason

Autonomy finds its main principles, like many and most of our philosophical understandings, from ancient Greece. The term "autonomy" is rarely, if ever, directly used in the works of Plato, Aristotle, and other Stoics. The ancient Greeks are in no way credited with introducing autonomy into philosophy. But, they *are* responsible for our emphasis on reason. Our understanding of autonomy would not be possible without our understanding of reason.

Therefore, I see it evident that autonomy's meaning is derived from much of Ancient Greek thought and is used as the basis of Enlightenment and Renaissance thinking.

<sup>&</sup>lt;sup>1</sup> Quote by Frederick Nietzsche, https://www.inspiringquotes.us/author/5088-friedrich-nietzsche/about-autonomy.

For the ancient Greek thinkers, the life of reason and rationality is the best life to live. In Plato's *Republic*, Socrates emphasizes that the most essential part of the soul is the rational part; that which deeply thinks and makes choices regarding one's body and life. It was Socrates' philosophy that declared that the nature of justice is health, fine condition, and well-being of the soul. The human soul is made up of wisdom (rationality), courage (spirit aiding rationality), and moderation (harmony among spirit and rationality). A soul is healthy when all parts of the soul are doing their own and proper work; life is not worth living when the soul is ruined. For example, a healthy body feels good, yet a sick body does not feel good because some part is not doing its proper work. If one lived with a sick soul, they would never be happy.

Our understanding of autonomy today has hints of this philosophy present. Autonomy places a large emphasis on leaning into human rationality and leading ones' own life. It follows that for Plato and Socrates, the best life is that in which *eros*, or love, is directed to the truth. It is a life in which a human caters to the wellbeing of their soul by being rational, courageous, and moderate. They make decisions in accordance with a balance to the individual parts of their own soul. By doing so, all of their other virtues fall into place.

Aristotle proposes that the function of human beings is to reason, and happiness is a rational activity of the soul in accordance with virtue (*Nicomachean Ethics*). In addition to this, he also argues that the most excellent person is the one who is the most self-sufficient (*Nicomachean Ethics* 9.9). This belief has rich hints of individual autonomy. Individual autonomy is, as argued though disputable, unique to the nature of human beings. The ancient Greek emphasis on using human reason and the power of our rational thought is what paved the way for Enlightenment and Renaissance thinkers to create and develop the notion of autonomy.

### Kant & autonomy

One of the central Enlightenment thinkers and a well-known German philosopher, Immanuel Kant, made major contributions to the work of metaphysics, epistemology, ethics, political philosophy, and aesthetics. During his time, ethical theories were traditionally grounded in the natural law tradition; an action is wrong, or immoral, because it goes against God's command. One desires to act morally because it is pleasing to God or in order to avoid God's punishment. Kant believed that in the natural law tradition, morality was simply a matter of self-interest. Yet, morality encompasses so much more than that. Kant also wanted to recognize each persons' ability to think rightly for themselves. Therefore, unsatisfied with the moral law tradition of his time, and greatly inspired by philosopher Jean-Jacques Rousseau, Kant set out to craft a new understanding of morality that drew upon the greatness of human capacities.

Rousseau argued that everyone must have the capacity for self-governing moral agency.<sup>2</sup> This capacity gives people human value and dignity and establishes that all people are equal. From this presupposition, Kant then argues that all human beings should have in them the innate possibility to figure out on their own what the right thing to do is; human beings should dictate to themselves their own law. Far from being enchained by personal appetites and desires, this lawgiving leads to our own freedom. The freedom to dictate one's law—rooted in practical reason—unto oneself is the root behind Kant's notion of autonomy. With hints of ancient Greek philosophy present, Kant declares, "Autonomy... is the property the will has of being a law unto itself (independently of every property belonging to the objects of volition)" (Kant 108). In other words, the autonomous individual acts in accordance with their self-chosen plan as directed by

<sup>&</sup>lt;sup>2</sup> For further reading on Rousseau, please see Christopher Bertram's, "Jean Jacques Rousseau" in *The Stanford Encyclopedia of Philosophy*.

reason (Dickenson and Parker). An individual and the choices derived from their very will shall be uninterrupted from the influence of external desires and authority.

For Kant, autonomy is closely connected to morality, and the Categorical Imperative is the supreme principle of morality: insofar as one acts according to the Categorical Imperative, one is acting autonomously. A categorical imperative, as opposed to a hypothetical imperative, is a formulation in which one "ought to" do something for the sake of that thing in and of itself, rather than to want or "ought to" do something for a given desire or as a means to an end. It is from this view that autonomy becomes connected to morality. Kant argues that an action is morally permissible if it is consistent with practical reason, or the Categorical Imperative: because the Categorical Imperative originates in our own reason, we are acting according to a law we give ourselves (auto-nomos). Kant has several formulations of the categorical imperative, and the most famous of these states that one must act so that "the maxim of your action were to become, through your will, a universal law of nature" (Kant 24).

How Kant derives the Categorical Imperative and develops a system of ethics from it is quite complex and beyond the scope of this paper. What is relevant concerns the centrality of autonomy in his ethics: the decision to perform morally right actions, or to be a moral individual, rests solely and firmly within the individual. According to Kant, it is through our intrinsic human ability to reason that we are autonomous; we are to make our own decisions and will that which we tell ourselves to. An autonomous will is determined neither by the desires of the agent nor the desires of others (Stoljar 12).

# Mill & autonomy

Branching from Kant's development of autonomy, John Stuart Mill focuses on a similar, yet still unique, notion of autonomy. Where Kant focuses on the morality of autonomy, Mill

emphasizes a naturalistic account of autonomy in human behavior and action. He primarily develops this throughout his piece, *On Liberty*. Autonomy, liberty, and independence are all central ideas in Mill's work on what constitutes human excellence. Our focus, specifically, is on Mill's understanding of autonomy.

Similar to the Ancient Greek thinkers, Mill hardly, if ever, uses the word autonomy in his works. Yet, he argues that fostering individuality is essential to ownership and development of the human self. To do otherwise is a waste of human dignity and worth. He writes, "He who lets the world, or his own portion of it, choose his plan of life for him, has no need of any other faculty than the ape-like one of limitation. He who chooses his plan for himself, employs all his faculties" (Mill 55). More eloquently, he proclaims that humans are not machines to be built from a model or instruction manual, but rather, they are like trees that grow and develop independently of all others, or "according to the tendency of the inward forces which make it a living thing" (Mill 55).

Human persons can only act according to their own will and desires in a society where they are protected from the tyranny of the majority. It follows that humans are solely autonomous in a free society where they can develop as "persons of individuality and character" (O'Neill 31). Autonomy requires that one owns their beliefs, desires, and actions; one does not choose an action based on what they desire in a moment in time, but rather based on "the expression of [their] own nature" (Mill 56). It is through this that an individual is autonomous not on the basis that they do what they want, when they want, and how they want, but rather, they act and carry themselves with a great degree of self-knowledge, control, and deep personal understanding.

A society that exists to support and allow for individuality is a society that Mill proposes as ideal. Individuality in the sense that "no person is an entirely isolated being" (74), but

individuality that allows each person to be free to develop their own way. This is arguably the society of the Western world today, with a caveat to our understanding that humans aren't atomistic beings. We have taken Mill's individuality as autonomy, where individuals act according to their own wills, protected from the influence of the masses, and conflated it with Kant's moral autonomy, which treats individuals as non-relational, independent entities.

Autonomy in modern day social settings

Over time, our understanding of autonomy has become highly individualized. To be independent and solely reliant on the self has become gradually romanticized to the point that we see more value in striving toward our own fulfillment and development, rather than being open to fulfilling the development and needs of all persons. A particularly Western ideal, autonomy in social settings (outside of theoretical armchair philosophy) is no longer fully understood to be one's own person, but to think only of oneself.

Perhaps no one vocalizes this idea of radical individuality and autonomy better than Ralph Waldo Emerson, a 20th century American essayist who for some is considered the "ultimate guru of autonomy" due to his contributions to the philosophical movement of his time (Zehner). Emerson's focuses on morality, autonomy, self-reliance, and nonconformity are deeply embedded in the "American" way of life. Specifically, he adds to how our modern understandings of autonomy in health care are flawed. In "Self-Reliance," Emerson claims that:

Society everywhere is in conspiracy against the manhood of every one of its members... in which the members agree, for the better securing of his bread to each shareholder, to surrender the liberty and culture of the eater. The virtue in most requests is conformity. Self-reliance is its aversion.

While Emerson is not oblivious to the fact that individuals are obligated to inhabit a social world, he nevertheless sees no reason for such individuals to surrender their self-governance— to ever abide by another's' beliefs or values— at the sake of their own desires or needs; their "life is for itself".

Emerson's self-reliance is heavily influenced by Kant's moral philosophy. He believes that "self-reliant" individuals should act according to their own wills and to trust and follow their own beliefs and values. It is to his understanding that men who live by conforming to the needs, desires, or thoughts of others in society dishonor the sacredness of "the integrity of [their] own mind". Rather, to not conform— to "act singly"— is to be the autonomous man that God willed. To Emerson, our autonomy, our actions, and our freedom to live our own lives according to our own will is inalienable. To men, it is natural. To Americans, it is crucial. To me, it is flawed.

The patient's autonomy always, always should be respected, even if it is absolutely contrary the decision is contrary to best medical advice and what the physician wants.<sup>3</sup>

### AUTONOMY IN MEDICAL ETHICS AND HEALTHCARE

In a country that prides itself on freedom, liberty, and individualism, our flawed understanding of autonomy pervades almost every sphere of our lives. It is practically inescapable. At the end of the 20th century, departing from solely the sphere of morality, autonomy began to be frequently found in bioethics. A rapid increase in technological advancement in the field of science consequently led to an increase in ethical concerns, specifically ones regarding the rights and abilities of the individual. As a result, the significance of autonomy is prevalent in a vast amount of bioethical concerns today: genetic engineering, assisted reproduction technology, abortion, cloning, death and dying, and patient-provider relationships. While its role in the conversation and implications of all bioethical topics is important, I will focus solely on autonomy in medical ethics and health care delivery for the sake of this project.

The introduction of autonomy into medical ethics

Along with nonmaleficence, benevolence, and justice, autonomy is one of the four central pillars of biomedical ethics (Beauchamp & Childress). However, that was not always the case. In the American Medical Association's 1847 Code of Medical Ethics, it states that it is "a sacred duty" of medical providers to "avoid all things which have a tendency to discourage the patient

<sup>&</sup>lt;sup>3</sup> Jack Kevorkian,

https://quotefancy.com/quote/1271263/Jack-Kevorkian-The-patient-s-autonomy-always-always-s hould-be-respected-even-if-it-is.

and to depress his spirits" ("Code of Medical Ethics of the American Medical Association"). In other words, medical providers were encouraged to act in a way that *they* thought was best for the patient, rather than what the patient might believe to be best. If it was discovered that a patient had cancer, for example, then it was acceptable for the doctor to decide whether to tell the patient the diagnosis or not. Paternalism, or behavior regardless of the will of the other person, was often the norm. With Kantian morality in mind, autonomy was introduced as the alternative to heteronomy, or paternalism, in biomedical ethics.<sup>4</sup>

In a 19th century society where respect for individuals was being violated in the realm of healthcare, where historically marginalized groups were experiencing further instances of oppression regarding their health, <sup>5</sup> and where totalitarian practices were becoming more common in the United States, a recognition of autonomy was critical. There was a significant pull towards the philosophies of Kant and Emerson that emphasized individual rights and dignity. Therefore, seeing a high value in placing respect for the individual patient, the World Medical Association released the 1964 Declaration of Helsinki more than a century after the 1847 Code of Medical Ethics. This was a major turning point in medical ethics. Rather than the physician using paternalistic practices to determine what was best for their patients, it became a duty "to protect the life, health, dignity, integrity, [and] right to self-determination" of patients, as well as "to promote and safeguard [their] health, well-being and rights" ("Declaration of Helsinki 1964").

The language of "right to self-determination" clearly speaks to our modern understanding of

<sup>&</sup>lt;sup>4</sup> "Western medicine long operated in a Hippocratic tradition, the chief principle of which suggests that the role of the doctor is to 'use his or her judgment to try to benefit the patient and protect the patient from harm'... medicine in the twentieth century left the Hippocratic tradition behind and sought a new principle that might avoid the pitfall of paternalism... [i.e] personal autonomy" (Genuis).

<sup>&</sup>lt;sup>5</sup> Although healthcare injustices and oppression will be discussed at large later in this work, see Evelynn Hammonds' and Susan Reverby's "Toward a Historically Informed Analysis of Racial Health Disparities Since 1619".

autonomy. This important change in ethics as outlined in the Declaration of Helsinki took the focus away from the physician and onto the patient. It puts the patient in charge of making their own choices regarding their own body and health. There began to form a significant emphasis on the value of not only a patient's individual choice, but the patient's will to make an informed decision in the first place. In theory, it discarded general heteronomous practices and leaned deeper into the value placed on liberty, individuality, and rights in American society. Arguably, it has been successful in doing just that.

What autonomy looks like in healthcare delivery

Autonomy eventually made its way from the philosopher's armchair to the patient's chair. Thomas Beuchamp and James Childress, two medical ethicists who are best known for their work, *Principles of Biomedical Ethics*, are largely responsible for this development. Highly read in medical and dental schools by future healthcare professions all across the country, Beuchamp and Childress highlight autonomy as one of the main pillars of bioethics;

We start with what we take to be essential to personal autonomy, as distinguished from political self-rule: personal rule of the self that is free from both controlling influences by others and from personal limitations that prevent meaningful choice, such as inadequate understanding. The autonomous individual freely acts in accordance with a self chosen plan... A person of diminished autonomy, by contrast, is in at least some respect controlled by others, or incapable of deliberating or acting on the basis of his or her desires or plans. (121)

Simply put, an autonomous individual makes their own decisions while a heteronomous individual has others make decisions for them. In the examination room today, autonomy looks like a doctor informing the patient what treatment options are available to them, providing a

recommendation, and then acting only with the consent of the patient. The patient actively makes the choice between "yes" or "no" rather than the doctor or anyone else making the decision for them. In essence, our emphasis on respect for patient autonomy is seen not only as morally desirable in healthcare delivery, but also encouraged and nurtured. Based on your own experiences in a healthcare setting, you may recall moments in which you have actively chosen to pursue one treatment plan over another. You may be able to specifically pinpoint a moment in time when your autonomy was being recognized and acted upon. It could have been telling your dentist you do not want a full denture but a bridge instead. Or, it was signing an informed consent form before receiving immunizations at your annual primary care checkup. Autonomy, or more specifically autonomous actions, in healthcare can be as simple as these examples. It can also be far more complex. To recognize and respect individual autonomy in health care is not always as simple as hearing a "yes" or "no" from your patient, or having them give consent to treatment. What happens when abiding by one patients' autonomy inhibits the autonomy of those around them? What about when a decision is more than just a "yes" or "no"? What if there are other outside factors at play that must be considered? In dilemmas such as these, case studies serve as helpful stories that highlight real dilemmas in which individual autonomy comes into question.

#### Peter Noll<sup>6</sup>

Peter Noll was 56-years-old when he was diagnosed with urothelial carcinoma (bladder cancer). Research to date revealed to Peter that through proper treatment—radiation and surgery—death was highly likely to be prevented. His medical professional who found the cancer presented him with his treatment options, encouraged him to seek further medical

<sup>&</sup>lt;sup>6</sup> To see the full case study story of Peter Noll, refer to Chapter 9 of Donna Dickenson's, Richard Huxtable's, and Michael Parker's, *The Cambridge Medical Ethics Workbook*".

attention, provided him the odds of survival, and laid out the likely side-effects and/or altercations to his way of life. Peter declines any and all treatment; in his book, *In the Face of Death*, he specifically states:

I don't want to get sucked into the surgical-urological-radiological machinery because I would lose my liberty bit by bit. With hopes getting more and more reduced my will would be broken and in the end I will end up in the well-known dying chamber, [to] which everybody tends to give a wide berth— the outer office of the cemetery.

(Dickenson and Parker 192)

With the knowledge that surgery and radiation are not 100% successful at removing the cancer, that he will need a catheter post-surgery, that he will no longer be able to have sexual intercourse, and that he has a 50% chance of relapse, Peter found more comfort in denying treatment and seeking "certainty about [his] death instead of a mere statistical possibility of death or surival" (Dickenson and Parker 193). A painful and lonely year later, and after planning his own funeral,

Peter Noll passed away.

The case of Peter Noll is an example of the radical exercise of individual autonomy. Although given advice and options from his medical professionals on treatments to prevent death from this disease, Peter makes the choice to pursue his own self-given path of "self-controlled dying" (Dickenson and Parker 193). In Peter's perspective, his right to refuse treatment is a decision of his own that impacts only himself. Neither his doctors, family, or friends can take that decision away from him because in doing so they strip him of his autonomy. Peter's case is not simply a matter of refusing an immunization, choosing one medication over another, or consenting to anesthesia or not for a wisdom tooth removal. His decision is a matter of life or death. It is cases such as Peter's that are not only more frequent than we would like to think, but

that allow us to see how truly complex the principle of autonomy is in healthcare. "Noll argues that personal autonomy and patient choice ought to be the guiding principles in medical ethics", and his medical professionals have to abide by that (Dickenson and Parker 194). I do not aim to argue that Peter should not have had the choice to make his own medically-informed decision regarding cancer treatment, but perhaps something is missing from both Peter's reasoning in making the decision and how his physicians presented his options in the first place.

## A Father's Kidney<sup>7</sup>

John is a middle-aged man whose daughter suffers from kidney failure. After spending three out of the seven days of her week hooked up to a dialysis machine for six-hours a day, John's daughter and his entire family were becoming more physically and emotionally miserable. His daughter has already had one attempted kidney transplant in the past, yet it failed due to her body rejecting it. Not wanting to spend her life attached to a machine, John's daughter and her medical professionals sought another suitable donor for a second kidney transplant. John was a suitable donor, but after being made aware of this in private by the doctors, he refused to donate his kidney to his daughter on the basis that the transplant success is unknown and he does not know what medical complications he would face post-surgery. When his daughter's physician told him that she cannot lie to his family about his compatibility, John agreed to the transplant out of fear of how his family would react if they knew he refused.

In this case, both John and John's daughter are patients. While John's daughter is actively undergoing treatment, John has the choice to engage in a kidney transplant or not. In initially making the private choice to not donate his kidney to his daughter, John exemplifies not only the

<sup>&</sup>lt;sup>7</sup> For the full story, see *The Patient in the Family: An Ethics of Medicine and Families* by Hilde Lindemann Nelson and James Lindemann Nelson.

<sup>&</sup>lt;sup>8</sup> Perhaps it is important to note that kidney transplant surgeries are medically reported to be minimally invasive and include minimal complications.

"individualistic values which underlie patient-centered medicine", but also "modern medicine's overriding focus on the benefit of the individual patient" (Dickenson and Parker 208). According to our healthcare system's principles of bioethics, there was nothing ethically wrong with John's initial decision. Although he was acting autonomously both in initially saying no and then agreeing to the transplant, something does not sit right with his initial decision; the physician was aware of this and therefore refused to lie to the family about John's compatibility. As taught and emphasized in Western healthcare, John's initial decision was truly autonomous in the individualistic sense: he was the "author of his own life" (Raz 369). Therefore there was nothing medically nor ethically wrong. Yet, clearly some other factor was at place that pulled John in the direction of donating his kidney. What might that be, and does our understanding of autonomy encompass it?

#### **Paulina**

Paulina is a young, single, Puerto Rican mother who lives in the Southwest side of Syracuse. Nervous and overwhelmed, Paulina arrived at the Syracuse Amaus Dental Clinic one early April morning with swelling and pain in her mouth. Through her broken English and tears, she confessed that she was in extreme pain and unable to eat solid foods. Living on food stamps and a diet that consisted mostly of processed, carbohydrate-rich foods, Paulina's teeth were covered almost completely in cavities. Within two hours of arriving at the clinic that day, the doctors told Paulina what they could do, had her sign an informed consent sheet, and proceeded to pull most of her teeth that were no longer salvageable, leaving very few treated teeth that would remain only if they were properly cared for. Bloody gauze and pain medication in hand, Paulina was sent on her way.

Paulina's story is not a unique one. With a significant portion of the United States population without dental insurance or consistent access to professional dental care, pop-up

dental clinics experience high patient turnover on a regular basis. Neither the front desk workers, dental assistants, nor dentists had ever seen Paulina in her life. Nevertheless, they were able to provide her with immediate/emergency dental care that day to help ease the excruciating pain she had been experiencing. Although Paulina spoke little English, her English-speaking dental professionals that day were able to relay the necessary information regarding treatment to her. By agreeing to receive the treatment, or by signing an informed consent form, Paulina seemingly acted autonomously. No one at the clinic made the treatment decisions for her. Paulina checked "yes"; she exercised her right as a patient to make a decision about her dental care without the dentist telling her what she *has* to do. In a positive light, it is great that Paulina received treatment that day and some of her pain was relieved. It is great that the dentists did everything in their capability to treat Paulina. And it is great that Paulina knowingly consented to the treatment in the first place. In a different light, however, something may be missing from this entire medical encounter. Perhaps something is missing from all of the above case studies.

## Ш

Yet in the different voice of women lies the truth of an ethic of care, the tie between relationship and responsibility, and the origins of aggression in the failure of connection.9

# RELATIONAL AUTONOMY: ITS IMPORTANCE TO MEDICAL ETHICS AND HEALTHCARE

As highlighted in the above sections, the way autonomy is understood can vary greatly. In general, it is understood that autonomy is tightly linked to qualities of self-rule, self-determination, freedom, individuality, and independence. The above cases show that not only are these traits impossible to completely obtain in reality, but they are also not desirable. I believe there is no such thing as an autonomous self-made individual. On the contrary, we live in a society of vulnerable individuals who need one another to thrive and survive. It is my understanding that the basis of our healthcare system forgets this. Healthcare forgot this when Peter Noll made the decision to decline treatment without a care for how it would affect his friends and family. It forgot this when John's medical decision conflicted with familial ties and morals. And it forgot this when Paulina was sent on her way loaded up on pain medication that one April afternoon without one dentist there knowing anything about Paulina's life, community, or responsibilities.

I propose that a feminsist ethics of care approach, specifically relational autonomy, is desperately needed in our healthcare system instead. Relational autonomy denies the possibility of total self-sufficiency. It reinforces social relationships and socio-historical circumstances. It

<sup>&</sup>lt;sup>9</sup> Carol Gilligan, *In a Different Voice*, Chapter 6.

halts the unattractive ideals of Western autonomous personhood. It recognizes our sense of community and ethos of care for one another. Relational autonomy is the response to a cry of help that our healthcare system desperately needs.

What is feminist ethics of care?

Although accepted by many, the notion of autonomy came to be under scrutiny in the 20<sup>th</sup> century. Contrary to Kant's, Mill's, and Emerson's individualistic conceptions of autonomy, feminist thinkers began to argue that people do not exist individually and in abstraction. Rather, people exist in society in relation to one another. No decision, act, or way of life is utterly atomistic when we survive in community with others, in families, or in relationships. Therefore, our understanding of autonomy needs to be in tune with that. Feminist ethics aims to do that, first laying the groundwork by addressing the role of gender in philosophy:

The point of feminist ethics is, ideally, to change ethics for the better by improving ethical theorizing and offering better approaches to issues including those involving gender. Feminist ethics is not limited to gendered issues because the insights of feminist ethics are often applicable to analyses of moral experiences that share features with gendered issues or that reflect the intersection of gender with other bases of oppression. Feminist philosophical endeavors include bringing investigations motivated by feminist ethics to bear on ethical issues, broadly conceived. (Norlock)

Although born from addressing gender disparities in morality and ethics, feminist ethics has grown to re-think entirely how we understand our traditional notions of ethics. By attaching feminism to ethics, we not only see how the lived experiences of women differ from those of men, but we also address the intersectionality of ethics. Feminist ethics pays attention to all different identities and perspectives. In doing so, it addresses how power operates in philosophy,

society, and nature, and how we can, as a result, understand and combat the various resulting oppressions. In recognizing how our traditional, patriarchal conceptions do not grasp the reality of the lived experiences of many, feminist ethics is not merely a branch of ethics, but is instead 'a way of *doing* ethics'" (Norlock).

## **History of feminist ethics**

Feminist ethics gained traction in the field of philosophy in the later half of the 1900s. While philosophy may or may not have attempted to address questions of gender before then, the philosophers doing so nevertheless were addressing a primarily male audience in a patriarchal society. Feminist philosophers recognize that "[rarely] in the history of philosophy will one find philosophical works that notice gender in order to criticize and correct men's historical privileges or to disrupt the social orders and practices that subordinate groups on gendered dimensions" (Norlock). But more than that, feminist ethics is a way of doing philosophy that sees that social order and behavior is not only gendered, but depends on race, sexuality, disability, and much more.

Simone de Beauvoir, a French philosopher, intellecutal, and activist, focussed on feminist themes in her work.<sup>11</sup> While her work is not directly tied to autonomy— and for the sake of this project, medical ethics— she argues that philosophy, in general, and our understanding of human behavior is premised on patriarchal systems. Therefore, if we are to speculate and philosophize about women and all others' place and behavior in society, then we need to expand our circle of thought. Her philosophy, "that *woman* has been defined by men and in men's terms, [and] that

<sup>&</sup>lt;sup>10</sup> Not only was there little to no work done by female philosophers by the 1960s and 70s, but there was "the historical sexism of Western culture... A woman could be a philosopher only if she 'thought like a man'". For further reading, see "philosophical feminism", <a href="https://www.britannica.com/topic/philosophical-feminism">https://www.britannica.com/topic/philosophical-feminism</a>.

<sup>&</sup>lt;sup>11</sup> For further reading on Simone de Beauvoir, please see "Simone de Beauvoir (1908-1986)", <a href="https://iep.utm.edu/beauvoir/">https://iep.utm.edu/beauvoir/</a>.

ethical theory must attend to women's social situation and their capacity to be moral decision-makers," is crucial to feminist conceptions of autonomy (Norlock).

Hints of Beauvoir are nevertheless present in the works of Susan Sherwin. Sherwin is a leading Canadian feminist philosopher who has helped bride the gap between feminist philosophy and bioethics (Sherwin, *Feminst and Medical Ethics*). According to Sherwin, feminist ethics is an analysis of unequal power dynamics: "it awknowledges the social roots of a person as a being who develops within a specific social context and who is, to a significant degree, a product of that context" (Sherwin, *Feminist Persepctives in Medical Ethics* 23). Sherwin took much inspiration from the work of Carol Gilligan, <sup>12</sup> who saw that "mainstream ethical theory has been carried on in a voice that is overwhelmingly masculine—the voices of women have been largely excluded or ignored" (Sherwin, *Feminist Persepctives in Medical Ethics* 18). If we take that to be true, as I aim to do, then clearly our traditional understanding of ethics needs to re-evaluated accordingly. If, unlike the traditional experience of a man, women and others in society have a lived experience that depends upon their relations with others, as well as their duties to their families and communities, then classical ethics, specifically autonomy, fails to encompass this dependence.

Susan Sherwin's work highlights that feminist ethics often corrects "distortions within mainstream bioethics that occur when insufficient attention is paid to the role of gender in the analysis offered" (Sherwin, *Principles of Health Care Ethics* 79). This is not to say that gender should be the sole basis of analysis when it comes to ethics. Rather, it is to say that looking at the

https://www.qcc.cuny.edu/socialsciences/ppecorino/ethics\_text/Chapter\_12\_Feminism/What\_is\_it.htm.

<sup>&</sup>lt;sup>12</sup> Although outside the scope of this paper, Gilligan's contributions to feminist theory are significant and of interest. For further reading, please see Chapter 12.1, "Feminism: What is it?" in Philip A. Pecorino's "Ethics", https://www.gcc.cuny.edu/socialsciences/ppecorino/ethics\_text/Chapter\_12\_Feminism/What\_is

relationship between gender and ethics may propose a correction to the patriarchal way in which we have come to understand ethics and morality. In other words, "traditional ethics focuses on questions and methods that are of particular concern to men (interactions that occur among strangers within the public sphere) and it neglects or trivializes questions and methods that are typically associated with women (relations within the private sphere such as families and communities)" (Sherwin, *Principles of Health Care Ethics* 80). Gender is one way (of many) that corrects how we understand ethics. With gender being one correction to traditional ethics, it is to my understanding that Sherwin's feminist ethics also focuses on questions and methods that are associated with varying sexual orientations, races, ethnicities, and abilities. Through using gender as a starting point and expanding to other aspects of identity, feminist ethics is arguably a more inclusive way of doing ethics.

Feminist ethics of care does not operate in abstraction. It instead grasps the reality of one's need to balance their relationships and responsibilities to oneself and others. This way of doing ethics is one that centers our concern and response to fellow human needs. It is one that more realistically portrays human life as collective rather than individual. Feminist ethics of care, as introduced by Sherwin, opens the conversation to relational autonomy.

What is relational autonomy?

Relational autonomy, a feminist approach to ethics and autonomy, is arguably a better understanding of autonomy than the classical interpretations in ethics. Simply defined:

'Relational autonomy' is the label that has been given to an alternative conception of what it means to be a free, self-governing agent who is also socially constituted and who

<sup>&</sup>lt;sup>13</sup> Sherwin writes, "Most believe that we must attend to the complex ways in which gender interacts with other aspects of social injustice—particularly those based on race, sexual orientation, age, socioeconomic class and disability— and that we must work to promote social equality in all areas" ("Feminist Approaches to Health Care Ethics" 79).

possibly defines her basic value commitments in terms of interpersonal relation and mutual dependencies. Relational views of the autonomous person, then, valuably underscore the social embeddedness of selves while not forsaking the basic value commitments of (for the most part, liberal) justice. (Christman 143)

Classical autonomy, in theory, can call upon the unalienable human dignity of all persons. Yet, in practice, it falls short of reality. If we truly understand autonomy to be the will to self-govern, or for an autonomous person to be the author of their own life, then how does that correlate with the idea that the actions one wills do not only depend upon, but also directly impact, those who one lives in society with? Just as we are free, self-governing persons, we are also social creatures. Radically individualistic notions of autonomy which have been accepted as the norm in American society and much of Western philosophy, are a false depiction of the reality in which we live. Alternatively, relational autonomy acknowledges the inherent freedoms of individuals to govern their life, and also recognizes how their actions impact and *are* impacted by others.

Relational autonomy derives from feminist ethics because it corrects the patriachal lens— a lens that fails to grasp that all people, including men, are relational beings— to include what being autonomous realistically looks like for others in society. Most people cannot make autonomous decisions or act in one moment in time impacting others. We have people that we not only depend upon but also that depend on us. Therefore, if, "an ethics of action is incomplete when evaluation is done in abstraction from the relationship holding between the participants performing them and those affected by them", then "it is clear that the relationships studied in ethics must attend to the interdependent, emotionally varied, unequal relationships that shape our lives" (Sherwin, *Feminist Persepctives in Medical Ethics* 21).

On that note, relational autonomy does not require self-sufficiency. If anything, it requires the opposite. This view of autonomy encourages us to realize that relationships with and among others are both significant and necessary for a good life and fully functioning society. Therefore, relationships ought to be considered when understanding ethics, and specifically when trying to understand what it means to be autonomous. The more traditional Kantian and Millian accounts of ethics and autonomy are atomistic. In other words, they are:

Abstracted from the social relations in which actual agents are embedded. Such a conception of the self is associated with the claim that autonomous agents are, and ought to be, self-sufficient, which in turn is associated with the character ideal of the 'self-made man'. (Stoljar, "Feminist Persepctives on Autonomy")

I hope that it is apparent that this total self-sufficiency is *anything but* what we experience in our daily lives. Our relationships and responsibilities to others should therefore be taken into account when we attempt to create the ethical frameworks that *do* impact our lives.

Why relational autonomy in healthcare opposed to classical autonomy?

The very notion of classical autonomy is born from a misguided patriarchy; <sup>14</sup> the lived experience of the privileged men who first framed the notion of classical autonomy greatly differs from the realistic and non-individualistic human experience for most people. As a result, to take the classical notion of autonomy as true, then we consequently deny that very autonomy to women and all others; "If autonomy is somehow conceived as inimical to being a woman—because, for example, being a woman involves valuing social relationships of care whereas being autonomous devalues such relationships—one denies women, in particular, the social and political advantages associated with the label "autonomous" ("Feminist").

<sup>&</sup>lt;sup>14</sup> For further reading, see *Stanford Encyclopedia of Philosophy* "Feminist Perspectives on Autonomy".

Perspectives on Autonomy"). For example, a single, lower-middle class, Black mother with three infant children simply does not have the luxury to live her life through actions that only account for her own wellbeing or lack any concern or responsibility to others. Rather than living in a vacuum, relational autonomy recognizes that gender, race, class, sexual orientation, age, disability, and marital status can all impact a patients' autonomy (Sherwin, *Readings in Health Care Ethics* 16). This is especially true when we consider the role that autonomy plays in healthcare and medical ethics.

More than its damaging impacts to healthcare and medical ethics, classical autonomy is also not a universal possibility even if we wanted it to be. To act autonomously, in classical terms, is premised on an assumption that we live in an equal society where everyone has the choice to act in a way that is unconcerned with how our actions affect others. Relational autonomy accounts for a more realistic picture of the unequal society in which we live:

One of the reasons that relational autonomy theory may have had traction in disciplines beyond philosophy is that it rejects the methodological individualism that is the default paradigm in philosophy. "Methodological individualism" is the assumption that facts about the social world, and explanations of social phenomena, are ultimately reducible to facts about individuals, such as their intentions, goals, beliefs, and desires. (Mackenzie)

In other words, our reality cannot be reduced to the experience of the atomistic individual. The idea that any individual—regardless of gender, social class, sexuality, or race—can achieve the radical individualism that is highly acclaimed in philosophy and the American rhetoric is a myth. Although it may seem desirable, all individuals (especially those who identify as women) have responsibilities that fall outside of themselves. Therefore, our social reality is composed of more than solely actions and desires that can be reduced to the individual.

Even if one does believe that society can be reduced to individuals, there still exists a problem for those who cannot act autonomously in the first place. The Western notion of autonomy in healthcare implies a complete, unconstrained freedom of choice, especially when it comes to patient-provider relationships. I believe that a healthcare system premised on this value of autonomy is, and will continue to be, a healthcare system of disconnected individuals; it misrepresents the nature of personal relationships. The emphasis on "independence and self-sufficiency in Western [medicine] makes it difficult for people to see the value of connectedness, dependence, and the like" (Schermer 151). Although respect for patient autonomy is displayed in informed consent, respect for the patient, and patient choice, there fails to exist a practice that recognizes the factors that are present when making decisions in the first place. A patient can check "yes" or "no" to a procedure or treatment, but in most instances their decision does not impact only them.

By returning to the case studies of Peter Noll, the father's kidney, and Paulina, we can see how using relational autonomy provides more depth and clarity to the scenarios.

#### **Peter Noll**

I cannot imagine what someone like Peter Noll feels when receiving the diagnosis of a terminal illness. Nor can I imagine what went on in Peter's mind that led him to the decision to forego treatment. However, I can somewhat understand what Peter's loved ones felt when they heard the news and his decision. Noll's stance that personal autonomy and total patient choice should be guiding principles in healthcare stands in harsh contrast to what his close friends and family may feel. For example, his friend Ruth found the news very difficult to accept:

You see, you're upsetting people with your decision... You scandalize [your friends]- you are showing them that death is in our midst and you are acting it out before their very

eyes; they suddenly are forced to think of what they have always suppressed. And, of course, they think only of themselves. Which makes it all the worse. They cannot help imagining what their own fate will be at some future time. (Dickenson and Parker 274) Clearly Ruth is distraught. With such a high value placed on what the patient wants, on the patient's choice, we forget how our choices impact those who are in close relation with us. Classical autonomy forgets that "decisions like that taken by Peter Noll are always inevitably going to affect people other than the patient him or herself. How would we feel about Peter Noll's decision if he was the single parent father of dependent children, for example?" (Dickensen and Parker 275). How would we feel if we all lived our life making choices in a way that we only considered how the outcomes would impact ourselves?

With Peter Noll's case in mind, I argue that relational autonomy is a better ethical principle compared to personal autonomy. Relational autonomy informs our decision making in a way that more realistically depicts the world in which we live and the relationships which we have. With that being said, an emphasis on relational autonomy may not completely change Peter's decision to forego treatment. However, it changes the thought process to arrive at the decision. Rather than jumping right to the decision to decline medical treatment for his cancer, Peter would reflect on the bonds he has with his close friends, his family he would leave behind, and the people whom he has touched at some point in his life. Sure, Noll made his decision by being the author of his own life. But, the story that he writes can never be attained in a social vacuum; Peter's story depends on the social circumstances in which he finds himself in. By taking time to really think about how his decision weighs on both himself and his peers, I argue that he would have arrived at a more relationship-informed, care-centered choice.

With total individual autonomy at the forefront of our medical decision making, individuals consequently do not feel constrained by others' hopes and expectations:

[If] autonomy is a matter of independence, it is very easy to see why it bears hard on relationships of trust. Independent people may be self-centered, selfish, and lacking fellow-feeling or solidarity with others— in short, the very people in whom one would have [the] least reason to place trust and who might encourage a culture of mistrust.

(O'Neill 24)

I know that a world like that is not a world I ideally want to live in; I imagine that it is a world most people do not want to live in. It is a world without trust, and therefore a world without powerful and strong relationships. Not one person is self-made. So why should our medical decisions be?

# The Father's Kidney

While individual autonomy played a central role in John's initial decision to withhold donating his kidney to his daughter, it was the unconscious realization of relational autonomy, i.e. the impact of his refusal on his family, that made him change his mind. John's initial choice illustrates how "modern medicine's overriding focus on the benefit of the individual patient has distorted the ways in which family members interact with one another and in particular with those who are sick" (Dickenson and Parker 208). On the contrary, John's final decision to save his daughter and donate his kidney was made on the basis that his individuality, or identity, is informed by his relationship with his family. Not only his sick daughter, but John's *entire* family depended on him. This concept is well articulated by Alastair Campbell:

The need to respond to and be responded to by others never leaves us. It is never a matter of whether to choose to experience dependency, since for most of us dependency is a

main feature in our lives. It is rather a question of deciding when demands made *by* us or *upon* us for dependent relationships are inappropriate and unjustified and of discovering how we are to hold in balance the autonomy of ourselves and of others with the necessary dependencies which connect us. Thus, a stress on autonomy is (let me suggest rather tendentiously) the *minor* key in medical ethics—the major key should be to discover how to foster appropriate and nurturing dependency. ("Dependency Revisited: The Limits of Autonomy in Medical Ethics" 105)

Perhaps John came to his final decision by finding the balance between his own autonomy and the appropriateness of the demand placed upon him due to his relationship with his family. No matter the decision made, John acted autonomously in both instances; relational autonomy does not strip one of their personal autonomy, but rather it places one's individuality into social context. It reinforces not only what we owe to ourselves, but more so, what we owe others. I believe that John's case highlights that "if we aspire to encourage and develop autonomy, then we must be aware that autonomy is not simply an individual ideal. It is an ideal which has implications for how we relate to others. Put bluntly, a world of autonomous individuals will be, more or less, a world of strangers" (Dickenson and Parker 206). It will be a world where a father is utterly ashamed and embarrassed to deny medical assistance to his daughter, but does it anyway.

### **Paulina**

In the case of Paulina, it may be argued that the physicians who attended to her that day did nothing wrong; they took her in, assessed her oral health, and treated her in the best way that they could. I do not intend to argue that the dentists did something *explicitly* wrong in the way that they attended to Paulina. However, I do aim to focus on the way in which her dental

experience and recovery could have been improved by approaching it from a relationally autonomous lens.

As a young, single, Puerto Rican mother who lives below the poverty line, Paulina did not receive treatment that accounted for the roles, relationships, and responsibilities she held outside of that dental clinic. While she recovers from the extensive amount of work she had done, who would take care of her children? If Paulina acquired an infection from the treatment, is it realistic for her to skip a day of work? If these questions were reflected on or asked on the day that treatment was provided to Paulina, perhaps the care she received would have looked different.

By recognizing the relational autonomy Paulina holds, rather than total individual autonomy, we see that "the nature of specific relationships is an important element of ethical analysis, i.e., that an ethics of actions is incomplete when evaluation is done in abstraction..." (Sherwin, *Feminist Persepctives in Medical Ethics* 21). No matter the view of autonomy taken, Paulina would have left the clinic that day still with the knowledge that she made the autonomous decision regarding the care she received. But, she would have also left knowing that the care she received was informed by the responsibilities she holds as a mother, active community member, employee, co-worker, and much more. "From the perspective of feminism, it is clear that the relationships studied in ethics must attend to the interdependent, emotionally varied, unequal relationships that shape our lives" (Sherwin, *Feminist Persepctives in Medical Ethics* 21). More so, as Paulina's case explicates, the medical and dental care we provide must also attend to these relationships. Relational autonomy is something that cannot simply remain in the armchair of philosophy. It must also find its way to the chair of the patient.

Summary

The case studies of Peter, the father and his daughter's kidney, and Paulina all emphasize the importance of recognizing the sociability and interdependence of human beings. They show us that no decision, as isolated as it may seem, affects the lone individual. Just as the infection in my mouth may spread to my jaw, neck, brain, and heart, the medical decision of a patient spreads to those present in the patient's life. With that being the case, the realization of relational autonomy in health care is something that falls on the shoulders of both the provider and the patient. Just as it is the physician's ethical responsibility to account for the *whole* person in front of them, so it is the patient's as well. Specifically, just as the dentists who cared for Paulina should have taken into account her relationships outside of the clinic, so should have Peter Noll reflected on how his decision to forgo treatment impacted his loved ones and not just him. In praising individuality and self-rule, Western healthcare has become blind to the value of human interdependence. I believe that directing our attention to relational autonomy in both the healthcare we give and receive will not further blind us to who we are. Instead it will open our eyes to who we have the capacity to be as both individuals and a society.

Of all the forms of inequality, injustice in health care is the most shocking and inhumane.<sup>15</sup>

# RELATIONAL AUTONOMY: A CORRECTION TO THE OPPRESSIONS OF MODERN MEDICINE

The mistreatment of underserved populations in medicine on both a personal and systemic level, the general lack of trust in the healthcare system, and the absence of care for one another in public health concerns all have one thing in common: an underlying (either conscious or unconscious) significance granted to individualistic autonomy. It is understandable that respect for autonomy and respect for the individual became crucial in Western healthcare. In addition, it is understandable that it has been at the center of bioethics and medical ethics for nearly half a century. With its introduction into medicine being backed by the need to empower the patient, it is possible that emphasis on classical autonomy has the capacity to do the opposite. Many of the injustices we see present in the healthcare system, such as those listed above, are rooted in an ethics of individualism. I call for a new way of doing medical ethics to help correct the injustices present. More precisely, I call for an ethics of care in the Western healthcare system.

In addition to its applicability to the lived reality of most, relational autonomy is one way of doing ethics that more directly addresses injustices present in the Western healthcare system. Its emphasis on care for *each other* shifts our attention from self-driven treatments to other-driven solutions. Similar to the lack of concern for the other that is present in other

<sup>&</sup>lt;sup>15</sup> Rev. Martin Luther King Jr. at the Second Annual Convention of the Medical Committee for Human Rights, Chicago, March 25, 1966.

systemic injustices in the United States, healthcare is also impacted by this as it presents itself in classical autonomy. By approaching healthcare ethics from an ethics of care perspective, specifically relational autonomy, I argue that we can more directly address and correct the injustices faced by the marginalized and oppressed in the healthcare system. We must begin to see that it is not merely individuals who are impacted by the decisions we make— or are forced to make— regarding our health, but it is also individuals' loved ones, families, neighbors, and communities that are impacted and contribute to the decision-making as well. When we start to acknowledge our vulnerability and co-dependency as human beings as a necessity and strength for survival, we also actively move in the direction of progress in the realm of modern medicine and care.

Why is classical autonomy damaging to healthcare ethics?

Classical autonomy is not only a misinformed ethic in healthcare, but it is— in many cases— damaging to the care a patient actually receives. First, in enforcing a standard that praises individuals for being self-sufficient, this mode of healthcare ethics has come to equate dependency with moral inadequacy. As a result, "The weak and the needy are increasingly being seen as an inconvenient burden [that] the strong and successful must only grudgingly bear" (Campbell, 101). Rather than acknowledging the basic fact that we need support to survive, our healthcare system is structured in a way that shuns individuals and families who rely on free services. Furthermore, when provided those free services, the care that marginalized populations receive is often inadequate and does not properly reflect how they will recover outside their current medical setting. Paulina's case study from above is an example of this.

I find that relational autonomy, or ethics of care in general, has a way of reframing our conventional opinion surrounding free healthcare services. It may encourage one to not view free

healthcare clinics or universal healthcare as "handouts" to the needy. Rather than shunning individuals and families for being dependent on the systems that are in place that are *meant* to support them, it would embrace them and aid them in moving forward. Classical autonomy is the "philosophy of self-reliance" that has supported a "mixed [healthcare] system with extra benefits for the more successful" (Campbell, 101). As a result of this system, we have normalized an inhumane, individualistic tendency to deny care to our neighbor on the basis of income, ethnicity, sexuality, gender, and much more. It has normalized this in a way that we cannot even see what's wrong with our behavior and the healthcare system to begin with.

In addition to classical autonomy influencing the actual structure of our healthcare system, it also plays a role in damaging the delivery of care experience for a patient. Specifically, by giving priority to total individual choice (regardless of the outcomes), we do not empower patients, rather we make them more vulnerable (Walker). How do we account for the total individual choice given to the elderly, widowed grandfather who relies on his children to aid him in making decisions regarding his health? What about the Spanish-speaking woman who needs her sister to access her medical charts in order to translate the doctor's orders? How about the young college student who does not fully understand what their physician is recommending, yet consents to the treatment anyways? These are all possible instances where the decisions made in the doctors' office are informed and supported by people beyond just the one in the examination chair. I do not aim to portray that a patient should not be given the choice to make their own decisions regarding their own health. Instead, I aim to show how a patients' choice is dependent on many people and factors outside of themselves. When we actively ignore that, we put patients in more harm regarding their health. Whether or not the intent to harm is there, the negative impact still stands.

Why can classical autonomy not truly be achieved by all in healthcare?

There are many factors that restrict and deny marginalized individuals' autonomy in healthcare. These individuals are then left incapable of achieving the notion of autonomy that our healthcare system so proudly upholds. Factors that restrict autonomy can be both internal and external; internal factors are those that relate only to the patient themself, while external factors lie outside of the patient. These factors include, but are not limited to: age, physical ability, mental conditions, social status, economic status, access to critical information, healthcare professionals' implicit biases, etc. (Leino-Kilpi et al. 64). To take social class, for example, those of lower social class may not have critical information accessible to them regarding their health, and are therefore left without the information to make a well-informed, autonomous medical decision. Whether consent is given or not, the *informed* consent is nevertheless absent. This results in patients of lower socio-economic status being diminished or denied their true autonomy versus being empowered by it (Leino-Kilpi et al. 65). While the right to refuse or accept a treatment is valuable to a patient:

[This] right does not secure any distinctive form of individual autonomy or independence... A limited right to refuse does not require capacities for independent, reflective choice, but it may be used to transfer formal responsibility for choice of treatment (and even for failure of treatment) to patients - who may feel quite powerless. (O'Neill 26)

In summation, the patients who experience restrictions to autonomy— whether it is one restriction or many— are left with the notion of autonomy that, while attractive, is an unobtainable illusion.

What is present in all of these restrictions to achieve autonomy is the assumption of total equality among individuals in society. But, as Dr. Catriona Mackenzie points out:

[To] lead a self-determining life, what matters is not absence of interference as such, but rather freedom from domination and from subjection to arbitrary forms of power and interference. On this view of freedom, self-determination requires substantive socio-relational equality of status, and this in turn requires not only that the basic liberties must be legally, politically and socially entrenched and resourced, but also that these liberties must be equally accessible to, and equally able to be enjoyed by all members of a society. (Mackenzie)

This understanding of self-determination is just as pervasive in healthcare as it is in everyday life. But yet, there are social, economic, and political barriers that often stand in the way of patients acting through self-determination, or in our case, acting autonomously. In addition to existing at the interpersonal level, the many systemic inequalities that exist often bar a patient from acting autonomously even before they step foot into the doctors' office. For example, it is known that as "one of the most economically disadvantaged demographics" in the United States, "African Americans still experience illness and infirmity at extremely high rates and have lower life expectancy than other racial and ethnic groups" (Taylor). But also, as they step into the medical setting, Black Americans are less likely to have physicians of color as their care provider, more likely to experience implicit biases due to the color of their skin, and more likely to be ignored regarding their pain or health complications. <sup>16</sup> Far from conclusive, all of the above

<sup>&</sup>lt;sup>16</sup> For a more conclusive look at the structural injustices that people of color experience in healthcare, see "Racial Discrimination in Healthcare: How Structural Racism Affects Healthcare".

inequalities will factor into the ability of a patient to make an individual decision rooted in self-determination, or classical autonomy.

How does relational autonomy account for vulnerable populations?

When we widen our scope of what autonomy realistically consists of, a relational understanding of our humanity and the decisions we make (or outside factors make for us) comes to mind. With an awareness of the systemic injustices above, "relational autonomy theory [aims] to explain how gender and other kinds of social oppression, such as racial oppression, can threaten a person's social *status* as an autonomous agent and can impair the development or exercise of the *capacity* for autonomy" (Mackenzie). For example, classical autonomy in health care decisions requires that the patient has the ability to act on their own set of values and choices. Yet, for a Black, Indigenous, or other individual of color, there are several oppressive conditions and relations in Western society that prevent them from cultivating the self-confidence and self-governance required for said autonomous decision-making. The healthcare provider you choose to see or healthcare practice you choose to attend is closely tied to what health insurance you have, which is connected to employment in the United States; "Studies of white employers reveal that racial stereotypes are used to deny employment opportunities to [Black] applicants", therefore limiting the employment opportunities for Black individuals in America (D R Williams & T D Rucker). The education one has surrounding their own health and public health is closely connected to their social and economic standing<sup>17</sup>; "[Black] persons in search of housing are still systematically steered toward neighborhoods having a greater number of minorities, lower home values, and lower median income" (D R

<sup>&</sup>lt;sup>17</sup> "Education leads to better, more stable jobs that pay higher income and allow families to accumulate wealth that can be used to improve health." For further reading, please see Anna Zajacova's and Elizabeth M Lawrence's, "The Relationship Between Education and Health: Reducing Disparities Through a Contextual Approach."

Williams & T D Rucker). The ability to make healthy choices regarding ones diet—aiding in the prevention of hypertension, obesity, and heart disease—depends on the food that is accessible and affordable in ones vicinity; "Food desert' has become a common term to describe low-income communities—often communities of color—where access to healthy and affordable food is limited...[and is] the result of systematic racism and oppression in the form of zoning codes, lending practices, and other discriminatory policies rooted in white supremacy" (Sevilla). It is with these systemic injustices and so many more that we can only begin to see how decisions surrounding an individual's health need to include an awareness of social and relational conditions present in our society.

Perhaps injustices in healthcare are "the most shocking and inhumane" because when it comes to healthcare autonomy, we have disregarded one of the most crucial aspects of our humanity—social relationships. To think holistically about health, we need to be able to look beyond the explicit physical and mental wellbeing of the lone individual. We need to understand how one's health got to a certain condition to begin with. We must think practically about treating the patient rather than just the symptom or illness. Relational autonomy points us in the right direction to do this. I believe, like many other feminst philosophers and bioethicists, that relational autonomy is a productive way to critically analyze atomistic assumptions of autonomy in health care. It is through this analysis that we can recognize "that self-governance is a socially constituted capacity, which can only be developed and exercised with extensive interpersonal, social and institutional scaffolding" (Mackenzie). Through this recognition we can only hope to start taking corrective action in Western healthcare, bioethics, and beyond.

<sup>&</sup>lt;sup>18</sup> Rev. Martin Luther King Jr. at the Second Annual Convention of the Medical Committee for Human Rights, Chicago, March 25, 1966.

## CONCLUSION

My aim is to neither throw out the value of classical autonomy nor disregard the importance of the work proposed by many academics in philosophy. Rather, I aim to expand the conversation. Philosophy is a study that is never complete, and the insights brought forth by Kant, Mill, and Emerson many years ago is work that *can* be and *should* be constantly re-thought and revised. Feminist ethics of care is one way of doing the rethinking. The value of autonomy and what role we want it to play in not only healthcare, but in our lives at large, can be efficiently rethought through relational autonomy.

At the end of the day, our notion of autonomy will reflect what we see as just and reasonable. Classical autonomy assumes a perspective of justice that places a great amount of value in individual liberties and freedom. Relational autonomy, on the contrary, sees justice more so as something that promotes compassion, care for our neighbors, and equity. As the COVID-19 pandemic in the United States has made very clear, we value our personal liberties and freedoms in the Western world almost as much as we value our own lives. I do not believe that relational autonomy asks of us to forgo those liberties and freedoms. Rather, relational autonomy points us in the right direction to use our own autonomy to recognize and enhance the autonomy of others. I truly believe that we can maximize respect for autonomy while simultaneously maximizing the pursuit of the common good for all. In the case of COVID-19, when one arrives at the decision to abstain from vaccination despite not having medical reasons that would prevent them from doing so, how exactly did they arrive at that decision? To arrive at the decision from a belief like Peter Noll's— it is a medical decision that remains isolated to their own health— is one thing. To arrive at the decision after critically reflecting on who of their peers may be immunocompromised and at high-risk of contracting and becoming seriously ill from the virus,

is another thing. In my opinion, it is not the final decision that is the issue when it comes to health. The issue is not that Peter Noll chose to forgo cancer treatment. It is not that the father said no to donating his kidney to his daughter. The issue is not that Paulina had her teeth pulled out that day. It is not that someone is not vaccinated against COVID-19. The issue is *how* we arrive at our decision. How do we frame our questions to have a more holistic understanding of how our decisions impact others?

While I am no expert when it comes to systemic reform, I believe that the re-framing of questions regarding public health needs to happen long before the decisions regarding public health are made. It should happen before the patient is given a diagnosis by the doctor; it should happen before the patient even sets foot in the medical or dental office. To understand our decisions surrounding autonomy at the public health level, we need to understand it first at our individual level. It is to my understanding that many popular works in philosophy forget this. While Emerson, Kant, and Mill may convince you otherwise, the world we live in is not the atomistic, individualistic, and theoretical world philosophized by these men many years ago. Because of that, we cannot rightfully act and make decisions in these ways; the current environment we have created in the United States throughout the COVID-19 pandemic is evidence for this. If relational, as opposed to classical, autonomy was at the forefront of COVID-19 conversations, I wonder how the tension surrounding something as simple as wearing a piece of fabric over your mouth may have dwindled. I wonder if vaccination status would have increased, or maybe it would not have had such strong ideological assumptions tied to it. Perhaps

<sup>&</sup>lt;sup>19</sup>The ethics behind getting vaccinated is a topic that is far from the scope of this paper. It is more thoroughly discussed in the following sources: "Ethics of vaccine refusal" by Michael Kowalik, "The 'Ethical' COVID-19 Vaccine is the One that Preserves Lives: Religious and Moral Beliefs on the COVID-19 Vaccine" by Alberto Giubilini et al, and *The Ethics of Vaccination* by Alberto Giubilini.

the state of the world and our country would look exactly the same. But, as an advocate for relational autonomy, I believe it would look quite different.

Just as classical autonomy did many years ago, relational autonomy would transform our healthcare system because philosophy in practice is transformative. In fact, that is why I was drawn to philosophy in the first place. I fell in love with philosophy because it forever wrestles with how to make sense of the world in which we live. Like many professions, it uses a myriad of tools to accomplish this. As a dentist may use handpieces and floss to care for their patient, philosophy uses ethics, metaphysics, logic, and epistemology to care for the world. These philosophical tools will aid us in a quest for a better world for all.

I cannot emphasize enough how important philosophy is to all professions, especially health care professions. It is for this reason that I felt called to dedicate this project to one specific ethical topic in the realm of philosophy and health care. I am neither the first nor the last to take up this topic; philosophy is an ongoing conversation. Regardless, I hope that you walk away with the satisfaction of engaging in this conversation; engaging in philosophy. While the conversation on relational autonomy is not new to the world of philosophy or health, it was a conversation that was new for me not long ago. This is a conversation that I aim to engage with in the years to come, and I hope it can be a conversation for others as well.

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